

STEPPING UP, STEPPING BACK, BEING PUSHED, AND STEPPING AWAY:
THE PROCESS OF MAKING TREATMENT DECISIONS FOR CHILDREN WITH
CANCER BY PARENTS WHO NO LONGER LIVE TOGETHER

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Doctor of Philosophy

by

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The undersigned, appointed by the dean of the Graduate School, have examined the dissertation entitled

STEPPING UP, STEPPING BACK, BEING PUSHED AND STEPPING AWAY:
THE PROCESS OF MAKING TREATMENT DECISIONS FOR CHILDREN WITH
CANCER BY PARENTS WHO NO LONGER LIVE TOGETHER

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DEDICATION PAGE

To my husband Alan for his unwavering support during this education journey.

To my son Joe who sacrificed time with mom and now understands why I worked so hard.

To my parents who instilled my passion for learning and always doing my best.

and

To the parents who participated in this study and all the other parents of seriously ill children who've taught me how to better care for them over the years.

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ABSTRACT

The purpose of this study was to describe the process of treatment decision making for parents of children with cancer who no longer lived together. Fifteen biological parents and stepparents of eight children with cancer who had made a major treatment decision in the past were interviewed. Using grounded theory techniques, the process of *stepping up*, *stepping back*, *being pushed*, and *stepping away* in making treatment decisions was described by parents. The process depicted differing levels of parent involvement based on the parent's position in the family, involvement with the child before diagnosis, and stage of treatment. Psychosocial consequences for biological parent were linked to their decision making responsibility for the ill child. Stepparent effects were linked to interpersonal conflicts amongst the parents. Parents described a largely adaptive process of making treatment decisions for their children with cancer; including the additional burdens and challenges they faced because of their specific family circumstances. The findings from this study have implications for helping to better prepare nurses and other health care providers to care for similar families.

CHAPTER ONE: REVIEW OF THE LITERATURE

A diagnosis of a serious or life threatening illness in a child immediately thrusts the parents into a world of fear and uncertainty. The treatment decisions parents make on behalf of their children have been described as the “stuff of nightmares” (Anderson & Hall, 1995, p. 15). Parents make complex medical decisions during periods of overwhelming emotional distress and uncertainty. Research indicates that emotional distress and uncertainty contribute to decisional conflict (Entwistle, Sowden & Watt, 1998; Guerriere & Llewellyn-Thomas, 2001; O’Connor, 1997) and regret (Clark, Wray & Aston, 2001). An improved understanding of parental treatment decision making processes could lead to the development of interventions to assist parents during this difficult time and reduce acute distress and chronic decisional conflict or regret.

Treatment Decision Making Research

A paradigmatic shift from paternalism to collaboration in health care, in combination with an increased emphasis on the ethical constructs of autonomy, beneficence, and justice in health care, has led to great interest in treatment decision making research across disciplines (Pierce & Hicks, 2001). Although scientists within many disciplines (e.g., communication, nursing, medicine, sociology, psychology, social work) study decision making, nursing scientists have focused primarily on how patients identify and consider options, weigh influencing factors, and make their decisions about children’s treatments (Degner, 1998; Hinds et al., 2001; Llewellyn-Thomas, 1997; O’Connor, 1997; Pierce & Hicks, 2001).

I conducted a thorough review of the parent treatment decision making literature. I searched the major databases for the disciplines of nursing (CINAHL), medicine (Medline), psychology (Psyc Abstracts) and sociology (SocioFile). Using the keywords decision making; decision making, ethical; decision making, family; in combination with treatment; and parent(s), I obtained vast numbers of citations that were not specifically related to my subject area in addition to relevant citations. I then conducted historical searches of the relevant studies I obtained from the database searches. Finally, I conducted author searches of investigators known to be conducting research about parental treatment decision making. Together, these search strategies yielded the studies used in this integrated review of the parent treatment decision making literature. Because my research targeted the parent treatment decision making process, I excluded studies of child involvement in treatment decision making. Studies focused solely on the informed consent process or parent-physician communication that did not refer to investigation of decision making processes also were excluded.

The parent treatment decision making literature was difficult to obtain via traditional computer database search strategies. Searches often did not include studies known to me. Therefore, I relied heavily on bibliographic searches and author searches to obtain relevant references. Over the course of my study, I noted that the parent treatment decision making literature was increasingly available through more traditional database search strategies. This increase in database sensitivity appears to be related to the increasing number of studies conducted in the field.

Decisional contexts studied by researchers have included: (a) limitation of or withdrawal of care treatment decisions made in the neonatal and pediatric intensive care

unit (e.g., Kirchbaum, 1996; Orfali, 2004; Sudia-Robinson & Fister, 1995; Votta et al., 2001; Wocial, 2000), (b) general treatment (e.g., Gross & Howard, 2001; Hallstrom & Elander, 2004; Wuest & Stern, 1990), (c) cancer (e.g., Gagnon & Reclitis, 2003; Pyke-Grimm, Degner, Small & Mueller, 1999), including informed consent (e.g., Kupst et al., 2003; Levi et al., 2000; Liaschenko & Underwood, 2001; Pletsch & Stevens, 2001; Ruccione et al., 1991; Wiley et al., 1999), (d) end-of-life decisions (e.g., Hinds et al., 1997, 2001;) and (e) other childhood chronic illnesses (e.g., Angst & Deatrck, 1996; Guerriere & Llyewllyn-Thomas, 2001; Higgins, 2001; Letourneau et al., 2003).

Descriptive studies have been the most common type of research on parental decision making, and retrospective, qualitative research methods have dominated this body of work. Table 1.1 summarizes the studies reviewed based on researcher discipline and study method.

The majority of the research conducted to date has neither been informed by nor led to the development of an explanatory theory to understand the parental treatment decision making process. Researchers referred to a theory in only 23 of 86 studies reviewed. The theories used in parental treatment decision making research included family management style (Deatrck, Angst & Moore, 2002; Snethen et al., 2007), Janis and Mann's decision theory (Higgins & Kayser-Jones, 1996), descriptive-decision model (Hinds et al., 1997, 2000, 2001), Hill's ABCX theory (Kirchbaum, 1996), uncertainty theory (Kodadek & Feeg, 2002), Thompsons' ethical decision making model (Overbay, 1996), Lyon's moral reasoning (Pinch & Spielman, 1990, 1996), Brody's transparency model of informed consent (Sudia-Robinson & Freeman, 2000), medical family therapy (Wissow et al., 2001), ethical principles (Pinch & Spielman, 1993; Wocial, 2000),

O’Conner’s decisional conflict (Guerriere & Llywellyn-Thomas, 2001; Guerriere, McKeeber, Llywellyn-Thomas, & Berall, 2003), family systems (Kennedy, Oakland & Brotherson, 2000), family centered care (Letourneau, Neufeld, Drummond & Barnfather, 2003), Degner’s and Beaton’s control preferences (Pyke-Grimm et al., 1999), Thorne’s and Robinson’s health care relationships (Pyke-Grimm et al.), Derdarian’s information needs model (Pyke-Grimm et al.), the Health Belief Model (Gross & Howard, 2001), and Cox’s interaction model of client health behavior (Gross & Howard, 2001). Only two studies were designed to test aspects of specific theories (Guerriere & Llewellyn-Thomas, 2001; Guerriere et al.). Instead, most of the theories served to inform the investigators’ thinking either in developing the study or in explaining results. The lack of theory development and use in the area of parent treatment decision making limits investigators’ ability to test and incorporate their findings into a more global understanding of the process and could delay discovery of clinically relevant interventions in the future.

In an attempt to organize my understanding of parental treatment decision making within pediatric oncology, I worked with two colleagues to develop a conceptual model for treatment decision making focused on the childhood cancer population (Stewart, Pyke-Grimm & Kelly, 2005) (Figure 1.1). We organized the parental treatment decision making research by focusing on empirical support for linkages among contextual factors, process factors, and potential outcomes (Llewellyn-Thomas, 1997). Through an analysis of the research findings, we found evidence for specific contextual factors that influenced the role a parent prefers and/or assumes during treatment decision making for their child with cancer (Stewart et al.). These contextual factors included the illness factors of

prognosis/severity of illness and uncertainty, the person factors of educational level, culture, distress and knowledge/experience, and the relationship factors of trust in the health care provider and support.

For this review, I incorporated research findings from all aspects of parental decision making on behalf of a child, including perinatal and neonatal decision making. I identified two broad themes in parental treatment decision making in these studies, context and process. These two themes correspond to my original conceptual model (Stewart et al., 2005) and are also described in theoretical descriptions of the treatment decision making process in general (Llewellyn-Thomas, 1997; Pierce & Hicks, 2001). I found evidence in this review for four subcategories of the context of parent treatment decision making: Time (urgency), uncertainty, emotional distress, and limited choices. I identified seven subcategories of the process elements of parental treatment decision making: Influencing factors, information, support, parental involvement, physician control, regret, and relationship. The category of regret and, to a certain extent, relationship, may be potential outcomes of the parental treatment decision making process. I retained these categories in the broad theme of process because the findings were limited and researchers to date have not focused on outcomes to the same degree as they have processes. I outline research findings by defining each category and subcategory and summarizing the evidence for each.

Contextual Treatment Decision Making Elements

Parents make a variety of treatment decisions for their children with different diseases, in diverse treatment environments, and under varying levels of emotional stress. Contextual elements surround the parent's treatment decision making experience.

Time. Parents described their experiences of treatment decision making in terms of their perceived urgency to make a decision. Diseases like cancer have a fast trajectory and parents feel a great sense of urgency because of the immediacy of the threat to the life of a child (Pletsch & Stevens, 2001). There was tension between the time needed for parents to make their decisions and the need to start treatment quickly (Kodish et al., 1998) with parents recommending having more time to make decisions (Eder et al., 2007). This sense of urgency made parents feel pressured (Levi, Marsick, Drotar & Kodish, 2000), and they felt as if they had limited or no choice in a treatment decision (Liaschenko & Underwood, 2001).

In a critical care environment if the need for immediate treatment was urgent, parents universally made decisions that would potentially extend the life of their child (Kirchbaum, 1996). In contrast, in diseases that had a slower trajectory (for example, diabetes), parents had more flexibility to make their decisions (Pletsch & Stevens, 2001). These decisions were made over a long period of time with parents vacillating between choices (Angst & Deatrck, 1996; Daniel, Kent, Binney & Pagdin, 2005). When parents perceived that they had more time to make decisions, they were able to consider the child's quality of life in their decision making (Kirchbaum). Parents involved their children in the decision making process to a greater degree when the time to make a decision was less urgent (Angst & Deatrck; Daniel et al.). Parents who had a higher level of education needed more time to make decisions (Ruccione, Kramer, Moore, & Perrin, 1991).

Uncertainty. Uncertainty arises from ambiguity, vagueness, unpredictability and lack of information (Mishel, 1981) and pervades parents' lives when their children are ill

(Stewart & Mishel, 2000). It is a well known stressor of parents of children with chronic illness (Stewart & Mishel). Uncertainty stems from characteristics of the individual, the illness, and the environment as influenced by significant others and health care providers (Stewart & Mishel).

A number of factors increased uncertainty for parents. A feeling of being pressured to make a decision and a lack of support (Guerriere & Llewellyn-Thomas, 2001) and deciding to participate in a randomized clinical trial increased levels of uncertainty in parents (Pletsch & Stevens, 2001). In contrast, parents' involvement in life support withdrawal decision making led to decreased uncertainty (Votta et al., 2001). A nursing intervention designed to improve parent understanding of complex care of premature infants reduced parental uncertainty (Penticuff & Ahearn, 2005).

Parental uncertainty led to negative consequences such as decreased trust in health care providers (Orfali & Gordon, 2004). Under stress, uncertainty was related to misunderstanding of information (Higgins, Kayser-Jones & Savedra, 1996). Parental uncertainty increased parents' desire for information (Guerriere & Llewellyn-Thomas, 2001).

The medical provider's ascription of medical certainty to choices affected parental decision making (Singh, Cuttler, Shin, Silvers & Beuhauser, 1998). In one study of decision making in the neonatal intensive care unit, parents were not involved in decision making for their infant. The medical team managed uncertainty by making group decisions before going to parents. All care was constructed to reduce parental uncertainty in the decisions made by the health care team (Orfali, 2004). This paternalistic environment led to more favorable parent coping outcomes than for parents whose

children were in a unit that employed a more autonomous model of parent treatment decision making (Orfali & Gordon, 2004). Researchers questioned the impact of parental uncertainty, powerlessness, and an inability to anticipate the child's future on their ability to effectively make decisions in the neonatal intensive care unit (Orfali & Gordon).

Emotional distress. Emotional distress was a negative effect of the circumstances surrounding parental treatment decision making. Emotional distress typically referred to shock, stress, anxiety, and depression.

Parents reported emotional distress and turmoil surrounding their treatment decision making experiences (Able-Boone, Dokecki & Smith, 1989; Kupst, Patenaude, Walco & Sterling, 2003; Levi et al., 2000). They used phrases such as “it was like stress unbelievable” (Levi et al., 2000, p. 7) to describe these experiences. They were often emotionally overwhelmed (Higgins et al., 1996), and researchers reported clinical levels of anxiety (Pochard et al., 2001; Ruccione et al., 1991) and depression (Pochard et al.) in parents during times of decision making. This state of shock was an obstacle to obtaining informed consent (Kodish et al., 1998; Waissman, 1990) and often led to passive behaviors by parents in which they deferred the decisions to physicians (Pinch & Spielman, 1990).

In a recent study, Reynolds and Nelson (2007) studied the hypothetical decision making responses of parents and adolescents. They found that intense emotions related to treatment decisions could override an analytical appraisal of the decision. Perceptions of risk were developed rapidly and seemed to be more related to affective responses than to actual probability. They proposed that the disconnection between the information conveyed by physicians and how this information was interpreted by patients and

families was mediated by their emotional reactions. This scenario is often seen by pediatric oncology clinicians during the decision making process and merits further study.

Limited choices. Parents described feeling that there was either no choice in making decisions about their children's treatment (Higgins & Kayser-Jones, 1996; Hinds et al., 1997; Levi et al., 2000; Zwaanswijk et al., 2007) or limited choices (Deatrick, Angst & Moore, 2002). Choices were perceived by parents and do not refer to the practice of health care professionals limiting choices presented to parents during decision making.

The timing and threat associated with their child's illness affected parents' perception of the choices available to them (Pletsch & Stevens, 2001). In some cases parents saw no viable options for their children (Sims, Boland & O'Neill, 1992). Sometimes parents even feared their choices (Wiley et al., 1999). In childhood cancer, parents believed that randomized clinical trials reduced their choices (Wiley et al.). Death was not a choice for parents who had to make critical decisions for their seriously ill children (Higgins & Kayser-Jones, 1996). Some parents couldn't conceive of a time to limit or withdraw care for their critically ill newborn and this tempered their desire to participate in decision making (Schlomann & Fister, 1995).

Process Elements of Parental Treatment Decision Making

The process elements of parental treatment decision making refer to those factors that parents encounter before, during, and after their decision making experiences. It also refers to actions that parents or professionals take to ease the decision making burden for parents.

Influencing factors. Influencing factors referred to those things that parents take into account when making treatment decisions for their children. Parents considered a number of factors; of primary importance was the effect of the decision on the child. Parents considered the child's prognosis (Gross & Howard, 2001; Hinds et al., 1997, 2000; Kodadek & Feeg, 2002; Meyer, Burns, Griffith, Truog, 2002), side effects of the proposed treatment (Hinds et al., 2000, 2001; Singh et al., 1998; Wuest & Stern, 1990; Yeh et al., 1999), potential suffering (Hinds et al., 1997, 2000, 2001; Kirchbaum, 1996; Kodadek & Feeg; Meyer et al.; Yeh et al.), and the impact of the decision on the child's quality of life (Abe, Catlin & Mihara, 2001; Hannan & Gibson, 2005; Kirchbaum; Meyer et al.; Vermeulen, 2004). Psychological outcomes that the decision had on parents were related to the child's survival or long term effects (Pletsch & Stevens, 2001). Parents also considered the child's stated preference for treatment or the parents' perception of what the child's preference would be (Daniel et al., 2005; Hinds et al., 1997, 2000, 2001; Kirchbaum; Singh et al.; Vickers & Carlisle, 2000).

Parents took into account the effect of decisions on their family as a whole (Corrow et al., 2002; Higgins & Kayser-Jones, 1996; Kirchbaum, 1996; Kodadek & Feeg, 2002; Wuest & Stern, 1990). They also considered social factors, such as concerns about discrimination (Cassidy & Bove, 1998), and financial, career and family stability (Higgins & Kayser-Jones; Higgins et al., 1996; Kennedy, Oakland & Brotherson, 2000). Most parents did not consider the financial impact of the disease on their family in making decisions for their ill children (Corrow et al.; Kodadek & Feeg; Pinch & Spielman, 1993; Singh et al., 1998).

Parents also reported psychological and emotional factors affecting their decision making (Higgins & Kayser-Jones, 1996; Higgins et al., 1996; Kennedy et al., 2000). Higgins et al. demonstrated that minimal attention was devoted to social or psychological/emotional factors by either physicians or social workers in decision making consultations; disease and treatment factors dominated these conferences. Parents felt that their “decision shaped and was shaped by who they were as a family” (Kirchbaum, 1996, p. 69).

Parent decisions also were shaped by cultural and religious beliefs, especially for decisions regarding refusal or withdrawal of treatment for terminally ill infants and children (da Costa, Ghazal, & Al Khusaiby, 2002; Hammerman et al., 1997; Roy, Aladangady, Costeloe, & Larcher, 2004; Simon & Kodish, 2005). Parents who observed a fundamentalist religion could not decide to withdraw treatment from a terminally ill neonate. Decisions to withhold treatments were easier to make and parents often included religious leaders in decision making (da Costa et al.; Roy et al.). Religious beliefs also helped parents decide for their ill children (Hinds et al., 2001; Kirchbaum, 1996; Kodadek & Feeg, 2002). They felt that God would decide the fate of a child or that trusting in God was a reason to trust the physician (Simon & Kodish).

Information. Information was a general term that referred to knowledge that was either communicated by the health care team about the child’s condition or sought out by parents. Overwhelmingly, parents wanted information to assist them with decision making (Able-Boone et al., 1989; Angst & Deatrck, 1996; Corrow et al., 2002; Deatrck et al., 2002; Hinds et al., 2005; Kavanaugh, 1997; Kennedy et al., 2000; Kodish et al., 1998; Letourneau, Neufeld, Drummond & Barnfather, 2003; Levi et al., 2000; Pinch &

Spielman, 1993; Wocial, 2000; Zwaanswijk et al., 2007), no matter how distressing (Wharton, Levine, Buka & Emanuel, 1996). Information influenced their decisions (Hinds et al., 1997, 2000, 2001) and increased their perceived ability to participate in decision making (James & Johnson, 1997; Kirchbaum & Knafl, 1996; Penticuff & Aheart, 2005). A lack of information led to a passive role in decision making (Pinch & Spielman, 1990, 1993; Schlomann & Fister, 1995), left parents unprepared to decide (Waissman, 1990), or contributed to uncertainty (Guerriere & Llewellyn-Thomas, 2001). Parents reported not being given adequate information (Eder et al., 2007; Guerriere et al., 2003; Kennedy et al.; Ranchod et al., 2004) and, conversely, some parents reported being overwhelmed with the amount of information they received (Eder et al.; Higgins et al., 1996; Levi et al., 2000). They reported decreased understanding because of the devastating nature of the information (Levi et al.) and felt frustrated with information they didn't have (Wiley et al., 1999) or couldn't understand (Higgins et al.). Parents and their health care providers reported significantly different perceptions in the adequacy of information provided to parents (Brotherton et al., 2007).

A telling comparison of the differential effects of information and experience on parents' treatment decision making was illustrated in Pletsch and Stevens' (2001) study of decision making in parents of children with cancer and diabetes. Lack of information and experience was the hallmark of parental decision making experiences in cancer compared to parents of children with diabetes who experienced partnerships with health care providers.

Support. Providing parents with sympathy or encouragement encompassed support. Support came from staff, family or other parents of children with the same condition.

Parents desired non-judgmental support during decision making (Corrow et al., 2002; Higgins et al., 1996; Kennedy et al., 2000; Letourneau et al., 2003; Levi et al., 2000 Pochard et al., 2001). Desired types of support included emotional support, counseling (Corrow et al.), and simply having someone be there to share the experience (Kavanaugh, 1997). Parents identified family and friends (Levi et al.; Snethen et al., 2006; Wharton et al., 1996) and other parents of children in similar circumstances (Eder et al., 2007; Corrow et al.; Kennedy et al.), in addition to health care professionals, as potential sources of support. Support was not uniformly positive in effect – the continuum of support included mixed support from family members (Letourneau et al.) and criticism of the parents’ decision by family and health care professionals (Pector, 2004). Some parents perceived a lack of support (Able-Boone et al., 1989; Guerriere et al., 2003; Higgins et al.),

Support by staff positively influenced parental decision making (Gross & Howard, 2001; Hinds et al., 1997, 2000, 2001; Levi et al.) and inspired parents’ confidence in their day to day management of their child’s condition (Kirchbaum & Knafel, 1996). Lack of support contributed to increased uncertainty (Guerriere & Llewellyn-Thomas, 2001; Orfali & Gordon, 2004), actual conflict with parents (Orfali & Gordon), and led to parents dropping out of cancer therapy (Yeh et al., 1999).

Parental involvement. Parental involvement referred to the role that parents assumed in making treatment decision for their children. Parents’ perceived involvement

in decision making ranged from the rare extremes of autonomous control (Angst & Deatrick, 1996; Higgins, 2001; Kirchbaum & Knafl, 1996; Ranchod et al., 2004) to non-involvement or permission-granting only (Able-Boone et al., 1989; da Costa et al., 2002; Pector, 2004; Pinch & Spielman, 1990; Sudia-Robinson & Freeman, 2000). Parents sometimes expressed a desire for the physician to make the decision (Brinchman, Forde & Nortvedt, 2002; Eder et al., 2007; Higgins; Levi et al., 2000; Wharton et al., 1996). Other researchers classified parental involvement in decision making as passive (Gagnon & Recklitis, 2003; Pinch & Spielman; Pyke-Grimm, Degner, Small & Mueller, 1999), collaborative (Gagnon & Recklitis; Pector, 2004; Pyke-Grimm et al.), and active (Gagnon & Recklitis; Pyke-Grimm et al.) or parent initiated (Pector). Parents and their health care provider did not always similarly perceive parental involvement in decision making, with parents reporting less involvement than the health care provider (Brotherton, Abbott, Hurley & Aggett, 2007). In quantitative studies, the largest proportion of parents assumed a collaborative role, followed by passive and active (Gagnon & Recklitis; Pyke-Grimm et al.).

Researchers who observed decision making in the neonatal intensive care unit described a decision making process that began with team discussions of the treatment options and initial decisions that were then taken to parents for their input (McHaffie, Laing, Parker & McMillan, 2001; Orfali, 2004). Despite clear physician control of the options presented to parents, the majority of parents perceived that they were in control of the decision making process and were unaware of the team discussions (McHaffie et al.). Parental coping was not related to their involvement in decision making for their

premature infants but was related to the emotional care and support provided by the staff (Orfali & Gordon, 2004).

Parental involvement in decision making was enhanced by their participation in the child's care (James & Johnson, 1997; Vickers & Carlisle, 2000; Wuest & Stern, 1990) and increased with their expanded experience with the child's disease (Orfali & Gordon, 2004; Sims et al., 1992). As their child's prognosis decreased the parents' involvement in decision making increased (Hinds, 1997). Involvement in decision making helped parents to understand their child's situation, reduced their uncertainty (Votta et al., 2001), and led to increased feelings of control (Wocial, 2000). In the neonatal intensive care unit, health care professionals wanted parents to be involved in decision making to help enhance the parent's sense of responsibility for their premature infant (Able-Boone et al., 1989).

Physician control. Physician control over decision making referred to specific actions taken by physicians to direct the treatment decision making process and influence decisions made for children under their care. Physicians exerted substantial control over the decision making process. They either made decisions alone (Orfali, 2004) or after consulting with their colleagues (Anderson, McCall, Leversha & Webster, 1994; Blakeley, Ribeiro & Crocker, 2000; McHaffie et al., 2001; Orfali; Ranchod et al., 2004) and then brought these decisions to parents. Neonatologists wished to remove parental responsibility for the outcomes of the decision and thus removed parental responsibility for making the decision. They did not want to burden parents with decision making because of their lack of expertise (Able-Boone et al., 1989) and the emotional burden associated with the experience (McHaffie et al.). In general, these paternalistic practices

were primarily limited to the neonatal and pediatric intensive care units, but occurred in many different countries, including the United States.

Physicians controlled decision making by limiting options made available to parents (McHaffie et al., 2001; Orfali; Waissman, 1990) or by using a language of medical certainty/uncertainty in describing these options (Orfali). Physicians shaped information given to parents to define the decision making situation and to shape the families' reactions (Waissman). Some parents preferred physician control over decision making (Birchman et al., 2002) and shared congruent perspectives in decisions made (Higgins & Kayser-Jones, 1996).

Researchers also described physicians allowing parental decision making authority (Orfali, 2004). They would take parents' views into account by involving them in decision making directly or by sounding out their opinions (Cuttini et al., 1999; McHaffie et al., 2001). Some physicians expected partnerships in decision making with parents (Vermeulen, 2004). Ethnic differences may have influenced the degree to which physicians involved parents - Xu and colleagues (2004) found significantly lower participation in decision making for Hispanics than for non-Hispanic whites.

