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Social Support, Parent-Child Communication And Reactions To Pediatric Cancer Medical Procedures

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SOCIAL SUPPORT, PARENT-CHILD COMMUNICATION AND REACTIONS TO PEDIATRIC CANCER MEDICAL PROCEDURES

by

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DISSERTATION

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DEDICATION

This dissertation is dedicated to my insightful and supportive husband, Mike Naughton, who made this seem conceivable by providing humor, love and encouragement.

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CHAPTER 1

Introduction

Aim

The purpose of this study is to investigate the relationships among social support, parent-child communication during pediatric cancer treatment-related medical procedures, and parent and child reactions to these procedures. It addresses gaps in the previous literature by examining the associations between observed parent-child communication behavior, parent self-reported social support data, and parent and child responses to treatment. This chapter will address the sociological nature of this research, the role of social support in this context, childhood cancer incidence rates, types and treatments, the purpose of this research and its aims, and the significance of this research.

This sociological research will use the Stress Process Theory (Pearlin, Lieberman, Menaghan, & Mullan, 1981) to examine the relationships between parent-child communication, social support, and parent and child reactions to treatment procedures. The sociological study of stress has typically focused on how social conditions can affect stress outcomes (Lackey, 2008). For families of children diagnosed with cancer, a major stressor identified in the literature has been the frequent and painful medical procedures a child must undergo as part of treatment (Ljungman et al., 2003). In their research, Pearlin and colleagues (Pearlin, Lieberman, Menaghan, & Mullan, 1981) discuss the sources of stress, the mediators of stress, and the manifestations of stress. One possible mediator of stress in the pediatric cancer context may be social support.

Social support is the verbal and nonverbal communication that helps manage uncertainty about a situation, the self, another, or a relationship and functions to enhance a perception of personal control (Albrecht & Adelman, 1987; Braithwaite, Waldron, Finn, 1999). Cutrona & Russell (1990) describe social support as “emotional support, the provision of aid and security during times of stress that leads a person to feel s/he is cared for by others” (p. 322). The literature points to the benefits of social support in alleviating stress, facilitating coping, and enhancing health and medical outcomes (Albrecht & Goldsmith, 2003); however, the role of social support in potentially alleviating distress in the specific experience of pediatric cancer treatment-related medical procedures has not previously been explored.

According to the American Cancer Society, roughly 12,000 children under the age of 15 were diagnosed with cancer in the United States in 2012 (ACS, 2012). While still a relatively rare disease among children, childhood cancer rates have been rising over the past several decades. Due to advances in treatment, nearly 80% of children diagnosed with cancer will survive five years or more (ACS, 2012). In spite of advances in treatment, childhood cancer is still the leading cause of disease-related death in children (ACS, 2012), taking the lives of more children than AIDS, asthma, diabetes, cystic fibrosis, and congenital abnormalities combined (PAC2, 2012). Childhood cancer incidence rates have increased 21% since 1975 (ACS, 2011). The five-year relative survival rate for all adult cancers combined is roughly 68% (NIH, 2010).

Childhood cancers are different from adult cancers. Childhood cancers typically develop in rapidly growing tissue and organs during the first eight weeks in utero and during the postnatal period (Izraeli & Rechavi, 2004) and are often the result of DNA changes in cells (ACS, 2013). Most cancers in children are likely the product of developmental accidents that take place during pregnancy; adult cancers typically arise in cells that cover the surfaces of ducts and cavities exposed for prolonged periods of time to a variety of environmental carcinogens (Izraeli & Rechavi, 2004). Due to this significant difference, most cancers in children cannot be prevented and are not amenable to early diagnosis (ACS, 2013; Izraeli & Rechavi, 2004). In the next several paragraphs, the most prevalent forms of childhood cancer are discussed.

The most common form of childhood cancer is acute lymphoblastic leukemia (ALL). This disease is a fast-growing cancer of the white blood cells used to fight infections. In ALL the bone marrow makes too many immature cells (NCI, 2012). In order for various immune receptors to develop efficiently, lymphoid cells have a natural genetic instability that predisposes them to rare genetic accidents that lead to ALL (Izraeli & Rechavi, 2004). Another common form of childhood cancer is cancer of the central nervous system (CNS).

CNS cancers are the second most common type of cancer in children. The nervous system, like the lymphoid system, is rapidly developing and also involves a natural instability in order to develop properly (Izraeli & Rechavi, 2004). CNS tumors are relatively slow growing, but some have a more aggressive nature, like medulloblastoma, retinoblastoma, and neuroblastoma (NCI, 2012). Medulloblastoma is a brain tumor that begins in the lower part of the brain and often spreads to the spine. Retinoblastoma can form in the tissues of the retina and typically develops in children under the age of five (NCI, 2012). Neuroblastoma can develop in immature nerve tissue and adrenal glands in young children. Cancers of soft tissues are also common forms of childhood cancer.

Musculoskeletal and soft tissue cancers develop at any age but are often diagnosed more frequently during adolescence when children are going through significant musculoskeletal development (Izraeli & Rechavi, 2004). Osteosarcoma, Ewing sarcoma, and rhabdomyosarcoma are three common forms of musculoskeletal cancers. Osteosarcoma is a bone cancer that typically affects the large bones of the arm or leg (NCI, 2012). Ewing sarcoma can develop in the bones of the leg, arm, chest, trunk, back, or head. Ewing sarcoma can also develop in tissues other than bones (NCI, 2012). Rhabdomyosarcoma is a cancer that occurs in muscles attached to bones that help the body move and is the most common type of soft tissue childhood cancer (NCI, 2012). While the above-mentioned cancers have differences and similarities, treatment options are tailored to specific types of cancer and stages of the disease.

There are several ways to treat childhood cancers, and treatment options are based on type and stage of cancer. Possible treatments include chemotherapy, surgery, and radiation, and in many cases more than one treatment type is used (ACS, 2012). Most children in treatment for cancer are treated at a children's hospital that is a member of the Children's Oncology Group (COG). COG institutions typically exist within a university, and most are affiliated with a children's hospital. Children receiving care at these institutions obtain the most up-to-date, advanced, and best available cancer treatment (ACS, 2012). A specialized medical team including pediatric and radiation oncologists, pediatric surgeons, nurses and nurse practitioners trained and experienced in pediatric oncology treat children diagnosed with cancer. Most children's hospitals offer the services of psychologists, child life specialists, social workers, rehabilitation and physical therapists, educators, and nutritionists to assist in the care of the child with cancer (ACS, 2013).

The advantageous treatment of childhood cancer has been one of medicine's greatest success stories with the favorable survival rate attributed to the sensitivity of these cancers to chemotherapy and to the collaborative empirical clinical trials conducted in Europe and the United States (Izraeli & Rechavi, 2004; NCI, 2013). ALL, in particular, has a high success rate at 80%, which is often attributed to aggressive treatment regimens. Children in treatment for ALL are typically in treatment for two to three years and take roughly ten different drugs throughout the treatment protocol. Intensive induction and consolidation therapies occur in the first six months of treatment and consist of frequent hospitalizations for administration of drugs or for fighting infections due to immune suppression. Induction therapy is the first treatment provided and is typically part of a combination of treatments (i.e., chemotherapy followed by radiation) (NCI, 2013). After induction therapy, and once cancer is no longer present in the body, consolidation therapy may begin. The goal of consolidation therapy is to kill any cancer cells that may still be in the body but are not detected and includes radiation, stem cell transplants, and chemotherapy (NCI, 2013). Induction and consolidation are followed by a prolonged period of less intense maintenance therapy during which the child can return to almost all normal activities (Izraeli & Rechavi, 2004). Maintenance therapy is designed to help prevent cancer from returning and can include chemotherapy and the use of vaccines and/or antibodies (NCI, 2013).

Most children diagnosed with cancer will survive (ACS, 2012); however, the treatment of cancer is often a heavy burden for a family to bear. Children who survive cancer are expected to live an average lifespan, so quality of life and long-term late effects of treatment have become a major focus of research (Izraeli & Rechavi, 2004). Although pediatric cancer treatment often results in a cancer-free status, the diagnosis, on-going treatment, and long-term psychosocial implications of childhood cancer continue to be major stressors for children and their parents.

The purpose of this study is to examine the relationships between social support, parent and child communication during cancer-related medical procedures, and parent and child reactions to treatment procedures. Questionnaire data, demographic information, and video-recorded treatment procedure interactions of families who are currently enrolled in an NIH-funded R01 study ("Resources, Parent-Child Communication and Adjustment to Pediatric Cancer," Penner: PI; NCI #R01CA138981-05) were utilized. An established coding system (Cline et al., 2006) was applied to video-recorded pediatric cancer treatment episodes collected as part of larger ongoing study (Penner et al.). The relationships between parent social support, parent-child communication during treatment procedures, and parent and child reactions to treatment procedures were examined.

Three aims and three hypotheses were developed for this dissertation:

Aim 1: To determine the relationship between parent social support and (a) parent and child reactions to treatment procedures and (b) child cooperation during treatment procedures.

Aim 2: To determine the relationship between parent-child communication during treatment procedures and parent and child reactions to treatment procedures.

Aim 3: To determine the relationship between parent social support and parent and child communication during treatment sessions.

Hypothesis 1: Parent social support will be related to parent and child reactions to treatment procedures. When parent social support is greater, reactions to treatment will be less distressing for both the parent and the child and the child will be more likely to cooperate during the procedure.

Hypothesis 2: Parent and child communication during the procedure will be related to parent and child reactions to treatment procedures. Parents who communicate in a supportive manner, as opposed to an invalidating manner, will have more positive reactions to treatment and have children who have more positive reactions to treatment procedures.

Hypothesis 3: If both parent-child communication and social support are related to parent and child reactions to treatment, it would stand to reason that there is a relationship between parent social support and the communication occurring during treatment episodes. When parent self-reported social support is greater, parents and children will be more likely to communicate in a supportive manner, as opposed to in an invalidating manner.

Significance

This dissertation research is valuable for several reasons. First, childhood cancer continues to be a major stressor for children and their parents and is associated with long-term psychosocial issues for both children and their families. Cancer is the primary cause of disease-related death for children in the United States (ACS, 2012). Childhood cancer causes serious psychological and physical stress for the family (Faulkner, Peace, & O'Keefe, 1995), including anger, depression, stress, guilt, and confusion (Grootenhuis & Last, 1997; Janes-Hodder & Keene, 1999; Masera et al., 1998; Reay, Bignold, Ball, Cribb, 1998). According to the American Cancer Society (ACS, 2011), childhood cancer is often treated as a chronic disease, which has its own set of challenges and stressors. Parents and children identify cancer treatment as the worst aspect of having cancer (Ljungman, Gordh, Sorensen, & Kreuger, 1999).

Second, observational data is important in examining the complicated relationship between parent-child communication and procedure-related outcome variables. While several studies have examined parent and child interactions during cancer treatment-related medical procedures, for the most part they have relied on observers in the exam room or audio recordings. There is value in having a video recording of an interaction to analyze and having multiple raters/observers watch the recordings. Having a recording is less obtrusive than having an observer present in the exam room during the procedure, and having a visual recording provides an opportunity to achieve better rater reliability.

Third, while there has been extensive research done in the area of social support and illness, no research could be identified that examined the role of social support in relation to parent and child reactions to pediatric cancer treatment-related procedures. It will be important to determine if the social support available to parents has an effect on the specific stressor of a cancer-related medical procedure. If so, interventions could be developed to develop, increase, or maintain support networks for families with children who receive frequent and stressful medical procedures for many chronic conditions and childhood illnesses, including cancer.

This research, examining the role of social support on parent and child interactions during treatment procedures, is both novel and important. It is novel in its use of video-recorded interactions in which children are undergoing invasive and distressing cancer-related medical procedures. These data are rare, and it has been valuable to consider the naturally occurring behavior of families experiencing cancer treatment-related procedures. This research will expand on the literature of social support by adding data specific to how social support may be related to parent-child interactions during distressing medical procedures as well as how social support may be related to parent and child reactions to these procedures.

This dissertation is organized in the following manner: the next chapter reviews the literature and provides an overview of the sociological study of stress, pediatric cancer as a stressor, the impact of childhood cancer on parents, parent child communication during medical procedures, and social support, and also covers the theoretical framework and the model for this research; the third chapter provides an overview of the methods used in this study; the fourth chapter presents the results for the descriptive and bivariate analyses; the fifth chapter provides the results for linear and logistic regression analyses; and the sixth chapter summarizes the findings, describes the study's limitations, and suggests directions for future research.

CHAPTER 2

Literature Review & Theoretical Framework

Introduction

This literature review is divided into six major sections: the first section reviews the sociological study of stress, including a review of pediatric cancer as a stressor; the second section reviews the impact of pediatric cancer on parents; the third section reviews how parent behavior influences child reactions to medical procedures; the fourth section reviews the social support literature, both generally and specifically as it relates to childhood cancer; the fifth section discusses the gaps in the literature; and the last section provides an overview of the theoretical framework for this study.

Review of the Sociological Study of Stress

The sociological study of stress has examined how social conditions affect stress outcomes (Link & Phelan, 1995; Lackey, 2008; Selye, 1982; Turner, 2010). Selye (1982) argued that each individual defines stress differently and that much of the literature does not attempt to develop a clear definition of stress. He reasoned that a variety of different situations could produce a stress response, either physiological (pain, upset stomach) or emotional (fear). Several stress theories have been developed through the years, including the sociological work of Pearlin and colleagues (1979, 1981) on the stress process and Thoits' research on stress and health (1982, 2010).

Several stress theories have been developed through the years. Pearlin and colleagues (Pearlin et al., 1981) developed a sociological theory of the stress process in which they suggest that three concepts form the stress process model. They identified the sources of stress, the mediators of stress, and the manifestations of stress; these concepts are described below. Pearlin

(1989) argued that the study of stress provided an opportunity to study how well-being is affected by societal structures and individuals' repeated life experiences. He posited that the stress process arises from and is influenced by societal structures, and that these structures determine the stressors people experience, the mediators they are able to call upon, and the way in which they experience stress. Research into the areas of the sources of stress has focused on life events and life strains. Life events have been categorized as single events, like a hurricane destroying the family home, that lead to stress by creating new strains or intensifying existing strains. Life strains are strains or stressors that are ongoing, and are the product of a life event. Examples of a life strain could be caring for a loved one with Alzheimer's disease or dealing with the aftermath of a destroyed home from a hurricane. For example, the life event of having a home destroyed by a hurricane could produce the life strains of loss of clothing/financial and personal documents, the stress of finding a new place to stay, issues that arise in dealing the the insurance company and loss of work to handle these issues. Coping and social support have often been studied as mediators of stress. Considerable research exists on the manifestations of stress, from microbiological and physiological to emotional and behavioral outcomes.

The first concept in the stress process model is the source of stress. Early research on the sources of stress focused on two general forms of stress, stress generated by life events and stress produced from ongoing continuous problems. Life events are major single events (i.e., home destroyed by hurricane, death of loved one) that can cause stress or distress to an individual. Research in the area of life events differentiated life events based on the desirability of the event (Gersten, Langner, Eisenberg, & Simcha-Fagen, 1974; Mueller, 1979), by the level of control people had over the event (Fairbank & Hough, 1979), or by whether or not the life event was anticipated (Pearlin, 1980). Pearlin and Lieberman (1979) argued that life events may create new strains or intensify existing strains. These strains are the product of the life events. For example, a life event may be the loss of a job, and the strains from that event could include economic hardship or loss of identity. These new or stronger strains are what actually cause the stress, not the life event itself. The same authors identified self-concept and role strain as potential stressors. They argued that life events, and the strains they generate, are likely to cause stress when they result in a change in self-concept or value. Pearlin (1982) later argued that different people experience similar life events and strains differently (or may not experience the event as a stressor at all); stress is a subjective concept, and the same life event does not cause stress in all people.

The second concept in the stress process model is the mediator. The intensity of the stress individuals experience cannot be predicted by the intensity of the source of stress. People confront stressful situations with a variety of emotional and cognitive resources that can alter the stressful situation or mediate the impact of the stress (Pearlin et al., 1981). Individuals can use these mediators to defend against the stressful assault. In the stress literature, social support and coping resources are two mediators that have been studied extensively (Cutrona & Russell, 1990; Krause, 1986; McEwan & Seeman, 1999).

The third concept in the stress process model is related to the manifestations or outcomes of stress. Considerable variability exists in the literature in how the manifestations of stress are measured. Pearlin and colleagues (Pearlin et al., 1981) argued that stress is a response by an organism to conditions that are experienced as noxious; however, there is less agreement on where this response is manifested in the organism (physiological functioning, emotional functioning, metabolic systems, cardiovascular systems, etc.). Pearlin et al. (1981) also argued that the methods by which researchers attempt to measure the manifestations of stress could impact what can be examined. With survey research, the subject must be aware of a conscious manifestation of stress and must be able to articulate and/or rate feelings or emotions. Physiological data, biomarkers like blood or saliva, could provide data on stress, but these data are often difficult to collect and have limits as well, including invasiveness and stability (Piazza, Almeida, Dmitrieva, & Klein, 2010).

A childhood cancer diagnoses would be a major stressor for a family. The implications of cancer treatment and the ongoing strain it places on the family would categorize childhood cancer treatment as a chronic life strain (Pearlin, 1980; Pearlin & Lieberman, 1979; Pearlin et al., 1981). Manifestations of the stresses caused by childhood cancer will be examined later in this literature review under the heading "Pediatric Cancer Treatment as a Stressor."

Thoits' (2010) review of the sociological stress research outlined five major findings and three policy implications related to research conducted since Selye's work in 1956. The first finding argued that while earlier stress research found significant ties between acute life changes (e.g., death of spouse, job loss) and negative health outcomes, investigators had not examined the ongoing strains (e.g., living in a dangerous neighborhood, caring for a child with a disability). Eventually more thorough studies of life experiences were conducted that included one-time stressors (life event) as well as ongoing strains (life strain). Turner and colleagues (Turner, Wheaton, & Lloyd, 1995) examined ongoing stressors and stressful events by interviewing 1393 adult residents of metropolitan Toronto. Participants provided data regarding life stress, including measures of stressful life events, life strains, and major traumas. Participants were also asked about their mental health status by responding to questions about depression. The investigators found that the correlations between life strains and psychological distress were stronger than the associations between stressful events and psychological distress. They also found that experiencing traumas increased the likelihood of experiencing future stressful events and chronic strains. The diagnosis of cancer for a child would be an acute life change; however, because treatment is long term, often several months to three years, a childhood cancer diagnosis produces chronic strains. This dissertation research will examine the specific stressor of treatment-related medical procedures for families of children diagnosed with cancer.

The second finding Thoits identified was the unique contribution by sociologists who studied differences between social groups in their exposure to stress and its effect on health. Variability in responses to stress based on ethnicity, age, gender, marital status, socioeconomic status, income, education, and professional prestige were examined. In a study of family structure, stress, and psychological distress, Avison and colleagues (Avison, Ali, & Walters, 2007) interviewed 518 single and 502 married mothers twice each and also collected self-report measures on depression, history of psychopathology in one or both parents, financial strain, caregiver strain, strains between work and home , and life events. The authors found that single mothers had higher rates of depression, were more likely to have parents with substance abuse issues, and had experienced significantly more stress and strain than married mothers, including financial stress that was more than twice that of married mothers. Geronimus and colleagues (Geronimus, Hicken, Keene, & Bound, 2006) examined data from the National Health and Nutrition Examination Survey for racial and gender differences in age-related allostatic load scores. Allostatic load is the physiological burden created by stress (McEwen & Seeman, 1999). Data collected included questionnaires containing indices of health and social factors and a clinical examination. The sample included 1560 adults 18-64 years of age who self-identified as non-Hispanic black or non-Hispanic white. They found that non-Hispanic black men and women had a higher allostatic loads than non-Hispanic white men and women at all ages.

Difference in allostatic load scores increased with age for all groups in the study. The authors also examined poverty and found that non-poor blacks had higher allostatic loads than poor whites. Black women carried the highest allostatic load of all groups under study (black men and women, white men and women). This dissertation research will examine differences in parent-child communication patterns, social support, and reactions to treatment procedures by gender, age, and ethnicity.

The third finding Thoits identified in the stress and health literature was that members of minority groups are burdened by discrimination stress, which affects health outcomes. Researchers have identified groups (e.g., women, racial/ethnic minorities) that experience more discrimination strains than those not as burdened by discrimination stresses. In a study of racial differences in pre-term and low birth weight deliveries, Mustillo and colleagues (Mustillo et al., 2004) examined data from the CARDIA study, a study of factors that influence the development of heart disease, including experiences of racial discrimination. The investigators identified 352 female participants that had delivered babies while in the CARDIA study and found that African American women reported substantially more racial discrimination, had fewer economic resources, were more likely to be single, were more depressed, were less likely to drink, and were more likely to smoke. Additionally, there was a statistically significant and positive association between racial discrimination and the delivery of preterm and low birth weight babies for African American mothers. While this dissertation research does not specifically study discrimination stress, it does examine differences based on gender, age, and ethnicity.

In a study of the relationship between discrimination and substance abuse among gay, lesbian, and bisexual adults, McCabe and colleagues (McCabe, Bostwick, Hughes, West, & Boyd, 2010) used data from the 2004-2005 National Epidemiologic Survey on Alcohol and

Related Conditions to examine whether sexual orientation minority groups who reported more discrimination were more likely to have substance abuse disorders. Data were collected from 577 individuals who completed face-to-face interviews that included questions about discrimination and substance use as well as questions pertaining to demographics, including sexual orientation. The authors found that substance abuse disorders were more common among those who reported discrimination and that substance abuse disorders were highest among those who reported multiple forms of discrimination.

The fourth finding Thoits identified in the literature is related to stress proliferation, which is the idea that one stressor will lead to another stressor and so on. One example Thoits provides is that caregiving for a loved one may lead to interruptions at work, which may lead to decrease in income, which could lead to financial hardships, and so forth. The literature speaks to the cumulative advantage/disadvantage theory (Hagan & Foster, 2003; McLoyd, Aikens, & Buron, 2006), which posits that advantages and disadvantages experienced early in life build over the lifespan and lead to increased disparities (Thoits, 2010). In short, people who have more money, resources, and support gain more of it over time, and people who have less increasingly lose what they have over time (Dannefer, 1987). This finding may have implications for this dissertation research as children who have a negative experience during a treatment-related procedure may become distressed with other aspects of cancer treatment. For example, if a child has a negative experience with a treatment-related medical procedure early in treatment, the child may develop anxiety or apprehension about coming to the clinic even when the child is not having a procedure and may begin to act out, lose appetite, or become hostile with their parent(s).

Umberson and colleagues (Umberson, Williams, Powers, Liu, & Needham, 2006) provided an example of this theory in their work on marital quality and health over the lifespan. The investigators used face-to-face interview data from 1049 white and African American individuals who participated in all three interview waves of the Americans' Changing Lives study. The investigators had access to measures of marital quality, life course, sociodemographic variables, and self-reported health. Findings showed that, not surprisingly, self-reported health declines over time, but that marital strain accelerates the decline, and that the association between marital stress and health gets stronger with age.

In a study examining the accumulation of disadvantage over the lifespan, Walsemann and colleagues (Walsemann, Geronimus, & Gee, 2008) investigated the relationship between educational advantage in youth and health during middle age. The authors used data collected between 1979 and 2002 from 9050 individuals who participated in the National Longitudinal Survey of Youth. Information was collected from participants via interviews where respondents answered questions regarding health-induced work limitations, educational advantage, school demographics, educational attainment, and sociodemographic characteristics. The authors found that individuals who had educational advantage during their youth were less likely to have health-induced work limitations later in life. The authors argued that educational advantage is related to a sequence of selection events that in turn lead to additional advantages. The authors also found that the gap in health between those with fewer and those with greater educational advantages widens with age and that the magnitude of health disparities over the lifespan is modified by education advantages in youth.

Thoits' fifth finding identified personal resources that can buffer the impact of stress on health. Thoits specifically identified that higher levels of mastery, self-esteem, and social support can ameliorate the negative effects of stress. Thoits defined a sense of control/mastery as a "generalized belief that most circumstances in one's life are under one's personal control" (p. 546). She defined high self-esteem as "a perception of oneself as a good, valued, and competent person" (p. 546) and social support as "emotional, informational, or practical assistance from significant others, such as family members, friends, or coworkers" (p. 546). She argued that these coping resources increase the ability to cope with a stressful demand. Increasing or improving the coping resources available to an individual was amenable to interventions. This dissertation research will examine the role of social support in buffering the negative effects of cancer-related treatment procedures for both children and their parents.

Interventions using social support and coping strategies were developed to help people buffer the negative effects of stress in their lives. In a study examining psychological resilience and social support for soldiers returning from Operation Enduring Freedom and Operation Iraqi Freedom, Pietrzak and colleagues (Pietrzak, Johnson, Goldstein, Malley, & Southwick, 2009) used survey data from 272 veterans of the two campaigns. Participants were asked about resilience, their combat experience, post-traumatic stress, health status, support from their unit in the war zone, and post-deployment social support. Results indicated that higher levels of resilience and post-deployment social support were related to lower levels of traumatic stress and depression in the veterans. If findings from the current study indicate that social support can buffer the negative effects of cancer-related medical procedures, an intervention could be developed and tested that creates, maintains, or expands parents' social support resources to ultimately improve child and parent reactions to treatment procedures.

The sociological study of stress has a strong research history and continues to provide insight into how stress impacts our physical and mental health. Thoits' work on the sociological study of stress and the buffering effects of social support provide evidence that social support in the pediatric cancer treatment experience could buffer the negative effects of undergoing cancer-related medical procedures. Next, the specific stressor of childhood cancer treatment will be examined.

Pediatric Cancer Treatment as a Stressor. Although cancer is the leading cause of children's disease-related death in the United States, many pediatric cancer cases are curable (NCI, 2013). As a result of medical advances, there is an increased population of childhood cancer survivors; therefore, childhood cancer is often treated as a chronic disease (ACS, 2011). Despite a relatively high survival rate, childhood cancer poses serious psychological and physical stressors to both the child and the family (Faulkner et al., 1995). A childhood cancer diagnosis can cause emotional upheaval for a family, bringing with it denial, fear, and shock (Alderfer et al., 2010; Grootenhuis & Last, 1997; Masera et al., 1998). Families also experience anger, depression, stress, guilt (Reay et al., 1998), and confusion (Janes-Hodder & Keene, 1999). Parents of children with cancer also report difficulty in managing uncertainty about the future (Grootenhuis & Last, 1997). All the aforementioned issues are what Pearlin would consider manifestations of stress.

Parents experience distinct forms of stress when confronted with their child's cancer diagnosis. Chesler and Barbarin (Chesler & Barbarin, 1987) identified five types of stress experienced by parents of children with cancer: intellectual, instrumental, interpersonal, emotional, and existential. Intellectual stressors include the need to know as much as possible about the disease and its treatment and prognosis (Chesney, Rounds, & Chesler, 1990; Ljungman et al., 2003). In a recent study of information-seeking behaviors and the decision-making processes of parents of children with cancer, Kilicarslan-Toruner and Akgun-Citak (2013) interviewed 15 parents of children in an inpatient unit at a hospital in Ankara, Turkey. Parents participated in semi-structured interviews in which they were asked questions regarding what information they wanted to receive after diagnosis, where they found information, what problems they faced when seeking information, what decision-making situations they faced regarding treatment, what problems they encountered with decision-making, and what the medical staff's impact was on information-seeking and decision-making. The authors used content analysis to analyze the transcripts of the interviews. Results indicated that parents sought information from several sources, including doctors, nurses, other parents, and the internet, and that their information needs changed over the course of their child's treatment.

Instrumental stressors include issues related to finances and time management. A diagnosis of childhood cancer can cause serious financial hardships for the parents, requiring out of pocket expenses for treatment and absence from the workforce. Out of pocket treatment and diagnostic costs and loss of income can account for 25% of a family's disposable income in the United States (Barr et al., 1996). In a pilot study conducted by The Childhood Cancer Foundation, Candlelighters Canada, the British Columbia Cancer Agency, and Health Canada, Limburg and colleagues (Limburg, Shaw, & McBride, 2008) examined the non-medical costs associated with a childhood cancer diagnosis and the impact of such a diagnosis on the family. The project utilized data on 111 families whose child had been diagnosed under the age of 20 and who had been diagnosed at least two years prior to the study. Participants completed questionnaires that inquired about parent's employment status, income, and the financial impact of cancer at diagnosis and at the time of questionnaire. Results indicated that 44% of mothers and 11% of fathers left their jobs because of the diagnosis, and in eight families both parents left their jobs. Parents of children under the age of ten and parents of children diagnosed with leukemia were more likely to leave their jobs. Most were able to return to work within one year of their child's diagnosis. In a similar study, Eiser and Upton (2006) administered questionnaires to 145 parents of children diagnosed with cancer under the age of 16 in the United Kingdom. Parents responded to questions regarding their demographics, the child's clinical information (diagnosis, time since diagnosis, treatment status), current expenses related to the child's cancer, employment status, and financial support accepted from the government and charities. The authors found that the heaviest financial burden occurred in the first six months of treatment when frequent hospital stays were required and money had to be spent on overnight accommodations, food, care for siblings, and travel to hospitals. The authors found that single parents felt increased financial stress because they already were experiencing financial worries.

Limburg et al. (2008) examined the experiences of families in the Canadian health care system, and Eiser and Upton (2006) investigated the experience of families in the United Kingdom. In both the United Kingdom and the Canadian systems, medical insurance is not directly tied to employment as it typically is in the United States. Surprisingly, in a 2011 review of the literature on the economic burden of childhood cancer and the family, Tsimicalis and colleagues (Tsimicalis, Stevens, Ungar, McKeever, & Greenberg, 2011) identified 13 publications addressing the subject, and of those 13 articles, only two were conducted in the United States. The first, published in 1979, outlined the nonmedical costs associated with pediatric cancer treatment, and the second, published in 1983, outlined the medical costs. The same lead author, Shirley Lansky, wrote both articles. Only the article discussing the nonmedical costs will be discussed here, as the article concerning the medical costs did not provide information on the medical cost burden on the family. Lansky and colleagues (Lansky et al., 1979) administered questionnaires to 70 families who had a child in treatment for cancer. The first questionnaire was a weekly log of nonmedical expenses related to the child's cancer. Parents also provided information on the level of care the child needed during the same week. Parents participated in interviews that assessed the child's performance status. A second questionnaire was given to both parents (if both were available) and asked about loss of income. Results indicated that transportation, food, and miscellaneous items were the biggest expenses and that the level of care the child needed was the strongest predictor for every category of expense. These factors, in addition to frequent medical procedures, likely contribute to stress in parents of children with cancer.

Interpersonal stress includes the stigma of childhood cancer, problems with parent-child relationships, post-traumatic stress symptoms, anxiety, and communication and spousal tensions. Barakat and colleagues (Barakat et al., 1997) examined parents of children with cancer and found these parents had higher post-traumatic stress symptoms (PTSS) compared to peers with healthy children. In a related study, Bruce and colleagues (Bruce, Gumley, Isham, Fearon, & Phipps, 2011) examined PTSS in children who survived childhood brain tumors and in their parents and found that 35% of survivors and 29% of parents reported severe levels of PTSS. In another study of stress in parents of children with cancer, Kazak and Barakat (1997) found that higher levels of stress related to parenting during treatment were related to higher levels of anxiety in both mothers and fathers. In a similar study, Chesney and Chesler (1996) found that parents of children with cancer report feeling inadequate as caregivers and blame themselves for the child's illness. In a recent study of cancer-related stressors for children with cancer and their parents, Rodriguez and colleagues (Rodriguez et al., 2012) administered questionnaires to parents of children with cancer between the ages of 5-17, and children between 10-17 years old completed these questionnaires themselves. A total of 290 parents and 106 children completed the questionnaires. Participants answered questions regarding their demographic and the child's medical information, cancer-related stressors, perceived stress, and post-traumatic stress symptoms. Results indicated that parents felt that cancer caregiving was the biggest stressor they were facing. Forty-one percent of mothers and 30% of fathers had PTSS scores at the clinical cutoff to predict PTSD.

