Factors Associated with Parents’ Understanding of their Child’s Cancer Prognosis

Dissertation

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By

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Abstract

**Purpose:** Obtaining an accurate understanding of a child’s cancer prognosis may allow for informed parent decision making, as well as an ability to balance aggressive treatment with maintaining the child’s quality of life throughout the disease course. Research has shown that parents tend to overestimate their child’s cancer prognosis relative to physicians. The current study examined an integrated model that included parent adjustment, coping, and health literacy variables for its ability to account for differences in the accuracy of parents’ understanding of their child’s cancer prognosis.

**Methods:** Seventy-seven mothers and forty-two fathers of children with cancer completed questionnaires regarding their own adjustment, coping, and sources of medical information. Physicians reported on the content of their communication with parents regarding the child’s prognosis. Both parents and physicians estimated the child’s chance of 5-year survival using a visual analogue scale. Assessments occurred within 3-8 weeks of a child’s new diagnosis or relapse of cancer. Mothers were on average 36.89 years old ($SD = 7.57$), and 92% ($n = 71$) were Caucasian. Sixty-eight percent ($n = 52$) were married, and mean years of education was 14.90 ($SD = 3.53$). Fathers were on average 40.45 years old ($SD = 7.01$), and 98% ($n = 41$) were Caucasian. Eighty-three percent ($n = 35$) were married, and mean years of education was 15.26 ($SD = 4.04$). Children were on average 10.77 years old ($SD = 3.88$); the majority were male (52%; $n = 40$) and
Caucasian (90%; \( n = 69 \)). Diagnoses included leukemias (26%; \( n = 20 \)), lymphomas (36%; \( n = 28 \)), brain tumors (12%; \( n = 9 \)), and other solid tumors (26%; \( n = 20 \)).

**Results:** Both mothers and fathers reported a more favorable prognosis for their child than physicians. Agreement between physician and mother prognosis estimates was moderated by mothers’ symptoms of depression and anxiety. Agreement between physician and father prognosis estimates was moderated by fathers’ use of secondary and disengagement coping, as well as father age and sources of medical information.

**Conclusion:** Results provide partial support for an integrated model of parent prognosis literacy that highlights various coping, adjustment, and health literacy variables as important factors that play a role in mothers’ or fathers’ understanding of their child’s cancer prognosis. In addition, findings indicate that the specific factors involved in influencing prognosis understanding vary between parents. Additional research on these and other factors is needed to assist in developing clinical interventions aimed at improving informed parental knowledge during a child’s cancer treatment.
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Chapter 1: Introduction

Approximately 12,000 children under the age of 20 are diagnosed with cancer annually in the United States (Ries et al., 2005). Although childhood cancer is relatively rare, incidence rates have increased from an estimated 11 cases per 100,000 children in 1975 to 16 per 100,000 children in 2002 (Ries et al. 2005). In recent years, it has been projected that 1 in every 330 children will develop cancer by the age of 20 (SEER 2003). The life-threatening nature of pediatric cancer sets it apart from other childhood chronic illness, such as asthma and diabetes. Over 2,300 children die each year from the disease or its treatments, making cancer the leading cause of death by disease in children ages 15 and under (Ries et al. 2005). Fortunately, survival rates for childhood cancer have risen sharply over the past 30 years. This is primarily due to the development of enhanced therapies at pediatric cancer centers that collaborate in phase III clinical trials with the Children’s Oncology Group (COG). In the United States, more than 75% of children with cancer are now living five years after diagnosis, compared to only 60% in the mid-1970’s (Ries et al. 2005).

A major challenge for parents of a child diagnosed with cancer is accumulating accurate information in order to make informed decisions regarding treatment. Parents serve a unique role as gatekeepers who receive the majority of medical information and
manage communication between healthcare professionals, the ill child, and other family members (Clarke, Davies, Jenney, Glaser, & Eiser, 2005). Thus, parents must gain an accurate understanding of the medical situation in order to determine how best to talk with their child about his or her illness, as well as what information should be disseminated. Families must then establish the roles that others will play in treatment decisions, particularly regarding input from the ill child. Having accurate knowledge of the child’s prognosis may aid informed discussions and decisions about treatment from diagnosis to survivorship or the end of life.

Communication between the medical team and family members evolves over time in response to the child’s changing situation. For example, almost immediately following diagnosis, parents must decide whether to enroll their child on a clinical trial, as over 90% of eligible children with cancer are treated on phase III clinical trials through COG (COG, 2008). When treatment does not work, families may face some of the most difficult decisions at the end of life. Multiple studies suggest that children with cancer receive aggressive treatment in the last weeks of life and experience significant symptom burden (e.g., pain and fatigue) (Jalmsell, Kreicbergs, Onelov, Steineck & Henter, 2006). Meyer et al. (2002) reported that over half of bereaved parents felt that they had little or no control over their child’s final days, with nearly a quarter indicating they would have made different decisions during this time. Obtaining an accurate understanding of the child’s prognosis may allow for informed decision making and an ability to balance aggressive treatment with maintaining the child’s quality of life throughout the disease course.
Research on individuals’ understanding of prognosis is currently limited and has tended to focus on adults with cancer as opposed to children or parents of children with cancer. This research indicates that adults generally have inflated estimates of their prognosis relative to actual disease progression (Weeks et al., 1998). This inaccuracy may be particularly likely for adults with late-stage cancers. Among those with a form of terminal cancer, 60% incorrectly reported that their disease could be controlled with treatment long-term (Eidinger & Shapira, 1984). Patient predictions regarding their disease may also be less accurate than clinician estimates, as evidenced by studies using physicians as a reference point for patient estimates of cancer prognosis (e.g., Lee, Fairclough, Antin, & Weeks, 2001). For example, Weeks et al. (1998) found that 82% of adults with stage III or IV lung cancer rated their likelihood of six month survival to be higher than physician estimates. The limited research available regarding childhood cancer has found that parents, like adults with cancer, often overestimate their child’s prognosis relative to physicians, with mothers and fathers reporting a similar understanding of their child’s prognosis (Wolfe et al., 2000; Edwards et al., 2008). Among children within the first year of a new cancer diagnosis, 61% of parents were more optimistic than the child’s primary oncologist regarding prognosis (Mack, Cook, Wolfe, Grier, Cleary, & Weeks, 2007). For these parents, the degree of optimism varied greatly, with prognosis estimates that ranged from 1%-80% higher than physician estimates (Mack et al., 2007).

Given preliminary evidence that many parents may be overly confident in their child’s chance of disease-free survival above and beyond physician estimates, researchers
have begun to conceptualize the factors that influence parent’s understanding of their child’s prognosis. Mack and colleagues have recently proposed a heuristic model of prognosis literacy (Figure 1) that incorporates theories of stress and coping, as well as health literacy (i.e., an individual’s understanding of basic health information and services needed to make appropriate health decisions) (Mack et al., 2007; Kickbusch, 2008).

Figure 1. *Mack et al.’s (2007) Heuristic Model of Prognosis Understanding*

Specifically, their heuristic suggests that parent characteristics (e.g., education, race, coping style), patient characteristics (e.g., prognosis, disease status), and physician characteristics (e.g., communication style) all influence aspects of parent-physician communication. Subsequent aspects of communication (e.g., communication quality, sources of parent information) in turn influence parents’ understanding of their child’s likelihood of cure. Apart from parent-physician communication, Mack hypothesizes that parent and physician characteristics may also directly influence parent prognosis literacy.
To our knowledge, Mack’s (2007) work represents the first attempt to study the effect of multiple factors on parents’ understanding of their child’s cancer prognosis. Although small portions of the heuristic have been supported, their conceptualization of prognosis literacy should be considered speculative, as most aspects have yet to be supported by empirical literature. As such, the general purpose of this study is to adapt Mack’s initial notion of prognosis literacy into a series of testable models that are based on existing theories of stress, coping, and adjustment, and more experimentally, health literacy. Moreover, because they have not clearly articulated the ways in which stress, coping, adjustment, and health literacy variables influence each other, and in turn, parents’ understanding of their child’s cancer prognosis, our study aims to enhance their heuristic by specifying the nature of these associations. Specifically, we postulate a variety of moderating factors that will inform our subsequent analyses. The initial models that guide our conceptualization of parent prognosis literacy are displayed below (Figures 2a and 2b) and represent an extension of Mack’s attention to stress, coping, and adjustment theory based on research from the cancer literature and other pediatric illness populations. These models illustrate our understanding of parent depression and anxiety as moderators in the association between physician and parent estimates of prognosis.
Figure 2. Model of Hypothesized Relations between Physician Estimates of Prognosis, Parent Depression, and Parent Estimates of Prognosis

Note. + = positive association; - = negative association

* Association between physician and parent estimate of prognosis will be weakened for individuals with low or high levels of depression and strengthened for individuals with moderate levels of depression.

Figure 3. Model of Hypothesized Relations Between Physician Estimates of Prognosis, Parent Anxiety, and Parent Estimates of Prognosis

Note. + = positive association; - = negative association
Symptoms of distress in parents that are associated with childhood cancer may appear soon after they gain initial knowledge of their child’s diagnosis and prognosis. Hearing a child has cancer is extremely stressful for parents, and a primary fear is whether their child might die. Initial consultations with the medical team may involve disclosure of the child’s estimated prognosis, and the resulting stress can influence parents’ adjustment over time (Wijnberg-William, Kamps, Klip, & Hoekstra-Weebers, 2006). In general, studies indicate that parents may exhibit symptoms of anxiety and depression soon after a child’s cancer diagnosis that are higher in comparison to norms or controls; however, these symptoms typically decline to normative levels after the first year of treatment (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000; Gerhardt et al., 2007; Pai et al., 2007). Mothers in particular have been noted to be at risk for anxiety and depression following their child’s diagnosis of cancer (Gerhardt et al., 2007; Wijnberg-William, Kamps, Klip, & Hoekstra-Weebers, 2006).

Research suggests that parent distress may go on to moderate the association between physician and parent estimates of prognosis; moreover, anxiety and depression may differentially influence parent prognosis accuracy. Specifically, the impact of depressive symptoms on parents’ ability to retain medical information may function in a more complex fashion according to symptom severity. Introduced by Alloy and Abramson (1979), the notion of depressive realism states that symptoms of depression are positively associated with accuracy in judgment, such that depressed individuals process information more precisely than those who are less or non-depressed (Dozois &
Dobson, 2001). Supporting the depressive realism phenomenon, previous studies of adults with cancer have found health risk accuracy to be positively associated with depressed status (Keller, Lipkus, & Rimer, 2002). However, also established is the idea that symptoms of depression are linked to the presence of a more pessimistic explanatory style and bias toward negative thoughts (Beck, 1976).

In an effort to reconcile these contradicting bodies of literature, Strunk, Lopez, and DeRubeis (2005) recently conducted a study on individuals with varying levels of depression and found that depression-related biases change over the spectrum of symptom severity. Specifically, the authors found that individuals with low levels of depressive symptoms exhibited a slight optimistic bias, consistent with research from both Alloy and Beck. However, as symptoms increased to the moderate level, this optimistic bias disappeared, allowing individuals improved accuracy in judgment. Finally, in the case of severely depressed individuals, accuracy was replaced with a pessimistic bias. Thus, it is possible that only moderate to severe depressive symptoms can counteract parents’ tendencies to report a more favorable prognosis for their child than physicians, although we would expect severe symptoms of depression to be associated with an excessively negative view. Thus, Figure 2 shows both a positive and negative moderating association to illustrate our hypothesis that the direction of the effect will differ for mild, moderate, and severe depression. No studies to date have examined the differential effects of anxiety and depression as moderators of the association between physician and parent estimates of a child’s cancer prognosis.
Contrary to depression, the presence of anxiety at any level of severity may lead to a poorer understanding of prognosis. Many parents do not understand key aspects of their child’s illness, treatment, and prognosis near diagnosis, when initial anxiety is likely to be elevated (Miller, Drotar, Burant, & Kodish, 2005). In line with a cognitive-motivational view of anxiety, awareness of a threatening or anxiety provoking stimulus is accompanied by a tendency to shift one’s attention away from threat (Lang et al., 1990; Matthew and Sebastian, 1993). This “vigilance-escape” pattern of attentional bias in anxious individuals may interfere with habituation and thus encourage the continued use of avoidance strategies in order to reduce emotional discomfort (Mogg & Bradley, 1998). For parents of a child with cancer, this may mean an evasion of information related to their child’s disease. Accordingly, parents who describe themselves as more shocked or in a state of disbelief during consultations with their child’s physician retain less medical information than non-distressed parents (Clarke et al, 2005). The above research leads to the hypothesis, depicted in Figure 2a, that anxiety should moderate the association between physician and parent prognosis estimates such that the association will be stronger for parents with less anxiety symptoms and weaker for parents with more anxiety symptoms.

The inclusion of coping in Mack’s (2007) heuristic of parent prognosis accuracy is supported by literature suggesting that parents’ ability to cope with the stress of their child’s cancer prognosis may affect the accuracy of prognosis estimates. Figure 3 represents our understanding of parent coping as a moderator of the association between physician and parent prognosis estimates.
The association between the broad construct of coping and successful adaptation to specific stressors is a salient topic in psychology. Coping has been defined by a wide range of criteria, including type of stressful precursor, goal of response, and intentionality (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). Recently, Compas et al. (2001) suggested a model of stress responses that are distinguished along two dimensions: (a) voluntary vs. involuntary and (b) engagement vs. disengagement. They define coping as conscious, volitional efforts to regulate emotion, cognition, behavior, physiology, and the environment in response to stressful events. Voluntary responses (i.e., coping) are distinguished as active efforts to engage with or disengage from a stressor and resulting emotions. Voluntary engagement coping is further differentiated
into primary and secondary control strategies, depending on the goal of the response. Primary control coping aims to change the stressor or one’s emotional response (e.g., problem solving, emotional modulation, emotional expression), and secondary control coping aims to adapt to the stressor or one’s emotional response (e.g., cognitive restructuring, acceptance, distraction, positive thinking). The aim of voluntary disengagement coping, on the other hand, is to consciously avoid the stressor (e.g., avoidance, wishful thinking). Involuntary responses can also be broken down to reflect unconscious efforts to engage (e.g., intrusive thoughts, rumination, emotional arousal, physiological arousal, and impulsive action) or disengage (e.g., emotional numbing, cognitive interference, escape, and inaction) from the stressor at hand. However, for the purpose of this study, involuntary stress responses will not be examined, as there is currently insufficient research to frame specific predictions, as well as potential overlap with measures of distress already included in our model.

