

The Role of a Medical Family Therapist: An Ecological Systems Look at Pediatric Illness

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ABSTRACT

This research explores the question of what role medical family therapists play on a health care team when working with serious pediatric illness. Seven participants from three different health care settings were interviewed. Results were organized within the ecological systems framework (Bronfenbrenner, 1979) according to the various ways participants became a part of the family's illness experience. Participants identified roles directly with the family, with the health care team, and within the larger health care system. Clinical implications are identified concerning the preparation of the health care system for the continued growth and evolution of the field of medical family therapy.

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Chapter One: Introduction

Problem and Setting

Parents' expectation when entering parenthood is that their children will outlive them and their hope is that their children will be healthy and happy. Illnesses are expected to come and go, and the diagnosis of a chronic, life-threatening pediatric health condition disrupts the family life cycle, forcing all family members to adjust to the new reality of pediatric illness. Despite advances in the medical field which have improved survival rates, hundreds of thousands of families are faced with these health conditions every year. Ten thousand new pediatric cancer diagnoses were expected in 2008 (National Cancer Institute, 2008), 165,000 children are hospitalized each year for brain injuries (Centre for Neuro Skills, 2009), and over 3 million children in the United States have special health care needs that require out of the ordinary medical, mental health, and prescription medication services for long periods of time, sometimes throughout the lifespan (Data Resource Center, 2006).

According to the National Coalition on Health Care, "national health care spending is expected to reach \$2.5 trillion in 2009, accounting for 17.6 percent of the gross domestic product" (2009, p. 1). These numbers are clear: health care is expensive and is impacting the entire United States economy. By nature of their diagnoses, children with chronic, life-threatening conditions require more services than are routinely required, and more services means more money spent. One way to reduce the expense of health care would be to reduce the utilization of health care services. Family therapy is one evidenced way to achieve this reduction (Law & Crane, 2000). In a population of average people requiring no special health care services, Law and Crane found that patients showed a 21.5% reduction in their use of services after receiving family therapy. For those who are high utilizers of health care, such as children with chronic health conditions, the differences in utilization of health care were even more striking after family therapy (Law, Crane, & Berg, 2003). These patients showed a 50-57% decrease in their use of services after receiving family therapy, with significant decreases beginning after only 6 months of therapy. The largest decrease in services (57%) was seen among patients whose mental health care focused on the entire family system rather than focusing on the actual medical patient. Thus, family therapy not only reduces the use of

health care services among the average population but especially among those with chronic illnesses, in a cost effective manner that allows multiple people to be seen in one session.

It is noticeable that therapy is especially helpful in the family context, because all significant others in a patient's life are indeed impacted by the illness experience (Morse & Johnson, 1991). Research has found that it is important to focus on the family during treatment for pediatric illness, as each family member experiences distress, anxiety, emotional concerns, and adjustment difficulties (e.g. Patterson, Holm, & Gurney, 2004). Parents are introduced to a host of new health care providers and must learn new medical terminology, procedures, and at-home care protocols. Family members witness the child's pain and suffering. The illness often requires the family to rebalance family roles, emotional expression, and time management so that the illness can be incorporated into the family structure (Streisand, Kazak, & Tercyak, 2003). Throughout the literature, the family's functioning level is identified as a critical risk or protective factor influencing family members' psychological adjustment (see Wallander & Varni, 1998). As health professionals provide care for these families after diagnosis, it is important that the care include a focus on the family's emotional and psychological experience.

Medical physicians' hectic schedules and job expectations do not allow them the time or expertise to help family members with the psychological and emotional adjustments necessary after diagnosis. These children's health care needs are not only expensive but are also time-consuming, even without a thorough consideration of the family's mental health needs. Over the past decade, hospital staff have become increasingly busier and more hurried, often experiencing extra stress, burnout, and poor work organization as a result (Ygge & Arnetz, 2004). Children with chronic health conditions further stretch staff resources, and parents are now expected to provide more medical care not only in the home but also while staying with the child in the hospital. As hospitals interact with the family and determine treatment protocols, a multi-disciplinary health care team that includes mental health professionals provides the most comprehensive treatment for the pediatric patient and family (e.g. Phelps, et al., 2009). Fortunately, a national survey of family physicians indicates a growing interest in collaboration with family therapists in order to provide a needed focus on family mental

health issues (Clark, Linville, & Rosen, 2009). These mental health providers are effective in providing crisis intervention as well as long-term counseling and support.

One specialized mental health discipline that is ideally suited for participation on a multi-disciplinary health care team is medical family therapy. This specialty “act[s] as the bridge between medical and mental health disciplines by shifting the team’s focus to a comprehensive, biopsychosocial perspective” that enhances the family’s experience of treatment (Phelps, et al., 2009). Medical family therapy is guided by the biopsychosocial model, put forth by George Engel as a response to the medical field’s biomedical focus on illness (Engel, 1977; Engel, 1980). The biopsychosocial model suggests a more systemic consideration of the patient that includes not only the biological and medical aspects of the illness but also the social, psychological, and emotional context within which the patient experiences illness. As the medical and therapy communities gained confidence in this model over time, the discipline of medical family therapy was introduced as an approach to family therapy connecting the biological symptoms of the illness with the psychosocial experience of the family, culture, and community (McDaniel, Hepworth, & Doherty, 1992).

The placement of a medical family therapist on the health care team encourages both the medical professionals and the family to value the social, psychological, and emotional impact of illness. When working with pediatric patients, it is especially important that the entire family be involved in treatment and that the entire family’s mental health needs be addressed. Children are dependent upon their parents for support and guidance through the illness experience, and the family’s adjustment to the illness can influence the child’s physical health. Yet the field of medical family therapy is new within the medical community, and it is unclear in the literature to what extent these professionals are utilized and what their role is when they are brought onto the health care team. Early literature on medical family therapy focused within primary care, without a particular consideration for specialty populations such as pediatric critical illness (e.g. McDaniel, Hepworth, & Doherty, 1992). This study explored the particular role of medical family therapists working as part of a multi-disciplinary health care team treating families facing a serious pediatric illness. A rich description of medical family therapists’ own perception of their role will expand the literature to more firmly establish

how this specialty interacts with and enhances a multi-disciplinary health care team, particularly in the unique and emotional event of serious pediatric illness.

Rationale for the Method

The present study provides a qualitative exploration of the role of medical family therapists on the health care team during a family's experience of chronic, life-threatening pediatric illness. The biomedical treatment model is not enough to adequately address the family's needs after diagnosis. Beyond the patient's symptoms and treatment protocol, the health care team needs to also engage mental health professionals to address the family's overall illness experience. Family therapy has been shown to be successful in the midst of chronic pediatric illness (e.g. Davey, Duncan, Foster, & Milton, 2008; Law, Crane, & Berg, 2003). Medical family therapists are specifically trained to address the family's mental health needs during an illness experience (e.g. Phelps et al., 2009). This research conducted a thematic analysis of medical family therapists' descriptions of their role on the health care team when working with families facing a chronic, life-threatening pediatric illness.

Previous research has focused largely on the family's experience of pediatric illness (e.g. Patterson, Holm, & Gurney, 2004). The health professionals' viewpoint has been considered chiefly for its influence on the family experience, and the professionals involved in research have frequently been medical physicians providing care for the medical aspects of illness. The perspective of mental health care providers has little reflection in the literature, with an even smaller focus on the particular perspective of medical family therapists. This research specifically explored the unique point of view of medical family therapists in order to enrich the literature by providing a description of the role they play within pediatric illness. A thematic analysis allowed for the various aspects of this role to be explored across different types of health care settings. The final description of medical family therapists' roles provides a rich description of their work with families and their participation as part of the health care team.

Theoretical Framework

This research is guided by the ecological systems theory (Bronfenbrenner, 1979). This theory identifies multiple system levels which form the context of an individual's environment. Each system influences the individual's development and growth: the

microsystem, mesosystem, exosystem, and macrosystem. An individual's microsystem is the immediate environment in which he or she lives, including relationships and organizations with which the individual has direct interaction. For example, a child's family members and school classmates fall within that child's microsystem level. The next level, the mesosystem, concerns the ways these different parts of the microsystem work together concerning the child. Here, the child's parents have direct interaction with the school system, perhaps by attending a parent-teacher conference, directly influencing the child as they work together. The exosystem is the next level, including other people and organizations which influence the child but without direct involvement with the child. Parents' work environments and the county school board are parts of an individual child's exosystem; the child does not interact with these organizations, but these organizations will influence the child's life. If parents are fired from their jobs or the school board decides to hire a new school principal, the child will be indirectly affected. Finally, beyond these levels is the macrosystem level. The macrosystem is even more remote from the individual, usually influencing the child in subtle, implicit ways that the individual may not even recognize. The macrosystem includes things such as cultural values, the economy, and societal laws and freedoms. These larger influences in an individual's life may be remote and abstract but do guide the child's development, as well as the people and organizations in other system levels of the child's environment.

Each of these system levels can be seen in a family's treatment for chronic, life-threatening pediatric illness. The child as a pediatric patient is involved in direct relationships with family members, medical physicians, and the medical family therapist working with the family. These relationships exist within the microsystem level. For the medical family therapist, their work directly with the family fits within this level. At the mesosystem level, various health professionals collaborate together on the health care team, influencing the child and the family. The health care team may also interact with the child's school system or community programs, with professionals on the team acting as a go-between for the family, moving between direct interaction with the family and outside conversations concerning the family. Beyond the health care team, the child's exosystem level includes the hospital system and the family's insurance company. These organizations influence the child's medical care and the family's experience of care

without direct involvement of the child. Finally, at the macrosystem level, the family is influenced by the current congressional health care debates, cultural beliefs about illness and healing, and the ethical guidelines for medical family therapists and medical physicians. Each of these system levels influence the pediatric patient and the family's illness experience.

The present study explored the role of the medical family therapist within these various system levels of a pediatric illness experience. Their mental health services with the child and family place them within the microsystem. Participation on the health care team engages them on the mesosystem level. Overall, their profession and their particular work with an individual family are influenced by people and things at the exosystem and macrosystem levels. The ecological systems theory guided both the development of this research and the analysis of data. Participants were specifically asked about their involvement in these various levels, with a focus on their work with the family, their work with the team, and the influence of the overall health care system. Results were then organized within this framework as well with a description of the themes concerning their role within the microsystem, mesosystem, and exo- and macrosystems.

