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RULING OUT THE 'BAD THINGS:' HOW PHYSICIANS MAKE MEANING OF PERSISTENT UNEXPLAINED ILLNESS IN CHILDREN

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RULING OUT THE 'BAD THINGS:' HOW PHYSICIANS MAKE MEANING OF PERSISTENT UNEXPLAINED ILLNESS IN CHILDREN

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by

STEFANIE VARGA

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Ruling out the "Bad Things": How Physicians Make Meaning of Persistent Unexplained Illness in Children

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ABSTRACT

This was a study of physicians' narratives regarding their medical experiences with children with persistent medically unexplained physical illness. The goal was to better understand those attitudes and beliefs that are involved in the construction of meaning regarding the child's symptoms of illness or pain. The study also sought to learn more about physicians' early life experiences with health and illness and their potential to shape diagnostic thinking and treatment. Ten physician participants were interviewed using an open-ended, semistructured interview methodology. Interviews were analyzed using an alternative narrative approach described by Mishler (1986, 1991) to identify key themes within and across interviews for comparative analysis. The subjective experience and dynamic discourse between interviewer and participant were also analyzed (Mishler, 1991; Paget, 1983).

Four key themes emerged: (1) the experience of certainty and uncertainty; (2) physician search for restitution; (3) the path to truth and the construction of the physician's illness narrative; and (4) the parallel anxiety between physician and parent. Findings suggested a "stages of training" model or developmental career theme associated with the ways in which physicians make meaning of persistent medically unexplained illness or pain in the child.

Implications for diagnosis and treatment include the possibility that the nature of the relationship between physicians and parents-- particularly the ability to negotiate
trust, intimacy, and power--may lead to a hidden and collaborative meaning making of symptoms that occurs in exclusion of the child. Certain early life experiences of the physician may also be brought to bear in the medical encounter with parent and child. Physicians would benefit from training in neutrality and negotiation of therapeutic goals with parents of sick children, as well as training to enhance self-awareness and understanding of the ways in which alliances and conflicts with patients and parents may occur as a result of family of origin issues.

Key words: child somatization, physician narrative, physician attitude, physician belief, physician stages of training, physician uncertainty
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Table 1: Demographic Summary of Participants
The flavor of this case is that there are still a lot of question marks. I can tell the story any number of ways, and I don't really know what the truth is. (JJ, family practice physician)

INTRODUCTION

At least one-third of physical symptoms for which patients seek medical care lack adequate medical explanation, even after extensive diagnostic work-up (Kroenke, 2003). "Somatization," which has been commonly defined as physical symptoms that are medically unexplained or inadequately accounted for on the basis of appropriate physical assessment (Lipowski, 1988), is a clinical problem that occurs in both adults and children, and is frequently found in primary care settings. In children, the phenomenon of somatization can be difficult to recognize given an overlap of symptoms with other disorders, such as anxiety and depression (Beidel, Christ, & Long, 1991; Bernstein, Massie, Thuras, Perwien, Borchardt, & Crosby, 1997; Garber, Zeman, & Walker, 1990; Garber, Walker, & Zeman, 1991; Pakalnis, Paolicchi, & Gilles, 2000). There is also evidence to suggest that somatization and organic illness can mimic one another (Litcher, Bromet, Carlson, Gilbert, Panina, Golovakha, Goldgaber, Gluzman, & Garber, 2001) and overlap (Okasha, Ismail, Khalil, El Fiki, Soliman, & Okasha, 1999).

Pediatricians and family practice physicians working in primary care settings are routinely challenged by reports of persistent unexplained pain or illness in children that is medically unexplained. Heterogeneity of symptoms, limited research and theory with respect to etiology and associated risk factors, and lack of developmentally appropriate diagnostic criteria for somatoform disorders in children have all resulted in significant
challenges in management, diagnosis, and treatment. Screening and identification of those children in need of mental health referral may be delayed due to limitations in physicians' appreciation for more biopsychosocial versus biomedical models of healthcare for children and limited information regarding the somatoform disorders. Delay in diagnosis of a somatoform or other mental health disorder in children with persistent unexplained somatic complaints and illness has been associated with long-term psychiatric dysfunction and functional impairment (Belmaker, Espinoza, Pogrund, 1985; Campo & Fritsch, 1994; Campo, Jansen-McWilliams, Comer, & Kelleher, 1999; Eminson, Benjamin, Shortall, Woods, & Faragher, 1996; Garralda & Bailey, 1986; Lavigne, Binns, Arend, Rosenbaum, Christoffel, Hayford, & Gibbons, 1998). Thus, the physician's role and its influence on the course and treatment of persistent unexplained illness or pain in the child may be critical, yet has not been systematically explored. This is particularly noteworthy considering that physician factors such as prolongation of uncertainty in diagnosis, generalized medical advice, lack of validation, and excessive reassurance of nonorganic causes are associated with maintenance and exacerbation of somatization (Campo & Fritsch, 1994; Stuart & Noyes Jr., 1999).

This study will explore how physicians perceive, understand, and manage persistent unexplained physical complaints and illness in children in their medical practice. What kinds of meanings are constructed by physicians regarding unexplained illness in children and what are the underlying belief systems associated with this process? To date, research into this issue has been lacking. The study will be qualitative and ethnographic in the sense that it attempts to understand the culture of physicians and the kinds of beliefs that are held within this context regarding the meaning of persistent
unexplained illness in children. Within the field of medical anthropology, ethnographic approaches have been most commonly applied to understand illness and medical treatment from the perspective of the patient; however, it stands to reason that similar approaches of inquiry with physicians will offer equally interesting and valuable findings. Increased understanding of how physicians conceptualize persistent unexplained illness in children may have important implications for the delivery of medical care and its experience by patients and their families. Physicians’ stories regarding children whom they have treated who present with persistent unexplained illness, as well as physician narratives regarding their own experiences with illness will be analyzed using methods of alternative narrative analysis developed by Elliott Mishler (1986).

This research is heavily influenced by the study of medical anthropology, which is concerned with the relationship between human behavior, social life, and health within the cultural context. It explores how knowledge, meaning, livelihood, and power are shaped by, and influence patterns of disease, experiences of health and illness, and treatment. Kleinman (1981) has advocated for the use of ethnographic methods, particularly narratives, to elicit meanings associated with illness and treatment. This approach seems equally important for understanding the beliefs, attitudes, and perspectives held by physicians regarding the meanings that are constructed regarding persistent unexplained illness in the child. While previous research has made anecdotal reference to the difficulties surrounding diagnosis and treatment of somatizing children and their families, there is currently no research that has given a voice to the physician regarding these experiences. As such, this study will be exploratory and descriptive.
CHAPTER ONE
BACKGROUND OF THE STUDY

My interest in child somatization stems from clinical training experiences in a medical setting in the southwest United States where the phenomenon of persistent and often chronic explained pain and physical complaints in children and adolescents were prevalent. Rates of unexplained pain, including abdominal and headache pain, as well as conversion type symptoms were frequently seen in children as young as 7 years of age, with DSM-IV diagnoses such as Pain Disorder and Undifferentiated Somatoform Disorder being frequently given. Physicians and mental health providers treating these patients and their families experienced challenges related to differential diagnosis. Feelings of frustration and exasperation were commonly reported by both physicians and the patients/families.

The current qualitative study emerged from attempts to collect data for an earlier quantitative study by the same author that explored possible psychosocial risk factors associated with pediatric somatization. The study attempted to investigate whether preadolescent females with persistent and unexplained somatic complaints exhibited unique psychosocial characteristics when compared to same age females with organic illness and psychiatric conditions, as well as those in good health. It was the hypothesis of this author that these unique characteristics might be associated with later development of a somatoform disorder, based on evidence that such factors have shown to have influence in adult populations.
Few participants were referred to the initial study, even after a year of data collection in various medical settings in two different states and cities. Attempts to discover why this was occurring revealed some important findings regarding how physicians experience and deal with young somatizing patients in their practice. For example, despite awareness of modern biopsychosocial theories of illness, physicians were observed to hold fairly dualistic perspectives regarding the mind and body. Conversation and interaction with physicians during the time of data collection also revealed a common set of attitudes and behaviors with respect to clinical management and treatment. Physicians generally voiced discomfort in referring cases to the original study given the ambiguity and complexity of cases, particularly concerning the presence of overlapping symptoms.

Determining whether the presenting symptoms and illness had an organic basis seemed to be the primary intent of most physicians. In cases where the child had received a basic medical work-up that revealed no clear organic findings, referral to specialists typically occurred, and the child and family were not always seen again by the primary care physician. Those that continued to be managed through primary care often remained in diagnostic "limbo." Physicians reported frequent use of informal diagnostic labels for lack of a clear ICD or DSM diagnosis. Physicians also repeatedly claimed that when a child did not have an active diagnosis, he or she did not qualify for the study, despite the fact that the child in fact met the qualifying criteria. Thus, lack of a clear diagnosis prevented many physicians from referring patients to the study. A certain kind of "resistance" was observed in physicians by the researcher in referring patients to the study. Few children with persistent unexplained pain and illness were referred for mental
health evaluations; however, in the rare cases when this occurred, patients were not followed up through primary care and thus were not able to be referred for the study.

In sum, the overwhelming impression from the initial study was a physician need or compulsion to rule out all possible medical explanations before considering other issues, including those of mental health nature. The most interesting finding from the initial study, although unrelated to the original research intent, was the observation and report by physicians of feelings of helplessness, frustration, and worry regarding their experiences with child somatization.

Given the challenges I was facing in finding suitable patients for the study, I expanded my data collection efforts to mental health settings. Given that some of the more complex "somatizing" cases were reportedly being referred to psychologists and psychiatrists, it was conceivable that eligible participants may be more readily found in mental health locations. Unfortunately, I had a similar experience with mental health clinicians; that is, a resistance in making referrals to the study. Clinicians spoke of cases where a diagnosis had not yet been given, or where "loose" labels were being used until a more formal diagnosis seemed appropriate. Clinicians expressed confusion as to whether the child's somatic complaints were secondary to an anxiety or mood disorder, or vice versa. A new challenge emerged: Many children who would have otherwise met criteria for the study had multiple overlapping mental health diagnoses. Clinicians reported that the clinical mix of cases involved greater chronicity and complexity than my research study was seeking.

The above discoveries led to a rethinking of my research focus and subsequent discussion with my core committee of those issues of potential and greater interest. This
process eventually evolved into a reshaping of the initial study into the current research study. Building on physicians' reports of their challenging experiences with children with somatization, particularly their difficulties with conceptualization of illness and differential diagnosis, I discovered that the literature on child somatization incorporated little discussion concerning the cognitive and emotional processes utilized by physicians in the management of children with somatization. No studies explored the belief systems held by physicians regarding persistent unexplained illness in children and what kind of influence these belief systems potentially had on diagnosis and treatment. The literature was limited to general statements of the clinical problem of somatization in children, in addition to anecdotal evidence of the challenge and frustration associated with these cases.

The current study is also informed by my clinical experience working in a pediatric setting in a city in the southwestern United States where physicians dealt with a higher incidence of cases of children with persistent somatic illness. My experience with these cases also illuminates my interest in the physician experience. It has been my experience that physicians frequently refer to psychological services those children with seemingly "psychosomatic" illness only after exhaustive medical testing has revealed no organic cause. My subsequent experience in behavioral health settings with these children and their families revealed much fear and frustration regarding the lengthy medical "work-up" process. Physicians also expressed a great deal of exasperation with this process, and more importantly, with their inability to find an answer, or medical solution for the child. Families referred to behavioral health were often, and understandably, defensive and frustrated at the suggestion that their child's problems were
"psychological," particularly after extended periods of somatically focused investigations. Thus, the process of medical testing, delay in diagnosis, and avoidance of addressing mental health issues early in this process generally left patients, families, and physicians dissatisfied and disconnected. Overall, I observed physician focus on biomedical models of health and illness combined with a general confusion regarding the somatoform disorders, limited consideration of psychosocial influences on illness behavior, and poor communication with families. My experiences with physicians in primary care settings during data collection for the initial study closely mirrored these clinical experiences.
A qualitative narrative research method was chosen for this study as it seemed most fitting to my purpose of exploring the lived experiences of physicians working with children with persistent unexplained illness. Discovering those values and beliefs that are involved in the construction of meaning of illness behavior in the child is interesting and important to understanding the clinical phenomenon of somatization in children. A qualitative narrative method is also consistent with my theoretical orientation in psychoanalytic theory and epistemology of social constructionism, constructivism and postmodern theory.

Social constructionism can be seen as emerging from the postmodern movement, being influential in the field of cultural studies. As a theory of knowledge, it explains how individuals and groups participate in the creation of their perceived reality (Berger & Luckman, 1966). The assumption is that social phenomena and social reality are created, institutionalized, and made into tradition by humans through an ongoing, dynamic process. Reality is reproduced by people acting on their interpretations and their knowledge of it. Social constructionism also supports the notion that knowledge, including the taken-for-granted common sense, is derived from and maintained by social interactions. When people interact, they do so with the understanding that their respective perceptions of reality are related, and as they act upon this understanding their common knowledge of reality becomes reinforced. Since this common sense knowledge is negotiated by people, human "typifications," "significations," and institutions come to be
presented as part of an objective reality. Thus, theorists within this perspective argue that what we know as "reality," is ultimately a social construction (Berger & Luckman, 1966).

Within epistemology, constructivism and constructionism share a common thread. Neither focuses on an ontological reality, but instead on the constructed reality. With respect to culture, constructivism further asserts that knowledge and reality are products of their cultural context. In this way, knowledge is contingent on convention, human perception, and social experience. Categories of knowledge and reality are actively created by social relationships and interactions, which in turn alter the way in which scientific episteme is organized.

Psychoanalytic theory, narrative psychology, postmodern theory, and medical anthropology all share a common thread of interest in the phenomenological account of experience and situated meaning within a cultural context. In particular, modern relational psychoanalytic theories focus on meanings that are co-constructed by both parties in a conversation or context, with communication carrying relational messages (Mitchell, 1988). This is true for researcher and participant, as well as therapist and client. The assumption that individuals tend to communicate what they think the other person can hear emphasizes "reflexivity," or the researcher's ability to actively reflect on their own role in gathering and interpreting interview data (Mishler, 1986).

This study is informed by several bodies of literature, including developmental perspectives and psychological theory regarding somatoform disorders in children, medical understanding regarding the 'somatizing' patient, the use of narratives in medicine and teaching, and medical anthropology and the social construction of illness.
A Brief History of Somatization

Historically referred to as "Briquet's syndrome," somatization in adults was first described by Briquet (1859), and was later described and elaborated by Guze (1967). Briquet observed that many of his patients developed psychosomatic symptoms before the age of 20, with one fifth beginning before puberty (Mai & Mersky, 1980). Around the turn of the century, the more commonly known psychoanalytic views of conversion emerged. For Janet, Charcot, and Breuer, easy hypnotizability and suggestibility in hysterical patients indicated a biological precondition to develop hysterical symptoms. Breuer and Freud (1955) later went on to observe that hysterical patients tended to suffer from repressed memories of traumatic events, with patients' conversion symptoms often disappearing when the memory of the event and its associated affect were brought into consciousness.

Freud's theories offer some insight into early theories of somatization (Freud, 1956; 1962). His ideas were integral in supporting the notion that psychological processes could be converted into physiological symptoms. He was the first to propose that ideas were rendered innocuous by being transmuted into some bodily form of expression. According to this perspective, psychologically traumatic experiences (such as sexual abuse) were believed to predispose patients to developing hysterical symptoms. Throughout his career he continued to emphasize the importance of traumatic childhood experiences in the development of hysterical symptoms.

Although the relevance and applicability of the historical literature regarding hysteria appears to provide a somewhat questionable foundation on which to build more precise conceptualizations of somatization, many modern concepts and theories regarding
the development of somatoform disorders continue to be based on the earlier work of psychoanalysts. In general, psychoanalytic theories propose that unconscious defenses block the experience of anxiety and force its indirect expression through bodily symptoms.

With respect to definition, the term "somatization" has been generally used to describe patients with somatic complaints that have not been found to have an organic basis. It is a generic term that subsumes a wide range of clinical phenomena. It is neither a medical or psychiatric diagnosis nor disease entity, but is best seen as a process that can be acute, subacute or chronic. Others have proposed alternative definitions to that offered by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association, 1994). For example, the definition proposed by Lipowski (1988) is most frequently cited in the medical literature. He defines somatization disorder as a tendency to experience and communicate somatic distress and symptoms unaccounted for by pathological findings, to attribute them to physical illness, and to seek medical help for them. This definition puts emphasis on the patient’s interpretation of the symptoms. Kellner (1991) conceptualizes somatization as involving the occurrence of physical symptoms that are not supported by recognizable or sufficient physical pathology; however, this definition does not rule out the presence of organic pathology altogether, nor does it make any assumption that psychological or emotional states are at the root of the problem, which Lipowski’s definition explicitly does. Lipowski’s (1988) definition of somatization is somewhat more encompassing as it does not exclude the possibility of physical illness coexisting with, masking, and/or facilitating somatization.
Somatization has also been considered in a broader, more etiologically neutral fashion as the experiencing and reporting of physical symptoms not clearly explicable in terms of a precise medical diagnosis or disorder. Aside from the presence of the symptoms, there is the medically unexplained or disproportionateness of symptoms to pathology, significant concern, distress, and impairment by the patient, and seeking of medical care. It is typically only as individuals become older that they exhibit the final two processes. In younger children, the parents may exhibit the concern and seeking of medical care (Kellner, 1991).

Contemporary theories of somatization involve sociocultural consideration. Shorter (1992) has provided an interesting theory of somatization that is both historically and culturally relevant. He has argued that somatization occurs as a result of unconscious selection from a wide symptom pool determined by individual and cultural factors, with symptoms being not random or unique, but learnt and cultural. Shorter demonstrates a succession of favored symptom choice in history, which is propelled by the medical profession. As medical theories and illness categories have shifted throughout history, somatoform symptoms have concurrently changed due to unconscious processes such as suggestion, legitimation, emulation, and compliance. Medicine in the 18th century was preoccupied with the nervous system, suggested by nervous complaints. In the early 19th century, spinal irritation and inflammation were most prominent (e.g., fits, convulsions, seizures, paralysis). By the 20th century somatic symptoms had become more discrete and sensory-based (e.g., headache, pain, fatigue), which Shorter blames on physician focus on the nervous system. Shorter's theory proposes that medical artifacts are negotiated between professionals and patients, leading to agreement that the complaints
in question are truly physical. Porter (1995) has also argued that cultural factors influence somatic symptoms. The establishment of a more individualist culture and greater introspection in the 20th century seems to have resulted in more private and personal expressions of pain (e.g., headache, chronic pain).

Currently, Western medicine tends to assume that if a medical investigation is negative and the problem is not physical, it must be “mental” (Sharpe, Mayou, & Bass, 1995). Thus, disease is most commonly viewed as having a biological basis. This view naïvely conceptualizes the mind and body as separate entities. While it seems neither accurate nor productive to regard patients’ somatic symptoms within this dichotomy, it seems to be the rule rather than the exception in current medical practice. Consideration of the integration of biological, psychological, and social aspects in the formation of somatic symptoms is critically needed (Sharpe et al., 1995). Bass (1990) has suggested that physical symptoms should be seen by physicians as being a part of a process of making meaning out of experience. While putting one’s emotional responses and issues into one’s body or bodily form is possible, this does not mean to imply that there is a dualistic and linear mind-body mechanism. The dualistic conceptualization of the mind and body fails to account for the holistic concept “where the person not only expresses himself in all dimensions, in mind, body, and action, but where, more than that, all these expressions occur simultaneously” (Bloom, 1997, p. 23).

**Developmental Perspectives**

Clear links between child and adult somatization have been supported (Fritz, Fritsch, & Hagino, 1997); however, knowledge regarding those variables that are critical
in effectively linking somatization as a typical method of coping to the development of long-term maladaptive illness behavior into adulthood does not exist. A lack of longitudinal studies of children with persistent unexplained pain and illness has limited our understanding of the developmental aspects of somatization and knowledge regarding prognosis. Nevertheless, unexplained and recurrent physical symptomatology in childhood does appear to predict similar symptoms in adulthood (Hotopf, 2002).

Studies have suggested that somatoform illness in children tends to follow a developmental sequence, with the number of physical symptoms increasing through childhood into adolescence (Garber et al., 1990; 1991; Offord, Boyle, Szatmari, & Rae-Grant, 1987). Although age may be an important factor in the type and frequency of somatic symptoms experienced and reported, few longitudinal studies have been carried out in the pediatric age group. Reports of unexplained physical symptoms in females tend to increase in frequency and intensity between the ages of 9 to 14 (Campo et al., 1999; Eminson et al., 1996; Garber et al., 1991; Hetland, Torscheim, & Aaro, 2002; Larsson, 1992; Oster, 1972; Walker & Greene, 1991). Somatization appears to peak in late childhood or early adolescence (Garber et al., 1991).

The function or purpose of persistent unexplained physical complaints and illness in children has been questioned. The process of developing a somatoform disorder is likely more complex than simple increases in the frequency and severity of unexplained somatic symptoms over time. For example, in healthy children, unexplained pain or physical complaints may represent a response to external stress or developmental crises. If this mechanism is not interrupted as time passes, the pattern may become entrenched
and specific to conflict or even generalized as a primary means of coping. Few studies have investigated such theories.

Difficulties with screening and early diagnosis of somatoform disorders in child populations can be blamed on the fact that no pediatric criteria for somatoform disorders exist. Research with children with somatization has been limited, especially longitudinal studies that have the potential to advance understanding regarding the developmental nature of somatization. Thus, children with persistent unexplained physical symptoms who do not meet criteria for a somatoform disorder tend to be managed by physicians for extended lengths of time before being referred to mental health. The need for more developmentally appropriate criteria for childhood somatoform disorders is further underscored by the fact that the pattern and number of symptoms experienced, the nomenclature used in reporting the symptoms (including the importance of parents in making the report), and the degree and type of functional impairment associated with somatoform disorders all differ in child, adolescent, and adult populations (Fritz et al., 1997).

**Factitious Disorder and Munchausen by Proxy**

Children with "somatization" often present with unexplained physical symptoms that are not intentional or under voluntary control and are understood by the patient and family as having a clear medical cause; however, they may be confused with disorders in which patients are intentionally simulating or creating their problems. For example, persistent medically unexplained illness or pain in the child may be confused with factitious disorders and malingering. For such cases, symptoms are intentionally
produced or feigned, or false information is given intentionally, whereas in somatoform disorders intentional deception does not occur. For the adolescent with a factitious disorder, self-injurious behaviors or simulated somatic complaints may be carried out consciously, but for unconscious reasons (e.g., the adolescent assumes a sick role to obtain the caring that comes with medical treatment). In contrast, malingering symptoms are produced in the context of readily apparent external incentives for the behavior, such as the avoidance of school or an uncomfortable group situation, economic gain, or avoidance of legal responsibility. In factitious disorder, there is typically no clear targeted gain. Those patients who are “malingering” typically have a very specific goal in mind as an outcome for the feigned symptoms. Factitious and malingering disorders in young children are very uncommon, being more frequently seen in late adolescence and early adulthood.

A DSM-IV diagnosis of factitious disorder is synonymous with the disorder referred to as Munchausen syndrome by proxy. Munchausen by proxy is understood to be a specific form of child abuse in which a parent fabricates or produces illness in a child and/or creates physical signs that persistently result in medical treatment. With older children, depending on their participation in the presentation, the child may be diagnosed with Factitious Disorder and the parent diagnosed with Munchausen by proxy (American Psychiatric Association, 1994).

A number of differential diagnoses may be considered when the primary caregiver is dealing with persistent reports and presentations of illness and pain in the child without clear medical cause. These include the somatoform disorders, neglect and failure to thrive, direct physical abuse injury, delusional parenting, anxious parents
combined with a vulnerable child, chronic illness in the child, help seeking parents, and factitious disorder by proxy, or Munchausen by proxy. For some health care professionals, awareness regarding the possibility of a Munchausen by proxy diagnosis is limited (Ostfeld & Feldman, 1996); while for others it may come more readily to mind when treating the child with apparently medically unexplained and persistent illness or pain. It is a diagnosis more commonly identified in young children versus adolescents (McGuire, 1989).

A list of possible signs and symptoms of Munchausen by proxy show great overlap with other disorders, including somatoform disorders, factitious disorders, and malingering. For example, persistent or recurrent illnesses for which a medical cause cannot be found; discrepancies between history and clinical findings; symptoms and signs that do not occur when a child is away from the mother or caregiver; unusual symptoms, signs, or hospital course that do not make clinical sense; persistent failure of a child to tolerate or respond to medical therapy without clear cause; a parent less concerned than the physician; some times comforting the medical staff; repeated hospitalizations and vigorous medical evaluations of mother or child without definitive diagnoses; a parent who is constantly at the child's bedside, excessively praises the staff, becomes overly attached to the staff, or becomes highly involved in the care of other patients; a parent who welcomes medical tests of her child, even when painful; and frequent comparisons of the child's medical problems to those of the parents. Additional warning signs of Munchausen by Proxy may include the accusing adult knowing more about what allegedly happened than does the child, distortion of the truth by mother or child of symptoms, manipulating information by omission, or fabricating information of
any kind, and a united front between mother and child; however, all of the above symptoms may also be present in other disorders, including the somatoform disorders.

Psychological Theories of Somatization

The predominant theoretical approaches to understanding 'somatization' tend to overlap, but are generally offered as distinct in the literature. Within this section I will briefly review the main theoretical standpoints from which persistent unexplained somatic symptoms have been viewed.

Psychoanalytic and psychodynamic theories tend to view unexplained physical complaints as being produced by the unconscious mind to serve a primary function or gain (e.g., repression of dependency needs, defense against threat to psychic equilibrium, protecting self-esteem from blame due to perceived failure). Symptoms may also facilitate secondary gain in the environment (e.g., avoidance of responsibility). The basic tenet of Freud's (1894) conversion hysteria theory was that anxiety aroused by unconscious conflict is converted into physical symptoms. As the conflict is intolerable to the conscious mind, it is not acknowledged. However, the more "socially acceptable" physical symptoms are a way of expressing distress. The person is not aware of this process, as it occurs at the unconscious level. The gain for the person is the reduction in awareness of the conflict and therefore the reduction in anxiety.

More recent psychodynamic theories of somatization include problems with expression of affect in language, or "alexithymia," which are considered to contribute to the expression of psychological distress through bodily symptoms (Sifneos, 1973). For example, Bucci (1997) has proposed that a disconnection occurs during development
between verbal and nonverbal information systems and between symbolic and subsymbolic processing forms. The nonverbal system incorporates representations and processes in all sensory modalities, including motoric and bodily forms. In terms of this model, somatization involves a dissociation within emotional schemata, between somatic activation patterns and the symbolic representation of objects. Following this line of reasoning, it might be hypothesized that since children's cognitive and verbal skills are less developed than adults, they are more prone to expressing distress in the form of somatic symptoms. Research has shown many links between "alexithymia" and somatization (Deary, Scott, & Wilson, 1997; Bach & Bach, 1995) and also pain disorder (Cox, Kuch, Parker, Shulman, & Evans, 1994).

Object relations theory suggests that deficiencies in the early mother-child relationship result in structural psychic deficits in the child, specifically an inability to use imagination and language to communicate distressing and unbearable feelings. A paucity of fantasy life and dream experiences has been associated with individuals who have difficulty expressing their emotions in words, which in turn leads to a propensity to use the body as a tool for communication. Research has demonstrated that individuals with preoccupied and insecure attachment styles tend to report greater numbers of somatic symptoms and have higher primary care costs and health care utilization (Ciechanowski, Walker, Katon, & Dwight-Johnson, 2002).

Cognitive-perceptual theories in psychology view persistent unexplained physical symptoms as resulting from a complex interaction between cognition, perception, mood, behavior, and physiology. Perceptual theory suggests that selective amplification and perception of bodily changes are associated with emotional processes such as anxiety or
depression. Theories in cognitive psychology view the patient's attributional style as determining how symptoms are perceived as well as what treatments are sought. Within this perspective, preoccupation and focus on somatic symptoms prevents psychological insight (Hawton, Salkovskis, Kirk, & Clark, 1989). Irrational beliefs have also been associated with misinterpretation or exaggeration of symptoms, which in turn lead to anxiety, depression and maladaptive coping.

Within the social learning perspective, persistent unexplained physical symptoms are viewed as "illness behaviors" that are learned from others, or from personal experience with pain and illness. Essentially these behaviors serve as a type of communication and validation of the "sick role." According to this perspective, somatization may serve an adaptive function by avoiding the stigma of mental illness (Bridges & Goldberg, 1985). Along these lines, Szasz (1960) argued that hysteria was not a disease, but rather a set of behaviors that did not fit with social norms and assumptions of medical materialism. Social learning theories in psychology provide a framework for understanding the social construction of illness and are closely linked with theory in medical anthropology. Advantages of social learning theories of somatization are their inclusion of social and cultural issues that are often overlooked as playing an important part in the maintenance of symptoms, as well as the success of certain therapeutic interventions. The theory focuses more on the meaning and function of somatization rather than its origins.

A perspective worthy of consideration given the goals of this study are pathophysiological theories of somatization and their relevance to persistent unexplained illness or pain in the child. Within these models, physiological processes are believed to
play a key role in the etiology of symptoms. The hypothesis is that activity of the autonomic nervous system and skeletal and muscular systems are defective, particularly overactive. Some examples include increased motility in the gut as an explanation for recurrent abdominal pain, hyperventilation in patients with unexplained chest pain, or neurological pathology resulting in heightened pain perception. Anxious and hypochondriacal adults have been found to have greater awareness of bodily functions (Tyrer, Lee, & Alexander, 1980). Such theories are less comprehensive when taken alone; however, they serve to encourage greater exploration of biological systems in contributing to symptoms that could potentially lead to rational treatment. Combination therapy including self-monitoring of pain, limiting attention to symptoms, relaxation therapy, and encouraging participation in regular activities has been found to be helpful for children with unexplained abdominal pain and headaches (Finney, Lemanek, Cataldo, Katz, & Fuqua, 1989; Larsson, 1992).

Most recently, theorists have argued for an integrationist approach to the understanding and treatment of somatoform disorders. Within this perspective, persistent unexplained somatic symptoms are viewed as involving multiple interacting factors, including biological, social, psychological, and cultural (Sharpe et al., 1995). Few studies have undertaken in-depth investigation of various contributing and interacting factors in the etiology and maintenance of child somatization.

**Medicine and the “Somatizing” Patient**

The medical literature on somatization tends to be somewhat limited in enhancing our understanding of the process of somatization itself. Origin of symptoms,
maintenance and exacerbation of symptoms, and treatment are speculated upon from a fairly narrow pathophysiological perspective. What seems most present in the literature is the statement of the fact that certain somatic symptoms cannot be attributed to any clear organic origin. Thus, the separation of mind and body in understanding the somatoform disorders continues to be present in medicine, with physiological processes being believed as playing a key role in the etiology of symptoms. Stress theory or theories regarding overactivity of the autonomic nervous system and skeletal and muscular systems dominate. Heightened awareness of bodily functions has also been proposed (Tyrer, Lee, & Alexander, 1980). This theory is less comprehensive when taken alone; however, it does encourage greater exploration of biological systems in contributing to symptoms that could potentially lead to more rational treatments besides psychotherapy, including self-monitoring of pain, limiting attention to symptoms, relaxation therapy, and encouraging continued participation in regular activities. Medicine’s awareness of the involvement of certain psychosocial factors as contributing to symptom expression exists in the literature; however, the process by which certain emotions or internal experiences become manifested by the body are more elusive. The focus in the medical literature of somatization, and particularly that of child somatization, is the ruling out of medical cause. When exhaustive searches fail to locate a physiological truth of illness, mental health referrals including those to psychology, social work, and psychiatry often ensue.

Studies that have explored the more personal beliefs, attitudes, intentions, and behaviors regarding health and illness focus more on the patient versus physician. An exhaustive literature search through several medical databases revealed many articles where reference is made to physician attitudes and beliefs regarding specific medical
illnesses or diagnoses. Articles that outlined personal perspectives and attitudes regarding treatment efficacy, as well as opinions regarding patient diversity could be easily found; however, data collection methods focus heavily on the use of surveys and questionnaires. Few, if any studies, explored physicians' early personal experiences with health and illness, let alone the ways in which certain attitudes and beliefs have been formed from these experiences and in turn shape their understanding of illness or pain in their patients. Research that has explored the impact of health beliefs on illness have centered on the patient as opposed to the physician. There is a substantial body of literature that addresses health beliefs of patients and their influence on the course of illness, prognosis, and recovery.

Few qualitative studies exist that have investigated how physicians' belief systems regarding illness may impact clinical practice. In a relatively recent qualitative grounded study by Yamada, Maskarinec, Greene, and Bauman (2003), medical students' narratives about personal illness experiences revealed significant themes, including the role of family members in illness episodes, influences of ethnicity or religion, experiences with socially unacceptable illnesses, experiences with death, appreciation of the moral trajectory of illness, and attitudes regarding the fallibility and limitations of medicine. The authors suggest that the physician narrative is central to increasing understanding of patients and providing patient-centered care.

Aside from the formal medical school curriculum, fundamental attitudes and perspectives regarding health and illness may be held by physicians that have the potential to impair professional growth and development, prevent the development of genuine relationships with patients and others, and lead to inadvertent negative attitudes
and behaviors in medical practice. It has been noted that traditional medical education provides little help in developing the skills required for self-awareness, specifically exploration of feelings in relation to their personal and professional roles and relationships with parents (Polliak, 1992).

Self-awareness is believed to be of necessity to mastering those interpersonal skills required of the physician for effective patient communication. Unfortunately, however, it is these aspects of medical training and practice that physicians find their skills most deficient. These deficiencies were observed in the 1950s by Michael and Enid Balint, who pioneered training seminars based on case discussions by groups of family physicians. The "Balint Groups" were usually led by a psychoanalyst over a period of several years. Although not generally utilized today in medicine, "Balint Groups" may represent an updated practical approach to the problems of most family physicians and other members of the primary care team.

It is important to recognize that contextual factors have an important influence on physicians' evolving explanatory models for commonly encountered problems, especially in the absence of formal training (Williams & Wood, 1986). For example, the clinical context of informal learning may influence practice with patients with persistent unexplained pain or illness for whom no clear medical diagnosis can be found. These patients, above all others, elicit feelings of frustration, sorrow, anger, and even despair, both in the physician and the patient. This is because physicians generally feel happier treating the patient in the traditional framework where the focus is placed on the presence of physical symptoms and diagnosis. Unfortunately, this limited, restricted, confining situation tends to de-emphasize communication with the patient and acknowledgement of
the whole person including personality, family, and social environment and their
influence on illness.

Socialization of physicians includes certain values and attitudes that are learned,
including a dynamic balance between detachment and concern, and clinical objectivity.
For example, in medical school, physicians often develop what has been called "detached
concern" as a means of coping with the helplessness and vulnerability they feel when
increasing demands are placed upon them, while simultaneously providing patient
empathy (Lief & Fox, 1963). Objectivity is the ultimate goal of physicians; however, this
can lead to emotional distancing from patients in clinical encounters and gaps in
communication in the physician-patient relationship (Hauser, 1981). Cynicism and
diminishing idealism have also been found in medical students during the passage
through medical school (Fox, 1957).

It is likely that the same beliefs that contribute to a patient's understanding of
illness, such as beliefs regarding the normality of illness, interactions with health care
providers, mind-body relationships, control over outcomes, ideas about the cause of
disease, cultural views of illness, expected roles and behavior, and the willingness to shift
beliefs as needed, similarly contribute to physician understanding of illness (Rolland,
1998). Physician beliefs may have important implications for treatment, yet there is a
lack of qualitative studies that have investigated these issues in-depth.

The Physician-Patient Relationship

There exist unspoken rules that seem to govern interactions with health care
providers. Among these are "the physician is the expert," the physician as being
responsible for change, and simple classification of symptoms as sufficient to determine successful treatment (Jabar, Trilling, & Kelso, 1997). Although society is implicated in the misuse of power, medical training can also be viewed as providing physicians with abilities beyond their training. Saba (2000) argues that the training of physicians fosters the belief that physicians can control disease, and by logical extension, control people with disease. Since the physician determines which treatments to present and asserts greater knowledge about the illness, the patient remains at a disadvantage. Consistent with a physician-centered approach, decisions about illness typically exclude family input (Goodrich & Wang, 1999).