According to Chesler and Barbarin (1987), emotional stress included shock, denial, anger, and fear. Children with cancer undergo numerous invasive medical procedures. The experience of undergoing these procedures can be classified into both the interpersonal stress as well as the emotional stress category. Children with cancer often experience years of intensive treatment and undergo frequent and painful medical procedures. Treatment includes repeated needle sticks, both intravenous and through a medi-port, lumbar punctures, bone marrow aspirations, and intramuscular injections. Children with cancer and their parents have reported that the treatment for cancer is worse than the disease itself (Hedstrom, Haglund, Skolin, & von Essen, 2003; Ljungman et al., 1999). Treatment often takes place over several months to several years, and repeated distress during medical procedures may affect treatment adherence and have serious implications for long-term psychosocial well-being (Barakat, et al., 1997; Stuber et al., 1997). Therefore, managing distress during medical procedures for children with cancer should be a priority for parents and medical professionals (Walco, Sterling, Conte, & Engel, 1999). The last type of stressor identified by Chesler and Barbarin (1987) is existential stress and includes parent confusion as to why the child developed cancer and questions about spirituality. Chesler and Barbarin point out that while this type of stress is draining, many families find that they become more resilient, having "gotten through" cancer and its treatment with their children.

A diagnosis of childhood cancer can undoubtedly place a great deal of strain on a family and cause a large amount of stress. Research has shown that families of children diagnosed with cancer face stress associated with information-seeking and decision-making, financial strain, issues with time management, strained family relationships, anxiety, PTSS, and fear. Parents shoulder most of this burden, and the next section will focus specifically on the impact of childhood cancer on parents.

The Impact of Pediatric Cancer on Parents

Gender. Most studies on parental reactions to and experiences with childhood cancer have focused on the mother; however, a few have incorporated fathers as well. Men and women differ in self-report measures of depression, anxiety, and psychosomatic problems (Davis, Matthews, & Twamley, 1999; Nolen-Hoeksema, 2001). Men and women react to stressful events differently, including those issues related to chronic illness and parenting (Clements, Copeland, & Loftus, 1990; Mastroyannopoulou, Stellard, Lewis, & Lenton, 1997). In addition to mothers and fathers varying in their response to a child's illness, the diagnosis and ongoing treatment of childhood cancer causes significant emotional upheaval for parents (McCubbin, Balling, Possin, Frierdich, & Bryne, 2002) and can disrupt family functioning (Martin, et al., 2012). In a study of communication, gender-role conflict, and social support, Hall (2010) gave questionnaires to 22 mother-father pairs who were participating at a survivorship event. The questionnaires asked about communication competence, emotional and instrumental support, gender-role conflict, state anxiety, and the child's treatment history. Findings indicated that more effective communication was related to higher satisfaction with emotional and instrumental support. Hall also found that fathers are able to reduce their anxiety by focusing on work.

The literature supports the notion that fathers and mothers may experience distress differently. Bonner and colleagues (Bonner, Hardy, Willard, & Hutchinson, 2007) examined the psychological functioning of parents who were the primary caregivers of children with cancer. Questionnaires were given to 23 fathers and 23 mothers of children with cancer that asked about their psychosocial well-being in relation to having a child with cancer. Results indicated that fathers reported more depressive symptoms than mothers, but there were no other differences between groups. One sociological finding of that study is that unmarried fathers who were the primary caregivers were more at risk for depression than fathers who were married. In their review of the literature examining gender differences in the psychosocial experiences of parents of children with cancer, Clarke and colleagues (Clarke, McCarthy, Downie, Ashley, & Anderson, 2009) found that mothers and fathers utilize different coping strategies in dealing with their child's cancer. The researchers conducted a search in four databases, and ultimately 30 papers were included in the review. In reviewing the literature Clarke and colleagues found that mothers appear to use more emotion-focused coping strategies (social support-seeking and information-seeking) while fathers use more problem-focused strategies. They also found that mothers reported a need to become tougher for the child and their family while fathers felt the need to focus on problem-solving. The same study found that mothers report using support-seeking strategies more frequently than fathers and that mothers report receiving more social support, especially emotional support, from family and extended networks. Another qualitative study of 16 fathers of children aged 1-17 receiving cancer treatment found that fathers are at emotional risk for depression, anxiety, and distress and are in need of supportive resources (Nicholas et al., 2009). In a related study, Wijnberg-Williams and colleagues (Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006) asked 162 parents (79 fathers and 85 mothers) of children with cancer to complete questionnaires two weeks after diagnosis, at six and twelve months post-diagnosis, and again at five years post-diagnosis. Questionnaires included questions on psychological distress and a measure of social support. Wjinberg-Williams and colleagues found no differences between mothers and fathers on the measure of distress but did find that fathers who were dissatisfied with social support had higher ratings of distress.

A child’s being diagnosed with cancer can be devastating and heartbreaking for families. Families are faced with questions that have no answers and fears that cannot be easily assuaged. Research shows that men and women handle the stress of childhood cancer differently and may need different forms of support at different times through the course of the child’s treatment. As stated earlier, children and their parents report that treatment is the worst thing about having cancer, and the next section will examine how parents may influence child reactions to treatment procedures.

Parent Influence on Child Reactions to Treatment Procedures.

Little research has addressed parent-child communication during painful medical procedures, and there are fewer studies in an oncology setting. The literature suggests that distress and pain do not decrease as the child experiences more procedures and could worsen in subsequent procedures if the child’s negative responses to treatment-related procedures are not addressed (Katz, Kellerman, & Siegel, 1980; Zeltzer et al., 1990). Previous research suggests that the behavior of medical staff and parents is associated with the child’s coping and distress during medical procedures. Several researchers have investigated the effects of parent behavior on children’s reactions to treatment procedures and found that parent behavior does influence how children react during these medical procedures. Blount and colleagues (Blount, Landolf-Fritsche, Powers, & Sturges, 1991) examined parent-child interactions during bone marrow aspiration or lumbar puncture procedures in 22 families of children with cancer. A trained observer was present during the child's medical procedure and rated the child's coping behaviors. Audiotapes of the interactions were transcribed and scored using the Child-Adult Medical Procedure Interaction Scale (CAMPIS) coding system, which includes codes for child procedure-related distress, a child's coping, and other child behaviors. The CAMPIS scale was designed to capture parent, child, and medical professional behaviors during a child's medical procedure. The scale measures who did the behavior, who the behavior was directed toward, and what the behavior was (i.e., humor, verbal pain, praise) (Blount et al., 1997). Results indicated that children who were high in coping scores had adults present who distracted them or coached them in the use of coping skills. Children who were low in coping scores had adults present who displayed more distress-promoting behaviors. In their review of the literature of caring for a child with cancer, Vance & Eiser (2004) reported that during medical procedures parents who were responsive and nurturing had fewer adherence issues with their children.

Manimala and colleagues (Manimala, Blount, & Cohen, 2000) examined the interactions of 82 children, their parents, and four nurses performing routine immunizations. Immunizations were video-recorded, and transcripts of the recordings were used to apply the CAMPIS (Blount et al., 1997) coding system. Before the immunization, parents were asked to indicate how upset they expected to be during the procedure and how well they thought they could help the child deal with the procedure. Before the immunization, children rated their fear using a FACES Scale, a six-item scale with faces at each point that progressively look more distressed (from 0-very happy/no distress to 5-the worst distress). After the immunization, parents were asked how upset they were during the child's immunization. Half of the families were assigned to a distraction manipulation in which parents were told that the child would be more afraid and distressed if the child were focused on the shot and would be less so if the child was focused on some distracting activity. The other half of families were assigned to a reassurance group and were told to reassure and comfort the child and that this would reduce the fear, anxiety, and distress the child experienced. The investigators found that children who were reassured needed to be restrained more often and exhibited more fear than children who were distracted. The authors argued that reassurance could often be ineffective because parents are unable to mask their own distress and anxiety when attempting to reassure their children during medical procedures and children can pick up on parental anxiety and fear.

In a related and more recent study, Bearden and colleagues (Bearden, Feinstein, & Cohen, 2012) examined the role of parent pre-procedure anxiety on child procedural anxiety during immunizations. Ninety children between the ages of four and six years old and their parents were the subjects of the study. Parents self-reported their state anxiety prior to the child's immunization, and parents, nurses and children reported on the child's procedural anxiety and pain immediately after the immunization. Results indicated that parents' pre-procedure anxiety was related to increased child procedure anxiety, which appears to increase ratings of child pain during procedures. Like Manimala and colleagues (Manimala et al., 2000), the authors argue that parents are likely communicating their own anxiety and distress to the child without intending to. In a similar study, McMurtry and colleagues (McMurtry, Chambers, McGrath, & Asp, 2010) recruited 100 children between the ages of five and ten years old who were having blood drawn in an outpatient laboratory and their parents. Children and parents were video-recorded during the blood draw, and an observer was present in the room to code parent and child behaviors using the CAMPIS scale. After the procedure, children rated the intensity of their parents' fear and happiness during the procedure using the emotional intensity scale (Wang, 2003). Children also watched short vignettes of their parents spontaneously offering reassurance and attempting to distract the child during the procedure, and children rated the amount of happiness and fear they felt the parents were feeling during each video clip. Results indicated that children were more likely to rate parents as afraid when they offered reassurance than when they attempted to distract the child. This investigation did not assess child distress but did provide evidence that children perceived parental reassurance as an indicator of parental fear. In another study examining the relationship between adult behavior and child coping and distress during venipuncture, Mahoney and colleagues (Mahoney, Ayers, & Seddon, 2010) video-recorded 50 children ages 7-16 years old undergoing a venipuncture and used the CAMPIS coding system to code and analyze the video-recordings. Children were also asked to indicate how anxious they were before the procedure. Results indicated that nurse behavior had a stronger correlation with child coping and that parent behavior was more strongly associated with child distress behaviors.

Studies of children's distress in the pediatric cancer context have focused on managing and easing distress by means of promoting active coping and offering reassurance (Dahlquist, Power, & Carlson, 1995; Dahlquist, Power, Cox, & Fernbach, 1994; LaMontagne, Wells, Hepworth, Johnson, & Manes, 1999). Manne et al. (1992) examined the adult-child interaction for 43 children between three and ten years old in treatment for cancer, their parents and medical staff performing the procedures. Manne and colleagues video-recorded children undergoing cancer-related medical procedures and used an adapted version of the Procedure Behavior Rating Scale and also used the CAMPIS coding system to code the interactions. Results showed that during invasive medical procedures, adults (parents and medical staff) had more influence on child coping than on child distress. In this study child coping was defined as attempts by the child to soothe himself/herself verbally, by deep breathing, or by attempting to distract himself or herself. Child distress was coded as crying, screaming, protesting, not complying with treatment procedures, and asking that the procedure be stopped. Blount and colleagues (Blount et al., 1989) observed 22 children between the ages of five and thirteen undergoing cancer-related medical procedures. Results indicated that adults promote specific child coping behaviors during medical procedures and these behaviors are related to adult coping behaviors. The authors suggest that children and adults adjust coping strategies in response to the varying demands of the clinic visit. The authors divided the clinic visit into phases and found that child distress type and severity varied across phases. They identified two types of distress, apprehensive and demonstrative. Apprehensive distress occurred when the child requested emotional support, sought information, and expressed fear verbally. Demonstrative distress occurred when the child cried, screamed, resisted the procedure, or expressed pain or emotion. Children in this study exhibited apprehensive distress most often in anticipation of the procedure and during the pre-procedure phase. Children exhibited demonstrative distress in response to the medical procedure (i.e., during the actual procedure phase). In a similar study, Dahlquist et al. (1995) argued that child distress during the procedure phase reflects pain and anxiety while child distress during the pre-procedure phase (anticipatory phase) reflects only child anxiety. Dahlquist et al. (1995) examined the impact of parent behavior during pediatric cancer procedures on child distress. The authors coded adult behaviors, including praise, criticism, reassurance, and nonprocedural talk. Child distress was determined by coding behaviors that represent verbal, vocal, and nonverbal indicators of children's distress. The study used sequential analysis to determine the sequencing of parent behavior and child distress. The authors found that parents affect children's distress by communicating their own anxiety and reinforcing child distress behaviors when the child becomes upset. Another study by the same lead author found that older children became more distressed when parents gave information and offered reassurance during the procedure (Dahlquist et al., 1994). The authors argued that parents are often anxious and agitated during treatment procedures and provide ineffective reassurance to their children. They authors also argue that parent emotional states could influence child distress through parental modeling of distress and/or by reinforcement of child distress behaviors.

Penner et al. (2008) and Harper et al. (Harper, Penner, Peterson, Albrecht, & Taub, 2012) both examined video-recordings and self-report data from 41 children between the ages of three and twelve and their parent(s). Video-recordings were taken from a routine cancer-related medical procedure. Penner et al. (2008) used data on parent trait anxiety, resilience, positive and negative emotions, social support, and state anxiety, personal distress and empathic concern on the day of treatment. In Dr. Harper's study, parents completed measures of child resilience and child temperament and for themselves they completed measures of their empathic affective responses to treatment before the procedure (empathic concern and state anxiety). In both studies, immediately after the procedure, children rated their own pain and parents, nurses and independent observers rated the child's pain and distress. Penner et al. found that parents who reported more empathic concern before the procedure had children who reported (and/or were rated as having) less procedure-related pain/distress. Harper et al. found that parents who had more positive empathic affective reactions to treatment procedures had children who experienced less pain/distress during their medical procedure.

In a review of practices to manage painful procedures for children with cancer, Hockenberry et al. (2011) point to the use of cognitive and behavioral interventions to distract children during procedures. Such interventions include using music, story telling, relaxation, guided imagery, and massage. In a review of interventions during pediatric cancer-related medical procedures, Kuppenheimer and Brown (2002) identified cognitive and behavioral therapies as effective in the management of distress by increasing children's sense of mastery over repeated exposure to a stressful situation. Dahlquist and colleagues (Dahlquist et al., 2002) conducted a nine-session intervention with six children between the ages of two and eight who were undergoing a port start, a venipuncture or an intramuscular injection. The children were given a V-Tech electronic toy to play with during each of their procedures as a method of distraction. Child heart rate was monitored before, during, and after the procedure using a portable electrocardiogram event recorder, and the parent-child interaction and the medical procedure were video-recorded. Observers rated the video recordings for child procedure-related distress, parents and nurses rated the child's fear before the procedure, parents rated their own level of distress during the procedure, and nurses rated the child's cooperation. Results indicated that the majority of children (five of six) had significant reductions in distress by using the toy for distraction during the procedure. Nurses reported that most of the children (four of six) were more cooperative when using the toy to distract themselves, and parents rated the children as less anxious before the procedure. Three of the children had lower heart rates during the distraction activity as well. Although parents were not the target of the intervention, parents whose children had less distress reported less distress themselves during the procedure. This study only had six participants, so findings should be considered in light of the small sample size.

One distraction method that could be used is art-making, and in a study of the use of art therapy during procedures, Favara-Scacco and colleagues (Favara-Scacco, Smirne, Schiliro, & Di Catalso, 2001) enrolled 32 children between the ages of two and fourteen to participate in either visual imaginative play, medical play, structured drawing, redundant reading, free drawing, or dramatization during their medical procedures. Their behavior before, during and after was observed for cooperation, compliance with the procedure and anxiety. When compared to a same age control, children in the art therapy group showed significantly more positive behaviors during the procedure than children in the control group. Children in the art therapy group also exhibited less anxiety before and during the procedure.

Research indicates that parents, as well as medical staff, influence how children behave during, and react to, cancer treatment-related medical procedures. Distracting children before and during procedures has been shown to reduce both parent and child distress during procedures. Parents who are anxious during procedures have children who are also anxious during procedures and parents can influence their children's coping behavior. Studies also show that child distress varies over the course of the clinic visit, which argues for the need to break the clinic visit into procedure phases. Now that I have outlined how parent behavior influences child reactions to treatment, I would like to discuss social support, first broadly, then specifically in this context. I will then discuss how parent social support may affect how children cope with cancer-related medical procedures. Previous research indicates that parent behavior affects child reactions during treatments; the next step is to examine if parent social support can affect how children react to treatments.

Review of the Social Support Literature

Several related but differing definitions exist for social support. Pearlin and colleagues (Pearlin et al., 1981) defined social support as the "access to and use of individuals, groups, or organizations in dealing with life's vicissitudes" (p. 340). Albrecht and Adelman (1987) defined social support as the verbal and nonverbal communication that helps manage uncertainty about a situation, the self, another, or a relationship and functions to enhance a perception of personal control. Cutrona & Russell (1990) described social support as "emotional support, the provision of aid and security during times of stress that leads a person to feel s/he is cared for by others" (p. 322). Several definitions exist for social support, but all seem to relate social support to social networks and social integration. In their review of the research on social relationships and health, Umberson and Montez (2010) argued that social ties influence health outcomes including mental and physical health, health behaviors, and mortality risk. They point to the development of interventions to strengthen social ties as a possible policy direction to improve short and longer-term health outcomes. The major policy goals they identify include: (1) promoting the benefits of strong social ties, (2) avoiding policies, interventions and programs that increase relationship burdens or undermine the positive aspects of relationships, (3) reducing social isolation, (4) reducing the negative effects of social ties, (5) coordinating related policies and programs, and (6) providing assistance and interventions where it is most needed and for groups who are most at risk.

A large body of literature suggests that social support is protective and can buffer the deleterious effects of stressful events as well as enhance physical and emotional well-being (Garwick, Patterson, Bennett, & Blum, 1998; Lynam, 1987; Thoits, 2010; Umberson & Montez, 2010). The buffering hypothesis states that "individuals with a strong social support system should be better able to cope with major life changes, those with little or no social support may be more vulnerable to life changes" (Thoits, 1982). In her review of the sociological stress literature, Thoits outlined how the provision of social support can reduce or buffer the impact of stressors on health and well-being (discussed earlier in the literature review). Social support researchers have argued that most of the positive health effects of social support are due to the buffering properties in the presence of stress (Caplan, 1974; Cassel, 1976; Cobb, 1976). House, Umberson, and Landis (1988) argued that the buffering effects are most evident in relation to a strong stressor.

Berkman and Syme's (1979) influential study of social connections and health found that people who were less socially connected had higher mortality rates than those who were more socially connected. This work provided the most compelling evidence at the time linking social relationships and mortality. In their study they used data from 4725 adults who participated in a study by The Human Population Laboratory of the California State Department of Health in 1965. More recent epidemiological work has found that people with low levels of social support have higher mortality rates (Holt-Lunstad, Smith, & Layton, 2010; Rutledge et al., 2004; Untas et al., 2011). More recently, Segrin and colleagues (Segrin, Burke, & Dunivan, 2012) recruited 456 individuals from 169 families to complete questionnaires measuring loneliness, general health, physical symptoms, and social networks. Results indicated that loneliness was positively related to negative physical symptoms and general health. They also found that the more family members a participant reported resided in the same community, the lower their likelihood of being lonely and that support from family and friends was negatively related to loneliness.

Not only has social support been linked to mortality but social support is a key component in the long-term adjustment that families make when going through the childhood cancer process (Barakat et al., 1997). In a study of 191 parents of children with cancer examining the receipt of social support, Hobfoll and Lerman (1989) interviewed mothers and fathers of children undergoing cancer treatment at the Belinson Medical Center in Petah Tiqva, Israel. Parents were asked questions regarding their personal coping resources including self-esteem and mastery, intimacy with a spouse/partner, support-seeking behavior, and social support received. Results indicated that mothers who possessed personal/social resources and were comfortable seeking help were able to utilize support reservoirs and felt that having those resources alone would ensure support. Simply, having access to support helped the mothers to feel supported, even if they never needed to call upon anyone for support.

Families of children with chronic health conditions who receive support from health care professionals and institutions, as well as from community members and family, have better access to resources that can improve family functioning (Farmer, Marien, Clark, Sherman, & Selva, 2004). Jackson and colleagues (Jackson et al., 2009) examined the role of social support in family coping by conducting semi-structured interviews with 88 parents of children with cancer at four points in time (at diagnosis, 6 months after diagnosis, 12 months after diagnosis and two years post-diagnosis). Parents were asked questions regarding social support, problem-solving and coping, family adaptability, cohesion, and crisis. Parents were also asked two open-ended questions: (1) “How has your experience with the hospital been so far?” and (2) “Is there anything else you would like to tell us about your family’s experiences since your child was diagnosed with a brain tumor?” The researchers found that different types of support are needed at different points in the illness experience. Parents in this study identified support from the hospital (informational support) and family and friends (emotional) to be effective in the coping process.

The presence or absence of social support may have a different effect on mothers and fathers. Katz (2002) examined gender differences in in adapting to a child’s chronic illness by administering questionnaires to both parents of children with a chronic illness. Questionnaires included measures of socioeconomic status and illness history, life events, self-esteem, social support, impact of the child’s chronic illness on the parent, marital adjustment, and father’s involvement in the care of child. Results indicated that the provision of social support has a greater impact on coping in fathers than in mothers because fathers have difficulty locating support; so when it is available, fathers benefit more from the support. Brody and Simmons (2007) examined the father's perspective of family resiliency during childhood cancer by interviewing eight fathers of children ages 4-16 in treatment for cancer. Interviews were qualitative in nature and broadly asked about the experience of diagnosis, interactions with medical professionals, support from family, community and workplace, changing relationships with family members, challenges, how the father has changed since diagnosis, and what advice he would give to other families. Results indicated social support played an important role in resilience for fathers, who reported obtaining support from medical staff, family, church, the community, and their workplace. Brody and Simmons also found that when fathers used social support in conjunction with constructive communication patterns (straightforward, positive, reassuring to the child, answering child's questions), they were more resilient and better able to adjust to the changes in family life.

In a related study, Wijnberg-Williams and colleagues (Wijnberg-Williams et al., 2006) conducted a longitudinal study with 162 parents of children with cancer examining psychological distress and social support both during treatment and five years post-diagnosis. They found that five years after diagnosis higher levels of dissatisfaction with current social support was related to higher levels of distress. They also found at follow-up that fathers who were less effective at mobilizing support continued to experience psychological distress. Additionally, the quality of support was more important than quantity of support in fathers. In another study looking at both fathers and mothers, Bayat and colleagues (Bayat, Erdem, & Gul Kuzucu, 2008) distributed questionnaires to 94 parents (50% were mothers) of children with cancer that asked about depression, state and trait anxiety, hopelessness, and social support. Results indicated that for both mothers and fathers there was a weak negative association between social support and depression, and mothers reported more anxiety and feelings of hopelessness than fathers. In a similar study examining social support in parents of children with cancer at a Swedish hospital, Norberg et al. (Norberg, Lindblad, & Boman, 2006) gave questionnaires to 184 parents (81 fathers and 103 mothers) asking about social support, support-seeking behaviors, and anxiety. Results showed that social support and support-seeking behaviors were negatively related to anxiety for both mothers and fathers and that mothers were more likely to use support-seeking behaviors than fathers.

Mothers and fathers differ in how they seek support and in what impact support has on distress, anxiety, and coping. Previous research indicates that social support has a greater impact on resilience and coping for fathers than for mothers and that the quality of support is more important for fathers than the quantity of support providers. For both parents, satisfaction with social support is related to decreased distress. To this point social support has been examined broadly, and the next section is going to discuss distinct types of social support.

Krause (1986) argued that specific forms of support need to be examined in relation to specific stressors. Four main types of social support have been identified in the literature (Brock & Lawrence, 2009). The first, emotional support, is the most prevalent and involves physical comfort as well as empathy. The second type of social support is esteem support and is provided through expressions of confidence or encouragement. The third type of social support is information support, which is the provision of information or advice. The fourth type of social support is tangible support, which includes active assistance in problem-solving. Research on social support has shown that social support functions in complex ways.

Previous research using video-recordings of children undergoing cancer-related medical procedures and their parents provides evidence that social support on days of clinic visits is associated with parent-child communication behavior during treatment episodes. Peterson and colleagues (Peterson et al., 2006) investigated the impact of having more than one parent (not always a parent, sometimes aunt or grandmother) present during a medical procedure on parents' touch behavior during procedures. Video-recorded interactions of children undergoing cancer-related medical procedures and their caregivers were analyzed for touch behaviors. Touch was coded continuously in real time into one of two categories: instrumental or supportive touch. Instrumental touch consisted of touch associated with performing a task, for example, helping the child lift his/her shirt, helping the child climb onto the bed, or forcefully restraining the child. Supportive touch was defined as potentially comforting or emotionally supportive touch or, more generally, touch that may indicate to the child that s/he is not alone. Some examples of supportive touch included holding hands, rubbing the child's arm, having the child sit on the parent's lap, or hugging the child. In nine of 29 cases, multiple caregivers attended treatment procedures with the child. Results indicated that children with more than one parent present experienced significantly more supportive touch than did those with solo parents. While these children experienced more supportive touch, it was not from the second parent but from the primary parent. This finding suggested that the presence of the second caregiver might function to provide social support to the primary caregiver who in turn is able to provide enhanced nonverbal support to the child. Having a second parent present during a child's medical procedure may benefit both the child and the primary parent.

Using the same data as Peterson et al. (2006), Penner and colleagues (Penner et al., 2008) examined the self-report data from 41 primary caregivers of children with cancer. Caregivers completed measures satisfaction with social support, trait and state anxiety, positive and negative emotions, resilience, personal distress, and empathic concern. Penner et al. found that satisfaction with social support was negatively related to negative emotions and trait anxiety and positively related to positive emotions and resilience. They also found that satisfaction with social support was positively related to parent state empathic concern and negatively related to negative emotions, state anxiety, and personal distress during clinic visits.

Previous work by this investigator and colleagues in the same context has laid the groundwork in establishing the importance of social support in the context of childhood cancer treatment procedures. The next step is to determine the relationship between parent support, parent and child communication during treatment episodes, and parent and child reactions to treatment procedures.

The previous section discussed how social support could have a buffering effect to help people cope with stress and negative life events. There are several different types of support, and support needs vary over the course of childhood cancer treatment. Parents may need more or less support at different times over the course of a child’s treatment and may need different forms of support at different times. Mothers and fathers differ in the forms of social support they find helpful and the effect social support has on coping (fathers benefit more from support than mothers). In the previous sections I outlined the sociological study of stress, how childhood cancer is a stressor, the impact of childhood cancer on parents, parent and child communication during treatment procedures, and social support. Distilling what has been examined and what has not, the next section will discuss gaps in the literature.

Gaps in the Literature

This research addresses two major gaps in the literature. First, while social support and coping in families of children with cancer has been examined (Jackson et al., 2009) as well as family functioning (Farmer et al., 2004), social support in the specific context of pediatric cancer-related treatment procedures has not been examined. While several researchers have examined social support in this context, no studies could be identified that specifically examine social support and its relationship to parent and child reactions to medical procedures. It will be valuable to determine if social support can have an effect on a specific, and repeated, stressor like a child's medical procedure.

Second, observational data are rare and valuable in the examination of parent-child interactions during cancer-related medical procedures. In the many studies examined for this dissertation research, few used video-recorded data. Several other studies used observational data, collected by a researcher in the room with the family, who rated the observed behavior on a scale. The presence of a researcher in the room while a child is undergoing a medical procedure could influence participant behavior and impact the nature of the interaction. Also, the ability to review interactions and code the behavior repeatedly increases the reliability and validity of the coding. Riddle and colleagues (Riddle et al., 2002) found that using video-recorded interaction data, versus audio-recorded, led to a more robust understanding of the interaction between oncologists and their patients. Video-recorded data are also important in achieving greater inter-rater reliability, which would only otherwise be possible if two research assistants were present during each interaction.

This research will address two major gaps in the literature, the lack of research examining the role of social support in buffering the negative reactions parents and children have to medical procedures and the novel use of video-recordings during the child's medical procedure. The next section will discuss the theoretical framework for this study.

Theoretical Framework

Theory. Pearlin and colleagues (Pearlin et al., 1981) developed a sociological theory of the stress process where they outlined the relationships between the sources of stress, the mediators of stress, and the manifestations of stress. The mediators of stress, or what Thoits refers to as the buffers of stress, are the resources (social support, resilience) that can decrease (or increase) the effect the stressor has on an individual (Lackey, 2008). The manifestations of stress are the emotional or physiological reactions to stress (i.e., high blood pressure, anxiety, distress) (Lackey, 2008). Pearlin and colleagues argued that well being is affected by societal structures and individuals' repeated life experiences. They argued that the stress process and related concepts are derived from and are influenced by societal influences and that these influences determine the stressors people experience, the mediators they are able to call upon, and the ways in which they experience stress.

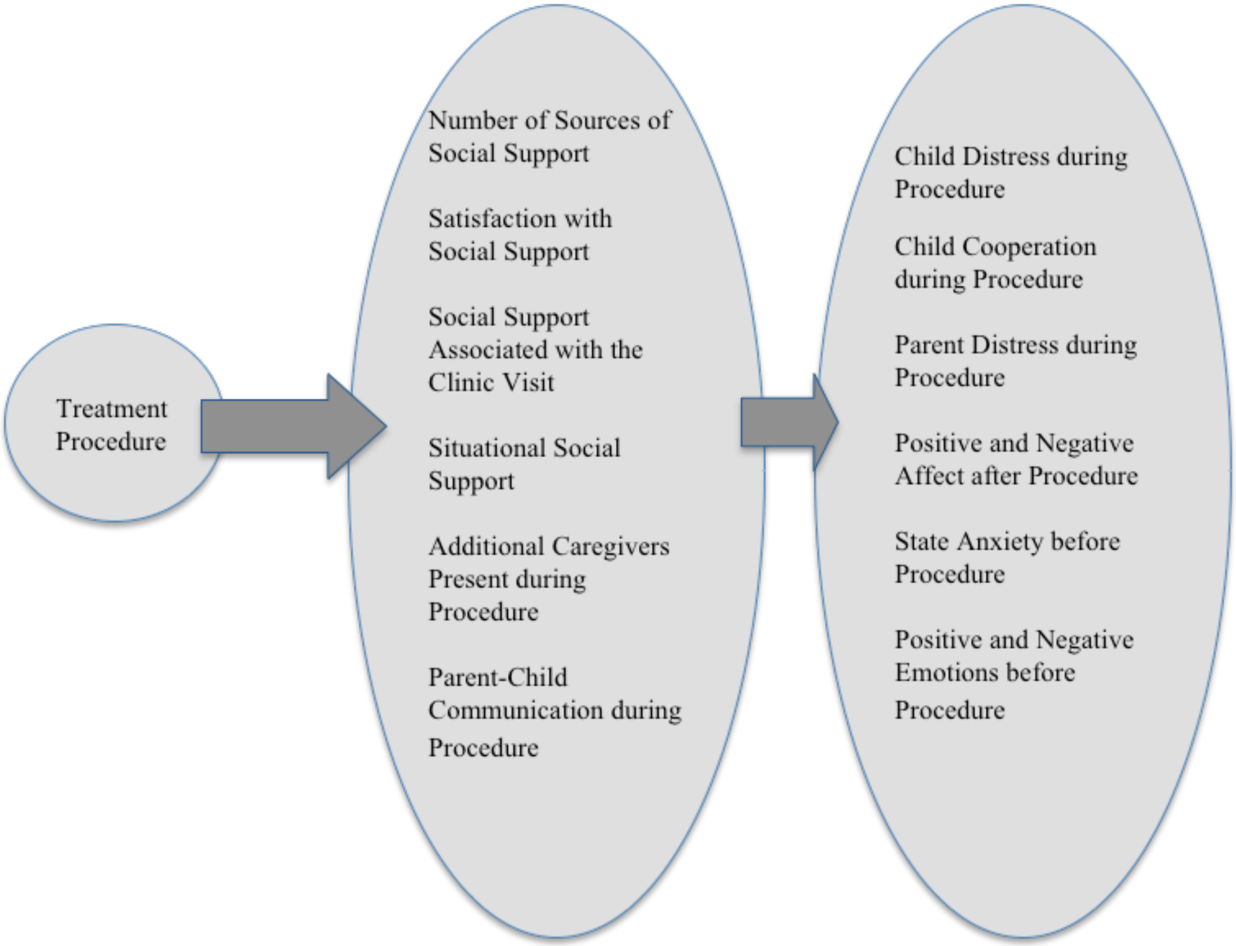
In the theoretical model for this dissertation research, the source of stress for the participants is the child's cancer-related medical procedure.

