THE PROCESS OF FAMILIES CREATING MEANING OF CHRONIC ILLNESS AND THE MEDICAL COMMUNITY

by

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Abstract

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The Process of Families Making Meaning of Chronic Illness and the Medical Community
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Families who have to cope with chronic illness or any other medical issue are often stressed beyond normal developmental stage compared to other families within that same developmental stage. Families who face medical issues may also be forced to accommodate other people and professions outside of their family (such as doctors, specialists, nurses and social services). Whether families acknowledge it or not, they incorporate their interactions with these “outside” people and assigns meaning to these interactions about how they view these “outside” people. There have been many models that address how families can build more positive relationships with the medical community (McDaniel, Hepworth, and Doherty, 1992; Roland, 1994). Other theoretical models address how to create a collaborative relationship between the medical community and other specialists (Seaburn, Lorenz, Gunn, Gawinski, and Mauksch, 1994;

Barnard and Alfuth, in press; Jacobs, 1993; McDaniel, Hepworth, and Doherty, 1992). However, these models have not yet demonstrated the impact of the medical community has in shaping families' meanings of their medical condition and their interactions with professional services and community supports.

The purpose of this study is to demonstrate how families process the meaning of the presenting medical issues as well as their interactions with the medical community. Joan Patterson and Ann Garwick (1994) published a theoretical model that demonstrated how families make meaning on multiple levels.

This study will focus on the adult caregivers within a defined family, such as the parents. The family must have at least one adult caregiver and one child that has a chronic illness. There will only be two families studied using a qualitative format of study. These families were selected based on the availability to the researcher and willingness to share their story with the researcher. The researcher has developed a questionnaire that contains questions of how the family makes their meaning of the chronic illness, medical community and other aspects of their life that contributes to their overall definition of their family.

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CHAPTER I

Introduction

Statement of the Problem

Families diagnosed with chronic illness have been observed and studied for more than thirty years in research journals and popular media. Prior to this time, efforts were made to understand mental illness such as schizophrenia as well as the complexities of dysfunction within these families. More recently the lens of family studies widened to include families that had chronic and acute physical illnesses rather than just mental illness; yet these chronic physically ill families were found to be in crisis and/or experiencing just as much stress as families with mental illness. Today, there has been a gradual shift to examine what is “working” for families that are coping with chronic illness and to examine their “strengths” even while they are experiencing these physical stressors. Instead of assuming an attitude that the “doctor (or professional) always knows best;” there is also a relatively new bend toward being “collaborative” with families from within the medical and mental health communities. Much remains to be done before we fully understand how families are affected by chronic illness, however, research has come a long way addressing these issues (Walsh, 1978; Falloon, Boyd, and McGill, 1984; Cole and Reiss, 1993; Rait et al., 1992; Pumariega, Pearson and Seilheimer, 1993; Wilson, Fosson, Kanga, and D’Angelo, 1996; Steele, Forehand and Armistead, 1997; Holden, Chmielewski, Nelson, Kager, and Foltz, 1997; Schilson, Braun, and Hudson, 1993; Medalie and Cole-Kelly, 1993; Mauksch and Leahy, 1993; Garwick and Millar, 1996).

Families who have to cope with chronic illness or any other medical issue are often stressed beyond normal developmental stage compared to other families within that same developmental stage. Families who face medical issues may also be forced to accommodate other people and professions outside of their family (such as doctors, specialists, nurses and social services). Whether families acknowledge it or not, they incorporate their interactions with these “outside” people and assigns meaning to these interactions about how they view these “outside” people. There have been many models that address how families can build more positive relationships with the medical community (McDaniel, Hepworth, and Doherty, 1992; Roland, 1994). Other theoretical models address how to create a collaborative relationship between the medical community and other specialists (Seaburn, Lorenz, Gunn, Gawinski, and Mauksch, 1994; Barnard and Alfuth, in press; Jacobs, 1993; McDaniel, Hepworth, and Doherty, 1992). However, these models have not yet demonstrated the impact of the medical community has in shaping families’ meanings of their medical condition and their interactions with professional services and community supports.

There have been hundreds of studies that have looked at chronic illness and family dynamics. The following citations represent only a small percent of research in the arena of chronic illness and the family: Gonzalez, Steinglass and Reiss, 1989; Drotar, 1997; Hamlett, Pellegrini, and Katz, 1992; Lafaille and Lebeer, 1991; Daniels, Moos, Billings, and Miller, 1987; Derouin and Jessee, 1996; McDaniel, Hepworth, and Doherty, 1992; McDaniel, Hepworth, and Doherty, 1993; Litchfield, 1993; Cole and Reiss, 1993;

McCubbin, Thompson, Thompson, and Former, 1998; and Rolland, 1994. Most of these and other studies conclude that there both needs to be more longitudinal data and qualitative components to the literature. These more in-depth studies either have shown whether or how chronic illness does affect the family dynamics and how families, in turn, respond to treatment. However, what is not obvious is how families incorporate or create meanings from these changes in their lives. How do they make sense of the illness in the context of their lives? Does the meaning and significance of illness prescribed for families; or is it something that they construct? Because this idea of making or creating meaning is an abstract concept, can families actually be conscious of that process by giving situations meaning that can change them internally as well as change what is occurring outside of the family? Furthermore, how can researchers ask the "right" questions about what seems ambiguous for families as they attempt to make sense of their illness? Thus, how families make sense of chronic illness and their interactions with the medical community is what this research paper will investigate.

Purpose of the Study

This paper will continue the efforts and suggestions of many research papers that indicate there is either none or not enough longitudinal, qualitative research to show how families do indeed incorporate various meanings from chronic illness and their experiences of the medical community into the process of recovery (Patterson and Garwick, 1994; Drotar, 1997; Hamlett, Pellegrini, and Katz, 1992; Lafaille and Lebeer, 1991; Rait et al.,1992; Derouin and Jessee, 1996; Pumariega, Pearson and Seilheimer, 1993; Holden, Chmielewski, Nelson, Kager, and Foltz , 1997). The purpose of this study is to demonstrate how families create meanings of the presenting chronic illness as well as their interactions with the supporting medical community. One could argue that families continue to create new meanings or change their current meanings due to occurrence of chronic illness and to interacting with the medical community (Wambolt and Wolin, 1989; Steele, Forehand, and Armistead, 1997; Holden, Chmielewski, Nelson, Kager, and Foltz , 1997; Lafaille and Lebeer, 1991; Wambolt and Reiss, 1989; and Rait et al., 1992). However, there needs to be corroborative research in that area to describe such happenings, to document the results and to create family theoretical models of functioning according to the demands that accompany different illnesses.

The phrase “create meanings” is hard to define, demonstrate or observe is because most people take it for granted since human beings process information and interactions every moment of their life. Thus, when a significant change occurs, this change is not necessarily a monumental moment, but rather a daily process. It is only when one steps back from their process and acknowledges that change has occurred within themselves as an individual and/or as a family that any attention is given to the “new” meaning. An example of change, a family that has been coping with a chronic illness for a long time, and now will reflect on how it has changed their interactions with other people, such as ability to go on family summer vacations or to live a long “productive” life. Another reason for the awkwardness of “meaning” is semantics of using that word to define a process. For the purposes of this discussion, this researcher will use the phrase “creating meaning” or “making sense of . . .” instead of using the term “making meaning.” In order to describe families creating meaning, this researcher will introduce concepts that help describe family functioning.

Some basic concepts, in the context of chronic illness, will be introduced here. These concepts are not necessarily the only areas families use to make sense of their lives, but rather these are the areas in which this researcher wanted to focus their attention. This researcher is using *systems theory* to explain how families as groups construct meanings. Each family member has a role in the family's functioning and thus a role in the family's ability to create meaning in regards to a situation or person. Both inside and outside forces may influence the family and their reactions/interactions to a given situation because family members are each connected to one another. The context in which the family has these reactions/interactions can be defined as the reality where this family exists. Thus, not only do they exist in this reality, but they also influence or co-create this reality which they inhabit or believe to be true. *Stress* is another concept that families with chronic illness face every day that is different from any other dynamic. The level of stress and the multiple stressors that these families can cope with on a given day would seem unbearable to other families. The stressors may include juggling the family schedule to fit all of the doctor's appointments to having in-home health care coming in on a daily basis. The concept of *loss* is very poignant for families with chronic illness. The degree of loss varies with each given situation. An example could involve for one family realizing that the affected family member may always be dependent on assisted housing or always need to be medicine-dependent for the rest of their life.

Families with chronic illness have many *strengths* that they always had before the diagnosis or have since developed. One strength that families with chronic illness need to develop is *adaptability* to new situations and stress in their lives. Another strength is the sense of *coherence* that the family may gain from relying on each other in time of change. Families with chronic illness also learn to *cope* well in order to function well with life's challenges. A type of strength that can give much meaning to families with chronic illness is the use of rituals. *Rituals* can further the bonding of family members and help create special meanings. *Resiliency* is yet another concept that describes a family's ability to "bounce back" from adversity rather than just cope with adversity. The last area of research for this discussion is the role of the medical community within the context of how families with chronic illness are affected by them. However, this is a collaborative relationship, all players have a stake in creating a good relationship that keeps the chronically ill family member's care in mind. Thus, families and medical staff need to be a team. All of these concepts have a role in how these families make sense of the world around them.

The following review of literature will discuss these concepts in greater depth and will demonstrate how they directly relate to the idea of families creating meaning within the context of chronic illness and the interactions with the medical community. The definition of terms contains concepts that are directly related to this research study and defined in a basic manner.

Definition of Terms

Create Meaning	This term is used to describe persons whom need to make sense of their lives, roles, beliefs, identity; in general and in this study, of their illness and their interactions with supporting medical staff. This process is accomplished by assimilating outside and inside feedback from the world around them. This process becomes more complicated when meanings are made within a family or multiple person contextual situations.
Chronic Illness	This term defines an illness that has a diagnosis and a prognosis for continual medical care that can be in remission, can lessen or can worsen in time. Rarely is there a cure for the illness, but rather has a “come and go” affect on the person and family.
Acute Illness	This term delineates the severity of illnesses that this research study is focusing. Illnesses with any severity can affect the family and their functioning. However, acute illnesses tend not to have the enormous impact that chronic illnesses have on the family. Thus colds, influenza, and other typical viral and/or bacterial infections do not have the long-term, lasting affects on a family as compared to chronic illnesses. With this in mind, acute illnesses could develop into chronic illnesses, which then would affect the family greatly.
Medical Community	This is a community of people that primarily delivers health care within the United States. These people include physicians, surgeons, nurses, medical assistants, lab technicians, and medical support staff. For the purposes of this paper, this term also includes medical social workers and any other mental health provider such as family medical therapists.

CHAPTER II

Review of the Literature

At this point in time of the literature review, this researcher could not find a research project or paper that discussed this topic with the same approach that looked directly at how families create meanings with chronic illness and their medical community. There are studies that take a more generic approach to understanding how families construct meanings to make sense of what occurs to them (Patterson and Garwick, 1994). However, there does not appear to be an empirical study or qualitative study that addresses the specific issue of how families create meaning from chronic illness and the interactions with their medical community. This researcher is going to draw from many other areas of research to bring together one idea of how this can happen and why this area needs to be researched. This discussion has set up a modest framework of concepts that are already used in family research studies that lend themselves well to the understanding of how families construct meanings. The concepts are not new or original, however combining them in this way with the focus on chronic illness and the role of the medical community is unique. This study is not a replication of any study, but is “borrowing” the concepts of interest to eliminate redefining these terms since they have been already defined, researched, and proven within the family studies field. These concepts have been arbitrarily chosen to be part of this study only because these concepts seemed to be the most useful for this researcher to examine. These concepts are not an exhaustive list and should be added to in future research. This researcher is just building upon what has already been studied thus there is always room for more research, a new way to look at “old” concepts, and to develop a better way to understand family functioning in general.

