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Communication and Uncertainty in Illness: The Struggle for Parents to Assign Meaning to an “Orphan” Illness

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Communication and Uncertainty in Illness:
The Struggle for Parents to Assign Meaning to an “Orphan” Illness

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ABSTRACT

This study explored the uncertainty experienced by parents of children with hemangiomas and vascular malformations (HVMs)—commonly known as birthmarks. Because HVMs do not belong to one specific discipline, they might be considered an “orphan” illness. The complexities of this condition impact parents’ experiences with complex uncertainty. Thirteen months of participant-observation combined with a survey approach were utilized to assess the uncertainty of parents and their communication with physicians at an HVM clinic. Two Communication theories—Babrow’s (1992) Problematic Integration Theory and Brashers et al.’s (2000) Communicative Management of Uncertainty Theory—and Mishel’s (1988) Uncertainty in Illness Theory, were used as theoretical frameworks to interpret results. The findings of this study highlight the interwoven uncertainties posed by “orphan” illnesses and how they influence parents’ communication and their ability to assign meaning to the illness experience. These complexities also suggest that existing measurement scales may not well operationalize the multilayered and complicated nature of uncertainty experienced by parents. Finally, the study suggests that existing theories on of illness uncertainty might be expanded to include unique uncertainties of “orphan” illnesses and distinctive characteristics surrounding parental uncertainty.
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INTRODUCTION

This study focuses on the uncertainty experienced by parents of children born with hemangiomas and vascular malformations (HVMs) and their communication with their child’s physicians. Previous research supports the claim that uncertainty is high in illness (Mishel, 1988), and for patients with HVMs, also known as birthmarks, uncertainty can be heightened and more complex because the condition is an “orphan illness” that does not belong to any one medical specialty (e.g., dermatology, oncology, otolaryngology, radiology, plastic surgery, etc.). HVMs are traditionally managed through coordinated efforts of multiple physicians from different disciplines. Additionally, individuals born with HVMs, their parents, and the physicians who treat them face a great deal of uncertainty because one uniform set of terminology does not exist to describe or diagnose the condition (Rieu & Festen, 1996). Patients who are newly diagnosed with an HVM come to a specialist with uncertain expectations about diagnosis, treatment, and prognosis, and often have an inability to assign meaning to the future progression of the condition.

The following literature review highlights the characteristics of illness uncertainty and provides a theoretical framework for examining the interwoven problematic integrations experienced (Babrow, 1992) and how individuals manage their uncertainty (Brashers, Neidig, Haas, Dobbs, Cardillo, & Russell, 2000). Additionally, the research on physician-patient interactions is summarized to identify the problematic and complex nature of the medical interview and how the physician-patient relationship influences illness uncertainty. The literature sets up the current study which explores areas of
uncertainty experienced by parents of children with HVMs and how they cope with the uncertainty of the illness experience.

Uncertainty and Communication Theory

Uncertainty is a concept frequently studied by communication scholars because it influences everything from interpersonal relationships, cross-cultural encounters, socialization in organizations, and coping with illness and stress (Brashers et al., 2000). It exists when a situation is “ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general” (Brashers, 2001, p. 478). Most people agree that uncertainty is embedded in everyday life and that our lives are full of unforeseeable possibilities, but most people also tend to live life as if it were ordered and predictable. This causes the unexpected to challenge basic human assumptions and can force individuals to shift their expectations, goals, values, and beliefs (Cohen, 1993). While uncertainty may appear to be a psychological state of mind, it deserves attention from communication scholars because communication is the way uncertainty is both produced and managed (Berger, 1987; Brashers et al., 2000).

Over sixty years ago, Shannon and Weaver (1949) suggested that uncertainty is a negative feeling and the more information a person receives about any issue or situation, the less uncertainty s/he will experience. Berger and Calabrese (1975) agreed that humans have a basic desire to reduce uncertainty in order to increase the level of predictability in situations, especially in initial interactions. In their uncertainty reduction theory (URT), they propose that the central premise to addressing uncertainty is to reduce
uncertainty about a situation, about others, about relationships, and even about the self. Several years later, Berger (1986) explained that uncertainty reduction theory can apply to many interpersonal interactions beyond personal relationships and initial exposure to certain situations. Clatterbuck (1978) claims that uncertainty can only be reduced if the information received is perceived as adequate for decision-making purposes during the interaction. The quantity of information received is not necessarily predictive of uncertainty reduction as much as the quality of the information and whether or not it is understood by the recipient (Sheer & Cline, 1995).

Berger and Calabrese (1975) proposed that when individuals enter a new situation, they take one of three routes, passive, active, or interactive, when attempting to reduce uncertainty about an interaction. Some people may reduce the uncertainty _passively_ by observing the situation to gain more information. Individuals who use this strategy choose to use simple observation in order to develop expectations, make predictions, and identify cues that reduce uncertainty. Another route used to reduce uncertainty is communicating to _actively_ ask others about the target person or situation to gain more information. This strategy still does not involve direct interaction, but seeks out the help of someone who is familiar with the target situation or person in question. This person provides their knowledge and expectations to help reduce uncertainty. Finally, according to the theory, the most direct route to reducing uncertainty is communicating _interactively_. Individuals using this strategy reduce uncertainty by directly interrogating the other person or using reciprocal self-disclosure in the situation.
According to URT, successful uncertainty reduction occurs when enough information is acquired to increase one's ability to predict and explain the situation or other's behavior. 

A common assumption in earlier studies on uncertainty is that uncertainty is always a negative state and must be reduced. However, recent studies have begun to challenge this assumption and suggest that “no object of thought is inherently good or bad; all objects, including uncertainty itself, must be evaluated” (Babrow, 2001, p. 562). Some researchers would even argue that a level of uncertainty may actually be functional in many situations because predictability can be perceived as boring, especially in many interpersonal relationships (Berger & Gudykunst, 1991). It also may be beneficial in situations of decision making or planning when the uncertainty allows an individual to maintain hope or optimism (Brashers, 2001). Another similar misconception of uncertainty is that information seeking is the most successful way to adapt to uncertainty. While more information could provide clarity, it is possible that adequate or relevant information may not be available, now or ever. So it would be more advantageous for an individual to avoid seeking inadequate information. More information may also increase uncertainty by increasing the amount of alternatives or suggesting negative or unwanted outcomes, so it may not be the best way for an individual to manage uncertainty (Brashers & Babrow, 1996). Most communication research has focused on how to cope with insufficient information more than it has focused on the ability to cope with a potential “information overload” (Babrow & Matthias, 2009).

Brashers et al. (2000) challenged the idea of a purely reductionist perspective of uncertainty and developed a Communicative Management of Uncertainty Theory
(CMUT) which proposes that individuals do not always perceive uncertainty as negative, and may communicate in different ways to manage their uncertainty. They found that individuals may not always wish to reduce uncertainty, but rather they seek coherence, or stability, in their lives, even if it means living with uncertainty. When an individual experiences uncertainty, they appraise the uncertainty using emotional responses to determine its potential for harm or benefit. For example, uncertainty may elicit a positive emotional response of excitement or hope, or a negative response of insecurity or anxiety. The valence of the appraisal then determines the way in which the individual manages the uncertainty. If the uncertainty is seen as a danger, an individual may choose to communicate to seek information (Hogan & Brashers, 2009). Seeking information may reduce uncertainty by clarifying alternatives. However, seeking information also has the potential to amplify uncertainty by increasing the number of possible alternatives or challenge existing beliefs (Brashers et al., 2000). If uncertainty is seen as an opportunity, or a way to maintain hope and optimism, the individual may choose to avoid information to maintain uncertainty or seek conflicting information that increases uncertainty (Hogan & Brashers, 2009). For some cases of uncertainty, the management process may involve an individual accepting and adapting to chronic uncertainty through continued reappraisal in managing the ebb and flow of a chronic illness (Brashers et al., 2000). This uncertainty management approach was developed out of research on individual’s living with HIV/AIDS where although the illness is terminal and involves pain, discomfort, and uncertainty, the uncertainty was not always thought to be a negative experience. The
individuals chose to use communication to manage their uncertainty in a variety of ways depending on their own evaluation of how the uncertainty influenced their life.

Problematic Integration (PI) Theory (Babrow, 2001) also recognizes that uncertainty is not a static concept to those experiencing it, but argues that it is situational. The theory suggests that people’s expectations when encountering a new situation or meeting a new person are comprised of both a probabilistic orientation and an evaluative orientation. The probabilistic orientation is grounded in a basic understanding of the surroundings, a belief, or an expectation (Hines, Babrow, Badzek, & Moss, 1997). These expectations are essentially definitions and perceived similarities used to make sense of the world and are said to be “probabilistic” because they have a level of certainty or probability (Babrow & Matthias, 2008) developed through social norms, scripts, and past experiences. The probabilistic orientation is developed through questions such as ‘What may have caused this?’ 'How are they likely to behave?' 'What should the outcome be?' and 'What are the situation’s or person’s characteristics?' These probabilistic orientations are often taken-for-granted associations that are made throughout the day with little conscious awareness (Babrow, 2001). For example, the expectations associated with going to the physician—including arriving at the physician’s office, waiting in the waiting room, seeing the physician, getting a prescription, and leaving—are fairly taken-for-granted in routine physician visits and serve as guides to action and expectations without much effort. However, when the situation is less routine and predictable, the probabilistic orientations also have the potential to be characterized by uncertainty. For example, when an individual learns a family member is dying of cancer, he or she might
begin to question how fast the cancer will progress, if the cancer is hereditary, if the chronic headaches he or she is also experiencing might be cancer, and many other orientations that are not ingrained in one’s normal routine. These orientations are characterized by uncertainty and an inability to make certain probabilistic integrations in the situation.

In addition to the probabilistic orientation, people also develop an evaluative orientation, or an overall sense of goodness or badness about a situation or person (Hines et al., 1997). A basic knowledge of the expected outcomes is not enough to make sense of one’s surroundings. An individual must also evaluate the value associated with those outcomes (Babrow & Matthias, 2008). This evaluative orientation is grounded in one’s response to questions like 'Is this event or object good or bad?' and 'Will the outcome be good or bad?' This evaluative component allows the individual to identify the value of the event or object, and combined with the probabilistic orientation, this guides the actions, feelings, and thoughts of the individual (Babrow, 2001). However, a primary component of PI theory is that the integration of the probabilistic and evaluative orientations can be problematic.

The probabilistic judgments and value judgments are interdependent and mutually influence each other (Babrow & Matthias, 2008). Because of this interdependence, an individual trying to integrate both orientations may be faced with a difficult task. For example, one’s expectations and desires may conflict, or a degree of ambiguity may interfere, with an individual’s ability to realize what is desired or to avoid what is unwanted. Additionally, ambivalent feelings can hinder one’s ability to make a decision
or even destabilize the evaluative orientation (Hines et al., 1997). These dilemmas are referred to as problematic integrations (Babrow, 1992). PI theory identifies four main types of problematic integrations that can occur and produce uncertainty. First, probabilities and values may diverge causing frustration, disappointment, or anxiety. Next, a situation may result in ambiguity or unclear probabilities and values. These situations may imply multiple meanings or uncertain outcomes. Third, probabilities and values may be mutually exclusive, resulting in ambivalent situations with the potential for equally attractive or unattractive alternatives. Finally, a situation may be perceived as altogether impossible where probabilities and values seem out of reach or unlikely.

Overall, these problematic integrations occur when probabilities and values weaken each other and threaten or question existing orientations such as existing beliefs, values, and behaviors (Babrow, 2001).

