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Parental Grief and Loss and the medical Staff Relationship: a Function of Attachment

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LOMA LINDA UNIVERSITY
School Science and Technology
in conjunction with the
Faculty of Graduate Studies

Parental Grief and Loss and the Medical Staff Relationship:
A Function of Attachment

by

Peter Christopher Gleason

A Dissertation submitted in partial satisfaction of
the requirements for the degree of
Doctor of Philosophy in Clinical Psychology

September 2011

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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ABBREVIATIONS

EOL	End of Life
PPC	Pediatric Palliative Care
PICU	Pediatric Intensive Care Unit
QOL	Quality of Life

ABSTRACT OF THE DISSERTATION

Parental Grief and Loss and the Medical Staff Relationship: A Function of Attachment

by

Peter Christopher Gleason

Loma Linda University, September 2011
Dr. Matt Riggs, Chairperson

Each year, too many parents must face the horrific ordeal of having to prepare for the death of their child; thought to be the most traumatic event in the life of an adult (Widger & Picot, 2008). It is in the desperate hours just prior to death that these parents, for many reasons, reach out for support to the medical staff around them. This process, particularly if negative, can leave scars that parents will carry for a lifetime (N. Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Tinsley, et al., 2008). However, there appear to be factors that serve to lessen the negativity of this time (Gerretsen & Myers, 2008; Tan, Zimmermann, & Rodin, 2005). Thirteen families agreed to participate, in this study, from several hospitals, each family having lost a child within the past year. Qualitative analyses of interviews with these families indicated that themes of communication, availability, and empathy were important in relation to the physician. Themes detrimental to the relationship with the physician included communication brevity and carelessness. Additionally, results suggested that these themes exist in an additive hierarchy, with no one theme ensuring the viability or destruction of the relationship, instead serving to buffer positive and negative influence. Recommendations for future research include

evaluation of the manner in which these themes impact each other, and ultimately the relationship.

CHAPTER ONE

INTRODUCTION AND LITERATURE REVIEW

Introduction

When facing the imminent loss of a child, parents are confronted with a hurricane of emotional turmoil and psychological distress. In such cases, families seek to support themselves by reaching out to those around them in desperate ways. As such, the relationship between family and health-care providers becomes increasingly of interest as a tool with which to provide for the unique needs of these parents.

The term *Palliative Care* refers to the style of treatment applied to patients near the end of life. While this style is relatively new and still being developed, several major obstacles already exist which hinder the application of treatment. First, while several organizations have attempted to clarify the concept, there remain many differences between cultures and norms that interpret the definitions differently (Liben, Papadatou, & Wolfe, 2008), contributing to a discontinuous field. Second, studies are finding that a majority of medical health care professionals do not feel that they are adequately prepared to meet the needs of patients receiving palliative care (Bagatell, et al., 2002; N. Contro, et al., 2002; Himmelstein, Hilden, Boldt, & Weissman, 2004).

Additional obstacles are specific to the realm of *Pediatric Palliative Care (PPC)*, one being that the end-of-life (EOL) time table which is typically associated with palliative care has not been adequately translated to the pediatric population (Morgan, 2009). Additionally, families of children who have received such care have made, along with positive feedback, also some sharp criticisms of those responsible for care (N. Contro, et al., 2002; N. A. Contro, et al., 2004; Mack, et al., 2005). These criticisms may

be related to the strong desire expressed by many families to care for their children at such a time within their own homes (Roth, Wang, Mimi, & Moody, 2009).

Due to the nature of any environment in which PPC is required, the needs of the family are exceptional. While death is tragic and sobering by its very nature, comfort is taken in the linearity which provides a feeling of predictability in what is otherwise a world of chaos (Gerretsen & Myers, 2008; Tan, et al., 2005). Yet this sense of order can be shattered when faced with an untoward loss, as in the case of a child. In such circumstances, families will look to new sources for comfort and understanding. Often they look to health care providers to fill this need (N. A. Contro, et al., 2004). In effect, the needs placed on the staff will be exceptional.

Palliative Care

History

The concept of palliative care was born of the theory and practice of hospice care. Cicely Saunders is credited with opening the first modern-day in-patient home for the dying, St. Christopher's Hospice, in 1967. This home was the first to apply a model of care similar to what would be found in a medical hospital, encompassing a multi-disciplinary strategy for care (Lugton & Kindlen, 1999).

Palliative care was officially defined by The World Health Organization (WHO) in 1990. This definition was built on six key tenets of what palliative care is: (1) death is a normal part of life; (2) not a tool to alter the temporal latency of death; (3) painful or stressful conditions are to be relieved; (4) spiritual as well as psychological avenues of care are to be included; (5) the active life of patients is to be supported as much as possible;

(6) the family of the patient require support for their own distress related to the patient's illness and impending loss (Lugton & Kindlen, 1999).

Modern Palliative Care

Palliative care has grown in recognition as a treatment strategy, building upon and clarifying the six original tenets. To do this, distinctions have been made between 'curing' and 'healing,' the latter being the goal of palliative care. Care strategies represent an emphasis on touch over technology, and relationships over number of days (Twycross, 2003).

Quality of life (QOL), as a concept, is highly subjective, but is generally thought to be a person's level of satisfaction with his/her current situation. Several life-aspects will have an influence over this satisfaction, including: pain or distress in the body; psychological distress causes of fears and worry, etc.; social stress perhaps caused by maintaining poor relationships or harboring old injuries; and spiritual distress. Twycross (2003) explains that quality of life can be explained in terms of understanding the relationship between the patient's goals and their current circumstance. Essentially, as goal's gain proximity to circumstance, quality of life improves. The narrowing of this gap is the goal of palliative care (Twycross, 2003).

In her writing of modern principles in palliative care, Cicely Saunders penned the following words: "...enable people to live until they die..." (Saunders, 2004). It is to this end that professionals engage in palliative treatment. Patients are people, not yet victims of the fate pronounced on them via their diagnosis, and as people are still able function in relationships and roles already established. These roles, extensions of who we are, do not

end when we learn that we will die, but rather when we finally do. As such, these relationships require remembrance and support.

Saunders (2004) addresses the medical staff as they are making decisions as to how best to inform palliative patients and their families. Sharing information, as opposed to concealing or deceiving, has the potential to be much more conducive to personal growth than the alternative. The path to the end is best traveled in truth, surrounded by close relations (Saunders, 2004). Denial of this principle can hinder the bereavement and mourning process experienced by the family, and also can diminish the healing process shared by all at this precious time in the family's history.

On speaking to the future of palliative care, Saunders (2004) voiced a concern for the spiritual needs of patients. In the field's earliest days, people interested in providing such a form of care were doing so at the risk of personal loss, but they did so often from a sense of spiritual compelling. Today, as the field spreads to new places and peoples, those choosing to work therein have several varied motivations for doing such work. Saunders (2004) was expressly concerned that many of these new care providers will not have the spiritual prowess or resources to share with their patients. As those who value a patient's spirituality fade in number, the future of multi-dimensioned patient care may come to lose an important dimension.

“If people know they are respected as part of the human family, the ending of life can be a final fulfillment of all that has gone before.” - Cicely Saunders (Morgan, 2009).

Pediatric Palliative Care

While half a million children are faced with a life-threatening illness each year (Himmelstein, et al., 2004), and recent statistics report that infant mortality is on the rise (Hoyert, Mathews, Menacker, Strobino, & Guyer, 2006), the unfortunate fact that children are in need of palliative care services is an ever-present truth.

Health care professionals and families alike are placed in these demanding circumstances at an increasing rate. Studies have found that as many as half (52%) of child deaths (age ≤ 25) happened in a hospital setting (Feudtner, et al., 2002), with the majority of those (75%) due to chronic illness. Organizations such as the American Academy of Pediatrics have acknowledged and called for the application of palliative principles to improve the care of these pediatric patients, but the transition of these principles from adults to children has not been a smooth one (Himmelstein, et al., 2004).

Diagnosis can heavily shape the goals and strategies of palliative treatment teams (Hays et al., 2006; Wolfe et al., 2000). The causes of death in children are different from those of adults, and for that reason the treatment plans developed for adults are not necessarily adequate for the pediatric population (Bioethics & Committee on Hospital Care, 2000). In fact, the recognition that palliative care for the pediatric population is a whole different animal than that of adults, eventually resulted in the development of a specific set of principles to address the specific needs of patients, families, and health care providers (Bioethics & Committee on Hospital Care, 2000).

The American Academy of Pediatrics (AAP) has recommended a standard to be set for integrating palliative care with pediatric care (Bioethics & Committee on Hospital Care, 2000). The first principle, respecting the patient and family, clarifies the need to

value the wishes of the patient, and to provide care for the family as well to the end so that they will survive the ordeal intact. The second acknowledges that an extra measure of care is needed beyond pain management, meaning forms of therapy aimed at increasing the patient's quality of life, such as support groups, creative therapy, counseling, or education (Bioethics & Committee on Hospital Care, 2000).

Recognizing that the providing of palliative care places unique demands on the health care providers, the third principles of the AAP outlined strategies for aiding the staff by provided bereavement leave, and by having remembrance days in order that providers may have the opportunity to process their own feelings and emotions (Bioethics & Committee on Hospital Care, 2000). The last two principals are in reference to the limits palliative. Whereas palliative care is not in and of itself a curative measure, often families will be unable to finance these measures of care. Its is believed that with increased research into the value of palliative care, amplified awareness by the greater community will result in easier access to funding sources and a widespread application of the palliative care principles (Bioethics & Committee on Hospital Care, 2000).

Barriers

As the unique discipline of pediatric palliative care begins to take form, there are many obstacles currently preventing the delivery of consistent and standardized services. One obstacle, for example, is the failure of health care professionals to uniformly come to a definitive consensus on what pediatric palliative care means (L. A. Thompson, Knapp, Madden, & Shenkman, 2009). Another domain of contention is over what represents the best form of training for residents who will eventually work on a palliative care team

(Feudtner, et al., 2002; Himmelstein, et al., 2004; Liben, et al., 2008). Finally, another major complication has come from the nature of the relationship between the health care providers, specifically the pediatric palliative care team members, and the family and patient receiving the care (Bioethics & Committee on Hospital Care, 2000; N. Contro, et al., 2002; Hays, et al., 2006; Morgan, 2009; Weisleder, 2008).

Agreement

The inability to concretely delineate the scope of palliative care in contrast to other forms of EOL care was illustrated in a study of 303 pediatricians from Florida and California, which found that 41.9% of participants could not differentiate between palliative care and hospice care in terms of services provided (L. A. Thompson, et al., 2009). Additionally, 31.9% of participants who stated that a difference does exist were unable to offer any specifics as to exactly what that difference is. Approximately 30-44% reported that palliative care services should be requested only after curative care has been discontinued. Further, 3-39% did not know what, if any, palliative care services were available in their area, and about 31-36% reported not knowing when to refer for palliative care services, or that they had never referred for its service (L. A. Thompson, et al., 2009).

Fortunately, while these same study participants were unable to define palliative care, up to 93% did endorse the need for supportive services, including pain and symptom management as well as counseling (L. A. Thompson, et al., 2009). These numbers paint the picture of a system with a significant disconnect between ideology and execution.

An example of why distinguishing a difference between these two modes of treatment can be vital is pain management, a service understandably found to be greatly valued by family (Contro, Larson, Scofield, Sourkes, & Cohen, 2002). In their interview of sixty-eight family members of deceased children, parents observed that providers of at-home hospice care were not qualified to provide pain management. Further, these parents noted a lack of access to experts in pediatric care, noting that continued contact with hospital staff was especially meaningful.

These findings indicate that cracks exist between the boundaries of palliative care and other forms of EOL care, and unfortunately, the families and their children continue to fall through these cracks. As a result, these families are not given access to much wanted-if not needed-services.

Referral Timing

The adult model of palliative care aims at providing services for the last six months of life (L. A. Thompson, et al., 2009). The pediatric palliative care model initially tried to follow this example, but several organizations have challenged this, calling for palliative services to begin at diagnosis (Morgan, 2009; L. A. Thompson, et al., 2009). Several obstacles currently hinder the timely delivery of services, including methods of reimbursement, attitudes of family and professionals toward death, and disagreement over which diagnoses will eventually result in death.

Reimbursement

All forms of treatment, be they experimental or controversial, must be paid for by some party. In an effort to bring billable structure to the chaotic practice of medicine, current reimbursement systems authorize the use of palliative treatments only when patient are believed to be within their last six months of life (Morgan, 2009; L. A. Thompson, et al., 2009). There are several reasons why this structure does not sufficiently transfer to the palliative population.

Strict criteria exist in order for palliative care to be reimbursed. When treatment outcome is uncertain, or the eventuality of death is not certain, reimbursement of treatment is often denied (Liben, et al., 2008). This is complicated by the lack of agreement over what diagnoses are indeed life-limiting (L. A. Thompson, et al., 2009). As opposed to their adult counterparts, fatal childhood disorders are much less commonplace, and this diminished frequency has hindered familiarity. (Himmelstein, et al., 2004). As a consequence of this lack of familiarity, standardized treatment protocols for many disorders do not exist throughout the field (L. A. Thompson, et al., 2009).

Programs such as Medicare/Medicaid also contribute to the difficulties of finding reimbursement for palliative services (Bioethics & Committee on Hospital Care, 2000). On one hand, studies have found that patients with diagnoses recognized by Medicaid as being life-limiting will receive palliative care services quicker than those who do not have Medicaid (L. A. Thompson, et al., 2009). It is important to keep in mind that these recognized diagnoses are relatively rare. The same study found that of 303 pediatricians surveyed in Florida and California, almost half (44.9%) reported that 0-20% of their patients had access to Medicaid (L. A. Thompson, et al., 2009).

The federal Medicare hospice program was designed from an adult model, and made provisions for care of patients within the last six months of life (Bioethics & Committee on Hospital Care, 2000). This does not translate effectively to children, as many disorders do not predict death with certainty, nor are timetables for death established firmly enough to meet the requirements for reimbursement. Some reimbursement programs have been known to require patients to relinquish curative treatments that might extend life, and to sign “do not resuscitate” orders in order to receive palliative care services (Bioethics & Committee on Hospital Care, 2000). In effect, these patients are given a choice between hope and treatment. Is it any wonder that palliative care has been associated with negative connotations by families and staff (L. A. Thompson, et al., 2009).

Attitudes

The prospect of a child facing death is especially tragic, a reality that family and professionals alike may seek to deny (Hays, et al., 2006; Morgan, 2009). One misconception of pediatric palliative care is that it cannot coexist with curative treatment, and thus palliative care is perceived as giving up on the child (Hays, et al., 2006). Because of this misperception, health care professionals can be reluctant to begin palliative care treatment.

The American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care stated pointedly that palliative care referrals should be given at the moment of diagnosis, not in exclusion to curative care but concurrently (Bioethics & Committee

on Hospital Care, 2000). Efforts such as these are no doubt aimed at reducing referral times while acknowledging known attitudinal barriers.

Diagnosis

As previously alluded to, there exists a great deal of variance in opinion of which pediatric diagnoses should be associated with a terminal prognosis. While cancer remains the leading killer of children in the USA (Morgan, 2009), many die of disorders that are much more rare (Sahler, et al., 2000). The fund of knowledge about a given disorder is positively correlated with the frequency of disorder, so that low frequency is correlated with lesser study, ergo lesser knowledge. The large number of uncertainties can make prognosis a frustrating ordeal for the physician (L. A. Thompson, et al., 2009).

Necessary and appropriate treatment goals are directly related to diagnostic prognosis. It is no wonder that uncertainty at the diagnostic level will immediately translate to uncertainty at the treatment planning level. The lack of agreement regarding pediatric disorders, as exemplified by highly individual definitions and values among professionals (L. A. Thompson, et al., 2009), results in a seemingly chaotic field of variation in acceptable treatment goals. With divergent opinions concerning what is urgent, the process of forming an interdisciplinary agreement can require time, with time being a precious patient commodity.