Preliminary evidence suggests that certain subtypes of coping may aid or hinder one’s understanding of prognosis. For example, among adults with cancer, the use of blunting (i.e., disengagement coping) was negatively associated and monitoring (i.e., primary control coping) was positively associated with patients’ expressions of medical questions regarding decision-making issues (Timmermans, van Zuuren, Van der Maazen, Leer, & Kraaimaat, 2007). The limited research available regarding childhood cancer has found that, like adults with cancer, parents understanding of medical information, and specifically prognosis, may be influenced by coping style. Mack et al. (2007) found that parent estimates of their child’s cancer prognosis tended to be more optimistic than
physician estimates when parents utilized disengagement coping. Thus, although initial research seems to identify coping as a moderator between medical information from physicians and parents’ subsequent medical understanding (Figure 3), more research is needed to determine the effect of differing coping styles on this association.

Given previous research focusing on the association between symptoms of psychopathology and subtypes of coping, as well as the similar hypothesized moderating effects of these factors on the association between parent and physician prognosis estimates, we further extend our understanding of parent prognosis literacy to integrated models that address both adjustment and coping (Figures 4a and 4b). As shown, parent depression and anxiety are hypothesized to mediate the moderating effect of coping on the association between physician and parent estimates of prognosis.
Figure 5. Model of Hypothesized Relations between Physician Estimates of Prognosis, Parent Coping, Parent Depression, and Parent Estimates of Prognosis

Note. + = positive association; - = negative association

P = primary control coping; S = secondary control coping; D = disengagement coping

*Association between physician and parent estimate of prognosis will be weakened for individuals with low or high levels of depression and strengthened for individuals with moderate levels of depression
Compas and colleagues (e.g., Compas et al., 2001) have conceptualized coping as a conscious, regulatory effort that comes in response to a stressful event or circumstance. In parents of children with cancer, active coping may occur soon after a child’s diagnosis and may be triggered by early events such as discussions with the medical team about prognosis and treatment. Coping is thus seen as a trait factor that is initiated by a specific stressor and hypothesized to influence one’s subsequent adjustment (Jaser et al., 2005). Previous research has identified subtypes of coping that are utilized by parents of children with cancer. In a retrospective study of parent coping during a child’s cancer
treatment, parents were most likely to report having used strategies of acceptance, problem solving, or optimism (i.e., positive thinking) (Barbarin, Hughes, & Chesler, 1985). This study also found caregiver differences, as fathers reported using more strategies of denial while mothers relied more on information seeking. Norberg, Lindblad, and Boman (2005) found that parents reported using more active problem focusing (i.e., being goal oriented, sorting things out) and palliative reactions (i.e., engaging in other activities, trying to relax), with no differences in the types of coping used by parents at 1-8 weeks, 18-30 months, and 60-120 months post diagnosis.

Research has supported the association between coping and adjustment in healthy populations. Both primary and secondary coping have been associated with fewer symptoms of depression and anxiety in adults and children, while disengagement coping has been associated with more internalizing symptoms (Conner-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000; Wadsworth, Raviv, Compas, & Connor-Smith, 2005). Similar patterns of coping exist in parents of children with cancer. In a review of studies examining psychological adjustment and coping in these families, social support, acceptance, and positive thinking were identified as factors that have been consistently linked to better adjustment outcomes, while disengagement strategies have been associated with higher levels of anxiety and depression (Grootenhuis & Last, 1997).

From a longitudinal perspective, Sloper (2000) found that 6 months after a child’s cancer diagnosis, the use of problem solving and support seeking strategies by mothers was related to lower levels of psychological distress at both 6 and 18 months post diagnosis. Similarly, Norberg, Lindblad, and Boman (2005) found that more frequent use
of active problem solving and less frequent use of avoidance behavior was related to lower levels of anxiety and depression in parents of children who were undergoing or had completed cancer treatment. In addition, clinical interventions developed to help parents adapt to the stresses of pediatric cancer emphasize the importance of strategies such as problem solving, social support, and information seeking in the development of adaptive coping skills (Sahler et al., 2006; Walsh-Burke, 1992). In this way, symptoms of depression and anxiety may be best thought of as an outcome of coping failure.

Accordingly, parents that use more primary or secondary control coping will experience fewer symptoms of anxiety and depression, which will account for coping’s ability to strengthen the association between physicians’ and parents’ estimates regarding a child’s cancer prognosis (Figures 4a and 4b). Likewise, we hypothesize that an increased use of disengagement coping following a perceived stressor will be characterized by increased symptoms of depression and anxiety. By virtue of such maladjustment, coping will interfere with parent prognosis accuracy in a mediated moderation model. In line with the conceptualization of depression by Strunk, Lopez, and DeRubeis (2005), we believe that severe symptoms of depression (e.g., characterized by high levels of disengagement coping) and mild symptoms of depression (e.g., characterized by low levels of disengagement coping) will weaken the association between physician and parent prognosis estimates, reflecting a pessimistic and optimistic bias in parents, respectively. In contrast, moderate levels of depression (e.g., characterized by moderate levels of disengagement coping) will strengthen the
association between physician and parent prognosis estimates, reflecting parent accuracy in judgment.

The cross-sectional nature of the current study presents several challenges for the formulation of hypotheses and subsequent data analysis. Namely, definitive conclusions as to the directional associations of these factors cannot be made, and alternatives to our integrated models may exist. Countering Compas and colleagues’ conceptualization of coping as a stress response that precedes adjustment, it may be that high levels of anxiety following a child’s cancer diagnosis leads to maladaptive coping, which in turn mediates anxiety’s influence on the association between physician and parent prognosis estimates (Figure 5). This alternative model is consistent with Mogg and Bradley’s (1998) vigilance-escape pattern of attention bias, whereas anxious parents may avoid information related to their child’s disease. As a longitudinal understanding of these associations is unable to be obtained, an analysis of both mediated moderation models of anxiety and coping seems warranted.
There are several methodological issues that limit the quality of existing research related to parents’ understanding of their child’s cancer prognosis. Most studies are single informant designs with low recruitment rates and variability in terms of time since diagnosis. The current study attempts to remedy such issues by using multiple informants to examine the factors that affect mothers’ and fathers’ understanding of prognosis during the discrete period directly following the child’s new diagnosis or relapse of cancer. Of particular note is our inclusion of fathers, who are consistently underrepresented in pediatric research (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). Although no a priori assumptions exist concerning gender differences in how these models will operate, we plan to examine mothers and fathers separately as
exploratory analyses. Moreover, our recruitment rate of over 90% yields a sample that is
assumed to be representative of the full range of diagnoses within our recruitment area.
Based on the existing research concerning stress, coping, and adjustment that has guided
our adaptation of Mack et al.’s (2007) heuristic of parent prognosis literacy, specific aims
and hypotheses of the current study are as follows:

Aim 1: To examine the accuracy of parents’ understanding of their child’s cancer
prognosis

Hypothesis 1a: Mothers and fathers of children with cancer will report a more
favorable prognosis for their child than physicians, but there will be a positive
association between physician and parent prognosis ratings and between mother
and father prognosis ratings.

Aim 2: To examine the influence of coping and adjustment on parents’ understanding of
their child’s cancer prognosis

Hypothesis 2a: Parent symptoms of depression will moderate the association
between physician and parent prognosis ratings, such that the association will be
weaker for parents with low levels of depressive symptoms (i.e., reflecting a
slight optimistic bias) and high levels of depressive symptoms (i.e., reflecting a
pessimistic bias) and stronger for parents with moderate levels of depressive
symptoms (i.e., reflecting accuracy in judgment).

Hypothesis 2b: Parent symptoms of anxiety will moderate the association between
physician and parent prognosis ratings, such that the association will be weaker
for parents high in anxiety symptoms and stronger for parents low in anxiety symptoms.

Hypothesis 2c: Primary and secondary control coping will be negatively associated with parent symptoms of anxiety and depression, while disengagement coping will be positively associated with parent symptoms of anxiety and depression.

Hypothesis 2d: Coping will moderate the association between physician and parent prognosis ratings, such that the association will be weaker for parents utilizing more disengagement coping and stronger for parents utilizing more primary and secondary control coping strategies.

Hypothesis 2e: Parent symptoms of depression and anxiety will account for (i.e., mediate) the moderating role of coping in the association between physician and parent prognosis ratings.

Hypothesis 2f: Alternatively, parent differences in coping will account for (i.e., mediate) the moderating role of anxiety in the association between physician and parent prognosis ratings.

Apart from an attention to stress, coping, and adjustment, Mack’s (2007) heuristic of parent prognosis literacy incorporates several variables that are tied to health literacy theory. However, little research exists to inform how these variables may influence parents’ understanding of their child’s cancer prognosis. Thus, Figure 6 represents a speculative extension based on the limited literature that is available regarding content of
physician communication, parent sources of medical information, and parent
demographic factors, all of which are hypothesized to be moderators in the association
between physician and parent prognosis estimates.

Figure 8. Model of Hypothesized Relations Between Physician Estimates of Prognosis,
Content of Physician Communication, Parent Sources of Medical Information, Parent
Demographic Factors, and Parent Estimates of Prognosis

Note. + = positive association; $^a$ = parent education; $^b$ = parent age

The primary source of prognostic information for parents is often the initial
consultation with the child’s doctor. Although medical guidelines and parental
preferences overwhelmingly support the clear honest disclosure of a child’s cancer
diagnosis and prognosis, the task of delivering bad news continues to be a source of stress
and uncertainty for clinicians (Monterosso, Kristjanson, & Phillips, 2009; Contro et al.,
Clinicians often report poor or inadequate training in delivering bad news to families,
leading to a dialogue that may favor the medical professional’s need to reduce his or her
own anxiety when discussing prognosis (Eggly et al., 1997; Schofield et al., 2001). Specifically, clinicians wishing to instill hope in families may chose to give limited or overly broad prognostic information with a greater focus on curative treatment rather than disease severity (Lamont & Christakis, 2001). Not surprisingly then, significant gaps in communication have been shown to exist between families and the medical team regarding a child’s prognosis. In previous research, physicians were aware of the terminal state of a child’s illness more than three months before parents (Wolfe et al., 2000), and many physicians have reported a preference for waiting until symptoms emerge before disclosing a terminal prognosis to the family (Keating et al., 2010).

The content of physician communication among adults with cancer has been shown to vary based on patient preference, with some patients requesting quantitative information (e.g., percentages, proportions) about their prognosis and others preferring more general terms (Lobb et al., 2003). However, given the difficulty that physicians often have communicating a prognosis, the delivery of specific numbers may prove particularly challenging. Accordingly, Mack et al. (2007) found that only 69% of parents of children with cancer recalled receiving a numeric estimate of prognosis from their child’s physician. Another study found that among parents requesting a numerical understanding of their child’s cancer prognosis, 73% received such information from their physician (Mack et al., 2006). Moreover, physicians may have difficulty providing concrete numbers or percentages simply due to a lack of empirical data, as many childhood cancers are rare and unpredictable in course, particularly following relapse. One might expect that parents who receive concrete numbers or percentages from their
child’s physician would have better agreement with physician estimates of prognosis compared to parents who received more general estimates or no direct information at all. However, more research is needed to determine the effect of varying methods of physician disclosure on parents’ understanding of prognosis.

The extent to which parents rely on physicians for medical information may also be related to their knowledge of their child’s prognosis. Although half of adults with cancer cite the medical team as the preferred primary source of health information, only 11% report their physician actually served in this role (Ybarra & Suman, 2008). In some cases, parents may be reluctant to seek out prognosis information from the medical team, as one study found that less than half of parents of children with cancer felt that they were well informed about whom they could talk to regarding medical questions (Meyer et al., 2002). Subsequently, parent perceptions of their child’s illness may be based on a variety of sources besides the medical team, including family, friends, and the media (NCI, 2007). The advent of the internet has been particularly instrumental in supplying medical knowledge, as it is estimated that over 50% of all internet users have utilized online healthcare information (Hesse, Nelson, & Kreps, 2005). Multiple and varying internet resources now exist for parents of children with cancer, including disease-specific websites and chat-rooms. Though readily available, information obtained outside of discussions with physicians may help or hinder parents’ ability to accurately understand their child’s prognosis. Interestingly, parents of children with cancer tend to be more optimistic than physicians when relying on non-medical sources of information (Mack et al., 2007).
Finally, and in accordance with Mack’s (2007) model, research on health literacy has cited personal characteristics as influencing parents’ understanding of disease prognosis. In a review of studies conducted with adults with a variety of illness conditions and their caregivers, education level and age were most commonly associated with health literacy (Paasche-Orlow et al., 2005). Specifically, higher education and younger age were related to greater illness knowledge. Research on parent characteristics has similarly found that parental understanding of pediatric congenital heart disease is associated with higher parent education (Beeri, Haramati, Rein, & Nir, 2001). In contrast, for parents of children with cancer, understanding of pediatric retinoblastoma treatment was found to be positively associated with parent age, regardless of education attainment (Panton et al., 2009). However, research specific to pediatric cancer is limited, and no studies to date have investigated the influence of parent age or education on parents’ understanding of their child’s prognosis.