Illness is one specific phenomenon that is characterized by a series of interwoven problematic integrations. Patients are dealing with symptoms, diagnosis, prognosis, and treatment where the level of ambiguity, ambivalence, and unknown expectations are prevalent (Hines et al., 1997) and because expectations play a significant role in illness experiences (Babrow, Kasch, & Ford, 1998), illness uncertainty is common. PI theory explains that these interwoven problematic integrations are common because problematic integrations create a link where one problematic integration develops from a previous dilemma, but may also lead to new problematic integrations (Babrow, 2001). In other words, answering one question about an illness often introduces a flow of new questions (Babrow & Dutta-Bergman, 2003). PI uses this concept to illustrate that uncertainty
cannot be isolated or taken out of context but exists in relation to other dilemmas. Furthermore, communication does not only manage or reduce uncertainty, but uncertainty exists within the communication of a given situation. This perspective stresses the idea that problematic integrations have a “fundamental interdependence” (Babrow 2001, p. 562) with other uncertainties and dilemmas, and researchers must take these linkages into consideration when studying uncertainty.

**Uncertainty in Illness**

Illness uncertainty has received increased attention from scholars over the past few decades. In 1988, Mishel studied illness uncertainty in individual’s dealing with acute illnesses. She defined *illness uncertainty* as the “inability to determine the meaning of illness-related events” (Mishel, 1988, p. 225). It also is considered “the inability to form a cognitive schema” (Babrow et al., 1998, p. 8). Mishel proposed that an individual who is diagnosed with an illness (or looking for a diagnosis) struggles to categorize certain events, which inhibits the ability to predict outcomes and assign value to situations (Babrow et al., 1998). Mishel (1988) identified uncertainty as being a product of many factors of an illness including severity, diagnostic specificity, personality traits, social support (available and provided), physician-patient relationships, and even demographics. Researchers have identified that the uncertainty can simultaneously be medical, social, and personal (Brashers et al., 2003), and Mishel (1988) identified four types of uncertainty in her Uncertainty in Illness Theory (UIT).

The first type of uncertainty is “ambiguity concerning the state of the illness” (Mishel, 1988, p. 255). Ambiguity is a component associated with all types of
uncertainty because all of the information available is not always interpreted the same depending on past experiences of each individual (Sheer & Cline, 1995). Illnesses are interpreted in multiple ways—not only by the person experiencing the illness, but also by family, friends, coworkers, and especially health care providers. All of these people collectively co-construct the meaning of an illness and the meaning can be unclear or may change frequently. Furthermore, people view illness in many different ways. Some perceive it as a punishment, a sign of weakness or failure, while others may find it liberating or opportunistic, and medical professionals may see it as a challenge to solve or an area for knowledge and growth (Babrow et al., 1998). For example, someone experiencing an illness may treat it as an opportunity to assess the value of life, but a spouse or partner may view it as a punishment, and these conflicting experiences can contribute significantly to illness uncertainty.

The second form of illness uncertainty is “complexity regarding treatment and the system of care” (Mishel, 1988, p. 255). Complexity contributes to uncertainty because it can challenge a person’s understanding of the illness, but it also can challenge one’s self-control or composure because it may lead to many frustrations. The most common complexity associated with illness uncertainty is multicausality—or an illness that is caused by, affects, and involves a large number of factors. The multilayered definition of many diseases can make it difficult for an individual to understand the illness and the available treatment options (Babrow et al., 1998).

The third form of illness uncertainty identified by Mishel (1988) is rooted in the “lack of information about the diagnosis and seriousness of the illness” (p. 255).
Sometimes an individual may not seek complete information or a physician may not provide complete information during the medical interview. Information may also be incomplete because the desired information is unknown. Many illnesses are still relatively unknown and the progression of the illness is not clear (Sheer & Cline, 1995). It is also possible that there is a lack of consistent information. When an individual is exposed to inconsistent information it can also increase uncertainty (Babrow et al., 1998). This leads to the final form of illness uncertainty which is “unpredictability of the course of the disease and prognosis” (Mishel, 1988, p. 225) which often stems from the first three types of uncertainty. When attempting to make sense of the illness, patients often experience uncertainty because the ambiguous, complex, and potentially incomplete information available does not provide sufficient cues to predict the course of the illness or assign correct meaning to the situation (Mishel, 1990).

As Mishel’s Uncertainty in Illness Theory illustrates, uncertainty may stem from concerns about the reliability, validity, and sufficiency of the available information (Babrow, Hines, & Kasch, 2000) and the ability to predict and make sense of the situation (Mishel, 1988). Uncertainty does not develop as a result of only one of these factors, but individual’s experiencing illness often deal with multiple and interrelated uncertainties (Hines, 2001), and as PI theory suggests, the integration of these multiple orientations and evaluations can be problematic. Illness uncertainty is also complicated by the co-construction of uncertainty by the patient, their family and friends, and health care professionals providing care. It is not an isolated experience for the patient alone, but a co-constructed, symbolic experience. In order for the uncertainty to be managed
appropriately, patients, family, friends, and health care professionals all must understand
the uncertainty that is associated with the illness experience and recognize the
complexities involved in the future of the illness, the possible treatments, and the
competing emotions and goals associated with illness (Babrow et al., 1998).

For individuals experiencing severe or chronic illnesses where treatment is
complex and the prognosis may be unclear or unavailable, uncertainty also becomes
chronic (Mishel, 1988). Just as the patient must manage their condition, they must also
manage the ebb and flow of uncertainty over the course of the illness (Brashers et al.,
2003). In addition to acute illnesses, patients dealing with conditions that are unknown or
do not have a clear treatment path, also find themselves in a difficult position because
decision-making becomes more stressful with the more ambiguity and uncertainty that
surrounds the condition (Cegala et al., 2008). For example, individuals born with
hemangiomas and vascular malformations face a great deal of confusion because one
uniform set of terminology does not exist to describe or diagnose the condition (Rieu &
Festen, 1996). They are also a challenge for physicians because each case appears
different and often involves other parts of the human body as well. One study found that
most physicians are willing to treat uncomplicated birthmarks, such as port-wine stains,
but they are less willing to treat and even diagnosis the rarer and more complicated
HVMs they see (Mathes, Haggstrom, Dowd, Hoffman, & Frieden, 2004). These complex
HVMs require care from physicians from multiple disciplines to diagnose and manage
the malformation (O’Regan et al., 2007). The most frequent specialists who treat these
conditions are dermatologists, vascular and plastic surgeons, radiologists, and
otolaryngologists (ear nose and throat physicians). The multidisciplinary nature of HVMs means that they do not fit neatly into any one traditional specialty. Because of this, patients risk being misdiagnosed or even mismanaged if the right team of physicians is not consulted (Mathes et al., 2004).

Another case where uncertainty is prevalent is in the parents of children who are ill or suffering from a disease or chronic illness. Uncertainty stems from the parents desire “to know that which is unknowable about their child’s future” (Santacroce, 2001). The uncertainty is highest during the diagnosis of the illness. Parents may experience severe anxiety over the uncertainty of the severity of the illness, the potential prognosis, and the unpredictability of the illness and its outcomes (Clarke-Steffen, 1993). Uncertainty also manifests in a fear of the pain the child may endure and the possibility of death (Binger, Albin, Feurstein, Kushner, Zoger & Mikkelsen, 1969). Parents typically experience uncertainty because they are not able to use previously established cognitive schema to make sense of the illness (Stewart & Mishel, 2000). When the parents assign meaning to the illness, they often do so negatively because of the perceived threat to the health of the child (Hoff, Mullins, Gillaspy, Page, Van Pelt, Chaney, 2005).

Because parental uncertainty often leads to sleepless nights and an inability to focus on daily activities, the family life is generally affected in a negative way (Clarke-Steffen, 1993). Long-term uncertainty associated with chronic illness can also cause high levels of stress in parents which hinders their ability to effectively monitor their child’s health (Santacroce, 1993). When a child’s symptoms change daily, it can be stressful for
the parents to maintain a normal routine and allow the child to grow up with normal milestones (Dodgson, Garwick, Blozis, Patterson, Bennet, & Blum, 2000). It also can negatively impact the parent’s ability to assist the child in transitioning to self-management of the condition. Some parents may also feel isolated by the burden and stigma manifested in caring for a child with an illness (Santacroe, 1993). Helping relieve parents of uncertainty can help them alleviate their distress and help them learn to live with the condition (Santacroe, 2001). This may also be beneficial for the health of the child with the illness and other members of the family (Santacroe, 1993).

Patients and parents depend on several sources to help them cope with their illness and manage the uncertainty they are experiencing. A patient frequently seeks support from physicians, family members, and other patients to learn more about the illness and how to cope with it. Resources such as the Internet and medical journals are also consulted. Overall, patients use basic coping strategies of information seeking or information avoiding based on the way in which the uncertainty is evaluated by the patient (Brashers, Hsieh, Neidig, & Reynolds, 2006). Because some patients do not wish to reduce their uncertainty about their illness (Mishel, 1990), Communicative Management of Uncertainty Theory (CMUT) (Brashers et al., 2000) is especially relevant in medical settings.

In developing CMUT (Brashers et al., 2000), the researchers examined how individuals living with HIV/AIDS appraise and manage their uncertainty using or avoiding information that is available. The study found that when illness uncertainty is appraised as a danger through emotions of fear or anxiety, patients may actively seek
information by going to the available resources to find information (e.g., Internet, physicians). Some may seek information passively by exposing themselves indirectly to information by attending support groups or making friends with others experiencing the same illness. When the illness is appraised as an opportunity because it leads to feelings of hope or optimism, some patients choose to avoid information to maintain uncertainty. They often avoided getting certain tests done to avoid confirming results of infection. Others may avoid attending support groups where others share their negative experiences with the illness or discuss the loss of loved ones. Others who appraised the uncertainty as opportunistic may seek information in order to increase their uncertainty adding alternatives and increasing uncertainty, but this is viewed as an opportunity. Finally, some individuals came to the decision that their uncertainty was simply a chronic condition. These individuals had the task of adapting to their uncertainty and considering it “a fact of life” (Brashers et al., 2006, p. 221). They did this by learning to live with both the negative and positive elements of uncertainty and focus on day-to-day activities rather than relieving or increasing uncertainties (Brashers et al., 2000). By reappraising the uncertainty, individuals can resolve any negative emotions (Babrow, 2001) and turn the uncertainty into an opportunity or view it as a test of character or an opportunity for self-exploration (Babrow, 1992). Brashers and colleagues propose all of these as possible options for managing uncertainty through communication behaviors.

In summary, illness uncertainty is a complex phenomenon that is frequent in almost any illness, regardless of its severity. The uncertainty for parents and patients diagnosed with hemangiomas and vascular malformations is extremely complex due to
the interwoven problematic integrations, incomplete information available, and multidisciplinary nature of the illness. To explore the uncertainty of parents of children with HVMs present in a multidisciplinary clinic, the following research questions are posed:

RQ1: What areas of uncertainty are most frequently reported by parents of children with hemangiomas and vascular malformations (HVMs)?

RQ2: How do parents of children with HVMs manage their uncertainty about their child’s condition?

RQ3: How knowledgeable do parents of children with HVMs feel about their child’s condition?

Physician-Patient Communication

Physician-patient relationships are unique relationships and deserve specific attention from communication scholars because of their complexity and importance in the lives of patients. Although there are many resources for individual’s to find information about illness, the interpersonal exchange between physician and patient is still the preferred and most adequate form of addressing illness concerns (Blanquicett, Amsbary, Mills, & Powell, 2007) and the conversation with the physician is often viewed as one of the most important tools in managing uncertainty (Brashers et al., 2006).

Physician-patient relationships are different from other interpersonal relationships for four distinct reasons. First, physician-patient relationships are usually not voluntary (Ong, DeHaes, Hoos, & Lammes, 1995). They occur because of some health-related event or situation that forces the patient to seek the advice or assistance of an expert.
Therefore, they include an inherent power dynamic (expert/non-expert) and are often paternalistic based in the traditional medial model. Because physicians provide patients with information that they need and prescribe treatments they may not have access to otherwise (Beisecker, 1990), they possess all six of French and Raven's (1959) bases of power--reward, coercive legitimate, expert, referent, and informational--during the medical interview. This can influence the physician-patient relationship and the communication that takes place during the consultation. As a result, physician-patient interactions often are seen as a one-down interpersonal relationship (Beisecker, 1990). One-down relationships are characterized by roles of dominance and submission where the person in control has the power to determine the actions of the relationship (Millar & Rogers, 1976). These power implications associated with the physician-patient relationship may increase both illness and relational uncertainty experienced by patients.