The humanity of medical staff also has a role to play in the timing of diagnosing and treatment planning. How easy it is while thinking about symptoms and a prognosis to forget about the patient! The staff who work with the patient and family each day cannot forget. There are many very human reactions to be expected in such situations. Staff may

feel uncomfortable with the high levels of emotion from families, or may feel guilt that they are not better able to care for these children (Sahler, et al., 2000). These feelings of the staff, together with how they choose to cope, be it with aggression or passivity, will influence the speed of decision-making in regard to eventual treatment.

Overall, obstacles to referral-timing range from institutional to interpersonal. Likewise, the actions taken to address these types of barriers will not be the result of any one person, team or board. Instead, overcoming these problems will require intelligent policy designs, training, learning, and constant diligence on the behalf of all involved.

Training

Many authors have voiced concerns that, despite rigorous programs, many new residents are not receiving careful or specific training for end-of-life care (Bagatell, et al., 2002; N. A. Contro, et al., 2004; Himmelstein, et al., 2004). One survey of new residents at Cornell Medical Center found 13% of respondents felt they were adequately prepared to work with dying patients (Bagatell, et al., 2002). The same authors reported findings from another study which reported that residents did feel comfortable working with dying patients a full two years into their residency. While progress is being made toward understanding the dying process, this understanding is failing to be translated effectually into medical training programs (N. A. Contro, et al., 2004).

The quality of care is influenced via several mechanisms because of limitations in training programs. First, residents are denied sufficient opportunity to confront their own feelings of unease with patient death (Bagatell, et al., 2002). Uncomfortable reactions such as avoidance can lead to stress and conflict between staff members, as well as

between staff and members of the family. Surveys of residents have found that not only did many feel uncomfortable broaching the topic of end-of-life care or related treatment options with patients and their families, but they also reported feeling uncomfortable about bringing up the topic with colleagues (Bagatell, et al., 2002). It may be impossible to judge how the length of palliative care referral delays has been negatively impacted by staff members feeling that they are not ready, with the patient or with themselves, to broach the topic.

Apart from remaining uncomfortable with their feelings toward death, another aspect related to poor end-of-life (EOL) training is that new residents have not had the opportunity to refine their skills at recognizing specific prognostic considerations. A study of third-year residents found that they had difficulty recognizing how at-risk for death some of the patients truly were (Schwartz, Goulet, Gorski, & Selwyn, 2003). Because of this, residents continued having difficulty with delivering bad news, as well as including the patient and family in treatment planning.

The pediatric training programs do not paint a brighter picture of patient care. Thankfully, the number of pediatric patients who receive EOL care is much lower than the number of adult patients. However, this means also that new doctors have far fewer training opportunities to prepare them for work with such patients (Bagatell, et al., 2002; Wolfe, Grier, et al., 2000). Studies show that pediatric patients who face death often spend the last month of their lives with significant suffering from at least one major symptom (Wolfe, Grier, et al., 2000).

Wolfe (et al., 2000) expounded on the discrepancy that was found to exist between family and physician reports describing the patient's QOL. According to the author

findings, parents typically rate the patient's suffering much higher than do the treating staff. While there may be more than one cause for such a discrepancy, the authors point out that this may be largely due to a suboptimal ability to recognize and appropriately treat symptoms in such conditions as a result of insufficient training (Wolfe, Grier, et al., 2000).

The recent emphasis on raising the quality of palliative care may go against the grain of training programs that stress curative care. As Wolfe (et al., 2000) points out, the primary focus of most cancer treatment is to cure, and the virtues of QOL can take a back seat. Perhaps training has so polarized curative care and EOL care that balancing the two concomitantly is not emphasized in training.

Communication

Communication between medical staff and the patient and family is highly valued by those receiving care (Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Friedrichsen, Strang, & Carlsson, 2000; Lo & Quill, 1999; Mack, et al., 2005; Schofield, Carey, Love, Nehill, & Wein, 2006; Steihauser, Christakis, et al., 2000). Not only is communication important to the family, but it is also a fundamental component of decision making and treatment planning (Hays, et al., 2006). Communication appears to be a pivotal juncture on which hangs patient/family satisfaction with the treatment experience.

Several positive qualities attributed to communication can ease palliative process for patient and family, including respect and support (Thompson & Ciechanowski, 2003), empathy (Tan, Zimmermann, & Rodin, 2005) and informational communication (Meyer,

Burns, Griffith, & Truog, 2002). However, quite a few negative communication traits have also been documented which can undermine the staff-family rapport, making an already difficult time for the family all the more unpleasant. Family members have reported that comments made by staff members have had lasting, very hurtful consequences (N. Contro, et al., 2002; Tinsley, et al., 2008). Tinsley (et al., 2008) observed that what may appear to be detached behavior and joking on the part of the medical staff may actually be a coping mechanism to help relieve the experienced stress and anxiety of the moment. Notwithstanding the nature of the behavior, how this is interpreted by parents and family members can leave quite a scar.

Other qualities of communication have been shown in the literature to be valued by families. A qualitative study of 68 family members of children who had died after receiving palliative care services found that one of the qualities most valued was that of familiarity with the staff member delivering difficult news (N. Contro, et al., 2002). Participants in this study also reported a preference for having a single person in charge of treatment, a single, familiar point of contact who has a thorough understanding of the treatment process.

Mack (et al., 2005) conducted a qualitative study of 144 family members of children who had died of cancer, surveying perceptions of quality of care. Findings indicated that quality of care was rated highest when several traits were present: the primary physician was trusted, difficult news was presented with sensitivity and caring, and the family felt adequately prepared for what was going to happen. The same study found that poor ratings for quality of care were associated with families who believed they had received conflicting information from staff. In fact, receiving conflicting

information was more detrimental to the families' whole experience than the amount of pain the child suffered, the duration of hospital stays, or the type of death (Mack, et al., 2005).

Steinhauser (et al., 2000) echoed the value families place on feeling prepared for what will happen. In a qualitative analysis of 75 participants with a sample from a variety of professions including nurses, chaplains, social workers, physicians, and family members; interviews and focus groups were conducted to gather opinions about their palliative care experience. The authors found that patients reported that their fear of symptom pain was frequently abated by clear communication and decision making with the staff (Steinhauser, Clipp, et al., 2000).

Sahler (Sahler, et al., 2000) found some characteristics that can erode the quality of family/staff communication. In situations where information is protected, such as when staff and family work together to withhold difficult news from the patient, the subsequent ability of the involved parties to have open, honest conversations may be undermined. This can be detrimental to the family's feelings of trust placed in the staff, despite their own participation in the decision. Additionally, due to empathetic fall-out, staff can miss the feeling of satisfaction associated with healthy patient relations (Sahler, et al., 2000).

Building on the idea that disparities in treatment understanding between staff and families contribute to the erosion of communication and the relationship, Wolfe (Wolfe, Klar, et al., 2000) found that physicians reported believing that curative care was no longer an option about one hundred days before the parents had the same understanding. In the study of 103 parents of children who died of cancer, forty-nine percent of the parents reported that they came to realize that curative care was no longer appropriate

through a discussion with the medical team, while 30% reported that they figured it out on their own.

Wolfe (et al., 2000) found that parents and medical staff had a similar understanding of prognosis during the early treatment phases. This is also when communication between both parties seemed to be the best (Wolfe, Klar, et al., 2000). However, as treatment complications arose and patient prognosis deteriorated, the disparity between the medical teams' prognosis and the parents' conceptualization of treatment goals grew. Concomitantly, satisfaction with communication was rated lower during this time (Wolfe, Klar, et al., 2000).

Attachment Theory

Several authors have begun employing attachment theory to explain behaviors in the medical setting, including treatment adherence (Ciechanowski, Katon, Russo, & Walker, 2001), illness pattern behavior (Feeney, 2000; Hunter & Maunder, 2001), staff-clients relationships in family practice (D. Thompson & Ciechanowski, 2003), as well as residential care (Dozier, Cue, & Barnett, 1994; Moses, 2000; Tan, et al., 2005), depression and bereavement (Murrell & Himmelfarb, 1989; Stroebe, et al., 2005), palliative or supportive care (Petersen & Koehler, 2006), and death and dying (Wilson & Daley, 1998).

History

Attachment theory was born in the mid 1940's as a response to the popular need-based behavioral theories of the time. Freud's psychoanalytic theory, for example,

attributed the infant's need for his mother to its being the product of the learned association of mother and food (Cassidy, 1999). In essence, the child did not need a relationship with his mother so much as he needed to have his primary needs met by his mother. The logic of these theories proposed that if food was good, and mother provided food, then mother was good.

John Bowlby, a long-time psycho-therapeutic patient and student of child psychiatry, was the first to begin putting the pieces together to form what would become the theory of attachment (Mikulinger & Shaver, 2007b). The child Bowlby has been described as emotionally flat, perhaps with anti-social tendencies. His siblings, also, have been described as having attachment struggles. This, together with Bowlby's years working with the maladjusted youth, left him with more questions than answers with respect to what the theories could then explain (Mikulinger & Shaver, 2007b).

Attachment theory was developed from the careful study and observation of the behavior of young animals. As early as the 1930's, studies were finding that baby animals would attach themselves to figures that were not meeting their primary needs (Cassidy, 1999). This inconsistency, together with the frustration Bowlby was feeling with the limitations in psychodynamic work, began to fuel an idea that would challenge the academic zeitgeist and potentially impugn his reputation as a researcher (Mikulinger & Shaver, 2007b). Freud's psychodynamic theory was based on sex-based needs and urges, and built on tools of unconscious experience and fantasy. Bowlby answered by emphasizing natural causes and behavior.

Overview of Attachment Thought

The theory of attachment provides answers to an array of intra- and interpersonal questions. Because of this work an understanding is provided for why one child will cringe and cry at being separated from his/her caregiver, while another will be joyfully unaffected. Spinning the clock forward, answers are again provided as to why one young woman will feel anxious and insecure at the absence of her spouse, while the other whistles on her way to work.

Attachment theory is based on the belief that some behaviors are innate. Over the course of selection, the most adaptive of these innate behaviors are those that survive and are strengthened over time. From this jump-off point, Bowlby hypothesized that infants who actively and successfully sought a relationship with a caregiver were more likely to be provided for, sustained, and to ultimately survive (Mikulinger & Shaver, 2007b).

Over the hours spent observing children of all ages, Bowlby noticed certain behavior patterns that seemed to emerge repeatedly (Cassidy, 1999). The most common behaviors, those that appeared to be most adaptive and associated with survival, were considered “normative” (Mikulinger & Shaver, 2007b).

Behavior patterns are considered by attachment theorists to be goal oriented. Goals can change as fluidly as new situations and stimuli can be experienced. When threats are absent, goals may include exploration and production. When a threat is perceived, be it something known to be harmful or just something novel, goals may swiftly change to those of safety or threat removal. The default goal is security (Mikulinger & Shaver, 2007b).

Activating Systems

Attachment needs are not always immediately pressing. In fact, the highest levels of appropriate attachment are quantified by the ability to de-prioritize attachment needs. When a need does arise, such as with the presentation of novel stimuli or separation from an attachment figure, a learned attachment system will be triggered (Mikulinger & Shaver, 2007a).

The activating system is a catalogue of learned behaviors that are organized by their ability to meet differing needs in various circumstances. These behaviors exist on a wide spectrum from subtle social cues to dramatic pleading.

Types of Attachment

In a classic study of the divergence in attachment behavior, Ainsworth and Bell (1970) introduced fifty-six infants, aged fifty-one weeks, to a strange situation. This study was guided by several assumptions related to attachment behavior, including that individuals are genetically predisposed toward attachment behavior, that attachment behaviors can be heightened or diminished based on a situation, and that adaptive and balanced attachment behavior represents movements toward exploration and gradual autonomy. Ainsworth and Bell (1970) manipulated the situation in order to heighten attachment behavior for purposes of observation. To achieve this, the researchers used proximity as their chief variable. The infants were placed in a novel room with their mother. Initially, the infants eagerly explore the room full of toys. In later trials, when a stranger is present, exploration decreases as attachment behavior is theoretically heightened. Additionally, when the mother is absent, exploration is further decreased.

A range of responses to the mother's absence was observed (Ainsworth & Bell, 1970). A moderate number of infants engaged in searching behavior, thought to be aimed at restoring proximity to the mother. In the absence of their mothers, some infants sought proximity with a stranger in the room. By the end of the experiment, about half the infants appeared to resist contact with their mother once proximity had been restored. From this range of reactions to a heightened situation, several types of attachment behaviors have been developed theoretically.

Secure

Some infants will develop working models of relating to their attachment figures in a manner that successfully results in the achievement of their attachment goals. Such people are considered to have secure attachment. The working models of these individuals will be the most flexible and will meet the needs of novel situations. The securely attached suffer less preoccupation with the threat of loss or separation, and are most free to employ their own industry and ability to explore the environment (Mikulinger & Shaver, 2007a).

Avoidant

When the attachment goal of finding security is not met, one type of reaction is to shut-down the entire attachment system. These people have learned that their primary attachment figure is not going to consistently meet their needs, or may even interfere with the meeting of these needs. In children, this is observed when a youth is not bothered by the removal of an attachment figure. Additionally, the reunion of the two may result in

feelings of frustration or agitation. In essence, the feeling of hurt associated with the constant failure of the attachment figure is deemed not worth the effort to be attached, and so separation is appraised to be the better alternative (Mikulinger & Shaver, 2007a).

Anxious

Whereas some people shut down when they sense attachment failure, others become increasingly vigilant to mend the failure and restore proximity to the attachment figure. This is observed in children who are visibly distressed at being separated from their attachment figure and are not sure how to interact with the figure once they have been reunited. Anxious attachment appears to be in response to irregular attention from the attachment figure, with the strategy that increasing the demands of ones needs is correlated with increased need fulfillment (Mikulinger & Shaver, 2007a).

Disorganized

In the three preceding strategies the common thread has been that, despite the level of success, each represented an organized system of behaviors developed to meet specific goals. The fourth strategy characterized a lack of such a strategy. This type of behavior, also known as *disorientation*, is observed in children who react to attachment loss or separation in ways that do not appear to be aimed at meeting any goal or having an intended purpose. These behaviors can include sitting under a table, hiding, or freezing and are considered to be learned responses to attachment figures who continue to struggle with their own personal attachment issues (Mikulinger & Shaver, 2007a).

Attachment Styles in a Medical Setting

Due to the nature of roles of parents and physicians, the respective attachment styles are conceptualized quite differently.

The Parents

The loss of a child is a special kind of loss, described as unnatural (Widger & Picot, 2008). The grief experienced by parents in these situations is of a unique nature, with possibly dire consequences if proper support is not available (Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008). These parents are vulnerable to deteriorating inter-personal relationships and clinical depression, as well as a host of symptoms co-morbid with these conditions (Ciechanowski, et al., 2001; Wijngaards-de Meij, et al., 2005; Williamson, Walters, & Shaffer, 2002).

Stroebe (et al., 2005) argues that the experience of grief is mediated, for better or worse, by attachment style. The authors suggest that secure individuals are flexible in their ability to observe their own emotions, coping behaviors, and relationship to the diseased. While in comparison, an anxious individual would present as obsessed with the loss, with chronic grief, and a preoccupation with the experience. Individuals with an avoidant attachment style would appear to distance themselves from the grieving process, denying a need to appreciate the loss they have experienced. Finally, disorganized individual may respond in an incoherent manner which potentially may never be resolved, perhaps taking a form similar to Post-Traumatic Stress Disorder (Stroebe, et al., 2005).