Given the above research concerning content of physician communication, parent sources of medical information, and parent demographic factors, exploratory aims and hypotheses related to health literacy variables for the current study are as follows:

Aim 3: To examine the influence of health literacy variables, including physician communication of numerical estimates of child survival, parent sources of medical information (i.e., physicians, other medical staff, other families at the hospital, family/friends, and the internet), and parents’ age and level of education, on parents’ understanding of their child’s cancer prognosis.
Hypothesis 3a: The content of physician communication will moderate the association between physician and parent prognosis estimates, such that the association will be stronger when physicians discuss prognosis using concrete numbers and weaker when physicians discuss prognosis using more general terms.

Hypothesis 3b: Source of information will also moderate the association between physician and parent prognosis estimates, such that the association will be stronger for parents relying more on information from physicians and weaker for parents relying more on information from other sources (i.e., other medical staff, other families at the hospital, the internet, or family/friends).

Hypothesis 3c: Parent age and education will moderate the association between physician and parent prognosis estimates, such that the association will be stronger for younger and more educated parents and weaker for older and less educated parents.
Chapter 2: Method

Procedure

This study is part of a larger, multi-site study of family adjustment to childhood cancer. All procedures were approved by the local institutional review board. Families were recruited from the Hematology/Oncology Division of a large children’s hospital. Eligible families had children who met the following criteria: (a) between the ages of 5-17 years, (b) within 3-8 weeks of a new diagnosis or a recurrence of cancer, and (c) English speaking. Families were excluded if children: (a) had a pre-existing chronic illness or developmental disorder, or (b) were no longer receiving curative treatment (e.g., hospice).

Families were recruited 3-8 weeks after their child’s new diagnosis or relapse of cancer. Families were initially screened for eligibility based on cancer registry data. A research assistant who was responsible for recruitment contacted the family in clinic or the hospital to assess interest, provide detailed information about participation in the study, and obtain informed consent/assent. Parents and children who agreed to participate signed consent or assent forms explaining procedures, potential risks and benefits, and medical privacy. During consent procedures, families were ensured that their participation in this study would not affect their child’s medical treatment. Permission
for a review of the child’s medical records was also obtained at this time. For the purposes of this study, only parent report data will be utilized.

Participating parents were given the option to complete a battery of questionnaires at the hospital or at home. Research assistants were available to aid those families needing assistance. The estimated completion time for the parent battery was 1.5 hours. After completing the questionnaires, families were paid $50 as compensation for their time.

For each family that participated, the child’s primary physician was asked to complete a brief questionnaire regarding the child’s medical information and communication with the family. This form was completed at approximately the same time as parent questionnaires.

Participants

Of 85 eligible families, 77 (91%) participated. Children were on average 10.77 years old ($SD = 3.88$); the majority were male (52%; $n = 40$) and Caucasian (90%; $n = 69$). Time since diagnosis or relapse was 5.9 weeks ($SD = 0.9$). Diagnoses included leukemias (26%; $n = 20$), lymphomas (36%; $n = 28$), brain tumors (12%; $n = 9$), and other solid tumors (26%; $n = 20$). A small percentage of children had relapsed (19%; $n = 15$). Because over 90% of eligible families consented to participate in the study, it is assumed that our sample was representative in terms of the distribution of age, gender, race, and diagnosis type within our recruitment area.

Data were available from 77 mothers and 42 fathers. Eighty-one percent of available fathers participated. Mothers were on average 36.89 years old ($SD = 7.57$), and
92% \( (n = 71) \) were Caucasian. Sixty-eight percent \( (n = 52) \) were married, and mean years of education was 14.90 \( (SD = 3.53) \). Fathers were on average 40.45 years old \( (SD = 7.01) \), and 98% \( (n = 41) \) were Caucasian. Eighty-three percent \( (n = 35) \) were married, and mean years of education was 15.26 \( (SD = 4.04) \). Modal family socioeconomic status \( (Mo = 42.26; SD = 22.82) \) reflected occupations in clerical, sales, or managerial positions (e.g., secretaries, sales clerks, office managers) (Nakao & Treas, 1992).

Measures

Demographics. This questionnaire assesses background information about the respondent (e.g., age, ethnicity, education). Socioeconomic status (SES) was computed using the Revised Duncan (TSEI), a contemporary indicator of SES sensitive to changes in occupational prestige (Nakao & Treas, 1992).

Medical data. We conducted a review of each child’s medical chart in order to obtain information regarding type of diagnosis, date of diagnosis, types of treatment (e.g., chemotherapy, surgery, radiation), date of relapse, type of relapse (e.g., local recurrence or metastatic disease), and illness or treatment-related complications.

Prognosis data and medical communication (Appendix A and B). Attending physicians and parents were asked to report on their perceptions of the child’s chance of disease free survival at five years post diagnosis on a 0% - 100% visual analogue scale. This method is similar to previous studies which have utilized 0% - 100% rating scales to quantify a child’s estimated chance of cure (e.g., Mack et al., 2007). Physicians were also asked to note whether the prognosis was communicated to the child’s parents in: (a) concrete/numeric terms, (b) general ideas, or (c) not at all. Parents were asked to note
whether or not they utilized each of the following sources of medical information: (a) physicians, (b) other medical professionals, (c) other families at the hospital, (d) the internet, and (e) family or friends. For our analyses, we coded participants as either (a) relying on information from medical professionals only, or (b) relying on information from at least one non-medical source in combination with medical professionals.

_Cancer specific stress and coping_ (Appendix 2). Parents completed the Pediatric Cancer Version of the Responses to Stress Questionnaire, a 57-item measure that uses a 4-point scale to assess three dimensions of voluntary coping: (a) primary control engagement (i.e., problem solving, emotional expression, emotional modulation), (b) secondary control engagement (i.e., cognitive restructuring, positive thinking, acceptance, distraction), and (c) disengagement (i.e., avoidance, denial, wishful thinking) (Connor-Smith et al., 2000). The RSQ also assesses perceived cancer-related stress on a 4-point scale, resulting in a total stress summary score. The RSQ has demonstrated good internal consistency, test-retest reliability, and convergent and discriminant validity (Connor-Smith et al. 2000). In a previous study that included parent self-report of coping in response to economic stressors, internal consistencies of the three factors on the parent form of the Economic Strain Version were primary control coping, $\alpha = .76$; secondary control coping, $\alpha = .83$; and disengagement coping, $\alpha = .72$ (Wadsworth, Raviv, Compas, & Connor-Smith, 2005). In this study, scores for the three dimensions of coping were recalculated on each scale as a proportion of total responses on the RSQ, and these proportions were used in all analyses. In previous studies, proportional scoring has been shown to be important for coping research, as it controls for the total amount of responses.
of each individual, thereby providing an index of the relative amount of each response category used (Thomsen et al., 2002; Jaser et al., 2008). Internal consistencies for the current sample were as follows: $\alpha = .62$ (mother primary control coping), $\alpha = .77$ (mother secondary control coping), $\alpha = .56$ (mother disengagement coping), $\alpha = .76$ (father primary control coping), $\alpha = .68$ (father secondary control coping), and $\alpha = .56$ (father disengagement coping).

_Psychological distress._ Parents completed the Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996) and the Beck Anxiety Inventory (BAI; Beck & Steer, 1990), two well standardized measures of symptoms of depression and anxiety in non-psychiatric samples. The BDI-II and BAI are both 21-item measures that use a 4-point scale to assess behavioral, cognitive, and motivational symptoms of depression and anxiety, respectively (Lindsay & Skene, 2007). Total scores are obtained by summing the ratings of the 21 items. Both instruments are widely accepted as highly reliable and valid tools for multiple patient populations and have the best discriminant validity for the self-report assessment of depression and anxiety symptoms in adults (Kunik et al., 2007; Steer et al., 1993). In a previous study of mothers of children undergoing bone marrow transplantation, internal consistency scores for the BDI-II and BAI ranged from $\alpha = .87$ - .89 (Manne et al., 2001). Internal consistencies for the current sample were as follows: $\alpha = .93$ (mother BDI-II), $\alpha = .92$ (father BDI-II), $\alpha = .93$ (mother BAI), and $\alpha = .92$ (father BAI).
Data Analyses

Prior to hypothesis testing, descriptive statistics (e.g., mean, frequency, standard deviation, range) were examined for all variables of interest. Within Aim 1, paired t-tests ($\alpha = .05$, two-tailed) were used to examine the differences in prognosis estimates between mothers, fathers, and physicians. Pearson correlations ($\alpha = .05$, two-tailed) were used to examine the associations between prognosis estimates for physicians and both parents, as well as associations between mothers and fathers (Hypotheses 1a).

Within Aim 2, Separate hierarchical regressions for mothers and fathers examined whether parent symptoms of depression moderated the association between physician and parent prognosis ratings (Hypothesis 2a). Prior to regression analyses, independent variables were centered to eliminate non-essential multicollinearity effects between first-order terms (i.e., the independent variable and the moderator) and the higher order terms (i.e., the interaction terms) (Holmbeck 1997). In Step 1, the predictor main effects (i.e., physician prognosis ratings) and the potential moderator main effects (i.e., parent depression) were entered. In Step 2, the interaction of predictor and potential moderator was entered. For significant moderators, post-hoc analyses were conducted to test the significance of slopes at selected values (i.e., simple slopes) and to examine the regions of significance for values of the moderator (Holmbeck 2002; Preacher, Curren, & Bauer, 2006).

Separate hierarchical regressions for mothers and fathers examined whether parent symptoms of anxiety moderated the association between physician and parent prognosis ratings (Hypothesis 2b). Prior to regression analyses, independent variables
were centered to eliminate non-essential multicollinearity effects between first-order
terms (i.e., the independent variable and the moderator) and the higher order terms (i.e.,
the interaction terms) (Holmbeck 1997). In Step 1, the predictor main effects (i.e.,
physician prognosis ratings) and the potential moderator main effects (i.e., parent
anxiety) were entered. In Step 2, the interaction of predictor and potential moderator was
entered. For significant moderators, post-hoc analyses were conducted to test the
significance of slopes at selected values (i.e., simple slopes) and to examine the regions
of significance for values of the moderator (Holmbeck 2002; Preacher, Curren, & Bauer,
2006).

Pearson correlations (α = .05, two-tailed) were used to examine the associations
between parent coping (i.e., primary control coping, secondary control coping, and
disengagement coping) and parent symptoms of anxiety and depression (Hypothesis 2c).
Separate hierarchical regressions for mothers and fathers examined whether parent
coping moderated the association between physician and parent prognosis ratings
(Hypothesis 2d). Prior to regression analyses, independent variables were centered to
eliminate non-essential multicollinearity effects between first-order terms (i.e., the
independent variable and the moderator) and the higher order terms (i.e., the interaction
terms) (Holmbeck 1997). In Step 1, the predictor main effects (i.e., physician prognosis
ratings) and the potential moderator main effects (i.e., parent coping) were entered. In
Step 2, the interaction of predictor and potential moderator was entered. For significant
moderators, post-hoc analyses were conducted to test the significance of slopes at
selected values (i.e., simple slopes) and to examine the regions of significance for values of the moderator (Holmbeck 2002; Preacher, Curren, & Bauer, 2006).

Further hierarchical regressions, run separately for mothers and fathers and for anxiety and depression, examined whether parent symptoms of depression and anxiety accounted for (i.e., mediated) the moderating role of coping in the association between physician and parent prognosis ratings (Hypothesis 2e). If the interaction of the predictor (i.e., physician prognosis ratings) and the moderator (i.e., parent coping) was significant (Step 2 of the previous moderation analysis), then the interaction of the predictor (i.e., physician prognosis ratings) and the moderator (i.e., parent coping) as well as the mediator (i.e., parent depression) were entered in the model in Step 1 of the mediated-moderation analysis. If the predictor X moderator (i.e., physician prognosis ratings X coping) interaction became significantly attenuated after controlling for the mediator (i.e., depression or anxiety), then depression (or anxiety) may at least partially mediate the moderating effect of coping on the association between physician and parent prognosis ratings. Post-hoc analyses using a bootstrapping technique were conducted to examine whether there was a significant decrease in the moderating effect of coping after accounting for parent symptoms of depression or anxiety to clarify the extent of mediation (Preacher, Rucker, & Hayes, 2007). This method allows for greater power by accounting for non-normal distributions, which can occur in smaller samples.

Alternatively, hierarchical regressions, run separately for mothers and fathers, examined whether parent coping accounted for (i.e., mediated) the moderating role of anxiety in the association between physician and parent prognosis ratings (Hypothesis
If the interaction of the predictor (i.e., physician prognosis ratings) and the moderator (i.e., parent anxiety) was significant, then the interaction of the predictor (i.e., physician prognosis ratings) and the moderator (i.e., parent anxiety) along with the mediator (i.e., parent coping) was entered in the model in Step 1 of the mediated-moderation analysis. If the predictor X moderator (i.e., physician prognosis ratings X anxiety) interaction became significantly attenuated after controlling for the mediator (i.e., coping), then coping may at least partially mediate the moderating effect of anxiety on the association between physician and parent prognosis ratings. Post-hoc analyses using a bootstrapping technique were conducted to examine whether there was a significant decrease in the moderating effect of anxiety after accounting for parent coping to clarify the extent of mediation. (Preacher & Hayes, 2004).

Within Aim 3, separate hierarchical regressions for mothers and fathers examined whether the content of physician communication moderated the association between physician and parent prognosis ratings (Hypothesis 3a). Prior to regression analyses, independent variables were centered to eliminate non-essential multicollinearity effects between first-order terms (i.e., the independent variable and the moderator) and the higher order terms (i.e., the interaction terms) (Holmbeck 1997). In Step 1, the predictor main effects (i.e., physician prognosis ratings) and the potential moderator main effects (i.e., content of physician communication) were entered. In Step 2, the interaction of predictor and potential moderator was entered. For significant moderators, post-hoc analyses were conducted to test the significance of slopes (i.e., simple slopes) for each
category of reported physician communication (i.e., concrete numbers, general terms) (Holmbeck 2002; Preacher, Curren, & Bauer, 2006).