The mediators of stress in this model are the social support resources available to the parent and the parent-child communication during the procedure. These will be analyzed separately. Measures of social support include the number of sources of social support and the caregiver's satisfaction with that number (Sarason, Levine, Basham, & Sarason, 1983), whether or not more than one caregiver was present for the treatment session, parent satisfaction with social support associated with the clinic visit, situation specific social support (Zimet, Dahlem, Zimet, & Farley, 1988), and the parent-child communication during the video-recorded interaction. Extensive evidence is available that points to the buffering effects of social support in diminishing the negative effects of stressful events or situations (Thoits, 2010). In this context, the social support resources available to a caregiver will mediate the negative effects of the stressful event of the child's cancer-related medical procedure.

The manifestations of stress for this research are measured at different points and include (1) parent emotional response to treatment procedures (Batson, 1991) and state anxiety (Spielberger, 1977) before the procedure, (2) child distress and cooperation during the procedure, (3) caregiver distress during the procedure, and (4) parent positive and negative affect (Watson, Clark, & Tellegen, 1988) immediately after the procedure.

Figure 1. A Model of Social Support, Parent-Child Communication and Parent and Child Reactions to Treatment Procedures.

Source of Stress	Mediators of Stress	Manifestations of Stress



Hypothesis 1: Parent self-reported social support will be related to parent and child reactions to treatment procedures. When parent self-reported social support is greater, reactions to treatment will be less distressing for both the parent and the child and the child will be more likely to cooperate during the procedure.

Hypothesis 2: Parent and child communication during the procedure will be related to parent and child reactions to treatment sessions. Parents who communicate in a supportive manner, as opposed to an invalidating manner, will have more positive reactions to treatment and have children who have more positive reactions to treatment procedures.

Hypothesis 3: If both parent-child communication and social support are related to parent and child reactions to treatment, it would stand to reason that there is a relationship between parent social support and the communication occurring during treatment episodes. When parent self-reported social support is greater, parents and children will be more likely to communicate in a supportive manner, as opposed to in an invalidating manner.

Although the success rate for childhood cancer treatment is high, the frequent and painful medical procedures associated with treatment are distressing for both children and their parents. Social support has the potential to buffer the negative distressing effects of treatment-related procedures. This study seeks to examine the relationships between social support, parent and child communication during treatment procedures, and parent and child reactions to the treatment procedures. Chapter Three will describe the methods used for this dissertation research.

CHAPTER 3

Methodology

The aim of this dissertation study was to examine the relationships between parent and child reactions to the child's cancer-related treatment procedure, social support and parent and child communication during these procedures. This chapter will describe the research methodology used for this research. This study utilized data collected as part of an ongoing National Cancer Institute-funded study (R01CA138981-05 and The Herrick Foundation, PI: L.A. Penner). The Penner et al. study investigates the relationship between resources, parent-child communication and adjustment to childhood cancer. This dissertation research was funded by Blue Cross Blue Shield of Michigan Foundation, Student Award Grant #1801-SAP and the National Science Foundation, Dissertation Improvement Grant #1068218.

Method

Eligibility Criteria. All children receiving cancer treatment-related medical procedures at Children's Hospital of Michigan and St. Jude's Children's Research Hospital and their adult caregiver (also referred to as "parent") were eligible for the Penner et al. study if (a) the child was between the ages of three and twelve; (b) the parent and child were able to speak and the parent could read English; (c) the child had been diagnosed with cancer within the last 18 months, and (d) as part of treatment the child experienced port starts (PS), lumbar punctures (LP) or bone marrow aspirations (BMA). While children with cancer typically experience several forms of cancer treatment, and many different medical procedures, for the purposes of the Penner et al. study, only children who experienced these three procedures were eligible for the study. A lumbar puncture (LP), or spinal tap, is performed to check the spinal fluid for cancer cells and to deliver chemotherapy directly into the spinal fluid. When an LP is performed the child will have a needle inserted in his/her back, along the spine, just below the waist. LPs are painful, even though a topical anesthetic is used at the needle insertion site. A bone marrow aspiration (BMA) is conducted to check for cancer cells in the bone marrow. A long, rather wide needle is inserted into the child’s hip and a sample of liquid bone marrow is taken and analyzed for the presence of cancer cells. BMAs are more painful than LPs and it is the practice, at both study sites, that during LPs and BMAs the child is sedated. The other procedure in this study is a port start. A port is a surgically implanted device that is most often located on the child’s chest. Under the skin there is a small tube that leads to the heart and by accessing the port to draw blood or deliver chemotherapy, instead of using a needle in an arm or hand, nurses are able to decrease the number of needle sticks a child experiences and it lessens the chances of the chemotherapy drugs burning the skin. The port is surgically implanted and used for several months to several years. For this study, video-recordings of the port being accessed to draw blood or deliver chemotherapy were used. Children younger than age 3 were excluded due to concerns about their ability to self-report about treatment-related distress. Children older than 12 were excluded due to concerns that maturational changes (e.g., puberty) might create confounds in the data. Non-English speaking children, parents, and staff were excluded due to a lack of resources to employ bilingual interviewers and coders. No children or parents were excluded on the basis of gender, race, or ethnicity.

Recruitment Procedures. When recruiting for the Penner et al. study, in accordance with HIPAA guidelines, the medical team identified potentially eligible children to a research assistant before or during a child’s regularly scheduled visit. The medical staff member first asked the parent or guardian if they would be willing to talk to a researcher about a study. If interested, the parent was approached by a research assistant and provided a brief description of the study. Parents who agreed to participate signed a written consent form, and verbal assent was obtained from the child. Data for the Penner et al. study was collected at six points in time. The initial data collection (baseline) with the child and his/her primary caregiver occurred a few weeks prior to a scheduled treatment session. The parent completed a battery of questionnaires including several measures used for this dissertation study (demographic and child medical history items and the Social Support Questionnaire). On the day of the child's scheduled cancer treatment, the procedure was video-recorded (as detailed below). Prior to the treatment-related medical procedure, parents completed several questionnaires, including the measures used in this dissertation research (situational social support, positive and negative emotions, state anxiety and social support related to that days' clinic visit). Immediately following the treatment episode, the caregiver, the nurse administering the procedure, and the child rated the child's distress; the nurse and parent rated the child's cooperation during the treatment episode; and parents rated their own distress during the treatment episode. Additionally, trained, objective coders rated child procedure-related distress and cooperation using the video-recordings. After the procedure, parents also completed an additional post-treatment questionnaire that included the Positive and Negative Affect Scale. Up to three individual treatment-related procedures were recorded for each family. The treatment-related procedures occurred on different days at least two weeks, and up to three months, apart. Children had been in treatment for at least one month before enrolling in the Penner et al. study, so they had already undergone a number of procedures before they were video-recorded for the study. For the purposes of this dissertation research, only the first treatment episode for each family was analyzed.

Video-recordings. Research assistants video-recorded treatment episodes in their entirety (before, during, and after treatment procedures) using equipment specifically developed for the

Penner et al. study. This system, which has been demonstrated to be non-intrusive (Albrecht et al., 2005; Penner et al., 2007; Riddle et al., 2002) featured a remote-controlled, portable system with digital processing technology that allowed simultaneous recording of the child, parent(s), and medical professionals (Albrecht et al., 2005). The system included high-resolution, digital video cameras with wide-angle lenses housed in boxes or domes, external microphones, and remote monitoring and recording capabilities. Camera units were mounted on shelves in the exam rooms or placed in the ceilings of surgical procedure rooms and were plugged into pre-wired wall jacks. Research assistants remotely monitored (in real time) activity from a private, secure site in the hospital. Camera angles were controlled using a touch panel/LCD monitor and directed to pan, tilt, and/or zoom as necessary to capture movement in the room. The signal was recorded onto miniDV format tapes, edited using an HP XW8000 workstation with Apple Final Cut Pro software. Resulting files were converted to MPEG2 formats and loaded onto DVDs for subsequent coding.

Data sources. Data from the Penner et al. study used in this dissertation include two sources: (1) self-report data (child and parent socio-demographic information, parent self-reported social support, anxiety, affect and emotional response to treatment; parent, nurse, observer and child reports of child procedure-related distress and cooperation during treatment episodes; parent self-report of parent procedure-related distress during treatment episodes) and (2) observational coding of video-recordings of treatment episodes involving pediatric patients, their parents, and medical professionals. An existing coding system was used to identify parent and child communication patterns during treatment episodes. All data from the Penner et al. study were de-identified (assigned an ID number). The self-report measures and video-recordings are linked by a coded identifier.

Study Participants. While the Penner et al. study is ongoing, I used data collected from families between November 2009 and May 2012. All participants in the Penner et al. study were available for selection into this dissertation study and, as previously stated, only the first video-recording from each family was used for analysis for this research. The research participants in the Penner et al. study were pediatric oncology cancer patients and their primary caregiver (parent or grandparent) who were video-recorded while the children received a treatment-related medical procedure. All children received outpatient pediatric cancer treatment (i.e., port accesses with topical anesthetic or lumbar punctures and/or bone marrow aspirations with general anesthesia). The sample for this dissertation research included 115 children who had been in treatment for an average of 3 months (*SD*=3.12, range 1-17 months) and their primary caregiver (see Tables 1 and 2). While children who received bone marrow aspirations or lumbar punctures under general anesthesia were videotaped, the actual procedure was not. For these procedures, the parent and child were video-recorded as they waited for the procedure in the surgical area, and they were video-recorded as the child was sedated. As soon as the child was unconscious, the parents left the surgical area and the video-recording ended. In these instances, the procedure was the act of sedation and not the bone marrow aspiration or the lumbar puncture itself because the parents did not stay for the actual procedure and the child was asleep.

Coding Procedure Phases. Given previous findings showing variability in coping across different phases of the procedure (Dahlquist et al., 1995; Peterson et al, 2006), each procedure phase (before, during, after) had been previously coded separately using intervals that were used in a previous study (Peterson et al., 2006). These phases are pre-procedure, procedure, and post-procedure. Only 42 of the 115 observations had a post procedure phase so for the purposes of this dissertation research, only video-taped pre-procedure and procedure phases were used. *Pre-*

procedure includes waiting and general preparation time prior to the procedure; *procedure* begins with immediate preparation for the procedure and concludes when the procedure is finished. Coding for procedure phases was completed by Ms. Peterson and one research assistant as part of the Penner et al. study. The average pre-procedure duration was 31.71 minutes (*SD*=23.26, range .25 seconds-105.52 minutes) while the average procedure phase was 4.34 minutes (*SD*=5.07, range .27 seconds 48.27 minutes).

Coding Parent and Child Communication Patterns. Cline and colleagues (Cline et al., 2006; Cline et al., 2005a; Cline et al. 2005b) developed a coding scheme using data collected at Children's Hospital of Michigan as part of a previously completed National Cancer Institute funded study (#R01CA100027, PI: T.L. Albrecht). The coding scheme is based on symbolic interactionism theory where authors relied on the concept of *definition of the situation* (Goffman, 1959; Hewitt, 1976; Stebbins, 1969; Thomas & Znaniecki, 1918) to develop a typology of parent-child communication patterns. In symbolic interactionism, reality is constructed through patterns of behavior that are reinforced over time. The first task in a social situation is to identify the definition of the situation. These definitions of the situation establish participant roles and rules for behavior (McCall & Simmons, 1978) and goals for the interaction (Stebbins, 1969). Definitions of the situation clarify the label for the situation or context and the appropriate behavior or social norms for the situation. There are two distinct types of situations identified in the literature: routine and problematic (Hewitt, 1976; McCall & Simmons, 1978). Routine situations are those that are familiar and readily named. In routine situations roles for the participants are known in advance and participants can anticipate patterns of behavior. Often these patterns of behavior are habitual. Problematic situations are novel, ambiguous, uncertain, and are outside the bounds of experience for participants. These situations require special effort to comprehend and define. Pediatric cancer treatment is a problematic situation, requiring parents to improvise a definition of the situation.

Cline and colleagues identified four global communication patterns: *normalizing, invalidating, supportive,* and *distancing.* Parent behavior was not operationalized but a global categorization of behaviors was applied based on examples provided by Cline in the codebook. Parents engaged in varied communication patterns across the interactions. According to Cline et al., when the parent defined the situation as a normal situation they essentially communicated to the child “WE are NOT in this situation.” Parents used this definition of the situation to engage in everyday activities (e.g., play, reading, non-medical conversations) and the parent’s role was as a guide to normalcy. When parents defined the situation as invalidating they communicated to the child “YOU are NOT in this situation.” In this definition of the situation, the parent denied the validity or reality of the child’s experience or denied the child’s ability to be a credible source in defining the situation. The parent’s role in this definition of the situation was as a combatant or judge. Behavior in this situation included lying to the child about treatment, ridiculing/laughing at the child’s responses to treatment, denying or minimizing the child’s pain or distress (“That didn’t hurt,” “Don’t be a baby”). Parents who defined the situation as supportive communicated to the child “I am WITH you in this situation.” Parents who defined the treatment situation as supportive were verbally and nonverbally attentive to the child’s needs and offered comfort and empathy. The parent’s role in this definition of the situation was as an active and protective partner. Behavior in this context included providing supportive verbal and nonverbal messages (e.g., touching supportively), following the child’s topic of conversation, acknowledging the child’s fear or distress, and offering help to the child. Parents who defined the situation as distancing communicated to the child “YOU are in this situation, I am NOT.”

Parents who defined the situation as distancing were uninvolved bystanders or observers. The parent often left the situation physically and/or emotionally. Behavior in this situation included leaving the room for lengthy periods of time, maintaining substantial physical distance from the child, talking with other people while ignoring the child, focusing on getting the procedure over and generally initiating little interaction with the child.

Parent communication in this context functions as a proposed definition of the situation, however situational definitions are co-constructed. Interactions proceed smoothly when participants share a situation definition, however sometimes participants struggle over the definition of the situation. According to Cline, patterns of behavior reflect differences in parent-child convergence (mutual understanding) about the definition of the treatment situation. For example, high convergence occurs when a child accepts the parent's proposed definition of the situation (acts consistently with this definition; e.g., plays when encouraged by the parent, as occurs in a *normalizing* communication pattern). In contrast, low convergence occurs when parents challenge or even ridicule children's definition of the situation, as they do with *invalidating* communication. High convergence dyads occur in normalizing and supportive communication patterns while low convergence dyads can be seen in distancing and invalidating patterns.

Each video-recording was previously divided into phases for the larger NCI-funded study. The phases include pre-procedure and procedure. Coders were given information regarding which parent/caregiver they were to code (in cases where more than one caregiver was present) and the time that each phase began. Coders were instructed to watch a phase, take notes, and when that phase was complete coders assigned a code for that phase before viewing the next phase of the same tape. Each phase was assigned one code (supportive, normalizing, invalidating or distancing) and codes were exhaustive and mutually exclusive. (See Appendix A for codebook.)

Coder Training

Consistent with training for previous coding using the same coding system, coders were trained as a group before coding any interactions independently. Five undergraduate psychology students coded the video-recorded interactions. Coders were presented with the coding system via PowerPoint presentation that identified the logic of the coding system and identified all the codes and provided examples of each code. Coders reviewed the codebook and watched previously coded video-recordings and discussed how the interactions had been coded. Further training consisted of all coders viewing a set of interactions (a set previously coded by research assistants that have achieved inter-rater reliability), coding the interactions independently, and then coming together as a group to discuss the codes. Coders viewed twelve video-recordings before inter-rather reliability was achieved. Each video-recording was independently coded by two coders. Interactions in which the coders did not agree on a code for any phase, were independently coded by a third judge for a consensus code. Inter-rater reliability for both phases was achieved, with a Cohen’s kappa of .81 for the pre-procedure phase and .92 for the procedure phase.

Questionnaires

The initial baseline questionnaires for the Penner et al. study contained questions about parents’ own and their children’s demographic characteristics and children’s medical history (e.g., time in treatment, type of cancer, procedures experienced). These baseline questionnaires contained the Social Support Questionnaire (Sarason et al., 1983) as well as several scales that were not used for this dissertation (i.e., depression, resilience). All scales used in this dissertation can be found in Appendix B. Using The Social Support Questionnaire parents report size and satisfaction with their social support network. The SSQ has high internal consistency (> .90) and scores relate to adjustment to negative life events where the higher the satisfaction with social support the better adjustment will be (Sarason, Sarason, Shearin, & Pierce, 1987). Questions include "Whom can you really count on to accept you totally, including both your best and worst points?" and "Whom can you really count on to care about you regardless of what is happening to you?" Participants were then asked to rate on a six-point Likert scale how satisfied they were with that kind of support (from very dissatisfied to very satisfied). The coefficient alpha in this study for satisfaction with support was .93.

On the day of treatment, prior to the child's treatment procedure, parents completed a questionnaire packet that included a measure of situational social support, a scale that measures parent emotional state, and state anxiety as well as several measures not used for this dissertation research (i.e., caregiving goals).

Situational social support during the previous week was assessed using the 12-item Multidimensional Survey of Perceived Social Support (MSPSS) (Dahlem, Zimet & Walker, 1991; Zimet et al., 1988). This measure is comprised of subscales for family, friends, and significant other. Zimet and associates (Canty-Mitchell & Zimet, 2000) provide evidence for the scale's validity and test-retest and internal reliabilities (alphas > .90). Items include "My family really tries to help me" and "I can count on my friends when things go wrong." Participants rated on a five-point scale the extent to which they agreed with the statements (very strongly disagree to very strongly agree). In this study the alpha coefficients for all three subscales were over .94. In analyses, the entire scale was used. Full scale reliability in this study was .95.

The Emotional Response Questionnaire (ERQ) (Batson, 1991) was used to measure parents' positive and negative emotional responses immediately prior to the child's treatment procedure. The empathic concern subscale measured positive affective responses to another's distress. Parents were asked to indicate the extent to which they, at that moment, felt emotions like sympathy, warmth, and compassion using a five-point scale (1=Not at all like I feel, 5=Exactly like I feel). The personal distress subscale measured negative affective responses to another's distress using the same five-point scale with items including disgust, alarm, and worried. Coefficient alphas for both subscales of the ERQ exceeded .80 and the scales have demonstrated construct validity (Batson, 1991; Otten, Penner, & Altabe, 1991). In this study the coefficient alpha for the empathic concern subscale was .78 and for the personal distress subscale it was .89.

The State-Trait Anxiety Inventory (STAI) for Adults (Spielberger, 1977) was used to assess parent state anxiety immediately before the child's treatment procedure. The STAI is a widely used self-report measure of anxiety in response to a specific situation. Parents were asked to indicate the extent to which they felt emotions like nervousness, content and high-strung using a five-point scale (1=Not at all like I feel, 5=Exactly like I feel). The STAI has good internal consistency (alphas > .85) and construct validity (Spielberger, Sydeman, & Owen, 1999). In this study the coefficient alpha was .94.

After the child's treatment related medical procedure, another set of questionnaires was administered. Children completed a one-item measure of distress. Children's distress was assessed using global rating scales immediately after completion of treatment episodes. Following Manne et al. (1992), children's perceptions of distress was assessed via the FACES scale (Wong & Baker, 1988). The child was presented a series of six face drawings and asked to point to the face that best shows "how much you were upset" during the procedure with responses ranging from "not upset at all" to "the worst." The primary caregiver, the nurse performing the procedure, and an independent observer viewing the recorded interaction rated the child's distress using the same scale. Immediately after treatment episodes ended, the primary caregiver rated their own distress on the same FACES scale.

Parents also completed the Positive and Negative Affect Scale (PANAS) (Watson et al., 1988). The PANAS has high internal consistency and validly assesses affective reactions to specific stimuli (Watson et al., 1988). Parents were asked to indicate on a five-point scale the extent to which each of 20 items described them at that moment (1=Not at all like I feel, 5=Exactly like I feel). Items include alert, enthusiastic, and determined. In this study, the coefficient alpha for the positive affect subscale was .86 and for the negative affect scale it was .89.

Because negative responses to treatment may make children more difficult patients, child cooperation associated with the treatment episode was also assessed. Using a one item seven-point global ratings scale (from "Totally Cooperative" to "Totally Uncooperative") the primary caregiver, the nurse performing the procedure, and an independent observer rated children's cooperation during the treatment episode.

Demographic Characteristics: In order to examine correlates of social support and parent-child communication patterns, several demographic variables, including ethnicity, parent and child age, and parent and child gender, were examined. Treatment related variables including how long the child had been in treatment and the child's diagnosis were also examined.

Data Preparation and Analysis

At the time of analysis, data had been collected on 147 families (52 from Children's Hospital of Michigan and 95 from St. Jude). Only 128 of these families had completed at least one taping and/or had completed the relevant data for this study. While the Penner et al. study collected video-recorded treatment sessions up to three times throughout participation in the study, for the purpose of this dissertation, only the first video-recording from each family was used. Of the 128 families, only 115 completed data for all variables used in analysis.

Self-report data for the Penner et al. study was continuously entered into SPSS on an ongoing basis. Data was entered by a research assistant and 100% verified by another research assistant to achieve accuracy of data entry. Codes for the typology were entered into this database and data entry was 100% verified to achieve accuracy. Values for sporadic missing data (<1% of all items) were imputed using substitution of the sample mean. Data were inspected for outliers but none were identified. Statistical analyses were performed using the IBM statistical Package for the Social Sciences, Release 20.0.

Child procedure-related distress and child cooperation were rated by trained objective observers who coded the video-recordings and were blind to parent, child, and nurse ratings of distress and cooperation. Ninety of the 115 cases (78%) in this sample were coded for child procedure-related distress by at least two independent observers and a Cohen's kappa of .97 was achieved. Ninety-four of interactions (82%) were coded by multiple raters for child cooperation and a Cohen's kappa of .95 was achieved. Sufficient reliability for the coding of child procedure-related distress and cooperation was achieved and therefore, not all interactions were coded by two observers.

Nurses, parents, observer and children all rated child procedure-related distress and all combinations of raters were correlated: nurse and parent (r = .588, p < .000), parent and observer (r = .498, p < .000), child and parent (r = .672, p < .000), nurse and observer (r = .671, p < .000), nurse and child (r = .578, p < .000), and observer and child (r = .520, p < .000). Nurses, parents and independent observers rated child cooperation with the procedure and all combinations of ratings were correlated: Nurse and observer ($r = .750$, $p < .000$), nurse and parent ($r = .617$, $p < .000$), and parent and observer ($r = .651$, $p < .000$). As all ratings of child procedure-related distress and cooperation and strongly correlated, ratings were collapsed into a single rating of distress and a single rating of cooperation. The single rating was the average of parent, nurse, child and observer ratings of child procedure-related distress and nurse, parent and observer ratings of child cooperation.

Due to the infrequent occurrence of some of the categories the four typology categories were collapsed into two categories for analysis. Distancing occurred in only one pre-procedure phase and two procedure phases. Invalidating occurred in 15 pre-procedure and procedure phases while normalizing occurred in only seven procedure phases. Due to the infrequency of codes, supportive and normalizing were combined and distancing and invalidating were combined. Both normalizing and supportive behavior indicate to the child that the parent is with them in the situation. Either they are both in the situation or neither one of them are in the situation, but they are together. Conversely, both distancing and invalidating behavior indicate to the child that s/he is alone. Distancing behavior sends the message that the child is in the situation alone and invalidating sends the message that they are not in the situation at all. Normalizing is by nature a supportive and positive behavior while distancing and invaliding behaviors would not send a positive message to the child. Therefore combining these four codes into two codes is logically sound. Hereafter, supportive/normalizing typology codes will be referred to as supportive and invalidating/distancing codes will be referred to as invalidating.

Definition of Terms

Social Support: The verbal and nonverbal communication that helps manage uncertainty about a situation, the self, another or a relationship and functions to enhance a perception of personal control (Albrecht & Adelman, 1987). Scores obtained from the Social Support Questionnaire (Sarason et al., 1983), the Multidimensional Survey of Perceived Social Support (Zimet et al., 1988), and a one-item measure of social support related to the clinic visit will be used to assess parent self-reported social support.

Childhood Cancer: A major life-threatening disease comprised of several separate diagnoses.

Child: The child in this study, in treatment for cancer, between the ages of 3 and 12.

Parent: The adult participant who defines themselves as the primary caregiver of a child diagnosed with cancer. In this study it is the mother, the father or the grandmother.

Limitations

This dissertation research is limited in three important ways. First, results from this research are not generalizable to the population of children in treatment for cancer because data were collected from only two children's hospitals, located in the Midwestern and Southern United States, and the sample size is small, although that is typical in pediatric cancer research. Secondly, findings cannot be generalizable because children families were enrolled in the study only if the child were between the ages of three and twelve years old. Infants/babies under age three, teenagers, and their parents may have very different experiences than the children and parents enrolled in this study. Lastly, we are limited by the collection of self-report data from parents. Self-report data can be limiting and in order to compensate for this limitation, multiple reports of distress and video-recordings were used to observe parent-child interaction. In this study, data that was not self-reported was also used alongside the self-report data.

Protection of Human Subjects

The larger study received initial HIC approval on March 25th 2009. The Wayne State University Behavioral Institutional Review Board granted an exempt status for this dissertation research on October 11th 2010 (see Appendix C). The study is exempt because it is a secondary analysis of existing data and participants will not be recruited or contacted for any purpose for this research.

Video-recordings for the Penner et al. study are stored in a locked file cabinet in a locked room within the office suite of the Behavioral and Field Research Core (BFRC). Only research assistants employed by the BFRC and faculty members of the Population Studies and Disparities Research Program within the Department of Oncology have access to the video-recordings. Additionally, only those staff members who are listed as key personnel on the Penner et al. study have access to view the video recordings. Coders checked out one video-recording at a time and coded the interactions in a designated cubicle within the BFRC to code. No video-recordings left the BFRC office suite at any time. All coders were added as key personnel to both the Penner et al. study and this dissertation study. Additionally, all coders completed the CITI training modules on Responsible Conduct in Behavioral Research prior to viewing any video-recordings.

CHAPTER 4

Results Descriptive & Bivariate Analyses

Introduction

This chapter is divided into four major sections, beginning with descriptive statistics about the sample. The second section examines the differences between various groups in the sample. The third section covers parent-child communication patterns and descriptions of the two categories of behavior (supportive and invalidating communication patterns). The fourth section discusses correlations examining the relationships between social support and parent and child reactions to treatment and parent and child communication before and during procedures. I hypothesized that increased parent social support will be related to less child and parent distress and more child cooperation during procedures. I also hypothesized that parents who communicate more supportively, as opposed to invalidating, will have more positive reactions to treatment procedures and have children who have more positive reactions to treatment procedures. My third hypothesis was that parents who have more social support would be less likely to invalidate their children, or be distant, before and during procedures.

Description of Sample

The primary caregiver/parent is the parent who signed the consent form and is the person who primarily brings the child to the clinic appointments. However, this person is not always a parent; in this study grandmothers are also primary caregivers). The mean primary caregiver age was 34.41 years (*SD*=7.01, range 20-54 years) (See Table 1). Caregivers were predominately female (82.6%) and the relationships to the child included mother (79.1%), father (17.4%), and grandmother (3.5%). Caregiver ethnicity included Caucasian (76.5%), African American (17.4%), Hispanic (3.5%), American Indian/Alaska Native (1.7%) and Other (.9%). The majority of parents were married (66%), more than a third (34%) had a high school education or less, and almost half (44.3%) of the parents reported incomes less than $39,000.

Table 1. Descriptive Statistics for Parent Demographics

Variables Tested	N	% Sample	Mean	Range	SD
Age	115	n/a	34.41	20-54	7.01
Gender					
Male	20	17.4%	n/a	n/a	n/a
Female	95	82.6%			
Ethnicity					
White/Caucasian	88	76.5%	n/a	n/a	n/a
Black/African American	20	17.4%			
Hispanic/Latino	4	3.5%			
American Indian/Alaskan	2	1.7%			
Other	1	0.9%			
Relationship to Child					
Mother	91	79.1%	n/a	n/a	n/a
Father	20	17.4%			
Grandmother	4	3.5%			
Marital Status					
Married	76	66.0%	n/a	n/a	n/a
Never Married	11	9.5%			
Divorced	14	12.2%			
Separated	7	6.1%			
Widowed	2	1.8%			
Domestic Partnership	5	4.4%			
Education					
Middle School	2	1.7%	n/a	n/a	n/a
Some High School	13	11.3%			
Diploma/GED	24	20.9%			
1-2 years College	21	18.3%			
Associates/Trade School	18	15.7%			
3-4 years College	5	4.3%			
Bachelor's Degree	21	18.3%			
Master's Degree	9	7.8%			
Professional Degree	2	1.7%			
Income					
Less than $10,000	16	13.9%	n/a	n/a	n/a
$10,000-$19,000	16	13.9%			
$20,000-$39,000	19	16.5%			
$40,000-$59,000	13	11.4%			
$60,000-$100,000	35	30.4%			
Greater than $100,000	12	10.4%			
Missing	4	3.5%			

Families were recruited from two large children's hospitals, Children's Hospital of Michigan (CHM) in Detroit (37.4%) and St. Jude's Children's Research Hospital (SJ) in Memphis, Tennessee (62.6%). On average, children were 6.39 years old upon entering the study (*SD*=3.12, range 3-12 years) and had been in treatment, on average, for 3 months upon entering the study (*SD*=3.25, range 1-17 months) (See Table 2). Children were predominately male (60.9%). About three-quarters were Caucasian (75.7%) while African Americans totaled 18.3%. The most common cancer diagnosis was Acute Lymphoblastic Leukemia (ALL, 79.1%) followed by several other, less common cancers. Children had been in treatment for several weeks before being approached for entry into the Penner et al. study, so the children had already experienced several cancer-related medical procedures. One hundred and two children had experience lumbar punctures as part of treatment and over 70% of children (*n* = 72) had experienced at least one lumbar puncture in the two months before joining the study. Eighty-four children experience bone marrow aspirations as part of treatment and 61.6% (*n* = 69) had experienced at least one bone marrow aspiration in the two months before joining the study. Many children with cancer have a medi-port located on their chest for the administration of chemotherapy and to ease blood draw. In this study 72 children had medi-ports and almost 75% (*n*=54) of children had their port accessed between one and ten times in the two months before joining the study.