In the presence of such profound loss, together with the increased dependence on others necessitated by receiving medical care, it is no surprise that attachment behaviors are activated during these times (Tan, et al., 2005). While attachment behaviors are based on models formed by early relationships (Mikulinger & Shaver, 2007b), it has also been suggested that physicians and medical staff can serve a surrogate “secure base” (Gerretsen & Myers, 2008). In such cases, the physician would be able to help guide the attachment behaviors through the meeting of security needs to an appropriate end.

A problem with this idea is that it is often difficult to recognize and understand the attachment behaviors that are being observed. Hunter and Maunder (2001) sought to provide an understanding of how behaviors manifested by the differing attachment styles might be presented. Secure parents were described as being able to cope with the situational stress, appear coherent, and put their trust in the medical staff. Anxiously attached behavior in parents may manifest a dependent feel; they are at-ease with the physician present but unable to reassure self on their own. Such parents begin to engage in any behavior that will lead to more frequent attention from the physician, with behavior strategies becoming increasingly desperate as early attempts fail. Avoidant behavior may be observed in parents who appear to be nonchalant about the treatment process, as their belief is that no one will be able to help them (Hunter & Maunder, 2001). These parents may be disturbed by what they see as too much attention or may construe it as a sign that something is wrong. Disorganized behavior, on the other hand, may take the form of chaotic help-seeking, and may attempt to split the staff by putting pressure on them to meet the needs of the parents. Parents may resist any behavior that

will take the pressure off from whoever they believe to be responsible for meeting their needs (Hunter & Maunder, 2001).

The Medical Staff

Regardless of the attachment behavior, it is the reaction to these behaviors that many authors have suggested will ultimately determine the quality of the parents' experience during this time (Hunter & Maunder, 2001; Tan, et al., 2005; D. Thompson & Ciechanowski, 2003). While the importance of the relationship between staff and parents/family has been richly discussed (Bagatell, et al., 2002; Ciechanowski, et al., 2001; Dozier, et al., 1994; Gerretsen & Myers, 2008; Heller & Solomon, 2005; Moses, 2000; Weisleder, 2008), discussions rarely consider roles played by the staff's own attachment styles in the forming of this relationship.

The struggle physicians face in determining which forms of involvement will best serve families was underscored by Tinsley (et al., 2008). In a study of 41 family members of children who died following an unsuccessful CPR intervention, families reflected on what it had been like to be either involved or not. Of the family members not present during CPR, 60% reported that they would have been a comfort to their child had they been present, while 40% reported that the death would have been harder to cope with. Of those who were present, 70% reported believing their presence comforted their child. Interestingly, of the 49% of the sample who were not present for CPR, 40% had not been invited by staff. To account for this, Tinsley (et al., 2008) suggests two possible causes. First, family inclusion during CPR is a practice that has been gaining momentum only in recent years. Second, physicians have the difficult task of determining which families

will benefit from being included, as opposed to families that may be distressed and hurt by involvement.

Dozier (et al., 1994) has suggested that the relationship of physician-patient parallels the caregiver-child relationship from which initial attachment behaviors are learned. In both cases, the latter is dependent on the former for the meeting of basic security needs, namely health and comfort. However, Dozier (et al., 1994) is careful to point out that they are different in one primary way: the patient's attachment behaviors have developed within the context of the caregiver-child relationship, and the physician-patient relationship is one of these developed behaviors. By default, the patients will initially relate to their physicians the same way they related to their caregivers, but that will not necessarily lead to a successful, adaptive relationship (Dozier, et al., 1994).

Thompson and Ciechanowski (2003), in a review of literature and case study data, outlined what they believe to be the natural pull physicians might feel when working with parents presenting with one of these attachment strategies. Parents with avoidant attitudes, who do not believe the physician will be able to help them, are likely to be dismissive or unappreciative of treatments, leaving the physician feeling rejected, frustrated and angry, and wanting to disengage from treatment. Anxiously attached parents, who believe they need to proactively seek to maintain a close proximity with staff, are likely to leave the physician feeling anxious, angry, overwhelmed, and struggling to maintain professional boundaries (D. Thompson & Ciechanowski, 2003). Parents with disorganized attachment, believing that they cannot trust others nor themselves, may leave the physician feeling rejected, hurt, confused, incompetent, and even hostile toward the family.

As much as the attachment styles of patient/families affect the physician/patient relationship, so do the attachment reactions of the medical staff affect the relationship. Tan (et al., 2005) suggests that avoidant behavior on the part of medical staff is a common reaction to emotionally charged or attention-seeking behaviors, and this avoidant reaction is born of the staff member's own attachment needs and insecurities. However, Tan (et al., 2005) also reported research results finding that patients with attachment needs can have high self-rated experience with medical teams, provided they are able to be secure, reliable, and consistent.

The reactions of physicians to the attachment needs of particular patients can threaten the communication and continuity that are the heart of the ideal physician/patient relationship (Heller & Solomon, 2005; D. Thompson & Ciechanowski, 2003). Gerretsen and Myers (2008) suggest that the experience of anxiety and distress felt by patients can be relieved by the perception of availability of staff. The idea is that structured physicians can communicate that they are involved with care even when they are not physically present, and that with consistency and time, patients will be soothed by this knowledge. Hunter and Maunder (2001) conceptualize the role of the physician as an external regulator, responsible for containing the parents' distress with a concerned and reliable structure. This structure can consist of establishing a set time to visit with the parents, and then consistently meeting at a set time, for a set duration. These behaviors have been shown to improve parent-rated hospital experiences, despite attachment needs (Hunter & Maunder, 2001).

We have seen the myriad of needs that patients and families can bring to the medical team, above and beyond the medical diagnosis. These needs, through pushing or

pulling, demanding or dismissing, can threaten to push staff away and damage the very relationship which will serve to ease their overall experience. These attachment behaviors can be overcome and the relationship between families and physician and staff preserved, if physicians are able to recognize them and consistently protect the framework of the relationship.

Statement of the Problem

Studies have shown that parents' attitude toward the circumstances surrounding the loss of their child can be greatly influenced, positively or negatively, by the quality of their relationship with hospital staff (Heller & Solomon, 2005). One of the greatest indicators of relationship quality is communication (Mack, et al., 2005; Sahler, Frager, Levetown, Cohn, & Lipson, 2000).

Attachment theory has been used to understand the varied and complicated reactions parents have to the pediatric palliative care process (Hunter & Maunder, 2001; Stroebe, Schut, & Stroebe, 2005). From this perspective we are able to see that the serious nature of such an experience can leave these parents feeling especially vulnerable and dependent on others (James & Johnson, 1997). It is from this position that these desperate parents reach out to the medical staff, similar to how a child reaches out to those who are responsible for his/her wellbeing (Tan, et al., 2005). The strategies parents use to obtain a sense of security can range from proximity seeking to dismissal and avoidance, with a whole spectrum in between (Hunter & Maunder, 2001).

As parents are wrestling with all the emotions and inner conflicts stirred up by these unfortunate circumstances, medical staff can have a wide variety of reactions to

these behaviors (Tan, et al., 2005). Many physicians do not feel prepared to meet the medical demands of the patient in such situations, even less prepared to support the parents (Bagatell, Meyer, Herron, Berger, & Villar, 2002). Other staff have reported that they are not familiar with the support option available to the family (N. A. Contro, Larson, Scofield, Sourkes, & Cohen, 2004) . Many other obstacles exist hindering the ability of staff members to successfully meet the needs of these desperate parents.

The purpose of this project is to gain a better understanding of the staff/family relationship by dissecting the contributing factors brought on both sides, the medical staff and the patient's family. While a number of studies have outlined the many barriers to healthy, satisfying relationships, little is known about how to adequately surmount these barriers. Using theory-based explanations of family member's behavior, together with an itemized conceptualization of factors influencing medical staff reactions to these behaviors, an explanation will be prepared showing how the viability of this critical relationship can be protected.

The descriptive and exploratory aim of this study is representative of qualitative research as we seek the subjective understanding of families while continuing to focus on the evidence base for palliative supportive care and while generating ideas for future interventions and study. The focus of this study is to gain insight into the factors that families report as being decisive in determining the experience to have been positive or negative (figure 1.).

The hypotheses of this study are:

1. Parents who report feeling satisfied with their relationship with the physician will also report higher levels of satisfaction with communication, including clarity, consistency, and level of experienced comfort related to communication with the physician.

2. Higher levels of reported relationship satisfaction with physicians will be correlated with higher levels of structured availability.
3. Higher levels of reported relationship satisfaction with physicians will be correlated with higher levels of perceived physician empathy.
4. Higher levels of brief and/or careless communication will be associated with lower levels of relationship satisfaction.
5. Higher levels of hovering or avoidant physician availability will be correlated with lower levels of relationship satisfaction.
6. Higher levels of empathetic rigidity or discouragement will be associated with lower levels of relationship satisfaction.
7. Higher levels of brief/careless communication will be associated with higher levels of avoidant availability.
8. Higher levels of brief/careless communication will be negatively associated with physician's perceived sincere empathy.
9. Higher levels of structured/consistent availability will be positively associated with higher levels of feeling prepared, of clear communication, and of sincere empathy.

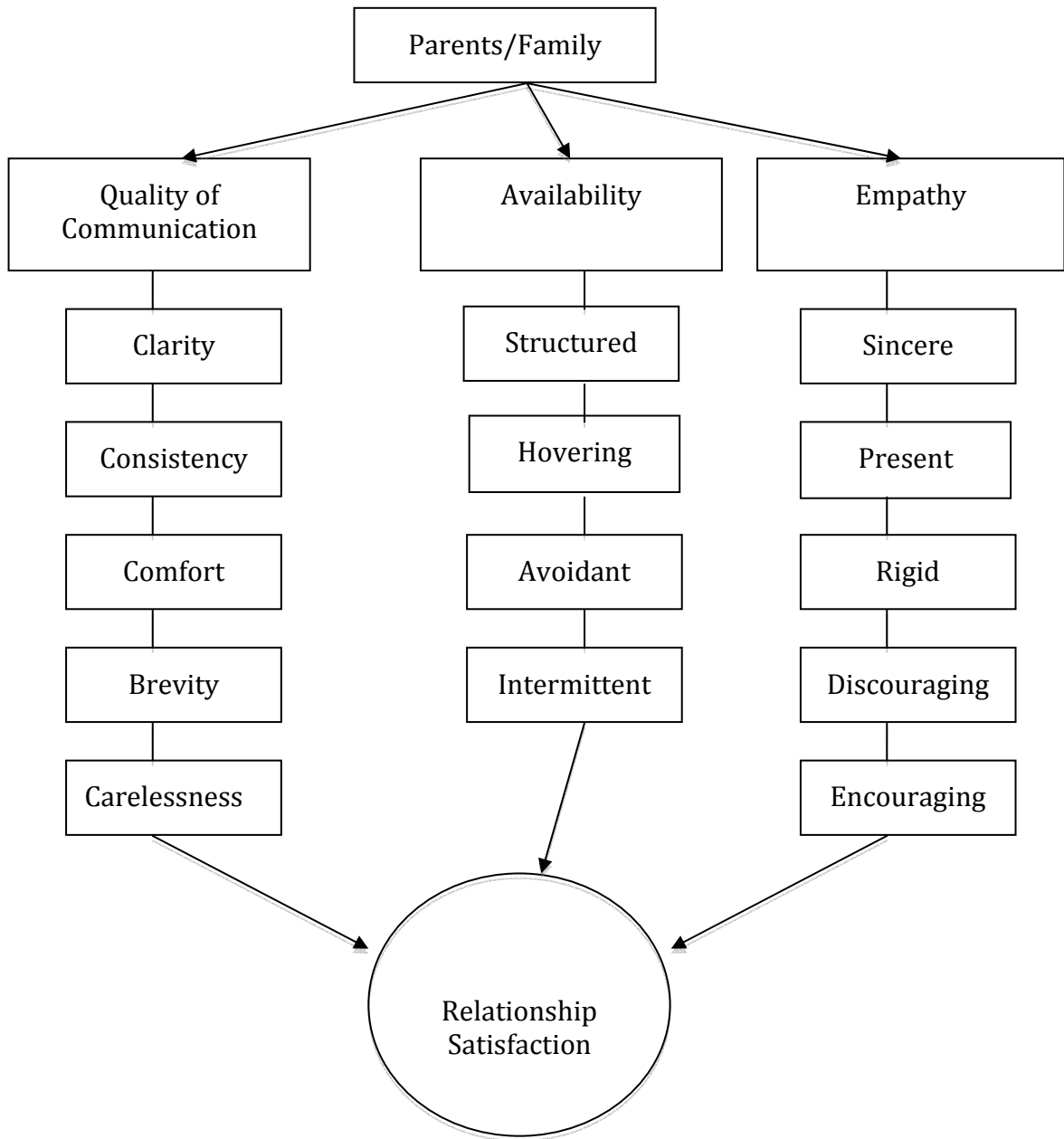


Figure 1. Conceptual relationship of variables mediating the relationship between parents/family and satisfaction with their relationship with the physician.

CHAPTER TWO

METHODS

Study Design

The current study is part of a larger IRB approved multi-site study entitled “Exploration of the Experiences of Parents regarding the Death of Their Child in a Pediatric Intensive Care Unit or Pediatric Cardiac Care Unit”. This study used a qualitative-quantitative mixed methods design to investigate the experiences of families as they interact with physicians and other hospital staff while navigating pediatric EOL stressors in a sample of families who received services from participating medical centers, including: Akron Children’s Hospital in Akron, OH; Kosair Children’s Hospital in Louisville, KY; Miami Children’s Hospital in Miami, FL; Cincinnati Children’s Hospital in OH; Saint Francis Medical Center in Lynwood, CA; Cook Children’s Medical Center in Fort Worth, TX; Children’s Hospital in Los Angeles; Hackensack University Medical Center in NJ; University of Minnesota Children’s Hospital; Inova Fairfax Hospital for Children in Falls Church VA; and Miami Children’s Hospital.

Setting the current study apart the larger project is the inclusion of a theoretical framework provided by the theory of Attachment to specifically identify relationship stressors and aids between physician/staff and patients/families. The theory of Attachment was used to guide the qualitative portion of the study as well as the content from the questionnaire utilized in the parent research study. Techniques for qualitative analysis, including coding and pattern coding, were employed as outlined by Miles and Huberman (1994) as well as Holliday (2002). The subjects were recruited, as per study protocol, from the Pediatric Intensive Care Unit (PICU) of hospitals listed above. The

geographical regions covered by these facilities serve a wide variety of patients, with varying backgrounds and demographic considerations.

Setting

The human subject protocol for the project was approved by each hospital's institutional review board. Participation was voluntary, and informed consent was obtained from all participants. Mortality statistics for the PICU were researched, and a number of families were identified as having had a child die in the PICU between six months and a year prior to recruitment, a period chosen specifically for the study, providing distance from the death but not so remote as to affect recall ability. All families were first contacted via a letter introducing them to the study and requesting participation. This letter was followed up with an additional mailing with the announcement that the family would be contacted via phone by a study coordinator. Subsequently, the phone interview was conducted.

Qualitative Analyses

As no standard form of assessment (i.e., questionnaire or survey) had been constructed to provide insight into the interpersonal relations between medical staff and patients families processing EOL stressors, formative research was required to understand the specified behaviors. The study generally followed the guidelines of the social anthropological approach (Miles & Huberman, 1994), as such an emphasis was placed on descriptive observation, condensation of raw data, and fluid analyses of emergent themes. An open-ended questionnaire solicited qualitative feedback from

patient's families regarding their experiences with medical staff in an attempt to build upon hypothesized patterns of attachment behavior.