Separate hierarchical regressions for mothers and fathers also examined whether parent sources of medical information moderated the association between physician and parent prognosis ratings (Hypothesis 3b). Prior to regression analyses, independent variables were centered to eliminate non-essential multicollinearity effects between first-order terms (i.e., the independent variable and the moderator) and the higher order terms (i.e., the interaction terms) (Holmbeck 1997). In Step 1, the predictor main effects (i.e., physician prognosis ratings) and the potential moderator main effects (i.e., parent source of medical information) were entered. In Step 2, the interaction of predictor and potential moderator was entered. For significant moderators, post-hoc analyses were conducted to test the significance of slopes (i.e., simple slopes) for participants that (a) relied on medical information from physicians only and (b) relied on medical information from at least one, non-medical source in combination with physician information (Holmbeck 2002).

Finally, separate hierarchical regressions for mothers and fathers examined whether parent demographic characteristics (i.e., parent age and parent education) moderated the association between physician and parent prognosis ratings (Hypothesis 3c). Prior to regression analyses, independent variables were centered to eliminate non-essential multicollinearity effects between first-order terms (i.e., the independent variable and the moderator) and the higher order terms (i.e., the interaction terms) (Holmbeck 1997). In Step 1, the predictor main effects (i.e., physician prognosis ratings) and the
potential moderator main effects (i.e., parent age or parent education) were entered. In Step 2, the interaction of predictor and potential moderator was entered. For significant moderators, post-hoc analyses were conducted to test the significance of slopes at selected values (i.e., simple slopes) and to examine the regions of significance for values of the moderator (Holmbeck 2002; Preacher, Curren, & Bauer, 2006).

Using GPOWER (Erdfelder, Faul, & Bucher, 1996), the sample of 77 mothers produced ample power (.85) to detect medium effects for paired t-tests \( (d = .30) \) and correlations \( (r = .30) \), while the sample of 42 fathers produced ample power (.98) to detect large effects for paired t-tests \( (d = .50) \) and correlations \( (r = .50) \). The sample of 75 mothers also produced ample power (.79-.85) to detect medium effects for multiple regressions \( (f^2 = .15) \) with two and three predictors, while the sample of 42 fathers produced ample power (.88-.92) to detect large effects for multiple regressions \( (f^2 = .35) \) with two and three predictors.
Chapter 3: Results

Variables of Interest

Descriptive statistics for coping, adjustment, and demographic variables of interest are presented in Table 1, while descriptive statistics for medical variables are presented in Table 2. BDI-II and BAI Total Score distributions for mothers and fathers are presented in Table 3, based on ranges specified by Beck et al. (1996) and Beck and Steer (1990). On average, mothers and fathers of children with cancer were not distressed. Pearson correlations between continuous predictor (i.e., physician prognosis estimates and parent coping, adjustment, age, and education) and outcome variables (i.e., mother and father prognosis estimates) are provided in Table 4. In order to examine the normality of variable distributions for mothers, fathers, and physicians, Standardized Skew Indices (SSI; Malgady, 2007) were calculated by dividing the raw skew statistic by two times the squared standard deviation of the variable of interest (SSI = Skew/2SD^2). Thus, SSI’s will vary from -1 to 1 with the lower and upper bounds representing the extreme values of skewness (Malgady). Although cutoff scores similar to significant *p* values have not been developed for the SSI, the values in the current sample range from -.00 - .14 and are sufficiently small to assume non-disruptive levels of skewness. A statistic similar to the SSI has not been developed to evaluate kurtosis; however, raw
kurtosis values between -3 and 3 are generally accepted as not departing significantly from normality (Maxwell & Delaney, 2004). Kurtosis values for variables of interest are all within acceptable limits, with the exception of mother prognosis ratings (6.89), father symptoms of depression (6.13), father symptoms of anxiety (3.94), and mother education level (7.90), whose values suggest a slightly leptokurtic (“too tall”) distribution. Wuensch (2005) reported that while behavioral researchers are rarely interested in questions that focus on the kurtosis of a distribution, high kurtosis values should alert researchers to investigate possible outliers in the tails of a distribution. In probing for outliers, we did not find any values in the distributions of the four above variables that could be categorized as invalid data points. Rather, this data provided valuable information about subsections of our sample (i.e., the small percentage of fathers who were severely depressed).

Aim 1: To examine the consensus of parents’ understanding of their child’s cancer prognosis.

Hypothesis 1a. Means, standard deviations, and ranges for physician and parent prognosis estimates are presented in Table 2. As expected, both mothers and fathers of children with cancer reported, on average, a more favorable prognosis for their child than physicians, t(74) = -6.16, p < .01, and t(42) = -5.18, p < .01, respectively. However, prognosis estimates between physicians and mothers, r(77) = .44, p < .01, and between physicians and fathers, r(42) = .56, p < .01, were significantly correlated (Table 4). The range of prognosis discrepancies between physician and parent estimates was 0-67% for mothers and 2-41% for fathers. Mother and father prognosis estimates did not
significantly differ from each other, \( r(42) = .419, p = .68 \), and they were not significantly correlated, \( r(42) = .26, p = .10 \), although there was a trend toward association in the expected direction.

**Aim 2: To examine the influence of coping and adjustment on parents’ understanding of their child’s cancer prognosis.**

*Hypothesis 2a.* As hypothesized, mother symptoms of depression moderated the association between physician and mother prognosis estimates, \( R^2 = .32, F(3, 70) = 11.15, p < .01 \) (Table 5). The simple slope reflecting agreement between physician and mother prognosis estimates was -0.19, \( t(74) = -1.02, p = .31 \), at lower levels of depression (-1 SD); 0.25, \( t(74) = 3.70, p < .01 \), at moderate levels of depression (Mean); and 0.16, \( t(74) = 2.06, p < .05 \), at higher levels of depression (+1 SD) (Figure 7). Examination of the region of significance revealed that the simple slope was significant for values of mother depression equal to or higher than 10.00 (i.e., z-scores of mother depression equal to or higher than -0.52). Results of post hoc tests showed that the slope relating physician prognosis estimates to mother prognosis estimates was weaker for mothers with lower levels of depression symptoms and stronger for mothers with moderate or higher levels of depression symptoms. The overall regression model including physician prognosis estimates, father symptoms of depression, and the interaction between physician prognosis estimates and father symptoms of depression was significant, \( R^2 = .36, F(3, 37) = 7.05, p < .01 \); however, the interaction term did not significantly contribute unique variance in the prediction of father prognosis estimates (Table 4).
Hypothesis 2b. As expected, mother symptoms of anxiety moderated the association between physician and mother prognosis estimates, $R^2 = .32$, $F(3, 71) = 11.00, p < .01$ (Table 5). The simple slope reflecting agreement between physician and mother prognosis estimates was -0.21, $t(74) = -1.21, p = .23$, at lower levels of anxiety (-1 SD) and 0.24, $t(74) = 3.60, p < .01$, at higher levels of anxiety (+ 1 SD) (Figure 8). Examination of the region of significance revealed that the simple slope was significant for values of mother anxiety equal to or higher than 6.19 (i.e., z-scores of mother anxiety equal to or higher than -.59). In contrast to hypotheses, the slope relating physician prognosis estimates to mother prognosis estimates was stronger for mothers with relatively higher levels of anxiety symptoms and weaker for mothers with relatively lower levels of anxiety symptoms. Again, the overall regression model including physician prognosis estimates, father symptoms of anxiety, and the interaction between physician prognosis estimates and father symptoms of anxiety was significant, $R^2 = .36$, $F(3, 37) = 6.80, p < .01$, but the interaction term did not significantly contribute unique variance in the prediction of father prognosis estimates (Table 5).

Hypothesis 2c. As hypothesized, mother use of primary and secondary control coping was negatively associated with mother symptoms of depression, $r(77) = -.54, p < .01$, and $r(77) = -.55, p < .01$, respectively. Similarly, father use of primary and secondary control coping was negatively associated with father symptoms of depression, $r(42) = -.70, p < .01$, and $r(42) = -.72, p < .01$, respectively. With regard to anxiety symptoms, mother use of primary and secondary control coping was negatively associated with mother symptoms of anxiety, $r(77) = -.34, p < .01$, and $r(77) = -.46, p < .01$. 


Father use of primary and secondary control coping was also negatively associated with father symptoms of anxiety, $r(42) = -.44, p < .01$, and $r(42) = -.62, p < .01$, respectively. Mother use of disengagement coping was positively associated with mother symptoms of depression, $r(77) = .34, p < .01$, but not anxiety. Father use of disengagement coping was unrelated to father adjustment; however, a trend for an association between father disengagement coping and father depression, $r(42) = .29, p = .06$, was found in the expected direction (Table 4).

Hypothesis 2d. The extent to which the three types of coping moderated the association between physician and parent prognosis estimates was examined in three equations separately for mothers and fathers, with regression models presented in Table 6. The overall regression models including physician prognosis estimates, mother coping (i.e., primary control, secondary control, or disengagement coping), and the interactions between physician prognosis estimates and each type of mother coping were significant, $R^2 = .27, F(3, 68) = 8.18, p < .01$; $R^2 = .20, F(3, 68) = 5.75, p < .01$; and $R^2 = .20, F(3, 68) = 5.65, p < .01$, respectively. However, the interaction terms did not significantly contribute unique variance in the prediction of mother prognosis estimates. Similarly, the overall regression model including physician prognosis estimates, father primary control coping, and the interaction between physician prognosis estimates and father primary control coping was significant, $R^2 = .34, F(3, 37) = 6.27, p < .01$, but the interaction term did not significantly contribute unique variance in the prediction of father prognosis estimates. In line with hypotheses, father secondary control coping was found to moderate the association between physician and father prognosis estimates, $R^2 = .45, F(3,$
The simple slope reflecting agreement between physician and father prognosis estimates was $1.83, t(74) = 3.13, p < .05$, at lower levels of secondary control coping (-1 SD) and $1.29, t(74) = 3.39, p = .20$, at higher levels of secondary control coping (+1 SD) (Figure 9). Examination of the region of significance revealed that the simple slope was significant for values of father secondary control coping equal to or below .27 (i.e., z-scores of father secondary control coping equal to or below .25).

Contrary to expectations, post hoc tests showed that the association between physician and father prognosis estimates was weaker among fathers who used more secondary control coping and stronger among fathers who used less secondary control coping.

Father use of disengagement coping also moderated the association between physician and father prognosis estimates, $R^2 = .41, F(3, 37) = 8.63, p < .01$. The simple slope reflecting agreement between physician and father prognosis estimates was $-1.06, t(74) = -1.82, p < .05$, at lower levels of disengagement coping (-1 SD) and $-0.69, t(74) = -1.58, p = .12$, at higher levels of disengagement coping (+1 SD) (Figure 10). Examination of the region of significance revealed that the simple slope was significant for values of father disengagement coping equal to or below .14 (i.e., z-scores of father disengagement coping equal to or below .15). As expected, the association between physician and father prognosis estimates was stronger among fathers who used less disengagement coping and weaker among fathers who used more disengagement coping strategies.

Hypothesis 2e. Because the interactions between physician prognosis estimates and both father (a) secondary control coping and (b) disengagement coping were significant in predicting father prognosis estimates, we were able to examine whether
father symptoms of depression and anxiety accounted for (i.e., mediated) the moderating role of secondary control coping and disengagement coping in the association between physician and father prognosis estimates. Regressions for these mediated moderation models are presented in Tables 7-10. The overall regression models including physician prognosis estimates, father secondary control coping, and the interaction between physician prognosis estimates and father secondary control coping remained significant after the inclusion of either symptoms of depression, $R^2 = .45$, $F(4, 36) = 7.40, p < .01$, or anxiety, $R^2 = .45$, $F(4, 36) = 7.36, p < .01$. However, because the beta weights for the interaction between physician prognosis estimates and father secondary control coping increased with the addition of either depression or anxiety (i.e., father symptoms of depression and anxiety did not serve as significant mediators in the model), probing the significance of the overall mediated moderation was not warranted. That is, whether the interaction of physician prognosis estimates and father secondary control coping became significantly attenuated after the addition of either adjustment variable in the regression equation (Tables 7 and 8). Similarly, the overall regression models including physician prognosis estimates, father disengagement coping, and the interaction between physician prognosis estimates and father disengagement coping remained significant after the inclusion of symptoms of either depression, $R^2 = .42$, $F(4, 36) = 6.46, p < .01$, or anxiety, $R^2 = .41$, $F(4, 36) = 6.31, p < .01$. Because the beta weights for the interaction between physician prognosis estimates and father disengagement coping were stable with the addition of either depression or anxiety (i.e., father symptoms of depression and anxiety did not serve as significant mediators in the model), probing the significance of the
Hypothesis 2f. Alternatively, we also sought to test whether parent coping accounted for (i.e., mediated) the moderating role of symptoms of anxiety in the association between physician and parent prognosis estimates. Regressions for these mediated moderation models are presented in Tables 11-13. As stated previously, mother symptoms of anxiety were found to moderate the association between physician and mother prognosis estimates, with post-hoc tests showing that the association between physician and mother prognosis estimates was weaker among mothers with lower as opposed to higher levels of anxiety symptoms (Figure 2). In testing for mediated moderation, the overall regression equations including physician prognosis estimates, mother symptoms of anxiety, and the interaction between physician prognosis estimates and mother symptoms of anxiety remained significant after the inclusion of primary control coping, $R^2 = .34$, $F(4, 67) = 8.43$, $p < .01$, secondary control coping, $R^2 = .32$, $F(4, 67) = 7.74$, $p < .01$, or disengagement coping, $R^2 = .32$, $F(4, 67) = 7.76$, $p < .01$. However, because the beta weights for the interaction between physician prognosis estimates and mother symptoms of anxiety remained stable with the addition of each type of mother coping (i.e., mother primary control, secondary control, and disengagement coping did not serve as significant mediators in the model), probing the significance of the overall mediated moderation was not warranted. That is, whether the interaction of
physician prognosis estimates and mother symptoms of anxiety became significantly attenuated after the addition of primary control, secondary control, or disengagement coping in the regression equation (Tables 11-13). As with mothers, the overall regression equation including physician prognosis estimates, father symptoms of anxiety, and the interaction between physician prognosis estimates and father symptoms of anxiety was significant, $R^2 = .36, F(3, 37) = 6.80, p < .01$. However, because the interaction term did not significantly contribute unique variance in the prediction of father prognosis estimates, we were unable to test for the potential mediating effect of coping in the mediated-moderation model.