In addition to power structures, the physician-patient relationship revolves around issues that are important to the health and well-being of the patient. The issues often are complicated and may involve high levels of emotion and uncertainty due to the impact illness can have on one’s life (Ong et al., 1995). When the issues being discussed impact the life of the patient, it seems obvious that communication is critical, and researchers must take this in to consideration when studying the medical interview and its influence on uncertainty.

Another important aspect to consider in physician-patient relationships is the vastly different experiences and comfort levels that physicians and patients have in the health care environment (Ong et al., 1995; Cegala, McNeilis, McGee, & Jonas, 1995).
Physicians, nurses, and other health care professionals are familiar with the health care environment because it is where they work and develop their technical skills. They are rewarded for obtaining highly specialized knowledge and must see many patients during the work week. Physicians feel comfortable in the medical environment, but “what is routine for the medical staff is often a crisis for the patient” (Cegala et al., 1995, p. 181). Patients have a very different perception of the medical environment in comparison to physicians and other health care professionals. A hospital or clinic setting is less familiar to most patients. In some cases, patients lack basic knowledge of the health care system. Patients also may lack understanding of the terminology needed to adequately describe their symptoms to the health care professionals. Furthermore, in the midst of trying to adapt to an unfamiliar setting, patients also often are suffering from physical and emotional discomfort and illness related uncertainty (Cegala et al., 1995). The difference between the physicians’ and patients’ comfort level in the health care environment also adds to the power dynamics of the medical interview and because they are systemic differences, as such they may be hard to change. Therefore, it is important for communication scholars to study the physician-patient relationships more in-depth because effective communication can have an important impact on the healthcare of patients (Blanquicett et al., 2007).

The three primary functions of the medical interview, regardless of whether it is the first visit or returning visit, (1) are developing an interpersonal relationship between the physician and patient, (2) exchanging information about the patient’s illness, and (3) making decisions about treatment (Ong et al., 1995). The communication that takes place
during the medical interview is crucial because it is the way in which physicians and patients complete these functions by exchanging information in order to build a relationship to make decisions (Street & Millay, 2001). An effective physician-patient interaction can have significant impact “on the patients’ behavior, well-being, adherence to treatment, recall and understanding of medical information, quality of life, level of anxiety, and outcome” (Blanquicett et al., 2007, p. 423). Additionally, the relationship between the physician and the patient can be considered a form of social support. Outside of the medical diagnosis and treatment, physician behaviors can help to reinforce patients’ self-confidence or positive outlook about their health, which may also positively influence the health outcomes (Kaplan, Greenfield, & Ware, 1989).

The relationship between a physician and a patient can be an important element in the patient’s ability to manage uncertainty associated with illness (Brashers et al., 2006). A physician can help patients appraise their uncertainty by discussing overall implications of the illness (Brashers et al., 2006; Mishel, 1988). For example, the illness may not be as threatening as the patient perceives. A physician can educate the patient and help to reappraise the uncertainty as more positive than before. Once the illness has been appraised, the physician can either provide information to a patient who is seeking more information or withhold information from a patient who clearly wishes to avoid information. What this suggests is that the ability for patients to manage their uncertainty depends on the patients expectations being met during the medical interview because a violation of expectations can lead to more uncertainty in patients (Mishel, 1988).
Unfortunately, unmet expectations seem to be one of the primary sources of misunderstanding in the medical interview (Mishel, 1988). While the exchange of information is the primary goal for both the physician and the patient, there also is the potential for confusion and misunderstanding in the medical interview (Cegala, 2006a). Patients and physicians tend to have different expectations about the medical interview which can lead to a great deal of uncertainty and miscommunication (Blanquicett et al., 2007). For example, research has consistently indicated that patients have a high desire for information in the medical interview (Beisecker & Beisecker, 1990; Waitzkin, 1984), but they are often hesitant to ask for information and actually contribute very little to the conversation (Harrington, Noble, & Newman, 2004). Patients very rarely meta-communicate about their communicative goals during the medical interview, and may not understand their goals, so physicians are not likely to meet those expectations without input (Brashers et al., 2006). This passivity leads many physicians to perceive a low desire for information, so they tend to underestimate the patients’ needs (Sheer & Cline, 1995).

On the other hand, it is very difficult for physicians to gauge the needs of patients because expectations regarding the medical interview are different person to person. Factors such as age and education can influence a patient’s needs (Street, 1990). Frequently, physicians tend to assume that a patient who does not ask questions does not desire additional information (Beisecker, 1990). Also, it is common for physicians to overestimate the amount of information s/he actually provides to a patient, and many physicians overestimate the medical knowledge of patients (Cegala, Gade, Broz, &
McClure, 2004; Cegala, 1997). It has also been found that physicians may try to control a patient’s uncertainty by not revealing uncertain information or to obscure any cues of uncertainty (Brashers et al., 2006). Physicians are socialized in the medical culture “to believe that patients do not want to be fully informed about the limits of medical knowledge” (p. 12), and that the emotional responses to the disclosure of uncertainty are not appropriate for the medical interview. These false assumptions lead to less elaboration or clarification of information and a less than adequate exchange of information overall. These problematic conversations can lead to more uncertainty due to the misperceptions about the amount of information desired and the actual amount of information exchanged (Cegala, McNeilis, McGee, & Jonas, 1995). These unmet expectations can cause the patient to feel uncertain about the illness after leaving the physician’s office (Blanquicett et al., 2007) because of the ambiguity and ambivalence experienced during the medical interview. These problems found in the physician-patient conversation should be addressed because research has indicated that patients are generally more satisfied with their medical experience, and even experience less health problems, when their desire for information is fulfilled during the medical interview (Haskard et al., 2008).

The problems associated with interactions between physicians and patients can be further explored by understanding the elements of the traditional physician-patient medical conversation. Most communication scholars who have studied physician-patient communication agree that there are two dominant forms of communication during the medical interview – information exchange and relational communication (Cegala,
McGee, & McNeilis, 1996; Ong et al., 1995; see also Watzlavick, Beavin, & Jackson, 1967, for a discussion of report and command functions in Communication). Information exchange refers to the information about symptoms, diagnosis, prognosis, treatment, and other medical topics, while relational communication consists of communication cues that establish the interpersonal relationship between the physician and the patient (e.g., cues of power, status, expertise, decision-making control, etc.). A physician who is relationally competent is seen as caring, concerned, and trustworthy. Both elements of the medical interview influence illness uncertainty for patients.

**Relational Communication**

Recent communication research has focused on the interpersonal relationship between physicians and patients, especially both parties’ efforts to convey care and respect for the other. Relational messages often provide emotional support, build rapport, and confirm the messages of the other person (Bensing, 1991; Suchman & Matthews, 1988). In one study (Cegala et al., 1996), physicians defined competent relational communication as an ability to establish a friendly and trusting environment, the extent to which they displayed care and concern for the patient, demonstrated sympathy, and were responsive to the needs of the patients. The patients in the same study defined relational competence as open, friendly communication, showing genuine care and interest in the patient’s problem, and providing emotional support and confirmation. An interesting finding of this study was that neither the physicians nor the patients provided any descriptions of competent relational communication on the part of the patient. This highlights that both physicians and patients put the responsibility of establishing positive
relational communication in the hands of the physician – possibly because of the inherent power that exists in the physician-patient relationship.

Relational communication behaviors tend to occur during non-medical talk during the medical interview and several studies found that they do not occur very frequently (Cegala, 1997). However, when they do occur, they carry a great deal of significance for the physician (Roter, 1989). A physician who is deemed relationally competent often has patients who are more satisfied with the communication. For example, in pediatrics, parents placed a great deal of value on messages of support and sensitivity from the physician, not only for their own concerns but also the needs of their ill child (Street, 1991). Furthermore, one study (Street, Gordon, Ward, Krupat, & Kravitz, 2005) found that patients are more likely to participate actively in the conversation when the physician used more supportive and partnership-building talk. The same study found that female physicians used more relational communication than did male physicians and physicians in general tended to use more supportive communication with white patients.

Patients who are unsatisfied with their physician’s relational communication often blame it on insensitivity, inability to participate in decision making, a lack of expressed empathy, and a misinterpretation of needs (Kreps, 1988). A lack of relational communication threatens the patients trust, loyalty, and respect for the physician as well as a general distrust in the health care system (Cegala et al, 1996). Research on relational communication in physician-patient literature emphasizes that the relational uncertainty patients may experience about the actual visit with the physician, not about the illness, also influences the broader illness uncertainty. This uncertainty can stem from the social
power distance experienced by patient and physicians or from a concern about how to interact with the physician during the conversation (Waitzkin, 1984).

While there is some evidence that physicians’ relational communication is correlated with patient satisfaction (Roter, Hall, & Katz, 1988), more recent research has indicated that both patients and physicians place more value on effective information exchange as a more competent communication behavior than relational rapport (Cegala et al., 1996). For example, both physicians and patients believe a competent patient is one who is well-prepared for the consultation, is well informed about his or her condition and symptoms, provides detailed descriptions about the condition, and seeks information when needed (Cegala et al., 2004). Yet, many patients are unable to enact these expectations in an actual medical interview. In regards to the physician, it is possible that a physician who provides adequate and personal information may be perceived as more caring and have more satisfied patients than a physician who is nice and caring, but does not provide sufficient information (Cegala, 1997).

**Information Exchange**

While we live in a society where patients can find an abundance of information via the Internet, interpersonal communication with a physician is still the most commonly used method for patients with medical concerns to gain medical information (Blanquicett et al., 2007). The information that physicians provide patients plays a crucial role in the patient’s ability to deal with both the uncertainty of the illness and the actual illness itself (Brashers et al., 2006). Some scholars even argue that a successful exchange of information during the medical consultation can have as positive an influence on a
patient’s medical condition as the prescription of drugs or procedures because of the impact on regimen adherence (Street, 1991, as cited in Blanquicett et al., 2007). Effective communication also influences the patient's understanding and recall of information exchanged during the consultation (McGee & Cegala, 1998). Although communication seems positive and helpful, several studies have shown that “communication failures among physicians are a leading cause of preventable disability or death […]” (Frank & Lawless, 2005, p. 68). A successful medical interview involves the physician and patient exchanging information about the patient’s medical history, symptoms the patient is experiencing, the physician’s diagnosis of the condition, and future visits and treatment options that the patient and physician come to agreement on (Cegala, 2006a). But expectations of both the physician and the patient often cause misunderstanding and miscommunication about these areas.

The traditional information exchange of a medical interview occurs in three separate phases. The interview begins with (1) the history-taking portion, moves to (2) the physical examination, and ends with (3) the post-examination conversation where diagnosis and treatment options are discussed (Cegala, 1997). During each phase of the interview, the physician and patient have different goals which influence the role they play in the information-exchange process. One important aspect of the medical interview that often is misunderstood by patients is that the physician and patient act as both information seeker and information provider over the course of the visit (McGee & Cegala, 1998). What is important for patients to understand is that they need to take on an active communication role and act as both information provider and information
receiver in the exchange. This is important because the patient cannot receive the information s/he desires without first providing information to the physician (Sheer & Cline, 1995), but the patient should also seek information in order to gain a better understanding of the illness and treatment options. Therefore, the communication roles have been found to switch halfway through the medical interview (Cegala, 1997).