Individual Interviews

From September 2008 through February 2011, a total of thirteen phone interviews were conducted. Interviews were conducted in English and in Spanish, as many parents were bilingual. The reason, stated by parents, for declining participation was that they did not want to talk about the death of their child. Other families declined without explanation. Because the original goal was to explore parental perspectives, parents were not asked to recruit siblings and extended-family members into the study. The original open-ended phone interview questionnaire can be found in Appendix A.

Content from the interviews was recorded and transcribed verbatim (with consent). Emerging themes were coded and analyzed as outlined by Miles and Huberman (1994). These themes were then used to guide development of content for the quantitative questionnaire, designed to serve the primary means of analyses for the study goals.

Data Analysis

Following the guidelines for a transcendental realism study (Miles & Huberman, 1994), the qualitative information was coded and organized by theme. For the creation of the quantitative questionnaire, emergent themes that correspond with the empirically supported presupposed themes, including such domains as communication, empathy, and availability, were included.

Interview transcripts were reviewed and important themes coded as they emerged.

As the scope of this study has been established, essentially the physician/parent relationship, coding is advantageous. By transforming important components and key words into codes which can be numbered and counted, this qualitative data becomes quantifiable. Codes are labels that are assigned to meaningful units in the transcript and can be a specific word, phrase, or combination of words. The purpose of coding is to capture the meaning of the transcript while making the data manageable (Miles & Huberman, 1994).

Once the transcripts had been coded, pattern coding was employed to identify reoccurring themes and begin to identify the nature of the relationship between the meaningful pieces, key to hypotheses testing. Pattern coding is the process of applying a second level of codes to perceived relationships among the first level codes (Miles & Huberman, 1994).

Pattern Coding

Once the first-level coding was completed, condensing units of data, pattern coding was employed to discover themes and constructs existing among these units. As described by Miles and Huberman (1994), pattern coding is similar in function to cluster analyses in quantitative data. Pattern coding has four distinct functions: (1) data reduction, (2) encouraging engagement in analyses during data collection, promoting greater focus on later work, (3) providing a road map for understanding incidents of interest, and (4) provides themes for understanding incidences between cases.

CHAPTER THREE

RESULTS

Descriptives

Interviews (n = 13) were conducted with patient families whose child died while in a medical environment in the past 6 to 12 months. Of the children, fifty-seven percent (n = 7) were female. Known ages ranged from 2.5 months to 16 years, however ages were unavailable for many of the children (n = 9), as these data were not required a part of the larger study. The majority of children involved in this study received EOL care at Children's Hospital of Wisconsin (n = 5), followed by Loma Linda Children's Hospital (n = 4), Children's Hospital of Illinois (n = 2), Hackensack University Medical Center (n = 1), and Kosair Children's Hospital (n = 1). Finally, twelve of the thirteen interviews were completed by mothers of the children, with one interview completed by a father. Also, cause of death data were not collected as part of the larger study, thus were unavailable.

Preliminary Qualitative Analysis

Codes

In order to prepare data for analysis to study the hypotheses themes, content coding was performed. The following key themes were developed from a careful review of the literature, as well as interview responses describing family views of their relationship with physicians and other hospital staff. Interview data was coded to define parent's relationship with physicians as well as nurses and staff along three dimensions: communication, availability, and empathy (see Table 2).

Table 1

Demographic Frequencies

	N	Percent
Patient Gender		
Female	7	53.85%
Parent Interviewed		
Mother	12	92.3
Hospital Participation		
Children's Hospital of Wisconsin	5	38.62
Loma Linda Children's Hospital	4	30.77
Children's Hospital of Illinois	2	15.38
Hackensack University Medical Center	1	7.69
Kosair Children's Hospital	1	7.69

Communication

The first category of codes, related to communication, centered on the varying aspects of communication that are theorized to correlate with either positive or negative interactions. The theme of communication with a physician was initially coded independent of positive or negative connotation (PR-C), before examination of positive and negative connotations of communication could be performed.

The positive aspect of communication included several areas of interest. First, themes addressing the clarity of communication with the physician were coded (PR-CCL). Second, codes were assigned to themes of communication resulting in feelings of preparedness parents expressed toward what they could expect to happen with treatment (PR-CPP). Additionally coded were content involved having in a structured, reliable framework in which parent's could expect communication with the physician (PR-CST). Finally, positive themes related to the degree of distress relieved by communication with the physician were coded (PR-CCMF).

Table 2

Frequencies of Theme Emergence Relative to Physician and Nurse/Staff

<i>Physician Relationship</i>			<i>Nurse/Staff Relationship</i>				
	<i>N</i>	<i>F</i>	<i>%</i>		<i>N</i>	<i>F</i>	<i>%</i>
<u><i>Communication</i></u>				<u><i>Communication</i></u>			
PR-C (<i>General</i>)	13	7	54	SR-C (<i>General</i>)	13	5	39
PR-CCL (<i>Clarity</i>)	13	4	31	SR-CCL (<i>Clarity</i>)	13	1	8
PR-CPP (<i>Preparedness</i>)	13	2	15	SR-CPP (<i>Preparedness</i>)	13	0	0
PR-CST (<i>Consistency</i>)	13	3	23	SR-CST (<i>Consistency</i>)	13	0	0
PR-CCMF (<i>Comfort</i>)	13	3	23	SR-CCMF (<i>Comfort</i>)	13	3	23
PR-CB (<i>Brevity</i>)	13	5	39	SR-CB (<i>Brevity</i>)	13	2	15
PR-CCR (<i>Careless</i>)	13	5	39	SR-CCR (<i>Careless</i>)	13	4	31
<u><i>Availability</i></u>				<u><i>Availability</i></u>			
PR-A (<i>General</i>)	13	3	23	SR-A (<i>General</i>)	13	10	77
PR-AS (<i>Structured</i>)	13	1	8	SR-AS (<i>Structured</i>)	13	4	31
PR-AH (<i>Hover</i>)	13	0	0	SR-AH (<i>Hover</i>)	13	0	0
PR-AA (<i>Avoidant</i>)	13	3	23	SR-AA (<i>Avoidant</i>)	13	2	15
PR-AI (<i>Intermittent</i>)	13	0	0	SR-AI (<i>Intermittent</i>)	13	0	0
<u><i>Empathy</i></u>				<u><i>Empathy</i></u>			
PR-E (<i>General</i>)	13	5	39	SR-E (<i>General</i>)	13	12	92
PR-ES (<i>Sincerity</i>)	13	3	23	SR-ES (<i>Sincerity</i>)	13	3	23
PR-EP (<i>Presence</i>)	13	1	8	SR-EP (<i>Presence</i>)	13	6	46
PR-ER (<i>Rigidity</i>)	13	6	46	SR-ER (<i>Rigidity</i>)	13	4	31
PR-ED (<i>Discouraged</i>)	13	1	8	SR-ED (<i>Discouraged</i>)	13	2	15
PR-EE (<i>Encouraged</i>)	13	2	15	SR-EE (<i>Encouraged</i>)	13	2	15

Themes that represented the negative aspects of communication with physicians included reference to brevity, noting short, non descript, or even abrupt communication with the physician (PR-CB). Also, the theme of carelessness was coded, representing parents who acknowledged feeling that the physician's communication was rude, hurtful, or thoughtless (PR-CCR).

Availability

The second grouping of codes is related to the physical availability of the physician. The first theme represented any content in which parents made reference to the presence of the physician (PR-A). Second, content representing themes of contact that followed a consistent pattern of contact or availability (PR-AS) were coded. Next, codes were assigned to content related to parents who experienced the physician to be over-involved, or to have too much contact (PR-AH). Then, themes of behavior related to perceived avoidance of the parents on the part of the physician, including experiencing difficulty in finding or contacting the physician, or feeling that the physician was not involved were coded (PR-AA). Finally, content related to perceptions that physician availability was inconsistent were coded (PR-AI).

Empathy

The third grouping of themes involved reference to the physician's emotional availability. First, any content referencing the physician as being concerned or caring was coded (PR-E). Second, themes of physician sincerity and genuine concern were coded (PR-ES). Third, themes related to parents perceptions that the physician was paying special attention to them were coded (PR-EP). Additionally, content related to the physician's being perceived as uncaring, distant, or coldly fact-oriented were coded (PR-ER). Then, perceptions that the physician discouraged hope were coded (PR-ED). Finally, content expressing that physicians had been encouraging were coded (PR-EE).

Other Staff Coding

The same theme groupings and content categories were assigned to content related specifically to nurses or other staff, as opposed to physicians. The purpose of this differentiation is to acknowledge the differences in roles played by staff and physicians. The scope of these differences includes, for example, rate and frequency of contact and communication.

First-Level Coding

Communication

The theme of communication was put forward with regards to physicians and/or staff on twelve occasions, with a higher rate of occurrence regarding physicians (54%) than other staff (39%). The value placed on communication was frequently discussed by the families. Positive attributes of communication included comments such as that physicians were ‘really open’ and that they ‘took a lot of time to tell us,’ making comments such as:

‘... really everybody including the doctors, the nurses made us comfortable. They were always informing us. (Interview 01.)

‘When he started to have respiratory failure on like the third or fourth day, I don’t really remember what day, but they walked us through it. Everything they did. If I was in the waiting room, they would come and get me to explain everything to me. I wasn’t really understanding it, but anyways they were great.’ (Interview 10.)

In contrast, communication with physicians and nurses/staff was also described with negative attributes. Families felt that there were ‘miscommunications’ in what they heard

from physicians and staff, describing it as ‘disrespectful’ and ‘really distant,’ commenting:

‘... at some point it was told by family members that they felt like we were having miscommunications. That they were still giving us hope in the room and yet they would go out to the waiting room and tell them in the waiting room that it just wasn’t going to happen. ...that made it frustrating for me and my girls. Because we couldn’t understand why, you know, the rest of the family wasn’t more hopeful with this.’ (Interview 02.)

‘... I don’t know if the doctor was completely honest in telling us what was going on. I mean despite that she couldn’t give us any answers they were pretty much gone and closed the covers.’ (Interview 103.)

For the purposes of the current study, Communication was conceptualized as being an over-arching theme under which several specific themes have emerged, including clarity, preparedness, consistency, comfort, brevity, and carelessness.

Clarity

Reference to clarity of communication was made on four occasions, the majority with regards to physicians (31%, other staff 8%). Families often emphasized clarity of communication when highlighting positive aspects of their interactions with physicians and staff. Specifically, despite learning unfortunate news, families appeared to value feeling informed and updated.

A perceived lack of clarity in communication was frequently linked with expressed frustration on the part of the families. Specifically, families who noted clarity as an issue most frequently cited it in terms of receiving mixed messages from different ‘teams’ of physicians and staff:

'... at some point it was told by family members that they felt like we were having some miscommunications. That they were still giving us hope in the room, and yet they would go out to the waiting room and tell them in the waiting room that it just isn't going to happen. [...] Because we couldn't understand why, you know, the rest of the family wasn't more hopeful with this. [...] ...it was my understanding that they just kind of being more grim with those in the waiting room than what they were being to us.' (Interview 02).

'... you feel like you're knocking on every team. Because they don't know what to do. Like if that team doesn't know, they say, 'The next team will probably try something else.' Or you ask them questions and they say they'll be back. Then you ask one team and they say 'I don't know who you talked to, I don't have anything on the chart.' It was really hard. [...] Because you just feel like they don't care.' (Interview 11).

Although clarity of communication was not a theme that emerged frequently, when present it was clearly linked with positive or negative experiences with physicians and staff.

Preparedness

The theme of communication resulting in feelings of preparedness for what was to happen emerged twice, both with reference to communication with physicians. In the first instance, the family related how a long and careful conversation with the physician helped ease their transition from being hopeful toward being prepared for what they would experience imminently. This family reported generally positive feedback about their experience, and will be revisited on the discussion of careless communication.

In the second instance, a family related feeling a lack of preparedness for what would happen. The reported experience of lacking preparedness also touched on themes of lacking empathy, the presence of blunt or negative communication, and experiencing a lack of hope from physicians or staff, as represented in the comment:

'... I had no direct indication that she would not survive. [...] But the body language of the doctors, from what I was seeing, told me that there was a definite possibility of something really serious happening soon. [...] Nobody told me or said anything at all, but from what I saw going on around me... I've never seen anything like that.' (Interview 09).

While in interviews overall feelings of preparedness as they relate to communication may not be a common theme, when present the theme is surrounded with clearly expressed positive or negative attributes toward the overall PICU experience.

Consistency

The theme of consistent communication emerged in twenty three percent of family interviews (n = 3), with all instances referring to communication with physicians. The theme of perceived consistency in communication was observed in conjunction with other positive themes such as feeling encouraged. One family was very positive about the their overall experience:

'... really everybody including the doctors, the nurses made us comfortable. They were always informing us. [...] There were no negatives.' (Interview 05).

Brevity

The theme of brief communication was initially conceptualized to include references to abrupt, short, or non-descript communication with physicians or staff. This theme emerged on six occasions, with the majority (n = 5) in reference to communication with physicians. Families reported mixed reactions to brief communication with feelings of appreciation:

'... one of her original oncologists, who was not around as much on the PICU floor, pulled me aside and said 'You have to tell us when to stop.' And I was shocked at her frankness. But I was happy because I'm a direct person myself and I think she felt she could talk to me like that.' (Interview 09).

Not all brief communication was viewed in such a positive manner. Other families reported experiences ranging from being void of any attribution of feeling, positive or negative, to possessing a distinct quality of bitterness.

'They tried to keep us posted, but they couldn't give us answers.' (Interview 03).

'Some of the nurses, um... and some of the doctors... when I would ask questions, they would say 'There's nothing more we can do.' You know. From there you could say 'we are going to try to change some medications.' Just some of the nurses are- I don't know. Not to be impolite, but it's like not even human.' (Interview 11).

Clearly represented are feelings of families, positive and negative, regarding experiences with communication.

Carelessness

The theme of careless communication is largely represented in the literature (N. Contro, Larson, Scofield, Sourkes, & Cohen, 2002; N. A. Contro, Larson, Scofield, Sourkes, & Cohen, 2003), and is indicative of perceptions of interactions with physicians and/or nurses/staff as being rude, hurtful, or thoughtless. The theme of carelessness emerged on nine occasions, in thirty-nine percent (n = 5) of interviews regarding physicians, and in thirty-one percent (n = 4) of interviews regarding nurses/staff.

'But one of the nurses - I'm not sure she's aware that I'm the mother of my son, but she was really distant-this one nurse said that-not even to me, but kind of talking to the other nurse like- "Oh, we're going to have an extra nurse here, I guess." ...I wanted to slap her in the face...' (Interview 07.)

'I don't really know. Sometimes nurses are good at what they do, but they aren't always good at, like, thinking about... beyond that. [...] They were really sweet and really good at what they did, but it's like... And some of them were young, so they didn't stop to think what kind of an impact that might have.' (Interview 09).

'Oh, and what didn't help is the fact that I had one nurse tell me I needed to stop talking to her. Told me and my family to stop talking to her. Because after that... after the nurse told me I could not talk to her anymore, that it was just going to make things worse.' (Interview 13).

'Well, one thing that me and my wife didn't like was there was a couple nurses that were sitting at the station talking, laughing at the nurses station. And we didn't like that; we felt it was disrespectful.' (Interview 03).

Availability

The theme of availability makes reference to perceived attributes of attachment style as displayed by physicians and staff. This theme, like communication, is conceptualized as an overarching framework under which there are several more specific patterns of availability types, including structured, hovering, avoidant, and intermittent. Families referred to styles of availability twelve times, ten of which specified the availability of nurses and/or staff. Availability was frequently referred to as 'so close,' 'personal,' or 'extremely helpful,' with more elaborate statements such as:

'They were just there for me and my girls the whole time.' (Interview 102.)