**Aim 3:** To examine the influence of health literacy variables (i.e., content of physician communication, parent sources of medical information, parent age, and parent level of education) on parents’ understanding of their child’s cancer prognosis.

**Hypothesis 3a.** Descriptive statistics for variables reflecting medical communication and source of information are presented in Table 2. Regression models for analyses within Aim 3 are presented in Table 14. Because only three physicians indicated that they did not communicate prognosis information to the family, these physicians were excluded from regression analyses examining medical communication. The overall regression equations for mothers and fathers including physician prognosis estimates, content of physician communication, and the interaction between physician prognosis estimates and physician communication were significant, $R^2 = .20, F(3, 71) = 6.39, p < .01$, and $R^2 = .20, F(3, 37) = 8.05, p < .01$, respectively. However, the
interaction term did not contribute unique variance in the prediction of mother or father prognosis estimates (Table 14).

_Hypothesis 3b._ Similarly, the overall regression equation including physician prognosis estimates, mother source of medical information, and the interaction between physician prognosis estimates and mother source of medical information was significant, $R^2 = .21, F(3, 68) = 6.12, p < .01$, but the interaction term did not contribute unique variance in the prediction of mother prognosis estimates (Table 14). In line with hypotheses, father source of medical information was found to moderate the association between physician and father prognosis estimates, $R^2 = .33, F(3, 37) = 8.39, p < .01$ (Table 14). The simple slope reflecting agreement between physician and father prognosis estimates was .31, $t(74) = 3.71, p < .01$, for fathers who relied on information from medical professions in conjunction with at least one other source (i.e., other families at the hospital, the internet, family or friends) and -.00, $t(74) = -1.05, p = .70$, for fathers who relied on information from medical professionals only (Figure 11). Regions of significance were not examined due to the dichotomous nature of the moderator variable. Contrary to expectations, the association between physician and father prognosis estimates was stronger among fathers who relied on information from medical professionals in conjunction with at least one other source and weaker among fathers who relied on information from medical professionals only.

_Hypothesis 3c._ Finally, parent age and education were examined as potential moderators in the association between physician and parent prognosis estimates. With respect to parent age, the overall regression equations including physician prognosis
estimates, mother or father age, and the interactions between physician prognosis and
mother or father age were significant, $R^2 = .22$, $F(3, 71) = 6.69, p < .01$, and $R^2 = .52$,
$F(3, 37) = 13.51, p < .01$, respectively. Although the interaction of physician prognosis
estimates and mother age did not contribute unique variance in the prediction of mother
prognosis estimates, father age was found to moderate the association between physician
and father prognosis estimates (Table 14). The simple slope reflecting agreement
between physician and father prognosis estimates was $2.25, t(74) = 4.13, p < .01$, for
younger fathers (-1 SD) and $1.68, t(74) = 3.22, p = .32$, for older fathers (+1 SD) (Figure
12). Examination of the region of significance revealed that the simple slope was
significant for values of father age equal to or below 43.82 (i.e., z-scores of father age
equal to or below .48). In line with expectations, post hocs showed that the association
between physician and father prognosis estimates was weaker among older fathers and
stronger among younger fathers. With respect to parent education level, the overall
regression equations including physician prognosis estimates, mother or father education
level, and the interactions between physician prognosis estimates and mother or father
education level were significant, $R^2 = .20$, $F(3, 71) = 5.73, p < .01$, and $R^2 = .33$, $F(3, 37)$
= 6.19, $p < .01$, respectively. However, neither interaction term contributed unique
variance in the prediction of mother or father prognosis estimates (Table 14).
Chapter 4: Discussion

With advances in medicine leading to increased survival rates for a number of childhood cancers, it has become especially important for parents to accumulate accurate information in order to make informed decisions regarding treatment (Ries et al., 2005). When treatment does not work, obtaining an accurate understanding of the child’s prognosis may give parents the ability to balance aggressive treatment with maintaining the child’s quality of life throughout the disease course. Research on parents’ understanding of their child’s cancer prognosis is limited, with previous studies finding that parents tend to overestimate their child’s prognosis relative to physicians (Wolfe et al., 2000; Mack et al., 2007). A heuristic model of prognosis accuracy by Mack et al. proposed that parents’ understanding of their child’s cancer prognosis may be influenced, in part, by parent (e.g., coping, education) and physician (e.g., communication quality) characteristics. The current study adapted Mack et al.’s initial notion of prognosis accuracy into a series of testable models that are based on existing theories of stress, coping, adjustment, and health literacy in order to better understand the factors that influence parent’s understanding of their child’s cancer prognosis. In general, several factors were identified that were related to parent estimates of their child’s prognosis; however, support for the integrated model was found to differ for mothers and fathers.
Consistent with previous studies (Wolfe et al., 2000; Mack et al., 2007), we found that parents of children with cancer reported, on average, a more favorable prognosis for their child than physicians, and there was a positive association between physician and parent prognosis estimates. The average discrepancy between physician and parent prognosis estimates was 23 percentage points for mothers and 19 percentage points for fathers, with 84% of mothers and 83% of fathers estimating a more optimistic prognosis. In comparison to previous research on prognosis accuracy in parents of children with cancer, our sample is slightly more optimistic, as Mack et al. found that 61% of parents overestimated their child’s prognosis relative to physicians, with a discrepancy range of approximately 0-65%. This difference could be due to the timing of our study, as children in Mack’s sample were further removed from diagnosis (i.e., 3.5 months on average), which may have provided additional opportunities for parents to acquire and process information regarding prognosis. In addition, Mack’s sample contained a larger percentage of children with brain tumors (23% vs. 12%), which tend to have poorer prognoses than pediatric leukemias or lymphomas (National Cancer Institute, 2010). However, given parents’ tendency to be more optimistic about their child’s prognosis relative to physicians, this difference in diagnostic makeup between studies seems like it would actually yield less room for parents to overestimate prognoses in the current sample.

Mother and father prognosis estimates were not associated with each other, although there was no significant difference between prognosis estimates for the two groups of parents. Previous studies examining mothers and fathers separately also found
no gender differences in their understanding of prognosis at diagnosis (Edwards et al., 2008). However, research comparing caregivers is limited, as most studies have not analyzed mothers and fathers in separate groups and have been predominantly comprised of mothers (≥ 79%) (Wolfe et al., 2000; Mack et al., 2007). Moreover, research on prognosis literacy among adults with cancer has largely failed to compare male and female participants (Weeks et al., 1998; Eidinger & Shapira, 1984). A trend toward an association between mother and father prognosis estimates in the expected direction, $r(42) = .26$, presents the possibility that we simply did not have enough power to detect the effect. Specifically, our limited number of father participants may have constrained our ability to detect a significant association, as this sample size only allows for large effects to present as reliably significant.

Given that we found significant discrepancies between physician and parent prognosis estimates, the remainder of our study sought to examine potential factors related to parents’ understanding of their child’s cancer prognosis, using physician prognosis estimates as a predictor of parents’ understanding of prognosis (e.g., Lee, Fairclough, Antin, & Weeks, 2001). Expanding on Mack’s (2007) notion that individual parent factors affect prognosis accuracy, we first focused on the potential impact of parent adjustment on agreement between parent and physician prognosis estimates. Both mothers and fathers in our sample yielded average BDI and BAI scores that were within the mild symptom ranges (i.e., BDI Total Score of 14-19; BAI Total Score of 8-15). Given that the BDI specifies a score of above 20 to indicate a significant problem with depression, 26% of mothers and 21% of fathers in our sample were classified as
experiencing clinically significant symptoms. Similarly, the BAI clinical cut-off score of 16 designated 27% of mothers and 14% of fathers in our sample as clinically anxious. Levels of depression and anxiety for parents in our sample were slightly elevated in comparison to normative populations, as point prevalence estimates of clinically significant levels of depression in North America range from 8-10% for women and 3-5% for men, while point prevalence estimates of clinically significant levels of anxiety range from 4-8% for both genders (Kessler et al., 2005). Although mean levels of distress in parents of children with cancer may be higher than norms or controls within the first year of treatment, most parents typically fall in the mild or moderate range and well below clinical cutoffs (Gerhardt et al., 2007; Dolgin et al., 2007).

Regarding time since diagnosis, research has found that symptoms of distress in parents are most likely to be elevated immediately following the child’s diagnosis of cancer (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). Although further removed from diagnosis (i.e., 18 months on average), Gerhardt et al. (2007) found that a similar percentage of mothers (i.e., 28%) and a higher percentage of fathers (i.e., 38%) experienced clinically significant symptoms of distress as compared to our sample. This may be due to differences in the measurement of psychological adjustment, as Gerhardt et al.’s research utilized a single, global measure of distress that was based on nine dimensions, including both anxiety and depression. Using the BDI, Dahlquist, Czyzewski, and Jones (1996) found that only 7% of mothers and fathers experienced clinically elevated symptoms of depression at 20 months post diagnosis, with no significant differences found in the proportion of
clinically depressed parents at 2 versus 20 months post diagnosis. Future research should continue to clarify the levels of distress experienced by parents when a child is newly diagnosed with cancer.

As expected, we found that agreement between physician and mother prognosis estimates differed based on mother symptoms of depression; however, the nature of this association was different than originally hypothesized. In line with Strunk, Lopez, and DeRubeis’ (2005) argument that depression-related biases change over the spectrum of symptom severity, agreement between mother and physician prognosis estimates was weaker for mothers with lower levels of depressive symptoms relative to our sample and stronger for mothers with moderate to higher levels of depressive symptoms relative to our sample. Specifically, mothers with relatively low levels of depressive symptoms were overly optimistic when compared to mothers with relatively moderate to severe depressive symptoms. Thus, as expected and in line with previous research (Allow & Abramson, 1979; Beck, 1976), mothers with lower levels of depressive symptoms seemed to be exhibiting an optimistic bias. However, as mother symptoms of depression increased from relatively low to moderate, this optimistic bias disappeared, allowing mothers to align their prognosis estimates more strongly with physician estimates.

According to Strunk, Lopez, and DeRubeis (2005), as individuals move from moderate to severe symptoms of depression, accuracy in judgment is replaced with a more inaccurate (i.e., pessimistic) bias. However, we found that mothers high in depressive symptoms relative to our sample estimated their child’s prognosis similarly to mothers who had relatively moderate levels of depressive symptoms. Specifically,
mothers with relatively high levels of depressive symptoms made, on average, lower prognosis estimates than mothers with relatively low levels of depressive symptoms. The fact that we did not find expected differences in prognosis estimates between mothers with relatively low, moderate, and high levels of depressive symptoms could be due to the nature of our sample. As detailed above, most parents in our sample were functioning relatively well and showed limited elevations in depressive symptoms, which is consistent with studies suggesting that the majority of parents of children with cancer are quite resilient and do not exhibit severe psychopathology (Gerhardt et al., 2007; Pai et al., 2007). For mothers, the average values of our low, moderate, and high depressive symptom groups were 5.09, 15.31, and 25.53, respectively. Based on clinical BDI cut-offs, these values fall into the minimal, mild, and moderate ranges. Thus, while our high depressive symptom group represents the high end of our sample of mothers, it is not representative of persons whose symptoms would be categorized as clinically severe by BDI standards (i.e., BDI Total Score of > 28). Therefore, mothers of children newly diagnosed with cancer may not be experiencing depressive symptoms that are severe enough to produce a strong pessimistic bias.

Mother symptoms of anxiety, as expected, also influenced the agreement between physician and mother prognosis estimates, but as with depression, the nature of this effect was not as expected. We found that agreement between mother and physician prognosis estimates was stronger for mothers with high levels of anxiety symptoms relative to our sample and weaker for mothers with low levels of anxiety symptoms relative to our sample. On average, mothers with relatively low levels of anxiety symptoms appeared
more optimistic when compared to mothers with relatively high levels of anxiety symptoms. This finding contradicts the previously established cognitive-motivational view of anxiety, which states that the awareness of a threatening or anxiety provoking situation is accompanied by the tendency to shift one’s attention away from threat, or in this case, information related to the child’s cancer (Lang et al., 1990). Like depression, it may be that our sample of mothers did not display enough variability to detect expected differences in our low vs. high anxiety groups. Average BAI scores of 2.06 and 22.02 for our low and high anxiety symptom groups fell in the minimal and moderate ranges, respectively.

However, it may also be that in some cases, the experience of anxiety, albeit not severe symptomatology, causes an increase in one’s ability to accurately absorb and retain information. Lonigan and Phillips (2001) first established effortful control (EC) as an important moderator in the association between cognitive input (i.e., threatening information) and emotional processing (i.e., symptoms of anxiety). EC involves both attentional control (e.g., attention focusing, attention shifting, persistence in tasks) and inhibitory control (e.g., activating/inhibiting behavior as is necessary to respond adaptively) (Eisenberg et al., 2004). Indeed, Derryberry and Reed (2002) showed that only those anxious individuals who were also low in EC exhibited a bias toward threat-relevant stimuli. It may be that mothers with relatively high levels of anxiety symptoms did not possess levels of EC adequate to inhibit their initial attentional bias toward anxiety-provoking information relevant to their child’s disease, thus maintaining more medical information relative to non-distressed parents. Mothers that were more anxious,
if also lower in EC, may have been prompted to seek out additional information from the medical team or additional sources of medical knowledge. The assessment of attentional control in parents of children with newly diagnosed or relapsed cancer may shed more light on the association between symptoms of anxiety and health literacy. In addition, assuming opposite directionality between adjustment and understanding of prognosis, the ability to accurately absorb and acknowledge prognosis information when a child’s chances of survival are low may subsequently cause these mothers to experience higher levels of anxiety symptoms. Finally, it may also be that mothers with low levels of anxiety represent a group of parents that are actually choosing to reject, as opposed to not seek out or retain, medical information pertaining to their child’s prognosis. When facing the stress of childhood cancer, it may be more adaptive for parents to adopt a definitive stance that their child will survive, despite medical information and a poor prognosis that may suggest otherwise.