More holistic and relationship-oriented approaches to medicine require physicians to learn ways in which to discuss their own beliefs about illness and the process of healing. The fit between the physician and patient’s beliefs has important implications for compliance (Rolland, 1998). For example, patients tend to have the desire to recruit social support and the contrary biomedical beliefs of the physician; however, the opposite is also possible if a physician is relationship-oriented and the family prefers a biomedical explanation. Rakel (1992) states, “When caring for a patient, the doctor must remain aware of his or her own personal experiences and beliefs that may influence that care” (p. ix). Polliak (1992) similarly notes that “Physicians are inevitably influenced by personal and cultural background and values, life experiences, beliefs and prejudices, educational and professional status, perception of the role of the physician and the individual, and the positive or negative feelings and emotional responses that the patient evokes” (p. xiv).
The idea of fit between physician and patient beliefs becomes especially important when the physician is unable to find a biological cause for symptoms, such as the case with patients with somatization. While such cases require a discussion of the impact of psychosocial factors, this may be a problem if physicians are not open to exploring psychosocial issues and their impact on health and illness. The most common pattern that emerges in cases where psychosocial factors are found to be influencing illness is that patients will generally hold to the belief that biological problems are causing physical symptoms. When a physician determines that psychosocial factors are influential and discounts the beliefs of the patient, the tendency is for the patient to argue against the physician's position. This, in turn, leads to the physician labeling the patient as "somatizing" or "difficult." Labeling the patient creates an impasse and inspires the patient to search for another doctor, thus starting the cycle all over again. Although the child with persistent unexplained illness is referred to as the identified patient, it is typical for conversations regarding symptoms, diagnosis, and treatment to occur between the child's parent and the physician. Thus, parent beliefs regarding the meaning or causes of a child's illness and what are expected from the consultation likely plays an important role in medical management of such children. Understanding of the relationship between parents of children with persistent unexplained illness and their physicians and the fit of "beliefs" regarding the meanings of illness have not been explored, but is likely to have implications for the course of illness and treatment.

Today, the ability of the physician to explore the entire spectrum of possibilities with respect to the factors influencing illness is determined to some extent by the increasingly imposed time constraints of managed care. Consequently, current health care
trends have made relationship-oriented approaches to medical treatment difficult to employ (Goodrich & Wang, 1999), leading some physicians to reduce their efforts in this direction (Saba, 2000). As the demands on physicians' time increase, the burden of intervention typically falls to mental health professionals.

Thus, discussion of the subjective experiences of the physician has not played a prominent role in the theoretical model of modern medical science. Medicine today continues to place emphasis on the physician's impressions and interpretations of the patient's story and complaints, physical examination, and subsequent medical tests. Thus, diagnoses and recommended treatments are provided based on the professional and personal authority of the physician and the patients' trust. Discussion of the doctor-patient relationship has not been included in the core of modern scientific biomedicine.

Use of Narratives in Medicine and Teaching

Theorists have claimed that "narrative psychology" refers to a viewpoint or a stance within psychology that is interested in the "storied nature of human conduct" (Sarbin, 1986). This perspective emphasizes how human beings deal with experience by constructing stories and listening to the stories of others. Psychologists studying narratives are challenged by the notion that human activity and experience are filled with "meaning," and that stories rather than logical arguments or lawful formulations, are the vehicle by which that meaning is communicated. This dichotomy is expressed by Jerome S. Bruner (1986, 1990) as the distinction between "paradigmatic" and "narrative" forms of thought which he claims, are both fundamental and irreducible to one another. Sarbin (1986) proposes that "narrative" becomes a root metaphor for psychology to replace the
mechanistic and organic metaphors which have shaped so much theory and research in the study of psychology over the past century.

A general assumption of narrative analysis is that telling stories is one significant way that individuals construct and express meaning. Human beings think, perceive, imagine, and make moral choices according to narrative structures (Sarbin, 1986). It is believed that stories provide descriptive phrases, pictures, and meanings that occur in patterned ways, which in turn are held together by implicit or explicit uses of plot. Stories also are thought to inherently reflect human sentiments, goals, purposes, valuations, and judgments, which are fundamental in the shaping and organization of episodes, actions, and accounts of actions, reasons for subsequent action, and causes of what is happening (Sarbin, 1986). There has been wide recognition by anthropologists, linguists, psychologists of the narrative or "storied account" as being important to understanding events and experiences of the individual. The interview, whether in therapy or research, serves as an instrument for storymaking and storytelling (Mishler, 1986). Mishler argues that storytelling and story comprehension are natural and pervasive modes of communicating meaning. Schafer (1980) has also examined the practice of psychoanalysis from a narrativist viewpoint and suggests that the narrative metaphor be used to illuminate human action, consistent with humanistic theories and contrasting sharply with conventional, mechanistic, positivist, and formistic theories.

Narrative study has been used in medicine as means to increasing understanding of the patient. More recently there has been an interest in the narrative interview and study of physicians and other healthcare personnel regarding their experiences with patients. The use of narrative analysis to interpret physicians' stories offers a unique
opportunity to gain insight into how meaning is constructed and expressed in medicine at the personal level. More importantly, it helps to understand how these meanings influence the provision of medical care. Contemporary thinking regarding physicians' feelings derives from Balint and his recognition that the doctor-patient relationship was more subtle and had a powerful influence on the patient. His approach emphasized the use of transference and countertransference in diagnosis and treatment. According to Balint, doctors' feelings were recognized as having a clear function in the consultation (Balint, 1957).

Storytelling in medicine dates back to the beginnings of medical knowledge, with medical journals in the early 1800s providing stories of illness and accounts of their use in teaching; however, modern times have seen a decline in storytelling in the medical field, due to an emphasis on scientific theory and the classifications of symptoms and disease. Thus, the value of stories to modern medicine has been generally perceived as limited. There still exists an emphasis on evidence-based clinical practice and an expectation to act on the basis of randomized clinical trials. Personalized and particularistic reports have led to concerns of errors in diagnosis and treatment, if generalized. In our time-driven managed care era, listening to stories has also been considered nonessential and unimportant. Borkan, Miller, and Reis (1992) have noted that since stories in medicine have traditionally been referred to with pejorative terms such as "anecdotal" and "unscientific," physicians have either lost, or at least neglected their ability to listen to, and to tell stories regarding their experiences with patients.

Doctors' Stories
Borkan and colleagues (1992) found that physicians’ stories are more than simple recollections of encounters with patients, but provide opportunity to reveal things about themselves, including feelings, reconstructions, and representations of events. While the truths in physician narratives are inherently partial, constrained by the incompleteness of the representational process, their ability to provide insight regarding the process of diagnosis, with the implicit and explicit formulations, reframes, resolutions, and feelings regarding interaction and meaning making in illness are critical. According to their research, physicians more often share “restitution narratives,” or stories with a clear resolution (Borkan et al., 1992; Hunter, 1991). The “restitution narrative” is a term that was originally coined by Frank (1995), a medical anthropologist and physician, to describe one type of story told by patients who have faced a critical illness. The patient restitution narrative focuses on the gifts that illness can impart. The happy story endings imply that suffering comes to us, but that it cannot overwhelm us. Restitution narratives told by patients cast the professional in the role of hero and as all powerful in curing the patient. This type of restitution narrative arises from the expectation that medicine will get you better. Within this framework physicians are often regarded as heroes and experts, and patients as the tragic or long-suffering victims that are cured of their afflictions.

Restitution narratives told by physicians are not so dissimilar from those told by patients, with one exception. The patient tells of the effect of the illness on a life, whereas the doctor tells the story of the identification and treatment. When physicians do tell stories, they are often more willing to describe the patient’s illness experience and are reticent to delve into their own roles and deliberations, thus the story of the identification
and treatment. When physicians find that they cannot give good news or cure the patient, they may feel terrible and even impotent. Thus, restitution narratives are often shared over stories that invoke a sense of failure that comes with accepting death or failed treatment. An example of a restitution narrative shared by a physician in the pilot study is provided below:

I'm thinking of....a girl. I did a house call on this one. Fourteen year old basketball player who had intermittent abdominal pain and she had had a bit of a workup, not very extensive, and they didn't get into it very far. I had a relationship with them, both the family and the 14 year old. She was under ENORMOUS pressure to be perfect....she was a top student, a great athlete. Everything about her was supposed to be perfect! I got a call on a Saturday, and she had just finished a basketball game. She was declared to be fainting...she was having hyperventilation. The parents were declaring that she was dying... or something to that extent (smirking). What happened was that she was the star player on her basketball team, and there had been all this tension around being perfect, and her abdominal pain had kind of exploded then. She didn't know what she had, and she was VERY upset. It came down to this one basketball game. She missed the throw, and she felt just crushed. Right after that game she started hyperventilating....almost had a seizure right there on the floor, and there was a big deal surrounding it. They called an ambulance, and they declared her to be fine....When she got home she started to feel the same way again, weak and hyperventilating.

So under those circumstances, I went to see the family. When I was there, we finally got to the question of, for her, whenever she had the least perfect result.... like a B in a class, or whatever it was, in this case missing the lay-up..... it was an abject period. The parents hadn't been aware that this had been happening, of what was going on. I got there at the time of the crisis. In this case they (the parents) could rethink the focus. It had been abdominal pain and it had just been developing, it had not really solidified yet. It had just started a few months prior. I hadn't really tied into it yet. I had seen her a couple of times and I was dragging my feet to do the big evaluation..... This event came up and I think it short-circuited what would have smoldered and smoldered....

After I talked to her, it all stopped RIGHT THERE (facial look of surprise). Once she could laugh at the fact that imperfection is a part of life! It's such a concrete example, with this sporting event. And for some reason it just crystallized for her, that you know, she was a still a great team player, and it was just a game, and
they played others. She could put it into perspective. But it accelerated when she realized that her body could express itself in this odd way.

Interviewer: How did you help her come to this realization?

Well, part of it was that, again, the crucible of a symptom that was very dramatic and public and a big deal...there were people around...it was humiliating to her and terrible! She thought, it must be something very terrible for me to collapse like this. So, under that crucible, she would start to hyperventilate again, and we would short-circuit it together. Then I just kind of talked her down. Then I prescribed the symptom...and then we just laughed at how odd that was. That she could try to bring it on one night, and we could describe it. The parents stuck with me on that.... Once we talked about it, it got better. Again, because it hadn’t really been established, and I knew we could short-circuit it, short-circuit the whole thing. But you know, she was not symptomatic for very long at all. It hadn’t really been built in yet.

The above story contains many components of a typical restitution narrative. In the story, the physician plays the role of hero and expert, essentially coming to the rescue of the victim and “short-circuiting” a problem that had the potential, reportedly, to become even more challenging. The fact that the physician is called to make a house call, following the essential failure by EMTs to help the patient further emphasizes his role as hero. The physician does acknowledges some “luck” in his timing, admitting to initially “dragging” his feet to conduct medical tests; however, ultimately is able to provide a happy ending for the patient. He reasons that his “cure” for the child is successful due to timing. He tells how her symptoms were not long-standing and entrenched. The physician’s excitement and positive affect while telling the story further emphasized his reexperiencing of the incident as restitution – a happy ending for the child and the parents, as well as an achievement for himself as a physician and the field of medicine. The story he tells has high drama, and he tells it with enthusiasm so that I feel
as though I am watching the incident in real time; first as a fan at the game, and then an observer (or perhaps even the physician) in the child’s home.

Whether the narratives of physicians who have provided care and treatment to children with persistent unexplained physical complaints and illness will reveal the same bias toward telling restitution narratives is unknown. My clinical experience in a pediatric setting and observations from the initial study and pilot interviews revealed a physician preference to present neatly wrapped stories where a solution or cure was provided. Otherwise, the stories were not typically shared without further probing.

Stories that have no closure or end to the story do not seem satisfying for physicians, as the path and final outcome are not clear (Hunter, 1991). These stories have been referred to as “quest narratives” (Borkan et al., 1992). It is interesting to note that “quest narratives” as initially defined and told by the patient tend to describe a challenge to be met (Frank, 1995). Ill people who tell quest narratives typically see themselves on a journey in which heroic acts will be necessary and where good can overcome evil. Conversely, the same stories may represent a failure to physicians, as no solution has been found (Hunter, 1991). It is possible that the quest narrative for the physician is similar to the chaos narrative of the patient, as described by Frank (1995). That is, chaos narratives are not really stories, for they tend to have no real plot. Its teller circles round and round, describing, from a perspective of deepest despair, the grim details of suffering. There is no solution or hope of restitution. Frank observes that chaos narratives, though torturously painful for those enduring them, often remain unspoken. Like the chaos narrative to the patient, the quest narrative for the physician may be the most difficult, as it offers no end in sight for resolution or cure.
“Failure narratives” are not usually shared as they portray an inability to heal and inherently suggest confusion and helplessness. A few authors have shared their narratives of failure. Borkan (in Helman, 2006) recently provided an example of a narrative of his experience working in a foreign country. He is faced with resuscitating a young bride at the scene of a car accident. His chaos narrative ends with the death of the young patient. While the emergency log is written in medical vernacular, his narrative captures the emotions, the sights, and the sounds of the incident. He says,

_Time spread out and slowed to a trickle. The road was quiet save for the deep whirring sound of the floodlights generator and the peaceful whoosh of the resuscitator. How beautiful is the desert wind and vista at night: all around us the parched desert browns, grey, and black of the valley, mountains, and sky, save for the inestimable stars, her pale skin, and open green eyes. The army doctor raised his gaze from the woman and said, "All is done." I looked at his somber expression and nodded without comment or outward show of emotion. We stopped, covered her body with a blanket, not thinking to close her eyes. I went to the side of the road as she was placed on the stretcher and into the ambulance. I am unsure whether I spoke to the husband, unsure of whether I filled out the accident report or let it go, or even what I had felt. Had I risen without sentiment, detached, or had I cried over the loss of life, promise, and my failed efforts? After some minutes, I slid into my car and drove back into the enveloping darkness toward my home. The community of 300 was dark when I returned, except for the spotlights surrounding the perimeter fence, a few communal buildings, and the cowsheds. When I reached my doorstep, I listened for chatter, but my wife and children were asleep, breathing softly and assuredly. I shed my bloodied clothing at the door and left it in a pile on the porch. Then I bathed long and hard—feebly attempting to clean off the pale of death—had a glass of wine, said a blessing on each of my children, and fell into a troubled sleep. Reflection could come later.

Ultimately, the author modifies his chaos narrative into a restitution narrative by sharing those aspects of the incident that offer opportunity for reflection, mindful practice, and self-healing. He states,
For me, this story is highly personal and stands out from among the myriad of narratives that have been accumulated during the course of 2 decades of family medicine. Several factors are responsible, perhaps foremost being the narrative's ability to exemplify elements of the complex role of a solo family physician in a remote area: the actor and witness to the struggles of life, woven into the framework of pristine natural splendor, communal cohesion, cultural diversity, and my own developing professional and family identity. (see Helman, 2006)

My observations from clinical experience and informal conversations with physicians suggest that physicians are more willing to share failure narratives over quest narratives, as there still exists an ending or a sense of closure. In some cases physicians' failed attempts may be blamed on lack of patient compliance, poor advice or treatment by others, or patient and family factors. Findings from the pilot interviews revealed quest narratives to be the most frustrating, given that they were still evolving and provided unanswered questions. With respect to somatization and the inability to find a medical explanation for illness, physician frustration seems to run high. Thus, quest narratives may represent, in fact, more of a failure than a true failure itself.

The telling of one's experience with illness relates not only to the patient and family, but also the physician. There are a small number of autobiographical studies of physicians' personal experiences with critical and fatal illnesses (see Joseph Heller, Audre Lorde, and Reynolds Price, Marianne Paget). These accounts offer some insight into the physicians' beliefs and values and how these shape the experience and interpretation of illness. In spite of these autobiographies, survey studies remain most common, which outline physicians' perspectives of certain disease categories, prognosis, and treatment options, followed by studies that focus on the value of the patient
narratives to gain insight and develop an in-depth understanding of the life of the patient and inform treatment. No qualitative studies to date have investigated, specifically, how physicians' narratives regarding their developmental experiences with illness shape their beliefs and values about health and illness or color the meaning that is constructed regarding the similar illnesses in their patients. Physicians may be challenged to improve practices and provide more genuine clinical caring by sharing their own personal stories with illness and reading similar narrative accounts of other professionals.

Medical Anthropology and the Social Construction of Illness

Stories of illness and healing are often arresting in their power to illuminate aspects of practice and experiences surrounding illness that might otherwise be neglected. Recognizing that physicians' narratives and not only patient narratives hold value in increasing awareness and understanding of how past experience and belief systems shape the meanings that are given to the patient and his or her experience and the provision of care are critical. In dealing with patients with unexplained and persistent somatic complaints, these narratives are even more important, due to diagnostic and treatment challenges. The use of narratives and the integration of social and cultural methods into the routine training of doctors will lead to more genuine and appropriate clinical practice.

Medical anthropology stresses the importance of adopting suitable cultural perspectives, making one's interpretations within that framework, and relying on direct observation. It argues for an ethnographic approach to moral practice in medicine, one that embraces the infrapolitical context of illness, the responses to it, the social institutions relating to it, and the way it is configured in medical ethics.
General assumptions of medical anthropological frameworks include (a) that biology and culture matter equally in the human experience of disease; (b) that the political economy is a primary epidemiological factor; and (c) that ethnography is an essential tool to understand human suffering due to disease.

The distinction between modern and postmodern illness is rarely addressed in the medical literature. This study's goals are consistent with theories in medical anthropology, but also postmodern perspectives, both of which are "biocultural" rather than "biomedical" in their framework. Within the field of medicine, postmodern theory assumes that we are made of stories -- cultural, familial, interpersonal, psychological, emotional, and biologic, as opposed to only genes, organs, and laboratory measurements. Major players in the physician narrative movement support the key concepts that are central to the postmodern perspective; that is, emphasis on particulars, multiple perspectives, context, and emotional as well as rational understanding. The narrative approach comprises an evolving variety of practices rather than one unified theory.

**Narrative Medicine: A New Field of Study**

In spite of the value of physicians' personal narratives to improving medical care, narratives in medicine have traditionally focused on the value of the patient narrative -- or stories that are told to physicians and then shared with other physicians as a means to increasing competence in medical care. Medical programs are now placing an increased focus on narrative education. Rita Charon, a pioneer and national authority in the field of literature and medicine, has written and lectured extensively on literature's salience to medical practice and the doctor-patient relationship, narrative competence, medical
ethics, and empathy in medical practice. Her research has focused on communication between doctors and patients, seeking ways to improve the ability of doctors to understand what their patients tell them.

The term "Narrative Medicine" was created by Charon to connote a form of medicine practiced with narrative competence and marked with an understanding of these highly complex narrative situations among doctors, patients, colleagues, and the public. Columbia University's medical school offers the only program in narrative competence, in which medical students learn how to better "read" their patients' stories through literary studies. Within this program medical students are coached to write reflectively about their practices to more accurately understand what their patients go through and also what they themselves endure in the care of the sick. Kleinman (1989, 1997) has written of the need for a medical-care system that more fully serves humanity by considering the non-medical aspects of illness. Narrative studies of physicians' experiences may be a means to achieving this goal. The need for change in the education of physicians during medical school to reflect this broader view has been supported by other physician authors, including Melvin Konner (1988) and Charon (2002). Kathryn Montgomery Hunter (1991) has written extensively on the value of personal and patient narratives to medical knowledge. Kathryn Montgomery Hunter, a professor who teaches and coordinates humanities programs at a medical school, observed firsthand how academic medical centers function. She behaved as an ethnographer and joined various teams during their multiple rounds and conferences for 2 years, observing the process whereby the patient's story is told to, and interpreted by the physician, who then tells another story of the patient in case format to other physicians, with the final story being recorded in formulaic
chart entry. She found that the valuable cautionary tales and anecdotes shared between physicians are often lost in the process of transfer to case reports and clinical-pathological conferences. She emphasizes how these unedited narratives of physicians are central, and not peripheral to medicine.

The majority of physician authors have provided autobiographies of their medical training experiences and the stories of interesting patients; however, several well-known physician writers, such as Richard Selzer (1999) and Oliver Sacks (1995) have written more personal narratives of their physician experiences. Still, the majority of these writings rarely delve deeply into the emotional side of medicine. When they do so, emotions tend to be intellectualized with even the most heart-wrenching stories being told in an objective and clinical voice, offered as learning experiences to the medical reader. For example, excerpts from Selzer's diaries, while entertaining and sometimes illuminating, tend to intellectualize the physician's emotional experience. Selzer's writings tend to distract the reader by intermixing his medical experiences with reflections of art and historical literature.

Oliver Sacks' stories focus on the mysterious and puzzling aspects of medicine. Many of his writings also include reflections on fascinating hypotheses that have been discarded or debated. Sacks also often takes his readers to exotic locations providing descriptions of geography and historical information. What is surprising, is that Sacks' books that are not about medicine or contain clinical tales provide a more in-depth view of the doctor as a complete human being with passions and perspective.

Donley and Kohn's (2002) collection of short memoirs and stories by doctors are an example of narrative medicine. In the book, physicians describe memorable moments
in medical education and practice. What is unique about these stories is that they are entirely written in the physician's own voice, having been encouraged to write about their experiences in whatever form they chose. What emerged ranged from essays to poetry. The stories describe the rewards in medical life as well as the struggles they entail. Many of the writings revolve around one patient or case that represents a landmark in the physician's career, and again, tend to focus on themes of restitution. However, all are compelling as they come from a variety of voices, perspectives, and situations, while offering insight into the emotional experiences of the physician. Other physician narratives such as Young (2004) provide accounts of their journey into doctoring. Such stories tend to be light, optimistic, and not overly complex or deep, being suitable for the medical student.

Learning to write and talk in medicine plays an important role in medical training, particularly learning the vocabulary and technical knowledge it conveys. Even more important is learning to tell a medical story that is "good" and clearly connected to a particular context and audience. Most often this telling of stories takes place in medical rounds. Good and Good's (2000) study of the evolution of competence or professional selfhood as a physician sheds some light on the nature of doctors' stories. They interviewed Harvard medical students about their experiences in training, focusing on how they developed the knowledge and skills appropriate to their work as physicians. They discovered that physicians learn to present cases as diagnostic stories and are encouraged to present only the information relevant to persuade the audience of the differential and final diagnosis. Presenting information that is deemed unimportant, such as the reason for the patient's seeking of medical care, patient's story, and experience of
the illness, is typically avoided. For example, a third year medical student described how patient stories are edited for particular contexts, organized chronologically, and presented as diagnostic puzzles appropriate for telling to senior physicians. The researchers' findings demonstrated how physicians are trained to delete the personal side of the disease experience, including the perspectives and feelings of both patients and physicians. Their interviews also revealed that physician anxiety is often high as they learn to process complex information while coping with their own and their patients' difficult emotions; however, these feelings are often not shared with other physicians.

Narrators typically provide stories and plots that embody their ideal selves, successes, and happy endings (Mattingly, 2000). Also relevant to doctor's stories, is the finding that narratives are typically ordered around endings, which play a key role in shaping the meaning of the narrated events (Mattingly, 1998). Mattingly (2000) describes the "healing drama" as significant for the narrator as it typically embodies connections to the past and to the future, and expresses a wish to transform the ordinary into an extraordinary moment, or vice versa.

The above findings regarding physician narratives suggest that the stories told by physicians in this study regarding their experiences with families and the challenging child patient with persistent unexplained illness will (a) embody the ideal self as physician healer; (b) center around themes of restitution, with stories beginning at the end; (c) be characterized by objectivity, clinical information, descriptions of symptoms and diagnostic information, resembling case presentations, such as those presented in rounds; and (d) often not include physician's emotional experiences while treating the patient.
The Joint Construction of Meaning and the Interview as Discourse

Grounded theory and narrative methods in psychology share some fundamental assumptions and values, yet also seem in direct contradiction with respect to the place and importance that context holds in the analysis of data. Although not part of the grounded theory rhetoric, grounded theorists are concerned with, or are largely influenced by emic understandings of the world. That is, they use categories drawn from respondents themselves and tend to focus on making implicit belief systems explicit. In this way, narrative and grounded theory methods are similar.

Glaser's (2002) descriptions of theory and theorizing using conceptualization within a grounded theory method are in direct contradiction to Mishler's (1986) alternative method of narrative analysis. For example, Glaser states that one of the most important properties of conceptualization for generating grounded theory is that concepts be abstract of time, place, and people. His claim is that this transcendence of context, by consequence, makes grounded theory abstract of any one substantive field. Glaser (2002) criticizes other grounded theorists (e.g., Strauss & Corbin, 1998) for lacking understanding of what it means, theoretically, to be abstract of time, place, and people. Grounded theorists attempt to "decontextualize" text in order to find patterns and themes. In fact, he criticizes all those who attempt to link knowledge, loosely, with time and place. He argues that such theorists tend to force descriptions, irrespective of emergence, on the theory to locate its conditions, to contextualize it, and to make it "appear" accurately pinned down, thereby losing its true abstraction and, hence, generalizability. Glaser (2002) claims that "without the abstraction from time, place, and people, there
can be no multivariate, integrated theory based on conceptual, hypothetical relationships" (p.8). Furthermore, grounded theorists such as Glaser (1998) argue that grounded theory ignore the concern to understand the world of the research participants as they construct it. Grounded theory is not an enquiry that makes sense of, or is true to the understanding of ordinary actors in the everyday world, nor does it attempt to uncover patterns the participant does not understand or is not aware of, especially the social fictions involved.

Within grounded theory, categories are generated from the data and properties are generated concepts about categories. According to Glaser (2002), once discovered, concepts leave the level of people. They become the focus of the research, to be later applied to social psychological behavior. In contrast, narrative thinking is not context free, concrete and testable, but rather relative and heavily dependent on context. Narratives are personal to the storyteller and incorporate feelings, goals, needs, and values, thus the same episode may be rendered differently by each individual, and even more so by the interpreter of the story. Stories are open to interpretation by the subject. Ultimately, narrative thinking is contextual and strives to account for social reality. The outcome of narrative thinking is construction of a story that has both cognitive and social components. Stories help determine what the storyteller believes and what others believe, which in turn are likely to influence future actions. Stories can be incorporated into cognitive structures which represent the knowledge and experience of the storyteller and audience. The narrative itself can embody the context and organization of a person's world knowledge and beliefs.
Coding and conceptualization that "transcends" context, including grounded theory methods such as those described by Glaser, overlook the argument that meaning is contextually grounded, inherently and irremediably. Coding in grounded theory attempts to determine the "meaning" of an isolated response to an isolated question, or code it as it has been stripped of its natural social context. Mishler (1991) underscores how typical coding practices in qualitative research, such as grounded theory, depend on implicit assumptions as to the relationships between meaning and language. Rather, assumptions should be brought to the forefront and used for critical reflection.

Mishler (1991) offers an alternative type of analysis of narrative evolving from his observation that typical interviews tend to become preoccupied with ascertaining meaning of respondents' answers to questions in the absence of those contextual grounds of understanding. He notes how everyday sources of mutual understanding are often eliminated by the research situation itself. Mishler (1991) proposes that meanings are contextually grounded, which requires a different approach to interviewing than the common survey or structure interview. Mishler's alternative approach to analysis of interviews allows one to understand how meaning is grounded in and constructed through discourse. Contextual issues such as effects of responses on question form and order, consideration of cultural fragments of meaning in eliciting and interpreting responses, and the joint construction by interviewers and respondents of particular contexts of relevance, all hold importance in this approach.

Mishler (1991) proposes an alternative, context-sensitive research approach to interviewing. Rather than limiting one's focus to the actual questions and responses of interviewers and respondents, departures from text questions are seen as being
representative of a process inherent to the interview as discourse. These departures, according to Mishler, are significant sources of data, rather than exceptions or "errors" that occur in the interview process. How questions are asked within the interview context, consideration of the course of the interview itself, examination of prior exchanges between interviewer and respondent, and variation in how particular questions are asked are all important to the meaning that evolves from the data. Interview questions should be thought of as a circular process through which meanings are created in the discourse of respondent and interviewer as they attempt to make sense of what they are saying to each other. His method encourages the researcher to explore how the narrative is influenced by the interview situation, and what role the interviewer plays in its production.

Finally, it is important to note that some forms of narrative analysis involve the breaking down of stories into their individual pieces or structures, including causal patterns, which is, essentially, to reduce and eliminate context. Furthermore, what has been referred to as a "good story" has little meaning to a researcher with interests in discovering meaning. There should be no rigid rules concerning what qualifies as a "good" or "bad" story. For example, Stein and Policastro (1984) state that good stories are structurally complete and contain all prototypical features (i.e., protagonist, predicament, resolution, outcome, reaction, and causal elements); however, to reduce stories to their basic elements inherently strips away context and suggests that a certain competence is required for good storytelling. Stories that do not contain all prototypical features and seem structurally incomplete are still stories that carry meaning for the narrator. We should assume that stories are natural ways of recounting and making
meaning of experience, regardless of their ability to meet certain criteria or fit a specific formula. Mishler (1991) notes how responses to structured questions in interviews can be treated as stories or narratives, and can in fact be subject to methods of narrative analysis. Departure from typical methods of analysis of questions and responses in coding systems emphasizes problems of language, meaning, and context, all of which are critical to understanding the function of interviews.
CHAPTER THREE

STATEMENT OF THE PROBLEM AND RESEARCH QUESTION

Child somatization continues to be a puzzling clinical phenomenon, both in medicine and mental health. Heterogeneity of symptoms, inconclusive and inconsistent findings regarding etiology, possible risk factors associated with onset and maintenance, and a poor research base, as well as the lack of developmentally appropriate criteria for somatoform disorders in children, have all contributed to this problem. There is a predominance of description and anecdotal evidence in the medical and mental health literature surrounding physicians' challenges managing and diagnosing children with unexplained and persistent illness. The majority of children with somatization are managed in primary care. Thus, investigation into the physician perspective on this topic seems imperative.

Diagnosis is central to the practice of medicine, choice of treatment, and prognosis; however, it has been studied less than its importance warrants (Mishler, 1999). It is often taken for granted and occurs silently, both within and outside of medical settings, often not being the topic of reflection or questioning. Our current knowledge regarding the diagnosis of somatoform disorders in younger populations is significantly limited. Thus, this study proposed to explore the beliefs, values, and attitudes of physicians regarding persistent unexplained illness in children, which is hoped to deepen our understanding of the meanings that are constructed and how diagnosis and treatment stems from these processes.
Behind the formal use of medical clinical cases in medical education lies a whole genre of wisdom literature that includes physicians' recounts of and reflections on patients that they have treated. What these narratives have to teach us, especially when dealing with somatization, is how the patient's and the physician's experience of illness influences the meanings that are constructed regarding illness and pain, which shape diagnosis and treatment. Asking physicians to describe their experiences with patients with persistent unexplained illness, particularly about the difficult moments they face, their mistakes, conflicts with the patient and other physicians, and achievements, provide us with a narrative theory in the analysis of medical practice and diagnosis of somatization in children. In general, exploring the inner life of physicians will lead to a better understanding of the affective and moral dimensions of medical work, including diagnosis and treatment.

Consideration of patterns of attitudes, expectations, and values that have been learned during the entire course of growing up holds equal importance to those that were learned through the passage of medical training. Further learning may evolve from or continue in those situations where a physician has been, or becomes a patient themselves. Therefore, I am interested in learning more about physicians' developmental experiences and speculating about the ways in which these experiences may inform the meanings that are constructed regarding illness and how these in turn inform decisions regarding diagnosis and treatment of patients.

The study explored the narratives of a group of physicians regarding their experiences with child patients with unexplained and persistent illness as well as their own stories of personal illness. The beginnings of practical knowledge and an experience
base concerning management, diagnosis, and treatment of children with persistent and unexplained physical illness can be found in physicians' stories or narratives about memorable cases. These case studies illuminate clinical practice in a way that quantitative methods cannot. "Cases reveal what people do and how they feel about what they do in a way that theory and empirical research, indispensable as they are, can never reveal." (Baird & Doherty, 1987; p. 1).

**Study Implications**

Physician narratives have the power to help professionals reclaim their caring role in the care of suffering patients. Since physicians are shaped by their experiences with patients and their responses to illness, the ways in which they respond to and reflect on pain, suffering, illness, courage, and hope are believed to be critical to effective diagnosis and treatment. The physician's most potent therapeutic tool may be the reflective self, attuned to the patient through engagement, compassion, and personal awareness (Borkan, 2006).

If doctors are to write more accounts of their dealings with patients, it may help others to better understand the issues faced by them. Those physicians who do not write might take comfort from reading what others have written. Reading medical narratives can suggest to physicians and students that acts of healing encompass acts of interpretation and contemplation alongside the more technical and scientific aspects of medicine. Physicians' stories of their own roles, deliberations, and also beliefs and attitudes about the patient and the illnesses they face may encourage reflection into the professional lives of physicians.
The value of interviewing physicians and hearing their stories regarding individual cases of children whom they have treated with persistent and unexplained physical illness is a heightened understanding of the challenges associated with management, diagnosis, and treatment. It is hoped that the results of this study will increase understanding of the relationship between the physician and the "somatizing" child patient and his or her family, as well as the management, diagnosis, and treatment of such children in primary care. Furthermore, since the primary care physician often represents the first "stop" for children with somatization underscores the importance of this study. The assumption here is that the process of investigation and management at this primary care level will determine the ways in which such cases will go on to be managed, and the perspectives from which these cases will likely be approached at subsequent levels of referral and care. Greater awareness and understanding of the belief systems involved in the making of meaning of persistent and unexplained illness in children will inform clinical care, particularly those challenges regarding differential diagnosis and mental health referral.

Physicians do not often recognize the importance of their own stories to diagnosis and treatment. They are trained to be objective and thus emotionally distanced from their patients; however, insight into the underlying personal feelings, beliefs, and attitudes regarding their experiences may be enlightening and valuable to the medical field regarding the treatment of somatization in childhood. The ways in which physicians constitute disease and how they experience the patient's experience of illness or sickness in the context of their own developmental experiences is also of critical importance if we
are to know more about the process of diagnosis of somatoform disorders across the life span.

This study sought to answer the following research questions:

1. How do physicians make meaning of persistent medically unexplained illness in the child?

2a. What are physicians' attitudes, values, and beliefs that play an important role in the construction of the illness narrative for the child?

2b. How do these attitudes, beliefs, and values influence medical management, diagnosis, and treatment provided to the child with persistent unexplained illness?

3. How do the patient and families' explanations and beliefs regarding the meaning of illness in the child influences (a) the meanings that are constructed by the physician, (b) the physician's choice of treatment, and (c) the most appropriate diagnosis for the child?

4. To what extent do physicians' developmental experiences, particularly early life experiences with health and illness in their families of origin, shape their self-identity as a doctor and their beliefs and attitudes regarding the meaning of illness in the child?
CHAPTER FOUR

PLAN OF INQUIRY AND APPROACH TO ANALYSIS

This study employs focused interview narrative to examine variation and commonalities in the perceptions and responses of individuals who have similar experiences. Mishler (1986) brings attention to the phenomenon of the “story” that emerges from the interview and discourse between interviewer and respondent. While respondents also tell stories in response to direct, specific questions if not interrupted by interviewers, researchers are more likely to elicit stories through relatively unstructured and focused interviews where respondents are invited to speak in their own voices, control the introduction and flow of topics, and extend their responses beyond a typical “turn.” Therefore, this study uses an in-depth, open-ended informal conversational interview, with the aid of an interview guide. The informal conversational interview allowed for questions to flow from the immediate context and to build on the preceding ones, expanding information and ability to move in new directions to seek elucidations and elaborations as needed. An informal conversational approach was selected as it was estimated to allow the interviewer to be responsive to the individual differences and situational changes within the context of the interview. Questions were individualized to establish in-depth communications while making use of the immediate context and situation. The informal conversational interview requires rapid insights and formulation of questions to occur “in the moment” by the interviewer.
The interview guide that was used allowed for exploration of key issues and questions with all respondents in order to ensure that essentially the same basic information was obtained from all research participants. While the same questions were asked of each participant, the interview guide allowed for adaptation of the wording and sequence of questions to specific respondents in the context of the actual interview as data collection proceeded. The interviewer was free to build a conversation on a certain topic, to word questions spontaneously, and establish a conversational style or discourse. Probes were used to deepen the response to questions, to increase richness of the information obtained, and give the participants cues to the level of response being sought. Based on the pilot interview findings, it was expected that clarification probes and feeling probes would be required to more fully understand physicians' answers and to explore the affect associated with certain topics. As Patton (1990) notes, probes are always a combination of verbal and nonverbal cues. For example, allowing the respondent to continue following a pause, or providing silence at the end of a response indicated that it was acceptable for the respondent to continue.

Findings from the pilot interview suggested that in order for the interviewer and respondent to engage in a genuine two-way communication or discourse, the interviewer would need to communicate clearly what information was being sought, why it was important, and to let the respondent know how the interview was progressing. Beyond the simple asking of questions, reinforcement and feedback was provided to participants throughout the interview. For example, from time to time, statements of encouragement, recognition, and appreciation were offered. Examples of some phrases that were used, included, "It is really helpful to get such a clear idea of...;" "I appreciate your
willingness to express your feelings on this issue." and "I think that what you are saying is very interesting and important."

It is recommended that those engaged in the study of personal narratives interview their respondents more than once (Mishler, 1999). Second interviews offer opportunities to clarify, elaborate, and change interpretation to responses and understand how perspectives may change. The "situatedness" of "tellings" offer insight into how stories change with retellings and how the researcher's interpretations may require revision. Second interviews also offer the researcher an opportunity for further critical reflection and reexamination of the findings. Therefore, in the initial interview, I asked respondents if I might return to talk with them a second time. In first interviews where I did not feel that I understood the meanings intended, or felt that I required elaboration or further description, second interviews offered an opportunity to revisit the topic and obtain a richer description.