'They really made a positive effort to keep coming down and keep doing things... they were very positive in their approach with her.' (Interview 09.)

Not all comments on availability were positively constructive in nature. Families expressed negative concerns about staff such as ‘pretty much gone’ and ‘nobody around.’

Structured

The structured form of availability is conceptualized to represent reliable, consistent patterns of contact or availability. The theme of structured availability emerged in reference to nurses/staff in thirty-one percent of the interviews (n = 4), however reference was made to physicians in only eight percent (n = 1) of the interviews. One family reported valuing the fact that they felt they had the same nurse for the entire visit. Still another family reported feeling that the staff made a special effort to be consistent with their child:

‘But they really made a positive effort to keep coming down and keep doing things...’ (Interview 10).

The theme of structured availability, while it is not always present in family interviews, certainly appears to be present in relation to positive experiences with received care.

Hovering

The theme of hovering availability was conceptualized to represent physicians and nurses/staff who are perceived by family to be over-involved in treatment. This theme was constructed as a means of identifying specific behavior which may represent behaviors with strong attachment attributions; however, this theme did not emerge in the interviews.

Avoidance

The theme of avoidance references families who reported finding physicians or nurses/staff difficult to contact, or felt that they were not involved in the treatment process. The theme of avoidance emerged on five occasions, in twenty-three percent of interviews in relation to physicians (n = 3), and in fifteen percent of interviews related to nurses/staff (n = 2).

'I don't know if the doctor was completely honest in telling us what was going on. I mean despite that she couldn't give us answer, they were pretty much gone and closed the covers.' (Interview 03).

'That was about it because they pretty much just left us alone for the most part.' (Interview 13).

'The third day after I had (name omitted), I was still trying to pump milk for him and for any reason the pumping machine quit and there's nobody around me around four in the morning. And the pumping machine just quit.' (Interview 07).

The theme of avoidance was typically accompanied by expressed feelings of negativity toward families' experiences. Of note is the subjective experience of perceived avoidance.

Intermittent

The intermittent theme of availability is conceptualized to represent a style characterized by a fluctuation between consistency and avoidance. Such a style was thought to share traits with a disorganized attachment style. This theme did not emerge in any interviews.

Empathy

The third and final of the theory-based anticipated themes, empathy, is conceptualized to represent the level of personal care experienced by family. The theme of empathy emerged on fifteen occasions, in ninety-two percent (n = 12) of interviews referencing nurses/staff, and in thirty-nine percent (n = 5) making reference to physicians. Like communication and availability, empathy is considered an umbrella theme under which there are several more specific themes, including: sincerity, presence, rigidity, discouragement, and encouragement.

Sincerity

The theme of sincerity was designed to represent families' perceptions of physicians and/or staff as genuinely caring for the patient. The theme of sincerity emerged on six occasions, in twenty-three percent (n = 3) of interviews in reference to physicians and also in twenty-three percent (n = 3) in reference to nurses/staff. The most commonly used expression referred to how much "compassion" physicians and nurses/staff had on families and their children.

'I think they are very compassionate, the doctor... the staff. Um, they gave us privacy for the last moments with our son. And they... the environment was so quiet and clean, they played the right music for us. They let our minister come. They provided a nice house for us to gather around (name omitted) and ask questions.' (Interview 07).

Presence

The theme of presence was developed to represent the expressed feeling of families that physicians and or nurses/staff were present and paying special attention to

their child. Presence emerged as a theme in forty-six percent (n = 6) of interviews referring to nurses/staff. Presence emerged once (8%) in reference to physicians.

'...one nurse that took really great care of her. She would sing to her and was just... she was great. And she was like a member of the family.' (Interview 101.)

'... the one thing that helped him (the patient) was the two nurses that he absolutely adored there.' (Interview 02).

'Social workers were amazing. They were very good throughout the whole bone marrow transplant process. But they were exceptional the day she died. Some of them were actually off work and on vacation with their families. Like I said it was Christmas Day, and they came into the hospital to be with us.' (Interview 08).

Rigidity

The theme of rigidity was conceptualized to embody perceptions toward physicians/nurses/staff as displaying uncaring, distant, and fact-oriented characteristics. Rigidity as a theme emerged on ten occasions, in forty-six percent (n = 6) of interviews in reference to physicians, and in thirty-one percent (n = 4) of interviews in reference to nurses/staff.

'I guess the only thing I didn't like was how mechanical some of the doctors and nurses seemed. To some of them it was almost like just another job to them. There was one time where they needed to push on her chest to make her heart go because it wasn't working... and someone dropped a bottle that broke and the people were laughing and joking and teasing her a little. They just didn't seem to care.' (Interview 01).

'I would like to make a comment here. Where they just close the doors and leave them. There are room for three patients. And sometimes some of the mothers are not there and they are crying and crying. And some of the kids have heart problems or breathing problems or are throwing up. So who is going to know until they go in maybe fifteen or twenty minutes after? [...] That's why I would never leave my son on his own.' (Interview 11).

'... there was only one nurse the whole week that was actually nice. Nice and, like, sympathetic in a way to our feelings and my daughter's care. Which every other nurse she had I wished I would have... I wish I had just told them they needed to leave and to get another nurse.' (Interview 13).

Discouragement

The theme of discouragement was designed to capture perceptions that physicians and/or nurses/staff had discouraged the family's hope for the child's outcome. The theme of discouragement emerged in fifteen percent (n = 2) of interviews referencing nurses/staff, and in 8% (n=1) of interviews referencing the physician. The single interview discussed feeling hurt that the physician was not sharing openly, implying that the physician understood that their child was not going to survive, and yet did not share this.

Encouragement

The theme of encouragement was designed similar to discouragement, encapsulating perceptions that physicians and/or nurses/staff fostered hope and encouragement toward outcome. The theme of encouragement emerged in fifteen percent (n = 2) of interviews referring to physicians, and in fifteen percent (n = 2) of interviews referring to nurses/staff. One family referred to the fact that being allowed to talk to their unconscious child, as if she was awake, was greatly encouraging.

Tests of Hypotheses

Pattern Coding

Once initial data had been summarized using first-level coding, pattern coding techniques, as described by Miles and Huberman (1994), were employed to establish themes and constructs existing among the data. Initial importance was placed on themes related to the research questions, in an effort to evaluate their validity.

Study Hypothesis 1

Parents who report feeling satisfied with their relationship with the physician will also report higher levels of satisfaction with communication, including clarity, consistency, and level of experienced comfort related to communication with the physician.

As families were not directly asked about their satisfaction level as part of the initial interview, a new thematic unit was constructed from the data. This satisfaction unit was comprised of three separate yet related themes found through the data, including: helpfulness, effort making, positive attribution such as ‘great’ or ‘nice.’ At least one of these three themes was present in a majority of the interviews (n = 12; see Table 2), with several interviews having more than one of these themes (n = 6). Interviews in which multiple themes related to satisfaction are conceptualized as representing higher levels of satisfaction. The theme of helpfulness was present in describing physician involvement in the majority (n = 7) of the interviews endorsing satisfaction. The theme of effort making, often used to describe the level of care provided by the physician, was discussed in five

of these interviews. Finally, the theme of relational descriptors, often used to describe the physician as “great” or “like part of the family,” was present in five of these interviews.

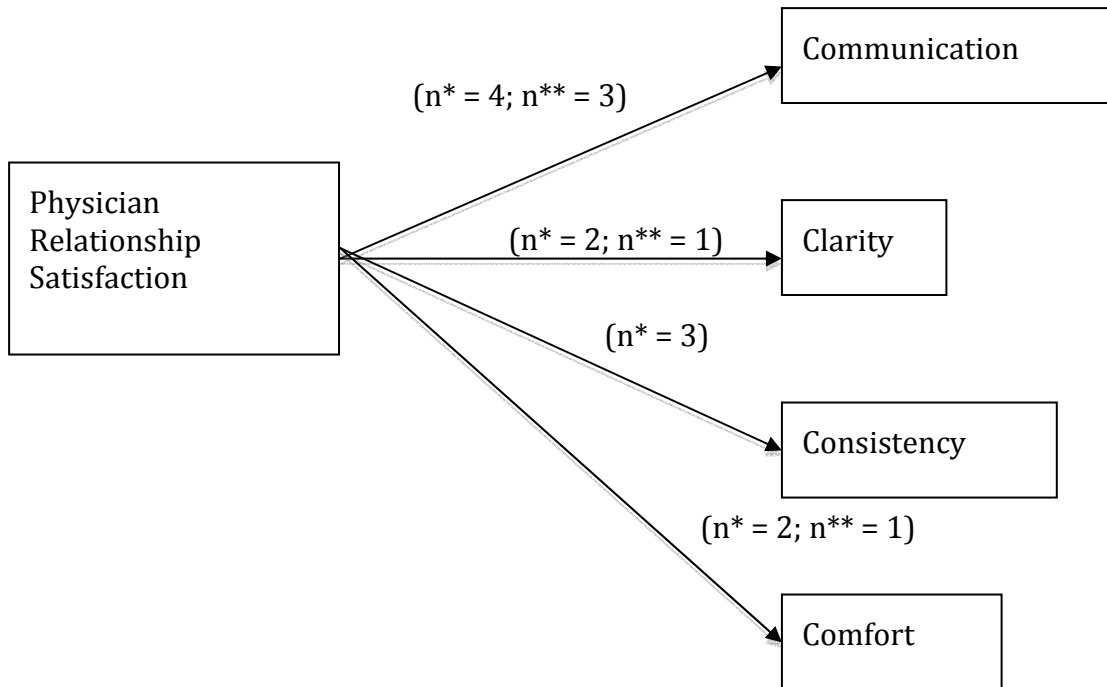
Of the families to report satisfaction with the physician, two major themes emerged, consistent with the research questions. First, communication in general was listed as an important factor in half of these interviews (n = 6). Within communication, the theme of clarity in communication was cited in half of the interviews (n = 3). Additionally, the themes of consistency in communication and also comfort related to communication were cited in three interviews each.

Table 2.

Frequencies of Positive Attributes

Positive Relational Attribute	n
Helpful	6
Did all they could do	5
Great	7
One Attribute	6
Two Attributes	6
Three Attributes	0

Of the families that discussed multiple attributes of satisfaction (n = 6), three made positive references toward physician communication, two made positive reference to clarity of communication, one made positive reference to consistency of communication, and one made positive reference to comfort related to communication with physician (see Figure 2).



* Pathway supported by families indicating a single positive relational attribute of the physician.

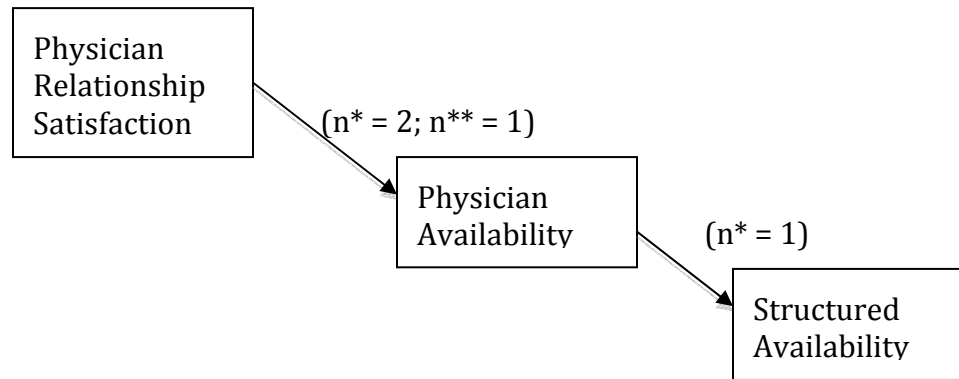
** Pathway supported by multiple positive relational attributes.

Figure 2. Strength of relationship between physician relationship satisfaction and communication, with components of communication including clarity, consistency, and comfort.

Study Hypothesis 2

Higher levels of reported relationship satisfaction with physician relationship will be correlated with higher levels of structured availability.

Using the created relationship satisfaction variable, twelve families were identified as expressing at least some level of satisfaction. Of these families, three family (n = 3) discussed physician availability, and one of the families described physician availability as structured. The families that did discuss availability answered questions briefly and without detail; however, specific mention was made of the consistency with which the physician communicated (see Figure 3).



* Pathway supported by families indicating a single positive relational attribute of the physician.

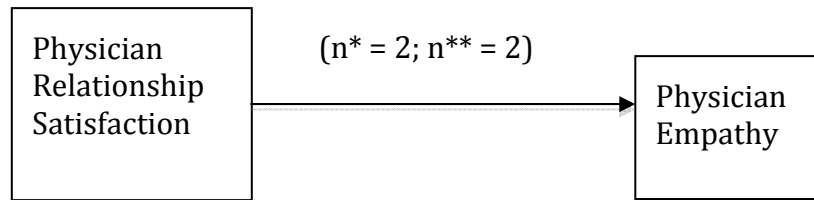
** Pathway supported by multiple positive relational attributes.

Figure 3. Model and strength of the relationship between satisfaction with physician relationship and physician availability, with structured availability as a subtype.

Study Hypothesis 3

Higher levels of reported relationship satisfaction with physician relationship will be correlated with higher levels of perceived physician empathy.

As described previously, families were not explicitly asked about their level of satisfaction with the physician; consequently, several empathetic variables were used to determine satisfaction, with twelve families meeting the criteria. Among these twelve interviews, five addressed empathy generally (PR-E), three addressed physician sincerity (PR-ES), two addressed physician encouragement (PR-EE), and one addressed physician presence (PR-EP). Overall, the themes of physician empathy emerged slightly less frequently than themes of communication (see figure 4).



* Pathway supported by families indicating a single positive relational attribute of the physician.

** Pathway supported by multiple positive relational attributes.

Figure 4. Strength of modeled relationship between relational satisfaction with physician and perceived physician empathy.

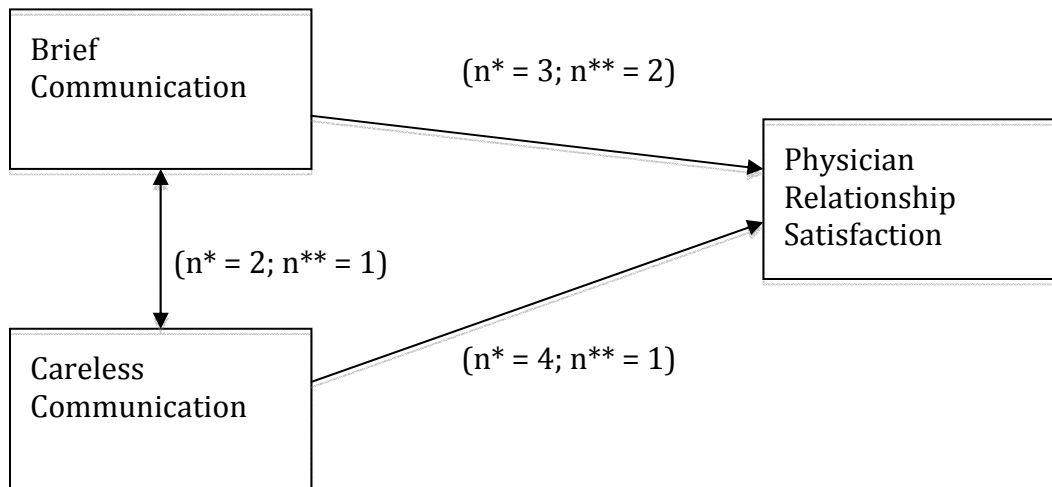
Study Hypothesis 4

Higher levels of brief and/or careless communication will be associated with lower levels of relationship satisfaction.

