Pediatric Chronic Illness: How East Indian Children and Their Mothers Negotiate Culture and Hospitalization

A thesis presented to

the faculty of

the College of Health and Human Services of Ohio University

In partial fulfillment

of the requirements for the degree

Master of Science

Carrie M. Cligrow

June 2010

© 2010 Carrie M. Cligrow. All Rights Reserved.
This thesis titled

Pediatric Chronic Illness: How East Indian Children and Their
Mothers Negotiate Culture and Hospitalization

by

CARRIE M. CLIGROW

has been approved for
the School of Human and Consumer Sciences
and the College of Health and Human Services by

____________________________________________
Margaret M. Manoogian
Associate Professor of Human and Consumer Sciences

____________________________________________
Randy Leite
Interim Dean, College of Health and Human Services
ABSTRACT

CLIGROW, CARRIE M., M.S., June 2010, Family Studies

Pediatric Chronic Illness: How East Indian Children and Their Mothers Negotiate Culture and Hospitalization (171 pp.)

Director of Thesis: Margaret M. Manoogian

India is currently experiencing a societal metamorphosis as Westernization is impacting many aspects of daily life. This is particularly true in the area of health care where traditionally Western diseases are becoming widespread, making Western medicine necessary for treatment. This qualitative study explored how East Indian mothers and their children, ages 6 to 12 years, negotiate their health care, family relationships, and cultural contexts when children are hospitalized with chronic illness. Semi-structured interviews were conducted with mother-child dyads (N = 5 dyads) who were natives of East India receiving care from a major hospital in Bangalore, India. Bowen’s family systems theory guided the design and analysis of this study. Findings underscore tensions within families as a result of utilizing Westernized health care in the context of family health cultures. These tensions revealed how individuals based on their education levels and traditional beliefs understood and communicated health differently. Research findings have implications for how child life specialists can better serve patients and families in a culturally sensitive manner.

Approved: _____________________________________________________________

Margaret M. Manoogian

Associate Professor of Human and Consumer Sciences
ACKNOWLEDGMENTS

Many people came together and went out of their way to ensure the success of this great endeavor and for that I am grateful. I would like to thank my committee members whose diverse areas of expertise formed a solid foundation for this project. Dr. Jenny Chabot’s commitment to expanding and strengthening the field of child life helped me to realize the potential in conducting such research. Dr. Nagesh Rao’s cultural expertise proved invaluable when connecting with the people of India. Dr. Margaret Manoogian’s editor’s pen and familial insights were key in the organization and documentation of this work. The support and guidance offered by my faculty advisors made this project a true success.

I express gratitude to the Sachidananda Murthy family for opening their hearts and home to me as I found my way in India and to Kiran, Chinna, and Rakesh for bringing a small part of India to me before I ever left. Thank you to Leela for connecting me to India’s first ever child life program.

Thank you to the chronically ill children and their mothers who participated in this study. Their willingness to share their fears, hopes, heartaches, and triumphs made this project possible. I am sincerely appreciative that they permitted me to share their most intimate experiences with others. It is my heartfelt hope that their participation in this study was an opportunity for self-reflection in which they came to realize their amazing strengths and courage.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>3</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>4</td>
</tr>
<tr>
<td>Chapter 1: Introduction</td>
<td>8</td>
</tr>
<tr>
<td>Chapter 2: Review of Literature</td>
<td>16</td>
</tr>
<tr>
<td>Chronic Conditions and Their Impact on Children</td>
<td>17</td>
</tr>
<tr>
<td>The Family Unit: Disease Management</td>
<td>20</td>
</tr>
<tr>
<td>Learning to Cope</td>
<td>22</td>
</tr>
<tr>
<td>Spirituality of Children</td>
<td>23</td>
</tr>
<tr>
<td>Spirituality of Parents</td>
<td>24</td>
</tr>
<tr>
<td>The Family Unit: Family Interactions</td>
<td>25</td>
</tr>
<tr>
<td>Social Support: Sources of Strength and Conflict</td>
<td>27</td>
</tr>
<tr>
<td>Health Care and Family Culture</td>
<td>32</td>
</tr>
<tr>
<td>Recognizing the Need for Culturally Sensitive Health Care</td>
<td>34</td>
</tr>
<tr>
<td>Professional Implications: Cultural Care at Work</td>
<td>35</td>
</tr>
<tr>
<td>The Meeting of Two Worlds: Cohesion and Friction in India</td>
<td>37</td>
</tr>
<tr>
<td>Western Medicine in an Eastern World</td>
<td>38</td>
</tr>
<tr>
<td>Conceptual Framework</td>
<td>44</td>
</tr>
<tr>
<td>Chapter 3: Methodology</td>
<td>47</td>
</tr>
<tr>
<td>Recruitment</td>
<td>47</td>
</tr>
<tr>
<td>Study Site</td>
<td>47</td>
</tr>
<tr>
<td>Sample</td>
<td>51</td>
</tr>
<tr>
<td>Description of the Sample</td>
<td>51</td>
</tr>
<tr>
<td>Informed Consent Process</td>
<td>52</td>
</tr>
<tr>
<td>Interview Procedures</td>
<td>52</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>57</td>
</tr>
<tr>
<td>Chapter 4: The East Indian Children and Their Mothers Relationship in the Context of Health</td>
<td>61</td>
</tr>
<tr>
<td>Participant Profiles</td>
<td>62</td>
</tr>
<tr>
<td>Nidhin and Mary</td>
<td>62</td>
</tr>
</tbody>
</table>
CHAPTER 1: INTRODUCTION

This study focuses on the intersection of chronically ill pediatric patients, family health culture, and hospitalization because what happens within this context can have a life long impact. Children are socialized within their family’s health culture and no matter what beliefs and values shape this family system, a chronic diagnosis has huge implications. Whether or not these implications are positive or negative is greatly influenced by the interactions shared between families and health care professionals. I am specifically interested in looking at this dynamic in Bangalore, India because of the societal metamorphosis that is currently taking place. In addition to widespread Westernized health care in the city, India’s first child life program is being implemented in a local hospital. While the purpose of child life programs is to meet the psychosocial needs of pediatric patients and their families, these programs are structured in the framework of Western cultures. This difference adds another dimension to the challenge of offering culturally sensitive care to Bangalore’s pediatric patients and their families.

Family caregiving is critical because of the rise in pediatric chronic illnesses. Chronic illness, as defined by Jessup and Stein (1985) is a long-term illness that is incurable or has symptoms that limit day-to-day functioning in some way. While modern technology has enabled treatments that were previously confined to the hospital setting to occur at home, rising costs and insurance restrictions have limited health care professional home visits; as a result, family members have had to learn more advanced home health care treatments sometimes involving complex medical equipment. Families
feel the effects of these responsibilities within their family relationships and their interactions with the outside world (Aneshensel, Pearlin, & Schuler, 1993).

With pediatric chronic conditions, family caregiving can start at birth and last through adulthood. Research has shown 15% to 18% of US children are living with a chronic condition (Perrin, Lewkowicz, & Young, 2000) and 10% have illnesses that demand regular care (Sexson & Madan-Swain, 1993). As a result, these families and their children negotiate their daily lives in ways that differ from their healthy peers (Perrin et al., 2000). The extensiveness of these health care demands is directly related to the severity of the diagnosis. Many children have illnesses such as asthma, diabetes, and epilepsy that need to be managed on a daily basis through diet, medication, and activity restrictions to limit sporadic health complications related to these chronic conditions (Rollins, Bolig, & Mahan, 2005). Other illnesses such as cystic fibrosis develop increasing challenges over time as the disease progresses. Still other ailments such as cancer can alter a family’s routine instantly and for an unknown period of time.

A pediatric chronic illness impacts family routines in a number of different ways. With a pediatric chronic illness, it becomes necessary for parents to monitor their child’s physical well being closely. At the same time, it is unhealthy for the family if the pediatric diagnosis becomes the focal point of family activities (Knafl, Breitmayer, Gallo, & Zoeller, 1996). Parents also must ensure that medical equipment is kept sterile at home at the risk of jeopardizing their child’s health while attempting to avoid excessive anxiety (LePontis, Moel, & Cohn, 1987; O’Brein, 2001). Expected to act as medical
professionals and as parents, mothers and fathers feel challenged to raise their chronically ill children within typical developmental time frames (LePontis et al., 1987).

In addition to the physical demands of a chronic illness, families must contend with both psychological and emotional challenges. For instance, Solomon and Breton (1999) found that chronically ill children are much more likely to develop mental health concerns such as depression than their healthy peers because of social isolation and alienation. Bleil, Ramesh, Miller and Wood (2000) found a correlation between a family’s ability to function and a chronically ill child’s ability to cope. Physicians and parents work to alleviate such complications by encouraging typical life experiences and teaching healthy coping skills for these children (Shepard & Mahon, 2000). In addition to meeting the emotional needs of a child with a chronic illness, parents must also appreciate and anticipate the needs of their other children (Rollins et al., 2005).

Despite the overarching impact of a pediatric diagnosis within families, the daily responsibilities for providing care often fall upon the mother putting her at greater risk for depression (Enskar, Carlsson, Golsater, & Hamrin, 1997; Gallo & Knafl, 1998). Conventionally, women have done the majority of paid and unpaid work associated with caregiving and childrearing as these responsibilities typically have been viewed as the domain of women and essential expectations of their roles within families (Cancian & Oliker, 2000). According to Cancian and Oliker (2000),

People tend to see caring as part of a women’s biological make-up or as a fundamental personality trait that corresponds to women’s reproductive role. They do not view care giving as skilled work that is learned through
practice and shaped by cultural values and economic incentives.

Moreover, activities are seen as caring because women do them. (p. 3)

In addition, it is commonly believed that caring is an innate feeling as opposed to a learned skill (Cancian & Oliker, 2000). Conversely, for families with a child with a chronic illness, care providers must learn to render treatments at home (Rollins et al., 2005).

While family management of chronic illnesses has been well studied in the United States, it needs to be explored in the context of East Indian families in India where chronic illnesses are reaching epidemic proportions (PricewaterhouseCoopers, 2007). The site for the current study is Bangalore, India because of the increasing occurrences of chronic conditions as well as the cultural diversity found in this country. India is undergoing a great deal of changes that are largely fueled by its immense and young population and is projected to be the most populace country in the world by 2035. Currently, with 20% of the world’s people under the age of 24 residing in India, it is the world’s youngest nation (Gupta, 2008). More children live in India than are citizens of the United States of America, and 3 out of every 10 children in the world are Indian (Burnett, 2010). As these current children come of age, it is projected that they will continue to imitate and adopt lifestyles that traditionally have been viewed as Western.

This trend is particularly true in Bangalore, India where a plethora of factors have led to a dramatic transformation in young individuals’ attitudes and lifestyles (Laxman, 2006). In recent years, the city has undergone a total metamorphosis in many aspects of life including standard of living and entertainment. The standard of living in Bangalore
initially increased due to the mass information technology that was available there, earning the city the nickname, “the Silicon Valley of the East” (Discover, 2010). This establishment of reliable information technology led to a large influx of Western medical technology and, as a result, Westernized health care facilities emerged throughout the city. With the opportunity to practice “American medicine” in Bangalore, many health care professionals migrated to the city from throughout India and the United States (Knox, 2008). As a result, the city has grown immensely resulting in a very dense population of diverse cultures. The development of these two fields, informational technology and Westernized health care, as well as the promise seen in them has contributed to increased spending habits of the 7.2 million city residents.

Western influences visible in Bangalore’s young are in stark contrast to the experiences of previous generations in India. Western values have influenced the dress, entertainment, and dietary practices of the local population, particularly its youth. While these changes have brought economic freedom and a sense of independence for India’s young, it has not been without cost. The consumption of the Westernized diet has led to dramatic increases in lifestyle diseases when compared to previous generations (PricewaterhouseCoopers, 2007). Conventional East Indian medicines cannot combat those diseases that are new to the region (PricewaterhouseCoopers, 2007). The continued development of the city further escalates the occurrence of these types of diseases. First, many of the career opportunities available in Bangalore are highly sedentary in comparison to traditional Indian labor resulting in higher rates of obesity. The increase in sedentary activities for children such as video games are leading to childhood obesity;
city living is also contributing to this dangerous health trend as children can no longer roam freely (PricewaterhouseCoopers, 2007). Second, the dense population has led to an increase in exposure to pollution resulting in health problems. These issues are further compounded due to India’s infrastructure. Families who reside in rural parts cannot get into the city for regular Westernized treatments that may be required of chronic conditions. Therefore, these families are forced to move to the city to receive necessary treatment resulting in more exposure to pollution and inactive life styles (Bagchi, 2008).

Once a chronic condition has been diagnosed, families are forced to renegotiate their family health routines. This is particularly challenging when hospitalization is involved because of the various cultures that intermingle in a medical setting. This challenge is magnified in Bangalore where various castes, languages, and religions interact on a regular basis. Additionally, the merging of Westernized health care and conventional Eastern health practices present another cultural challenge that must be negotiated in the hospital. Parents and their chronically ill children must learn to navigate through the hospital culture of medical language, treatment protocols, and caring for their sick child in the context of hospital rules and medical staff. Furthermore, parents must learn to work with hospital staff to ensure that their family’s health culture is being respected through the care their child is receiving.

Therefore, the specific goals of the current study were: (a) to examine how health is communicated between East Indian mothers and their children in regards to the child’s chronic diagnosis; (b) to investigate how mothers perceive the interactions between themselves and hospital staff as well as between their child and hospital staff in the
context of their family health culture; and (c) to understand how children perceive and understand health and illness as they are socialized within their families and greater cultural contexts of society.

Leininger’s (1996) theoretical contributions to our understanding of culture provides the framework for this study. In this model, culture is defined as the way of life for a specific group of people with its values, patterns, beliefs, practices, and norms that are passed on, shared, and learned from generation to generation. Furthermore, Bowen’s (1978) family systems model will provide a broad family perspective for investigating the context and environment in which families function through the emotional bonds they create. Additionally, this theory enables family members to be studied individually and as parts of a unit as well as the interactions individuals and families have with outside entities such as health care professionals. The research questions posed for this qualitative study were: (a) How do East Indian mothers of children, ages 6 to 12 years, who are hospitalized with chronic illness view the personalization of the health care they receive in terms of their family culture?; and (b) how do East Indian children negotiate their health care experiences regarding their perceptions and understanding of health and illness as socialized within family and cultural contexts?

By undertaking this study, I hoped to gain an intimate understanding of how chronically ill, East Indian 6 to 12 year olds and their East Indian mothers perceive and understand their hospital experiences in the context of family culture. Therefore, the outcomes of this study could have tremendous influence on the lives of families as well as health care professionals. The merging of Western and Eastern health practices that is
currently occurring in India influences how families feel about and successfully negotiate their child’s care and path to well being. For families, new insight on how to best negotiate their way through this multifaceted health system culture could be gained. Additionally, families may increase their understanding of how their child’s diagnosis is impacting each member of the family including the child themselves. For health care professionals, guidance could be offered on how to best interact with patients of various cultural backgrounds. Child life specialists may gain insights about how the culture(s) of children and their mothers shape such health care encounters and thus inform the child’s health care team members. As a result, health care professionals may be able to prescribe treatments that work within the family’s culture, which would lead to increased compliance. Increased compliance may ultimately lead to greater patient satisfaction, which may result in a more rewarding experience for health care professionals. The results of this study have potential not only to illustrate the need for culturally sensitive health care, but also to establish the framework for how to achieve it.
CHAPTER 2: REVIEW OF LITERATURE

The purpose of this study was to understand how culture influences health care interactions from the perspectives of chronically ill children and their mothers. Chronic diagnoses create a great deal of stress for families. Because of the serious nature of chronic illnesses, core family beliefs and practices often are revealed. Several cultures come into play when health care providers, patients, and their families interact in this context. The current study focused on how pediatric patients and their mothers perceive and understand their illness, their family context for care, and their relationships with the medical staff and facility. Research questions included: (a) How do East Indian mothers of children, ages 6 to 12 years, who are hospitalized with chronic illness view the personalization of the health care they receive in terms of their family culture? (b) How do Indian children negotiate their health care experiences regarding their perceptions and understanding of health and illness as socialized within family and cultural contexts? A critical review of health care of chronically ill children requires a focus on both the family context of the child and the environment in which the family lives. In this literature review, I will first highlight the impact of a chronic illness on children and their families, including the developmental challenges of hospitalization on children and the availability of social support for children and families. Second, the influence of culture in the production of health in families and the health care environment will be explored. Third, I will critique the role of health care professionals and the negative and positive effects associated with their understandings of culture. Because this study will be conducted in Bangalore, India, I also will provide a broad overview of the East Indian
context that highlights the traditional Indian family structure, as well as the implications of Westernizing the current health care system. Finally, I will outline Bowen’s (1978) family systems theory, a theoretical approach based on eight concepts that relies heavily on families’ emotional ties to one another, as the conceptual framework utilized for this study.

Chronic Conditions and Their Impact on Children

Children who suffer from chronic medical illnesses are typical children who are forced to deal with atypical circumstances. In addition to coping with developmental tasks of each stage of childhood, children with chronic medical conditions have to address the psychological and physical complications that may result from a medical diagnosis (Patterson & Gerber, 1991; Woodgate, 1999). However, complications that result from chronic conditions often prevent children from participating in activities that are necessary for healthy development. These impediments include activity restrictions, doctor appointments, medicine side effects, and physical restraints (Vessey & Maguire, 1999). Developmentally, hospitalization appears to have the largest effect on children in middle childhood, between the ages of 6 to 12 years (Coyne, 2006; Rollins et al., 2005).

Piaget (1964), a developmental theorist well known for his theory of cognitive development, based his international model on a developing child’s ability to make cognitive connections to understand or respond to the physical environment (Dasen, 1972; Dasen & Mishra, 2000; Miller, 2002). Piaget explained that a child’s cognitive structure becomes more complex as the child develops (Inhelder & Piaget, 1964). He underscored concrete operations as the main purpose of middle childhood, the
developmental stage of children 6 to 12 years. Within this stage, children learn seriation, or how to put things in order. Children also learn the concept of reversibility, the ability to understand that objects can take on new shapes and return to the original shape during this stage. Most importantly for this study, Piaget (1964) recognized the elimination of egocentrism during this stage, referring to a child’s ability to recognize that other individuals have different points of view.

Regardless of the task, hospitalization can create significant challenges for healthy pediatric development (Rollins et al., 2005). Bossert (1994) found intrusive events such as injections, blood work, intravenous insertion, surgery, and pills to cause the greatest amount of concern in children 6 to 12 years. Pain, nausea, and medication side effects were classified as physical pain and were the second leading cause of anxiety in children. The third leading cause of concern that Bossert (1994) found was therapeutic intervention. This included, but was not limited to, physical examinations performed by doctors, dressing changes, and disturbances while sleeping. Confinement to units, holding still during procedures, and required bed rest fell under restricted activity and was found to cause stress in this age group. Separation from parents caused concern for school-aged patients and they experienced homesickness for their friends and pets.

Children also experienced environmental concerns involving health care professionals who appeared angry and related medical equipment that provoked fear (Rollins et al., 2005). For instance, children may feel that “cords and wires on walls look like monsters at night” (Bossert, 1994, p. 39). Chronically ill children found intrusive events to be more stressful than their acutely ill peers (Bossert, 1994). While gender did
not seem to influence what 6 to 12 year olds perceived as stressful, it did influence their development (Bossert, 1994; Vessey & Mebane, 2000). While there is little research on the influence of gender on developmental outcomes, boys appeared to demonstrate more behavioral issues such as acting out than their female peers (Vessey & Mebane, 2000). This difference could be credited to the expectations that emerge through the caregiving that children receive based on their sex. In countries that highly value female modesty and chastity, it is particularly challenging to take care of girls once puberty has occurred in comparison to their male peers (Katbamna, Baker, Ahmad, Bhakta, & Parker, 2001). Gender norms also impact the expectations and care provided by parents to their chronically ill children. Hill and Zimmerman’s (1995) study found that parents perceive sick sons less capable of taking care of themselves and therefore more impaired by chronic conditions. As a result, parents tended to spend more time and energy on chronically ill boys than girls despite similarities in their conditions. Furthermore, boys tend to hide their health conditions more than girls resulting in jeopardized compliance of medical regiments (Williams, 2002).

Inconsistencies within the literature may be due to the lack of information gathered directly from school-age children regarding their appraisal of hospital stressors. Research also fails to recognize the implication of the personal characteristics that each child has (Bossert, 1994). Lazarus and Folkman (1984) found that all children experience stress while in the hospital, but what was viewed, as being stressful and its intensity was determined by individual traits. These characteristics included health status, gender, and trait anxiety. Health status should be considered because of the implications of a chronic
condition versus an acute illness as well as the severity of the condition. Gender needs to be considered by health care professionals because of potentially learned responses such as being strong for boys and being emotional for girls due to the socialization they receive in their family culture. Trait anxiety, defined as one’s general level of anxiety, is necessary to gauge responses to stress (Bossert, 1994; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

The Family Unit: Disease Management

Preliminary reactions by family members when children receive a pediatric chronic diagnosis frequently include shock, anger, despair, confusion, and denial (Coyne, 2006; Shepard & Mahon, 2000). Once the intensity of these emotions has passed, a family’s response to a child’s chronic diagnosis is greatly influenced by their typical coping strategies around health and illness (Dragone, 2000; Shepard & Mahon, 2000). The majority of families who receive a chronic diagnosis learn to cope moderately well through adaptive tasks (Ahmann & Rollins, 2005; Clawson, 1996; O’Brien, 2001).

Knafl, Breitmayer, Gallo, and Zoeller (1996) studied how families managed their child’s chronic condition extensively and provide a framework in which to understand how families respond and behave when a child is diagnosed with a serious illness. They outlined a five-stage continuum of family management styles, illuminating diverse strategies to negotiate children’s diseases within the context of families. Families who were able to continue on with life in their typical way after receiving a chronic pediatric diagnosis were classified as thriving. These parents viewed their child as typical and the children saw themselves as being healthy as treatment regimens became a part of the
family’s routine. Families who adapted to managing the disease as a part of their daily activities, yet saw their “child as a tragic figure whose life chances had been compromised as a result of the illness,” were in the *accommodating* stage (p. 319). Parents in this stage had a tendency to emphasize the seriousness and potential complications of the disease while mothers bore more of the health care responsibilities than fathers. Common traits of families in the *enduring* stage were defined by difficulty. Parents shared negative views of their situation and stressed the tremendous amount of effort that it took to manage the illness. Some children in these families perceived themselves as being unhealthy in comparison to their peers. Families in the *struggling stage* were defined by parental conflict. Parents did not agree on how to best manage their child’s chronic illness or their expectations of one another. Mothers were typically more negative on their outlook of the disease and felt that fathers were insufficiently involved in health care. *Floundering* families were characterized by confusion. Parents tended to exhibit negative attitudes while children remained positive. Children often were viewed as troublemakers and created challenging parenting situations. Parents viewed the illness as a detestable restriction on family activities. This negative outlook compounded the family’s uncertainty in how to best manage the disease, resulting in ineffective treatment of the illness. Overall, some parents manage their child’s disease by parenting consistently both pre and post diagnosis although parental management styles are not absolute (Knafl et al., 1996).
Learning to Cope

Additionally, accepting a chronic diagnosis is critical to a family’s ability to cope. As family members attempt to address a child’s illness, numerous factors influence their response. For instance, Palmer (2001) found that family management of a child’s condition depended greatly upon the specific diagnosis and treatment protocols. Specifically, the severity of the diagnosis as well as the limitations that it put on the child’s ability to function as they did before caused parents to live in the past and present. Known as parental straddling, parents strive to view their child as typical while simultaneously dealing with the limits of their diagnosis (Johnson, 2000).

Mastering the daily management tasks of the pediatric chronic illness also is influential in how well a family handles their child’s illness. Individual treatment protocols affect parents differently depending on what is required. For instance, the daily management of conditions such as diabetes and asthma focus on controlling the symptoms while the protocol of cerebral palsy requires diligence to prevent complications (Rollins et al., 2005).

Because of the guilt that parents often feel in “neglecting” their healthy children, they have difficulty accurately perceiving how siblings are coping (Shepard & Mahon, 2000). Inconsistent and contradictory effects of chronic illness on siblings have been found (Walker, 1999). Earlier studies on siblings often fail to use control groups and found a high incidence of behavioral problems in siblings (Walker, 1999). Recent studies with stronger designs reveal fewer problems in sibling adjustment (Rollins et al., 2005). In reviewing the literature, Gallo, Breitmayer, Knafl, and Zoeller (1992) found that
siblings might feel negative or positive effects as well as an absence of effects caused by the diagnosis of a chronic illness. Parental attitudes play a critical role in the responses shown by siblings (Shepard & Mahon, 2000). Children who are well informed in a manner that is developmentally appropriate about their sibling’s condition and are permitted to participate in that child’s care tend to have more positive reactions. Children who are left uninformed or feel neglected tend to respond in a negative manner (Shepard & Mahon, 2000).