While the structure of the medical interview appears simple and is often taken for granted, research has continued to find that the information exchange during the medical interview often is problematic (Cegala, 2006a). One of the most consistent findings in physician-patient communication research is that physicians provide more information to some patients than they do to others (Street, 1991). Generally, patients who are middle to upper class suffering from more severe illnesses receive the most information in the medical interview (Beisecker & Beisecker, 1990). Additionally, the information given to patients is not always tailored to their individual needs. For example, in one recent study, participants reported that they had remaining unresolved issues or unanswered questions after the medical consultation (Blanquicett et al., 2007). It also seems there is very little effort made to ensure patients accurately understand the information (Shaw, Ibrahim, Reid, Ussher, & Rowlands, 2009). When the patient and physician have different perceptions about information exchange it can lead to misunderstandings and uncertainty (Cegala et al., 1995).

Health literacy is another factor that can cause misunderstanding during the information exchange during a medical interview. Health literacy is considered the ability to access and understand basic health information needed to make decisions about
health care and treatments (Shaw et al., 2009). Unfortunately, even average literacy levels achieved with a high school education do not adequately prepare a patient for a conversation with a physician because literacy is not synonymous with health literacy (Blanquicett et al., 2007). Most Americans read at an eight-grade reading level, but medical and health information is often written at a tenth-grade reading level or higher (Safeer & Keneen, 2005). To make the problem worse, physicians tend to overestimate the health knowledge of patients (Cegala et al., 1997) and do not make the effort to clarify patients’ understanding using information verifying (Cegala et al., 2004). Previous research has indicated that a more informed patient is more likely to participate in an effective information exchange with a physician (Cegala et al., 2008). However, Blanquicett et al., (2007) argue that improving health literacy requires basic medical knowledge, including basic medical terminology, and also requires initiative/motivation. If the medical interview can be improved, it is possible that health literacy problems could be reduced and the information exchange in the medical interview will be more effective and specific.

In order to better understand the complex information exchange during the medical consultation, it is important to understand the three primary methods of effective information exchange – information-seeking, information-giving, and information-verifying (Cegala, McGee, & McNeilis, 1996). All three components are performed by both the physician and the patient in the medical interview in order to gain information about history and symptoms and to make decisions about diagnosis and treatment (Cegala, 1997).
Information Seeking

Information-seeking is any communication attempt to gain more information by either party (Cegala, 1997). This behavior occurs most frequently through question asking. However, not all information-seeking attempts are direct. Patients often use indirect, or “embedded” (Cegala, 1997, p. 170) questions. These are indirect questions that occur in the form of a statement and are often made by patients who are reluctant to ask a direct question (McGee & Cegala, 1998). McGee and Cegala (1998) provide the example:

A patient might say, ‘I think I’m always tired because I sleep in so late.’ In this instance, the patient is actually asking the physician if sleeping in late could cause his problems with feeling tired, even though the utterance is in the form of a declarative statement. (p. 415)

The way in which a question is formed influences the response that is developed (Roter & Frankel, 1992) and research has found that it also is related to elements of power and control located in the medical interview (Cegala, 1997). For example, physicians tend to use more direct questions, but patients frequently use embedded questions, which are more protected and less vulnerable as a defense against seeming ignorant to the physician who has more power and knowledge (McGee & Cegala, 1998).

The questions used during the medical interview are a tool for seeking information about many different topics including the diagnosis, treatment, and prognosis (Cegala, 2006a). Therefore, in addition to questions being categorized by different formats, they also can be categorized by the type. Illness questions relate to the
diagnosis, prognosis, or etiology of the illness. *Treatment regimen questions* ask about medications, diet, or lifestyle changes. Questions that ask specifically about tests or procedures can be labeled as *medical procedure questions*, and *non-medical questions* focus on billing, clinical processes, or other issues not related to personal medical conditions (McGee & Cegala, 1998). Each type of question is important in the information exchange process to achieve a better understanding of the condition and treatment.

During the medical interview, physicians engage in more information seeking-behaviors than do patients (Beisecker & Beisecker, 1990). Physicians perform 91% of the question asking and frequently use closed questions (Cegala, 1997; Street, 1991). Even though patients tend to claim they want as much information as possible from the medical interview (Beisecker & Beisecker 1990; Street, 1991), they engage in much less information-seeking behaviors, and when they do seek information, they do so in an indirect way with embedded questions (Cegala, 1997). Additionally, some patients may not seek information about their illness if they believe it could be upsetting (Brashers, 1995). This is one way that patients manage their uncertainty if they associate it with negative feelings (Brashers et al., 2000).

*Information Giving*

Information-giving is defined as providing the other person in the medical conversation with information (Cegala, 1997). This can be either voluntarily solicited information or a response to a direct question or statement and may be single-word answers or longer detailed descriptions. In one study, the researcher coded information-
giving behaviors as solicited answers, elaborations, unsolicited information, expansions, justifications, and explanations (Cegala, 1997). The amount and type of information given depends on a lot of characteristics. The two most important are the patients’ and physicians’ communicative styles (Street, 1991). Street’s (1991) study found that patients who ask questions, show concerns, and express opinions receive more information from physicians. Furthermore, physicians often provide more information if they sense uncertainty or anxiety in the patient. Patients who were more educated and younger also received more information than their counterparts. These factors illustrate how different the medical interview can be from patient to patient. The frequency of information-giving behaviors by physicians and patients are similar to information-seeking behaviors (Cegala, 1997). Patients respond with significantly more solicited answers over the course of the medical interview than physicians. Furthermore, physicians often provide information only when asked for it whereas patients tend to offer unsolicited information about their condition.

*Information Verifying*

Finally, information-verifying is an attempt to increase shared meaning and mutual understanding. Patients and physicians can do this through questions and restatements that clarify information in order to increase and promote understanding (Cegala, 1997). This information exchange behavior is important due to the consistent findings that misunderstandings occur frequently due to poor communication during the information exchange of the medical interview (Waitzkin, 1984). In Cegala’s (1997) study, information-verifying was coded as conditionally relevant questions, formulations,
restatements, and bracketing. Another study categorized information-verifying behaviors as repeats of information, summarizing information already provided, and clarifying questions (McGee & Cegala, 1998).

Previous research has found that patients engage in significantly lower amounts of information-verifying behaviors than physicians. Although it is important for both physicians and patients to verify the information exchanged in the medical interview, it is especially important for patients to check their understanding of their own condition (Cegala, 1997). This finding is seemingly problematic because the physician is clarifying what he or she believes the patient needs, but the patient is not providing cues as to where s/he needs more clarification. Information-verifying behaviors are a clue for physicians that the patient desires more information (McGee & Cegala, 1998). A more successful medical interview may occur if the physician provides the patient with a window to express concerns and expand on symptoms in their own words (Frederikson, 1995). If a patient summarizes or restates information provided by the physician, it may be an effective way for both the physician and patient to determine whether or not the information was understood correctly (Cegala, 1997).

Many studies have focused primarily on information-seeking and not information-verifying, but those that have, have found that information-verifying leads to the patient receiving more information during the interview, a better recall of the medical consultation, and greater satisfaction (McGee & Cegala, 1998). Although these findings are significant, more attention is needed to further understand information-verifying behaviors (Anderson & Sharpe, 1991). This research could provide great insight into
increasing the patients understanding and decreasing uncertainty. Increasing patients' skills in verifying their understanding may have a more significant impact on the medical interview than simply asking questions.

*Patient Participation and Self-Advocacy*

Historically, the physician has held much of the power in the medical interview (Beisecker, 1990), until more recently when research has focused on a shift to patient-centered care. The patient-centered care model identifies seven primary dimensions of a patient-centered medical visit including: (1) respect for patients’ values, preferences and needs, (2) coordination and integration of care, (3) information, communication, and education, (4) physical comfort, (5) emotional support and alleviation of fear and anxiety, (6) involvement of family and friends, and (7) transition and continuity (Lambert, Street, Cegala, Smith, Kurtz, & Schofield, 1997, p. 28). Overall, research on patient-centered care focuses on more participation by patients, more mutual decision-making, and stronger, more trusting relationships between patients and physicians (Lambert et al., 1997). Patient-centered care proposes that physicians take into consideration “patients’ ideas, expectations, and feelings regarding illness, and addressing their psychosocial context” (Epstein et al., as cited in Cegala & Post, 2009, p. 203). By transitioning to patient-centered care, it is possible that the traditional, paternalistic model of physician-patient interaction can be altered, and patients can feel they gain more control over their own health and healthcare decisions.

The patient-centered care model has become more prevalent as Americans are becoming more active medical consumers and have expressed a desire for more
participation in decision-making about their health (Beisecker, 1990). Research has indicated that this approach to physician-patient relationships can be beneficial for patients because physicians who demonstrate patient-centeredness are often perceived as being more trustworthy (Blanquicett, 2007). For example, one study found that patients are more satisfied when they perceive that their relationship with their physician is treated as a partnership where the patient has a relatively similar level of control in the decision making and information exchange (Anderson & Zimmerman, 1993). With an increasing focus on the role of the patient, most research suggests that enhanced patient participation in the medical interview is beneficial for the patient (Cegala, 2006a), and patients have a stronger sense of control over their health (Street & Millay, 2001).

A great deal of research has been done on improving communication in the physician-patient interview, and communication skills are now being incorporated into medical school educations (Harrington et al., 2004). However, much of the research has focused on impacting the physicians’ communication skills and few interventions have focused on the patients’ ability to be more active (Cegala, Lenzmeier, & Broz, 2003). The shift to a more patient-centered medical model (where the patient takes on the role of consumer) has increased patients' expressing their desire for information (Beisecker & Beisecker, 1993). The more informed the patient is the more active s/he is able to be in the decision-making process. More participative approaches to the medical interview have been found to lead to a more collaborative approach to decision making where the physician does not decide what is best for the patient, but rather the patient and physician come to an agreement based on both perspectives (Frederikson, 1993). Research has also
indicated that patients who are more participative in the conversation obtain more information during the interview than do less verbally active patients. Therefore, it is more likely that educated, higher income, older, and female patients may receive more information because they tend to have communicative styles that are more participative and verbal (Street, 1991).

With this research suggesting that more participation can be beneficial, researchers have begun to focus on how to promote patient self-advocacy—patient involvement in the decision-making process regarding their own health (Brashers, Haas, & Neidig, 1999). Patient self-advocacy includes three primary dimensions—increased illness education, increased interpersonal assertiveness, and a potential for mindful nonadherence (a willingness to reject treatment suggested by a physician that does not meet the patient’s needs or expectations). Overall, when patients gain better knowledge and understanding about their illness, not just information, they become better equipped to be assertive during the medical interview and also may feel more comfortable challenging the authority of the physician and taking part in health care decision making (Brashers et al., 1999). Measuring patient self-advocacy is a way in which researchers can gain a better understanding of more participative communication on behalf of the patient as our society continues to move toward more patient-centered health care (Brashers et al., 1999).

Another factor that may relate to patient participation and also impact the physician-patient relationship is health locus of control. Over the past twenty years, locus of control has been identified as a factor in predicting and explaining health-related
behaviors (Wallston & Wallston, 1981). Whether an individual believes that their own behaviors determine their health or external forces determine their health is considered a person’s health locus of control. **Health-internals** are people who possess an internal locus of control, or people who believe that their behaviors have the most significant influence on their health. **Health-externals** believe that external forces such as physicians, friends and family members, and the environment they live in influence their health (Wallston, Wallston, Kaplan, & Maides, 1976). This also influences a patient’s interaction with a physician. An individual who is highly external on the locus of control scale may appreciate the power a physician demonstrates and appreciates a physician who acts as the expert. A patient who has an internal locus of control would respond more positively to a physician who puts the responsibility to follow recommendations and improve their own health in their own hands. Finally, a patient who has a strong **Health-chance** locus of control may be the least likely to comply with physicians orders because they do not see the link between health behaviors and health outcomes (Dahnke, Garlick, & Kazoleas, 1994).