Relationships. The connections that occurred between parents and health care team members were important. The relationships described by parents occurred primarily between the parents and their child's physician. Despite the negative connotations that may be associated with limited parental role and physician control of decision making, parents were generally satisfied with the decision making process, viewing it as occurring within a caring, trusting relationship with their physician (Hsiao, Evan & Zeltzer, 2007; Wocial, 2000) who shared the decision making (Kavanaugh, 1997).

Trusting the physician was a critical component (Letourneau et al., 2003; Kirchbaum & Knafl, 1996; Pletsch & Stevens, 2001). These parent-physician relationships helped to inspire confidence in parents to care for their seriously ill children (Sims et al., 1992).

Regret. Regret was a feeling of sorrow, disappointment or dissatisfaction for decisions made. Regret also included doubts after the decision was made and time had passed.

In general, parents had a globally positive outlook of their decision making experiences regardless of the choices they made (Corrow et al., 2002). Although the majority would make the same decision again (Kluwin & Stewart, 2000), some parents reconsidered their decisions (Hallstrom & Elander, 2004; Meyer et al., 2002). Parents needed to know that everything was done to help their child in order to live with their decisions (Vickers & Carlisle, 2000).

Regret was more likely when parents changed their mind about a procedure (Corrow et al., 2002). Parents questioned their decisions if the child's condition deteriorated or they saw no benefit in Phase I cancer trials (Deatrick et al., 2002). Doubt about decisions to limit or withdraw care in the neonatal intensive care unit was related to uncertainty and distress related to their child's dying (McHaffie et al., 2001). Parents of children with cancer reported greater decisional regret than adult cancer patients (Simon, Siminoff, Kodish & Barrant, 2004), highlighting the potential influence of surrogate decision making on decisional outcomes. In a longitudinal study of parents whose children were in the neonatal intensive care unit, some parents expressed doubts about their decisions (Pinch & Spielman, 1993), implying that regrets may increase over time and that the choices parents made will affect them forever (Brinchman et al., 2002).

Researchers have focused on how individual parents make decisions on behalf of their ill children. They have not studied how parents interact with each other when making decisions about a child's treatment, nor have they considered parents as couples or dyadic systems. Analyses of both quantitative and qualitative data have been limited to individual parents' responses without attempting to examine dyadic interactions even when data were obtained from both parents (Lianschenko & Underwood, 2001; Pletsch & Stevens, 2001).

Another gap in the literature are descriptions of decision making by parents from diverse family structures. This is a significant gap because these families comprise a sizeable proportion of families.

Treatment Decision Making in Post-Separation Families

Nursing researchers typically have defined families as households, ignoring the significant number of family systems living in multiple households (Ganong, 1995). This is a serious omission, because the widespread incidences of divorce, cohabitation, and remarriage have resulted in significant structural diversity among American families. Based on census data from 2001, approximately 40% of married US citizens will divorce (Kreider, 2005). Cohabiting relationships are less stable than marriages; less than 25% of women from a nationally representative sample were still cohabiting after 15 years (Bramlett & Mosher, 2002).

Most people who divorce or separate from cohabiting partnerships either remarry or enter into another cohabiting relationship – in the National Survey of Family Growth 70% of divorced women were either cohabiting or remarried within 10 years after their initial relationship ended (Bramlett & Mosher, 2002). Taking into account the prevalence

of divorce, researchers have estimated that about one-third of the children in the United States will live in a remarried or cohabitating stepfamily household before they reach 18 years of age (Bumpass, Raley & Sweet, 1995).

The effect of treatment decision making in post-separation families is unknown. Only six of the 86 studies I reviewed included marital status as a demographic descriptor of the parents. No investigators considered parents' treatment decision making for their ill children when the parents no longer lived together.

Based on the large body of research on the dynamics of post-separation families, however, there is reason to suggest that decision making of formerly married parents, some of whom have re-partnered or remarried, may differ from that of married parents (Crosbie-Brunett & Ahrons, 1985; Johnston, 1994; Madden-Derdich & Leonard, 2000; Pruett & Hoganbruen, 1998). In the next section I review the research on post-divorce families that has relevance for parental decision making about children's treatments.

Potential Effects of Divorce or Separation on Parents' Treatment Decision Making

Family systems theory defines the family as a group of interrelated individuals organized as units to attain family functions or goals (Friedman, Bowden & Jones, 2003). Any change in one part of the family has an impact on the entire family system. Thus when studying divorce or separation, researchers must study the impact on a family as a whole, as well as the effects of family reconfiguration on individual members. While having a child with a serious illness creates significant marital stress, there are no significant data to support an increased divorce or separation rate in families having a child with a chronic illness (Lansky et al., 1978). However, there is also no reason to expect that such parents would be expected to remain married at rates higher than the

national average. Therefore, it would be expected that a similar proportion of parents of minor age children with chronic illness will experience marital dissolution. Current data from the 2001 Census suggests that 16.8% of divorced men and 56.9% of divorced women live with their own minor children (Kreider, 2005).

Pre-separation communication and decision making styles between parents were predictive of more cooperative parental relationships after divorce (Coysh, Johnston, Tschann, Wallerstein & Kline, 1989). In general, women were more affected by post-divorce family issues, tensions and conflicts than were men (Fine, Ganong & Demo, 2005). Most often mothers devoted more time than fathers in caring for children (Marsiglio, 1993) and are thus often primarily responsible for health and illness care of children. The added stress of a child's illness, coupled with lingering maternal conflict from the prior relationship, could affect co-parents' ability to work together to make treatment decisions for a child.

I found only two studies investigating the impact of post-divorce relationships in childhood chronic illness, and no studies of the separation of cohabiting parents. In a qualitative study of 13 divorced mothers of children with cystic fibrosis, researchers found that mothers, as the primary caregivers for their ill child, often initiated divorce as fathers gradually distanced themselves from the child (Ganong, Doty, & Gayer, 2003). After divorce, the fathers' involvement with their children lessened over time. These fathers knew little about their child's illness and often returned the child to the mother during visits if the child became ill. Mothers had very little support and extreme time and financial pressures trying to balance work and caring for an ill child. Their only respite was hospitalization of the child for an acute exacerbation of the illness.

In a second study by Gayer and Ganong (2006), differences in mother's caregiving experiences were examined in diverse family structures. Compared to married and re-partnered mothers, single mothers received significantly less help to care for their ill child. Married fathers provided more help than separated or divorced fathers. Stepfathers provided more assistance with care than did non-residential fathers. These authors did not examine decision making as one of the caregiving tasks.

Co-parenting

Co-parenting is defined as both parents' involvement in making decisions about a child's education, health care, religious training, and social activities (Ganong & Coleman, 2004). Co-parenting has become normative due to a movement within the judicial system to give parents joint or shared legal custody unless there is a reason not to do so and because increasingly both parents want to be involved in childrearing decisions (Coleman, Ganong & Leon, 2007; Mason, Fine, & Carnochan, 2004). Maccoby and Mnookin (1992) identified three types of co-parenting patterns based on the amount of discord and communication regarding children after divorce. Frequent arguments and the undermining of each other's parental role constituted discord. Three to four years after separation the following patterns emerged: Cooperative co-parenting (high communication and low discord) represented 29% of parents, disengaged co-parenting (low communication and low discord) involved 41% of the sample, and conflicted co-parenting (high communication and high discord) characterized the remaining 24% of parents. Conflicted co-parents had often experienced intense legal conflicts during their divorce and were more hostile to one another. They expressed extreme distrust in the

other parent's ability to care for the children and often had discrepant parenting styles (Maccoby & Mnookin).

Despite the trend toward more parental sharing of legal and physical custody, estimates are that up to three-fourths of all parents experience conflictual co-parenting, ranging from an inability to work together at all and high conflict, to differences in opinion about childrearing (Whiteside, 1998). Co-parental conflict can produce complicated, anxiety-producing decision making experiences for parents of children with serious illness.

However, not all divorced parents engage in co-parenting. Often, the nonresidential parent, typically the father, reduces contact with their child over time (Ganong & Coleman, 2004). In my clinical experience, however, these absent co-parents often resurface after diagnosis of cancer in their child and exert influence on the treatment decision making process. These clinical situations are emotionally charged and difficult to manage during the crisis of diagnosis of cancer in the child.

Regardless of whether divorced parents have negotiated a working co-parental relationship or not, the crisis of a child's diagnosis with a life-threatening disease, along with the increased stress that accompanies such diagnoses, may present challenges to parents who are faced with the necessity of making decisions together. If one parent has had sole physical custody, or even if a parent has had physical care responsibilities a majority of the time, she or he may resent the intrusion of the less-involved parent after a child has been diagnosed. Younger children in particular are likely to be living with their mothers all or most of the time, and women faced with multiple demands of raising children and working may feel like they have "earned" the right to be the sole decision

maker for their children, regardless of what the legal custody decrees might be. For other families, conflict between parents may have resulted in the parent with physical custody serving as a gatekeeper to the child, reducing opportunities for co-parenting and for nonresidential parent-child interaction (Levine & Pitt, 1995; Madden-Derdich & Leonard, 2000). A serious illness may change this gate-keeping in unknown ways – nonresidential parents may become more involved or they may be even less involved with a sick child as the residential parent circles the wagons. There is a need for descriptive research to help health care professionals understand the dynamics of co-parental decision making after divorce.

Parental Cohabitation and Decision Making

A relatively large proportion of divorced parents cohabit with a new romantic partner (Bramlett & Mosher, 2002). For some of these parents, cohabitation is a step in the courtship process, and they eventually remarry their cohabiting partner (Ganong & Coleman, 2004). For an unknown number of others cohabitation after divorce is an alternative to remarrying.

Although there has been little research on the family dynamics of cohabiting couples when there are children from prior relationships (Ganong & Coleman, 2004), a few aspects of family functioning may be surmised. For instance, it is likely that cohabiting partners are not as actively involved in making decisions about children from prior relationships as parents are (Ganong & Coleman), although they may side with their partners in disputes about children with the children's nonresidential parents.

Given the dearth of research on cohabiting parents' decision making, nothing is known about how cohabiting partners are involved, if at all, in making treatment

decisions about the chronically ill children of their partners. Of course, they would have no legal rights to make decisions, but they may serve as emotional supports, as co-parents, as helpers who reduce various strains that parents experience, or they may add to the parents' strains – we simply do not know.

Effects of Parental Remarriage or Re-Partnering

Parents that remarry create stepfamily households. These households are not reconfigured nuclear families; instead, they are inherently more complex than nuclear families. Stepfamilies have more people, roles and relationships, thus creating greater demands for problem solving and communication. They also often are emotionally different from first marriage families (Ganong & Coleman, 2004).

Family therapists have championed the need for clinicians and researchers to consider the unique dynamics of stepfamilies (Ganong & Coleman, 2004). It is surprising that few studies in childhood chronic illness have explored the impact of diverse family structures on family coping (Ganong, 1995). A review of recently published family nursing textbooks (Broome, Knafl, Pridham, & Feetham, 1998; Friedman et al., 2003; Hanson, 2001) revealed no specific reference to studies of stepfamily responses to childhood chronic illness.

Stepfamilies vary considerably. Ganong and Coleman (2004) define a stepfamily as “one in which at least one of the adults has a child (or children) from a previous relationship” (p. 2). This definition does not limit stepfamily status to members of a single household but extends the definition to those who share membership in two households (Ganong & Coleman). The expanded interest in stepfamily research in the last 20 years has been attributed to divorce replacing bereavement as the primary

precursor to stepfamilies (Ganong & Coleman). The addition of a stepparent as a new parent figure rather than as a replacement parent creates a more complex family structure that continues to challenge researchers and clinicians as they consider what to do with the phenomenon of stepparents (Ganong & Coleman). We do not know what influence stepparents have on the treatment decision making of their stepchildren with serious illness.

In the qualitative study conducted by Ganong and colleagues (2003) mothers who re-partnered (via marriage or cohabitation) anticipated help with their ill child from their husband/partner but instead found themselves with added responsibilities of caring for stepchildren. Conflicts arose between these mothers and their stepchildren and stepfathers regarding discipline of the ill child. When the ill child's father remarried, these mothers increased their vigilance for the care of the sick child during visits to their new stepfamily (Ganong et al). These poignant descriptions provide a clear mandate for different clinical approaches for these stepfamilies as compared to first married families and underscore the need to target diverse family structures, including stepfamilies, in future research.

Aim of the Study

The aim of this study is to describe the process of treatment decision making by parents who no longer live together for their child with serious or life threatening illness. How do parents who no longer live together make treatment decisions for their children with cancer? Researchers must begin to address the impact of family diversity on all aspects of coping with childhood chronic illness. Therefore, the proposed study is designed to expand our understanding of parents' experiences in treatment decision making by exploring the unique challenges facing parents who live in two households.

CHAPTER TWO: RESEARCH DESIGN AND METHODS

Research Design

Decision making is a process and grounded theory techniques are appropriate methods to explore psychological and social processes (Sandelowski, Davis, & Harris, 1989). The elements of causal conditions, action strategies, and consequences are common components of grounded theory methods (Strauss & Corbin, 1998).

This grounded theory study was designed to answer the research question, “How do parents who no longer live together make treatment decisions for their children with cancer?” Although I had initially proposed to study parents in post-divorce families only, this phrasing provided a better description of the wide variety of family structures (e.g., never married, separated, and divorced) in which children and parents live.

Sample

When I proposed this study, I wanted to understand co-parents’ treatment decision-making for their children with cancer when the parents did not live together. I was working in a setting that did not have an adequate cancer population from which to identify potential parent participants, however, so I designed the study to include parents of children with a variety of chronic illnesses. Before data collection began, I moved to another clinical setting that had a much larger cancer population, so I changed my plans to sample parents of children with cancer. I also decided to include parents of children with sickle cell anemia to provide a contrasting illness context. In the end, however, only two parents of children with sickle cell anemia were recruited and while many of their experiences mirrored the parents of children with cancer, their stories made only a

minimal contribution to the overall process description. Therefore, I limited my final sample to parents of children with cancer who: (a) were divorced, separated, or never married; (b) lived in separate households, and (c) had made a major treatment decision in the past year.

In accord with one of the major tenets of grounded theory, I planned to use theoretical sampling to identify potential participants. Theoretical sampling “evolves during the (research) process” (Strauss & Corbin, 1998, p. 202). Theoretical sampling is concerned with the representativeness of concepts, rather than with the representativeness of a sample of a particular population (Strauss & Corbin, 1990). Participants are initially selected because they can inform the phenomenon under study. Ongoing participant selection occurs on the basis of the evolving theoretical relevance of concepts (Strauss & Corbin, 1998). The goal of theoretical sampling is to maximize opportunities to compare experiences to determine how categories vary.

However, as I was faced with the realities of recruiting study participants in a reasonable time frame, I found it necessary to combine theoretical and purposeful sampling techniques. I initially interviewed every parent referred to me. After conducting the first two interviews, I learned that there were distinct differences between how the custodial parent (the parent with whom the child with cancer lived, called custodial parent in this dissertation), the co-parent (the child’s nonresidential parent, called co-parent in the dissertation), and the stepparent experienced treatment decision making. This was verified after analyzing the first four interviews. After this, I attempted to interview as many adult members from each child’s family as were available to try to fully understand the differing roles each adult had in making decisions for a child with

cancer. Given my time constraints, I did not have the luxury to theoretically sample. I was fortunate that the families referred to me were sufficiently diverse to ensure considerable variability in experiences.

In grounded theory research, the total number of participants needed is not determined at the beginning of the study. The final sample size and composition are determined when theoretical saturation occurs during analysis. Theoretical saturation occurs when no new relevant data emerge to describe category properties or dimensions and their possible variability (Strauss & Corbin, 1998). I reached theoretical saturation after interviewing 12 parents of children with cancer. The final interviews were used to confirm the evolving theory. The final sample included 15 adults from 8 families.

Setting

Childhood cancer provides an excellent context for parental treatment decision making research. A number of important contextual elements of parent treatment decision making such as prognosis, uncertainty, experience, and distress accompany the diagnosis of childhood cancer (Pierce & Hicks, 2001) and thus provide opportunities to examine parent experiences leading to an explanation of the overall process. I recruited participants from the center for cancer and blood disorders in a large metropolitan, freestanding children's hospital that serves a diverse population of primarily urban and suburban children. The center for cancer and blood disorders provides comprehensive care for children with cancer and blood disorders and for children undergoing hematopoietic stem cell transplantation. Over 200 children with cancer are diagnosed annually and treated on the main campus and in two community-based clinics. Parents were recruited from all clinical sites.

Protection of Human Subjects

This study was approved by the University of Missouri Health Sciences (MUHS) Institutional Review Board (IRB) on 3-15-2006. The MUHS IRB maintained primary IRB oversight for this project. Before initiating study procedures at the study site, I obtained approval from the local institutional IRB in collaboration with site staff (Refer to Appendix 2.1 for all IRB supporting documents).

Measures

I employed minimally structured interviews to collect data. As recommended by expert researchers in parental treatment decision making, I linked the interview questions to a specific decision (Hinds et al., 1998). The initial interview guide (Appendix 2.2) was divided into three phases. The first phase consisted of questions to describe the family and the circumstances of the separation/divorce. The second phase elicited questions to describe the child's diagnosis history. These two sections helped to elicit rapport before the interview questions focusing on the treatment decision making experience. In the final section, the first question consisted of an initial grand tour question, "Please tell me everything you can remember about what it was like for you making the *specific treatment decision*." Additional questions, sensitized by the conceptual model, were used as a starting point for the interviews. I made minimal changes to the overall interview guide, but added new probes based on the ongoing analysis. I collected demographic information at the end of the interview.

I allowed the substance and direction of each interview to vary based on the participant's responses (Sandelowski et al., 1989). Questions were asked in whatever order that made sense within the context of the interview. For example, as the study

progressed I focused on constructing the genogram and within this framework I was able to ask a majority of the questions relevant to the separation/divorce circumstances and current custody arrangements. In an interesting twist to constructing genograms, I found that when I framed the questions about family structure starting from the child rather than from the parents to child, I did not generate the same judgmental feelings that I had felt in earlier interviews of complex inner city African American families. In one interview the father spontaneously began talking about his decision making experience early in the interview and so I continued with those questions and came back to queries about the family structure.

I probed to elicit information about details of the person's experiences and to obtain further explanation and clarification in combination with silence to allow the individual to fully express his or her thoughts and feelings (Sandelowski et al., 1989). The final interviews became more structured as analyses neared completion in order to fill in categories and to assure that the relationships between categories were well-established and validated (Strauss & Corbin, 1998).

Data Collection Procedures

Participant Accrual

The inclusion criterion for selecting potential participants for this study were having made a major treatment decision within the past year for a child who had cancer, the child was less than 18 years of age, and the parent spoke English. Twelve months was close enough to the decision that parents were able to recall the experience adequately, but allowed enough time for parents to have processed the experience. A number of retrospective descriptive studies of parental treatment decision making interviewed

parents as early as 4 months and up to 8 years after a decision was made (Brinchmann, Forde & Nortvedt, 2002; Hannan & Gibson, 2005; Hinds et al., 1997; Kirschbaum, 1996; Wocial, 2000). About a year into data collection, I extended the time frame for decision making beyond the past year to ensure obtaining the number of participants needed in a reasonable period of time.

Daily decisions involved the planning and delivery of routine care (Sudia-Robinson & Freeman, 2000). In contrast, major treatment decisions involved a significant change in the treatment of a child's chronic illness and included such things as consent for a clinical trial, hematopoietic stem cell transplant, or surgical procedure. These decisions were often characterized by a formal conference with the child's treating physician to discuss the pros and cons of the treatment and often included signing a consent document. I excluded end-of-life decisions as recruitment of parents after the death of their child could have potentially placed too much of a burden on these parents.

As an employee of the children's hospital, I had established a working relationship with multiple team members from this center and its outlying clinics. I did not have a clinical relationship with any of the parent participants, however. I obtained letters of support from the center medical and nursing directors prior to obtaining IRB approval and approaching any parent participants. In addition, before I began data collection, I presented the study to the physician and nursing team members via study synopsis and slide/tape presentation.

The primary treatment team from each center identified potential families and initially approached the parents to determine their willingness to talk with me about participating in the study. I worked with social workers and nurse practitioners to identify

potential participants. Although enthusiasm among treatment team members was strong after presenting the study to them, I found that I had to routinely contact them to keep this study on their radar screen. In the end, it was the nurse practitioners who facilitated recruitment most effectively for me.

I provided recruitment letters (including contact information and permission to contact) for distribution to potential participants whose children were being treated at each center's clinic (Appendix 2.3). Parents signed these "permission to contact" forms and I then called them or met with them in the clinic to explain the study further and to arrange for an interview if they were interested in participating in the study. When a parent agreed to participate, I scheduled an interview and obtained informed consent (Appendix 2.4).

The index parent for a child was whichever parent I contacted first. Recruitment of other family members was completed as possible, but was not mandatory for study entry of the index parent. The index parent was asked to identify other family members that I might contact and/or provide information to other family members or care providers regarding the possibility of their participation in the study. I contacted these potential participants as described previously using a separate recruitment letter (Appendix 2.5).

Two parents of children with sickle cell were interviewed but not included in the final sample. Three parents declined to participate (two of whom were former partners of parents in the final sample). Two parents could not speak English. Finally, the clinicians caring for one child's family determined that it would not be in the parent's best interest to participate.

Interviews

The interviews were conducted in a private setting at a time that was convenient for the parent. I conducted six interviews in the clinic or hospital, six interviews in the parent's home or office, and three interviews by phone.

Phone interviews were conducted only when preferred by the parent. When I conducted interviews by phone, the informed consent document was sent to the parent in advance, who read and signed the consent and either faxed or mailed it back to me. I did not initiate any interviews until I had a signed consent document from the parent. I verified the parent's continued understanding of their rights as a research participant before the start of all interviews.

I audio taped each interview, which was transcribed verbatim. No parent refused to be audio taped, and I did not experience any audio taping malfunctions. I completed detailed field notes immediately following the interview and included these field notes in the analysis. Individual interviews ranged from 45 to 90 minutes. Participants were given a \$25 gift certificate as a token appreciation for their participation.

Data Management

Verbatim transcripts and transcribed field notes were imported into ATLAS.ti (2004) software. Upon receipt of a completed transcript from the typist, I validated the transcription against the original audio tape. At this time, names were changed to the first initial of each name in the transcripts. These transcriptions were then imported into the data analysis software. Access to the data files was protected by password and used only by the investigator. Printed copies of the analysis were reviewed by my advisor. Files were backed up to an external hard drive available only to the investigator.

Analysis Plan

The grounded theory method is an inductive, iterative process exemplified by simultaneous data collection and analysis. Data collection, analysis, and development of theory stand in reciprocal relationship to each other (Strauss & Corbin, 1998). The analytic procedures consisted of three types of coding techniques (i.e., open, axial, and selective) and memoing. During coding the data were deconstructed, conceptualized, and rebuilt in new ways. Analytic procedures used during the coding process included making comparisons and asking questions, procedures known as the constant comparative method of analysis (Strauss & Corbin).

Memos

Memos were written from my thinking about the data and analysis. Memoing helped me gain analytical distance from the data and moved my thinking from description to theorizing. Memoing helped to stimulate creativity and pointed out holes in my thinking. Diagrams complemented memos to help me gain distance from the data. The transcribed interviews and field notes, written memos, and diagrams constituted data for this study.

I focused on writing memos to capture my thinking, insights, and questions regarding my reading of the transcripts and subsequent coding decisions. I developed a memoing scheme that mirrored the ATLAS.ti analysis software. ATLAS.ti allows analysts to comment on each quotation and code category and to attach memos to individual quotations in the transcript. My memos focused on specific quotations in the transcript, potential categories, my interviewing techniques, coding and other analytic decisions, and thoughts about what might be included in the discussion or clinical

practice issues. I also captured my thoughts about future analyses as they came to me during coding. Once I developed categories, I wrote extensively about each category initially, first simply defining the category, then linking categories to subcategories, and finally theorizing about relationships among categories. I used memos to catalog my coding decisions, thus forming an audit trail. As I read and re-read the transcripts during the subsequent phases of analysis, these memos helped me reorient my thinking about the specific quotation and meaning derived from the parent's words. Appendix 2.6 provides examples of memos I wrote during my analysis.

Open Coding

Although Strauss and Corbin (1998) described three discrete types of coding, in reality these coding methods are interrelated and at times occur simultaneously. Open coding is a process whereby the analyst closely examines the data, initially line by line, to name and categorize phenomenon. The data are broken into discrete parts, examined, compared, and questioned. Codes used during this phase of analysis are often the participant's own words (in vivo codes) or other labels created by the analyst based on her knowledge of the substantive area. Coded data that are conceptually similar or related in meaning are further grouped into categories. Categories are considered concepts or labeled phenomenon and are developed by identifying their properties (general or specific attribute) and dimensions (location of property along a continuum or range) (Strauss & Corbin, 1998).

I employed line by line coding for the first 4 interviews, carefully reading the transcript and labeling quotations. In the ATLAS.ti program a quotation is created and then named. All subsequent coding is conducted via the quotations. A quotation consisted

of a word, phrase, or passage that represented a unique thing. Corbin and Strauss (1998) described this process as an act of conceptualizing. In conceptualizing, the researcher breaks the data down into discrete incidents, ideas, events or acts as recounted by the participant and names them. I tried to use the participant's words whenever possible in labeling quotations. Appendix 2.7 provides an example of a passage from the database that demonstrates sequential line by line coding quotation labels, and their respective code category assignments. Because quotations are grouped according to a specific incident or idea, the passage does not include all parts of the conversation.