**Spirituality of Children**

Many families rely heavily on their religious and spiritual beliefs for strength. Fowler’s (1995) faith-development theory hypothesizes that children develop their own sense of faith during middle childhood and therefore find great comfort in it. This faith stage known as mythical-literal is closely linked to the individual child’s experiences and social interactions (Barnes, Plotnikoff, Fox, & Pendleton, 2000; Rollins et al., 2005). Some scholars “consider religious and spiritual orientations as significant as ethnicity, race, culture, social class, and gender because many fundamental beliefs are rooted in religion” (Clutter, 2005, p. 352). One study that examined the relationship between health, religion, and spirituality for children demonstrated that spiritual and religious practices are prevalent and often perceived by children as helpful (Barnes et al., 2000).

Other children are negatively affected by spirituality and religious beliefs. For patients who practiced religious or spiritual traditions that emphasize guilt, children’s self-esteem may suffer as they view themselves as being at fault or the illness as a punishment (Barnes et al., 2000; Capps, 1995). Characteristics of 6 to 12 year olds who
are suffering from spiritual anguish include reluctance to ask questions for fear of response (Rollins et al., 2005). Depending on their religious beliefs and health prognosis, children may not want confirmation that they brought this illness on themselves. Additionally, with impending death, children’s distorted understandings of who God is may cause fear (Rollins et al., 2005). Children who are suffering spiritual anguish are aware of caregivers’ desperation and may understand this desperation as an inability for doctors to heal them (Capps, 1995).

**Spirituality of Parents**

Many mothers and fathers seek support in their spiritual and religious beliefs as well. Parents look to their spirituality to understand and find meaning in their child’s illness (Barnes et al., 2000). The emotional release found in meditation and the hope found in prayer often provides parents with a strong sense of comfort (Rollins et al., 2000). Beliefs in spiritual beings also empower parents to offer their ill child comfort in ways that are only possible through spirituality, particularly around issues pertaining to death (Barnes et al., 2000). Some religions cause parents to feel they are being punished for a bad deed through their child’s illness; others may interpret it as a test of their faith (Barnes et al., 2000). While parents may find great comfort in their faith, it sometimes functions as an obstruction to biomedical care (Barnes et al., 2000; Jenkins, Le, McPhee, Stewart, & Ha, 1996). This dilemma, while caused by a typically positive influence, can render negative effects on families (Hart & Schneider, 1997).
The Family Unit: Family Interactions

The idea of “family” care promotes the impression that family members share health care responsibilities of the chronically ill member equally. Contradictorily, Gerstel and Gallagher (1993) found that the gender norms that define women as nurturing and responsible for the home automatically assigned caring for ill family members, especially children, as a part of a woman’s expected role. In some cultures, gender roles regarding caregiving are quite rigid. One study on caregiving in South Asian communities found that men who took on this role were stigmatized and viewed as being unworthy of respect. These negative views were magnified if the male gave up his career to care for an ill family member (Katbamna et al., 2001). Additionally, there is a gender gap in the type of work that men and women do in caregiving as well as in the manner that caregiving tasks are carried out (Cancian & Oliker, 2000). Men tend to perform tasks that are managerial and emotionally unattached in nature. When men are the primary care providers, they receive a great deal of outside support to aid them in that role (Cancian & Oliker, 2000). Women tend to view caregiving as an obligation and carry out this responsibility in a more expressive and supportive style with less outside assistance. This gendered nature of caregiving impacts the lives of females more so than men through an increased work load for the family and decreased opportunity for interaction with the outside world (Cancian & Oliker, 2000).

Despite the stress of providing constant care to their child, mothers often feel that their relationships with their child grew stronger regardless of their child’s diagnosis (Hardy, Routh, Armstrong, Albrecht, & Davis, 1995). Type of diagnosis appears to
influence the perceived closeness of the child-mother relationship. Children who had cancer shared more intimate relationships with their mothers than did healthy children or children with AIDS (Hardy et al., 1995). Pediatric cancer patients frequently identify their mothers as providing the most support and encouragement (Enskar, Carlsson, Golsater, & Hamrin, 1997; Kvist, Rajantie, Kvist, & Siimes, 1991; Rechner 1990; Woodgate, 1999). For some older school-aged children and younger adolescents, the constant presence of mothers was overbearing, which prompted children to feel as if they were treated like younger children (Woodgate, 1999). Some discrepancies were found in how children and mothers understood the closeness of their relationships; mothers often perceived their relationship with their child as closer when compared to children’s perceptions (Hardy et al., 1995). Regardless, school-age children with cancer benefited from the support parents offered in the forms of hope and positive attitudes.

Hockenberry-Eaton, and Minick (1994) found that with 7 to 13 year olds with cancer, emotional support from parents was critical. Behaviors such as telling them that they loved them and treating them as typical children were important to children with chronic illnesses (Woodgate, 1999). Additionally, Sheeran, Marvin, and Pianta (1996) found a correlation between changes in the parent-ill child relationship and parental stress associated with the chronic illness. Parental acceptance versus nonacceptance of their child’s diagnosis is an accurate predictor of strong or weak child-parent attachment (Sheeran et al., 1996). Parents feel that providing treatment that causes their child pain negatively impacts their relationship because children no longer see their parent as the ultimate safe person (Shepard & Mahon, 2000).
Parents often prioritize the needs of their sick child at the expense of other family relationships. Consequently, marital relations often suffer. Although divorce is not more common in such family structures, stress and lack of affection are typical (Jackson, 2000; Jackson & Vessey, 2000). Mothers spend their time with the ill child while fathers tend to divide their time between work, healthy children, and the child with special needs (Feudtner, 2002; Nelson, 2002). In some cases, this division of family labor may create conflict. For instance, Clements, Copeland, and Loftus (1990) found that married mothers were resigned to the fact that fathers would not participate in the health care of their chronically ill child resulting in feelings of resentment. These feelings were intensified, as mothers felt more socially isolated due to the burden of caring for a chronically ill child. Numerous mothers had to quit working outside of the home to care for their child or because qualified childcare providers were unavailable (Clements et al., 1990). In spite of marital stress, both parents tended to be concerned about the impact of a chronic illness diagnosis on siblings of the ill child. Parental concerns focus primarily on having time for the sibling and ensuring that the needs of the ill child do not become the responsibility of siblings (Clements et al., 1990).

Social Support: Sources of Strength and Conflict

According to St. Jude Children’s Research Hospital, social support is a network of family, friends, neighbors, and community members that are available in times of need to give psychological, physical, and financial support. For children 6-12 years of age, psychological support is critical for healthy development (St. Judes, 2010). For minors suffering from chronic conditions such as cancer, “a strong social support system is
especially important in helping them cope, considering they have the potential to experience a “dual crisis” in having to deal with complex normative developmental tasks as well as cancer-related stressors” (Woodgate, 2006, p. 122). Strong social support systems are correlated with quality of life for this vulnerable population (Hinds, 1990).

From the perspective of parents, discussions addressing parental roles in the hospital often are absent, but necessary (Garwick, Kohrman, Wolman, & Blum, 1998). Studies have shown that parents want to be involved in the care of their hospitalized child in various capacities including emotional support, non-medical care, and entertainment (Romaniuk & Kristjanson, 1995). Because parents feel uncertain about their role in the hospital and controlled by hospital staff, many parents are dissatisfied in their abilities and opportunities to fulfill these basic tasks for their children (Rollins et al., 2000; Romaniuk & Kristjanson, 1995). Parents may hesitate to address this issue because of the immense social gap they feel between themselves and health care professionals. While professionals are well versed in the world of health care, parents initially navigate through it as outsiders, unfamiliar with medical vocabulary and hospital layout (Sobo, 2004; Sobo & Seid, 2003; Sobo, Seid, & Gelhard, 2006).

As parental roles evolve and confidence is gained, parents shift toward advocacy for their child in health care settings (Burke, Kaufmann, Costello, & Dillion, 1991). Parents learn to advocate for their child through seeking information. Parents often proceed with caution however, balancing their personal investment in their child with the scientific expertise of doctors (Jerret, 1994). Some parents take charge due to the perceived reluctance of a medical professional’s inability or unwillingness to meet their
child’s needs (Burke et al., 1991). Still, other parents fight for the special services their child may need that otherwise may not have been secured (Johnson, 2000), including home health care programs (Rollins et al., 2005).

In addition to the support children received from their parents, children also receive support from their peers. School-aged children need to maintain their relations with healthy friends while developing friendships with cancer patients similar to themselves (Woodgate, 1999). These relationships may be sources of great strength as well as stress. For instance, while relationships with other cancer patients may provide relevant first-hand knowledge, empathy, compassion, and understanding, it also may result in coping with their deaths (Enskar et al., 1997; Woodgate, 1999). While healthy peers are unable to provide similar support, their support may have positive implications for the emotional well being of the child with cancer. Similar to parental support, the positive attitudes, hope, and typical treatment provided by healthy peers were found to be helpful (Woodgate, 1999). However, it also was found that children as young as seven years old equated hair loss due to treatment with the loss of their healthy friends (Aamodt, Grassl-Herwehe, Farrell, & Hutter, 1984). Some school-age children with cancer believe that their healthy friends become uncomfortable when signs of the disease are physically visible (Woodgate, 1999).

Supportive behaviors by health care professionals also were a source of comfort for children in this developmental stage (Aamodt et al., 1984; Gaynard et al., 1998). Patients appreciated behaviors that included “instilling hope, informing ill children of what will happen, and inventing treatments that help children with cancer” (Woodgate,
School-aged children emphasized the need to have a good relationship with at least one hospital worker in order to have a source for knowledge and some sense of control over their situation (Enskar et al., 1997; Woodgate, 1999). In hospitals that offered child life services, child life specialists were frequently the main support people for pediatric patients on the health care team (Gaynard et al., 1998).

Child life specialists are skilled professionals with proficiency in assisting children and their families in negotiating and overcoming challenges in life. Child life specialists use their backgrounds in child development and family systems to encourage coping through play, preparation, instruction, and self-expression activities (Child Life Council, 2010). More specifically:

[Child life specialists] provide emotional support for families, and encourage optimum development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization. Because they understand that a child’s well being depends on the support of the family, child life specialists provide information, support and guidance to parents, siblings, and other family members. They also play a vital role in educating caregivers, administrators, and the general public about the needs of children under stress (Child Life Council, 2010).

Child life specialists play a key role in tailoring offered support to meet the needs of individual families.

The majority of research shows that the more support available to hospitalized and chronically ill school-age children, the better their adjustment (Woodgate, 1999);
however, there are significant gaps in the literature. For this reason, it is critical that research is done with school-age children with the intent of examining their perceptions of and thoughts on social support. Also a child’s age, diagnoses, and gender should be taken into account as these qualities have been addressed in various other related studies and should be considered (Rollins et al., 2005).

While families of chronically ill children also may benefit from social support systems, they often experience a loss of them. Fear and reluctance of friends and family as well as fear and guilt from parents prevent the utilization of some forms of social support (Clements et al., 1990; Kohlen, Beier, & Danzer, 2000). A common support system that is lost is that of a babysitter. In some cases, families decline the help of childcare providers, as they do not feel comfortable leaving their child due to their health conditions. In other instances, the babysitter may be unwilling or unable to care for the child in all of the necessary ways because of the diagnosis (Hatton, Canam, Thorne, & Hughes, 1995). Mothers are more critical of and dissatisfied with the social support they receive than fathers (Patterson, Garwick, Bennett, & Blum, 1997). Mothers generally view offers from unknowledgeable peers as unhelpful; this negativity is intensified if a peer unknowingly says something found to be offensive to the parents (Garwick, Patterson, Bennett, & Blum, 1998). Social support networks are lacking in availability for men and siblings, yet have shown to be beneficial for men and siblings to work through their emotions (May, 1996; Rollins et al., 2000).
Health Care and Family Culture

Children are socialized and exposed to health rituals within the context of their family beliefs (Jackson & Vessey, 2000; Rollins et al., 2005; Thibodeaux & Deatrick, 2007). As a result, children learn at a young age what their family understands to be healthy and ill in addition to what constitutes as healthy life choices and preventative care. Denham’s (1999) research in Appalachian Ohio revealed prevalent findings that defined family health practices within this cultural group. Early socialization from parents, especially mothers, helped to define what one considered to be an important health resource. While the whole family participated in family health routines, mothers were most often responsible for family well being. Additionally, family health was directly impacted by the beliefs and values that families shared even when the origin or purpose of such a practice was unknown. Furthermore, families learned to practice these health rituals in the context of a larger society (Denham, 1999).

Denham’s (1999) findings are similar to those of McCubbin, Thompson, Thompson, McCubbin and Kaston (1993) who define family schema as a “structure with fundamental convictions and values shaped and adopted by the family system overtime which creates the family’s unique character and serves as an overriding shared informational framework against through which family experiences are processed and evaluated” (p. 1064). Family schemas, which are highly resistant to change, may include honoring one’s cultural heritage and respecting elders. The family schemas identified in Denham’s (1999) research as a part of the purpose of family health routines included supporting developmental processes, avoiding sickness, acquiring and sharing health
resources, and constructing family health paradigms. A family’s schema shapes the family unit’s response to a chronic diagnosis in order to provide stability to family life. A family’s schema is influenced by culture, through the mediating process of family paradigms (McCubbin et al., 1993). Defined as a family’s worldview, family paradigms include the cultural and ethnic values and beliefs that are the framework through which families see and understand the world (McCubbin et al., 1993). The family paradigm that develops in response to a chronic diagnosis determines the specific coping strategies that a family will employ to adjust to the new condition (McCubbin et al., 1993; Patterson, 1988).

While chronically ill children can be submersed within their family’s health culture, the family itself lives and functions within the greater context of society and culture (Thibodeaux & Deatrick, 2007). Therefore, when families negotiate the care of a chronically ill child, multiple cultures are at play. These cultures include the ethnic groups that are interacting, the family culture of the patient, and the culture(s) of the health care professionals (Spector, 2002).

Many previous studies focused on the cultural aspect of a family’s understanding of health by merely offering stereotypical lists of family practices and behaviors based on broad clumpings of ethnic groups (McCubbin et al., 1993), such as classifying Japanese, Chinese, and Korean Americans together as Asian Americans (McCubbin et al., 1993). While these ethnic groups have some commonalities in their way of life, they have a great deal of differences. This dependence upon the stereotyping across cultures will continue until the absence in scholarly research is addressed.
Recognizing the Need for Culturally Sensitive Health Care

Leininger (1996) first recognized health care as a cultural phenomenon in the 1950s when she realized that care and culture were two significant parts of life that were neglected in medical settings. In order to fill this void, Leininger founded the field of transcultural care within nursing and developed her culture care theory as the result of many studies executed in Western and non-Western cultures (Leininger, 1988, 1996, 2002, 2003). With the introduction of this theory and new domain, numerous scholars began to study health care through a cultural lens with the intention of incorporating research-based knowledge of cultural care into nursing curricula (Boyle & Andrews, 1995; Dobson, 1991; Leininger, 1988, 1996, 2002, 2003).

The key purpose of Leininger’s theory is to discover what culturally based practices are universal, yet defined by an individual’s culture, and to explain how practices may influence one’s understanding of health, well being, illness, or death (Leininger, 2002). The primary focus of cultural care frameworks is to train health care professionals based on commonalities, and to provide care that is respectful of patients’ cultural viewpoints. This is viable when ethnocentric assessments are avoided (Baker, 1997). The beliefs of Leininger (1996, 2002) and Orque, Bloch, and Monrroy (1983) are parallel in reference to the importance of a provider’s self-knowledge. Individuals first must understand and recognize their own culture as well as their cultural biases and prejudices in order to gain awareness of their personal subconscious behaviors. This realization enables health care professionals to provide care that avoids cultural pain, unethical treatment, and imposition of practices (Leininger, 1996, 2002).
Leininger’s culture care theory is unique as it is the only nursing theory that focuses on culture—interrelationships and comparative care (Leininger 1988, 1996, 2002; Rosenbaum, 1997). This model includes the holistic and multidimensional approach to services that enables the discovery of comprehensive culturally based health care practices and meanings (Leininger, 1988, 1996, 2002). Global commonalities and differences can be discerned by employing this approach (Leininger, 1996).

Professional Implications: Cultural Care at Work

Helman (1998) recognized that both professional and lay health care exchanges are tied to culture in some manner and need to be viewed in their proper context in order to be understood (Dobson, 1991; Leininger, 1996; Orque et al., 1983). The anthropologic perspective recognizes popular, folk, and professional sectors as three interconnected systems of health care (Kleinman, 1980), while Leininger divides health care practices into professional and lay care. Health care is further complicated with the inconsistencies found in professional Western health care systems (Helman 1998; Leininger, 1988). Inconsistencies include the criteria for diagnosis and prescribed treatments as well as differences in cultural responses to behaviors and stigmas associated with them (Helman, 1998; Payer, 1989). Anthropologically, norms are understood to be beliefs and behaviors that shape a society or culture. Brink (1999) concluded that social norms define what is deemed to be acceptable and unacceptable behaviors within particular Western health care systems.

Similarly, Scott and Meyer (1994) found that health and illness are understood through culture. While practitioners in Western systems fully recognize how culture and
ethnicity can be used to predict the distribution of an illness as well as the genetic and sociological characteristics that are present, they fail to consider a family’s cultural response to symptoms and diagnoses (McCubbin et al., 1993). The latter is critical for health care professionals to understand and consider because “cultural differences in the meaning of symptoms can lead at times to a delayed diagnosis of potentially serious conditions” (Trollope-Kumar & Last, 2010, ¶ 2).

Researchers have found that many doctors feel that the cultural background of the families do not affect the care offered by the health care system (Joseph-DiCaprio, Garwick, Kohrman, & Blum, 1999). In comparison, Berlin, Johansson, and Tornkvist (2006) found different outcomes with pediatric nurses. These investigators examined cultural competency in the context of nurse-child interactions of different cultural backgrounds. Because they felt their cultural competence was inadequate, nurses reported being dissatisfied with the quality of care they were able to offer their international patients. Concerns also were raised about the large number of culturally diverse patients and the lack of work place guidelines for nurses to follow when in these exchanges. Nurses recognized a need for offering culturally competent care, but felt resources were unavailable for them to gain such skills (Berlin, Johansson, & Tornkvist, 2006).

Culturally effective pediatric health as defined by the American Academy of Pediatrics (2004) is “the delivery of care within the context of appropriate physician knowledge, understanding, and appreciation of all cultural distinctions leading to optimal health outcomes” (¶ 5). Scholars in the field refer to culturally sensitive care as a global phenomenon that transcends cultural boundaries (Brink, 1999). This unification of culture
recognition and health care is especially critical with the diagnosis of a pediatric chronic condition.

Health care professionals must truly understand a family’s cultural background when a child has a chronic illness because parents will potentially provide the majority of care for this child at home. As cultural beings, parents mediate their child’s care based on their beliefs and practices (McCubbin et al., 1993; Rehm, 2000). By treating a child’s chronic condition in the cultural framework of the family, the health care provider has the potential to influence medical management, fulfillment of prescribed protocol, treatment outcomes, and overall patient satisfaction (Joseph-DiCaprio et al., 1999).

The Meeting of Two Worlds: Cohesion and Friction in India

Traditionally, the family has been viewed as the most important institution in the collectivistic culture of India. As a result, family integrity, family loyalty, and family unity are highly regarded across society (Triandis, 1988). Mullatti (1992) identified the Indian family as the governing body of not only the individual, but also the community. Nearly 83% of the population practices the Hindu belief system (Ramakrishna & Weiss, 1992), which values extended family and kinship ties (Shangle, 1995). Conventional families obey patriarchal ideology, practice strong family values, and encourage traditional gender roles. Families are understood to be strong, close knit, enduring, and resilient (Mullatti, 1995; Shangle 1995).

Today, younger generations are beginning to forgo rural, or country, dwellings and the joint family structure, a multigenerational household including extended family members, as a result of modernization and urbanization, or the gathering of larger
populations forming cities. Although joint families and country life are no longer the social norm, many of their key strengths are still practiced (Mullatti, 1995). While geographic proximity, career association, and hierarchal authority are becoming ways of the past, Shangle (1995) found that past practices are kept alive through frequent family visits, economic support, child rearing guidance, and traditional involvement in marriage ceremonies, births, and deaths. The modified extended family in India is preferred in spite of the practical moves toward a pseudo-Western culture and nuclear family in the middle and upper classes (Chekki, 1996; Mullatti, 1995; Segal, 1998).

As gender roles are evolving in India, clear-cut expectations of masculinity and femininity still exist (Mullatti, 1995). Boys are taught to be assertive, domineering, and independent while girls are socialized to be self-sacrificing, nurturing, and accommodating. Females are taught to value family above all else. As a part of this role, women are expected to care for children and elderly family members as well as perform all the household chores (Mullatti, 1995).

Western Medicine in an Eastern World

Health practices are learned at home throughout childhood in India. The majority of this health socialization is based on India’s ancient and widespread use of Ayurvedic principles (Ramakrishna & Weiss, 1992). There are variations from region to region and between castes in how Ayurveda is carried out, but the underpinning beliefs of Ayurvedic traditions are universal among followers. This is made evident today through the social changes that are taking place in India. Traditionally, lower castes are beginning to emulate upper castes as upper castes are undergoing “Westernization,” striving to imitate
the lifestyle of Americans (Ramakrishna & Weiss, 1992). As social statuses are evolving in India, “pan-Indian” beliefs concerning Ayurvedic ideas are continuing to be a major influence in how health is viewed (Ramakrishna & Weiss, 1992).

Westerners view the body as a complex machine. In contrast, the Ayurvedic notion of the body understands health to be a delicate balance between the physical, social, and supernatural environment and illness the result of disturbances that can occur in different realms (Kinsley, 1996; Trollope-Kumar & Last, 2010). Ayurveda is based on a holistic approach that incorporates the body, mind, soul, and emotions versus the reductionist approach of Western medicine that focuses solely on the body. Patients are considered active participants in the healing process and view disease as a necessary part of life. In contrast, the biomedical method treats patients as passive receivers who have an ailment that must be overcome. Physicians are perceived as guides in Eastern systems and as experts in the West. While diagnoses and treatments are individualistic and qualitative in Ayurvedic practices, they are standardized and quantitative in Allopathic systems (Kinsley, 1996; Trollope-Kumar & Last, 2010).

Despite these contrasting perspectives of health, Allopathy, as Western medicine is termed in India, is the preferred type of health care where it is available in India for acute illnesses. Traditional means of health care are still preferred for chronic conditions (Ramakrishna & Weiss, 1992). In some cases, patients combine these methods at their discretion. Because these practices are used congruently, health care practitioners in India are most successful when they are knowledgeable in both systems. For instance, a patient who is prescribed a Western medicine may inquire what Ayurvedic diet practice will best
coincide with the Western treatment (Ramakrishna & Weiss, 1992). In more extreme cases, symptoms may be misinterpreted due to cultural differences. Chest pain in Western society is regarded with a sense of urgency while in the Ayurvedic tradition, it can be associated with an emotional imbalance. This misunderstanding can lead to delayed diagnoses and less time for doctors to react (Ramakrishna & Weiss, 1992).

Perhaps the largest challenge that health care professionals are facing in India with the implementation of Western medical technology is developing ethics based on India’s conventional morals and wisdom that still provide the same level of protection for professionals and patients as the current Western ethics do in a Western setting (Sarnaik, Daphtary, & Sarnaik, 2008). Nearly all religions and cultures have commonalities related to health ethics and India proves to be no exception (Sarnaik et al., 2008). In fact, India has the opportunity and potential to develop an ethical health care framework that is transcultural (Sarnaik et al., 2008). Autonomy, beneficence, and justice are three basic principles of health that currently guide Western medicine and with some redefining in how they are applied can compliment Eastern wisdom.

Autonomy is the right of individuals to make decisions regarding their health care with the information provided to them by their physician(s). In Western settings, there is great debate over defining the necessary criteria to be deemed competent in making informed health decisions as patients. This issue is compounded further when pediatric patients are involved. Relevant to child life specialists and other health care professionals who work directly with children, the principle of autonomy and defining competence has “dual relevance: the competence of maturing children to participate in decision making
and the competence of surrogate decision makers to act on the children’s behalf” (Klein, et al. 2000, p. 5-6).