The study used Mishler's narrative analytic approach (1986) to interviewing. His method does not offer rigid guidelines with respect to interpretation and analysis, but emphasizes the ways in which meanings of events and actions are expressed in language, as well as the interpretation of offers, requests, and their ensuing responses as being dependent on models of analysis that includes their connectedness to each other. Mishler emphasizes the importance of the joint construction of meaning within the interview between interviewer and respondent, and the interpersonal factors that influence the information that is shared. His method challenges standard qualitative approaches where responses are isolated from context, coded within frameworks of standard code-category systems. As Mishler states,
...the story contains the sequence of socially meaningful acts without which it would not be a story; its analysis therefore provides the basis for a direct interpretation of a complex unit of social interactions, in comparison to the standard approach where such inferences are based on decontextualized bits and pieces (1986, p. 241).

A more complete discussion of the methods of analytic narrative analysis can be found in the “Narrative Analytic Approach to Analysis” section, below.

**Participants**

Sampling in qualitative designs are different from conventional sampling, in that they are based on informational rather than statistical considerations in which the purpose is to maximize information rather than facilitate generalization. Guba and Lincoln (1985) suggest that sample size is sufficient when the amount of new information provided per unit of added resource expenditure has reached the point of diminishing returns. Qualitative researchers suggest that between 7-10 informants are needed in order for clear themes to emerge (Lofland & Lofland, 1984; Maxwell, 2005).

I conducted approximately 10 semi-structured interviews with physicians. Ten participants allowed for detailed descriptions and variety of experiences of the topic being explored and was also manageable given the financial and time restrictions of this work. I recruited four pediatricians (3 females, 1 male), three family practice physicians (2 males, 1 female), and three pediatrics residents (2 females, 1 male). Only physicians with experience in their medical practice treating children or adolescent patients under age 18 who have presented with persistent unexplained physical complaints and illness were interviewed.
Procedures

Recruitment of Participants

The physicians for this study were selected through convenience sampling in which the researcher selects whatever informants are available who might reward her with information relevant to the topic of inquiry (Honigman, 1970). Convenience sampling was also judged appropriate given the purpose of the study as exploratory and descriptive. Criterion sampling was also utilized, since it was a criterion that the physicians who were interviewed have experience in their medical practice with children and adolescents with persistent unexplained physical complaints or illness. Locating informants occurred through personal networks. I began with the utilization of professional contacts to identify individual family practice and pediatricians willing to participate in the study. Physicians were then contacted by form letter which outlined the purposes of the study and that included a contact email address and phone number of the researcher to express an interest in participation. Professional contact with the Head of the Department of Family Medicine at a local educational institution was also enlisted to provide support and encourage participation by departmental faculty and associated physicians in practice in the greater city limits. When additional participants were needed, existing participants were asked to forward a form letter of recruitment by mail or email to one or two other physicians who might also be interested in participating in the study.

The nature of narrative research is such that as the data is collected, important subgroups of participants are often revealed. For example, findings from the pilot
interviews suggested differences in values and perspectives regarding the meaning of illness and treatment of somatization among pediatricians and family practice physicians. It also became apparent after the two pilot interviews that possible differences in the age, gender, and years of medical experience potentially influences the types of beliefs and attitudes that are held. Where existing data began to suggest distinct thematic concerns in ways associated with potential subgroups, it was my intent to increase my sample size until the subgroups comprised at least two physicians to allow for some comparison of the findings. No subgroups or categories emerged that required additional comparison of findings.

Based on the pilot interviews, three initial variables were explored for differences in the narratives produced by respondents. These included pediatric versus family practice physicians, gender, and years of experience. A separate group of residents in early training were included to account for fewer years of experience.

**Instruments**

Two instruments were utilized in this study. The first was the *Narrative Interview Guide*, and the second was a brief *Background Questionnaire* (see Appendix B).

**Interview Protocol**

Interviews were conducted at a time of convenience for the physician in a comfortable location of choice that offered privacy and as little possibility for interruption. Interviewer and respondent were typically seated face to face and the interviews were digitally recorded. In all cases, I attempted to establish an atmosphere of
trust. Given my experience of some initial apprehension and tension at the beginning of the pilot interviews, I took additional time to answer any questions and speak informally with the respondents before the digital recorder was turned on. Before beginning the interview, I provided a brief description of the study, had consent forms signed, and had the physician complete the Background Questionnaire. At the conclusion of the interview, I turned off the digital recorder and asked each respondent if he or she had any other thoughts they would like to share "off the record."

The following introductory statement was made before starting the digital recorder:

"This research study is interested in learning more about physicians' experiences working with children with persistent unexplained illness, such as chronic unexplained stomachache or headache pain. During our conversation, I may refer to persistent unexplained pain complaints and illness in children using the term 'child somatization.' What I am really interested in is giving voice to physicians' experiences. I'm aware that there is not just one voice to that experience. I want to understand what it is like for physicians to manage these kinds of patients and their families. I am interested in hearing about your feelings as well as your attitudes, values, and beliefs regarding the phenomenon of somatization in children. I am also interested in learning more about your interactions with the families of such children, and your personal experiences with illness and illness in those close to you.

I would like for our time together today to feel less like a formal interview and more like a conversation or dialogue on this topic."
While I understand that it is sometimes difficult for physicians to take off their "professional" hat and talk informally about their experiences, I am hoping that you will feel comfortable enough to share some of your personal as well as professional feelings with me on this topic.

I will be tape-recording this interview and will also be simultaneously taking notes as we go along. If at any point you feel uncomfortable and wish for the tape-recorder to be turned off, please let me know. Also, if at any point you feel uncomfortable about the information that you have shared and wish to have it deleted from the tape-recorder and transcription, or wish to terminate the interview, you may do so."

**Interview Guide**

Since it was the goal to have a flexible and conversational interview on the topic of interest, the first question in the interview guide was the only question consistently asked of each participant. Subsequent questions that followed were provided only as a guide. Where there was opportunity to ask these questions, I did so; however, they were not always asked in the order presented below, nor with the exact wording. The intent was to gather information about the topic of interest in as natural of a way as possible within the context of the joint discourse.

1. I would like to ask you to share a story about an experience you have had working with a child or adolescent patient with persistent unexplained illness or pain. Perhaps it was a very memorable or interesting case for you.
**FEELING PROBE:** What kinds of feelings did you have working with this child and his or her family?

**FEELING/ELABORATION PROBE:** As you reflect back on this case today, do you have any thoughts, feelings, or insights that were not apparent to you while treating the child?

2. What kinds of beliefs do family members hold regarding unexplained illness in their child?

**ELABORATION PROBE:** Does the family play a role in the illness of the child?

3. I would like to ask you two additional questions that are of a personal nature. You do not have to answer these questions, if you choose.

3a. How was illness regarded in your family of origin?

3b. Have you had personal experience with persistent unexplained pain or illness, either yourself, or in a family member or someone close to you?

The pilot interviews and subsequent conversations with core committee members regarding these interviews helped the researcher to understand more about the ways in which physicians speak about their patients in the context of a research study and the ways in which their understanding of somatoform illness are influenced by their developmental, medical training, and medical practice experiences. Observations from the pilot interviews suggested that physicians not only hold views about their child patients with unexplained illness, but also the family members of such children. In addition, early developmental experiences, particularly those relating to illness in the
physician's family of origin seem to influence the beliefs that are held regarding somatization and the meanings that are constructed regarding illness in the child. Physicians often wish to share stories of healing and strive to be objective, therefore, additional probes to get at information related to "failed cases" or "hitting a brick wall" were used, as well as probes that encouraged respondents to speak about their feelings, personal attitudes, and beliefs that shaped their approach to diagnosis and treatment.

Sources of Data

Sources of data include verbatim text of the transcribed interviews, process memos recorded during the interviews regarding aspects of interaction between researcher and respondents, and notes recorded concerning notable aspects of the context of the interview (e.g., setting), nonverbal behaviors of the respondents, personal experience of the interview, and tentative questions and hypotheses. Additional sources of data included the completed background questionnaires.

My method of narrative analysis attempted to preserve speech as dialogue and discourse (Paget, 1983). By displaying speech as prosodic rather than grammatical text, the dynamic construction of talk was preserved. Meaning can be seen in the ways things are said, revealing the openness and richness of talk and leading to the construction of knowledge through subjective experience. Editing speech of its essential aspects, such as the inflection and rhythm of voice leads to the reworking of meanings and loss of the dynamic construction of what is being said. Therefore, the transcripts are verbatim and unedited. They included hesitations, false starts, sighs, tempo-and gaps in speech, and details of enunciation. Increases in volume were noted through capitalization. Since
spontaneous speech is produced as a series of pauses, speaking rhythms and accents, bursts of sound, and dialect, these were noted in the transcripts wherever possible. Stumbles and restarts, and false starts will also be noted.

Immediately following the interview I took notes regarding my observations of key themes and issues discussed, as well as observations about the person's behavior and affect. I also documented my own experience of the interview and any questions that emerged, as well as possible hypotheses. For example, following the second pilot interview, I noted that I often felt cut-off and interrupted by the respondent at moments when I spoke. The physician tended to speak over me and continued with increasing volume until I dropped off. I wondered about the meaning of this aspect of his speech. For example, might it have indicated a sense of discomfort during the interview, poor development of rapport, or anxiety regarding the nature of the questions? It is possible that his continuous pressured speech reflected an effort to avoid uncomfortable affect. Listening again to the tape and reviewing the interview transcript revealed that the tempo of his speech often became accelerated when he came close to feeling states. Conversely, it was noted that I had a tendency to make comments and rescue us both from the discomfort of silence when it occurred. It is interesting to note that the respondent and interviewer both experienced a sense of discomfort during the interview. This may have been due to a previously established informal student-mentor relationship. Interacting in a more professional manner, that is, engaged in a research study, may have resulted in feelings of embarrassment, the need to impress, and a tendency to act in a more artificial professional manner (for both the physician and myself).
CHAPTER FIVE
DATA ANALYSIS

Narrative Analytic Approach

I used a mode of interviewing described by Elliott Mishler (1999) that attends to how respondents and researchers together negotiate the meanings of questions and responses, as well as effects of the researcher-participant relationship. For this reason, I allowed the interviews to be more respondent-guided in order to listen to the ways of "telling" in one's own voice. Similar to a free-associative interview, my aim was to elicit the subjective frame of reference to the respondent's experiences by not restricting what was discussed. In a conversational interview, the interviewer tends to refrain from overly directive questions or instructions, allowing for spontaneous associations as well as responses to more structured questions (Osherson, 1980).

Consistent with a psychodynamic orientation, I paid close attention to the intersubjective nature of the interview. Here I refer to the situational context of the interview itself (Mishler, 1986; 1999). Psychodynamic therapists implicitly recognize the importance of the intersubjective elements in the therapeutic process. I do not mean to imply here that I regard the interview as a therapeutic process. Rather, I suggest that my theoretical and clinical orientation leads me to listen, ask questions, and interpret the data in ways consistent with psychodynamic ways of thinking. Thus, the subjective experiences of both the respondent and researcher are regarded as valuable to the process of the interview, the information shared, how it was shared, and its interpretation. Much like the therapeutic process, the interaction of the basic beliefs of the interviewer and
respondent are in creative flux. The values and beliefs of each influence the nature of the
dialogue and exchange of ideas as we are both co-contributors of the interview process.

It is important to note that while I approached the interviews from an analytic
framework, I attempted to restrain myself from analytic commentary, confrontation, and
interpretation where it was not warranted, in order to remain respectfully attentive and to
encourage respondents to keep speaking. I attempted to only ask questions and probe
where further information was deemed important, as well as when I had not fully
understood the information shared. I used validating comments where I felt they were
necessary, and encouraged respondents to continue by allowing silence during pauses and
hesitations.

In order to create a shared language, I took care to grasp the intended meaning of
each communication of each participant, listening actively to the verbal as well as the
paraverbal aspects of speech. I attended to nonverbal communication and what it told
about the information being shared, or emotional stance of the respondent. I made note of
protolinguistic phenomena, such as variations in the tempo of speech production or shifts
in posture or eye contact. I also listened for tone, timing, attentiveness, mood, and
silences, and noted smiles, frowns, quizzical looks, and other facial and bodily
expressions during interviews. For example, acceleration of speech tempo often
increases with certain affective states such as anxiety or hypomania (Gedo, 1996).
Moments of silence may be representative of reliving moments or events, retrospective
self-evaluation, or even the experiencing of uncomfortable emotional states (Gedo,
1996). Given that silence tends to make both participants uncomfortable, I resisted the
urge to 'rescue' the respondent and myself from these moments of reflection and allow
for continuation. At other moments I chose to respond directly to a comment in order to be supportive, evocative, or questioning in an effort to enhance the exploratory dialogue (Schafer, 1992).

In light of my theoretical orientation in psychodynamic psychology, an alternative analytic approach to analysis of the interview content included my notes and interpretation of possible defense mechanisms, transferences, and countertransferences by myself and the respondent. I regard these phenomena as both normal and useful to the interview process, and a means to understanding the subjective account and the values, attitudes, and beliefs of the respondent. Osherson (1980) notes that, "Psychodynamic observers are often accused of "over inferring" from, or reading into, people's descriptions, yet it seems to me that a natural order and consistency emerge that should be readily apparent when people are allowed to talk freely about their lives and concerns" (p. 6). Thus, I paid special attention to my inner experiences during the interview and how these influenced my interpretation of the data. While neutrality and suspension of values and beliefs are valued in the interview, it is important to note that the idiosyncratic responses of each interviewer and each respondent differed, and played a fundamental part in the shape and course of the interview. Therefore, I made special effort to understand the ways in which my presence and aspects about identity and personal experiences, choice of questions and responses, and suppositions affected the interviews themselves and my subsequent interpretations of the data (Kvale, 1983).

Insight into the defense mechanisms used by physicians may suggest a tendency of use of similar defenses in medical practice, and may offer insight into one's attitudes and beliefs regarding constructed meanings of illness. Examples that may arise include
denial, omnipotent control, intellectualization, rationalization, displacement, and reaction formation. By way of example, in the first pilot interview, the female pediatrician spoke about her negative feelings in a way that struck the listener as emotionless. She delivered much of the interview in a casual detached tone, suggesting that while the idea of feelings, particularly negative feelings such as frustration and anger were theoretically acceptable to her, the actual expression of them was inhibited. Physician A noted her need to avoid “feeding into” the patients beliefs about illness and the patient’s mother’s desire to receive medical treatment. Her behavior reflected one of the main facets of the physician’s role of being affectively neutral. Furthermore, it revealed a basic conflict of competing interests of the physician and patient. Physicians’ avoidance of becoming enmeshed in the patient’s illness may be a way to preserve objective judgment. Latter portions of the interview included descriptions of a hypochondriacal mother and sister who made her feel overwhelmed, and a sense of frustration and regret regarding her care of the most difficult cases in her practice that presented with unexplained somatic complaints. The physician’s stories also suggested a fear of mental illness. Thus, intellectualization may be one of the preferred ways that physicians cope with feelings of anxiety regarding needy patients and fears of mental illness.

I paid attention to the use of metaphor, since metaphors can often relate to the storyline, or can be the same as a storyline. The “unpacking the metaphor” in psychoanalysis for example, helps to arrive at generative and regulatory connotations in speech (Schafer, 1992). For example, in the first pilot interview, physician A frequently used a feeding metaphor to refer to believing or indulging the patient’s wish for attention and treatment for persistent unexplained illness. She used the phrase “feeding into the
whole cycle,” as well as other words relating to feeding, including the word “gut,” and “bite.”’” The use of a feeding metaphor for attention, particularly in the child, were illuminating in light of her family experiences with a mother described as unavailable and somatizing, and continuing to seek attention from physicians. I was also tempted upon further reflection of the text to think about this feeding metaphor in relation to the interview itself and the physician’s participation in my study. Did she have reluctance to participate or concern regarding the topic of inquiry? Did she feel like she was “feeding into” my study hypotheses? This physician expressed her limited understanding of the psychiatric category of somatoform disorders and used the latter half of the interview to obtain information and clarification from the researcher on the topic. As an interesting aside, I had brought this physician a lunch to enjoy during our interview. Thus, the feeding metaphor in the interview could relate to a number of possible interpretations including her own beliefs, attitudes, and self-representations as a pediatrician as well as the situational context of the interview itself.

I attended to and made note of the use of certain phrases or words that indicated themes within the storyline or underlying affect states, particularly those that indicated consistency and coherence of theme. For example, in the first pilot interview, the physician stated, “Its (i.e., the symptoms) just “screaming” depression, but they deny depressive symptoms.” It is important to note here that while the physician’s intended use of the term “screaming” was to refer to the patient’s illness presentation, but when analyzed further, it may indicate her own internal experience of frustration in dealing with the patient who does not have a straightforward diagnosable illness.
Findings from the two pilot interviews as well as previous conversations with physicians within the context of the initial study were consistent with Good and Good's (2000) findings that physicians tend to tell stories that revolve around diagnosis. I have also observed that many physicians' stories tend to revolve around diagnosis. At times the stories that were shared did not seem like stories at all, but rather a clinical presentation or checklist of key physical symptoms followed by an explanation of the process of differential diagnosis. In light of the literature and my own research findings, it was expected that the stories physicians would share in the context of the interviews would not depart radically in style from those stories presented in medical settings. Since it is typical for physicians to tell stories in clinical contexts that are brief, focused on diagnosis, and edited for feelings and personal perspectives, additional questioning and probing into the more human aspects of medical care including attitudes, feelings, and perspectives of treatment experience were often required.

**Structural Analysis**

Interpretation of the interview content combined several methods of narrative analysis.

**Thematic analysis of the narrative.**

Data (including transcriptions and researcher's memos) were analyzed for themes, first within each interview, and later across all interviews for comparative analysis. Using Agar and Hobbs' (1982) method of analysis, I examined the interview content for different levels of coherence. This notion of coherence allows the analyst to make some
hypotheses about the world of the interview and the background knowledge that both participants bring to the interview, without losing sight of the richness of the text. Hypotheses derived from coherence analysis acknowledge the separation of the cognitive world of the interviewer and the respondent. For example, I routinely made assumptions about each respondent as a physician, the nature of the interview situation as occurring between a psychologist and physician, and the fact that the physician is telling the story to a listener whose world is, for the most part, unfamiliar with medicine and what it is like to be a doctor.

Coherence theory uses the structure of the text to illuminate the underlying belief systems of the respondent. Agar and Hobbs' (1982) work on themes describes how recurrent content areas can be abstracted from the interviews and examined for relationships that hold them together. In coherence theory, global coherence describes how utterances move forward the overall intent or point of the story. The speaker has global goals that he is trying to accomplish. Furthermore, in a coherent text or story told by the respondent, there are often certain chunks of content called themes that figure repeatedly through the text. Identification of themes included recurrent implicit underlying assumptions about the speaker's world, beliefs, and goals. Threads of recurrent themes impart what Agar and Hobbs (1982) call themal coherence. Certain utterances express general cultural themes or values that give insight into the speaker's beliefs and goals.

According to Agar and Hobbs' (1982) model, everything a respondent says is relevant to, and has a place in the story. Hence, efforts were focused on determining how parts of the story fit together. This included how utterances expressed the physicians'
recurrent assumptions, beliefs, and goals, as well as attempts to determine the core narrative (Agar & Hobbs, 1982; Mishler, 1986). I explored the overall point of the story as well as how it began, how it was elaborated, and how it became a narrative with a plot, subplots, and series of different stories.

Respondents provide a coherent and continuous account as well as separate episodes or stories that can be connected to create an overall narrative (Mishler, 1986). Although discontinuities may be revealed in the story, as well as new beginnings and endings, attention was paid to the development of the same story or theme throughout. Respondents often provide interviewers with epilogues that aim to capture the "whole story," which are helpful in understanding the global theme. Special attention was also paid to the flow of the physicians' stories, with focus on the plots and subplots within and how these are tied together.

Efforts were made to determine the most relevant features of variability and discontinuity in the stories that were told. I used the comparative approach described by Elliott Mishler (1999), whereby similarities and differences among respondents' accounts of (a) their experiences with child patients with persistent unexplained illness, (b) personal experiences with illness, and (c) beliefs, values, and attitudes regarding somatization, were explored.

**Contextual Issues Within the Interview/Interpersonal Function of the Narrative.**

I used methods similar to those described by Paget (1983) and Mishler (1991), which included examination of the subjective experience and the dynamic discourse between interviewer and respondent.
Consistent with Mishler’s method, attention was paid to the situational context. The situational context of the research interview can provide a means of understanding and interpreting the ways in which the presence of the interviewer and his or her assumptions affect the quantity and quality of information shared, the interview process or dynamic discourse, and ongoing social interaction.

Making note of the affective responses and interactions of the interviewer can provide additional sources of information in the analysis of the data using the theme of postmodern relational psychoanalytic perspectives of reflexivity (Denzin, 2004; Richardson, 2004). Psychoanalytic perspectives of reflexivity emphasize the reciprocal sharing of knowing between analyst and analysand. The analytic act of recording the narrator’s life and stories occurs through self-interpretation by the analyst. The speech acts are parallel because both are the product of each person reflecting on one another, thereby influencing and changing one another and the interview content. Within the narrative interview, respondents will too reframe their experiences in the act of retelling their stories to fit the immediate situational context. Thus, respondents’ responses to questions were assumed to reflect a general orientation or responsive stance and intent to represent them in a particular way. Reflexivity is an integral component of narrative analytic analysis given the researcher’s striving to be constantly aware of how his or her values, attitudes, and perceptions are influencing the research process, the formation of the research questions, the data collection, and the ways in which the data are analyzed and theoretically explained.

Mishler’s method emphasizes contextual issues, including the effects of the interview situation and the role of the interviewer. He suggests that these aspects of the
interview be addressed systematically by focusing on their interpersonal functions within the interview and how they influence the joint production of discourse. Attention to how the role of the interviewer may influence the story that is told, how it is constructed and developed, the way it is told, and what it means are of central importance. By example, in one pilot interview the interviewer's presence may have led physician B to feel a need to present his ideal public self as a caring and healing physician. This was noted through a continuous optimistic attitude and presentation of stories that described difficult but successfully solved cases. In general many of the cases he described had happy endings. The physician also communicated a wish to provide valuable information that would be both esteemed by the researcher and beneficial to the study's cause. In this case, the interviewer had an existing relationship with the physician as mentor, which likely influenced the type of information shared and the way in which it was shared.

I explored how the interview questions, silences, and responses of the interviewer entered into the story's production. It is also important to note that stories told in one kind of context differ from stories told in another context. For example, the first pilot interview took place in a small patient examining room with the physician seated on the usual examining stool, and the interviewer on a chair beside the examining table. This type of interview setting elicited more diagnostic and medical information than stories and feelings. The physician seemed to take on more of a detached, clinical and professional stance than physician B, who shared feeling states more willingly in what was judged to be a more comfortable personal office setting. Findings such as this from the pilot interviews offered insight into how different interview settings might elicit contrasting information.
Paget (1982, 1983) interviewed physicians and found that the dynamics and subjective experiences of the interview greatly influenced the type and depth of information shared. She observed how the interviewer’s and physicians’ answers, silences, hesitations, and formulations continually informed the evolving flow of conversation. Like Paget, Mishler’s method of analytic narrative analysis stresses the importance of how an interviewer and respondent work together to produce a story by the form and intent of questions and responses, acknowledgements, and silences. Attention to the ways that the interviewer and respondent manage shifts and transitions are important and therefore are included in the analysis. As an interviewer, I paid special attention to the affective components of the interview (see Denzin, 2004), and attempted to be sensitive and responsive to the respondent’s expressions of feeling. When appropriate, I asked the respondent to elaborate at moments when he or she expressed affect either nonverbally or verbally.

_The Image of ‘Self’ or the Personal Identity of the Physician Within the Story._

Mishler (1991) has noted that any interpretation of a personal account or telling about one’s self in both clinical and nonclinical contexts includes a form of self-presentation that is a personal social identity. Within analytic thought, the question is often asked “What is the storyline and what is the relation of this storyline to self-representation?” Similar themes and storylines may indicate a subconscious attempt to pull together and communicate important aspects of the conceptualization of self-representation and object representations as well (Schafer, 1992). Analysis of physician identity and self-representation was deemed important to this study and the research questions as they
were assumed to influence physicians’ interactions with patients, degrees of empathy, constructed meanings of illness, and diagnoses and treatments that are considered worthy.

Expressions, confirmations, and validations of one’s identity that emerged throughout each interview process and across all interviews are explored and analyzed for commonality of themes. It is important to note that in order for this to occur, there needed to be some basic understanding of what is valued for one’s identity in the particular culture of interest. For the story to make sense as an identity-claiming story, the narrator often makes assumptions that he and the interviewer share a similar view of what this constitutes. While it was expected that this information will become clearer over the course of data collection, it was assumed by the researcher that strengths in medical knowledge and understanding, confidence in practice, a degree of empathy, and the ability to provide clear answers and solve medical problems were of high value both personally to physicians, and to the medical field in general. These assumptions emerge from the general medical literature and writings by physician authors; however, it is important to note that physicians’ narratives and physicians’ reports of their feelings toward their patients, as well as anecdotal evidence from the specific literature concerning clinical management of somatization in children has been very limited.

While searching for those aspects of the data that communicate aspects of self-identity, I kept in mind that there were many narratives of the self. I attempted to interpret how these presented selves may be consistent or in conflict with one another. Schafer (1992) suggested that listeners regard the narrator’s storyline not as containing one true self, but one person as “agent.” The respondent should be viewed as a narrator narrating the self or numerous selves to develop desirable versions that conform to one’s
own expectations or another's. In this way, it was possible that the physicians being interviewed would present stories that present themselves with certain appealing attributes. For example, in the second pilot interview, the physician consistently presented stories where his character seemed to be the "hero." He recalled cases where he had been challenged, yet presented himself as optimistic, reflective, and sensitive to the patient and medical issues.

Reduction of the Data and Presentation of Findings

Within the final report, case summaries were provided for each physician in an effort to reduce the hundreds of pages of transcripts and provide a synopsis of the most important findings. These summaries included basic demographic information for each physician, as well as a summary of the thematic content of the interview, contextual issues, interpersonal function of the interview, and physician self-identity suggested by the text. The most important aspects of each physician's experiences and what they revealed with respect to (a) the meanings that are constructed regarding unexplained persistent pain in the child, (b) component attitudes and beliefs that are integral in shaping diagnosis and treatment of the child with somatization, (c) the influence of families within the context of treatment of the somatizing child, and (d) how physicians' developmental illness experiences may influence management, diagnosis, and treatment of children with persistent unexplained illness are explored. Each of these sections correspond to a research question. Additional themes and issues that became apparent over the course of interviewing and data analysis are included in the case summaries. Comparative analysis of themes follow the individual case summaries.
Reduction of available data in the final draft includes interview excerpts selected on the basis of their relevance to the key themes and issues, or those that demonstrated the conclusions that were made. These themes emerged gradually through the process of data collection and interpretation.

Similar to those studies that have focused on the in-depth narrative interview of a small group of participants regarding a common experience (e.g., Mishler, 1999, Osherson, 1980), I present the results of this research in a way that attempted to retain the richness of the physicians' accounts by including the most relevant, rich, and detailed unedited portions of the transcripts within the final discussion. I discuss the interview methodology and provide excerpts to demonstrate meanings and information that support the conclusions being made.

**Issues of Reliability and Validity**

The terms "validity" and "reliability" are grounded in the paradigm of quantitative methodologies and thus are not generally employed by qualitative researchers carrying out narrative or grounded theory analysis. In qualitative research, assumptions regarding the "correct" analysis do not exist. Rather, the term "trustworthiness" is suggested to be a more appropriate term for how to evaluate narrative analysis based on induction rather than deduction (Mishler, 1986). Narrative researchers are encouraged to ask themselves whether there are clear warrants for the claims that are made, whether other investigators would make similar judgments of the adequacy, and whether the findings and interpretations are "trustworthy" in the sense that they could be relied on by others (Mishler, 1986).
Qualitative researchers typically concede methodological weaknesses when faced with questions of validity and reliability. Qualitative studies have been especially vulnerable to criticism given their lack of fixed design and random sampling, and inability to produce statistics that specify the representativeness of the data. However, qualitative studies can produce valuable results that provide methodologically valuable empirical implications of the qualitative researcher's behavior. In particular, analytic qualitative studies anticipate and appreciate the social relations that emerge in the research process. An outline of how issues of reliability and validity are addressed in this study follows.

1. Representativeness. The general goal of scientific research is generalization of results and theory. For qualitative research, particularly narrative analytic studies such as this one, external validity may be argued to depend on internal variety. This means that the more differences discovered within the data, the greater the number of comparative cases and expanding validity of conclusions and theory. When researchers examine human experience of a phenomenon from "within," or through interview and observation, their basis for generalization, or qualitative variation, expands greatly (Katz, 1983). In fact, qualitative studies are strategically biased toward more variation than random sampling.

For the current study, variations in the research setting and differentiation of respondents created an internal variety used to generate rival interpretations and theory. Nevertheless, there are some limitations in generalizability that need stating. First, since the study explores the experiences of pediatric and family practice physicians in Minnesota, there was a risk that the resulting interpretations and findings would hold
relevance only for physicians practicing medicine in the same location or those with similar cultural beliefs. Second, one third of the physicians interviewed worked for a large healthcare organization with affiliation to the University of Minnesota Medical School which houses one of the largest and most prestigious medical training programs in the country. Physicians working for this organization often hold prestigious academic posts, provide training to students in the program, and thus may hold certain unique perspectives regarding the value of certain focuses in health care. For example, I discovered that the Family Medicine program places emphasis on the value of integrated health care. Such attitudes may be unique to this medical school. Thus, the attitudes and beliefs held by these physicians may not be reflective of the general attitudes and beliefs of all physicians in Minnesota or other states. For comparison, other physicians working in a variety of medical settings in the area for private practices and other healthcare clinics were recruited. These physicians include both pediatricians and family practice physicians working in rural and city clinics. In order to account for differences in attitudes and beliefs based on experience, physicians in their early years of residency were also recruited for the study.

2. Reactivity. The closer and more involved the researcher to the participants, the greater the risk of reactivity. The extreme of this tends to occur in field studies involving participant observation. Within the narrative analytic interview, there is much flexibility and fluctuation in the behavior of the interviewer and respondent, and therefore the risk of reactivity is present. Although it was the goal of each interview to generate information relevant to the research questions, the ways in which the interview questions
were asked, and the flow of the interview varied from interview to interview. Differences in the behavior of the respondents including the types of stories they shared, and how they were shared, was expected to be influenced by the behavior of the researcher.

Reactivity need not be a methodological weakness of the study. This is because interaction between researcher and participant within the narrative interview and analysis provides a substantive data resource. Within the analytic narrative interview, all behavior is relevant to the researcher's objectives (Mishler, 1986). Observations and findings are context-sensitive. Thus, the narratives were analyzed taking into consideration how the data relates to the researcher's presence and behavior. Physicians' reactions to my role as a psychological researcher in some cases provided valuable data on the dominant physician culture and attitudes toward mental health and somatoform disorders.

I attempted to shed the rigid researcher role and allow the interview to be respondent-guided. This approach allowed for increased flexibility. Defining the role of the researcher at the outset can lead to difficulties. Katz (1983) argues that with qualitative analytic studies "the negotiation of access is ongoing, continuing from situation to situation and from the beginning to the end of each interview, in the researcher's efforts to establish and maintain rapport" (p. 139).

There can be methodological strength in variation of research methods, and researcher and respondents' behaviors. A lack of preestablished methods and flexibility in the researcher's role minimized the problem of creating irrelevant and artificial data. Rigid control of the research situation only leads to hypersensitivity to accidental and unplanned variations in researcher or participant behavior (Katz, 1983).
I worked without a fixed questionnaire, but rather an interview guide. In order to avoid that the differences reported in the data and analysis were merely a reflection of differences in my behavior, I engaged two peer-reviewers who had access to the verbatim transcripts, process notes and memos, and ongoing and evolving interpretations.

3. Reliability. In the traditional sense, verification of the reliability of interpretations in narrative study and analysis is difficult given the extent of idiosyncratic observations and subjectivity of analytic interpretations. However, from a sociological perspective, the analytic method confers a unique power to the researcher to make personal judgments regarding the reliability given repeated independent encounters with the data. Katz (1983) argues that contrary to statistical analysis, “the analytic qualitative approach does not separate the evaluation of reliability, or consistency in interpretation from the evaluation of validity or the mesh between the researcher’s concepts and the meanings expressed by the participants” (p. 148).

The nature of exploratory research is such that there exist a lack of awareness of whether or not the data being collected are supporting or contradicting an existing hypothesis. This study explores an area of interest and research question for which there was no answer. Limited information exists concerning the ways in which physicians make meaning of persistent unexplained illness in children. While the research questions have been shaped by previous related research on child somatization, anecdotal evidence found in text, and informal observations and conversations leading to some basic hunches and assumptions, there existed no preconceived hypotheses, categories, or themes, thereby reducing the risk of disconfirming or confirming hypotheses.
While verbatim transcripts and process memos and notes were made available to the peer reviewer and other readers who requested them, only a fraction of the data appears in the final report. I do not specify the criteria by which this data are selected. Case summaries provide a more detailed picture of each respondent and synopsis of the interview. I include detailed notes regarding the background context of the interviews and final text. I qualify concepts to the best of my abilities and put forth my basic assumptions and hunches and rationale for my interpretations in selecting the data for the final report.

The concerns regarding lack of fit between the data and analysis in the narrative study are warranted given that there exists the possibility that alternative interpretations of the data may exist, that the researcher has not captured the respondent's meaning accurately, and that there may be inconsistent implications of the data presented in different parts of the text. Furthermore, the analysis evolved from interpretative commentary rather than the data itself. In addressing these issues, I examined the data for disconfirming examples, and also used two peer reviewers to increase awareness of alternative interpretations. Special care was taken during the research process to carefully document all observations in addition to the interview data and explain the ways that inferences and interpretations of analyses are grounded in, and related to my theoretical framework (Mishler, 1986). Ongoing peer access to the unedited transcripts, process notes and memos, and analytic process, further protects from inarticulate data gathering and lack of fit between data and analysis. To avoid misinterpretation of the respondents' meanings, I conducted second interviews when possible. This avoided casual analysis and provided opportunity to substantiate my grasp on the meanings
intended and clarification and elaboration. Also relevant to lack of fit is the analysis of
the different aspects of the situational context and the influence of the relationship
between respondent and researcher.

4. Replicability. The nature of narrative analytic interview and analysis is such that
decisions are not pre-fixed for gathering data and therefore a format for testing findings
by repeating the study is difficult. Ad hoc decisions were routinely made within the
interviews regarding the types of questions asked, when and how to probe, and whether
to gather additional data through subsequent interview. Since the methods may change
during the research process, replication would be problematic.

The exploratory nature of the current study, its goals of thick description,
changing methods throughout the process, narrative analytic analysis that is informed by
context, and lack of predefined hypotheses, all make replication problematic, if not
impossible. However, testing of findings without repeating the original research is
possible. Qualitative researchers may wish to pick up where the original study left off in
search of a contradiction or further study to document new types of phenomena and
comparative cases, all of which are valuable for theoretical purposes (Katz, 1983).

Statement of Subjectivity

Qualitative ethnographic research involves intensive researcher interaction with
informants and ongoing immersion in the data. While this interaction may be considered
one of the strengths of qualitative research by facilitating the emergence of data that
would be difficult to otherwise obtain, it is important to consider the ways in which the
researcher's beliefs and previous experiences affect both the data collection and analysis. Kvale (1983) warns that "the interviewer should be conscious of the interpersonal dynamics within the interaction and take it into account in the interview situation and in the later analysis of the finished interview" (p. 178). For this reason, qualitative researchers frequently make explicit their own experiences, training, potential biases, assumptions, and hunches. I have listed below some of my own life and professional experiences as well as hunches and assumptions which seemed relevant to this study and interpretation of the data.

**Researcher's Experiences.** I am a married woman with a 3-year-old son. I am in good health and have never been hospitalized for illness. In early childhood I experienced occasional gastrointestinal difficulties and abdominal pain that was not medically investigated. In fact, these difficulties were not addressed by my parents nor mentioned to the pediatrician. At times there was a great deal of conflict and stress in my home, and I believe that these difficulties may have been associated with this stress. In adulthood I have occasionally experienced gastrointestinal difficulties that wax and wane during times of anxiety and stress. I have a back injury that occasionally flares up and causes me pain for which I receive chiropractic treatment and physical therapy. I am in otherwise good health.

My husband is in good health and has had no more than routine contact with health care professionals. My son is currently in excellent health. Neither has been hospitalized.
Members of my family of origin have had varying difficulties with their health. My mother has intermittent unexplained stomach pain and has been diagnosed with irritable bowel syndrome. My brother is in excellent health, although has also experienced intermittent gastrointestinal difficulties during times of stress and has been told he has irritable bowel syndrome. Neither my mother nor brother has received any kind of medical treatment for their stomach difficulties. My father has hypertension and possible metabolic syndrome (prediabetes) for which he takes medication.