Research Question

This research asked the question: what role do medical family therapists fill on the health care team when treating families with the recent diagnosis of a chronic, life-threatening pediatric health condition? This study focused explicitly on pediatric illness because the literature demonstrates that the entire family system is heavily influenced by a child's illness and the family's adjustment also influences the child's adjustment (e.g. Patterson, Holm, & Gurney, 2004). The specific focus on medical family therapists' role acknowledges the impact of pediatric illness on the family system and expands the understanding of this new specialty field. One assumption that has guided the developmental of this research is that medical family therapists work with the family system, not only individual family members, in an effort to address mental health needs and promote emotional and psychological adjustment over the course of the illness experience. It is furthermore assumed that medical family therapists hold a unique role on the health care team that is distinct but connected to other health professionals on the team.

Chapter Two: Literature Review

The literature on serious pediatric illness has focused largely on the family's experience and personal needs during diagnosis and ongoing treatment. Research has not yet explored the particular role of the medical family therapist in these families' care, especially as part of a multi-disciplinary health care team at the health care setting where pediatric patients are receiving care. This literature review will present an overview of families' struggles and needs during the pediatric illness experience with the intention of highlighting their needs from the health care team. The role of the health care team will then be explored, including particular risk factors for poor adjustment that should be considered in the team's assessment. Literature on the field of medical family therapy is then presented, as well as literature concerning protocols currently existing for health care addressing pediatric illness. This study will also add to the literature by presenting a thematic description of the role of medical family therapists within the pediatric illness experience, outlined by the ecological systems framework.

The Family's Experience of Illness

Research proposes that the family's experience of illness begins before the event of diagnosis. In reviewing the literature about pediatric hospital emergencies and trauma, Brunnuell and Kohen (1991) found that families began to experience an emotional reaction as soon as they suspected something was wrong, before arriving at the hospital or doctor's office to receive a diagnosis. These families' emotional experience of the hospital event was determined by their own labeling of the event as an emergency or non-emergency, regardless of the opinion of hospital staff. The family's experience of this emergency will be guided by their past experience with illness, knowledge of the child's symptoms, family culture, life stress, and ability to analyze. The literature describes the subsequent event of diagnosis as a traumatic family life event. In interviewing 14 parents of children with chronic illness, Ygge and Arnetz (2004) found that parents experience the diagnosis as a time of chaos and turmoil, a time when parents need clear guidance and support. Similarly, when Carpenter and Narsavage (2004) spoke with 9 families in a phenomenological study about the experience of caring for a child with cystic fibrosis, the diagnosis was described as an all-encompassing, life-shattering event. The diagnosis elicited overwhelming feelings of fear, isolation, guilt, and powerlessness and initiated a

series of family adjustments to incorporate the diagnosis and its implications into the family system. Specific needs were identified for the diagnosis event, including a need for information about how to care for the child but a greater concern for the emotional aspects of the family's adjustment. Families needed the health care team to help them "develop a sense of control and a belief that the ride will not always be bumpy," a finding that highlights the family's mental health needs specific to the time of diagnosis (p. 31).

The diagnosis of a chronic, life-threatening pediatric illness, as a stressful and important family event, will likely initiate a search for meaning and purpose in the diagnosis. In conducting five experiments with various populations of undergraduate students (ranging from $n=56$ to $n=160$), Wong and Weiner (1981) found that the search for meaning, finding a reason why an event occurred, is most common after a stressful event and after an important event. In both simulated conditions (e.g. reading about a hypothetical situation in which someone completed a task) and real conditions (e.g. taking a real class exam), all participants in Wong and Weiner's studies were faced with one of four outcomes and then allowed an opportunity to ask questions about the outcome. The four potential outcomes were: failure when there was an expectation to succeed, failure when there was an expectation to fail, success when there was an expectation to fail, and success when there was an expectation to succeed. Across experiments, results showed that participants search to find a reason for the outcome after a stressful event (failure when there was an expectation to succeed) and after an important event (a real class exam). Attributional search was focused in specific areas: participants were first and foremost focused on the source or cause of the event and secondly were focused on their own control of that causal factor.

This search for meaning and purpose is indeed seen among families receiving a pediatric diagnosis. "Constructing meaning is a way to manage the uncertainty associated with illness and treatment," Matteo and Pierluigi suggest from their qualitative interviews with 72 parents of children with cancer (2008, p. 136). Sixty-nine percent of parents responded to the diagnosis event by searching for information about possible causes for the illness, and 87% of these families had formulated their own theories about the cause of the cancer, both scientific and nonscientific. Matteo and Pierluigi warn that this need

to find a rational meaning for illness can trigger self-blame and prevent the family from coping with and adjusting to the diagnosis.

Wong and Weiner (1981) offer a similar warning from their research, noticing that participants' personal, internal search for meaning was sometimes different from the public explanation provided. For their participants, in the midst of publically blaming outside factors such as the fairness of a test, there was an internal questioning of their own culpability in failing a test. When considering parents facing a pediatric diagnosis, it is likely that a similar internal blaming process may occur, one which may hinder adjustment to the illness experience. Research further suggests that the family's construction of meaning in the illness experience is directly impacted by the relationship formed with the child's health care providers. Qualitative research by Lindblad, Rasmussen, and Sandman (2005a) identified that parents of children with non-life-threatening disabilities found meaning and identity from the support provided by health care professionals during the illness experience. This support allowed parents to be acknowledged and validated as individual people and competent caregivers, encouraging a meaningful identity for the parent in the illness experience. Health care professionals' support also allowed for children's identity development as they too were acknowledged as unique people worthy of help.

Throughout the literature, it is clear that in the midst of adjusting to the diagnosis and finding meaning in the illness, each family member has unique and important mental health needs. In both quantitative (Varni & Katz, 1997) and qualitative (Patterson, Holm, & Gurney, 2004) studies, pediatric cancer patients have been found to experience depression, anxiety, stress, fear, self-consciousness, sadness, and anger during the ongoing illness experience. A review of the literature through an attachment theory lens also notes that healthy siblings experience feelings of anger, anxiety, depression, and emotional detachment during the illness experience as well as a reduction in physical and emotional access to parents as caregivers and attachment figures (Murray, 2000). Parents too report strong personal emotional reactions, including feeling numb, overwhelmed, guilty, fearful, and helpless, as well as strains on the couple relationship such as conflict over coping styles and changing parenting roles (Patterson, Holm, & Gurney, 2004).

In addition to individual family members' mental health needs, the family system as a whole is further impacted by the pediatric illness experience. In their interviews with parents of children with cystic fibrosis, Carpenter and Narsavage (2004) described the family's ongoing cycle of falling apart, pulling together, and moving beyond each new struggle. Patterson and colleagues (2004) also recognized that parents "were the most articulate about the strains they experienced at the family level," with 100% of families describing at least one family strain during the pediatric cancer experience (p. 396). These family strains included a struggle in balancing multiple family needs (i.e. school, childcare, work, treatment, etc.), loss of normal family life, conflict with the extended family, and conflict within family subsystems. In a quantitative study of 116 parents of children with cancer, Streisand, Kazak, and Tercyak (2003) identified numerous indicators of poor family functioning during treatment, including family-wide communication difficulties, inhibited emotional expression, and more trouble with problem solving, family roles, family affect, and behavior control.

From before diagnosis occurs and throughout the treatment and maintenance phases of care, the demands of chronic, life-threatening pediatric illness are considerable. At a minimum, the medical needs of the child inflict pain, financial strain, and family role changes. Families express an ongoing need not only for information and medical treatment but also for emotional and psychological help and support (e.g. Lindblad, Rasmussen, & Sandman, 2005a). As the health care team engages in treatment with the family, it is not enough to address the pediatric patient's medical needs. The health care team must consider the impact on the entire family system which is caring for and supporting the ill child. Over the past several decades, physicians and researchers have begun to better incorporate the family's mental health needs into treatment of pediatric illnesses, opening the health care team to include the family system and mental health professionals.

Risk and Protective Factors

As the health care team addresses the family's mental health needs, a variety of areas should be assessed as potential risk or protective factors. Some of these factors are explicit, such as the child's age at diagnosis. A quantitative longitudinal study of 34 families of pediatric cancer patients found that the child's age at diagnosis could be a risk

factor for particular areas of negative adjustment (Barrera et al, 2003). Younger children were more likely to have behavioral problems after diagnosis, while adolescents were more likely to report a lower quality of life during the first year after diagnosis. The health care team will want to consider the child's age at diagnosis, and will also want to consider the particular type of diagnosis. In a review of the literature concerning psychosocial functioning in pediatric cancer patients, children whose diagnoses involved a significant impairment of the central nervous system or a brain injury or tumor were more likely to develop mental health problems during the illness experience (Patenaude & Kupst, 2005). Children with these types of diagnoses were more likely to experience cognitive, social, and adjustment difficulties as well as more social isolation and behavioral problems, compared to other types of cancers and illnesses. Treatment protocols that are less predictable were also more distressing for the family, particularly if the protocol was relatively new or experimental. Immediately at the time of diagnosis, before the team even begins to interact with the family, information regarding potential areas needing mental health support is already available to the health care team.

Various empirical studies and literature reviews provide compelling evidence for the health care team to assess the family's overall functioning, which has a strong impact on family members' psychological adjustment after diagnosis. Phipps and Mulhern (1995) explored adjustment among 65 pediatric cancer patients undergoing bone marrow transplants. Results revealed that perceived family cohesion and expressiveness could act as a protective factor, promoting resilience and correlating with better pediatric adjustment. Family conflict was identified as a risk factor, associated with poorer pediatric adjustment regardless of the patient's reported stress level. Wallander and Varni's 1998 review of the literature concerning psychosocial effects of pediatric illness supported this research, identifying good family functioning, as evidenced by family cohesion and expressiveness, as a strong protective factor. In 2002, Knafl and Gillis presented a literature review on what types of research have been conducted in the area of family response to chronic illness. Again, family functioning was identified as a critical factor in adjustment. Variables influencing family functioning during chronic pediatric illness were family cohesion, adaptability, and conflict. Family resources, hardiness,

social support, ability to find meaning in the illness, and overall well-being were consistently associated with better family functioning.