ATLAS.ti allows the analyst to create a number of reports. I used the following type of report to classify open codes into categories. I printed the open codes for all four interviews (Range 73-147 quotations per interview) as below and grouped them together into conceptually similar categories. I then recoded all four interviews assigning categories to each quotation.

5:1 Did not divorce because of children (42:50)

5:2 Separated because of personality differences (54:56)

5:3 Parents purposefully live close together (62:64)

5:4 Parents work together for children (no formal cust.. (67:71)

~5:5 Since ill, child lives with mother (75:79)

Comment:

Here is a description of how custody changed in relationship to the child's diagnosis. I know this comes up in future interviews. Thus far it has gone both ways actually, but one parent assumes primary custodial care during illness.

~5:6 Flexible custody arrangements (81:84)

Comment:

Very flexible and child centered arrangements

I identified major categories by examining the number of quotations assigned to each category. The larger categories all required further refinement and the generation of

subcategories to label the properties and dimensions of the category. I created a report of all quotations from all coded interviews into a single de-contextualized report. I studied this document to uncover variations within the category. These variations were labeled and defined.

I then re-analyzed quotations and assigned the subcategories. Smaller categories were either retained as such or incorporated as a subcategory of a major category. Not all categories were incorporated into the final conceptual model. I created four major categories, *Biological parent(s) involvement in decision making*, *Stepparent involvement in decision making*, *Disease impact on biological parent relationship*, and *Disease impact on stepparent relationship*. For each major category I found between 10 and 20 subcategories. Some, but not all, subcategories were shared between categories. Typically, these shared subcategories were contextual or outcome subcategories and not process subcategories. In total, I created 93 categories and subcategories. Appendix 2.8 contains the subcategories for the four major categories existing prior to axial coding.

Axial Coding

The goal of axial coding is to systematically develop and relate categories. During axial coding the open coded data are re-integrated by identifying connections between categories leading to the development of a model. The model links subcategories to categories in a set of relationships including causal conditions, context, intervening factors, action and interactional strategies, and consequences (Strauss & Corbin, 1998). Causal conditions are events or incidents that lead to the phenomenon (antecedents). Context is the set of properties that describe a phenomenon along a dimensional range and influence action/interaction. Intervening conditions facilitate or constrain the

action/interaction strategies. Action/interactional strategies are processes that describe the phenomenon's change over time or purposeful actions taken either in response to or to manage a phenomenon. Consequences are the outcomes or what happens as a result of action/interactional strategies (Strauss & Corbin).

Strauss and Corbin (1998) described four steps to determining category relationships in axial coding: (1) hypothetically relating the subcategories to categories by describing the relationships between the subcategories and the phenomenon (category), (2) verifying these hypotheses within the data, (3) identifying the properties of categories and subcategories and their dimensionality within the data, and (4) beginning to explore variation of these within the data. Once I came to this stage of coding, I employed several methods to help me hypothesize relationships between subcategories and comparing these proposed relationships within the data.

I initially sorted all the subcategories listed in Appendices 2.8 into four preliminary models for the four major categories based on the subcategory code label only. From this examination, I constructed four tables representing models for each of the four major phenomena. I reviewed all major categories, their subcategories and the accompanying memos, asking questions about where this subcategory fit into the model for the category. Was this subcategory a causal condition, context, intervening factor, action/interaction strategy, or a consequence? I focused on the category of Biological parent(s) involvement in decision making first. I reviewed all quotations for each subcategory and examined where the quotation fit in the interview. Opening the category brought up a quotation list. I then asked the following questions. What was happening prior to this quotation? What happened next? What notes did I write about this quotation?

Did this make sense to me based on my understanding of this experience as a clinician or as a researcher? I then wrote what the hypothesized relationships were based on the data. These hypotheses were developed into tables for the major categories of Biological parent(s) involvement in decision making and Stepparent(s) involvement in decision making. These tables are located in Appendices 2.9 and 2.10.

When I struggled with assigning a subcategory to the model, I returned to the data and my memos using the constant comparative analytic technique. I also talked to my work mentor, my advisor, and members of my committee about my theorizing. During some conversations I became aware of here-to-fore hidden meanings. I also reviewed Corbin and Strauss (1998) as I thought about the data and what I was finding and where I was stuck. Going back to this reference was very helpful in thinking through the various parts of the process model. This exercise helped me to also uncover a problem that I had with my dataset. I realized that I actually had data supporting two distinct psychosocial processes, making treatment decisions and how the disease impacted parental relationships. I recognized why I could not reconcile the two; the relationship impact was contextual to the decision making process such as the diagnosis of cancer and resultant emotional turmoil. They were not inter-related, but instead the relationship impact was background to the decision making process. I therefore elected to put aside the emerging model for disease impact on biological and stepparents and focused on the model regarding my research question. I plan to re-visit these data in the future and explore these very interesting serendipitous findings in a future study of how a diagnosis of childhood cancer impacts parental relationships in post-separation family structures.

Selective Coding

The process of selective coding involves integrating and refining categories by determining a core category. The core category represents the central phenomenon around which all other categories are integrated. This is accomplished by relating all categories around the core category by means of the paradigm, validating these relationships against the data and filling in categories that need refinement. When categories require ‘filling in,’ the analyst reviews memos and data, or goes back to the field to selectively gather further data through the use of theoretical sampling (Strauss & Corbin, 1998).

The tools used to accomplish selective coding include writing a story line, making use of diagrams, and reviewing and sorting memos. The goal is the creation of densely developed categories where all salient properties and dimensions are identified. Once accomplished, the resulting theory will exhibit variation, precision and increased explanatory power.

I found this process the most challenging part of my dissertation research experience. I spent hours thinking about the data, and reviewing memos and axial coding tables. I discussed my findings with colleagues and sought help from my dissertation advisor. In the end I had to write my way out of the conundrum. I wrote a storyline memo as a means to help me integrate the two major categories (*Biological parent involvement in TDM* and *Stepparent involvement in TDM*) and subcategories. I then drew a number of figures trying to capture the process in an abstract form. From these activities, I uncovered the core process or the selective code, “Stepping up, stepping back, being pushed and stepping away.” The psychosocial process will be detailed in Chapter Three.

Methods to Ensure Rigor

I integrated a number of steps into the research design to insure the scientific rigor of the study. In the constructivist paradigm, researchers use different criteria to evaluate the quality of a study; they replace the criteria of validity and reliability with trustworthiness (Polit & Beck, 2004). The hallmarks of trustworthiness are credibility, dependability, confirmability, and transferability (Polit & Beck).

Credibility refers to the believability of the findings established by the researcher (Leininger, 1994; Polit & Beck, 2004). I undertook prolonged contact with participants through intensive interviews (Leininger; Polit & Beck; Sandelowski et al., 1989). Additionally, I drew participants from a variety of disease teams assuring differing parental treatment decision making experiences based on interaction with different care providers. I triangulated data by gathering information from custodial parents, co-parents, and stepparents as indicated by the unfolding analysis (Polit & Beck; Sandelowski et al). I engaged in peer debriefing through intensive interactions with my dissertation advisor and committee members (Polit & Beck).

I conducted member checks with the final study participants, thus providing them with an opportunity to verify the emergent findings (Leininger, 1994; Polit & Beck, 2004; Sandelowski et al., 1989). Dependability and confirmability refer to the objectivity of the data and focuses on how researchers verify the data's accuracy, relevance or meaning (Leininger, 1994; Polit & Beck). My dissertation advisor provided ongoing review of my decision trail and data collection/analysis through regularly scheduled telephone conference calls and e-mail exchange of transcriptions and reports generated from the ATLAS.ti program related to the ongoing analysis. My dissertation advisor reviewed all

transcripts, category coding decisions, and accompanying memos (Leininger; Polit & Beck; Sandelowski et al, 1989). I ensured transferability in writing the findings, providing enough description in the research report to allow readers to evaluate the applicability of the findings to other contexts, such as parental TDM in other chronic illness contexts (Leininger; Polit & Beck).

In grounded theory, the act of simultaneous data collection and analysis yields “a constant interplay between the researcher and the research act” (Strauss & Corbin, 1998, p. 42). This interplay requires the researcher to maintain a balance between objectivity and sensitivity. Successful maintenance of this balance represents a unique challenge to ensuring scientific rigor. I worked to maintain objectivity or accurately representing the subject’s responses by thinking comparatively, comparing incident to incident, and staying grounded in the data. Obtaining multiple viewpoints helped to validate the emerging theory. Sensitivity or insights that give meaning to the data “happen to prepared minds during interplay with the data” (Strauss & Corbin, p. 47). My combined clinical professional experience and extensive analysis of the parental TDM literature provided a strong foundation to give meaning to the data obtained in this study.

CHAPTER THREE: FINDINGS

This chapter begins with a description of the 15 parents who interacted to make childhood cancer treatment decisions and their 8 families. Next, the psychosocial process of *stepping up, stepping back, being pushed, and stepping away* will be explained using examples from parent experiences to illustrate key concepts of the process.

Demographic Characteristics of the Parents

Fifteen biological parents and stepparents of children with cancer were interviewed from the metropolitan Washington, D.C. area. I interviewed 3 stepparents (2 stepfathers and 1 stepmother), 7 custodial parents (6 custodial mothers and 1 custodial father), 3 co-parents (all non-custodial fathers), and 2 parents who shared custody equally (1 mother and 1 father from the same family).

Parents' ages ranged from 20 to 50 years (mean = 38.5). Six parents described their race as black (5 African American and 1 Jamaican) and 9 were Caucasian. The parents came from a variety of socioeconomic (SES) backgrounds (Hollingshead 2 factor index classification ranged from upper-middle to lower). The Hollingshead two factor index describes SES status based on a combination of occupation and educational level. I used this measure of SES status because it allowed me to index SES without having to ask parents what their income was. I was concerned that parents might be reluctant to divulge this personal information in the interview. The index is computed by assigning the occupation of the person to one of seven categories (higher executive/major profession to unskilled worker) and multiplying by a weight factor of 7. This number is added to the product of educational level (seven categories: Graduate degree to < 7 years

of education) and a weight value of 4. The index groups people into one of five classifications: Upper, upper-middle, middle, lower-middle, and lower (Miller, 1991).

At the time of interview, 4 parents were living with a partner, 8 were single, and 3 were remarried. The biological parents had been separated or divorced between 8 months and 14 years. These 15 parents represented 8 families. I interviewed both biological parents and a stepparent in three families, and both biological parents in 1 family. For the rest of the families only a single biological parent participated in this study. The circumstances of the divorce and/or separation of the biological parent participants, their current marital status and custody arrangements are summarized in Table 3.1.

Demographic Characteristics of the Children with Cancer

The children with cancer ranged in age from 15 months to 17 years. Four were boys and 4 were girls. Their diagnoses and associated decisions are listed in Table 3.2.

Demographic Characteristics of the Families

Genograms were constructed at the beginning of each interview. This process helped me better understand the families and provided a reference for names subsequently used by parents. Being able to use the family members' names when probing for details of the parent's experience helped build trust during the interview. Two children with cancer had no siblings, others had 1, 2, or 3 full, half- or stepsiblings living in their primary household. They had up to 5 half- or stepsiblings living in their secondary household. Most children had two biological parents and one stepparent involved in their lives during their treatment for cancer. Two biological fathers' and one biological mother's involvement with the child reduced dramatically after the diagnosis. I created pseudonyms for each family member named in the transcripts. Table 3.2 lists

each family and their associated pseudonyms as used throughout the presentation of the findings.

The Process of Making Treatment Decisions

Treatment decision making for the child with cancer in family structures in which parents do not live together is situated in a highly charged emotional atmosphere. The child's diagnosis creates a crisis in two households. The disease exacts a toll on parental and sibling relationships and increases overall stress for all family members. It is within this context that parents must interact to make complex medical decisions for their ill child.

Stepping up and stepping back, pushing, and stepping away represents the process of parental treatment decision making by parents who no longer live together. This organizing construct depicts differing parental involvement in treatment decision making based on the parent's position in the family (*custody arrangements*), involvement with the child before diagnosis (*co-parent's relationship with child, the family's history of decision-making*), and stage of treatment.

Parent Position in Family

Parents' described three parental positions: (a) custodial parent, (b) co-parent, and (c) stepparent. The custodial parent was the parent with whom the child primarily lived during treatment. In general, the custodial parent's role in the child's life was that of primary caregiver. This parent was fully involved in the child's life before diagnosis.

Co-parents were non-custodial parents, with neither primary nor sole physical custody of the child, nor did they have legal custody to make decisions, although there was one exception to this. Co-parents' involvement in the child's life ranged from being

completely uninvolved to sharing legal and physical custody and having equal involvement in the child's life as the other parent. The minimally involved parents were primarily non-custodial fathers, with the exception of a biological mother who switched custody with the biological father when the child was diagnosed with cancer. In this family the biological mother relinquished legal medical decision making authority and physical custody to the father after diagnosis.

Finally, stepparents were the biological parents' romantic partners either by marriage or cohabitation. Stepparent involvement in the child's life ranged from significant to minimal. The length of time the stepparent had been involved in the child's life ranged from months to many years.

From this point forward when I refer to parents I mean all adults in the immediate family, including biological parents and stepparents. When I refer to the specific position each parent has in the child's family I will distinguish the *custodial parent* as the biological parent with whom the child primarily resides and who often, but not always, has sole legal custody and decision making authority. The *co-parent* is the non-custodial biological parent, and the *stepparent* is the partner, either by marriage or cohabiting relationship, of one of the biological parents.

*Stepping Up: Biological Parent Involvement in Treatment Decision Making at the
Diagnosis of Cancer*

Treatment began with the diagnosis of the child. The majority of treatment decisions (7 of the 8 decisions) discussed by the parents occurred during the diagnostic and initial treatment phases of therapy. In childhood cancer, the diagnosis and relapse timeframes are quite similar in terms of contextual elements of the cancer experience.

Parents experience similar emotional reactions during these times and are faced with the need to make major treatment decisions having potentially significant impact on their child's well being. One family described their experiences making a bone marrow transplant decision after the child's leukemia relapsed.

Parents of children with cancer came to the treatment decision making experience in the midst of a diagnosis of a life threatening illness in their precious child. The diagnosis immediately thrust parents into a world of fear and uncertainty. Parents used words like "fear," "uncertainty," "stress," "helpless," "isolation," and "painful," to describe these experiences. A few positive emotions also were described, primarily related to how the child with cancer gave the parent the strength and encouragement to move forward.

Major treatment decisions were defined as those that represented a significant change in the child's treatment. These decisions were often accompanied by formal conferences with the treatment team and informed consent. In this study, the biological parent's role was as the primary decision maker and the stepparent's role was one of support. Major treatment decisions were made at a treatment crossroad, either at diagnosis of the child's cancer or at relapse.

The custodial parent was typically the parent who first learned of the diagnosis, but the crisis of the diagnosis brought all family members to the child's bedside. Parents were formally sought out by the treatment team to discuss the child's diagnosis and treatment recommendations. A number of the major treatment decisions made by parents (4 of the 8 decisions) in this study were made during the diagnosis period. During this period, both of the child's biological parents spent many hours together in the hospital

attending to their ill child. When the former spouse was re-partnered, parents were confronted with the new partners of their former spouses/partners as all family members rallied around the child during the initial crisis. The sheer numbers of family members present heightened the complexity of the crisis of diagnosis, while increased contact with the former spouses and their new partners created additional anguish for biological parents who had previously chosen or were forced not to be with the father or mother of this child.

The Biological Parent Imperative for Treatment Decision Making

During the initial diagnosis period the parent imperative for major treatment decision making (*parent imperative for decision making*) drove parental involvement of both biological parents. An important facet of the imperative for parent treatment decision making was the biological parents' feeling that no one else could know the child as intimately as they could - because of the intense connection they felt toward the child, no one else could understand what it was like to have the child diagnosed with cancer and face the possibility that the child could die. Debbie, a biological mother, poignantly described the anguish of having to make decisions for her child: "And you think that nobody understands . . . I don't think anyone know how I feel to think that you may lose, a --- Richard is a beautiful child..."

She also expressed strong opinions about whether her partner (the child's stepfather, Donald) should be involved in the child's treatment decision making: ". . . you (stepfather) could never, you are not in my place, you're not his father, you didn't born him, you didn't help create him so it's a difference. It's a difference." In the end,

all parents agreed that it was the biological parents' responsibility to make these decisions. One father said:

This is a very personal thing to have your children, your children get sick and it is mom and dad's responsibility to take care of you and I think Marcia (biological mother) would say the same thing. Like if Marcia wound up living with someone, they could offer advice but I still think Marcia is going to talk to me (to make decisions).

The *parent imperative for decision making* compelled custodial parents to *include the other parent* in major decision making, despite their previous relationship conflicts. Custodial parents talked about doing the right thing and working hard to *include the other parent*. It was the co-parent who was first called when the custodial parent was told the preliminary diagnosis by the family physician.

Mary (custodial mother): Well, he (biological father, Max) was the first person I talked to, I try everything in my power to do the right thing even if I don't like doing the right thing so before I called my mother I called him to explain to him what has just taken place and where we are and you need to come.

Parental Mutuality in Major Treatment Decision Making

Custodial parents demonstrated more mutuality in making major treatment decisions (*parent mutual decision making*) with the co-parent immediately after diagnosis of the child's cancer than they had prior to the diagnosis when making every day decisions about their children (*choice conflict between parents*). When a parent had sole custody, the custodial parent worked harder to *include the co-parent* during this time of crisis.

I (custodial mother, Mary) did everything in my power to make sure that if we had to sign papers and he (biological father, Max) wasn't there, I asked them to wait as much as they could before signing so that everything would be on the same chord.

When the *co-parent was not involved*, single mothers lamented not having someone to share the burden of making the decision (*weight of making decisions*).

I (Kate) think it's so much easier for parents that are together rather than going through this by their self. I feel like I would be doing so much better and decisions would be easier because everything is on me and it's like - that's hard. I can't talk to anybody and be like we'll, well what shall we do? Because there is no 'we,' you know, he's not involved. So I just think it would be so much nicer if I had somebody that loved her as much as me to share everything with. You know, all the decisions, talk about her treatment and just everything and you know that's probably the biggest thing is just going through it alone.

Information manager. Although co-parents were generally included in major decisions after the diagnosis, a parent who had sole physical and legal custody often exerted *control of decision making* by being the *information manager*. Since the custodial parent was usually physically present for all decision making and hospital encounters, they determined how and when to relay information to the co-parent. Most often, and especially in the beginning, the custodial parent took great care to relay information to the co-parent (*Include other parent*). It seemed that the *parental imperative for decision making* encouraged the custodial parent's commitment to relaying information to the co-parent during the diagnostic period and major treatment decision making.

Stepping Up: Co-parental Involvement in Major Treatment Decisions

Typically, co-parents stepped up to decision making (*Parent steps up to decision making*) at diagnosis. There was a greater range of participation of co-parents than of custodial parents, however. Co-parents' involvement ranged from a completely shared and mutual process with the custodial parent (*Mutual parent decision making*) to deferring decision making to the custodial parent (*Parent defers decision making*) to not being involved at all (*Co-parent not involved*). Sometimes the co-parent was *pulled from*

decision making by the second family. The co-parent's involvement was heavily influenced by their involvement in parenting the child pre-diagnosis.

Mutual Decision Making

The parental imperative for decision making compelled some co-parents to be involved in treatment decision making at diagnosis (*Parent steps up to decision making*). Some pairs of parents worked together to make treatment decisions relatively easily during the diagnosis period. The stress of the situation broke down pre-existing barriers to working together on behalf of their ill child (*Focus on the ill child*). These parents focused on the tasks at hand, putting aside previous conflict. One mother (Mary) gave advice to other mothers in her situation.

Separate what was going on outside the hospital and what's going on in this hospital right now and only what is pertaining to my child. If it's not about the child, it is very hard, very hard, but if it is not about this child we aren't talking about it. Doesn't have anything to do with what's going on in that hospital as it pertains to this child, we're not talking about it. And I kept saying that and it helps. Not discussing it, not discussing property, not discussing child support, I'm not discussing who needs to visit, not discussing what visitations. That has nothing to do with what is going on right now. We aren't going to discuss this. Grow a tough skin and we talk only about what's going on right now.

Co-Parent Defers Treatment Decision Making

Non-custodial parents who weren't significantly involved in the child's life before diagnosis were the ones who most often deferred treatment decision making (*parent defers decision making*). These parents seemed to think that the custodial parent was better equipped to make the treatment decision. Unfortunately, I could not recruit any of these non-involved parents to this study and so only have the opinions of custodial parents to describe this facet of the process. This biological mother (Donna) describes her experience with the child's father deferring decision making.

Uh, I guess like look at your (biological father's, Andy) child, what would you think would be best for her? I would like, don't keep saying well you the mother; you know what's going on. OK you the father, you should also be here to know what is going on.

She later rationalized the father's lack of involvement in their child's treatment decision making: "I think, since he (biological father, Andy) haven't been there . . . I don't know if he know how to feel to help make the decisions in her health because he haven't been around." This father was incarcerated when the ill child was born and only began to visit his daughter just prior to the diagnosis. He was not involved at all in decision making or care after the diagnosis.

Stepping Back: Stepparent Involvement in Treatment Decision Making

Stepparents' involvement in major treatment decision making was distinctly different from the experience of biological parents. While the biological parent's imperative was directed toward making decisions, the stepparents' involvement was limited to supporting their partners (*Support/listen; Offer opinion/discuss decision making*) and sometimes just being present for treatment discussions (*Stepparent present*), but not participating in making the decision.

Supporting Partners During Decision Making

The stepparent's involvement in decision making centered on helping their partner cope with this difficult process. One way they provided support was by seeking information for their partner and for themselves (*Seeks out information*). For instance, one stepmother helped by researching treatment centers when the biological parents were contemplating a second opinion. Her husband (Alan) recounted, "She (stepmother, Alice) was doing a lot of research and it made her feel good. It made me feel good that she was researching like what the best hospitals were" A stepfather (Donald) sought

information his partner was not willing to hear to help them both prepare for what might lie ahead for the child.

I did that so Debbie (biological mother) could stay focused on the positive, ah, you know on the outcome of all positive situations because I didn't want her to get no feedback, I got so much negative (feedback from the physicians), you know, something she didn't want to hear so I kept that within me. . . . I let her sober up the good points about the situation and I just took [in] all the negative points of the situation and she didn't [have to] see it that way.

Another supportive function that stepparents employed was emotionally supporting their partners (*Support/listen*). One father (Alan) stated, "Eighty percent of the dialogue and decisions are made between me and Marcia (biological mother) and Alice (stepmother) gives her input and support." Alice (stepmother) said in her interview, "I think my role is to support Alan (stepfather) as much as I can."

Offering Advice (Tentatively)

Although stepparents usually were willing to offer their opinion (*Offer opinion/discuss decision making*), most purposefully stepped back from decision making (*Stepping back from decision making*), acknowledging their place in this process. A stepfather (Donald) recounted:

She (biological mother, Debbie) was already hurt, she was already in pain and I didn't want to, so many times I wanted to but I didn't want to do it no more so, you know you have to be a man about the situation and take a step back and use, you know, let her make those decisions and let her live with the decisions she made because I know that we talked, some decisions we talked about and, except the decisions that she already made up that she was going to go through with so, you know, I left it alone.

This mother (Carmen) described her second husband's involvement in treatment decision making:

He (stepfather, Bob) was there for Connor (child with cancer). He wasn't a decision maker and . . . He and I talked about do we put him in the study,

do we not, and all that. But he, as much as he likes to be in control, he really just sat back and was there to hold my hand and be there for Connor.

One stepfather (Donald) described, “Most of the decisions that I’ve made is I wanted his mom to know that where I came from.” A biological mother (Kate) said of her boyfriend (Buster), “He gave me advice and stuff.”

Pushing Away: Stepparents Excluded From Treatment Decision Making

Not only did stepparents voluntarily step back from the responsibility of making major decisions about the stepchild with cancer, they sometimes were pushed away by the biological parent who was their partner (*Stepparent excluded*). Biological parents excluded stepparents from the decision making process primarily because of their belief that only a biological parent had the intimate knowledge necessary to make a treatment decision of this magnitude (*parent imperative for decision making, you don’t know my child*). Another reason that biological parents gave for excluding the stepparent was to spare them blame for a bad outcome (*Blame for negative outcome*). In response to questions about who was involved in the treatment decision making process this mother (Debbie) discussed her reasons for excluding her partner, “because, if I would have the least little took his (stepfather, Donald) advice and it didn’t work out . . . to keep the decision upon me and myself I would have no one else to blame.”

Being pushed away caused conflict in some relationships (*Conflict with stepparent*). This father (a co-parent, Max) described the effect of being excluded on his wife (a stepmother).

It affected it; she (stepmother, Darla) thought that she should have been there. She wanted to be a part of it, she respected my decision but she voiced her own as well. She is a very strong woman when it comes to voicing her opinion. But it didn’t affect it to a point that, you know, well

yea, it did, it did it bothered me a lot at first but it didn't bother me to the point that I was, O.K. well I am going to deal with this anyway. I still came home and dealt with my life here.

While stepparents experienced some conflict when excluded from treatment decision making, they also recognized their roles in the process.