My interest in child somatization has emerged in part from my own history with some unexplained stomach pains, but primarily from those training experiences providing assessment, therapy, and brief consultation to specialty care clinics at a children's hospital in the western United States. In Utah, persistent unexplained pain and physical complaints in children is quite common. Diagnoses of Undifferentiated Somatoform Disorder, Pain Disorder, and Conversion Disorder are frequently given. It has been speculated by practicing clinicians in the state that these rates are high due to certain cultural and family values. I have consulted with, and provided therapy to children with persistent and unexplained illness through neurology, gastroenterology, and outpatient psychiatry. I have personally witnessed the struggles of both the healthcare providers and children and their families during the investigation process and search for diagnosis. As a result of these experiences, I have become interested in the onset, course, and treatment of persistent unexplained illness in children and adolescents, the research and diagnostic criteria for somatoform disorders, and most recently, the interactions of the treatment system and the child and the family. I view difficulties in diagnosis and treatment as arising due to a poor research base, inappropriate diagnostic criteria, limitations in
physician knowledge relating to somatoform disorders in children, and conflicting beliefs in the child and family and physicians regarding the meaning of physical pain symptoms and illness.

**Hunches and Assumptions.** In spite of the emphasis on biopsychosocial perspectives of illness, I suspect that physicians would continue to hold fairly dualistic perspectives regarding the mind and the body when it came to treating persistent unexplained physical illness in the child.

I suspect that physicians do not always consider psychosocial issues early in the process of management or treatment of children with persistent unexplained illness and do not typically involve mental health professionals until a rule-out of organic illness has been completed.

I suspect that the perspectives and beliefs of the family regarding the meaning of illness in the child have a powerful influence on the kinds of medical investigations that are carried out by physicians, as well as approaches to treatment, and diagnoses that are considered.

I suspect that physicians' previous experiences with children with somatization and their families in practice, as well as personal developmental experiences with illness all influence the beliefs that are held regarding the meaning of persistent unexplained physical complaints in the child. I assume that health and illness beliefs and interactions with patients contextualize each other in a reciprocal fashion.
I assume that the extent of knowledge that physicians possess regarding somatization and experience with such kinds of patients and their families influence the kinds of beliefs and values that are held regarding persistent unexplained pain in children.

I assume that patients and physicians each enter the healthcare relationship with beliefs that significantly affect their interactions, the diagnoses that are suspected or considered, and choice of treatment.

I suspect that differences in beliefs between the child and the family and the physicians often go unrecognized, or there may be an unspoken rule to not comment on, or address such differences.
CHAPTER SIX

PILOT INTERVIEW OBSERVATIONS AND FINDINGS

With IRB approval, I conducted two pilot interviews, both of them using an open-ended format. The first was semistructured and incorporated more questions, and the second utilized more of an informal conversational approach.

Participants

The two physicians who agreed to participate in a pilot interview differed in a number of respects and thus offered an opportunity for comparison. The first respondent, whom I will call “Physician A” is a female pediatrician in her mid 30s, with approximately 8 years of postresidency practice. The second respondent, who I will call “Physician B,” is a male family practice physician, in his late 50s, with approximately 28 years postresidency. Both are married and have children. Physician A has two young children under the age of 7. Physician B has two children who are in college. Physician B is the Head of the Department of Family Medicine at a local university that is known to place a strong emphasis on the integration of family medicine and family therapy, teaching, and research. Physician B works in a community practice that does not place particularly strong emphasis on the integration of psychosocial issues in treatment.

Revising the Interview Guide

The interview guide used for the pilot interviews was modified for several reasons. First, it was determined that there were too many questions. Asking the
respondent to begin with a story about a memorable case opened up the interview and allowed for opportunity to learn more indirectly about the values, beliefs, and attitudes regarding somatization than did direct questions. As physicians spoke about their experiences, they were reminded of other experiences that were similar or offered some contrast. Prompts regarding the feelings associated with described cases were often necessary. Physicians seemed most comfortable speaking in a brief clinical manner that is characteristic of a presentation for rounds, rather than providing stories that encompassed the human side of being a physician.

Several questions asked during the pilot interview were not deemed useful, either because they tended to steer the physician toward more “clinical talk” as opposed to sharing stories with feeling, or because answers to these questions were often provided indirectly through the sharing of stories and discussion of memorable cases. These questions were:

1. Are there factors, other than physical symptoms, that you consider to be important when making a differential diagnosis with a child with somatization?
2. At what point do you feel that a mental health referral is needed for a child with unexplained pain or illness?
3. What do you consider to be the biggest challenges in managing these kinds of cases?

In general, asking fewer questions allowed for the respondent to talk at length and lead the conversation in directions they felt comfortable. Findings from the interviews suggest that the most valuable questions were those that elicited information related to
the personal experiences of the physicians with the patient and the family and early life experiences with illness.

**Interview Observations**

1. The two pilot interviews provided critical information regarding the logistics of the research interview, including setting, time limits, and general interview format. I believe that these factors influenced the general flow of the interview, richness of the data, and extent to which I was able to enter into a discourse with the respondent. A comfortable and quiet setting for subsequent interviews will be ideal. The first interview took place in a cramped examining room, resulting in an interview that felt surprisingly clinical and formal. Within the clinic setting, opportunities for disruption existed and put a strain on both the interviewer and respondent. The second interview took place in a large, quiet, faculty office that allowed for optimal privacy and minimal interruption. The seating of interviewer and physician facing one another allowed for the most open, informal, conversational interview. Allowing only one hour for the interview was not sufficient. Future interviews should allow 1.5 hours at a minimum. It was further decided that there should be an opportunity for a second interview in instances where the researcher might need clarification, elaboration, or desire a second “telling” of the story. Second interviews will offer further critical reflection of the findings and opportunity for the researcher to share some initial interpretations or observations regarding the data. It was noted that the interviewer should speak louder and investment in a higher quality tape-recording device occur.
2. The interpersonal context influenced the types of stories that were told. On the most basic level, differences in the age and gender of researcher and physician created a particular dynamic as well as power differential. In addition, the degree to which the researcher and physician had a shared level of knowledge on the topic of interest influenced the types of answers provided and the general feel of the interview. Number of years in practice and experience in the field of medicine, particularly with the types of patients of interest to the study also influenced the physician's level of comfort with the interview. In analyzing the data, consideration of the how dynamics of the interview are influenced by differences in gender, age, and knowledge in the researcher and respondent will be important and will allow the researcher to arrive at a fuller and more adequate interpretation of the respondents' answers, and in turn, the beliefs and values that are shaped within the interview context.

3. The way in which the interview was introduced, including a description and outline of the study, set the stage for the overall “feel” of the interview. In the first interview, an outline of the study and its goals were formally stated. Given that what was most desired were storied accounts from the physician, or an entering into a “joint discourse or informal conversation,” the second interview was begun by sharing with the respondent the true interests of the study and what kind of information was most desired. The importance of entering into a dialogue and the sharing of stories was stated. Within the first interview, questions were
stated in a way that failed somewhat in eliciting stories and did not include as many feeling statements, personal insights, or shared information regarding beliefs and values. Use of the term "clinical experience" in the first interview resulted in clinical report, description of medical procedures, detailed symptom lists, and medical jargon. Clearly asking the physicians to tell a "story" rather than describe their "experience" led to greater richness in data. It was also determined that the number of semistructured questions should be significantly reduced. The initial question, or request by physicians to share a story or series of stories of their experiences with the types of patients of interest to the study seemed to lead to an open dialogue or conversation that included the sharing of values and beliefs.

4. Asking physicians about their personal experience with persistent unexplained illness (in oneself or the family) opened up an entirely new and fascinating dialogue relating to health and illness beliefs. This question also allowed the physicians to take off their "professional hat" and talk more openly about their values and beliefs and their relationship to early illness experiences. It was noted that both respondents had difficulty dropping their professional medical "hat" and talking more informally about their personal beliefs and values. Both physicians seemed to do a great deal of filtering and editing of their statements. Physicians avoided statements that were negative in tone or could be perceived as suggesting negativity toward the patient. It was noted that when the tape-recorder was shut off, physicians were more comfortable engaging in casual conversation that
included negative statements as well as disclosure of personal information relating to themselves or the families.

5. The pilot interviews revealed the importance of physician control of the interview process. The extent to which physicians were permitted to speak at length, without interruption, allowed for greater richness of data, particularly reflection statements and moments of affect. The value in allowing additional time for searching, reflection, an extended response, as well as rephrasing of questions by the interviewer to provide necessary clarification was realized in the second interview. In both interviews, physicians sought validation through questions such as, “Am I being helpful to you?” The goal of subsequent interviews will be to give more control to the respondent-physician and to “empower” and “enlist” him or her in the participation and collaboration process (Mishler, 1986). Statements of validation and appreciation will be provided.

6. With respect to the interpersonal dynamic of the interview, I became aware of the following:
   
a) A general tendency in both physicians to “back away” from affect when it came up in the interview, especially negative affect. I believe that this is due to the value that is placed on objectivity and professionalism in the medical culture. Bringing forth one’s subjective views and feelings on a given subject is perhaps experienced as “unprofessional” and uncomfortable to the physician, given their training to be “objective.”
Review of interview memos and transcripts suggested that when feelings came up in the interview, the interviewer's best action was to accept and embrace these feelings through silence or validation. Allowing the physician to continue to speak, particularly following pauses, led to increased richness of the data. Interruptions tended to break the flow of conversation and led to a change in direction of the interview, often away from affect.

b) My personal tendency, at times, was to jump in and "rescue" the physician from uncomfortable moments of affect, which were often followed by pauses and hesitation. In the second interview I was more aware of this and allowed the physician to continue and did not "fill in" the pauses and breaks with further questions or statements. This allowed for a greater flow in the interview that was respondent-centered. Also, it allowed for continuation of a narrative.

c) Less is more. The fewer questions asked and the less I spoke, the more the interview flowed and evolved into a joint discourse. In subsequent interviews I need to allow the interview to be more guided by the respondent.

**Summary of Findings**

Conducting the two pilot interviews provided some interesting findings regarding the ways in which physicians make meaning out of persistent unexplained illness in children and the belief systems underlying this process. I have outlined my observations
below. Comparison of the interview data revealed both similarities and differences in the beliefs and values that shape the meanings that are constructed regarding persistent unexplained illness in children.

Consistent with the literature, both physicians shared stories of cases that were resolved. These have been referred to in the literature as "restitution narratives." Both physicians reported feelings of negativity and helplessness when powerless to "cure" the patient. A central theme that emerged was that if one could not find that elusive "cure" or "answer," feelings of hopelessness were certain. Both physicians spoke of their preference for having total control over the case, noting that involvement by third parties were frustrating and led to conflict and even triangulation in the doctor-patient relationship. This was certainly an interesting finding, given the need for greater coordination and interaction between primary care physicians, specialists, and mental health practitioners.

Unresolved cases or those still in progress were associated with feelings of frustration and incompetence. Neither physician chose to tell stories that did not, in some way or another, represent success. Physician B had a greater number of years experience and knowledge on the topic and surprisingly, had a more positive outlook regarding the most challenging somatizing patients. He spoke of the "hard to cure" patients as exciting and offering an opportunity to help the patient better understand his or her illness. He referred to himself as a "hopeless optimist." Physician A, who has fewer years experience and knowledge regarding the somatoform disorders, responded in ways that were typical of the literature; that is, the nature of her stories suggested feelings of frustration, confusion, and helplessness. Years of experience, extent of knowledge
regarding the phenomenon of somatization, and gender all seemed to play a role in the kinds of meanings that were constructed and the degree of comfort in "not knowing" the answer or being unable to find a solution.

Repeated and careful review of the transcribed interviews and search for common themes revealed that physicians' personal developmental experiences with illness or illness in their family of origin had significant ties to the values and belief systems held regarding somatization. The stories that the physicians chose to tell, including the types of patients and their difficulties, often echoed their own experiences. For example, physician B shared a dramatic story of a young athlete he treated who suffered from hyperventilation, syncope, and feelings of panic during physical activity. Later in the interview he described his own experiences as a young football player with asthmatic experiences that were effectively treated with placebo. This physician's personal experience with unexplained illness and the placebo effect had a powerful influence on the shaping of his beliefs regarding the power of the mind over the body and locus of control regarding one's health. He spoke of his inspiration to help his patients come to the same realization.

Physician A spoke of her mother as being riddled with pain and illness her entire life. Her description matches an individual with pain disorder or perhaps hypochondriasis. These "mystery illnesses" have continued to plague her mother into old age. Her experiences with a mother whom she believes was a somatizer has led to her tendency to regard illnesses that are not tangible as possibly not illnesses at all. As a parent herself, she says, "don't treat it unless you are absolutely sure it's a problem." She believes that sick parents or those who focus a great deal on bodily complaints in the
child result in one of two things: a child who somatizes and becomes an adult with a somatoform disorder, or a child who is resilient, strong, and does not "feed into" the illness. Her identity is clearly aligned with the latter. She states, "I don't want to keep feeding into that by giving them all this attention" and later, "in a way, you are feeding into the whole cycle." She used the term "stoic" to describe her patients and parents who resist seeing symptoms as a sign of serious illness. How her stories relate to her own identity or perception of herself as objective, strong, avoiding her emotions, and resisting the urge to worry about physical symptoms comes across clearly; however, in the back of her mind she admits to worrying about the "bad things." Like Physician B, Physician A also spoke of the value of the placebo for somatizing patients. These beliefs directly contradicted her attitude regarding the importance of "not feeding into" reports of illness and providing the desired treatment.

Physician A's beliefs were clearly of a dualistic nature regarding the mind and body. For her, physical illness needs to be tangible in order to be real. Mental illness is a mysterious and perhaps even frightening thing for her. The same physician described child and adolescent patients that seemed deceiving in their presentation – for example, sweet, talkative, friendly, happy, even sociable, and yet still presenting with symptoms and illnesses that could not be clearly explained. She says, "and they have such fatigue, and body aches, and it's just screaming depression, but they really absolutely deny being sad or down or depressed or anything, and you know, those are the hardest!" She wonders about malingering, describing two child cases who she believes have "created" physical symptoms.
Both physicians described an experience of "going with the gut" or using intuition in their practice with somatizing children, yet continue to rely on medical tests and labs to rule out organic disease. The statement below indicates the extent to which one physician can consider the psychological:

"You sometimes need time, to not see the patient for a while, and then your gut kind of kicks in and tells you whether there might be something going on psychosocially. Um, ya, it's hard, you certainly don't always know. You aren't consciously thinking about it. You are keeping the ruling out of the bad things in mind."

In comparing the two interviews, it became obvious that physician A's (female pediatrician, fewer years experience) beliefs regarding illness and the role of the mind and body were clearly dualistic, while physician B's beliefs (male, family physician) were biopsychosocial. For physician B, the emotional and the physical selves are truly one. The stories he told suggested an appreciation for how the body can manifest the psychological. His own experiences with illness have led to his interests in how powerful the "mind" and life experiences can be in shaping the illness "experience." I use the term "experience," because in many of the cases presented there really was no particular "illness" per se, but rather an "experience" of illness. The physician noted how this is especially the case with children. The body offers itself as a powerful tool to learn about the less tangible aspects of the self.

The ways in which each physician's beliefs regarding health and illness, and particularly the meaning of persistent unexplained illness influence their practice of medicine was noted. Physician A tends to look for the tangible. She likes to focus on things she can see and feels most confident checking for physical symptoms. She
performs extensive testing to rule out organic illness. She prefers those physical illnesses that are straightforward and offer the best chance for diagnosis through rule-out. For example, she spoke about headache and how the pain complaints tend to wax and wane and are subjective, versus stomach pain which can be investigated using symptom checklists, monitoring of weight, and medical tests. In the back of her mind there is the everpresent worry about the “bad things” that could potentially be overlooked. These worries reinforce her tendency to do a complete rule-out. Only after this has been done, will she consider the psychological. She noted during the interview that at times she challenges herself and tries to hold back on the whole armamentarium of tests. She noted that sometimes illnesses simply “resolve” on their own, with time. In such cases, she provides simple reassurance to the child and parent, and provides follow-up appointments. Her reliance on excessive reassurance and delay in diagnosis were interesting to hear in light of the literature that has found both as being associated with maintenance and exacerbation of somatization in patients.

Physician B, given the extent of his expertise and experience, is typically only called to consult on those cases where no organic cause can be found. This physician speaks with patients and the parents about the spectrum of possibilities regarding illness. He emphasizes the psychosocial influence on the child and explores the role of family and environment on the child. In spite of this biopsychosocial approach, in the back of his mind he also worries about what serious organic issues might be overlooked.

Both physicians expressed clear beliefs regarding gender and its association with somatization. Stories were predominantly about preadolescent or adolescent female patients. The degree to which the gender of the physician and interviewer influences the
stories that are told and beliefs shared in the interview context is meaningful and should be considered in subsequent interviews.

Summary of Themes that Emerged from the Pilot Interviews.

1. There is a clear presentation of "identity" throughout both physician interviews. Ideas regarding one's sense of "self-identity" were present both in the stories regarding physician experiences with patients, as well as personal experiences with health and illness and illness in their families of origin.

2. Clear beliefs exist regarding gender and child somatization. How these beliefs influence treatment and meaning making of illness and diagnosis is unclear.

3. While relying primarily on their experience and medical knowledge, both physicians reported using "intuition" and their "gut instincts" when dealing with child patients with somatization. Core beliefs regarding what somatization really is, are likely to influence these experiences.

4. The experience of "not knowing" and what this is like and how it differs for female and male physicians seems very important to explore. Regardless of gender, physicians do not find it professional or appropriate to discuss their feelings or subjective values and beliefs on such issues, particular the subject of mental illness. Uncertainty and incompetence in the physician is not easily tolerated. One's identity as a problem solver and "healer" is powerful and shapes the ways in which illness is understood and treated.

5. Early experiences with health and illness shape physicians' belief systems and the meanings that are constructed regarding persistent unexplained illness in children.
6. Physicians tend to hold either a dualistic view of the mind and body, or an integrated one. "Illness" and the "illness experience" can be understood as two entirely different things. One is a clinical and tangible entity, while the other tends to be a subjective phenomenon.

7. Regardless of physicians' medical knowledge, training, and experience, there seems to be fear surrounding mental illness. The psychological world versus the physical world is a scary place. Mental illness is mysterious and confusing.

8. There exists great fear in missing something organic. The rule-out process enables the physician to cope with these fears.
Science promises rigor of thought and procedure, and a triumph over uncertainty. It is a specious triumph, deceptive for patients and physicians, but perhaps essential as an ideal. (Kathryn Montgomery, 2006, p. 171)

The flavor of this case is that there are still a lot of question marks. I can tell the story any number of ways, but I don't really know what the truth is. (JJ – Family Physician)
CHAPTER SEVEN

RESULTS

The results chapter includes several subsections. The first subsection outlines the demographics of the sample in a table, followed by a brief description of the participants. The participant summaries serve to introduce each physician and provide a reference point for the examples used in the illustration of core themes. Quotations are used to convey a sense of the person. Names and identifying details have been changed to protect the anonymity of the participants and their families. Given the assumption that meaning is inseparable from context within the narrative, I have attempted to use substitutions that do not take away from the meaning of physicians' stories.

The second subsection provides a sample analysis or case study of one participant. This case was selected as an exemplary case for its ability to shed light on some of the most common themes while demonstrating method of analysis.

The final subsection of the results chapter presents the key themes of the analysis, integrating different data sources to explore these themes, including content material, associative flow and interview dynamics, and explorations in transference and countertransference.

Participants were interviewed in various locations, various times of the day, and varying lengths of duration. Most locations were quiet and involved minimal interruption. Given limitations in scheduling, many participants chose to meet during their lunch. Others preferred to meet at the end of the workday. In some cases, the researcher was invited into the participant's home. Interviews lasted approximately 1-2
hours and occurred most frequently in examining/clinic rooms, private physician offices, or conference rooms.

Participants were asked to begin by sharing a story of their experience treating a child or adolescent patient with "persistent medically unexplained physical complaints or illness." I encouraged each to think about a particularly memorable case, whether it be successful, or "hit the brick wall." Most had no difficulty bringing to mind a memory or story. For most, the telling of the narrative flowed easily into a dialogue on the topic of interest. Participants' beliefs and attitudes regarding child somatization and their ideals with respect to medical management and treatment emerged from the narrative themes and plots, as well as general conversation. When appropriate, I attempted to elicit participants' more personal views and shift away from the clinical in an effort to learn more about the social and emotional aspects of their work. I concluded each interview by inviting participants to share stories of their early life experiences with illness and uncertainty in their family of origin. I also asked participants whether they wished to share anything "off the record."

The analysis of the interview transcripts revealed common content themes, both within interviews globally, and across interviews. The data evolved into a rich body of information with a thematic coherence that helped shape the answers to my research questions. In addition, there were common elements associated with the dynamic process and associative flow of interviews that provided additional insight into the ways in which physicians make meaning of unexplained illness and pain in the child.
The Participants

Demographic Summary

All participants were physicians. A total of 10 participants: 6 females and 4 males were interviewed. Seven of the participants were pediatricians and 3 of the participants were family physicians. Three of the participants were second year pediatrics residents. All participants were Caucasian and born in the United States, with the exception of one who was Canadian. The median age of participants was 38 years. The median number of years of medical practice, post residency, was 9. A table below lists each participant and his/her demographics.

The physicians reported seeing an average of 10 children with persistent medically unexplained physical complaints, illness or pain annually. Residents reported seeing the highest number of patients with unexplained illness or pain, followed by developmental-behavioral specialists, pediatricians, and family practice physicians. Family practice physicians reported also seeing adult patients with persistent medically unexplained illness and pain in their practices.
<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Specialty</th>
<th>Years of Practice</th>
<th>Married</th>
<th>Children Ages</th>
<th>Teaching Faculty</th>
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<td>F</td>
<td>Late 20s</td>
<td>Pediatrics</td>
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<td>0</td>
<td>YES</td>
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<tr>
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<td>M</td>
<td>Early 30s</td>
<td>Family Medicine</td>
<td>3</td>
<td>NO</td>
<td>0</td>
<td>YES</td>
</tr>
<tr>
<td>Rick</td>
<td>M</td>
<td>Mid 50s</td>
<td>Developmental-Behavioral Pediatrics</td>
<td>26</td>
<td>YES</td>
<td>2 Adults</td>
<td>NO</td>
</tr>
<tr>
<td>Kay</td>
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<td>Pediatrics</td>
<td>2nd year resident</td>
<td>NO</td>
<td>0</td>
<td>YES</td>
</tr>
<tr>
<td>Christy</td>
<td>F</td>
<td>Early 40s</td>
<td>Family Medicine</td>
<td>8</td>
<td>YES</td>
<td>2 Preteens</td>
<td>NO</td>
</tr>
<tr>
<td>Grant</td>
<td>M</td>
<td>Early 40s</td>
<td>Family</td>
<td>9</td>
<td>YES</td>
<td>2 Toddlers</td>
<td>NO</td>
</tr>
<tr>
<td>Amy</td>
<td>F</td>
<td>Late 40s</td>
<td>Developmental-Behavioral Pediatrics</td>
<td>16</td>
<td>YES</td>
<td>2 Preteens</td>
<td>YES</td>
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<td>7</td>
<td>NO</td>
<td>0</td>
<td>NO</td>
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<tr>
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<td>Pediatrics</td>
<td>2nd year resident</td>
<td>NO</td>
<td>0</td>
<td>YES</td>
</tr>
<tr>
<td>Penny</td>
<td>F</td>
<td>Late 40s</td>
<td>Pediatrics</td>
<td>16</td>
<td>YES</td>
<td>2 Preteens</td>
<td>YES</td>
</tr>
</tbody>
</table>

**Jane**

Jane, a second year pediatrics resident in her early 30s, told her stories with energy, suggesting a passion for her work. Within Jane’s narrative, the theme of anxiety regarding her struggles as a young resident with the “unknown,” and her continued learning and evolution as a physician emerged.

**JJ**
JJ, a family practice physician in his 30s, told stories that conveyed a sense of perseverance to discovering the truth of his patients' pain and illness. He seemed to identify strongly with feelings of competence and being "in the know" as a physician, and his somatoform patients seemed to challenge these feelings significantly.

Kay

Kay, a second year pediatrics resident in her early 30s, had no difficulty sharing her feelings of frustration and even annoyance with her child patients with persistent medically unexplained illness or pain, and the parents of such children. Strong assumptions of blame were evident in her plots, as well as a pervasive "us-versus them" theme.

Rick

Rick, an experienced developmental-behavioral pediatrician, told stories that conveyed a sense of genuine caring for his patients with unexplained illness. His physician identity as "all knowing" and the associated struggles for authority in the physician-parent relationship was a key theme in his narrative.

Christy

Christy, a family practice physician in her 40s, tended to see the truth of a child’s pain to exist somewhere in the environment, or the patient’s reaction to it in the form of stress. Her narrative incorporated themes of the importance of family dynamics, chaos in families, and the role that dysfunction plays in health and illness.
Grant

Grant, a family physician in his early 40s, told only one story during his brief interview. The nature of this story, which he returned to again and again over the course of the interview, gave a sense of his strong self-confidence, or ability to always find the answers to problems.

Amy

Amy, a developmental-behavioral pediatrician, told stories that indicated a greater comfort with uncertainty than the other participants. Amy was able to see beyond the mere paradigm of administering a treatment and trying to cure the patient, instead focusing on the management of the symptoms, both medically and psychologically.

Lota

Lota, a pediatrician, told stories that conveyed the enormity of her concern of potentially overlooking or missing a diagnosis. The role this fear seemed to play in her medical management of such cases, and diagnosis, was significant. Adding to this fear was also a fear of disappointing the child’s parents.

Penny

Penny, an experienced pediatrician, shared “hit-the-brick wall” cases, or “failure” narratives. She likened the physician-parent relationship as a “delicate dance” in
maintaining trust and providing reassurance to parents, while maintaining her integrity as a physician.

Jake

Jake, a second year pediatrics resident, seemed quite attached to diagnoses and their necessity to his work as a physician. There was a running thread in his narrative of the shared disappointment of physician and parents in failing to arrive at an end point.

An Example of Method and Preview of the Core Themes

This section will be dedicated to an in-depth analysis of one interview which is meant to give the reader a sense of the interview process and method of analysis. More importantly, the goal is to help the reader understand how I made sense of each physician's narrative and the meanings contained within. Given that meaning emerges within a relational context, I have provided not only a rich description of content themes, but also examples of associative flow and the dynamics of the interview as sources of data.

After analyzing each interview individually, I began to search for commonalities across the interviews, and then went back again to find contradictory examples to answer my research questions. My goal here is to provide an overview of the core themes as they emerged in one interview, with elaboration in later sections.
Case Study: Jane

Jane invited me into her home for the interview on a Saturday afternoon. She lives in a small apartment near the university hospital given her demanding hours as a second year pediatrics resident. It was a week before Christmas, and so she spoke excitedly about having some time off to see family. She also spoke about her upcoming trip to South America for vacation.

The small talk before the interview gave me a sense of Jane’s enthusiasm regarding medicine. She spoke of her dedication to volunteer work with Somali refugee immigrants in her own neighborhood. She hopes to travel and practice medicine in a location outside of the United States when she completes her residency training.

As we conversed, Jane puttered around her small kitchen making coffee and preparing a snack. There was an ease in talking with her that I attributed to her feeling comfortable in her own home, it being Saturday, and her not having to work. The anticipation of Christmas seemed to put a spring in her step. She told me about borrowing her friend’s car to pick up a Christmas tree before her parents’ visit. She joked about the size of the car and its likely inability to carry the tree she wished to purchase. She had a sarcastic sense of humor that was entertaining.

Before beginning the interview, I asked Jane a few personal questions to learn more about her as a person and not just a doctor. Jane was born on the East Coast and attended a small private girls’ college before beginning medical school in the South. She enjoys music, particularly choral singing. She is single. She loves traveling. As I gathered a little more information over coffee, there emerged a pleasant rapport that allowed easy transition into the interview.
After going over the paperwork and setting up the recorder, I invited Jane to tell me a story about an experience she had had with a child or adolescent with persistent unexplained illness or pain. She hesitated momentarily, and then said that two came to mind. She asked which one I preferred: “the pain complaint one, or the non pain-complaint one?” I welcomed her to share whichever she preferred, or both. Her eagerness to tell stories conveyed a sense of an enjoyment for her work, in spite of its challenges.

Jane’s first story was of a young female patient with persistent and unexplained knee pain. The family was Somali, which she indicated led to significant barriers in communication, yet she did not seem overly concerned by this fact. I let her speak at length, interrupting only momentarily to clarify certain details of the case or ask questions regarding the child’s age, the chronicity of her pain, and family dynamics. Jane spoke quickly and almost with a sense of urgency, suggesting a certain degree of nervous energy or anxiety.

From her first story, Jane’s sense of dedication to families, particularly mothers, and to her discovery of the truth of the child’s pain became evident. Her perception that a child’s pain is often “written off” by primary care doctors and merely labeled as “growing pains” was associated with some irritation and her subsequent striving to be that “different” physician to provide answers and cure. Her experience with mothers’ disappointment in arriving at no conclusion was poignant. While inclined to dismiss the importance of the child’s knee pain as others had (particularly in light of insignificant medical findings), Jane’s need to be a different physician overpowered such inclinations. The importance of paying attention to the mother’s concerns and take them seriously was a common theme in her stories. I wondered about an inner conflict for Jane: facing the
reality of her medical tests and clinical hunches that the pain in the child was "nothing," while coping with an internal need to not let go of the search for truth. She said, "So basically I got to the point then... where I was thinking.... WELL, I think you should always take parents seriously when they tell you, you know, that they THINK, really think there is something wrong with their child."

As I listened to Jane continue, what I heard in her narrative was a struggle to make sense of the unknown and deal with her anxiety regarding the uncertainty of the child's pain and suffering and negotiating the same uncertainty in the parent. The struggle to continue the search for an answer in spite of a sense of wanting to let go, was powerful. She said,

*She wanted me to tell her what to do, BUT, she didn't want me to tell her to do nothing (small laugh). I mean, so you know... it was a challenging case for me... because I wanted to tell her to do nothing... and she wanted me to tell her to do something.*

While in the end Jane decided to let go, and essentially seemed to reject the parent and child through a "watch and wait" approach, I could not help but notice that she returned again and again to the case during our time together, in what seemed to be a search to make meaning of the unknown. She seemed to be questioning her actions. What may have been missed with the child with knee pain? She expressed a sense of bafflement with the nature of the symptoms as intermittent, on both sides, and persistent. She invited me as a nonmedical listener to join her in questioning the unknown; all possibilities, including the bizarre, the simple, the most feared. The number of unknowns in the situation quickly added up for her. She wondered aloud what was the child's real age (since refugees often falsify information and she seemed like a very tall 8-year-old),
did the child have tuberculosis, was it some unknown African infection, were her symptoms related to torture from a refugee camp, were the symptoms psychological, was the mother lying, was there something lost in the translation with this family?

Jane’s first story was followed by a sense of contemplation regarding the ways in which this case was educational to her, both from a “medical standpoint,” and in learning how to support a family in their fears of the unknown while performing her work with some objectivity. I wondered about her worry of allowing her emotions to spill over as she told me of the constant inner pressures to not “over-react.” Her continued worry of what might have been missed, what the “something else” was that might have been going on, and her need to remain affect neutral and objective led to an elaborate balancing act. When her discomfort discussing the case was too much, she summed up, “So...that’s that case. It was a good one...one that was resolved. In the end the pain went away.”

There was a running theme in Jane’s narrative of her tendency to become identified with the anxiety and fear of mothers in facing unexplained illness or pain in the child. Her second story provided a good example of this. She told of a little girl brought to the emergency room who reportedly could not walk. Jane told the story noting the humor of it all (from a physician’s perspective). As she imitated the child in her description, I could not help but laugh a little myself. In hindsight I wondered about the ways in which our shared humor might have been protecting us from experiencing the real anxiety of the unknowns of the pain and uncertainty of illness of this case. In the end Jane explained the symptoms as a way of the child avoiding her father in a messy divorce and custody battle. I wondered about the nature of Jane’s hesitation and possible need to avoid disrupting the child’s way of coping with the difficulties in her world when she told
me of her treatment. Although nothing medically could be found to explain the child's inability to walk, she admitted the child for one night. Her story gave a sense of the collaborative stance Jane took with the mother, and the mirroring or parallel experience of anxiety and desires to protect the child from further pain and suffering.

Jane spent little time pondering her second case, seeming happy to have entertained me with it. She then jumped quickly into another. Before leaving the case, I quickly asked her to tell me a little more about how she made sense of the child's symptoms. Was she experiencing pain? Here I was seeking a deeper understanding of Jane's meaning making of the pain and illness of the child.

_But she very clearly...and to me it seemed like she really believed that she had pain._

Could she have?

_I...I think so! I think she really had some pain. I think she really had pain in her legs. Or she was perceiving pain in her legs! A lot of pain... It's perceptual. I mean...SHE WAS perceiving pain in her legs. I don't think that she was making it up. But...and I asked her...I asked her mother that. Because I couldn't think a good way to ask the girl that. I said, "Do you think she is making up this pain?"...and her Mom agreed. She said... I really don't think she is....I think this is sort of what her body does...when it kind of senses that she is in a dangerous situation..._

There emerged in Jane's narrative a theme regarding her need to involve mothers and parents in her meaning making of the child's symptoms of illness and pain.

Jane's narrative gave a sense of her believing the reality of pain in the child with medically unexplained symptoms; however, as she was about to leave the second story behind, I wondered about Jane's commitment to this concept.
And who can say if she actually had pain or not? Um... I wish there was some way to know... You know, I wish there was some... limus test... that you could put some sort of sticker on their skin that could tell you whether or not they are having... that they are actually having pain as they said they did. Because I think it's just fascinating... you know... was she so subconsciously frightened that her body invented this pain for her? I mean... not invented, but created the pain for her? Or... Was it more of a conscious thing? She was thinking to herself, here's a situation where I could potentially get into trouble. How can I get out of it? I felt with her... that it was more subconscious.

In the end, the pain that cannot be explained medically for Jane only seemed to have the potential of being truthful in the sense of objective reality. Thus, her ideas about the truth of unexplained illness and pain seemed still in process of being fully shaped.

Before moving to another case, I sought to understand more about Jane's feelings in arriving at the end of a case with essentially no medical answer. How does she really make sense of it all? From this dialogue emerged strong themes of helplessness and powerlessness; however, such feelings seemed to be acceptable to her as being fundamental to her identity as a resident. She admitted to a lack of knowledge.

You really, particularly as a resident... such as myself, you really have to...(long pause)...I think that for me it makes me not hesitate at all to call in... multiple second opinions...and say, hey! I need help thinking about this.... And I need someone else to see this kid, and tell me based on your experience, which is hopefully more than mine, do you think this is growing pains? Or do you think this is .... Something else.

The theme of uncertainty in Jane's narrative was strong and came up again and again in dialogue. She told me that in not knowing, there always exists a need to go "digging." The association to the search to find answers here was powerful. She says, "It's always nice when kids have more obvious (laughs a little)... when there is obviously
something more physically wrong... you know? It's nice to be able to chase that. It's difficult when you don't know what to chase, and what not to chase."

Jane shares a final case before we venture into the topic of her childhood and her more personal experiences with uncertainty and illness. The final story, building as the others did in pursuit of resolution conveyed Jane's sense of helplessness in facing unexplained pain in the patient. I sensed certain anguish in Jane's witnessing the child in pain, and being helpless to take it away. At the root of her experiences there also seemed to exist a looming fear of failure; that is, failing herself as well as the parent in providing explanation or diagnosis. Her sense of disappointment and bearing the weight of the same for the parent seemed to take its toll for Jane.

Jane's experiences with uncertainty in medicine became even more meaningful in her telling of her childhood. Her fear of the unknown and anguish in facing pain without cure as a physician held a certain parallel to her own experiences with migraines in childhood. I wondered about her identification with the mother's anxiety as she described her own mother.

At the other end there are the... you know, the "Oh my God, you scraped your knee! We're going to the emergency room!" type of parents. My mom is toward that end....She took illness... very seriously. And you know, everything that happened, we had to go to the doctor. I mean, it wasn't like a crisis, but things were always....It was a big deal.

Later, she elaborates,

This has been happening for my whole life. When I was a kid... I mean every little thing, we had to go to the doctor for it, have it checked out...and...you know, everything had to be taken seriously and evaluated. Now that I'm out of the house (I'm the only child), it's...my Dad! So she calls me every day, and she'll be like, "oh, you know today... your Dad... his arm twitched once! What do I do?" And it's so... it's so... well I'd say that illness is taken very seriously, and thought about often in my house.
Jane's description of her experience with debilitating migraine headaches with vomiting in childhood helped to provide a frame for understanding the ways in which she faces the search for the truth of unexplained pain in her child patients, and the anxiety associated with the uncertain truth of that pain. She tried to make light of it all, and seemed to protest that it did not bother her; however, her descriptions of her mother's sense of anguish in not knowing the cause of her pain, her struggle with physicians to find diagnosis, and her constant attentions and reminders to Jane of the possibility of facing ongoing pain were quite revealing. Jane's experience of her mother's anguish seemed more central than her own pain in experiencing migraines. I wondered about the anxiety that was being stirred up as she spoke about these experiences, particularly when she attempted to quickly sum up and provide a happy ending. She told me that when she hit puberty, her headaches just "suddenly disappeared."