This challenge is even greater in India. The concept of autonomy itself is in conflict with India’s high context culture and potentially with their patriarchal family structure. Women and children do not seek medical help unaccompanied; the person accompanying them expects to participate fully in the visit through sharing medical history, assisting in the exam, and discussing potential diagnoses and treatment (Ramakrishna & Weiss, 1992). Another challenge presented by this ethic is what Indian’s choose to share with ill family members:

They [families] do not want to disclose the seriousness of an illness to the patient or speak about impending disability or death for two reasons: Speaking of possibilities may render them too real and a traditional Indian does not speaklightly of death; and many people think that if a patient knows the gravity of the illness, he or she will give up hope and die. (Ramakrishna & Weiss, 1992, p. 269)

A doctor is obligated to protect and do no harm to patients according to the ethical guideline of beneficence. In addition, physicians are to act as a patient’s advocate, doing what is best for them despite the outside influence of family (Sarnaik et al., 2008). Again this Western ethic contradicts what India values in some capacities. India is a high context society, and therefore decisions are made based on what is best for the family unit and with the opinions of male family elders being held in the highest regard (Mullatti, 1995). Furthermore, doctors are perceived as being guides in conventional Indian health care as opposed to experts as seen in Western medicine (Trollope-Kumar & Last, 2010).
The Child Life Council (Klein et al., 2000) acknowledged these potential points of tension within their ethical guidelines:

> Perspectives on doing good can differ significantly; each person in a family and caregiver on a team has a unique and individual perspective on what might constitute doing good for a particular child or youth. The range of views held within the group of interested, committed, and well-intentioned individuals may be slight, but it may also be so broad as to represent opposing points of view. (p. 4)

The ethical principle of justice, defined as “the duty to be fair, impartial, and equitable and to avoid any discriminatory practices” (Klein et al., 2000, p. 6), has two distinct parts and therefore may be the most challenging. The first part of this principle is intended to ensure equal treatment of those with similar diagnoses. Part two, known as distributive justice, guarantees that no individual or group gets a disproportionate share of society’s resources or capabilities while also requiring that no one be denied a reasonable amount of care (Sarnaik et al., 2008). This is a particularly large challenge in India because of limited resources, the traditional caste system, and demographics.

Before India can begin to address the complications that arise out of placing a Western health system in an Eastern world, India must address the strengths and weaknesses of its health care infrastructure (Sarnaik et al., 2008). India is in a positive position to begin to do this for two main reasons. First, India can learn from the systems already in place in the Westernized world. Second, India can design models that draw on the strengths from various segments of society including their advanced computer
technology, established charities, and public private health care sectors (Gupta, 2008). A basis of this model must emphasize the importance and beneficence of preventative health practices, the availability of care for all people, and affordability. This must be achieved in a way that works within India’s established social structure (Bagchi, 2008; Gupta, 2008).

It is detrimental that India drastically augments its health infrastructure. On average, 27,000 students graduate from Indian medical schools each year (Bagchi, 2008), however India exports more doctors than any other country in the world (Knox, 2008). Of the doctors and nurses that remain in India, 75% of them reside in cities while 70% of patients live in villages (Bagchi, 2008; Gupta, 2008). In 2005, India had one doctor for every 1,722 patients and the need for nurses is even more substantial (Bagchi, 2008). Such severe shortages of health care practitioners leaves little time or resources for culturally sensitive care.

Further impacting this shortage is the flourishing economy that is increasing urbanization and expanding the middle class. This extra money provides an opportunity for members of the middle class to utilize health care services more frequently (Burnett, 2010; PricewaterhouseCoopers, 2007). A minimum of 50,000 Indians now can afford to purchase Western medicine (India Brand Equity Foundation [IBEF], 2010; PricewaterhouseCoopers, 2007). In addition to buying Western medicine, Indians are enjoying Westernized diets that are high in fat and sugar. As a result of this unhealthy eating pattern, lifestyle diseases such as cancer, diabetes, and childhood obesity are
reaching epidemic proportions. This trend is projected to continue with life style illnesses surpassing infectious diseases in India within 10 years (PricewaterhouseCoopers, 2007).

Conceptual Framework

The conceptual framework that guides this study is based on Bowen’s (1978) family systems theory. This theoretical approach views families as emotional units. The premise of this theoretical approach is that family members affect each other so deeply in thoughts, feelings, and actions that they often share the same emotions (Bowen, 1978). This theory is presented through eight interlocking concepts: (a) triangles, (b) differentiation of self, (c) nuclear family emotional system, (d) family projection process, (e) multigenerational transmission, (f) emotional cut off, (g) sibling strain, and (h) societal emotional process. Triangle, as the smallest and most stable system, represents a three-person relationship. Emotional tension can be withstood in this system for an extended period of time without the assistance of an outsider because of the three stability points. While this arrangement creates an outsider, it forces issues to be addressed. Within the context of this study, the triangle applies in many ways. The most significant application of this concept for this study is the triangle formed between the parents, the chronically ill child, and medical staff persons. Another significant triangle is experienced between the child, mother, and father.

Differentiation of self is an individual’s susceptibility to peer pressure that is developed in childhood and directly influences how one thinks, feels, and acts in the context of others. This concept will provide insight on how and why mothers in this study interact with health care professionals in certain ways.
Nuclear family emotional system examines the four basic relationship patterns in a family system and outlines four areas of potential conflict including: marital conflict, dysfunction in one spouse, impairment of one or more children, and emotional distance. It is common for all four of these conflicts to arise in such stressful situations as a family coping with a serious pediatric illness. Family projection process describes the primary way in which parents share their emotional issues with children. Because of the emotional strain that parents experience with the hospitalization of a child, this concept will be of particular benefit to this study.

Multigenerational transmission process should yield interesting developments within the current research because of the changing cultural and familial dynamics within the field. Emotional cut off occurs when people managing unresolved feelings withdraw themselves in order to avoid further strain. Sibling strain is addressed with the incorporated work of Walter Toman (1976) to better understand how birth order affects one’s experience of marriage, parenting, and childhood. The inclusion of this knowledge will contribute to my understanding of social support from within the family. Lastly, societal emotional process addresses how all of the previous concepts can apply to non-family groups because emotional systems govern individual societal interactions.

A number of research studies and theories have contributed to the study of health care encounters. As a result, the understanding of family culture, pediatric chronic illness, and health care professionals has contributed to the development of stronger and more holistic pediatric health care models. However, inconsistencies are found in the implementations of adult based models on pediatric care as well as the enforcement of
Westernized medical practice on non-Western patients. The present study will investigate the intersection of family culture, pediatric chronic illness and hospitalization, as well as interactions with health care professionals. By interviewing chronically ill pediatric patients and their mothers, the information gained throughout data collection will highlight how mothers renegotiate health communication as well as family health culture in a hospital setting. Furthermore, by interviewing chronically ill children and their mothers, information will be gained concerning the parallels and discrepancies in child-mother perspectives on the child’s current health understanding and status. Researchers and professionals associated with health care settings may benefit greatly from the information uncovered in the current study by increasing their knowledge and understanding of the specific needs of chronically ill children and their mothers facing health care encounters. This increased knowledge and understanding may lead to more effective and culturally sensitive health care services resulting in greater patient and professional satisfaction.
CHAPTER 3: METHODOLOGY

The purpose of this qualitative study was to investigate how hospitalized, chronically ill children and their East Indian mothers perceive the personalization of their health care experience. Particularly, this study examined the recognition of and respect for individual family cultures regarding the interactions between patients and their health care professionals. Furthermore, this investigation explored how mothers and children communicated health related issues within the context of their family culture. The research questions presented for this qualitative investigation were: (a) How do East Indian mothers of children, ages 6 to 12 years, who are hospitalized with chronic illness view the personalization of the health care their family is receiving?; and (b) how do Indian children negotiate their health care experiences regarding their perceptions and understanding of health and illness as socialized within family and cultural contexts? The implementation of this study will be explained in the following sections.

Recruitment

This qualitative study utilized a convenience sample (Berg, 2007) targeting pediatric patients and their mothers. These child-mother dyads were receiving professional health care services from a midsized hospital in Bangalore, India.

Study Site

The study site, a private hospital in Karnataka State’s capitol, Bangalore, is located in south central India. With 7.2 million people, Bangalore is India’s 5th largest city and holds the world record for the highest population growth in a 20-year period (Bangalore, 2008; Karnataka, 2010). With just 41% of the population being native to Bangalore, it is a true cosmopolitan.
Natives of other parts of India comprise 47% of Bangalore’s population while Europeans represent 6%. The remaining 6% is representative of the world (Discover, 2010). Bangalore is home to India’s largest Anglo-Indian population. Five languages are widely spoken and understood throughout the city (Discover, 2010; Karnataka, 2010) and the literacy rate is 85.74% (Bangalore, 2008). Furthermore, India’s richest residents live in Bangalore while the poverty line is least of all cities in the world (Bangalore, 2008; Discover, 2010; Karnataka, 2010).

Approximately 1/3 of Bangalore’s families live below the poverty line (Sreekumar, 2009). As the fastest growing city and known for its advanced information technology in India, Bangalore is becoming a leader in the health care sector (Vijaya, 2000). Many health care professionals are attracted to Bangalore because of this technological advancement, isolating the city from the widespread doctor and nurse shortages throughout India (Vijaya, 2000). Additionally, Bangalore has many private and public hospitals with the study site being just one.

This hospital is setting the standard for quality health care in India. In addition to being recognized throughout South India as a prominent center for tertiary care, this hospital is recognized around the world for its success rate in curing patients which is double the world average (Name of Hospital, 2008). In 2000, TUV Rhineland certified this hospital to be in compliance with the International Organization for Standardization. In addition, this institution received India’s prestigious Golden Peacock National Quality Award in 2005 considered the “holy grail of corporate excellence quality” ([ - ]1, 2010). More recently, the National Accreditation Board for hospitals (NABH) accredited the study site hospital for providing high quality patient care. With 600 beds, 275 consultants, and 43 specialties, this hospital is equipped

---

1 The notation [ - ] indicates indentifying information that has been omitted to preserve the anonymity of individuals and institutions.
to offer diverse and multifaceted care. In addition, this hospital’s International Patient Care Center is in place to meet the cultural and linguistic needs of diverse patients. Within this center, services are offered in 11 different languages to meet the needs of patients from around the world including North America, Europe, Africa, and the Middle East. Dieticians on staff are trained to meet the dietary customs and restrictions of foreign patients and their families. Hospital rooms are furnished with extra beds, couches, refrigerators, and televisions to ensure the comfort of patients and family members who are far from home ([ - ], 2010). Furthermore, this hospital is implementing India’s first child life program through this foundation.

This child life oriented foundation is a newly formed, nonprofit organization based in [state]. In addition to being home to the founders, [state] is known to be a global leader in child life center programming. This factor was critical to the foundation as its purpose is to aid children and their families by implementing a child life service program for hospitalized children in India. This program seeks to positively impact the medical experiences of children and their families. The services provided include developmental, educational, and therapeutic interventions in a manner that acknowledges individual family needs and respects different coping methods ([ - ], 2010).

To recruit participants for this study, an informant, Ms. Priti Patel, the president and founder of this nonprofit foundation, was identified and utilized. In addition to being a native of India, Ms. Patel had first hand experience with the child life center at [State] Children’s Hospital; she utilized the services with her chronically ill daughter from the time of her diagnosis in 1999 to her death in 2003. During a period of remission, Ms. Patel and her daughter, Aanandita, journeyed to India. While there, they visited a cancer hospital and noticed the need for a child
life program like the one that had helped them. This inspired them to help the children of India. Through her efforts and in memory of her daughter, this foundation was developed in Bangalore, India for chronically ill children who are being served at this hospital. This new program blends Western and Eastern cultures and practices.

Ms. Patel served as my primary informant who aided me in making contact with current pediatric psychosocial team members at the study site hospital. I had five conversations with Ms. Patel to explain the general scope and purpose of this study, to determine the feasibility of this investigation, and to aid in the recruitment of potential participants. I also utilized her expertise to help in determining what topics would be included within each set of interviews as well as what was culturally appropriate to address.

Due to the nature of this study, participants were not recruited until Institutional Review Board approval was secured. Before my arrival to Bangalore, I arranged with Ms. Patel to contact the pediatric psychosocial team, a group of highly trained professionals that work with children and families in health care settings including clinical psychologists and social workers, to help with identifying potential child-mother dyads that they felt would be able and willing to participate in this research. Psychosocial team members also helped in recruiting participants, who were interested in this study and who had the health and energy to participate. Psychosocial team members had a great deal of insight on the emotional stability of families and approached those that seemed to be most comfortable and open with this process. The psychosocial team provided a brief overview of this study to willing participants and got a verbal acceptance from mothers and patients individually before I contacted them directly.
Once I arrived in Bangalore and met with the psychosocial team members, I made initial contact with potential participants, starting with mothers to confirm their interest and gain parental consent, in their hospital rooms after confirming with their psychosocial team that they were able to participate within the scope of their current health status. During this time, I confirmed participants’ willingness to participate and answered any questions after explaining the study in more detail.

Prior to conducting any research, I spent time at the study site to increase my comfort level with an East Indian hospital setting, typical occurrences, and language use. I also hoped that my presence would increase the comfort levels potential participants felt with me. Additionally, I used this time to ask questions regarding the meaning behind cultural nuances and language that I, as an outsider, was unfamiliar.

Sample

Child participants were required meet the following criteria: (a) natives of India who speak and understand English; (b) pediatric patients between the ages of 6 and 12 years in the study site hospital in Bangalore, India; (c) diagnosis of a pediatric chronic disease; and (d) having a mother who was involved with the child’s health care and willing to participate in the study.

Description of the Sample

Participants in the current study included both children who were pediatric patients at the study site hospital and their mothers. Five child-mother dyads (N = 10) were targeted for this study. Four of the mothers self-identified as being Hindu and 1 mother self-identified as being Protestant. Three of the mothers identified Bangalore as their home while the remaining two
mothers identified outside villages. The ages of the children participants ranged from 6-12 years with an average of 8 years. Only one child reported having a sibling. The educational levels of the mothers ranged from no formal education to a doctoral degree. Their family incomes ranged from 8,000-41,000 rupees (170-880 US dollars) per month. The average monthly income was 17,500 Rupees or 375 US dollars.

Informed Consent Process

Ohio University’s Institutional Review Board approved the informed consent and assent documents on August 11, 2008 (see Appendices A and B). Mothers were given informed consent forms that I offered to read aloud if desired prior to starting the interview; these forms requested consent for participation of both mothers and children. Due to the age of minor participants, I read the assent form in developmentally appropriate language. I addressed any questions or concerns that arose before acquiring participant signatures.

While all the mothers were of age to provide informed consent, their minor children were required to sign the assent form. Children only were approached to sign the assent form after written consent had been obtained from their mother for them to partake in this study. These signed consent and assent forms were stored in a locked file for the duration of this study. Upon completion of this research, all consent and assent forms will be destroyed to protect the confidentiality of all participants.

Interview Procedures

Upon the completion of recruitment, participants were interviewed in a mutually agreed upon private location within the hospital. Every effort was made to meet the personal desires and schedule needs of participants. Participants were interviewed individually to gain
multiple perspectives and encourage honest and open conversation after discussing and signing the informed consent / assent forms. Each dyad was interviewed consecutively with the mother interviewed first. Conducting the mother’s interview prior to her child’s interview allowed the researcher to obtain the required signatures as well as insight as to what each child had been told about their reason for hospitalization. Attaining this information enabled the researcher to avoid unintentionally revealing information to the child that the mother wanted concealed. While it was the researcher’s intention to audiotape each interview with participant permission, heightened hospital security forbid the use of any recording device. Because of this, the researcher took copious notes before, during, and after each interview. In order to ensure the accuracy of notes, the researcher asked participants to repeat quotes when necessary and appropriate. Although participants slightly rephrased their wording on occasion during this process, their exact words were hand written by the researcher. In order to conduct each interview in a timely manner, the researcher developed a method for taking short hand notes that included the use of symbols and initials. For example, only the first letters of names that participants referred to were recorded, common words such as doctor, medicine, etc. were assigned quick icons, and emotion words were represented through common facial expression symbols. Immediately following each interview, the researcher read over the data collected and wrote down more specific details where necessary and appropriate. Additionally, notes pertaining to the environment were recorded at this time.

Three of the 5 mother participants expressed appreciation for conducting the interviews without any recording device as they said they felt more comfortable to speak freely and openly. Additionally, one mother felt that the time the researcher used to write
quotes allowed her to form more articulate thoughts because English was her second language. Furthermore, this time seemed to increase the comfort levels of child participants as it allowed them to more fully engage in play throughout the interview, distracting them from the interactions main purpose.

In order to encourage elaboration and stories, open-ended questions were incorporated into two semi-structured protocols (see Appendices C and D). Before the protocol underwent compliance review, three individuals, to ensure cultural sensitivity and relevancy, reviewed potential questions. The first reviewer, native to Bangalore, reviewed the questions for cultural literacy and understanding. The second reviewer, native to India and currently residing in the United States, had extensive experience negotiating both the United States’ and Indian health care systems as he suffers from a pediatric chronic condition. The final reviewer offered the perspective of an Indian mother who had lost a child to a chronic condition in the United States health care system. The insights that these individuals provided elicited a wealth of knowledge in a culturally sensitive framework.

The final protocols were semi-structured with open-ended questions to promote rich description from both child and mother perspectives. The protocols for both children and their mothers were similar in nature, yet addressed differing perspectives and developmental levels. At the commencement of each interview, mothers were asked to tell their child’s story. The second portion of the interview addressed how each family understands and practices health. The third part of the interview process dealt with family management of the child’s health condition at home. The fourth part of the interview dealt with the influence of the child’s illness on other family members. The concluding portion of the interview addressed the expectations mothers
had of themselves, family members, and medical staff. In recognition of cultural norms, mothers were asked to fill out a brief profile addressing their family demographics upon completing the interview process (see Appendix C).

While the researcher intended to collect data from the children in the forms of art renderings and photographs as these methods have been found to assist children in expressing themselves more fully (American Cancer Society, 2010; Councill, 2003; Sundaram, 1995), heightened hospital security did not permit the necessary supplies. Out of respect for their cultural norms, child participants were provided with small toys prior to beginning the interview. After this, children were asked to share their personal story. Children were asked questions regarding the differences they perceived between the health care they receive at home and at the hospital. Children also were asked about how their relationships with family members changed since becoming ill. They were questioned about the interactions they share with their health care professionals.

When necessary, additional probes were used to clarify participant responses to interview questions. Interviews with mothers lasted approximately 1 hour on average depending on the participant’s willingness to talk and freedom to be away from her child. To be sensitive to the health status and developmental needs of the child participants, children’s interviews lasted approximately 25 minutes. I was sensitive to participant fatigue and any signs of illness. During all interviews, mothers and children were encouraged to ask for clarification regarding questions and were made aware that they could pass on questions that caused discomfort. Depending on the needs of each participant, breaks were incorporated into the interview process. The hospital’s psychosocial team worked closely with each dyad to address any issues that may arise as well.
For their participation, children received toys that child life centers utilize as means of distraction and coping. These included finger paint, crayons, key chain, bouncy ball, stickers, and a pillowcase and backpack to decorate.

As anticipated many of the participants requested elucidation regarding the purposes of this project as well as my qualifications as a researcher. To help alleviate these concerns, I spent time interacting with hospital staff, patients, and family members prior to collecting research. Mother and child participants alike showed great interest in my experience as an American. Mothers expressed special interest in the career field of child life that I planned to pursue after graduation. Each participant in this study was eager to share his or her experiences. Additionally, participants were given the option of having a member of their psychosocial team present during their interview. In the case of two mothers who wished to have a translator, a psychosocial team member was present. A medical staff member was outside of the room, but near by in case of a medical emergency during all interviews with child participants.

All participants answered every question asked during the interview. Furthermore, each participant answered honestly to the best of my knowledge. Many of the mothers expressed that participating in this interview caused them to see how their child’s diagnosis had impacted their daily lives. Additionally, many participants used this interview as an opportunity to vent their frustrations with the illness itself, family members, or outsiders. At the conclusion of their individual interview, many expressed interest in receiving a summary of this study. I informed participants that a summary would be provided to a hospital contact once the study was completed.
Data Analysis

Approximately 24 hours after the completion of each interview, I followed up with each mother participant to read over my notes and ensure the accuracy of all quotes as suggested by Berg (2007). One mother elaborated further on how their family health rituals had been changed to accommodate her child’s medical needs. All mothers approved the accuracy of all information gathered during their individual interview prior to the start of analysis.

Participant and informant names were kept confidential through the use of pseudonyms. Additionally, the child life foundation and hospital study site was kept confidential by remaining unnamed. Due to the nature of the hospital setting, many participants knew of one another’s participation in the current study, which made it critical that each participant was reminded of confidentiality concerns. Identifiable characteristics have been altered or eliminated to ensure that each participant remains unidentifiable to other participants or readers of this study.

Due to the large volume of data, multiple copies of each transcript and color-coding were utilized to aid in precise qualitative data analysis. This approach facilitated data analysis by allowing the researcher to assign a code system to the primary transcript while categorizing secondary transcript copies into specific themes. This approach enabled me to examine a single or multiple interviews concurrently.

Data analysis was done as suggested by Glesne (2006) and Berg (2007). Critically reading the transcribed interviews several times, I initially coded the general themes, key words, and phrases that emerged. For example, how health and illness were understood and practiced prior to the pediatric chronic diagnosis developed as essential
issues shaping how health was currently practiced and understood within these dyads. Within this initial step, I concentrated on any instance discussed by participants that mentioned health practices. Additionally, I coded how the diagnosis of a chronic condition impacted these practices and understanding. Furthermore, some general themes around family health culture and the utilization of Western care arose and were coded. Instances of initial reactions to a pediatric chronic diagnosis were noted. Also, themes around family coping styles were coded. Moreover, instances of being a child with a chronic condition and mothering such a child as well as the expectations surrounding these roles were coded.

The 27 codes used to categorize the data included: (a) Relationship Between Child and Mother Regarding Health (how health was understood and practiced prior to diagnosis, upon initial diagnosis, and currently as illness has become part of family routine); (b) Mothers’ Understanding of Pediatric Diagnosis; (c) Implications of Pediatric Chronic Diagnosis on Day to Day Life (changes in child’s typical routine, mother’s typical routine, and their routine together); (d) What Health Related Information Mothers Share with Their Child (how mothers decide what information to share and what to conceal, how shared information is addressed); (e) Western versus Traditional Medicine (how mothers decide what treatment methods to use on their child, how this decision was made, and the repercussions of such a decision); (f) Socio Economic Status of Family; (g) The Implications of Education (influence of education on child-mother relationship, mother-health professional relationship, and child-health care staff relationship); (h) Geographic Proximity to Western Care; and (i) Implications of Pediatric Chronic Diagnosis on Relationships with Family Members and Important Outsiders.
These broad coding efforts assisted me in further categorizing and organizing my data so that I could develop strong subcodes. For example, I concentrated on how families utilized Western medicine in conjunction with traditional health practices. Moreover, any mention of how this blending was done in a health care setting was coded. Leininger’s (1996) cultural care model, guided data examination as it illustrated the implications of one’s culture on health care encounters. In addition, interviews were examined within the contextual framework of Bowen’s (1978) family system’s theory to better understand how the child-mother relationship is influenced by a pediatric chronic diagnosis and hospitalization. Also, dyads were studied to see where they fell on Knafl’s (1996) continuum of family functioning around pediatric chronic illness.

Mother and child dyads were analyzed together for common understandings as well as separately to examine different developmental perspectives. These differences and commonalities were explored in Bowen’s (1978) framework, which is based on the emotional ties that families share regardless of perceived closeness. Each of the chronically ill children and their mothers who participated in this study had varying roles within their families. The chronically ill children were analyzed to establish how their diagnosis influenced how they perceived themselves in the context of their family as well as how the diagnosis directly impacted their individual family role. Likewise, mothers were analyzed to determine how their child’s diagnosis influenced their family relationships and their role as a mother of a chronically ill child.

I chose to utilize qualitative methodology for this study to gain an intimate understanding of the intersection of family health culture and Westernized medicine in India.
from the perspectives and experiences of the chronically ill 6-12 year olds and their mother. By examining health care encounters from the view of children and their mothers, I gained a comprehensive understanding of how Westernized health care encounters were similar and distinct from home health care practices. The qualitative approach for this study, additionally, enabled me to gather information directly from a population that is typically underrepresented. This methodology allowed for a more accurate and comprehensive understanding of the pediatric health care experience as information was gathered directly from pediatric patients. It also allowed for an in-depth exploration of home health care practices versus Westernized health care from the perspectives of pediatric patients and their mothers. Finally, this approach provided insight into the experiences of a population that is often not studied due to age restrictions and vulnerabilities and may have the potential to be used as a framework for future studies.
CHAPTER 4: THE EAST INDIAN CHILDREN AND THEIR MOTHERS
RELATIONSHIP IN THE CONTEXT OF HEALTH

This study focused on how family health culture shaped the relationship between the chronically ill children and their mothers, each dyad’s understanding of chronic health issues for the child, as well as the implications of practicing family health rituals in the context of a private hospital in Bangalore, India. As mentioned previously, the research questions which guided this study included: (a) how do East Indian mothers of children, ages 6 to 12 years, who are hospitalized with chronic illness view the personalization of the health care they receive in terms of their family culture?; and (b) how do East Indian children negotiate their health care experiences regarding their perceptions and understanding of health and illness as socialized within family and cultural contexts? Bowen’s theory and Leininger’s cultural perspective provided a framework for comprehending how the experiences of chronically ill children and their mothers are influenced by family relationships and their interactions with health care professionals (Bowen, 1978; Leininger 1996).