Contrary to expectations, father symptoms of depression and anxiety did not influence the agreement between physician and father prognosis estimates. As previously stated, our limited number of father participants may have constrained our ability to detect medium and small effects. The fact that the interactions of physician prognosis estimates and symptoms of depression and anxiety yielded similar standardized beta weights between mothers (i.e., depression = .25, anxiety = .31) and fathers (i.e., depression = .22, anxiety = .24) suggests effects sizes that may approach significance in a larger sample of fathers. Furthermore, although relatively equal proportions of mothers and fathers in our sample were characterized as severely depressed or anxious, fathers
were, on average, less depressed and anxious than mothers, with more fathers falling in the minimal ranges for depression and anxiety. In addition, while mother prognosis estimates were negatively associated with mother symptoms of depression, $r(77) = -.34, p < .01$, and anxiety, $r(77) = -.24, p < .05$, father prognosis estimates were unrelated to father adjustment. Thus, it may be that our sample of fathers did not display enough variability in symptoms or prognosis estimates to find expected effects.

Given the established links between adjustment and coping style, we continued to expand on Mack et al.’s (2007) notion of prognosis literacy by focusing on coping as another parent characteristic that may potentially affect the level of agreement between physician and parent prognosis estimates. Consistent with previous studies (Wadsworth, Raviv, Compas, & Connor-Smith, 2005; Norberg, Lindblad, & Boman, 2005; Sloper, 2000), mother and father use of primary and secondary control coping was negatively associated with symptoms of anxiety and depression, while mother use of disengagement coping was positively associated with symptoms of depression. Contrary to expectations, mother use of disengagement coping was unrelated to mother symptoms of anxiety. However, the hypothesized positive association between mother symptoms of anxiety and disengagement coping (i.e., denial, avoidance, wishful thinking) seems incompatible with our findings that mothers with relatively high levels of anxiety symptoms were more accurate in their prognosis estimates. Father use of disengagement coping was unrelated to father adjustment, but there was evidence of a trend toward an association between father disengagement coping and father depression, $r(42) = .29$, in the expected direction.
The mean proportion scores for disengagement coping for both mothers and fathers were lower than those of primary or secondary control coping, meaning that parents spent the least amount of time on disengagement-related activities. When adults reported using similar mean levels of primary, secondary, and disengagement coping strategies, studies have found significant associations between disengagement coping and internalizing symptoms (e.g., Connor-Smith & Compas, 2004). Therefore, it may be that parents in the current study were simply using less disengagement coping, which is understandable given the challenge of enacting disengagement strategies when a child is on active treatment.

Interestingly, Phipps, Fairclough, and Mulhern (1995) found a positive association between blunting and time since diagnosis, such that children who were at least one year post-diagnosis used more avoidant coping strategies. However, another study found that parents of children with cancer who were eight weeks, 30 months, and 10 years post diagnosis used similar levels of avoidant coping strategies (Norerg, Linkblad, & Boman, 2004). The inclusion of families who are further removed from diagnosis or the longitudinal study of families over time may help to clarify the evolving role of disengagement coping and adjustment over the course of the cancer experience. Most of the literature on coping and adjustment has consistently found small to moderate effects between disengagement coping and adjustment (Wong & Heriot, 2007; Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000).

Contrary to expectations, no evidence was found that mother or father primary control coping influenced agreement between physician and parent prognosis estimates.
Previous research linking the use of monitoring (i.e., primary control coping) with increased efforts to understand medical decision making issues included adults with cancer who were farther removed from diagnosis and/or receiving palliative therapies (Timmermans, van Zuuren, Van der Maazen, Leer, & Kraaimaat, 2007). Thus, it may be that the strategies considered by Compas and colleagues to encompass primary control coping (i.e., problem solving, emotional expression, emotional modulation) are differentially effective for parents of children who are newly diagnosed. Although approximately 20% of mother and father self-reported stress responses during this time can be described as primary control coping, such strategies may not significantly promote parents’ initial understanding of their child’s disease and chance for survival.

In line with hypotheses, father use of secondary control and disengagement coping influenced agreement between physician and father prognosis estimates; however, the influence of secondary control coping was not in the expected direction. Specifically, agreement between physician and father prognosis estimates was weaker among fathers who used more secondary control coping and stronger among fathers who used less secondary control coping. Fathers that used more secondary control coping were overly optimistic compared to fathers who used these strategies less. Most of the research on coping as it relates to prognosis accuracy has examined the influence of disengagement coping strategies such as avoidance (Timmermans, van Zuuren, Van der Maazen, Leer, & Kraaimaat, 2007; Mack et al., 2007). The Responses to Stress Questionnaire conceptualizes secondary control coping as a collection of ‘accommodative’ strategies that include cognitive restructuring, acceptance, positive thinking, and distraction.
(Thomsen et al., 2002; Connor-Smith et al., 2000). These strategies have been shown to be particularly helpful for patients dealing with uncontrollable stressors (e.g., disease or pain), as they promote adaptation through the regulation of cognition and attention (Schanberg, Lefebvre, Keefe, Kredich, & Gill, 1997; Thomsen et al., 2002).

It is plausible that fathers’ use of secondary control coping may differentially affect prognosis accuracy based on the specific strategies used. For example, the use of distraction strategies (e.g., “I keep my mind off of my child’s illness by exercising, seeing friends, doing a hobby, or watching TV”) that cause fathers to focus their attention away from the details of their child’s disease may hinder the retention of medical information and lead to inaccurate views regarding prognosis. In addition, acceptance strategies (e.g., “I realize that I just have to live with the way things are”) may promote efforts to accurately understand disease information. However, a reliance on positive thinking (e.g., “I tell myself that everything will be all right”) or cognitive restructuring (e.g., “I think about the things that I am learning from this situation or something good that will come from it”), as they are measured by the RSQ, may lead to an overly optimistic outlook of the child’s chances of survival (Connor-Smith et al., 2000). More research is needed on parents’ use of specific strategies within the domains of primary, secondary, and disengagement coping in order to clarify the impact of differing types of coping on understanding of prognosis.

It is important to note that similar effects for secondary control and disengagement coping were not found for mothers. These results are surprising given our increased power to detect significant effects for mothers in comparison to fathers. As
previous research has examined the influence of coping on understanding of prognosis for mothers and fathers together (i.e., Mack et al., 2007), it may be that mothers’ knowledge of medical information is less affected by the type of coping that they use. In addition, the finding that our mediated moderation analyses were not significant may reflect the fact that parent coping and adjustment, although associated with each other, may function in different ways to influence prognosis understanding in mothers and fathers. Specifically, the agreement between physician and mother prognosis estimates seems to be influenced by symptoms of depression and anxiety, while agreement between prognosis estimates for physicians and fathers is influenced by certain types of coping.

Finally, given the scarcity of research examining Mack’s (2007) hypothesis that health literacy variables may influence parent prognosis accuracy, we sought to test whether agreement between physician and parent prognosis estimates differed based on varying types of physician communication content and parent sources of medical information, as well as varying levels of demographic factors. Contrary to expectations, the way in which physician’s communicated prognosis information to parents (i.e., in concrete/numeric terms or general ideas) did not influence agreement between parent and physician prognosis estimates. The majority of physicians (i.e., 72%) in our sample reported that they had communicated prognosis information about the child in concrete or numeric terms. This is similar to Mack et al.’s finding that 69% of parents of children with cancer recalled receiving a numeric estimate of prognosis from their child’s physician. Unlike previous studies suggesting that the delivery of frank and accurate prognostic information may be more likely for adults with ‘intermediate’ as opposed to
‘short’ anticipated survivals, the content of prognostic information delivered by our physicians was unrelated to physician prognosis estimates (Lamont & Christakis, 2001). Although promising, these numbers suggest that some families may still not be receiving complete information, as a previous study of adults with cancer found that approximately 80% wished to receive full details regarding prognosis (Barnett, 2005). In addition, approximately 30% of parents of children undergoing end-of-life care felt that they were not well-informed about their child’s chance of survival (Meyer et al., 2002). The failure to deliver a prognosis may be due to the multiple challenges that physicians face when providing such information, including the wish to instill hope in families and the lack of established prognosis data for those childhood cancers that are rare and unpredictable in course (Lamont & Christakis, 2001). As such, physicians may benefit from increased training in the delivery of prognostic information, regardless of the severity of prognosis.

As expected, we found that agreement between physician and father prognosis estimates varied depending on where fathers reported obtaining medical information. Specifically, fathers that relied on a combination of information from medical professionals and outside sources (i.e., other families at the hospital, the internet, family or friends) had prognosis estimates that were more highly correlated with those of physicians. Previous research has found that the majority of adult oncology patients preferred to discuss illness-related questions with their doctor (Barnett, 2005). Similarly, only three of the fathers in our sample reported that their child’s medical team was not a source of medical information. Thus, our findings suggest that concordance between physician and father estimates was increased when fathers were able to access reliable
sources of medical information above and beyond these professionals. For example, almost half of fathers (i.e., 47%) cited using the internet to gain knowledge of their child’s cancer. With the continued increase of medical websites being developed and monitored by legitimate health organizations (e.g., American Cancer Society, National Cancer Institute), parents may have little difficulty obtaining accurate information regarding pediatric cancer. Alternatively, the acquisition of medical knowledge from outside sources, regardless of validity, may assist parents in formulating specific questions that serve as the basis for continuing discussions with the child’s medical team.

It is interesting that variability in where mothers reported gaining medical information did not affect agreement between physician and mother prognosis estimates. Mothers and fathers in our sample were similar in terms of the number that relied on at least one non-professional source of medical information; however, we did not collect data on the frequency with which different information sources were utilized. Traditionally, mothers are more likely to assume the majority of responsibility for their child’s medical care (e.g., doctor’s appointments, hospital stays), while fathers often assume primary financial responsibilities (Quittner et al., 1998; Chesler & Parry, 2001). Because of this trend, it may be that mothers are provided with more opportunities to access medical professionals. Thus, they are more likely to derive the majority of their medical knowledge directly from the healthcare team, whereas fathers may rely more on mothers or other sources to obtain medical information.

Finally, we found that agreement between physician and father prognosis estimates differed based on father age, such that agreement was stronger for younger
fathers and weaker for older fathers. This finding is in line with the bulk of previous research on adult health literacy, which has linked younger age with greater illness knowledge (Paasche-Orlow et al., 2005). Given that no studies to date have examined the influence of parent age on prognosis understanding, it may be that the stress of being an adult patient and that of parenting an ill child are similarly affected by health literacy variables. Older fathers in our sample, as compared to younger fathers, may have had more life experiences with cancer prior to their child’s diagnosis, that is, related diagnoses in other family members or friends. The tendency to compare their child’s disease with anecdotal information or previous experiences with adult malignancies may unintentionally cause older parents to adopt an inaccurate understanding of prognosis.

Older parents may also be more reluctant to ask for clarification of prognosis from the child’s medical team after the initial consultation, as a study of adults undergoing medical consultations found that older patients were less likely to ask medical questions and to receive diagnostic information from physicians (Street, 1991). In addition, previous research on computer literacy in the United States has found that regular computer usage is negatively associated with adult age (e.g., Newburger, 2001). Thus, younger parents who are better versed in using technology (e.g., the internet) to acquire information may be more likely to utilize online health resources as a way to gain knowledge of their child’s disease (Baker, Wagner, Singer, Bundorf, 2003). Finally, age may affect the ease with which one navigates a modern pediatric medical system, with younger parents feeling more comfortable interacting with the medical team and negotiating medical decisions on behalf of their child.
In contrast to age, parent education level was unrelated to prognosis accuracy. Research that has found significant effects for parent education has tended to utilize participants with a wide range of educational levels (i.e., 0-23 years of schooling) (e.g., Beeri, Haramati, Rein, & Nir, 2001). On average, our sample of mothers and fathers had 2-3 years of post-secondary education, with only 4% of mothers (n = 3) and 10% of fathers (n = 4) obtaining education at the graduate or professional level (i.e., above 16 years of education). Thus, it may be that our parents did not differ enough in their educational attainment for significant associations to be detected. In addition, it may be more informative to examine the influence of education based on type of education obtained (e.g., college, technical school) as opposed to years of education, as previous research utilizing education type has found significant associations with health literacy in adults with diabetes (e.g., Schillinger et al., 2002). Finally, some studies have suggested that education level may not be an appropriate indicator of health literacy. Williams, Davis, Parker, and Weiss (2002) found that 60% of adult family practice patients had reading skills (i.e., another common indicator of health literacy) that were at least three levels below the highest school grade they attended. Thus, future research may wish to consider the examination of specific cognitive and academic variables (i.e., reading level, comprehension abilities, and language skills) as they relate to disease literacy.