As I read her story, I wondered more about Jane's sense of helplessness attached to her child-self in coping with unremitting pain and the parallel experiences of her mother in creating a sense of shame and sorrow as being the cause of much of her mother's anguish. Associated with her mother's preoccupations seemed to exist for Jane some underlying resentment and even anger, believing she was "held back" from enjoying her childhood. Jane said, "You know...I really just wanted to be a kid." Jane concluded her story in humor, pointing out her continued occasional migraine and compulsive need to protect her mother from knowing. She stated, "I think it was really stressful for my mom...just me having those headaches. So I don't mention it anymore."
Jane's experiences providing medical care to children with persistent medically unexplained physical complaints and illness tended to parallel her own experiences in childhood, revealing strong identifications with the mother's sense of suffering and the child perhaps representing the root of this experience. In analyzing her narrative, I wondered about her internalization of her mother's anxiety and resulting identification with parents' helplessness, anguish, and frustration in her medical encounters. The plot of her stories tended to center around her drive to repair that relationship and provide the restitution she was unable to as a child (i.e., by providing diagnosis and treatment). The more invested her efforts in this, the greater seemed to be her feelings of inefficacy when failing to meet this goal.

The associative flow of Jane's narrative of medical cases as building in their intensity of pain and "bizarreness" perhaps tells something about her own tendency to experience the uncertain and unknown as fearful. There are many images of her helplessness and frustration in experiencing pain without explanation. I found Jane's experience with her mother to be quite moving, almost feeling the anxiety myself of her worried mother's intrusion into what should have been the happy experience of her childhood. In contrast, Jane spoke quickly and did not show much emotion when telling of her own experiences.

In retrospect, I wondered about the ways in which I might have protected Jane from experiencing her own sorrow and pain associated with her experiences as a physician. Perhaps responding more empathetically to allow continuation of her narrative and opportunity to experience these feelings more fully would have been beneficial. I was indeed more reserved in my responses and missed opportunities to ask for
elaboration. In hindsight I wondered about my capacity to see her as a person in all of her humanness, with her sorrows and anxieties, and not just as the clinically objective and affect-neutral doctor.

In the case study of Jane above, we see a preview of the key themes that are common to the other participants' narratives: the theme of fear of failure and loss of control, the struggle to negotiate uncertainty with the family of the child, the shaping of attitudes and beliefs in medicine regarding the interaction of the mind and body, the struggle for power and intimacy in the relationship with the parents of the sick child, the physician identity and its importance to the search for the truth of illness and pain, and finally, the power of influence of early life experiences with uncertainty and illness and one's capacity as a physician to respond empathetically to the child and parent. I will elaborate these themes as well as others throughout this dissertation, as they are presented, with variations, by the participants of this study.

**Key Themes**

Four key themes form the core of the findings in this section. A presentation of the findings include various data sources including content material, associative flow and the interview dynamics, and explorations in transference and countertransference. These themes are, (a) the experience of certainty and uncertainty, (b) the search for restitution, (c) the path to truth and the construction of the physician narrative, and (d) the parallel of anxiety between physician and parent.

*The Theme of Certainty and Uncertainty*
One of the strongest themes that came across in the interviews was the negotiation of uncertainty and the associated anxiety and even dread this stirs up for the physician when treating the child with unexplained physical complaints, illness, or pain. Each of the 10 interviews revealed this as a common and central theme in the narrative. In particular, participants’ sharing of failure and quest narratives became a stepping stone to the discovery of the common theme of uncertainty in the data.

There was a running thread of anxiety related to participants’ inability to find an answer or diagnosis for the child with unexplained pain or illness. These feelings of anxiety seemed related to a fundamental sense of helplessness in “not knowing,” fears of failure, medical error, and loss of control. These fears appeared frequently in the narratives and seemed powerful in shaping the physicians’ search for the truth of illness or pain, as well as their construction of illness narratives. Participants’ anxiety regarding the uncertainty of pain and illness in the child was powerful in its capacity to influence the quantity and quality of interactions with the child and the family, as well as shape the process of medical investigation, differential diagnosis, and treatment.

The literature consistently describes patients with persistent and medically unexplained illness or pain as presenting a challenge for physicians. This is likely because these patients tend to threaten physicians’ feelings of competence and challenge the general “worldview” that problems can and should be easily solved by the “knowing” physician with all the tools of science at his or her fingertips. As I interviewed participants, I found myself wondering if perhaps uncertainty and “not knowing” represent a type of existential anxiety for the physician. After all, the doctor is supposed to be knowledgeable and able to solve the patient’s problems. This kind of thinking
seems fundamental to their identities. Narratives indicated that the question mark, the open-ended, and the mysterious are not well tolerated concepts in medicine.

_Fear of Failure, Medical Error, and the Loss of Control_

The possibility of error or experiencing failure seemed to be ever present in the mind of participants in their search for meaning of a child’s symptoms of illness or pain. An undercurrent of worry associated with the fear of failure or error was present in each narrative, even those who seemed to have a higher tolerance for uncertainty. The need to make decisions and take action in the face of sometimes only limited information, being unable to provide answers to parents, coping with the “not knowing” whether their decisions were correct, and the worry over what might have been overlooked were all associated with significant mental anguish for the physician. In my study, those physicians who experienced worry over uncertainty most intensely had either witnessed a mentor experience medical error, or had experienced failure themselves. While the sorrow and pain of a mistake recollected was not much dwelled upon, it became evident that it was something that was always in the “back of the mind” of each participant, to varying degrees.

I will use Lota as an example: a young pediatrician whose narrative strongly portrays the sense of insecurity and uncertainty of not knowing when dealing with a child whose pain or illness is medically unexplained. There was a strong sense of anxiety and distress that came through in Lota’s narrative. My personal experience of Lota was that she was pushing me away in some way. The quality of her speech was pressured and she had a great deal of physical energy. She tended to just “gush” information into me as if a
container, in a rather nervous and unorganized way. I wondered whether this was Lota’s way of avoiding questions for which she would not have answers, indicating her intolerance for uncertainty.

Lota began her interview by telling a story of a young female patient with stomachache for whom she had not yet reached diagnosis. In this case, Lota seemed particularly identified with the worry and helplessness of the parents. As a means of coping with this worry and in an attempt to gain control over her sense of helplessness, she explained her order for further testing to locate the truth of the child’s symptoms. Her sense of “not knowing” and the anxiety this stirred up for her became evident.

*I would hate for her to have something and to not know about it. I mean, what if there is something serious going on... and you don’t want to miss anything... because you always hate if something is happening and something’s going to... you’re going to miss something... and so... then you’re kind of left with that, like you know... what to do next...*

Throughout our conversation, Lota seemed compelled to return and reflect aloud on her puzzlement with this case, giving the listener a sense of her internal struggle to make sense of what was truly going on, yet she continued to doubt herself. She said, “I feel like we’re doing everything normal — I mean, everything is normal and we’re still not getting anywhere... and we try different things! I mean usually things get better with medication or things like that.” With a sense of frustration she suddenly seemed compelled to leave the case behind, stating, “I want to make sure there is nothing serious going on... but I really can’t find anything! I’m just still trying to work out if it’s something else.” I wondered whether Lota’s protest was to convey this fact to me, or rather convince herself of the “rightness” of her actions. Her first story helped me to
understand more about her dedication to finding answers and cure to the child and family, but more importantly the high expectations she seemed to place upon herself in her unrelenting search for meaning and certainty.

For Lota, as for others, the chasing of the origin for pain and the belief that it resides somewhere in the body becomes clearer. The focus on the body as holding the truth of illness and pain as opposed to elsewhere, seemed associated with greater anxiety and uncertainty. This seemed connected to the fear regarding the potential of medical failure or error, and the potential feelings of incompetence and sorrow that might ensue. Several times in the interview, Lota states her worries that hint to a sense of shame associated with potential error. She says, "I would feel bad... I would just feel so bad." More than ever, Lota’s interview material provided an example of the ways in which the recurrent theme of missing a diagnosis and the risk of causing harm to the patient (and disappointing parents) is ever present in the physician’s mind.

Near the end of the interview with Lota, the listener was better able to understand from where her insecurities and fears of medical error stem. In the context of sharing her beliefs regarding the process of "normal body healing" (i.e., the unusual and mysterious way that symptoms can disappear in the absence of diagnosis or treatment), the metaphorical "chink" in her physician armor was revealed. She told me, as an aside, about her experience with misdiagnosis in a young male patient with Down syndrome. She told me how the patient had complained of persistent headache pain and was managed in primary care for some time before the eventual discovery of a terminal brain tumor. Lota did not dwell much on the details of her failure, and she tended to gloss over
any feelings of grief or sorrow, but rather used the story as example to convey the reasons for her current discomfort with uncertainty.

You know, he had some vomiting episodes that were severe... and then he went to the hospital and he had brain cancer. That's very unusual, but – I mean, he always said NO to everything! So it's like if he's going to come in and complain to me which he – you know, didn’t, because he says no to everything when I ask. But you know, certain people you know when they complain and don’t complain and what you do and what you can work with... it's hard. I just need to be careful now.

From Lata’s disclosure, the listener is alerted to the formation of a belief that shapes her medical management of children, that is, giving value to the subjective reports of patients puts her at an increased risk for investigative or diagnostic error. In this situation, Lata’s patient’s report of symptoms was inconsistent and ultimately inaccurate. While the example Lata provides is somewhat drastic given the patient’s cognitive impairments and minimal capacity for insight or complex reasoning, what does become evident is how the power of this experience, particularly her misdiagnosis, may potentially continue to shape her search for the truth of unexplained illness or pain in her child patients. The shame that Lota may have experienced with her medical error may serve to reinforce her tendency to worry about what might be “missed” in subsequent investigations with other patients with similar unexplained symptoms.

Many other physicians in the study spoke of what Rick referred to as the “shadow of a doubt” ever present in his mind of the physician when treating the child with unexplained illness or pain. Rick also shared an experience with failure openly, but without really connecting to any sense of shame or sorrow. His experience was somewhat
different than Lota’s, for while also coping with his own sense of guilt, the child’s mother also returned to shame him for his error.

*I VIVIDLY REMEMBER!* (speaking suddenly very loudly) um... this lady...this was fairly recent in practice... maybe 5 years ago... still working in the inner cities... ah.. (big sigh)... a lady from a disadvantaged background, kind of a defiant manner... not easy for me to have a therapeutic alliance with. Her child was ... ah, maybe 7, 8, or 9 months old... kind of colicky... and we had fiddled around with working with this and that, and he was growing okay, so I kind of said... “You know, it’s just his temperament. So... nothing serious... BUT... he did turn out to have um.... a partial obstruction of some kind, which she VERY decidedly came in to tell me about it...after the fact (pause) And those!

The above quote gives a sense of the power that failure or the fear of failure has for the physician in the search for the truth of illness and pain in the child patient. What was different about Rick, is that he seemed to have some degree of insight and understanding as to how this experience continues to shape his thinking and medical approach. Like Lota, the worry over error seems to hold a fairly constant place in Rick’s mind. He suggested that for many physicians, the possibility of error is a real one.

*I don’t think (louder) ...um, ANYBODY is immune, from that kind of...uneasiness. I think that the great fear of course is...once you begin to feel 70, 80% sure that it’s not an organic illness... you can’t ... get rid of that shadow of a doubt that ...and everybody’s been wrong about this. Everybody’s had that gut feeling that it was...an emotional origin... and then you are wrong... or somebody discovers...something serious.

The flow of associations in Rick’s story reveals the coherent theme of uncertainty: the shadow of a doubt that remains in spite of “almost” certainty, unease in trusting his “gut feelings,” fear of personal failure, and worry over disappointing parents. His narrative gives a sense of the fallibility of the physician to provide certainty.
JJ, a young family practice physician practicing less than 5 years, also told stories that conveyed the sense of confusion and discombobulation that comes with uncertainty in his practice. JJ’s attempts to piece together the fragments of the patient’s story and create an illness narrative that made sense to him became a central theme in his narrative. In general, there was a running thread of anxiety and confusion associated with his interactions with patients with unexplained pain. Phrases such as “I can never piece together what’s going on…” “I have no idea…” “I might never find out when it started…” “I might never find out what it’s really like ... his headache” all give a sense of his struggle to make sense of the patient’s symptoms.

JJ provides an exemplary example of the drivenness of the search for the truth of pain and the physician’s sometimes unwillingness to accept uncertainty. For JJ, this search left him feeling confused, helpless, and inefficacious. The associations and metaphors of his stories speak to this helplessness. For example, speaking about his frustration in treating his Somali patients with unexplained pain, JJ mentions the movie “The Gods Must be Crazy.” While on the surface JJ used this movie to convey his patients’ sense of bewilderment and astonishment regarding the tools of Western medicine, on a deeper level he provided a valuable metaphor reflecting his own struggles with uncertainty as a physician. Initially one might interpret this metaphor as reflecting JJ’s sense of himself as the White man and as god-like, struggling with control and omnipotence or superiority; however, it is not entirely clear with whom JJ truly identifies: Is it the all-knowing White man or is it the Native, feeling confronted by experiences he cannot understand? After analyzing JJ’s narrative, I wondered whether JJ felt more like the dumfounded native, confronting a mystery that he really could not understand.
Many other participants told stories that indicated the same worry or preoccupation with missing information or misdiagnosing a child with medically unexplained illness or pain. Participants' fears did not seem as connected with failing the patient, as they did with being wrong, experiencing error, or failing. Christy, a family practice physician, described this sense of dread over potential error, saying, "even with patients of my own, it's hard to know what to work-up and what to just reassure... because I know that the one time you reassure them, THAT'S the time it's going to be something real." Jane, a resident with little patient experience, also seemed to continually question herself, wondering what she had missed. The phrase "something else going on" appeared over and over again in her narrative. Kay, also a resident, provided vivid images of the anxiety that comes with facing uncertainty. Her reference to the movie "One Flew Over the Cuckoo's Nest" conjured a sense of fear of psychosis, but more importantly, hinted to her internal struggle facing the unknown and coping with feelings of powerlessness and helplessness. Kay often referred to her patients' unexplained illness or pain symptoms as "bizarre," "weird," and "freaky"—all terms that invoke fear of the unknown. Her mention of the film occurred at a point in the interview where she begins to approach her feelings of helplessness facing the unknown of illness and pain.

**Physician Defending Against Uncertainty**

The mechanisms used to defend against experiencing anxiety and uncertainty of pain or illness in the child, or uncertainty that comes with facing conflict in the relationship with parents included intellectualization, rationalization, avoidance, depersonalization, displacement, and reaction formation. Rationalization and
intellectualization were by far the most common defense mechanisms evident in the narratives.

Take JJ, whom we recall as experiencing intense anxiety as a physician related to uncertainty, or "not knowing" the truth of illness of his adolescent patient with headaches. He returns again and again in the interview to question aloud what he might have done differently, what more he could have done, and what he may have missed. JJ defends against his anxiety by rationalizing his behavior as a physician. For example, that JJ did not seem to ask many questions and did not hear the patient narrative in its entirety were attributed to time constraints, poor reporting of symptoms by the patient, and cultural barriers. JJ's rationalizations regarding his lack of time and other barriers associated with the medical situation serve to avoid his hearing the patient's true illness narrative with all of its pain and anguish. He says:

*If I get 20 minutes with the guy, which is really by the time he comes, 15 minutes late, and his interpreter gets there, and they're all there together...and for me to be able to do any paperwork, and by the time he gets roomed, which means vital signs and what not,... I mean, he's already 30 minutes past his appointment time anyway. So, I'm essentially starting at negative time to get anything done! So... it's always just hard to just triage.... I need to focus on immediate problem solving... so I can never piece together what's really going on with this guy.*

Kay was similar to JJ in her tendency to defend against the anxiety that comes with uncertainty, particularly facing the same in the parents of the child. I wondered about her rationalizing her tendency to push the patient away, when she said, "*and just, you just don't have time to sit down and go through every little thing with them. You're too busy and getting pulled in too many directions.*"
Avoidance and rationalization seemed to be the most common ways that physicians made sense of their experiencing ambivalence, confusion, and ineffectiveness. In fact, reliance on treatment methods such as "watch and wait," expecting "normal body healing," reassuring patients that nothing is wrong, and prescribing placebos (e.g., acid reducer for abdominal pain) combined with close follow-up, might all be seen as examples of avoidance.

Intellectualization of feelings was also evident in the narratives. Physicians struggled to experience their feelings in the interview, avoiding in particular negative feelings such as sorrow or anger that were clearly associated with certain patients. Participants used phrases that hinted at negative feelings that seemed only to brush the surface. For example, "frustration" was a popular term for feeling states such as anger, and "worry" was a term frequently used to characterize fear or anxiety. Physicians spoke in ways that suggested the presence and theoretical acceptance of negative feelings, but tended to avoid their actual experience. I am not meaning to say here that the participants were unfeeling or did not have feelings during the interview, but rather that they either had difficulty verbalizing them or perhaps purposefully avoided their experience. For example, saying "it's just too bad" or "it was so sad" demonstrated the ways in which physicians may separate their feelings from the self and displace them to the situation or context. In a way, this may serve to neutralize the feared emotion for physicians who are supposed to be clinically detached and always objective in their analysis of patients.

Kay and Grant offer some insight into the different ways that physicians defend against feelings of vulnerability and the anxiety in facing the unknown. Grant tended to cope by creating a truth that made sense to him, making use of his profession, and
discarding the rest. Kay, on the other hand, did not yet seem to feel able to fully trust her knowledge and experience as a resident, and instead sought the truth of illness as confined to the body. When the truth of illness or pain could not be found there, or was suspected to reside elsewhere (e.g., in the mind or environment of the patient), Kay tended to pull away from the patient through behaviors of invalidation or blaming. Ultimately, Kay seemed to be telling about her rejecting patients and those families for whom she felt her medical tools and knowledge could not help. She had no trouble admitting to being “not at all equipped to handle” cases of uncertain illness.

Amy: A Tolerance for Uncertainty

Amy, a developmental-behavioral pediatrician, emerged as a unique participant in that her capacity to tolerate uncertainty seemed much greater than the other participants. With confidence and candor, she voiced her intent to always remain humble and face uncertainty head-on. Because of this, she seemed able to extend her meaning making of illness beyond the body to the environment of the child, as well as the psyche. Amy spoke of her embracing a biopsychosocial approach, never restricting her search for the truth of pain or illness to the body. This was evident in her narratives which included descriptions of the child’s symptoms, as well as the circumstances surrounding them, the parent and environment in which the illness was framed, and the ways to which it was reacted. Her story offers a richness that many of the other participants’ did not. Her narrative focused not only on the illness and possible diagnosis, but other important details that serve to bring the child and family to life. Amy’s description demonstrates an ability to honor all aspects of the child and the dynamics of the family. In the end, her
narrative gives the listener a sense of the ways in which she searches for the truth of illness and pain while accepting a sense of uncertainty in the process.

So, with these kinds of patients, the process of figuring out, you know, is this an organic illness that I'm just not--nobody has been smart enough yet to figure out, or is this a--really a psychosomatic illness, you know, doesn't have any basis in any type of organic disease or pathology, or is this a little bit of both? And I--and as a developmental behavioral pediatrician, that's my, you know, my medical hat plus the behavioral health hat is, I'm hardly ever an either/or kind of person. And you know, and so, it's not an either/or situation for me. You know, and then just being humble. It's just so--you know, the medical person, you've just got to stay humble.

Although able to tolerate higher levels of uncertainty in her work compared to the other participants, Amy's greatest struggles with not knowing and facing uncertainty do lie not in the biomedical realm, but rather in understanding the ways in which the mind and body together present a certain confusing truth about illness.

Certainty and the Physician Identity

In analyzing the narratives I searched for evidence of self-representation that influence physicians' constructed meanings of illness. Within the storyline each participant seemed to communicate important aspects of the conceptualization of self-representation and object representations.

Participants' stories suggested an inclination to view oneself first as a doctor, and second as a person. The implications of this to the meaning making of illness, approach to locating the truth of this illness, and the dynamics of the relationship with the parents and child in doing so, are significant. If the physician sees him/herself as omnipotent and infallible as a healer, then the fear of failure seems dominating and powerful, as is the
resulting experience of anxiety of “not knowing” or being unable to arrive at an explanation or answer. The more participants seemed identified with the doctor “self,” the greater their struggle in facing uncertainty. Associated with the powerful physician identity seemed a forceful pursuit of answers or explanation for the symptoms of pain and illness. Rick’s identity as a doctor seemed strongly associated with his fixation to find answers and achieve certainty. His self-presentation in his stories was as a physician who is more knowledgeable and an authority in understanding illness. This type of self-presentation seemed linked with certain expectations of trust and deference from parents.

The listener can hear the sense of self-importance as he speaks:

> It happens all the time...a parent will become converted to... a theory...and reading this stuff from the Internet....to tell you about it! Um...most of it is, ahh...Is what they call, junk science! You know...it's got the veneer of being scientific, but there's really very little substance to it...maybe nothing published...ah...in a respectable journal...uhm... people are so CAPTIVATED by it though, that they absolutely have to have you sign it so they can have the testing done to give it a...some substance to the truth.

The centrality of the physician identity to the storylines of participants’ narratives seemed greater for those with more years of experience and medical training. For example, Rick and Amy, both physicians who have been practicing for many years and who have advanced training and specialized knowledge demonstrate how important the physician identity may be to the pursuit of certainty. Related to the concept of the “physician identity” was also the finding of an intergenerational pattern of the physician career in the lives of participants and possibly a more learned or entrenched sense of the physician as conquering the unknown. Those participants with a physician parent seemed to have a more imbedded identity of the physician as one who is “all knowing” and
powerful in providing restitution to the patient. The strength of the participant's physician identity was also evident in the images and associations in the narrative. Both Amy and Rick had a parent who was a physician, and what was common for both was their telling of stories that contained images of the "hero" physician, suggesting an admiration and perhaps idealization of the role. Amy, JJ, and Penny also told stories in which the physician seemed infallible.

*Early Life Experiences with Illness and Uncertainty*

Most striking about physicians' narratives was their telling of experiences with uncertainty and illness in early life and the close parallels they held to their most memorable (and often difficult) patient cases. In more than half of the participant sample, a parallel experience existed. That is, participants' descriptions of their most memorable child cases were comparable in some way to early life experiences for the physicians relating to uncertainty of illness. Bowen's family of origin theory (1972) may help to explain this phenomenon, which suggests that threats to neutrality and increased anxiety for physicians when working with some patients are due to unconscious feelings and emotions generated from one's past. In many cases in which physicians do not feel effective, identification with the patient or a family member may lead to a "fusion" to the patient's system of illness leading to loss of neutrality, ineffectiveness, and failure to accomplish therapeutic goals (Mengel, 1986).

JJ provides a nice example of how the experience of facing uncertainty of illness in the patient may be influenced by early life experience with uncertainty and illness. When speaking about his past, JJ described himself as an anxious adolescent coming to
grips with the serious demands of adulthood. He recalled often worrying about the needs of others, and feeling as though he were carrying the "weight of the world" on his shoulders. During JJ's adolescence, he recalled coping with unexplained migraines, for which he received relaxation and biofeedback therapy leading to their disappearance. I wondered about how JJ presented his experiences with uncertainty and illness as being easily resolved and his possible expectations of the same with his patients.

It does not seem to be a coincidence that JJ's most memorable case was a young adolescent boy with unexplained headache. The boy, a Somali refugee who had lost an eye in crossfire, experiences headache in that location. JJ seemed particularly identified with his patient's struggle with the awkwardness of adolescence, the fear and anxiety of not knowing the truth of the pain, his isolation in facing that pain, and his related struggle to cope with the anxiety of becoming a man and taking on new responsibilities. In providing restitution, he refers the boy to a neurologist for medication, but also to an ophthalmologist for eye reconstruction, to "help him feel better about himself." JJ tells of his search for restitution for his patient.

I think he has less anguish. About the whole headache and eye thing...now his eye is set up...he's doing better, we treated the acne, he feels better about himself, ...um...he wears cool sunglasses now...he's ... I think he feels less... I think he feels better about everything. About himself...um...because he comes in looking a lot better. He was always...he comes in smiling...and you know, we joke about his cool sunglasses, and ...so... but... I don't know what happened! How did he get better? Is he really better? I don't know.

In analyzing JJ's narrative, I wondered about his capacity to stay neutral and objective given the parallels of this case to his own early life experiences with illness and uncertainty. JJ seemed to struggle to "differentiate" himself from this patient, which in
some ways may have prevented him from being effective. I asked JJ about his own sense
of worry and frustration over the patient’s pain, versus that of the boy’s himself.

Worry...not so much for him! In retrospect, ... this is what I’ve learned! He was
less bothered by it than I was! So he’d say headaches! He’d rate it 8/10... he’d
say he couldn’t do anything during the day....But he seemed not too bothered by
it! Even now, he doesn’t seem too bothered by it! It’s not like he came in saying...
“God, I don’t know what I’m going to do, I can’t function! I mean ....I was the
one saying oh! We gotta do something about this!

Rick, an experienced developmental-behavioral pediatrician, provides another
eexample of the parallel experience of anxiety associated with uncertainty in the patient
and the early life experience of the physician. Rick describes his most memorable case as
treating a young boy with unexplained stomachaches. He tells how the boy not only faced
uncertainty in facing his own pain and illness, but also experiencing his father’s
deteriorating multiple sclerosis. Rick tells me that the boy’s sister had also experienced
psychosomatic symptoms as well as anxiety. He frames the patient’s illness symptoms
within the context of extreme family strife. His story revealed clear empathy and striving
for restitution for both the child and family, acknowledging the uncertain sadness and
fatality of the situation. I wondered about Rick’s identification with the child and his
vulnerability and helplessness when he stated his belief that the boy only needed to “have
certain needs met.” There was certain emotionality in his telling of this story that was
later explained in his telling of his personal struggles as a boy facing the terminal illness
of his mother: multiple sclerosis. He described to me his sense of helplessness and fear,
the eventual loss and grief, and his efforts to find a way to cope and have his “own needs
met” while his father attended to his mother and tended to neglect his and his brother’s
anguish. What Rick brings to his clinical encounter with this child, who faces the same kind of uncertainty as he did when young, is a sense of empathy as well as acknowledgement of the reality of pain. Also, there is his belief and appreciation for the ways in which family stress (in this case the illness of a parent) can become manifest in the body. The listener gains some appreciation for the idealized image of the male physician as hero and healer in Rick’s narrative. For the patient, Rick takes on this hero role and attempts to provide perhaps a restitution he never received himself.

*The Co-Construction of Uncertainty*

Montgomery (2006) argues that seeing medicine as science and the need for doctors to be all-knowing is not only the physicians’ doing, but also patients and the families that push them to be certain. While I imagined myself during the interviews as representing a confident researcher with a clinical interest in the topic, upon further reflection, I discovered evidence of my own vulnerability in speaking with physicians about the uncertainty of illness and pain. This led me to wonder about my self-representation in the interview, and personal experience as a potential patient facing the uncertain. How had participants perceived me? Was it first as a researcher, or was it as a potential patient honoring the physician as scientific, logical, and “all-knowing?” While in the first few interviews I became aware of my tendency to idealize the physician as knowledgeable and certain, over time I began to sense the rational and interpretative nature of the knowledge each participant shared, and its *uncertain* usefulness. That is, in facing the uncertainty of the physician’s knowledge and ability to heal, my human vulnerability as a potential patient and disappointment in facing this were revealed.
I asked myself a few questions that become relevant to the analysis of not only the major themes, but also the dynamics of the discourse and shared construction of meaning. In what ways had I pushed the physicians toward an expression of certainty in their responses and construction of the patient narrative in order to satisfy my own needs as a potential patient? I am referring here to the ways in which patients may enable physicians to accommodate the claim that their work is certain and scientific. Participants' identification with their 'all knowing' physician selves may have felt compelled to offer the certainty of their knowledge and present themselves as infallible.

My enabling or subconsciously encouraging physicians to be “certain” or “all knowing” in the interviews is important to the notion of collaborative meaning making among participant and researcher. As I sat with participants and asked questions that eventually led to conversation and discourse, it was together that we attempted to make meaning and find a truth regarding the uncertainty of illness and pain in the child. Our co-constructed narrative was likely driven by our parallel need to manage the anxiety this uncertainty stirred up. For participants, part of this anxiety may have stemmed from the goals of the study; that is, facing the sometimes uncertain nature of illness and pain and sharing that experience with a nonmedical professional. Also, my own transference of feelings of positive regard and esteem for the doctor participants were brought to bear in the interview, influencing the interpersonal dynamic and information shared.

As I listened to participants' stories, I did not yet have insight or understanding as to how my questions and responses may have subtly shaped those of the participants. Only in my analysis of the interviews and discovery of the recurrent thread of uncertainty common to each narrative was I able to become more cognizant of my parallel experience
of anxiety regarding the sometimes uncertain nature of illness and pain. Reviewing the transcripts, I located places where my questions to participants may have seemed overtly focused on the medical details, gathering information regarding the history of symptoms and the illness sequence. In this way, I became interested, as the physician, in making sense of the unknown. It is also possible that the way in which I posed my questions regarding the medical details of the case were perceived as a type of inspection or scrutiny leading to exposure. Were my questions regarding the mental health components of the cases perceived as a testing of their knowledge or lack thereof? In the analysis of the exchanges between researcher and participant, it is easy to see how the knower might be compelled to poke holes in the knowing.

There was an experience of anxiety in hearing firsthand of physicians’ experiences with uncertainty. This anxiety seemed to stem from my identification with either the parent or child patient. Was there a sense of resistance on my behalf as a parent hearing participants express a sense of puzzlement and confusion in making sense of unexplained illness in the child? Given that society in general wants to think of physicians as powerful, dedicated, and perfect figures, my discomfort in seeing the humanness of the physician may not have been so unusual; however, what is important is the way in which this anxiety influenced my responses and the co-construction of meaning in the interview setting. For example, there were clearly moments during the interview when I may have prevented physicians from elaborating further on their experience of anxiety in the medical encounter. Responses that validated their experience (e.g., “I see” or “Right”) may have served to cut short a response, whereas my silence may have led to a continuation of the narrative and further exploration of feelings by the
participant. It is possible that subconsciously I was also preventing or protecting physicians from experiencing their own anxiety and other negative emotions such as sorrow and anger. These emotions would serve to emphasize their human and imperfect nature, and which may not be comforting to the idealizing patient.

In my analysis of the narratives, I also became aware of my own sense of helplessness in hearing their descriptions of the uncertainty of pain in the child and the physicians’ inability to provide relief. Certain descriptions of medical procedures or the witnessing of symptoms of pain and suffering in the child were difficult to hear. My choice of response or even lack of response in the face of difficult conversations with the participants served to influence the information that was shared, as well as the way in which it was shared. In what ways had I colluded with physicians in their need to protect themselves from experiences of sorrow, anger, and anxiety related to their most difficult cases? Take a simple example, such as my responding with a certain tone of astonishment and a facial expression of wincing as a resident described an invasive and painful chest procedure performed on a female child with unexplained chest pain. My reaction, which may have suggested fear and sensitivity to hearing the gruesome medical details, may have led the participant to eliminate from her narrative those aspects or details that might offend or upset me. In this way her initial direction in the telling of the story was shifted. What may have been missed was a deeper or more personal description of her feelings of vulnerability and uncertainty in facing the unknown and, more importantly, how she copes with these feelings as a physician. As Elliott Mishler so aptly points out, individuals tend to communicate what they think the other person can, or wishes, to hear (Mishler, 1986).
The above examples give us some insight into the shared construction of meaning and importance of context to sharing of information. In this case the research situation may provide one type of parallel experience that offers insight into how the physician might cope when faced with a certain degree of angst or fear in the parent. The physician’s tendency to avoid emotion, intimacy, confrontation, and conflict in any given medical encounter with a parent and child may not only be due to his/her own needs, but also those of the parent.

**The Uncertainty of Culture**

Factors associated with the medical context or the patient’s culture appeared to be associated with uncertainty and feelings of helplessness in the participants’ narratives. Most striking was the degree to which cultural factors played a role in the uncertainty of understanding the experience of illness or pain in the child. In all 10 interviews, the theme of coping with the uncertainty of different cultural beliefs regarding the bodies of children and parents of non-Western origin emerged. For many of the participants, there was a true feeling of powerlessness that came with a lack of knowledge and understanding of the experience of pain and illness in refugee families from Africa. Hmong children and their parents were also mentioned as patients for whom physicians struggled to make meaning of illness and locate the truth of pain.

The physicians unfamiliar with the cultural or socioeconomic background of the patient seemed to have significant difficulty understanding their patients’ illness narratives and reframing this within Western medical ideals. More than simply problems with communication, there seemed to be an overwhelming lack of understanding of the
meaning associated with pain in different parts of the body and cultural understanding as to what is necessary for healing.

The body and its importance in locating the truth of illness for patients from other cultures created further uncertainty for participants. Not knowing or understanding the importance of the body and one’s beliefs regarding its role in the cause of illness was something physicians struggled to comprehend. Furthermore, the difficulty with “naming” certain illnesses and describing treatments seemed to further impair participants’ capacity to provide restitution. While some participants defended against their experience of anxiety associated with cultural ignorance in caring for the patient, others acknowledged their feelings of helplessness with such patients, as well as fear and sorrow for the uncertainty of certain traumas possibly experienced by their refugee patients.

For example, Lota spoke at length regarding the cultural differences between herself and her patients, and her increasing awareness of being unable to communicate effectively.

I remember a Chinese woman and she would just cry all the time,... and I tried to explain to her the symptoms were, you know, depression. But she was concentrating on her stomach pain. And then, you’re like okay, well you’re trying to explain – you know what I mean? It’s very HARD. It’s hard and I’m thinking – then I’m thinking well if you had a physician that was from your culture, you know, would their explaining things better to you make it easier?? You know, because... if she was seeing a Chinese practitioner that practiced Chinese medicine and said that her Ying and Yang were not meeting, and told her you need to do this and... the water and fire...You know what I mean? And things like that would probably be more helpful than me trying to make sense of it all.
Jane also described her treatment of a refugee female child with unexplained knee pain. The sense of isolation and helplessness Jane seemed to feel while treating this patient was compelling. She said, "I mean, she could describe the symptoms to me, but I think that when it came down to expressing just exactly why she was so concerned, THAT became harder." Here we get a sense of the ways in which the language barrier adds further to making sense not just of the child's illness itself, but its experience by the patient. The barriers to her making sense of the child's pain and the anxiety this creates are further fueled by a lack of information regarding the child's possible experiences in refugee camps.

The theme of the medical context as providing additional sources of uncertainty and frustration came through in the participants' narratives. Limited time for appointments came up repeatedly as explanation for their inability to obtain a narrative from the child or parents. In lacking all of the necessary information to provide accurate diagnosis and treatment, participants spoke of their increased sense of anxiety of not locating the cause of illness or pain, and worry over missing some important piece of information or misdiagnosis. The fear of medical error and liability loomed, leading participants to make their rule-out or diagnosis by 'exclusion' as sweeping as possible - referring to others for more extensive testing and scheduling of follow-up appointments to track symptoms. Many participants expressed a sense of isolation within the practice in making sense of the patient's pain and illness due to poor communication and collaboration between treatment providers in-house as well as in tertiary centers. Thus, the sense of helplessness in the isolation in facing the uncertainty of the patient's illness made diagnosis all the more appealing.
The Search for Restitution

Closely related to the discomfort with uncertainty and seeking of certainty was participants' seeking of restitution for the patient. This search for "restitution" was a common theme in all of the physician narratives. For the participants in this study, restitution was not limited to its usual definition of restoring the patient to normal functioning or cure, but seemed to encompass a range of healing. Thus, restitution seemed to exist on a spectrum: The lowest end was simply locating the cause of symptoms of illness or pain. Farther along the continuum was the naming or diagnosis of symptoms, and finally associated treatment. At the farthest end of the continuum of restitution came healing in its various forms which will be elaborated below, including the elimination of pain or illness altogether in the form of cure and return to normal functioning or health. While several studies have described "restitution" for physicians, few have defined it or elaborated on the ways in which it may differ for each physician. Also included on the spectrum was satisfying parents' notions of restitution, which typically involved the ruling out of the most serious diseases, such as cancer.

Common to the narratives were feelings of helplessness, inefficacy, and even impotence in not being able to provide restitution. Similar to the struggle with uncertainty, lack of diagnosis and failure to provide healing led physicians to feel lost. This led to either a "letting go" of the search or a redoubling of efforts to eliminate feelings of uncertainty and continued endeavors to provide restitution.
Participants’ need to provide restitution seemed evident from their telling of failure or “unresolved” stories. Borkan et al. (1992) has suggested that “failure narratives” are not usually shared by physicians since they portray an inability to heal and inherently suggest confusion and helplessness. This finding may not be valid given that very few studies have explored physicians’ telling of stories regarding their experiences with patients, and those that do fail to distinguish between stories in written versus spoken form. In contrast to Borkan’s findings, physicians more often shared stories of failure or “quest narratives.” This was interpreted as one might interpret the search for an ending to an unfinished or unresolved story in therapy, as an attempt by participants to make sense of, or construct a new kind of narrative in the context of the interview. This supports modern relational psychoanalytic theory and its focus on the co-construction of meaning by both parties in a conversation or context (Mitchell, 1988). Participants’ tendency to more easily recall and share stories that were unresolved or still in progress may also be explained in part by the Zeigarnik effect (Zeigarnik, 1967), a cognitive bias in which people remember uncompleted or interrupted tasks better than completed ones. Regardless of the reason, striving for resolution and closure of the unsolved case, even if only in the participant minds, emerged as a common theme in the narratives.