A patient who is an active participant during the medical interview can greatly influence the results of the interview (Cegala, Street, & Clinch, 2007). Patient participation is the way in which patients display self-advocacy during conversations with health care providers (Cegala, 2006b) and is a communicative function of the medical interview that “underscores the relational nature of the physician-patient dyad by emphasizing coordination of behavior and mutual influence (Street et al., 2003, as cited in Cegala, Street, & Clinch, 2007, p. 178). Research consistently shows that physicians
provide more information to high-participation versus low-participation patients (Cegala, Street, & Clinch, 2007). Patient participation during the medical interview is defined by four primary dimensions – (1) information seeking, (2) assertive utterances, (3) information provision, and (4) expression of affect (Cegala, Clinch & Gade, 2003). By using these four dimensions of participation, patients address topics that are of importance to them. High participation patients can prompt physicians to respond to those questions more directly than they may have if the patient has low participation during the interview (Cegala, 2006b). For example, if a patient explains in great detail the symptoms s/he is experiencing and also expresses concerns that a close relative also had similar symptoms and ultimately died of cancer, the physician is more likely to recognize the patient’s fear of cancer and be able to reassure the patient that s/he is not suffering from a terminal illness (Cegala, 2006b) which a physician may not routinely address with a low-participation patient who does not show any signs of concerns. This example illustrates that a physician consulting with a high-participation patient is more likely to volunteer more information about the patients’ illness including treatment options, side effects, and more detailed descriptions of the condition and treatments, than that same physician would with a low-participation patient (Cegala, 2006a; Cegala, 2006b).

In addition to getting more information from the physician, high-participation patients also provide the physician with more information in order to make a more accurate diagnosis and suggest better treatment options to the patient (Frederikson, 1995). The more information the patient provides about symptoms, daily activities, emotions
about the illness, and other concerns, the more the physician will understand how the illness is affecting the life of the patient which can better contextualize the symptoms for the physician (Cegala & Post, 2009). This also allows the physician to identify any relevant psychosocial issues, such as needed illness education, explanation, or reassurance (Cegala et al., 2007).

Communication researchers agree that interpersonal communication is bound by implicit and explicit rules that determine appropriate turn taking and response types during a conversation (Watzlawick, Beavin, & Jackson, 1967). As illustrated in the example above, these rules also apply to the medical conversation. The cues provided by the patient can influence the physician’s response and the conversation develops more in line with the patients needs (Cegala, 2006b). Results from several studies have indicated that a high-participation patient can lead the physician to “more accurately understand the patient’s goals, interests, and concerns, thus allowing the physician to better align his or her communication with the patient’s agenda” (Cegala, Street, & Clinch, 2007, p. 181) which is extremely important considering previous research claims that unmet goals and expectations during the medical interview lead to the most misunderstanding during the interview (Blanquicett et al., 2007). This active participation has been found to result in a more individualized interview and has the potential to greatly impact uncertainty. It also allows the patient to have more power in the medical interview (Cegala & Post, 2009). Therefore, training seeking to improve the medical interview should include a discussion with the patient about the differences between high-participation and low-participation patients.
In order to encourage enhanced participation, patient communication skills training has received increased attention (Cegala, 2003). While some may assume that simple education about an illness leads to more participation, research has shown that interventions can result in trained patients being more participative than untrained patients, whether well-informed or uninformed about the illness (Cegala et al., 2000). Several studies indicate that the amount of participation from a patient in the medical interview can be changed with relatively modest interventions (Anderson & Sharpe, 1991; Cegala, Lenzmeier, & Broz, 2003; Harrington et al., 2004). Accordingly, coached patients engaged in more active communication, using higher amounts of information-seeking and verifying behaviors than patients who were not trained (McGee & Cegala, 1998). A patient-centered approach is an important alternative because a considerable amount of research has shown that changing a physician’s style of communication during the medical interview is extremely challenging. A patient who provides physicians with topics that are of most importance to them help guide the physician to align with their goals and ultimately leads to a more effective communication exchange (Cegala et al., 2007).

The research on physician-patient communication, for instance, has focused almost solely on question-asking as the primary method of exerting assertiveness (Cegala et al., 1996; Street, 1992). Although some studies have shown that patients trained to ask questions actually asked more questions than non-trained patients, other research has shown no significant difference between trained and untrained patients (McGee & Cegala, 1998). While some research has found that trained patients ask more questions
than untrained, patients are still asking a relatively low number of questions during the medical interview (Cegala et al., 1996). Due to a lack of medical knowledge and overall low health literacy (Blanquicett et al., 1997), patients may not know what questions to ask or may fear that they will appear uneducated if they ask a “stupid question” (McGee & Cegala, 1998).

Only a few studies have tested information provision skills (Cegala & Lenzmeier Broz, 2003). Most other studies briefly mention information provision by suggesting the patient addresses concerns or to be sure to explain symptoms clearly to the physician, but they do not explicitly include information provision in the training materials (Cegala, 2003). More importantly, information verifying has also been briefly mentioned in some training materials, but it has been primarily defined in terms of asking clarifying questions (Harrington et al., 2004). However, Cegala et al. (2000) found that information verifying done through summarizing can be a very effective tool for patients because it allows the patient to confirm understanding by phrasing the information using comfortable language and in a way that makes sense to the individual. This behavior can lead to a better overall understanding of information and better recall after the medical consultation. Additionally, summarizing indicates a higher level of cognitive processing and understanding than asking questions. It means that the patient has processed the information well enough to “synthesize essential information” (p. 220). According to Cegala and colleagues, this illustrates the way in which trained patients have the potential to be “more cognitively and communicatively engaged” (2000, p. 220) during the medical interview than untrained patients, regardless of how informed they are.
What the research on collaborative communication between physicians and patients suggests is that patients must be more educated about their illness in order to participate in the conversation and in overall decision making (Cegala, McClure, Marinelli, Post, 2000). As the research indicates, due to low health literacy or lack of medical knowledge, patients may not have the resources or may be hesitant to ask effective questions (Blanquicett et al., 2007; McGee & Cegala, 1998). During the medical interview where both immediate understanding and future recall of information is vitally important to educate the patient, more attention should be placed on information-verifying skills (Cegala, 2003), through not only clarifying questions but also restatements and summaries. This may be a behavior that patients would be more comfortable engaging in than asking questions because it is using information already provided by the physician to gain more understanding (Harrington et al., 2004) and it may be a better tool for patients to increase their knowledge of their illness to become better educated. Furthermore, one study also indicated that an intervention focused on encouraging patients to check their understanding was more effective than simply encouraging the patients ask questions (Robinson & Whitfield, 1985).

The Physician-Parent-Child Relationship

Another factor in physician-patient communication that is relevant for this study occurs when the traditional physician-patient relationship includes a child and a parent. In pediatric medicine, communication has several distinct features and is complex for several reasons. First, the medical interview includes more than one person interacting with the physician and as a result the patient (the child) usually communicates very little
during the conversation (Nova, Vegni, & Moja, 2005). The physician may ask the child for information, but during the diagnosis stage of the medical interview, the physician most often interacts primarily with the parents or guardians (Van Dolmen, 1998). This occurs because the physician-parent-child relationship is categorized as a triad, which is inherently more complicated than the normal physician-patient dyad (Tates, Elbers, Meeuwesen, & Bensing, 2002). As a result, the physician and parent engage in conversation and exclude the child. This frequently happens because the parent represents the child in the conversation and takes the role of expert interpreter for the child's experiences (Tates & Meeuwesen, 2000). As two adults break off into a separate dyad, it becomes difficult to include all three participants in the conversation (Tates, Meeuwesen, Elbers, & Bensing, 2002). Children often have very little participation in the conversation, however, they often understand more than both the parents and physician assumes since s/he is the one living with the illness (Tates & Meeuwesen, 2001). Therefore, the child is the expert on the illness symptoms and his or her experiences are more reliable and valid than that of the parents or physicians. A great deal of research indicates that if the child is old enough to understand the illness and the symptoms, the child should be encouraged to participate in the medical interview. The contribution does not need to be equal, but it should be included (Garth, Murphy, & Reddihough, 2009). Allowing the child to tell his or her story could greatly improve the child’s medical experience and lead to better treatment options (Meeuwesen, & Kaptein, 1996).
A child with a chronic illness is involved in a physician-parent-child triad for a great portion of his or her life (Garth, Murphy, & Reddihough, 2009). Therefore, it is important for the child to learn to take control of his or her experiences with health care so when the child is older, s/he understands how to effectively interact with physicians, make health decisions, and have the overall ability to manage the illness (Tates, Elbers, Meeuwesen, & Bensing, 2002). At a young age, the child observes and is socialized by parents or guardians involved in the medical interview. A parent who has high-participation during the interview, and who also encourages participation from the child, socializes the child to be more active during the medical interview and this can carry on into adulthood (Tates, Meeuwesen, Elbers, & Bensing, 2002). Additionally, because parents are the primary agents involved in promoting the health and well-being of their children, they often provide direct care at home, take the child to see health care providers and other health services, and they also model the attitudes and behaviors that socialize their child and influence the child’s long-term health behaviors. Because they play such an important role, parents’ health locus of control may significantly impact a child’s well-being and how the parent socializes their child’s personal health locus of control (DeVellis, DeVellis, Blanchard, Klotz, Luchok, & Voyce, 1993).

In sum, uncertainty has traditionally been treated as a psychological issue associated with health (Mishel, 1988), but a communicative approach to managing uncertainty can be extremely enlightening because communication is both the source of uncertainty and the mode through which uncertainty is managed (Brashers et al., 2000). Therefore, the medical interview is a communicative context which influences the
management of uncertainty and can be either decreased, maintained, or increased depending on the communication that takes place (Brashers et al., 2000; Brashers et al., 2006). The problematic communication that occurs in many medical interviews may affect the illness uncertainty of parents and patients, so effective communication during the physician-patient interview may have the ability to lead to better physical health outcomes, adherence to treatment options, better self-management of chronic illnesses (Haskard, Williams, DiMatteo, Rosenthal, White, & Goldstein, 2008), and a stronger ability to cope with illness uncertainty (Brashers et al., 2006).

In order to explore the uncertainty that exists in the physician-parent-child relationship, and the influence of health locus of control and patient-self advocacy on uncertainty, the following research questions are posed:

RQ4: Do parents of children with HVMs have uncertainty about how to interact with the multiple physicians often involved with treatment?

RQ5: Does a relationship exist between or among illness uncertainty, relational uncertainty, disease specific health locus of control, and patient self-advocacy for parents of children with an HVM?

RQ6: Do any differences exist in illness uncertainty, relational uncertainty, disease specific locus of control, and patient self-advocacy between parents based on demographic categorizations?

METHOD

This study was conducted using a combination of participant-observation and a patient (parent) survey approach. Participant-observations and data were collected at a
multidisciplinary hemangioma and vascular malformation clinic within a large Midwestern children’s hospital.

Participants

The sample consisted of 55 parents of children with HVMs recruited to participate in the study. Participants included first time visitors and return visitors who came to the clinic by appointment. The researcher asked parents to participate in the study when they arrived and solicited informed consent at that time. Youth assent was attained if the child (patient) was between the ages of eleven and seventeen years of age.

A total of 55 questionnaires were completed and returned for analysis. The participants included 46 females (86.8%) and 7 males (13.2%) (2 participants did not indicate their gender), ranging in age from 19 – 50 (mean = 32.9 years). The respondents had either attended or completed high school (27.8%), attended or completed college (44.4%), or attended or completed graduate school (27.8%). Respondents had average incomes of below $30,000 (25.9%), between $31,000 and $75,000 (38.9%), and over $76,000 (35.2%). The gender of the children included 39 females (73.6%) and 14 males (26.4%) (range = 0-17 years).