I (stepparent, Alice) actually was not involved in that process (treatment decision making) at all, which, when I found out later it kind of upset me. Not that my decision would have, not that my opinion would have really weighted much, as well it probably shouldn't.

Stepparents were also excluded from the treatment decision making process by the treatment team. This stepfather (Bob) was extensively involved in the diagnostic phase of his stepson's treatment. However, he was specifically excluded from the treatment discussions by the treatment team.

...they do a lot of consultation before they go and start the treatment and it was really kind of a [chuckle]... I got upset, I was asked to leave the room by one of the nurses there that I thought, and I certainly wasn't going to make a big deal out of it with Connor (child with cancer) in his situation so I just left but I had a conversation with Carmen (biological mother) about it afterwards. It's like you know, that really made me feel weird. I mean I've been here supporting this all the way through and then all of a sudden Bart (biological father) shows up and I need to leave the room. I honestly didn't like that very much.

The exclusion appeared to be the standard approach taken by team members rather than in response to obvious conflict amongst the parents based on the biological father's interpretation of the same situation, "I don't think he (stepfather, Bob) was allowed, to tell you the truth. I think he was there one time and [the doctor] said this is a meeting for just mom and dad."

Stepparents were also excluded by the former spouse of their partners because they made them uncomfortable (*Confronted with the other*). This mother (Marcia)

described the stress associated with having to interact with her former husband's new partner.

And this initial hospitalization was extremely difficult because she (stepmother, Alice) wanted to be there to support him (biological father, Alan). Therefore [she] was in my (biological mother) space constantly when I was dealing with the worst thing I have ever dealt with in my entire life.

The stressful nature of the stepparent's presence was magnified when the stepparent was the cause of the marriage breakup. One biological mother (Mary) commented on a time she was asked to leave the room so that the biological father and his new wife could visit the ill child, she said, "He (biological father, Max) comes with his lovely wife (Darla) and I am to leave so they can come visit. Huh, that's nice. [Laugh, Laugh] I don't think that was necessary at the time . . . can't understand."

Daily Treatment Decision Making

After the shock of the initial diagnosis or relapse waned and the major treatment decisions were made, parents were faced with making daily decisions about their children's care. These daily decisions corresponded to the day-to-day management of the illness and occurred later in treatment. More differences were noted in parental involvement in daily treatment decision making than during major treatment decisions.

Pushing Away: Custodial Parents' Involvement in Daily Decisions

As decision making moved away from diagnosis and toward the daily decision making needed in illness care, custodial parents assumed more control (*Parent control of decision making*), and were more likely to make decisions independently (*Inform parent about decisions made, Excluding parent from decision making*). The lone custodial father

(Tyler) talked about how things changed as treatment progressed. Note the shift from collaboration to simply informing the co-parent about what was happening to the ill child.

I try to present to her (non-custodial mother, Kathy) as much of the facts as I can and then I try to explain to her why I think it is a good idea to have made the decision I had made with regards to that and then I leave it at that. She asks me questions sometimes, not often, and I answer them as best I can and it's not a difficult process, it's really not. You know, at this point there's not, this point I keep her more informed than anything else. We had to go for a blood transfusion last week, when that came about I called her and told her that we were going for a blood transfusion, I called her when we got the results of the scans, that the tumors had shrunk and I told her I would call her Monday or Tuesday we go back for Chemo Therapy on Monday and I suspect we will talk to the doctors about what all these things mean and I told her I would call her and inform her what's going on then.

The custodial parent was usually the parent who took the child with cancer to appointments and therefore was the person who received primary information from the treatment team. They worried about whether the co-parent could manage all the intricacies of the therapeutic regimen when they were not there to hear information from the treatment team first hand. This mother (Marcia) worried about the child's central line care. When I interviewed her, the child was admitted to the hospital for treatment of a possible infection of the central line.

If he (non-custodial father, Alan) was with me watching me, if he was getting the same treatment training as me I have confidence in him, but he's not getting that same training. Like when her Broviac care, they trained us both; however, I was the one she was going home with. I'm the only one who did it on her in the hospital, and I'm the one who flushes it every day. He flushed it maybe twice. He's never changed her dressing.

This same mother also worried about making sure she got information first hand, another aspect of being an *information manager*.

I (Marcia) think that this hospital has done a very good job of acknowledging the fact that we are divorced and I am the one who cares for her. Because it was me that they made sure changed the Broviac in

front of them. And you know, I'm leaving tonight, I've been here since Monday . . . and I've already arranged that if they discharge her tomorrow they can give him (the non-custodial father, Alan) all the discharge instructions; that's fine, but they need to call me and give them to me as well because I can't have him telling me. I'm the one who has to follow through with those discharge instructions and this hospital has been very, very um good at ah honoring those kind of requests. Because they know. I mean it's not because I don't want him to have the information that I don't have, it's that I need to hear it from the doctors, not from my ex-husband on how to care for her so.

By being an *information manager*, the custodial parent ensured that the treatment regimen was properly administered when the child was in the co-parent's home during visitations. As one co-parent father (Alan) expressed:

Marcia (custodial mother) is very organized, thank goodness. It's good to have an organized person on something like this so she will hand over a list of all the medicines, and the times. . . . She's got it all written out.

Sometimes being the *information manager meant that*, as time passed, the custodial parent's commitment to sharing information waned and old patterns of communication and decision making resurfaced. One co-parent talked about being excluded during a later phase of treatment.

Interviewer: During this Radiation Treatment time there was some withholding of information from you?

Max (non-custodial father): Yes, there was a disconnect.

Interviewer: There was a disconnect and from your perspective mom was, Mary (custodial mother) was doing that?

Max: Yes, she was hoarding it, I call it . . . she's just trying not to involve me. You know, she wanted to do it herself, she wanted to feel, that O.K., mom is here for you, daddy's not. I didn't like that part.

Unless the co-parent attended every clinic visit, he had to rely on the custodial parent to relay information. The same non-custodial father (Max) did not receive scan results and lacked information about the current treatment plan.

I think in the third week I was really shut out, you know, I didn't know when he (child with cancer) was going, [chuckle], I didn't know, like what

they had, I didn't get the results, you know, I wanted more results at the time. What happens after Radiation? You know, so I didn't get a lot of information but the first three weeks I was real heavily involved.

When parents had a conflicted relationship pre-diagnosis, mutual decision making (*Parent mutual decision making*) was not easily accomplished over the entire course of treatment. Mistrust was common. For instance, one mother (Marcia) talked about the potential for missing something when information was not properly communicated to both parents by the treatment team,

It's just hard because he's (non-custodial father, Alan) not going to be there and if they tell him something tonight and then I bring her home on Sunday and something comes up, well we told her dad that. Well, you told her dad and he's not here.

Parents appreciated efforts by the treatment team to communicate with both parents directly. Unfortunately, this practice was more often an exception rather than the norm as it required additional time and effort by the clinicians. Ensuring that information was adequately passed from parent to parent was especially important when a child with cancer lived in two households in which the parents did not get along.

The lone exception to the tendency for custodial parents to control both information and decision making was a pair of parents who had shared custody arrangements. These two parents of a child with acute lymphocytic leukemia who underwent a hematopoietic stem cell transplant discussed their mutual decision making:

Debbie (custodial mother): I could tell that his (biological father, Michael) heart was just as broke as mine each time we talked and he would go, 'Well Debbie, what are we going to do?' I called him daddy like the kids, so I'm like 'Well daddy, this is what they say have to be done,' he's like, 'Oh well, we just we just have to do it.' So all the decisions were, you know, we talk as if we were at the meeting together, and you know, we talk about how we felt about it and we talk about what the doctor said and then he was just always, well what do you think, or what should we do and it was always mutual. Everything was mutual.

Michael (non-custodial father): Well, actually all the decisions was between me and her (biological mother, Debbie). You know, whatever has to be done we discussed it and talked to the doctor and we said O.K. let's go home and let's think about it and we did everything we had to do together. It wasn't Debbie (custodial mother) deciding to do something, you know, I'm like that's not a good idea or vice versa. We listened, we figured out what we had to do and we did it.

One way parents exhibited mutual decision making was in the process of sharing information. These parents, who shared custody equally, eventually established a routine of e-mail communication with the treatment team. Initially it seemed that one parent was purposefully trying to exclude the other from the communication exchange, but eventually they created a routine that worked well for them. The mother (Carmen) explained the early conflict:

[The nurse practitioner] and I were talking on the phone and then I would e-mail him (biological father, Bart) what she had said. He was feeling left out and so then he reached out to both [the nurse practitioner] and [the pediatric oncologist] on his own. And I never had a written communication with them through e-mail that I didn't copy him on. And I think he was trying to take some control back, because then he started e-mailing them without telling me, you know, sort of and I said O.K. We have got to stop this. They don't need to be talking to us individually, and so then he started copying me again after that.

The father (Bart) described his satisfaction with using electronic mail to facilitate communication between the parents and with the treatment team.

Thank God for e-mail cause I think that certainly helped. You know when it goes to one person and the person has to communicate through a phone or something, things can be forgotten and then someone can take that personal. You know you didn't tell me about that; really that maybe wasn't what was intended that you know, it was just not as important as something else that was communicated.

Pushed Away, Stepping Away, Pulled Away: Co-parent Involvement in Daily Decisions

Although, co-parents typically stepped up to decision making (*Parent steps up to decision making*) at diagnosis, their involvement in treatment decisions decreased as time from diagnosis passed. There were several reasons for this.

Pushed Away

Most custodial parents pushed the noncustodial co-parents away so that they could control decision making about the child's treatment. Parents who appeared to have a conflicted separation and parenting process preceding the child's diagnosis demonstrated similar patterns during daily decision making. Although some co-parents fought this process, some did not, and a few succumbed to a variety of pressures on them to remove themselves from daily management of the child's treatment. One non-custodial father (Max) relayed his experience:

Well, during that part of the Radiation I wasn't really informed and I told her (custodial mother, Mary), I said, you know, you told me that we were going to agree on keeping each other up-to-date. So part of his radiation treatment was during the time I was supposed to get him (child with cancer, Karl) and I said well I can take him . . . and ah, I told her I would take him so ah she didn't agree to all of that and it made it very difficult for me to do so . . . so finally I said well, you know, if you're not going to let me be involved, we will have to go back to court. You know, and then finally she did.

Stepping Away

For some co-parents, their level of commitment to participating in treatment decisions waned as time from the diagnosis passed. One non-custodial father's (Max) comment illustrated this decreasing involvement over time.

It was a no brainer for the first three weeks. I was going to be at the hospital, but after I felt that he (child with cancer, Karl) was getting out of danger then I felt a little bit better about not going every day and stuff like that.

These co-parents most frequently deferred decision making to the custodial parent (*Parent defers decision making*). Of course, a few co-parents were never involved with their children, even before the diagnosis (*Co-parent not involved*). This custodial mother (Mary) talked about her child's father's lack of involvement:

He (non-custodial father, Max) has not helped with anything. He's not helped with any... And when they told [us the child needed] . . . radiation every day for six weeks, [he said] 'I (non-custodial father) don't know that I'm gonna be able to make that because you took me to child support court. I have to work these part time jobs.'

Pulled Away

When re-partnered, the co-parent was sometimes pulled from the decision making process by their second family (*Parent pulled from decision making by second family*). This occurred sometimes at diagnosis but most often later in treatment. Whenever co-parents were pulled away from the decision making process, they experienced distress.

I say, it affected me (non-custodial father, Max). I am trying to see my son, it was emotional, it was an emotional battle. I was trying to see my son, I was trying to be there for my son and I know she (stepmother, Darla) wanted me at home.

Stepping Up (Gingerly): Stepparent Involvement in Daily Decisions

By and large, stepparent involvement in daily decision making or illness care increased as time from the diagnosis lengthened. As time from the diagnosis passed, the custodial mother was more able to let the child go for their routine visitations to their fathers' households. When the child was in the fathers' homes, the stepmother was often called upon to assist with illness care such as giving medications (*Stepparent involved*). However, these stepparents often had not had the same amount of education regarding the child's care needs as the biological parents:

I (stepmother, Alice) felt like I didn't get enough information because I do care for her (child with cancer, Maggie) when she is here and do this cancer thing. She has been here and I have had to give her her meds and hey, and um you know take care of her, flushing her stuff and all that stuff, I felt that enough information wasn't given to me.

Stepparents still respected the primary role of the biological parents (*Parent imperative for decision making*) and adapted their daily treatment decision making and caregiving accordingly. Stepparents tread lightly when they had a different opinion from the biological parents. They stepped back from decision making at this point and acquiesced to the biological parent's decisions (*Stepping back from decision making*).

Alice (stepmother): So as a stepparent not being able to say I'm taking her to the doctor really sucks because you see a kid that is obviously not feeling well and that was very frustrating so -

Interviewer: I'm hearing you sort of respected your role in that situation?

Alice: Yeah, right. It wasn't my role to do and that's where you have to definitely have to bite your tongue sometimes and go - and kind of realize how the other person (biological mother, Marcia) would feel and not everyone is as O.K. with everything as I am.

After the crisis of the diagnosis passed, parents returned to their previous patterns of communication and collaboration in caring for their child with cancer. As time from diagnosis passed, these families developed strategies for the routine exchange of important treatment information when the child moved from one household to another. However, there remained an undercurrent of stress related to who held the information about the child's disease and ongoing treatment and how this was shared among the adults responsible for caregiving. Most often it was the custodial parent who obtained the information firsthand from the treatment team during clinic visits. This information could be withheld from the other parents either purposefully or through omission as their complicated lives continued (*Information manager*). While the need for open lines of communication was paramount during this time, few families demonstrated an ideal

communication plan. The treatment team did little to ensure all family members received the same information unless all parents were present for treatment encounters.

Consequences of Making Treatment Decisions

The diagnosis of childhood cancer created significant stress among family members. Treatment decision making for a child with cancer, regardless of family structure, is done within a context of stress and anxiety. Parents fear for their children's lives, and virtually every aspect of cancer treatment is associated with a variety of stressors – anxiety about the unknown future they are facing, worries about the consequences of their treatment decisions, concerns about the child's health and general well being, and stress associated with economic burdens, time pressures, and the demands of trying to meet the emotional and physical needs of other family members. These sources of stress are universal among parents of children with cancer, and the parents in this study were no different in having to deal with these stressful conditions. Parents who no longer live together because of separation or divorce faced additional stressors because of their family situations, and these unique family-related factors affected treatment decision making processes.

For biological parents, treatment decisions were made with someone with whom they may have had a conflicted and even hostile relationship in the past. The decisions were sometimes made in the presence of third parties that represented pain and heartache from the past, and yet the parents typically felt compelled to set aside past issues to focus on their child's cancer and how best to treat it. In such ambiguous contexts, the consequences of decision making for parents took on multiple meanings and the

outcomes of decision making had consequences for individual parents and their family relationships.

For stepparents, having a stepchild diagnosed with cancer added ambiguity to what were often unclear relationships prior to the diagnosis. Stepparents also faced a variety of stressors in such situations, and although their relationships with the diagnosed child may have lacked the emotional intensity of parents' relationships, they also lacked support from partners or health care professionals. Their roles were to provide support in a variety of ways to their partners and the sick child, and yet they had no function in treatment decision making. Even when stepparents knew and accepted these roles, they experienced stressful outcomes that affected their sense of well being and their relationships.

Consequences for Biological Parents

Interpersonal Conflicts and Treatment Decision Making

Although not all parents had conflicted relationships with their former partners prior to diagnosis, most did, and the stress of having a child with cancer exacerbated it. One mother (Mary) stated, "We (biological mother and father, Max) still had to go in another room at the hospital to fight, it was horrible."

Even functional working relationships among separated parents had moments in which the parents could not agree about treatment alternatives or they fought about other issues. For instance, after the first crisis of diagnosis was dealt with, some mothers in particular, but in one instance a father, felt the need to *hoard the ill child*. These parents kept the child close to them and in doing so violated previously agreed upon or legally

mandated custody agreements. In some cases the biological parents worked this out and in other cases it caused additional conflict in the relationship.

Former partners sometimes found it *hard to be together*, causing increased conflict. This occurred predominantly when the parent had not initiated the divorce or separation. One biological mother (Mary) expressed:

Max (biological dad) was my best friend and I felt like he had snatched the rug from under me so, you know, together this wouldn't have been anything that we couldn't handle together, it would have been tough but we would have been able to do it, but now having to go through this and then having to always to keep my guard up. . .

Another mother (Sally), recently separated, found it hard to be with the child's father. It was like rubbing salt into an open wound.

I think I had more frustration personally but it's not so much between him (biological father, Scott) and I. It's my own personal frustration just because again I'm thrust into a situation of having to deal with him all the time when . . .

For these parents, the additive stress of dealing with their former spouses or partners and the associated emotions and old wounds magnified the distress they experienced. By *focusing on the ill child* most parents found the strength necessary to combat the emotional maelstrom. Over time, this became harder for most parents, and hoarding the child led to hoarding information so that contacts with the other parent would be minimized.

At diagnosis biological parents were forced to interact with each other to make major treatment decisions for the ill child, but once the crisis past and the routines of treatment established, biological parents returned to their previous patterns of relationship and communication patterns. This mother (Carmen) described changes in their communication patterns that occurred during diagnosis but that now have returned to old

habits, “You know, we (biological mother and father, Bart) stick to business. We communicate by email. When everything was going on with Connor (child with cancer) he (biological father) would answer his cell phone when I called but now he’s not answering his cell phone again and so...”.

Some parents had to confront "the other" person (the stepparent) who may have caused the demise of their previous relationship. This was particularly stressful for these parents because they were unwilling to leave their child to make room for the stepparent to visit the ill child. This difficulty was most magnified at diagnosis and waned over time. One mother talked about her difficulties being *confronted with the other person*, “she’s (stepmother, Alice) not supposed to be in my space, she’s not supposed to be in my home and there we were in this little hospital room, myself, my ex-husband and his girlfriend that he had the affair with.” Families in which the stepparent was not related to the marriage breakup did not experience this stressor to the same degree. This biological father (Bart) talked about the stepfather’s involvement in the initial treatment decision making process. In this family the parents had separated long before the mother met her new husband and the biological father had a different response to the stepfather’s involvement as compared to the previous example.

He (stepfather, Bob) was somewhat involved in a few things that happened early on with Connor (child with cancer), just being there for Carmen (mother). He wasn’t, I don’t know that he was there for any other reason other than Carmen wanted him there. Now I never questioned that and I never had a problem with it but I think that’s the reason why he was there and I think that gave us, him and I, an opportunity to kind of meet each other and have an understanding between each other, that kind of thing.

Avoiding Blame

Avoiding blame (*Blame for negative outcome*) was a psychosocial consequence to the decision making process. Biological parents talked about concerns regarding being *blamed for negative outcomes* by their former spouse/partner. However, no parents shared specific instances in which one parent blamed another for treatment outcomes related to choosing one course of treatment over another, nor were there any instances of parents blaming one another for negative outcomes related to major treatment decisions made together.

However, biological parents described instances when they took one course of action over another to prevent being blamed for a negative outcome. In one instance both the mother and father paid careful attention to preventing infection in their child. The mother described her thoughts about what was different in this situation, comparing being divorced and still being married.

Marcia (biological mother): You're just afraid to make a mistake and I think almost as a divorced person I am more afraid to make a mistake because I don't want him (biological father, Alan) to blame me for anything, and I know he feels the exact same way. I mean, he is like a hand washing fanatic and because he does not want her (child with cancer, Maggie) to get even a sniffle under his watch and -

Interviewer: Has that ever happened?

Marcia: No.

Interviewer: Where she has had a complication on one of your watches and----

Marcia: Well, ah, not because of this but she broke her arm with him over the summer and it was a very difficult phone call for him to make. She had fallen out of her bunk bed, ah but [pause] um . . . I mean it's just, we just were afraid to make a mistake I mean even as a team we were afraid to make a mistake, you just want the best for your daughter.

Interviewer: So, what I am hearing and I just want to make sure I understand is that you don't want to make a mistake because it's your daughter.

Marcia: Right.

Interviewer: You've got to do what is right for your daughter, the best, but you've got that added layer of I don't want to make a mistake because then my ex might bring it back to me in some...

Marcia: Exactly, exactly

Interviewer: In some negative...

Marcia: Exactly. One hundred percent. Even with this infection. I called him today because they have isolated the bacteria and so the attending told that it typically lives in water. Well how did she get exposed to it if it lives in water? Marcia, how did that happen? Well, I don't know. But I don't believe that would happen between a married couple because they would be living in the same home, they would be experiencing the same things, ah so . . . there is definitely . . . added pressure.

Biological parents' worried about avoiding blame for both major and daily treatment decision making. One parent described her worry about future negative outcomes because she took the lead in arranging for referrals for initial diagnosis and treatment planning even though the other parent was fully involved in making the final treatment decision.

Carmen (biological mother): Cause you know I expected a lot more push back from him (biological father, Bart) just because of the nature of our relationship and he really didn't do that and maybe the pediatrician that he spoke to who refers children here all the time reassured him that there wasn't any place better for Connor (child with cancer) to be, and were that it was just that he trusted the fact I knew the people here and that they would do their best for Connor.

Interviewer: Sure, sure. What was that like for you?

Carmen: It was a little stressful because I was really worried if they didn't cure him (child with cancer) that it would be my fault in the end or if something went wrong that he (biological father) would blame me but thank God I didn't have to deal with that.

Biological parents also purposefully excluded stepparents from treatment decision making to avoid blaming them for negative outcomes. In a sense this parent was trying to protect the partner from negative consequences of treatment decision making:

Because, if I (biological mother, Debbie) would have the least little took his (the stepfather's, Donald) advice and it didn't work out, why again I would blame myself so you know, to keep the decision upon me and myself I would have no one else to blame.

Decision Making Loneliness

Although some custodial parents pushed co-parents away from decision making and some co-parents gradually stepped back from such responsibilities themselves, a complaint of biological parents was the loneliness they felt in making decisions for their children. Ironically, even the few couples who shared decision making expressed this as well. This mother (Debbie) described this feeling of loneliness:

You know, you feel alone in this. You, you really feel alone, you have dad (biological father) but you feel alone. . . . I think when a serious illness like this . . . I think families become afraid and um, because it needs so much involvement they tend to back away and you tend to feel that so you tend to feel alone. So you [are] just alone with your decisions. It always seems like me, God, his dad and the doctors. That's it.

Another parent (Kate) said:

I want everything to be right. I want to make sure everything is right, at least to the best that I can do so it was more of a lot of reflecting and I was really sad, even though I wasn't going through it by myself I still felt like I was by myself.

The enormity of the decisions to be made, the risk of consequences, the emotional toll, and the burden of the responsibility to make decisions all contributed to the burden or *weight of making decisions*. When single parents faced making decisions alone, the weight was harder to bear. Note how this single mother (Kate) could only repeat, "it's hard" in response to a question about what is different about making the decisions alone.

Interviewer: Do you think that you would have a different way you felt about the decisions if you were able to share them with someone who loves Kayla (child with cancer) as much as you do?

Kate (single mother): No, I just think it would be easier.

Interviewer: What do you think would be easier?

Kate: Just making the decision. I'd feel better about it knowing that I wasn't the only one making the decision.

Interviewer: Is there anything you can do to help bridge some of that need at all?

Kate: No. [Very sad chuckle]

Interviewer: No?

Kate: I mean I'm perfectly capable of making all the decisions by me but of course it's just the fact of being lonely and feeling alone when I have all these great people who love me and are there for me, it's just the fact that Kayla (child with cancer) is not their's you know they will never understand what I am going through. Ever, you know. It's just not possible for them, even if they tried to think about how it would feel, they just can't. They don't know how hard these decisions are really. You know they are just a decision to them. They just tell me what they think. To them it's not as crucial as it is to me.

Interviewer: And what makes it crucial?

Kate: Just, I don't know. To be honest, it's just hard.

Interviewer: Uh Huh.

Kate: I don't know.

Interviewer: It's hard.

Kate: Yeah.

Interviewer: It's just hard.

Kate: Yeah.

Interviewer: And it's hard because ----

Kate: Just doing it by yourself, you know.

Interviewer: O.K.

Kate: I think it would be easier for parents to do it together and talk about it together rather than one person trying to do what they think is best.

Interviewer: Right, Right.

Kate: I just think it would be, it would just make you feel better knowing that you're not the only one who made this decision and you're not the only one who thinks this is what's best.

The sheer size of the decision to be made contributed to overall distress and difficulty for parents. These were high stakes decisions; their beloved child's life or future quality of life was held in the biological parent's hand (*Decision making aftermath*). One mother (Mary) said, "That's what worried me, I was making a decision that could comprise him (child with cancer) the rest of his life, facing things like he may not grow."

What worsened this decision making aftermath? It was not related to involvement in treatment decision making but instead was related to disease-related circumstances that

were out of the control of these parents. Things like poor prognosis, having limited choices, and uncertainty wrought a more arduous experience.

A strong faith, the child's doing well and a sense of altruism (when the decision was related to entering a clinical trial) helped parents cope with this aftermath. One mother (Sally) replied "of knowing it was going to help someone else" in response to a question about what helped the parent to make the decision about going on a clinical trial. Despite the huge toll placed on parents to make these decisions, they rarely expressed overt regret with the decisions they made. Most parents did not think back on their decisions and stated emphatically that they felt they made the right decision. One parent (Marcia) said, "We're going to move forward with it. [Chuckle] You know, we will take it one step at a time, we're not looking back at it." And another (Sally) said, "Yeah, yeah I always think, I always feel we did the right thing."