Table 2. Descriptive Statistics for Child Demographics

Characteristic	N	% Sample	Mean	Range	SD
Site					
St. Jude (SJ)	72	62.6%	n/a	n/a	n/a
Children's Hospital of Michigan (CHM)	43	37.4%			
Age	115	n/a	6.39	3-12 years	3.12
Time in Treatment	115	n/a	3 months	1-17 months	3.25
Gender					
Male	70	60.9%	n/a	n/a	n/a
Female	45	39.1%			
Ethnicity					
White/Caucasian	87	75.7%	n/a	n/a	n/a
Black/African American	21	18.3%			
Bi-Racial	4	3.5%			
Hispanic/Latino	2	1.7%			
Other	1	0.9%			
Diagnosis					
Acute Lymphoblastic Leukemia (ALL)	91	79.1%	n/a	n/a	n/a
Lymphomas	8	6.9%			
Wilm's Tumor	5	4.3%			
Astrocytoma	2	1.7%			
Rhabdomyosarcoma	2	1.7%			
Sarcoma (unspecified)	2	1.7%			
Other Cancers	2	1.7%			
Ewings' Sarcoma	1	0.9%			
Osteosarcoma	1	0.9%			
Retinoblastoma	1	0.9%			
Procedures in the Past 2 Months					
Lumbar Punctures					
1-5	72	70.6%	n/a	n/a	n/a
6-12	30	29.4%			
Bone Marrow Aspirations					
1-3	69	82.1%			
4-7	15	17.9%			
Port Starts					
1-5	17	23.6%			
6-10	37	51.3%			
> 10	18	25.0%			

Differences Between Groups

In order to see if there were differences in parent and child reactions to treatment, parent self-reported social support, child clinical and demographic characteristics, and parent and child communication based on specific attributes, several t-tests were conducted and all reported findings were significant at the $p < .05$ level. Differences on the variables of interest based on the following groupings were examined: data collection site, the type of anesthesia used, gender, parents who were alone and those who had another adult present during the procedure, cancer type, child ethnicity, and parent communication. The variables of interest included: the duration of the pre-procedure and procedure phases, the length of time the child had been in treatment, child age, the number of procedures the child had experienced in the two months before joining the study, parent age, the number of invalidating statements the child had experienced during the pre-procedure and procedure phases, parent anxiety before the procedure, parent procedure-related distress during the procedure, parent empathic concern and personal distress and positive and negative affect after the procedure, child procedure-related distress and cooperation during the procedure, situational social support, social support associated with the clinic visit, and the number of people parents report provide them with support and their satisfaction with that number.

Types of Procedures. Children who experienced a port start procedure were given a topical anesthetic to numb the needle insertion point while children who experienced a lumbar puncture or bone marrow aspiration experienced the procedure under general anesthesia. Because both procedures involved general anesthesia, lumbar punctures and bone marrow aspirations are combined and compared to port starts. For children who had a procedure under general anesthesia, the act of sedation was the procedure coded for parent-child communication, distress, and cooperation, as the child was not awake, nor was the parent present, during the actual procedure. Independent samples t-tests for the type of anesthesia used for the procedure that was video-recorded for this study indicated several differences, including the duration of the pre-procedure and procedure phases, the duration of time the child had been in treatment, the child's age, the number of invalidating statements the child experienced during the procedure, parent empathic concern, and child procedure-related distress and cooperation (See Table 3).

Table 3. Differences of Means for Type of Procedure (Topical or General Anesthesia)

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Pre-Procedure Phase	2.90	0.005	74.1	55 (TA), 60 (GA)	3.96 (TA), 1.73 (GA)
Duration of Procedure Phase	4.90	0.000	62.3	55 (TA), 60 (GA)	.86 (TA), .24 (GA)
Time in Treatment	3.22	0.002	84.3	55 (TA), 60 (GA)	.52 (TA), 1.29 (GA)
Child Age	2.16	0.033	113	55 (TA), 60 (GA)	.44 (TA), .37 (GA)
BMAs in two months	- 4.16	0.000	93.7	53 (TA), 59 (GA)	.23 (TA), .16 (GA)
Port Starts in 2 months	2.06	0.042	101	50 (TA), 53 (GA)	.83 (TA), 1.07 (GA)
Proc. # Invalidating Statements	3.25	0.002	56.7	55 (TA), 59 (GA)	.66 (TA), .10 (GA)
Empathic Concern	2.05	0.043	113	55 (TA), 60 (GA)	.71 (TA), .60 (GA)
Child Cooperation	- 3.30	0.002	71.2	55 (TA), 60 (GA)	.24 (TA), .10 (GA)
Child Procedure-Related Distress	2.90	0.005	90	55 (TA), 60 (GA)	.22 (TA), .13 (GA)

TA=Topical Anesthesia, GA=General Anesthesia
Duration of phases is in minutes. Time in treatment is in weeks. Child age is in years. Empathic concern was rated 1-5 (higher ratings =more empathic concern). Child cooperation was rated 1-7 (higher ratings = more cooperation). Child Child procedure-related distress was rated 1-6 (higher ratings = more distress).

The durations of the procedure phase were significantly different by the type of procedure the child experienced. Both the pre-procedure and procedure phases were longer for port starts. This is typical of these procedures as children who experience a port start often wait in an exam room for their blood work to return from the laboratory and for their chemotherapy infusion to be mixed by a pharmacist. Children who are scheduled for a procedure under general anesthesia do not have to wait under the same circumstances. Additionally, port starts take longer to administer than sedating a child for a procedure under general anesthesia. Children who experienced a procedure under general anesthesia had typically not been in treatment as long as children who had a port start. This is explained by the treatment protocols that children adhere to when they are diagnosed with cancer. Typically, bone marrow aspirations and lumbar punctures happen more frequently earlier in treatment and occur less frequently the longer the child is in treatment. Younger children were more likely to have a port start than a lumbar puncture/bone marrow aspiration. Children with ALL typically have more port starts than any other cancer diagnosis as treatment is so frequent. Children with ALL are typically diagnosed at a younger age than children with other cancers, thus the relationship between child age and the number of port start procedures in this sample. Parents of children getting a port start had higher empathic concern before the pre-procedure phase than parents of children getting an LP or BMA. Results showed that children who experienced a port start had more procedure-related distress than children who had a procedure under general anesthesia. Additionally, children who had a port start were less cooperative during the procedure. It may be the case that children experiencing a port start have more time to get nervous/anxious about the procedure than children going under general anesthesia. Children also know that when they are asleep for a procedure, they will not experience it or remember it and may, therefore, not be as nervous during those procedures. As previously stated, children had typically been in treatment for several weeks and experienced several treatment procedures before joining this study; therefore, children knew what to expect during these medical procedures. There was no difference by procedure type by parent age, parent ratings of their own procedure-related distress, any of the social support variables, the number of invalidating statements made during the pre-procedure, parent personal distress, state anxiety, or affect (see Appendix D).

In correlational analyses that follow later in this chapter I will control for procedure type because there were significant differences in the length of the pre-procedure and procedure phases, the length of time the child had been in treatment, child age, the number of invalidating statements during the procedure, parent empathic concern, child procedure-related distress, and child cooperation by the type of procedure.

Study Site. The two sites for this study are different in many ways. One significant difference reflects the residential location of the patients. CHM treats a local population, while SJ is national in scope. While children travel to Children's Hospital of Michigan (CHM) from the tri-country metropolitan Detroit area, families travel from all over the world to St. Jude Children's Research Hospital (SJ). On average, the clinic at CHM sees around 70 new patients a year with a new cancer diagnosis while the clinics at St. Jude, which is predominately a cancer hospital sees roughly 1400 new pediatric cancer patients a year.

Independent samples t-tests indicated significant differences by site that included the length of the pre-procedure and procedure phases, the duration of time the child had been in treatment, ratings of parent procedure-related distress, the number of invalidating statements the child experienced both before and during the procedure, parent empathic concern and personal distress (assessed before the pre-procedure phase), parent negative affect (assessed after the procedure), child procedure-related distress, and child cooperation (see Table 4). There was no difference by site on age, the number of LPs in two months, parent age, any of the social support variables, parent state anxiety, or positive affect (See Appendix E).

Table 4. Differences of Means for Study Site (SJ or CHM)

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Pre-Procedure Phase	5.11	0.000	54.2	43 (CHM), 72 (SJ)	46.41 (CHM) 22.93 (SJ)
Duration of Procedure Phase	2.17	0.032	113	43 (CHM), 72 (SJ)	5.65 (CHM) 3.56 (SJ)
Time in Treatment	4.06	0.000	57.7	43 (CHM), 72 (SJ)	4.67 (CHM) 2 (SJ)
Parent Procedure-Related Distress	2.34	0.021	113	43 (CHM), 72 (SJ)	2.84 (CHM) 2.22 (SJ)
Pre-Proc. # Invalidating Statements	2.36	0.022	54.2	43 (CHM), 71 (SJ)	2.40 (CHM) .75 (SJ)
Proc. # Invalidating Statements	2.45	0.018	56.2	42 (CHM), 72 (SJ)	2.50 (CHM) .60 (SJ)
Empathic Concern	2.85	0.005	113	43 (CHM), 72 (SJ)	19.81 (CHM) 17.15 (SJ)
Personal Distress	2.76	0.007	113	43 (CHM), 72 (SJ)	14.99 (CHM) 12.06 (SJ)
Negative Affect	2.61	0.010	113	43 (CHM) 72 (SJ)	18.51 (CHM) 14.95 (SJ)
Child Cooperation	- 3.55	0.001	49.9	43 (CHM), 72 (SJ)	5.39 (CHM) 6.49 (SJ)
Child Procedure-Related Distress	2.53	0.014	66.9	43 (CHM), 72 (SJ)	3.04 (CHM) 2.32 (SJ)

CHM=Children's Hospital of Michigan, SJ=St. Jude's Children's Research Hospital
Duration of phases is in minutes. Time in treatment is in weeks. Parent procedure-related distress was rated 1-6 (higher ratings = more distress). Empathic concern was rated 1-5 (higher ratings = more empathic concern). Personal distress was rated 1-5 (higher ratings = more personal distress). Negative affect was rated 1-5 (higher ratings = more negative affect). Child cooperation was rated 1-7 (higher ratings = more child cooperation). Child procedure-related distress was rated 1-6 (higher ratings = more distress).

Children at CHM had longer pre-procedure and procedure phases. The differences in how long it takes to conduct a procedure may have to do with the two distinct hospital systems and differences in hospital practices and procedure. Children at CHM have also been in treatment longer than children at SJ, but this may have more do with when they are recruited at each site than anything else. Children at SJ are enrolled into several studies upon diagnoses, both medical/treatment-related and psychosocial or longitudinal studies, and parents of children at SJ may be more easily approachable closer to the time of initial diagnosis than parents of children at CHM. Parents of children at SJ had less procedure-related distress, had less empathic concern and less personal distress before the pre-procedure phase, and less negative affect after the procedure than parents at CHM. Children at SJ also experienced fewer invalidating statements both before and during the procedure. This finding is likely related to parent reactions to treatment; parents may be less likely to invalidate if they are not distressed themselves, and parents at SJ are less distressed. Children at CHM were more distressed and less cooperative during the procedures. This may be related to differences between the two sites required further investigation.

While there were several significant differences between the two study sites, I will continue to analyze the data together because the children and parents are actually quite similar and do not differ by age, income, education, child diagnoses, social support, or anxiety. However, as the study site does play a part in the variables under study, in correlational analyses we will control for study site.

Gender. Independent samples t-tests examining child gender found no significant differences between male and female children on any of the variables examined in the previous analyses (See Appendix F). A t-test examining parent gender found significant differences between men and women in the number of invalidating statements they used during the pre-procedure phase, parent personal distress (assessed before the pre-procedure phase), child cooperation, and child procedure-related distress (see Table 5). Children with a female caregiver present experienced more invalidating statements during the pre-procedure phase. Fathers reported more personal distress than mothers, and children with fathers present were more cooperative and less distressed than children with mothers present.

Table 5. Differences of Means for Parent Gender

Variables Tested	t	P (2-tailed)	df	N	Mean
Pre-Proc. # Invalidating Statements	- 2.80	0.006	103	20 (M), 94 (F)	.40 (M) 1.57 (F)
Personal Distress	2.08	0.050	21.4	20 (M), 95 (F)	16.55 (M) 12.45 (F)
Child Cooperation	3.71	0.000	89.9	20 (M), 95 (F)	6.67 (M) 5.95 (F)
Child Procedure-Related Distress	- 2.91	0.005	59.6	20 (M), 95 (F)	.71 (M) 1.49 (F)

M=Male, F=Female
Personal distress was rated 1-5 (higher ratings = more personal distress). Child cooperation was rated 1-7 (higher ratings = more child cooperation). Child procedure-related distress was rated 1-6 (higher ratings = more distress).

There were no significant differences between male and female parents in regards to the duration of the pre-procedure and procedure phases, how long the child had been in treatment, child age, parent age, social support, the number of invalidating statements during the procedure, empathic concern, and state anxiety (See Appendix G).

The Presence of Another Adult. Independent samples t-test examining the impact of having additional adults present indicated a few significant differences between interactions where only one parent was present and those where more than one was present, including the duration of time the child had been in treatment, parent procedure-related distress, the number of invalidating statements during pre-procedure, parent state anxiety, and satisfaction with social support (see Table 6). Children who had been in treatment longer were more likely to have just one parent present. This may be explained by the burden of pediatric cancer treatment protocols. Children are often in treatment for several months to several years and it is not practical for both parents to be present for each appointment as it is likely that at least one parent is probably working. Parent procedure-related distress was higher when more than one parent was present. One explanation is that the addition of another parent may not increase parent distress but rather the other parent is present because the primary parent finds the treatment appointments distressing. When more than one parent was present, the child experienced fewer invalidating statements during the pre-procedure phase. Parents who have an additional caregiver present may invalidate less because they feel inhibited or constrained by the presence of another loved one. Parents who had an additional caregiver present during a treatment episode reported more anxiety, and again the additional parent may have been present because the primary parent was anxious about procedures. Parents who were alone reported more satisfaction with social support at baseline, and this may be because they felt supported in general and could come to the procedures alone.

Table 6. Differences of Means for Having an Additional Adult Present

Variables Tested	t	P (2-tailed)	df	N	Mean
Time in Treatment	- 2.47	0.015	113	71 (1) 44 (+1)	6.94 (1) 5.50 (+1)
Parent Procedure-Related Distress	2.41	0.018	113	71 (1) 44 (+1)	2.21 (1) 2.84 (+1)
Pre-Proc Num. Invalidating Stmts.	- 2.95	0.004	84.6	70 (1) 44 (+1)	1.93 (1) .47 (+1)
State Anxiety	2.52	0.014	75.9	71 (1) 44 (+1)	46.27 (1) 54.33 (+1)
Satisfaction with Social Support	- 3.18	0.002	57.5	71 (1) 44 (+1)	5.67 (1) 5.11 (+1)

1=One Parent, +1=More than One Parent
Time in treatment is in weeks. Parent procedure-related distress was rated 1-6 (higher ratings =more distress). State anxiety was rated 1-5 (higher ratings = more anxiety). satisfaction with social support was rated 1-6 (higher ratings more satisfaction).

There were no significant differences for parents who came alone versus those who came with others in the duration of the pre-procedure and procedure phases, the duration of time the child had been in treatment, parent age, social support, the number of invalidating statements during the procedure, empathic concern, personal distress, child cooperation, child procedure-related distress, and satisfaction with social support (See Appendix H).

Diagnoses. Ten different childhood cancer diagnoses are represented in the sample, with acute lymphoblastic leukemia (ALL) the most prevalent (79%). Each pediatric cancer has its own treatment schedule and chemotherapies, so independent samples t-tests were conducted to determine if there were any significant differences between ALL and the other forms of pediatric cancer in the sample. Children with ALL had shorter procedures, were younger, and had parents who reported less empathic concern and who reported more sources of social support (see Table 7). The length of the procedure was longer for children with non-ALL diagnoses, and this is likely due to the types of treatment for the various cancer diagnoses. Children with ALL were more likely to be younger and this was, again, likely due to the amount of time passed since diagnosis. Children with ALL are typically diagnosed at younger ages. Parents of children with other cancers reported more empathic concern than parents of children with ALL. Parents of children with ALL also reported more sources of social support than parents of children with other diagnoses. Treatment for ALL is typically longer than treatment for any other pediatric cancer, and it may be that parents with a child in treatment for several years rely more on social support.

Table 7. Differences of Means for Child Diagnosis (ALL and all other pediatric cancers)

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Procedure	- 2.20	0.038	24.2	91 (ALL) 24 (O)	3.48 (ALL) 7.61 (O)
Child Age	- 2.53	0.013	113	91 (ALL) 24 (O)	6.02 (ALL) 7.79 (O)
Empathic Concern	- 2.52	0.015	47.4	91 (ALL) 24 (O)	17.64 (ALL) 20.05 (O)
Number of Sources of Soc. Support	2.26	0.026	113	91 (ALL) 24 (O)	4.54 (ALL) 3.31 (O)

ALL=Acute Lymphoblastic Leukemia, O=Other Cancer
Duration of the procedure is in minutes. Child age is in years. Empathic concern was rated 1-5 (higher ratings = more empathic concern). Number of sources of social support was the raw number parents reported.

Children with ALL and children with other pediatric cancers did not vary significantly based on the duration of the pre-procedure phase, the length of time they had been in treatment, parent age, social support, parent procedure-related distress, the number of invalidating statements pre-procedure and procedure, parent personal distress, parent state anxiety, child cooperation, child procedure-related distress, and parent satisfaction with social support (See Appendix I).

Ethnicity. Although parents self-identified for themselves and their children into five ethnic categories, the vast majority of children were either white (75.7%) or African American (18.3%). In order to conduct a t-test, I compared white children to all other children (1.7% Hispanic, 18.3% African American, .9% Other, 3.5% Bi-Racial). The only significant difference was that parents of white children had less positive affect (*M*=27.38, *SD*=7.68) than other parents (*M* = 33.55, *SD* = 10.09; *t*(37.58) = 2.97, *p* = .005). Ethnicity had no relationship to the duration of pre-procedure and procedure duration, the duration of time the child had been in treatment, child age, parent age, any of the social support variables, parent procedure-related distress, empathic concern, personal distress, positive and negative affect, the number of invalidating statements used before and during the procedure, child procedure-related distress, and child cooperation (see Appendix J).

Based on the results from the t-tests conducted, both the type of anesthesia used (indicated by the type of procedure) and the location of data collection showed the biggest effect on the duration of the pre-procedure and procedure phases, the length of time the child had been in treatment, child age, the number of invalidating statements the child experienced, parent empathic concern, anxiety, negative affect, procedure-related distress, and child procedure-related distress and child cooperation. It is for this reason, I controlled for study site and anesthesia type in the correlational analyses. Additionally, in my prior research on the PEnner et al. study it was found that child age is significantly correlated with the duration of the procedure, parent positive affect, child procedure-related distress, and child cooperation; it is for that reason that I also controlled for child age.

Parent-Child Communication during Procedures

Descriptives. During the pre-procedure phase, 85.2% (*n* = 98) of parents behaved in a supportive/normalizing manner while 13.9% (*n* = 16) invalidated the child's experience or were distant while they waited for the child to undergo the procedure. One recording did not have a pre-procedure phase. During the actual procedure phase of the interaction, 84.3% (*n* = 97) of parents were supportive or normalizing while 13.9% (*n* = 16) invalidated the child's experience or were distant. Two recordings did not have a procedure recorded. Descriptions of actual interactions that exemplify each of the codes are included later in this chapter.

Differences between Groups. Independent samples t-tests examining difference between interactions in which the parents were supportive/normalizing during both phases or were invalidating/distant for at least one phase indicated significant differences in the duration of the pre-procedure phase, the number of invalidating statements the child experienced, child procedure-related distress, child cooperation, and parent satisfaction with social support (See Table 8).

Table 8. Differences of Means for Parent-Child Communication

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Pre-Procedure	- 3.05	0.003	113	87 (S/N) 28 (I/D)	28.08 (S/N) 42.98 (I/D)
Pre-Proc Num. Invalidating Stmts.	- 4.44	0.000	27.3	86 (S/N) 28 (I/D)	.30 (S/N) 4.62 (I/D)
Procedure Num. Invalidating Stmts.	- 3.68	0.001	26.2	87 (S/N) 27 (I/D)	.25 (S/N) 4.67 (I/D)
Child Cooperation	4.36	0.000	30.4	87 (S/N) 28 (I/D)	6.49 (S/N) 4.81 (I/D)
Child Procedure-Related Distress	- 3.99	0.000	34.6	87 (S/N) 28 (I/D)	2.25 (S/N) 3.63 (I/D)
Satisfaction with Soc. Support	- 2.39	0.019	84.2	87 (S/N) 28 (I/D)	5.38 (S/N) 5.70 (I/D)

S/N=Supportive/Normalizing, I/D=Invalidating/Distancing
Duration of procedure phases is in minutes. Child cooperation was rated 1-7 (higher ratings = more cooperation). Child procedure-related distress was rated 1-6 (higher ratings = more distress). Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Children whose parents engaged in supportive communication during both phases of the procedure were significantly more likely to have shorter pre-procedure phases and were less likely to experience invalidating statements from their parents during both phases. It may be that as the waiting time increases, parent patience decreases, and parents may be more likely to invalidate or become distant from the child. Children whose parents were supportive/normalizing during both phases reported less distress than children whose parents were invalidating/distant during at least one phase. There is no way to determine causality in this relationship, and it may very well be that parents invalidate in response to an already distressed child rather than the children becoming distressed because they are being invalidated. Children whose parents were supportive/normalizing during both phases were rated as more cooperative than children whose parents were invalidating/distant during at least one phase. Again, this may be a reciprocal relationship where children are cooperative because the parents are supportive/normalizing or parents are supportive/normalizing because the children are being cooperative. Parent-child communication had no relationship to the duration of the procedure phase, the duration of time the child had been in treatment, child age, the number of procedures in the two months before joining the study, parent age, state anxiety, parent procedure-related distress, empathic concern, personal distress, positive and negative affect, situational social support, social support associated with the clinic visit, and the number of sources of social support (see Appendix K).

While it is not possible to explain causality from these data, it is interesting that there are differences in the different communication patterns parents use during their child's cancer related medical procedure. Future research could use sequential analyses to examine how the interactions unfold and how the communication unfolds during the pre-procedure and procedure phases.

Examples of Parent Communication Patterns. The first example of a supportive interaction is a Caucasian mother and her 3-year-old son who is in the clinic for a port start procedure to receive chemotherapy. During the pre-procedure phase the child watches a movie on a portable DVD player, and his mother watches the movie over his shoulder while sitting next to him. When the nurses come in to do the procedure, the child is animated and talks to her about a new toy he just got. He is distracted by the new toy and ignores the nurse when she asks him to get on the exam table. His mother lifts him up on the table and he immediately begins to cry. He says "I can't do it" while crying, and both the nurses and his mother say "Yes, you can" in sing-song voices. He says "It hurts, I don't wanna do this," and mom sits in the chair next to the exam table and holds his arms down and tenderly says "We know, honey. We know." Mom speaks softly to the child and strokes his cheek with her hand while he cries out "I wanna get up. I don't want this." One nurse puts her weight on his legs and holds his arms down while mom holds his hands and stays close to his head. As soon as the nurses are done with the procedure, the mother pulls the child up to a sitting position, hugs him and kisses his head. He cries and yells while his mother puts his shirt back on him. When the mother gets the child's shirt on, she picks him up and holds him while rubbing and patting his back.

Another example of a supportive interaction is an African American mother and her 7-year-old son. During the pre-procedure phase the child is standing and leaning up against the bed working through an activity book while his mother sits in the chair beside the exam table and answers the questions he asks. When he asks her "Where do I have to go?" in regards to a puzzle, she says, "Count it out. Look here" and points to page while counting "One, two, three, four,…" The nurse enters the room and tells the mother that they are going to teach her how to give subcutaneous injections and the mother will give the child three shots this week and three shots next week at home. The child stops working on the activity book and turns to face the nurse. He says "I get shots today?" to which the nurse responds "No. We're going to teach your mom how to do it, and she is going to do it at home. Today I will give you your medicine through your port." He seems nervous and doesn't say anything but just looks at the floor. His mother waits a few seconds and softly says "Don't get discouraged." After a few seconds of silence, she says "Come here and let me explain it to you," but the child does not respond and does not move. She softly says "I want you to be a big boy about it, okay?" After a few more seconds of silence she says "Today you are just getting it in your port, and then you are going to sleep" to which he replies "I don't want to get shots." She says "Come here" and he slowly walks to where she is sitting and stands in front of her while leaning on her legs. She puts her arm around him and leans in to speak closely to him while softly caressing his head, "We're just doing your port today, okay? Just the port." He starts to pick at the top of his hand and she says "You're not supposed to be doing that. You want me to bite it off?" She then grabs his hand

and pretends to gnaw on the top of his hand. She then grabs his arm and pulls him in for a hug, and he puts his head on her shoulder and leans in to her embrace. When the nurse returns to access the child's port, he climbs up on the exam table without being asked and sits and faces the nurse. His mother stands and places herself next to the exam table. He looks upset, and the nurse says "It's okay to be scared, babe" and the mother gently grabs the child's head and kisses his cheek then hugs him. She then helps him lie down while he begins to softly and silently cry. The nurse says "You are such a brave boy. You are such a brave boy. It's okay." His mother moves to the head of the exam table so she can be close to where his head is positioned. His mother leans over his head and kisses his forehead and wipes his tears with a paper towel. She tells him "You've got your cream on. Okay, big boy? You've got your cream on" (reference to the topical anesthetic). When the nurse is cleaning the port area on the boy's chest he says "I'm scared" in a whimper. The nurse says "It's okay to be scared" and the mother says "Remember I told you I don't care if you cry. If you want to cry, you can." At the instant the needle goes in the child does not react. His mom says "That's my brave boy" and kisses his face.

Common supportive behaviors include listening to the child's fears or concerns and responding empathically. In the example above the child said that he was scared, and the mother responded by telling him that it was okay to be scared and that he could cry if he felt the need to. Showing understanding of what the child is experiencing is another strong supportive behavior. Staying at a close proximal distance to the child is another way to show support in this context. Staying close makes the parent available to touch the child or respond to the child quickly should the child reach out for the parent.

Invalidating. The first example of an invalidating parent is the Caucasian mother of a 10-year-old boy who is in the clinic to receive a port start procedure. During the pre-procedure phase the child is lying on the exam table watching a movie and his mother stands in front of the exam table. She is leaning back on the table, watching the movie, and intermittently talking to the child about the movie. When the nurse comes in with the cart with the medical equipment on it, there is little reaction from the mother and child. The nurse briefly leaves and returns with a waste pan. When she enters she says “All right” and hands the child the waste pan. He begins to whimper, and she says “You got it. You got it” (in reference to the waste pan). The child then curls into a fetal position on the exam table and quietly whines. The mother says to the nurse “He has actually been taking his pills, so I don’t know what his problem is” dismissively while waving her hand in the child’s direction. A few seconds go by and the mother says “(child’s name) they are recording you acting like a baby” in reference to data collection for this study. The nurse tries to explain that they have a full waiting room and that she has to get him going so she can see the other kids, and the child says “Go do them,” to which she responds “I can’t. I have your stuff ready now. I have to do you first.” The mother asks him to sit up and he does not. She then wraps her arms around him and pulls him up and sits him against the wall on the exam table while he makes quiet whimpering noises. The child raises his knees to block his chest and puts his head in his hands and folds himself into his knees. The nurse puts her hands on his legs and tries to pull them down but he does not budge. She then says “Okay, come on. I’m going to count to ten.” She begins to count and the mother says to the child “Hold my hand. Come on.” She repeatedly says “Come on” to the child until the nurse reaches ten. After the nurse has counted to ten, she again tries to pull his legs down and out of the way, but he resists. As she pulls his legs down he moves his upper body down as well so he is hunched over his legs. The nurse then pushes his shoulders back away from his legs while his mother (sitting beside him) pulls his shoulders back as well. He yells “Ow! You are pinching me!” and the mother replies “Yeah. Well, it got you to sit up, didn’t it?” while smiling at the nurse. He keeps his head tucked down and his arms across his chest. The nurse backs away and says “Okay, I’m going to have (nurse’s name) do it. Bye-bye” and leaves the room. He yells “Noooo!” and loudly cries, and she says “Okay, are you ready?” He replies “I’m scared!” and his mother says “It’s okay to be scared. It’s not okay to act like this.” The nurse walks back over to him and says “Legs down” while pulling his legs down away from his chest and “You know I know how to do it.” He continues to whimper but when asked to hold his shirt up out of the way he complies. He asks his mother to hold the waste pan close to his face (in case he vomits). While the nurse cleans the area and gets ready to insert the needle the child whimpers. The mother says “Quit freaking out. Quit freaking out.” The nurse counts to three and quickly inserts the needle. Within three seconds of the needle insertion the child vomits into the waste pan. The mother says “You are done. What was the freakout about?” as the child vomits. He says “It hurts” and the mother replies “It hurts? Well, making yourself throw up – I’m pretty sure that would hurt.” When the nurse leaves, the child sits on the exam table with his head tucked between his knees silently.

Another example of an invalidating parent is an African-American mother of a 4-year-old boy. During the pre-procedure phase the mother and child play a card game while they both sit on the exam table. They play the game for about 10 minutes and then the mother lies down on the table while the child sorts and looks through the cards. After about 5 minutes she gets up and sits on a chair next to the exam table and reads a magazine. She says “It takes forever” every few minutes (in reference to the duration of the clinic visit). Throughout the pre-procedure phase the child tries to get her attention by saying “Momma” or “Mom” and she ignores him while looking at the magazine. When the nurse enters with the cart the child is sitting on the chair and does not react. She says “How are you today, power hitter?” and the child puts the cards down and gives her a big smile. His mother says “Come on, (child’s name)” and pats the exam table, but he smiles and says “No.” The mother and the nurse both laugh, and the mother says “Come on, (child’s name). We’re not going to cry” and then he begins to whine in protest. His mother looks at the nurse and rolls her eyes while saying “Oh, my God.” The mother goes over to the child and picks him up and places him on the exam table and then sits on the exam table next to him. The nurse approaches and the child pulls away from her. She says “I just have to take the cream off” and he starts to cry while his mother pulls him back to lean against her so she can hold him. His mother says “It’s not going to hurt.” The nurse takes the cream off (the topical anesthetic) and mother says “That’s it. Did it hurt?” This is clearly a lie because the needle was not in yet. The child cries and says “It hurts!” and the mother responds by saying “It doesn’t even hurt. Don’t cry.” When he says again that it hurts she says “How do you know?” (He knows because he has had this procedure several times in a few months). Mom picks him up and sits in the chair with him on her lap so she can hold him while the nurse accesses his port. He continues to cry and begins to wiggle and the nurse says “Do we have to get someone in here to help hold you?” and his mother says “Yeah” while rolling her eyes. The nurse continues to try to access his port without additional staff to help her. He says “I don’t want that!” and the nurse says “I know” and the mother, frustrated, says, “You have to! Stop!” The nurse is able to access his port and mom yells “That’s it! Stop it!” While the nurse is giving his chemo, he cries and coughs, and mom says “That’s it, (child’s name), that’s it. Don’t cry. We’re done.” He is holding a video game and she takes it away and says “No, because you cry like that.” The child continues to cry even when the nurse backs away and is done with him. The mother says, “Want to sit next to me?” and he says “No.” She says “Next time (name) is going to come with you because you cry like that.” After the nurse leaves the room the mother says, “Why did you cry?