As I listened to the participants’ stories, I wondered about physicians’ sense of vulnerability associated with the reliance on the tools of medicine to provide restitution. Jane expresses her feelings of vulnerability.

*It’s a case where you really do have to say... you know...well this is the history, this is the physical examination, and this is the feeling I get from the patient. This is how I put it all together. I guess I would say it makes you feel helpless. It’s so hard to just say...well, we just don’t know.*
Jane's quote provides an example of one kind of restitution on the spectrum: finding an answer or explanation, or diagnosis. Aside from Jane's narrative, there was an undercurrent of frustration and sense of powerlessness in almost all participants' stories in their being unable to reach diagnosis. The longer it took to reach this form of restitution, the greater the sense of helplessness in the physician. More importantly, if the pursuit of diagnosis was shared by the family, this frustration was even more powerful. I elaborate on this topic further in the section on the parallel of anxiety in the relationship between participant and physician.

Related to the inability to provide diagnosis and treatment emerged seeking to relieve patients from their pain and failing. Reactions to this by participants ranged from anguish to anger. Watching a person in pain, particularly a child, and feeling powerless to help, was an experience that was humbling for the physician. Jane describes with emotion what it was like to watch a female adolescent with unexplained pain.

*It was...excruciating... to see this girl... I mean, she was screaming and writhing, and wailing, clutching her chest. She could not ... would not move her right arm at all, because she said to move her arm at all, it really hurt. And so... just watching her... I mean, we could hardly get near her... and it was just miserable. And we still didn't know why this was happening.*

Kay, also a young resident with strong ideals, defined restitution as falling on the farthest end of the spectrum, that is, to provide cure and return the child to normal functioning. Her frustration and sense of incompetence seemed to stem from her inability to achieve this goal. Also interesting was that her definition of restitution seemed closely tied to her defining the truth of illness within a biomedical framework. She says, "It's just really frustrating. I mean, clearly there's nothing going on with these kids and I'm
not at all equipped to handle... to help them. And I'm not sure who really is.” It was not entirely clear whether Kay's disappointment in not accomplishing her goals had more to do with failing the patient and family, or her own sense of shame and the sorrow of failing herself. She seemed defended to experiencing any feelings fully, but rather chose to intellectualize her experience. The quotation below provides an example of her frustration with herself and discontentment in failing to reach her goals.

*I'm mean... it's just sad. In a way you feel like you aren't getting anywhere (sounding irritated)... I mean you're not helping the kid at all and you're not convincing the parent in any way that maybe they could just go home. Ultimately you want to get the child home and back to a normal life... minimize the problem that way. You'd like to have some kind of answer... it's just kind of what we're more trained as... in the medical field. That's what we do. We do the medical testing... we diagnose... that's what we do. I guess that's just probably because of the way we are trained... we are just trying to think in that way.

Jake, a resident like Kay, reflects on the ways in which he uses the tools of medicine to frame illness in his work and provide answers and solutions. His narrative sheds further light on a certain reliance on physician 'know-how,' that seems common to the more junior participants in the study. Within his narrative, one begins to see his discovery that the physician's tools are not always far-reaching. Jake's stories convey his strong attachment to diagnoses, and for this reason perhaps his definition of restitution lies lower on the continuum. He sees his role as finding answers and providing relief or reduction of symptoms, not total elimination. Regardless of his definition, like Kay and Jane, Jake disappointingly often finds himself left with unanswered questions in treating the child with medically unexplained illness or pain. Jake does not seem to experience the same intensity of frustration or shame as does Kay, nor is he as defended in
experiencing emotions; however, he notes equally his disappointment in failing to reach his goal. He says, "you get to the end of your workup and they still have symptoms and you're stuck with this obscure diagnosis that may or may not fit."

As Jake continues in his narrative, we see his acknowledgment of the disappointment of the family, yet he seems to feel more entitled to his frustrations and disappointments. He is similar to Kay in that he creates a kind of us-versus-them dichotomy between himself and the patient and parents in the pursuit of restitution.

And it's actually more frustrating for physicians than it is for parents, because parents are more willing to accept, "well, if it's not cancer, you know, it might be persistent, it might be annoying, but I'm not worried about it. But the physician keeps worrying. So... then you send 'em back to their primary care doctor and who knows what happens? And so... it's sort of ungratifying actually.

So, for Jake as well as Kay, the seeking of restitution may be more of a personal goal rather than a shared one between physician and child/parent. The genuine needs of the patient and family and Jake's capacity for empathy seem to be missing in narrative.

_Holding On_

Christy, a family practice physician, seemed to experience a great deal of self-doubt and ultimately defeat in her search for certainty and restitution. She seemed to wonder aloud through the interview if she had done enough for her patients. She is not unlike some of the other participants who tended to question themselves rather than the tools of their profession in their search for answers.

Those participants like Christy who seemed particularly tied to a biomedical framework of pain and illness also seemed to have difficulty letting go of the search to
provide restitution. The approach of avoiding risk and managing the possibility of error may be thought of as a “risk management approach” which was common to most participant narratives in their attempts to make meaning of the patient’s symptomatology.

“Not letting go” of the search for restitution was a common theme in the majority of participant narratives. The drive or pursuit to put a name to illness, while lying on the lower end of the spectrum of restitution, seemed central to one’s ability to provide higher forms of restitution including the relief from pain, or cure. Jake spoke of the importance of diagnosis to treatment, saying, “you’re also unsatisfied because you want a diagnosis and you want to be able to tailor your treatment around some sort of diagnosis.”

For Penny, letting go, as long as the pain continues to exist, is not an option.

I think it leads to both frustration and fear as, you know, as docs, like not wanting to miss something. Um, but then you start feeling like, um, you don’t want to do too many tests and it’s not in the child’s best interest to put them through a lot of things that aren’t indicated, but how do you draw the line and still maintain trust? That’s why... I reassure the parents. And that’s the dance, you know, that I – I am fascinated by... and I am willing to do that dance. I do a lot of follow up. I am not going to push the family away. I will keep looking at what else we might do.

Lota also struggled to let go of the search for diagnosis and healing. Jane’s search for restitution and her willingness to let go tied into her identification with the parent sense of frustration in the search for answers and shared hope for healing. When able, Jane attempted to merge her own definition of restitution to match that of the parents.

Letting Go

Amy, a developmental-behavioral pediatrician, was unique in that her definition of restitution did not seem limited to diagnosis or even cure, but helping the child and
family to develop mature coping skills. Her narrative suggested her seeking to help families in a collaborative way, and to not let pain or illness control one’s life. She told me of her mantra to the child.

*It's functional, it's very pragmatic, functional, you know, your job is to be a kid, and have fun... and to be a student and to go to school and to, you know, be a member of your family and connect with your siblings and your parents, and that's your job right now. And my job is to help you do that, and to help you get your symptoms under control. And no, I don't know where you're coming from, but, you know, honestly, that's - to some extent that's immaterial. ...the painful reality is that no matter how you feel, you've got to go to school, and you've got to be a fifth grader.*

Amy's ideal of restitution is interesting in that it does not incorporate high levels of empathy or sensitivity to the experience of the patient; however, she is still able to honor the illness and pain of the child as real, and is motivated to provide a reduction of symptoms. She defines her sense of restitution.

*My own, you know, approach with the parents is basic--you know, when there is uncertainty and still questions left, to say, you know, I can only imagine how hard this must be not to have answers and not to know for sure, but let's together sort of weigh out the stress of all these doctors appointments versus the stress of, you know, letting some time go by to sort of figure out some things and let this, you know, these symptoms declare themselves. But in the meanwhile, I work with a lot of kids who have cancer or arthritis or whatever, and I, you know, I am - when I say that I want to help your child learn some coping skills, in no way am I saying that this is all in your child's head.*

Amy's notions of what restitution consists of and her ability to provide it may in part stem from her specialization. In her work she sees a lot of children with "unnamed" disability or handicap, as she notes when she says, "I mean... 50% of all mental retardation is unexplained." So, uncertainty and the "unknown" are in a sense,
fundamental to her practice. For Amy, what seems most important about illness is not its elimination or cure, but rather coping with the certainty of it, and developing coping mechanisms and functionality in spite of it.

In considering her notions of restitution and discussion in the earlier section of her tolerance for the uncertainty of illness, one wonders more about the influence of her early life experiences growing up in a family with a psychiatrist father and siblings with significant illnesses for which no cure existed. She describes her younger brother who had, "severe multiple disabilities and epilepsy and legal blindness and so forth" and her "other younger brother who had very, very severe schizophrenia. And it took many years...to get him diagnosed." So, in a sense Amy's experience with facing and coping with the chronicity of illness emerges, and she is able to shed some light perhaps on her capacity to approach illness in a practical way. The running theme of the importance of patients to be "functional" in spite of living with illness in her narrative is certainly notable. There is the notion of striving for something that is certain to be attainable and is practical. Her narrative is noted to contain themes of resilience, "keeping one's head," "balance," "holding it together," and maintaining a sense of humor in spite of the tragedy of illness.

Amy's more practical and unique definition of restitution as coping with pain and illness and being "functional" contrasts significantly to the idealistic types of restitution sought by residents. In fact, her narrative supports the notion that with more years of experience as a physician, ideas regarding what can be accomplished and what "restitution" really represents, are constantly evolving. Consider her telling of the hardest cases and their appeal to the perhaps idealizing resident, believing that he or she will be
the one to cure the patient. She says, "residents LIKE them...because they are new and fascinating, and they haven't been working long enough to know that these are the hardest cases of all, and that they're not going to be happy at the end."

There are ways in which perhaps the physician's definition of restitution differs from that of the parent. This seemed most obvious when an "us-versus-them" dichotomy emerged in the medical encounter. Amy also offers her thoughts on this, and how it jeopardizes the possibility of reaching a shared notion of restitution.

And, you never want to get into an us-and-them kind of attitude when you're working with your patients, because that's not helpful. And, you know, and I just - and it is sort of this funny dance that you do, a real balance that you have to achieve that comes with just years of experience with--at one and the same time.

The funny "dance" that Amy refers to here is perhaps discovering the parents' definition of restitution and meeting these needs, while also meeting one's own goals as a physician. These goals may be different or similar, depending on the case. This may be related to what Rick refers to as the need for "therapeutic alliance" when there is a "collision of theories."

Rick is much like Amy, in that his specialization as a developmental-behavioral pediatrician requires him to regularly face the certainty of disability and need for "functionality," or ability to cope with illness or pain that will not go away. Rick also shares a similar history to Amy, in his witnessing serious illness in a family member for which no cure existed. Perhaps the witnessing of illness and feeling helpless or powerless to change it evolves into a physician stance of acceptance regarding the uncertainty of illness and pain (and need to cope rather than searching for cure). Grant's
search for restitution also seemed focused on helping parents accept that some illnesses cannot be explained or named, and thus coping with a certain degree of pain but not letting it control one's life.

Common to all participants' searches for restitution was ruling out the most serious causes of illness, particularly those that are terminal. The need to rule out the "bad things" is not confined to the physician, but also concerns the parents. Few spoke of the child's personal search for restitution and what that might encompass, which is a topic of importance and requires additional study. It does, however, beg the question as to how much the child's illness narrative is truly honored by the physician. I discuss the implications of this finding in my discussion.

The narratives suggest that when no name can be given to the pain or illness of the child, restitution can in some ways still be achieved by eliminating the most serious medical explanations through "rule-out." In the previous section on certainty and uncertainty, I discussed how the elimination of the most feared diagnoses serves to establish one kind of "knowing" in the face of uncertainty. Here I raise the issue again to impress how ruling out the "bad things" is also relevant to the second core theme: that is, its situatedness on the spectrum of restitution.

The Path to Truth and the Construction of the Physician Narrative

Many of the participants' narratives involved themes concerning where the truth of the patient's experience of illness and pain reside. Their understanding of this seemed
critical to their medical management, diagnosis, and treatment of children with persistent medically unexplained pain or illness. The locations of the truth were varied: in the tests of the physicians, the bodies of the patients, the subjective reports of the patients, the minds of the patients, or the environments of the patients. While for most participants the truth of pain and illness was commonly interpreted within a biomedical framework, the truth for each physician held unique meaning, and this meaning evolved into the physician’s illness narrative. Regardless of where each sought the truth, the core or recurrent theme throughout the narratives related to the seeking of this truth and the construction of meaning existed. Below I explore the different ways or models of searching for the truth and the associated subtypes of illness narratives that emerged. Certain images and associations in the data provided additional sources of analysis in the discovery of this core theme.

Images in the Search for Truth

The images used by participants to describe their efforts to make meaning of a child’s pain and illness revealed much about the nature of the search. The process of investigation and discovery of meaning was through endeavors that may or may not be successful. For example, there was JJ’s image of putting together puzzles, and its association with a sense of completeness and finality. Jane and Kay’s associations to “digging,” “chasing” and “fishing” emphasized a hopefulness of discovery, but possibility of failure. Certain images in the narratives of the search for truth and meaning also suggested fear or even dread. For example, in exploring the psychosocial, Christy likened the experience to “opening Pandora’s box.” Two physicians spoke of their
caution in confronting the unknown, using the phrase "hedging." The use of metaphor to convey the sense of feeling lost and helpless, such as "feeling blind," and "being snowed," was also used. Facing the unknown, Penny spoke of "the elephant in the room," - giving the listener a sense of the trepidation that can creep into the clinical encounter with the child and the parents. Participants also used metaphors that described the ambiguity and complexity inherent to differential diagnosis. Common phrases that supported this included "shades of gray," "never black and white," and "gray zone."

*Kay, Jake, Christy, and Lota: Medical Tests and the Body*

I return in this section to the relevance of physicians’ tendency to rule out the "bad things" in the search for truth. Regardless of the different ways that participants searched for the truth of illness, what seemed most common was first ruling out the most critical diagnoses. This seemed to leave the physician in a better position to reduce risk of medical error, achieve some peace of mind, and perhaps grant reassurance to the parent.

For Kay, the path to the truth of a child’s illness or pain seemed relatively straightforward and clear: a full medical work-up and then referral to a specialist when extensive testing supported no organic cause. For Kay, real illness or pain could be explained in terms of medical tests and investigations. In this way Kay's illness narrative was likened to an objective reality or truth. Kay provided an example of medicine's tendency to define what is "real" through science and objectivity. When no organic findings for a child's pain or illness could be found, Kay's narrative suggested the truth of illness or pain to be "not real," or to reside in the mind of the patient or parent. Mental illness, a murky and frightening concept for Kay (and definitely an area in which she
feels out of her domain of expertise), seemed to cause considerable anxiety for her in the medical encounter. Kay's stories regarding her experiences with children with medically unexplained illness and pain included associations of fear, intolerance, and blame related to medically unexplained pain and illness.

Kay's narrative provides some insight into the ways that putting the truth into medical investigations and tests helps to avoid the experience of uncertainty and the anxiety that comes with it. Kay seemed to find security in the objectivity of medicine, finding the subjective reports of illness by the child or parents and their felt emotions to challenge her sense of competence as a "knowing" physician. Parents who did not place the same degree of trust in medicine and her tests often met a similar fate with Kay: rejection or referral elsewhere. For example, in her story about a boy with unexplained stomach pain for which no tests could provide organic explanation, she said, "We barely got him out quick... and just sent him back to outpatient... and said "make it happen there."" Her quote gives a sense of the anxiety she feels in facing the failure of the tools of her trade, and her wishing to get "rid" of the patient. I wondered whether this anxiety related to feelings of incompetence for Kay. Kay spoke of her experiences with children with unexplained pain seemed as "a nightmare" with "no clear endpoint." In the battle to find an organic cause and perhaps convince the parent of the same, she noted, "You just can't win." Providing further evidence of her reliance on medicine's tools and tests, she said,

I think that the initial frustration with those kinds of patients comes out of the...where is the endpoint with this? How the heck are we going to get them home? Because with other admissions it's obvious...they come in say with respiratory distress...we give oxygen, and then they can go home.
Kay’s limiting her search for the truth of pain and illness as resting in medicine’s tests and tools, created a certainty of facing difficulty with patients with persistent and medically unexplained illness or pain.

Jake, a resident like Kay, also placed a certain faith in medicine’s tools in discovering the cause of pain and illness in his child patients; however, ultimately the body was seen as holding the truth. Tending to hold the psychosocial only in the back of his mind, he said that he would first “think it’s physical, you know, and kind of disregard the psychological aspect.” This quote gives a sense of how the biomedical components of illness and pain loom large for Jake.

For those participants like Jake who saw the body as holding the truth to illness and pain, the struggle to see pain as “real” if not supported by a medical test of some kind, was also common. Kay conveyed her sense of faith in the tests of medicine:

*There’s a lot of neuro stuff you see...like you see the kids with 24 hour EEG monitor or whatever... with the complaint of seizures.... Where they’ll... I mean it’s...basically they’ll be faking it...and you can usually tell from their history that they are.*

My attempts to enter into a discourse with Kay regarding the nature of what seemed to be her more negative feelings toward her patients with unexplained pain, such as frustration or sorrow, were relatively unsuccessful. When I asked questions or attempted to enter into a discourse, Kay tended to pull away or silence me. The phrase, “I don’t know” appeared frequently in her transcript. This suggested a certain defended stance and uncooperativeness in the interview. Using an analytic approach, examining
the interpersonal dynamics of the interview and the flow of associations help to shed light on the relevant themes in Kay's narrative her search for the truth of illness or pain in the child, which do seem tied to her interpersonal struggles with families. As mentioned earlier, content analysis of Kay's narrative suggests that she spends little time considering the patient's perspective, resting much of her judgment in the tools of her profession, particularly its tests. A more analytic narrative supports the same: that is, her tendency to stonewall and failure to enter into a dialogue with the researcher questions her use of similar approaches in the medical encounter with her patients and parents. Kay may push away families by disregarding their own illness narratives. Her putting the truth of illness into tests and objective measures may be a way in which she defends against her anxiety regarding uncertainty and her potential failure to provide restitution to the patient.

In questioning the reality of the patient's pain, physicians tended to first frame the patient's symptoms within a medical theory that made sense first to them, and second give some credence to the subjective experience of the patient. These included theories of stress and coping, "sensitive systems," heightened pain perception, and cognitive distortion. For example, both Rick and Lota spoke of heightened pain perception as explanation for illness or pain of nonorganic origin. Jane also found herself contemplating the role of the subconscious in pain perception and the role it plays in the expression of illness.

Clinging to medicine's facts and the body as holding the truth of illness and pain was evidenced by participants' lingering worry and discomfort when a patient's pain disappeared on its own. JJ noted with puzzlement that sometimes the "problem just runs its course, they got some support, they've worked through some stuff, they've had enough
tests and placebo effect... SOMETHING has changed. It's just that I don't know what that is. And I really wish I knew.” There seemed to exist a sense of doubt and fear for participants regarding the mysteries of the body. Lota also referred to the process of “normal body healing” as one fact in medicine to explain symptoms that go away without treatment, noting how this phenomenon can be unnerving.

Searching for the truth of pain and illness in body was also evidenced by participants’ inability to accept another kind of truth, even when the family seemed convinced of such a possibility (e.g., a psychosocial or emotional cause). Consider Lota’s story of a 3-year-old girl with unexplained breathing difficulties. She tells me how the parent lightheartedly proposed attention-seeking behaviors (i.e., in the child) as one possible explanation for the symptoms. This seemed to send off alarm bells for Lota, whose understanding of the truth of “real” pain and illness seemed confined to the body.

I said to her... let me know what's going on with this! I mean, try this, because in the back of my mind I want to make sure I'm not missing anything, but I know her heart and lung tests were normal, but at the same time... I'm always like, okay you need to update me because I don't want to miss anything and I'm not, you know I'm not there when she has trouble breathing!

Attempting to reassure the mother then, Lota tells her, “I still don't want to ignore something that could be in the back of your head. So that's why follow-up is good for keeping in contact.” The irony of Lota’s statement is that the so-called worries she believes the mother to have may be more simply a projection of her own. The fears in the back of one’s head do not seem to reside in the mother, but rather inside Lota. Thus, while she allows the family to consider causes of the truth of illness or pain to reside in places other than the body, Lota seems continually drawn back to her own beliefs and
assumptions. The illness narrative that Lota constructs begins, but also ends with the organic.

The less experienced participants in the study, particularly the residents, told narratives that suggested a search for the truth of illness and pain from a somewhat idealistic view of medicine as providing the knowledge and tools to solve problems of the body. This may be the result of seeing only the most serious cases of somatization within hospital settings. Residents' stories tended to convey an idealistic faith in their education and the tools of medicine (predominantly tests) to finding the answers. This provides further support for a stages of training model in understanding how physicians search for the truth of illness and pain.

The Truth of the Child’s and Parent’s Report

The question as to what value should be given to the patient’s subjective experience of pain and illness was a theme that emerged in many of the participants’ narratives. There seemed to be a distancing and sense of isolation for the physician in understanding the child’s experience. Participants seemed to ask themselves, What is the child’s illness narrative, and more importantly, is it real? The child’s illness narrative did not seem to play a very central role in the physician’s construction of the illness narrative.

Consider JJ’s sense of isolation and confusion in trying to make sense of his male adolescent patient’s story of persistent unexplained headaches. He says, “If I could sit down with him for 2 hours, I MIGHT get somewhere, but I might not! The bottom line is that I might never find out when it started... I might never find out what it's really like... this headache he has.” Unable to truly appreciate and honor the patient’s narrative, one
gets a sense of JJ’s struggle to create a new truth, or explanation that makes sense to him.

Kay, like JJ, does not place much value in the child’s narrative, nor the parent’s subjective reports. Kay seems to find such descriptions by parents confusing and distracting. She says,

> And when his mother kept saying, “you know.. I know he LOOKS good to you guys, but he’s NOT QUITE RIGHT. You know, there is something a little different about him than usual.” And that is really hard... that’s another really hard, kind of complaint... because you’re like: “well...he looks fine to me!”

Kay does not seem to spend much time weighing the value of the parent’s report against her own clinical and objective judgments. While she recognizes that parents know their children well, she ultimately does not see much wisdom in their reports and ultimately seems to pathologize family systems.

Although tending to see the body as holding the truth of pain and illness, Jane was able to at least consider the input of the parent as holding some value in addition to her medical tests. In her treatment of a young female child with knee pain, she said, “because it was something that I would have been convinced was totally benign, but the mom kept describing it to me as ‘she just doesn’t even want to go to school. She was convinced it was something else going on.’

In knowing a little about Jane’s developmental history, we gain a better understanding of her tendency to give value to the parent report. Recall in the case study the description of Jane’s experience with headaches of unexplained origin in adolescence, possibly leading to an internalization of shame and guilt in being ill, and identification with a mother’s frustrations and sense of helplessness in facing that pain. Here we see
how Jane's history with uncertainty and illness may lead her to be more aligned and identified with the parents with unexplained illness or pain; particularly mothers. Yet, in spite of a tendency to hear parents' reports, Jane still questions the truth of the pain that is not supported by the tools and tests of medicine.

The Truth of Physician "Know-How"

The power of physician "know-how" came through as an important factor that for some participants strongly influenced the construction of the illness narrative. Many of the participants described certain "hunches" or "gut instincts" regarding where the truth of the child's illness or pain resided. Interestingly, many of these hunches suggested the truth to lie somewhere other than in the organic; however, participants could not seem to bring themselves to explore such notions without the support of some scientific test or measure. Fears of upsetting the patient, negotiating conflict, or ultimately being rejected by the family also influenced the decision to ignore such hunches or gut instincts.

Although rare, a few participants seemed to have a greater sense of self-confidence in trusting their own instincts. For example, if one looks at where the truth about illness resided for Grant, it seemed apparent that he saw that truth in himself. Like the other participants, he mentioned discovery and ruling out the really serious illnesses first, but he seemed much less concerned about missing something or coming up with a wrong diagnosis. Grant's narrative suggested that he does not rely so much on the "tools" of his profession, but rather focuses on his own judgment and knowledge as a physician, as well as a person, to find the answers. He extends his knowledge beyond the body and mind of the patient to the significant relationships in the patient's life, the patient's culture, and their interpretative contribution to the perception of illness.
Grant's stories and overall disposition during the interview suggested a difficulty admitting to weakness. I wondered about the strength of Grant's physician identity, which at times seemed to feel omnipotent. Grant seemed unwilling to admit to being dumbfounded by chronic pain that remained unexplained in physical terms. Rather, he somehow attempted to find the cause elsewhere, such as in the behavior of the parent, or in the culture of the patient. For example, in his story about a young boy with stomach pain, the absence of worry about missing something serious or even satisfying the need for reassurance in the parent for more testing was surprising. He said,

And, uh, you know, with — with the findings that I got with my evaluation, uh, this past time, I didn't feel it for him to see a gastroenterologist or to go to any big expensive scans or exams — just didn't warrant that. I had no trouble saying that to her.

Grant's sense of confidence emerged as a strong theme in his narrative. I asked whether there were any cases in which he had felt like he had hit a brick wall, or could not make sense of what was going on. He answered:

(Sigh, sort of a chuckle) No, not really. It's been, uh, most of the cases, like I said, seem to be in a response to some sort of ongoing stressor. And, uh, I—I think a part of the...the, uh, road to discovery there is sort of working through that...that it's not something, uh organic.

The interpersonal dynamics of the interview with Grant may offer additional insight into the ways in which he searches for the truth of pain and illness and creates a personal illness narrative for the child that in many ways disregards the perspective of the parent. For example, in my interview with Grant, I felt more like a student than a
colleague. Grant seemed to regard the interview as more about educating the researcher, giving the same kind of attention one would give a student to help with a project as a courtesy. It did not feel that the interview was a genuine exchange between interested parties, but rather like one person imparting some knowledge to another, and perhaps a less knowledgeable person. In the analysis, the interview was perceived to be somewhat rushed and lacking in depth in terms of creating a dialogue that was truly engaged and exploratory and enriching for both parties. Using an analytic approach, one wonders how Grant’s interaction with the researcher during the interview might hold certain parallels to his interaction with parents in the medical consult with the sick child. To what extent does Grant enter into a meaningful dialogue in the search for truth of a child’s persistent unexplained pain or illness symptoms? To what extent does Grant honor the parents’ knowing of the child, their perceptions regarding symptoms when constructing his own illness narrative? Content analysis of Grant’s interview material suggests that while giving some credence to the reports of the parent and child, he viewed himself as more knowledgeable, always in control, and always knowing what to do. That is, he seemed to proceed in a way that made sense to him rather than the patient or family. In this way, Grant avoided the discomfort of uncertainty by not facing it – that is, by finding or creating a new truth that makes sense to him.

*The Truth of the Environment*

Few participants’ narratives indicated a search for truth that extended beyond the patient’s body, deferring medicine’s knowledge and tools to a focus on the illness as
experienced by the "whole" of the patient. Such participants tended to give greater value to the environment as holding the clues regarding the truth of illness.

Penny, an experienced pediatrician, provides a nice example of the ways in which the physician can think beyond the body as holding the truth of unexplained illness or pain. Her approach is interesting in light of her training during a time and at the same institution where George Engel pioneered the biopsychosocial approach. Penny's stories conveyed her striving to frame the child's illness and pain within this model. She said:

I want to make sure that I'm looking at all the different possibilities, both the biological, but also the impact of psychological and social and community factors as well. So, I really try and approach things with trying to hear - and even how I interview - how the symptom might affect someone's feeling about it and someone's feelings might affect the symptoms.

The search for the truth of illness and pain as residing in a place other than the body, particularly the mind of the patient or the family, was described as often met with resistance from parents. For example, Penny began the interview by sharing a story of her suspicions and her ensuing search for the truth of a young girl's stomach pain in the relationship between the child and mother, and ultimately the family environment. This search was met with resistance and ultimately rejection by the parent.

And what I remember was that each time she came in, the girl seemed more and more withdrawn. She still had these stomach aches. I tried to refer them to the in-house psychologist but they were not really open to that. I think we got farther and farther apart because, I think the more I pushed in that direction, the more difficult it became. And, then she didn't come back and she didn't come back to the clinic. So, I don't know - either things settled down or what happened after that.
When listening to her story, I perceived Penny’s sense of frustration in her struggle to know when to trust her own instincts and hesitantly explore certain “hunches,” fearing how they would be received by the parent. It seemed as she spoke, that she not only wanted to convince me, but also herself, that while truly believing in the biopsychosocial approach, in many ways it has failed her. In spite of this, what was most intriguing about Penny was that she was the only participant who seemed truly interested in the child’s narrative. She conveys the difficulties she experiences in her attempts to get at the narrative of the child:

*One of the things I always do, with any kind of complaint, is trying to hear the story – of what’s been going on… and really try to hear. For this child, the mom talked for her…so it was really hard to get a sense of what was really going on. And that was the part of the vagueness of trying to find out….It’s frustrating, at times, with not really being able to get my bearings in terms of what was really going on, the vagueness is so hard.*

I asked Penny to share with me her “hunches” about what kind of truth the environment might have held for this child’s stomach aches.

*Yeah. I think, um, worrying about, uh, (long pause) an anxiety disorder in the girl, or the mom or both,… and maybe even abuse in terms of either the girl or the mom or something in the house that was happening where the girl didn’t want to leave and was worried about her mom and didn’t want to go to school and couldn’t really talk about it or?… just – I think the thing I was worried about the most was more just the anxiety and how it was just playing – they were playing off of each other in a way, and that mom was – seemed more anxious than a lot of moms. It was escalating… there seemed to be some elephant in the room that you think isn’t being named, even though you don’t know what – you know, is it an elephant or is it a horse or is it – what kind of animal is it? There’s some kind of animal that no one’s naming but I don’t know what it is. That’s the vagueness. Or, the story changes a bunch. That’s really hard. And, that’s, I think it leads to both frustration and fear as, you know, as docs, like not wanting to miss something.*
In Penny's quote above, we see how her search for the truth of pain and illness extends beyond herself as a physician, her tools, and her work. She seems to hold few expectations and explores all different kinds of truths with the family.

The Truth of the Mind

A common theme in many participants' stories was a sense of hesitation in exploring the psyche as potentially holding some portion of the truth of unexplained illness and pain. This seemed related in part to physicians' assumptions and biases related to mental illness, as well as uncertainty in facing the parents' feelings regarding the same.

A sense of fear surrounding the possibility of having to face and manage emotionality or those behaviors consistent with mental illness in the child and parents was a common one for many participants. The associations, images, and metaphors in the narratives regarding mental illness gave a sense of the ways in which participants conceive of body and mind as either separate or related. Take for example Christy, who speaks of this fear in the following quote.

You ask about, you know, are there things going on at school or whatever, abuse in the past perhaps? And it opens up Pandora's Box! So here I am in the middle of a busy day, I'm already a half hour or 45 minutes behind schedule with no time, then all of the sudden a patient decompensates in front of me emotionally. I ask...what do I do with this poor person in front of me? What do I do?

I wondered about Christy's hesitant explorations of the psychosocial in the medical encounter and their being shaped by past negative medical experiences. Here the
reader is reminded of the power of the physician's perception of error or failure, associated experience of guilt and shame, and the role this may play in determining the search for the truth of illness and pain. Christy described an experience with a young adult female patient with abdominal pain who she asked about previous abuse. She told me that the "she decompensated... right there in that chair (pointing to where I am sitting). Her brother had sexually abused her over a long period of time as a child and she had never admitted it before.... and so shortly after that, she ended up in the hospital for several weeks and... she's never been the same since." I wondered about Christy's sorrow related to this experience, as she described her involvement with the case.

Well, I hospitalized her. And...you know I felt partly responsible that, you know what somehow that I handled it wrong. (8 second pause) Yeah, it was hard to hear about that because I don't know if, if I handled it differently would she have a different outcome now? What if I had never asked that question?

Participants' hesitancy in exploring the mind or psyche as holding some truth regarding illness or pain of a child seemed also related to fears of facing resistance and even anger in patients. Christy offers insight into this as well, when she says:

Making sense of what is going on is a frustrating process because, I guess a lot of it's because the stigma that goes along with mental illness, depression, anxiety, and patients are often unwilling to accept that as a diagnosis, and so there doesn't seem to be, I don't know, closure, or a resolution, and they still have these symptoms...

Penny, like Christy, also seemed to experience a sense of fear and avoidance in raising the topic of mental illness in the medical encounter. Jake also seemed aware of the
stigma associated with mental illness in families, leading to his own resistance in discussing such topics.

Participants' defending against their own anxieties regarding mental illness included rationalizing that it was not their job to approach such topics. For others, such as Christy, there existed the belief that the patient or child's parents were somehow responsible for coming to appreciate the role of the psychosocial on their own terms. Many participants' stories, such as Christy's, Kay's, and Jane's suggest that the physician's actions ought be confined to the tools of the medical profession. Regardless of the different ways in which participants attempted to make meaning of persistent and unexplained pain and illness, a common theme was avoiding the psychological in the medical encounter due to either personal feelings of anxiety and incompetence with respect to handling issues of mental health, or fear of being confronted with the same in the parent.

In summary, path of truth, or actions taken in the efforts toward locating the causes of patients' pain was explored in different ways. There seemed to exist a sequence from putting the truth into the tests (including those of the specialist), then the environment including parents, family, the school, the mental health of the patient (with referrals), and finally resting in the unexplained and dealing with the certainty of that. For some, the search for truth ended or came to rest within the body. For many, the search seemed to never end, and this involved a departure from the sequence and a "back and forth" movement in the search between the body and other forms of truth. Ultimately, the search for truth and the final illness narrative that was constructed related to some important factors, including physician level of tolerance for uncertainty,
definition of restitution, and developmental history with illness and uncertainty. For only one participant did the search conclude with a sense of acceptance of uncertainty. For some the search was cut short by being rejected by families or by their getting "rid of" their patients through referral where they became "lost in the system."

For all physicians, the truth of the pain and illness was carefully and hesitantly explored due to some kind of anxiety or fear. These fears or anxieties often led to a stop in the search. Examples of fears included facing mental illness in the patient, discomfort in watching the patient experience pain and being unable to provide relief, feelings of incompetence and the associated risk of experiencing error or failure, a discomfort with emotionality in the patient or parents, fear of intimacy in the medical encounter, or fear of confrontation or conflict. The ways in which participants searched for the truth and the illness narratives they constructed seemed influenced by their stage of medical training. In addition, personal factors including those developmental experiences with uncertainty and illness played a role in the search for truth of pain and illness in the child.

**Parallel Anxiety between Physicians and Parents**

A core theme in the participants' narratives was the parallel experience of anxiety and helplessness between physician and parents. This parallel anxiety often permeated the physician-parent relationship. The anxiety felt was associated with various sources: the struggle for power and the negotiation of intimacy in facing the uncertainty of illness
in the child, the seeking of restitution, the search for truth of pain, and construction of the illness narrative.

Managing Anxiety in the Medical Encounter

Common to participants’ narratives, was the theme of experiencing a greater sense of anxiety when facing the same in the parent. The sources from which anxiety stems in the medical encounter for physician or parent may be similar or different; however, in most cases the parallel of anxiety seems to rest in simply confronting the uncertainty of pain or illness in the child. In isolation, the physician’s anxiety may stem from several separate sources that when combined, have the potential to become overwhelming. First, physicians cope with their own anxieties related to facing the uncertainty of pain and illness. When the parent experiences the same anxiety in facing uncertainty, the physician’s sense of anxiety increases as s/he is unable to provide restitution and eliminate the anxiety for the parent. A second source of anxiety emerges from a different kind of “not knowing;” that is, the not knowing how to manage or contain emotionality in parents and negotiate the parallel anxiety in the medical encounter. Kay’s narrative in particular conveys the way in which physicians struggle to manage their own anxiety while facing the same experience in the parent. The degree to which one or both are able to manage the potential spiral of anxiety becomes significant. Kay really seems unable to tolerate the anxiety of certain parents, so she attempts to rationalize her own failures and blame the parent as a defense.

Those parents I try to ... I personally avoid trying to deal with at all, because they are... I mean it’s somewhat immature of me to say... but...because I mean, you get pulled in there and I mean... they get really excited sometimes about every
little physical complaint... and just, you just don't have TIME to sit down and go through every little thing with them. You're too busy and getting pulled in too many directions... You feel you aren't getting anywhere. I mean, you're not helping the kid at all, you're not convincing the parent in any way that maybe they could just go HOME.

Just as some participants seemed better able to tolerate uncertainty and thus manage the anxiety that comes with it, the narratives gave a sense of the different ways in which physicians perceive parents to tolerate uncertainty and the anxiety it creates. Amy offered a comparison in the ways in which physicians and parents experience anxiety regarding uncertainty.