The literature identified further areas for the health care team to assess and consider. Risk factors include the child's functional limitations, parents' psychosocial stress, and the perception of both daily stressors and disease-related stressors (Wallander & Varni, 1998). The influence of non-disease-related daily stressors was echoed in Knafli and Gillis's review of the literature as well (2002). A three-month quantitative study of 70 pediatric transplant recipients and their caregivers also found that the family's levels of hope and illness-related uncertainty are important areas for assessment (Maikranz et al., 2007). Higher hope and lower illness-related uncertainty were protective factors, correlated with greater adherence to treatment protocols as well as lower levels of anxiety and depression. Wallander and Varni (1998) also identified hope as a family protective factor, along with peer social support, the child's positive self-image, optimism, problem-solving ability, parents' marital satisfaction, practical resources, and service utilization. Ferraro and Longo (1985) suggest health professionals focus on supporting the family's ability to effect change in the family or prevent unwanted change by building protective factors. Some of these protective factors have already been identified in other research (e.g. support networks, a strong marital relationship), but other factors suggested by Ferraro and Longo should be taken into consideration by the health care team as well. Family members' physiological functioning, psychological resiliency, nutrition, rest, motivation, belief system, sibling support, and illness-related knowledge can all have a strong influence on families' mental health during the illness experience.

The Role of the Health Care Team

As the health care team assesses for these various risk and protective factors, the literature also suggests things that families want from the health care team. Aside from the provision of adequate and timely medical services, one of families' top needs is to have an emotional and psychological connection with health care professionals. It is important that the entire family feel involved in the care of the child and cared for by the health care team. A quantitative study of 164 parents of children with disabilities found a positive correlation between parents' perception of family-centered care and their own emotional well-being (King, King, Rosenbaum, & Goffin, 1999). When parents felt they

were receiving family-centered care, they experienced greater satisfaction with services and increased emotional well-being.

A later study suggests that families' top needs during the illness experience, which are emotional and psychological in nature, are met within the family's relationship with health professionals. In 2005, Heller and Solomon conducted a qualitative study with 36 parents whose children had died after receiving care for a life-threatening condition. These parents spoke about their need to feel known by the health care team as individual people and to be approached as such, rather than being approached as cases or symptoms. For the 78% of parents here who reported having a relationship with at least one reliable, caring health care professional, it was these human relationships that parents highlighted as the most important aspect of their child's care. The top needs identified by parents in this study suggest that parents care more about the emotional and psychological relationship with providers than the technical aspects of medical treatment.

Similarly, Lindblad, Rasmussen, and Sandman (2005a, 2005b) explored parents' and health care professionals' experience of having a supportive relationship during a child's illness experience. These researchers conducted in-home interviews with 16 parents of children with non-life-threatening disabilities (2005a) to explore their experience of being supported by health care professionals, as well as nine interviews with family-recommended professionals working with families of children with disabilities (2005b). For parents, the experience of being supported by the health care team was vital in adjusting to the emotional and psychological shock of diagnosis. Parents who did experience support from the health care team found it easier to adjust to the illness experience: they felt more confident, experienced more security and hope, and could cope better with uncertainty. For parents, being supported by health professionals made them feel validated as a person and as the child's competent caregiver, their child was acknowledged as a unique person who was worthy of help, and their worries were eased in daily life as they found hope for their child's future. Parents who lacked support from the health care team, however, reported a number of unsettling results. These parents distrusted the health care team, felt overwhelmed and exhausted most of the time, and felt a barrage of distressing emotions: sadness, confusion, frustration, insecurity, and powerlessness. Without a supportive relationship with the health care team, families

found themselves unable to adjust and move on from the shock of diagnosis, largely because of the mental health needs that went unmet.

Lindblad and colleagues also noted that an emotionally supportive relationship between families and the health care team was also meaningful for the health care professionals (2005b). For the health professionals, being a supporter of these families and having an emotional and psychological connection was grounded in a personal and professional philosophy about how to work with these families. These professionals found meaning in sharing the family's experiences and holding hope for the future, being a trustworthy partner of the parents and engaging with family members as unique people, and enabling parents to gain competence and confidence in parenthood as the child's caregiver. Health professionals found personal meaning in their work with these families by being in tune with themselves and the family and saw caring as part of human activity rather than a job duty.

It is important that the health care team view their work with the family as a collaborative effort to help the family as a whole adjust to the illness experience. Collaboration is important not only between different professionals involved on the health care team, but also between the health care team and outside systems involved in the family's life. Power, DuPaul, Shapire, and Kazak (2003) put forth a critical analysis of community resources and health care research to explore the best ways to promote children's health. These authors identified the need to integrate the different systems involved in a child's life in order to best meet the child's health needs, including the hospital system, primary care settings, the school system, and the community environment. Parents are often forced to step in as a go-between as their child moves throughout these systems because these systems often work in isolation. Power and colleagues suggest that the health care system find a way to engage more directly with the other systems involved in a child's life.

In a book chapter addressing the same issues of collaboration, Power (2006) focused specifically on the need for collaboration between the health care team and the school system. Collaboration between these systems not only ensures that the child's academic needs are being met but can provide insight for the health care team into how the child's illness and treatment are impacting their daily life. Power highlights that the

school environment is critical for self-regulation and social skills, and that children with serious and chronic medical needs often face problems with academic performance and peer relationships. When a health professional who has a continuous relationship with the child and family and who knows them as individuals is able to collaborate with the school system, the school will better understand the child and family's needs, the burden on parents will be eased, and the health care team will gain an understanding for themselves of the child and family's coping and response to interventions.

The health care team plays a pivotal role in family's adjustment to the pediatric illness experience. While taking into consideration a family's particular risk and protective factors, the health care team can enhance adjustment and prevent long-term mental health problems. Collaboration is vital both within the health care team and between the health care team and outside systems, ensuring that the child receives appropriate medical care while the entire family is able to adjust well to the illness experience. While many mental health professionals may work with patients facing serious illness and may get involved in collaboration with medical professionals, therapists trained in providing family therapy may be best suited to work with these families. In the midst of pediatric illness, the entire family system needs to be involved in treatment. In these circumstances, a medical family therapy can be particularly useful on the health care team to address the entire family's emotional and psychological needs.

Medical Family Therapy

Medical family therapy is a specialized health discipline that has been developing over the past several decades, enhancing the family's treatment experience through a comprehensive biopsychosocial perspective. The biopsychosocial model was put forth as a response to the medical field's biomedical focus on illness with the recognition that a patient's illness cannot be understood without consideration of the emotional and social context in which the illness experience unfolds (Engel, 1977; Engel, 1980). In their 2006 theoretical paper outlining the evolution of the biopsychosocial model, Pereira and Smith outlined the influences of medical care and therapeutic mental health care in utilizing and shaping this model. The biopsychosocial model was introduced just as the medical community was beginning to focus on family medicine and the therapy field was beginning to focus on family therapy. In early family therapy, research on illnesses such

as schizophrenia and eating disorders began to explore the role of family communication, styles, patterns, and beliefs. Meanwhile, physicians in the medical community were beginning to utilize a systems perspective that placed the physician within the family system, emphasizing the importance of the physician-patient relationship. Physicians began to invoke counseling skills in their own sessions, only referring the patient and family out for family therapy if the mental health needs exceeded the physician's own counseling skills. As Clark, Linville, and Rosen found in their 2009 national survey of family physicians, this treatment style continues within the medical community today, with 100% of physicians surveyed indicating an interest in collaboration with marriage and family therapists.

As the family therapy and family medicine fields evolved, Pereira and Smith (2006) notice that neither field fully embraced the biopsychosocial model. In practice, there remained a split model: physicians first considered the biomedical context and then addressed any necessary psychosocial aspects, while therapists worked in reverse, considering the psychosocial context before addressing the biological and medical aspects. Pereira and Smith highlight that there remains today an inadequate emphasis on the interaction between these various systems. In their exploration of the development of the biopsychosocial model, they highlight the introduction of medical family therapy, a specialty which aims to more fully embrace the biopsychosocial model. Yet although this specialty field may enhance medical and mental health care for patients facing serious illness, the field is still evolving and the particular role of medical family therapists is not yet well-defined. Their techniques fit primarily within the marriage and family therapy field, but are being integrated within the medical community in a new way. Research has not yet explored their role on a multi-disciplinary health care team, particularly with critical illness and with specific patient populations.

Medical family therapy was first suggested by McDaniel, Hepworth, and Doherty in 1992 as an approach with families that connects the biological symptoms of the illness with the psychosocial experience of the family, culture, and community in which the patient lives. Medical family therapy explores each of these contexts with the goals of promoting personal agency, so that individuals can be knowledgeable about their illness and make personal choices in dealing with the illness, and enhancing the quality of

supportive relationships during the illness. The key difference between medical family therapy and other family therapy theories lies in the focus on the biological illness. While many of the techniques outlined by McDaniel and colleagues are shared with other family therapies, the key for medical family therapists is to relate the physical symptoms to psychosocial issues while still engaging the family. Collaboration is vital for medical family therapists, as no one professional can obtain expertise in the biological, psychological, social, and systemic aspects of the illness experience (McDaniel, Hepworth, & Doherty, 1992; Peterson & Briggs, 2008). Medical family therapists would thus be ideally situated on a health care team working with families experiencing pediatric illness, as collaboration is necessary on such teams to ensure the family's comprehensive treatment.

In their explanation of medical family therapy, Peterson and Briggs (2008) highlight the strengths and weaknesses of this discipline. They note that medical family therapists shift their focus from healthy versus unhealthy to a more broad focus on the family's adaptation to the illness experience. Although the assessment, techniques, and discussions are not unique to medical family therapy, the change resides in the use of medical language, psychosocial experiences unique to the particular illness, and close collaboration with others involved in the patient's treatment. The biopsychosocial perspective is noted as a strength of medical family therapy, as well as the focus on helping the entire family deal with the illness experience and providing help for physicians who have heavy time constraints and little mental health training. Limitations, however, lie in the feasibility of medical family therapy in today's health care system. The reality of third-party payers and the financial cost of treatment limit the possibility for medical family therapy, and as such this biopsychosocial model may not be available for many families facing chronic, life-threatening pediatric illness.

Considering that the field of medical family therapy is relatively new, it is important that research expand upon the role of these professionals within the medical community. As a subset of the marriage and family therapy field, these professionals are trained to work within a systemic framework, addressing relational issues in the context of biological illness. Research within this field is still evolving, and has thus far focused primarily on medical family therapists in a primary health care setting (McDaniel,

Hepworth, & Doherty, 1992). In such a setting, the medical family therapist has close collaboration with the medical professionals and generally works with any patient population requiring services. This study sought to expand the research within the medical family therapy field by focusing more closely on serious illness with a particular patient population: critical pediatric illness. This research adds a new, in-depth view of the medical family therapists' role within this specialty population, strengthening the literature in this new specialty field and providing support for the expansion of medical family therapy beyond primary care and throughout the national health care system.