You shouldn't cry like that. You need to be a tough guy." He says "I am not a tough guy." He silently watches a movie while he is getting his chemotherapy through his port.

Correlations

The first aim of this dissertation is to examine the relationship between parent self-reported social support and parent and child reactions to treatment procedures. The first hypothesis was that the more social support a parent had access to, the less the parent and child would be distressed and the more the child would cooperate during procedures. In order to achieve this aim and test this hypothesis, we will first examine the correlations between parent and child reactions to the treatment procedures and parent self-reported social support controlling for child age, study site, and procedure type.

Results indicated a significant and negative relationship between the number of sources of social support and parent procedure-related distress such that the more sources of support a parent reported the lower their procedure-related distress (see Table 9). The number of sources of social support was also significantly correlated with child procedure-related distress (negatively) and cooperation (positively) such that the more sources of support a parent reported the lower child procedure-related distress and the higher child cooperation. Social support associated with the clinic visit and situational social support were both significantly and positively related to parent positive affect. The number of people present at the procedure was not related to reactions to treatment.

Table 9. Partial Correlations between Social Support and Parent and Child Reactions to Treatment (controlling for child age, study site and procedure type)

Variables Tested	Number of Sources of Soc Sup	Satisfaction with Num. Sources	Soc. Sup. Assoc. W/ Clinic Visit	Situatioal Soc. Support	Parents Present During Procedure
State Anxiety	- 0.124	- 0.108	- 0.090	- 0.122	- 0.140
Parent Procedure-Related Distress	- 0.301	- 0.163	- 0.186	- 0.115	- 0.109
Empathic Concern	- 0.067	0.052	0.100	0.168	- 0.109
Personal Distress	- 0.135	- 0.128	- 0.053	- 0.116	- 0.162
Positive Affect	0.113	0.154	0.292**	0.263**	0.013
Negative Affect	- 0.107	- 0.080	- 0.024	0.003	- 0.085
Child Cooperation	0.228*	- 0.067	0.176	0.053	- 0.072
Child Procedure-Related Distress	- 0.26**	0.066	- 0.057	0.052	0.049

**p<.05, **p<.01, ***p<.001*

State anxiety was rated 1-5 (higher ratings = more anxiety), parent procedure-related distress was rated 1-6 (higher ratings = more distress), empathic concern was rated 1-5 (higher ratings = more empathic concern), personal distress was rated 1-5 (higher ratings = more personal distress), positive and negative affect were rated 1-5 (higher ratings = more positive/negative affect), child cooperation was rated 1-7 (higher ratings = more cooperation), child procedure-related distress was rated 1-6 (higher ratings = more procedure-related distress).

The second aim of this dissertation research was to examine the relationship between parent self-reported social support and parent-child communication during treatment procedures. Controlling for child age, study site, and procedure type, the only significant relationship was between the number of parents present during the procedure and the number of invalidating statements the child experienced before the procedure (see Table 10). If more than one parent/caregiver was present during the procedure the child experienced fewer invalidating statements during the pre-procedure phase. There was no significant relationship between the parent-child communication patterns and parent self-reported social support, thus the third hypothesis was not supported.

Table 10. Partial Correlations between Social Support and Parent-Child Communication (controlling for child age, study site and procedure type)

Variables Tested	Parent-Child Communicaton (0=supportive, 1-invalidating)	Pre-Procedure Number of Invalidating Stmts.	Procedure Number of Invalidating Stmts.
Number of Sources of Soc Sup	0.060	0.059	- 0.084
Satisfaction with Num. Sources	0.162	0.067	0.114
Soc. Sup. Assoc. W/ Clinic Visit	0.043	- 0.104	- 0.003
Situatioal Soc. Support	0.100	- 0.014	0.158
Number of Parents Present During Procedure	0.130	0.241**	0.102

**p<.05, **p<.01, ***p<.001*
Number of sources of social support was the raw number parents reported, satisfaction with social support was rated 1-6 (higher ratings = more satisfaction), social support associated with the clinic visit was rated 1-5 (higher ratings = more satisfaction), situational social support was rated 1-5 (higher ratings = more social support), number of parents present during the procedure was coded as 0-one parent or 1-more than one parent.

In summary, families in this study have a lot in common; for example, most parents were mothers, most children were male, and the majority of children had been diagnosed with ALL. However, families differed on several key variables based on group affiliation; for example, children at SJ were less distressed during procedures than children at CHM, and female caregivers reported more personal distress after procedures than fathers did. However, although there are several differences between groups, these differences are representative of families with a child diagnosed with cancer. Controlling for study site, child age, and procedure type, I found that social support was related to lower parent and child procedure-related distress and better child cooperation and parent positive affect. In order to look more closely at these relationships and what factors may predict parent and child reactions to treatment, in the next chapter I conduct further analyses to better understand these relationships.

CHAPTER 5

Results-Linear and Logistic Regression Analyses

Introduction

This chapter reports the findings from linear and logistic regression analyses in order to test the three hypotheses. This chapter is divided into two main sections. The first section reports the findings testing hypotheses 1 and 2. This section will cover which variables predict parent and child reactions and child cooperation before and during treatment procedures. Within this section there are several subsections reporting results for each reaction before and during the treatment procedure (i.e., parent anxiety, child cooperation). A basic model containing demographic predictors of parent and child reactions to treatment was first tested in each section followed by a model predicting each of five measures of social support. These social support measures include: satisfaction with situation-specific social support (assessed the day of the child's treatment-related medical procedure), social support associated with the clinic visit on the day of the medical procedure, and the number of sources of social support and satisfaction with the number of sources (assessed at study entry). The second section reports findings from logistic regression analyses in order to test hypothesis 3. This section covers results that indicate the relationship between social support and parent-child communication during procedures.

Parent State Anxiety

Basic Model: Predictors of Parent State Anxiety. Parent state anxiety was collected from parents before the child experienced the medical procedure (before the pre-procedure phase). Almost 13% of the variance in this model (F = 3.34, p = .003) can be explained by the study site, the type of procedure, whether more than one parent was present, whether the parent was white, the child's diagnosis, whether the parent used an invalidating communication pattern during the clinic visit, and child age. These variables are included in the other models shown in

Table 11 and will be referred to as "basic predictor variables." Significant predictors of parent anxiety included the study site (*b* = -11.920, *p* = .003) and procedure type (*b* = 11.247, *p* = .007) (see Table 11 Basic Model). Parents whose children were in treatment at SJ had less anxiety than parents of children at CHM. Institutional policies and procedures at the two hospitals need to be investigated in order to explain the differences between the two sites in this study. Additionally, children who experienced a procedure under general anesthesia (LP or BMA) had parents who had more state anxiety prior to the procedure. For these procedures, parents are separated from their children for an hour or so while the child gets the procedures, and it may be that parents are more anxious about these procedures because they cannot be present. It is also possible that parents are aware of the risks of general anesthesia and are anxious about their child being sedated. According to the Society for Pediatric Anesthesia's website, risks include dizziness, nausea, vomiting, sore throat, and agitation upon waking from anesthesia.

Situational Social Support as Predictor of State Anxiety. The next column adds situational support as a predictor of parental anxiety. Almost 13% of the variance in this model (*F* = 3.102, *p* = .003) can be explained by the basic predictor variables and situational social support (see Table 11, Model 1). As with the basic model, significant predictors of parent anxiety included the study site (*b* = -12.090, *p* = .003) and procedure type (*b* = 11.926, *p* = .005). Parents whose children were in treatment at SJ or who had a child who had a port start at either hospital had less anxiety. The addition of situational social support did not increase the explanatory power from the basic model, and situational social support was not a significant predictor of parental anxiety.

Social Support associated with the Clinic Visit as Predictor of State Anxiety. Over 14% of the variance in this model (*F* = 3.188, *p* = .003) can be explained by the basic predictor variables and social support associated with the clinic visit (see Table 11, Model 2). The explained variance was higher than the basic model. As with the previous two models, significant predictors of parent anxiety included the study site (b = -12.530, p = .003), procedure type (b = 12.352, p = .005) and whether the parent was white (b = 7.601, p = .034). Parents whose children were in treatment at SJ, who had a child who had a port start, or who were white had less anxiety. Social support associated with the clinic visit was not a significant predictor of parental anxiety.

Number of Sources of Social Support as Predictor of State Anxiety. Almost 13% of the variance in this model (F = 3.049, p = .004) can be explained by the basic predictor variables and the number of sources of social support (see Table 11, Model 3). As with the previous models significant predictors of parent anxiety included the study site (b = -11.816, p = .003) and procedure type (b = 10.845, p = .010). The number of social support sources was not a significant predictor, and adding this variable did not increase the explained variance compared to the basic model.

Satisfaction with Social Support as Predictor of Parent Anxiety. Almost 12% of the variance in this model (F = 2.910, p = .006) can be explained by the basic predictor variables and satisfaction with social support (see Table 11, Model 4). As with the previous models, significant predictors of parent state anxiety included the study site (b = -11.974, p = .003) and procedure type (b = 11.344, p = .007). Parents at SJ and parents of children who had a port start had less anxiety. The satisfaction with social support sources was not a significant predictor, and adding this variable decreased the explained variance compared to the basic model. None of the social support variables decreased parental anxiety as shown in Table 11.

Table 11. Coefficients of the Full Model of Parent Anxiety for the Basic Model, Situational Social Support, Social Support Associated with the Clinic Visit, Number of Sources of Social Support and Satisfaction with Social Support (Standard Errors in Parentheses)

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	- 11.920 (3.946)**	- 12.090 (3.943)**	- 12.530 (4.095)**	- 11.816 (3.948)**	- 11.974 (3.968)**
Procedure Type	11.247 (4.105)**	11.926 (4.141)**	12.352 (4.326)**	10.845 (4.125)**	11.344 (4.137)**
Number of Parents Present	- 5.663 (3.150	- 4.915 (3.211)	- 5.026 (3.264)	- 5.238 (3.179)	- 5.351 (3.351)
Ethnicity	6.069 (3.346)	6.233 (3.343)	7.601 (3.533)*	6.237 (3.350)	5.942 (3.390)
Diagnosis	3.790 (4.101)	3.583 (4.098)	3.083 (4.253)	2.856 (4.207)	3.622 (4.161)
Parent-Child Communication	0.216 (3.876)	0.543 (3.881)	1.544 (4.072)	0.109 (3.878)	0.356 (3.925)
Child Age	0.044 (.485)	- 0.024 (.488)	0.142 (.508)	0.034 (.485)	0.041 (.487)
Situational Soc. Support		- 2.084 (1.803)			
Soc. Sup. Assoc. w/ Clinic Visit			- 1.232 (1.557)		
Number of Sources of Soc. Sup.				- 0.610 (.613)	
Satisfaction with Soc. Sup.					- 0.525 (1.857)
Constant	48.726 (5.557)***	57.104 (9.128)***	51.402 (8.610)***	51.375 (6.163)***	51.499 (11.276)***
Observatons	114	114	107	114	114
Degrees of freedom	107	106	99	106	106
R-squared	0.179	0.190	0.205	0.187	0.180
Adjusted R-squared	0.126	0.129	0.141	0.126	0.118
Significance	0.003	0.003	0.003	0.004	0.006

**p<.09, **p<.01, ***p<.001*

Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent, 1=more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child as was the child's raw age in years. Situatioal social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Parent Procedure Related Distress

Basic Model: Predictors of Parent Procedure Related Distress. Parent procedure-related distress was collected immediately after the child's medical procedure; parents rated on a six-point scale how distressed they were when the child had the procedure. Over 7% of the variance in this model (*F* = 2.264, *p* = .035) can be explained by basic predictor variables (see Table 12 Basic Model). The only significant predictor of parent procedure-related distress was study site (*b* = --.821, *p* = .020). Parents of children in treatment at SJ were less distressed than parents of children in treatment at CHM.

Situational Social Support as Predictor of Parent Procedure Related Distress. Over 7% of the variance in this model (*F* = 2.119, *p* = .040) can be explained by the basic predictor models and situational social support (see Table 12, Model 1). As with the basic model, the only significant predictor of parent procedure related distress was study site (*b* = -.834, *p* = .018). Parents whose children were in treatment at SJ had less distress. Situational social support was not a significant predictor and adding it to the basic model did not make a difference in explained variance.

Social Support associated with the Clinic Visit as Predictor of Parent Procedure Related Distress. Over 10% of the variance in this model (*F* = 2.535, *p* = .015) can be explained by the basic predictor variables and social support associated with the clinic visit (see Table 12, Model 2). In this model, the only significant predictors of parent procedure related distress were study site (*b* = -.917, *p* = .009) and the procedure type (*b* = .725, *p* = .049). Parents whose children were in treatment at SJ and/or had a child who had a port start at either hospital had less distress. While social support associated with the clinic visit was not a significant predictor of parent procedure-related distress, its addition to the model increased the percent of variance explained.

Number of Sources of Social Support as Predictor of Parent Procedure Related Distress. Almost 13% of the variance in this model (*F* = 3.072, *p* = .004) can be explained by the basic predictor variables and the number of sources of social support (see Table 12, Model 3). The only significant predictors of parent procedure related distress included the study site (*b* = -.796, *p* = .021) and the number of sources of social support (*b* = -.146, *p* = .006). Parents of children in treatment at SJ had less distress. Parents who reported more sources of social support had significantly less distress, and the amount of explained variance increased with the addition of the sources of support variable.

Satisfaction with Social Support as Predictor of Parent Procedure Related Distress. Eight percent of the variance in this model (F = 2.242, p = .030) can be explained by the basic predictor variables and satisfaction with social support (see Table 12, Model 4). The only significant predictor of parent procedure-related distress was study site (b = -.844, p = .017). Parents at SJ had less distress than parents at CHM. Satisfaction with social support was not a significant predictor nor did its inclusion increase the amount of explained variance in parent procedure-related distress.

Table 12. Coefficients of the Full Model of Parent Distress for the Basic Model, Situational Social Support, Social Support Associated with the Clinic Visit, Number of Sources of Social Support and Satisfaction with Social Support (Standard Errors in Parentheses)

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	- 0.821 (.349)*	- 0.834 (.349)*	- 0.917 (.345)**	- 0.796 (.338)*	- 0.844 (.348)*
Procedure Type	0.440 (.363)	0.494 (.366)	0.725 (.364)*	0.344 (.354)	0.482 (.362)
Number of Parents Present	- 0.469 (.278)	- 0.409 (.284)	- 0.296 (.275)	- 0.367 (.272)	- 0.334 (.294)
Ethnicity	0.044 (.296)	0.056 (.296)	0.020 (.297)	0.084 (.287)	- 0.011 (.297)
Diagnosis	0.147 (.362)	0.130 (.363)	0.162 (.358)	- 0.077 (.361)	0.074 (.364)
Parent-Child Communication	0.111 (.343)	0.137 (.343)	0.357 (.343)	0.085 (.332)	0.1725 (.344)
Child Age	- 0.057 (.043)	- 0.063 (.043)	- 0.022 (.043)	- 0.060 (.042)	- 0.058 (.043)
Situational Soc. Support		- 0.167 (.160)			
Soc. Sup. Assoc. w/ Clinic Visit			- 0.236 (.131)		
Number of Sources of Soc. Sup.				- 0.146 (.053)**	
Satisfaction with Soc. Sup.					- 0.227 (.163)
Constant	3.301 (.491)***	3.972 (.807)***	3.887 (.725)***	3.936 (.528)***	4.498 (.988)***
Observatons	114	114	107	114	114
Degrees of freedom	107	106	99	106	106
R-squared	0.129	0.138	0.170	0.188	0.145
Adjusted R-squared	0.072	0.073	0.103	0.127	0.080
Significance	0.035	0.040	0.015	0.004	0.030

**p<.09, **p<.01, ***p<.001*

Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent,1=more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child age was the child's raw age in years. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Empathic Concern

Basic Model: Predictors of Empathic Concern. Parent empathic concern was collected from the parents before the child experienced the medical procedure (before the pre-procedure phase). The basic model examining whether the basic predictor variables could predict empathic concern was not significant ($F = 1.861$, $p = .083$) (see Table 12).

Situational Social Support as Predictor of Empathic Concern. Over 8% of the variance in this model ($F = 2.279$, $p = .027$) was explained by the basic predictor variables and situational social support (see Table 13, Model 1). The only significant predictor of empathic concern was situational social support ($b = 1.245$, $p = .032$). Parents who had more social support had more empathic concern for their children before the treatment procedure (before the pre-procedure phase). Adding this variable to the basic model increased the amount of explained variance.

Social Support associated with the Clinic Visit, Number of Sources of Social Support, and Satisfaction with Social Support as Predictors of Empathic Concern. Models 2, 3, and 4 used the basic predictor variables and three different measures of social support. None of these models were statistically significant. Thus, social support did not predict empathetic concern.

Table 13. Coefficients of the Full Model of Empathic Concern for the Basic Model, Situational Social Support, Social Support Associated with the Clinic Visit, Number of Sources of Social Support and Satisfaction with Social Support (Standard Errors in Parentheses)

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	- 1.853 (1.270)	- 1.751 (1.249)	- 1.873 (1.315)	- 1.845 (1.276)	- 1.783 (1.270)
Procedure Type	- 0.270 (1.322)	- 0.676 (1.312)	- 0.128 (1.389)	- 0.299 (1.334)	- 0.394 (1.324)
Number of Parents Present	- 1.143 (1.014)	- 1.590 (1.018)	- 1.302 (1.048)	- 1.112 (1.028)	- 1.543 (1.073)
Ethnicity	1.423 (1.077	1.331 (1.060)	1.379 (1.134)	1.435 (1.083)	1.586 (1.085)
Diagnosis	1.550 (1.320)	1.673 (1.299)	2.123 (1.365)	1.483 (1.360)	1.765 (1.332)
Parent-Child Communication	0.892 (1.248)	0.696 (1.230)	1.174 (1.307)	0.884 (1.254)	0.712 (1.256)
Child Age	0.079 (.156)	0.120 (.155)	0.106 (.163)	0.078 (.157)	0.083 (.594)
Situational Soc. Support		1.245 (.572)*			
Soc. Sup. Assoc. w/ Clinic Visit			0.617 (.500)		
Number of Sources of Soc. Sup.				- 0.044 (.198)	
Satisfaction with Soc. Sup.					0.673 (.594)
Constant	18.028 (1.789)***	13.025 (2.893)***	15.164 (2.764)***	18.220 (1.993)***	14.475 (3.610)***
Observatons	114	114	107	114	114
Degrees of freedom	107	106	99	106	106
R-squared	0.109	0.147	0.135	0.109	0.119
Adjusted R-squared	0.050	0.082	0.065	0.042	0.053
Significance	0.083	0.027	0.064	0.128	0.086

**p<.09, **p<.01, ***p<.001*

Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent, 1= more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child age was the child's raw age in years. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw number parents reported. Satisfactio with social support was rated 1-6 (higher ratings = more satisfaction).

Parent Personal Distress

Basic Model: Predictors of Parent Personal Distress. Parent personal distress was collected before the recording of the pre-procedure phase and before the child experienced the medical procedure and is a subscale of the Emotional Response Questionnaire (Batson, 1991). This measure assessed parent emotional response before the pre-procedure phase. Parent procedure-related distress, discussed earlier, is related specifically to the child's procedure and parents rate their distress after the procedure. Eleven percent of the variance in this model (*F* = 3.003, *p* = .006) can be explained by basic predictor variables. Significant predictors of parent personal distress included the study site (*b* = -4.592, *p* = .001) and procedure type (*b* = 3.082, *p* = .036) (see Table 14). Parents whose children were in treatment at SJ had less personal distress than parents of children at CHM. As previously stated, the differences in the study sites and how differences may affect parent and child reactions to medical procedures need further investigation. Additionally, children who experienced a procedure under general anesthesia (LP or BMA) had parents who had more personal distress prior to the procedure. For these procedures, parents are separated from their children for an hour or so while the child gets the procedure and are not present to witness the actual procedure. General anesthesia also carries several risks and parents may understand these risks and therefore have more personal distress during these procedures.

Situational Social Support as Predictor of Personal Distress. Over 10% of the variance in this model (*F* = 2.714, *p* = .009) can be explained by the basic predictor variables and situational social support (see Table 14, Model 1). As with the basic model, the only significant predictors of parent personal distress included the study site (*b* = -4.637, *p* = .001) and procedure type (*b* = 3.261, *p* = .028). Parents whose children were in treatment at SJ and/or had a child who had a port start at either hospital had less personal distress. Situational social support was not a predictor of personal distress and had no impact on the adjusted R-squared.

Social Support associated with the Clinic Visit as Predictor of Personal Distress. Over 10% of the variance in this model (*F* = 2.576, *p* = .013) can be explained by the basic predictor models and social support associated with the clinic visit (see Table 14, Model 2). As with the previous two models, significant predictors of parent personal distress included the study site (*b* = -4.532, *p* = .003) and procedure type (*b* = 3.196, *p* = .043). Parents whose children were in treatment at SJ and/or who had a child who had a port start at either hospital had less personal distress. Social support associated with the clinic visit was not a significant predictor and did not impact the explained variance.

Number of Sources of Social Support as Predictor of Personal Distress. Almost 11% of the variance in this model (*F* = 2.725, *p* = .009) can be explained by the basic predictor variables and the number of sources of social support (see Table 14, Model 3). As with the previous models, the only significant predictors of parent personal distress included the study site (*b* = -4.558, *p* = .001) and procedure type (*b* = 2.952, *p* = .045). Parents whose children were in treatment at SJ and/or had a child who had a port start at either hospital had less personal distress. The number of sources of social support was not a significant predictor and the adjusted R-squared was similar to the basic model.

Satisfaction with Social Support as Predictor of Personal Distress. Over 10% of the variance in this model (*F* = 2.632, *p* = .011) can be explained by the basic predictor variables and satisfaction with social support (see Table 14, Model 4). As with the previous models, the only significant predictors of parent personal distress were study site (*b* = -4.622, *p* = .001) and procedure type (*b* = 3.135, *p* = .034). Parents whose children were in treatment at SJ and/or had a child who had a port start at either hospital had less personal distress. Satisfaction with social support was not a significant predictor nor did it increase the amount of explained variance. Thus, none of the social support variables decreased parental personal distress in any of the models shown in Table 14.

Table 14. Coefficients of the Full Model of Personal Distress for the Basic Model, Situational Social Support, Social Support Associated with the Clinic Visit, Number of Sources of Social Support and Satisfaction with Social Support
(Standard Errors in Parentheses)

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	- 4.592 (1.394)**	- 4.637 (1.396)**	- 4.532 (1.476)**	- 4.558 (1.395)**	- 4.622 (1.401)**
Procedure Type	3.082 (1.450)*	3.261 (1.467)*	3.196 (1.559)*	2.952 (1.458)*	3.135 (1.460)*
Number of Parents Present	- 1.823 (1.113)	- 1.625 (1.137)	- 1.854 (1.176)	- 1.686 (1.124)	- 1.651 (1.183)
Ethnicity	1.219 (1.182)	1.259 (1.184)	1.655 (1.274)	1.273 (1.184)	1.148 (1.197)
Diagnosis	2.176 (1.448)	2.122 (1.452)	2.203 (1.533)	1.876 (1.487)	2.084 (1.469)
Parent-Child Communication	- 0.549 (1.369)	- 0.462 (1.375)	- 0.210 (1.468)	- 0.583 (1.371)	- 0.471 (1.386)
Child Age	0.163 (.171)	0.145 (.173)	0.204 (.183)	0.160 (.172)	0.162 (.173)
Situational Soc. Support		- 0.550 (.639)			
Soc. Sup. Assoc. w/ Clinic Visit			- 0.156 (.561)		
Number of Sources of Soc. Sup.				- 0.196 (.217)	
Satisfaction with Soc. Sup.					- 0.290 (.655)
Constant	13.265 (1.963)***	15.477 (3.233)***	13.148 (3.103)***	14.1017 (2.178)***	14.795 (3.981)***
Observatons	114	114	107	114	114
Degrees of freedom	107	106	99	106	106
R-squared	0.164	0.170	0.172	0.171	0.166
Adjusted R-squared	0.110	0.107	0.105	0.108	0.103
Significance	0.006	0.009	0.013	0.009	0.011

*p<.05, **p<.01, ***p<.001

Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent, 1= more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child age was the child's raw age in years. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Parent Positive Affect

Basic Model: Predictors of Parent Positive Affect. Almost 14% of the variance in this model (F = 3.531, p = .002) can be explained by the Basic predictor variables. Significant predictors of parent positive affect included parent ethnicity and child age (see Table 15). White parents had less positive affect than parents who were not white (b = -6.208, p = .001). There may be a cultural component at work here, whereby whites have fewer positive emotions during stressful situations. This finding requires further investigation. There was a significant and positive relationship between child age and positive affect (b = .689, p = .009), such that parents of older children had more positive affect. This is likely because younger children require more attention and may be more distressed during clinic visits, and older children may be easier for parents to work with.

Situational Social Support as Predictor of Positive Affect. Over 21% of the variance in this model (*F* = 4.663, *p* = .000) can be explained by basic predictor variables and situational social support (see Table 15, Model 1). Significant predictors of parent positive affect included parent ethnicity, child age, and situational social support. As was true in the basic model, white parents had less positive emotions than non-white parents (*b* = -6.428, *p* = .000). Parents of older children had more positive affect (*b* = .787, *p* = .002) than parents of younger children. In this model, higher ratings of situational social support (*b* = 2.982, *p* = .002) were also significantly related to parent positive affect and increased the adjusted R-square of the model compared to the basic model.

Social Support associated with the Clinic Visit as Predictor of Positive Affect. Almost 21% of the variance in this model (*F*=4.533, *p*=.000) can be explained by the basic predictor variables and social support associated with the clinic visit (see Table 15, Model 2). As with the previous two models, significant predictors of parent positive affect included parent ethnicity, child age, and social support associated with the clinic visit. As was the case in the first two models, parents who were non-white (*b* = -6.517, *p* = .000) and parents of older children (*b* = .619, *p* = .018) had more positive affect. Parents who reported they had social support the day of the clinic visit (*b* = 2.625, *p* = .001) had higher positive affect. The addition of the social support measure increased the explained variance in Model 2 compared to the basic model.

Number of Sources of Social Support as Predictor of Positive Affect. Over 15% of the variance in this model (*F* = 3.528, *p* = .001) can be explained by the basic predictor variables and the number of sources of social support (see Table 15, Model 3). The only significant predictors of parent positive affect included the parent ethnicity (*b* = -6.364, *p* = .000) and child age (*b* = .698, *p* = .008). White parents had less positive emotions than non-white parents, and parents of older children had more positive affect. The number of sources of social support did not predict positive affect.

Satisfaction with Social Support as Predictor of Positive Affect. Over 13% of the variance in this model (*F* = 3.261, *p* = .002) can be explained by the basic predictor variables and satisfaction with social support (see Table 15, Model 4). The only significant predictors of parent positive affect were parent ethnicity (*b* = -5.935, *p* = .001) and child age (*b* = .695, *p* = .008). White parents had less positive emotions than non-white parents, and parents of older children had more positive affect. Satisfaction with social support was not a predictor of positive affect. Thus, two of the four measures of social support predicted positive affect in Table 15, situational specific social support and social support associated with the visit.

Table 15. Coefficients of the Full Model of Parent Positive Affect for the Basic Model, Situational Social Support, Social Support Associated with the Clinic Visit, Number of Sources of Social Support and Satisfaction with Social Support (Standard Errors in Parentheses)

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	2.966 (2.106)	3.210 (2.020)	2.778 (2.076)	2.869 (2.087)	3.082 (2.105)
Procedure Type	0.901 (2.191)	- 0.071 (2.122)	0.640 (2.193)	1.273 (2.181)	0.694 (2.195)
Number of Parents Present	1.009 (1.681)	- 0.062 (1.645)	0.405 (1.654)	0.615 (1.680)	0.340 (1.778)
Ethnicity	- 6.208 (1.785)**	- 6.428 (1.713)***	- 6.517 (1.791)***	- 6.364 (1.771)***	- 5.935 (1.799)**
Diagnosis	- 0.421 (2.188)	- 0.126 (2.100)	1.158 (2.156)	0.444 (2.224)	0.063 (2.208)
Parent-Child Communication	1.248 (2.069)	0.780 (1.988)	1.179 (2.064)	1.347 (2.050)	0.947 (2.082)
Child Age	0.689 (.259)**	0.787 (.250)**	0.619 (.258)*	0.698 (.256)**	0.695 (.259)**
Situational Soc. Support		2.982 (.924)**			
Soc. Sup. Assoc. w/ Clinic Visit			2.625 (.789)**		
Number of Sources of Soc. Sup.				0.565 (.324)	
Satisfaction with Soc. Sup.					1.123 (.985)
Constant	26.006 (2.965)***	14.021 (4.677)**	15.603 (4.365)***	23.553 (3.258)***	20.077 (5.983)***
Observatons	114	114	107	114	114
Degrees of freedom	107	106	99	106	106
R-squared	0.188	0.260	0.268	0.210	0.198
Adjusted R-squared	0.135	0.205	0.209	0.151	0.137
Significance	0.002	0.000	0.000	0.001	0.002

$*p<.05$, $**p<.01$, $***p<.001$

Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent, 1= more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child age was the child's raw age in years. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Parent Negative Affect

Basic Model: Predictors of Parent Negative Affect. Over 9% of the variance in this model (F = 2.634, p = .015) can be explained by the basic predictor variables. Significant predictors of parent negative affect included study site (b = -5.798, p = .002) and the type of procedure the child had (b=3.930, p=.038) (see Table 16). Parents of children in treatment at CHM had less negative affect than parents whose children were in treatment at SJ. Parents whose children had an LP or BMA had more negative affect. This may be because when children undergo an LP/BMA they cannot eat or drink for 12 hours before the procedure, but the procedure is often later in the morning. Children may be irritable and difficult to manage, placing more stress on the parents.

Situational Social Support as Predictor of Negative Affect. Over 8% of the variance in this model (*F* = 2.283, *p* = .027) can be explained by the basic predictor variables and situational social support (see Table 16, Model 1). Significant predictors of parent negative affect included study site (*b* = -5.798, *p* = .002) and the type of procedure the child had (*b* = 3.929, *p* = .041). As with the previous model, parents of children in treatment at SJ had less negative affect. Parents of children who had a procedure with general anesthesia had more negative affect. Situational social support did not predict negative affect.

Social Support associated with the Clinic Visit as Predictor of Negative Affect. Over 10% of the variance in this model (*F* = 2.528, *p* = .015) can be explained by the basic predictor variables and social support associated with the clinic visit (see Table 16, Model 2). As with the previous two models, significant predictors of parent negative affect included study site (*b* = -5.959, *p* = .002) and the type of procedure the child had (*b* = 4.733, *p* = .019). As with the previous model, parents of children in treatment at SJ and/or parents whose children had a port start at either hospital had less negative affect. Social support associated with the clinic visit did not predict negative affect.

Number of Sources of Social Support as Predictor of Negative Affect. Over 8% of the variance in this model (*F* = 2.323, *p* = 024) can be explained by the basic predictor variables and the number of sources of social support (see Table 16, Model 3). Significant predictors of parent negative affect included study site (*b* = -5.773, *p* = .002) and the type of procedure the child had (*b* = 3.833, *p* = .045). As with the previous model, parents of children in treatment at SJ and/or parents whose children had a port start at either hospital had less negative affect. The number of sources of social support did not significantly predict negative affect.