This literature review will discuss many concepts of family functioning and how these concepts contribute to the family’s making sense of the meaning of their illness. These concepts are theoretical in nature and have been objectively defined by other family social researchers. The concepts will be applied to the underlying dynamic of how families create their meanings. These concepts include family reality, family stress, family loss, family strengths – focusing on family adaptability, family coherence, family coping, family rituals; family resiliency, the role of the medical community, and how families create meaning from these concepts. These concepts are the context and the areas where change and meanings are made for families; however, the discussion will begin by focusing on the importance of using the family as the focal point of research and not the individual person.

One could argue that change happens at the individual person first, before it affects others around them. Lafaille and Lebeer (1991) cited Robert Assagioli’s idea of “Self” and “I” to address this concept. Assagioli writes that the “I” is considered to be the personality that yourself and others recognize as who one is as a person. This is how one acts and reacts to situations and experiences. The “Self” is considered to be the core of everyone and encompasses beliefs, values, and subjective ideas of spirituality; with meaningfulness and connection of all of these things. Though these ideas of the individual person ("I") are important, there are few people that live in a solitary situation that never interact with others in some context. Family interaction exists on the most basic level: "Self". Thus the individual "Self" affects and is affected by other relationships, mainly familial. These interactions can be defined by the most basic tenant of systems theory, the whole is greater that the sum of its parts. "Everything that happens to any family member is seen as having an impact on everyone else in the family. This is because family members are interconnected and operate as a group, or system" (Olson and DeFrain, 1994). Thus when another force, or stress is added, the familial "system" must chose to adapt to that stress unconsciously or consciously.

Because outside forces affect families as much as inside forces within the family, change occurs which compels the family to adapt to those changes. How much change is allowed depends on the family. This is especially true if this stressor was to be a child, within a family system, diagnosed with a chronic illness. These concepts also come from systems theory. Families try to maintain a level of homeostasis, or functional balance. This homeostasis is challenged when there are too many forces or stressors that demand the family re-adjust. This force or stressor can come from outside the family; such as the medical community; or inside the family; such as a parent's observations. The family will try to achieve its former homeostasis (i.e., by "going back to the way things were"), however a change will need to occur and thus a "new" homeostasis will be achieved. This is the point of change within this process. It is here that families can "look back in time" and comprehend how much they have changed and it is at that point when families can make sense of their new meaning (Olson and DeFrain, 1994).

Families have to adapt to changing patterns, expectations, roles, beliefs, etc. to cope with the chronic illness. These changes that the family goes through are how and where the family make their meaning. These areas of making meaning will be discussed further in detail and the possible impact they have on the family.

Family Reality

Families exist not within a vacuum of functioning, but within a context, for example neighborhoods, communities and society. The definition of reality could be stated as the interpretation of what one holds, exists, and functions as truth. However, families interact with outside and inside people that shape and change or at least challenge that “truth” almost on a daily basis. Lafaille and Lebeer (1991) describe “frame of reference” as a part of reality that directly influences one’s reality. The frame of reference is where one gathers data that shapes one’s reality. “The more conscious one is of one’s frame of reference, the better and the more alert one is to the tentative connection between the frames of reference and reality” (p.19). Thus reality is much more than truth, but also identity, views, beliefs, etc., about the inside and outside worlds.

The reality becomes much more complicated when more people become co-creators and co-existers in that reality. This becomes even more complicated when each family member interacts with different people within different contexts at any given point in time that influences the family reality. Thus, when discussing the concept of reality, one must keep in mind its multiple dimensions. Family theorists, Reiss and Steinglass in some of their published works (Reiss, Steinglass, and Howe, 1993; Gonzalez, Steinglass, and Reiss, 1989; Wambolt and Reiss, 1989.) discuss the idea that families create identities and it is through these identities (or realities) that they cope, function, and view the given situation, especially in regards to chronic illness. They define family paradigm as the covert family agreement on the internal workings of the family, such as the structure, decision-making, emotional demonstration, and the level of closeness. Family identity is how the family views and shows themselves to the outside world. This could demonstrate the medical community's influence on the family's functioning, such as compliance or noncompliance with a set of instructions. Thus family reality is a twofold concept: (a) how the family understand themselves in regards to their inside world and (b) how the family understands the outside world as well as the outside world having influence on the family.

The concept of reality becomes more complex when families are faced with chronic illness as compared to acute illnesses or "normal functioning families. They are influenced by what the outside and inside world is telling them to think, to act, to belief and to feel not only about themselves as a family, but also about the chronic illness. Part of the change process is how the family was functioning before the diagnosis of the chronic illness and the other part of the change process is how the family is going to adapt to the chronic illness in the future. This change process adds more stress into the family dynamics.

Family Stress

A definition of stress is any positive or negative change or reaction within a functioning system. Stressors are the actual external events that can cause an emotional and/or physical reaction. The idea for families to avoid stress is nearly impossible since stress can occur on any level of functioning such as physical, mental, familial, relational, or societal. As with many other areas of functioning, stress does not happen in a linear fashion or usually occurs one at a time. Stress is also a multi-dimension, layered concept that affects each person within a system differently. Stress is a result of causing and/or demanding change when the family system can no longer function where it has been in the past. This is most likely to occur when one too many stresses "pile-up" to cause a "crisis" that forces the family system to move or change its functioning to adapt or cope with the "new" reality (Olson and DeFrain, 1994, p. 460-469). Thus "many of the serious stressors in life are collective stressors," and the family can consciously or unconsciously choose how to cope with each of these stressors (Antonovsky, 1998, p.17). The issue is not whether the family will be able to avoid stress, but how to cope with it and adapt to the change stress brings them.

Another aspect of stress is the amount of stress a family can endure. Not all families that have a family member with a chronic illness are doomed to difficulty and hardship automatically. The issue of how the family was functioning before the diagnosis of a chronic illness was assessed and how the diagnosis affects the family's healthy functioning. Thus, the idea is not that the chronic illness or medical condition "caused" this family crisis, but rather one more stressor was too much for the family system to keep its homeostasis. "Indeed, severe and chronic illness acts like a magnifying glass for families. Everything is exaggerated is seen in bold relief, in high intensity, so that those issues that families are dealing with in the normal developmental process can become amplified and distorted. Ordinary life transitions become overwhelming obstacles in a family, already carrying a heavy burden of illness" (McDaniel, Hepworth and Doherty, 1993). Thus for families that have a chronic illness to be able to achieve homeostasis is not only important, but vital for them to survive the continual stress of the chronic illness.

Family Loss

Families that experience many stressors at any given point in time need to adjust to be able to cope effectively with the new stressors. Because of these adjustments, families may feel a sense of loss due to the fact that things will never be the same within the family again. This sense of loss is also complex and tends to be a multi-layered concept. Thus, when a family member is diagnosed with a having chronic illness, the family must change to the demands of the new information, as well as the demands in the future.

> Loss is a powerful nodal experience that shakes the foundation of family life and leaves no member unaffected. It is more than a discrete event; from a systemic point of view, it can be seen to involve many processes over time . . . The meaning of a particular loss event and responses to it are shaped by family belief systems, which in turn are altered by all loss experiences. Loss also modifies the family structure, often requiring major reorganization of the family system (Walsh, 2000, p. 178).

This quote from Froma Walsh states this complex concept of family loss succinctly. When loss happens to a family, all members react to it even if they “pretend” they are not reacting, as that in of itself that is reacting to the loss. Loss can force a family together to cope with the stressor or it may force them apart if there is a divergence in the family’s identity in how to cope with the stressor. For example, a family could make a decision to have the affected member go through a risky procedure that may or may not enhance the life of the affected member, at the cost of the affected member’s life. If the family is united in their decision, then the family could rely on each other for support. If the family has divergence of opinions, the decision will be at a greater cost to family’s ability to function and cope together (Patterson and Garwick, 1994). The issue here is how families respond to loss and how they react to it.

Family Strengths

"Strengths" is a current buzzword in family social studies. Lately, strengths have been the focus in family research studies. Strengths are also a key point for family therapists to focus on as well. Strengths of the family help the family to cope with adversity. Strengths can be seen as physical abilities, such as family members helping more within the family, or emotional abilities, such as a family surviving a trauma that has made them stronger as a family. Some other strengths that this discussion focuses on are **adaptation**, **sense of coherence**, **coping** and the use of **rituals** in looking at chronic illness within a family.

Family Adaptability. Adapting to life's challenges and changes are the most important abilities that a family needs to be able to function within its context. Adaptability is the ability for the family to be flexible enough to adjust to inside or outside demands of change, to cope effectively with the stressors/stress and situations as well as to move through transitions that one may or may not expect (Walsh, 1993). Another way of examining this concept is the family's ability to restructure their orientation or view of their inside and/or outside world (Patterson and Garwick, 1994). Thus when a stressor such as chronic illness comes upon a family, some families have a tough time of adapting to all the demands that this new stressor puts upon the family. This dynamic multiplies and becomes more complicated if the family did not have many strengths in the beginning. Stressor overload or the inability for the family to adapt to the changes is when crisis becomes apparent. The reality of families with chronic illness is that the stressor of chronic illness will never go away unless that type of chronic illness has a cure. Thus the family's ability to adapt to the chronic illness will be a life long process and possibly affect the family even after death.

Family Coherence. "Sense of coherence" is a term used to look at people and their ability to function in life. Aaron Antonovsky (1998) began this discussion of how a person views the world, made sense of the stimuli that interacts with each person constantly, and how one organizes their resources to cope with all these situations in a meaningful way. Sense of coherence is the term Antonovsky developed to describe this phenomena. Thus coherence envelops three areas: manageability, meaningfulness, and comprehensibility. "Manageability involves the extent to which one perceives that the resources at one's disposal are adequate to meet the demands imposed. Meaningfulness refers to the extent to which one feels that life makes sense emotionally . . . Comprehensibility refers to the extent to which one perceives stimuli as making cognitive sense” (Brooks, 1998, p.229). If a family’s sense of coherence is functioning at such a low level that the family is barely able to handle what is happening in the present, imagine what one more new stress would do to an already fragile functioning system. Thus a more developed sense of coherence will lead to a better ability to adapt to a changing inside and outside world.

Coherence also has another connotation in reference to family functioning. David Olson (1993) defined family cohesion as “the emotional bonding that family members have toward one another” (p. 105). This is how the family feels close or distant to each other. A family may be physically together and yet still feel emotionally distant from each other and live like strangers. Thus, how the family functions, how they take in stimuli that surrounds them, and how close they feel to each other plays a major role in how the family is able to cope.

Family Coping. Coping skills are important for families. Just like with stress, coping can be both positive and negative in how the family approaches the situation. Family coping often demands both cognitive and behavioral aspects of each family member and the family as a whole. Thus, a family may adjust their “coping strategy that functioned to alter meanings so as to make a situation manageable” (Patterson and Garwick, 1994). Coping is the nuts and bolts of how the family reacts to a given stressor. Chronic illness can be a stressor that makes demands upon a family to adjust to change constantly. In this situation, the family’s resiliency or endurance becomes a factor in how the family will cope with the stress(ors).