Suggested Treatment Models and Family Interventions

Within the literature, various professionals have put forth suggestions for how to best work with families facing a chronic, life-threatening illness in order to enhance the family's psychological adjustment. One model, pertinent to illness of any scope or severity, is the illness-constellation model (Morse & Johnson, 1991). This model posits that "although illness physiologically affects one individual, the experience of illness, and in particular a serious illness, can affect and involve the entire family and other significant people in the experience of suffering, pain, and threats to life" (p. 315). The illness-constellation model looks at the illness experience as a constellation of the patient's physical symptoms and behavioral responses along with the impact of the illness on the family. Regaining normalcy is a legitimate task for this model, and the model describes a four-stage process that families move through during the illness experience.

In the stage of uncertainty, the patient and family experience simultaneous but different awareness of symptoms, suspecting the illness and considering its seriousness for the patient. Their experience then moves from suspicion to the stage of disruption, wherein the patient and/or family have decided that the illness is real and seek help. This is the stage in which diagnosis occurs, either as a result of seeking help or as the event that tells the family that help is needed. This stage, the stage of disruption, is the crisis stage: the patient is dependent upon the health care team and the family suffers alongside the patient. Roles change, distribution of control changes, and the patient and family may have very different experiences at this point in the illness experience. This stage is followed by a third stage of striving to regain self, a time of meaning making where the patient focuses on preserving their sense of self and the family commits to the patient's

fight. Finally, the patient and family enter the stage of regaining wellness where the patient attains mastery with the help of the family. Throughout these stages, there is a role for medical and mental health professionals to be working with the family to achieve this model's task of regaining normalcy.

Other treatment models have been suggested for particular diagnoses and patient populations. Davey, Duncan, Foster, and Milton (2008) described a pediatric HIV/AIDS clinic that partners mental health professionals with medical physicians for a focus on the entire family. Seventy-five percent of this clinic's patients receive regular family therapy, and the clinic has observed that as they have gradually increased the family-focused portion of care, the health care team has been able to better address mental health needs and reduce family chaos in medical visits. Another protocol has been put forth by health professionals working with pediatric Type-2 diabetes (Phelps, et al., 2009). This program involves very close collaboration between the family and a multi-disciplinary health care team which includes medical providers, diabetes educators, medical family therapists, and dieticians or nutritionists. When families receive care from this clinic, they visit with each of these professionals in a flexible environment that takes into account their particular needs on a visit (e.g. if the family is experiencing poor communication as of late, more time will be devoted to family therapy in that visit). In exploring how therapists can work with sickle cell disease, Kaslow and Brown (1995) similarly highlighted the need for multidisciplinary treatment that includes a focus on mental health. These two researchers suggest that therapists need to focus on education, prevention, stress and coping skills, enhancing family relationships, and building socioecological protective factors such as peer relationships.

Other treatment models have been suggested that are less disease-specific but still particular to serious illness, including a model of intervention from Morison, Bromfield, and Cameron (2003) that supports families through the course of chronic and terminal pediatric illnesses. The goals here are reducing trauma symptoms, increasing adaptive coping, and providing counseling and support for the entire family. The focus for the family is on building hope, empowering family members, reconnecting the family system, enhancing coping and resilience, and re-framing the illness experience to one of meaning and purpose. This suggested model of intervention is non-linear, flexible, and

focused on the prevention of mental health problems through a variety of ways: informal crisis support counseling, therapeutic peer groups for various family subsystems, parent mentoring programs and support groups, patient social events, and formal individual, couple, and family therapy.

Several themes can be identified throughout these various protocols suggested for health professionals working with families experiencing chronic, life-threatening pediatric illness. First, each of these models place a heavy emphasis on preventive mental health work with the entire family system. Although medical treatment for the child's diagnosis is important, all recommended models suggest the health care team deal with the biological-medical aspects of care simultaneous with the emotional and psychological aspects of care. The health care team automatically engages the family in the treatment process and introduces a preventive focus on mental health and emotional support. Although the particular focus of mental health work will vary as the health care team begins to understand a particular family's needs, each of these protocols expects that the family's treatment will include a focus on mental health.

A second theme is that these models each rely on active collaboration between different health disciplines and the family system. A multi-disciplinary health care team is engaged in treatment throughout the family's care. Medical physicians, family therapists, and specialists particular to a diagnosis (e.g. a diabetes educator) are all included on the team. The family's treatment is not isolated within one sphere of influence, but is rather considered from each of these different perspectives so that treatment is as comprehensive and biopsychosocially appropriate as possible. Finally, these models all identify a need for the health care team to remain flexible with the family. As particular needs are identified, care should be re-focused to that area, although not to the exclusion of other disciplines. The team works together to support the family as needed, with an ongoing focus on prevention and treatment.

Within any protocol, family interventions have been shown to be effective in helping the family adjust appropriately to the pediatric illness experience. Wysocki and colleagues (2006) found that adolescents with diabetes experienced improved family communication and overall family relationships after 6 months of a behavioral family system therapy intervention. Families ($n=104$) received either standard care, 12 sessions

of an educational support group, or 6 months of the family intervention. The behavioral family intervention resulted in decreased family conflict and increased adherence to medical protocols, although researchers did note that this style of intervention might not be feasible in most clinical settings due to cost and other factors. Another family-based group intervention for healthy siblings and their parents has been studied twice by Lobato and Kao (2002; 2005), receiving high parent satisfaction. First, an integrated group intervention for 54 healthy siblings and their parents was found to improve sibling knowledge, connectedness, and behavioral problems while reducing reports of negative sibling adjustment (2002). The same intervention was evaluated more closely with 43 healthy siblings and their parents, again resulting in improved sibling knowledge, sense of connectedness, and sibling global functioning (2005). Improvements in both studies were maintained at a 3-month follow-up. As medical family therapists work with these families, preventive and flexible work with a biopsychosocial perspective that includes family interventions has been found to be helpful.

These suggested protocols for work with families facing chronic, life-threatening pediatric illness emphasize the importance and effectiveness of family mental health interventions. The medical family therapy field is trained and prepared to fit well within these various models of intervention, providing effective mental health care to families experiencing illness. This study illuminates the role of medical family therapists on the health care team when working with these families. A rich description of their role will continue to better the medical community's understanding of how families adjust to illness and the place medical family therapists can have within that adjustment experience.

Literature Review Conclusion

While chronic, life-threatening pediatric illness is a devastating experience for the family, the literature shows that health care providers have a strong influence on the family's adjustment to the illness. As the illness occurs within the family environment, the health care team should address each part of the family system. A multi-disciplinary team is called for, to ensure that medical physicians and mental health professionals are involved in supporting, understanding, and caring for the family system. Because pediatric illness in particular involves the entire family system, mental health

professionals should be included who have particular training working with families. As such, medical family therapy is a specialty field ideally situated to take part on health care teams working with families facing serious pediatric illness. These professionals can provide a biopsychosocial perspective that takes into account the family's unique factors and needs.

Yet research has not yet defined the role of a medical family therapist on these health care teams, focusing primarily on primary care settings with a broad range of patients. A clear definition of this role will enhance both the medical community's treatment of families facing serious pediatric cancer and the therapy community's understanding of this new treatment specialty. This study provides a rich description of medical family therapists' role on a multi-disciplinary health care team with families facing serious pediatric illness. They have a role with the family as well as within the health care team as a whole. The results of this research will begin to create a more clear, well-rounded description of that role. Such a definition will establish credibility within the medical and therapy communities and will also provide direction for medical family therapy training programs and future changes in the health care system.

Chapter Three: Methods

Design of the Study

A qualitative research design was utilized, providing a thematic analysis of the role medical family therapists have on a multi-disciplinary health care team working with families who have received the diagnosis of a chronic, life-threatening pediatric health illness. For the purposes of this study, a chronic, life-threatening pediatric health illness was defined as any illness or injury potentially threatening the child's life and requiring ongoing medical treatment. Examples of such diagnoses would include pediatric cancer, a traumatic brain injury, or cystic fibrosis. Participants were recruited who self-identified as medical family therapists working with children with these health conditions. In-depth interviews were conducted to explore participants' personal description of their role on the health care team when working with these families. Interviews addressed participants' interactions with the families themselves as well as with others on the health care team, professionals in the hospital setting, and professionals outside of the hospital system.

Procedures

Potential participants were identified through general online searches as well as personal contact with faculty and alumni of the Virginia Tech Marriage and Family Therapy program. Professionals whose job descriptions seemed to fit participant criteria were contacted personally by the co-investigator on this research study, via email to assess their availability and identification as a medical family therapist. All professionals contacted were invited to identify any colleagues who may also fit the eligibility criteria. These professionals were then contacted for the same purposes and again asked to identify colleagues who may be eligible for this study. In this manner, participants were recruited purposefully and through a snowball sampling method (Miller, 1986). Any professionals contacted who met eligibility criteria were informed of the purpose of the study and were invited to participate. The co-investigator then scheduled a time for a phone interview and again asked for any other recommendations of eligible colleagues. If professionals were contacted because of a personal recommendation, the research did not disclose the identity of the professional who suggested them as a potential participant. The co-investigator conducted individual telephone interviews with each participant, each lasting approximately 60 minutes. The informed consent was sent electronically three

days before the scheduled interview and then reviewed at the start of the telephone conversation. Verbal consent was recorded and then the semi-structure qualitative interview was audio-recorded. The interview explored the participant's role on the health care team, including their interactions with the family, with other professionals on the team, and with other professionals outside of the team. The interview also explored the participant's training and preparation for their role. Appendix A includes the full list of interview questions and probes.

Participant Demographics

Participants were recruited nation-wide and were invited to participate if they self-identified as a medical family therapist working regularly on a multi-disciplinary health care team with families facing serious pediatric health problems. Each had training specific for medical family therapy and their work focused on the family's mental health needs during the illness experience. Eight participants were interviewed for this study, although one was later excluded from analysis due to a lack of experience with pediatric patients. Of the seven participants included in analysis, two were male and five were female. No data was gathered concerning ethnicity or age, and this demographic information could not be estimated because interviews were conducted over the telephone. One participant worked in a primary care setting, working in a basic pediatrician's office where the participant and pediatrician saw patients primarily for routine medical care. Two participants were from the same specialty care setting, a medical office outside of a hospital that focused only on pediatric patients with severe obesity-related health issues. The final four participants worked in a hospital setting as part of the palliative care unit, providing pain management and end-of-life care for patients in the hospital's several intensive care units. These participants held the job title of transitions counselors. Two participants in the hospital setting had primary experience with pediatric patients and two had primary experience with adult patients with some secondary exposure to working with pediatric patients.