Satisfaction with Social Support as Predictor of Negative Affect. Over 8% of the variance in this model (*F* = 2.326, *p* = .024) can be explained by the basic predictor variables and satisfaction with social support (see Table 16, Model 4). Significant predictors of parent negative affect included study site (*b* = -5.846, *p* = .002) and the type of procedure the child had (*b* = 4.015, *p* = .036). As with the previous model, parents of children in treatment at SJ and parents whose children had a port start had less negative affect. Satisfaction with social support was not predictive. In Models 1-4, no measure of social support predicted negative affect.

Table 16. Coefficients of the Full Model of Parent Negative Affect for the Basic Model, Situational Social Support, Social Support Associated with the Clinic Visit, Number of Sources of Social Support and Satisfaction with Social Support (Standard Errors in Parentheses)

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	- 5.798 (1.801)**	- 5.798 (1.811)**	- 5.959 (1.873)**	- 5.773 (1.808)**	- 5.846 (1.809)**
Procedure Type	3.930 (1.874)*	3.929 (1.902)*	4.733 (1.978)*	3.833 (1.889)*	4.015 (1.886)*
Number of Parents Present	- 1.416 (1.438)	- 1.417 (1.475)	- 1.398 (1.492)	- 1.313 (1.456)	- 1.142 (1.528)
Ethnicity	0.766 (1.527)	0.766 (1.535)	1.088 (1.616)	0.807 (1.534)	0.655 (1.546)
Diagnosis	0.517 (1.871)	0.517 (1.882)	0.727 (1.945)	0.292 (1.926)	0.371 (1.897)
Parent-Child Communication	0.384 (1.769)	0.384 (1.782)	1.208 (1.862)	0.358 (1.776)	0.507 (1.789)
Child Age	- 0.225 (.221)	- 0.225 (.224)	- 0.221 (.232)	- 0.228 (.222)	- 0.228 (.222)
Situational Soc. Support		0.004 (.828)			
Soc. Sup. Assoc. w/ Clinic Visit			- 0.127 (.712)		
Number of Sources of Soc. Sup.				- 0.147 (.281)	
Satisfaction with Soc. Sup.					- 0.460 (.846)
Constant	19.395 (2.536)***	19.380 (4.192)***	19.126 (3.937)***	20.034 (2.822)***	21.821 (5.141)***
Observatons	114	114	107	114	114
Degrees of freedom	107	106	99	106	106
R-squared	0.147	0.147	0.170	0.149	0.149
Adjusted R-squared	0.091	0.083	0.103	0.085	0.085
Significance	0.015	0.027	0.015	0.024	0.024

**p<.05, **p<.01, ***p<.001*

Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent, 1= more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child age was the child's raw age in years. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Based on the previous analyses, the strongest predictors of parent reactions to treatment are the study site, child age, the type of procedure, parent ethnicity, and, in a few models, social support. The next set of results examines what factors predict child reactions to treatment procedures.

Child Cooperation

Basic Model: Predictors of Child Cooperation. Child cooperation was rated by nurses, parents and independent observers and an average score of the three raters was used for analysis. Thirty-nine percent of the variance in this model (F = 11.4, p = .000) can be explained by the basic predictor variables. Significant predictors of child cooperation included whether the parent used an invalidating communication pattern during the clinic visit (b = -1.278, p = .000) and child age (b = .182, p = .000) (see Table 17). Children whose parents used an invalidating communication pattern during the clinic visit were less cooperative than children whose parents were supportive/normalizing during both phases. It is not possible to know from these data whether the invalidating communication pattern preceded the child cooperative behavior or was in response to it. As could be expected, older children were more cooperative during procedures.

Situational Social Support as Predictor of Child Cooperation. Over 39% of the variance in this model (F = 10.140, p = .000) can be explained by the basic predictor variables and situational social support (see Table 17, Model 1). As with the basic model, whether the parent used an invalidating communication pattern during the clinic visit (b = -1.300, p = .000) and child age (b = .186, p = .00) were significantly related to child cooperation. Children who were invalided and children who were younger were less cooperative during the procedure. Situational social support did not predict child cooperation.

Social Support associated with the Clinic Visit as Predictor of Child Cooperation. Almost 42% of the variance in this model (F = 10.651, p = .000) can be explained by the basic predictor variables and social support associated with the clinic visit (see Table 17, Model 2).

Whether the parent used an invalidating communication pattern during the clinic visit (*b* = -1.431, *p* = .000), child age (*b* = .165, *p* = .00) and social support associated with the clinic visit (*b* = .217, *p* = .045) were significantly related to child cooperation. Children whose parents used an invalidating communication pattern during the clinic visit were less cooperative than children whose parents were supportive/normalizing during both phases. Older children were significantly more cooperative during procedures and parents who reported more social support associated with the clinic visit had children who were more cooperative during the procedure. This social support measure increased the adjusted R-square from the basic model.

Number of Sources of Social Support as Predictor of Child Cooperation. Over 40% of the variance in this model (*F* = 10.639, *p* = .000) can be explained by the basic predictor variables and the number of sources of social support (see Table 17, Model 3). Whether the parents used an invalidating communication pattern during the clinic visit (*b* = -1.263, *p* = .000) and child age (*b* = .183, *p* = .000) were significant predictors of child cooperation. Older children and children whose parent used a supportive communication pattern during the clinic visit were more cooperative during the procedure. The number of sources of social support did not predict child cooperation.

Satisfaction with Social Support as Predictor of Child Cooperation. Over 38% of the variance in this model (*F* = 9.882, *p* = .000) can be explained by the basic predictor variables and satisfaction with social support (see Table 17, Model 4). As with the basic model and the previous models, whether the parent used an invalidating communication pattern during the clinic visit (*b* = -1.278 *p* = .000) and child age (*b* = .182, *p* = .000) were significantly related to child cooperation. Satisfaction with social support did not predict child cooperation.

In every equation, whether the parent used an invalidating communication pattern during the clinic visit and the age of the child were both significant predictors of child cooperation. Younger children and/or children whose parent used an invalidating communication pattern during the clinic visit were less cooperative during the procedure. In one model, social support associated with the clinic visit was also a predictor of child cooperation during the procedure. None of the other measures of social support were predictive of child cooperation.

Table 17. Coefficients of the Full Model of Child Cooperation for the Basic Model, Situational Social Support, Social Support Associated with the Clinic Visit, Number of Sources of Social Support and Satisfaction with Social Support (Standard Errors in Parentheses)

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	0.298 (.288)	0.310 (.288)	0.165 (.281)	0.284 (.285)	0.298 (.290)
Procedure Type	0.315 (.300)	0.268 (.302)	0.153 (.296)	0.369 (.298)	0.315 (.302)
Number of Parents Present	- 0.160 (.230)	- 0.212 (.235)	- 0.097 (.224)	- 0.218 (.229)	- 0.159 (.245)
Ethnicity	- 0.001 (.244)	- 0.011 (.244)	- 0.040 (.242)	- 0.023 (.242)	0.001 (.2548)
Diagnosis	- 0.330 (.299)	- 0.316 (.299)	- 0.482 (.291)	- 0.204 (.304)	- 0.331 (.304)
Parent-Child Communication	- 1.278 (.283)***	- 1.300 (.283)***	- 1.431 (.279)***	- 1.263 (.280)***	- 1.278 (.287)***
Child Age	0.182 (.035)***	0.186 (.036)***	0.165 (.035)***	0.183 (.035)***	0.182 (.036)***
Situational Soc. Support		0.143 (.132)			
Soc. Sup. Assoc. w/ Clinic Visit			0.217 (.107)***		
Number of Sources of Soc. Sup.				0.082 (.044)	
Satisfaction with Soc. Sup.					- 0.001 (.136)
Constant	5.045 (.406)***	4.470 (.667)***	4.446 (.590)***	4.687 (.445)***	5.052 (.823)***
Observatons	114	114	107	114	114
Degrees of freedom	107	106	99	106	106
R-squared	0.427	0.434	0.463	0.445	0.427
Adjusted R-squared	0.390	0.391	0.419	0.403	0.384
Significance	0.000	0.000	0.000	0.000	0.000

**p<.05, **p<.01, ***p<.001*
Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent, 1=more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child age was the child's raw age in years. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Child Procedure-Related Distress

Basic Model: Predictors of Child Procedure-Related Distress. Child procedure-related distress was rated by nurses, parents, independent observers and the children themselves. All ratings were correlated, thus, average of all four raters was used in analysis. Almost 33% of the variance in this model (*F* = 8.991, *p* = .000) can be explained by the basic predictor variables. Significant predictors of child procedure-related distress included whether the parent used an invalidating communication pattern during the clinic visit (*b* = 1.114, *p* = .000) and child age (*b* = -.200, *p* = .000) (see Table 18). Children whose parents used an invalidating communication pattern during the clinic visit were more distressed than children who had a parent that was supportive/normalizing. It is not possible to know from these data whether the invalidating communication preceded the child procedure-related distress behavior or was in response to it. As could be expected, younger children were more distressed during procedures.

Situational Social Support as Predictor of Child Procedure-Related Distress. Over 32% of the variance in this model (*F* = 7.800, *p* = .000) can be explained by the basic predictor variables and situational social support (see Table 18, Model 1). Significant predictors of child procedure-related distress included whether the parent used an invalidating communication pattern during the clinic visit (*b* = 1.110, *p* = .000) and child age (*b* = -.199, *p* = .000) (see Table 18. Model 1). Children whose parent used an invalidating communication pattern during the clinic visit were more distressed than children who had a parent that was supportive/normalizing during both phases. As could be expected, younger children were more distressed during procedures. Situational social support was not predictive of child's distress.

Social Support associated with the Clinic Visit as Predictor of Child Procedure-Related Distress. Almost 35% of the variance in this model (*F* = 8.153, *p* = .000) can be explained by the basic predictor variables and social support associated with the clinic visit (see Table 18, Model 2). Whether the parent used an invalidating communication pattern during the clinic visit (*b* = 1.251, *p* = .000) and child age (*b* = -.197, *p* = .000) were significantly related to child procedure-related distress. Children who had a parent that used an invalidating communication pattern during the clinic visit were more distressed than children who had a parent that was supportive/normalizing during both phases. Younger children were more distressed during procedures. Social support associated with the clinic visit did not predict child’s distress.

Number of Sources of Social Support as Predictor of Child Procedure-Related Distress. Thirty-five percent of the variance in this model ($F = 8.688$, $p = .000$) can be explained by the basic predictor variables and the number of sources of social support (see Table 18, Model 3). Whether the parent used an invalidating communication pattern during the clinic visit ($b = 1.097$, $p = .000$), child age ($b = -.202$, $p = .000$), procedure type ($b = -.628$, $p = .044$) and the number of sources of social support ($b=-.097$, $p=.036$) were significant predictors of child procedure-related distress. The addition of the number of sources of social support resulted in the highest amount of explained variance in Table 18. As in the previous models, children whose parents used an invalidating communication pattern during the clinic visit were more distressed and younger children were more distressed. Children who had an LP/BMA were less distressed than those who had a port start. Children who have an LP/BMA are asleep during the painful part of the procedure and have no memory of the procedure itself, so they are more likely to be less distressed because of this factor. It is interesting to note while children are less distressed, the parents of children getting an LP/BMA are more distressed. They are sitting in a waiting room, away from their children. The more sources of social support a parent reports, the less distress the child experiences during a procedure. This is a very intriguing finding in that support the parent receives inadvertently seems to help the child be less distressed. Parents who have more social support may be better equipped emotionally, or even with tangible resources, to help the child during treatment.

Satisfaction with Social Support as Predictor of Child Procedure-Related Distress. Over 32% of the variance in this model (*F* = 7.800, *p* = .000) can be explained by the basic predictor variables and satisfaction with social support (see Table 18, Model 4). As with the previous models, whether the parent used an invalidating communication pattern during the clinic visit (*b* = 1.107, *p* = .000) and child age (*b* = -.200, *p* = .000) were significantly related to child procedure-related distress. Children whose parent used an invalidating communication pattern during the clinic visit and/or younger children were more distressed. Satisfaction with social support did not predict child procedure-related distress.

In every equation predicting child responses to treatment procedures, whether the parent used an invalidating communication pattern during the clinic visit and the age of the child were both significant predictors of child procedure-related distress. In one model, the number of sources of social support and the type of procedure were also predictors of child procedure-related distress during the procedure. While parents cannot change the age in which children develop cancer nor the types of procedures childhood cancer treatment requires for treatment of these diseases, it may be possible to modify the way parents communicate with the children and the social support available to them. The only social support measure that was predictive of child procedure-related distress was the number of sources of social support.

Table 18. Coefficients of the Full Model of Child Distress for the Basic Model, Situational Social Support, Social Support Associated with the Clinic Visit, Number of Sources of Social Support and Satisfaction with Social Support (Standard Errors in Parentheses)

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	0.146 (.299)	0.148 (.301)	0.142 (.302)	0.163 (.294)	0.149 (.301)
Procedure Type	- 0.564 (.111)	- 0.572 (.316)	- 0.404 (319)	- 0.628 (.308)*	- 0.569 (.314)
Number of Parents Present	0.048 (.239)	0.039 (.245)	0.053 (.241)	0.115 (.237)	- 0.033 (.254)
Ethnicity	- 0.165 (.254)	- 0.167 (.255)	- 0.181 (.260)	- 0.138 (.250)	- 0.159 (.257)
Diagnosis	0.274 (.311)	0.277 (.312)	0.392 (.314)	0.126 (.314)	0.282 (.315)
Parent-Child Communication	1.114 (.294)***	1.110 (.296)***	1.251 (.300)***	1.097 (.289)***	1.107 (.297)***
Child Age	- 0.200 (.037)***	- 0.199 (.037)***	- 0.197 (.037)***	- 0.202 (.036)***	- 0.200 (.037)***
Situational Soc. Support		0.025 (.137)			
Soc. Sup. Assoc. w/ Clinic Visit			- 0.072 (.115)		
Number of Sources of Soc. Sup.				- 0.097 (.046)*	
Satisfaction with Soc. Sup.					0.025 (.141)
Constant	3.836 (.421)***	3.737 (.696)***	3.973 (.635)***	4.257 (.459)***	3.702 (.855)***
Observatons	114	114	107	114	114
Degrees of freedom	107	106	99	106	106
R-squared	0.370	0.371	0.397	0.396	0.371
Adjusted R-squared	0.329	0.323	0.349	0.350	0.323
Significance	0.000	0.000	0.000	0.000	0.000

**p<.05, **p<.01, ***p<.001*

Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent, 1=more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child age was the child's raw age in years. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Based on the models tested in this chapter, two of the strongest predictors of parent and child reactions to treatment are study site and procedure type. Parents of children at SJ had less anxiety, less procedure-related distress, less personal distress, and less negative affect than parents of children in treatment at CHM. Parents of children who had a port start at either hospital also had less anxiety, less procedure-related distress, less personal distress, and less negative affect. Parent ethnicity was also a predictor of how anxious the parent was and how much positive affect the parent reported. Parents who were white had less anxiety and, interestingly, less positive affect. It may be that while whites in this situation had more general anxiety the day of the child's treatment, non-whites may have more positive affect on those days. This is an interesting finding that cannot fully be explained with these data and would require further analysis. Child age was also a predictor of parent positive affect with parents of older children reporting more positive affect. All four social support measures were predictors of parent and child reactions to treatment procedures. Parents who had more sources of social support and children whose parents had more sources of social support both had less distress during the procedures. Parents who were satisfied with their social support specifically related to the clinic visit had more positive affect and had children who were more cooperative during the procedure. Parents who had more situational social support had more empathic concern and more positive affect as well. Not surprisingly, children who were older had less distress and were more cooperative during procedures. Children who had a port start were also more distressed than children who had an LP/BMA. Whether the parent communication in an invalidating manner during the clinic visit predicted child procedure-related distress and cooperation but not any parent reactions to treatment. Children who had a parent who communicated in an invalidating manner were more distressed and less cooperative than children who were not. As previously stated, it is not possible to know if this relationship is causal as children may be invalidated because they are already distressed and uncooperative. The next section will cover the logistic regression analysis used to determine the relationship between social support and parent-child communication during the procedures.

Logistic Regression

In order to examine the relationship between parent social support and the way parents and children communicate during the child's cancer-related medical procedure I conducted logistic analyses. Several models were tested using the same basic predictor variables used in the linear regression models, and adding in individually each measure of social support (social support associated with the clinic visit, situation social support, number of sources of social support and satisfaction with social support). Social support was not a significant predictor of parent child communication patterns in any of the models (See Table 19).

Table 19. Logistic Regression Estimating the Effects of Social Support on Parent-Child Communication Patterns

Variables Tested	Basic Model	Model 1	Model 2	Model 3	Model 4
Site	0.12***	0.121***	0.146***	0.121***	0.121**
Procedure Type	0.338	0.315	0.238	0.335	0.304
Number of Parents Present	2.552	2.347	2.319	2.561	1.907
Ethnicity	1.036	1.035	0.916	1.040	1.264
Diagnosis	0.609	0.656	0.551	0.595	0.749
Child Age	0.908	0.918	0.870	0.908	0.911
Situational Soc. Support		1.344			
Soc. Sup. Assoc. w/ Clinic Visit			1.115		
Number of Sources of Soc. Sup.				0.987	
Satisfaction with Soc. Sup.					2.355
Log-liklihood	94.000	93.290	86.200	93.980	90.500
Cox & Snell R-Squared	0	0	0	0	0
Nagelkerke R-Squared	0	0	0.374	0	0
Degrees of freedom	1.000	1.000	1.000	1.000	1.000
Number of cases	115	115	115	115	115

**p<.05, **p<.01, ***p<.001*

Site was coded as 0=CHM, 1=SJ. Procedure type was coded as 0=port starts, 1=LP/BMA. Number of parents present was coded as 0=one parent, 1=more than one parent. Ethnicity was coded as 0=non-White, 1=White. Diagnosis was coded as 0=ALL, 1=all other pediatric cancers. Parent-child communication was coded as 0=supportive/normalizing, 1=invalidating/distancing. Child age was the child's raw age in years. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit. Number of sources of social support was the raw numbe parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

Study site was consistently significant across all models, continuing to show, as in previous results, that where the child is treated has an effect on several outcome variables, including whether the parent used an invalidating communication pattern during the clinic visit. Children in treatment at CHM had parents who were more likely communicate in an invalidating manner than children in treatment at SJ. Differences in study location needs to be examined further to explore institutional differences as well as differences in hospital procedures.

No detectable relationship between parent self-reported social support and the way parents communicate with their children before and during treatment procedures could be determined. It may be that having (or not having) social support does not influence the way in which parents communicate with their children or it may be that the sample was too small to detect any relationship.

Several measures of social support were predictors of parent and child reactions to treatment procedures. In most models, the strongest predictors of parent and child reactions to treatment were child age, study location and the procedure type. The next chapter will provide an overview of this study, a discussion of the findings, the implications of the findings, and directions for future research.

CHAPTER 6

Conclusions

This chapter begins with an overview of the research project and the methodology, followed by a discussion of the major findings. Study limitations, policy implications and suggestions for future research are also discussed.

Summary

The purpose of this study was to examine the relationships between social support, parent-child communication during pediatric cancer-related medical procedures and parent and child reactions to treatment procedures. This study used Pearlin's (1980, 1989) Stress Process Theory as a model, whereby the sources of stress were the procedures, the mediators of stress were parent social support resources, and the manifestations of stress were the parent and child reactions to treatment. The specific objectives of this dissertation were:

1) To determine the relationship between parent social support and a) parent and child reactions to treatment procedures including parent anxiety, positive and negative emotions, personal distress, empathic concern and distress related to the medical procedure as well as child procedure-related distress and cooperation.

2) To determine the relationship between parent and child communication during the procedure and parent and child reactions to treatment procedures.

3) To determine the relationship between parent self-reported social support and parent and child communication during treatment sessions.

Background

Though cancer is the leading disease-related cause of death in children in the U.S., many cancers are curable (NCI, 2013). Despite a relatively high survival rate, childhood cancer poses serious psychological and physical stressors both to the child and to his/her family (Faulkner et al., 1995). Parents and children report that the numerous invasive and painful medical procedures associated with treatment are worse than the disease itself (Hedstrom et al., 2003; Ljungman, Gordh, Sorensen, Kreuger, 1999). Research suggests that while children are in treatment for several months to several years, treatment related distress and pain do not decrease as the child experiences more procedures and may worsen over time if the child's negative reactions to treatment are not addressed early (Katz et al., 1980; Zeltzer et al., 1990). Although childhood cancer often results in a cancer-free outcome, the diagnosis, lengthy and exhaustive treatment, and long-term psychosocial implications continue to be major stressors for children and their families.

This dissertation used the stress process theory (Pearlin, 1980, 1982, 1989; Pearlin & Lieberman, 1979; Pearlin et al., 1981) to examine the specific stressor of children's cancer-related medical procedures. The stress process theory posits that there are three main components to stress: the sources of stress, the mediators of stress and the manifestations of stress. The sources of stress are different for everyone and even the same stressor may vary in how it is perceived by individuals. The mediators of stress are the cognitive and emotional resources people can call upon to mediate the impact of the stress. The manifestations of stress are the outcomes of stress, or what happens when people experience stress. These include emotional, as well as physical, reactions including anxiety, fear, and increased blood pressure or tension headaches. Children with cancer and their parents have reported that treatment-related medical procedures are worse than the disease itself (Hedstrom et al., 2003) therefore, in this study, the source of stress was defined as the child's medical procedure. Previous research has indicated that the way parents communicate with children affects child reactions to treatment procedures (Dahlquist et al., 1995; Manne et al., 1992) and social support has been shown to buffer the negative affects of having a child diagnosed with cancer (Jackson et al., 2009; Wijnberg-Williams et al., 2006). Thus, the moderators of stress in this study were parent-child communication during the child's treatment procedure and parent social support. The manifestation of stress was operationalized as parent and child reactions to treatment procedures, including parent anxiety, positive and negative emotions, positive and negative affect, parent and child procedure-related distress and child cooperation.

Social support is the verbal and nonverbal communication that helps manage uncertainty about a situation, the self, another or a relationship and functions to enhance a perception of personal control (Albrecht & Adelman, 1987). The social support literature suggests that social support is protective and can buffer the deleterious effects of stressful events as well as enhance physical and emotional well-being (Garwick et al., 1998; Thoits, 2010). While social support has been studied in the pediatric cancer context, there is no research on how social support may be related to parent and child reactions to the child's cancer-related medical procedure. This research examined the relationship between social support and parent and child communication during the child's medical procedure and parent and child reactions to treatment procedures.

This study was funded by a Blue Cross and Blue Shield of Michigan Student Award Grant (#1801-SAP) and a National Science Foundation Dissertation Improvement Grant (#1068218) and used video and questionnaire data from an ongoing National Cancer Institute funded study (#R01CA138981-05, Penner: PI) that investigates the relationships between social support, parent-child communication during the child's cancer related medical procedure and parent and child reactions to these procedures.

Children between the ages of three and twelve were enrolled into the Penner et al. study if the child had been diagnosed with cancer within the last 18 months, the parents read and spoke

English and the child received lumbar punctures, bone marrow aspirations or port starts as part of treatment. Families were recruited from Children's Hospital of Michigan in Detroit, MI and St. Jude Children's Research Hospital in Memphis, TN. One hundred and fifteen children and their parents comprised the sample used in the analyses for this dissertation research. Upon study entry, parents completed a measure of social support that asked the number of people the parent could count on for support and their satisfaction with that number. At study entry parents also completed a demographic questionnaire and a medical history questionnaire for their child. On the day of the child's regularly scheduled visit, parents completed a self-administered questionnaire before the procedure that measured situational social support, social support associated with the clinic visit, state anxiety, empathic concern and personal distress. The parent and child were video-recorded in the exam room while they waited for the procedure and during the procedure. After the procedure parents rated their own procedure-related distress and their child's procedure-related distress and cooperation during the procedure and completed a measure of positive and negative affect. The nurse who administered the procedure and independent observers who later watched the video-recordings also rated the child's procedure-related distress and cooperation. The average of nurse, parent, observer and child ratings of child procedure-related distress and Independent observers watched the video-recordings and coded parent-child communication using an established coding system (Cline et al., 2006).

Variability in the data was evident so T-test analyses were conducted to look for difference between several groups. Based on results from these analyses, partial correlations, linear regression and logistic regression analyses were conducted to ascertain the predictors of parental distress, child cooperation, and parent-child communication.

Linear and logistic regression models were employed for hypothesis testing. The linear regression was used to test the first and second hypotheses. Four indicators of social support were entered separately into each equation, including social support associated with the clinic visit, situational social support, the number of sources of social support, and satisfaction with social support. Situational social support was measured using the Multidimensional Scale of Perceived Social Support (Dahlem, et al., 1991). Parents are asked to rate on a five-point scale the extent to which they agreed with statements like “my family really tries to help me.” The Social Support Questionnaire (Sarason et al., 1983) was collected at baseline and asks parents to report the size and satisfaction with their social support network. On the day of treatment, before the procedure, parents were asked to indicate their satisfaction with social support received that day related to the clinic visit. The variables for parent-child communication were binary and indicated whether or not the child had been invalidated at all during the clinic visit. Coders viewed the video recordings and determined, based on training and an extensive codebook, whether or not the parent was communicating supportively, or in a normalizing, distancing or invalidating manner. A small number of parents were coded as distancing, invalidating or normalizing so categories were combined and the codes became supportive/normalizing and distancing/invalidating.

The outcome variables included state anxiety assessed before the pre-procedure phase (State-Trait Anxiety Inventory for Adults; Spielberger, 1977), parent procedure-related distress after the procedure (Faces Scale; Wong & Baker, 1988), parent positive (empathic concern) and negative (personal distress) emotions before the pre-procedure procedure phase (Emotional Response Questionnaire; Batson, 1991), parent positive and negative affect after the procedure was completed (Positive and Negative Affect Scale; Watson et al., 1988), child procedure-related distress (Faces Scale; Wong & Baker, 1988), and child cooperation during the procedure (seven point scale, from not at all cooperative to completely cooperative). Logistic regression was conducted to test the third hypothesis where the outcome variable was whether or not the parent communicated in an invalidating manner during the interaction. Table 20 below summarizes the findings from the multivariate analyses. An "S" means that the social support variable significantly predicted the dependent variable.

Table 20. Summary of Significant Findings on the Impact of Type of Social Support on Parent and Child Reactions to Treatment Procedures and Parent-Child Communication

Outcome Variables	Type of Social Support			
	Situational Social Support	Associated with Clinic Visit	Number of Sources of Social Support	Satisfaction with Social Support
Parent State Anxiety				
Parent Procedure Related Distress			S	
Parent Empathic Concern	S			
Parent Personal Distress				
Parent Positive Affect	S	S		
Parent Negative Affect				
Child Cooperation		S		
Child Distress			S	
Parent-Child Communication				

Hypothesis 1. When parent social support is greater, reactions to treatment will be less distressing for both the parent and the child and the child will be more cooperative during the procedure. Out of 24 regressions using four measures of social support, six were predictive of parent and child reactions to treatment. Social support appears to have a greater impact on parent outcomes compared to child outcomes. Situational social support predicted parent empathic concern before the procedure and their positive affect after the procedure. Social support associated with the clinic visit predicted parent positive affect after the procedure and child cooperation during the procedure. The number of sources of social support predicted parent and

child procedure-related distress. Not all forms of social support predict parent and child reactions to treatment and some were better predictors than others. Levels of satisfaction with social support did not predict any of the dependent variables.

Hypothesis 2. When parents communicate in a supportive or normalizing manner during the interaction, as opposed to an invalidating or distancing manner, parents and children will have more positive reactions to treatment procedures and the children will be more cooperative. Several models indicated that children who had parents who were invalidating were less cooperative and more distressed during the procedure. However there was no relationship between parent-child communication and parent reactions to the treatment procedures. It is not possible to detect causality in these data. It may be that parents are invalidating an already distressed and uncooperative child, or it may be that children are not cooperating and are distressed and thus parents invalidate. The lack of findings for parent reactions to treatment may also be related to the low number of parents who invalidated their children. More research would need to be conducted to further test this hypothesis.

Hypothesis 3. When parent self-reported social support is greater, parents and children will be more likely to communicate in a supportive or normalizing manner as opposed to an invalidating or distancing manner. There was no evidence to support this hypothesis. Only 24.3% (*n* = 28) of parents in this study communicated in an invalidating manner with the child during the clinic visit. It may be that the sample was too small to detect the relationship between social support and parent-child communication patterns.

There are several reasons why this dissertation research had so many non-significant findings. It may be that some outcome measures are more personality measures than responses to cancer treatment procedures. For example, parent positive and negative affect and state anxiety may be more related to parent personality than parent reactions to treatment procedures. Although these measures were used to measure state anxiety and emotions the day of a treatment procedure, they may actually be measuring parents' general anxiety and emotional state. The overall study and analyses generated several significant results. Some findings were not directly related to the aims or the hypotheses but were nonetheless interesting and are discussed below.

Child Age. In several models child age was significantly associated with parent positive affect, child cooperation and child distress. Not surprisingly, older children were more cooperative and less distressed than younger children. Older children may be more mature, and may have had more experiences with doctor's offices, even for just routine immunizations, than younger children. Older children may simply be more mature and better able to handle the distress involved with getting a cancer treatment related procedure. Parents of older children had more positive affect immediately after the procedure. It may be that because older child are less distressed and more cooperative during the procedure, parents of older children have more positive affect.

Ethnicity. Regression analyses showed that White parents had less anxiety and less positive affect than non-White parents. White parents had less anxiety before the procedure but less positive affect after the procedure. There may be an interesting cultural component at play in these results as it seems counterintuitive that White parents would have both less anxiety before the procedure and less positive emotions after the procedure. More research is needed in order to further investigate these findings.

Study Site. The study site was the single strongest predictor in several analyses in this dissertation. Children at CHM had longer waiting times, longer procedures, experienced more invalidating statements before and during the procedure, were more likely to be invalidated and were more distressed and less cooperative than children at SJ. Parents at CHM were more distressed, had more empathic concern, more personal distress, more negative affect, and more anxiety. The decision was made to conduct the analyses with the sites together because the sample would have been too small to be meaningful had they been separated. However, study site accounted for a great deal of the variability in this sample.

The two locations in this study were different in several ways. First, children in treatment at CHM typically come to the hospital from the Metro Detroit area while at SJ, children come from all over the country, even the world, for treatment. Parents of children at SJ never see an invoice or a bill while parents of children at CHM likely have to spend a fair amount of time and energy making sure hospital bills are paid and copays are met. Indeed, Eiser and Upton (2006) found that the costs associated with frequent hospital stays, including overnight accommodations, food, care of siblings, and travel to hospitals caused increased financial stress for parents of children with cancer.

This research is not the first to uncover differences between children in treatment at SJ and those in treatment elsewhere. A recent study on survival rates (Pui, et al., 2012) compared data from the SEER registry to data from the SJ registry and found that black children with several forms of cancer listed in the SEER registry had lower survival rates for both time periods under investigation (1992-2000 and 2001-2007). However, for children treated at SJ there were no significant differences in survival. The researchers argued that at SJ, where children are treated regardless of their ability to pay, disparities disappear and therefore with access to treatment all children can achieve high survival rates.

Parent Gender. Based on the literature (Clements et al., 1990; Mastroyannopoulou et al., 1997) men and women vary in how they react to stress, including the stress from having a child with a chronic illness. Results indicated that mothers and grandmothers made more invalidating statements to the child and that children who had a father as the primary caregiver were more cooperative and less distressed. It was also found that fathers had more personal distress than mothers and grandmothers. It was expected that there would be more significant results based on parent gender however only 17% of the sample were fathers. It may be that with a larger sample more findings would have been significant.