Another important aspect of coping with chronic illness is how the family incorporates the role of chronic illness into their family. Gonzalez, Steinglass and Reiss (1989) coined the phrase “putting the illness in its place”, meaning to what degree does the family allow the chronic illness to dictate to the family how the family should function. Chronic illness is a type of stressor that can change over time. After the initial reorganization around the diagnosis of the chronic illness, reality is then changed by the realization that this illness may affect the family forever. It is unlikely that the chronic illness will demand the family to organize itself around it in the same way as was necessary. The family must adapt to the daily demands of the chronic illness, as well as organizing itself around normal transitions that all families go through, such as birth of a new family member, children going to school, employment changes. These “normal” transitions can also cause stress upon the family. The family has to put energy in not only coping with normal demands, but also specialized demands of chronic illness. “A process unfolds in many chronic-illness families in which family life is increasingly organized around illness-generated needs and demands, to the detriment of family coherence and the normative developmental needs of individual family members and the family as a unit. This process, perhaps best described as an accommodation of the family to the illness, has as its ultimate consequences as suppression of non-illness family priorities and a neglect of normative family developmental issues due to the focus on illness-generated exigencies” (Gonzalez, Steinglass and Reiss, 1989). There must be a balance in which the family focuses on the family member with the chronic illness (and the chronic illness, itself) as well as also “normal” family functioning; such as care for the other children, private time for the parents of the family, and other functions that families without a chronic illness may take for granted.

Family Rituals. The anthropology field has studied family rituals for many years. It has been only in the last decade that family social researchers have looked at the usefulness and the role of rituals in keeping families together and healthy functioning. Rituals can be used as a protective factor as the "glue" or as a "buffer" during the times of stress and change, especially if that change or situation is too difficult for the family to cope with at that time. A family ritual can be defined as "a symbolic form of communication that, owing to the satisfaction that family members experience through its repetition, is acted out in a systematic fashion over time. Through their special meaning and their repetitive nature, rituals contribute significantly to the establishment and preservation of a family's collective sense of itself, which we have termed the 'family identity'" (Wolin and Bennett, 1984).

Rituals give families a sense of belonging within the familial system. Rituals do not have to be complicated or time consuming, but rather a repeated behavior that has meaning within it by all who participate. Something as simple as reading books at bedtime to something complex, such as holiday celebrations with extended family members. However, if families are not able to adapt and change their rituals to "fit" for the family due to developmental changes then the "stuck" rituals can be pathologizing than helpful. An example would be if Grandma always had Christmas celebration at her house, but since her death no one in the family has celebrated Christmas at their house and recreated the ritual to "fit" the need of the family in this present situation. Thus the family is "stuck" in what to do next or until someone begins to recreate the ritual again.

Families need to be able to adapt in order to keep things balanced and to reduce the stress that the change brings upon them. The important aspect of rituals is the meaning that is associated with the ritual and how the family gains their identity from the ritual.

Family Resiliency

Resiliency is where families have their strengths, sense of coherence, ability to adapt and their ability to cope. This is the family's ability to carry on even when multiple stressors are affecting the family at once. "Resiliency can be defined as the capacity to rebound from adversity strengthened and more resourceful. It is an active process endurance, self-righting, and growth in response to crisis and challenge . . . Resilience entails more than merely surviving, getting through, or escaping a harrowing ordeal . . . the qualities of resilience enable people to heal from painful wounds, take charge of their lives, and go on to live fully and love well" (Walsh, 2000, p.4). Thus resiliency is more than strengths, abilities, coping skills, etc., but rather how the family uses these mechanisms to help them function through life. Another part of resiliency is how the family utilizes outside resources. The medical community will play a major role for a family with a chronically ill family member, especially if that member needs constant monitoring by a physician.

Family and the Medical Community

The history of medical science has been to diagnosis what is wrong with a patient and to find a medical procedure to cure the patient. However, as medical technology has become more advanced, medical science is saving more and more medically fragile patients that would not have survived even twenty years ago. The complexities of using medical technology is not the focus of this discussion, but rather the idea that by using this technology as a society we are creating more advanced issues for families. "Medical science has been concerned mostly with uncovering the physical elements that go wrong when the body becomes ill, with the aim of correcting them . . . But this does not always work, and today modern medicine, faced with many disorders that it cannot resolve, is often touched by a feeling of powerlessness" (Lafaille and Leber, 1991). The focus of this study is not to discuss the repercussions of using medical technology to save a family member's life. Most people would agree that that decision would one of the hardest decisions to make, affecting the entire family. However, since we are using medical technology to keep more "fragile" people alive, then the issue concerns how families work with outside resources and how the outside resources work with families.

As stated before, there are models that describe the relationship between the medical community and families with a chronic illness. After the initial diagnosis of the chronic illness and the possible future implications for the family, the role of the medical community can be as varied with each chronic illness. For some families the chronic illness, such as asthma or diabetes, can be managed through lifestyle changes and regular follow-ups with a family physician. For other families the chronic illness can be more demanding on the functioning of the family and use many medical resources, for example cystic fibrosis or multiple illnesses at once – blindness, mental retardation, and hydrocephalus. These examples are just the physical manifestations of the chronic illness; however, there are also the developmental, emotional, and mental manifestations as well. Typically, the more physically severe the chronic illness manifests itself, the more likely other areas of functioning are to be as affected. Thus for a time of diagnosis, "time is of the essence" to prevent any further damage or to reverse any possible affects of the chronic illness. This reversal may be in the form of medical information and education about the chronic illness and how to treat it at home, (i.e., home insulin testing). Sometimes the medical community may need to be included in more intensive action, such as using a ventilator for the child to breathe, or recommending home services be put in place for the family member. If the medical community and families are on the same collaborative team the best care can be given and received for each family member. Thus, how the family views the medical community is essential to a good relationship and visa versa. Both sides are asking themselves, "are these people going to be helpful when we need them or are they going to be resistant to what we ask?" Each interaction with the other shapes how each view and reacts to the other, thereby creating meaning for the relationship, their view of each other, and their responses to each other.

Families Creating Meaning

The process for a family to create meaning is complex To create meaning incorporates all of these concepts of human functioning. This process usually occurs on an unconscious level and mostly within a minimal amount of time is used for this process. One decision or situation can create lasting impact to the family’s system, story, views and ideas about the given situation. The interactions that families are a part of can ultimately shape and mold them into something different from one moment the next. However, not all interactions can shift the family system dramatically or be felt by all members, but yet it has changed the internal interactions within the family system. Attitudes about illness and the medical community may not be explicitly discussed within the family; however, there may be family discussions about health. An example of this, would be a father who never got sick or ill, so when a heart attack happened to him either he could deny that it was serious or view this as a “wake up” call and change many things about himself. Both of these decisions affect not only him, but also the whole family.

To define “meanings” and how families “create meanings” is an elusive process, but one that is within the grasp of the stress theorists. For example, Joan Patterson and Ann Garwick (1994) published a theoretical model that demonstrated how families make or create meaning on multiple levels of family functioning in regards to chronic illness. Level one is defined as the understanding of a situational event that affects the present situation or the outlook of the family. This level is also affected by the families’ collective internal or external locus of control, which may affect the given situation even further. Level two, according to the authors, is defined as the family’s identity in regard to the illness. Some of the aspects of life that can be affected are the family’s structure, roles, rules, routines, and sense of purpose that the family collectively shares. This is also the level where the family wants to find and/or maintain balance in any given situation or circumstance, for example newly diagnosed chronic illness or a new regimen of care. Level three is the family’s worldview that includes expectations, goals, and the orientation to “outside” and “inside” of the family. This level is where the medical community and other “outside professional” services interact with chronically ill families. These levels of meaning begin the discovery of the process of how families do make or create meaning in their lives. The authors defined family meanings as “the interpretations, images, and views that have been collectively constructed by family members as they interact with each other; as they share time, space, and life experience; and as they talk with each other and dialogue about these experiences” (p.288). The authors theoretically demonstrate that family meanings exist on various levels and they create a theoretical model of how this process takes place. However, what they didn’t examine is their theoretical model working with actual families demonstrating the process. They did use antidotal demonstration of their theory, but families demonstrating the model was not discussed at length in their paper. In fact, they concluded that more qualitative research needed to be done with their model and theory. This study will try to show how families demonstrate this process with the context of chronic illness and the medical community.

The role of chronic illness and the medical community are just contexts for the family to make meaning from those interactions with itself. There is nothing unique about chronic illness and the medical community in the theoretical sense as anything can be a part of the process of creating meaning. However, there are unique dynamics of how families create meaning with chronic illness, and with the medical community being the context the family uses to create their meaning. There is also the aspect that each family is going to create its own unique meaning since each family is unique, even if families deal with similar issues. Froma Walsh states this dynamic nicely by writing, “it is not family *form*, but rather family *processes*, that matter most for healthy functioning and resilience" (2000, p. 16). Thus one could infer that it is not the actual stressor that affects the family that ultimately the family creates its meaning, but from the actual process that the family goes through to create its meaning.

All of these areas of family functioning contribute to the process of how families create meanings in their lives. Hamlett, Pellegrini, and Katz (1992) stress the importance of all these concepts having a role within family functioning.

> The quality of relationships within the family appears to exert an important effect on the management of the illness and the psychological outcome of the child [or family member]. The unique characteristics and strengths of the family are likely to strongly influence the child's and family's appraisal of the stressors associated with the illness and, as a result, shape the coping response of the child and family. The competencies and resiliency of a family may serve as a protective factor, defending the child from the disruptions and crises attendant to chronic illness (p.35).

In conclusion to this literature review, all the studies that have been quoted thus far have in their own unique way have said that families have created meaning, but yet not expressly so. This research paper will explicitly ask families how did you create meanings in this area of chronic illness and the medical community. This researcher has been unable to find either a quantitative or a qualitative study that has examined the question of how families create meaning from chronic illness and the role of the medical community. The purpose of this study embodies more than just the research questions, but rather tries to define the actual process of families creating meaning. The concepts that were used to give the discussion perimeters of examination; were chosen for their usefulness in depicting family functioning. This allows room for other concepts to be added to later expanded idea of how families create meanings. The concepts covered were family reality, family stress, family loss, family strengths – focusing on family adaptability, family coherence, family coping, family rituals; family resiliency, role of medical community, and how families create meaning from these concepts. These concepts have already been researched thoroughly and their usefulness to describe family functioning, especially families with chronic illness. These concepts were then used to create a questionnaire (Appendix A) that asked families for their process in how they created their meanings from the chronic illness and the medical community.

This research study has taken concepts that have been thoroughly researched and applied to family functioning in the areas of research and therapy. There have been theoretical models of family functioning and explanation of “why” families function the way they do, such as Circumplex Model (Olson, Russell and Sprenkle, 1989), FAAR Model (Patterson and Garwick, 1994), and several models of John Rolland that describe the interface of family functioning and chronic illness (Rolland, 1994, p. 13, 43, 54, and 57). The underlying purpose of this study was to put theory into practice and to demonstrate if the families actually do “create meanings” from their experiences of chronic illness and from the medical community. This is not to reinvent theories or models of family functioning, but in response to the “triple threat” quoted by David H. Olson, it is a good theoretical idea needs to encompass “theory, research and practice”. If theories do not make sense to the intended audience of family therapists and families then what is the purpose of research studies. This researcher’s desire is to add not only new application of ideas to the theoretical body of research, but also have it be beneficial to people and for them to make practical use of it.

CHAPTER III

Methodology

This research study construction is very basic. The research study was not designed to be either purely theoretical or quantitative. It is a pilot qualitative study using a very small sample.