First, I outline participant profiles for each participant dyad consisting of a pediatric patient and his/her mother. Second, I provide the framework for discussing the broad themes that emerged across interviews. The chronically ill, hospitalized children and their mothers shared their understandings of health and illness and the implications that a diagnosis of a pediatric chronic illness had on their lives together. Furthermore, participants discussed how the child-mother relationship was shaped by other family members’ responses to the diagnosis as well as the education level of both child and
mother. The primary themes used to categorize the results in this chapter include: (a) the complexities of health: what is understood and shared; (b) health communication: what is shared by mothers of chronically ill children; (c) integrating Western medicine into East Indian health traditions: how traditional families negotiate change; and (d) culturally sensitive health care: what child and mother perceive.

Participant Profiles

The subsequent profiles highlight participants’ characteristics, their health beliefs, and the prevailing traits that depict their current situations within each dyad. These traits include: (a) the nature and quality of the dyad’s living situation; (b) the implications of the pediatric diagnosis on day-to-day life including health beliefs and family relationships; and (c) the influence of education and financial resources on health care practices and treatment.

Nidhin and Mary

Nidhin was a 7-year-old, Protestant boy with a chronically ill mother. Because of his parents’ traditional health beliefs that dictated that speaking of impending disability or death may cause them to become too real (Ramakrishna & Weiss, 1992), Nidhin remained unaware of his own chronic condition, termed “poison blood” by his mother. Although a diagnosis was never stated in medical terms, the researcher inferred the chronic condition to be AIDS. This inference was based not only how Mary, Nidhin’s mother, spoke of their condition, but also on how the medical staff interacted with this dyad. Health care professionals had no physical contact with Nidhin or Mary without gloves and they provided them a private and isolated room despite the overcrowding in
other rooms. Since Nidhin contracted his disease from his mother when she was birthing him and he appears physically healthy, he believes his hospital stays are so he can take rest; his medicines are simply vitamins to increase his strength. While Nidhin was aware that his mother was sick, as he often had to care for her at home, he did not know that they shared a common illness. Nidhin recognized his mother as his main caregiver when she was able along with his father and aunt. Because Nidhin and his mother took care of one another, he reported having a close relationship with her. He was very comfortable with the hospital setting, as he has frequented it since he was an infant between his mother’s and his own hospital stays. Nidhin planned to be a doctor when he grew up because of the positive experience he had while being hospitalized.

Mary was a 30-year-old, Protestant mother with one child. With an eighth grade education, Mary sporadically worked cleaning houses and doing laundry. With just two more years of formal education, her husband worked full time in a factory earning 10,000 rupees, just over 215 United States dollars per month. Mary was infected with what she identified as “poison blood,” when she had Nidhin and, therefore, he is her only child. Her son, Nidhin, and husband coreside with Mary. While Mary reported a strong relationship with her son and husband, her relationships with her family of origin were estranged because of the disease she passed on to her child. The relationship she shared with her husband’s family was distant as they were unaware of her or Nidhin’s illness. Because Mary’s nuclear family life remained stable after Nidhin’s diagnosis, they would be classified as thriving on Knafl’s (1996) continuum. Like Nidhin, Mary believed her son and husband were her main sources of support. Although her sister hid their contact
from Mary’s parents, Mary believed she offered a great deal of physical and emotional support when necessary. Home caregiving responsibilities for Nidhin appeared to fall greatly upon Mary’s husband and sister, as Mary’s failing health did not allow her to perform physical labor. The knowledge that Mary’s and Nidhin’s doctors bestowed upon her enabled her and her husband to parent Nidhin to the best of their abilities and resources without being overwhelmed by the demands inherent with parenting a chronically ill child. Mary acknowledged that Nidhin reciprocated such care by providing assistance to her during her frequent bouts of illness. While Mary felt intense guilt over Nidhin’s illness, she had confidence in his recovery.

_Giri and Renuka_

Giri was a 6-year-old Hindu boy with an unknown chronic condition. Giri’s diagnosis was unknown to him in part because neither his parents nor his doctors could identify his illness. While Giri knew he tired easily and had trouble breathing, he was unaware of how serious these chronic complications were because of his young age. Additionally, his parents’ health beliefs implied that if Giri knew the severity of his condition he might lose hope and die (Ramakrishna & Weiss, 1992). Giri believed his hospital stays helped him to grow stronger. He felt that his mother, maternal grandmother, paternal grandparents, and father were his caregivers at home. He reported a particularly close relationship with his mother on days that his symptoms were more severe. Because Giri frequented the hospital since he was very young, he found comfort in its familiarity. While he thought the doctors and nurses hurt him with shots and forced
him to drink ill-tasting tonics, Giri acknowledged that they were nice to him and were making him feel better.

Renuka was a 34-year-old stay-at-home, Hindu mother with one child. While Renuka had completed high school, her husband had attained a university degree and worked as a professor earning 20,000 rupees, approximately 430 United States dollars per month. Because Renuka’s son, Giri, was born in ill health, he was her only child. Her son, husband, and mother and father-in-law coreside with Renuka. While Renuka had reported having a strong relationship with her husband and his parents in the past, the relationship was currently estranged. Renuka acted against her family’s traditional health beliefs by disregarding the recommendations made by the family astrologist, which in turn brought her family great shame. Because Renuka and her husband were in great conflict upon Giri’s diagnosis initially, they were defined by the struggling stage of Knafl’s (1996) continuum; they seemed to be moving toward the enduring stage as they had difficulty living with Giri’s condition. As a result of this tension, home caregiving responsibilities for Giri seemed to completely fall upon Renuka; she believed Giri to be her main source of support. The guidance that Giri’s doctors provided to Renuka enabled her to manage Giri’s care in a manner that recognized her role as his mother. Despite the concerns that Renuka had over Giri’s health, she had faith in his recovery.

Mahesh and Usha

Mahesh was a 12-year-old Hindu boy who was more educated than his mother. Because of this, Mahesh was able to find out his diagnosis of cancer without his mother’s knowledge or blessing. As a consequence, Mahesh’s relationship with his mother became
strained as he felt his mother was lying to him by not disclosing his diagnosis. Because Mahesh knew it was against his mother’s beliefs to reveal a diagnosis to the sick, he did not want her to know that he knew. However, upon realizing the severity of his condition by looking it up in the dictionary without his mother’s knowledge, Mahesh’s behavior changed causing his mother concern. As a result, the hospital counselors were consulted and it was learned that Mahesh knew his diagnosis. Despite the strain in their relationship, Mahesh felt close to his mother and believed that she was his main care provider at home. Mahesh reported positive interactions with the hospital staff as they taught him about his treatment and bridged the gap between his mother’s traditional way of life and his current situation. As a result of this experience, Mahesh aspired to become a doctor.

Usha was a 34-year-old Hindu mother with two children, Aabha aged eight years and Mahesh aged 12 years. With no formal education Usha was a stay-at-home-mother and her husband managed the family rice farm earning 8,500 rupees or 180 US dollars per month. Together along with Usha’s husband, the family coresided with Usha’s husband’s parents. Usha reported having a strong relationship with her entire family – family of origin, in-laws, and extended kin. The relationships she shared with her family were tight-knit as they saw the day-to-day reality of Mahesh’s illness; Usha felt they all offered her a great deal of physical and emotional support. Additionally, it appeared that at home caregiving responsibilities were shared between family members, with each person contributing what they could. Usha and her family were defined by the accommodating stage on Knafl’s continuum as they managed Mahesh’s disease as part of
their daily activities while believing his life opportunities were jeopardized as a result of his health condition. The support and assistance that the hospital staff offered Usha and her family allowed them to care for Mahesh at home while not being overwhelmed by the constant demands of parenting and treating a chronically ill child. Usha recognized that Mahesh acknowledged the family’s care by interacting with them in a positive manner and expressing his appreciation. While Usha was aware of the cancer’s severity, she had hope for Mahesh’s healing.

*Rohan and Basanti*

Rohan was a 6-year-old Hindu boy who suffered from asthma since he was an infant. Because of the nature of his illness, Rohan only knew the fundamental symptoms and treatment of his chronic breathing problems. As dictated by traditional health beliefs (Ramakrishna & Weiss, 1992), his parents kept him unaware of the potential complications of his illness. Therefore, Rohan believed he was hospitalized to gain strength. He felt that his mother and father were his primary caregivers at home. Rohan reported loving his mother, but was frustrated with her for not letting him play freely outside with his friends because of his breathing problems. Despite only having short stays in the hospital, Rohan recognized the hospital staff as being friendly and providing medicine to make him feel better. As a result, Rohan reported being comfortable in the hospital setting.

Basanti was a 29-year-old Hindu mother of one child, Rohan. Similar to Mary and her husband, Basanti was a homemaker relying on the 8,000 rupees, approximately 170 US dollars, her husband earned each month as a factory worker. Basanti reported having
a 6th grade education while her husband attended formal school for 10 years. Basanti, her husband, and Rohan coresided with Basanti’s husband’s parents. Basanti reported having a strong relationship with her extended family that was made stronger by Rohan’s diagnosis. She cited her family as her main source of support. Because Basanti and her family addressed Rohan’s illness as a part of their daily lives, but saw him as a “tragic figure,” they were classified as accommodating on Knafl’s (1996) continuum. As a part of traditional family and gender roles, Basanti was Rohan’s primary caregiver at home although it appeared that all family members looked after him. Basanti reported having limited, yet positive interactions with the hospital staff as Rohan’s hospital stays were short and infrequent. Despite the guilt she felt for raising Rohan in a polluted city, she had confidence in his improvement.

**Vidya and Saumya**

Vidya was an 8-year-old Hindu girl with epilepsy and mental retardation. While her highly educated parents firmly believed in the power of knowledge, Vidya’s condition prevented her from truly understanding her own health. Vidya believed she was in the hospital because she had been in pain. While she did not recall the episode, Vidya said her mother told her she had been shaking. Vidya reported that her mother and father both cared for her at home; it appeared that Vidya’s mother performed more of the caregiving as Vidya joked about calling her “doctor.” Vidya had mixed feelings about the hospital staff depending on the role that they played in her treatment. Vidya reported positive interactions with the nurses and counseling services because they allowed her to
play and made her laugh. She reported negative thoughts, however, toward the doctors because they caused her pain and made her wear “funny things.”

Saumya was a 33-year-old Hindu mother with one child, Vidya. Saumya and Vidya coresided with Saumya’s husband. Saumya and her husband both had doctoral degrees and worked as university professors. They had a combined household income of 41,000 rupees, roughly 880 US dollars. Saumya reported having a strong relationship with her and her husband’s extended families despite the recent demographic distance to which they were adjusting. Saumya believed her relationship with Vidya to be positive in spite of the lack of emotional and cognitive growth in her daughter. Because Saumya and her family had a realistic understanding of Vidya’s condition and the limitations that it forced upon her, yet managed her disease as a part of their typical routine, they were classified as accommodating on Knafl’s (1996) continuum. Saumya credited herself as well as her husband for taking on the primary caregiving responsibilities for their daughter at home by utilizing the information the hospital staff provided on parenting a chronically ill child. Saumya reported that her daughter’s naiveté regarding her mental retardation allowed her to bring her parents joy. Although Saumya was coming to terms with the limitations that epilepsy and mental retardation put on her daughter, she was learning to see the blessings in the life that Vidya now led.

The Complexities of Health: What is Understood and Shared

How chronically ill children and their mothers understood and practiced health within their family culture as well as in greater society as presented throughout this study were as complex as they were unique. The pediatric chronic condition was examined
from both the chronically ill child’s perspective as well as the mother’s perspective in order to thoroughly investigate how they understood and communicated health. The subsequent section speaks to: (a) how the child and mother defined health prior to diagnosis, and (b) how this definition changed upon receiving a diagnosis of a chronic condition.

Definitions of Health: Children and Their Mother’s Understanding

As discussed previously, children are socialized within their family culture and a part of this socialization includes fundamental health beliefs often taught and modeled by mothers (Jackson, 2000; Jackson & Vessey, 2000; Johnson, 2005; Thibodeaux & Deatrick, 2007). When asked what it meant to be healthy, the majority of child participants reported physical characteristics and abilities. Three chronically ill children, Mahesh, Rohan, and Giri, defined health by the athletic abilities of some of the country’s top cricket players. When questioned what he thought it was to be healthy before he became ill, Mahesh responded, “Sachin Tendulkar is healthy. I want to grow to be him. He is top cricket player for India. He is strong and can run fast.” When asked if his understanding of health changed after being diagnosed with cancer, Mahesh spoke more holistically. Mahesh had not considered mental strength being a part of health until he lost his physical strength. He stated:

Before I fell sick, I thought health was just in my muscles and my body. My mom always tell me to play outside and run to become strong. She tell me to take rest so I don’t wear my body out. She tell me I have to take care of my body to grow up strong like the cricket players. Now I know
my mind must be strong too. Sometimes I feel so sad that I have cancer.
My mom says I must be mentally strong to beat the cancer so I can play
cricket again. I must be strong in my muscles and my mind to be healthy.

Mahesh’s definitions of health before and after his diagnosis may have been
reflective of the maturation that he experienced as a result of the seriousness of his
chronic illness. As denoted by Patterson and Gerber (1991), hospitalized children
between 6 and 12 years face the typical developmental tasks of middle childhood in
addition to the complications brought on by a chronic illness. Achieving these atypical
tasks may have influenced Mahesh’s broadening definition of what it means to be
healthy.

Furthermore, Mahesh’s mother, Usha, offered a similar definition of health prior
to her son being diagnosed that illustrated how health was communicated in their home
postdiagnosis. She said, “A healthy person is strong and smart and spiritual. They are
balanced.” While the qualities that Usha felt created a healthy person remained the same
post Mahesh’s diagnosis, how she understood these qualities shifted: “The difference is
now I have fear of how health can go and come. Our son was healthy and one day he was
not. I hope he is healthy one day again.” Usha’s post diagnosis understanding of health
illustrated just how fleeting health can be.

Similar to Mahesh, Rohan reported that professional cricket player Dhoni was the
epitome of health: “Dhoni is healthy. He is tall and strong and fast and plays cricket
everyday. He can run and run without his mom scolding at him.” When asked how he
deefined health currently, Rohan stated: “A healthy person can play and do what their
friends can do. They get Krishna blessings and have strengths in them. I can’t do that stuffs.” As implied by the findings of Vessey and Maguire (1999), Rohan’s comprehension of health before and after his diagnosis was most reflective of what his condition allowed him to do physically. Additionally, it encompassed qualities beyond physical abilities to include spirituality and the typical developmental tasks and behaviors practiced by his peers. Just as Mahesh’s definition of health seemed to mirror his mother’s after his diagnosis, Rohan’s understanding of health was similar to his mother’s postdiagnosis.

Basanti, Rohan’s mother, reported the following as a description of a healthy individual:

A healthy person is someone who can do what most of their peers can do in all capacities. They can work hard all day to take care of their family either from the land or in a factory. They know how to think right and they try hard. They are smart even if they don’t have a chance to study books. They know to ask gods’ blessings. That is a healthy person, smart, strong, and good with god.

Basanti, like most traditional Indians (Kinsley, 1996; Trollop-Kumar & Last, 2008), understood health to be a collection of traits beyond physical well being. Basanti explained a healthy person as, “someone who is healthy has physical health, mental health, and spiritual health.” She was consistent in this view even after Rohan began to experience more severe complications of his asthma. Basanti’s understanding of health did change in one facet, however. She stated, “I know now that he [Rohan] can look
healthy and be sick at the same moment.” Basanti expressed how looks could be deceiving when gauging one’s health in that while her son appeared to be the same physically, she had to bear in mind the limitations of his new diagnosis at all times. As previously discussed, Johnson (2000) labeled this phenomenon as straddling.

Just like Rohan, Giri cited Mahendra Singh Dhoni as the quintessence of health. Giri offered, “Dhoni is healthy. He is fast and strong and never misses matches. My dad tells me he eats vegetables to be strong. Even I eat vegetables to be strong like Dhoni.” When asked if he thought of health differently now that he was in the hospital, Giri reiterated that the well known cricket star was healthy. Giri’s mom, Renuka, characterized health by describing people as well. She stated, “My husband and I are healthy. We don’t have any troubles. We don’t fall sick. A healthy child can run and breathe and laugh and play games. My son can’t always do that.” Since Giri struggled with his health for the majority of his life, Renuka’s perceptions of what it meant to be healthy shifted with his well being. She stated:

When I speak of my son, what is healthy for him isn’t healthy for other kids I see. Giri has good days and bad days. On good days, I see a healthy boy. On bad days, I see a sick boy. If I have a day like his good days then even I am sick because I have good health on all days. So, health depends on the person and their good days and their bad days. I know because I see my son’s health change.

Renuka developed a new understanding of health that was dependent upon an individual’s day-to-day health status based on the nature of her son’s well being.
Instead of defining health by referencing athletes, Nidhin and Vidya focused more on their immediate surroundings. When asked how he defined health prior to becoming ill, Nidhin candidly remarked:

My mom is sick. Even she was sick before I was born so her health is weak. My dad is healthy. He is always healthy. I am my mom’s son and my dad’s son so I go with them. I am not sick, but I am not all healthy either. Even I have my mom’s sick and my dad’s health. Health, your bloods and strengths and bodies come from your mom and dad. Mom and Dad and doctor tells me.

It was evident by his definition of health that Nidhin was unaware of just how much truth was in his definition of health. When probed about his current understanding of health, Nidhin responded, “I don’t know. I am healthy. I have my hairs, ears, legs, and hands like my friends. So I am not sick.” Nidhin’s understanding of hair as being a sign of good health was supported by the findings of Aamodt et al. (1984). Furthermore, his definition of health was clarified in light of his mother’s explanation of health. His mother Mary stated:

They [a healthy person] don’t fall sick. I mean fever, cold, cough is normal illness. They are healthy person because they heal. They can be active all the time. They are clean and eat nutritious food. I am active and eat nutritious food. I make my son to do this practice too. Even my son and I aren’t healthy because we won’t heal.
Similar to Basanti’s understanding of health after her son’s diagnosis, Mary reported a new understanding of health that included her son’s physical appearance. When asked how her definition of health evolved with the diagnosis of Nidhin, Mary said:

I used to feel my son is not sick because he does not look sick. I thought we were lucky, but he is sick. He is very sick. So, I learned a really sick person can look like a healthy person. It depends on what kind of sick they are.

Like Nidhin, Vidya defined health in terms of her parents. She said, “Mom is healthy because she pretty. Dad is healthy because he strong. I healthy because I am little girl.” When probed about what she thought it was to be healthy after becoming sick, Vidya said, “I was paining so I’m sick.” Vidya’s understanding of health only included physical characteristics and sensations. This narrow understanding of health may have been a result of the limitations of Vidya’s cognitive abilities.

Vidya’s mother, Saumya, offered a much more indepth explanation of health. Saumya stated:

A healthy person leads a balanced life. They ask gods for blessings everyday. They are clean. They take head baths and use oil sometimes. They exercise, walk and run to keep physically strong. They eat many fresh fruits and vegetables and drink hot water. Healthy people sleep early and wake early. A healthy person is most of the time happy and angers slow.
Saumya incorporated physical, emotional, and spiritual traits into her definition of health. This more holistic definition of health allowed for a greater shift in Saumya’s understanding of health upon receiving her daughter’s diagnosis. Saumya explained:

When Vidya fell sick it was hard. We did everything we thought people had to do to be healthy. We lived balanced lives with god, emotions, and physical self. I even still believe that these things are important to be healthy, but now I see health different. Health is something we can always work for, but can lose at a moment. Health is temporary so are healthy people. She [Vidya] was healthy one day and so sick the next. Health is a blessing. A healthy person is blessed.

As a result of Vidya becoming ill, Saumya adapted her definition of health to reflect her realization that people do not have as much control over their health as she originally thought.

Summary

As evidenced by the shifts in the definitions of health offered by the chronically ill children and their mothers, communicating of health underwent varying degrees of change in the aftermath of the diagnosis of a chronic pediatric illness. As Denham (1999) emphasized, mothers pass on to their children what they believe it is to be healthy. For three of the chronically ill children, Giri, Mahesh, and Rohan, receiving a chronic diagnosis seemed to open up communication regarding what it means to be healthy between child and mother. In the case of the fore mentioned child-mother dyads, definitions of health and how health is practiced paralleled more closely between child
and mother after ill health played a more evident role in daily life. This phenomenon may be explained by Bowen’s family system theory (1978) in that an alteration in one person’s behavior or beliefs in a family unit is predictably followed by reciprocal changes in the behavior of other family members.

While Giri, Mahesh, and Rohan were aware that they were ill to some degree, the remaining children, Nidhin and Vidya, were unaware of their current ill health. Nidhin’s mother worked to keep him unaware of his condition, while Vidya’s health condition prevented her from knowing her predicament. Regardless of the reasoning behind their naiveté, Nidhin and Vidya did not appear to share congruent definitions of health with their respective mothers.

In analyzing the initial definitions of health offered by child participants, Mahesh, Rohan, and Giri, emphasized the physical health of famous cricket players in terms of speed and strength; their understanding of health was mainly physical. This comprehension may be the result of their mothers encouraging them to actively play outside prior to diagnosis, while eliminating this activity upon diagnosis. Post diagnosis, Giri still cited cricket players as being healthy, while Rohan had developed a more realistic understanding of physical health. He learned to recognize physical health as the ability to do what his peers can do. Rohan’s mother Basanti and Giri’s mother Renuka, along with the findings of Piaget (1964), supported Rohan in this recognition of typical peers developing along the same timeline.

As opposed to seeing cricket players as role models of health, Nidhin and Vidya defined health in terms of their respective parents. While Vidya’s mother, Saumya
believed herself to be healthy, this viewpoint from Nidhin proved to be paradoxical. Nidhin believed himself to be healthy and saw his mom as healthy despite acknowledging that his mother is sick and part of her ailment is a part of himself. Similarly, both mothers, Mary and Basanti updated their understandings of health to include the realization that one can appear healthy despite being sick in light of their children’s diagnoses. Perhaps the most noteworthy insight regarding defining health was revealed through the comparison of Usha’s and Saumya’s post diagnosis understandings. While Usha had no formal education and Saumya had a doctoral degree, both mothers stressed the realization that health is temporary. This insight may illustrate the universality yet uniqueness of practicing health.

From a theoretical perspective, a concept from Bowen’s (1978) family system theory, the multigenerational transmission process, provides insight. This concept recognizes that the small adjustments an individual or family makes to the practices and beliefs of the previous generation will result in large changes in future generations. In other words, how these mothers were defining health for their children had to be altered in light of their chronic diagnosis. As these children become adults and potentially parents themselves, and as new medical technology and treatments become available, these children will redefine health as they mature. As a result, how these children will define health for their children may be drastically different then the definition their grandparents put forth for their parents. This concept will be explored in more concrete examples later in the chapter.
Health Communication: What is Shared by Mothers of Chronically Ill Children

As emphasized by Denham (1999), each family member participates in the family’s health routines and rituals primarily under the guidance of mothers, who are most frequently responsible for family well being. While traditional East Indian culture dictates that the ill must remain unaware of the severity of their condition to spare their will to live (Ramakrishna & Weiss, 1992), mothers may have great influence over what the child, other family members, and nonfamily members know and understand about a chronic diagnosis and home care. What information is shared with the chronically ill child, extended family members, and important outsiders is greatly shaped by what the diagnosis is, the type of care demanded, and the age gender, and intellect of the ill child (Hill & Zimmerman, 1995; Palmer, 2001). Specifically, what information is shared between the child and mother, and what extended family members and important outsiders are told regarding a child’s health status will be attended to in the following section.

Living With a Chronic Diagnosis: What Mothers Share With Their Children

The age of children at the time of diagnosis as well as their knowledge about their illness influenced if and how they recalled their lives prior to diagnosis. Because Nidhin and Rohan were diagnosed as infants, health beliefs and practices had not yet been consciously passed on to them. As a result, there were few changes in health rituals for the children to adapt making it easier for mothers to limit their child’s awareness of their chronic condition. Nidhin’s mother Mary explained, “My son suffers from what I got so I understand most of it. Difference is he has a child’s body and has had it all his life. I got
poison blood before my son was born, but I was grown. I understand his illness, but no child should have to suffer like Nidhin.”