The current study has several additional limitations which should be considered. First, limitations exist regarding the characteristics of our sample. Although our study utilized both parents when available to report on coping, adjustment, and prognosis estimates, we were limited in our number of father participants as compared to mothers.
Mothers often describe themselves as the primary caretaker and the parent that is most active in their child’s treatment; however, data from fathers are equally important in order to examine differences between caregivers (Phares et al., 2005). Results of this study provide support for the fact that different factors influence how mothers and fathers initially come to understand their child’s cancer prognosis. Thus, future studies in this area should continue to make specific efforts to include data from fathers or multiple caregivers. Our study also lacked a control group, which would have enabled us to compare differences in coping, adjustment, and preferences for obtaining health information between pediatric cancer and other chronically ill or healthy populations. Finally, as detailed above, our sample was relatively homogeneous with regard to physician estimated prognoses, as over half of children were rated as having above a 70% chance of 5-year survival. The inclusion of more children with high risk diagnoses would have allowed for the generation of conclusions regarding the factors influencing parents’ understanding of prognosis when the child’s chance of survival was low.

Second, we were limited in our measurement of variables related to parents’ understanding of prognosis and health literacy. Specifically, we utilized primary physician prognosis estimates as a benchmark for parent prognosis accuracy, as is common in research examining parents’ health literacy (Lee, Fairclough, Antin, & Weeks, 2001). Given that families may interact with various physicians and other health professionals following diagnosis, an examination of a family’s interactions with all medical team members may enable a more thorough conceptualization of the way that prognosis information is communicated and obtained. The utilization of disease specific
survival rates may also provide an additional marker of physician and parent accuracy. In addition, the examination of models based on caregiver status (e.g., primary caregiver for the child), as well as gender, may aid in identifying specific reasons for differences in understanding of prognosis. With regard to our exploratory hypotheses, we utilized only basic information regarding physician-parent communication and parent sources of medical knowledge immediately following a child’s cancer diagnosis. The collection of more detailed information regarding the specific content and timing of initial prognosis conversations, the frequency of these conversations over time, trends in terms of who initiated medical discussions (e.g., parents or the medical team), and the communication style of physicians, as well as the utilization of additional research methods to obtain such information (e.g., the use of observation and coding for medical conversations) may shed more light on the on-going process of acquiring knowledge of the child’s prognosis.

Finally, our study did not allow for the investigation of additional factors that may be relevant to parents’ understanding of prognosis. Although our hypotheses were based on Mack et al.’s (2007) heuristic model of prognosis understanding, other factors, such as hope or dispositional optimism, have been found to be associated with disease-specific prognosis rates or prognosis accuracy in adults with cancer, children with other illnesses, and parents of children with cancer (Allison, Guichard, Fun, & Gilain, 2003; Mack, Wolfe et al., 2007; Sung e al., 2009). Thus, such factors may also be important in understanding differences in parents’ health literacy. In addition, this study did not assess factors that may be influenced by differing levels of parents’ understanding of prognosis over the course of treatment. Future research should examine treatment
decision making, communication with the ill child, satisfaction with clinical services, long-term psychological functioning of parents, and other related factors, as they may further highlight the importance of prognosis accuracy following diagnosis. Such research appears warranted, given the implications of an accurate or inaccurate understanding of prognosis with regard to these variables.

Overall, our study provides partial support for an integrated model of parent prognosis accuracy that highlights depression, anxiety, coping, source of medical information, and parent age as important factors that appear to play a role in mothers’ or fathers’ understanding of their child’s cancer prognosis. In addition, while mother and father prognosis estimates did not differ from each other, our findings indicate that the specific factors involved in influencing prognosis understanding may vary between parents. This research points to the early examination of these factors in order to identify parents who may have difficulty understanding prognosis over the course of treatment.

Although the majority of parents in our sample were generally functioning well and were more optimistic in their prognosis estimates than physicians, distress did not influence the association between physician and parent prognosis estimates in the expected manner. Clinically, medical professionals may be more likely to provide frequent and continuous information when parents appear distressed. However, given that the subgroup of mothers who reported relatively higher symptoms of depression and anxiety tended to be more accurate with regard to their child’s prognosis, increased efforts by all medical team members to ensure prognostic understanding may actually be most beneficial to those mothers who are adjusting well. For fathers, the emphasis on
alternative coping skills to replace some secondary and disengagement strategies may be particularly helpful in promoting their understanding of prognosis, while both mothers and fathers may benefit from interventions targeted at teaching primary control coping skills to aid healthy adjustment.

Health literacy variables may be particularly important for fathers. Given that fathers may be less likely to have regular access to the medical team, recommendations for additional sources of medical information (e.g., books, internet resources), particularly for those who are older, seems warranted to promote their medical knowledge. Finally, a more thorough and continuous assessment of parent preferences for type and content of disease-related communication, and the subsequent tailoring of information that is delivered by medical team members, may improve parents’ prognosis accuracy, regardless of their coping preferences or psychological functioning. The initiation of such efforts and the development of appropriate interventions may prove beneficial in helping parents to have more accurate perceptions of their child’s prognosis in order to make informed treatment decisions throughout the course of the disease.


on the quality of pediatric palliative care. *Archives of Pediatric Adolescent Medicine, 156*, 14-19.


Sung, L., Klaassen, R.J., Dix, D., Pritchard, S., Yanofsky, R., Ethier, M.C., & Klassen, A.


Appendix A

Parent-rated Prognosis Data and Medical Communication

When a child is diagnosed with cancer, there is a lot of information that parents must gather and try to understand about their child’s expected outcome or prognosis from treatment. One purpose of this research is to try and understand how parents come to understand their child’s prognosis and/or communicate this with their child.

1. What do you think the chances are that your child’s treatment will be successful and they will be disease free when they are 5 years from diagnosis? (Please place an “X” anywhere on the line that corresponds to your answer)

0% ---------------------25%---------------------50% ---------------------75%----------------100%

2. Where did you get this information? (Please check all that apply)

___ My child’s Doctor
___ Other medical professionals
___ Other families at the hospital
___ My own research (e.g. Internet)
___ Family or Friends

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Appendix B

Physician-rated Prognosis Data and Medical Communication

To be completed by the child’s primary oncologist.

1. What do you think the probability or chances are that this child’s treatment will be successful and they will be disease free when they are 5 years from diagnosis? (Please place an “X” anywhere on the line that corresponds to your answer)

0% ---------------------25%---------------------50% ---------------------75%----------------100%

2. How directly have you stated this information to this child’s parents?

_____ We have not discussed the child’s prognosis in these kinds of terms (1)

_____ I have given them a general idea of this prognosis but we have not discussed it in terms of numbers (2)

_____ I have told the parents this information in concrete / numeric (3)
Table 1

Means and Standard Deviations for Coping, Adjustment, and Demographic Variables of Interest for Mothers (N = 77) and Fathers (N = 42) of Children with Cancer

<table>
<thead>
<tr>
<th></th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M \pm SD$ / (Range)</td>
<td>$M \pm SD$ / (Range)</td>
</tr>
<tr>
<td>PCC-RSQ</td>
<td>0.20 ± 0.04 / (0.11 - 0.30)</td>
<td>0.20 ± 0.04 / (0.08 - 0.30)</td>
</tr>
<tr>
<td>SCC-RSQ</td>
<td>0.26 ± 0.05 / (0.16 - 0.41)</td>
<td>0.26 ± 0.05 / (0.14 - 0.36)</td>
</tr>
<tr>
<td>DC-RSQ</td>
<td>0.13 ± 0.03 / (0.08 - 0.19)</td>
<td>0.13 ± 0.02 / (0.09-0.18)</td>
</tr>
<tr>
<td>Depression-BDI</td>
<td>15.31 ± 10.22 / (0.00 - 44.00)</td>
<td>13.76 ± 9.43 / (0.00 - 53.00)</td>
</tr>
<tr>
<td>Anxiety-BAI</td>
<td>12.04 ± 9.98 / (0.00 - 53.00)</td>
<td>8.64 ± 8.97 / (0.00 - 42.00)</td>
</tr>
<tr>
<td>Age (Years)</td>
<td>37.05 ± 7.38 / (24.00 – 57.00)</td>
<td>40.45 ± 7.01 / (27.00 – 58.00)</td>
</tr>
<tr>
<td>Education (Years)</td>
<td>14.90 ± 3.53 / (9.00 – 18.00)</td>
<td>15.26 ± 4.04 / (10.00 – 20.00)</td>
</tr>
</tbody>
</table>

Note. PCC = primary control coping; SCC = secondary control coping; DC = disengagement coping; RSQ = Responses to Stress Questionnaire; BDI = Beck Depression Inventory; BAI = Beck Anxiety Inventory.
Table 2

*Means and Standard Deviations for Prognosis Data and Percentages for Content or Source of Medical Information for Physicians, Mothers (N = 77), and Fathers (N = 42) of Children with Cancer*

<table>
<thead>
<tr>
<th>Source of Medical Information</th>
<th>M ± SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s Prognosis Estimated by Physician</td>
<td>61.78 ± 29.14</td>
<td>0 – 96.00</td>
</tr>
<tr>
<td>Child’s Prognosis Estimated by Mother</td>
<td>81.65 ± 19.41</td>
<td>0 – 100.00</td>
</tr>
<tr>
<td>Child’s Prognosis Estimated by Father</td>
<td>84.85 ± 14.97</td>
<td>35.00 – 100.00</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physician Content of Communication</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concrete/Numeric Terms</td>
<td>72.20 (57)</td>
</tr>
<tr>
<td>General Ideas</td>
<td>21.50 (17)</td>
</tr>
<tr>
<td>None</td>
<td>3.80 (3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mother Source of Medical Information</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Professionals Only</td>
<td>33.30 (24)</td>
</tr>
<tr>
<td>Medical Professionals+</td>
<td>66.70 (48)</td>
</tr>
</tbody>
</table>

Continued
Table 2 Continued

<table>
<thead>
<tr>
<th>Father Source of Medical Information</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Professionals Only</td>
<td>31.70 (13)</td>
</tr>
<tr>
<td>Medical Professionals+</td>
<td>63.40 (26)</td>
</tr>
</tbody>
</table>

Note. Medical Professionals+ = medical professionals in combination with at least one other source of medical information (i.e., other families at the hospital, the internet, family or friends).
Table 3

Distribution of Beck Depression Inventory-II (BDI-II) and Beck Anxiety Inventory (BAI) Total Scores for Mothers (N = 77), and Fathers (N = 42) of Children with Cancer

<table>
<thead>
<tr>
<th>Range</th>
<th>BDI-II N (%)</th>
<th>BAI N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
</tr>
<tr>
<td>Minimal</td>
<td>39 (50)</td>
<td>23 (55)</td>
</tr>
<tr>
<td>Mild</td>
<td>18 (24)</td>
<td>10 (24)</td>
</tr>
<tr>
<td>Moderate</td>
<td>10 (13)</td>
<td>7 (17)</td>
</tr>
<tr>
<td>Severe</td>
<td>10 (13)</td>
<td>2 (4)</td>
</tr>
</tbody>
</table>

*Note.* BDI Total Score ranges: minimal (≤ 13); mild (14 – 19); moderate (20 – 28); severe (> 28). BAI Total Score ranges: minimal (≤ 7); mild (8 – 15); moderate (16 – 25); severe (> 25).
Table 4

*Pearson Correlations between Physician Prognosis Estimates, Parent Prognosis Estimates, Coping, Symptoms of Depression and Anxiety, Age, and Education Level for Mothers and Fathers of Children with Cancer*

<table>
<thead>
<tr>
<th></th>
<th>Phy.PE</th>
<th>Par.PE</th>
<th>RSQ-P</th>
<th>RSQ-S</th>
<th>RSQ-D</th>
<th>BDI</th>
<th>BAI</th>
<th>Age</th>
<th>Educ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phy.PE</td>
<td>-</td>
<td>.44**</td>
<td>.11</td>
<td>.09</td>
<td>-.08</td>
<td>-.19</td>
<td>-.08</td>
<td>.05</td>
<td>.20</td>
</tr>
<tr>
<td>Par.PE</td>
<td>.56**</td>
<td>-</td>
<td>.24*</td>
<td>.16</td>
<td>-.03</td>
<td>-.34**</td>
<td>-.24*</td>
<td>.10</td>
<td>.11</td>
</tr>
<tr>
<td>RSQ-P</td>
<td>.08</td>
<td>.01</td>
<td>-</td>
<td>.24*</td>
<td>-.51**</td>
<td>-.54**</td>
<td>-.34**</td>
<td>.14</td>
<td>.08</td>
</tr>
<tr>
<td>RSQ-S</td>
<td>.16</td>
<td>.26</td>
<td>.32*</td>
<td>-</td>
<td>-.52**</td>
<td>-.55**</td>
<td>-.46**</td>
<td>.11</td>
<td>.05</td>
</tr>
<tr>
<td>RSQ-D</td>
<td>.12</td>
<td>.10</td>
<td>-.45**</td>
<td>-.29</td>
<td>-</td>
<td>.34**</td>
<td>.11</td>
<td>-.10</td>
<td>-.10</td>
</tr>
<tr>
<td>BDI</td>
<td>-.08</td>
<td>-.11</td>
<td>-.70**</td>
<td>-.72**</td>
<td>.29</td>
<td>-</td>
<td>.61**</td>
<td>-.20</td>
<td>-.08</td>
</tr>
<tr>
<td>BAI</td>
<td>-.09</td>
<td>-.10</td>
<td>-.44**</td>
<td>-.62**</td>
<td>.17</td>
<td>.77**</td>
<td>-</td>
<td>.07</td>
<td>.05</td>
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Continued
Table 4 Continued

<table>
<thead>
<tr>
<th></th>
<th>Phy.PE</th>
<th>Par.PE</th>
<th>RSQ-P</th>
<th>RSQ-S</th>
<th>RSQ-D</th>
<th>BDI</th>
<th>BAI</th>
<th>Age</th>
<th>Educ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-.15</td>
<td>.16</td>
<td>.38*</td>
<td>.29</td>
<td>-.22</td>
<td>-.38*</td>
<td>-.32*</td>
<td>-.32*</td>
<td>.16</td>
</tr>
<tr>
<td>Educ</td>
<td>-.03</td>
<td>.00</td>
<td>.57**</td>
<td>.26</td>
<td>-.32*</td>
<td>-.32*</td>
<td>-.35*</td>
<td>.40**</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. Correlations above the split reflect mother variables (N = 77) and correlations below the split reflect father variables (N = 42); Phy.PE = physician prognosis estimates; Par.PE = parent prognosis estimates; RSQ-P = primary control coping; RSQ-S = secondary control coping; RSQ-D = disengagement coping; BDI = symptoms of depression; BAI = symptoms of anxiety; Educ = years of education; *p < .05, two-tailed. **p < .01, two-tailed.
Table 5