Participant-Observation

The participant-observation was conducted over a 13-month period. The researcher visited the clinic weekly to observe physician-patient medical interviews and interactions between physicians from multiple disciplines. The clinic sees approximately twenty patients each week and up to five new patients each week. Patients are typically referred to the clinic by their pediatrician. At the clinic visit, patients are assigned a
primary physician depending on their individual needs, but also see other physicians because most HVMs require a team of multiple specialists. This clinic has physicians from hematology/oncology, dermatology, pediatric surgery, otolaryngology, and radiology.

The participant observation was a reflexive process because I have had my own personal experiences with HVMs that undoubtedly influence my observations and participation in the clinic. I was born with a venous malformation on my right neck, cheek, ear, and tongue. During my childhood, I saw several physicians, including my pediatrician, a dermatologist, and a plastic surgeon, but I did not receive a diagnosis or treatment because no physician knew exactly how to treat it. My parents and I monitored it, but I did not seek out treatment until I was in high school. My mother finally located a clinic--nearly 800-miles from our home. I visited this HVM clinic several times over the next few years and had multiple treatments including laser treatments, sclerotherapy (used to shrink the veins), and a rescission surgery that actually removed parts of the birthmark. The birthmark will never go away, but the treatment and surgery were done to maintain swelling, reduce deep pigmentation, and debulk the area. The twenty-four years I have lived with an HVM, and my parents' struggle to help find treatment, reflexively influences my observations for this study.

I served both as an observer in the clinic, and also was asked by the clinic to serve as a patient consultant to family's visiting the clinic based on my experiences of growing up with an HVM. Field notes were taken throughout my clinic participant-observations, and I also participated in a patient communication skills training intervention with
parents. Data from the training intervention portion of the study will be analyzed in a follow-up analysis. The thesis is focused on participant-observations and survey data collected. A constant comparative thematic analysis of the observations was performed (see below for a more detailed explanation of the constant comparative procedure).

Instrument

Questionnaire data was collected over a two-month period toward the end of the participant-observation. All participants were asked to complete the questionnaire in the waiting room and return it before seeing the physicians. The study utilized a 48-item questionnaire (Appendix A). A Likert-scale of 1 (strongly disagree) to 5 (strongly agree) was used in the measurement of four scales found to be valid and reliable in previous studies. The four measures included: (1) The Disease Specific Health Locus of Control Scale (Dahnke et al., 1994), which measures internal (seven items), external (five items), or chance (five items) orientations toward a health locus of control. Dahnke et al. (1994) reported reliabilities of (a) .80, .72, and .72 for the internal, external, and chance scales, respectively, for a cancer population, and (b) .80, .78, and .78 for the internal external and chance scales, respectively, for an anemia population. The reliability for the current sample was .74. (2) The Illness Uncertainty Scale used by Sheer and Cline (1995) was adapted from Mishel’s (1981) Uncertainty in Illness Scale, and a Cronbach’s alpha of .80 was reported. The reliability for the current sample was .78. (3) The Relational Uncertainty Scale was developed by Sheer and Cline (1995) to measure the uncertainty related to interacting with physicians. Sheer and Cline (1995) reported a Cronbach’s alpha of .83. The reliability for the current sample was .82. (4) The Patient Self-
Advocacy Scale was adapted from Brashers, Haas, and Neidig (1999) to reference parents rather than patients themselves. The scale is used to measure patient self-advocacy and focuses on three areas; (a) illness and treatment education, (b) assertiveness in health care interactions, and (c) potential for nonadherence with treatments. Brashers, Haas, and Neidig (1999) reported a Cronbach’s alpha of .78 in an HIV/AIDS sample, and .78 in a general population sample. The reliability of the current sample was more moderate at .63.

Data Analysis

Measurement scales were analyzed using SPSS. A correlation matrix explored the criterion validity of the scales. Two independent-sample t-tests were used to investigate group differences on the measures between parents that were new visits versus return visits, and also based on low versus high education levels. And finally, an ANVOA with post-hoc comparisons was run to explore group differences based on low, medium, and high-income levels.

In addition to the scales, open-ended questions were included at the end of the questionnaires to complement and further explore issues of uncertainty management. The open-ended responses were analyzed for themes through a process consistent with the constant comparison approach (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Open-coding was used to identify categories and sub-categories within the data. These categories were inductively derived from the data. Then, through a process of axial coding, the researcher organized the categories into themes (super-ordinate categories). These themes emerged inductively and also in line with the researcher’s knowledge of
the previous research. Sub-categories and categories were combined into larger superordinate categories until saturation occurred and no new categories emerged (Glaser & Strauss, 1967).

QUALITATIVE AND QUANTITATIVE FINDINGS

Participant Observations

Over the course of 13 months, participant-observation was conducted at the hemangioma and vascular malformation clinic. The goal of the participant-observations was to identify critical moments of uncertainty, problems during physician-patient medical interviews, and observations of the complex functioning of a multidisciplinary clinic. In addressing research question 1 ("What areas of uncertainty are most frequently reported by parents of children with hemangiomas and vascular malformations (HVMs)?"), three primary themes characterizing areas of uncertainty emerged during the observations: (1) uncertainty about the condition, (2) a lack of focus on assigning meaning to the condition, and (3) a need for increased information verifying.

Uncertainty about the Condition

A conversation that occurred with the clinic's medical director illustrated the uncertainty surrounding HVMs. She described the condition using the metaphor of an "orphan" illness (D. Adams, personal communication, October 7, 2009). Because HVMs do not fit neatly under the care of any one specialty, they receive less attention in medical education and medical research. As a result, HVMs are easily misdiagnosed by primary care physicians or mismanaged due to the complexity of coordinating multiple specialties required for care (Mathes et al., 2004).
The prevalence of misdiagnosis of HVMs is an area of large concern for both parents and physicians. The uncertainty surrounding misdiagnosis was illustrated in a family visiting the HVM clinic for the first time. The family had seen their local pediatrician and was referred to the specialty HVM clinic. Because it was the first visit, the family saw each physician on site that day--indicating a fairly long visit. As the physicians were wrapping up the conversation and preparing to leave the room, the mother indicated that they had already seen a specialist and were diagnosed with “KT Syndrome” and came to the clinic to get a second opinion. The physicians were certain the child had been misdiagnosed and explained to the parents that KT Syndrome is a different condition and their child did not have it. Unfortunately, it turned out that KT Syndrome is one of the types of vascular anomalies that their insurance company did not cover because of its side effects and potential influence on the child's future health. The insurance company dropped the coverage of the daughter because of the KT Syndrome diagnosis. The physicians were concerned that the insurance company would not reverse this decision even with a corrected diagnosis. Facing great uncertainty, the family had to begin deciding how they would appeal to the insurance company to reinstate coverage.

For this family, the more information they received, the more uncertain they became. Although receiving a second opinion and seeking more information about the condition seemed the best way to reduce uncertainty, the complexity and unfamiliarity of the condition led to conflicting diagnoses and incomplete information which can increase uncertainty by increasing the potential outcomes and reducing the ability to assign meaning to the situation (Brashers et al., 2000). This example also highlights the chain of
uncertainty that results from illness-related dilemmas (Babrow, 2001). Not only did the parents experience uncertainty about the condition itself, the burden of seeking a correct diagnosis among conflicting information, but also the recent financial burden from a loss of insurance. This example illustrates the interwoven problematic integrations associated with an orphan illness.

In addition to the potential for misdiagnosis, the rarity of the condition also complicates the process of finding a physician. Several patients who visited the HVM clinic were referred physician to physician until someone happened to recognize the condition and knew how it is managed or knew to send the family to a specialist. Additionally, the parents often traveled long distances to visit the clinic. One parent traveled over five hours to visit the clinic because it was the closest multidisciplinary team that studied their child's condition. The unfamiliar nature of this condition may make it inconvenient and difficult to visit the physician because of managing work and life issues (e.g., having other children), especially if frequent visits are necessary. But it also may be more difficult for patients in rural areas or those who lack the funding to travel to see specialists.

Assigning Meaning to the Illness

At the multidisciplinary HVM clinic, patients would see up to four physicians, all from different specialties, during their visit. Although this was a very thorough examination, the families were left with a lot of information from multiple perspectives. Additionally, when the parents were discharged, the nurses provided them with handouts about the diagnosis (or multiple potential diagnoses) to complement the physicians’
information. However, during the medical interview there were very few discussions of the meaning or implications the condition has on the child’s life. At times, parents would be left with much medical information, but the lifestyle influence of the illness was not discussed. This is an area of concern because a central facet of illness uncertainty is the ability to assign meaning to the illness and the illness experience (Mishel, 1988).

Because I am an adult with an HVM, the medical director at the clinic would frequently ask me to talk with a patient and families after the physicians were through with their examination. The physicians had given the parent(s) all of the information they could, but the physicians wanted me to go in and explain how I have managed my condition, how it influenced my life growing up, and how I dealt with the psychological implications of a condition with visible physical characteristics that are often stigmatized. One young boy in first grade was visiting the clinic. He’d been teased at school because his birthmark was visible on his face. He thought he was ugly and didn’t believe his parents when they tried to convince him otherwise. I went in to the room to talk with him about how I dealt with kids asking me about my birthmark and how he felt about how his birthmark was affecting him at school. Before I went to see the young boy, the physicians told me that he would not speak with them so I assumed he would not speak with me either. However, when the physicians left the room he readily answered my questions and shared information with me about his experiences.

On several occasions over the 13 months of observation at the clinic, parents thanked me for spending time with them and talking with them about my personal experiences. They were able to ask me about how it influenced me in school, if I could
still play sports, what type of pain I experience and how I manage the daily stress of a physical condition - getting asked about it or explaining it to others. The questions they asked me were not questions that physicians could answer for them, but were the questions that gave them the ability to assign meaning to the condition and develop a cognitive schema that included more than medical information, but also the implications this condition can have on their child’s life and future interactions with other people. Because parents and patients rely heavily on physicians for information about the condition in an attempt to manage uncertainty (Blanquicett et al., 2007), this example highlights the need for more time spent discussing the implications of the condition beyond the medical field as can be seen with the families in this study and their expressions of uncertainty surrounding these issues.

**Observing the Need for Information Verifying**

The participant observations of physician-patient conversations illustrated a need for more information verifying during the medical interview. These observations revealed that, in line with the physician-patient communication literature, patients (parents) are hesitant to ask questions. One parent even mentioned that she does not want to feel dumb because she thinks that what the physicians tell her is all she needs to know. She felt if she asked for clarification she appears uneducated and because she is the mother, she should be the expert about her child. However, she explained that when she gets home, she cannot explain the child's condition to her family and does not fully understand what physicians have told her.
Another parent visiting the clinic saw several physicians about their child’s HVM. The parents seemed satisfied with the information, but right before the physicians left the room, the mother casually asked if the birthmark was cancerous. The physicians paused and began to re-explain what they had told the mother. Without bringing up her concern about the risks of cancer, the mother may not have clarified whether or not this condition was cancerous or even expressed her concern for this possibility, but it illustrates that the medical interview, even when perceived to be successful, may still be problematic. When the mother did check to make sure the condition was not cancerous, it prompted the physicians to re-explain the condition and verify that the mother had made sense of the situation. Initially, for this mother, the meaning she assigned to the condition was different than the physicians and it took additional clarification to achieve shared meaning.

This example illustrates that active participation leads to more personalized information about the condition, but also illuminates other concerns parents may have (Cegala et al., 2007). However, it also suggests that the need to check understanding about the condition is equally, if not more important, than simply asking questions. Information verifying and checking understanding may lead to more accurate cues for parents to make sense of their child’s illness and ability to predict potential outcomes.

In sum, the participant observation highlighted the problematic nature of physician-parent-child relationships with regards to assigning meaning to the illness. Additionally, the complex nature of HVMs is the source of many distinct areas of uncertainty for parents and physicians. These areas of uncertainty were further explored
by analyzing parents' self-reported perceptions of their uncertainty through open-ended survey responses.