Other parents' responses indicated some doubt or even mild regret. The doubt was always related to something that might affect the child's outcome. One mother (Sally) said, "I felt comfortable, really, really comfortable of making it [the decision] but I still had a thing about the rest of something going wrong." Another mother (Marcia) whose child had experienced a complication related to one of the clinical trial medications talked about her feelings.

Interviewer: Do you ever think back on your decision?

Mother: Just because of the eye.

Interviewer: What do you think about ---

Mother: I just think if we hadn't done it then her vision wouldn't be jeopardy.

Interviewer: Did you wish you would have chosen otherwise or -

Mother: I'm not sure ah, because I have, I have the ability to pull her from it. She has, she just got asparaginase yesterday and she has two more doses that are not necessary for the Standard Protocol. So we could pull her from it but we haven't even discussed it because I think ah, eradicating

leukemia from her little body has to come first and the vision is secondary. I wish the vision hadn't been affected but ah, unless we get leukemia taken care we are not going to have a daughter that needs to see. So I would rather have a daughter that was blind in one eye than no daughter at all. Ah, so although it has entered my mind, I'm afraid to do it. I'm just afraid that she will be that one in ten so—

And another mother (Kate) who was in the midst of the decision making process acknowledged that it was too early to know if the decision made was best, “Right now I just don't know. I mean I feel I'm making the best decision but it's like I won't know. I really won't until after whatever happens, happens.”

Consequences for Stepparents

Stepparent involvement in treatment decision making caused potential conflict with either the stepparent's partner or the other biological parent. Stepparents' consequences of conflict with their partner resulted from being excluded from treatment decision making, “so I (Alice) really don't know a whole lot about it and that makes me angry.” Conflict with the other biological parent resulted from stepparents' presence during hospitalization. This mother described the tension that occurred when she and her ex-husband's new partner were present together during the initial hospitalization.

Marcia (biological mother): I just hate being in that, cause the doctor comes in and is talking to both of us, we look alike, she (the physician) has no clue, the doctor has no clue which one is Maggie's (child with cancer) mother so I decided very early on, Hi, I'm Marcia, I'm Maggie's mom and this is her dad's girlfriend, just to let everybody know the dynamics of what they are dealing with and any questions are to be addressed to me, not her.

Interviewer: Uh Huh. Did that ever happen?

Marcia: It did, it did and an attending once told me that I was the gatekeeper of that room and that the tension in there was very thick and if I needed to have her (stepmother) removed and have her not able to visit for a while, then that was something they could write in the chart because it was ah very evident, it was when they were coming back telling us whether it was ALL or AML and ah, [Chuckle], Alice (stepmother) was right there in the room and space and I needed that to be a very private

moment between, this, this chokes me up [crying], between the doctor and her dad and I. Not [long pause] somebody who doesn't belong there.

Interviewer: Right.

Marcia: In my mind. I mean Alan (biological father) feels very differently. Alan wants her there. She is his support and she can support him but I don't think the support to him should be at the expense of me. And so, that's that. [Sniffle, Chuckle]

One stepparent (Donald) was upset by his partner's consulting with other family members and not him. He did not mind the mother talking to the biological father (*Parent imperative for decision making*) but was frustrated when she consulted others. He felt this was his role.

It's like you know, damned what I say or damned what I do, you (biological mother, Debbie) going to go back and you going to listen to them or somebody told you something. I don't know how they could tell you something. I'm the one that's underneath you, or I'm the one that's around and I'm the one that's giving one hundred ten percent and they not giving not even two percent. So you know, there's been situations like that a lot of times and I want to walk away because I feel that wasn't right.

A father (Max) talked about his wife (Darla, stepmother to the ill child) wanting "to be more involved in the process but it was a lot of conflict there." The latent meaning implied conflict both between the couple and conflict with the former spouse. This conflict was most pronounced at diagnosis surrounding the major treatment decision and diminished over time as the families established new routines in response to the child's illness. This stepparent (Alice) talked about routines now established months after the diagnosis.

That aspect of it has gone pretty well, again I had to bite my tongue sometimes but when she's (child with cancer, Maggie) here Alan (biological father) and I pretty much make our decisions, if it's something major Marcia (biological mother) made me promise like now especially if something happens and she (child with cancer) gets sick to call her (biological mother) before we go to the hospital or whatever, which I understand.

Conclusions

Decision making consequences were not well defined by parents. All parents experienced relationship conflict related to who was involved in the decision making process. The degree of relationship conflict experienced after the child's diagnosis was related to the degree of conflict present in the family before diagnosis.

Biological parents experienced a unique set of decision making consequences that were not shared by stepparents. These consequences haunted the biological parents and appeared to be linked to the phenomenon of *parental imperative for decision making*. With the exception of single mothers descriptions of the additional burden of making decisions alone, biological parents descriptions of the weight of making decisions and decision making aftermath were not linked to involvement in treatment decision making but related to factors outside of the psychosocial process.

The consequence of avoiding blame for negative outcomes is a fascinating finding that has not been previously described in the parent treatment decision making literature. Because the research to date has focused almost exclusively on individual parent experiences, it is hard to know whether this finding is unique to the post-divorce/separated parent family context or if it is linked to how people interact to make decisions. In this study, I focused on learning how the parents interacted in making the treatment decisions and because of this have uncovered here-to-fore unexplained aspects of the treatment decision making process. These findings and the associated implications for research and practice will be discussed in the next chapter.

CHAPTER FOUR: DISCUSSION

Introduction

Stepping up, stepping back, being pushed, and stepping away described the process of how parents who no longer live together interacted to make treatment decisions for their children with cancer. The process, as described by parents, depicted differing levels of parent involvement in the decision making process based on the parent's position in the family, involvement with the child before diagnosis, and stage of treatment. Parents experienced a variety of psychosocial consequences related to the treatment decision making process. Consequences differed for biological parents and stepparents. Biological parents' consequences were linked primarily to their decision making responsibility for their ill children. Stepparents' consequences were linked primarily to interpersonal conflicts related to current inter-parental relationships. I will discuss these findings in light of what we know about treatment decision making research in childhood cancer, current knowledge regarding establishing a parental alliance after separation and divorce, and how the cancer experience affects parents and families.

Parental Treatment Decision Making in Childhood Cancer

Previous treatment decision making research in childhood cancer focused on individual parents' experiences. To date, research on parents' decision making when their children have cancer has focused on the factors parents considered when making decisions (Hinds et al., 1997, 2001), the quality of informed consent processes (Angiolillo et al., 2004; Broome, M. E., 2001; Kodish et al., 2004; Levi et al., 2000; Ruccione, Kramer, Moore & Perin, 1991; Wiley et al., 1999), or parents' preferences for

involvement in treatment decision making (Pyke-Grimm, Degner, Small & Mueller, 1999; Pyke-Grimm, Stewart, Kelly & Degner, 2006; Stewart, Pyke-Grimm & Kelly, 2005, 2007). These researchers did not study parental interaction, but individual parent responses.

My study explored both parents' individual experience with treatment decision making and also how parents perceived that they interacted with co-parents and stepparents (when present). By asking parents questions about how the other parent(s) were involved in the decision process, I discovered new information about what occurs between parents when making cancer treatment decisions for their ill children.

The Parent Imperative for Making Treatment Decisions

The biological parent imperative for making treatment decisions for their child with cancer predominated parent interviews. Both biological parents and stepparents acknowledged this decision making primacy. The parental role of decision maker was described as a natural extension of the parent's role in childrearing in two separate studies (Pyke-Grimm, Stewart, Kelly & Degner, 2006; Stewart, Pyke-Grimm & Kelly, 2007). In these studies, parents described an exclusive knowledge of their child in combination with their obligation to act in the child's best interest as the driving forces regarding their participation in treatment decision making. Other researchers echoed the primacy of the parenting role in parent's descriptions of their treatment decision making experiences (Bluebond-Langner, Belasco, Goldman & Belasco, 2008; Hinds et al., 2001; Holm, Patterson & Gurney, 2003).

In this study, parents made clear that it was the biological parent's role to make treatment decisions, and stepparents had no such role. The justification for this limitation

stemmed from biological parents' descriptions of their exclusive understanding of what it is like to have a child diagnosed with cancer. Both biological parents and stepparents linked this understanding to a difference in their emotional connection to the child. But there were also inferences to differences in emotional bonding because of a biological connection, as exemplified in this mother's statement, "you're not his father, you didn't born him, you didn't help create him, so it's a difference." Whether this connection was related to prevailing ideologies about the special emotional ties between parents and children (Ganong & Coleman, 2004) or to inherent evolutionary differences in bonds based on genetic ties (Booth, Carver & Granger, 2000; Davis & Daly, 1997), is unknown.

The parent imperative for treatment decision making compelled custodial parents to reach out to the co-parent and for co-parents to *step up* to be actively involved in the treatment decision making process. When the co-parent *stepped up to decision making*, the behavior reflected a natural extension of the parenting role. The majority of co-parents stepped up to decision making after their child's diagnosis with cancer. However, when the co-parent did not step up to decision making, it reflected the co-parent's previous level of parenting commitment or other personal factors. There were three instances where this occurred. In two of the families, the child's father had not established legal parental rights. Both of these fathers were not married to the mother when the child was born and had not contributed economically to the support of the child before diagnosis, both predictive of little or no father involvement (Coltrane, 2004). In the third instance, a custodial mother relinquished her decision making authority and physical custody of the child after diagnosis to the child's father. This mother experienced personal medical and social issues that likely contributed to this action.

Herrerias (1995) identified these as potential factors influencing a mother's decision to relinquish custody.

I was not able to recruit any of the parents who did not participate in treatment decision making to my study; therefore, I do not know the reasons for their lack of involvement. Two possible explanations of why they were not involved may be considered. The parent could feel tremendous guilt related to their previous absence of interaction and investment in their child's life now that the child's life was threatened by a serious illness. Alternatively, parents may have stayed away because they did not know their child well and they simply did not know what to do or how to interact with the child or the other parent. It is also possible that they were not fully informed about their child's illness. Researchers have noted that maternal gatekeeping often played a role in limiting paternal involvement (Ahrons & Miller, 1993); however, in this study the single mothers attempted to engage the fathers in the treatment decision making process after diagnosis. Despite repeated attempts by the single mother, the father never engaged in the process.

What concerns me is how these parents cope with the potential guilt or regret they may live with for years to come. As clinicians do we need to encourage involvement of these absent parents? Will this help or hinder the overall decision making process? Clearly further research is needed to know for sure.

Crisis events such as having a child diagnosed with cancer could possibly motivate people to abandon old patterns of behavior and adapt new ones. One non-custodial father demonstrated this phenomenon. The father, who had previously been minimally involved in the child's life, stepped up and became the child's primary caregiver. He described feelings of redemption in now having a chance to care for a child

whom he had essentially abandoned years previously. Results from a recent study of fathers of children with chronic health conditions indicated that a child's illness can serve as a "catalyst for [fathers'] more meaningful involvement with their child" (McNeill, 2007, p. 422). Unfortunately the example was an exceptional experience as compared to other non-custodial fathers who were not part of their children's lives prior to the diagnosis. However, as child health advocates, clinical staff must capitalize on all opportunities available to improve the lives of the children for whom they care.

Treatment Decision Making Consequences

Parents talked about feeling alone when they made their decisions. This finding has not been reported before. Parents did not report a lack of support as previously described (Guerriere, McKeeber, Llewellyn-Thomas & Berall, 2003), but they felt alone in the decision making process; in fact, one mother said, "Even though I wasn't going through it by myself I still felt like I was by myself." Was the feeling of aloneness a result of the relationship dissolution and separation from the child's other parent? One single mother related her difficulty to not having someone to share the decision making process with, "It would just make you feel better knowing that you're not the only one who made this decision and you're not the only one who thinks this is what's best." Alternatively, is this an emotion experienced by all parents as they face the burden of making difficult treatment decisions for their children?

In previous studies of parental coping with childhood cancer, married parents reported differences in their individual coping that interfered with their ability to support one another during the child's illness (Chesler & Barbarian, 1986; Hughes & Lieberman, 1990). Is this a manifestation of the feelings of aloneness? Based on my findings, I

cannot determine the answer. Future research needs to be designed to understand the dyadic interactions of parents that may contribute to the distress, anxiety, and depression parents experience in response to having a child diagnosed with cancer. Researchers must ensure recruitment of both parents to studies of family responses to cancer, including treatment decision making.

In this study, parents reported familiar themes of high stakes and heavy burden of having to make treatment decisions for their child with cancer (Stewart, Pyke-Grimm & Kelly, 2007). The decisions to be made could impact the child's life and weighed heavily on parents' minds and emotions. However, parents felt comforted by knowing that their decision to place their child on a clinical trial might help others. Altruism has been reported by both parents (Simon, Eder, Kodish, & Siminoff, 2006) and children (Hinds et al., 2005) as factors used to make a decision to participate in a clinical trial.

In previous research, parents of children with cancer reported a generally higher level of regret when compared to adults with cancer (Simon, Siminoff, Kodish & Burant, 2004) or questioned their decisions when they saw little benefit from experimental therapy (Deatrick, Angst & Moore, 2002). While the majority of parents spoke of not looking back at their decisions, one parent touched on the issue of regret as a possible consequence when the child experienced serious side effects when treated according to the experimental treatment plan. Another parent talked about it being too soon to know if the decision was best for the child. There were no instances of parents blaming each other for negative consequences, or having feelings of regret in response to their decision making experiences with their former spouses/partners or stepparents. Conversely, parents reported that they took great care in their decision making to avoid being blamed

by their former spouse or partner or they specifically excluded stepparents from the decision making process to avoid future blame if things did not go well. Few studies of decisional regret have been conducted in parental treatment decision making, despite the concept's potential significance as a long term outcome of interest (Entwistle Sowden & Watt, 1998). Researchers have only begun to define the construct of decisional regret and develop acceptable measures (Brehaut et al., 2003). Whether parents in bi-nuclear family structures have a greater risk for decisional regret than other parents is unknown at this time.

The Parental Alliance and Making Treatment Decisions

When asked to give advice about making treatment decisions to another parent in their circumstances, parents universally talked about the need to focus on the ill child's needs. Indeed, parents in this study did focus on the needs of the ill child, at least during the diagnostic phase of treatment, and in making initial treatment decisions. For some, the ability to put aside old differences with co-parents dissipated over time, leading to more conflict. For others, parental relationships and collaboration strengthened over time. Consistent with previous research (Amato, 2000; Whiteside, 1998), families in which the biological parents had been separated for a longer time exhibited more stable patterns of communication and decision making than those for whom the separation or divorce was more recent. These more experienced families had established their parenting alliance (Whiteside) prior to the added stress of the cancer diagnosis.

Biological parents who recently separated talked more frequently about the emotional pain of the break-up in addition to the pain of their child's diagnosis than did parents whose divorce or separation occurred years before. These more recently separated

biological parents also reported increased difficulty interacting with stepparents than did parents who separated years previously. Amato (2000) characterized divorce as a crisis event. Previous research overwhelmingly endorsed increased parent and child distress in the first 2-3 years after separation (Hetherington & Kelly, 2002; Whiteside, 1998). Therefore, families who have experienced a recent separation or divorce could be at increased risk for negative psychosocial outcomes with the addition of a significant stressor such as diagnosis of a life threatening illness in a child member. Clinicians working with these families must be aware of this potential for added distress and offer preventative psychosocial interventions accordingly. Parents may need extra support and referral for counseling to help them cope with the added crisis. They may need separate conferences with team members in situations in which all family members cannot comfortably be together in the same room. Proactively providing support and counseling could prevent more significant problems later in treatment.

In general, differences in post-diagnosis treatment decision making mirrored post-divorce parenting descriptions found in the literature. Maccoby and Mnookin (1992) described post-divorce parenting as ranging from cooperative (high communication, low discord), to disengaged (low communication, low discord), to conflicted (low communication, high discord). While I did not conduct an assessment of parental cooperation using standardized measures, a few questions uncovered the degree to which these parents worked together or not in caring for their child with cancer. Cooperative parents described their former partners as good parents. They increased their frequency of communication to accommodate an increased need to relay important medical information to each other. Disengaged parents adjusted their schedules to accommodate

the increased need to spend time in the clinic or hospital with their children. They were able to politely be together during medical appointments. The level of cooperation increased immediately after diagnosis but returned to previous patterns after a few months. Conflicted parents found it difficult to be together for necessary joint conferences and clinic appointments. While communication increased during diagnosis, it quickly returned to previous levels within a few weeks.

I did not incorporate the family therapy literature into this study and discussion because I focused on describing the treatment decision making process in post-separation families. In future studies, I will need to examine the family therapy literature to identify evidence-based counseling interventions that could be incorporated into an intervention protocol designed to facilitate the co-parental alliance during treatment decision making after diagnosis of cancer. Nurses will need to be able to assess these families, intervene as indicated, and refer families appropriately to mental health professionals. It is possible that these families may warrant automatic referral at diagnosis. Future research is needed to uncover these important nuances of family centered care required for the post-separation family structure. In addition, current models of family centered care such as the family management style (Knafl, Breitmayer, Gallo & Zoeller, 1996; Knafl & Deatrick, 2003) will need to be studied in post-separation families to determine what, if any, differences exist in diverse family structures.

Electronic mail was a preferred method of communication for parents who had strained relationships. By using electronic mail, parents could avoid direct contact and the resultant conflict with each other. Another benefit of using electronic mail was the ability for all parents to receive direct communication from the clinical team without the added

stress of having one person translate information back and forth. By hearing information first hand, trust was maintained by all parties. Reducing direct communication is a recommended intervention for families with high conflict divorces (Johnston, 1994). The use of electronic mail to facilitate communication in conflicted families has been previously reported (Schrodt et al., 2006).

In this study, parents engaged together for initial treatment decisions but as time passed, their cooperation waned for daily treatment decisions. The non-custodial parent typically was less involved in daily decision making as compared to initial major treatment decision making. Since the non-custodial parent was usually the father, some of the difference could be explained by known differences in caregiving activities between mothers and fathers (McGraw & Walker, 2004).

The Information Manager- A Maternal Gatekeeping Function?

The majority of quotations in my dataset about being an information manager referred to the custodial parent, typically the mother. The mother was usually present for hospital and clinic visits and took primary responsibility for the child's caregiving. These mothers talked about organizing clinic appointments, medications, and other aspects of the day to day care of the child with cancer. The reluctance to relinquish these responsibilities is consistent with descriptions of maternal gatekeeping in the literature (Allen & Hawkins, 1999). However, by being in charge of information the mother could also control many aspects of the child's care, including when and if the child could go for their scheduled visits to the non-custodial parent. This behavior resembled more of the gatekeeping function used by some divorced mothers to control child visitation as

compared to the gatekeeping beliefs and behaviors of mothers that influence fathers' involvement in child caregiving (Allen & Hawkins).

A busy clinician interacts primarily with the parent present for clinic encounters. However, in family structures in which parents do not live together, clinicians must take care to ensure both parents receive information first hand whenever possible. The clinician cannot assume that the parent present in clinic will reliably relay information onto the child's other parent. While most parents are present at diagnosis and for major treatment decision making conferences, this study demonstrated that some custodial parents did not always remain committed to communicating with their ex-partners. At a minimum, joint communication via encouraging joint clinic visits, electronic mail or conference calls should be considered for major evaluation points during treatment. In addition, teaching about symptom management and home care procedures such as central line care must be taught to all parents at diagnosis. In other childhood chronic illnesses, co-parental involvement in care varied (Ganong, Doty & Gayer, 2003; Gayer & Ganong, 2006) with a resultant impact on home care (Ganong et al). No researchers have studied the impact of separation or divorce on home care of children with cancer.

Impact of Childhood Cancer on Post-Separation Families

When a child is diagnosed with cancer, most families experience initial and recurrent distress, but in general cope and adjust well over time (Kazak et al., 2007). Using a social ecological framework, Kazak (2005) has led one of the most comprehensive treatment and research programs regarding child and family responses to childhood cancer. According to Kazak (2006), the impact of the family and its subsystems on the child's adjustment are primary to understanding the potential for

psychosocial difficulties experienced after diagnosis. Among the risks for ongoing psychosocial problems include: single parent families, large families, financial difficulties, and parental psychopathology. Indeed, a marital status of single, separated, or divorced was considered to be a higher risk indicator in 26.2% of 107 families who completed a brief psychosocial screening tool over a 12 month period (Kazak et al., 2001).

Unfortunately, most researchers have not considered families as a whole, but instead collect outcome data based on individual parent responses regarding parent and family psychological adjustment. Fathers are largely ignored in these studies (Drotar, 1997; Seagull, 2000). In addition, clinicians also only see limited members of the family during clinic visits and thus only have a limited understanding of the entire family's response to the child's disease and treatment.

It is therefore impossible to know if making treatment decisions by parents who no longer live together represents a risk for negative psychosocial outcomes in the family or simply represents a different type of parent treatment decision making experience. These parents described more emotional issues that first marriage parents would face (e.g. *confronted with the other*). But did these stressors represent added risk or simply their experience? It would seem logical that, in general, parents who no longer live together face increased stress in the childhood cancer experience. Stressors such as parenting and managing the illness alone, ongoing conflict with the former partner or spouse, or the hurt or anger in having to deal with the "other" person add to the emotional tumult associated with a diagnosis of childhood cancer. However, these families described an ability put aside their differences and to focus on their child, at least in the

beginning. Some also described improvements in their relationships with their former partners.

Relationship improvements have been previously reported in married couples after cancer diagnosis (Barbarin, Hughes, & Chesler, 1985). What is unknown is whether remarried couples experience marital stress after cancer diagnosis in the child differently from first marriage couples. Studies in childhood cancer show that marriages demonstrated distress most pronounced at diagnosis and decreasing over time, but not necessarily an increase in dissolution as compared to normative controls (Dahlquist, Czyzewski, & Jones, 1996; Lansky et al., 1978). In many of these studies, it is not possible to know whether only first marriage or a combination of first and subsequent marriages compromised couple samples. In this study, remarried biological parents experienced a range of responses from separation from their second spouse to strengthening of the relationship.

Hoarding the Ill Child

Several mothers and one father talked about the need to keep the child with cancer close to them, even if it meant breaking previously agreed upon custody arrangements. The need for a parent, typically the mother, to be physically close to their child at all times is a routine event in pediatric cancer treatment centers. Parents often do not leave the child's bedside. In the past, this phenomenon was characterized as a pathological response (Lansky & Gendel, 1978); however, more recent salutogenic interpretations of parent responses described this behavior as a demonstration of good parenting in the face of extraordinary circumstances (Young, Dixon-Woods, Findlay & Heney, 2001; Young, Dixon-Woods & Heney, 2002). However, for parents who no longer live together, legally

mandated time apart from the child created potential for additional heartache. The majority of these parents were able to work together to negotiate this emotional minefield. In one family, however, the father threatened court proceedings to negotiate time with his son. Clinicians must be alert to this possible response and assist parents to negotiate their needs in ways that benefit the child and entire family.

Stepparent Experiences

This is the first study to specifically ask questions regarding stepparent experiences in childhood chronic illness. In addition to the stepparent experiences reported by biological parents, stepparents' own reports added a new dimension to the phrase, "the forgotten parent" (May, 1996). Previously this term was reserved for fathers of ill children. In this study stepparents were not just forgotten, but at times, specifically excluded from treatment discussions. They had little direct access to the clinical team. Based on stepparent reports, these parents walked a delicate balance between supporting the ill child, supporting their partner, supporting their own biological children and negotiating uncharted waters in coping with their own childhood cancer experience. They faced role ambiguity, not knowing how or when to act. One stepmother said, "I know there were other stepfamilies up there and I think we are all kind of floundering because the rules are not defined."

Such uncertainty and confusion about one's place in a stepchild's life is not unique to the cancer experience. Stepfamily members often cannot agree on what role a stepparent should assume; stepparents are uncertain about their role in the family (Coleman, Ganong & Fine, 2000; Ganong & Coleman, 2004). Clinicians may not have an appreciation of the complexities within stepfamilies. Future research and care must move

toward an understanding of the entire family and the impact of childhood cancer on all family members. Future research must focus on studying the unique experiences of these “forgotten” family members in addition to carefully describing study samples to include an appreciation of the potential impact that complex families bring to the disease and treatment experience.

Marginalized Parents?

In some of these parents’ narratives there were hints of possible marginalization by the health care team. Hall, Stevens and Meleis (1994) originally defined marginalization for nursing knowledge development. This concept has been typically reserved to define vulnerable groups and health disparities; however, others can be pushed to the margin, depending on their circumstances. The original definition described a process that, at times, seemed similar to stepparents’ experiences and to the co-parent’s experience, especially when in a conflicted post-separation relationship. The process of being “peripheralized” (Hall et al.; p. 25) was seen when the health care team excluded stepparents from treatment decision making consults and conferences without assessing whether their presence was problematic to the other biological parents. The co-parent was excluded through simply not being present during clinic visits and thus not having access to information such as when the next appointments were scheduled or results of diagnostic procedures. When clinicians recognize a potentially conflicted post-separation or divorce parental relationship, they must reach out to the co-parent at treatment evaluation time points at a minimum. Reaching out can simply include anticipatory guidance about these possibilities, or be formalized as a care recommendation. While the co-parent does have a responsibility to seek out information regarding their ill child, they

may have expected communication to continue as it had during the initial treatment phases and be caught off guard when communication fell off after the crisis of diagnosis passed. Because research in this area is so scarce, we simply don't know. By studying potentially marginalized individuals, such as stepparents and co-parents, researchers may indeed discover new explanations from the margins that can further our understanding of the whole process (Hall, Stevens & Meleis).