Parent Social Support and Child Reactions. Another intriguing finding is that some forms of social support that parents have are related to child reactions to treatment. A critical finding of this dissertation research is that social support has various dimensions and not all of these dimensions are related to parent and child reactions to treatment. Previous research has indicated that parent behavior during medical procedures impacts how children react to procedures (Blount et al., 1991; Manimala et al., 2000) and that it is likely that children can read parent anxiety and fear through parent communication. Parent satisfaction with social support was not predictive of parent and child reactions to treatment while situational social support, social support associated with the clinic visit, and the number of sources of social support were related to parent reactions. Social support associated with the clinic visit and number of sources of social support were the only forms of social support related to child reactions to treatment.

In this study, increased parent social support was related to decreased child distress and increased child cooperation. It is interesting that a resource available to the parent would have a relationship with child reactions to treatment. It may be that children have the same social supports that their parents do, or it may be that parents who feel supported are better able to support their children. It is not possible to determine causality from these data but further investigation could examine the mechanism by which parent social support impacts child reactions to treatment.

Summary. In this research of social support, parent-child communication and parent and child reactions to treatment procedures, results showed that social support plays a role in moderating the stressful and negative affects of treatment related procedures in this context. Some forms of social support had significant findings while others did not. Satisfaction with social support appears to be a strong predictor of parent and child reactions to treatment. While it was anticipated that social support would have a positive relationship with parent-child communication during procedures, that finding did not prove to be significant.

Limitations

As is true in most recent on special populations, this study had limitations. First, the sample size is small and it is not known whether more subjects would have changed some of the findings of the study. Pediatric cancer is relatively rare and observational and behavioral studies in this context typically have small sample sizes. While participants in this study vary in several ways, they reflect the population of families going through treatment for this disease.

Second, it was not possible to enroll families at the time of diagnosis. Earlier work (Penner et al., 2008; Penner, Harper, & Albrecht, 2011) conducted as part of the Penner et al. study showed that at the time of initial diagnosis parents were so overwhelmed that it is not practical or appropriate to recruit them for a study not directly related the child's treatment. It has been the strategy of the research team collecting these data to intentionally wait several weeks after diagnosis before approaching families about participation.

Third, this study utilized self-report data from parents. Given the problems with self-report data (Bernard, Kilworth, Kronenfeld, & Sailer, 1984; Henry, Moffitt, Caspi, Langley, &

Silva, 1994), it is possible that inaccurate parent reports may mask relationships between some variables under investigation. However, this study did not solely rely on self-report data but also used observational data and statistically significant findings with these data were also found. Additionally, these data were collected at one point in time, and the observational data in particular should be assessed with some caution. The video-recordings were made at one time, one day and we have no way of knowing if the parent and child interaction that day is indicative of how they usually act with one another or if the day that we recorded was a good day, a bad day or any sort of anomalous day.

Fourth, data was collected at only two study locations. The addition of a second site provided rich and valuable data, but it would be unwise to generalize about the sites in this study. The study sites may not be indicative of how children with cancer are typically treated or how parents typically react to treatment procedures. However, for the purposes of this dissertation research it was valuable to have two distinct sites provide data, one hospital that is larger, well-funded and resource-rich and one that is smaller, regional and resource-lacking.

Fifth, it is not possible to determine causality from these data. For example, parent situational social support assessed before the procedure was related to parent positive affect after the procedure. It is not possible to know whether the social support reported before the procedure caused the positive emotions after the procedure or if parents already had positive affect when they reported their social support. Sequential, observation analyses could be conducted to address causality research questions.

Policy Implications

This research supports the hypothesis that social support is related to parent and child reactions to treatment. This suggests that improving social support for parents could improve child and parent reactions to treatment procedures.

Findings from this study identified two policy implications. First, identifying modifiable factors to decrease children's distress and increase cooperation during treatment procedures has important implications for families of pediatric cancer patients and the medical staff who administer such procedures. Findings from this study showed that parents who had more social support had children who were less distressed and more cooperative during procedures. Interventions or peer-mentoring programs could be developed to increase parent social support and ultimately increase child cooperation and decrease child distress, making children more manageable patients. Successful interventions to increase social support and coping strategies have already be developed and tested (Thoits, 2010). The role of social support in the specific context of pediatric cancer treatment procedures has not been explored until now, and these findings indicate that social support can play a role in buffering the negative effects of the distressing pediatric cancer-related medical procedure for both children and their parents.

Second, the strongest predictors of parent and child reactions to treatment were child age, procedure type and study site. While parents cannot change the age at which children are diagnosed with cancer, nor can they change the procedures hospitals use to treat cancer, parents can choose the hospital where their child will be treated. Parents of children at St. Jude were less anxious before the procedure, had less procedure-related distress, reported less personal distress before the procedure, and had more negative affect after the procedure. It is unclear from these data why parents at SJ appear to have less distress overall yet have more negative affect after the procedure. Further research needs to be conducted. Child distress and cooperation did not vary based on study site. As previously stated, this dissertation research is not the first to uncover differences between St. Jude and other children's hospitals. It is important to identify what factors determine why study site makes such a big difference in parent and treatment-related psychosocial outcomes.

Future Research

Future research should examine the ways in which parent social support relates to the way children and parents react to treatment procedures. We are not able to determine from these data whether or not parent social support affects parents who in turn affect child reactions to treatment or whether parental social support directly affects child reactions to treatment procedures. It may be worth investigating how parent resources could relate to child cooperation and distress. It may be that children have the same social support resources as parents do, by nature of the familial relationship. It could also be that parents who feel they are supported are in turn better able to support the child during stressful medical procedures. Future research could set out to answer these questions.

Sequential analysis may also be beneficial in explaining these data. It would be important to know whether parent invalidating behaviors occur in response to an already distressed child or if children become distressed and parents, in turn, invalidate the child. It would also be beneficial to examine parents who invalidate to see what triggers the behavior, what their emotional state/affect is when they invalidate and how the child reacts to the invalidating behavior. If there are factors that can be modified, and we know children who are invalidated are more distressed and less cooperative, an intervention to decrease invalidating behaviors, and thus increase cooperation and decrease distress, could be developed.

Future research should also examine the differences in the two study locations. Indeed, the larger R01 Penner et al. study is currently examining several ways in which the study sites differ, including how chaotic the interactions are, how long it takes to do the actual procedure, how long the families wait in the exam room for the procedure and who is present (in and out of the room) during the interactions. Future research could also examine more structural attributes including where people live when the child is in treatment, the costs associated with cancer care, the convenience of treatment schedules, how is treatment and paid for. Since treatment at SJ is completely covered, and families never receive an invoice, it would be important to examine just what the impact of that is on key outcomes.

Study location may have implications for both parent and child outcomes. This dissertation research showed that where the child was treated had a relationship to both parent and child reactions to treatment and on how parents communicate during procedures. St. Jude is a well-resourced, top of the line cancer hospital, however, Children's Hospital of Michigan is also a well-respected pediatric specialty hospital. The U.S. News and World Report rankings for 2013-14 ranked CHM as #7 in pediatric specialties and #41 in pediatric cancer while SJ is ranked #1 in pediatric specialties and #5 in pediatric cancer.

The differences in study site are more nuanced. While the sites differ in many ways, and SJ is clearly ranked higher than CHM by the U.S. News rankings, the differences between study sites, and the impact these differences have for families are subtle. Future research should examine structural differences between the two study locations. Researchers should also examine how the interactions vary between sites.

Future research could examine the effect of an intervention to increase social support in the pediatric cancer treatment context. Several social support interventions exist but none have been identified that worked in this specific population. Future research could develop an intervention to expand families' social networks and then follow families over time and measure several quality of life, health and psychosocial outcomes to determine what effect, if any, social support has in this context.

There are several ways in which the study sites differ and future research should investigate the impact of treatment location on psychosocial outcomes for both children and their parents. If there are processes or systems in place at one institution that make the treatment experience more tolerable for families, other institutions may be able to adopt these practices.

Parent social support is important in the pediatric cancer medical procedure context. Children with cancer, and their parents, would benefit from increased social support resources, which could improve long-term psychosocial functioning for both children in treatment for cancer and their parents.

APPENDIX A: PARENT-CHILD COMMUNICATION CODEBOOK

CODE BOOK

(Revised: October 3, 2011)

Parent's Definition of the Situation

General Guidelines:

Context: remember that the child is highly vulnerable in this context.

For each pediatric video recording, you will code only the primary caregiver (may be a grandparent, aunt, guardian, etc. rather than a biological parent; these are specified in advance by the investigator) once for each of three possible time periods: pre-procedure (waiting and preparation combined), procedure, and post-procedure. Some cases may begin with the procedure (rather than pre-procedure); the post-procedure phase may be short for port start procedures and in most general anesthesia procedures, there will not be a post-procedure. In cases when the child receives two procedures: count both procedures as a single procedure time. (Time periods are specified in advance by the investigator.)

The codes reflect four different approaches used by parents in "defining the situation" involving a child's potentially painful and/or distressing treatment procedure. Codes are exhaustive and mutually exclusive; that is, only one code can be used per time frame per parent. Although a parent may use behaviors from a mixture of approaches to define the situation in a given time period, coders should use a gestalt/global approach, identifying the most dominant approach used by a given parent. In most cases, the most dominant approach will be the approach used most frequently in that time period. However, as identified in the rules below, invalidation represents an exception.

Note that we are not judging the parents or their intentions. We cannot know what they are thinking or why they engage in particular behaviors. Rather, we are assessing patterns of communication behavior.

Procedures:

Using the recording sheet provided, record one code (from 1 to 4) for the identified primary caregiver only for each time period. Code tapes in the randomized sequence provided.

Take at least a brief break between coding phases within a case. If you are conflicted about coding a given phase, re-visit and review that phase after a break.

Review the code book before you start coding on each coding day.

CODES

Parent’s Definition of the Situation

Some General Rules:

1. Parents should not be penalized (i.e., judged as uninvolved) for time spent talking with the doctor (e.g., conducting an examination, talking about test results or treatment), the social worker, or the research assistant (RA). These should be viewed as necessary tasks. Typically talking to the doctor or social worker occurs during pre-procedure; typically talking with the RA occurs during post-procedure. However, parents *choosing* to engage in talk with nurses or with each other during the clinic visit (versus attending to the child) can be considered uninvolved with the child.

2. Third parties in the room may function to take attention from the patient. If the doctor (or in some cases, the nurse or social worker) are discussing medical issues (scheduling, treatment, etc.), the parent’s attention is appropriately shifted to a third party. If the parent is talking with the nurses, other family members (including children), or friends about non-necessary topics, understand those times generally as being non-attentive to the patient.

3. A parent who is present and intermittently monitoring a sleeping child or one beginning sedation (i.e., the clinical goal at that time would be to keep the child quiet/settled) should be considered as attentive to the child’s needs. That parent is indicating availability to be with the child as needed.

4. A parent who is filling out questionnaires should not be considered uninvolved for the time needed to complete the questionnaires. This should be viewed as task imposed by the research situation rather than a case of failing to be involved with the child.

1. **Normalizing: “We are NOT in this situation.” [Parent reframes situation as “normal.”]**

   Explanation:
   Code 1 reflects a parent redefining the medical situation as some other “normal” situation encountered in everyday life outside of the medical situation (or actively participating when a child initiates reframing activities such as reading or playing a game). These reframing activities may function to distract the child from the fact that he/she is in a medical context in which he/she will experience a treatment procedure that may be painful and/or distressing. The role taken by the parent is a guide to normalcy (reframer).

   Category 1 includes cases when the child initiates the “normalizing” activity (e.g., game playing, reading, etc.) with the parent and the parent readily joins the normalizing activity (and thereby accepts the child’s definition of the situation as his/her own).

   If the child is involved in solo play and is happily doing so, (i.e., playing with an electronic game and appears to be satisfied/comfortable with that activity) the parent should be coded as supportive. The parent is not actively involved in the normalizing behavior but is supporting the child in the child’s normalizing behavior. **The parent must be engaged for the behavior to be normalizing.**

   Category 1 includes “everyday nonmedical” talk. Consider if this talk is sustained (e.g., recounting in detail what we did last weekend) versus intermittent, isolated or addressing a topic briefly but the topic is not developed.

   Rules:
   The reframing (e.g., play) may be initiated by either party, but must involve joint (mutual) and active participation by the parent. For example, if a child initiates play but the parent refuses to engage in the play, the response does NOT count as reframing. In this case, the parent has rejected the child’s attempt to reframe/redefine the situation as nonmedical. [See Code 2, Invalidation.]

   The child playing alone is not reframing. [Remember: We are coding the *parent’s* definition of the situation.] However if the child is playing alone and appears to be content doing so, the parent should be coded as supportive.

   Repetitive unsuccessful attempts at reframing a situation as “normal” when the child is distressed functions as invalidation (i.e., deny the child’s reality of the situation as medical and distressing).

   A parent who is being supportive while engaging in normalizing activities should be considered to be normalizing. That is, the parent is “taking the child into a normal situation” and being supportive in that “normal” context/situation.

   Examples:
   Playing (structured games or verbal play; e.g., mutual teasing).

Doing homework or engaging in other learning activities (e.g., naming game, verbal testing).
Reading or telling stories.
Talking about nonmedical situations, topics, or activities (e.g., family outings, holiday activities), in sustained conversation.
Watching a movie

Invalidating: "You are NOT in this situation." [Invalidating the child's experience, including the worth, value, or validity of the child and/or the child's experience.]

Explanation:
Code 2 reflects a parent actively denying or attacking the validity (merit, worth, accuracy) of the child's experience, including the child's experience of the medical situation and/or reactions/responses to medical treatment. A parent may invalidate the child's experience by denying its existence; ignoring the child's attempts at interaction [note: silence when a response is expected is invalidating]; lying about what has occurred or is about to occur; responding with anger, frustration and/or irritation at the child's reaction to medical treatment (past or present); diminishing the strength or seriousness of the child's response; laughing inappropriately (e.g., laughing *at* the child's distress or side effects; laughing *while* the child is highly distressed regardless of the reasons for laughter); criticizing or name-calling (including with regard to the child's reactions, past or present, to the medical treatment); sarcasm directed to the child; and persisting in multiple attempts to normalize the situation when the child has indicated that he/she is unable or unwilling to treat the situation as normal.

The role taken by the parent is combatant, judge, or misrepresenter.

Invalidation is invalidation regardless of whether or not it is medically related; invalidation is especially
powerful in this context when it *is* medically related.

Rules:
Because this approach to defining the situation is so potentially powerful, a pattern or series of invalidating remarks or behaviors among other behaviors, which otherwise might be coded as 1, 3, or 4, should be coded as 2. Invalidation is accomplished primarily through verbal and vocal messages. If a parent engages in invalidation **three times** during a given phase, that parent should be coded as invalidating for the entire phase.

Each time you encounter invalidation by a parent, please record the phase, the time, and a description of what occurred. [This will aid in determining when a parent has engaged in invalidation three times.] Record every invalidating behavior regardless of the number of times it occurs (i.e., less than or greater than three times).

Examples:
"That wasn't so bad," when the child reacts negatively as if distressed or in pain.
"Nobody's hurting you," while a child is crying during a procedure.
"Are you going to be loud?" [implied negative judgment]

"That was just a little poke," when the child reacts negatively as if distressed or in pain.
"We're all done," when the procedure is not done [or when the child's perception is that the procedure is not done; e.g., the port may be accessed but injections are still occurring]
"Why do you have that mean look on your face?" [implied negative judgment]
"She'll scream no matter what we do" [to medical staff in presence of child]
"You have no reason for crying."
"You're not supposed to be screaming and crying like a baby."
"You just don't care do you?" [irritated tone]
"You wore me out with your fit."
Criticism regarding nausea/vomiting, weight gain, past or present emotional responses to medical treatment involving painful and/or distressful procedures.
Namecalling regarding nausea/vomiting, weight gain, and past or present emotional responses to medical treatment involving painful and/or distressful procedures (e.g., "You're such a baby.").
Angry or judgmental reactions to a child's pain or distress.
Reacting with disbelief at a child's pain and/or distress.
Laughing at a child's crying or struggling.
Joking with others in the room while the child is clearly distressed.
Persistent attempts to discuss nonmedical topics when the child is highly distressed, ignores those attempts at discussing nonmedical topics (or attends to them only momentarily) and focuses instead on the medical situation.
Refusal (for non-medical reasons) to engage in the child's attempts to define the situation as normal (i.e., the child attempts to initiate playing a game, reading, etc.).
Child defines situation as normal (playing, reading) and parent interrupts the normal activity and draws the child's attention back to the medical situation.
Child calls out "Mommy" and gets no response from the parent. [Note: Each instance of the child calling for a parent and getting no response is a separate invalidation and should be recorded as such.]
Tickling a child who is crying/distressed.

3. **Supportive: "I am WITH you in this situation." [Parent functions as a partner and/or protector.]**

Explanation:
Code 3 reflects a parent's response that functions to join the child as an active and protective partner in the medical situation. The parent's responses are attentive, protective, empathic, supportive, and/or comforting. The parent acknowledges and validates the child's experience of the situation and/or accepts or yields to the child's definition of the situation. [Exception: child initiates normalizing behavior; see rule below.] The parent listens to the child (nonverbally and/or actively by paraphrasing or repeating the child's words); nonverbal listening (i.e., attentiveness is indicated by behaviors such as: sustained or patterned eye contact/visual monitoring of the child, indicating availability to respond as needed; appropriate smiling, appropriate head nodding, forward leaning).

The role of the parent is partner, protector, and/or comforter.

Note: Silence is a behavior. Being generally silent is an indicator of noninvolvement unless accounted for by some other factor (e.g., child is asleep, for medical reasons needs to be resting or quiet, parent is listening to the doctor; child is otherwise occupied by necessary tasks; child is occupied by solo play – e.g., playing an electronic game and appears to be satisfied/comfortable with that activity).

Rules:
The parent validates the child's experience of the situation and/or accepts/yields to the child's definition of the situation. However, if the child initiates or engages in reframing (e.g., playing a game, reading) and the parent accepts and participates in the play or reading), the appropriate code is 1 (normalizing).

Strong empathic responses should be given additional "weight," if patterned though sporadic in occurrence.

A parent who is being supportive while engaging in normalizing activities should be considered to be normalizing. That is, the parent is "taking the child into a normal situation" and being supportive in that context/situation

Examples:
Supportive touching: such as holding, hugging, cuddling, lying down with child, brushing child's face/hair with hand.
Active listening and/or nonverbal attentiveness.
"It's OK to be scared."
"It's OK to cry."
Maintaining consistent presence in the room. (Not leaving or leaving only for short period of time.)
Maintaining a close personal distance with the child.
Acknowledging and responding to the child's questions, requests, and needs.
Offering help (implicitly or explicitly)
Showing understanding or taking the child's perspective on the medical situation.
Following the child's topic of conversation.
Acknowledging the child's pain, fear, or other responses.
Engaging in medical talk with the child, especially when the child initiates that talk.
Complimenting, rewarding, and/or offering positive reinforcement to the child (in the present or in reporting past experiences).

4. **Distancing: "You are in this situation (alone), I am NOT." [Parent physically and/or emotionally leaves/abandons the child.]**

Explanation:
Code 4 reflects a parent reflecting the role of an uninvolved bystander or distant observer. The distancing parent is disengaged from the child. The parent leaves the physical presence of the child, either by maintaining relatively great personal distance or by leaving the room

entirely for extensive periods of time. The child effectively is left on his/her own to cope with the medical situation (at least with regard to the primary parent). The parent avoids the child's experience of the medical situation physically and/or emotionally. The parent may be engaged in active and even animated conversation with companions, the other parent, or the medical staff, but does not reflect active or animated engagement when talking with the child. Talk with the child tends to be perfunctory; touch tends to be instrumental (task-oriented) rather than supportive, protective, or comforting. The parent reflecting this definition may appear to be "reluctantly present" in the situation. The parent may focus primarily on discussing medical matters (largely with the medical staff) and may talk as if the child is not present.

Because of the necessity of proximity for a parent to monitor a child's needs and responses, personal distance is an important (but not sole) cue regarding involvement. If a parent stands or sits where he/she cannot see the child's face, that parent cannot readily monitor the child's reactions and needs, nor is that parent within reach to touch the child.

Rules:
For example if a parent is physically absent for most of the time period but is invalidating (3 times) in the brief time he/she is in the room, code the parent as invalidating.

Examples:
Leaving the room for lengthy periods of time.
Maintaining substantial physical distance from the child.
Talking with other people but largely not including the child.
Parent is focused on "getting the procedure over" (focused on time or schedule versus the child).
Initiating little interaction with the child.

APPENDIX B: MEASURES

Child’s Age____ Child’s Gender____

1. When was ***(child’s name)*** first diagnosed with cancer? Month_______Year____

2. How old was he/she at that time? _______

3. What was the initial diagnosis?

___ Craniopharyngioma (Brain Tumor) (01)
___ Medulloblastoma (Brain Tumor) (02)
___ Astrocytoma (Brain Tumor) (03)
___ Ependymoma (Brain Tumor) (04)
___ Brain Tumor (Unspecified) (05)
___ Brain Stem Giloma (06)
___ Ewing’s Sarcoma (07)
___ (**ALL**) Acute Lymphocytic Leukemia (08)
___ (**AML**)Acute Myelogenous Leukemia (09)
___ Liver Cancer (10)
___ Wilm’s Tumor (11)
___ Other __________________(23)

___ Hodgkin’s Lymphoma (12)
___ Non-Hodgkin’s Lymphoma (13)
___ Lymphoma (Unspecified) (14)
___ Soft Tissue Sarcoma (15)
___ Extracranial Germ Cell Tumor (16)
___ Synovial Sarcoma (17)
___ Neuroblastoma (18)
___ Retinoblastoma (19)
___ Osteosarcoma (20)
___ Rhabdomyosarcoma (21)
___ Sarcoma (Unspecified) (22)
Location of sarcoma_______________

4. Has ***(child’s name)*** ever received a spinal tap? Yes ___ No ____ ***(if no, go to #10)***

(If yes) Think back ***(2 month marker***), how many spinal taps has s/he received since ***(2 month marker)***? (STATE THE DATE TWO MONTHS AGO) _____

How many since the initial diagnosis? ____

5. Has s/he ever received a bone marrow aspiration? Yes ___ No ___

(If yes) Think back ***(2 month marker),*** how many bone marrow aspirations has s/he received since (***two month marker***)? (STATE THE DATE TWO MONTHS AGO) ____

How many since the initial diagnosis? ___

6. Does your child have a port? Yes ___ No ____

(If yes) Since (***2 month marker***), has s/he had the port accessed either for a blood draw, for chemo or to be flushed? Yes __ No __

How many since ***(marker)***? ___

7. “To which of the following racial/ethnic groups does your child belong?”

_1__ Hispanic/Latino
_2__ American Indian/Alaska Native
_3__ Asian
_4__ Black or African American
_5__ Native Hawaiian or Pacific Islander
_6__ White
_7__ Other (please specify) ____________________________
8 Bi-racial (if more than one checked)

8. Adult 1: ***Primary Caregiver (Person completing all questionnaires for the study)***

Age__ Gender____ Relationship to Child_______________

“To which of the following racial/ethnic groups do you belong?”

_1__ Hispanic/Latino
_2__ American Indian/Alaska Native
_3__ Asian
_4__ Black or African American
_5__ Native Hawaiian or Pacific Islander
_6__ White
_7__ Other (please specify) ____________________________
8 Bi-racial

9. What is your current marital status?

_1__ Never Married _2__ Married _3_ Separated
_4__ Divorced _5_ Widowed _6_ Domestic Partner

10. What is the highest level of education you have completed?

_1__ No formal schooling
_2__ Elementary School (6th grade or less)_
_3__ Middle School (7th, 8th or 9th grade)
_4__ Some High School (10th, 11th, or 12th grade)
_5__ Completed High School or GED
_6__ One or two years of college (no degree)
_7__ Completed Associate’s degree or Trade School
_8__ Three or four years of college or less (no degree)
_9__ Completed Bachelors Degree
_10__ Completed Masters Degree
_11__ Completed Doctoral or Professional Degree

11. Including your own income, what is the annual gross (before taxes) household income?

_1_ Less than $10,000
_2__ $10,000 - $19,999
_3__ $20,000 - $39,999
_4__ $40,000 - $59,999
_5__ $60,000 – $100,000
_6__ Greater than $100,000

12. What is your current employment status?

___Unemployed
___Retired
___Employed Part-time → How are you paid ___Hourly __Salary __Commission
___Employed Full-time → How are you paid ___Hourly __Salary __Commission

Social Support (Sarason, Sarason, Shearin, & Pierce, 1987)
The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the persons' initials and their relationship to you. Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how satisfied you are with the overall support you have.

If you have had no support for a question, circle the words "no one," but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all the questions as best you can. All your responses will be kept confidential.

Whom can you really count on to be dependable when you need help? (Give initials and relationship to you)

0. No one
1. 2. 3.
4. 5. 6.
7. 8. 9.

How satisfied?	Very Disappointed 1	Fairly Disappointed 2	A Little Disappointed 3	A Little Satisfied 4	Fairly Satisfied 5	Very Satisfied 6

Whom can you really count on to help you feel more relaxed when you are under pressure or tense? (Give initials and relationship to you)

0. No one
1. 2. 3.

4. 5. 6.

7. 8. 9.

How satisfied?	Very Disappointed 1	Fairly Disappointed 2	A Little Disappointed 3	A Little Satisfied 4	Fairly Satisfied 5	Very Satisfied 6

Whom can you really count on to accept you totally, including both your best and worst points? (Give initials and relationship to you)

0. No one
1. 2. 3.

4. 5. 6.

7. 8. 9.

How satisfied?	Very Disappointed 1	Fairly Disappointed 2	A Little Disappointed 3	A Little Satisfied 4	Fairly Satisfied 5	Very Satisfied 6

Whom can you really count on to care about you regardless of what is happening to you? (Give initials and relationship to you)

0. No one
1. 2. 3.

4. 5. 6.

7. 8. 9.

How satisfied?	Very Disappointed 1	Fairly Disappointed 2	A Little Disappointed 3	A Little Satisfied 4	Fairly Satisfied 5	Very Satisfied 6

Whom can you really count on to help you feel better when you are feeling generally down in the dumps? (Give initials and relationship to you)

0. No one
1. 2. 3.
4. 5. 6.
7. 8. 9.

How satisfied?	Very Disappointed 1	Fairly Disappointed 2	A Little Disappointed 3	A Little Satisfied 4	Fairly Satisfied 5	Very Satisfied 6

Whom can you count on to console you when you are very upset? (Give initials and relationship to you)

0. No one
1. 2. 3.
4. 5. 6.
7. 8. 9.

How satisfied?	Very Disappointed 1	Fairly Disappointed 2	A Little Disappointed 3	A Little Satisfied 4	Fairly Satisfied 5	Very Satisfied 6

Day of Treatment Measures
Pre-Procedure

Emotional Response Questionnaire (Batson, 1991)

We want to know about your feelings right now, just before your child's procedure begins. Below are descriptions of different kinds of feelings. Read each one carefully and decide how well it describes you. Then please *CIRCLE* the number beside it that best describes how you feel at this moment:

	Not at all like I feel	**A little like I feel**	**Somewhat like I feel**	**Very much like I feel**	**Exactly like I feel**
Sympathetic	1	2	3	4	5
Alarmed	1	2	3	4	5
Warm	1	2	3	4	5
Troubled	1	2	3	4	5
Tender	1	2	3	4	5
Disturbed	1	2	3	4	5
Softhearted	1	2	3	4	5
Grieved	1	2	3	4	5
Compassionate	1	2	3	4	5
Distressed	1	2	3	4	5
Upset	1	2	3	4	5
Moved	1	2	3	4	5
Worried	1	2	3	4	5
Perturbed	1	2	3	4	5

State Anxiety (Spielberger, 1977)

	Not at all like I feel	**A little like I feel**	**Somewhat like I feel**	**Very much like I feel**	**Exactly like I feel**
Calm	1	2	3	4	5
Secure	1	2	3	4	5
Tense	1	2	3	4	5
At ease	1	2	3	4	5
Worried over possible misfortunes	1	2	3	4	5
Comfortable	1	2	3	4	5
Self-confident	1	2	3	4	5
Nervous	1	2	3	4	5
Relaxed	1	2	3	4	5
Content	1	2	3	4	5
Pleasant	1	2	3	4	5
Jittery	1	2	3	4	5
Rested	1	2	3	4	5

Anxious	1	2	3	4	5
High-strung	1	2	3	4	5
Over-excited	1	2	3	4	5
Joyful	1	2	3	4	5
Regretful	1	2	3	4	5
Upset	1	2	3	4	5
Worried	1	2	3	4	5

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988)

	Very strongly disagree	**Strongly disagree**	**Neither agree or disagree**	**Strongly agree**	**Very strongly agree**
There is a special person who is around when I am in need.	1	2	3	4	5
There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5
My family really tries to help me.	1	2	3	4	5
I get the emotional help and support I need from my family.	1	2	3	4	5
I have a special person who is a real source of comfort to me.	1	2	3	4	5
My friends really try to help me.	1	2	3	4	5
I can count on my friends when things go wrong.	1	2	3	4	5
I can talk about my problems with my family.	1	2	3	4	5
I have friends with whom I can share my joys and sorrows.	1	2	3	4	5
There is a special person in my life who cares about my feelings.	1	2	3	4	5
My family is willing to help me make decisions.	1	2	3	4	5
I can talk about my problems with my friends.	1	2	3	4	5

Social Support Associated with the Clinic Visit
We want you to think about preparing your child for today's clinic visit. You may or may not have had support preparing for the visit from other people, such as your spouse, other family members, another child, or a friend that could help with things like: listening to your concerns, helping to calm your child the night before the visit, transportation to the visit, companionship during the visit, etc..