Survey Open-Ended Responses

Sources of Uncertainty

To further explore Research Question 1 (“What areas of uncertainty are most frequently reported by parents of children with hemangiomas and vascular malformations?”), open-ended survey questions were used to ask parents to explain any uncertainty, anxiety, questions, or concerns they had about their child’s condition. Of the total participants (n=55), forty-seven responded to this question. Through a constant comparative analysis, the most frequently reported areas of uncertainty were: (1) The Future (40.4%), (2) Surgery/Treatment Options (31.9%), (3) Other Potential Health Risks (29.8%), (4) Child’s Pain Level (19.1%), and (5) Psychological Concerns (14.9%). Each theme is discussed in the following sections.

The Future. Parents who expressed uncertainty about the future were primarily concerned about how the HVM would influence their child as they begin to grow up. These responses did not refer to specific treatments or current symptoms that their child experienced now, but referred to a more general concern of how this condition would influence their child. A mother of a 4-year old girl wrote, "I am most concerned about how my child's illness will affect her life.” Another mother of a 12-year old girl also stated:
[I] Just want to be able to help my child and someone to tell me all what’s going on and is this something she will have to live with rest of her life, getting her pain controlled, and getting her back to being the run of the mill child.

These responses indicate that parents do not just have uncertainty about visiting the doctor, about what medications to take, or the diagnosis, but they are largely concerned with the impact this condition may have on their child’s ability to be a “normal” child.

This area illustrates Mishel’s (1988) definition of uncertainty in illness as an inability to make sense of or assign meaning to illness experiences. These parents are struggling with the inability to predict the future for their child and cannot assign value to the situation. This example also highlights the role of problematic integrations in illness. According to PI theory (Babrow, 1992), problematic integration is caused by an ambiguous dilemma where the probabilities and values lead to unknown outcomes or multiple meanings. These parents are unable to form a probabilistic orientation because of the unpredictability and unknown nature of their child’s condition. Furthermore, they are unable to determine a clear evaluative orientation about whether this will be a positive or negative experience because the potential outcome is unclear and the parents do not possess an existing cognitive schema to make sense of the illness (Steward & Mishel, 2000). As PI theory explains (Babrow, 2001), problematic integrations develop in a chain-like process, so this dilemma about the future only breeds new and more complex uncertainties for parents of children with HVMs.

Surgery/Treatment Options. Uncertainty about surgery and treatment options was the next most frequently reported area. Parents varied on their specific concerns about
surgery; ranging from whether surgery was even an option, to how difficult it would be, or whether or not additional surgeries would need to be done. Because treatment options for HVM are not consistent in the medical research, it seems fitting this category is high on the list of areas of uncertainty. It is not always possible for physicians to give parents a confident answer when asked about surgery. One mother of an 11-week old daughter expressed concern about the physicians’ uncertainties about surgery. She stated, "On the first visit, it seemed that the derm[atology] resident and the surgeon were discussing the treatment option in front of me as 'experimental' and I wasn't sure they really felt it would work."

These statements highlight three of Mishel’s (1988) four types of illness uncertainty: 1) complexity regarding treatment and the system of care, 2) lack of information about the diagnosis and seriousness of the illness, and 3) unpredictability of the course of the disease and prognosis. Because consistent information about treatment and surgery for all HVMs has not been established, physicians are not always able to provide complete information regarding the diagnosis and seriousness of the illness. This lack of information does not provide parents with the cues needed to make sense of and predict outcomes or assess valence (Mishel, 1990). Most importantly, this chain of uncertainty illustrates the potential for one dilemma to trigger multiple problematic integrations which increases the complex nature of the parents’ uncertainty regarding their child’s condition.

Another mother of a 17-week old daughter expressed concern about surgery after she had received multiple opinions about the treatments. The day she completed the
questionnaire was her first visit to the clinic. She shared her story about potential surgery and how she found the specialized clinic stating:

We were [originally] referred to a pediatric surgeon. His advice was to remove it, we opted to observe for another month, but the size continued to increase and became very painful. I was concerned it was infected so the surgeon offered to perform surgery that next Tuesday….The radiologist strongly recommended we find a ‘clinic’ who specializes in hemangiomas/vascular [malformations] for a second opinion. He did not agree with surgeon to remove it the next day. The surgeon wanted to go through with the surgery, but we went on the Internet & found this clinic. That night before the scheduled surgery I was very anxious & tearful. I couldn't put my finger on it, but going ahead with surgery with a general pediatric surgeon did not ‘feel’ right. I felt we needed a second opinion from someone who specializes in this area and does this all the time….I am still anxious a bit, b/c I don't know what the [treatment] will entail, but I do feel I am at the correct place, with the right expertise to get the best care for our precious baby girl.

This mother’s story illustrates the unclear and conflicting information that is out there about treating HVMs and how that can breed uncertainty--not only about the surgery, but about the future of the child and the implications the condition may have on their lives. The multiple opinions this mother received were conflicting with her desire to help her child--so that more information was increasing her uncertainty (Brashers et al., 2000). Not only did the information prevent her from predicting the outcomes of the illness and
possible treatment options, it also hindered her ability to assign meaning to the situation. Although the mother placed more trust in the specialist she found, she still expresses uncertainty for her daughter’s condition. Her dilemma not only highlights all four of Mishel’s types of uncertainty (1988), and a series of interwoven problematic integrations (Babrow, 1992), it also illustrates the large role physicians play in uncertainty management (Brashers et al., 2000) for illness-related uncertainty and can be the source of uncertainty for patients and parents (Brashers et al., 2006).

In the mother’s story, she indicated how concerned she was about her daughter’s condition, so she scheduled surgery with the local pediatric surgeon. However, when the radiologist indicated hesitancies, the mother was forced to re-evaluate her decision and she began to question the first surgeon. Additionally, it prompted her to do research online about physicians who specialize in HVMs. The story begs the question, would she have followed the same path and had the same uncertainty if the radiologist had not disagreed with treatment? How did uncertainty influence her decision-making process?

This example illustrates how complex illness uncertainty management is when the decision-making process is multilayered and consistent information is not available.

In addition to conflicting information about surgery and treatment options, many parents have uncertainty about the basic risks of performing surgery. One mother of an 8-year-old son expressed her uncertainty that was a result of her concerns about the future, but also concerns about surgery. She had a desire to do everything she could to treat the condition, but also felt hesitant because of the risks of surgical procedures. She
stated, "Since I am unsure about the future, I want things taken care of now, but I am afraid of the risk of surgery."

This mother’s concern illustrates the way in which probabilistic orientations and evaluative orientations destabilize each other in illness experiences (Babrow, 2001). As a parent, this mother wants to treat her child’s condition as early as possible to ensure a healthy future for her child, or to avoid future obstacles, but the potential risks of surgery are complicating the decision to undergo surgery. From her perspective, the outcomes create an ambivalent dilemma posed by mutually exclusive outcomes--if she does surgery, she is helping her child, but it may mean putting her child’s health in danger. On the other hand, if she does not do surgery, she is not providing the most thorough health care for her child, but is avoiding the potential risks of surgery. This example highlights a paradoxical dilemma that may exist more frequently for parents of children who are ill than for adults who are making medical decisions about their own health care. It may be more difficult for a parent to decide to undergo or withhold surgical treatment for their child because the pain and risk factors are not their own.

*Other Potential Health Risks.* In addition to surgery and treatment, several parents indicated a concern for how their child’s HVM would affect other parts of the child’s body. Several participants indicated that their child’s birthmark was affecting at least one other area of the body. One mother who was visiting the clinic for the first time stated, "My main concern is that she will lose her vision if the hemangioma grows. I worry that I could let it go too long before I bring her back." Another mother, whose
child had a hemangioma near the child’s nipple, was concerned that the nipple would be damaged or completely removed if the physicians performed surgery.

The concern for other health risks illustrates the uncertainty of a multidisciplinary orphan condition. This context complicates the decision-making process (Brashers et al., 2003) and prevents the parents from predicting outcomes and then evaluating those outcomes. Again, this example highlights the complex nature of illness uncertainty and the problematic integrations associated with caring for one specific condition, but also having to worry about how that treatment may influence other elements of the child’s health. This stresses the inability to isolate or remove uncertainty from the context of the situation or the interrelated chaining of uncertainties. Although parents express uncertainty regarding their child’s birthmark, that uncertainty also has a reciprocal relationship with uncertainties about other health concerns.

*Child’s Pain Level.* Pain was a concern for several parents. The mother of a two-and-a-half year old son expressed how difficult it is for a parent to gauge how much pain their child is in. She stated:

My son's lump has grown in size and I worry how big it's going to get, and I pray it doesn't hurt him. I know he doesn't like it to be touched but I don't know what it feels like every time he sits down.

While Mishel’s (1988) four types of uncertainty seem to capture how patients experience uncertainty, this specific example suggests that parents may experience a fifth form of uncertainty--caused by separation from experiencing the illness symptoms and the ability to use them to manage uncertainty. In the uncertainty in illness literature on
couples coping with a serious illness, it suggests that the partner of someone who is ill often experiences additional uncertainty because they do not know how their partner is feeling, must rely on their partner for cues regarding pain or discomfort, and must trust that their partner is managing or addressing the pain appropriately (Goldsmith, 2009). These same concepts may apply to parents of children with serious or chronic illnesses and HVMs. The ability to predict outcomes or assign meaning to the illness becomes further complicated when the parent lacks the sensations of physical cues associated with illness.

**Psychological Concerns.** Parents frequently expressed concern about their child being teased in school or asked about their birthmark by complete strangers. One mother expressed concern about the birthmark being in a prominent place on her son’s body. She explained, "[His] Birthmark is in a visible place on [his] neck and [I’m] afraid that kids will make fun of him now and later on." Another mother of a 7-year old girl, who has been to the clinic more than ten times, explained how she tries to prevent these potential psychological issues, but is still uncertain about the future. She explained, "I think the not knowing what will happen with her illness is the hard part. I have tried to raise my daughter to be confident, but the questions and the teasing from other kids makes it hard."

Another mother referenced the concerns her 8-year old son already has about his birthmark and the compression garment the physicians prescribed for him to control pain and swelling. She explained that her uncertainty came from "[t]he concerns of how his peers react as he gets older to his compression hose. He doesn't want people thinking he
wears 'panty hose.'" The stigma that may surround these malformations is obviously a concern for parents and may be a prominent source of uncertainty. The uncertainty that stems from social stigma may be a useful addition to the existing categories of illness uncertainty (Mishel, 1988). Goffman (1963) first conceptualized stigma as “the situation of the individual who is disqualified from full social acceptance” (p. 9). In recent health and psychology literature, stigma is becoming a more recognized and studied concept and is prevalent in HIV/AIDS and mental illness studies (Weiss, Ramakrishna, & Somma, 2006), but the potential relation stigma has to uncertainty has yet to be fully explored. The anticipation of social stigma that the participants explained indicates the need for theories of uncertainty and uncertainty management to further explore the implications of social stigma—especially resulting from a physical abnormality.

Managing Uncertainty

Given the areas of uncertainty that have emerged thus far for parents of children with HVMs, it was also a goal of this study to identify the resources parents try to use to manage uncertainty to recognize what uncertainty management strategies participants are using (Brashers et al., 2000). In exploring research question 2 ("How do parents of children with HVMs manage their uncertainty about their child’s condition?"), parents were asked to explain where they sought out information and answers to their questions, how they handled their uncertainty, and dealt with any stress associated with their child’s condition. Of the total participants, 47 responded to this item. Parents’ responses to this question were analyzed using constant comparative analysis to identify emerging themes.
The most frequently reported sources of information were: (1) Health Care Professionals (95.7%), (2) Internet (70.2%), and (3) Social Support Networks (31.9%). These themes will be discussed in the following sections.