In addition to wanting to protect her son from the discrimination that she often faced as a result of her “poison blood,” Mary did not want Nidhin to know of his illness because of the family’s traditional health beliefs that dictated Nidhin remain unaware of his diagnosis. Mary elaborated:

I didn’t tell my son he’s sick because I don’t want him to know he is sick. I’ll tell him to take his medicines to become strong because he is growing boy. He believes me because he has taken medicines since he was small kid. I don’t want Nidhin to lose hope and die. I do tell Nidhin that if he bleeds he must tell us (Nidhin’s parents) very soon so he doesn’t lose his strength. I cannot tell him that if he bleeds he could make someone else fall sick. Someday, I will have to when Nidhin becomes a man. I pray to gods everyday that Nidhin doesn’t lose hope and die when he comes to know.

While Mary acknowledged that Nidhin’s poison blood has implications for his future, she felt it did not noticeably impact how he presently lived and understood his day-to-day life. She admitted, however:

My son is curious and asks many questions. He wants to be a doctor so he asks many questions about my health because he knows I’m sick. He doesn’t know we have the same thing. He doesn’t know he is sick…I don’t know what he would do if he knew now.
As his mother wished and typical of traditional East Indians (Ramakrishna & Weiss, 1992), Nidhin expressed minimal understanding of his health situation stating, “my mom says if I take medicines I will be stronger like dad and can play with the bigger kids.” With that said, Nidhin recognized anxiety in his mother saying, “she is always worrying for me. I think because she is sick almost everyday. I want to be a doctor so I can help.” Nidhin expressed no real concern or acknowledgement of his own health condition.

Similar to Mary, Rohan’s mother, Basanti expressed limiting Rohan’s knowledge regarding his chronic asthma sharing, “He is too young to know and understand his illness. He just need to know to take rest and have hopes.” In contrast, Basanti reported, “I told him [Rohan] that his lungs are growing slower than his body so he must take rest until they grow too.” Basanti felt that by telling Rohan this “close truth, Rohan will always have hope of playing rough and growing to be old.” While Basanti did not want her son to know the extent of his illness, she did make him aware of the day-to-day implications that it had for him by severely limiting his activities. She explained, “I tell Rohan he can play calm, slow games. He cannot run even for just two minutes.” While Basanti believed she was doing what was best for her son, Hill and Zimmerman’s (1995) study found that mothers were frequently more over protective of chronically ill sons than daughters. Regardless, according to Basanti, “Rohan is too small to care why he can’t play. He is sad because he can’t play.” This limited transmission of information to Rohan may be reflective of Basanti’s own understanding and beliefs regarding asthma (Rollin’s et al., 20005): “There is not much to understand about asthma. His lungs are
narrow and don’t work properly.” Despite talking lightly of Rohan’s condition, Basanti did admit to “always keeping his inhaler close.”

Rohan expressed an understanding of his asthma that was reflective of his mother’s wishes. He reported:

I know I have small lungs. My mom tells me. Sometimes I can’t breathe properly like when I run and play cricket. My mom says sometimes the air is dirty so I can’t play at all on those days. She tells me when I grow old my lungs will be old too and then I can run and play cricket and stuffs.

While Rohan expressed some understanding of how his asthma affected his day-to-day life, he seemed unaware that this condition would most likely put these restraints on him for life. Furthermore, Rohan did not share interest in learning more about his asthma, but was simply disappointed that he could not participate in the typical developmental and cultural activities of children his own age. Bossert (1994) found this disappointment to be common among chronically ill school agers.

Usha also held the traditional beliefs shared by Mary and Basanti in wanting to spare their sons the full truth regarding their illnesses so as not to provide them reasons to lose hope and die. Usha reported:

My husband and I are traditional people with old beliefs. We wanted to protect our son from the truth about his illness so he wouldn’t stop fighting it. My husband and I just told Mahesh that his body needed to rest for a while because he used it all the time. We told him that medicine and sleep and nutritious foods would make him strong again. We told him
things so he would fight the illness. Now he knows the truth. He learned the truth because he is smart boy. He memorized the words I couldn’t read at the hospital and looked for their meanings. The counselors [from the hospital] told us he knew and in his child mind he made things worse. He believed things were bigger than they are so we had to tell him the truth. Now he knows the truth, but doesn’t believe. He thinks we are protecting him again. But we have told him the truth so he will gain hope again and fight.

While Usha attempted to practice traditional health beliefs, her son Mahesh’s personality and intellect prevented this. As found by Trill and Kovalcik (1997) and experienced by Usha, it was difficult to hide a cancer diagnosis from a patient. Usha explained:

Mahesh wants to know everything. He has always been curious and smart. He wants to know everything even if we [parents] don’t want him to. If we don’t tell him, he can find out and we can’t do anything because he can read. Reading is knowledge that my husband and I don’t have, but we want Mahesh to have a better life. That is risk we take.

Furthermore, Usha admitted not having a good understanding of Mahesh’s condition despite the doctors’ efforts in explaining his diagnosis.

Usha’s perception of her son’s knowledge regarding his cancer appeared to be accurate as Mahesh reported:

At first, I didn’t know that I have cancer; my parents did not tell me. But later, I found that I had cancer. I felt very bad and I was sad. I saw a word
[oncology] at the doctors every time. I looked in dictionary and it said cancer. Now I know that word. I didn’t want parents to know I know because they worry more. But I thought if I not sick like mom tells me, then why medicines, more rests, and different foods?

Mahesh explained his reaction when he came to know that he had cancer: “I couldn’t control myself because I was so sad and angry. I misbehaved toward my family. That is how everyone came to know that I knew I had that illness.” While Mahesh recognized that he acted out inappropriately, Vessey and Mebane (2000) found this to be a common response of chronically ill male children.

Saumya and Vidya experienced the opposite predicament with Saumya having vast intellect and a desire to share with her daughter Vidya who was incapable of understanding. Saumya shared, “I understand it [Vidya’s diagnosis] very well. The staff explained the medical terminology to us and my husband and I researched her conditions.” Regarding what she had told Vidya about her chronic condition, Saumya explained:

Vidya doesn’t understand that she is sick. Because there is something wrong in her brain she will always be like young kid and young kids can’t understand this. They know what it is to fall ill, but they don’t know what it is to not get healthy again. Maybe this is Vidya’s blessing.

As discussed with her mother, Vidya did not seem to understand that she was ill and, therefore, offered no evidence of how such a diagnosis impacted how she lived and
understood her life postdiagnosis. This may change as her friends continue to grow and develop intellectually at a much greater pace than Vidya.

Renuka and her son Giri were in a unique situation as the doctors did not know what was wrong with Giri. As a result, Renuka reported:

I don’t know what is wrong with my son. So, we just told him we are trying to make him better. I pray to gods that we will know soon. When we do come to know what Giri is suffering, I will tell him because he knows something is wrong. Because only gods know why Giri falls so sick, even I understand what it is like to know you are sick and not know why. I will end Giri’s mental anguish and tell him when I come to know.

While Renuka stated she would inform Giri of his chronic condition she did acknowledge, “He doesn’t care what he has. He just wants to feel better and play with other kids.” Like his mother, Giri acknowledged being sick by stating, “I don’t play with my friends. I get tired too soon and I cannot breathe because I am sick.”

What Extended Family Members and Important Outsiders are Told

Shangle (1995) found India to be a culture that continues to value the role of extended family and kinship ties in child rearing, spiritual practice, and modeling gender roles despite the recent shifts toward Westernization. As a result of this Westernization, joint families are no longer the social norm increasing the importance of kinship ties (Mullatti, 1995). Because of this, families must decide who needs to be made aware of a child’s chronic condition and at what risk. Nidhin provided some insight saying:
I wish my neighbor auntie didn’t know I was weak. I don’t like her because she always scold me and don’t allow my friends to play with me. Mom says it is because auntie doesn’t want me to get hurt before I grow strong. Sometimes, even mom doesn’t let me play with other kids.

Mary, Nidhin’s mom, offered the following:

Our illness is a shame to our family. My sister helps us without our family knowing. My husband’s family doesn’t know how sick we are, but his parents are no more. His brothers and sisters and cousins still live in the village. We never see them when we fall sick so they don’t know. My neighbors heard gossip because one worked at doctors and now they are all afraid of me and Nidhin. They don’t talk to us or let children play with my son.

Mary’s personal experience as an individual with poison blood influenced her behaviors and decisions regarding her son’s health care and sharing of information. She shared:

I know that it hurts when people look at you like you are dirty or leave you in fear or ignore you. I know the shame too. My family won’t speak to me – only my sister without no one knowing. I don’t want my son to know any of that. I prayed to gods to keep him safe from that.

Rohan, on the other hand, appeared grateful that his extended family and friends knew of his condition. He shared, “Sometimes when I play rough, I can’t breathe and someone who is caring toward me gives me medicines so I am not scared anymore. All the aunties are caring toward me.” Similarly, Basanti, Rohan’s mother, reported:
I worry less when Rohan is with others who know his condition and how to give his medicines. Our family all knows how to help him. I showed all Rohan’s sisters [teachers] at school and neighbor aunties. Sometimes I still worry because I know aunties are letting him play too rough.

Because the symptoms of Rohan’s asthma could occur at any time and were possible to treat anywhere, Basanti may have been more confident in enabling others to help manage his condition according to Rollins et al. (2005). In regards to people who were unaware of Rohan’s condition, Basanti offered, “Some people judge me because I don’t let Rohan run with other kids. They don’t see his asthma. They see boy with health.” Rohan and his mother were not alone in this situation. Mahesh shared a comparable experience:

Sometimes people don’t believe that I am sick. Even I didn’t believe it when I came to know because I don’t look sick. I was healthy until I fall down playing cricket and now some of the boys say I pretend to be sick because I am not good at cricket. They don’t know I was fantastic cricket player before I fall down. I want those boys to know I am sick so they stop taunting me. At first, my teachers scold me for bunking studies until they came to know I was ill. Now they are good toward me and help me.

Similar to the findings of Woodgate (1999), Mahesh found the support provided by his healthy peers and community members who knew his condition instilled a sense of normalcy and hope. Just as Mahesh recognized the benefits of having people know about his cancer, so did his mother, Usha. She offered:
We live with my husband’s parents and they want to know everything. They think it is unfair that they are old and he is young, but they want to know so they can help. They are great support. The whole family is.

Because of the nature of Vidya’s chronic conditions, mental retardation and epilepsy, it was impossible to keep the diagnoses hidden. Vidya herself acknowledged, “People know I’m different. Friends cry and get scared when I shake. Then I feel sorry toward them.” As cited by Clements et al. (1990), Vidya experienced the common loss of friends due to the fear and reluctance her chronic condition induced in others. Saumya shared this sentiment by stating:

When Vidya has seizures, adults have to know what to do to help her and because her friends get scared when this happens I have told all their parents so they can help their children understand Vidya’s condition….All of our family knows about Vidya. They are very worried about Vidya and me and my husband. They wish we are all closer so they can help. They know this is a heavy burden but thank gods everyday that we are in city with wise doctors.

Although Vidya’s condition was easily evident to others, Saumya recognized the value in personally sharing her daughter’s situation as well.

Similar to Vidya and Saumya, Giri and Renuka could not hide the symptoms of Giri’s condition. Giri acknowledged this when he stated, “Teachers scold me for bunking so much school. My friends miss me a lot. They see me sick, but don’t believe how sick. They say I lazy.” Ironically, Giri’s family held a perspective from the opposite extreme.
In reference to his extended family and father, Giri shared, “They all believe I was going to die so they didn’t love me. Only mom loved me, but now they are learning to love me.” This phenomenon of family pulling away from the newly diagnosed is recognized in the work of Coyne (2006) and Shepard and Mahon (2000). Renuka supported these sentiments acknowledging that other family members were hesitant to form close bonds with Giri in order to protect themselves from the anticipated pain of losing him based on the family astrologer’s reading.

In reference to nonfamily members, Renuka stated, “I feel others judge me because I don’t let Giri play. They see healthy boy, but I know he is not healthy. He is very sick.” When speaking of her husband and extended family, Renuka was much more direct:

At first when Giri was born, he was very sick so we took him to see long time family astrologer who said there is no hopes in him to live. The family believed astrologer and had no hopes for him so the family didn’t want to know anything about him. They told me he would die very soon. I didn’t believe them. From now, he is doing better and family want to know more about Giri.

Because Renuka was alone in supporting her son upon his birth, she was hesitant to share the details of Giri’s health: “I worry the family will leave Giri if his health turns so I tell them little. I don’t want them to hurt him again.” Like the participants in Jackson and Vessey’s (2000) study, Renuka prioritized Giri’s needs over all other family relationships.
Summary

According to the narratives provided by mothers and children, mothers were found to be the main teachers and communicators of health knowledge, understanding, and beliefs to children (Denham, 1999). Furthermore, when child and mother dyads appeared to be in agreement on the child’s condition, health rituals seemed to be carried out with fewer tensions (McCubbin et al., 1993; Patterson 1998). Therefore, mothers had to consciously communicate health knowledge and reveal illness in a manner that they could negotiate not only for themselves, but also for their children. As suggested by Denham (1999), how this health knowledge is addressed is deeply rooted in culture even when the reasoning behind certain practices is unknown. For example, Nidhin, Giri, Rohan, and Vidya’s understandings of their chronic conditions seemed to mirror their mother’s beliefs about what they thought their children knew. While Mahesh secretly learned of his diagnosis resulting in tensions with his mother, conflict was resolved with the disclosure of his knowledge. This occurrence and resolution of tension may be explained by the concept entitled triangles in Bowen’s (1978) family system theory. In this case, Mahesh, Usha, and Mahesh’s father created the triangle, or the three-person relationship system. By concentrating on what is wrong with a child or in this case intentionally hiding what is wrong with a child, parents may motivate the child to rebel as Mahesh did. While Mahesh was the outsider during the time of tension with his parents, his father became the outsider in light of Mahesh’s knowledge as Usha strived to mend her relationship with Mahesh.
Four of the 5 children in this study reported a very simplified, if not absent explanation of their health conditions; 3 of the 5 mothers cited the common practice of not giving patients reasons to lose hope as explained by traditional health beliefs as the reasoning for this lapse in understanding (Ramakrishna & Weiss, 1992). For these mothers, Mary, Basanti, and Usha, the majority of the information they shared with their child regarding their current health status was dictated by the condition and / or treatment itself and they neglected to address any long-term complications and / or treatments. Because Mary had the distinct advantage of modeling Nidhin’s treatment due to their shared diagnosis, she was able to divulge less information to Nidhin himself by presenting treatment in an air of normalcy. Usha, on the other hand, was unable to prevent Mahesh from learning his diagnosis because of his educational advantages and frequent trips to medical care facilities.

As Usha learned the hard way, the best efforts of Mary and Basanti to manipulate their children’s health knowledge in such away that “protects” their children from the truth cannot defeat their children’s intellectual growth, physical development, and overall maturation. While the findings of Rollins et al. (2005) recognized honesty as key in developing a healthy bond between a mother and a chronically ill child, one is left to wonder how these mothers will negotiate the tensions that may arise when their children learn their true health status. In regards to divulging complete and accurate health information, Mary was arguably facing the largest consequences of any of the mothers; her child, Nidhin, was the only participant with a contagious disease. While she acknowledged the need to tell Nidhin the truth someday, will she recognize when that
someday is and will Nidhin believe her? If Mary fails to inform Nidhin before he engages in unsafe behavior that is becoming more common among East Indian youth (Chekki, 1996), then someone else’s child may become infected and Nidhin would then have to negotiate the consequences.

While the negative repercussions of concealing the truth may seem to be overwhelming, Mary, Basanti, and Usha saw benefits in this behavior, in the normalization that it provided their children. As maintained by Robinson (1993):

This perspective supports hope. This enables persons and families to carry on through adversity because of the hope for a brighter or more liveable future. It involves a wellness orientation that focuses on abilities rather than deficits while avoiding saturation with the problem (p. 23).

The remaining two mothers, Saumya and Renuka, expressed a desire to inform their children, Vidya and Giri respectively, about their conditions. As the highest educated individual in this study, Saumya articulated her belief that knowledge is power and therefore wished to empower Vidya with the details of her condition. Ironically, Vidya’s mental capabilities prevented her from comprehending her health status and Saumya recognized this ignorance as her daughter’s blessing. While the choice to inform Mahesh of his condition was taken away from Usha due to Mahesh’s intelligence, the ambiguity of Giri’s condition has never afforded his mother Renuka the option. This uncertainty surrounding Giri’s illness has provided Renuka insight regarding the concealment of truth causing her to believe in disclosure.
With the varying amounts of disclosure from their mothers, the pediatric participants in this study showed different levels of awareness surrounding their personnel health. Whereas Mahesh sought out full disclosure as a possible reflection of his intellectual capabilities and interests, Rohan and Giri did not seem to mind the vagueness surrounding their conditions as much as the consequence of not being permitted and/or able to play. Even as Vidya’s mental capabilities limited her awareness surrounding her health status, Nidhin seemed to be oblivious to his well being. The way each child understood their current health status and the degree to which they were ill had great implications for this study. For example, because Nidhin did not seem to know he was in ill health, he could not know how his condition influenced all other facets of his life.

In addition to disclosing diagnostic information to their children, mothers had to decide whom else to disseminate their children’s health data and what specific details to share if any. Because of the symptomatic nature of Giri’s, Vidya’s, and Rohan’s conditions, their symptoms could not always be hidden. Whereas Renuka expressed discomfort in the vulnerability of Giri’s condition, Saumya and Basanti employed what Robinson (1993) termed desensitization. This approach “was used to normalize interactions with others when visible differences could not be covered up” (p.19). Saumya and Basanti practiced this strategy by educating important outsiders such as teachers and friend’s parents about responding to their children’s symptoms. While the diseases themselves made the decision to disclose information regarding Renuka’s,
Saumya’s, and Basanti’s children’s health, the choice was taken from Mary by a neighbor.

Even though the motives were different, Mary and Renuka both felt judged by outsiders. Mary and her son were alienated by those who knew their diagnosis because of the stigma it carried. Those who did not know Giri’s diagnosis judged Renuka because she did not allow her healthy appearing son to play rough as is customary for Indian children (Mullatti, 1995). Additionally, their families abandoned both of these women – Mary for the shame her illness brought and Renuka for the shame of disregarding her husband and astrologer. The loss of relationships with Mary’s family, the temporary absence of Renuka’s family as well as the distant relations that these women were now in with their husbands’ families, can be explained by the concept of *emotional cutoff* as cited by Bowen (1978). This concept addresses how family members handle unresolved emotional issues between themselves. For example, Mary, with the exception of her sister, had no contact with her family of origin and practiced avoidance with her husband’s family rather than deal with the underlying emotional tensions. Renuka has estranged contact with her family as a result of their underlying emotional issues. Conversely, the only remaining mother, Usha, was initially upset that her son knew his health status, but was presently pleased that he and others now knew. As experienced by Basanti and Saumya, Usha received support from extended family and community members who knew her situation.

As revealed in dyads, each child was in agreement with their mother regarding the disclosure of their health status to outsiders. Rohan, Mahesh, and Giri felt that their peers
stopped teasing them and teachers stopped punishing them upon learning of their diagnoses. Additionally, these outsiders began to show support through encouragement and extra help. Although she could not seem to vocalize it, Vidya seemed to benefit from her mother’s disclosure as her friends’ understandings increased. Dissimilarly, Nidhin, like his mother, experienced a lot of negativity from outsiders who knew his condition despite himself not knowing the reasoning behind their hurtful actions.

Integrating Western Medicine into East Indian Health Traditions:

How Traditional Families Negotiate Change

As found by Jackson and Vessey (2000), children are socialized and exposed to health rituals within the context of their family system. While mothers in particular may do their best to submerge their chronically ill child within their nuclear family’s health culture, the family itself lives and functions within the much larger framework of extended family, society, and culture (Thibodeaux & Deatrick, 2007). Because of this, families must learn to function within the various cultures at play including, their specific community and ethnic networks, the nuclear and extended family culture of the patient, and the culture(s) of the health care professionals (Spector, 2002). How these cultural interactions ensue influences how initial treatments are sought, how tensions are addressed, and what resolutions are met. The subsequent section addresses: (a) the health care practitioners typically sought by children and their mothers; (b) how children and their mothers perceive their changing health practices and rituals; (c) how family roles shift in light of new health practices and rituals; and (d) the implications of the aforementioned changes on the child-mother relationship.
A pediatric chronic diagnosis brought some degree of change in each family. The degree of change and tensions was dependent upon the nature of the diagnosis and family dynamic (Dragone, 2000; Shepard & Mahon, 2000). Because Nidhin was born with poison blood and his condition remained stable throughout his life, he had not experienced any major shifts in his plan of care. Nidhin offered, “I have always been guided to pray to god, go to church, and take medicines to make me strong. These stuff make me to feel better.” As mentioned by Nidhin and found by Barnes et al. (2000), the correlation between health and spirituality for children were prevalent and comforting. Mary, Nidhin’s mother, echoed this belief in part, stating:

We go to church every Sunday and pray to God to keep us healthy and safe. Our disease isn’t traditional so our treatment can’t be, not completely. I used to go to my husband’s family elders but their treatments don’t work for our illness. I learned long back before my son that the traditional medicines don’t work for us. We have need to go to Western doctors even when it is cold or cough so that we can live.

Because Mary suffered the same illness as her son, she already had an established health routine that worked for her allowing her to alleviate tension when developing Nidhin’s plan of care.

Similar to Nidhin, Giri’s plan of care was developed when he was an infant, long before he could understand the tensions of merging traditional and Western health care. Giri stated:
My mom has always been caring for me, taking me to doctors. Every time at hospital, she is there. Mom tell me grandma and grandpa and dad even were afraid of doctors. Since I am brave to see doctors, grandma and grandpa and dad are little brave now.

While Giri’s mother taught him the absence of his family members represented a lack of courage on their parts, Renuka knew differently. She recognized their absences as a result of the shame she brought on her family by disregarding the traditional Indian values of wives being submissive to husbands and men leading medical encounters for women and children (Mullatti, 1995; Ramakrishna & Weiss, 1992). Furthermore, Renuka exacerbated the situation by utilizing Western medicine. She explained:

Before Giri, if it was just cold or fever we make medicines at home, but if it is something related to my son, we come to the doctors. If the situation is serious, we always go to the astrologist. We go to him to marry, to name our children, and about jobs. We believe him for everything so when Giri fell ill, we went to him. He told us to take our baby from the hospital because he would die; he said we shouldn’t waste money. The doctors at the hospital said Giri would die too…. We were at that hospital because it was close to home and my husband had influence over doctors. He had confidence in them so I went along, but Giri got worse. I couldn’t believe the doctors and astrologist or my husband. I couldn’t let my son die so I ran to [study site hospital] in the middle of the night with Giri to save him.

Renuka shared the implications this action had on her family relationships:
First, my family was upset toward me because I didn’t listen to the astrologer and my husband’s friend doctor. It was first time I stood against my husband. I didn’t want to give up on my son. But now they are feeling better with the kind of treatment my son is getting and his progress to be healthy. After some time, I hope they will forgive me all.

Renuka experienced the merging of traditional and Western medicine with great tension in her family.

Mahesh and his mother were in a similar predicament. Mahesh reported:

When I was small, small kid I never been to doctors. Then I fell sick now and am always at doctor. That is how I knew something was really bad on me. Head baths and oil and rituals did not heal me. I was still sick after many prayers to gods. All those things that worked when I was kid did not work now. So, I know there was something wrong too. Mom was scared to go to doctor. Even she had never been.

Because health care socialization begins at a very young age (Thibodeaux & Deatrick, 2007), Mahesh had a solid understanding of how his family had practiced health before he was diagnosed with cancer at the age of 12.

Usha discussed the challenges brought on by these shifts in practicing health care:

We always went to our family elders, but this time they couldn’t help us so we went to pharmacist. We have used pharmacist before, but not a lot. Even pharmacist could not help us. Pharmacist told us ‘go to hospital straight away.’ We had never used hospital before Mahesh was sick this
time. This was hard for my family. Really hard for the family elders, but we all love our son, Mahesh, very much and we know he needs these doctors and medicine. We had to learn to practice Western medicines, but only for Mahesh.

While Usha felt that practicing Western medicine was a challenge to her family beliefs, she felt that the family acknowledged the necessity of this shift. Furthermore, Usha was not alone in feeling forced to utilize Western medicine as the population of India is experiencing epidemic increases in lifestyle diseases including cancer (PricewaterhouseCoopers, 2007).

Not only was Rohan diagnosed as a baby prior to learning his family health rituals, Rohan was raised in a family that was merging traditional health practices and Western care resulting in an easier transition. Rohan said, “In my family, we pray to gods and go to doctors for health. We ask for blessings and drink hot water. We do everything.” Basanti’s thoughts paralleled those of her son. She expressed, “We live with my husband’s parents. We usually seek their guidance at home. Then we come to doctors. We know when Rohan needs to come to hospital and when our family rituals will help. His illness has not altered our health routines. We just keep his inhaler close.”

As evidenced by Ramakrishna and Weiss (1992), Rohan and Basanti were only two of the many Indian natives who merged traditional and Western health practices as if it was a natural part of life.