Structure of Data Gathering

This research study used the qualitative method for the structure of the study and to analyze the obtained data. The qualitative method allows this researcher to ask questions that are more in-depth without a set of answers that are already prepared such as a Likhert scale or “yes or no”. The qualitative method also gives the researcher more freedom by not creating a set of fixed item responses for the participants. The participants are allowed to say anything without the bias of the researcher’s preconceived ideas.

Since the focus of the paper is to understand how families create meaning, this paper will be using a narrative method and theory for its basis. A narrative method views family members as being authors of their own life who give or find meaning in their life by the kind of story they relay of their life. The idea of “storying the experience” is how people track the sequences of their lives. Thus both past, present and future experiences shape the person's story and how they relate their story to other people. These experiences can be both positive and negative as well as occurring inside and outside of the family. "Not only do the stories that persons have about their lives determine the meaning that they ascribe to experience, but these stories also determine which aspect of lived experience are selected out for the ascription of meaning" (White and Epstein, 1990). Narrative method naturally accentuates the meaning people give to their life experiences. This method is a good "fit" for obtaining answers to the questions in order to discover how families create meaning.

Another reason to use narrative method is the idea of "re-storying." One of the goals in using narrative method in a therapeutic sense is to help clients depathologize their experiences by re-storying or giving the experience a different meaning. The same story will evolve into a more healthy way of understanding the same situation by using different words. Most families can't do this on their own without the help of an outside perspective to encourage the family to give a different meaning to the same story (White and Epstein, 1990). An example of this would be for a family to view in-home respite care as a time to rest from the demands of a chronically ill child with multiple disabilities, instead of viewing in-home care as an invasion of their family's privacy. The family may re-story this experience either with someone outside of the family, like a family therapist, or by their own realization that they cannot care for their child alone without outside support.

Lafaille and Lebeer (1991) add to the idea of "storying" by stating that when an experience or story is told by families, the actual telling of the story creates a new experience of the story, which may influence the family to change the story and give it new meaning. Thereby the family gains both “objective and subjective data” through the story to yield in-depth meaning of the experience.

This researcher’s role has been to act as an observer of the families interviewed. However, she will also look for ways in which these families have “re-storied” their experiences as well as their roles, beliefs and meanings as they have moved through the developmental stages of the life cycle and stages of the illness. This researcher did not take an interactive role during the interview other than to ask questions, ask clarification and possibly to process new meanings if they were discovered.

Participants

The participants that were chosen for this research study had at least one adult caregiver and one child member with any kind of chronic illness. There were two families (n=2) that volunteered to be part of the study with one family in mind if one of the other families chose either not to participate further or could not do it for whatever reason. The “extra” family was not needed for this study. The member with the chronic illness was a child of the family not limited in age.

Families were recruited by word of mouth from among a population who were friends, family members or neighbors of fellow colleagues at a family physician clinic in the Minneapolis/St Paul metropolitan area in Minnesota. These subjects were gathered in this manner for two reasons. One reason was for the ease of the researcher since the researcher did not personally know of families who would fit the parameters that were set. The second reason was to avoid going through a hospital human subjects review since that process would delay the research project for a considerable amount of time. In this case, all participants have been protected through the human subjects review through University of Wisconsin - Stout College system (Appendix B for sample of consent form).

Instruments

The researcher developed a questionnaire that tried to capture how the family created meaning of chronic illness, medical community and other aspects of their life that contributed to their overall meaning of their family. All of the questions asked were open-ended, interview questions that elicited the families' stories of how the process happened versus short, quick "yes" and "no" answers or a rating. Another way that the families' stories were elicited was using the circular technique developed by Milan Family Center from Milan, Italy. Circular questioning, when used, helped to further the understanding of the underlying patterns and feedback loops within the family's meanings and/or their story. This researcher also used circular questioning to elicit what one family member thought or viewed about what other family member's relationships were like in the family. Thus, they became a co-observer with the researcher (Selvini, Boscoio, Cocchin, and Pratz, 1980). Using circular questioning allowed the researcher and the participants to learn a different perspective of creating meaning for the family. By having one member speak for the other member may give insight into how family member's "really" feel or view chronic illness and the medical community.

The questionnaire kept the chronic illness and the medical community a “step removed” from the families and the researcher. The questions also gave families the ability to be an observer in how chronic illness and the role of the medical community affected the family. The answers that the families relayed are how they created meaning from these experiences. Narrative theory describes this ability as “externalizing themselves and the relationship to the problem” (White and Epstein, 1990, p. 39). This ability to externalize the situation is not used to be “disconnected” from the experience, but to gain a new perspective on the situation and possibly create a new meaning or story.

Although narrative theory was the primary theory, other theories were used to gain insight into the families’ process as well as in the development of the questionnaire. Structural theory primarily focused on organizational patterns within the family. These questions focused on roles, rules, expectations, structure of the family, and other pragmatic issues. Another theory used was the behavioral theory, which focuses on the family’s ability to communicate both inside and outside of the family. Questions that used this orientation ask how the family interacts with other systems.

Procedures

The procedure for this research study was inspired from a master’s thesis authored by Merian Campbell Litchfield for the completion of her program. This researcher based her research paradigm from the three methodology levels of research examination: meetings scheduled to explore the evolving health story of each family, to discover the family’s ability to make sense of the chronic illness and the role of the medical community through the use of their narrative, and lastly to use reflection and introspection of any meaning derived of being a participant of the study (Litchfield, 1993). This researcher felt that this research paradigm made the most sense in the collection the family's health story as well as empowering the families to be willing participants in this study.

This procedure was set up by the researcher ahead of time before contacting the participants, however, the participating families needed more flexibility. Therefore, the researcher allowed the families to be part of the decision-making process of how the research study would be conducted.

This study was conducted in the participant's homes with the agreement that interview meeting was fully dedicated to this study. The adult participants were given the choice to conduct the interview in one meeting or in numerous meetings, whatever was convenient with their schedules. Both of these families chose to do the interview in one meeting due to time constraints with their lives. The meeting was audiotape recorded, transcribed and later to be analyzed by the researcher. The participants also agreed to turn off the phone or not answer it, turned off the TV or met in another room and the children either in another room or were not present for the interviews. This helped with less background noise for the audio recording (see Appendix B).

Unknowns and Limitations

Since this study was qualitative and the questions elicited more than "yes or no" answers, most of the questions have been asked about perception and/or feelings about a situation. Thus, talking about emotions and personal perceptions could elicit surprises between family members or from themselves. Thus the extremes could occur from this type of discussion, greater understanding or greater discord. Some families could choose to discontinue the study due to time constraints or loose interest in the study or the interview that has asked too many personal questions. Fortunately, this did not happen in this research study.

Another limitation of this study was the small sample size in which the fact that participants were not randomly chosen. Another limitation was that the participants were friends, family or neighbors of colleagues of the researcher. They were chosen due to their willingness to be involved within the research's parameters.

Data Analysis

The data that this researcher gained from the open-ended replies and also circular questioning was thoroughly analyzed for themes that come out of the families' stories. Themes that were concentrated on were the concepts from the literature review. Thus, concepts of family reality, family stress, family loss, family strengths focusing on adaptability, coherence, coping, rituals; family rituals and finally the role of the medical community were the focus of the results section of this research study.

Attention was given to the family's awareness to the themes and the processes of change. Since this research study elicited the family's story and as each family had a unique story, nothing was predicted how the family answered the questions. The only prediction that this researcher made was that the conceptual themes were discussed and seemed important to the families and thus they answered the questions. The families' stories generated the hypothesis of functioning and collaborative relationships later discussed within the results section of the paper. The researcher also paid attention to the similarities and differences between the themes as they were displayed within each family. The researcher explained how the role differences or similarities play with each family and families in general.

Reliability and Validity

Since this was a qualitative research study, reliability and validity was used differently than in a quantitative research study. Some reliability came from using the same questionnaire for both families to answer. The researcher was able to ask more specific questions if a question needed to be clarified or if another line of questioning was needed for the whole story to be elicited. Face validity was present from the researcher's experience with working with families with health issues. Because this researcher was attuned to the content that the families give, some content validity was achieved through the disciplined approach the researcher took in structuring the questions for a family to give consistent replies while they gave their own unique story. The researcher was trained as a medical family therapist who had skills for asking questions that elicited the "health" story of the family unlike other trained therapists who may not realize the role that chronic illness can play within families.

Role of Researcher

This researcher did her best to remain solely an interviewer while collecting the data for this study as opposed to an interactive role with the family in creating “new” experiences. Although in reality, the researcher became part of the process of the narrative just by being the one asking the questions to the families. “Therefore, when health is the focus of research in the development of knowledge for practice, research becomes a shared process of inquiry through which participants are empowered to act to change their circumstances” (Litchfield, 1993). The ultimate goal for this research study was to affect the “knowledge for practice.” Thus, this researcher always had an underlying expectation for the questions being asked to assist other professionals understand of how to collaborate with families that are affected by chronic illness. This researcher embraced the idea of being a “student” throughout this process of collecting data and recording the family health story. Since the focus of the paper was concerned how families create meaning, which would be considered an abstract idea, the focus of this paper was the process of how the families evolved in their story and the meaning that they gave to that process.

The expectations that this researcher had for the families were for them to narrate their story through the answers they gave the researcher. Another expectation was for the families to be able to discuss the concepts (mentioned in the literature review section) through the questions that were asked. Another underlying expectation was to gain advice from the families in how they felt the medical community could ally with them against the chronic illness rather than against them as a family unit.

CHAPTER IV

Results

The discussion with these families has involved the direct responses of the participants and their family's story regarding the theoretical concepts of family functioning. The themes from their stories have been elicited to demonstrate how families create meanings or make sense of the situations that take place in their lives. The following results report is how two families made sense of the chronic illness of their children and also the interactions that they had with the medical community.

In order to do the participants justice in telling their stories, this researcher will use a narrative style of writing to describe them. This researcher will also use direct quotes from their story to help demonstrate their ability to create meanings. Please note that all identifying information has been changed in order to give these participants complete privacy.

Family Reality Discussion

Family reality was defined as whatever the family holds, exists and functions as truth and this is created by the "frame of reference" that they use to observe the world inside and outside of them. These families were described by general information that has helped in create their family reality. Family reality then in a sense is the pragmatics or structure of the family.

Family A. This family is a Caucasian single-parent family that is headed by the mother, Janet who is forty-eight, Janet has a her daughter, Anna who is eighteen. Anna was diagnosed from birth with Down Syndrome, a chromosomal abnormality that has led to above and beyond the normal health care given to other children. However, the family did have to wait twenty-one days after Anna was born for the final diagnosis because Anna did not have all of the characteristics of Down Syndrome. The doctors were 99% sure, but they wanted to be 100% certain. The doctors performed a blood test to confirm the diagnosis. Janet did not consider Down Syndrome as a chronic illness, but Anna does have chronic health issues that are related to the Down Syndrome. Janet presently, as well as when Anna was born, considers her family to be her mother, father (who is now deceased), brother and sisters and their families. All of these family members live in a neighboring state, several hours away. Janet is a middle class person who obtained a two-year associate degree. Anna will be attending a transition program for students with disabilities after this year and is considered to be a high school senior. Janet has gotten been married and there has never been a continuing relationship with Anna's father after she was born.

Janet describes herself as being the primary caregiver with the help of babysitters and daycare. She was forced to pay for help because her family members were not in the local area. However, she would have her mother watch Anna if she was on a long trip or absent from Anna. When Anna was first born until age three, Janet lived in a rural

Minnesota town that did not have a lot of local resources for her to utilize. Since then, Janet and Anna have moved and now live in the metropolitan area of the Twin Cities in Minnesota. Janet describes herself before Anna's diagnosis, as always working at employment that demanded much of her time. But she also described herself as enjoying reading and visits with people. However, she states that everything changed when Anna was born and only recently has she been able to read again.