All participants had been working in their current health care setting for at least one year. One participant was close to completion of a master's degree in marriage and family therapy. All other participants had either a master's degree or a doctoral degree in family therapy, excepting one participant in the hospital setting with a master's degree in

case management and on-the-job training and experience in family therapy. Two participants had intensive post-graduate education in medical family therapy, and the others had minimal elective medical family therapy education.

Analysis

Each audio-recorded interview was transcribed verbatim, and both the co-investigator and primary investigator, who was the committee chair for this research study, independently applied thematic coding to each transcript. Analysis was done using the constant comparative method (Strauss & Corbin, 1998). Analysis began with open coding of an individual interview to identify important words, phrases, and concepts from the interview. These were compared across all interviews, with each interview being read first as an independent interview and then compared back to previously-identified concepts from earlier interviews. This continuously deepened the researcher's understanding of the data, and concepts identified from earlier interviews were used to guide future interviews. Saturation was met as interviews began to reinforce the themes already identified and failed to identify new concepts. At this point, no further participants were recruited or interviewed. After open coding identified general themes, these themes were refined and definitions were created of each. Themes were organized within the ecological systems framework (Bronfrennbrenner, 1979) according to the medical family therapist's role in the family's different system levels. It was also considered how the themes shifted within each health care setting. The final product will be a list of final themes that describe medical family therapists' self-described role on the health care team when working with families facing chronic, life-threatening pediatric illness.

Chapter Four: Results

The results of this study are organized according to the ecological systems framework (Bronfenbrenner, 1979). Each pediatric patient lives out their illness experience within the systems of this framework, and the medical family therapist has a role within each of the child's systems. After outlining the trustworthiness and credibility of this study, the role of the medical family therapist within each of these ecological systems will be explored. First, themes concerning their role within the child's microsystem will be identified. This includes their work directly with the family. Next, data will be presented concerning their role on the health care team, which acts within the child's mesosystem as the team works together to influence the child's health care. Themes will then be identified within the exo- and macrosystem levels concerning how these roles were defined and influenced by the larger systems of the health care setting administration and the United States health care system. These themes provide clinical implications for the field of medical family therapy.

Trustworthiness and Credibility

As many participants were interviewed as possible to provide saturation of the data. Each interview was transcribed verbatim, ensuring the accurate representation of each participant's experience (Strauss & Corbin, 1998). Interviews were read through and analyzed after they occurred, to allow for reflection before continuing with future interviews. As interviews occurred, this reflection expanded to include consideration of how their experience fit with others from the same health care setting and an overall look at participants' experiences across settings. Both the primary investigator and co-investigator identified all themes independently. Most of the themes identified were seen across cases, suggesting that the role of the medical family therapist on the health care team working with serious pediatric illness is generalizable to many health care settings. Each setting provided nuances and a different structure for the health care team, but the medical family therapist's role on that team remained similar. The interview questions elicited an in-depth description of each participant's role on the health care team from a number of angles, including their perception, the family's perception, their preparation, and different types of communication and collaboration. That such an in-depth description was obtained suggests validity for the interview questions used.

A Role in the Microsystem: Working with the Family

Within the ecological systems theory, the medical family therapist is considered a part of the pediatric patient's microsystem. They have a role directly with the child and family, becoming a part of the child's immediate environment. Several themes emerged from the data highlighting participants' roles with the family in the midst of serious pediatric illness. Participants identified their need to provide emotional support to the family, as well as the importance of maintaining flexibility in their role. They also spoke specifically about the difficulties of working with pediatric patients and outlined their role as the systems thinker, looking at the entire family system during the illness experience.

Theme 1: Medical family therapists provide emotional support for the family.

Participants identified themselves providing emotional support for the child and family in the midst of pediatric illness. Their work with the family focused on processing bad news, coping with grief reactions, and supporting the family through the illness experience. Across settings, participants saw this as a key purpose in their being invited onto the health care team to work alongside the medical staff.

The doctor can come in and spend maybe 15 minutes and share that bad news and then say 'well, I'm going to leave you here with the counselor to talk more about it.' And they don't feel like they're leaving them after a horrible discussion, they're leaving them in good hands. So we can then spend another hour with them, basically processing what the doctor just told them.

I think that the families feel like we are their advocate. That we are there to hear their story and be their support, their emotional strength. We get real connected... So we are that connection that they feel comfortable with. So they probably don't even realize the role that we have on the team. They see us more as their ally.

While participants in all settings identified a key part of their role with the family as providing emotional support, the amount of interaction with the family did differ

across settings. In the primary care setting, the medical family therapist had less opportunity to provide emotional support for the family during a serious pediatric illness, because specialty medical needs were referred out to another facility. However, in this setting, the medical family therapist did have the unique role of working with families as a one-time consultant or being called in to work with the family for longer-term counseling.

Like the primary care setting, participants in the specialty care setting had the option of providing families with longer-term counseling if the family needed that extra emotional support as they sought change relating to their medical problems. Otherwise, the specialty care medical family therapists only saw the family during routine or specially scheduled office visits that occurred every few months. In the hospital setting, however, the option for longer-term therapy was unavailable for participants. Yet this setting did allow for much more frequent and intense contact with families, particularly influencing the emotional support they were able to provide.

I see them every day. Now, that can involve a five minute visit or it can be a 45 minute visit like it was today. It depends on, one, how the patient is feeling and if she's willing to engage with me, and as well as the family. Often times the family will say, 'you know, I really don't want to speak with you today, I had a really bad night or the patient had a really bad night. The nurse didn't come when I wanted her to come.' So they won't talk. But sometimes I can walk in the room and I can't leave, I can stay for two hours. And they'll just open up like a faucet and everything comes out.

Participants in this setting saw families daily to provide emotional support, but were only able to utilize brief therapy interventions because patients were rarely in the hospital for more than a few weeks.

And that's a thing that in this environment is very different. It's a different type of family therapy. We do a lot of brief interventions, because we don't deal with all of these family issues, we have to take them where they to help them move quickly

through making some of the most traumatic decisions that they will ever make in their life. So we have to help them to take what they are as a family and work through these situations.

Theme 2: Staying flexible to the family's identified needs.

In their role with families facing serious pediatric illness, medical family therapists engaged in a wide variety of job duties and found that their work had to shift with the family's current emotional state and the child's illness and treatment protocol. Participants identified a number of roles that they fill and spoke to the need to remain flexible in how they approach both the health care team and the families with whom they work.

[I would describe my role as] probably facilitator, advocator, liaison, and therapist. So, you play many roles depending on what's going on.

First and foremost, in each health care setting, participants highlighted the need for a thorough assessment of family dynamics and the influence of the illness. It was the medical family therapist's job to stay flexible and tailor their work with the family according to what this assessment revealed about the family's needs.

Generally, in this [hospital] setting, we would do very similar to what you would do if you were in private practice and you had clients come into your offices. The initial meeting is an assessment, kind of a joining with the patient, with the family, determining what are the goals of care, what needs to be done here. And doing that assessment and then following up with some sort of appropriate intervention.

The reason I'm in there with the doctor is because when he's asking all these questions, I'm getting a better picture of what their family looks like. I'm getting a much better picture through the motivational interviewing questions of kind of where they are in terms of change, their readiness to change. And I'm also getting an idea of what's important to them, um, as far as is clothing or teasing or, um,

different things are kind of their biggest concerns. And then through that I'm kind of assessing biopsychosocial, and also some spiritual, and how this all fits together with who this person is. Kind of assessing if there's any underlying family dynamic issues that are contributing to their weight gain, if there's any... the doctor focuses obviously more on the underlying medical causes, but any other psychological causes, I'm assessing for, um, any barriers to change, anything that might make implementing nutritional changes or physical activity changes difficult.

Theme 3: The role is heightened by pediatric illness.

While this entire study focused on pediatric illness, participants did highlight the impact that the patient's age has on their work with the family, as well as on their own need for emotional support. For many participants, working with pediatric patients did change their role in identifiable ways. One way was that the patient's age impacted their role by the impact it had on the family system. Participants saw families struggling more deeply when the sick family member was a child as opposed to an adult.

I think families have a harder time, in my opinion, when it's – not that they don't when it's an adult – but when it's a child, they have a deeper sense of hopelessness and just a deeper grief. I don't really know how to explain it other than that. So I think your work is, at least while they're in the hospital, it's very intense.

Participants also spoke of the impact that working with ill children has on their own emotional health. Their own emotions and reactions to a family were often heightened when the patient was a child, influencing their ability to work with the family. Participants needed their own emotional support in order to fully engage in their role with the family. This was particularly noticeable in the hospital setting, where participants were working with pediatric patients in the intensive care unit at a critical point in their illness experience and often near the end of life.

I mean, I really have a hard time – I have a five year old and a three year old. So I'll be honest with you, it's really hard for me to go over there and work with the pediatric patients in the ICU [intensive care unit] there. So, it's not something that even we enjoy doing. Because, I don't know, I think for anybody it's unnatural for a child to die. That's how you feel. But, we have difficulty too going over there working with those patients. So it's really important for us to have a lot of support within our palliative care team. We do a lot of debriefing and [participant 004] is always available to talk with us after we've worked on an especially hard peds case.

Theme 4: Utilizing a systems theory framework.

Another clear theme of the medical family therapist's role was their need to be thinking about the entire system. In other words, their work with pediatric patients was not confined to the patient alone, but incorporated the entire family system. Across settings, medical family therapists sought to include as many key players in a patient's life as possible. Part of their role was working with the entire family as they navigated the health care system for a particular family member's medical needs.

As a medical family therapist what my heartbeat will always be family therapy. At my core, I am a family therapist. That being said, I have a systemic lens. I can never turn that off. Fortunately and unfortunately.

That's the focus, I think, of this transitions in palliative program. It's the whole picture. The psychosocial aspect of dealing with all the key components of it, whether it's spiritual, emotional, psychosocial – whatever it might be, that's our focus. To go in and address not only the patient but also the family, because oftentimes the patient is not even involved in their own health care. There's another person making decisions for that person, so in that aspect you have to be able to go in and deal with that family. So we focus on all of it.

I'm there to be the medical family therapist or family therapist. And I've just found that the best use of my time while I'm in the room with the physician is to think about all those different things and how they integrate and how they can impact someone's health... But I've felt that the times I've been most effective and that have been most effective for the family is really giving the family a sense that we're interested in seeing them as a whole. We're interested in seeing the bigger picture and seeing how all these things relate and how they come together to form a picture of the whole person and the whole family.