Vidya too saw the blending of traditional and Western medicines as a natural part of life because of the behaviors that her mother in particular modeled. Vidya shared:
I do what my mom do because she is pretty and smart and loves me. When she asks me to take my medicines, I take them without crying too much. She tells me I am brave for doctors’ [Western] treatments and for grandma [traditional] treatments. I am very brave girl.

While Vidya was unable to understand the differences between traditional and Westernized health practices, she was able to articulate how both were used in her life.

Saumya elaborated:

When I was kid we used traditional Indian medicine – Ayurvedic diets and rituals. When my eldest brother went to America for studies, he taught us to do things differently. My husband’s family was the same. When we were married, we combined everything. We use Western medicine to help Vidya, but we also give her Ayurvedic diet. We want to cure her through diet if we can. We want to heal her naturally, but we know we need some prescriptions.

Additionally, Saumya confessed:

In this city [Bangalore], it is just my husband, me, and Vidya. When any of us fall sick, we go to pharmacist or doctor depending on symptoms. There are pharmacists and doctors all over – not like at home in village. Usually the pharmacist can tell us what medicine to use or if we need to go to doctor. We just go because it is easy, but we also do traditional things.
While Saumya noted the accessibility to doctors in the city as emphasized by Gupta (2008), she and her husband negotiated their daughter’s illness by continuing the practices that were started in their nuclear families.

*Evolving Health Rituals: Perceptions of Chronically Ill Children and Their Mothers*

As health needs changed and families struggled to adapt in the aftermath of a chronic diagnosis, children and mothers learned to negotiate their old roles while concurrently learning how to function in their new roles as a chronically ill child and a parent of a chronically ill child. Most families learn to handle a pediatric chronic illness diagnosis reasonably well through making adaptations to their long-established practices and beliefs (Ahmann & Rollins, 2005; Clawson, 1996; O’Brien, 2001). The five dyads who participated in this study proved to be no exception. Nidhin and his mother, Mary, provided insights on how their family rituals have evolved with a chronic diagnosis. Nidhin reported, “Mom makes me to brush my teethes everyday twice morning and night, they [parents] make me to drink hot water and I take some energy medicines to become stronger like my friends. I see them to do healthy stuffs too.” Mary’s perspective on health practices was very similar to her son; she offered:

*We pray everyday to God. We go to church every week. We brush teeth every morning and night. I know many people don’t do that. We make are son to do that. We clean our house everyday. We sweep two times even. We throw trash everyday. We give our son milk everyday. Our son takes head bath everyday. We give to him oil baths on some days too. Our*
family learned to do these things each day together since Nidhin fell sick.

It is now our good habits.

Nidhin and Mary were not alone in their transition to practicing altered health rituals as a family unit in light of a pediatric chronic diagnosis. Mahesh and Vidya experienced similar modifications along with their mothers, Usha and Saumya respectively. Because these dyads responded to pediatric chronic diagnoses as unified teams with each family member adjusting their health routines, their family lives will be expected to become more stable over time (McCubbin et al., 1993).

Mahesh explained how his family health rituals changed quickly upon receiving his diagnosis. Mahesh stated:

Mom use to scold me to take bath after playing outside, to washing my hands before I eat and even after I eat. She use to scold me to go to bed. Now mom and even my dad watch me to do these things and scold me if I don’t do them properly. They make my sister to do these things too. Even they [mom and dad] do them now every time to gain more health.

Usha recognized and elaborated on the same altered health practices as her son:

Every time now that Mahesh is sick, we all take head baths every three days and dry our hairs so we don’t get headache. We pray to our gods together. We eat slowly and with our family. We eat vegetables and drink hot water. We brush our teeth. We sweep the floor everyday and practice yoga. We go for walks in the sunshine and sleep early. We rise early too. Too much sleep can make us fall sick. We all do these rituals everyday.
As reported to be common by Rollins et al. (2005), Usha added that her family has started practicing traditional rituals again to keep their children safe. She shared:

In my family, we believe in evil eye so we performed special ritual to protect our kids when they were small. Now that Mahesh fell ill, we perform this ritual again. We burn special grass and say special prayers to protect them. We all pray together and burn incense together. We use new Western medicine and our traditions.

While Mahesh’s illness forced him to use Western medicines, it also revived some old family traditions.

While these activities may seem to be irrelevant in the world of health care, Vidya included coloring and singing as a part of her family health routine. She shared, “We just do the same stuffs over and over. We sing when we put toys away. We study books a lot.” The Child Life Council has recognized such activities as providing children with a sense of normalcy and therefore making healthcare encounters less traumatic (Child Life Council, 2010).

Saumya, Vidya’s mother, offered a much more specific explanation of their new family health rituals:

As a family, we are more sensitive to any symptoms of oncoming illness. We take these signs more seriously and care for them right away. When we see them in each other, we take care of each other and take more rest. We are more conscious of the health benefits of our food. We know how her [Vidya’s] illness is made better or worse with nourishment so it must
impact our health too. That is the biggest change. We eat differently as a family.

According to Ramakrishna and Weiss (1992), Saumya employed a common strategy of blending traditional and Western health care methods by practicing Western treatments and Ayurvedic diets.

In the case of Rohan and his mother Basanti, the necessary adjustments to accommodate Rohan’s health needs have been so subtle that he does not recognize them as being related to his chronic condition. When asked what his family does differently because of his chronic condition Rohan responded, “Nothing is different. Mom always makes me to eat vegetables and Dad makes me to help Mom clean the house.” Basanti understood these requirements differently in the context of her asthmatic son. She expressed:

We give Rohan sugar very less. It gives him very much energy so he want to run. When he run his asthma come out. Before he could move so fast on his own we did not know to worry, but now we know. Today Rohan is old enough to help clean house. We make him to help clean, sweep and sweep, everyday. If house gets dirty he breathe in unclean air and asthma starts all over again. We make him to sweep very much these days because he track so much dirt in from outside. We have to be strict because of his asthma. He thinks we make him to do such things because he is older now simply. He does not know it is because of his health.
While Rohan’s family adjusted some of their health practices to better meet his medical needs, Rohan saw these behaviors as merely responsibilities that came with age. Although Rohan and Giri were both ill at very young ages, Giri was more aware of what household practices were influenced by his unknown chronic condition. Giri expressed:

Everyone is more gentle with me at home because I fall sick all my life. Mom and Grandma tell me they do everything for me to keep me safe. We eat healthy food and live in very clean house. We use medicines from America and medicines from when Grandma was kid like me. My family loves me very more so they do everything like me so I don’t feel bad to be different.

While Rohan did not equate his household responsibilities as directly related to his health needs compared to his mother, Giri acknowledged nearly all of his family’s behavior being linked to his chronic condition. Renuka, Giri’s mother, shared in this perception. When asked how Giri’s diagnosis altered their family health routines, Renuka explained that Giri’s illness completely reshaped their entire lives including their health rituals. She elaborated:

We used to only go to astrologer for all things in life including health. In spite of astrologer saying my son would fail, I took my son to a new doctor and I was taught to not ask any healthy opinions from the astrologer no more, but to consult doctors. At home now we drink hot water everyday and prepare our food with black pepper and turmeric. We
prepare homemade tea. We follow Ayurvedic principles at home. We usually take Western medicine when we have headaches or don’t have stuffs to prepare Ayurvedic treatments. We apply oil to our heads to keep our body temperature down. We take oil bath and sometimes we eat ragi ball. We use new and old medicines to keep healthy. We all changed for Giri. We do everything for him these days.

Though Renuka confessed that her family’s health rituals and beliefs revolved around Giri’s constant needs, she purposely blended traditional and Western means to appease her family elders. Renuka shared, “My family needs traditional ways – medicine and diet and stuffs - to feel balanced, but Giri needs Western medicines to live. I try to do what is right by everyone, but I will do what is right for Giri.” McCubbin, et al., (1993) recognized the need that Renuka expressed her family elders having as part of the family’s long standing traditions that were highly resistant to change.

_A Chronic Diagnosis: The Redefining of Family Roles_

While the term “family” care endorses the belief that all family members provide equal care to a chronically ill child, Gerstel and Gallagher’s (1993) findings that female gender norms tended to dictate that women [mothers] care for ill family members proved to be true for most of these dyads. Despite evolving gender roles in India, specific expectations of masculinity and femininity still exist dictating that women are to be responsible for caring for family members and performing household chores (Mullatti, 1995). Correspondingly, many mothers understood caregiving to be an inherent part of their family responsibilities and fulfilled this role with very little outside support as is
common in most cultures (Cancian & Oliker, 2000). Katbamna et al. (2001) cited the flipside of this gender norm in the stigmatization men faced when taking on these caregiving roles as being unable to control or provide sufficiently for their family in South Asian communities. Regardless of whether families follow traditional gender roles in caring for their chronically ill child or meet these needs in nontraditional ways, family roles shift (Robinson, 1993; Sheeran, Marvin, & Pianta, 1996).

Although Nidhin recognized his mother, father, and aunt as his primary caregivers at home, the tasks they each fulfilled in those roles were consistent with the above findings. Nidhin stated:

My mom and dad and aunt are all caring toward me. My mom prepares sweets and play with me. Mom helps me doing my homework…and she tells stories and prepares food for all family. Dad gives to me toys and takes me out for rounds on his motorbike. Auntie prepares food for me and mom and dad even. Auntie cleans my house even.

When asked to whom he felt closest, Nidhin responded, “I love my mom. She is always worried about me and I take care of her like she care for me. I am close to all of family even.” Despite these sentiments, Nidhin’s recognition of multiple caregivers supported Hardy et al. (1995) that children with AIDS do not feel a stronger bond with their mother post diagnosis.

Mary, Nidhin’s mother, recognized the same family members as Nidhin’s primary caregivers, but with a much different understanding of the reasons behind their indepth involvement. Mary reported:
I take care of my son when I am healthy enough to. That is my duty because I want to be a good wife and mother. When I fall sick, my sister watches him. Nidhin is always sick, even when he doesn’t feel sick. My husband must work to afford medicine. I feel sorry toward him to make him to work very much for us. It is hard because other people are always there to judge him. My illness brings to him so much shame and sadness about our son.

Nidhin and Mary were not the only dyad that faced family turmoil when reddefining roles in light of a pediatric chronic diagnosis. Similarly, Giri reported multiple family members to be his primary caregivers. These individuals included his mother Renuka, grandmothers, grandfather, and father respectively. When asked how these family members care for him, Giri answered, “Mom drops me to school, she plays with me, and prepares food for all. Dad gets me toys. My grandfather takes me to the playground and we go for walk in the early mornings. My grandmothers let me to do whatever I want.” Identifying his mother and grandmother as his closet bonds, he elaborated, “I feel closer to my mom because she always love me and say that I will be sick no more someday. Everyone else had doubts so they afraid to love on me and believe in me. Mom tells to me.”

In their 2000 study, Jackson and Vessey found that parents frequently put the needs of their ill child ahead of all other family relationships. As Giri mentioned, his mother Renuka demonstrated behaviors that maintained these findings. Renuka shared:
I usually take care of my family. Since my mother-in-law is also sick, my mom is helping me to take care of my family. I brought shame to all in my family when I took Giri for medical help. Even my mom was shamed by me, but now I work hard to care for everyone and bring honor back to my family, mostly even to my husband. He is good provider and even good man though he was ready to let our son to die because astrologer said.

Similar to the mothers in Clement’s (1990) study, Renuka felt resentment toward her husband for playing little to no role in meeting the health care needs of Giri.

While the previously discussed dyads experienced tensions between parents, Mahesh initially experienced turmoil with his mother during the transition of family roles that resulted upon learning of his diagnosis. Mahesh explained:

Since I fall so sick I was able to help my mom and care for my younger sister no more. I even could help my father no more. That was very hard for me. I was very angry toward my mom because I felt she did not care for me proper and made me sick. Now I know different but it is still hard very more. I had to learn to let my younger sister to care for me and to watch my mom to struggle with taking care of all. My father even became angry at times because my mother could not keep up in caring toward me and my sister and the house.

Comparable to the findings of Rechner (1990) and Woodgate (1999) that elaborated on how pediatric cancer patients often identify their mothers as their primary supporters and encouragers, Mahesh identified his mother to be his primary caregiver while at home.
Despite the initial tensions they faced, Usha agreed with Mahesh’s view of her as being his primary caregiver. She stated:

I am Mahesh’s mother so it is my duty to care for him. I do all I can do. I make him to drink hot water, hot soup, and prepare foods that are easy on his stomach. I can’t help him with his schoolwork because I can’t read. One of the neighbors does that. My husband bathes him because Mahesh is not a little boy anymore. My husband lives as strong traditional man on outside, but at home, he care toward Mahesh even doing woman’s work if that is what Mahesh need. On the good days, even my husband carry Mahesh to the park to watch his friends play and to get sun.

As supported by Katbamna et al. (2001), Usha acknowledged the challenges gender presented when caring for her son; while Mahesh was too mature for her to bathe him, performing a traditionally female task jeopardized his father’s reputation. Recognized by Feudtner (2002) and Nelson (2002), the way that Mahesh’s father divided his time between work and caring for Mahesh was common for fathers of chronically ill children. Regardless, these shifts in family roles resulted in a more intimate bond between Mahesh and Usha as supported by Hardy et al., (1995).

Like Mahesh and Usha, Rohan and Basanti practiced traditional gender roles and expectations in their family. Rohan shared that his mom and dad did all of his home care. He elaborated, “My mom prepares foods and cleans the house. She makes things to be nice for dad and me. Dad works outside so we can have money.” Basanti, Rohan’s mother, got straight to the point and explained, “I am Rohan’s mother and Sunil’s wife so
it is my job to take care of my family – not just my son. I do for them what any good wife and mother would do.” It was made evident by Basanti’s comment that she valued traditional gender roles.

Unlike any other dyad, Vidya and Saumya fostered an environment of care that was not based on gender norms. When asked who took care of her at home, Vidya shared, “My mommy does. Sometimes I call her doctor (laughing). My daddy does too.” When asked what each one of them did for her, Vidya stated, “Mommy and daddy both prepare food and clean and color and tickle with me. Daddy carries me up high even.” Vidya verbalized how both of her parents cared for her while at home.

Saumya made it evident that it was not coincidental that Vidya recognized herself and Vidya’s father as her primary caregivers. Saumya shared:

My husband and I both care for Vidya. She is our daughter together and she needs both of us, especially now that she fell sick. My husband and I need each other to care for her. My husband studies with her in the evenings while I prepare foods. I wake with Vidya and we study in the mornings before school. Sometimes I drop Vidya to school and sometimes my husband does. Some days I pick Vidya from her sitter and sometimes my husband does that too. It doesn’t matter. It all depends on when we teach.

Saumya went on to clarify that similar to the research findings of Hatton et al. (1995), she and her husband rarely relied on a babysitter to care for Vidya due to complications resulting from her chronic condition such as her seizures.
Challenges in the Child-Mother Relationship

A pediatric chronic diagnosis greatly influences the child-mother relationship. How this relationship is altered may be shaped by the gender and development of the child, the education of the mother, and the overall family dynamic (Bourne & Walker, 1991). The dyads in this study proved to be no exception. Although Nidhin was unaware of the severity of his condition, he sometimes hid symptoms from his mother in order to care for her. Nidhin shared, “Sometimes I feel ill and don’t tell mom because she is sick and I am healthy. I need to take care of mom because Dad says I am strong one when he is gone.” Williams (2002) revealed that boys, like Nidhin, often jeopardized compliance of the medical care plan by hiding their health conditions and symptoms. Nidhin’s attempts to hide his own health needs to care for his mother, Mary, only compounded the sense of guilt she experienced. Mary articulated:

I feel bad everyday because I think I have given illness to Nidhin by birthing him. I love my son, but everyday I see him, I see my mistake.

And even now, he can’t be child because he has to care for me.

When asked what she expected of herself as the mother of a chronically ill child, Mary offered, “I want to protect my child from pain and let him be a child. It is hard because I see myself at fault. I keep him from living my dreams for him.” While Giri’s mother, Renuka, shared Mary’s sentiments, Giri did not share opinions with Nidhin.

Giri expressed, “I like how everyone is caring toward me and gives to me treats because I am sick. I don’t even have to do anything.” This sentiment appeared to parallel the findings of Hill and Zimmerman (1995) in that parents tend to perceive ill sons as less
capable of self-care than ill daughters as Giri’s mother seemed to encourage Giri’s perspective. Renuka offered:

I will always fight for what is best for my child. He is only one I will ever have. I fight my husband and family to care for my child. I care for him at home and at hospital. I care for Giri’s needs before my husbands or anyone’s. He is my son. My son is most important in my life.

As supported by Hardy et al. (1995), Renuka felt her relationship with Giri grew stronger because of these tensions despite there being no recognition of this from Giri. Renuka made it clear that Giri’s needs came first in their family.

Usha held a similar belief to Renuka in raising her son Mahesh. Mahesh also was aware of this perspective as he illustrated:

My mom loves me so much she does everything for me. I use to care for my sister, but now my mom has taught her to care for me. I feel sorry for that, but I cannot do the stuffs any longer. It is hard for Aabha [sister]. Sometimes I see her to cry. I am very weak and ill so my mom makes me to take rest very often. My sister must do what was mine to do before I fall sick.

As found by Shepard and Mahon (2000), parental attitudes may greatly shape a sibling’s response to a chronic diagnosis and as discussed by Mahesh, his sister was directly involved in his care.

When Usha was asked about mothering Mahesh, she responded:
It is hard. I will do all I can to take away his pain. I must learn to read to do his medicines. It is hard. It is a lot to learn and understand. I am scared about it. My husband and daughter try to learn about it all too.

Usha elaborated about how her role as a mother was challenged by parenting a child with a long-term illness:

It is hard because Mahesh is so smart and we cannot keep things from him very easy. It is hard too because we have made Aabha [Mahesh’s sister] to grow up fast and to do mother responsibilities for Mahesh because he is too weak. Aabha is good. She knows Mahesh cannot take care, but does not know the true reasons why. I think Mahesh likes Aabha to care for him. I care for Mahesh too. We all take care, except Mahesh because his illness is so strong and he is weak today. Tomorrow we all hope him to be strong.

While Mahesh had a hard time knowing his sister was struggling with the changes brought about by his chronic diagnosis, his mother seemed to be unaware of how deeply Mahesh’s situation impacted Aabha. This was found to be a commonality among parents dealing with siblings of chronically ill children (Shepard & Mahon, 2000).

Rohan was aware of how caring for him would not afford his mother the time to care for a sibling. He stated:

My mom is always caring toward me and doing everything. She always to make someone to stay with me in case I cannot breathe properly. She tell me she had no other children because she need to give me all her love.
Basanti, Rohan’s mother, supported this belief and shared:

I do the best I can do as a mother. That is how I view myself – as a
mother. Not as a mother of an ill child. I want to be a good mother so I had
children no more so I could love Rohan all the times he need me.

Continuing, Basanti stated:

My husband and his parents support me in caring for Rohan, but I fear it is
living in this dirty city that makes him to have asthma. I wish for us to
move back to village to breathe clean air for our boy. I feel this would cure
him and feel guilt that my husband’s work won’t allow us to leave city and
support family.

Rohan and Basanti were not the only dyad that felt this way. When asked about
her relationship with her mom specifically, Vidya stated, “I love mommy. She is most
always with me. Daddy too. They don’t make me to go to babysitter no more. They care
for me always.” Saumya’s input clarified her daughter’s perspective. Saumya expressed:

I cried and cried when she [Vidya] fell ill. I had deep mental anguish
because I thought I caused these problems in my child. I love my child. I
did not want to hurt her. We moved to city and then she had first seizure. I
thought unclean city caused her seizures. Doctors tell me seizures will
never go away even in village. I feel sorry we have no other children to
care for Vidya when we are gone, but now we cannot start our family
again. Vidya needs us too much.
When asked what she expected of herself as Vidya’s mother, Saumya said, “I expect myself to love and accept my child as who she is in time – even if it is not how I dreamed it would be. She is my child and I love her very much.” While Saumya’s concerns about loving her daughter in light of a chronic diagnosis were found to be common by researchers (Robinson, 1993; Sheeran et al., 1996) Saumya’s acceptance of Vidya’s condition will greatly strengthen their child-mother bond.

Summary

All mothers felt that Western medicine was necessary in the treatment of their chronically ill children despite East Indian’s general preference for treating chronic ailments with traditional means (Ramakrishna & Weiss, 1992). Because 3 children, Nidhin, Giri, and Rohan, were noted to be sick as infants, they were unaware of their family’s process in merging Western and traditional means of health care. While this transition was relatively uneventful for Vidya because her family had been utilizing Western and traditional care, Mahesh recognized the drastic shifts his family took in caring for him.

Because Mary had a common illness with her son, Nidhin, Western medicine was already being practiced in their home upon Nidhin’s birth. In the homes of Renuka and Giri and Usha and Mahesh, traditional means of health care were being exercised when the children were found to be ill. Western and traditional health practices were being utilized simultaneously in the homes of Basanti and Rohan and Saumya and Vidya upon their pediatric chronic diagnoses.
Upon review of this data, the medical approach that was being practiced prior to a pediatric chronic diagnosis influenced how each family adjusted. While Mary continued on as she had been doing for years, the other mothers had to make at least minimal adjustments. Saumya introduced more Western medicines to treat Vidya while making a more conscious effort in choosing Ayurvedic foods to treat her daughter’s condition. Basanti employed an approach where traditional treatments were attempted prior to Western methods. Additionally, Basanti used Western and traditional techniques concurrently regarding rituals. For example, they would pray for healing while actively pursuing Western treatment. Usha blended Western and traditional care exclusively for Mahesh; all other family members continued on with their traditional methods untouched. Western medicine was reserved mainly for Giri in Renuka’s household, but not solely. Others would utilize Western means in response to time constraints and unavailability of more traditional methods.

As previously mentioned, Bowen’s (1978) concept of multigenerational transmission process provides insight into what each generation of each family may have been experiencing as this blending of Western and traditional health care was occurring. While arguably all of the child-mother dyads experienced this process, it may have been most apparent in Saumya’s interview. Saumya shared that her family did not practice Western medicine until her brother introduced those methods to them while studying in the United States. Now as a result of Vidya’s chronic condition as well as residing in the city, Saumya was teaching Vidya to practice health in a much different way then she
herself was raised. While she was instilling the value of an Ayurvedic diet in Vidya, she was also utilizing Western medicines.

While Saumya, Basanti, and Usha felt supported by their families for the adapted health practices they employed, Renuka faced great family conflict. It remains unclear if this conflict was the result of utilizing Westernized medicine for Giri or if it was the result of shaming her husband and family by disregarding her husband’s and astrologer’s advice. Bowen (1978) would have identified this turmoil as the nuclear family emotional system, specifically under marital conflict. It is within this concept that Bowen recognized the mutual blaming between spouses. In this particular instance, Renuka felt that her husband was wrong for not doing all she felt he could have done to save Giri, while Renuka implied that her husband was upset with her for disregarding his role as the family leader. Additionally as Bowen would have predicted for this situation, compromises were made as the spousal relationship was returning to what was typical; more “traditional” family members began taking Western medicine on occasion distinguishing a point of tension.

In regards to evolving health rituals, Nidhin and Rohan seemed to share perspectives with their respective mothers. Mahesh did not credit the revival of old family rituals such as evil eye as a response to his diagnosis, while his mother, Usha, did. Giri was unaware that the family astrologist ever had a part in his family’s health care customs. Again, Vidya’s mental capabilities as well as the slight adjustments that her family made may have prevented her from recognizing changes in their family health care routines. The majority of participants, children and mothers alike, cited giving more
attention to personal hygiene, diet, and household cleanliness. While Mahesh reported
more monitoring from his parents in terms of how he carried out health related behaviors
such as teeth brushing and hand washing, Usha and Saumya acknowledged putting forth
a concerted effort to do activities such as eating as a family.

Renuka stated that she does everything for Giri and he accordingly believes that
his family does, in fact, do everything for him. As a part of Bowen’s (1978) nuclear
family emotional system, Renuka’s behavior of doing everything for her son is known as
impairment of children. Under the consideration of Bowen’s theory, Renuka’s conduct of
doing everything for Giri represented the excessive worry she has for him as well her
idealized understanding of his condition. This extreme monitoring, if Bowen’s theory
holds true, will result in Giri having trouble differentiating himself from the family,
internalizing family tensions, and difficulty with appropriate socialization.

On the contrary and to his mother’s knowledge, Rohan believed that his family
does nothing at all specifically for him. This seemed to be peculiar as Giri’s family with
the exception of his mother initially abandoned him, while Rohan maintained his family’s
support. Perhaps, Giri’s family was pampering him in an attempt to make up for lost time
as Rohan’s family has long-since learned how to function as a family with a chronically
ill child.