Janet explains the only times she stayed in a hospital where when she was born and when Anna was born. She describes herself as not growing up with any preconceived belief that hospitals are bad places. "The hospital was just the hospital. We had friends that worked there. We were very familiar with our family doctor growing up. I did not believe that it was a bad place or where only really sick people go." She described that her experience of delivering Anna was wonderful. "The hospital staff was wonderful. They let me stay a couple extra days because she was jaundiced and born the day after Christmas so we were there all day until New Year's Eve. I had a real good experience." Janet states that there were no negative family beliefs about illness that were passed down from her parents.

This is a very brief description of the family reality that Janet and Anna live with which has been affected by their family of origin and interactions with other systems.

Family B. This family is a Caucasian dual-earner, two-parent headed household, Ken, who is forty-eight, Marie, who is forty-five, James, who is 15, and Eric, who is 12. James was diagnosed August 1999 with seizure disorder, epilepsy, and Eric was diagnosed with asthma at age two. James has had two other occurrences of seizures, at eighteen months old and at 7 years old after a serious bout with chicken pox. The doctors told the family when James was seven that he could develop a diagnosable seizure disorder, unless the earlier seizures were isolated incidences. Eric had a serious case of bronchitis at six months old that lasted from October until May of that same year. The bronchitis then developed into asthma, which was later diagnosed. Everyone in the family was present at the time of each diagnosis for each of the children. There are other family members that do live locally; however, both of the parents described their family as those who live in their household. Ken has a master's degree in engineering and Marie will be graduating next year with her MBA. James will be in 10th grade in high school, and Eric will be in 7th grade in junior high school. They describe their family as being upper-middle class. Marie described herself as being the primary caregiver of the family. Ken and Marie reported that they also used daycare while the children were growing up.

Marie described the family before the boys' diagnoses as the same as it is now. They went into the hospital when Eric was two with an asthma attack. The only thing that changed for them at that time was that Eric now had to take a nebulizer treatment for thirty minutes three times per day. She reminisces that James did not like that and he would have rather gone to the park than to wait for his brother's treatments. "We really tried not to have things change that much . . . He went to daycare, took swimming lessons, played tennis, baseball and other things." In regard to James' diagnosis, Marie described the way they handled the situation differently than with Eric, especially with friends and neighbors.

> The only thing that we did differently with James's case was that afterwards we called the parents of his five closest friends to let them know what had happened

> so they would not to be alarmed. I just called let them know that he needs to get sleep, so if there are sleepovers he needs to go to bed at a reasonable time. He really should not be riding bikes alone or doing in-line skating alone; there are really some things that he should not be doing alone. And just to make the parents aware of that, so he does not go off by himself alone or whatever. Just to let them know that if anything should happen, this is what to look for and this is what you should do.

Both Ken and Marie did remark that there were no changes from their ideas of illness or the medical community since the diagnoses of their children.

This is a very brief description of the family reality that Ken, Marie, James and Eric live with which has been affected by their family of origin and interactions with other systems.

Family Stress Discussion

Part of the elusiveness of describing stress within families is that most families would probably not describe themselves as being "stressed out" unless they were in the middle of a crisis or some sort of definable stressful situation. Both of these families did not remark that they had gone through a stressful time in their families, thus this researcher will assume that there was no stressful crisis. However, the researcher will infer stress that the families have either coped through or have experienced, even though they do expressly say so.

Family A. Janet first describes how much the family functioning had to change for her. First, she became a new mom, single parent, sole provider and then had to cope with a child with a disability. Just becoming a “new” parent is enough stress for one person to deal with, but Janet also had to deal with the complexity of raising a child with a disability by herself. Janet described a situation with one of her first babysitters and how that added stress to her life when Anna was first born.

> The first babysitter just did not work out very well. There was a lot of transition trying to find someone else. The first one wanted to make her an older child than she was, like feed right away. She wanted to feed her solid foods at two months and babies just don’t do that. My doctor said don’t do that and so I listened to him. So I had to find another sitter right away and that was hard to do. At that time we were living in a small town in Southwest Minnesota and spent a lot of time doing that.

The area of childcare for Janet is especially important to her and has been a lifelong concern for her.

> When I would get to work or whatever, I knew I had to have Anna in a place where I could trust them. And they were very good caregivers including the daycare center where she was for so long. It was a business, but then I felt she was taken care of there because it wasn’t a big place. So I really didn’t worry about her when I was away . . . I never worried about her much when I was at work or away. She was in good hands, I felt. I only had one sitter for a short time in between places that I did not feel comfortable with and I did pick her up early every day and bring her back to work with me. I was just having a hard time

> finding someone else so I kind of put up with her for just two months. I would just go and pick her up. I would hate having the bus drop her off here at work so I had the bus drop her off there and I would go and pick her up. I would only let her be there only for an hour everyday. I just didn't feel comfortable enough.

This area of stress with childcare has changed radically for Janet and Anna since Anna is getting older and can handle more responsibility.

Janet also described a situation with the school district in the rural town that was not willing to provide services to Anna. This caused stress for their family from the community lack of support for them.

> When I lived in the small town in Southwestern Minnesota, I had approached the school system and the superintendent about some sort of program I could get her in, especially when she was a newborn. I have heard that there are so many different people that say the sooner the stimulation and the better off they are going to be. He said 'oh, no we could not do that.' 'Why? One child, what difference is that going to make?' And he said, 'Well, then everybody will want to move here to our school district because we are going to pay for this.' Well, it's just one kid. The word is not going to 'get out.' I'm sorry (frustrated tone). I still remember him saying that to me and I am thinking 'how ridiculous'.

This point in time for Janet was very stressful her to cope with a child with a disability. Janet did her best to provide for Anna as well as to also face a community system that was not going to be supportive towards her.

Although, Janet was receiving help from the county during that time, the help was stress relieving as well as stress causing.

> Right away [after Anna was born] we got started with a program, someone from a county program came to our house once per week to help with activities such as moving her legs and moving her arms. To do basic things to get her to do things and for her to be more involved with everything, constant stimulation. Things like that. That was a weekly thing and that was a big deal. She came to the house weekly and we had to work with that schedule. I had to take time off of work in order to be home. And that went on through the whole time we lived there for three years after she was born. This service was from three months to three years.

This situation for Janet, demonstrates that stress can be positive (someone coming into the home to do services) and negative (rearranging work schedule) for families that have a chronic illness that have to decide if in-home services are needed for them.

Family B. This family seemed to try to keep the family's functioning homeostasis in check at all times. Part of this was for the family not to overreact to the chronic illnesses that both of the boys been diagnosed with. Marie explains:

> Their illnesses have not affected anything. If you are asking that because of asthma and you don't expect much out of them because of added stress may cause an asthma attack – not an issue. With epilepsy, added stress can cause seizure – no that's not taken into consideration when chores are taken into consideration or things like that. They are part of the family and we are feeling like we are not expecting too much out of them.

The way this family reacts to stress is to cope with the situation and move on. Thus overreaction to the chronic illness is not done in this family. There is also an element of confidence within this family that if something were to happen they would be able to manage it.

There are specific stresses due to chronic illness that this family has to cope with in order to function which other families do not have to consider affecting them. Marie states:

> It [Eric's asthma] is not a severe case, but it is considered "moderate level" because he has to take medication twice per day. He has to do his inhaler or he would have more severe problems. But as long as he does that and as long as the humidity doesn't change so drastically he is fine. We did go out a couple of years ago on vacation to Ohio, and the humidity was a big change. And that could have affected our vacation, he could have ended up in the hospital. But lucky he didn't because he had his medication and he was fine . . . Whenever the weather changes and the humidity increases or decreases, he is going to have a cough. I don't get too worked up about it, but you can expect a cough. When the weather changes, he brings his emergency inhaler or has it in a bag with him.

Marie then comments on the awareness for James' specific precautions for James' epilepsy.

> We did learn from Dr. Smith [James's neurologist] the five things she listed right away [not to do]: no taking baths - you have to take showers, no swimming alone unless you are with friends, staying off the highways, gets plenty of sleep, and consumes no caffeine . . . You do have to be careful with what he can do. And at times you have to remind him of that.

The theme here as well as through out their interview was to cope with the situation or stressor and move on from it.

Family Loss Discussion

Family loss is a concept including a variety of types of loss. Some of those losses that families with chronic illness deal with are physical loss, loss of ability to do something, developmental loss with the child, and loss of a child not meeting parent's expectations. Family loss is a process; part of that process is family acceptance of the chronically ill member of the family.

Family A. Janet had always known from the instant when her child was born, she began to cope with a lifelong chronically ill child.

> At first, when the county worker came to my house, Anna was less than six months old and she was telling me (and I thought I had it bad and could not think of anything worse) about an older child that she saw every week also. He [the neighbor's child] was just down the road ten miles and he had seizures all the time and was probably close to twenty. His mother cared for him twenty-four hours a day, seven days a week and she was tied down. The mother was probably in her mid forties, at the time and the county worker told me she looked like an old woman because that is all she had ever done was take care of her son. She had no other life. And I thought, 'Anna still is just a baby, but she is doing just fine'. From that point on, my attitude just changed. I thought to myself how

> could this woman do that. She never gave him up for someone else to take care of him. Nothing. She could never have a day off. Nothing. And I thought, 'I don't want it to be like that'. That really changed my attitude. I wish I could thank that county worker for telling me about that woman. I probably did at the time, but this really changed my life.

Janet also explains further of developmental losses that she and Anna have faced together.

> And then the fact that she wore diapers for so long. It took her a long time to get trained through the night. She did not have too much trouble during the day. She was trained at age six for the day, but she was a lot older for the night. That is something that other people don't necessarily have. Her speech is bad. I understand most of the things that she says. But a lot of people don't. Because of that she is more quiet. I think she knows that there is a difference . . . I can understand her, but the kids can't understand something and 'they'll ask what is she saying?' And I'll say 'that is what she is talking about'. But there are a few things that even I can't understand. She is pretty good about spelling and she spells words out for me and then I can usually get it.

Functioning developmental losses are not the only losses that Janet and Anna have faced together as a family. Janet describes Anna's ability to be involved in high school "rites of passage."

> She hasn't [been involved with prom]. I don't know if they invite others. I know that one year the seniors invited their "pals" to do a lot of stuff together. And the five of them went to prom together and I thought 'how neat'. I think she would

> get a kick out of it, but I am not sure who she would go with. I don't want to take her to prom, but I don't know how they would do that. Maybe a paraprofessional could go along with her that would be the best thing. She would enjoy getting all dressed up for it.

Along with the loss of certain school activities, Anna has a hard time talking to people. It is not because she lacks the skill in communicating, but that her skill is not as proficient as others. Thus she is really shy and quiet. This also hinders her ability to make friends.

> I feel bad that she does not have more friends, but that is because I think she is so shy. I truly believe that. Every year when we have school conferences, the main thing is her quietness. That can't get her to talk out loud except the last quarter of the year, then she begins too. And it has always been the last quarter of every year that she does this. So that is not the time to start. She needs to start the first quarter. The teachers will say that at school she could have a lot friends because kids like her. She does not stand out in the crowd and she is easy to get a long with, but she doesn't talk to anybody. She does not have any friends. And I am not sure what I can do for her to get her to talk and have friends.