Strengths of the Study

My study represents the first attempt to examine the experiences of members of diverse family structures in childhood cancer. Grounded theory was an appropriate research method to explore an uncharted psychosocial process. The method provided a venue to allow parents to describe their unique experiences. In using this method, I was able to formulate a conceptual understanding of the treatment decision making process used by parents who no longer live together. In addition to talking about how they made treatment decisions, including the tools they used to make decisions, parents also talked about the impact of the cancer diagnosis on their relationships with one another. The interview transcripts contain a rich dataset that will provide additional information about the unique experiences of these diverse families.

Previous treatment decision making research has been conducted primarily on Caucasian and more recently Hispanic families. I not only had a sample containing diverse family structures, I also had a culturally and economically diverse sample. Forty percent of the parents in my sample were African American. The families represented a range of single-parent, separated, divorced, cohabitating and remarried structures.

Limitations of the Study

The 15 parents who participated in this study recounted rich descriptions of their treatment decision making experiences and in doing so provided a deeper understanding of this process for parents who no longer live together. The findings are not generalizable to all separated families, but they are representative of these 15 parents' experiences in treatment decision making. I was not able to recruit any Hispanic families (who represent a major ethnic minority of children diagnosed with cancer in this country) to the study due to language barriers.

I was not able to recruit all parent members from all families, and thus had to rely upon one parent's account of another family member's experiences. In the case of post-separation families, the reporting family member was the person's former partner. Previous relationship conflict that contributed to the eventual relationship break up may have distorted the descriptions given by parents about their former partners and spouses.

Theoretical sampling is the preferred method for recruiting study participants in grounded theory studies. Due to participant availability, I was not able to theoretically sample parents from families based on the unfolding analysis. This may have limited my ability to formulate full dimensionality in all categories and uncover additional linkages between important constructs in the psychosocial process.

I purposefully chose to study only parents' treatment decision making and thus did not obtain information about the child's involvement in treatment decision making. An increasing number of researchers have studied the child's involvement in treatment decision making (Bluebond-Langner, Belasco, Goldman & Belasco, 2007; Hallstrom & Elander, 2004; Hinds et al., 2005; Hsiao, Evan & Zeltzer, 2007; Olechnowicz et al.,

2002; Zwaanswijk et al., 2007). How the child participates in the treatment decision making process in this family structure should be studied in the future.

Implications for Future Research

I obtained data from multiple parent viewpoints in four families but analyzed the data at an individual parent level. A secondary analysis of these data conducted from the family level unit of analysis is warranted. Looking at these data from a dyadic and/or triadic perspective could provide further explanations about the relational interactions involved in the treatment decision making process. I purposefully interviewed parents individually; however, adding conjoint interviews could uncover additional interaction factors. Alternatively, one could consider analyzing videotaped or audiotaped transcripts of the actual decision making encounter with the treatment team and comparing parents' involvement in the consent conferences with their reports of the process. Audiotaped consent conferences as a data collection method was used successfully by Kodish and his colleagues (1998).

The transcriptions contain other intriguing data that need to be examined in future analyses. Parents talked about how the diagnosis of childhood cancer impacted relationships with their current and former partners. These relationship findings were background to the treatment decision making process but warrant close examination in the future. I plan to analyze these data, supplementing with additional interviews as indicated.

Parents also discussed the methods or tools that they used to make treatment decisions that reflect and support my previous collaborative research. I plan to examine these findings with my collaborative research partners. We may decide to incorporate my

findings into our emerging model of parent treatment decision making (Stewart, Pyke-Grimm & Kelly, 2007), or consider other analyses of our two datasets. Additionally, the large number of qualitative treatment decision making studies conducted with parents of children with cancer justifies conducting a metasynthesis to provide a comprehensive picture of the state of the knowledge in this area. A metasynthesis would be an intriguing collaborative project that could move the science forward, preparing the way for future tests of clinical interventions designed to facilitate the parent treatment decision making process.

We still do not know whether or how the parent treatment decision making process changes over time. Researchers have yet to study this important aspect of parental treatment decision making. In my study parents described differences in co-parental decision making shortly after diagnosis as compared to later in treatment. Researchers need to examine whether other differences in parents who are in married or post-separation relationships exist. Therefore longitudinal assessment of parent involvement in treatment decision making across the disease and treatment continuum is needed to confirm and describe more fully these differences.

To my knowledge, this is the first study to explicitly examine the unique experiences of stepparents in childhood chronic illness. In fact, one stepfather remarked that my interview with him was the first time anyone had ever asked his opinion since his stepson's diagnosis. The three stepparents that I interviewed provided a fascinating description of coping with childhood cancer that has here-to-fore been absent. The stepfamily is affected by the childhood cancer experience but they are separated from the

typical supports made available to the biological family members. Their experiences merit further study and understanding.

It is imperative that researchers carefully categorize whether “married” parents in research are from first or subsequent marriages. Research findings could differ significantly if analyzed separately. On the other hand, it is also important to catalog single parents from the perspective of whether they are the sole parent or whether they have not yet re-married but have strong support from the co-parent and/or stepparents. In this study, the experiences of single mothers, who had no additional support, differed significantly from single mothers, who had an actively involved co-parent who was re-married.

This research should also be replicated in other disease contexts. Treatment decision making in the intensive care unit carries life threatening impact. Do parents who no longer live together interact differently in other disease circumstances? The potential impact of co-parental stepping back or stepping away from decision making as treatment continues could have a greater impact on adherence to treatment and disease management in other chronic illness such as diabetes or asthma.

Clinical Implications

A number of important practice recommendations come from the findings. Table 4.1 summarizes questions to consider when assessing inter-parental decision making needs in post-separation families. At diagnosis, the clinician must assess the nature of all family relationships, including the stage of separation or divorce. Constructing a genogram is an efficient method to catalog the complexities of and understand the relationships in these families.

If there are obvious conflicted relationships, clinicians must create emotionally safe spaces for the biological parents to interact during children's hospitalizations and treatment decision making encounters. However, a global assumption that the stepparent is never welcomed cannot be made. Families varied in the reported stress to a biological parent caused by a stepparent's presence. Therefore, assessment of the biological parents' preferences should be undertaken at diagnosis and then honored throughout treatment. When families are cooperative it is not necessarily problematic to have all parties at the table during new diagnosis and consent conferences. When families are conflicted, clinicians may need to conduct separate conferences. To assume that a stepparent is never welcome could place undue restriction on a stepparent's important role in the ill child's life. Additionally, this universal practice would remove a vital support to one of the parents involved. Stepparents understand the primacy of the biological parent's involvement. The stepparent's primary motivation is to support their partner/spouse and the ill child.

Biological parent(s) may or may not adequately relay information to other parents including stepparents. Stepparents, especially stepmothers, may be involved in caring for the child during scheduled visitations. Stepparents must receive education firsthand whenever possible. If there are specific home care needs, procedures must be taught to all family members. Assess how often the child is in both households and teach accordingly.

After the diagnosis crisis abates, the co-parent's involvement in the child's care may lessen. The degree of involvement may reflect the degree to which the co-parent was involved in the child's life before diagnosis. It is important to communicate directly to both parents as the custodial parent may withhold information from the co-parent.

Electronic mail sent simultaneously to both biological parents is a potentially useful communication method. It was preferred by parents who no longer live together, especially if they have a conflicted relationship.

Single parents described their decision making experiences as particularly stressful. While biological parents reported feeling alone with their decisions, their experience was not the same as for parents who had to decide alone. Single parents experienced a greater burden and talked about wishing there was another person, who knew the child as they did, to share this burden. These parents will likely require additional support and counseling to help them through the decision making process.

Conclusions

Stepping up, stepping back, being pushed, and stepping away represents the first attempt to describe the complexities involved in making treatment decisions for children with cancer by parents who not longer live together. Parents described a process that reflected their parenting practices before the diagnosis of childhood cancer and that evolved over the course of the child's treatment trajectory. As treatment decision making occurs in the context of coping with a cancer diagnosis, this study also provides a glimpse into complex family coping after diagnosis of cancer in the child.

Previous research in families and chronic illness focused on descriptive and explanatory studies that rarely included diverse family structures (Knafl & Gilliss, 2002). Or if they did, the researchers dichotomized parent samples into married and single. These category labels would not identify the presence of stepfamilies or supportive post-separation family networks that surrounded a single mother. Therefore post-separation families' responses to childhood cancer are largely unknown.

Despite the expansion of family nursing research (Gilliss & Knafl, 1999; Knafl & Gilliss, 2002), scholars have yet to address the lack of knowledge regarding the impact of childhood chronic illness on diverse family structures. Since about one-third of the children in the United States will live in a remarried or cohabitating stepfamily household before they reach 18 years of age (Bumpass, Raley & Sweet, 1995), it is imperative that family nursing researchers begin to address this gap. This study provides an initial step in this process.

The majority of the parents who participated in my study described a largely adaptive process of making treatment decisions for their children with cancer. They poignantly described the additional burdens and challenges they faced because of their specific family circumstances and made excellent nursing care recommendations. Their voices and stories will better prepare nurses to care for similar families in the future.

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Table 1.1: Parental treatment decision making research methods as conducted by different disciplines

Discipline	RN	MD	Psyc.	Soc.	Ethics	Nutr.	MultiD
Research method							
Qualitative	32	2	3	2	2	1	8
Quantitative	9	6	1				10
Mixed methods	4	2	1				4
Longitudinal	3						
Prospective	10	4		2	2		6
Retrospective	26	3	5			1	12
Secondary analysis	4						1

N=86 studies reviewed

Table 3.1: Divorce/separation circumstances and custody arrangements

Family ID	Divorce/separation circumstances	Time since divorce/separation	Current marital status: Mother/Father	Custody arrangements
A	Lived together-now separated	10 years	M- Re-partnered, living together F-Single	Maternal primary custody during diagnosis Joint currently Mutually agreed upon
B	Never married	N/A	M-Single, has boyfriend F-Living with another person	Maternal full custody Father never established legal rights
C	Lived together-now separated	2 years	M-Single F-Remarried	Maternal primary custody Recent legal proceedings to establish custody arrangements
D	Never married	15 years	M-Single F-Remarried, currently separated	Maternal full custody prior to diagnosis with limited visitation by father. Father legally obtained decision making authority shortly after diagnosis. Child currently lives with father.
E	Married-divorce pending	1 year	M-Single F-Re-partnered, living together	Maternal primary custody Legally mandated with separation agreement
F	Married-now separated	8 months	M-Single F-Re-partnered, living together	Maternal primary custody Legal proceedings on hold due to financial Mutually agreed upon
G	Never married	N/A	M-Single, has boyfriend F-Single	Maternal full custody Father pursuing legal rights before diagnosis
H	Divorced	5 years	M-Remarried F-Single	Joint custody Legally determined with divorce decree

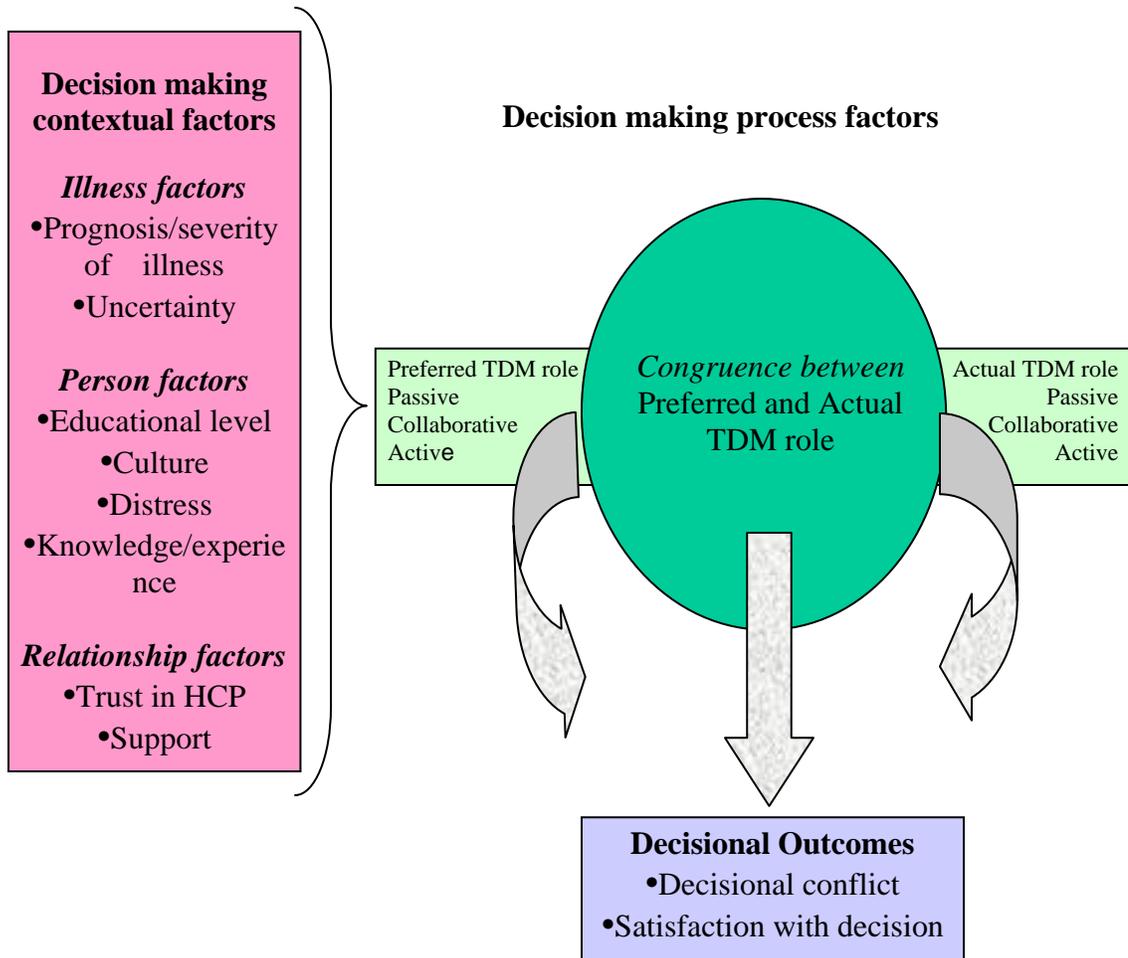
Table 3.2: Child diagnoses, family pseudonyms and associated treatment decisions

Diagnosis (Family letter)	Decisional context	Decision timeframe	Pseudonyms
Acute lymphoblastic leukemia (A)	Hematopoietic stem cell transplant	After relapse	Mother: Debbie Father: Michael Stepfather: Donald Child: Richard
Neuroblastoma (B)	Autologous stem cell transplant	During initial treatment	Mother: Donna Father: Andy Boyfriend: Randy Child: Tricia
Brain tumor (C)	Radiation therapy (whether or not to use)	During initial treatment	Mother: Mary Father: Max Stepmother: Darla Child: Karl
Hodgkins lymphoma (D)	Emergency surgery	At diagnosis	Mother: Kathy Father: Tyler Stepmother: Susan Child: Sharon
Acute lymphoblastic leukemia (E)	Clinical trial	At diagnosis	Mother: Marcia Father: Alan Stepmother: Alice Child: Maggie
Acute lymphoblastic leukemia (F)	Central venous line placement and Clinical trial	At diagnosis	Mother: Sally Father: Scott Stepmother: Lily Child: Aaron
Brain tumor (G)	Radiation therapy (type)	During initial treatment	Mother: Kate Father: Wilson Boyfriend: Buster Child: Kayla
Hodgkins lymphoma (H)	Clinical trial	At diagnosis	Mother: Carmen Father: Bart Stepfather: Bob Child: Connor

Table 4.1 Treatment decision making assessment of parents who no longer live together

Assessment parameter	Clinical implications
Length of time since separation* (Amato, 2000; Whiteside, 1998)	< 2 years since separation <ul style="list-style-type: none"> • Greater risk for increased conflict > 2 years since separation: <ul style="list-style-type: none"> • Patterns of communication well established • More stabilized and predictable family relations
Patterns of current family decision making (e.g. How do you make decisions about the child's school activities, discipline, sports?)#	Predictive of treatment decision making patterns
Construct genogram <ul style="list-style-type: none"> • Place child with cancer in the middle and work outwards# 	Efficient way to capture structure complexities in a post-divorce family
Obtain specific details about the divorce and child custody arrangements# <ul style="list-style-type: none"> • Copy of divorce decree if possible. • Non-residential parent involvement • Stepparent involvement • Time spent in visitation 	Will provide contextual understanding of parent interactions and possible conflicts. <ul style="list-style-type: none"> • Need for duplicate teaching
Biological parents preferences for stepparent involvement in treatment decision making discussions#	<ul style="list-style-type: none"> • Both biological parents must be comfortable with stepparent involvement. • May need duplicate discussions with stepparents.
Preferred method of communication amongst parents#	<ul style="list-style-type: none"> • Will facilitate continued interaction with all parents. • Make use of E-mail or conference calls to facilitate other parent involvement
*Evidence from the literature	#Evidence from study findings

Figure 1.1: Working conceptual model of parental treatment decision making in childhood cancer



Appendix 2.1: Human subjects protections description and supporting documents

Protection of Human Subjects

This study was submitted to the University of Missouri Health Sciences Institutional Review Board, who maintained primary IRB oversight for this project (See attached IRB approval letter and renewals). Before initiating any study procedures at the study site, I obtained approval from the local institutional IRB in collaboration with site staff.

Each parent and family member's name was changed to the first initial of the name in the transcripts upon receipt from the typist. These transcriptions were then imported into the data analysis software. In the presentation of findings each parent participant was given a pseudonym to help protect subject anonymity during presentation of the findings but to help the reader to identify with the participant on a more personal level. A master list linking parent subject to pseudonym was kept in a locked cabinet throughout the study. After completion of the analysis and publication of the findings, this list will be destroyed. Access to the data files employed password protection to provide additional security. Files were backed up to an external hard drive available only to the PI.

Potential Risks to Subjects and Protection against Risks

It is possible that participating in an interview such as the one proposed could bring up distressing feelings for parents or other family members. Therefore, at each site a psychologist or social worker was identified to refer parents who exhibit distress during or after study participation. This person was acquainted with the proposed study

procedures but was not otherwise be involved in the conduct of this study. There were no instances of needing to refer a parent participant to the psychologist or social worker.

Risk-Benefit Ratio

Few data exist to guide clinician interventions in this area. Information obtained in this study will guide future research designed to evaluate TDM procedures that will most effectively reduce the distress experienced by parents during TDM for their child's illness.

Recruitment and Consent Procedures

The principal investigator was trained in the procedures for ethical subject recruitment before the study opened and completed initial and ongoing IRB compliance testing at the University of Missouri and the study site. A description of the study was given or read to potential parent subjects who then indicated their willingness to be contacted by the PI for inclusion into the study. The PI then contacted potential subjects, described the study procedures and obtained informed consent of the parent subjects willing to participate in the study. In addition, procedures to assure protection of protected health information were followed as outlined in HIPAA (HIPAA authorization embedded in the consent form).

Inclusion of Women Children and Minorities

There were no exclusions of parent participation in this study on the basis of gender or ethnic background. There was a requirement that parents were able to speak English as the study investigator was only fluent in this language. Unfortunately, I missed the opportunity of recruiting two Hispanic families due to this language barrier. Future studies will be designed to ensure participation of all eligible parent participants.

Recruitment of both fathers and mothers was prioritized. As mothers historically predominate as research participants in studies such as this, the proposed study fully represented women's experience in this area.

This study was designed to examine parents' responses to treatment decision making and therefore children were not eligible as study participants. This study represented beginning research in this area and focused on parent experiences initially as they are legally responsible for treatment decision making in their children. Knowledge of the child's role in treatment decision making will be an important focus of future research once the parents' roles are explicated.

IRB approval documents for MU Health Sciences IRB and Children's National Medical Center IRB follow

HS IRB Behavioral Sciences Application Signature Page

Project Number: 1058860

Review Number: 53832

Project Title: Parental Treatment Decision Making for Children with Serious Illness by Parents Who No Longer Live Together

Principal Investigator: Katherine P Kelly

CERTIFICATION

The undersigned certifies that the information provided in this document is complete and accurate. The undersigned assures that modifications to the originally approved project will not take place without prior review and approval by HS IRB, and that all activities have been and will continue to be performed in accordance with federal, state, local and University of Missouri - Columbia policies and regulations.

Katherine P. Kelly 3-3-06
 Signature of Principal Investigator Date

same _____
 Document Prepared By Date

FOR HS IRB USE ONLY	
APPROVED/ACKNOWLEDGED	<u>[Signature]</u>
HS IRB Authorized Representative	
DATE OF SIGNATURE:	<u>3/15/06</u>
Full Board:	Expedited: <u>Exempt</u>
APPROVAL/ACKNOWLEDGED DATE:	<u>03/15/06</u>
APPROVAL EXPIRATION DATE:	<u>03/15/07</u>

UNDR 45CFR 46.101(b)(4)

Please send signature page and supporting materials to:

Health Sciences IRB
125 Folk hall; Dc074.00
One Hospital Drive
Columbia, MO 65212



https://irb.missouri.edu/eirb/forms.php?action=Print_Signature_Page&proj_num=1058860... 3/3/2006

HS Exempt Annual Update Signature Page

Project Number: 1058860

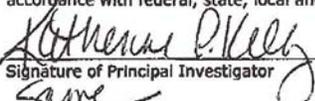
Review Number: 60963

Project Title: Parental Treatment Decision Making for Children with Serious Illness by Parents Who No Longer Live Together

Principal Investigator: Katherine P Kelly

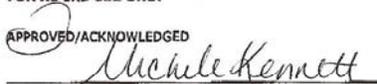
CERTIFICATION

The undersigned certifies that the information provided in this document is complete and accurate. The undersigned assures that modifications to the originally approved project will not take place without prior review and approval by HS IRB, and that all activities have been and will continue to be performed in accordance with federal, state, local and University of Missouri - Columbia policies and regulations.

	<u>4/11/07</u>
Signature of Principal Investigator	Date
<u>same</u>	
Document Prepared By	Date

FOR HS IRB USE ONLY

APPROVED/ACKNOWLEDGED


HS IRB Authorized Representative

DATE OF SIGNATURE: 4.16.2007

Full Board: Expedited: Exempt:

APPROVAL/ACKNOWLEDGED DATE: 4.16.2007

APPROVAL EXPIRATION DATE: 3.15.2008

Please send signature page and supporting materials to:

Health Sciences IRB
125 Folk hall; Dc074.00
One Hospital Drive
Columbia, MO 65212

https://irb.missouri.edu/irb/forms.php?action=Print_Signature_Page&proj_num=1058860... 4/11/2007

HS Exempt Annual Update Signature Page

Project Number: 1058860

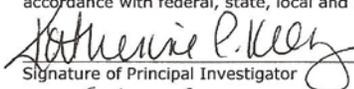
Review Number: 67562

Project Title: Parental Treatment Decision Making for Children with Serious Illness by Parents Who No Longer Live Together

Principal Investigator: Katherine P Kelly

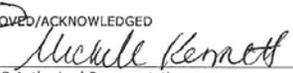
CERTIFICATION

The undersigned certifies that the information provided in this document is complete and accurate. The undersigned assures that modifications to the originally approved project will not take place without prior review and approval by HS IRB, and that all activities have been and will continue to be performed in accordance with federal, state, local and University of Missouri - Columbia policies and regulations.

	2-4-08
Signature of Principal Investigator	Date
same	2-4-08
Document Prepared By	Date

FOR HS IRB USE ONLY

APPROVED/ACKNOWLEDGED



HS IRB Authorized Representative

DATE OF SIGNATURE: 2-12-2008

Full Board: Expedited: Exempt:

APPROVAL/ACKNOWLEDGED DATE: 2-12-2008

APPROVAL EXPIRATION DATE: 3-15-2009



Please send signature page and supporting materials to:

Health Sciences IRB
125 Folk hall; Dc074.00
One Hospital Drive
Columbia, MO 65212

https://irb.missouri.edu/eirb/forms.php?action=Print_Signature_Page&proj_num=1058860... 2/4/2008



111 Michigan Avenue, N.W.
Washington, DC 20010-2970
(202) 884-5000

INSTITUTIONAL REVIEW BOARD (FWA00004487)
REPORT OF ACTION
PROTOCOL APPROVAL LETTER
November 2, 2006

Katherine P. Kelly, RN, MN, PhD (cand)
Principal Investigator
Patient Services/Nursing/Center for Cancer and Blood Disorders

Title: Treatment Decision Making for Children With Serious Illnesses by Parents Who No Longer Live Together
IRB PROTOCOL #: 3929

Dear Ms. Kelly:

The IRB has reviewed and approved the protocol referenced above for 12 months. The IRB determined that the study meets the criteria for expedited review under category, 45 CFR 46.110 (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. This IRB approval will expire on **November 1, 2007**.

When enrolling participants, all Informed Consent documents should be stamped "IRB Approved with the approval dates." Please convey the IRB's decision to co-investigators, if applicable.

Please note that it is the Investigator's responsibility to ensure that the Continuing Review Report is submitted to the IRB in a timely fashion.

Federal Human Subjects Regulations require that the IRB review all active protocols at intervals appropriate to the degree of risk, but not less frequently than once per year. When continuing review of a research protocol does not occur prior to the end of the approval period, IRB approval expires automatically. This protocol will expire on November 1, 2007. There is no grace period extending the conduct of the research beyond the expiration date of IRB approval.