A Role in the Mesosystem: Part of the Health Care Team

Medical family therapists are also part of the pediatric patient's mesosystem, interacting with the health care team and the family concerning the child's health and medical care. Their role as systems thinker, both with the family and on the health care team, was only one theme that emerged concerning their role in the child's mesosystem. Participants also highlighted their role in providing emotional support to the members of the health care team. Further themes concerning their role on the health care team were that they were a part of the health care team, they acted as mediator between the family and the team, and that their role on the team was directly impacted by the severity of the child's diagnosis.

Theme 1: Medical family therapists provide emotional support for the team.

The theme of emotional support was seen again, in a slightly different vein, within the medical family therapist's role on the health care team. Participants identified themselves not only providing emotional support for the family, but also for the other staff on the health care team. This was a more informal role within the health care team than it was with the family, but was particularly important with the physicians and nurses who also worked with these pediatric patients. Participants saw this role as stemming from their identification on the health care team as the person trained and prepared to deal with emotions and grief.

And then they [the nurses] get emotionally involved, because these are very young kids who are dying, some are sick with cancer, and other manners of things going

on with them. So they get emotionally affected. So not only do we have to watch the patient and the family, we also have to be the resources for the nurses as well. And the chaplains, they come in and provide a spiritual aspect for the nurses and the families. But I think at the end of the day, they really just want to sit down and say, 'okay, tell me what just happened. Even though I'm a nurse and I'm trained and I have a license and all these other things. Tell me why this two-year-old, why this child died.' How am I going to be able to get up now as we clean the bed, get this patient tagged, and there's another sick child waiting to come right behind this child. And that nurse has to get right back up and get right back into action again. So, I think all the nurses, they're familiar with me and they know anytime they want to talk, whether it's hospital-related or just personal, things going on at home, things with their own kids in school, I think the relationship has been set that they realize we all are there for each other.

Theme 2: Part of the health care team.

Participants clearly identified themselves as part of the medical team, working alongside physicians and nurses to take an active part in families' health care. This was true across settings, but each setting did have a particular referral process for how the medical family therapist was brought onto the team. In the primary care and hospital settings, participants were invited onto the health care team only after a family had entered the setting and begun receiving care from physicians or others on the team. The specialty care setting was unique in that participants were included as part of the team from before a family even came into the health care setting. Medical family therapists in this setting attended every medical encounter between the family and the physician, performing some assessments even before the patient's first encounter with the physician and therapist. Regardless of how and when participants in each setting became part of the health care team working with a family, they viewed themselves as part of the health care team.

I would say that there's no hierarchy. In terms of, all of our services are seen as unique and individual but together put in the same package we're the best that

there is to offer collectively. In terms of, not necessarily [my individual name], but medical family therapy. Not necessarily any specific physician but the physicians' role in general. So I think there's a mutual respect, and with that they certainly seek me out.

I see myself as part of the team. And I think most of the providers, especially those I have worked frequently with, would agree with that.

Theme 2a: They have the psychosocial role.

Medical family therapists were clear that their role on the health care team was not that of a medical provider. The physicians and nurses were on the health care team to provide for the patient's medical needs, while the medical family therapists were on the team to address psychosocial issues within the illness experience. For many participants, this is why they were brought onto the health care team, to ensure that the medical staff could address clinical issues while the therapists covered psychosocial issues.

[My role is] dealing with the psychosocial issues. With the biopsychosocial model, that the physician and nurse might be dealing with a clinical situation, whereas what I'm doing is the psychosocial piece.

I'm dealing with a family or a patient, I don't address clinical issues, even though I might know what's going on because I've seen it so many times, I don't address those issues... That way they don't get confused what it is that I do. I'm their therapist, and that's not my role, to take on the medical aspect of it. Either I get a nurse or some other clinically trained person to answer those medical questions.

Theme 2b: They remain in the doctor's shadow.

Participants were also clear that although they were a vital part of the health care team, their role was an addendum to that of the physician. The doctor's role on the health care team was primary. Medical family therapists were usually brought in after the physician, and their focus was on important family dynamics, but still secondary to the

child's critical medical diagnosis. While participants often had the freedom to complete their own assessments and do their own psychosocial work with the family, their work sometimes flowed from the physicians' assessments or noted concerns.

I think that the primary care providers are kind of the gatekeepers, in that I'm not going to know that the family is there and struggling unless they let me know. Unless they say 'we really could use your help on this particular case.' So when I get involved, it depends on them.

And probably they see us, a lot of times, as an extension of themselves. In that, they may not have time to sit down and talk with a family, but that's what we're all about – taking the time to listen, actively listening, and paying attention to what's going on. We can become another set of ears for them. And if they have specific things that we need to address, they would mention that in the referral. Sometimes they will give very specific instructions for what they need. But we always go beyond that, into the emotion.

Theme 2c: Team communication is critical.

Across health care settings, the communication within the health care team was critical to the medical family therapist's being part of the team. Communication took place in a number of ways: written medical records, face-to-face conversations, phone calls, and emails. While the primary focus of communication was between members of the health care team, including the medical family therapist, the communication between the health care team and outside providers was also highlighted.

We're constantly talking to one another, constantly on the phone with one another. That's really a process that takes place throughout the day. And we seem to have good outcomes with patients when our communication is pretty open. I think that is the number one key to having success with a patient or a family is having good communication within the medical team.

So I might be involved in, for example, communicating with a tertiary care provider who is not on-site. I might be involved with talking with people from school, or trying to be in touch with all other collaterals who might have something to contribute or something to share about that particular child or family's care. And that's the thing that I expect that I will do. Often the medical providers are very interested to do that; some of them have the time and some of them don't. So that's kind of the way that I stake out a useful spot on the medical team also.

Theme 3: Standing up with the family.

Participants had an important role in the mesosystem as mediating communication between the family and the rest of the health care team. Their conversations with families were oftentimes more intimate than conversations between the physician and the family, revealing new awareness of family dynamics and their influence on the child's health care. Medical family therapists took the role of mediating communication between the family and the medical staff.

To me, we're the one who pulls together the team. We get involved with the patient and family through nurses or physicians that ask us to get involved. Once we're involved, we're kind of guiding what happens next. We're assessing where is the family in accepting what is going on and then helping everybody on the health care team stay on the same page with the discussions that we're having. So, I always call us the glue. We're the ones that keep everything moving forward.

Participants also identified a need to advocate for the family and ensure that the team and the family were clearly understanding each other.

Your main goal is making sure that the patient's best interest is first and foremost with the family, with the physician, and with the medical staff. Because a lot of times people lose sight of that, just because of their own emotions or – for lack of

a better word – their own agendas. So I think trying to keep the patient's best interests first and foremost in everybody's minds is what we try to do.

I think part of my job before going into a care conference is to meet all the key players before the meeting. Often times in that interaction with the family I can realize who may be kind of a hothead, and I can put them further from the doctor if possible. Even if it's a husband or a wife, I will try to sit between them and the doctor. If he or she is crying, that way I can put a hand on their shoulder or I can push tissues or whatever. That kind of gives them a barrier, a buffer between the doctor and the family. So my role is kind of to make sure everybody is in the right place at the right time.

In standing up for the family, participants again saw themselves holding a systemic view of the family's treatment, utilizing systems thinking in their conceptual thinking about families and illness as well as in their practical work of assessment and participation on the health care team. In the midst of the physicians' and nurses' medical care, chaplains' spiritual care, and the other professionals brought in for various purposes on the health care team, the medical family therapists' role consisted of holding the larger picture intact for both the family and the team.

I think health care is so disjointed that each person is doing their job and we're the ones standing back and looking at it saying 'how does this all fit together.' And that's the systems theory, to me, what we're going. We're putting the whole 'how does this system come together to make things happen?'

It's about having a sense of the bigger picture, the bigger system. And we're always taking the meta-view to the entire system, trying to understand if and when trouble may arise. Using systems interventions to negotiate that.

Theme 4: The role is impacted by the diagnosis.

The patient's particular diagnosis had an important impact on medical family therapists' role on the health care team. The impact of the diagnosis did differ across health care settings. By nature of the hospital setting, participants were only working with children facing critical illness or injury, often near the time of the child's death. Their role often did not shift with the child's particular illness, because the health care team was working with the family at a critical point in that illness experience. The family's psychosocial experience in that setting did not vary much according to the particulars of a diagnosis. In contrast, the participant in the primary care setting saw a big shift in her role on the health care team depending upon the child's diagnosis. Without a serious diagnosis, the medical family therapist here was typically not involved on the health care team. But with a particularly serious diagnosis, the child would be referred to an outside specialty care setting to receive more intensive medical care. This would then limit the primary care participant's involvement on the health care team, if the child and family were able to receive psychosocial services at the specialty care setting. Thus, in the primary care setting, the medical family therapist's work with the family focuses primarily on diagnosis experience or with the maintenance of a chronic illness.

With any new diagnosis, I think there tends to be a lot of fear, a lot of anxiety, a lot of confusion. So my role with them is not, I wouldn't necessarily see it as crisis management, but it is about how the family can get the tools that they need, get the information they need, to be able to manage this particular illness.

Chronic illness was not mentioned by participants in the hospital setting, but was highlighted by participants in both the primary care and specialty care setting. With a chronic illness, participants' role on the health care team took more importance. Their work with family dynamics and assessment of family functioning became more prevalent to the health care team's overall treatment goals, because those treatment goals would be over the long term and they would be seeing the family more frequently.

They really seem to defer to me more with chronic illness. With obesity, with diabetes, we have a child now that we're seeing intensely that has leukemia, so those kinds of things I think they really appreciate the psychosocial component of and how it is impacting the family. They really defer to the patient's psychosocial stability or state. They run their treatment goals by me more so than they would with a patient with a less serious illness. So I would say it's a much more intense collaboration with our seriously ill patients than with our, you know, head cold patients... I would say that it's more intense because we do see them more frequently. But it's also more intense because we appreciate that the family is more vulnerable. So I think that heightens everyone up in terms of the physician, in terms of myself, to make sure that this family is taken care of. We have a stronger wrap-around approach for them.

A Role in the Exo- and Macrosystem: Clinical Implications

Several themes were identified concerning medical family therapists' roles within the larger health care system. From their employment in a particular health care setting, they were involved in the child's exosystem. Within this system, participants highlighted their acceptance within the administration as part of the health care team as well as the way their role was handled within their particular setting's administrative structure. Medical family therapists are also a part of the larger health care system in the United States, thus holding a role within the child's macrosystem. Here, participants identified their need to create their own role and also identified several ways that the health care system needs to better prepare for medical family therapists to have a role on medical health care teams. Finally, participants identified several ways that they were inadequately prepared for their work, including education and the medical family therapy field in general, which suggest clinical implications for the future of this specialty health field.