As previously described, families were not explicitly asked about their level of satisfaction with the physician; therefore several empathetic variables were used to determine satisfaction, with twelve families making positive statements in some form regarding feelings of satisfaction toward the physician.

Of the total number of interviews (n = 13), five discussed themes of brief communication, and six discussed themes of careless and hurtful communication. Additionally, four of the interviews discussed both themes. Of these interviews in which both themes were discussed, positive comments made toward relationship satisfaction included helpfulness (n = 2), doing their best effort (n = 1), and being described as “great” or “nice” (n = 1).

Of the interviews with multiple indicators of satisfaction (n = 5), two also had themes of brief careless communication, with one interview having both themes. This



* Pathway supported by families indicating a single positive relational attribute of the physician.

** Pathway supported by multiple positive relational attributes.

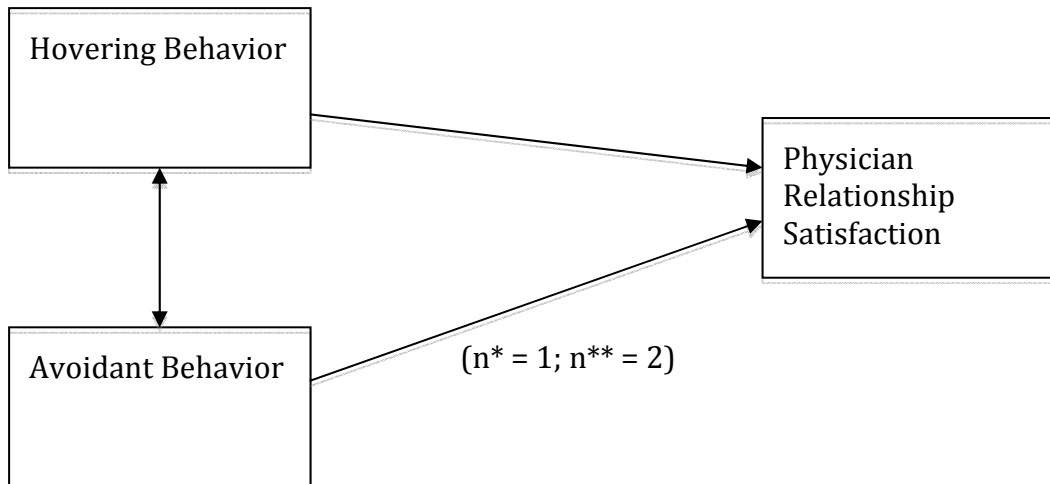
Figure 5. Strength of modeled associations between brief communication, careless communication, and satisfaction with relationship with physician.

pattern, of simultaneously having multiple positive and negative attributions, emerged in the field and will be further discussed later (see figure 5).

Study Hypothesis 5

Higher levels of hovering or avoidant physician availability will be correlated with lower levels of relationship satisfaction.

Families did not describe physicians as hovering or providing too much contact (n = 0). Themes of physician avoidance surfaced in three interviews, the majority of which were interviews in which single satisfaction indicators were present (n = 2). However, one interview revealed multiple indicators of satisfaction, relating how impressed the



* Pathway supported by families indicating a single positive relational attribute of the physician.

** Pathway supported by multiple positive relational attributes.

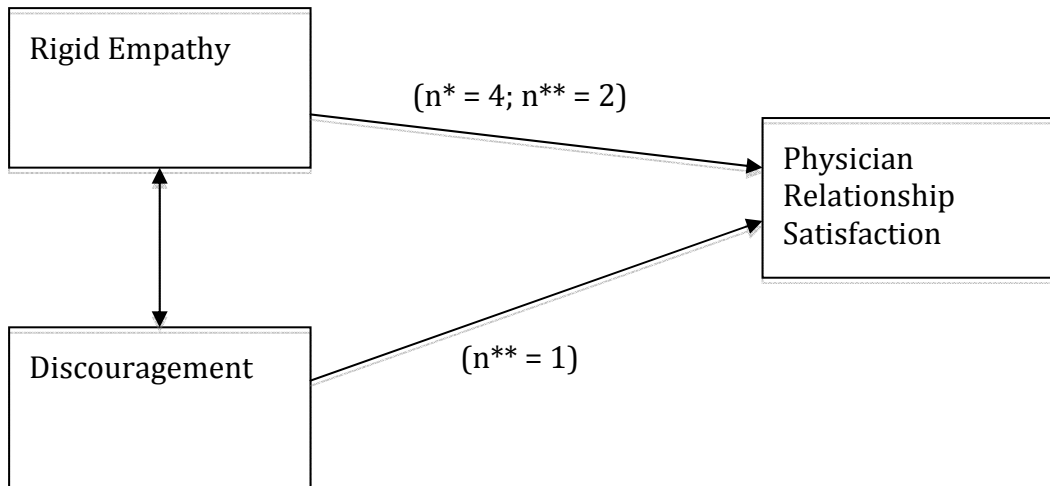
Figure 6. Strength of modeled pathways between perceptions of hovering behavior, avoidant behavior, and physician relationship satisfaction.

family had been that the physician had come in on Christmas to visit with their child (see figure 6).

Study Hypothesis 6

Higher levels of empathetic rigidity or discouragement will be associated with lower levels of relationship satisfaction.

Of the thirteen family interviews, six discussed themes of physician rigidity (n = 6) and discouragement (n = 1). The majority of these interviews also displayed minimal attributions of satisfaction with physician relationship, with three interviews citing only one attribution of the possible three different attributions, and one interview citing no attributions of satisfaction with physician relationships. However, two of the interviews



* Pathway supported by families indicating a single positive relational attribute of the physician.

** Pathway supported by multiple positive relational attributes.

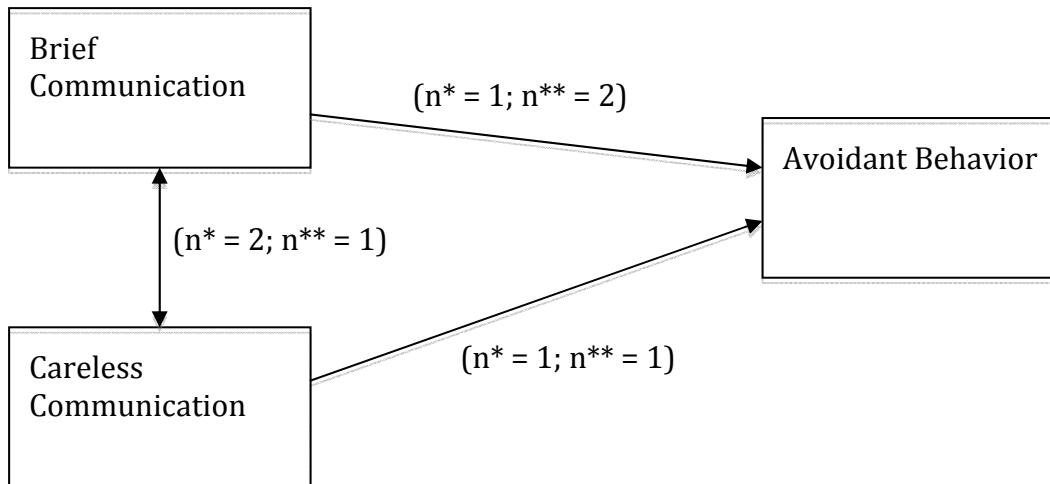
Figure 7. Strength of modeled relationships between empathetic rigidity, discouragement from physician, and physician relationship satisfaction.

which discussed physician rigidity, and the one reference to discouragement, also discussed multiple attributions of satisfaction (see Figure 7).

Study Hypothesis 7

Higher levels of brief/careless communication will be associated with higher levels of avoidant availability.

As previously discussed under hypothesis four, out of the total number of interviews ($n = 13$), five discussed themes of brief communication, and six discussed themes of careless and hurtful communication. Additionally, four of the interviews discussed both themes. Of these interviews in which both themes were discussed, positive



* Pathway supported by families indicating a single positive relational attribute of the physician.

** Pathway supported by multiple positive relational attributes.

Figure 8. Strength of modeled relationship between communication brevity, careless communication, and perceived physician avoidance.

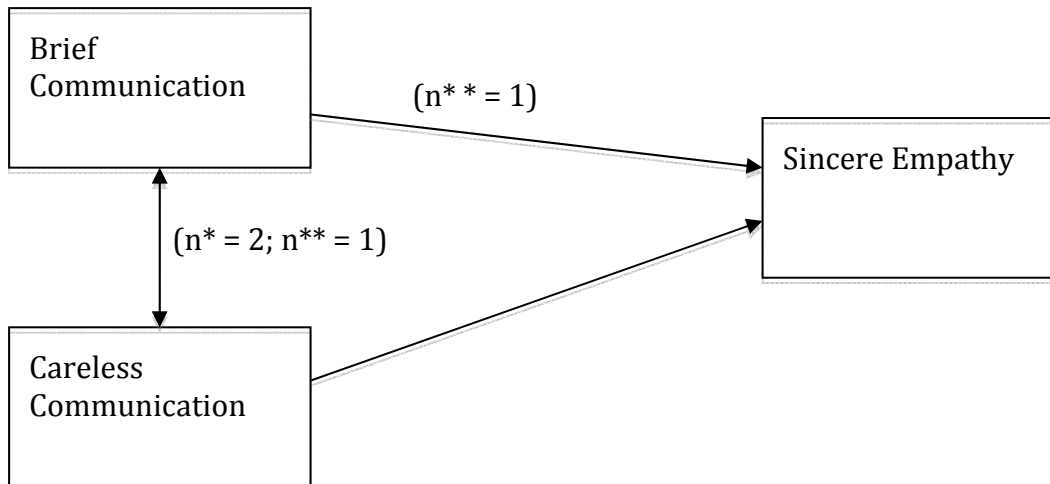
comments made toward relationship satisfaction included helpfulness (n = 2), doing their best effort (n = 1), and being described as “great” or “nice” (n = 1).

The theme of physician avoidance was discussed in three interviews, and three times it did surface in the same interview as did brief communication; twice with careless communication (see Figure 8).

Study Hypothesis 8

Higher levels of brief/careless communication will be negatively associated with physician’s perceived sincere empathy.

Scoring profiles for communication brevity and carelessness, as well as physician empathy, have been previously discussed in questions three, four and seven. Of the



** Pathway supported by families indicating a single positive relational attribute of the physician.*

*** Pathway supported by multiple positive relational attributes.*

Figure 9. Strength of modeled relationship between communication brevity, careless communication, and perceived empathetic sincerity.

thirteen interviews, seven discussed themes of communication brevity or carelessness.

Additionally, seven discussed themes of physician empathy, and three specifically discussed sincerity. However, of the three interviews that discussed sincere empathy, one also discussed communication brevity, and not one discussed communication carelessness (see figure 9).

Study Hypothesis 9

Higher levels of structured/consistent availability will be positively associated with higher levels of feeling prepared, clear communication, and sincere empathy.

The theme of structured and consistent availability (PR-AS) surfaced in only one interview, without the accompaniment of feeling prepared (PR-CPP), clear communication (PR-CCL), or sincere empathy (PR-ES). Feeling prepared appeared in

two of the interviews, clear communication appeared in four of the interviews, and sincere empathy appeared in three interviews. Additionally, these themes overlapped in only one interview, which discussed feeling prepared and clear communication.

Additional Patterns

While the study hypotheses were related to specific pattern constructs related to Attachment Theory or literary review, additional unanticipated patterns emerged from the interview data, and were examined.

Honesty

The theme of honesty, specifically a perceived lack of honesty, as pertains to communication with the physician, was discussed by two families (n = 2). Upon further pattern analyses, these families also both described physician communication brief (n = 2) and careless (n = 2), and one family endorsed communication as rigid (n = 1). Additionally, neither family recognized the positive attributes of empathy or communication clarity.

Familiar Caregiver

The theme of a single caregiver being present through treatment emerged in five of the thirteen interviews. Further analyses of these five interviews revealed that the majority experienced the physician as being rigid (n = 4). Also, more than half experienced the physician's communication as brief (n = 4) and careless (n = 3).

Additional emergent themes included comfort (n = 3), communication clarity (n = 2, and feeling prepared (n = 2).

Fluctuation

While the majority of families appeared to respond consistently , positively or negatively, about their relationship with the physician, four of the thirteen families displayed response patterns that appeared to fluctuate between these poles. Further analyses of these four families identified additional themes as including emotional rigidity (n = 3), careless communication (n = 2) and brevity (n = 2), and availability (n = 2).

The Odd Case

One family, of the thirteen participating, discussed no positive attributes of their relationship with the physician. Further analysis of this case indicated the recognition of the following attributes: brief and careless communication, and also emotional rigidity.

Quantitative Analyses

Questionnaire

A questionnaire was specifically designed to answer the research questions through quantitative data analyses. The content of the questionnaire was built on the foundation provided by a review of the literature, focusing on common themes including communication, availability, and empathy. Within these themes, additional input for the questionnaire came from first-level analyses of early interviews (n = 10). Once the

questionnaire was completed, augmenting the initial open-ended interview became the primary function. Due to the low number of completed questionnaires ($n = 3$), the data collected with this tool could not be used to evaluate the research hypotheses, however, it is being utilized in the larger ongoing study.

The questionnaire consisted of eleven items, each referencing some aspect of the research questions (see Appendix B). Each item was created on a 7-point, Likert-type scale, with 1 equal to 'Strongly Disagree', and 7 equal to 'Strongly Agree', so as to be treated as continuous data, appropriate for use with analysis of correlation.

The first item was drawn from themes of communication, with specific reference to clarity of communication. Communication in general was discussed in half ($n = 5$) of the initial interviews, and clarity of communication was referenced twice. This item was conceptualized as contributing to hypotheses 1 and 9.

The second questionnaire item referenced feeling prepared for what to expect as a result of communication with the physician. This theme emerged twice ($n = 2$) in the initial interviews, and is specifically referenced in the literature as being important to families. Also, this item was conceptualized as contributing to research question 9.

The third item on the questionnaire referenced specifically the theme of consistent communication. Again, this theme has been cited in the literature as being important to families. This theme emerged in 30% of the initial interviews ($n = 3$). Additionally, this item was conceptualized as contributing to hypotheses 1 and 9.

The fourth item referenced themes of brief or unhelpful communication with the primary physician. This theme was discussed in three of the initial interviews, and was thought to contribute to hypotheses 4, 7, and 8.

The fifth questionnaire item referenced careless or hurtful communication. This theme emerged in 40% (n = 4) of the initial interviews, and was conceptualized as contributing to hypotheses 4, 7, and 8.

The sixth item referenced perceptions of physician availability. Despite the literature's strong support for this theme, physician availability was discussed in general only once. The decision to include the item was based on the level of import ascribed in the literature. This item was conceptualized to contribute to hypotheses 2, 7, and 9.

The seventh questionnaire item referenced perceptions of physician avoidance. This theme emerged in three of the initial interviews, and was conceptualized to contribute to hypotheses 5 and 7.

The eighth item referenced perceptions that the physician was hovering, or over-involved in treatment. This theme never emerged in the initial interviews; however the item was included in the question based on its relationship to attachment-like behaviors as supported in the literature. Additionally, this item was conceptualized as contributing to hypothesis 5.

The ninth questionnaire item referenced perceptions of sincere physician empathy. The theme of empathy in general emerged in three of the initial interviews, while sincere empathy specifically emerged in two initial interviews. This item was developed to contribute to hypotheses 3, 8, and 9.

The tenth item referenced perceptions of empathic rigidity, and was referenced in 40% (n = 4) of the initial interviews. The item was conceptualized as contributing to hypotheses 6.

The eleventh and final questionnaire item referenced feeling that physician contact discouraged hope. This theme emerged in one of the initial interviews. The item was included due to empirical support, and was conceptualized as contributing to hypothesis 6.