All chronically ill children in this study identified their mothers as primary
caregivers. As cited by child participants and supported by Cancian and Oliker (2000),
emotion work was primarily performed by these children’s female family members, who
in 3 dyads, were their mothers. Mary was one of the two exceptions to mothers being the
primary caregivers at home as she was physically unable to perform necessary caregiving tasks because of her own ill health. Nidhin, Mary’s son, recognized these limitations and adjusted his behavior accordingly by hiding his own symptoms to care for her. This behavior of Nidhin’s would be the result of what Bowen (1978) termed the *family projection process*. More specifically, Mary may have been parenting Nidhin in such a way that she projected her own personal feelings and problems upon Nidhin. Over the long term, this projection has been found to limit the functioning of children while increasing their susceptibility to emotional disturbances (Bowen, 1978).

In addition to being the second exception of not being the primary at home caregiver, Saumya also seemed to be the only mother who did not attempt to honor traditional gender roles. Perhaps Saumya held such different views from the other mothers in this study because she differed from them greatly in regards to her educational and professional attainment. Moreover, these achievements were more equivalent to those of her husband, making Saumya and her husband more equal partners than any of the other parental couples.

While Saumya and her husband seemed to negotiate Vidya’s care as equals, Mary and Usha expressed concern over the shame brought upon their husbands by performing typically female tasks. The shame perceived by Mary may have been intensified by her own admitted sense of guilt and the stigma associated with “poison blood.” Usha seemed to be concerned about the possibility of shame falling upon her husband if outsiders came to know the role he played in Mahesh’s caregiving. This situation with Mahesh’s father
was paradoxical in that by bathing his son, he is performing a traditionally female task while protecting the modesty/purity of his wife and Mahesh.

As evidenced by Cancian and Oliker (2000), the gendered nature of caregiving significantly increases the workload for families, especially women. Mahesh recognized this and expressed anger at himself for making his mother and sister work so hard. Mahesh’s father expressed anger toward Usha perhaps because what she failed to do increased the threat of shame upon him. Mahesh and Usha were not the only dyad dealing with the stress of shame and anger.

While Renuka had intense anger toward her husband for giving up on their son, she acknowledged that she brought him great shame by ignoring his advice regarding Giri. Renuka may have attempted to negotiate her emotional turmoil - the mixture of guilt for failing her husband and rage at him for failing Giri – by manipulating Giri’s perspective on home health care. As previously implied, Renuka and Giri were the only child-mother dyad that cited different at-home caregivers. Even though Renuka truly believed that she was Giri’s at-home care provider, she seemed to manipulate him into believing that his father and grandparents were also very involved. This decision may aid in reconciliation of family relationships while creating an environment more conducive to Giri’s well being. This approach also may assist Renuka in her own healing process.

To reiterate, Bowen’s family system theory is founded on the belief that families are emotional units. Each member of the family is affected by one another’s actions, emotions, and beliefs. As tensions rise within the family unit, so does anxiety. Heightened anxiety levels may result in family relationships being more stressful than
comforting (Bowen, 1978). As a traditional East Indian wife and mother, Renuka had the responsibility of attempting to accommodate everyone – Giri, her husband, and in-laws in order to relieve this stress. This liability, according to Bowen (1978), may become too much causing health problems such as Renuka’s delusions regarding other people’s babies.

Parenting a chronically ill child induced feelings of guilt for 3 mothers, Mary, Basanti, and Saumya. While Mary felt culpable for Nidhin’s illness because she passed it directly on to him, Basanti and Saumya felt their children became ill as a result of decisions that they had made. While both of these mothers felt moving into the city with polluted air caused their children’s health conditions, Saumya also felt the pressure she put on Vidya to academically excel contributed to her condition. Coincidentally while, Saumya felt guilty that she has no other children to care for Vidya when she no longer can, Mahesh felt guilty for burdening his mother and sister with his care.

Whereas Usha already had Aabha at the time of Mahesh’s diagnosis, the remaining four mothers claimed they would not have any more children because of their present child’s illness. Saumya, Basanti, and Renuka recognized the amount of time that was required to care for a chronically ill child at home. While these mothers did not seem to mind dedicating this time to their children, Vidya, Rohan, and Giri respectively, their children recognized the 24 hour care they were receiving. The stigma and contagious nature of Nidhin’s disease may have prevented his mother from having access to outside assistance in caring for him. As supported by Hatton et. al, (1995), fear of something going wrong or failing their child seemed to prevent the others from seeking and / or
accepting outside assistance. The diversity in the education levels, financial stability, and health care practices of these mothers illustrate the universality of motherly concerns when parenting a chronically ill child.

Culturally Sensitive Health Care: What Child and Mother Perceive

Parents typically provide the majority of care for a chronically ill child at home (McCubbin et al., 1993). Because of this, it is critical for health care professionals to truly understand a family’s cultural background and the practices that may occur outside the purview of medical professionals. It is the beliefs and practices of this cultural background that parents typically base their child’s care (McCubbin et al., 1993). When health care professionals recognize this and work within this framework, plans of care are more likely to be successfully followed by family care providers and chronically ill children themselves (Joseph-DiCaprio, 1999).

Interactions with Medical Staff: What Child and Mother Experience

While traditional Indian cultures dictates that men are to accompany and fully participate for women and children during medical encounters (Ramakrishna & Weiss, 1992), Westernized health care and hospitalization seemed to challenge this long-standing belief. When asked about his interactions with the medical staff, Nidhin stated:

    Doctor Uncle speaks nice to me. Sister Aunty [nurses] play with me and give me toys and let me play with my friends in the hospital playroom.
    They give medicine for me to become stronger. They know I want to become doctor so they tell me many things.

Nidhin’s mother Mary elaborated on this sentiment:
We have been coming here for many years now. We have come to know many of the sisters and doctors and counselors. They are good people; they always work to make us better when we fall sick. It is comfortable. It feels like home. Now they have toys for Nidhin to play with even. The staff is very nice. Since we are long term patients, they always treat us good.

Mary expressed the belief that her son would have passed away if it were not for the medical care they received. Mary acknowledged the respect of the staff by saying:

My role as Nidhin’s mother is recognized because they have not told him what I have, that we have the same sickness, or what he has. Some of the counselors don’t like this, but they honor my wish because I am his mother. I am his family by blood.

Mary said she was permitted to bathe Nidhin and tell him stories while in the hospital, but most importantly “when we are both admitted at the same time, they let us share a bed or have two that are together. They try and keep our family together.”

When asked specifically about practicing her family routines, religion, and cultural values in the hospital setting, Mary felt she could do so with ease. For example, Mary shared:

Even though most people are Hindu and we are Protestant, they [hospital staff] let our Pastor come in and pray with us. We read Bible to Nidhin and say bedtime prayers when we are here. We pray together speaking out loud. The workers respect this.
When asked how the staff supported her family values more directly when interacting with Nidhin, Mary shared, “They [hospital staff] ask us before they give treatment to our son. They explain treatment to us. They acknowledge that he is Protestant and not Hindu when they speak with him. They only tell Nidhin what we let them to tell.” Concerns and questions were readily addressed according to Mary. She stated:

Many times, doctors are not available; the sisters [nurses] call the doctors’ cell phone and see if they are available. Or they check the doctors’ schedule and let us know when to meet them. When the sisters know the answer to our concerns, they tell us, but they never take risks. They don’t want us to have bad information or empty hope.

Mary summed up her interactions with medical personnel by stating, “The staffs love my child; they take good care of us.”

Giri agreed that the hospital staff treated patients well. He offered, “The doctors speak nice to me. They allow me to play in the playroom with other kids. They allow my friends and cousins to come visit me and spend some time with me. They give to me good foods.” Acknowledging that not everything was perfect, Giri said, “I don’t like it when they give to me injections [shots] and tonics that don’t taste good to drink.” His sentiments paralleled the findings of Bossert’s (1994) study that revealed children 6-12 years found shots and medicine to be two of the most stressful aspects of medical encounters.

Renuka, Giri’s mother, agreed with him regarding interactions with the medical staff. Renuka shared:
The staff is very, very patient. They give good response when I ask them same questions over and over. I recognize that even when I was mentally upset or distraught the staff and the doctors were nice to me and answered my questions politely. I am convinced with the kind of treatment my son is getting and I can see him getting better, compared to the other hospitals and doctors.

Renuka also recognized how with the guidance of these medical professionals, she herself was getting better. She shared:

I use to see other babies as my own and try to take them from their mothers. Now I have many hopes in my son so I don’t see other sons as mine. Doctors here gave that to me. They say I must care for myself and my baby. They show me to stay awake all night with Giri and sleep during day when he sleep. They taught me to care for Giri when even they cannot.

Renuka continued to share how the hospital counselors supported her in healing the relationships she shared with her family members:

The counselors know how important spirituality is to my family and how I went against spirituality to save my son. They [counselors] know how this hurt my family but saved Giri. They tell me that now Giri is my gift to them [family]…a gift from gods to them. I know they are wise. Giri is from gods. They saved me and Giri and our family here. They are very wise doctors and people.
Renuka made it evident that she credited the hospital staff with not only her son’s physical health, but also her own mental health, and her family’s overall well being.

Being an intelligent child with the hope of becoming a doctor himself, Mahesh said:

The doctors are good to me. Since I am curious to know about me and others in the hospital, they teach me about these diseases…. They explain what they are doing, that makes me to understand my body better. Sisters [nurses] make humor when they are around me.

When asked how the staff could do better Mahesh responded, “They give to me medicines to cure my disease, but I am not confident I have a permanent cure for my disease, but doctors say hope is always.” Mahesh believed the doctors exercised extra care because of his intellect.

Regardless of the reasons, Usha agreed with her son Mahesh that he was receiving quality care from the medical staff. She stated, “My son is getting good care here. The counselors and sisters have taken the time to know my son. That is how we know he knows he has cancer. They are treating him. At other hospital, they treat disease cancer.”

When asked if the staff respected her son as well as herself and family, Usha answered:

The staff is very good to all of us here. They discovered what was bothering my son mentally and made us understand that we needed to tell him the truth. They explained to us so we could see for ourselves. They let us make decisions for our son, but they give us guidance. They listen to us even though we aren’t educated. They know we are sacrificing for our son.
More specifically, Usha felt her role as Mahesh’s mother was recognized on a regular basis. She explained:

They know I am his mother. They let me to bring him food sometimes. They ask me to comfort him. They tell me what is going on with him so my husband and I can make decisions. When my husband is here, they talk to him because he leads our family. They respect my role in my family so I respect them.

The medical staff also respectfully acknowledged Usha and Mahesh’s family routines. Usha shared, “Our routines are all different because Mahesh is here. My mom takes care of my daughter so I can be here. My husband comes when he can. It is over one hour journey. The doctors always speak to my husband when he comes even when it is Saturday.” Additionally, Usha felt the staff was sensitive to their cultural needs. She explained, “We are Hindu and they let us pray to our gods and do many of our rituals here in the hospital. We can’t perform our evil eye rituals and sometimes I think we need too with the sisters [nurses]. My husband spoke to them and they stopped. Now Mahesh doesn’t smile often, but he is feeling better.” Usha summed up her relationship with the medical personnel by stating, “They know my family and respect what they do. They teach us to treat our son’s disease with their medicines and our medicines. Mahesh needs both to heal. I am grateful toward them for knowing [this].”

Unlike Mahesh and Usha, Rohan and Basanti had very little to share about their interactions with the hospital staff. This may be due to the brevity of Rohan’s admissions. Rohan stated, “I am not here much, but doctors speak nice and give medicines to me.”
They give medicine to me when I cannot breathe properly and make me better so I can go home very soon.” Basanti, Rohan’s mother, appeared to share this perspective, “We have been here many times, but never for longer than three days. My son is comfortable with them so I know they treat him well. The staff respects us. Sometimes it is hard for me because I worry about cost. It takes great money to be here so staff works fast to send Rohan home safely. I am grateful for quick healing.”

Similar to Rohan, Vidya did not have a great deal to say about her interactions with medical personnel. When asked, she said, “I like the sisters [nurses]. The doctors hurt me and make me to wear funny things. I like the talking lady [counselor]. She is silly.” When asked to elaborate, Vidya continued, “Doctors are mean and hurt me, see (holding out her finger with a band aid). The sisters bring me many stuffs to color.”

While Vidya seemed unaware of the greater picture of what was going on around her, her mother was certainly in tune to their surroundings. When asked how she felt about the care Vidya was receiving from the hospital, Saumya replied:

We [Saumya and her husband] are very pleased about the treatment and interactions that Vidya is receiving here as well as the communication that we have had with the staff…. We feel that she [Vidya] is getting the best care possible here. They care about her more than they care about our money.

Saumya reported that she and her husband felt very respected and recognized as Vidya’s parents. She offered:
The staff is very respectful. They explain procedures to Vidya immediately before they do them so she knows what is going on. They are gentle and loving with her. They address us all by name. The counselors understood how worried my husband and I were about our daughter. They worked with us to help us recognize that we did not cause our daughter’s illness. They have taught us how to interact with her in a way that does not put so much pressure on her. They did this within our family values.

Saumya also expressed appreciation for the manner in which staff members respected their family routines. Doctors worked around Saumya and her husband’s schedules in order to discuss treatment with them both together. Nurses interacted with Vidya around her sleeping schedule. Saumya stressed, “The staff answers my questions and provides me the necessary details for me and my husband to research things further. They are very helpful and caring.”

Saumya felt that the hospital staff went beyond their role as medical personal. She said, “The staff is very supportive of us. We may get more support because our family is still in [city]. I think they are also sensitive to us because we are both educated. This makes them feel they can talk to us about all aspects of Vidya’s care. They feel like we’ll understand.” Saumya elaborated on how the staff respected their traditional values when possible: “The staff has worked with us so we could come to know what foods will help our daughter. They are working with us so we can give medicine to her very less. They treat her as Vidya, not as the illness she has. The staff is patient with her. They treat her as a young kid because that’s where she is in her brain even though her body shows that
she is older.” Saumya summed up her thoughts on the staff by saying, “I am very pleased with the doctors and sisters and counselors. When I need a family they are there.”

**Summary**

Overall, each mother was pleased with the quality and personalization of the care they were experiencing while hospitalized. Additionally, all of the children spoke positively of their interactions with doctors and nurses with the exception of Vidya. She felt the doctors hurt her as did Giri, but unlike Vidya, he recognized the benefits of these encounters. Usha and Saumya expressed appreciation for the staff recognizing their children as individuals as opposed to the diseases they were being treated for. Interestingly, Saumya, the wealthiest mother in this study, and Basanti, the poorest mother both mentioned the role money played in their interactions with hospital staff. While Saumya noted that the staff did not care about her money, Basanti expressed gratitude for the staff working quickly in acknowledgement that hospitalization was a drain on the family budget. Another observation that must be noted is the acknowledgement that three mothers shared regarding the “extra” time that doctors devoted to them. While Mary credited this extra attention to the longevity and frequency of her and Nidhin’s hospitalizations, Saumya cited her educational attainment and professional standing as the motive behind doctors working closely with her. Contrastingly, Usha believed her lack of educational achievement and professional standing to be the reason behind the thorough explanations she received from doctors. While Vidya did not seem to acknowledge the explanations she received from the
doctors, Mahesh and Nidhin believed the extended explanations they were given to be the result of their desires to become doctors.

As traditional in Eastern health systems (Kinsley, 1996; Trollope-Kumar & Last, 2010), Saumya and Usha perceived their doctors as guides. This view may have been in part due to the medical staff assisting these mothers in blending traditional and Western medicine with their children’s plan of care. Mary firmly believed she and her son needed Western medicine and therefore sought out Western doctors. Accordingly, Mary perceived her doctors to be experts as is typical in the West (Kinsley, 1996; Trollope-Kumar & Last, 2010). In the case of Renuka, she spoke of her interactions with the doctors as if they were guiding her, but her actions seemed to portray her perception of doctors as experts. For clarification, one of the concepts in Bowen’s (1978) family systems theory is differentiation of self. It is within this concept that an individual’s susceptibility to peer pressure is considered. While Renuka’s family had been basing important decisions on an astrologist’s reading for generations, she immediately agreed to never seek health care advice from an astrologist again at the request of the doctors. Renuka’s willingness to agree to this without any questions or thought seems to depict a perception of doctors as experts. Furthermore in light of Bowen’s theory, this snap decision may indicate that Renuka may be vulnerable to peer pressure. Contrastingly, Saumya for example, appeared to have a low susceptibility to peer pressure according to Bowen’s theory. While she followed the doctors’ advice for medicine, she questioned them directly, researched matters on her own, and made the doctors work around the
Ayuvedic principles regarding diet. Regardless of seeing their doctors as guides or experts, each mother felt that they were recognized in this role regarding their ill child.

Each mother also felt their spiritual practices and beliefs were recognized and respected in the hospital setting. While Usha could not perform the traditional evil eye ritual due to the use of fire, she shared that her husband addressed the over complimentary behavior of the nurses toward Mahesh. The nurses responded as he requested per Usha and as a result, the need for the ritual itself dissolved. This act of advocacy for Mahesh may have illustrated his parents’ increased comfort level with the hospital staff (Jerret, 1994). Each mother was appreciative of how medical staff interacted with their child in the framework of individual family values including spirituality. As found by Rao, Lee, and Torres (in press), “People in some cultures…believe that spirituality plays an important role in their overall well being, whereas in other cultures, e.g., most Western cultures, it is not common to relate spirituality to health” (p. 4).

According to Mary, Renuka, Usha, Basanti, and Saumya doctors and nurses, readily addressed their questions and concerns. The manner in which each mother described the medical staff attending to these matters seemed to be personalized to each of them. While Usha reported that medical plans and procedures were explained in a way that she could understand, Saumya felt the doctors discussed Vidya’s plan of care in an intelligent manner providing her with information for further research. Renuka spoke to how the health care team responded very patiently to her repeated questions while working with her to overcome her mental anguish. Mary felt the staff truly cared for
Nidhin because of the way the nurses would contact the doctors in order to address her needs in a timely manner.

Each concept presented in Bowen’s theory (1978) applies to nonfamily groups including the organization of health care systems. This phenomenon is explored in the concept titled *societal emotional process*. This process depicts how the emotions that preside over individual families transfer to the greater context of societal organizations and governments at large. This is pertinent to this study as families negotiate the blending of Western and traditional means of medical care. This merging directly shapes patient doctor interactions, compliance with prescribed treatments, and the type of medical care sought out by the general public. While the doctors discussed within this study seemed to be making temporary adjustments to appease the mothers of chronically ill children, India’s over all health care infrastructure must be altered in order to meet the needs of the aforementioned concerns on a more permanent and consistent basis.
CHAPTER 5: CONCLUSION

In the context of a chronic pediatric diagnosis, health beliefs and practices may undergo significant changes. Whether the experienced changes are positive or negative, chronically ill children and their mothers must learn to reestablish how health is communicated and experienced, renegotiating their roles as a chronically ill child and a mother of a chronically ill child. The purpose of the current study was to examine how chronically ill children and their mothers negotiated the intersection of family health culture and hospitalization. In addition to examining this merging of family health practices and hospitalization, this study examined how mothers perceive the interactions between themselves and hospital staff as well as between their child and hospital staff. Furthermore, this study examined how medical professionals offer culturally sensitive care and how they can improve in this regard from the perspectives of mothers with a chronically ill child. This study was borne from the desire to comprehend more about the intersection of family health culture and hospitalization and how this encounter is impacted in light of a pediatric chronic diagnosis.

Study Findings

Mothers as Teachers and Models of Health

The perspectives of both the chronically ill child and their mother were examined throughout this study. Studying both of these perspectives contributed to the overall understanding of how health is communicated within each family system. Based on participant insights, mothers appear to be the primary teachers and role models of health practices and beliefs within families. They also were self-described and depicted by their
ill children as being the initiators of change in family health practices and beliefs upon the diagnosis and throughout the treatment of a chronic diagnosis. While mothers may not have sat their children down and directly told them that new health practices were the result of a specific diagnosis, mothers clearly adapted how they discussed and modeled health practices as evidenced by the parallels found in what each child and mother shared. The unity of child-mother health beliefs was seen in their similar definitions of health as well as their feelings regarding the knowledge of outsiders knowing their health conditions. Furthermore, many parallels may be drawn between child and mother as to which rituals and practices were utilized to maintain their health. While children’s perceptions may have been inaccurate, their mothers had an accurate understanding of their child’s misconceptions almost throughout.

*Family Health Culture Transitions*

Regarding the health culture transitions that each family had to undergo as a consequence of their child’s chronic diagnosis, child-mother dyads varied greatly in the ease of this transition. In dyads whose families followed very traditional health practices and beliefs, the transition was more difficult than for those dyads whose families had begun practicing Western medicine prior to their child’s diagnosis. In the case of one dyad, this modification was nearly nonexistent as the mother participant shared her son’s diagnosis.

Likewise, whether or not children and their mothers had the support of other family members during this transitional period greatly influenced how each dyad fared. Dyads that had the support of their families while merging their traditional health
practices with Western methods seemed to have the smoothest transitions. This occurred regardless of how families negotiated this blending as long as the family was in agreement. A dyad negotiated this transition by reserving Western medicine strictly for the chronically ill child, while other dyads embraced the use of Western medicine as a family, with all members partaking. The majority of dyads practiced their traditional health routines concurrently with Western medicine. While this approach seemed to ease the transition of families, it created the largest challenge for health care professionals. This approach demanded that doctors among other medical professionals have a fundamental understanding of both traditional and Western medicines to ensure that the blending of these two methods did not counteract one another or create further complications.

_Truth Concealment_

By utilizing a dyad approach in this study, the intentional concealment of diagnoses and prognoses by mothers were revealed as an attempt to protect their children. Three mothers attempted to employ this approach, with two of them being successful at the time of this study. The mother who was unable to conceal the truth from her child expressed concern over him knowing and the damage that may have been caused in their relationship because she was not open with him. While the traditional health beliefs of these three women emphasized that concealment of ailments was to keep them in a spirit of hope, benefitting patients, these women recognized the pressure from Western doctors and medical professionals to reveal the truth. Specifically, Western medical ethics dictate that patients have a right to full disclosure of their condition and members of the
psychosocial team recognize the apparent benefit in sharing open and truthful dialogue on a patient’s psychological well being.

Ironically, of the remaining two dyads, both mothers desired to have full disclosure with their children and yet were unable to do so as one child lacked the mental capabilities of comprehending her health condition and the other because doctors had no answers to offer. While one of these mothers led a relatively Westernized lifestyle and believed knowledge to be power, the other mother understood the fear of not knowing and how one’s mind can make the unknown worse than reality. The opposite views presented by traditional and Western medicine in diagnosis and prognosis disclosure, while both valid, presented mothers with yet another hurdle to navigate at the intersection of family health culture and hospitalization.

Further compounding the issue of disclosure or concealment of a diagnosis from patients is the influence of one’s culture and understanding of truth. As found by Torres and Rao (2007):

American doctors believe that the patient needs to know everything in a very straight-forward and direct manner in order to be truthful. There is a need to be truthful by being as explicit as possible so that no doubt or double interpretation may emerge from the doctor’s statement. (p. 283).

The directness of the language used by such medical professionals is reflective of the greater culture in which they live. For example, the majority of Westerners are socialized to view themselves as independent beings. “This sense of being independent from others is also related to the notion that full disclosure allows the patient to make decisions on
his/her own as he/she is the owner of his/her own body” (Torres & Rao, 2007, p. 284).

Contrastingly, Torres and Rao (2007) found that doctors practicing in India communicated diagnoses and prognoses through the use of ‘half-truths’ by conveying differing amounts of information to patients over varying lengths of time dependent upon the patient’s psychological well being. Again, this phenomenon was rooted in the mainstream culture of India that is collectivistic in nature, meaning the majority of communication is done indirectly. Specifically:

A patient from a collectivistic culture would tend to understand the context of his/her visits to the doctor, would try to read the non-verbal clues of the environment and what the doctor is telling the patient about his/her condition. The doctor would tend to protect the patient’s face and psychological state and would tend to use more indirect strategies of communication. (Torres & Rao, 2007, p. 280)

As illustrated by Torres and Rao (2007), the intersection of an individual’s family health culture, the culture at large, and the culture(s) of medical professionals influences what and how truth is disseminated in health care encounters.

*Education Attainment and Health Care Encounters*

It became evident throughout this study that educational attainment was influential on health care encounters for the chronically ill children and their mothers alike. The children who expressed interest in achieving a higher education, especially those who hoped to pursue Western medicine, acknowledged that the doctors spent a great deal of time talking with them. These same children cited their aspirations to
become doctors as the motive behind these extended interactions. For the chronically ill child who learned of his condition through his own intellectual abilities, his educational attainment caused tension at home initially while developing closer ties with hospital professionals. By the completion of this study, this child’s predicament increased the understanding and open communication between his family and hospital personnel. While helping this child to mend his relationship with his family, medical staff members began to form a more open and trusting relationship with his family despite their differences in formal education.