It varies all over the map, just like for physicians. You know, for people to cope, there's some--and, you know, people joke about if you're a doctor who's really, really uncomfortable with uncertainty then you're going to probably go into surgery. If you're a doctor who can handle uncertainty, maybe you'll go into medicine or pediatrics. If you're a doctor who is like really, really comfortable with uncertainty, you'll be a psychiatrist. And so...and the same thing, there are parents - some parents who are, you know, really very comfortable with uncertainty and saying, well, I don't expect you to have all the answers or, I don't expect them. More often than not, the parent is still--you said, you know, like what you were saying before, that it's a rare parent who's comfortable with uncertainty. It's a rare parent who's kind of come to some peace with the diagnosis of, you know, somatoform disorder. And usually that, you know, that would be a parent who is very psychologically savvy or, you know, maybe--whatever.

The narratives suggest that, while common, the degree of anxiety felt by parents and physicians can differ, resulting in a dynamic relationship whereby one may influence the other, and vice versa. The degree of parent anxiety and intolerance for uncertainty that exists in the medical encounter does seem to influence physicians' decisions and medical behaviors. When parents are better able to tolerate the anxiety that comes with
“not knowing” and place some trust in the physician to provide restitution, the physician finds a position of power. Narratives suggested that confidence by parents tended to lead to a “letting go” of control in the medical encounter, and perhaps subsequent reduction of anxiety for the physician (and perhaps comfort to proceed with self-confidence).

Struggles for Power in the Search for Certainty, Truth, and Restitution

Participants’ narratives gave a sense of the negotiation of power in the relationship between physicians and parents in influencing the physician’s search for truth and constructed illness narrative. Penny seemed acutely aware of the power her relationship with parents had in the search to make meaning of the child’s illness.

There is a sense... of just not wanting to be too paternalistic, like, well, I know what is best for you and because someone needs to decide that that’s right for them... like... just trying to figure out how to do that DANCE....You start feeling like, you don’t want to do too many tests and it’s not in the child’s best interest to put them through things that are not indicated... and then... how do you draw the line and still maintain trust with those parents?

The issue of who holds more power in determining the path to the truth of pain and illness for the child seems to be an issue. Penny explained to me that the majority of parents want to be heard and want their ideas embraced, while for others that would create some anxiety. She said,

For some people, that really challenges the roles and the doctor-patient relationship because if the doctor’s asking what YOU think... ... Giving parents some power.... It’s more than they expected or know what to do with or how to do it... and for some people... they want a doctor to take control, but then, on the other hand, they don’t want them to take too much control.
Like Penny, Amy described the “dance” of negotiating power as well as intimacy in the relationship with parents of children with unexplained pain and illness and the need to avoid an “us-versus them” mentality. Rick conveyed the clash of ideas that can occur between physician and parent, and how struggles for power in making meaning of a child’s illness are challenging. He spoke of parents’ “theories” and their need for the physician to give “credence” to that theory. He explained his experience with and need to negotiate the “collision between a hypothesis or theory that’s already out there, in the mind of the parent.” Rick’s stories also conveyed the importance of the relationship with families to the truths that are explored, and the quality of care that he feels able to provide. While qualifying his statement that it “probably shouldn’t be a factor.” Rick noted that if there is an established relationship with the parent, and if he has “known them a long time” that the struggle for power is diminished significantly. He says, “you admire the job that they’re doing with their child, I guess... it’s harder to push... and they say, ‘we love you... you’ve taken good care of us and we know you don’t entirely buy this... but would you hesitate to offer us... help with this?’”

Rick shares several stories of families who pushed his boundaries, and for whom he gave up some of his power. I wondered about his ability to compromise his integrity and indulge parents in their need for certain tests or explorations and his ‘fusion’ with families, or what he referred to as “admiration and love for the family.”

Whether physicians enter into a “battle” for control and force their own agendas, or acquiesce or take a back seat in power in the relationship with parents, seemed to depend on various factors within a developmental theme including years of experience and
associated strength of the physician identity, the “rootedness” of attitudes and beliefs regarding where the truth of illness resided, and developmental history.

The least experienced and most experienced physicians expressed stronger ideals related to their physician role of authority. Jane, Kay, Jake, Rick, Penny, and Amy; all tended to voice preferences for certain “types” of parents, providing further support for the importance of the interpersonal in the construction of the illness narrative. For example, Amy and Rick, both highly experienced and specialized pediatricians, expressed a preference for working with more educated and compliant parents who were hinted at as more willing to concede authority or power to them. Penny, Rick, and Amy also told stories that conveyed a greater sense of satisfaction and perceived efficacy working with the reverent or respectful parent. The reasons for this may not only have to do with years of experience and training, but also past experiences.

When considering the interpersonal dynamics between physicians and parents in the search to create some truth of the uncertain pain or illness of a child and the anxiety this stirs up, issues of transference and countertransference offer another source of data to explain the findings. I begin with Amy to provide example of the importance of early life experiences in influencing the negotiation of power and intimacy with parents. Through Amy’s stories there was a continued hinting to her sense of satisfaction working with certain kinds of mothers that she described as compliant and deferential. Her recollection of memorable cases contained the image of a certain kind of idealized mother as organized, even keeled, respectful, punctual, and most importantly, as acknowledging the importance of the physician’s knowledge and opinions. She says, in reference to a
dedicated mother of a chronically ill child patient: "that's what made my job as the physician so much easier...was that...the mother."

What each of Amy's stories had in common was the presence of a dedicated, even-keeled, organized, and sensitive mother, perceived by Amy to be able even in the face of severe stress and illness in the child to maintain a balance of empathy for the child and a sense of humor. This image of the non-neurotic, emotionally in-control parent makes her appearance again in her telling of her own mother, for whom she clearly had enormous respect. Amy spoke of her ability to care for her two sick brothers "while maintaining a sense of humor." I wondered, given Amy's descriptions, of her transference of positive feelings to certain kinds of mothers that reminded her of her own. When asked about a "hit the brick wall case," Amy told me that her greatest challenge was in working with those families where she perceived significant relational dysfunction and a lack of respect for another.

Illness almost always evokes feelings of helplessness, and such feelings can and often do cause even adults, even those in powerful positions such as the physician, to feel like a child. Thus, in the triadic relationship of physician-parent-child, one might ask which adult will experience such feelings. While the medical literature has emphasized the power differential of the physician and patient, and the tendency for the patient to behave more like the helpless child and the physician as parent, in my interviews there was also evidence to suggest the contrary. That is, physicians also seemed vulnerable to becoming identified with the child and the ill child's experience of turmoil, creating a sort of reversal of the parent-child interaction in the medical encounter between the physician and parent. My explanation for this phenomenon is that experiences with
uncertainty and helplessness in the medical encounter, particularly with the child, may serve to bring to mind physicians' early life experiences with illness and uncertainty. One must keep in mind in this discussion that there is both the conscious and unconscious experience by physicians of the child's illness.

In hearing participants tell their stories, I noted that many seemed to feel helpless in their efforts to convey to parents the "rightness" of their opinions. Here again we are reminded of the struggle for power and knowledge that occurs between parents and physicians in making meaning of illness or pain in the child. Many participants told stories of instances in which they tried to "convince" the parents of the certainty of their knowledge or the tools of medicine, in the process invalidating the parent and child's experience. In fact, there was frequent appearance of the word "convince" in the context of participants telling of narratives regarding their interactions with parents whom they considered to be their most difficult cases. Such battles often led to either physician rejection of the patient and family through referral, parent seeking of a "second opinion" elsewhere, or continued treatment within an atmosphere with an undercurrent of hostility and resentment, avoidance of confrontation, or open conflict. In some cases physicians went to great lengths to avoid confrontation or conflict with parents, including appeasing through excessive and unneeded testing.

Information regarding the dynamics of the research interviews provides an additional source of data concerning the theme of control. Participants' ability to share control and engage in a flexible dialogue or conversational type interviews may also reveal certain parallels regarding their negotiation of the same in the physician-patient encounter. Those participants who were more collaborative in the interview tended to
share stories that contained themes conveying the value of mutual meaning making with families in the search for truth of a child's illness or pain. Those who were more willing to enter into a dialogue with the researcher tended to share narratives with themes of honoring the narrative of the patient and parent. In contrast, participants who were controlling of the direction and flow of the research interview, or who attempted to push me away, shared stories with themes of preference for power, compliance, and deference in parents and patients.

To gain a better understanding of the dynamic between the physician and parent as they struggle to make meaning of the child's illness, I examined when I felt more like a child or a parent in the interview, and what that might signify with respect to how physicians negotiate uncertainty and not knowing in the clinical encounter. For example, I tended to feel more like the child when physicians were controlling the interview (e.g., by talking over me, ignoring my comments or questions) and presented as "all-knowing" (e.g., sharing assumptions of being right, omnipotent, or as providing the healing and cure). When physicians became frustrated or openly expressed anger or confusion in the interview, I also experienced discomfort being confronted by what I perceived to be weakness. In these situations I may have attempted to protect them from their uncomfortable emotions through distraction or by pulling away. My experience of the human emotions of grief, sorrow, or shame in the participants was also at times uncomfortable, and this is likely due to my partiality of seeing the physician as "all knowing" and omnipotent.

When the participants pulled away or seemed purposefully evasive in the interview, I felt and even behaved as might a parent, pushing for information, seeking
elaboration, clarification, or less often confronting or challenging. Such behaviors tended to result in a further pulling away or being silenced by physicians. Participants such as Grant and Kay who were strongly defended against feelings of fear and sadness, presented as confident and even arrogant and angry at times, but above all else, "all-knowing." The above dynamics in the research setting give us some insight into their parallels with the dynamics that might occur in physicians' medical encounters with families.

It would seem that the more confident and knowledgeable the parent, the less comfortable the physician with "not-knowing," and thus the stronger the fears of failure and resultant struggle for authority and power in the relationship. The more compliant and adherent the parent (i.e., passive and child-like), the easier it is for the physician to avoid feelings of anxiety, helplessness, fear, or any reminder of his or her uncertainty. A strong sense of fear in the parent may lead to heightened feelings of the same in the physician. Heightened feelings of fear and anxiety in the parent regarding the uncertainty of illness in the child might lead to either a pulling away or even more dedicated efforts by the physician to locate the truth. Who the physician and parent become most identified with in the medical encounter can influence not only the medical approach, but also capacity for empathy and ability to become a container for the other’s anxiety, fears, and worries about mortality.

*Issues of Trust and Intimacy in the Search for Truth of Illness and Pain*
Issues of trust and intimacy between parents and physicians emerged as an important factor in facing the uncertainty of a child's illness, the search for the truth, and construction of the illness narrative.

Physicians' stories suggested a clear striving for the ideal "affect-neutral" relationship with the patient and parents, perhaps attempting to protect themselves by emotional distance. I also became aware of different degrees of emotionality and comfort with closeness and intimacy associated with similarities and differences in intercultural and interpersonal background, as well as transference and countertransference. In treating the child with unexplained illness or pain, transference and countertransference of feelings for the physician could relate to the parent, the child, or sometimes both.

Analysis of the narratives suggested that participants' feelings and behavior toward the child or parent in the medical encounter seemed influenced by these relationships to important figures from early life, typically parents. It is likely that parents also experience transference of feelings with the physician, further complicating the interplay of emotions in the relationship. I provide my analysis of those transferences and countertransferences for physicians that appeared in the narratives, and how they inform the theme of trust and intimacy with parents in the medical encounter.

I begin with Jane, who, as one of the less experienced participants, struggled to connect emotionally with her patients. In particular, Jane seemed intent on connecting with a certain kind of honesty with parents that she found lacking. Her experience with this seemed highly frustrating. Regarding one family with whom she seemed unable to develop a rapport, she said:
Honestly, I want to pull them (the parents) aside and just say, "What....What is your problem?" (loudly) I just want to get to the heart of what they're... "What's your problem with the situation? What do you WANT?" I mean...not in an accusatory way, but really in a way to get them to be totally honest.... to get them to say what they really expect.

The anger that comes through in Jane's reaction above, hints to a countertransference of feelings to parents that possibly impacts her ability to develop trust and intimacy with parents. Given Jane's history with unexplained illness and an anxious mother, Jane's struggles with mothers in particular may be relevant to her work with children who experience unexplained pain.

Participants' narratives suggested that perhaps the physician's emotional closeness with the parents of their child patients, say in more established relationships, allowed a sense of freedom to extend investigations beyond the body. Many participants spoke of having an easier time shifting away from their usual "clinically detached" stance to a more intimate approach when an established relationship with the family existed. This phenomenon seemed to be more common to physicians with more years experience. The established relationship involved a sense of trust allowing the physician to explore all possibilities of illness or pain, including those biological and psychosocial. For example, Lota reported greater ease in exploring causes of illness other than those strictly medical with parents with whom she has an established relationship.

Well, I need to talk to Mom more because I – we just got those labs back and the ultrasound and it's normal! And so – but normally...she's just like a nice – you know, girl to come in and I know the mother well, I know the father well, and it just seems like the mom is very - um, in tune to feelings because she has a son who's older that has depression and things like that, and so it seems like she'd be in tune to that. So.. I could raise the issue, that it could be possibly something psychosomatic.
Greater intimacy between physician and parent seemed more associated with the risk of disappointment. That is, the greater the degree of trust, intimacy, and communication between the physician and parents, the greater the risk of the physician disappointing. These feelings seemed to be associated for the physician with fear of failure, perhaps leading to an even stronger pursuit of ruling out all organic causes of illness. Lota's story of her work with a family with whom she has an established and trusting relationship stirs up these feelings of anxiety. Her worries of failure and disappointing the family seem to drive her thinking and approach to diagnosis and treatment.

Physician narratives conveyed the challenges that come with emotional closeness both with the child and the parents in the medical encounter, particularly the child with unexplained pain. While the distance from the child could be explained in part by factors including the age of the child (with the younger being less verbal) and perhaps a general preference to converse with another, the distancing from feelings in the relationship with parents was telling. Physicians tended to rationalize their tendency to pull away from families, finding it easier to protect themselves and to remain clinically detached. Physicians rationalized that intimacy with parents would, (a) take more time than what was given, (b) be difficult to manage and control, and (c) demand more responsibility than they felt capable of handling. What I interpreted from this was that physicians experience a certain kind of fear of becoming overwhelmed by emotions that are fundamental to intimate contact. I refer here to both becoming overwhelmed by the parents' experiencing of negative emotions such as sorrow, fear, and anger as well as the
experiencing of similar emotions in the self. Perhaps this is another way in which “not-knowing” is avoided with parents. This may be explained in part by the emphasis in medical education on clinical objectivity and its necessity in decision making and diagnosis; however, there may also simply be an avoidance of experiencing human illness in its vulnerability and helplessness and the negative emotions that it carries.

The stories physicians told also revealed attempts to avoid difficult or sensitive discussions with parents that might lead to confrontation or conflict. Sensitive discussions included those of the most feared diagnoses, the importance of psychosocial factors as contributing to onset or exacerbation of symptoms, and parent response to illness behaviors in the child. There was a general avoidance also of discussion of mental health and its potential role in the child’s illness due to cultural stigma in both parents and physician. Avoidance of difficult topics associated with emotionality was essentially a means to avoiding the experience of negative emotions and preserving the doctor-patient/family relationship. Kay, a resident colleague of Jane’s, provides an example in her narrative of the tendency to avoid having the difficult conversations with parents or patients that may lead to confrontation or conflict. Kay avoids difficult conversations with parents that might lead to emotionality, since they would unduly place strain on her relationship with the family. She says, “I mean, clearly there’s nothing going on with these kids and I’m not at all equipped to handle... to help them. And I’m not sure who really is. We tend to get psych involved and then just punt to them. Because they are the ones that deal with this.”

*The Importance of Rejection*
There was a sense of fear in participants' narratives of being rejected by the family, and this seemed to drive physicians’ tendencies to avoid confrontation or conflict in relationships with parents. Likewise, physicians who experienced families to be too burdensome, whether for reasons of their inability to reach agreement regarding investigation, diagnosis, or treatment, also rejected families through referral to specialists.

The sense of discouragement and feelings of inefficacy experienced by physicians when rejected by families emerged in the telling of stories. Rejection by patients seemed to represent an entirely different kind of failure for physicians. For example, Penny described her experience of being rejected by the mother of a female child with abdominal pain who was unwilling to explore anxiety as one possible explanation for her daughter’s symptoms and her resulting sense of sorrow. Following this story, Penny immediately jumped to a new case, perhaps in an effort to protect herself from experiencing those negative emotions, or perhaps to avoid judgment by the researcher. I elected to bring Penny back to the story and her feelings rather than allow her to continue. With rejection by the family there seemed to emerge a great sense of loss for Penny, and lingering feelings of worry for the child and family’s well-being. Telling me of her worries seemed to bring her anxiety again to the surface. I observed this in her lowered head perhaps out of some sense of shame, and the pressured nature of her speech as she barely paused to take a breath. I also felt her sense of helplessness in the struggle to do right by her patients, which in her mind included bringing up the more sensitive issues of family dynamics and their possible relevance to the expression of illness. In Penny’s story, she essentially leaves the medical realm, attempting to shift the mother's
focus from the search for the truth in the body to the environment; however, she is unsuccessful in her efforts. She said,

_Usually after a couple of visits, there’s more of a sense of trust and a coming together and working together and things with parents, um...things get less vague over time. And, in that situation, it was like there was more distance and more vagueness. And, trust was, um, eroding... the more questions I would ask or, um, and that was—so, even trying to figure out how to involve the psychologist, you could tell that that was frustra—that was threatening._

The narratives suggest that physicians are by no means innocent when it comes to rejection. Stories suggested that participants often rejected families, but perhaps more covertly or with a subtlety that served to invalidate patient concerns. Methods such as the “watch and wait approach,” placebo, repeated follow-up to monitor symptoms without further testing, and referral to specialists were examples of ways in which participants rejected or managed to “get rid of” the patient. The imagery used to describe the rejection of patients conveyed perhaps an underlying sense of anger and tendency to depersonalize. The image of the patient as unimportant and existing merely in print was conveyed in phrases such as “blow them off,” or “write them off.”

**Intimacy and Blame**

Attitudes regarding the potential role parents may play in the onset or maintenance of the child’s illness and how these attitudes often lead to blame and ultimately rejection of families was a common theme in participants’ narratives. The ways in which physicians search for the truth and construct an illness narrative for the child seem to incorporate certain assumptions regarding the locus of control of illness or
pain, which in turn influence diagnosis and treatment. Physicians may see organic illness as out of a person’s control, whereas with somatoform illness where the mind is believed to have greater involvement in illness perception and expression, there may be more associations of blame. What physicians label as parent innocence or blame related to the child’s persistent unexplained illness or pain seems to influence the dynamics of the parent-physician relationship.

Kay provides an example of how certain attitudes of blame and innocence regarding the parents of the sick child influence her interpretation of illness and pain, differential diagnosis, and treatment. Her narratives conveyed a tendency to frame pain and illness in terms of where the blame resides – in the parent or the child? There did not seem to be much speculation on her behalf regarding whether the pain was real. In Kay’s mind, if not supported by medical testing the pain must be feigned or falsified, either by the child or parent. Persistent unexplained illness for Kay seemed to represent something bizarre and not really illness in the true medical sense, but more of a psychiatric issue. The style of her storytelling was brief but frequently interwoven with comments that revealed her assumptions of blame. Some quotes gave a sense of this: “It is the fault of the parent,” and “We can accuse them...we can say we don’t believe you, we think you are doing this to your child.” While recounting her experiences with families of children with somatization (many of whom she viewed as dysfunctional in some way), she said, “I’m just not sure what was wrong with them!” When asked to talk about how she made sense of the child’s illness, she said, “It’s just bizarre...it speaks more to the parent issues,” and “A lot of times it’s a problem with the parental...you know, the problems with the parents.” Kay shared her belief with me that perhaps parents enjoy having a
sick child, or having a child hospitalized, although she acknowledged that such a concept may not make perfect sense. Still, Kay maintained some commitment to its truth, rationalizing that for some reason, such parent "might have something to gain from having a sick child." In hearing the sense of blame that Kay placed on the parents and even the child in locating the truth of the child's unexplained illness, I wondered about her possible sense of discouragement and feelings of inefficacy as a physician, and the projection of such feelings onto the patient. By "blaming her victims" as a defense, this perhaps makes it easier for Kay to reject challenging families through avoidance, invalidation, or referral to other specialists.

**Issues of Transference, Countertransference, and Intimacy**

In many cases, the parent's positive regard for the physician is not merely a function of transference, but also of factors rooted in the physician-patient/parent relationship including cultural background, physician's communication skills, and personal warmth. The transference of positive feelings from parent to physician may play an important part in the healing relationship. If the parent transfers onto the physician feelings of childhood love or admiration associated with internalized images of his/her own parent as providing comfort and healing, the physician may be in the ideal paternal or maternal role to provide restitution to that parent and his/her child. Alternatively, the parent of the sick child may transfer feelings of anger and frustration to the physician, reliving feelings of mistreatment or abandonment in the relationship with his/her own caretakers, which then become transferred to the physician.
Jane provides a number of stories that hint to transference of certain feelings to mothers of children with unexplained pain. Jane, having experienced persistent unexplained migraines as a child, seemed to experience transference of both positive and negative feelings to demanding parents driven to diagnosis, as was her own mother. In some cases, Jane seemed to become identified with the child’s helplessness in facing pain of an unknown origin and struggling to manage and contain the anxiety and anger of the concerned and assertive parent seeking diagnosis. Her first story of working with a mother who wanted an answer as to the source of her adolescent daughter’s knee pain suggests that Jane’s transference leads her to try to please the parent by providing reassurance and excessive testing in pursuit of a diagnosis (perhaps when not entirely warranted). Jane clearly identified with the frustration and sorrow of the parents, perhaps having internalized the helplessness and shame of her child self who struggled with pain without name. Jane essentially gives value to the parent’s worry, and makes a best attempt to eliminate it. She said, “I think you should always take parents seriously when they tell you, you know, that they THINK, really THINK there is something wrong with their child.” In fact, many of Jane’s stories had a common theme of her wish to take away the anxiety and uncertainty in the parent. How her medical decisions regarding diagnosis and treatment become driven by her own anxieties and transference in certain situations is worth pondering.

Grant also provides an example of how transference and countertransference of feelings in the medical encounter interfere with intimacy and closeness, or the development of an alliance. Grant’s language during the interview evoked associations of harsh and overbearing parents with unreasonable expectations. His stories suggested a
clear alignment or identification with his vulnerable and helpless child patients whom he imagined to be at the mercy of parents with mental health issues. He essentially told one story, which was more a case presentation than anything else, containing “facts.” But the listener is able to get a sense of the emotion behind Grant’s telling of the case. Later in the interview Grant tells of his own experiences with his parents who viewed illness as a weakness. He spoke of his need as a child to “snap out of it” and “pull yourself up by the bootstraps.” The association to minimizing, ignoring, and even invalidating parents was moving but painful to hear in Grant’s description of his childhood. The language Grant uses to describe the way he and his brothers learned to cope with illness was poignant. He says they learned to “keep their mouths shut, suffer with it, because... well that’s what I did.” Shifting back to Grant’s description of his most “memorable” case, it is not hard to see the parallels to his own childhood and the possibilities of transferences and countertransferences that abound. Grant’s story of a sweet 5-year-old boy whom he describes as a “…delightful little guy, especially when his mother isn’t around correcting every little misstep that he has” presents with persistent stomachaches of unknown origin. I could not help but note Grant’s use of more child-friendly medical terms, such as “tummy pain,” giving a sense of his identification with and empathy for the child. He described the child’s “domineering mother” with annoyance, and the “emotionally distant” father who “tended to ride his butt for being a baby, or any other sorts of things.” In telling his story, Grant does not spend much time on the details of the family, but almost immediately moves to diagnosis, explaining his “…pretty good idea of what’s been going on, but still you have to sort of take it seriously.” He describes his time alone with the child in the medical setting with a smile and a brightness about him that suggest
genuine concern for the child’s well-being. I wondered about his subtle statements of worry for the child and their possible association to memories of his own childhood, when he said, “he is a kid that could, could become very disheartened, disenfranchised... and maybe have real problems with society.”

Grant’s tendency to identify with his child patients and see the parent as being somehow at fault or possibly at the root of the child’s pain is particularly worth noting given his sense of self-confidence in creating a truth of illness that makes sense to him. His clinical judgment then may not be, as he believes, entirely logical or rational, but driven by subconscious emotional factors linked to his own childhood. The potential interpersonal factors that come into play in Grant’s struggle for power and negotiation of intimacy (and all of the defenses employed in the process) ultimately influence diagnosis and treatment of the child.

Kay offers an example of a participant whose interview provides further insight into her capacity to be intimate with families, particularly parents. In analyzing the ways in which transference and countertransference might interrupt Kay’s ability to form trusting relationships with her patients and their families, the interview context and the dynamic between myself and Kay provided additional information for interpretation. I personally experienced Kay as evasive, avoidant, negative, blaming, and even hostile in the interview. In reviewing the material and thinking about why this was the case, I wondered whether the way in which I asked questions seemed much like that of a parent.

As Kay told stories that overtly indicated her belief of parents as being largely responsible for a child’s illness, I found myself becoming defensive and pushing her for information to support this belief. Upon reflection, Kay’s interaction with me during the
interview likely paralleled her interactions with parents in the medical encounter. Kay's transference of negative feelings toward the demanding and assertive parent suggested a possible internalization of her vulnerable child self experiencing an intrusive and questioning parent. While Kay chose to not share with me the details of her childhood or experience with uncertainty and illness in her own family, I wondered about her possible experience with the overbearing or demanding parent. What Kay did tell me was that she experienced migraines with vomiting as a child, but that she coped by sleeping or lying down. I imagined then the possible fear and vulnerability of the ill child seeking escape from possible scrutiny, anxiety, and worry by the parent. I wondered how in the clinical encounter with the sick child, Kay brings to bear her own experiences of avoidant coping and lingering feelings of anger and blame toward the parent who is either intrusive or neglectful. Her capacity then for empathy for the parents of her sick child patients may be limited, especially in the case of parents she experiences as demanding or overly emotional.

Kay's narrative suggests a stronger identification with the sick child versus the parent, but her own negative feelings get in the way of her capacity for empathy here also. I present Kay's example as a means of helping the reader understand the subtle ways in which transference and countertransference may negatively influence the decisions and actions taken by the physician when dealing with the child with persistent unexplained pain. There is no mistaking in Kay's stories her rejection of parents or families who exhibit any possible signs of mental illness, or those whom she perceives to be "overly emotional," "bizarre," or "weird." She openly admits to her tendency to avoid
such parents and families. Perhaps this is Kay's way of coping, or doing what is
necessary in order to remain clinically objective as a physician.

The above examples of Jane, Grant, and Kay offer some insight into the ways in
which the physician's relationship with the sick child and the child's parents, particularly
struggles for power and the negotiation of intimacy, may be influenced by past
relationships and experiences with uncertainty and illness.
CHAPTER EIGHT
DISCUSSION

The most common feature of the somatoform disorders is the presence of physical complaints and pain that suggest a general medical condition, but that are not fully explained by a general medical condition, the results of a substance, or a mental disorder (American Psychiatric Association, 1994). Individuals with persistent physical complaints and pain that are medically unexplained are frequently encountered in general medical settings. Prevalence rates vary considerably and depend on various factors, including the specific disorder, demographic variables in the population studied, whether the interviewer is a physician or nonphysician, and method of assessment, but are believed to range from 0.2-2% (American Psychiatric Association, 1994). The prevalence rates of somatization in children and adolescents are less clear. Community studies indicate that between 2 and 30% of all children seen in medical centers report somatic symptoms that have no apparent physical cause or medical explanation (Carter, Edwards, Kronenberger, Michalczyk, & Marshall, 1995; Garber et al., 1991; Goodman & McGrath, 1991; Hay, Hayward, Levin, & Sondheimer, 2005). In community studies, 20% of apparently otherwise healthy children report unexplained somatic complaints such as abdominal pain, headaches, and low energy at least once a week (Garber et al., 1991). In a literature review of the epidemiology and identification of behavioral health disorders in children in primary care, the prevalence is 12-27%, yet the detection of such problems within the primary care setting is low (Weitzman & Leventhal, 2006).
Although prevalence of somatoform disorders in younger populations is unclear, the literature has provided a clearer picture of child somatization as being a significant and puzzling clinical phenomenon, both in the field of medicine and mental health. Current knowledge regarding etiology, diagnosis, and best treatments for somatoform disorders in children is significantly limited due to heterogeneity of symptoms, limited research with younger populations, and lack of developmentally appropriate criteria. Since the majority of children with unexplained somatic complaints present in primary care settings, this study was interested in exploring the role physicians may play in the diagnosis and treatment of the child with medically unexplained illness or pain. The goal of this study was to better understand how physicians perceive, create meaning, and manage persistent unexplained illness and pain in children in medical settings and how referrals to mental health are made.

What then do the results of this study say about the physician experience in treating the child with persistent medically unexplained illness or pain? What types of beliefs and attitudes shape the construction of the illness narrative for the child, and what role do families play in this process? More importantly, what are the implications of these findings regarding diagnosis and treatment of children with persistent pain or illness that is medically unexplained? In this chapter I will present to the reader the relationship between the study’s findings to the literature regarding the physician’s role in treating the child with persistent medically unexplained illness or pain. I present an overview of the study’s findings about the over-arching theme of uncertainty: its relevance to physicians’ search for the truth of pain and illness in the child, the anxiety it stirs up for both parents and physicians, and the construction of the illness narrative. I will also discuss the
relevance of the study’s findings to understanding theories of child somatization, and the implications for diagnosis and treatment in medical and mental health settings.

The Theme of Uncertainty

The theme of uncertainty, or physicians’ intolerance for it when treating the child with persistent unexplained pain, was a powerful theme in the narratives of this study. Perhaps this is not surprising, given cultural assumptions that medicine is a science and should offer certain truths regarding disease and illness. As patients we witness the benefits of scientific knowledge and technology in the saving of lives. Physicians are largely taught and continue to interpret illness within a biomedical approach, drawing on diagnostic skills and clinical experience using evidence-based study, scientific research, and objective judgment. Kathryn Montgomery says, “uncertainty is ritualized, professionalized, and then for the most part ignored by the patient who seeks help and the physician who must act on their behalf” (2006, p. 4). Thus, the search for certainty regarding disease and illness is shared by both patient and physician.

The results of this study suggest that reliance on biomedical models, while still common, may fail physicians in providing assurances and certainty, particularly when treating patients with persistent and seemingly medically unexplained symptoms of pain and illness. Biomedical or “what-you-see-is-what-you-get” representations in medicine tend to be clinical, impersonal and physician-centered, and overlook the importance of the patient’s illness narrative (Montgomery, 2006). When unable to locate the truth of
illness in the body, physicians often share their disappointment with the patient in the face of inconclusive or negative outcomes. Participants in this study shared stories of their sorting through exhaustive bodies of information in search of some kind of certainty; however, information often seemed to be missing, conflicting, and full of paradox, fallacy, complications, and anomaly. In the end, participants told stories with an over-arching theme of functioning in a context ridden with uncertainty and “not knowing,” which led to much anxiety.

Few studies have examined differing patterns of physician tolerance for uncertainty related to factors such as gender, stages of training, and specialty. No studies have examined levels of tolerance for uncertainty and their influence on assumptions regarding theory of mind and body, attitude toward certain tests and technologies, value of patient versus physician-centered approaches, and issues of cultural diversity. A recent European study examined tolerance for uncertainty in differing medical populations and found that women, junior physicians, surgeons, and generalist physicians have higher intolerance for uncertainty (Bovier & Perneger, 2007).

While the current study sample was not large enough to yield generalizations such as those proposed by Bovier and Perneger (2007), the stories told by pediatricians and family physicians did not seem to differ significantly in terms of the participants’ expressed levels of tolerance for uncertainty. Rather, the narratives in this study suggest that physicians’ level of tolerance for uncertainty, particularly when treating the child with unexplained illness or pain, may be more associated with past experience with uncertainty (i.e., the role of both medical experiences as well as early life experiences). While the common theme in the narratives of this study was the struggle with uncertainty
or "not knowing" and the anxiety this stirred up, the quantity of this anxiety and the nature of it and shaping one's search for the truth of pain and meaning making of illness for the child were distinct based on several important factors.

Findings from this study indicate a possible "stages of training" or developmental career theme associated with the way physicians make meaning of persistent medically unexplained illness or pain in the child. Less experienced physicians in the current study shared stories that were more concrete, diagnosis-driven, and associated with lower tolerance for uncertainty. Participants with more years of experience seemed to proceed less as the textbooks describe—top-down, deductively, and scientifically, but rather using case-based reasoning as their principal means of thinking and remembering, or "knowing" in medicine. In general, the more experienced physicians seemed better able to cope with higher degrees of uncertainty. All physicians followed a sequence of practice with the child, beginning with putting the truth into the tests, then the environment, and finally resting in the unexplained and dealing with the uncertainty of that. Less experienced physicians often did not extend their investigations beyond the body, whereas more experienced ones explored, albeit hesitantly, factors other than those biological.

The drive to name illness or locate its truth was a powerful theme associated with uncertainty in the narratives of the participants with less training, particularly the residents. This way of seeking the truth of illness seemed fundamental to the relative recency of their medical education and training. Research into the medical curriculum and the training of young doctors may help to explain the drive for simplicity and linearity of understanding regarding the causes of illness, which may stem in part from
fear of failure or medical error. As Montgomery (2006) notes, physicians are set apart from others not by their professional knowledge and skills, but their familiarity with death. First year medical students dissect human cadavers and receive almost 2 years focusing exclusively on pathophysiology, followed by practice in tertiary care hospitals where almost every patient is seriously ill. Students regularly encounter critically ill people and death during clerkships and residencies. The search for certainty through the biomedical approach is common. Montgomery states, “By residency they are absorbed and committed to objectivity – close observation, suspension of judgment until all information is gathered, skepticism about information they have not acquired or witnessed themselves, and when results don’t make sense, skepticism about their own procedures” (2006, p. 159). Thus, the acquisition of biomedical knowledge, search for certainty, and commitment to objectivity predominates for the junior physician. Dobie (2007) claims that although medical students, interns, and residents have a hopefulness for good relationships with patients, they are exposed to a “hidden curriculum” in medical school and early training that places the acquisition of biomedical knowledge above all else, which is often at odds with the development of awareness and relationship skills critical to the patient-physician relationship. It is only with more years of practice that physicians seem able to embrace more integrated models of care and come to enjoy richer and more healing relationships with patients. Participants with more years of experience in the current study seemed less exclusively committed to the biomedical approach to understanding disease and illness, having some appreciation for integrated approaches, such as the biopsychosocial. They also had higher tolerance for uncertainty and “not knowing.” Amy, Rick, and Penny
provide examples of three participants with nearly two decades of practice in medicine respectively. The narratives of these participants stood in sharp contrast to those with less than 5 years of practice such as JJ, Jake, Jane, and Kay, who all seemed more committed to searching for the truth of the child's illness and pain in the body, and experienced more intense levels of anxiety when faced with uncertainty. In contrast, the more seasoned physicians' stories suggested holistic frameworks and a collaborative stance with the patient and parents in making meaning of illness symptoms.

Montgomery (2006) speaks of this development in clinical thinking and knowing that occurs with physician experience. For the junior physician, the sum of case experiences is less, and thus the diagnostic process may be less defined. With their recent medical training foremost in their minds, residents and less experienced physicians often rely on the rule-out process. This is not to say that more experienced physicians do not also attempt to rule out the most serious medical causes of symptoms, but rather that they seem more comfortable accepting a certain degree of uncertainty in the process, as well as a capacity to appreciate less "scientific" forms of information in their search for the truth of illness and construction of the illness narrative for the child. Less "scientific" forms of information include the subjective reports of the child, parent reports, and information about the child's environment including the family and school.

Participants in this study who might be considered "mid-career" told stories that suggested experiencing change or a shifting of beliefs regarding the truth and meaning of pain and illness in the child, with increasing awareness about the self and personal biases, more mindful practice, and relationship-centered care extending beyond biomedical models. For participants such as Lota, Christy, and Grant, exploring the truth of
unexplained pain and illness in the child relied on certain "biomedical ‘facts,’” but also left open the door to other causes or truths besides the biological. We recall Christy’s hesitant exploration of her patients’ environments, including family dynamics and school functioning. Lota’s narratives also suggested an anxiety related to an internal conflict in shifting away from her medical school training and biomedical knowledge and honoring her “gut instincts” or hunches regarding emotional factors and their potential role in shaping the patient’s symptoms. Grant seemed to create a truth of pain and illness in the child that made sense to him, integrating the biological, psychological, and social. While more physician-centered in his approach, he seemed to resist seeing the child’s symptoms as evidence of a purely medical disease.

Dobie (2007) has argued that capturing the more human side of medicine and shifting away from the biomedical approach should not be a mid-career epiphany for physicians. To encourage development of communication and relationship-building skills in physicians, changes in the education of medical students, interns, and residents might include a “paradigm shift” to a culture in which teachers and learners consciously attend to their relationships with patients and work on self-awareness and mindfulness in practice, while still mastering biomedical knowledge. Changes in the medical curriculum that would facilitate and support continuous development of the physician would include writing narratives, keeping journals, and attending Balint or process groups to teach reflection and guide those reflections in ways that enhance students’ and residents’ understanding of themselves as individuals and in the relationships they form with patients. Self-awareness regarding physician attitudes and beliefs regarding the mind and
body and the value of entering into a collaborative relationship with the patient or family to create a shared illness narrative would also be beneficial.