Questionnaire Data

Due to the low number of completed questionnaires ($n = 3$), data from these questionnaires were not suited for the quantitative analyses for which they were originally intended. The means of these items are displayed in Figure 10. Note that item nine was omitted from the three administrations, resulting in no data for this item.

Of the items with which families expressed the strongest agreement, the two highest implied strongly contrasting experiences with physicians. On the first item, families highly agreed that the physicians communicated clearly with them ($\bar{x} = 5.33$, $SD = 2.89$). The second statements, which families agreed with to the same degree, described having felt that the physician did not want the family to have hope ($\bar{x} = 5.33$, $SD = 1.53$). The third item most highly agreed with represented families who felt that communication with the physician was brief and not helpful ($\bar{x} = 4.67$, $SD = 3.22$).

The two questionnaire items most strongly disagreed with do not appear to be conceptually related. On the first, families appeared to disagree with the statement that they felt prepared for what would happen with the course of treatment due to communication with the physician ($\bar{x} = 1.00$, $SD = 1.00$). On the second item, families disagreed with the statement that physicians were too present ($\bar{x} = 1.33$, $SD = 0.58$).

The remaining items revealed weaker levels of agreement or disagreement, with the majority expressing attitudes of agreement. Families tended to agree with the statement that their physician was available an appropriate amount of time ($\bar{x} = 4.00$, $SD = 2.65$). Families also appeared to agree with the statement that they perceived their physician as rigid, factual and uncaring ($\bar{x} = 4.00$, $SD = 2.00$). Additionally, families agreed with the statement that their physician communicated consistently with them ($\bar{x} = 3.67$, $SD = 2.89$). Also, families tended to agree with the statement that the physician avoided themselves or their child ($\bar{x} = 3.67$, $SD = 2.52$). Finally, families tended to disagree with the statement that they felt hurt because of careless comments made by the physician ($\bar{x} = 2.67$, $SD = 3.79$).

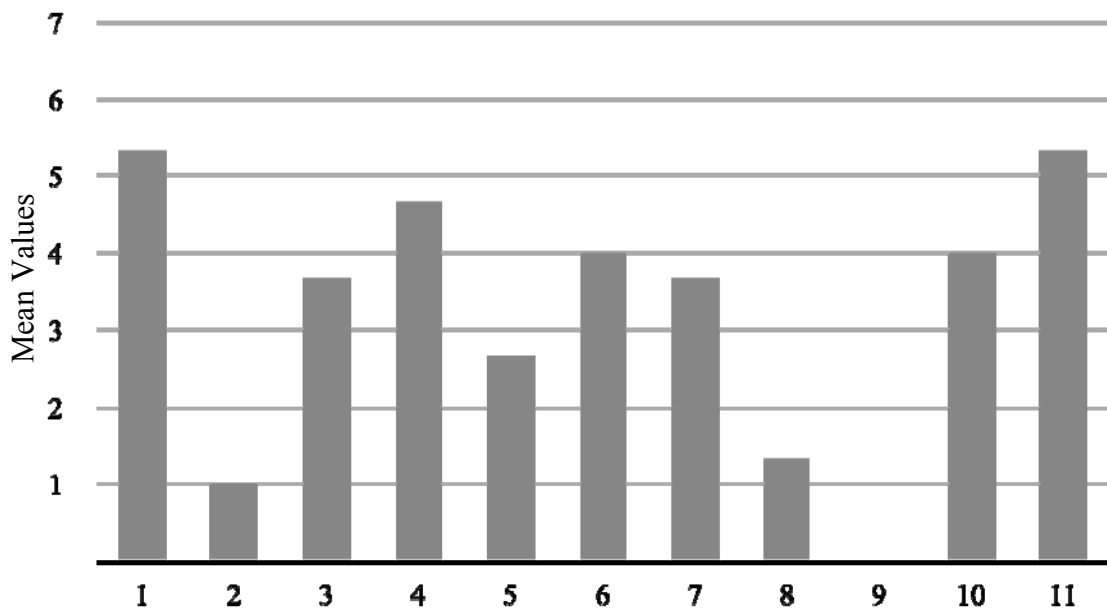


Figure 10. Mean responses to questionnaire items.

CHAPTER FOUR

DISCUSSION

While support grows for the hypothesis that grief experienced by parents at the loss of a child can potentially be blunted by the parent's relationship with the physician (Gerretsen & Myers, 2008; Tan, Zimmermann, & Rodin, 2005), little is known about the factors predicting positive or negative experiences of this relationship from the point of view of the parent. The function of this study was to identify important factors at work, as well as to gain an understanding of the relationship these factors have with each other.

Hypotheses Findings

Hypothesis One

The first hypothesis stated that families who felt satisfied with their relationship with the physician would also be satisfied with their experience in communicating with the physician. Additionally, these families would regard more specific attributes of the physician's communication style as positive, including the clarity of the communication, the consistency with which they were able to communicate with the physician, and the comfort experienced by them as a result of communicating with the physician.

This hypothesis functioned on two layers, both of which were confirmed to a degree. The first presupposition was focused on a positive relationship between satisfaction with the physician and communication, and this pathway was indeed confirmed by at least half of the families.

The second layer of the hypothesis focused on the more specific attributes which are conceptualized as the properties that build strong communication. Each of these-- clarity, consistency, and comfort--were clearly discussed by about one quarter of the families. Although these attributes were not discussed as frequently as was communication in general, they do provide evidence of the existence of a positive relationship with the physician, of satisfaction, and thereby they present additional support to the hypothesis.

These findings represent a significant convergence of theory and data. The role played by communication, and specifically positive communication, as a key experiential predictor of relations as rated by patients and families, is overwhelmingly supported in the literature (Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Friedrichsen, Strang, & Carlsson, 2000; Lo & Quill, 1999; Mack, et al., 2005; Schofield, Carey, Love, Nehill, & Wein, 2006; Steinhauser, Christakis, et al., 2000; Thompson & Ciechanowski, 2003; Tan, Zimmermann, & Rodin, 2005). This convergence indicates that the feelings expressed by this sample are similar to those expressed by peers, indicating the sample, despite the size, is representative of a larger cohort.

Hypothesis Two

The second hypothesis stated that families who were satisfied with their physician would also speak positively of the physician's structured availability in meeting their needs. Data from these family interviews did provide evidence for this relationship, as one of the families discussed these attributes of the physician.

The presupposition of this hypothesis maintained that families would positively discuss the physician as being available to a satisfactory degree; however this discussion appeared in one quarter of the interviews, or half as frequently as communication, perhaps indicating that physician availability is not as important or pressing as is physician communication. This point is further emphasized by the infrequency with which families recalled the pattern of physician availability as being structured. However, the lack of emphasis placed on physician availability may shift in the future, as the rearranging of roles in the medical environment is set to diminish the physician's ability to follow the patient throughout treatment, as well as the ability to be available to the patient.

Hypothesis Three

The third hypothesis supposed that families' level of satisfaction with the relationship they had with the physician would correlate with seeing the physician as more empathetic. As with communication, about half (n = 5) of the families that spoke positively about their relationship with the physician also discussed the physician as being empathetic in some respect, be it sincerity, encouragement, or presence. This emphasis on empathy provides clear support for the hypothesis.

The role of physician empathy has found less explicit support in the literature than has communication. In fact, most frequent references to empathy are made within the context of empathetic communication (Mack, et al., 2005). One possible reason for this difference may be the difficulty associated with assessing experiencing with empathy, as

opposed to communication. The construct of empathy is highly abstract, posing a challenge for raters to define, and a further challenge for participants to articulate.

These findings may represent the clearest evidence of understanding the role of an empathy construct that is independent of communication, or another construct.

Hypothesis Four

The fourth hypothesis stated that families who observed communication with the physician as being brief or careless would also express less satisfaction with their relationship with the physician. Although families frequently discussed communication with the physician as being brief, they also generally had multiple positive attributions to share regarding their relationship with the physician. This observation may indicate that brevity of communication is not as detrimental to the relationship as are other factors.

Careless communication was discussed by almost half of the families, and not one of these families shared more than one positive attribute of their relationship with the physician. Based on these comments, it would appear that perception of careless communication is observably more detrimental to the family-physician relationship than other factors, including brevity.

This delineation between forms of negative communication provides insight into what families are able to endure while attempting to maintain a positive relationship with the physician. Families appear able to accept communication that is less than what they expect. Perhaps a physician who is brief and abrupt remains easier for the family to conceptualize as someone who can or will help, as opposed to the physician who is

perceived as careless or hurtful. Perhaps the hope that families struggle to maintain is better fostered by brief communication, where little news may not be bad news. The distinction between careless communication and other negative forms of communication becomes critical, as the powerfully erosive nature of careless communication appears to distinguish this construct from others. In differentiation between brief and careless communication, the nuance may be in the information being delivered. Perhaps, when situations become dire, a communication style that was once viewed as brief, now is perceived as careless. What is exceedingly evident is the need to better understand careless communication, and what attributes are working together to form this construct.

Hypothesis Five

The fifth hypothesis stated that families who perceived the physician as being either over-involved in the treatment of their child or, on the other extreme, being avoidant of the family, would be less satisfied with their relationship with the physician. Of the thirteen interviewed families, not one described the physician as hovering or being over-involved. Of the possible explanations for this, one may be that families are not significantly distressed when the physician is over-involved. Perhaps, when concerned with the wellbeing of their child, no amount of contact with the physician is too much contact.

Conversely, the majority of families who observed the physician as being avoidant also had fewer positive attributions to make regarding their relationship. The families were not asked to describe the amount of contact they had with the physician,

and the variance between families' perceptions of what 'avoidance' equals is likely large. Unlike with careless communication, perceptions of avoidant behavior did not stop families from noting multiple positive attributes in the physician. This may indicate that, such as with brief communication, perceived avoidant behavior from the physician will not necessarily derail the physician-family relationship.

Hypothesis Six

The sixth hypothesis stated that families to who described their physician as uncaring, distant, or discouraging would also describe themselves as being less satisfied with their relationship with the physician. Of the thirteen families interviewed, one family discussed feeling discouraged by the physician. Additionally, this family had multiple positive attributions to share about the physician. This may indicate that discouraging communication, like brief communication and avoidant behavior, may not be as detrimental to the physician-family relationship as are other behaviors.

The majority of families who perceived the physician to be rigid and uncaring also had fewer positive attributes to share regarding their relationship. About one-third of these families were also able to share several positive attributes, implying that their relationship may not have impaired their perceptions. While this evidence suggests that perceived rigidity may not completely erode the relationship between family and physician, it will do damage to a majority of these relationships.

Hypothesis Seven

The seventh hypothesis postulated that families who frequently observe their

physician as engaging in brief or careless communication will also observe their physician as being avoidant of their family. Brevity and carelessness of communication were each discussed by families twice as frequently as were perceptions of avoidance behavior. However, a fair number of families who discussed brevity or carelessness did also discuss avoidant behaviors, suggesting that the hypothesized relationship between these constructs indeed exists.

A possible explanation of this relationship is that families, who view the physician as careless, also view the physician as avoidant, because critical experiences have predisposed these families to view all or several aspects of care in generally negative terms. Should this be true, a better understanding of what these critical experiences consist of is required. Given that understanding of careless communication is limited, the possibility remains this construct operates on an independent continuum, with more severe levels of careless being associated with concomitant experiences of avoidant behavior on the part of the physician. Additionally, as discussed previously concerning physician availability as relates to future medical practices, this theme may play an increasing role in patient/family satisfaction with care.

Hypothesis Eight

Building further on the empirically supported role of brief and careless communication as being critical to the physician-family relationship, the eighth hypothesis stated that families who frequently observe the physician as being brief or careless in communication will less frequently observe the physician as being sincerely empathetic. The roles of communication brevity and carelessness have been previously

discussed at length. The importance to families of physician empathy, referenced as including physician presence, encouragement, or sincerity, was observed in the majority of the family interviews. What is most interesting about these constructs is the pattern with which families responded. While seven families perceived the physician as being careless in communication, and seven families discussed the physician as being empathetic in some way, only one family discussed both. This unambiguous division among participating families provides clear support for the eighth hypothesis.

The detrimental and long-lasting effects of negative communication have been well documented (N. Contro, et al., 2002). This stands in vivid contrast to effects related to physician empathy, about which much less is known. As previously discussed, empathy is an abstract construct, difficult to measure or articulate, and typically associated with communication in the literature (Mack, et al., 2005). However undefined, this empathetic construct clearly encapsulates data having the unique characteristic of lacking the stronger negative attributes of communication.

One theory with which to explain this relationship is that empathy and careless communication somehow each represent the sum total of overall positive or negative satisfaction with care. Families who experienced their physician's as empathetic were unable to also view the physician as careless. Contrarily, families who experienced the physician as careless were unable to recall empathetic attributes. Apparently, these two constructs are unable to tolerate each other, and so do not coexist.

The outstanding nature of these findings declare the need for improved understanding of each construct. Additionally, further support is provided for the

importance of empathy to be conceptualized as an independent construct, without need of association with communication or other more supported constructs.

Hypothesis Nine

The ninth and final hypothesis of this study postulated that families who observe the physician making himself/herself available to the family in a structured or consistent manner would, would also be more likely to discuss attributes of communication including clarity and feelings of preparedness, and will also perceive the physician as being empathetic and caring. As only one family discussed the physician's availability as being structured, and this family did not describe the physician's communication or level of empathy, no support for this hypothesis was found. One reason for the lack of support may be that hypothesis was hinged on the presumption that structured availability would be a theme popularly discussed by families. As this is not the case, little opportunity for discovering a relationship between these concepts was provided.

Literary Integration

Communication

The overarching theme of communication received a great deal of attention in the literature as playing a key role in the physician-family relationship, through several differing avenues (Hays, et al., 2006; Mack, et al., 2005; Steinhauer, Christakis, et al., 2000). In agreement with this, communication was the most strongly supported of the themes discussed by participants, indicating a strong consistency between the disclosed

concerns of the families participating in this study and the participants of other studies previously discussed.

Within communication, the theme of consistency was strongly emphasized and in an inverted yet harmonious relationship with the literature. Specifically, the previously discussed study by Mack (et al., 2005) emphasized that families who received inconstant communication from hospital staff thought less of the quality of care they had received.

The strength with which the theme of comfort was discussed by families may serve as an indicator of steps taken by medical training programs in recent years. Contro, Larson, Scofield, Sourkes, and Cohen (2004) found that a number of medical student reported feeling that they were not skilled at comforting patients and families in EOL situations. The results of these analyses indicate that the comfort experienced by families resulting from contact with the physician was indeed relevant.

The emergence of the theme of communication clarity offers additional support to the underlying theoretical framework. As stated in a study by Steinhausser (et al., 2000), upon review of their own experiences with treatment, patients identified clear communication as one attribute mediating between positive and negative experiences.

Taken together, the validation of these communication themes provides evidence for the validity of this study. Specifically, the consistency with which participants agreed with those in the literature base suggests a representative sample.

Empathy

The emergence of the theme of empathy as pertinent, yet with less frequency than communication, mirrors the literature. Although several studies have identified physician

empathy as being important to families (Mack et al., 2005; Tan, Zimmermann, & Rodin, 2005), the role of communication is emphasized in a majority of studies. The role of encouragement in building empathy has been discussed in the literature (Holmberg, 2006; Skilbeck & Payne, 2003), and is supported by these results.

Availability

The role of physician presence, or availability, has also been linked to empathy, and ultimately to communication (Zachariae et al., 2003) as being a predictor of patient/family satisfaction. This relationship is supported by the frequency with which these themes were spontaneously addressed.