If the IRB approval expires, investigators must cease all research activities including:

1. Recruitment;
2. Screening and enrollment;
3. Intervention and interaction;
4. Follow-up; and data analysis.

New Study/Initial Approval (expedited)



111 Michigan Avenue, N.W.
Washington, DC 20010-2970
(202) 884-5000

The PI is required to inform the IRB immediately of any circumstances or new information which may potentially change the risk/benefit ratio. Please refer to the IRB Manual of Policies & Procedures (December 2001) for information concerning Modification Requests, Adverse Event Reports, and Continuing Review Reports. For further information, please call the Office for the Protection of Human Subjects, ext. 8470.

APPROVAL PERIOD: November 2, 2006 to November 1, 2007
Next Progress Report Due: August 1, 2007

RISK CATEGORY: Not More than Minimal Risk

Protocol Expires: November 1, 2007

IRB CHAIRMAN/VICE CHAIRMAN:

A handwritten signature in black ink, appearing to read "John L. Sever", is written over a horizontal line. Below the line, the name "John L. Sever, MD, PhD" is printed in a black, sans-serif font.

New Study/Initial Approval (expedited)



INSTITUTIONAL REVIEW BOARD (FWA00004487)
REPORT OF ACTION
PROTOCOL CONTINUATION LETTER
October 11, 2007

111 Michigan Avenue, N.W.
Washington, DC 20010-2970
(202) 884-5000

Katherine P. Kelly, RN, MN
Principal Investigator
Psychiatry and Behavioral Services

IRB #: 3929

Title: Treatment Decision Making for Children with Serious Illnesses by Parents Who No Longer Live Together

Dear Ms. Kelly:

The IRB has reviewed the Continuing Review Report submitted for the protocol referenced above and determined that the study meets the criteria for expedited review under category 45 CFR 46.110, (a) (7) *Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.* The study is re-approved for continuation until the expiration date. This IRB re-approval will expire on **October 7, 2008.**

When enrolling participants, all Informed Consent documents should be stamped "IRB Approved with the approval dates." Please convey the IRB's decision to co-investigators, if applicable.

Please note that it is the Investigator's responsibility to ensure that the Continuing Review Report is submitted to the IRB in a timely fashion.

Federal Human Subjects Regulations require that the IRB review all active protocols at intervals appropriate to the degree of risk, *but not less frequently than once per year.* When continuing review of a research protocol does not occur prior to the end of the approval period, IRB approval expires automatically. **This protocol will expire on October 7, 2008.** There is no grace period extending the conduct of the research beyond the expiration date of IRB approval.

If the IRB approval expires, investigators must cease all research activities including:

1. Recruitment;
2. Screening and enrollment;
3. Intervention and interaction;
4. Follow-up; and data analysis.

The PI is required to inform the IRB immediately of any circumstances or new information which may potentially change the risk/benefit ratio. Please refer to the IRB Manual of Policies & Procedures (December 2001) for information concerning Modification Requests, Adverse Event Reports, and Continuing Review Reports. For further information, please call the Office for the Protection of Human Subjects, 301-565-8488.

Approval Period: October 8, 2007 to October 7, 2008

Risk Category: Not More than Minimal Risk

Next Progress Report Due: July 1, 2008

Protocol Expires: October 7, 2008

Sincerely,

Naynesh Kamani, M.D.
IRB Chair



111 Michigan Avenue, N.W.
Washington, DC 20010-2970
(202) 884-5000

INSTITUTIONAL REVIEW BOARD (FWA 00004487)
MODIFICATION APPROVAL LETTER
October 31, 2007

Katherine P. Kelly, RN, MN
Principal Investigator
Psychiatry and Behavioral Services

IRB #: 3929

Title: Treatment Decision Making for Children with Serious Illnesses by Parents Who No Longer Live Together

Risk Category: Not More than Minimal Risk

Dear Ms. Kelly:

The MINOR modification # 1 was reviewed and approved on October 7, 2007. It is noted that the purpose of this modification is to make:

- (a) Changes in the enrollment time frame to improve participant accrual.
- (b) Administrative changes to update CNMC phone numbers, PI contact information, staff titles and to correct minor typographical errors.
- (c) Changes to extend study completion date.

The PI is required to inform the IRB immediately of any circumstances or new information which may potentially change the risk/benefit ratio. Please refer to the IRB Manual of Policies & Procedures (December 2001) for information concerning Modification Requests, Adverse Event Reports, and Continuing Review Reports. For further information, please call the Office for the Protection of Human Subjects, 301-565-8470.

APPROVED BY:

A handwritten signature in black ink that reads "N. Kamani".

Naynesh Kamani, MD
IRB Chair

Appendix 2.2: Initial interview guide

I'm interested in learning what it is like for parents to make major treatment decisions for their ill children. In particular I'm wanting to understand what it is like for co-parents (parents who were never married, separated or divorced) to make decisions for their ill child.

As we talk today I'd like for you to focus on the _____ decision you made for your child this past year.

Family Genogram and Chronology of Events surrounding the separation/divorce

The following questions are asked for the purposes of drawing a genogram and charting the sequence of family events. The genogram and events will be drawn and displayed on an easel pad to refer to as necessary during the interview.

Family Facts and Family Structure

I'd like to start by asking you to tell me about your family. I'd like to draw a picture to help me understand who is who in your family. (the target child will be designated by a capital C on this schedule)

Participant and Former Spouse Relationship:

How old are you?

How many children do you have?

What are the sexes and ages of your children?

How old is the Child who has _____?

How old is the Child's (use the Child's name) other parent?

What is your current marital status?

What is the marital status of the Child's other parent?

Tell me about your separation (and divorce, if applicable) from the Child's other parent –

When did you separate? [Get details about the separation process]

Who initiated the separation?

How long was the separation before the divorce?

When did you divorce [if applicable]?

What are the legal and physical custody arrangements for your children?

[Probe for information regarding how often and when children are in each parent's household]

Has this changed since the separation/divorce?

If so, please describe these changes

What have been your children's reactions to your separation and divorce?

Current Relationships and Children

If remarried or cohabiting, ask:

When did you move in with your current partner?
[If applicable] When did you get remarried?
How old is your spouse/partner?
What are the ages and sexes of your spouse/partner's children (if any)?
Where do your s/p's children reside most of the time?
[probe further to find out about living arrangements of children]
What have been your children's reactions to your remarriage/cohabitation?
Do you and your partner/spouse have children together?
If yes: what are the ages and sexes of those children?

Note: It is possible that there may be other relationships that occurred between the separation from the Child's other parent and the current relationship status of the person. This will need to be asked about as part of the genogram.

Post-divorce Parenting

Current Custody Arrangement

Can you describe how you and (former spouse) decided on your current custody arrangement (or parenting plan)?
Can you describe the frequency and types of contact your children have with (former spouse)?
What contact do you have with (former spouse) as a consequence of your custody arrangement?
Can you describe what topics you typically discuss with your former spouse when you have contact?
How important is it for you that your children stay in contact with (former spouse)?
Why?
What do you do to help your children have contact with (former spouse)?

Satisfaction

Is the current arrangement working for you?
If yes: How so?
If no: What would you change?
Are you satisfied with your custody arrangement (or parenting plan)? Is (former spouse) satisfied?
Why/why not?

Is there anything else you would like to tell me about your family?

Thank you this helps me to understand your family relationships.

Child Diagnosis History

Now please tell me about CHILD's diagnosis.
When was your child diagnosed?
How did you learn about CHILD's disease.
In general, how would you rate your child's health right now?
Did your separation/divorce precede or come after CHILD's diagnosis?

How did the diagnosis affect your relationship with CHILD's father/mother?

Thank you. That helps me to understand what you have been through.

Treatment Decision Making

Now let's talk about the recent decision _____.

Please tell me everything you can remember about what it was like for you making this decision.

Probes:

What kinds of things did you think about leading up to the decision?

What kinds of things were you feeling before the decision was made?

How was CHILD's other parent involved in this decision? What was this like for you?

Sometimes parents talk with other people before making a decision.

Who did you talk with about the decision?

What kinds of things did you talk about with your (if applicable) new spouse?

Other family members? Friends?

What helped you the most to make this decision?

Do you think back on the decision?

Do you have any advice for other parents in your situation?

Can you tell me how this DECISION is similar or different to how you've make other decisions for your child, e.g. school, sports, discipline? Probe for how co-parents collaborated or not in decision making.

Is there anything else you'd like to tell me about your experience making treatment decisions for your child?

Additional Demographic Information

What is your ethnicity?

Is anyone on the diagram of a different ethnicity from you?

If yes: What is their ethnicity?

What is your occupation and highest level of education?

What is (former spouse's) occupation and highest level of education?

What is (current partner's) occupation and highest level of education?

Follow-up

After I have a chance to study yours and other parents' responses, would you be willing to let me contact you for follow-up questions or another interview in the future?

Appendix 2.3: Parent treatment decision making study recruitment letter

Katherine Patterson Kelly RN PhD(c)

Doctoral Nursing Student
University of Missouri Sinclair School of Nursing
Columbia, MO 65212

October 10, 2006

Dear parent,

My name is Kathy Patterson Kelly. I am a doctoral student in nursing at the University of Missouri-Columbia. I am studying what it is like for parents who have never been married or have been divorced or separated to make important treatment decisions for their child with a serious illness. You are receiving this letter because you have made such a decision for your child in the past.

If you agree to be in the research study, you will meet with me for about 60-90 minutes to discuss your family, your child's disease, the circumstances of your divorce or separation, your current relationships and living arrangements, and the major treatment decision you made this past year. I will ask you about your thoughts, feelings and opinions about your family and making treatment decisions for your child. You do not have to answer any questions that make you very uncomfortable.

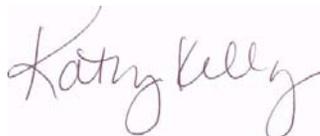
If you are interested in participating in this study, please provide your name and telephone number below and I will contact you in the next few days to arrange for an interview.

Name _____ Phone number _____

Your participation in this research study is completely voluntary and will not affect the care of your child in any way. If you decide that you do not wish to participate in this study after we talk, I will destroy your name and phone number. You will be given a copy of this letter after providing the information above.

I hope you will consider being in this research study. Learning directly from parents is an important way to understand the experiences so that we may help other parents. If you have any questions about this study, please feel free to contact me at the telephone number listed below. I appreciate you thinking about taking part in this study.

With warm regards,



Kathy Patterson Kelly RN, MN, PhD(cand)
Doctoral Nursing Student
University of Missouri Sinclair School of Nursing
Columbia, MO

Appendix 2.4: CNMC Parent Informed Consent Form



Consent Form Revised January 12, 2005

CHILDREN'S NATIONAL MEDICAL CENTER

Department of Nursing- Hematology Oncology Unit
111 Michigan Avenue, NW
Washington, DC 20010
(202) 476-5000

**PARENT CONSENT TO PARTICIPATE
IN A CLINICAL RESEARCH STUDY AND AUTHORIZATION TO
USE PROTECTED HEALTH INFORMATION**

TITLE OF STUDY: Treatment Decision Making for Children with Serious Illnesses by Parents Who No Longer Live Together

PRINCIPAL INVESTIGATOR: Katherine P. Kelly RN, MN, PhD (cand), Professional Practice Specialist, Department of Nursing – Center for Cancer and Blood Disorders

"You" refers to "You" or "Your Child" throughout this document

INTRODUCTION: We would like to invite you to be part of a research study at Children's National Medical Center. Before you decide if you would like to participate, we want you to know why we are doing the study. We also want you to know about any risks (anything unexpected that might happen) and what you will be expected to do in the study.

This form gives you information about the study. Your doctor or nurse will talk to you about the study and answer any questions you have. We encourage you to discuss this study with your family and anyone else you trust before making your decision. We will ask you to sign this form to show that you understand the study. We will give you a copy of this form to keep. It is important that you know:

- You do not have to join the study;
- You may change your mind and stop being in the study any time you want.
- If we make any important change to the study we will tell you about it and make sure you still want to be in the study.

IRB APPROVAL DATE:



IRB EXPIRATION DATE:



IRB Protocol No.: {3929}
Date: {9-26-07}
Page 1 of 9
Reviewed by IRB _____



A. PURPOSE OF STUDY

The purpose of this study is to learn what it is like for parents who do not live together (unmarried, separated, divorced) to make treatment decisions for their children with serious illnesses. We want to learn more about the kinds of things that parents think about when they are making decisions, any additional challenges parents who do not live together face in this process, and how making these decisions affects parents and families.

This research is being done because we need to learn more from parents, especially those who no longer live together about what it is like to make difficult treatment decisions for their children. Then we will be able to develop ways to help support parents in the future to make these difficult treatment decisions.

We are asking you to be in this study because you have made a major medical decision in the past for your child with serious illness and you live separately from your child's other parent.

Approximately 40 families of children with serious illness and their health care providers from Children's National Medical Center will take part in this study.

B. PROCEDURE

If you agree to be in this study, you will meet with the researcher, Kathy Patterson Kelly, for about 60-90 minutes in a private location at the hospital, by phone, or in any other location of your choosing. Ms. Kelly will interview you about:

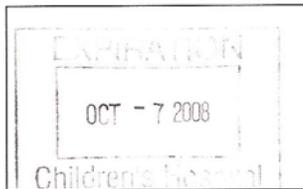
- your family and the circumstances of your separation or divorce (e.g. former spouse relationship, custody arrangements)
- your current relationships, living arrangements and co-parenting arrangements (e.g. if remarried, when this happened, stepchildren involved, your children's reactions, and satisfaction with current custody arrangements)
- your child's disease history (e.g. when child diagnosed, child's current health)
- the major treatment decision you made before (e.g. what it was like for you to make this decision, how your child's other parent was involved).

During the interview, the researcher will make a diagram of your family (genogram) to help understand who your family members are and their relationships. The researcher

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will ask you about your thoughts, feelings, and opinions about your family and making treatment decisions for your child. You may be asked to talk with the researcher a second time if new questions come up during the study. You may be asked to contact your child's other parent, stepparents, other family members, or your child's health care provider so Ms. Kelly may ask them to participate in this study as well. They do not have to agree to participate in order for you to be in this study.

Your interview with the researcher will be audio-taped and later transcribed word-for-word. Any identifying information, such as your name or that of your child, will be removed from the written transcript before it is shared with the other researchers working on this project. The audiotapes will be stored in Katherine Kelly's office in a locked cabinet during the study and erased at the completion of the study. No information from your interview will be shared with other family members.

The researcher may want to talk with your child's health care providers about their involvement in the treatment decision making for your child. When you agree to participate in this study, you also give permission for your child's health care providers to talk to Ms. Kelly about their involvement in the treatment decision making for your child.

Optional future research:

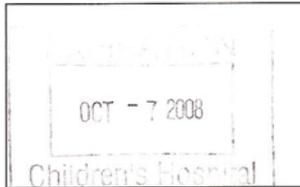
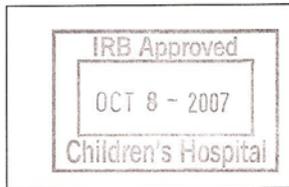
This study has been designed to answer the research question for this study. The researcher, Katherine Kelly or her colleagues, may find new questions as a result of this study that your data might help answer. This would be done in new research studies by Katherine Kelly or her colleagues. If you agree, Katherine Kelly or her colleagues might use your information from this study in future research studies. Nothing identifying you will be kept. Your participation in this optional future research is completely voluntary. You do not have to agree to the optional future research in order to be in this study. You will be given a choice to take part in this optional future research at the end of this consent form.

C. POTENTIAL RISKS/DISCOMFORT

The risks of being in this study may include feelings of sadness, anger, or loss associated with some of the experiences that you may be asked to describe or discuss. If talking, or thinking about your experiences makes you unusually anxious or upset, you

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may be referred to your team's social worker or psychologist for counseling if you wish. You can also stop the interview at any time or not answer a question that makes you uncomfortable. There is a small risk of breach of confidentiality in spite of our best efforts to keep your information private.

If you have any problems or changes in the way you feel, you should tell the investigator or other study personnel as soon as possible.

There may be risks we don't know about right now. We will tell you about any new information that might change your decision to stay in the study.

D. VOLUNTARY PARTICIPATION

Being in a research study is voluntary. You do not have to be in a study to receive care for your child's medical condition. If you choose not to participate, there will be no penalty or loss of benefits to which you or your child are otherwise entitled. You are free to decline to answer any questions in the interview. You have the right to request that the tape recorder be turned off at any point during the interview. You have the right to stop the interview at any time.

If you do not wish to complete the interview you will be asked to use the data already collected, if you do not wish to do this let the investigator know and she will destroy the audiotape and paper records with the exception of this form. If you later withdraw from the study, information and audio-tapes collected, recorded and analyzed during the study before you withdraw will be retained with your identifying information removed. The information that the researcher learned from you before you withdraw from the study will be included in the analysis of the data up to the point that you withdraw from the study.

E. POTENTIAL BENEFITS

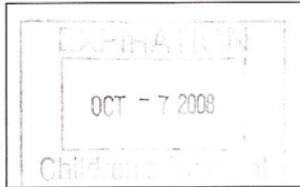
You may not benefit directly by participating. Sometimes people benefit from talking about their experiences. By being in this study, you may help others who deal with treatment decision making for children with serious illnesses in the future.

F. ALTERNATIVES TO PARTICIPATION

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Instead of being in this study, you may choose not to participate.

G. QUESTIONS – WHO TO CALL

We want you to ask questions about any part of this study or consent form either now or at any time in the future. If you have any questions about this study, call the Principal Investigator, Kathy Patterson Kelly at 202-476-2689. If you believe you have been injured as a result of being in this study, you should call the Principal Investigator, Kathy Patterson Kelly, at 202-476-2689. If you have any questions or concerns about your rights in this research study at any time, please call Children's National Medical Center's Manager of Patient Relations, the Chief Academic Officer, or the Chair of the Institutional Review Board of the Children's National Medical Center. All parties may be reached at (202) 476-5000.

H. CONFIDENTIALITY

We will keep the records of this study confidential. Only the people working on the study will know your name. The federal government can review the study records to make sure we are following the law and protecting the parents in the study.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY

In 1996 the government passed a law known as The Health Insurance Portability and Accountability Act (HIPAA). This privacy law protects your individually identifiable health information (Protected Health Information or PHI). The privacy law requires you to sign an agreement so researchers can use or share your PHI for research purposes. This describes to you how information about you may be used or shared if you are in a research study. It is important that you read this carefully and ask a member of the research team to explain anything you do not understand.

I authorize Kathy Patterson Kelly and her research staff to create, access, use, and disclose my PHI for the purposes described below.

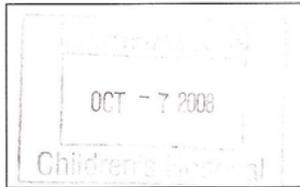
Protected Health Information that may be used and shared includes:

- Information that identifies you such as name, address, telephone number, date of birth, Social Security number, and other details about you
- Information that relates to your health or medical condition from your medical records

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- Information obtained from the study procedures outlined in this consent form, for example: things done to see if you can join the study such as physical exams, blood and urine tests, x-rays and other tests, and any other medical information we learn from you about your health history and family history
- Laboratory results obtained on specimens collected from you (blood, urine, tissue)
- Questionnaires or surveys you complete
- Interviews conducted with you by members of the research team
- Audio/ video recordings
- Other *[please specify]:

The Researchers may use and share my Protected Health Information with:

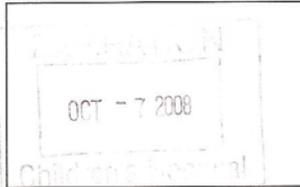
- ◆ The Principal Investigator, other Investigators, Study Coordinators, and all administrative staff in charge of doing work for the study;
- ◆ Government agencies that have the right to see or review your PHI, including but not limited to the Office of Human Research Protections and the Food and Drug Administration;
- ◆ Children's National Medical Center Institutional Review Board;
- ◆ Audit Committee of the Children's National Medical Center Institutional Review Board;
- ◆ Quality Improvement Program Coordinator and other staff in the Office for the Protection of Human Subjects at Children's National Medical Center.

In addition to the above people and organizations, the Researchers may also use and share my Protected Health Information with :

- Doctors and staff at other places that are participating in the study. The name(s) of the other place(s) that are participating in this study are
- Laboratories and other people or organizations that look at your health information in connection with this study. The name(s) of the laboratory(ies) being used in this study is (are)
- The Sponsor of the study and people that the Sponsor may contract with for the study. The name of the Sponsor is American Cancer Society.
- The Contract Research Organization (an organization that helps the Sponsor run the study). The name of the Contract Research Organization is
- The Data Safety Monitoring Board (a group of people who examine the medical

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- information during the study)
- The Medical Monitor for the Study (a person who reviews medical information during the study)
 - The Patient Advocate or Research Ombudsman (person who watches out for your best interest)
 - Any other outside entity who will receive health information
- Please list:

Should your health information be disclosed to anyone outside of the study, your information may no longer be protected by HIPAA and this Authorization. However, the use of your health information will still be regulated by applicable federal and state laws.

If you agree to participate in this research study, the research team, the research sponsor (when applicable) and the sponsor's representatives, may use Personally Unidentified Study Data. The Personally Unidentified Study Data does not include your name, address, telephone, or social security number. Instead, the researcher assigns a code to the Personally Unidentified Study Data. Personally Unidentified Study Data may include your date of birth, initials, and dates you received medical care. Personally Unidentified Study Data may also include the health information used, created, or collected in the research study. The research team or the research sponsor may share the Personally Unidentified Study Data with others to perform additional research, place it into research databases, share it with researchers in the U.S. or other countries, or use it to improve the design of future studies. They may also publish it in scientific journals, or share it with business partners of the sponsor and to file applications with U.S. or foreign government agencies to get approval for new drugs or health care products.

You do not have to sign this Consent/Authorization. If you decide not to sign the Authorization, you will not be allowed to participate in the research study.

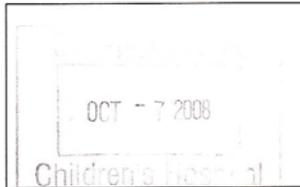
After signing the Consent/Authorization, you can change your mind and:

- ◆ Revoke this Authorization. If you revoke the Authorization, you will send a written letter to: Kathy Patterson Kelly to inform her of your decision at the following address:
Children's National Medical Center
111 Michigan Avenue NW

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Washington DC 20010-2970

- ◆ If you revoke this Authorization, researchers may only use and disclose the PHI that was collected for this research study before you revoked the Authorization.
- ◆ If you revoke this Authorization your PHI may still be used and disclosed if you should have an adverse event (unexpected side effect).
- ◆ If you change your mind and withdraw the Authorization, you will not be allowed to participate in the study.

You will be allowed to review the information collected from you for this research study until after the study is completed. This Authorization expires on 11-1-08.

If you have not already received a Notice of Privacy Practices from Children's National Medical Center, you may request a copy and will be given one. If you have any questions or concerns about your privacy rights, you may contact the Children's Hospital Privacy Officer at 202-476-4550.

I. COMPENSATION

When you have finished talking with the researcher, you will receive a Target gift certificate worth \$25.

Children's National Medical Center cannot promise that the risks we have told you about or other unknown problems will not happen. If you think that something unexpected happened because you were in the study, please call the Chief Academic Officer of the Children's National Medical Center at (202) 476-5000. We will give your child any emergency treatment needed.

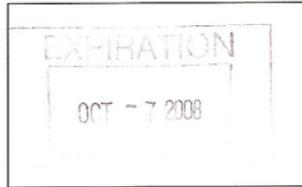
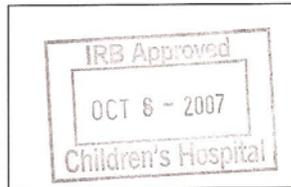
CONSENT/AUTHORIZATION:

I am the participant or I am authorized to act on behalf of the participant. I have read this information and will receive a copy of this form after it is signed.

By signing this form, you agree that you have talked to your doctor or nurse about the study and understand it, and you want to be in the study. You agree that we have talked to you about the risks and benefits of the study, and about other choices. You may decide to stop being in this study at any time and no one will mind and nothing will

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change about your medical care other than not being in the study. Copies of this form will be:

- (1) Kept in the study file by the Principal Investigator;
- (2) Given to you to keep.

OPTIONAL FUTURE RESEARCH: I agree for my transcript data to be used in future research studies. My transcript data will not identify me or my family.

Yes _____ No _____ Initials: _____

Please call the Principal Investigator Kathy Patterson Kelly at 202-476-2689 if you have any questions.

Printed Name of Participant: _____

Signature of Participant: _____ Date: _____
(Participant must be 18 years of age or older)

Witness (to signatures): _____ Date: _____
(may be investigator)

AFFIDAVIT OF PERSON OBTAINING CONSENT: I certify that I have explained to the above individual(s) the nature and purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised.

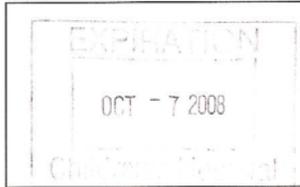
Printed Name of Individual Obtaining Consent: _____

Title: _____ Signature: _____ Date: _____

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Appendix 2.5: Second parent treatment decision making study recruitment letter

Katherine Patterson Kelly RN PhD(c)

Doctoral Nursing Student
University of Missouri Sinclair School of Nursing
Columbia, MO 65212

October 10, 2006

Dear parent,

My name is Kathy Patterson Kelly. I am a doctoral student in nursing at the University of Missouri-Columbia. I am studying what it is like for parents who do not live together to make important treatment decisions for their child with a serious illness. You are receiving this letter because you have made such a decision for your child in the past. Your child's other parent recently participated in this research study and has agreed to give you this letter inviting you to also participate in this study.