The mothers of the chronically ill patients also recognized educational attainment as an influential force in their health care encounters. How they understood this force, however, varied greatly between them. Those mothers with little to no formal education believed that hospital personnel spent extra time with them to explain their child’s condition and treatment plan in a manner that they could understand. In the case of one of these mothers, a thorough explanation and understanding was even more critical as her son had already surpassed her formal educational achievements. One mother, with a doctoral degree, viewed herself as more of an equal with the doctors and therefore understood their interactions to be more of an intellectual discussion as opposed to an explanatory session. This mother seemed to expect the doctors to explain her child’s diagnosis to her child in a manner similar to how the doctors explained diagnoses to the mothers of the other children. Regardless of educational achievements, the mothers within this study desired to do what they believed was best for their chronically ill
children. This shared pursuit across dyads depicts the individuality and universality of motherhood and teaching health practices.

Limitations

Several limitations existed regarding the current study. First, the dyads varied in their English fluency. Because all interviews were conducted in English, those who were more fluent had the ability to articulate their thoughts, stories, and questions more freely. Additionally, nuances may have been overlooked during interviews due to cultural differences as well as the age and developmental level of children. Second, the dyads that had a stronger understanding of their own or their child’s diagnosis had a greater wealth of knowledge from which to base their answers. Third, the hierarchal nature of the child-mother relationship, as well as the doctor-patient relationship, may have influenced the willingness of participants to speak openly about the implications of a pediatric chronic diagnosis on their family health culture influencing the quality of responses given. Finally, some participants may have been keener in participating, and provided more thorough responses.

Implications and Directions for Future Research

In order to gain a better understanding of how chronically ill children and their mothers navigate the intersection of family health culture and hospitalization, the examination of other family and important outsider relationships would provide greater insight and understanding. Only chronically ill children and their mothers were asked to share their experiences for the purposes of this study. Designing forthcoming qualitative studies to include the stories of important outsiders such as fathers, siblings,
grandparents, and health care professionals would enhance the information gained from this and future qualitative studies regarding the intersection of family health culture and hospitalization. This may be particularly important in cultures such as India where families are so highly regarded.

In addition to designing future studies that examine the experiences of important outsiders in light of a pediatric chronic diagnosis, insights may be gained by studying the experiences of children and mothers who share a common ailment. While the disease that Mary passed onto her son Nidhin was contagious, a great number of diseases are genetically influenced such as diabetes and certain types of cancer. By examining how child and mother manage their shared condition, significant insights may be gained pertaining to the child-mother relationship and more specifically how health and culture are practiced within this context.

Moreover, researching the implications of an unknown pediatric chronic condition on the child-mother relationship as well as the family’s basic understanding of health could contribute to the current literature. The information gained from doing such a study on this population may strengthen the health communication shared between child and mother as well as making health care encounters with medical personnel more effective.

Furthermore, the information gained in this study addressing the role of family health culture in a hospital setting may prove to be advantageous to medical practitioners such as child life specialist professionals. The data collected in this study could be applied to child life programs to include tailoring bedside activities and coping techniques to individual family culture beliefs and needs. While child life programs
presently include the aforementioned activities, the recognition of specific family health culture values is rarely acknowledged. By including family culture specific activities in child life services, the quality and personalization of such encounters will be greatly improved. As a result, chronically ill children and their mothers may be more apt to openly and honestly share their personal health beliefs and practices, which, in turn, provides child life specialists the tools they need to better perform their job. For example, child life specialists could relay the importance of a family’s health culture to other medical professionals including doctors. While child life specialists presently relay information regarding a child’s psychosocial needs to other health care team members, information specific to a family’s health practices and beliefs are often neglected. By including individual family health culture information collection in typical child life programming and relaying such information may greatly increase the quality and personalization of chronically ill children and their mothers’ health care encounters.

Before child life specialists can apply the aforementioned findings to their daily work, it is critical to assess how competent they feel when interacting with patients of different cultural backgrounds and belief systems. Potentially, the more confident child life specialists feel about their interactions with culturally diverse patients, the more apt they will be to tailor activities to specific cultural needs, beliefs, and values. Furthermore, if child life specialists are more assured of their abilities to interact with culturally diverse patients effectively and respectively, they may become more motivated to relay important family health culture information to other psychosocial team members. As a result of this
open and confident communication, patients and medical professionals may leave interactions with one another feeling more satisfied and fulfilled.

Assessing the roles that cultural and spiritual meanings and practice play in patients and/or their families’ understanding of health and culture is significant. Rao, Lee, and Torres, (in press) found that, “differences among cultures about health are not just about which medicine people use. Different conceptualization about health and different styles of medical system in each culture are related to cultures at a deeper level: beliefs about health and illness, (p. 4). As patients become more culturally diverse due to globalization, the need for health care professionals to offer culturally and spiritually sensitive health care increases (Rao, Lee, & Torres, in press).

While it is not the role of child life specialists to impress any belief systems upon those with whom they interact during a medical encounter, it is within the realm of child life to advocate for the respect and practice of a patient’s cultural and spiritual beliefs. It is also critical for all medical practitioners to understand that the production of health and the family management of disease occurs within a cultural context that demands different strategies and understandings as to how medical practitioners may best offer care to children and families. As Usha and her son Mahesh’s situation suggests, culture and spirituality are understood differently in Eastern and Western health care interactions. While Mahesh knew and respected his mother’s traditional Indian belief that disclosing a diagnosis to the ill will render them hopeless making the possibility of death all too real (Ramakrishna & Weiss, 1992), he preferred the Western practice of disclosure. Therefore, when Mahesh learned his diagnosis through his own intentional actions, he
attempted to hide his knowledge to protect his mother from losing hope in his ability to heal.

Health care practitioners from both Eastern and Western settings could learn a great deal from Mahesh’s insights regarding the implications of sharing and concealing diagnoses as well as how these techniques are employed. “The cultural context of physician–patient interactions should be addressed and considered. This is relevant because people from different cultural backgrounds may interpret behaviors differently” (Torres & Rao, 2007, p. 278). While individuals from high context cultures such as India prefer indirect communication styles, those from low context cultures such as the United States prefer direct communication that leaves no room for misinterpretation (Torres & Rao, 2007). If health care professionals could employ this knowledge when working with patients, interactions may become more effective.

In addition to child life services, other health care professionals who work directly with chronically ill pediatric patients and their mothers may gain further insights into the specific experiences, and health practices of individual families. By providing health care in a way that recognizes an individual family health culture and spirituality, psychosocial team members may assist families in developing strategies that successfully merge their traditional health beliefs and practices with Western medicine. Additionally, establishing hospital protocols that recognize family health cultures has been found to increase patient compliance and therefore increasing the satisfaction and success of health care professionals.
Finally, a longitudinal study that addresses the roles of fathers, siblings, grandparents, and health care professionals along with chronically ill children and their mothers, over a longer period of time would also contribute to the information gained in the current study. Following ill children, their mothers, and important outsiders for the duration of the medical treatment will offer additional insights into this population. By interviewing chronically ill children and their mothers at multiple points of time, transformations in their understanding and practicing of health can be acknowledged and studied to better understand how these transitions may be made easier. Studying the progression of the chronically ill child and their mother as they negotiate family health culture and hospitalization would be advantageous to the current literature.

Conclusion

As supported by the information collected throughout this study, a great deal may happen at the intersection of family health culture and hospitalization. The desire to maintain family health traditions and the need to utilize Western medicine is a challenging quandary for families to address. While the mothers of chronically ill children want nothing more than for their children to be healthy, they often struggle with the best way to achieve this without sacrificing too many family beliefs and practices. Redefining family health culture while clinging to the beliefs held most dear to save their child may be one of the greatest challenges faced by the mother of a chronically ill child.

The present study underscored the complexities of the intersection of family health culture and hospitalization in light of a pediatric chronic diagnosis. The majority of literature addressing culture and pediatric health care fails to present information attained
from pediatric patients themselves. To help negate this, the current study contributes to
the literature regarding culture and pediatric health care by acknowledging the children
who endure repeated health care encounters while maintaining who they are by providing
an outlet for their voices. Participants were typical, yet chronically ill children who
withstood medical treatments with the support of their mothers who helped them to
redefine their family health culture. Although the current study did not specifically
address other family members or hospital professionals and their accounts were not
included in this study, they were actively involved in offering medical treatment
respectful of family beliefs and health needs.

In spite of initial reactions to a pediatric chronic diagnosis, mothers were striving
to provide a stable and healing environment for their chronically ill child. The
determination and resilience of these mothers to provide the best medical care possible to
their child despite health belief contradictions, family tensions, and economic constraints,
was a true testament to a mother’s dedication to the well being of her child. Residing in
India, a country known for its long standing traditions, but currently undergoing a
societal metamorphosis, may have contributed to mothers’ responses to their child’s
ailment. Most of the families within the current study were aware of the societal changes
that were occurring, but it was their child’s diagnosis that forced the issues.

By employing a qualitative approach for this study, the perspectives of both the
chronically ill child and their mother could be examined closely. Focusing on both the
child’s and their mother’s perspective created an opportunity to critically look at how
children and their mothers understand health culture, practices, and beliefs both
independently and as a dyad. Furthermore, capturing the experiences of both child and mother highlighted how their personal experiences differed despite being so closely connected. In some cases, the experiences and understanding of the chronically ill children varied from their mothers, but in most cases, mothers seemed to have an accurate understanding of their child’s perceptions. These differences highlighted some of the underlying nuances regarding how mothers teach and model health to their children. Presently there are few studies that present school-agers’ experiences in their own words. Even more rare are studies that gain information directly from chronically ill school-agers as opposed to their parents’ interpretation of their experience. Therefore, the current study may contribute to the existing literature by presenting a new approach to gathering further knowledge regarding the intersection of family health culture and hospitalization in the context of a pediatric chronic diagnosis.

As noted by Naples (2003), we may better understand the lived experiences of others as we reflect upon the research process to improve how we investigate, comprehend, and communicate our findings. Therefore, as a student and young professional interacting with children and their mothers as they negotiate chronic conditions and health care institutions, I brought my own point of view into this research process. Admittedly, I held stereotypes and judgments regarding the choices parents make in the type of health care they pursue on behalf of their children. For example, I saw parents who were unwilling to utilize readily available, cutting edge medical treatments as making poor or selfish choices for their chronically ill child. I feel that this perspective has been greatly influenced and molded during my pursuits, studying and
working with agencies that serve this population. It is now upon reflecting back at the completion of this research that I understand how unfair and unjust these stereotypes and judgments were. The children who participated in this study were filled with the joy of life despite currently being hospitalized. Their mothers, proved to be dedicated warriors in pursuit of healing and doing what was best for their child despite unending personal sacrifices. While each child and mother wished for good health, they whole-heartedly made the best of their challenging situation as they supported and encouraged one another just by being themselves. Making their inner-strength evident, the chronically ill children strived to meet the typical developmental tasks for their age as they also conquered the tasks presented by their ailments. This same unwavering strength was present in the mothers of these children; they not only met the demands of parenting, but also successfully navigated the challenges of merging their traditional health culture with Western medicine to meet the demands of parenting a chronically ill child.
REFERENCES


APPENDIX A: ADULT CONSENT AND ASSENT FORM

Ohio University Consent Form

Title of Research: Pediatric Chronic Illness: How East Indian Children and Their Mothers Negotiate Culture and Hospitalization

Principal Investigator: Carrie Cligrow, Masters Student, Ohio University
Department: Child and Family Studies, Human and Consumer Sciences

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

Explanation of Study

With this project, I want to increase understanding of how Indian children, ages six to twelve years and chronically ill, and their mothers negotiate family health beliefs and hospitalization. The interview questions will address your family’s health culture in the context of a Westernized hospital. Additional questions will focus on the relationship you share with your ill child, the social support services that you utilize, and how you and your child cope with the stresses of hospitalization and illness.

Risks and Discomforts

Concerns could be raised about the emotional intensity of the data collected however the hospital’s psychosocial team will be working closely with your child and family to ensure that such feelings are addressed in a healthy manner.

Benefits

Mothers in this study may gain a new awareness about themselves as individuals and as parents of a hospitalized child. This enhanced awareness may make parents more aware of the services the hospital offers as well as help them realize their needs so that they can get them addressed by the appropriate hospital staff. Children may benefit from participating in this study by gaining awareness of their emotions. This study also may reveal the misconceptions some children may hold; as a result, a psychosocial team member can address these misconceptions with the child in a manner that helps the child to understand.

Confidentiality and Records

Every effort will be made to keep your study-related information confidential; however, there may be circumstances where this information must be shared with:
• Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
• Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU;

Contact Information

If you have any questions regarding this study please contact:

• Carrie Cligrow (Primary Investigator) Email: cc281601@ohiou.edu Phone: (xxx) xxx-xxxx
• Margaret Manoogian, Associate Professor, Family Studies (Faculty Advisor) Email: manoogia@ohio.edu Phone: (740) 593 2874
• If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740) 593-0664.

By signing below, you are agreeing that:
• You have read this consent form (or it has been read to you) and have been given the opportunity to ask questions
• Known risks to you have been explained to your satisfaction.
• You understand Ohio University has no policy or plan to pay for any injuries you might receive as a result of participating in this research protocol
• You are 18 years of age or older
• Your participation in this research is given voluntarily
• You may change your mind and stop participation at any time without penalty or loss of any benefits to which you may otherwise be entitled.

Signature_________________________ Date____________

Printed Name_____________________________________

If you are under 18, a parent or guardian must complete the following:

I give my child, __________________________, permission to participate in this study.

Signature_________________________________________ Date________

Printed Name_____________________________________

Version Date: June 2008
APPENDIX B: CHILD ASSENT FORM

Ohio University Assent Form
Pediatric Chronic Illness: How East Indian Children and Their Mothers Negotiate Culture and Hospitalization

My name is Carrie Cligrow. I am interested in talking to you about your experiences in the hospital. I would like to hear how your family and hospital workers treat you. My hope is to work in a hospital setting helping children as they undergo treatments for different illnesses. Your help in sharing your experiences will help other children and hospital workers to learn how best to work together to make other children better. If you decide you want to be in my study, I will ask you some questions about being in the hospital and being sick.

This study may help you know what makes you happy or sad about being in the hospital. This study also may let you know what you need from your mom or doctors so they can better take care of you. This study may also cause you to think about things that make you sad or scared. If this happens, your hospital workers will help you.

Other people will not know if you are in my study. I will put things I learn about you together with things I learn about other children who are in the hospital like you, so no one can tell what things came from you. When I tell other people about my research, I will not use your name, so no one can tell who I am talking about.

Your parents or guardian have to say it’s OK for you to be in the study. After they decide, you get to choose if you want to do it too. If you don’t want to be in the study, no one will be mad at you. If you want to be in the study now and change your mind later, that’s OK. You can stop at any time.

You can leave messages for me with any of your nurses. You can talk to me if you have questions about the study or if you decide you don’t want to be in the study any more.

I will give you a copy of this form in case you want to ask questions later.

Agreement

I have decided to be in the study even though I know that I don’t have to do it. Carrie Cligrow, the researcher on this study, has answered all my questions.

______________________________ ________________
Signature of Study Participant   Date
APPENDIX C: MOTHERS’ PROTOCOL

Date:

East Indian Mother Interview Protocol

Project Title: Pediatric Chronic Illness: How East Indian Children and Their Mothers Negotiate Culture and Hospitalization
Principal Investigator: Carrie Cligrow, Graduate Student, Child and Family Studies, Ohio University
Advisor: Dr. Margaret Manoogian, Assistant Professor, Child and Family Studies, Ohio University

Hello. My name is Carrie. Currently, I am going to college in America. I want to thank you for agreeing to be interviewed. I am interested in hearing about your experiences as a mother of a chronically ill child and how you negotiate their health care. I want to remind you that this interview is voluntary. You do not have to answer any question that you do not wish to. Remember you can stop the interview at any point and for any reason. All information that you share with me will be kept confidential and will not be shared with your child or health care professionals. Let’s begin.

Now let’s talk about your child.

1. Tell me about your child’s story.
   (Prompt: Why is your child here; type of illness; time of diagnosis, other information to understand nature of illness)
   - Tell me about how well you feel you understand your child’s illness?
   - What was your child’s life like prior to becoming ill?
   - How has this diagnosis influenced your child? (Prompt: emotional, physical, social?)

2. What is your understanding of your child’s illness? How do you feel about it? Have your feelings changed over time since diagnosis to today?

Now we are going to talk about how you and your family understand and practice health.

3. How would you describe a healthy person?
5. Can you identify some of your family traditional health beliefs?
6. How do you decide who to go to when you or your family member is ill?
7. How has your child’s diagnosis influenced your health routines in your family? How has your child’s illness impacted your view of illness and health?
Now I would like to ask you about how your family manages your child’s illness at home.

8. Tell me about your child’s primary caregiver at home. (Prompt: Who? Individual or shared responsibilities? What types of responsibilities?)
   - How has the caregiver responsibilities changed over time since diagnosis?
   - How has your role as a mother been challenged by this diagnosis?
   - What have you told your child about their diagnosis?
   - How much do you think your child wants to know about his/her illness?
   - How much do other family members want to know about your child’s illness?

9. Tell me about your interactions with the staff here at “name of hospital”.
   - How do you feel about the care your child is receiving?
   - Do you feel that the staff respects your child, you, and your family members? Do you feel your role as a mother is recognized? Why or why not?
   - How has the staff recognized and acknowledged your family’s individual routines?
   - How well does the staff address your concerns and answer your questions?
   - Do you feel that the staff offers sensitive care that is respectful of your cultural and religious beliefs? If so, how?
   - How does the staff respect your wishes regarding treatment and interactions with your child?
   - What recommendations do you have for the staff to improve their interactions with you and your child?

I am interested in how your child’s illness has influenced your other family members.

10. How did other family members react when learning of the diagnosis? What are their feelings today?
    - How has this diagnosis changed your relationship with the father of this child?
    - If there are other children at home, how has this diagnosis impacted your relationship with them?
    - What differences have you noticed in the interactions between your children since this diagnosis?
    - Does your sick child interact differently with his/he father? Siblings? Grandparents? Other family members?

11. Tell me about your family’s coping strategies.
    - How well do you feel you are adjusting to your child’s chronic condition?
    - How are you adjusting as a family?
    - What do you personally do to cope?
    - What do you do to cope as a family unit?
    - How do you help your child to cope?
• Does your child help you cope? If so how?
• Do you use faith or spirituality as a means of coping? If so how?
• How does the hospital respect or disrespect your family’s means of coping?

12. Tell me about social support.
• Who supports you in your role as a mother with a chronically ill child?
• How do these sources assist you?
• Is there anyone who creates hardship for you in caring for your ill child? If so, how?
• Did the hospital staff assist you in developing a support system?
• How does the hospital staff seem to respond to your sources of social support? (Prompt: family member inclusion? Visits? What else?)

13. Tell me about your expectations.
• What do you expect from the professionals taking care of your child?
• What do you expect of yourself as the mother of a chronically ill child?
• What do you expect of the father of your chronically ill child?
• How have your expectations in your child’s father changed since diagnosis? Since hospitalization?
• How have your expectations for your healthy child(ren) changed?

14. Tell me your thoughts for the future.
• What are your hopes for your child’s future?
• Have your dreams for your child changed since diagnosis?
• How have your dreams for the future changed for your family as a whole?

15. Share with me any last thoughts.
• Is there anything else you would like to say?
• Do you have any questions for me?
• May I contact you in the future to see how things are going for you and your family?

Demographic Questions
(Note: Answers to these questions will be hand written by the Principle Investigator)

1. What religion does your family practice if any?

2. Are you currently working? How many hours per week? What do you do?
3. What is your household’s monthly income?

4. What is your current living situation? (Prompt: live alone, nuclear family, extended family)

5. Please tell me about any family members that live with you (Prompt: ages, occupations).

6. Please tell me about any family that lives near by (Prompt: ages, occupation, how often you see them, type of relationship)

7. Please tell me about your family’s medical history (Prompt: prevalent diseases, general health)
Hello. My name is Carrie. How are you today? I go to school in America and I came here to learn about you. I want to thank you for agreeing to be interviewed. I am interested in hearing about your experiences as a chronically ill child and how you understand your health care. I want to remind you that this interview is voluntary. You do not have to answer any question that you do not wish to. Remember you can stop the interview at any point and for any reason. All information that you share with me will be kept confidential and will not be shared with your mom or health care professionals. Do you have any questions for me? Let's begin.

Now let's talk about you.

1. Tell me about why you are here.
   • Do you know why you are in the hospital?
   • How did you feel when you first found out you were sick?
   • Have you changed since getting sick? If so, how?

2. Tell me about what your family does to be healthy.
   • What has your family taught you about being healthy?
   • What do you do to make you feel better? How does your family help you to be healthy?

3. Who takes care of you at home? (Prompt: who is the person that does the home care, hospital shifts, etc.)
   • Who makes you feel better when you're at home?
   • What do they do for you? Can you give me some examples?

4. Tell me about the workers here.
   • How do you feel that doctors, nurses and other people in the hospital help you? Can you give me some examples?
   • Do you feel like the doctors and nurses are nice to you? Why or why not?
   • Do you think the doctors and nurses listen to you?
• In what ways do you think the staff is most helpful to you? How do you think the staff could do better?

5. Tell me about how being sick has changed your family.
   • Does your family treat you differently now? How?
   • Do you feel closer to your family?
   • Do you feel closer to your mom? Your father?
   • What about your brothers or sisters? (Prompt: ask about each one)

6. Tell me how you deal with your feelings.
   • How do you make yourself feel better?
   • What do you do when you are scared? Lonely? Or in pain?
   • How does your mom help you with your feelings? How do your other family members help?
   • Do the doctors or nurses help you with your feelings?

7. Is there anything else you want to tell me?

8. Do you want ask me anything?
APPENDIX E: HOSPITAL LETTER

To Whom It May Concern:

Hello. My name is Carrie Cligrow. I am currently a student at Ohio University in the Midwestern United States. I am earning my masters degree in Child and Family Studies with an emphasis in Child Life. In addition to family development courses I have successfully completed the following courses directly pertaining to Child Life: Foundations and Theory in Child Life, Early Childhood Development, Middle Childhood, Professional Practices in Child Life, Children and Families in Health Care Settings and Health Communications and Culture.

For my thesis I wish to research the intersection of chronically ill pediatric patients, family health culture, and hospitalization because what happens within this context can have a life long impact. Children are socialized within their family’s health culture and no matter what beliefs and values shape this family system, a chronic diagnosis has huge implications. Whether or not these implications are positive or negative is greatly influenced by the interactions shared between families and health care professionals. I am specifically interested in looking at this dynamic in Bangalore, India because of the societal metamorphosis that is currently taking place. I am specifically interested in [ - ] Hospital because of the utilization of westernized health care and the child life program that is being implemented through the [ - ] Foundation. While the purpose of child life programs is to meet the psychosocial needs of pediatric patients and their families, these programs are structured in the framework of western cultures. This difference adds another dimension to the challenge of offering culturally sensitive care to Bangalore’s pediatric patients and their families.

I have been in contact with Ms. Priti Patel of The [ - ] Foundation about the program that she is starting in [ - ] Hospital. As a future child life specialist, I am extremely interested in this process and the experiences that current pediatric patients and their families are having while receiving health care in this setting. I am hoping to gain insights and first hand experience in your hospital through volunteer work and conducting interviews with five of your pediatric patients and their mothers. I have worked with individuals native of Bangalore who are currently residing in the United States and familiar with both health care systems to ensure the cultural sensitivity and relevancy of all research questions. These questions pertain to individual family health cultures, the impact of a chronic diagnosis on family relationships, and their over all perceptions of their health care experiences. I am more than willing to provide a more detailed overview of my thesis proposal and protocol if you would like.

By undertaking this study at [ - ] Hospital, I hope to gain an intimate understanding of how chronically ill, East Indian 6 to 12 year olds and their East Indian mothers perceive and understand their hospital experiences in the context of family culture. Therefore, the outcomes of this study could have tremendous influence on the lives of families as well as
health care professionals. The merging of Western and Eastern health practices that is currently occurring in India influences how families feel about and successfully negotiate their child’s care and path to well-being. For families, new insight on how to best negotiate their way through this multifaceted health system culture could be gained. Additionally, families may increase their understanding of how their child’s diagnosis is impacting each member of the family including the child themselves. For health care professionals, guidance could be offered on how to best interact with patients of various cultural backgrounds. As a result health care professionals may be able to prescribe treatments that work within the family’s culture, which would lead to increased compliance. Increased compliance may ultimately lead to greater patient satisfaction, which may result in a more rewarding experience for health care professionals. This study has great potential to not only illustrate the need for culturally sensitive health care, but to establish the framework on how to achieve it.

I will be in Bangalore from August 2 until September 1 and would be extremely grateful for the opportunity to volunteer with your staff members in serving chronically ill pediatric patients during that time. The opportunity to conduct my thesis research in your cutting edge facility would be the experience of a lifetime. Please let me know if you have any further questions that I can address. I truly appreciate your considerations of me for this opportunity.

Warm regards,

Carrie Cligrow

cmcligrow@gmail.com