A unique characteristic of the PICU setting, as contrasted with other types of units, is that a physician is consistently available to patients and families. This fact may have influence on study participant's ratings of physician availability, as many had their experiences in such an environment. However, this may not be true in the future due to shifting trends in the allocation of care providing, negatively impacting this vulnerable physician-patient/family relationship.

Emergent Themes

In addition to the theoretical and empirically supported relationships having been presupposed, interest in further themes has developed from these results, for varying reasons.

Resiliency

Authors have discussed the detrimental effects of careless communication on the family/physician relationship (Tan, Zimmermann, & Rodin, 2005; Tinsley et al., 2008), and while the existence of this relationship has been further supported in these results, further information is suggested concerning the strength with which careless communication can erode relationships.

While several factors have been found detrimental, such as empathic rigidity and poor availability, these factors appear to be tolerated by family in the presence of other, positive factors. For example, families, who observed the physician to be avoidant of their family, were still able to discuss positive attributes of the physician, provided the physician displayed positive communication techniques. However, when the families reported incidents of careless communication, they were less able to discuss their relationship with the physician as being positive, despite the presence of other positive attributes.

This inter-attribution dynamic suggests new details about the family/physician relationship. First, these factors, positive and negative, appear to be weighted in their influence on the relationship. The presence of a single negative attribute, with perhaps the exception of careless communication, does not necessarily appear to doom the relationship. Instead the influence of these attributes appears to be additive, such that the accumulation of experiences will paint the relationship, positively or negatively. Additionally, some positive attributes appear to be protective in that when they are present, families are more resilient in their ability to remain positive even while exposed to negative experiences.

Honesty

The emergent theme of honesty perhaps more accurately conceptualized as dishonesty, was discussed by two families, who upon further analyses made several negative attributions toward their relationship with the physician, while making very few positive attributions. One family made the following comment:

' ... I don't know if the doctor was completely honest in telling us what was going on. I mean, despite that she couldn't give us answers they were pretty much gone... I would rather them be straightforward rather than be misleading. ' (Interview 03).

Although the theme of dishonesty only emerged in two interviews, the other themes with which it appears to be associated suggest that this theme may be powerfully destructive to the family/physician relationship. As previously discussed, careless communication has emerged as the strongest predictor of poor relationship satisfaction, and it emerged in every interview discussing perceived dishonesty. Additionally, each family that discussed dishonesty also described communication as being brief, and half of the families described the physician as being rigid or uncaring.

The importance of honesty as being constructive, or, inversely, destructive to the family/physician relationship has been explored (Bradley & Brasel, 2008; Fallowfield, Jenkins, & Beveridge, 2002). In a qualitative analysis of interactions between physicians, nurses and patients, Fallowfield, Jenkins, and Beveridge (2002) discussed some of the potential reasons why staff may be less than truthful with their patients. The discussion included assumptions on the part of staff that the truth may negatively impact treatment outcomes, or encourage relapse. Additionally, the authors discuss elevated feelings of

confusion, anxiety, and fear that patients may experience when they perceive the truth as being withheld.

Caregiver Familiarity

Families referred to having a single caregiver whom they identified as being involved in treatment throughout the process. These caregivers included doctors, nurses, and social workers. This theme emerged in a significant number of interviews (n = 5), and is supported in the literature as being important to families receiving palliative care services (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Friedrichsen, Strang, & Carlsson, 2000).

The pattern with which this familiar caregiver theme emerges with other themes appears to imply possible coping mechanisms on the part of families. Specifically, eighty percent of the families discussing this theme also described the physician as rigid with brief communication (n = 4). Additionally, the theme of careless communication, with relationally destructive properties previously discussed, was highly represented at sixty percent of interviews (n = 3). Comparatively, these families reported fewer positive attributes of the physician, with those reported including communication, comfort, clarity, and feeling prepared. The majority of these families, eighty percent (n = 4), identified the familiar caregiver as a non-physician (nurse, n = 3; social worker, n = 2). This pattern may indicate that families who are experiencing obstacles in their relationship with the physician may be prone to reach out toward other staff to meet their emotional needs.

Fluctuation

The theme of fluctuation represents the response pattern of families (n = 4) who oscillated between discussing positive and negative attributes of their relationship with the physician. This pattern appears to emerge in the presence of a combination of negative attributes including emotional rigidity and careless communication, as well as brief communication and physician availability. The thematic pattern of fluctuation may be indicative of a disorganized attachment style, or may simply represent families who struggle to remain positive despite the presence of negative experiences.

First-level Physician/Staff Thematic Discrepancy Analysis.

Although family's attributions of the relationships with nurses, social workers, chaplains, and other staff was not of primary focus, the emergent theme of the familiar caregiver warrants further examination of these relationships (see Table 1). While families made similar attributions to physician and staff on the majority of themes, there are several, including availability, empathy, and presence, which are dramatically different. Availability was referenced to nurses/staff by ten families, while only three families made the reference toward physicians. The conceptually similar theme of presence was also attributed to nurses/staff far more frequently than to physicians. This discrepancy may be accounted for by the difference in professional roles, such that some roles (i.e., nurses) may have frequent interaction with families, while the roles of other (i.e., physicians) limit the frequency with which family interaction can be made.

Families' attribution of nurses/staff displaying empathy more frequently than physicians cannot be easily explained as a consequence of professional role. However,

the importance of contact in developing empathy has been emphasized (Lo & Quill, 1999; Schofield, Carey, Love, Nehill, & Wein, 2006). Therefore, the assumption may be made that nurses and staff, having increased opportunity for contact with the patient and family, would thereby be more apt to develop a relationship with empathetic attributes. This fact may be critical when designing a rounded treatment team with the purpose of meeting the families' emotional needs.

The Odd Case

One interview, which offered no positive attributes of the physician, warrants further analysis. In this interview, the commonly discussed relationally negative themes of communication brevity and carelessness and emotional rigidity are present, and in the absence of any positive, possibly protective themes. Additionally, the attributions made to nurses/staff are also negative, for the most part. These nurse/staff themes included careless communication, empathetic rigidity, and discouragement, also lack of both availability and empathy.

There are many possible explanations for this pattern of responses. As discussed, families who have difficulty having their emotional needs met via their relationship with the physician appear to reach out to staff. However, if the family continues to have needs unmet, the result may resemble this pattern, which could be described as a complete detachment from medical personnel. Instances such as these require further examination, as the likelihood of long-term negative consequences for the family are likely.

Limitations

A significant limitation of the current study, a limitation that commonly plagues palliative care research (Kaasa & Radbruch, 2008), was the small size of the sample. Several explanations are available to help account for this. First, the topic can be traumatic for family to relive, and exposing a family to the memories and emotions surrounding the loss of their child is not without risk. Not surprisingly, therefore, more than one family, having initially agreed to participate, later declined after reviewing consent and the topic to be discussed.

Another explanation for the low amount of participation is avoidance. Some families, while willing to discuss the topic of losing their children, choose to avoid any interaction with hospital representatives. As families may not be in good financial standing with the hospital, they may take care to avoid the calls of those who might be making inquiries. Billing, insurance and payment status information were not collected as part of the current study; therefore it is impossible to determine how many, if any, of the possible participants were in good standing at the hospital they had utilized. The high frequency of unanswered calls may speak to this explanation.

An additional explanation for the low participation is the high frequency of disconnected phone numbers. As families were being contacted as long as a year after hospital records were updated, many might have moved or made other transitions. Also, families may have changed numbers in an effort to avoid bill collectors working on behalf of the hospital.

A second limitation of this study is due to the retrospective design. As all data were based on recollections ranging from six to twelve months, the recall bias of the information provided remains a noteworthy concern.

A third limitation is the representation of sample. Due to the exploratory nature of the study, demographic and socioeconomic factors were not pertinent. In addition, participants were self-selected in that each did not elect to refuse participation. Consequently, participants may have shared other, unmeasured attributes, such as ability to constructively process feelings of grief and loss.

Finally, a limitation with any qualitative research is vulnerability to experimenter bias (Miles & Huberman, 1994). The convergence of key findings with the literature -- for example the prominence of communication -- may suggest a tendency of the experimenter to select self-supporting data. However, the presence of non-convergence in several hypothesized constructs provides support for the objectivity of the experimenter.

Clinical Implications

Implications of these results apply to several areas of training and professional behavior and awareness. First, importance is stressed for physicians to understand that their relationships with patients and families are not only impactful in the short-term, influencing compliance and treatment adherence (Ciechanowski, Katon, Russo, & Walker, 2001; Zachariae et al., 2003), but also affecting long-term issues such as parental grief and loss.

Second, import is placed on recognition that the physician-patient/family relationship is resilient: physicians who show some positive attributes (e.g., positive

communication, availability) and who displayed negative attributes (e.g., brief communication, rigidity) were still regarded by families in a positive manner. Physicians would do well to understand that they can make mistakes and still be viewed as good physicians. However this grace appears to extend only so far, for the perception of being careless will damage this delicate relationship.

A third domain of clinical implications relates to the training of new medical residents and the importance of learning appropriate communication skills. Positive communication skills have been linked to improved compliance and treatment adherence (Ciechanowski, Katon, Russo, & Walker, 2001; Zachariae et al., 2003), and are linked now to patient/family satisfaction and positive relations with patient and family. Additionally, building communication skills sets to discuss difficult topics, including morbidity and mortality, will enhance the physician's sense of competency with these critical topics, previously cited as being an area of concern (Bagatell, et al., 2002; N. A. Contro, et al., 2004; Himmelstein, et al., 2004).

Future Research

While these results have served to confirm many of the positive and negative attributes associated with families' experiences with a physician, the existence of an additive hierarchy of these attributes is suggested. Although several negative attributes of physicians were identified, including brief communication and empathetic rigidity as examples, the presence of these did not necessitate an overall negative relationship with the physician. However, other attributes such as careless communication, were found to be associated with lower relationship satisfaction, suggesting that the presence of this

attribute does more to damage the relationship. Taken together, this evidence suggests that the presence of certain positive attributes can buffer, or protect, against certain negative attributes, with some negative attributes being more difficult to protect against than others.

Although this protective hierarchy may exist, our understanding based on these results is immature. Further research is required to clearly establish the positive and negative factors at work. Once the individual factors are unmistakably delineated, establishing the weight each plays in influencing each other factor, as well as the final relationship, will be fundamental.

Future research will benefit from the development of precise instruments designed to measure perceptions of satisfaction, as these perceptions play a significant and multifaceted role in treatment outcome. Additionally, capturing the perceptions of physicians and staff members toward treatment will provide an even greater understanding of the interplay between patient/family and physician/staff attachment behaviors. Also, as the attachment needs of patients and families can vary so widely, the ability to recognize and measure these needs on a case by case basis, and in an organized fashion, would be a significant gain in the field.

Revised Questionnaire

The initial questionnaire was developed in part by a review of relevant literature, and in part by first-level analyses of early interview data. The themes of the original questionnaire included communication, availability, and empathy. As data

analysis progressed, additional themes became prominent, demanding to be recognized on the questionnaire. These new themes included physician honesty, care provider consistency, and experiential consistency. In addition, new items were added specifically addressing family satisfaction regarding the key themes of availability, empathy, and the overall relationship with the physician. The revised questionnaire can be found in Appendix C.

The exploratory nature of the study served as a limitation of the questionnaire. First, the questionnaire is designed to measure previously unexplored constructs; and, as understanding of these constructs improves, the questionnaire must adapt likewise, becoming an increasingly precise measure. Additionally, again due to the exploratory nature of the study, demographic and socioeconomic items were not included on the questionnaire. This decision was influenced in part by the nature of families' strong feelings and memories elicited through experiencing the measure, with interest in limiting the length of the questionnaire.

The revised questionnaire has been adopted as part of the larger multi-site study, and will aid in the collection of quantitative data, to be used in future analyses.

Conclusion

While a number of the study hypotheses were supported with varying degrees of clarity, the support of others remains ambiguous. The complex network of factors serving to cloud these results, including the limitations of the study, will require further exploration, however this study elucidates the need for further research in pediatric palliative care, particularly as it relates to physician-caregiver relationships.

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APPENDIX A

EXPLORATION OF THE EXPERIENCES OF PARENTS

REGARDING THE DEATH OF THEIR CHILD

Interview Questions

1. Please describe when and how you became aware that _____ (insert child's name) might not survive their illness?
2. Was there anything that happened or a moment when you knew that (insert child's name) was not going to survive?
3. What things in the PICU helped you and your family? For example: people, processes, or systems*?
4. What things were not helpful to you and your family?
5. What things helped (insert child's name) during his/her experience?
6. What things were not helpful for (insert child's name)?
7. Please describe your hospital experience when (insert child's name) died?
8. Immediately after (insert child's name) death, was there anything that was helpful to you and your family from the hospital or people taking care of your child?
9. Was there anything that was not helpful?
10. What advice or recommendations would you give hospitals, doctors, and nurses taking care of dying children and their families?

Examples of people, processes, and systems:

People: - nurses, doctors, social workers, therapists, child-life specialists, chaplains, other medical consultants

Processes: -visiting, baths and bed changes, medical procedures, rounds, medications, pain and symptom management, staffing and continuity of care

Systems: Communications (with medical/nursing staff), accommodations for parents and visitors, access to transportation, information, food, etc.

APPENDIX B
QUESTIONNAIRE

“*Please rate your agreement with the following statements on a scale of 1 to 7, with 7 being “highly agree” and 1 being “highly disagree””:

*Note: Follow up scores of 1,2, 6, or 7 with: “Please tell me more about why you feel this way?”

11. “The primary physician communicated clearly with me”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

12. “I felt prepared for what would happen, with the treatment and illness, because of communication with the physician.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

13. “I feel that the physician communicated consistently with me.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

14. “I feel that communication with the physician was brief and not very helpful.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

15. “I felt hurt because of careless comments made by the physician.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

16. “I feel that the physician was available an appropriate amount of time.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

17. “I felt that the physician avoided my family or my child.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

18. “I feel that the physician was too present.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

19. "I feel that the physician was sincerely concerned with the well-being of my family."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

20. "I feel that the physician was rigid, factual and uncaring."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

21. "I feel that the physician did not want me to have hope."

1	2	3	4	5	6	7
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APPENDIX C

REVISED QUESTIONNAIRE

“*Please rate your agreement with the following statements on a scale of 1 to 7, with 7 being “highly agree” and 1 being “highly disagree”:

*Note: Follow up scores of 1,2, 6, or 7 with: “Please tell me more about why you feel this way?”

1. “The primary physician communicated clearly with me.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

2. “I felt prepared for what would happen, with the treatment and illness, because of communication with the physician.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

3. “I feel that the physician communicated consistently with me.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

4. “I feel that communication with the physician was brief and not very helpful.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

5. “I felt hurt because of careless comments made by the physician.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

6. “I felt satisfied with the way the physician communicated with me.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

7. “I feel that the physician was available an appropriate amount of time.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

8. “I felt the physician avoided my family or my child.”

1	2	3	4	5	6	7
---	---	---	---	---	---	---

9. "I feel that the physician was too present."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

10. "I felt satisfied with the physician's availability to me."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

11. "I feel that the physician was sincerely concerned with the well-being of my family."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

12. "I feel that the physician was rigid, factual and uncaring."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

13. "I feel that the physician did not want me to have hope."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

14. "I felt satisfied with the physician's level of empathy toward my family."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

15. "I felt comforted as a result of communication with the physician."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

16. "I felt that the physician was honest with me."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

17. "I would prefer to learn information from a consistent, familiar care provider."

1	2	3	4	5	6	7
---	---	---	---	---	---	---

18. "I felt that my experience with the physician, positive or negative, was consistent and did not change throughout the treatment process."

1	2	3	4	5	6	7
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19. "I feel satisfied with my relationship with the physician."

1	2	3	4	5	6	7
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