If you agree to be in this research study, you will meet with me for about 60-90 minutes to discuss your family, your child's disease, the circumstances of your divorce or separation, Your current living arrangements and relationships, and the major treatment decision you made this past year. I will ask you about your thoughts, feelings and opinions about your family and making treatment decisions for your child. You do not have to talk about things that make you very uncomfortable.

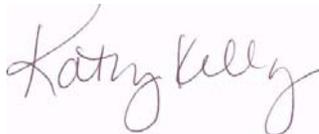
If you are interested in participating in this study, please provide your name and telephone number below and I will contact you in the next few days to arrange for the interview.

Name _____ Phone number _____

Your participation in this research study is completely voluntary and will not affect the care of your child in any way. If you decide that you do not wish to participate in this study after we talk, I will destroy your name and phone number. You will be given a copy of this letter after providing the information above.

I hope you will consider being in this research study. Learning directly from parents is an important way to understand the experiences so that we may help other parents. If you have any questions about this study, please feel free to contact me at the telephone number listed below. I appreciate you thinking about taking part in this study.

With warm regards,



Kathy Patterson Kelly RN, MN, PhD(cand)
Doctoral Nursing Student
University of Missouri Sinclair School of Nursing
Columbia, MO

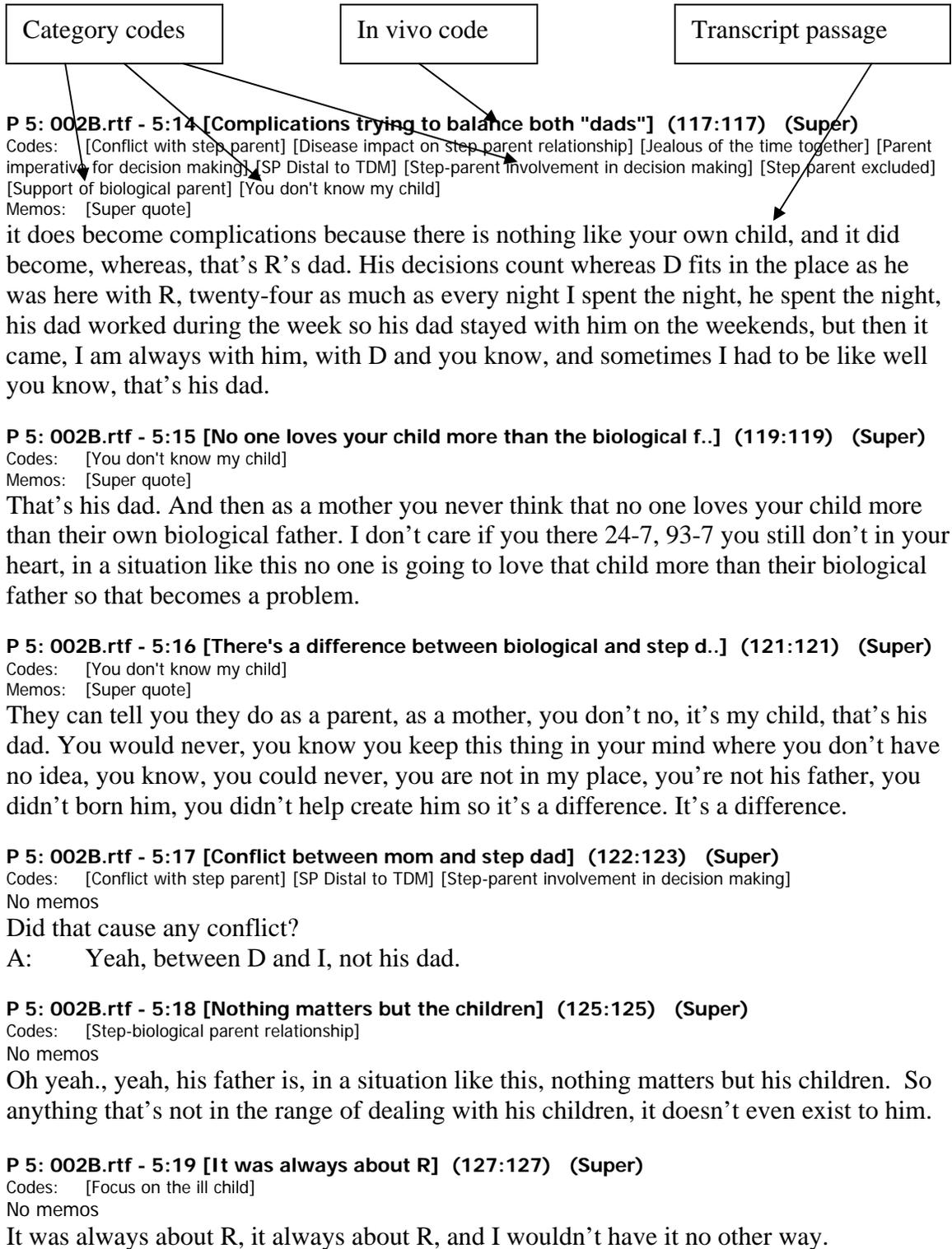
Appendix 2.6: Examples of memos employed in the analysis

Type of memo	Examples from the database
Analytic decision: Biological parent involvement in illness care/decision making	2-4-08 Need to go back through these, especially bio involvement in DM to determine the proximity between TDM and illness care as they are intertwined. My hunch is that the behaviors are the same for each but I need to confirm this in the data, or find out the circumstances where it is distinguished. This could make the final analysis write up and discussion easier. Same thing will need to be done for step parent involvement in illness care and TDM.
Coding decision	<p>1-23-08 I deleted <i>Going up and down the road code</i> and recoded all quotations into Stepping back (from the conflict). I'll paste my coding decision trail for that code below here.</p> <p>Definition: Fathers (so far only biological fathers) keep conflict of having to balance two families while they care for ill child to themselves, thinking about it while on the road, but purposefully not letting their issues interfere with their relationship with the ill child's mother at times to the detriment of their current relationship.</p> <p>12-5-07 I created this category to reflect the conflict in these so far only dads' lives as they try to balance being with, caring for and making decisions for their ill child and being there for their second family. This will also be found in interview 011. Interestingly both dads are having to travel I270, one of the worst commuting roads in DC area and so have lots of time to think on the road.</p> <p>This may be an eventual outcome of this process.</p>
Interviewing technique	Here (Qu5:81) I wish I would not have used the word time as she then picked up on this. I have done this several times in this interview. I think this is my clinician coming through rather than the inquirer. I need to be observant of this in future interviews.
Issues for discussion	<p>This memo will be used to highlight issues I am seeing that may need to be addressed in the discussion section. I will also include cites here as I come across them during this analysis phase.</p> <p>10-31-07 Need to read about father's coping with chronic illness. Interview 003 has lots of information regarding the step dad's role in holding the family together while the mom was at the hospital with the ill child. This is possibly (probably) also what other dad's feel/do. Look at the Broome eg all papers re: Father's informed consent and also other childhood cancer papers. May want to talk to Jeff Gage about this as well. Might e-mail him for a bib list?</p> <p>1-30-08 One thing that keeps coming back to me as I read these transcripts. The roles and relationships of these parents in decision making AND illness care blur a great deal. I suppose that makes sense but I need to think about how to tackle this in the analysis/discussion.</p>
Possible code: Keeping the home fires burning Also depicts audit trail	<p>10-26-07 This code may refer to the step-parent's role in taking care of hearth and home while biological parent cares for ill child. I do know this is very prevalent in 003, but it remains to be seen in other interviews and this is the only step parent I've had the chance to interview as yet.</p> <p>1-2-08 Added a code: Keeping the home fires burning and recoded all these as such. Unlinked the memo and added comments to the code definition.</p>
Future analyses-papers	2-29-08 Should I focus my dissertation on parent involvement in TDM only and leave the relationship issues to a future analysis/paper? Same for Decision making tools - this could be an elegant metasynthesis with my collaborative study and move our understanding along quite nicely as my

Type of memo	Examples from the database
	dataset is more diverse than the other.
Practice implications	<p>1-30-08 A couple of excellent practice implications come from I 010. First is related to flow of information to and from treatment team (typically via custodial parent) and then to and from co-parent.</p> <p>Second is the social work intervention done here to diffuse the tension at diagnosis by having the "other woman" around.</p>
Questions	<p>Next question is how am I going to integrate codes for both biological and step parents? It seems that issues are starting to cross over. I started trying to separate the two but now am really seeing applicability across codes. Qu12:54 is an example of how the bio dad purposefully is excluding step mom from decision making. Also bio parents have done this as well.</p> <p>1-10-08 in answer to above question, I am now going to separate step and bio, custodial and co-parent for many of the issues per recent discussion with Larry. Need to deconstruct for now to make sure I don't miss parts of the process. It is quite complicated and by lumping all together, it may not delineate all aspects of the process. For example, in the disease impact on parent relationship: Separated/divorced parent relationship may not be as affected as with the current partner. I 002 and I 003 a good example of this Mom states relationship with co-parent unchanged, but relationship with step parent very much impacted by the illness almost to the point of breaking them up.</p>
Quotation comment	<p>I: So, would you say it's increased or reduced your time? A: That's tough. It has increased my time with M it has decreased my time with J. I: Really? A: Because I spend more time down at the hospital and less time up in Hagerstown with J. J is at our next door neighbors and he loves it. He loves being with his best friend, next door neighbors but it's decreased all around. J has gotten the short end of the stick, because the attention is always towards her. So because child is now in hospital more, the father has more access to daughter with ALL but less time with healthy sib who stays with friends/family. In essence the father has to choose who he spends time with daughter (ill child) or son, but rarely both. This was seen in I009 (Family E) as well. Coded custody arrangements and Disease impact on family</p>
Code category Depicts audit trail	<p>Code: Current family relationships</p> <p>Definition: Global descriptions of current family structure and relationships. Includes both biological and step family descriptions. Descriptions of specific custody arrangements separated into another category.</p> <p>10-26-07 I will include custody discussion of step parents here and limit code Custody arrangements to the ill child only.</p> <ul style="list-style-type: none"> • This is also a code that is capturing discussion of how parents typically step parents keep the family together. • The current in this code refers to the relationships as discussed surrounding the decision making experience. <p>10-31-07 Will also capture impact of disease on step/half siblings and step parent's role there as well</p> <ul style="list-style-type: none"> • Will create a new code to capture disease impact on family to capture this stuff about impact on other family members. Will keep disease impact on parents separate as it may have more to do with

Type of memo	Examples from the database
	<p>TDM.</p> <p>11-6-07 Now adding current relationship between biological parents. May have to tease this out from rest later. in 005 lots of talk about negative relationship.</p> <p>1-2-08 Reviewed all quotes from I 1-9 and refined category definition. I unlinked a number fo quotes from I 6 that were much deeper references to other processes such as Keeping the home fires burning (added new category), Disease impact on relationship, and Stepping back.</p>

Appendix 2.7: Example of line by line coding from the dataset



Appendix 2.8: Major categories and subcategories prior to axial coding

Major category	Subcategories
Biological Parent(s) involvement in decision making	<p>Contextual subcategories</p> <ul style="list-style-type: none"> • Proximal to major TDM • Distal to major TDM (more closely resembles illness care) • Emotional context (burden/demands) of disease • Family history of making decisions • Parent imperative for decision making
	<p>Process subcategories</p> <ul style="list-style-type: none"> • Active parent decision making • Parent control of decision making (Custodial) • Information manager (Custodial) • Inform parent about decisions made (Custodial) • Excluding parent from decision making (Custodial) • Include other parent (Custodial) • Parent steps up to decision making (Co-parent) • Parent present for treatment decisions (Co-parent)Parent mutual decision making (Custodial and Co-parent) • Parent defers decision making (Co-parent) • [? Parent agree with decisions] • Co-parent not involved (Co-parent) • Parent pulled from decision making by second family (Co-parent)
	<p>Outcome subcategories</p> <ul style="list-style-type: none"> • Weight of making decisions (Custodial) – possible outcome • Blame for negative outcome (Both) • Choice conflict between parents (? Belongs here-in general few conflicts, when it occurs Custodial parent always wins or is this contextual to the process?)
Step parent involvement in decision making	<p>Contextual subcategories</p> <ul style="list-style-type: none"> • Parent imperative for decision making • You don't know my child • Step parent role in family (? Outsider to the illness experience)
	<p>Process subcategories</p> <ul style="list-style-type: none"> • Step parent involved • Seeks out information • Offer opinion/discuss DM with bio parent • Support/listen to bio parent • Bio parent informs step parent

Major category	Subcategories
	<ul style="list-style-type: none"> • Stepping back (from decision making) • Pushed back (from decision making) • Step parent excluded
Disease impact on biological parent relationship	<p>Outcome subcategories</p> <ul style="list-style-type: none"> • Conflict with other bio parent • Conflict with step parent <p>Antecedent subcategories</p> <ul style="list-style-type: none"> • Illness stress contributes to divorce <p>Process subcategories</p> <ul style="list-style-type: none"> • Hoarding the ill child • Work together for ill child only • Increased contact • Hard to be together (? Consequence) • Brought us a little closer (? Consequence) • Confronted with the other (? May also be contextual contributing to overall stress) • Mourns loss of support from other parent • Focus on ill child (Same as Work together for ill child only?) • Personal sacrifice <p>Consequences subcategories</p> <ul style="list-style-type: none"> • No impact on parent relationship • Walk away (from relationship) • Conflict with other bio parent (?) • Getting along (is this a goal of this process or the overall process?)
Disease impact on step parent relationship	<p>Antecedent subcategories</p> <ul style="list-style-type: none"> • Focus on ill child • Don't have it to give to relationship (stress magnifies pre-existing problems in the relationship) • Emotional context <p>Process subcategories</p> <ul style="list-style-type: none"> • Support of biological parent • Keeping the home fires burning • Personal sacrifice (making compromises in spending time with their own children) • Stepping back (from the conflict) • Can't do anything right (or consequence?) • Financial contribution to family • Jealous of time together <p>Consequences subcategories</p> <ul style="list-style-type: none"> • Relationship shut down (negative change related to slowdown/shutdown)

Major category	Subcategories
	<ul style="list-style-type: none"><li data-bbox="683 231 1122 270">• Walk away (from relationship)<li data-bbox="683 270 1003 310">• Rewarding at the end

Appendix 2.9: Axial coding table for Biological parents' involvement in decision making

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
Biological parents involvement in decision making				
Causal conditions	<i>Events or incidents that lead to a phenomenon (antecedent)</i>			
*	Parent imperative for decision making	Drives custodial parent to engage co-parent and/or co-parent to step up to TDM. Also rationalizes exclusion of step parent and/or step parent stepping back from DM.	5:14; 5:112; 6:85; 8:35; 10:58; 15:36	
	Co-parent relationship with child	Linked to whether co-parent will be involved in TDM. No or minimal relationship=no involvement in TDM	8:54; 10:21; 11:25; 11:46; 12:67	
Context	<i>Properties that describe a phenomenon along a dimensional range and influence action/interaction</i> <i>Describes how conditions intersect in time and space to create circumstances to which people respond with action/interaction strategies.</i>			
*	Proximal to major TDM	The proximity to the major treatment decision influences a number of things primarily degree of co-parent involvement and degree to which biological parents		

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
		work together		
*	Distal to major TDM	As the distance from the major treatment decision extends and the decision making process is more about day to day issues that really encompass coping with the child's illness, the custodial parent assumes more control in the process and at times excludes the co-parent from these decisions. In addition the co-parent involvement typically fades away as well. It's as if the crisis is over, and life is returning back to pre-diagnosis patterns.		
Intervening factors	<i>Facilitate or constrain the action/interaction strategies</i>			
	<i>Mitigate or alter impact of causal conditions</i>			
	Parent's former relationship	Predict potential for conflict and how parents interacted in TDM process		
	Family history of making decisions	Predict involvement and	10:88; 15:73	

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
		role parents take in TDM		
Action/ Interaction strategies	<i>Processes that describe the phenomenon's change over time</i>			
	<i>Purposeful actions taken in response to, or to manage a phenomenon</i>			
	ACTIVE PARENT DECISION MAKING			
	Parent control of decision making (Custodial)			
	<ul style="list-style-type: none"> Information manager (Custodial) 	Typically the custodial parent, sometimes used to control, information flows from custodial to co-parent to step parent. Often same as in previous relationship. Both proximal and distal. More holding back on information in distal context.	17:103	
	<ul style="list-style-type: none"> Inform parent about decisions made (Custodial) 	Usually distal. Must be an information manager to do this. Co-parent typically not as involved.	18:63	
	<ul style="list-style-type: none"> Excluding parent from decision making (Custodial) 	Primarily distal.		
	<ul style="list-style-type: none"> Include 	Primarily		

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
	other parent (Custodial)	proximal. Custodial parent reaches out to Co-parent to involve in the major decision making.		
	Parent steps up to decision making (Co-parent)	Both proximal and distal.		In one extreme case Co-parent takes over TDM and custody, in others Co-parent seems to want to prove their ability to care for child.
	Parent present for treatment decisions (Co-parent)	Difference between Steps up and Present is the effort taken by Co-parent to be part of TDM. All proximal to major TDM.		
	MUTUAL PARENT DECISION MAKING (Custodial and Co-parent)	Primarily proximal to TDM, Predicted by Family history of making decisions. Used information sharing often. Also linked reflected in custody arrangements. Eg. Shared	5:52, 18:47, 22:24	

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
		custody=mutual decision making Related to true shared custody (increases mutual TDM) preceding diagnosis and degree of conflict in relationship (reduces mutual parent TDM).		
	PARENT NOT INVOLVED IN DECISION MAKING (Co-parent)			Never able to interview a parent who was not involved in TDM-study limitation
	Parent defers decision making (Co-parent)	Both proximal and distal. Typically co-parent not really involved with child pre-diagnosis.	8:35	One extreme circumstance when custodial parent essentially signed over decision making authority.
	Co-parent not involved (Co-parent)	Proximal and distal again. Primarily when Co-parent not involved pre-diagnosis.		
	Parent pulled from decision making by second family (Co-parent)	Both Distal and Proximal. Able to be pulled more as time from diagnosis grew. Added lots of	12:62	

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
		stress to co-parent.		
Consequences	<i>What happens as a result of action/interaction strategies (consequences)</i>			
	Weight of making decisions (Custodial)	The enormity of the decisions to make contribute to overall stress and difficulty for parents but does not influence parent involvement in major TDM. Weight increased when parent makes decisions alone. High stakes=more weight. Parent's feel alone when they have to make decisions. Only reported by custodial parents.	5:52, 5:125	<p>Is this a consequence, especially the blame factor? Intervening factor because parents more likely to be involved in the big decisions and fall away with the lesser one? Or is this a Causal condition it drives involvement, or an outcomes? YIKES!</p> <p>After reviewing all quotes for this category, I am now convinced this is an outcome of involvement in the process, most commonly discussed by single parents</p>

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
				or custodial parents whose co-parent deferred involvement.
	Blame for negative outcome (Both)	Defer decision making to avoid being blamed for making a wrong decision. Doesn't involve step dad to avoid blaming him and causing stress in relationship. Both proximal and distal. Pay particular care to avoid being blamed for something happening to child. Co-parent actually blamed for child's current situation because of his lack of involvement (let insurance lapse)	1:52, 15:66	
	Decision making aftermath	Individual experience reported by all parents. A few references to joint-use we. What makes aftermath negative? Sicker, limited choices, being alone, life		

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
		threat, poor prognosis, make mistake, blame, uncertainty. What makes it more positive? Child involved, faith, doing well, altruism.		

Appendix 2.10: Axial coding table for Stepparents' involvement in decision making

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
Step parent involvement in decision making				
Causal conditions	<i>Events or incidents that lead to a phenomenon (antecedent)</i>			
*	Parent imperative for decision making	Drives custodial parent to engage co-parent and/or co-parent to step up to TDM. Also rationalizes exclusion of step parent and/or step parent stepping back from DM.	5:14; 5:112; 6:85; 8:35; 10:58; 15:36	
Context	<i>Properties that describe a phenomenon along a dimensional range and influence action/interaction</i>			
	<i>Describes how conditions intersect in time and space to create circumstances to which people respond with action/interaction strategies.</i>			
*	SP: Proximal to major TDM	Step parents acknowledge that their role is one of support and in the background. They do feel like an outsider to the process, especially in the beginning. They purposefully step back from the process, but will offer their opinions to their partner.		
*	SP: Distal to major TDM	The hallmark differences is in general much		

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
		more involvement in the day to day/illness care/coping TDM as compared the major TDM experience.		
Intervening factors	<i>Facilitate or constrain the action/interaction strategies</i>			
	<i>Mitigate or alter impact of causal conditions</i>			
	Step parent role in family (? Outsider to the illness experience)	Even strong role in family including very involved in illness care/ support does not impact role. Even when very involved in the child's life they are not involved in major TDM – proximal TDM; however they do have increased involvement in distal TDM or illness care.		Supposed to be support only. Outsider to experience, but still involved with child.
	You don't know my child	Underscores parental imperative for DM and justifies step parent exclusion (by both biological and step parents)	5:14, 5:25, 5:16,17:34, 20:52, 20:36	? Intervening factor-Yes because it is because of not knowing child or understanding what I'm going through that facilitates Parent

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
				imperative for decision making.
	You can't understand	No one but the other biological parent can understand what I am going through. This is a shared sacred experience even though we've split. Single parents whose co-parents are not involved wish for involvement.	Both 20:54 5:86, 6:17	? Intervening factor-Yes because it is because of not knowing child or understanding what I'm going through that facilitates Parent imperative for decision making.
Action/ Interaction strategies	<i>Processes that describe the phenomenon's change over time</i>			
	<i>Purposeful actions taken in response to, or to manage a phenomenon</i>			
	Step parent involved	Greater involvement with distal TDM (illness care). When proximal it was being present for discussions and this can cause conflict with the other bio parent because the step parent did not belong there. Step parents want to help, but unsure how. And need recognition for the contributions they make.	15:39, 16:40	Is keeping the home fires burning possibly part of this process, instrumental support? Especially for distal TDM. Biological parent deferred DM to step dad during a critical situation.
	Seeks out	Very active in	6:64, 6:82	Step parents

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
	information	step parents. Perhaps a part of support.	(wonderful how this step dad takes on the information so the bio mom doesn't have to)	seek information in support of their partner and for their own coping. Not as much as for a DM tool for themselves as they are really not that much part of the process.
	Offer opinion/discuss DM with bio parent	Both proximal and distal often coincides with information seeking.		
	Support/listen to bio parent	Primarily for proximal TDM, but does occur with distal as well	6:100, 15:39, 20:35	
	Bio parent informs step parent	Proximal TDM	7:120	
	Stepping back (from decision making)	Both Proximal and distal TDM	6:85, 6:93, 6:100, 6:101, 6:113, 17:122	
	Pushed back (from decision making)	By staff members not giving information to the mother		
	Step parent excluded	Excluded to keep from blaming step parent for bad outcome. And can lead to conflict with partner. Primarily	5:105, 12:61, 16:43, 17:91, 20:33	

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
		proximal TDM		
Consequences	<i>What happens as a result of action/interaction strategies (consequences)</i>			
	Conflict with other bio parent	Conflict with other parent when step parent seeks involvement. Partner may exclude step parent to reduce potential for this. Step parent doesn't have problem with co-parent involvement because of parent imperative for decision making.	6:52, 12:62, 15:36	Ex-Biological (not partner)-Step
	Conflict with step parent	When step parent excluded from the process is causes conflict at home with partner.	12:61, 17:91	Biological-Step Partner
	Decision making aftermath	Biological parents have the burden of living with their decisions for child with cancer, step parents respect this awesome burden. In general this is not linked very frequently to step parent involvement in DM but mostly with biological parent	6:98	

Making treatment decisions for a child with cancer by parents who no longer live together				
Paradigm model	Categories	Hypothesized relationships between categories	Grounding in data	Discussion
		involvement in DM		
	Blame for negative outcome	Step parents excluded from TDM by their partner to prevent blaming them for negative outcomes.	5:105	

Vita

Katherine Patterson Kelly was born August 21, 1958 in Amarillo, Texas. After attending public schools in Texas, Oklahoma, Mississippi, and Kansas, she received her Bachelor of Science in Nursing from the University of Kansas School of Nursing in 1980 and began her career as a pediatric hematology oncology nurse at the KU Medical Center in Kansas City, Kansas. In 1988 she received her Master's of Nursing from the University of Kansas School of Nursing and shifted into an advanced nursing practice in pediatric hematology oncology as a Clinical Nurse Specialist. She relocated to Columbia, Missouri in 1991 to continue her advanced nursing practice in pediatric hematology and oncology. There she began her doctoral studies at the University of Missouri Sinclair School of Nursing in 2002. Shortly after earning her candidacy, she moved to the Washington DC area and joined the Center for Cancer and Blood Disorders at the Children's National Medical Center where she conducted her dissertation research. During her academic tenure in Missouri, Katherine earned a prestigious American Cancer Society Doctoral Nursing Scholarship in 2004 and the Sinclair School of Nursing PhD Graduate Student Award for Overall Excellence in 2006. She is married to Robert Alan Kelly and they have a son, Joseph Patrick Kelly. They family now lives in Rockville, Maryland.