We want you to think about the kinds of help that you received related to today's clinic visit. Please circle the number that most describes your feelings about this support

Extremely disappointed 1	Mostly disappointed 2	Satisfied 3	Mostly Satisfied 4	Very Satisfied 5

Day of Treatment Measures
Post-Procedure

Positive and Negative Affect Scale (Watson, et al., 1988)

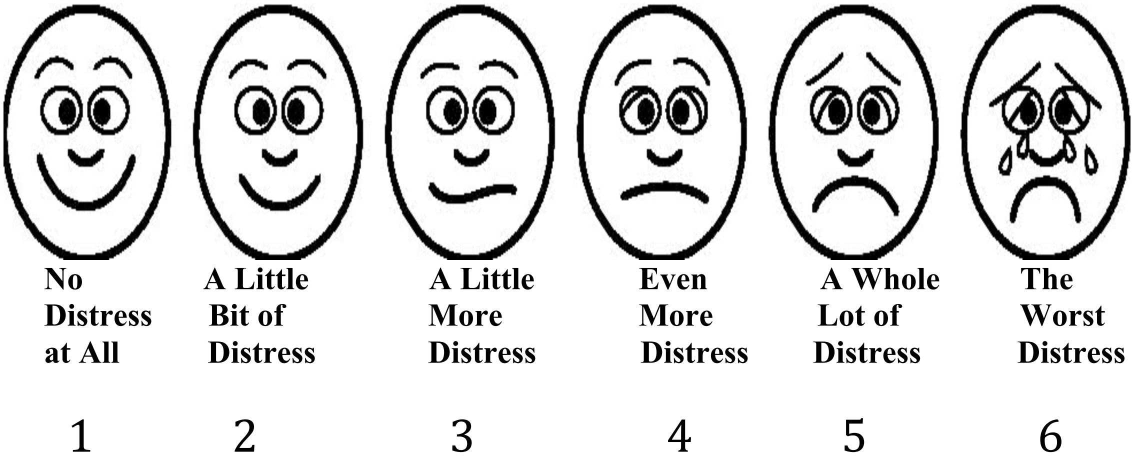
We want to know about your feelings right now, after your child's procedure has been completed. Below are descriptions of different kinds of feelings. Read each one carefully and decide how well it describes you. Then please <u>*CIRCLE*</u> the number beside it that best describes how you feel at this moment:

	Not at all like I feel	**A little like I feel**	**Somewhat like I feel**	**Very much like I feel**	**Exactly like I feel**
	1	2	3	4	5
Distressed	1	2	3	4	5
Excited	1	2	3	4	5
Upset	1	2	3	4	5
Strong	1	2	3	4	5
Guilty	1	2	3	4	5
Scared	1	2	3	4	5
Hostile	1	2	3	4	5
Enthusiastic	1	2	3	4	5
Proud	1	2	3	4	5
Irritable	1	2	3	4	5
Alert	1	2	3	4	5
Ashamed	1	2	3	4	5
Inspired	1	2	3	4	5

Nervous	1	2	3	4	5
Determined	1	2	3	4	5
Attentive	1	2	3	4	5
Jittery	1	2	3	4	5
Active	1	2	3	4	5
Afraid	1	2	3	4	5

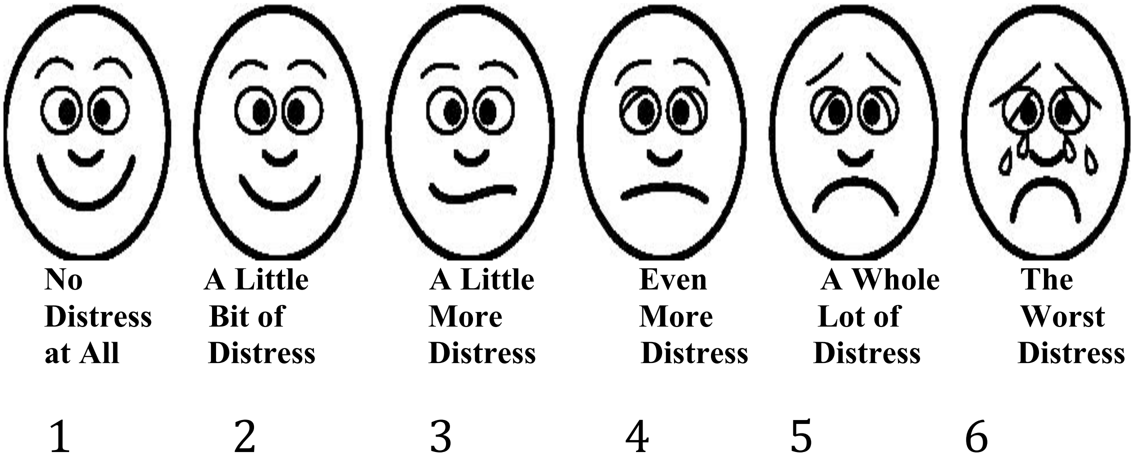
Distress (Wong & Baker, 1988)

The next set of faces below represent different levels of distress that **you** might have experienced today. Please circle the number that comes closest to your judgment of how much distress **you experienced today**. Please note: We are interested in your distress today, not your general level of distress.



Report of Child's Distress

The next set of faces below represent different levels of distress that **your child** might have experienced today. Please circle the number that comes closest to your judgment of how much distress the child experienced today. Please note: We are interested in his/her distress today, not his/her general level of distress.

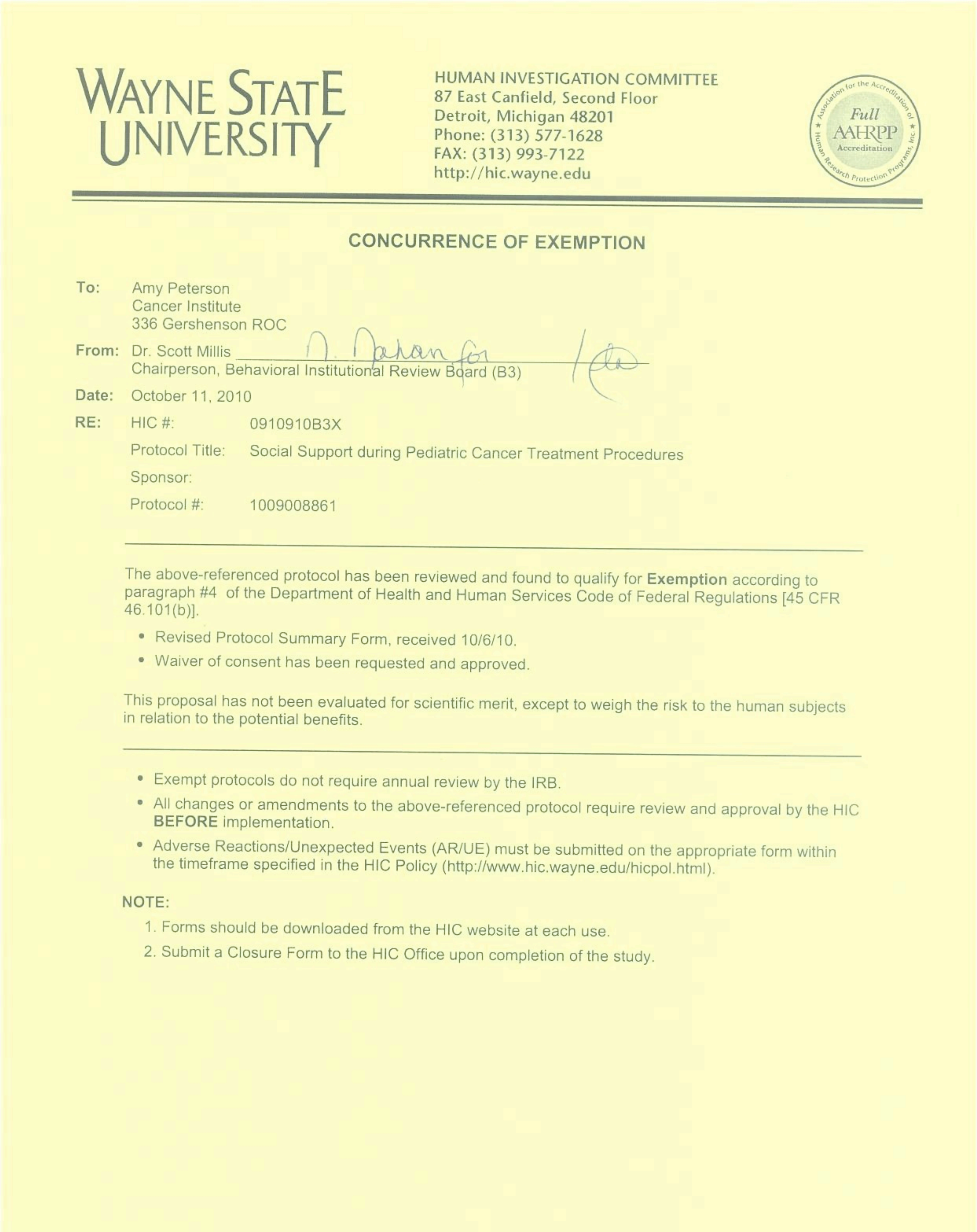


Child Cooperation

Please rate the extent to which the child cooperated with completing today’s treatment-related procedure. Please circle the number that comes closest to your judgment of how cooperative the child was with today’s treatment-related procedure. “1” means the child was “Totally Uncooperative” and “7” means the child was “Totally Cooperative.”

Totally Uncooperative						Totally Cooperative
1	2	3	4	5	6	7

APPENDIX C: HIC APPROVAL



WAYNE STATE UNIVERSITY

HUMAN INVESTIGATION COMMITTEE
87 East Canfield, Second Floor
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
http://hic.wayne.edu

CONCURRENCE OF EXEMPTION

To: Amy Peterson
Cancer Institute
336 Gershenson ROC

From: Dr. Scott Millis D. Dahan for
Chairperson, Behavioral Institutional Review Board (B3)

Date: October 11, 2010

RE: HIC #: 0910910B3X

Protocol Title: Social Support during Pediatric Cancer Treatment Procedures

Sponsor:

Protocol #: 1009008861

The above-referenced protocol has been reviewed and found to qualify for **Exemption** according to paragraph #4 of the Department of Health and Human Services Code of Federal Regulations [45 CFR 46.101(b)].

- Revised Protocol Summary Form, received 10/6/10.
- Waiver of consent has been requested and approved.

This proposal has not been evaluated for scientific merit, except to weigh the risk to the human subjects in relation to the potential benefits.

- Exempt protocols do not require annual review by the IRB.
- All changes or amendments to the above-referenced protocol require review and approval by the HIC **BEFORE** implementation.
- Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the HIC Policy (http://www.hic.wayne.edu/hicpol.html).

NOTE:

1. Forms should be downloaded from the HIC website at each use.
2. Submit a Closure Form to the HIC Office upon completion of the study.

APPENDIX D. NON-SIGNIFICANT RESULTS FOR DIFFERENCES OF MEANS BY ANESTHESIA TYPE

Variables Tested	t	P (2-tailed)	df	N	Mean
Parent Age	1.19	0.237	113	55 (TA), 60 (GA)	35.22 (TA), 33.67 (GA)
Pre-Proc. # Invalidating Statements	1.56	0.123	87.76	55 (TA), 59 (GA)	1.85 (TA), .92 (GA)
State Anxiety	- 1.64	0.104	113	55 (TA), 60 (GA)	46.78 (TA), 51.71 (GA)
Parent Procedure-Related Distress	- 0.25	0.803	113	55 (TA), 60 (GA)	2.42 (TA), 2.48 (GA)
Personal Distress	- 0.15	0.880	113	55 (TA), 60 (GA)	13.08 (TA), 13.24 (GA)
Positive Affect	- 0.29	0.775	104.2	55 (TA), 60 (GA)	28.63 (TA), 29.10 (GA)
Negative Affect	- 0.73	0.465	113	55 (TA), 60 (GA)	15.76 (TA), 16.76 (GA)
Situational Social Support	- 1.48	0.143	101.7	55 (TA), 60 (GA)	4.11 (TA), 4.33 (GA)
Social Sup. Assoc. w/ Clinic Visit	- 1.16	0.249	106	52 (TA), 56 (GA)	4.23 (TA), 4.45 (GA)
Number of Sources Social Support	0.01	0.993	113	55 (TA), 60 (GA)	4.28 (TA), 4.28 (GA)
Satisfaction with Social Support	0.05	0.963	113	55 (TA), 60 (GA)	5.46 (TA), 5.45 (GA)

TA=Topical Anesthesia, GA=General Anesthesia

Parent age was raw age in years. Number of invalidating statements was the raw number of statements made. Parent distress was rated 1-6 (higher ratings = more distress). Personal distress was rated 1-5 (higher ratings = more personal distress). Positive and negative affect were rated 1-5 (higher ratings = more positive/negative affect. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = more social support). Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

APPENDIX E. NON-SIGNIFICANT RESULTS FOR DIFFERENCES OF MEANS BY STUDY SITE

Variables Tested	t	P (2-tailed)	df	N	Mean
Child Age	0.32	0.751	113	43 (CHM), 72 (SJ)	6.51 (CHM) 6.32 (SJ)
Parent Age	1.28	0.203	113	43 (CHM), 72 (SJ)	35.49 (CHM) 33.76 (SJ)
State Anxiety	1.77	0.080	113	43 (CHM), 72 (SJ)	52.78 (CHM) 47.30 (SJ)
Positive Affect	- 1.41	0.160	113	43 (CHM), 72 (SJ)	27.40 (CHM) 29.76 (SJ)
Situational Social Support	- 0.52	0.603	113	43 (CHM), 72 (SJ)	4.17 (CHM) 4.26 (SJ)
Social Support Assoc. w/ Clinic Visit	- 1.32	0.189	106	39 (CHM), 69 (SJ)	4.18 (CHM) 4.34 (SJ)
Number of Sources of Social Support	- 0.56	0.577	113	43 (CHM), 72 (SJ)	4.12 (CHM) 4.38 (SJ)
Satisfaction with Social Support	0.33	0.739	113	43 (CHM), 72 (SJ)	5.49 (CHM) 5.44 (SJ)

CHM=Children's Hospital of Michigan, SJ=St. Jude's Children's Research Hospital

Child and parent age was raw age in years. State anxiety was rated 1-5 (higher ratings = more state anxiety). Positive affect was rated 1-5 (higher ratings = more positive affect. Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = more social support). Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction).

APPENDIX F. NON-SIGNIFICANT RESULTS FOR DIFFERENCES OF MEANS BY PARENT GENDER

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Pre-Procedure	1.74	0.085	113	20 (M), 95 (F)	39.84 (M) 29.99 (F)
Duration of Procedure	- 1.01	0.313	113	20 (M), 95 (F)	3.30 (M) 4.56 (F)
Time in Treatment	- 0.76	0.451	113	20 (M), 95 (F)	2.50 (M) 3.11 (F)
Child Age	1.10	0.282	27.07	20 (M), 95 (F)	7.10 (M) 6.24 (F)
Parent Age	0.84	0.406	113	20 (M), 95 (F)	35.60 (M) 34.16 (F)
Procedure Num. Invalidating Stmts.	- 1.24	0.219	112	20 (M), 94 (F)	.40 (M) 1.49 (F)
State Anxiety	1.72	0.088	113	20 (M), 95 (F)	54.98 (M) 48.17 (F)
Parent Procedure-Related Distress	0.70	0.486	113	20 (M), 95 (F)	2.65 (M) 2.41 (F)
Empathic Concern	- 0.53	0.595	113	20 (M), 95 (F)	17.60 (M) 18.26 (F)
Positive Affect	0.79	0.432	113	20 (M), 95 (F)	30.28 (M) 28.59 (F)
Negative Affect	1.03	0.306	113	20 (M), 95 (F)	17.80 (M) 15.96 (F)
Situational Social Support	- 1.53	0.129	113	20 (M), 95 (F)	3.97 (M) 4.28 (F)
Social Support Assoc. w/ Clinic Visit	0.29	0.771	106	20 (M), 88 (F)	4.40 (M) 4.33 (F)
Number of Sources of Social Support	- 1.93	0.056	113	20 (M), 95 (F)	3.34 (M) 4.48 (F)
Satisfaction with Social Support	- 1.91	0.070	22.02	20 (M), 95 (F)	5.02 (M) 5.55 (F)

M=Male, F=Female
Duration of procedure was in seconds. Time in treatment was in weeks. Child and parent age was in raw number of years. Procedure number of invalidating statements was raw number of statements. State anxiety was rated 1-5 (higher ratings = more anxiety). Parent procedure-related distress was rated 1-6 (higher ratings =more distress). Empathic concern was rated 1-5 (higher ratings = more empathic concern). Positive and negative affect was rated 1-5 (higher ratings = more positive/negative affect). Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit). Number of sources of social support was the raw number parents reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction with social support).

APPENDIX G. NON-SIGNIFICANT RESULTS FOR DIFFERENCES OF MEANS BY CHILD GENDER

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Pre-Procedure	1.569	0.120	111.5	70 (M), 45 (F)	34.24 (M) 27.77 (F)
Duration of Procedure	1.189	0.237	113	70 (M), 45 (F)	4.79 (M) 3.64 (F)
Time in Treatment	0.464	0.520	113	70 (M), 45 (F)	3.16 (M) 2.76 (F)
Child Age	1.516	0.132	113	70 (M), 45 (F)	6.74 (M) 5.84 (F)
Parent Age	1.212	0.228	113	70 (M), 45 (F)	35.04 (M) 33.42 (F)
Pre-Procedure Num. Invalidating Stmts.	0.735	0.464	112	70 (M), 44 (F)	1.54 (M) 1.09 (F)
Procedure Num. Invalidating Stmts.	- 0.084	0.933	112	69 (M), 45 (F)	1.28 (M) 1.33 (F)
State Anxiety	- 0.092	0.927	113	70 (M), 45 (F)	49.24 (M) 49.52 (F)
Parent Procedure-Related Distress	- 1.331	0.186	113	70 (M), 45 (F)	2.31 (M) 2.67 (F)
Empathic Concern	1.886	0.062	113	70 (M), 45 (F)	18.84 (M) 17.06 (F)
Personal Distress	1.074	0.285	113	70 (M), 45 (F)	13.61 (M) 12.45 (F)
Positive Affect	1.378	0.171	113	70 (M), 45 (F)	29.77 (M) 27.49 (F)
Negative Affect	0.177	0.860	113	70 (M), 45 (F)	16.38 (M) 16.13 (F)
Child Cooperation	0.532	0.596	113	70 (M), 45 (F)	6.13 (M) 5.99 (F)
Child Distress	- 1.773	0.079	113	70 (M), 45 (F)	2.40 (M) 1.44 (F)
Situational Social Support	- 0.362	0.718	113	70 (M), 45 (F)	4.20 (M) 4.26 (F)
Social Support Assoc. w/ Clinic Visit	- 0.530	0.597	106	66 (M), 42 (F)	4.30 (M) 4.40 (F)
Number of Sources of Social Support	- 0.046	0.964	113	70 (M), 45 (F)	4.27 (M) 4.29 (F)
Satisfaction with Social Support	- 1.909	0.059	111.9	70 (M), 45 (F)	5.35 (M) 5.62 (F)

M=Male, F=Female

Duration of pre-procedure and procedure were in seconds. Time in treatment was in weeks. Child and parent age was in raw number in years. Number of invalidating statements was raw number of statements. State anxiety was rated 1-5 (higher ratings = more anxiety). Parent procedure-related distress was rated 1-6 (higher ratings =more distress). Empathic concern rated was 1-5 (higher ratings = more empathic concern). Personal distress was rated 1-5 (higher ratings = more personal distress). Positive and negative affect was rated 1-5 (higher ratings = more positive/negative affect). Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support associated with the clinic visit). Number of sources of social support was the raw number the parent reported. Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction with social support).

APPENDIX H. NON-SIGNIFICANT RESULTS FOR DIFFERENCES OF MEANS BY NUMBER OF PARENTS PRESENT

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Pre-Procedure	- 0.39	0.697	113	44 (1), 71 (+1)	30.63 (1), 32.38 (+1)
Duration of Procedure	- 1.58	0.116	113	44 (1), 71 (+1)	3.40 (1), 4.93 (+1)
Parent Age	- 0.33	0.745	113	44 (1), 71 (+1)	34.14 (1), 34.58 (+1)
Procedure Num. Invalidating Stmts.	- 1.13	0.259	112	44 (1), 70 (+1)	.82 (1), 1.60 (+1)
Empathic Concern	0.75	0.454	113	44 (1), 71 (+1)	18.59 (1), 17.87 (+1)
Personal Distress	1.96	0.054	69.34	44 (1), 71 (+1)	14.56 (1), 12.29 (+1)
Positive Affect	- 1.08	0.281	113	44 (1), 71 (+1)	27.76 (1), 29.57 (+1)
Negative Affect	1.87	0.064	113	44 (1), 71 (+1)	17.88 (1), 15.308 (+1)
Child Cooperation	0.64	0.525	113	44 (1), 71 (+1)	6.18 (1), 6.01 (+1)
Child Distress	- 0.24	0.810	113	44 (1), 71 (+1)	2.55 (1), 2.61 (+1)
Situational Social Support	- 1.57	0.119	113	44 (1), 71 (+1)	4.07 (1), 4.32 (+1)
Social Support Assoc. w/ Clinic Visit	- 0.55	0.582	106	43 (1), 65 (+1)	4.28 (1), 4.38 (+1)
Number of Sources of Social Support	- 0.64	0.104	113	44 (1), 71 (+1)	3.81 (1), 4.57 (+1)

1=One Parent, +1=More than One Parent

Duration of pre- and procedure was in seconds. Parent age was in raw number of years. Procedure number of invalidating statements is the raw number of statements. Empathic concern was rated 1-5 (higher ratings = more empathic concern). Personal distress was rated 1-5 (higher ratings = more personal distress). Positive and negative affect was rated 1-5 (higher rating = more positive/ negative affect). Child cooperation was rated 1-7 (higher ratings = cooperaton). Child distress was rated 1-6 (higher ratings = more distress). Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support). Number of sources of social support was the raw number parents reported.

APPENDIX I. NON-SIGNIFICANT RESULTS FOR DIFFERENCES OF MEANS BY CHILD DIAGNOSIS

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Pre-Procedure	- 1.501	0.144	28.27	91 (ALL), 24 (O)	29.59 (ALL), 39.73 (O)
Time in Treatment	- 1.061	0.291	113	91 (ALL), 24 (O)	2.84 (ALL), 3.63 (O)
Parent Age	- 1.859	0.066	113	91 (ALL), 24 (O)	33.79 (ALL), 36.75 (O)
Pre-Procedure Num. Invalidating Stmts.	- 1.459	0.147	112	90 (ALL), 24 (O)	1.14 (ALL), 2.21 (O)
Procedure Num. Invalidating Stmts.	- 0.181	0.856	112	90 (ALL), 24 (O)	1.27 (ALL), 1.42 (O)
State Anxiety	- 0.117	0.907	113	91 (ALL), 24 (O)	49.26 (ALL), 49.70 (O)
Parent Procedure-Related Distress	- 0.189	0.851	113	91 (ALL), 24 (O)	2.44 (ALL), 2.50 (O)
Personal Distress	- 1.218	0.233	28.67	91 (ALL), 24 (O)	12.75 (ALL), 14.72 (O)
Positive Affect	- 0.027	0.978	30.27	91 (ALL), 24 (O)	28.87 (ALL), 28.93 (O)
Negative Affect	0.151	0.88	113	91 (ALL), 24 (O)	16.34 (ALL), 16.08 (O)
Child Cooperation	1.161	0.255	29.99	91 (ALL), 24 (O)	6.17 (ALL), 5.71 (O)
Child Distress	- 1.11	0.270	113	91 (ALL), 24 (O)	2.51 (ALL), 2.87 (O)
Situational Social Support	1.56	0.122	113	91 (ALL), 24 (O)	4.29 (ALL), 4.00 (O)
Social Support Assoc. w/ Clinic Visit	1.68	0.095	106	85 (ALL), 23 (O)	4.42 (ALL), 4.04 (O)
Satisfaction with Social Support	1.59	0.114	113	91 (ALL), 24 (O)	5.52 (ALL), 5.22 (O)

ALL=Acute Lymphoblastic Leukemia, O=Other Cancer
Duration of pre-procedure was in seconds. Time in treatment was in weeks. Parent age was in raw number of years. Nuumber of invalidating statements was the raw number of statements. State anxiety was rated 1-5 (higher ratings = more anxiety). Parent procedure-related distress was rated 1-6 (higher ratings = more distress). Personal distress was rated 1-5 (higher ratings = more personal distress). Positive and negative affect was rated 1-5 (higher rating = more positive/negative affect). Child cooperation was rated 1-7 (higher ratings = cooperaton). Child distress was rated 1-6 (higher ratings = more distress). Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support). Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction with social support).

APPENDIX J. NON-SIGNIFICANT RESULTS FOR DIFFERENCES OF MEANS BY CHILD ETHNICITY

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Pre-Procedure	1.215	0.227	113	28 (NW) 87 (W)	36.34 (NW) 30.22 (W)
Duration of Procedure	1.401	0.172	29.06	28 (NW) 87 (W)	6.12 (NW) 3.77 (W)
Time in Treatment	1.139	0.257	113	28 (NW) 87 (W)	3.61 (NW) 2.80 (W)
Child Age	0.978	0.33	113	28 (NW) 87 (W)	6.89 (NW) 6.23 (W)
Parent Age	0.853	0.395	113	28 (NW) 87 (W)	35.39 (NW) 34.09 (W)
Pre-Procedure Num. Invalidating Stmts.	- 0.021	0.983	112	28 (NW) 86 (W)	1.36 (NW) 1.37 (W)
Procedure Num. Invalidating Stmts.	0.039	0.969	112	28 (NW) 86 (W)	1.32 (NW) 1.29 (W)
State Anxiety	- 1.734	0.086	113	28 (NW) 87 (W)	44.77 (NW) 50.82 (W)
Parent Procedure-Related Distress	- 0.103	0.918	113	28 (NW) 87 (W)	2.43 (NW) 2.46 (W)
Empathic Concern	- 0.807	0.421	113	28 (NW) 87 (W)	17.48 (NW) 18.36 (W)
Personal Distress	- 0.705	0.482	113	28 (NW) 87 (W)	12.50 (NW) 13.37 (W)
Negative Affect	- 0.505	0.615	113	28 (NW) 87 (W)	15.68 (NW) 16.48 (W)
Child Cooperation	- 0.229	0.819	113	28 (NW) 87 (W)	6.02 (NW) 6.09 (W)
Child Distress	0.553	0.584	36.28	28 (NW) 87 (W)	2.74 (NW) 2.54 (W)
Situational Social Support	- 0.822	0.413	113	28 (NW) 87 (W)	4.11 (NW) 4.26 (W)
Social Support Assoc. w/ Clinic Visit	- 0.293	0.771	30.34	25 (NW) 83 (W)	4.28 (NW) 4.36 (W)
Number of Sources of Social Support	- 0.703	0.484	113	28 (NW) 87 (W)	4.00 (NW) 4.67 (W)
Satisfaction with Social Support	1.063	0.290	113	28 (NW) 87 (W)	5.60 (NW) 5.41 (W)

NW=Non-White, W=White

Duration of pre-procedure was in seconds. Time in treatment was in weeks. Parent/child age was in raw number of years. Nuumber of invalidating statements was the raw number of statements. State anxiety was rated 1-5 (higher ratings = more anxiety). Parent procedure-related distress was rated 1-6 (higher ratings = more distress). Empathic concern was rated 1-5 (higher ratings = more was rated 1-5 (higher ratings = moreempathic concern). Personal distress was rated 1-5 (higher ratings = more personal distress). Negative affect was rated 1-5 (higher rating = more negative affect). Child cooperation was rated 1-7 (higher ratings = more cooperaton). Child distress was rated 1-6 (higher ratings = more distress). Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support). Satisfaction with social support was rated 1-6 (higher ratings = more satisfaction with social support).

APPENDIX K. NON-SIGNIFICANT RESULTS FOR DIFFERENCES OF MEANS BY PARENT-CHILD COMMUNICATION

Variables Tested	t	P (2-tailed)	df	N	Mean
Duration of Procedure	- 1.924	0.064	28.94	87 (S/N) 28 (I/D)	3.57 (S/N) 6.75 (I/D)
Time in Treatment	- 1.617	0.109	113	87 (S/N) 28 (I/D)	2.72 (S/N) 3.86 (I/D)
Child Age	0.274	0.784	113	87 (S/N) 28 (I/D)	6.44 (S/N) 6.25 (I/D)
Parent Age	- 0.017	0.986	113	87 (S/N) 28 (I/D)	34.40 (S/N) 34.43 (I/D)
State Anxiety	- 0.183	0.855	113	87 (S/N) 28 (I/D)	49.19 (S/N) 49.84 (I/D)
Parent Procedure-Related Distress	- 0.990	0.324	113	87 (S/N) 28 (I/D)	2.38 (S/N) 2.68 (I/D)
Empathic Concern	- 1.749	0.083	113	87 (S/N) 28 (I/D)	17.69 (S/N) 19.57 (I/D)
Personal Distress	- 0.288	0.774	113	87 (S/N) 28 (I/D)	13.07 (S/N) 13.43 (I/D)
Positive Affect	0.223	0.824	113	87 (S/N) 28 (I/D)	28.98 (S/N) 28.56 (I/D)
Negative Affect	- 0.990	0.324	113	87 (S/N) 28 (I/D)	15.90 (S/N) 17.46 (I/D)
Situational Social Support	- 0.605	0.547	113	86 (S/N) 28 (I/D)	4.20 (S/N) 4.31 (I/D)
Social Support Assoc. w/ Clinic Visit	0.367	0.714	106	83 (S/N) 25 (I/D)	4.36 (S/N) 4.28 (I/D)
Number of Sources of Social Support	0.030	0.976	113	87 (S/N) 28 (I/D)	4.28 (S/N) 4.27 (I/D)

S/N=Supportive/Normalizing, I/D=Invalidating/Distancing
Duration of pre-procedure was in seconds. Time in treatment was in weeks. Child age was in raw number of years. State anxiety was rated 1-5 (higher ratings = more anxiety). Parent procedure-related distress was rated 1-6 (higher ratings = more distress). Empathic concern was rated 1-5 (higher ratings = more was rated 1-5 (higher ratings = more empathic concern). Personal distress was rated 1-5 (higher ratings = more personal distress). Positive/negative affect was rated 1-5 (higher rating = more positive/negative affect). Situational social support was rated 1-6 (higher ratings = more social support). Social support associated with the clinic visit was rated 1-5 (higher ratings = higher satisfaction with social support). Number of sources of social support was raw number of sources parent reported.

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ABSTRACT

SOCIAL SUPPORT, PARENT-CHILD COMMUNICATION AND REACTIONS TO PEDIATRIC CANCER TREATMENT-RELATED MEDICAL PROCEDURES

by

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Advisor: Dr. Janet Ruth Hankin

Major: Sociology (Medical Sociology)

Degree: Doctor of Philosophy

The purpose of this study was to investigate the relationships between social support, parent-child communication during pediatric cancer treatment-related medical procedures, and parent and child reactions to these procedures.

Cancer is the leading cause of disease-related death in children (ACS, 2012) and children and their parents both report that cancer-related medical procedures are worse than the disease itself (Hedstrom et al., 2003). Social support may serve as a buffer against parent and child negative responses to treatment.

One hundred and fifteen families were included in the analysis from two pediatric oncology treatment centers. Self-report questionnaire data and observational coding of video-recorded interactions in which a child experienced a cancer related medical procedure were utilized. OLS and logistic regression models were employed for hypothesis testing. Four measures of social support were tested to predict eight measures of parent and child reactions to treatment, including parent anxiety before the procedure, parent personal distress and empathic concern before the procedure, parent positive and negative emotions after the procedure, parent

and child procedure-related distress and child cooperation during the procedure. Multiple coders rated child distress and cooperation.

Various types of social support predicted parent and child reactions to treatment. Parents who had more situational social support, collected the day of a treatment procedure, had more empathic concern before the procedure and more positive affect after the procedure. Parents who had more social support associated with the clinic visit had more positive affect and had children who were more cooperative during the procedure. The more sources of social support a parent reported the lower their, and their child's, procedure related distress.

Parent social support is important in the pediatric cancer medical procedure context. Children with cancer, and their parents, would benefit from increased social support resources, which could improve long-term psychosocial functioning for both children in treatment for cancer and their parents.

AUTOBIOGRAPHICAL STATEMENT

I received my Bachelor of Arts in English (2003) and Master of Arts (2006) in Communication from Wayne State University. I began and completed my graduate education while working at Wayne State University School of Medicine in the Communication and Behavioral Oncology Program and the Behavioral and Field Research Core, where I have been a Project Director for over ten years. Through my experience as a Project Director, I developed a valuable and practical understanding of the behavioral research process and a deep respect for psychosocial research.

I received dissertation grants from the National Science Foundation and the Blue Cross and Blue Shield Foundation of Michigan. At the time this dissertation was completed, I authored nine peer-reviewed published journal articles and two under review. I have presenting research findings at nine national and international conferences. One conference paper received a top three paper award at the National Communication Association's annual meeting.

My research interests include social support, stress, pediatric cancer, adolescents and the sociology of family and health/illness.