Theme 1: The role is influenced by the structure of the health care setting.

Each health care setting had a unique role for medical family therapists, guiding their work with the families, their work with the health care team, and their overall place in the structure of the health care setting administration. In the primary care setting, the

participant was brought onto the team whenever the physicians felt it helpful. For the most part, this participant saw the patient independently of the physician and then communicated afterward with the rest of the health care team. This was drastically different from the specialty setting, where the health care team had the same structure for each family that entered the clinic: a pediatrician, a nutritionist, and a medical family therapist. In this setting, the medical family therapist was present for every physician encounter and also had the option for individual follow-up with the family.

But in the specialty settings, they believe there are no biological problems without psychosocial features, and no psychosocial problems without biomedical features. So they really want me present for every encounter.

In the hospital setting, the structure of the hospital administration was again different, influencing the medical family therapist's role and thus indirectly influencing the child's health care. Some intensive care units fully supported the integration of medical family therapists into the health care team and requested their participation at the beginning of a family's care. Other hospital units only involved medical family therapists on the health care team when a child was near to death. The administration of each unit directly influenced the role medical family therapists had on the health care team, influencing the child's ultimate health care in that health care setting. In the hospital setting, medical family therapists were an integral part of the health care team, often coordinating care conferences for the family and the health care team to sit down together and discuss the patient's care. They often saw families in conjunction with the physicians in order to provide the support families needed while freeing physicians to spend time in other areas of clinical care.

And the doctors have seen that that [our work with the families] really saves them time. It really gives them the opportunity to say what they need to say and then leave it with us to go through and talk more about it. And then we can go back and call the doctor an hour later and say 'they're really at this point ready to go with hospice.' But it took an hour of discussion to get there.

Each health care setting also varied in the follow-up care provided for families. In the primary care and specialty care setting, participants could refer families for longer-term counseling with themselves and maintain a long-term relationship with the patient and families. In the hospital setting, the palliative care unit offered a follow-up bereavement program for the next year, through which families receive phone calls, newsletters, and are encouraged to attend support groups. For the most part, this follow-up care did not include longer-term therapy with the participants because of the structure of the hospital setting.

Theme 2: Creating your own role.

Across settings and experiences, participants clearly articulated that their role within the health care system was evolving and self-defined. These medical family therapists had to stake a place on the health care team, educating physicians and other medical professionals as to their worth and value in families' medical care. This was true both in academic settings, with participants taking on the responsibility for finding a curriculum and internship site true to their own passions in medical family therapy, as well as in professional settings across the board: primary care, specialty care, and hospital settings.

We were not asked to come in and do this as family therapists, it just kind of happened ... As the hospital started looking toward starting a palliative care program, I kind of said 'hey, we really need to be a part of that.' And I think that's really how it happened. We just pushed our way on in there! And we kind of took some responsibility for it. And I think we are very fortunate that it turned out this way.

There were a few years ago when we were spending a lot of time educating the population as to what we are about and what our service is. We are a service to the hospital, we don't charge for our presence. So it has taken some time. But then once they, the majority of the population understood our roles, then we saw a remarkable increase in the referrals. We're probably up to about 2,000 plus

referrals per year for the counselors today. I think that has come out of the physicians, the clinical staff, becoming aware of how we can assist them.

Within the theme of creating your own role, it was also seen that these medical family therapists had to continually update the health care team and other staff in their setting on what their role was, sometimes changing their language and clarifying job duties so that the role would be clear.

Sometimes you're asked to do things that maybe it's not your role. And so in that, I'll talk to the physicians and say 'I'm not comfortable giving that information, I think that needs to be done at the physician level.' So sometimes the role can become confused as far as sharing information that really needs to be given by a physician. So we try to help keep clear boundaries, even with the medical team.

But we are so unique – most hospitals have social workers in their palliative care team. But we use counselors. And we use that term specifically. It was very confusing early on to use the term therapist because a lot of people have heard of that with physical therapists, occupational therapists, speech therapists. So there was little awareness of what a medical family therapist was, here in our hospital. So we changed it to counselor.

In each health care setting, participants identified themselves as creating a role within the setting. In the specialty care setting, one participant approached the clinic about getting an internship there as a medical family therapist. Her suggestion was welcomed, but she played a key part in initiating and creating that role, determining what assessments to use and how to most effectively interact with families and communicate with the rest of the health care team. The hospital setting had a similar experience, with one participant stepping forward to the administration to suggest a role for medical family therapists in the hospital setting. Their roles have then changed and continue to change over time.

Theme 3: Inadequate preparation of medical family therapists.

Within the larger health care system and medical family therapy field, all participants reported inadequate preparation for their work as a medical family therapist, particularly when working with seriously ill pediatric patients. There was little standardized curriculum or training for medical family therapists, and even less pediatric-specific preparation. Most participants had training in marriage and family therapy, but had to rely on elective classes and on-the-job training to prepare them for their work in their particular health care settings. The education and training available did not adequately prepare them for the roles described in this study, and participants spoke their role today in addressing these limitations in the field and encouraging greater training opportunities for future medical family therapists.

I did shadow for an entire day and then had two weeks of shadowing the previous intern and then I have had supervision with [Participant 002] throughout the past year for additional support and supervision, transitioning into the site... It's been particularly helpful because she started the site, she's very familiar with it, she's a very good mentor and has helped me to define what my role is there at the clinic.

I think there are things that probably could be taught more, geared toward critical illness and end of life, that's not taught. I don't know of anywhere that teaches what we do. We're trying to work on putting together some things to kind of show the process of what we do. But I really don't think there's anything out there that really goes through exactly how we've integrated into this health care team here.

Participants also struggled with the reality that they are working in an emergent field with little direction provided through the literature, standardized curriculum, or even many co-workers or mentors.

Medical family therapy – it's not that it's just a new health discipline now, there just hasn't been a lot published about it or written about it, outside of Susan McDaniel, Jerry Hepworth, Bill Dunn, and those folks. And their work focuses primarily in primary care. So in a specialty care setting, and especially a pediatric care setting, there's been limited knowledge in textbooks, limited knowledge in articles, and limited knowledge with my mentors in terms of how to do it. So, it would have been nice to have been matched with someone who could mentor me through the process... that would have been, I think, very helpful.

While participants were able to get the training and preparation that they needed for their particular jobs, it was often through self-initiation and the convenience of working near a local university with a focus on medical family therapy.

Theme 4: Preparing the health care system for the role of medical family therapists.

All participants noted that the receptivity of the health care system to the inclusion of medical family therapists on the health care team has changed over the past several years. As each participant came into a new health care setting and began to create their own role, the response of physicians and staff slowly became more and more welcoming over time.

Through our first year everything was very territorial. You know, 'who are you, what are you doing here, why are you seeing my patient.' And we had to kind of fight our way and earn respect in each case, one at a time. Then people would say 'hey, they're really making a difference here.' ... Our second year the doctors started saying 'hey, you know what, they're kind of helpful. They could come in with us.'

But I think as they've become accustomed to me and realized that, first of all that we're trained as therapists to try to help assess the situation and figure out what triggers can be used to get from one point to another, we've become more accepted. And now the doctors call us even before the hub consult is even faxed

over. The physicians have our number, they will call us themselves, the directors of the unit. The nurses have our number, they will call even before they put the consult in for us to come in. So the whole attitude is changing. So they kind of see my role as a very key role.

Participants commented on this shift being seen both within their particular settings and within the health care community as a whole.

Yet within a general shift toward greater appreciation for and inclusion of medical family therapists, the health care system seems to remain unaware of the real benefit of these professionals. Participants were aware that their role was not always well-appreciated or fully understood by the other medical professionals with whom they work.

The role that counselors serve, that they play in helping families go through these difficult transitions, I think it is so important. Because I think sometimes we are often overlooked in our roles, sometimes, in the hospital.

Although everyone calls me a psychologist, and I'm not. That's my only thing. [Laughs.] But I think that's just a residual of the fact that family therapy as a field is still growing and evolving, so I don't know that they can necessary discern the specificity, the differences between a family therapist versus a medical family therapists versus a psychologist. They just know that we are the touchy-feely, psychosocial people. So they call us a psychologist. Not all of them, but many of them do.

One area of the health care team in particular that remains unprepared for the presence of medical family therapists on the health care team is the issue of billing. Across health care settings that were studied, participants faced problems around reimbursement for their services.

And there's a lot of issues with how do we get reimbursement, how do we bill for the psychosocial component on the same day as the medical component. I mean, I

could talk about this for hours and it would bore you to tears. But the only resistance I really got was how do we bill for you – if you're here, we want to bill for you.

That's why the people you're going to be up against are the social workers, the clinical psychologists, the master's level people who are calling themselves something different and calling themselves something billable and reimbursable!

Chapter Five: Discussion

Medical family therapists across these health care settings were clear that they are a unique and vital part of the health care teams on which they work. They identified a variety of job duties and roles within their participation on the health care team. Participants' description of their role on the health care team echoed much of the literature on medical family therapy and the purpose of this specialized mental health field. Their described role was centered in the medical family therapist holding a systemic view of the whole picture: family dynamics, health care team interactions, and the interplay between the two. Participants provided a psychosocial frame that guided the physicians' work and the family's adjustment to the illness experience.

A large part of participants' role in the microsystem was established by a quick but thorough assessment of family dynamics, including the illness itself. This assessment guided the therapist's work with the family by illuminating what areas of the family system needed to be addressed. This fits with previous research highlighting the numerous ways that pediatric illness influences the psychosocial structure of the family (e.g. Streisand, Kazak, & Tercyak, 2003). Depending on how each family member was reacting and the needs and resources for the family, the medical family therapist's assessment allowed them to shape their work with the family to that family's particular needs and begin to understand and hold a systemic view of the family.

As participants spoke about their role on the health care team, it became clear that this role was strongly influenced and supported by participants' own behind-the-scenes psychosocial team. There was a strong sense of community, of medical family therapists sharing encouragement and frustrations together along the path to increased recognition and value on the health care team. This was particularly relevant when working with pediatric patients, which added an extra emotional burden for participants. All participants had a team of co-workers and supervisors that provided emotional support, which then provided them with the strength and perseverance needed to go back and take an active role on the health care team. This sense of community extended to the interviews themselves. The researcher, a marriage and family therapy graduate student, was invited into this community through participants' support and encouragement. This behind-the-scenes support indirectly influences all other aspects of the medical family

therapists' role on the health care team. As medical family therapists work with seriously ill pediatric patients within a sometimes unsupportive health care system, it is vital that these professionals find their own community of support.