These are the losses that Janet and Anna have coped through and are also coping with presently.

Family B. The losses that this family has faced may not be as dramatic in comparison to the other families, however the family has had to cope with changes due to the chronic illness. Ken stated that "maybe with Eric there are slightly lower expectations in what he can do for his little league team because he just doesn't have the endurance." Marie agreed with this and also explained more future oriented losses.

> The losses that I see for Eric and James are that they can't pursue the careers that they both want. I think you always want the best for your child and want them to do what they want you to do. You want them to be able and that is a loss knowing potentially what they want to do they may not be able to do. That is where you learn to be able to live within your body and what you have. It's like wanting to be a doctor, but knowing you don't have the mental capabilities to do it and so you go to plan B. You have another plan in mind for what you can do. There are going to be limitations and they are just going to have to find something else.

Ken and Marie have had to come to terms with what to expect from their children and how that shapes the way they view their children. That acceptance in of itself is a good gain for this family to be able to achieve its homeostasis.

> I know what I can ask of them because they are not super human beings that are absolutely perfect and up on pedestals. I think that I am more relaxed. I think you have expectations for your kids to be the President, or to be this, or to be that and then reality sets in and you go 'oh well'. You just have to realize that life is the way that it is and you have to move on from there.

The willingness for both of these families to accept where their children's functioning abilities are at is one of the most important factors for these families to be able to cope with the chronic illness.

Family Strengths and Resiliency Discussion

The assets that the family uses to function with adversity are also the strengths that they use to cope with stressors such as chronic illness. Both of these families could identify strengths that they used in order to function as well make their lives easier overall.

Family A – Adaptation. Janet has adapted to Anna's growth and development like all parents who have children. However, the difference with Janet and Anna's case, from Anna can only function to a certain point because of her disability and chronic health conditions.

> She was able to take care of herself about three years ago and she has really come a long way since then . . . until she was a freshman in high school, I had someone come into the house. That was the first time that she was not in daycare and in a regular daycare setting. Since she was a sophomore, the person could only watch her a few days per week so she was staying at home alone and then this past year as a junior she is able to stay home alone the whole week. She has matured so much since I have let her stay at home alone. It is unbelievable and now it is to the point where she is staying home alone all summer all day long, but I do go home for lunch. She is starting to do some cooking since my job demands have changed to the point where I do not make it home some evenings. She has had to make her own meals, which has been wonderful. She started to learn to use the microwave, can opener, and just few things that she can make a basic meal. I

> have juice or something made for her to drink. She has done very, very well and has matured very much. I just can't believe it.

However, with the gains that Anna has made in her ability to take are of herself, there are still areas where Anna's capabilities need to be acknowledged either for her as an independent person or as a dependent person.

> I feel like, and I know I am guilty, when I stop and think about it because I still do treat her like a 10 yr. old. It is difficult to separate her chronological age with where she is developmentally. Sometimes she is scary because sometimes she knows exactly what she wants and she is very vocal about it.

Janet later describes a situation where Anna's ability does affect the way her family views her and her abilities.

> She is capable of doing more than we [family and friends] give her credit for. But we do tend to baby her. For example, we have not been home for Easter, but we would always have an Easter egg hunt outside. She is not real good when you say something like "behind it" or "under it." And when we are looking for eggs and we say go behind that tree she doesn't understand those kinds of concepts. They are difficult for her. She is getting better. So then people tend to take her over to where things are and lead her along and show her, help her out more than the other kids. Then they leave the other kids to do their own thing. I would say we help her probably more than we should. In a competition, she would never do well except maybe athletics. She can out run any of them. But we do tend to baby her. I would say and treat her like the youngest [grandchild] instead of the

> oldest which she is the oldest grandchild. Sometimes not all the time, but sometimes we do.

Although Anna has these “weaknesses”, Anna also has many strengths that she brings to the home.

> She is very good to go grocery shopping with. Sometimes she remembers the list better than I do, what we need to get and things like that. She enjoys that. One quarter she worked at one of the local grocery stores from school and she liked that a lot and she spoke up about that that was one her favorite jobs. She just loved it and I don’t know why. She is very particular. If I leave a kitchen cupboard open she tells me to shut that door. She just hates it. If I don’t shut it then she will get up and she will close the door. It really drives her crazy.

Janet stressed the importance of not paying for daycare anymore now that Anna is able to stay home alone. This is a revelation that they both had to figure out if it was going to work.

> Well, just ask any one here [at work] on those first couple days, I was a nervous wreck. But financially, it was getting expensive. And most people do not have to pay for daycare until their kid is sixteen years old. I still was paying for daycare and that was a huge savings for me. Since she can be trusted and she has proven herself many times over, it is ideal. I can run to the grocery store or somewhere, and not have to have her along. I would never consider going out of town with her home alone. I am not quite comfortable doing that . . . It has freed me up a lot, the older that she has gotten.

Thus as Anna has gotten older and has been able to take care of herself, Janet has been able to gain more freedom and also has felt a financial ease.

Family B – Adaptability. Ken and Marie have tried to make the fewest changes possible for their family in the way they function. One of their themes that cam out during the interview was the way they tried to normalize both of the chronic illnesses and to have their boys take responsibility for their health.

> They are both responsible for taking their medication and then I [Marie] am responsible to get the medication. Eric, when he was younger, had to do the nebulizer and that was a thirty-minute treatment each time three times per day so you would have to plan for that. Doctor's appointments we have to schedule, and we see the doctors probably more than other kids, but I don't think too much. Other than that I don't see it being a major change. I think that there have been real subtle changes like going to the doctor once per month versus once per year like other kids do.

One way in which this family was able to adapt to the chronic illnesses was to "face" the chronic illness head on instead of overreacting to them. This family is a very good illustration of "putting illness in its place".

> We talk a lot about their illnesses even if they don't want to hear it. We have made them responsible to take their medications because I am only going to be here for a certain amount of time and then they are going to be out of the house. Maybe adjusting to limitations too. Like there is a plan A so there should be a plan B because in reality what they are both shooting for (thinking about careers)

> may not be options for them because of their health and that will be a big door slammed in their faces.

This family also has to keep the reality of the seriousness of the chronic illnesses that have been diagnosed their children. Perhaps part of the reason this family is able to cope well with chronic illnesses is that Marie's family of origin had to cope with chronic illness as well.

> Both illnesses can kill at any time. Something could happen; one could die from asthma and the other from a seizure riding a bike over a highway. But I [Marie] think James's [epilepsy] is more noticeable, for some strange reason, maybe because I lived with people who had asthma and it wasn't that big of a deal. Or at least it should not have been, but I think it was more of a big deal with my brother who had asthma. I do think with James that I make sure I am more aware that he is protected. Other than that it is the awareness and making sure that others are aware also, and that is it. We do not limit any activities that he has previously done. He still rides his bike. He still goes rollerblading. He still goes swimming with his friends. He still does the things; it's just that he and his friends are a little more cautious.

Marie goes on to further explain about her family of origin and the role that chronic illness played in shaping her views now.

> His [Marie's brother] asthma was not as bad as Eric's asthma. He only had asthma when mold was around so his was not quite as bad. I don't remember them taking him to a specialist like I did with Eric. The only time he did get asthma was when he went to my grandmother's house where it was an older

> house and damp. So that is when he would get asthma. And he would just take medicine and then we would go home and he would be fine, or he had to stay at my great aunt's house because of it. The occurrence was in that specific spot not because of the humidity. Other than that he does have emphysema and he will have to deal with that now, but growing up they maybe babied him a little bit because he had asthma and had to sit on the sofa. They didn't have inhalers back then so he probably was more impaired than Eric is now. So yeah, he probably was in more trouble then than Eric is now. They did what they could. Both of my parents were in the medical profession so he was not going to die. They knew what to do for him.

For both of these participating families, adapted to the chronic illnesses as well as adapting to the way they shape their lives is important if not essential to healthy functioning.

Another strength for both of these families is the level of coherence that each member has with the family as a unit.

Family A – Coherence. Janet explained that part of her sense of coherence came from a Mom's group who had children with disabilities. She also demonstrated that spending time with Anna was a major part of her sense of coherence as well.

> When I first moved up here, there was this mother's group, that has since been disbanded, that had a variety of different chronic illnesses. There was one other person who had a child with Down's Syndrome, but there were others that had completely different illnesses. The only reason that we met was for a kind of

> Mom's night out. Because I did not have any family here, I had to bring her with . . . That disbanded quite a while ago, but there are other organizations available. I don't go to the meetings. I just found those meetings to be too formal; too much of a meeting and not enough chatting about things that would pertain to us. So I just haven't gone to those. That was about all that I sought out. I haven't needed in-home care or anything like that. I know people that have and I felt that I work enough during the week that on weekends I don't need somebody to be with her on the weekends, especially when she was younger. I have never used that and some mothers thought that I was kind of crazy for not doing that, but they weren't working out of the home like I was.

The school district and the teachers that Janet interacted with were also part of her community of people that helped her keep her sense of coherence in regards to Anna. The educational community was able to give Janet advice for Anna and her ability to achieve in school. After Janet agreed to follow the teacher's advice and she has seen the positive results.

> She was there for a couple of years and she was same age as quite a large group of kids, but she was so small, tiny that the faculty recommended for her to be held back one year. They felt at the time that if she went into school with that larger group that she would have been overlooked. I am so thankful that I did that because I felt that would be the case. She has been much more comfortable. She is very shy and because she is so shy she gets "stepped" on, at least that is what I feel. I don't know if it is true, but that is what I feel like. She gets lost in the shuffle and I thank them to this day for keeping her back a year. We had

> wonderful, wonderful, wonderful teachers. The school district has hired wonderful teachers for the Special Ed program. I just can't say enough. I don't know how to describe it, but it's like they are family.

Thus part of Janet's ability to derive "manageability, meaningfulness and comprehensibility" is to use the resources from the school district which has allowed her, perhaps at the cost of her personal free time.

Family B – Coherence. Ken and Marie talked about their neighbors and neighborhood throughout the interview. They spoke of the support and willingness for all of the neighbors in their "network" to be involved in both of their sons care as well as for them to be involved in their neighbor's children care. Marie explained:

> My friend was talking with me about the fact with epilepsy, people [in the past] have thought it was a scarier disorder than the other ones. Because it is a neurological disorder and sometimes people are more hesitant around kids with epilepsy. Maybe it is the group and the neighborhood that we live in that are better educated and we do not have that problem here. There is no one who is overly concerned about James' epilepsy. Maybe people are learning more about epilepsy and it is becoming less scary than it used to be . . . we do have neighbor friends that watch him. We do have a network of neighbors. For both of the kids as matter of fact to make sure that they are both okay. When James had his seizure, Eric had called me and I called a neighbor and she came over to be with James and Eric right after the seizure, but before the ambulance got there.

By having this network of neighbors to look out for their children, this has given them a sense of peace and also a sense of coherence within the neighborhood. If Ken and Marie were not connected to their neighborhood, the situation with James could have ended another way, perhaps detrimental.

Marie also shared how the school district responded to James's epilepsy and how the both of them received support from the faculty.

> I did go to James's school and talked to the school nurse. And I did go to the teacher and talked to them about James and his epilepsy. And the school was very, very receptive. James has said that a couple of the teachers have asked him how his is doing and how he is feeling. I think that made him feel good that they were aware and concerned. The school has been very supportive. The school nurse even came with me when I talked with the teachers to be supportive and to answer any questions if they had any. The teachers were told that there were references downstairs and where the nurses' office was and was more than happy to talk to any of them. The school is very good because one in one hundred has epilepsy. So in his school there are at least two kids that have epilepsy and he is not the only one.