Regressions of Mother and Father Prognosis Estimates on Physician Prognosis
Estimates and Mother and Father Symptoms of Depression and Anxiety

<table>
<thead>
<tr>
<th>Step</th>
<th>Mothers</th>
<th></th>
<th></th>
<th></th>
<th>Fathers</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$R^2_a$</td>
<td>$\Delta R^2$</td>
<td>$R^2_a$</td>
<td>$\Delta R^2$</td>
<td>Variables Entered</td>
<td>Beta $^b$</td>
<td>Beta $^b$</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>.19</td>
<td>.19**</td>
<td>.32</td>
<td>.32**</td>
<td>Physician PE</td>
<td>.44**</td>
<td>.56**</td>
<td></td>
</tr>
<tr>
<td></td>
<td>.26</td>
<td>.07*</td>
<td>.32</td>
<td>.01</td>
<td>Depression</td>
<td>-.27*</td>
<td>.07</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>.32</td>
<td>.06*</td>
<td>.36</td>
<td>.04</td>
<td>Physician PE</td>
<td>.37**</td>
<td>.52**</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression</td>
<td>-.26*</td>
<td>.16</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Physician PE x Depression</td>
<td>.25*</td>
<td>.22</td>
<td></td>
</tr>
</tbody>
</table>

1  | .19      | .19**   | .32     | .32**   | Physician PE      | .44**   | .56**   |
|    | .23      | .04     | .32     | .00     | Anxiety           | -.20    | -.05    |
| 2  | .32      | .09**   | .36     | .04     | Physician PE      | .43**   | .57**   |
|    |          |         |         |         | Anxiety           | -.29**  | -.20    |
|    |          |         |         |         | Physician PE x Anxiety | .31**  | .24     |

Note. PE = prognosis estimate

$^a$ Mothers: step 1 df (2, 71); step 2 df (3, 70)
Fathers: step 1 df (2, 38); step 2 df (3, 37)

$^b$ Standardized beta weights; * p < .05, ** p < .01.
Table 6

Regressions of Mother and Father Prognosis Estimates on Physician Prognosis Estimates and Mother and Father Coping

<table>
<thead>
<tr>
<th>Step</th>
<th>Mothers</th>
<th>Fathers</th>
<th>Variables Entered</th>
<th>Mothers Beta</th>
<th>Fathers Beta</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( R^2 )</td>
<td>( \Delta R^2 )</td>
<td>( R^2 )</td>
<td>( \Delta R^2 )</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>.19</td>
<td>.19**</td>
<td>.32</td>
<td>.32**</td>
<td>Physician PE</td>
</tr>
<tr>
<td></td>
<td>.23</td>
<td>.04</td>
<td>.32</td>
<td>.01</td>
<td>PCC</td>
</tr>
<tr>
<td>2</td>
<td>.27</td>
<td>.04</td>
<td>.34</td>
<td>.01</td>
<td>Physician PE</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>PCC</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Physician PE x PCC</td>
</tr>
<tr>
<td>1</td>
<td>.19</td>
<td>.19**</td>
<td>.32</td>
<td>.32**</td>
<td>Physician PE</td>
</tr>
<tr>
<td></td>
<td>.20</td>
<td>.02</td>
<td>.35</td>
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<td>SCC</td>
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<td>Physician PE x SCC</td>
</tr>
<tr>
<td>1</td>
<td>.19</td>
<td>.19**</td>
<td>.32</td>
<td>.32**</td>
<td>Physician PE</td>
</tr>
<tr>
<td></td>
<td>.19</td>
<td>.00</td>
<td>.32</td>
<td>.00</td>
<td>DC</td>
</tr>
<tr>
<td>2</td>
<td>.20</td>
<td>.02</td>
<td>.41</td>
<td>.09**</td>
<td>Physician PE</td>
</tr>
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</table>

Continued
Table 6 Continued

<table>
<thead>
<tr>
<th></th>
<th>DC</th>
<th>.02</th>
<th>-.11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician PE x DC</td>
<td>-12</td>
<td>.32*</td>
<td></td>
</tr>
</tbody>
</table>

Note. PE = prognosis estimate; PCC = primary control coping; SCC = secondary control coping; DC = disengagement coping

a Mothers: step 1 df (2, 71); step 2 df (3, 70)

Fathers: step 1 df (2, 38); step 2 df (3, 37)

b Standardized beta weights; * p < .05, ** p < .01.
Table 7

Mediation by Father Depression of the Moderating Effect of Secondary Control Coping on the Association between Physician and Father Prognosis Estimates

<table>
<thead>
<tr>
<th>Step</th>
<th>$R^2^a$</th>
<th>$\Delta R^2$</th>
<th>Variables Entered</th>
<th>Beta $^b$</th>
<th>$t (40)$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.45</td>
<td>.45**</td>
<td>Physician PE</td>
<td>.42</td>
<td>3.20**</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>SCC</td>
<td>.38</td>
<td>2.62*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Physician PE x SCC</td>
<td>-.36</td>
<td>-2.60*</td>
</tr>
<tr>
<td>2</td>
<td>.45</td>
<td>.00</td>
<td>Physician PE</td>
<td>.42</td>
<td>3.12**</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>SCC</td>
<td>.42</td>
<td>2.22*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Physician PE x SCC</td>
<td>-.38</td>
<td>-2.52*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Depression</td>
<td>.06</td>
<td>.33</td>
</tr>
</tbody>
</table>

Note. PE = prognosis estimate; SCC = secondary control coping

$^a$ Step 1 $df (3, 37)$; step 2 $df (4, 36)$

$^b$ Standardized beta weights

* $p < .05$, ** $p < .01$. 
Table 8

Mediation by Father Anxiety of the Moderating Effect of Secondary Control Coping on the Association between Physician and Father Prognosis Estimates

<table>
<thead>
<tr>
<th>Step</th>
<th>$R^2$&lt;sup&gt;a&lt;/sup&gt;</th>
<th>$\Delta R^2$</th>
<th>Variables Entered</th>
<th>Beta&lt;sup&gt;b&lt;/sup&gt;</th>
<th>$t$ (40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.45</td>
<td>.45**</td>
<td>Physician PE</td>
<td>.42</td>
<td>3.20**</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>SCC</td>
<td>.38</td>
<td>2.62*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Physician PE x SCC</td>
<td>-.36</td>
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<td>.42</td>
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<td></td>
<td></td>
<td>SCC</td>
<td>.40</td>
<td>2.33*</td>
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<td>Physician PE x SCC</td>
<td>-.38</td>
<td>-2.52*</td>
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<td>.19</td>
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</table>

Note. PE = prognosis estimate; SCC = secondary control coping

<sup>a</sup> Step 1 $df$ (3, 37); step 2 $df$ (4, 36)

<sup>b</sup> Standardized beta weights

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

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Table 9

Mediation by Father Depression of the Moderating Effect of Disengagement Coping on the Association between Physician and Father Prognosis Estimates

<table>
<thead>
<tr>
<th>Step</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
<th>Variables Entered</th>
<th>Beta $^b$</th>
<th>t (40)</th>
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<tbody>
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<td>.57</td>
<td>4.39**</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>DC</td>
<td>-.11</td>
<td>-.79</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Physician PE x DC</td>
<td>.32</td>
<td>2.43*</td>
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<tr>
<td>2</td>
<td>.42</td>
<td>.01</td>
<td>Physician PE</td>
<td>.55</td>
<td>4.24**</td>
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<td></td>
<td>DC</td>
<td>-.08</td>
<td>-.57</td>
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<td>Physician PE x DC</td>
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<td>2.42*</td>
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</table>

Note. PE = prognosis estimate; DC = disengagement coping

$^a$ Step 1 $df$ (3, 37); step 2 $df$ (4, 36)

$^b$ Standardized beta weights

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

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Table 10

Mediation by Father Anxiety of the Moderating Effect of Disengagement Coping on the Association between Physician and Father Prognosis Estimates

<table>
<thead>
<tr>
<th>Step</th>
<th>$R^2$</th>
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<th>Variables Entered</th>
<th>Beta</th>
<th>$t (40)$</th>
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<tr>
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<td>4.39**</td>
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<td></td>
<td>DC</td>
<td>-.11</td>
<td>-.79</td>
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<td>Physician PE x DC</td>
<td>.32</td>
<td>2.43*</td>
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<tr>
<td>2</td>
<td>.41</td>
<td>.00</td>
<td>Physician PE</td>
<td>.56</td>
<td>4.29**</td>
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<td></td>
<td></td>
<td>DC</td>
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<td>Physician PE x DC</td>
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<td>Anxiety</td>
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<td>-.21</td>
</tr>
</tbody>
</table>

Note. PE = prognosis estimate; DC = disengagement coping

* Step 1 df (3, 37); step 2 df (4, 36)

* Standardized beta weights

* p < .05, ** p < .01.
Table 11

Mediation by Mother Primary Control Coping of the Moderating Effect of Anxiety on the Association between Physician and Mother Prognosis Estimates

<table>
<thead>
<tr>
<th>Step</th>
<th>$R^2$</th>
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<td></td>
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<td>Anxiety</td>
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<td>-2.72**</td>
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<td>Physician PE x Anxiety</td>
<td>.31</td>
<td>3.00**</td>
</tr>
<tr>
<td>2</td>
<td>.34</td>
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<td>Physician PE</td>
<td>.42</td>
<td>4.16**</td>
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<td></td>
<td></td>
<td>Anxiety</td>
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<td>-2.10*</td>
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<td>Physician PE x Anxiety</td>
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<td>PCC</td>
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</table>

Note. PE = prognosis estimate; PCC = primary control coping

$^a$ Step 1 df (3, 68); step 2 df (4, 67)

$^b$ Standardized beta weights

* p < .05, ** p < .01.
Table 12

*Mediation by Mother Secondary Control Coping of the Moderating Effect of Anxiety on the Association between Physician and Mother Prognosis Estimates*

<table>
<thead>
<tr>
<th>Step</th>
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<td>Anxiety</td>
<td>-.28</td>
<td>-2.72**</td>
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<td>Physician PE x Anxiety</td>
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<td>3.00**</td>
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<td>Physician PE x Anxiety</td>
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<td>-.07</td>
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</table>

*Note.* PE = prognosis estimate; SCC = secondary control coping

$^a$ Step 1 $df$ (3, 68); step 2 $df$ (4, 67)

$^b$ Standardized beta weights

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

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Table 13

Mediation by Disengagement Coping of the Moderating Effect of Anxiety on the
Association between Physician and Mother Prognosis Estimates

<table>
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<tr>
<th>Step</th>
<th>$R^2$&lt;sup&gt;a&lt;/sup&gt;</th>
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<th>Variables Entered</th>
<th>Beta&lt;sup&gt;b&lt;/sup&gt;</th>
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<td>Anxiety</td>
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<td>-2.72**</td>
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Note. PE = prognosis estimate; DC = disengagement coping

<sup>a</sup> Step 1 $df$ (3, 68); step 2 $df$ (4, 67)
<sup>b</sup> Standardized beta weights
* $p < .05$, ** $p < .01$. 
Table 14

Regressions of Mother and Father Prognosis Estimates on Physician Prognosis Estimates and Mother, Father, and Physician Health Literacy Variables

<table>
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<tr>
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<td>.02</td>
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### Table 14 Continued

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<td>Physician PE x Education</td>
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</table>

*Note.* PE = prognosis estimate; Information Source = source of medical information

*a* Mothers: step 1 df (2, 71); step 2 df (3, 70)

*b* Fathers: step 1 df (2, 38); step 2 df (3, 37)

*b* Standardized beta weights; * p < .05, ** p < .01.
Figure 9

Moderating Effect of Mother Symptoms of Depression on the Association between Physician and Mother Estimates of the Child’s Cancer Prognosis

Note. b = unstandardized regression coefficient; *p < .05, two-tailed; *p < .01, two-tailed; Dep = mother symptoms of depression.
Figure 10

*Moderating Effect of Mother Symptoms of Anxiety on the Association between Physician and Mother Estimates of the Child’s Cancer Prognosis*

Note. $b =$ unstandardized regression coefficient; Anx = mother symptoms of anxiety; **p < .01, two-tailed.
Figure 11

Moderating Effect of Father Secondary Control Coping on the Association between Physician and Father Estimates of the Child’s Cancer Prognosis

Note. $b =$ unstandardized regression coefficient; SCC = secondary control coping; *$p < .05$, two-tailed.
Figure 12

Moderating Effect of Father Disengagement Coping on the Association between Physician and Father Estimates of the Child’s Cancer Prognosis

Note. \( b = \) unstandardized regression coefficient; \( \text{DC} = \) disengagement coping; \(* p < .05, \) two-tailed.
Figure 13

*Moderating Effect of Father Source of Medical Information on the Association between Physician and Father Estimates of the Child’s Cancer Prognosis*

Note. $b =$ unstandardized regression coefficient; Dr. Info Only = medical information obtained solely from medical professionals; Dr. Info+ = medical information obtained from medical professionals in combination with at least one other source (i.e., other families at the hospital, the internet, family or friends); **$p < .01$, two-tailed.
Figure 14

Moderating Effect of Father Age on the Association between Physician and Father Estimates of the Child’s Cancer Prognosis

Note. $b =$ unstandardized regression coefficient; **$p < .01$, two-tailed.