The theme of creating your own role should be considered within the chronology of the medical family therapy field. This specialty of family therapy has only been an active part of the medical community for two decades (McDaniel, Hepworth, & Doherty, 1992). As the field grows and expands, it is likely that medical family therapists will have less need to create their own role. That need is already diminishing amongst settings that established a place for medical family therapists several years ago. The two participants from the specialty care setting spoke about how the one participant had paved the way for the other, creating more structure in the role of a medical family therapist within that particular health care team. The growth of the field was further reflected in the clinical implication theme concerning the preparation of the health care system. Much as Clark, Linville, and Rosen (2009) found a growing interest among family physicians in collaborating with family therapists, participants in this study have been increasingly welcomed and appreciated within their own health care setting. The longer they work within a health care setting, the more the team utilizes their role. However, this gradual establishment of the role of a medical family therapist is not universal. While the shift may overall be moving in the direction of increasing the presence of medical family therapists, participants continued to report that others on the health care team misunderstand their role and overlook their importance on the team. In the hospital setting in particular, the administration has put more limits on the involvement of medical family therapists on the health care team.

Clinical Implications

Each level of the ecological system framework influences the medical family therapist's role in other levels of the framework. Participants' interactions with the family at the microsystem level allowed them to stand up for the family as a mediator or advocate with the health care team, at the mesosystem level. At the same time, their role on the health care team is influenced by the preparedness of the health care system at the macrosystem level. Participants identified a clear need for the health care system to better support the growing field of medical family therapy. Medical family therapists' training,

acceptance into the medical community, and ability to appropriately bill for their services influence the family in more subtle ways that the family may be unlikely to recognize. The preparedness of the health care system also influences the training received on the exosystem level, as well as the structure of the health care setting at the same ecological level. Medical family therapists' training provides the skills needed to adequately communicate within a medical setting and address emotional needs of staff as well as family. The structure of each health care setting influences how, when, and why medical family therapists are invited onto the health care team. When the hospital setting chose to only invite these therapists onto the health care team near the end of the child's life, this changed their role on the team and with the family: the exosystem influences the meso- and microsystems. People and organizations at each level of the ecological systems framework influence the role of the medical family therapist when working with families facing serious pediatric illness.

As the presence of medical family therapy slowly increases, the theme identified about the preparation of the health care system will become more imperative. Children with health conditions clearly benefit from family therapy, as evidenced by Law, Crane, and Berg (2003) in the decreased use of medical services after these children receive family therapy. Yet this research shows that the health care system is not prepared for family therapists to become an active part of the medical health care team. The system lacks a formalized system for billing, which participants report as limiting to the work they can do with families and the role they can play on the health care team. As Peterson and Briggs (2008) acknowledged in their exploration of the medical family therapy field, this is a specialty that may not be feasible within the current health care system because of the current third-party payment system. This is an area of health care that must be addressed in order for patients to benefit from the services of medical family therapists.

The marriage and family therapy field in general also lacks adequate education and training for medical family therapists. Participants were generally able to find enough education and training to prepare them for their job, but only through their own perseverance to seek out that preparation. Much of this self-sought training was provided on the job rather than during their formal educational experience. It is critical that the

health care system and curriculum increase awareness of and preparation for medical family therapists as their presence in health care settings increases.

This research also suggests particular skills and abilities that medical family therapists must train in and prepare for if they are to be fully utilized by the health care team. Some of these skills include the ability to address emotional needs and deal with families facing grief and uncertainty. Other skills include a clear understanding of medical language, anatomy, and the biological elements of disease and illness. Medical family therapists must be flexible and able to adapt quickly to new circumstances, since they will be working with families during intense, critical points in the family's experience. Training particular to working with pediatric populations will also be helpful, considering the intensity of emotions surrounding pediatric illness. This is an area medical family therapists may struggle in today, as current curriculum does not yet specifically address medical family therapy with serious pediatric illness.

Limitations

Several limitations of this study should be noted. Many professionals are doing this work, participating on a health care team to work with families facing serious pediatric illness, but do not self-identify as medical family therapists. This issue of semantics is a limitation to this study. It is possible that other professionals are doing similar work and filling similar roles to these participants, but are choosing to self-identify as another professional. There are several possibilities for this, including the under-recognition of this new field of medical family therapy and the difficulties with billing if one does chose to self-identify as a medical family therapist. It was difficult to find participants for this study who fit the eligibility criteria, giving the impression that medical family therapists are not common in the medical community and are most frequently located near a university setting with a medical family therapy educational program. However, it may be that these are the areas most familiar with medical family therapy and therefore more likely to self-identify as such. There may be differences between individuals choosing to self-identify as medical family therapists and those who do similar work but self-identify as another professional specialty, and this study could not address this issue.

It should also be noted that many self-identified medical family therapists do not work frequently with seriously ill pediatric patients. While all participants in this study had experience with this population, several did not consider pediatrics their primary focus. It is unknown to what extent these participants may have answered questions according to their few pediatric patients, although the interviewer worked to clarify this as much as possible throughout the interview process.

Another limitation of this study was the uneven distribution of participants across health care settings. While the hospital setting had four participants, the primary care setting only had one participant. This was mediated somewhat by the understanding that within the hospital setting, only two participants had a primary focus in pediatrics. It was also a limitation that all interviews took place over the telephone, preventing the interviewer from picking up on non-verbal cues that may have led to deeper probing on some questions. Telephone interviews also did not provide for as full of an experience of participants' unique health care settings.

Future Research

Continued research is important as the field of medical family therapy grows and develops. As the health care system prepares for this specialty to continue becoming more prevalent on medical health care teams, research will provide clarity into the role of these providers and their influence on patients seeking medical care. One particularly interesting and relevant area of future research is to explore the similarities and differences between the various psychosocial professionals working in the medical setting. Child life specialists in the hospital setting, medical social workers, medical family therapists, clinical psychologists, health psychologists, and others may each have an important role on a health care team, and those roles need to be explored and differentiated. Future research may also explore families' perceptions of how medical family therapy is helpful to them and their experience of interacting with different professionals on their health care team. Another possibility for future research is to look more closely at different health care setting to identify how the medical family therapist's role shifts and what education and training is most effective for different settings. Research into the distinctions between patient populations, such as chronically ill pediatric patients versus an unexpected adult death, will also enhance the current

education and training available to future medical family therapists. As the medical family therapy field continues to grow, longitudinal research or a historical exploration of how the field has shifted over time will also provide greater understanding of and appreciation for medical family therapists.

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Appendix A: Interview Questions and Probes

1. Tell me about your training and experience in medical family therapy.

Probes may include:

- Clarifying educational and clinical background
- Details on training and experience with this particular population of pediatric illness
- If they ascribe to any particular theoretical framework

2. How do you generally get involved as part of the health care team working with these families?

Probes may include:

- The referral process and initial introduction to the family
- Which family member(s) are the IP and how it becomes family work
- If there are diagnosis-specific protocols for setting up a health care team

3. Can you tell me a little bit about how the health care team works?

Probes may include:

- A description of the different health disciplines reflected on the team
- A description of their professional interactions with the team
- The frequency, topics, contact methods of collaboration

4. How would you describe your particular role on the team?

Probes may include:

- Their role in relation to others' roles on the team
- How collaboration impacts their work with the family

5. How does your role on the team guide your work with the family? Could you briefly describe that work?

Probes may include:

- Their consideration of risk/protective factors for the family
- Any specific interventions used or topic areas covered

- Their interactions with the family concerning others on the health care team
6. Tell me about your collaboration with other professionals outside of the health care team concerning your treatment for the family.

Probes may include:

- Who on the health care team collaborates outside the team
 - Any advocacy work they identify themselves doing
 - Collaboration within the hospital setting and with outside settings (e.g. school system)
7. Considering all that we have talked about, how would you summarize your particular role on the health care team when working with families facing these types of pediatric illnesses?

Probes may include:

- How that role was defined (self-defined, agency-defined)
 - Their perception of the family's definition of their role
 - Their perception of other professionals' definition of their role
8. Are there any final thoughts you would like to share with me about your work on a health care team with these families?

Probes may include:

- How these thoughts influence their conversations with the health care team or with the family
- If these thoughts change their perception of things that have already been discussed

Appendix B: Informed Consent Form

Project Title:

The Role of Medical Family Therapists on a Hospital Multi-Disciplinary Team for Pediatric Illness

Research Investigators:

Dr. Angela Heubner (Principle Investigator)

Jessica Perkins (Co-Investigator)

Purpose of Research:

The purpose of this study is to explore the role of medical family therapists on a multi-disciplinary health care team when working with families facing chronic, life-threatening pediatric health problems.

Expectations of Participants:

You will be asked to meet with the researcher(s) to complete the consent form and conduct a 90 minute semi-structured interview.

Potential Risks

There is no more than minimal risk to participants. You may experience some distress in conversation about difficult professional experiences, with families facing pediatric illness or with difficult colleague interactions. You have the right to withdraw from the study at any time without penalty.

Potential Benefits

There is no compensation for participation in this study. You may experience indirect benefits from participation. You may find it helpful to talk about your professional experiences, both positive and negative, and to think critically about your work. New ideas may be developed that may benefit your future work. This research will benefit the therapist community by the enhancement of the literature of an in-depth perspective on medical family therapists' work.

Confidentiality

All information given is confidential. Identifying information will be removed from transcripts. Signed consent forms will be kept in a locked drawer. You will be given a unique identifying code, and the key will be kept in a separate locked drawer. Only this unique identifying code will be used on interview transcripts. In the event of publication, no identifying information will be presented.

Freedom to Withdrawal

You are free to withdraw from the research project at any time without penalty.

Approval of Research

This research project has been approved, as required, by the Institutional Review Board for projects involving human subjects at Virginia Polytechnic Institute and State University, and by the Department of Human Development.

Participants' Agreement and Responsibilities

I have read and understand what my participation in this project entails. I know of no reason that I cannot participate in this project. I have had all of my questions answered and hereby give my voluntary consent for participation in this project.

If I have any questions about this project or its conduct, I can contact any of the following: Dr. Angela Heubner, Principle Investigator (703-538-8491) or Dr. David M. Moore, Chair of the Virginia Tech IRB (540-231-5281).

Participant Signature

Date

Printed Name

Jessica Perkins, Co-Investigator

Date