With the neighbors and school communities aware of both the epilepsy and asthma that their family has to face, this family feels supported and both of them have commented that they rely on the support.

Another aspect to Marie's sense of coherence is her spirituality. She describes herself as a very spiritual person. How the impact of that influences the way she deals with life.

> I pray to God, but I don’t ask Him why. I just pray for them to be protected and safe like when James had his seizure and Eric was home and for the neighbor that was home and could take care of them. I knew he was being watched. He’ll be watched and he’ll be taken care of. I have a real peace and belief that God will take care of them. He has already. James could have had his seizure on the way home from babysitting and could have fallen on a major highway off his bicycle. There were many things that were being taken care of that were out of my control. We found wonderful doctors to take care of him and I have put my trust in them because they know what they are doing.

This belief has not only given peace to Marie, but also the ability to make sense of the situations around her and her family.

For both of the families, there came a point to describe that their situation is not as bad as it could be. This is interesting development for both families and demonstrates their abilities to cope with chronic illness that is affecting the family. This has also demonstrates that the family has coped and achieved a “new” homeostasis through the change process. Thus the family would have to adapt (change) in order to meet new demands of chronic illness and then reach another “new” homeostasis.

Family A – Coping. Janet’s first realization that her situation could have been worse was already described in the “Family Loss Discussion” section of this paper. She continues to compare her situation to others in the Mom’s group she attended when she first moved to this area.

> I went home from this and I said to myself, ‘I don’t have it so bad’. I really don’t. Some of the other mother’s had to feed their child through a tube, but I did not have to do any of that. When it has been just the two of us, I guess I just put up with it since I don’t know any different because she is the only child that I have. I just kind of have gone with the flow. I do what needs to be done and kind of go from there. I know that there are a lot of people who have it worse than me. I know that there are people who look at me and think how can she do it. But I don’t think I have it that badly.

This realization gave Janet perspective on what she does have to cope with in regards to Anna. Another aspect of keeping things in perspective was for how she cared for Anna.

> I have never known anybody who was mentally retarded before. So I think that was quite a challenge and my family didn’t know anybody. So it was different. But I think I have coped very well or at least I hope that I have coped very well. I guess I just looked at it like when she was young she was still a baby and tried to keep that in the back of mind instead of push, push, push. Let her be a child too.

Janet also describes her personal coping with being a parent and how she has coped with getting free time for herself.

> I always had my ‘out’ by dropping her off at the babysitter or daycare and going to work, or I could take a day off and go back to the house to clean or go shopping or whatever. I could do that, whereas the parents that were home all day didn’t have that, they were with their child all day. Of course I’m talking about before school started until the age five or six.

Janet used resources not only for Anna and her development, but also for Janet and what she needed.

Family B – Coping. Ken and Marie also have come to the realization that their situation with chronic illness in their family has not been as bad as it could be.

> It could be a whole lot worse like having someone with cystic fibrosis or any lung diseases or diabetes. Our kids get up, go to school, they get good grades, they come home and do what they need to do. I know that they need to be on medications for the rest of their lives, but there are just a whole lot of things that could be a lot worse.

Thus comparing themselves to other families with chronic illness keeps their family's reality in balance with how to react to the chronic illnesses that they face. Marie described how she viewed both of her boys' cope with their chronic illness.

> Well, I think James was a little concerned last year before he started on his medication for epilepsy in the fall. I was willing to call his friends, because he was not necessarily talking to them. I thought he should talk to them right away because he does sleep over and he does ride bikes with them. I think he needed to be more up front, and I thought that he was worried about it. He is an introvert and he did not want to talk about it. Then after he was put on medication in October I think he did finally relax, because he was worried that he was going to have another seizure at school, particularly, and that did not happen. He was fine and when it did not happen, they put him on medication and he felt better. But I found that out from a neighbor, she thought he was little distant.

She then continued to describe Eric and how he has coped with his chronic illness.

> I think that Eric is very aware that he notices people that are different. Because he has to do his inhaler and he knows other kids with asthma that have to do the inhaler too. I think that he looks at people and knows that other people have illnesses. They are no different than he is personality wise, they are nice people to be with, but they could be somebody in a wheelchair or a little unique and that is okay. Some people are afraid, but he is not afraid because people may have different problems in life that they have to cope with.

One way this family has been able to cope with their situation by realizing that their situation is not as bad as it could be. The feedback from the parents that says "we can cope with this" allows the children to be able to handle their chronic illness in a way that make sense to them.

Both of these families have a hard time describing family rituals that they have within their family. This is not unusual since most families do not describe day to day routines as "rituals." However, these families were able to come up with at least one.

Family A - Rituals. Janet described her rituals as routines that she did with Anna which lead into a fun activity. They also modified this ritual to "fit" the summer schedule, which was different from a school schedule.

> We have a routine everyday now at lunchtime when we go home. Well actually in the morning we have more of a routine. During the school year, we play Uno in the morning before the bus comes. We would get up early and we would play Uno. My daughter is extremely vicious and very good at it. When I come home

> at lunch, we have lunch and then we play cards. That's what we do. She also likes to play dominos, but Uno is her greatest thing. So all summer long, every day [at lunch] we play Uno. We don't play it in the evenings, only at lunchtime or when school starts we will play it before the bus comes. Of course it depends when we get ready in the morning, but to her that is the ultimate fun for her. She just loves to do that. That is a ritual that we do. We don't necessarily play on the weekends.

This time is very special for Janet and Anna. Janet talked very lovingly about it during this part of the interview and this researcher could tell that Janet got as much pleasure in doing this with Anna as Anna playing cards with her mother.

Family B - Rituals. Ken and Marie had a harder time coming up with a ritual that they did as a family. Marie described a ritual that she has done with her boys, but has since changed with their development.

> Since their bedtime is usually after mine, I used to go up and pray with them before they went to bed. But now they are going to bed after me and so now I am not staying up. Eric goes in and takes his medicine. James has gotten into the habit of taking his medication and then read for half an hour and then I go in and kiss them goodnight.

Although, both families had a more difficult time answering this question they demonstrated how the simplest things could be the most cherished things within a family.

Family and the Medical Community Discussion

Families with chronic illness view their relationships with the medical community by their interactions with them. This discussion will show how these families personally view the medical community both positively and negatively. The insights that these families provide are invaluable.

Family A – Medical Interactions. Janet has already described briefly some interactions with the medical community as positive as mentioned in the "Family Description" of the paper. However, as she describes in further detail, the reaction of the medical staff to her daughter's medical condition was hard for them to accept as well as for Janet.

> Actually it was the pediatrician that broke the news to me. My doctor didn't feel comfortable doing that and he was my family practice doctor. The pediatrician is the one that he called in to talk to me and he was wonderful. I think it was a difficult situation for him. The pediatrician in a way was helping me parent Anna at least in giving advice. Because she was Down Syndrome they wanted to watch her so every month we had an appointment in addition to any time that I needed to bring her in. I would go between the family doctor and the pediatrician, so every other month I would be with the other. I went to each appointment with a huge list of questions. I jot them down when I thought about them and the doctors were very good when I asked them all. They were good the both of them. The

> family physician left and so I stayed with the pediatrician for a while until I moved up here; he was very good.

This dialogue demonstrates that individual members of the medical community have feelings about discussing hard issues with their patients even though they are trained not to let that factor into giving hard news. Yet, as patients we need to have compassionate medical providers just for that reason; hard news is hard to bear alone.

Because of Janet's unique experience of moving from a rural town to a urban setting, she was asked to compare the two experiences and how situations would be different if she stayed in the rural town.

> Well, the Ears, Nose and Eyes doctor that we saw while we were living in Southwest Minnesota had his practice in a neighboring state. We would have to drive an hour to get there compared to now when we drive to the near suburb. The time factor of getting an appointment was a bigger deal. The hospital where she had her first surgeries was in the neighboring state. We had to go there. Everything was at a distance, even if it was at a neighboring bigger rural town were she was born, it was still forty-five minutes away. But that town did not have [certain specialties]. We are lucky to be living in the metro area and we still have access. And this has really helped us. We are close now to the Spine Center since we have found out that she has scoliosis. We have had only two appointments, but there is nothing that he can do for her. He wants to see her annually and verify her diagnosis. So if we still lived in the rural town, we would have had to drive from Southwestern Minnesota to the Twin Cities. I feel

> fortunate where I live. I think down there, there would have been more of a push to get it.

Janet ended her insight to the role of medical community in her life with this, “I think there is enough doctors around here that if you had kind of a negative experience with one there is usually another that you can go to waiting for you.”

Family B – Medical Interactions. Ken and Marie described their family as spending a lot of time visiting the doctors and making medical appointments to see all the specialists for their two boys. Although, there has been a lot of time doing that, Ken and Marie describe it as time well spent. Marie described an interaction with Eric and an asthma specialist.

> One time I was having problems with one of the allergy/asthma specialist we had, and they recommended another one to go to. In my opinion he was a jerk. He was in it for the money and not for the child. You end up with some of these doctors who are in it for the money and they aren’t very aware of the patient. The doctor and Eric actually got into a fight over the medication Eric was supposed to be taking and how much. And Eric was right, not the doctor. Eric was right because he listened. It was when he was supposed to be taking some medicine because he had an asthma attack and supposed to be weaning himself and the doctor said you are not supposed to be doing that. The chart said to do that so we did not want to go back to that doctor again. So we went to another specialist. The clinic was concerned that we were having a problem and they wanted to make sure we stayed with them. They thought and we thought they were a good group and they

> wanted us to stay with a person we were comfortable with. Eric was the one not being heard, not me. Eric was the one that explained the issue.

Marie continued with how the medical community could better communicate between the primary or family practice doctor and the specialists.

> Now that I think about it as soon as the children's hospital in the area they find out that a child needs a specialist, they are very hands off. Here you go to that specialist and then they take care of everything. I don't know if that is for a fact, but it would be very nice if they would do more talking to the specialists and find out. So maybe the primary physician's office could send out brochures or they have any information for group to go to. They can work in tandem with the specialist. But other than that it is the specialist that we get any information. I don't know if they communicate. I don't know if a specialist communicates with a primary pediatrician

Even though Marie spoke of these concerns, she has overall been very satisfied with the overall care she and her family have been given. Marie named all of the specialists that her family works with and they were all excellent in her point of view.

Families Creating Meaning Discussion

The question that needs to be asked is, "have these families created meaning from the chronic illness and their interactions with the medical community?" The answer would be "yes, of course." This researcher will use the stress theorist's model of the three level concept of Garwick and Patterson (1994).

Level one: the understanding of a situational event that affects the present situation of the outlook of the family. This can be best described with each family's motto. **Family A**'s motto was "Just go with the flow". Part of this motto could be from the fact that Janet has never experienced being a parent of a non-special needs child. Thus, her concept of reality is becomes whatever she is experiencing. "When it has been just the two of us, I just put up with it since I don't know any different because she is the only child that I have. I just kind of have gone with the flow." Also the knowledge that Janet does not have it as bad as other families has given her the ability to cope with change and adapt to that change.

Family B's motto was "Just deal with it" for Ken, Marie, James and Eric. The parents knew that James had to be protected in a different way due to his epilepsy condition. New rules for behavior had to be enforced that were not a part of the family dynamics before, such as no consuming caffeine or being alone while swimming or riding bike. For Eric, the family had to be aware of when the weather changes so that they could expect behavioral or physical changes in him such as coughing or perhaps labored breathing. This knowledge has helped the family to know how to react to given situations and they "just deal with it".