Expanding on the recent medical writings of Gawande (2007) and Groopman (2007), this study’s findings offer additional insight into the ways that particular types of medical experiences related to uncertainty may shape the ways in which physicians understand and interpret unexplained pain and illness in the child. In this study, the doubt and fear associated with potential medical error seemed to be particularly burdensome for physicians. The potential of error or failure led to anxiety that seemed related to experiencing shame and guilt in disappointing parents of the child patient, rather than anxiety related to self-failure or facing the implications of liability and patient death. For physicians with more years of experience and also greater capacity to attend to their relationships with parents and patients, this fear seemed particularly powerful. The more junior physicians seemed more concerned about the possibility of personal failure and the implications of liability versus their accountability to families. In the junior participants, there was also a greater tendency to depersonalize the patient and family, perhaps as a way to remain clinically objective. Gawande’s (2007) claims that the experience of error and failure can stay in the mind of the physician and lead to even more intense efforts to achieve certainty may be particularly relevant when treating the child patient.

The increased sense of accountability and potential risk of shame and guilt that may be felt in consultation with the parent(s) of the sick child may also serve to reduce the “state of mindlessness” phenomenon that Groopman has found to occur in more “seasoned” physicians. In the current study, participants with less experience told stories
that suggested a tendency to regard learned facts as unchanging and absolute in relation to the child, than did more experienced physicians. More experienced physicians did not easily commit patients to preconceived schemas and categories of illness. This study's findings suggest that the physician experiences and phenomena that Groopman describes may be more applicable to physicians working with adults than children.

The experiencing of doubt and intolerance for uncertainty of illness seems a common experience for all physicians; however, the quantity and quality of that intolerance and its source seems to differ based on physicians' early life experiences with illness and uncertainty. Those participants in this study who had early life experience with uncertainty of illness themselves or in a family member seemed to struggle in facing the same type of uncertainty in their patients. Consider Jane and JJ, who both told stories of experiencing headaches in adolescence. In their narratives, we see how their attitudes and beliefs regarding the truth of illness and pain may be shaped by these early experiences, which in turn influence medical investigations, diagnoses sought, and alliance with the child and family. For example, participants with early life experiences with illness or uncertainty seemed to find greater value in the subjective reports of patients and parents, had greater empathetic capacity for the child or parent, and became more easily identified or "aligned" with the child or family. Early life experiences with illness also seem to determine tolerance for uncertainty, the search for answers, and dedication to personal notions of restitution. We recall how Jane seemed particularly identified with the mothers of her patients and their anxiety, resulting in greater alignment with the parent. Jane also tended to embark on extensive rule-out processes for all biomedical causes in her search for restitution for her patients with unexplained pain.
Her approach with her child patients with unexplained pain may have been shaped by her experiences with persistent headaches of unknown origin as a young girl, her feelings of possible shame or guilt related to her mother's anxieties, and experience with an overbearing and concerned mother in pursuit of diagnosis and treatment. For JJ, his efforts to eliminate uncertainty, find answers, and solve the "puzzle" of his adolescent patients' unexplained pain and illness may have been shaped by his past experiences with headaches in adolescence that were (in his own mind) both easily explained and easily resolved.

It is interesting to note that in the interview narratives there emerged an intergenerational pattern of the physician career. That is, 7 of the 10 participants interviewed had at least one parent who was a physician, and 2 participants had two parents who were physicians. This finding is interesting in that it suggests the possibility of transmission of beliefs regarding the role and importance of the physician in locating the causes of illness, attitudes regarding mind-body dualism, and ability to tolerate uncertainty in practice.

A dependence on a more biomedical versus biopsychosocial attitude when caring for patients and one's own child may lead to a similar framing of illness in the child who becomes a physician. For example, more than half of the participants in the study had at least one physician parent. The majority of participants with physician parents told narratives that suggested a basic appreciation for the uncertainty of medicine, or a learning or acceptance for the uncertainty of illness. For example, in Penny's family there was a socializing of the reality of illness and the physician's inability to prevent it. She said, "I think it was a very balanced approach and, for the most part, you
don't...there was an understanding of the germ theory and that germs are out there and you get sick! It happens."

Those participants who did not have a doctor parent, shared narratives that tended to have in common the experience of a parent who minimized illness. For example, Lota, Grant, and Christy all spoke of parent expectations of continuing to attend school or engage in chores when ill. Those participants who reported having a parent who was a psychologist or psychiatrist had the experience of a parent who seemed better able to appreciate the role of emotions in illness and the mind-body continuum.

The Triadic Nature of the Medical Consult with the Sick Child

Emerging from the narratives are numerous themes involving of the negotiation required by physicians to share power and intimacy in the relationship with parents of the sick child. Though discussions in the literature refer to the importance of the physician-patient relationship in the interpretation of symptoms and subsequent the nature of care and treatment, here the physician-patient relationship in the consultation with the child is unique. In treating the child patient, there is a hidden and collaborative meaning making of symptoms that occurs between the parent(s) and physician as opposed to the child patient and physician. Thus, the nature of the relationship between physicians and parents, and the ability to negotiate trust, intimacy, and power in the medical encounter, is important. This was a common theme in the narratives of this study of physician
struggle to become aligned and avoid conflict with parents in the context of caring for the child. The interpersonal factors when treating the sick child have numerous implications for diagnosis and treatment.

The importance of the triadic nature of the medical encounter with the child has not been clearly addressed in the medical literature. A thorough review of books on topics such as the physician-patient relationship, the medical encounter, and textbooks in pediatrics did not reveal one chapter dedicated to this topic. The implication is that physicians may not be educated regarding the importance of the relationship with parents and its power to shape medical management of the child, nor do they receive medical training on how to negotiate power, trust, and intimacy in the medical encounter with parents. Pediatric textbooks emphasize the types of medical investigations and symptom checklists or criteria for disease and illness in the child, virtually ignoring the relationship with parents and its potential to influence medical approaches and decision making in diagnosing and treating the child.

The narratives of this study demonstrate how training in neutrality and negotiation of therapeutic goals with parents would benefit the relationship between physicians and parents. For example, the stories participants told suggested frequent transference and countertransference of feelings and behaviors in the physician that were generated with the parent of a child. I demonstrated in my analysis the ways in which the complimentary or conflictual nature of the physician’s relationship with the parents has the potential to shape the direction of the search for the truth of illness symptoms or pain in the child, the diagnoses considered, the extent of medical work-up and type of treatment. The stories told suggest that certain early life experiences of the physician were often brought to bear
in the medical encounters with parent and child. More importantly, the majority of physicians did not seem aware of its occurrence. Training for physicians is needed to enhance self-awareness and understanding of the ways in which each physician carries a context or system that can potentially impact his or her effectiveness in medicine. Mengel (1986) has written about physician therapeutic ineffectiveness and alliances and conflicts with patients due to family-of-origin issues.

The subjective experiences of physicians, including positive and negative feelings toward families, cultural assumptions, personal biases, and beliefs regarding the truth of pain and illness have not been given the attention they deserve in the medical literature. The narratives in this study suggest that negative feelings in the physician can be stimulated by parents and families, and do play a role in determining the causes of illness that are explored, selection of tests, and alliance with the family. In the participants’ stories we see how the nature of certain feelings, thoughts, and behaviors associated with early life experiences may be particularly powerful in their potential to become transferred to the parent and child patient. Recall Kay’s intense feelings of annoyance in dealing with “overly emotional” parents, or Grant’s sense of disappointment in facing parents with unrealistically high expectations of the sick child.

The importance of physicians’ stories as offering opportunities to reveal things about the self including feelings, reconstructions, and representations of events in medical practice, has been supported (Borkan et al., 1992). In particular, exploring negative feelings such as anger, helplessness, and fear associated with facing uncertainty of illness may be critical to increasing physicians’ self-understanding regarding the ways they perceive and understand illness in the child. Narrative writing has been used to
promote reflection and increased self-awareness among physicians, and provides an emotional outlet regarding difficult cases and concerns. Physician narratives offer the opportunity to integrate clinical experience and the medical curriculum (Dyrbye, Harris & Rohren, 2007; Levine, Kern, & Wright, 2007). Dobie (2007) has emphasized the need for medical students to learn about themselves, their values, their culture and beliefs, and how they bring these to bear in their relationships with patients.

*Missed and Unspoken Narratives*

Patient narratives provide a means by which physicians test their judgments. The narrative is essential to thinking and knowing in clinical medicine. The construction and interpretation of the story of the illness through first-hand knowledge has traditionally held critical importance in the field of medicine (Montgomery, 2006). Without it, the physician is helpless to determine what is to be valued in the search for diagnosis and treatment.

In the case of the very young child, the presenting or most salient complaints and the piecing together of information that might lead to a retrospective understanding of the events of pain or illness are not always available. Rather, initial reports of illness tend to come from the parent who brings the child to the physician. The physician is then prompted to select those medical tests that will either confirm or disconfirm the parents' report. The presenting complaint, the retrospective accounting of illness, and what is believed to be going on in the child is shaped more by the adults in the clinical encounter than the actual patient, the child. The narratives in the study suggest that parents'
representations of the child's illness and their ability to cope with uncertainty, influences the ways in which the child's illness might be interpreted, understood, managed, and treated by the physician.

While for the child patient the personal illness narrative may not be available due to barriers in cognition and language, findings from this study suggest that even when available, the child's narrative is often and imprudently overlooked by the physician, the parent, or both. Physicians and parents alike seem to be guilty of placing undue emphasis on the results of medical tests to explain the illness or pain of the child, feeling compelled to return to the medical "facts" in an effort to secure some form of certainty to reduce their own anxiety. While the narrative of the adult takes precedence due to its perceived maturity, sense of consistency, and descriptiveness, what is essentially lost is the true story of illness and the experience of pain that only the patient can tell. Physician and parent focus on the physical basis of illness obscures the emotional basis of pain and illness of the child. It is as though the child is acted upon merely as a body rather than a thinking, sensing, and feeling human being. In having no voice, the child also becomes helpless to prevent certain medical searches for causes that, while certainly feared in the physician and parent's minds, may be unnecessary and place the child at risk for iatrogenic injury.

I make the point above to demonstrate the interaction of parent and physician beliefs as to the search for the truth of illness in the child, and the co-construction of meaning that often occurs without the child's input. The child's direct reporting in the medical consultation, however immature, may be central to understanding illness and pain. In the majority of physicians' narratives, the child's own narrative held limited
value to the search for truth and understanding of the symptoms. What can be said of the integrity of the child's own narrative? In the medical literature there are no studies that have explored the illness narrative of the child with persistent medically unexplained illness or pain. A limited number of studies have addressed the illness narratives of children with chronic or terminal illnesses. In contrast, illness narratives of adult patients abound, which further suggests a tendency to regard the child merely as a body to be acted upon.

The child may in fact have valuable information regarding the truth of his or her symptoms of illness and pain. In a pilot interview for this study, one experienced physician said, "There is integrity in the child's understanding of his or her illness. In many cases they seem to know what is truly going on, even when parents and physicians are blind to the cause." If this is the case, why then do so many physicians disregard the narrative that the child brings to the clinical encounter? Is it because there is a comfort in making sense of uncertainty with another adult? Is the child silenced given that his/her report would only create further uncertainty? Is it because subjectivity tends to be synonymous with uncertainty in medicine, and this would provoke overwhelming anxiety in the physician? Or is it because looking truly at a child's pain would provoke overwhelming anxiety for the adult who shares this type of past? These are important questions that beg further investigation.

Willingness by physicians to hear the story of the child may also be related in part to a capacity for empathy that is associated with internalizations from early life experiences, leading them to be more or less able to identify with the sick child and his/her personal experience of pain and suffering. Several of the participants in this study,
while deeply entrenched in their anxieties regarding uncertainty and their inability to locate the truth or explanation of pain, demonstrated a willingness to hear the child's voice that seemed in some ways related to a personal history with unexplained pain, internalization of a similar type of experience, and capacity to identify. For example, Penny seemed particularly interested in hearing the child's illness narrative. The stories Penny told of her own childhood suggest identification with the sick child whose personal experience was ignored, spoken for, or claimed by the adult.

Aside from the unspoken child narrative, the findings from this study provide evidence of an entirely different missed narrative: the constructed illness narrative that occurs between physician and parents. Most of the narratives focused on the physician as providing diagnosis and the patient as being acted upon to be healed or cured. Physicians told stories of listening to symptoms reported by parents, pondering their meaning, and then imparting information they believed would be most helpful. For the parent, there was the description of symptoms, perhaps the reporting of some related environmental factors, and waiting for answers and treatment. The child's report here was often missing, but also in between there seemed to exist another unique story that involved the interpersonal dynamics and the personhood of the patient, parents, and physician which influenced the constructed narrative of illness. As noted earlier, in treating the child patient, the interpersonal dynamics between the physician and parents seem critical in shaping the construction of the illness narrative for the child. Thus, the meeting of the child, the parents, and the physician is co-evolving, and the illness narrative becomes a unique product of each's telling and responsibility to the other's story. The cultural identities and developmental experiences of the physician that can impact the narrative of
illness have not been often considered in the literature, but certainly appear to play a critical role.

*Child Somatization: The Fallacy of “Unexplained” Pain*

All of the participants’ stories demonstrate the ways in which anxiety in facing the uncertainty of illness can persist and continue to “infect” within the context of the relationship between physician and parents. There is a clear parallel in the experience of anxiety between physicians and parents when facing the child with unexplained illness or pain. The quantity and quality of this anxiety appears to play an important role in the shaping of the search for the truth of pain and illness by the physician. When anxiety regarding the unknown and potential fatality of illness is predominant in the relationship, the search for the truth through extensive medical investigation ensues. Neither the physician nor parent is easily able to consider causes other than those that are organic, as these are the ones that are most connected to the feared and fatal.

The narratives of this study suggest that it is often not until all forms of this uncertainty are eliminated that physicians and parents feel safe to consider other factors, such as psychological and social. True to their profession, physicians seem determined not to let go of the possibility of a biological cause, even while having certain “hunches” about the involvement of nonmedical factors. Sophisticated or highly experienced physicians and psychologically minded parents may be able to accept that a child’s pain or illness is not fully explained by medical causes and has an emotional component;
however, there is still a clinging to the possibility of a simple medical explanation. For this reason, to consider a child’s symptoms to be “medically unexplained” is a fallacy, since in the mind of physicians (and also parents), the possibility of a medical cause is never truly abandoned. Perhaps this is why physicians do not really consider a somatoform diagnosis to be appropriate or final, as physical pain and suffering in any patient leaves open the possibility of medical explanation and medical treatment. Perhaps there is a shaping of this belief regarding the importance of the truth of discovery in medical school that becomes fundamental to the physician self.

Though biopsychosocial theories of illness are taught and emphasized to physicians and mental health practitioners, doctors seem to remain very much tied to the biomedical realm when treating patients, even patients with so-called “psychosomatic” pain and illness. The fact that physicians are trained and work in a medical culture that continues to emphasize the biomedical, and the stigma of mental illness, prevents their embracing somatoform illness as a diagnosis in itself. With children and adolescents, the diagnostic waters become murky. While some physicians find themselves hesitantly exploring anxiety and depression in the child, the possibility of a somatoform illness seems far from their minds. A certain ignorance regarding what truly constitutes a “somatoform disorder,” or an understanding of the process by which the mind and body may work together to cause illness, also contributes to the problem.

There is evidence to suggest a certain “resistance” by physicians to incorporating psychosocial factors in their diagnosis and treatment of mind-body illnesses and disorders. Although the majority of physicians seem to recognize the importance of addressing psychosocial issues, nearly one third believe that addressing such factors
would lead to minimal or no improvement in outcome for the patient (Astin, Soeken, Sierpina, & Clarridge, 2006). Furthermore, few physicians indicate interest in receiving future training in these areas. Feelings of low self-efficacy to address psychosocial issues and the perception that such factors are difficult to control, lack of knowledge of the evidence base supporting the role of psychosocial factors, and lack of time and inadequate reimbursement to address the psychosocial domain exist. The finding in this study that physicians seem to identify lack of time, training, and inadequate reimbursement as significant barriers suggests that the current health care delivery system in some respects may be antithetical to the biopsychosocial model.

Attitudes regarding the truth of pain and illness, particularly reliance on biomedical versus biopsychosocial models of health and illness, may also be explained in terms of a developmental career theme. The medical literature suggests that more thorough review of systems and comprehensive history taking is more common in doctors who are not yet experts (Kassirer & Gorry, 1978). In more senior physicians, clinical experience may lead to more “gut instinct” or “hunches” that drive investigation. This may be an advantage in some cases, but also a disadvantage, as Groopman (2007) suggests, due to confirmatory bias and lack of mindfulness.

The limitations in physician knowledge of somatoform illness in younger populations have implications for medical education and training. In my interviews with physicians, I commonly heard the terms “conversion reaction” and “psychosomatic,” but rarely the terms somatization or somatoform disorder. Few physicians seemed to understand that a diagnosis of Pain Disorder may provide not only a suitable label for the child with persistent unexplained headache or stomachache symptoms believed to have
both medical and psychological components. Few physicians seemed to understand that a diagnosis of somatoform disorder did not relegate physical pain symptoms to the psychiatric realm, but offered the possibility of a medical explanation in combination with other contributing factors. Few physicians use standardized instruments or DSM-IV criteria to identify children with physical and behavioral health concerns in primary care setting (Weitzman & Leventhal, 2006). The implications for medical training of physicians in understanding the relevance of the mind-body continuum to the somatoform disorders and applicability of certain diagnostic labels for the child that embrace both the medical and psychological are needed. Research has demonstrated that discussion of psychosocial health is more common in woman providers and those who report greater confidence in mental health treatment skills, and less common when the child demonstrates physical pain (Brown, Wissow, & Riley, 2007).

The continued stigma of mental illness was a common theme encountered in the narratives of this study, which may explain in part a clinging to biological explanations and resistance to considering psychosocial factors offering alternative or co-existing causes of illness and pain. The majority of participants manifested an apparent hesitance, or discomfort discussing the mental health of their patients with persistent medically unexplained illness or pain symptoms. While some participants were more comfortable admitting to limitations in their knowledge on the subject of somatoform illness in children – not only the diagnostic labels and criteria associated with them, but also the process by which emotional factors can become manifest by the body--the majority of physicians exhibited an unwillingness to let go of the search in the biomedical realm and consider other causes of illness. Many seemed to consider a mental health referral and
The exploration of emotional contributors to illness to mean they would no longer be involved in the patient's care, and that the possibility of an organic explanation would no longer be considered. Essentially, the co-existence of medical and psychological explanations for disease and illness appeared to seem unfeasible to them. I wondered whether making a mental health referral for the physician was akin to failure as well as loss of the patient. It is possible that physicians resist exploring the psychosocial because it removes them from providing restitution to the patient. The possibility also exists that the physician has cultural beliefs regarding mental illness and its stigma that prevents him/her from exploring causes other than the biological.

Nowhere does the biopsychosocial approach seem more fitting than with patients with medically unexplained illness or pain. Here there exists an opportunity for physicians to explore with patients the processes by which the mind and body interact in health and illness, yet physicians seem to experience difficulty in doing so. The findings from this study, although exploratory and preliminary, suggest a resistance to embracing more holistic approaches in medicine. This may be an effect of practice not yet catching up with theory, lack of physician training in understanding how to raise mental health issues in the medical encounter with families, or a clinging to more scientific models. Pediatric settings hold the potential to be a key environment in which to address mental health concerns, given the frequent contact and trusted relationships many families have with their pediatricians. Education for physicians that encourage use of screening and discussion with families of the mind-body continuum are critically needed.
Implications for Diagnosis of Child Somatization in the Medical Context

Characteristics of physicians that might otherwise be regarded as virtues, such as appreciation of the individual and the anecdote, recognition of a person’s pain, attention to emotions, an awareness of one’s own emotional life and participation in the lives of others are often regarded as flaws when it comes to their practices. This study’s findings, while limited in generalizability given the small and broad sample, do suggest that physician awareness and understanding about the self and the ways in which one’s experiences shape the interpersonal experience in the medical encounter with the patient is neglected.

Physicians perceive their patients in certain ways and their interactions are shaped by these perceptions. The narratives in this study support what has been generally reported in the literature, and that is that physicians tend to deny their feelings, often failing to see the importance of insight into emotion and its link to effective treatment with patients (Maoz, Rabinowitz, Herz, & Katz, 1982; Montgomery, 2006). The doctor who is able to understand his or her feelings may have a greater capacity for empathy for the patient. Those participants in the study who demonstrated an insight into their feelings associated with certain personal, as well as medical experiences, seemed generally better able to connect with the child and the parent. In this study, those participants more capable of reflection and insight were those with more years of experience. Recall Rick, the most experienced physician in the study, who was able to share his personal feelings and insight regarding the types of patients he found most difficult with whom to form an alliance, his ability to connect his early life experiences
and associated feelings of sorrow and loss to his ability to emotionally connect with families dealing with chronic illness.

Qualitative study of medical students' narratives of personal experiences with illness has revealed important themes regarding the role of family members in illness episodes, influences of ethnicity or religion, experiences with socially unacceptable illnesses, experiences with death, appreciation of the moral trajectory of illness, and attitudes regarding the fallibility and limitations of medicine (Yamada, Maskarinec, Greene, & Bauman, 2003). Studies such as those by Yamada and colleagues demonstrate the power of the physician narrative to increasing physicians' understanding of personal beliefs, attitudes, and biases that may help or hinder their relationship with patients and the treatment they provide. Traditional medical education has been criticized as failing to provide the skills required for physician self-awareness, specifically exploration of feelings in relation to their personal and professional roles and relationships with child patients, but also the child's parents (Polliak, 1992). Additional study has demonstrated the value of narrative writing for physicians in increasing self-awareness include those by Levine, Kern and Wright (2007), who found that writing about difficult experiences coupled with reflection motivated medical interns to want to improve. Reflective journal essays pertaining to first year experiences of medical students with inpatients revealed the value of apprenticeship and experiential learning related to the physician role in relationships with hospitalized patients (Dyrbye et al., 2007).

Kathryn Montgomery writes about the mismatch between the way medicine is taught and practiced. Medical education may better serve physicians in helping to shape understanding of the provisional nature of much of clinical knowing. We return again
briefly to the theme of uncertainty and the way it shapes the practice of medicine. The anxiety associated with the experience of uncertainty, helplessness, and powerlessness with patients with pain or illness that seems unexplained is common, but perhaps even stronger for physicians whose work is dedicated to finding answers, solving problems, healing, and providing cure. Saba, Vener, and Sommers' (2000) argument that medical training fosters the belief that doctors can control disease, and by logical extension, control people with disease seems particularly relevant to this discussion. Since the physician determines which treatments to present and asserts greater knowledge about the illness, the patient remains at a disadvantage. Consistent with a physician-centered approach, decisions about illness typically exclude family input (Goodrich & Wang, 1999). Medical education and clinical training that emphasizes the necessity of coping with uncertainty of illness might help to ease physicians' drive for restitution and diminish ideals of power and authority between doctor and patient, while emphasizing the importance of enabling behaviors in the patient. When working with children with persistent medically unexplained symptoms, the necessity of coping with uncertainty seems paramount.

The findings of this study do not change what is already known about diagnosis and treatment of the child with persistent medically unexplained illness or pain. Child somatization remains a puzzling phenomenon and physicians represent the first line of investigation, diagnosis, and treatment of such children. What this study does suggest is that medicine does not interpret, diagnose, or treat somatization in the child as a psychiatric condition, but considers it largely from a medical standpoint. Physicians' understanding of the origin, maintenance, and exacerbation of somatoform symptoms in
children are framed within the medical ideal of searching and locating the truth of illness in the body, and its expressions of pain. Physicians hope to arrive at diagnosis and explanation for a child's symptoms that suggest causal simplicity. Regardless of years of experience or gender or life history, physicians struggle to consider what lies beyond the expression of illness by the body. Issues of causality or the importance of those factors related to the family, the environment, and most importantly the psyche as contributing to the manifestation of symptoms are not paid much attention by physicians or parents. Diagnosis of a medical condition is more often the goal, given that diagnosis offers clear treatment for pain and suffering, which is highly sought by physician and parents. Physician search to make meaning of that which is uncertain and locate the truth of illness explains why referrals to mental health of those children who present with a combination of physical and psychological symptoms are delayed.

While this study's narratives provide evidence of certain differences in the frameworks used by physicians to understand the connection between mind and body in illness, the biomedical view predominates. While having some appreciation and understanding for biopsychosocial models of illness, integrationist approaches to making sense of persistent medically unexplained illness or pain in the child tend to be under-valued. For the child with persistent medically unexplained illness or pain, or any child with pain for that matter, there is a sequential exploration of the biological, then social, then psychological. This furthers, as Penny notes in her interview, a separation of mind and body in understanding illness and pain by both physicians and families.

The narratives in this study suggest that physicians hesitate to explore the psychological in their search to make meaning of unexplained illness and pain in the
child. As Kay and Jane note, cases are often "punted" to mental health to avoid this last step. While some physicians seem comfortable exploring the psychosocial stressors in the family or environment of the child that may contribute to illness, there seems to be a certain existential anxiety in letting go of the search for a medical explanation. I could not help but note the willingness of participants to overlook or miss a diagnosis of depression in the search to rule out cancer or other fatal or chronic diseases. This may be because physicians tend to look for answers that first offer the opportunity for cure and healing than merely reduction in pain and suffering.

Limitations and Parameters of the Study

Although I attempted to vary my sample with respect to age and gender, all participants were White and of North American origin. All participants attended medical school and completed their residency training within the United States. Thus, the analysis of narratives and the importance of the findings should be framed within the context of Western medicine. In attempting to increase understanding and treatment of somatization in children and adolescents, the relevance of context holds importance. It would have been interesting to interview physicians who were born and raised in non-Western cultures, or possibly even educated in locations outside of North America. In considering the importance of context, the type of patients and presentations seen may vary according to location, medical opinion, diagnostic approach, and choice of treatment. For example, physicians practicing in the western United States may experience certain symptomatology in children more or less often, leading to differences
in understanding and illness constructions. My interest in the phenomenon of child somatization originated in Salt Lake City, Utah, where there seemed to be a disproportionate number of children presenting with persistent unexplained headache, stomachache, pseudoseizures, and conversion reaction. The prevalence of somatization in children in the Midwest appears to be much less. Future study of physician attitudes and treatment of child somatization may benefit from regional comparison.

In recruiting physician participants to the study, I communicated my goal of better understanding how physicians make meaning of persistent medically unexplained illness in children. It is possible that the group of physicians in this study represent a biased sample; perhaps only those with a heightened awareness of or appreciation for the importance of the topic may have responded to the letter of recruitment. Furthermore, some of those who participated were asked to refer other potential participants, leaving open the possibility of finding participants with similar viewpoints and attitudes in medicine.

Montgomery (2006) claims that physicians know and understand how clinical knowing actually works, and understand that uncertainty and imprecise application of their knowledge exists; however, her claim is that the grounds upon which they respond to patients belie this. She states that as physicians become more practiced, they become better at recognizing the need for patients to see them as confident and all-knowing. There develops a strong duty to respond to the patients—to act or to justify inaction. She says “What physicians know about the uncertainty and imprecise applicability of their knowledge is one thing; the grounds upon which they respond to a patient are another.” (p. 201). So, this begs the question as to whether participants in my study tended to see
me as a potential patient. If so, was anxiety in their narrative related to their experiencing the unknown or uncertain in their treatment of patients, or was it anxiety related to their discomfort in admitting and talking about their fallibility in my presence? In sharing their stories of clinical experiences with uncertainty and even failure with a non-physician, was there a sense of shame inherent in this exposure, embarrassment or perceived inferences of guilt? It is possible that as a researcher I did not have a full appreciation of the exposure inherent in my study and the nature of the questions.

While there were references in the narratives to the personal experience or witness of medical error, these references came up only in passing. In retrospect, I realize that I may have missed opportunities for elaboration which might have been useful to the analysis of themes, particularly given the recent emphasis in the medical literature on the ways in which fear of error and failure in medicine shapes physician behavior and the nature of care.

An inconsistency in the settings in which physicians were interviewed may have led to greater variability in the narratives that were shared by participants and thus the quality and quantity of the data available for analysis and interpretation. For example, one might assume that a physician interviewed in the comfort of his or her own home would have naturally felt more at ease and willing to share stories that incorporated the more personal aspects of his or her practice of medicine. In retrospect, participants interviewed in more clinical settings, particularly patient examining rooms in clinics, tended to share stories with more heavily weighted themes of diagnosis. It was also noted that the length of interviews that took place in participants homes tended to be greater and risk of interruption was less. In clinic settings, participants may have also
been more distracted by time constraints and the risk of work interruptions. It is also possible, however, that there may have been a methodological strength in varying the interview contexts; noted by Labov and Waletzky (1967), narratives and particularly the evaluative elements of narratives, as social phenomena. As social phenomena, narratives vary by social context and evaluative data extracted from narratives will vary by the social context within which they are collected. Consequently, it may be fruitful to gather narratives on the same topic of interest from otherwise similar participants/respondents in varying social contexts. Likewise, gathering narratives on the same topic of interest from similar respondents at different points in some developmental process (e.g., physicians at different career points) may yield differences in evaluative components and consequent insight into the process.

There is the matter of the differences in participants' medical experiences with children and adolescents with persistent medically unexplained illness or pain. It was noted that for those participants who had more clinical experience with such cases, there was greater ease in not only recollecting but also telling of stories. For some family physicians, there seemed to be a greater struggle to recount a story. There was a difference in the amount of data for analysis. This suggests that my findings might have been quite different if I had had a sample in which all of the participants had the same level of experience with somatizing patients or if all participants had been pediatricians.

Although there was variation of research methods, including the demographics of the sample and the methods used to gather data and researcher and respondent behaviors, there is a possible methodological strength in this variation. A lack of preestablished methods and flexibility in the researcher's role may minimize the problem of creating
irrelevant and artificial data, as is sometimes the case with content narrative analysis that is more quantitative and uses nonmetric multidimensional scaling. Rigid control of the research situation may lead to hypersensitivity to accidental and unplanned variations in researcher or participant behavior (Katz, 1983).

Recommendations for Further Research

This study was very much exploratory in nature. No narrative study exists that has explored the physician experience treating the child with somatization and how certain attitudes and beliefs that exist may shape the construction of meaning, diagnosis, and treatment of symptoms.

Given this study's findings regarding the different ways in which physicians make meaning of medically unexplained illness or pain in children and adolescents, and how certain constructions influence diagnosis, and treatment, future studies of larger physician populations accounting for commonalities and differences in medical specialty, geographic region, levels of training, age, and gender are needed. Perhaps also a comparison of meaning making of persistent unexplained illness in the child versus adult populations would reveal commonalities or differences in physician attitudes and beliefs. Given this study's findings regarding the feelings of anxiety associated with uncertainty in medicine, future research might undertake to measure physician intolerance for ambiguity and its association with the use of certain medical technologies, levels of referral, patterns of diagnosis and types of treatment used with patients with somatization.
Given my sense of participants’ discomfort in the telling of stories that described their experiences with failure or medical error, further narrative study might investigate the importance of shame in physicians. Few have written about the physician’s experience of shame and how it may influence clinical knowledge and decision making with respect to diagnosis and treatment. As Montgomery (2006) notes, physicians may be more vulnerable to shame given that they are self-selected for perfectionism when they enter the medical profession. Medical schools have been known to routinely use shame as a form of punishment for medical students, emphasizing that lack of dedication to study can lead to inadequacy of knowledge and skill, as well as medical error. In the narratives of the participants of this study, there was evidence of the experience of shame.

Finally, further narrative study of the importance of physicians’ early life experiences with illness and uncertainty in shaping their capacity for empathy for patients and families would be fascinating. The findings of this study suggest that physicians’ developmental experiences with illness and pain in the family of origin shape their experience of illness and the patient’s experience of that illness in the medical encounter.
REFERENCES


You have been invited to participate in a research study conducted by Stefanie Varga, a doctoral student in the Clinical Psychology Program at Fielding Graduate University, in Santa Barbara, CA. The student is working under the supervision of Samuel Osherson, PhD. This dissertation project is in partial requirement for the doctoral degree.

**PURPOSE OF THE STUDY:** This is a qualitative study of physicians’ narratives regarding their experiences treating children with persistent unexplained physical complaints and illness. The goal of this study is to learn more about the attitudes, values, and beliefs that physicians hold regarding medically unexplained pain and illness in the child, and how these potentially shape medical management, particularly differential diagnosis and treatment.

**INVOLVEMENT, POTENTIAL BENEFITS, AND RISK:** This study will involve one face-to-face interview that will last 1-2 hours. You may be asked to participate in a second interview that will last 30-60 minutes. Second interviews will provide an opportunity for the researcher to share some initial impressions from the first interview, as well as allow you to provide additional input or clarification of ideas. All interviews will be tape-recorded and transcribed verbatim. In addition to the interviews, you will be asked to fill out a short background questionnaire that should take no more than 5 minutes to complete.

There is no financial compensation for participating in this study. Potential benefits include the opportunity to reflect on your practice of medicine and the topic of interest in the presence of an interested interviewer. There are no perceived risks for participating in this study. If for any reason you experience emotional distress during the interview, please let the researcher know. You may choose to stop the interview or request that the tape-recorder be turned off at any point, without consequence. You may request that certain sensitive information be deleted from the tape-recording and/or transcription.

**WITHDRAWAL FROM THE STUDY:** Your participation in this study is voluntary. You may withdraw from the study at any time, before, during, or after completing the questionnaire and interviews, without negative consequence. Should you withdraw, your interview content, the researcher’s notes and memos, and your background questionnaire will be eliminated from the study and destroyed.

**CONFIDENTIALITY AND ANONYMITY:** The content of the audiotapes and the verbatim transcriptions will be made available to the dissertation Chair, Samuel Osherson, Ph.D., as well as a student reader/research assistant, who will sign a
confidentiality agreement (attached). Your name and identity, as well as other persons’ names mentioned in the interview that may compromise your anonymity will not be used in the transcripts. Your identifying information will be replaced with a pseudonym. If you are quoted in the final research report, it will be under the same pseudonym.

STORAGE AND SHARING OF DATA: The Institutional Review Board of the Fielding Graduate University retains access to all signed informed consent forms.

Your interview will be audio-taped using a tape-recorder with cassettes. The content of the tapes will be transcribed (verbatim) by the researcher to be used for analysis using a narrative analytic approach. The informed consent forms, questionnaires, notes and memos, and audiotapes will be kept in a locked filing cabinet in the researcher’s home. Transcripts will be in stored in MS Word Format on the researcher’s laptop with copies stored on 3.5 inch diskette. Diskettes will be stored in the same locked filing cabinet as the consent forms, questionnaires, and audiotapes:

Upon completion of the study, all material will continue to be maintained in the locked filing cabinet in the researcher’s home office for a period of up to five years, upon which it will be destroyed. Copies of personal emails between physicians and the researcher will be kept strictly confidential and will not be shared with any other persons. These emails will be destroyed when they are no longer needed, or when the final copy of the dissertation has been submitted for committee review.

PUBLICATION: The results of this study will be published in dissertation format. By signing this informed consent form, you grant permission for use of your disguised interview material and other research data in the dissertation report, and in any future books, articles, or conference proceedings that are based on this research. If you would like a copy of a summary of the study results provided to you, please initial HERE:

If you have any questions about any aspect of this study or your involvement, you may contact the researcher, Ms. Varga, at any time. You may also direct questions to Ms. Varga’s supervisor, Dr. Samuel Osherson, who can be reached at the phone number and address listed below.

Two copies of this informed consent form have been provided. Please sign both, indicating that you have read and understood the consent forms, and that you agree to participate in this research study. Return one to Ms. Varga, and retain the other for your files.

NAME OF PARTICIPANT (print): ________________________________

SIGNATURE: ________________________________

RESEARCHER: Stefanie Varga, M.A., M.Ed.

DISSertation ADVISOR: Samuel Osherson, Ph.D.
Appendix B

BACKGROUND QUESTIONNAIRE

DISSERTATION STUDY:
TREATING CHILDREN WITH PERSISTENT UNEXPLAINED PHYSICAL COMPLAINTS: THE PHYSICIAN'S EXPERIENCE

Researcher: Stefanie Varga, M.A. M.Ed., Doctoral student
Clinical Psychology Program, Fielding Graduate University

Name

Gender (Circle) F M

Education/Degrees Awarded: ____________________________________________

Area of Medical Practice: ____________________________________________

Place of Employment: _________________________________________________

Academic/Teaching Faculty: YES NO

Please circle: RESIDENT POST-RESIDENCY

If a resident, please state year of residency: _____________________________

Number of years in practice, post-residency: ____________________________

Do you have children: Y N Prefer not to answer

If yes, what are their ages? _____________________________________________

Approximately how many child/adolescent patients do you treat annually with persistent unexplained physical complaints and illness? __________

Do you also see adults in your practice who present with persistent unexplained illness and pain? Y N