Level two: the family's identity in regards to illness such as the roles, rules, routines, and their sense of purpose. Neither of the two families described themselves as "being a family with disabled children" nor did they view themselves as such. In fact, both families said that their families didn't have it so bad. In **Family A**, Janet tried to give Anna as many experiences as possible to be involved with other activities. Janet believes that most of their family functioning would not have changed all that much as it is presently, except for a few developmental issues such as the daycare, toilet training, and her communication. Otherwise Anna behaves in a typical teenage way; she loves music and vocalizes her wishes. For **Family B**, Ken and Marie have demonstrated throughout their interview that they tried to keep things as normal as possible for their children. They said that they were in charge of making rules and keeping the family structure intact as it always had been. They also kept the same level of routines (rituals), however those changed also with their children's age and development such as the children being able to stay up as late as the parents.

Level three: the family's worldview of the expectations, goals, and the orientation to the "outside" and "inside" of the family. For **Family A**, Janet may not have expressed any expectations or goals for Anna, although she does want Anna to have as independent a life as possible. Anna may live in a group home within a few years after she graduates from a transitional program that teaches her how to live independently as possible. Janet and Anna have both used "outside" resources to help them function "inside" their family. They view their communities that surround them as positive and supportive, are they are able to change their communities of support if they seem to receive negative feedback. For **Family B**, Ken and Marie have also shared how their expectations as parent's had to change because of their boy's abilities changed, such as the career options that they can chose or the level of competition in sports. As parents of two boys with chronic illnesses, they have not changed the way the household should function. Both boys are expected to contribute to the home, just like they always have. They also have used their surrounding communities for support as well as the families own capabilities.

Both of these families have demonstrated how chronic illness and the medical community have affect them and thus caused change within their family. Creating meanings from these experiences are as unique as each family is unique. Throughout the process of change the family comes to their meaning of the situation or belief. This is not a magical process, but rather given time and insight, families could create their own meanings and name them. This is why family stories are so important to help define a family and understand how that family interacts with the outside and inside worlds. When creating meanings for families regarding their chronic illness and their interactions with medical community, the context of the family's stories is what matters, not the process. Families do need to go through their individual change process in order to create their meaning.

CHAPTER V

Conclusion, Summary and Recommendations

This study was designed to begin the discussion of how families create meanings in the context of chronic illness and the medical community. This is an area that is just beginning to get research attention within the family social science arena. The family research community has made assumptions that families do create meanings because of how a family responses to change and creating a new homeostasis. What is not clear is “how” families go through this process. This pilot study is a beginning to examine expressly this dynamic process of families.

This study used concepts of family functioning that have been proven to be useful within the field of family research. These concepts were family reality, family stress, family loss, family strengths – focusing on family adaptability, family coherence, family coping, family rituals; family resiliency, the role of the medical community, and how families create meaning within these concepts. This framework of concepts was used to demonstrate how families create their meanings within these concepts of family functioning. This listing does not provide an exhaustive list on how to understand families, but rather these concepts were chosen due to their usability and have already been defined by past research. Thus, this study was building upon what has already been studied within the field of family research. The literature review covered in-depth each concept and how each concept could affect families with chronic illness. The literature review also examined the role of the medical community and discussed of how families create meanings.

The methodology of this study was very basic in its design. This pilot study was a qualitative study that used a small sample of two families. The narrative method was used to collect the data by recording the family's story. The questions were designed to elicit open-ended answers instead of "yes or no" or scaled responses. The narrative method allowed the participants to tell their story of the experience and ascribe the meaning to the situation as they saw fit. Also, since the participants were relaying the story to the researcher, the process of telling the story added to their meaning of the story. This researcher also used the circular questioning for Family B as they had two caregivers interviewed. This method was used to attain a richer description of each caregiver's view of the situation. The questionnaire also allowed families to have a "stepped removed" experience to observe how they viewed the role of chronic illness and the medical community within their family.

The two families who were chosen for the study were a convenient sample for this researcher. Each family had at least one child member of the family with a chronic illness and at least one primary caregiver who was interviewed. The study was conducted within one interview meeting. The meeting was audiotape recorded and transcribed to be analyzed by the researcher for themes. The children of these families were not asked to be a part of the interview as there would need to be a more complex human subjects review process.

The unknowns and limitations for this study were the possible emotions that the questions would elicit from the participants answering the questions. The researcher was prepared to give resources to the participants if needed. However, this was not needed. The main limitation was the small sample size (n=2 families) of the study. This small sample size was because it being this was a pilot study, and as qualitative research does take a lot of time to gather and analyze all of the data.

Eliciting the themes that came from the participants' answers to the questions (their stories) was the content for the data analysis. Other themes were not directly found within each families' narrative that each family relayed. This may be due to the fact the questionnaire was designed to elicit the story from prescribed concepts and not to elicit other concepts. The data analysis showed the differences and similarities of the themes that the families displayed in their stories.

Some reliability and validity were achieved throughout the study by using the same questionnaire with both of the families. The researcher then asked more questions that elicited more specific narrative from each of the families story. The researcher gave the study face validity by her experience working with families and their health issues. Thus, the content of the families stories was important to derive the meanings from them.

The researcher's role was to be strictly the interviewer. However, since each system affects each system, this researcher could not affect the way the families told their story. The researcher became part of that process and may add further meaning to the family and their story. The researcher's goal was to add the body of family research as well as to affect the "knowledge of practice" (Litchfield, 1993). Thus, this would affect the way families and the medical communities build collaborative relationships of healthcare.

The results of this study were mostly a narrative report from the participating families. The researcher changed her role from reporting the findings to narrator that clarified the missing information with her insight as well as observations of the interviews. Each of the family functioning concepts was discussed from the families' stories and there were no "new" concepts that were revealed.

Recommendations to continue with this area study would include much more than this one did. The researcher had to limit the scope of her focus thus why she used certain concepts in the literature review and not others. There are many more concepts and contexts that need to be studied in regards to how families create meanings.

Another suggestion that the researcher or observer could take would be to examine the family dynamics and structures. This would provide families with further feedback that could influence their story and then be part of the re-storying process. This feedback would expand, simplify and enrich the narrative from families regarding how they create their meanings. An example of this feedback would be the researcher commenting on the emotion behind the words that a member would narrative. Thereby, the researcher could infer different results by the tone of voice used without the person saying they feel that way.

The future for the area of families creating meaning is unlimited in scope and breadth. There are many more research findings to add to this area of study to make it more practical for people to use the construct of families creating meaning.

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Appendix A

Questionnaire Format – Sample

General Information

Names of family members

Ages of family members

Highest education earned

Ethnicity most associated with?   Socio-economic status?

How many years married or in the relationship?

Who has the illness?

When did the illness get diagnosed?

Who was in the family at the time of the diagnoses?

Who are the primary caregivers?

What was the family like before the diagnosis? (hobbies or activities outside the home)

What were the beliefs of illness, hospitals, and/or medical staff before the diagnosis?

**Where are they in the life cycle now and then?*

**In what ways did the family adapt to the illness?*

*These questions will not be asked directly, but will be answered either by researchers observations or by the other questions that indirectly ask these questions.

Role of Illness & Family

- How much has having a family member with chronic illness affect your family's functioning, calendar, caregiving, etc.?
- How have you coped with this illness? How have you seen the others cope with it?
- In what ways have you gained insight about this family and the illness? What aspects about this family have helped deal with the illness?
- What is the structure of this family? Who does what, when? How do you think (or know) that this has been, presently, or will be affected by the illness? How has this changed with the progression of the illness?
- Do you see or understand differences you have versus other families with same illness or other families face?
- If you have a family motto, what is it? Is this motto shaped by the illness or would this still be the same motto even without the illness? What kind of motto would you give to describe the family's present situation?
- What kinds of rituals do your family have (e.g. bedtime, bath time, game night)? Would this be different is there was no illness? Has the illness changed the rituals in your family?
- What are some of the "loses" as well as "gains" your family has experienced in regards to the illness?
- Does the family give the illness a role within the family consciously or unconsciously?

Role of Medical Staff

- In what ways has medical staff been most helpful to you as a family?
- In what ways has medical staff been least helpful to you as a family?
- In what ways have your family changed to incorporate or accommodate medical staff into your family (e.g., change behaviors, take medicine, services into the home)?
- How has your family dealt with interacting with medical staff, especially good or bad interactions with them?
- Has there been any disagreement or major change in your family due to advice or treatment recommended by medical staff? How has your family dealt with that?

Role of Community

- What types of resources do you use or support you have sought out that is outside of the medical staff and your “household”?
- How much of a role so these resources play in your family?
- How have they affected your family - positively or negatively – integrated or isolated your family?
- Growing up in your family, what beliefs or ideas did you learned from your family that you still believe today or shape the way you view illness and or medical staff?
- Has your spirituality or religious preference helped or hindered your experiences in general and then more specifically regarding illness? If so, how has it helped or hindered?

Appendix B

Sample Consent Form

This research study is being conducted to examine how families process the meaning of illness and the role of the medical community. The study will be asking a series of questions that will elicit the “story” of where you are now, where you have been, and how different people affected this process. These questions will gather how your particular family created these meanings, even without your knowing it.

Please read the following consent form and sign it if you are in agreement with the requirements, risks, benefits and the rights that you have as a participant. If you have any questions at any time, please contact me, Katherine M. Routt at (651) 890-4895 or at kat_pac@hotmail.com. Thank you for your considerations.

Requirements

At least one identified adult caregiver must participate in the study with as many other significant adult caregivers within the family. There must also be one child, at minimum, identified as the family member with the chronic illness.

There will be three meetings of one hour each in order to gather the information fully. Or if the family needs to restructure the interviews then the family and researcher will agree on the structure for the following meetings. Two meetings will be primarily for information gathering and the third will be a process meeting for the families to discuss anything that came from the other meetings.

Participants acknowledge that their answers will be audio-tape recorded and transcribed.
___________ initial

Agreement that the telephone is either turned off or not acknowledged during the meetings, including cell phones and pagers (unless it is an agreed upon emergency). The television is also turned off or that the interview is conducted a way from the television. The family will also make arrangements for the children to be located in another part of the home or not present within the home. All of these conditions are in place for aduiotape recording purposes as well as to keep distractability down to a minimum.
___________ initial

Risks

There is little or no risk to being a participant in this study and answering the questionnaire. The questionnaire may elicit aspects of your life that you may not have thought about which may cause some emotional or other discomfort. Please inform the researcher to process this response or to help you in some other way.

Benefits

Since this research study is to discover how your family has dealt with illness and the medical community, you may discover how much you have changed, your family has changed, or how much your views have changed. This is normal and mostly a welcomed discovery when there is time taken to discover these changes. Another benefit is for other families to read and acknowledge their growth in the future.

Confidentiality of Responses

Your answers will be kept in complete confidence and your name or any other identifying information will be changed to keep you anonymous. Only I, the primary researcher, will have access to your answers.
_________ initial

Right to Withdraw or Decline to Participate

Your participation in this study is entirely voluntary. You may choose not to participate without any adverse consequences to you or your family. Should you choose to participate and later wish to withdraw from the study, you may discontinue your participation at this time without incurring adverse consequences. The researcher asks that communication of such withdrawal be given.
__________ initial

I understand what I have read and agree to the above description, including the requirements, potential risks, benefits, and my rights as a participant. All of my questions about the study have been answered to my satisfaction and that I understand that I can ask questions at any time during the study. I hereby give my informed consent to participate in the research study.

Signature____ Date _________________