**Health Care Professionals.** The most frequently reported source of information for parents was health care professionals. This category included both nurses and physicians. Some participants mentioned their pediatrician, while others mentioned they only seek information from specialists in an HVM clinic. Additionally, a few participants indicated they would call or e-mail health care professionals to request information or ask questions, others only referred to their in-person visits with physicians, but no outside additional communication. However, responses were brief and did not probe deeper into their information management techniques with physicians.

The fact that Health Care Professionals were the most frequently reported source of information is consistent with the literature in physician-patient communication, that despite the turn toward patient-centered care and the increasing amount of information available on the Internet, patients still rely heavily on physicians for information and uncertainty management (Blanquicett et al., 2007). However, the Internet was also mentioned.

**Internet.** The next most frequently reported source of information for parents was the Internet. Several participants varied on when they used the Internet as a tool. Some indicated that they researched on the Internet prior to the medical interview in order to be prepared, develop questions, and appear educated during the interview. On the other hand, some participants used the information to confirm what they were told during the
medical interview and to maintain information between visits with the physicians. The order of seeking information from the Internet and seeking information from physicians may be a valid area to explore deeper to find out the way in which this influences uncertainty management, and also how it influences the physician-patient medical interview. It is possible there is a relationship between the amount of information seeking and patient (parent) information verifying behaviors, and when the Internet is utilized as a resource.

Because the Internet was also a frequently reported topic of managing uncertainty, researchers should not only focus on the physician-patient relationship, but the relationship among various resources and how they are coordinated to establish uncertainty management. Furthermore, the potential for conflicting information among or between resources may be a potential stressor for parents and lead to yet another problematic integration associated with the child’s condition.

*Social Support Networks.* The last most reported source for information was Social Support Networks. This category includes everything from discussing emotions and fears with family, spouses, and friends to sharing information and stories with parents and families who have been through the same experiences.

Unfortunately, the uncertainty literature does not spend much time focusing on the influence of social support networks on managing uncertainty, but it may play an important role on a parent’s ability to assign meaning to their child’s illness, to predict potential outcomes, and narrow the decision-making process. Because parents may lack an existing cognitive schema to fully understand the illness experience, parents who have
been through similar dilemmas may provide a voice of clarity for potentially ambiguous or ambivalent situations. Furthermore, family and friends who are removed from the immediate situation may be able to provide an outsider’s perspective to help make sense of the situation and aid in the decision-making process.

Knowledge and Confidence Level

After identifying the areas of uncertainty and how parents seek information regarding their uncertainty, to explore research question 3 (‘How knowledgeable do parents of children with HVMs feel about their child’s condition?’) parents were asked to assess their knowledge of their child’s condition, and how comfortable they felt explaining the condition to family, friends, teachers, and other acquaintances. Forty-five participants responded to this question and 42 responded directly about their knowledge. In total, 19.1% believed they were very knowledgeable about the condition, some felt they were becoming knowledgeable with each visit (26.2%), others felt fairly knowledgeable about basics of diagnosis but not prognosis or more in-depth explanations (31.0%), and still others believed they were not very knowledgeable at all about their child’s condition (23.8%). These frequencies reveal a rather wide range of knowledge regarding their child’s condition. While many parents may know the name of their child’s condition, the complexity of HVMs indicates that a deeper understanding of the condition is complicated and difficult to achieve—even for some health care professionals. A factor that may be important when exploring this area is the severity of the child’s condition. Those with more superficial, isolated anomalies may have a more
thorough understanding of the condition than parents whose children have complex or multiple anomalies.

Of the total respondents, 22 responded about their comfort level in explaining their child’s condition. Most (50.0%) reported being very comfortable explaining it to family, friends, and other acquaintances. Only 13.6% of respondents felt fairly capable of explaining, while 6 parents (27.7%) lacked confidence in their ability to give an explanation. Again, this area may require further analysis in relation to the severity of the condition.

Overall, parents did not report consistent knowledge or confidence in explaining their child’s condition. While these findings should be explored further through a more detailed analysis, they highlight the complexity of the condition, the inconsistent information available, and the diversity in experiences for parents dealing with HVMs. Issues of uncertainty and physician-parent-child communication are further explored in the results of the questionnaire data explained below.

Measurement Scale Results

To explore research question 4 (“Do parents of children with HVMs have uncertainty about how to interact with the multiple physicians often involved with treatment?”), Table 1 and Table 2 illustrate the means and standard deviations for the Uncertainty in Illness Scale, the Relational Uncertainty Scale, and Patient-Self Advocacy Scale. Parents responded on a five-point Likert-scale ranging from strongly disagree (1) to strongly agree (5). Table 1 illustrates relatively low levels of uncertainty reported by parents about their child’s condition. The means were significantly lower than expected
for parents of children with HVMs given the degrees of uncertainty observed and explained in-person in actual clinic interactions. Additionally, the anticipated and experienced uncertainty parents had about talking with physicians was reported to be low using these measures.

<table>
<thead>
<tr>
<th>Type of Uncertainty</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness Uncertainty</td>
<td>55</td>
<td>2.27</td>
<td>0.66</td>
</tr>
<tr>
<td>Relational Uncertainty</td>
<td>55</td>
<td>1.81</td>
<td>0.54</td>
</tr>
</tbody>
</table>

Table 1. Parents' Perceived Uncertainty

<table>
<thead>
<tr>
<th>Type of Self-Advocacy</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness Education</td>
<td>55</td>
<td>4.03</td>
<td>0.51</td>
</tr>
<tr>
<td>Interpersonal Assertiveness</td>
<td>55</td>
<td>3.87</td>
<td>0.60</td>
</tr>
<tr>
<td>Potential for Non-Adherence</td>
<td>55</td>
<td>2.31</td>
<td>0.64</td>
</tr>
<tr>
<td>Overall Self-Advocacy</td>
<td>55</td>
<td>3.40</td>
<td>0.39</td>
</tr>
</tbody>
</table>

Table 2. Parents' Perceived Self-Advocacy

The illness education self-advocacy mean for this sample was high--indicating the parents’ perceived education as an important factor in managing their child’s condition. Additionally, parents reported a rather high likelihood of engaging in assertive communication with physicians. In contrast with these areas, parents were relatively low on their potential for non-adherence. This suggests that, while an individual may consider themselves a strong self-advocate in terms of education and assertiveness, non-adherence may not be as closely related.

Table 3 provides frequencies of pure and mixed types on the health locus of control scale as reported by parents.
<table>
<thead>
<tr>
<th>Type of Locus of Control</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pure Types</td>
<td></td>
<td></td>
</tr>
<tr>
<td>External Others</td>
<td>20</td>
<td>36.4%</td>
</tr>
<tr>
<td>Internal</td>
<td>3</td>
<td>5.5%</td>
</tr>
<tr>
<td>Chance</td>
<td>5</td>
<td>9.1%</td>
</tr>
<tr>
<td>Mixed Types</td>
<td></td>
<td></td>
</tr>
<tr>
<td>External Others/Internal</td>
<td>13</td>
<td>23.6%</td>
</tr>
<tr>
<td>External Others/Chance</td>
<td>5</td>
<td>9.1%</td>
</tr>
<tr>
<td>High on All 3</td>
<td>1</td>
<td>1.8%</td>
</tr>
<tr>
<td>Low on All 3</td>
<td>8</td>
<td>14.5%</td>
</tr>
</tbody>
</table>

Table 3. Parents' Disease-Specific Health Locus of Control

The results of the Diseases-Specific Health Locus of Control Scale suggest that most parents place control in External Others (e.g., physicians and other health care professionals) when it comes to their child's HVM. Very few participants reported a locus of control defined as purely Internal (5.5%) or Chance (9.1%). An interesting result in this sample was the high percentage of parents who were high on both External Others and Internal (23.6%)--indicating these parents place a great deal of trust with physicians, but also feel the need for some degree of control over the health of their child. This may be unique to parents who trust their child’s care to physicians, but as parents, are compelled to accept responsibility and accountability for the health of their child.

*Criterion Validity of the Scales*

Research Question 5 (“Does a relationship exist between or among illness uncertainty, relational uncertainty, disease specific locus of control, and patient self-advocacy?”) was addressed by exploring the criterion validity of the scales. A correlation matrix shown in Table 4 was examined for associations among the Uncertainty in Illness Scale, Relational Uncertainty Scale, Patient-Self Advocacy Scale, and Disease-Specific Health Locus of Control Scale.
Table 4. Criterion Validity of Measures

In line with conceptual theory, the Uncertainty in Illness Scale, Relational Uncertainty Scale, and External Chance Locus of Control sub-scale were found to be positively correlated. Specifically, the Uncertainty in Illness Scale exhibited significant positive relationships with Relational Uncertainty (r = 0.44, p < 0.05) and External Chance Locus of Control (r = 0.32, p < 0.05), and significant negative relationships with the PSAS sub-scales of Illness Education (r = -0.36, p < 0.05) and Interpersonal Assertiveness (r = -0.27, p < 0.05). Relational Uncertainty also exhibited a significant positive relationship with External Chance Locus of Control (r = 0.32, p < 0.05), and also a significant negative relationship with the PSAS Illness Education (r = -0.40, p < 0.05) and PSAS Interpersonal Assertiveness (r = -0.45, p < 0.05). In addition, the Relational Uncertainty Scale exhibited significant positive relationships with the PSAS sub-scales of Illness Education (r = 0.44, p < 0.05) and Interpersonal Assertiveness (r = 0.32, p < 0.05), and significant negative relationships with the PSAS sub-scales of Illness Education (r = -0.36, p < 0.05) and Interpersonal Assertiveness (r = -0.27, p < 0.05). In addition, the Relational Uncertainty Scale exhibited significant positive relationships with the PSAS sub-scales of Illness Education (r = 0.44, p < 0.05) and Interpersonal Assertiveness (r = 0.32, p < 0.05), and significant negative relationships with the PSAS sub-scales of Illness Education (r = -0.36, p < 0.05) and Interpersonal Assertiveness (r = -0.27, p < 0.05).
Uncertainty Scale had a significant positive relationship with the PSAS's Potential for Non-adherence \( (r = 0.30, p < 0.05) \), again consistent with the scale operationalizations.

The PSAS Illness Education and PSAS Interpersonal Assertiveness sub-scales exhibited a significant positive relationship \( (r = 0.36, p < 0.05) \). Neither concept was found to be significantly related to the PSAS's Potential for Non-adherence, the third concept in the scale, but this is in line with the notion that this is a conceptually distinct strategy of choosing not to follow a physician's recommendations, rather than to participate/negotiate with physicians about treatment options. The one surprising finding was that the PSAS Interpersonal Assertiveness sub-scale was moderately, but significantly, correlated to External Others Locus of Control \( (r = 0.30, p < 0.05) \). At first glance this could appear counterintuitive, but upon closer examination of the scale items, the PSAS Assertiveness sub-scale assesses one's willingness to be more participative with physicians in discussing treatment options and the External Others LOC sub-scale assesses one's faith in credible others (e.g., physicians) to help improve your child's condition. Overall, the scales and sub-scales exhibited good criterion validity (conceptual consistency) across the measures and assessed the concepts in a manner consistent with previous studies.

*Exploring Group Differences*

In order to explore Research Question 6 ("Do any differences exist in illness uncertainty, relational uncertainty, disease specific locus of control, and patient self-advocacy between parents based on demographic categorizations?"), independent sample t-tests and an ANOVA were computed to investigate any significant differences. The
demographic categories analyzed were chosen because the literature on physician-patient communication indicates these categories may influence medical interview interactions. First, level of patient medical knowledge has been found to influence the medical interview (Cegala, 1997) and the patients’ uncertainty about the condition (Brashers et al., 2000), therefore, two groups were compared based on whether this was a first time visit to a HVM clinic specialist versus those who have visited the clinic multiple times. In addition, the literature suggests that education level and income may play a role in the amount of information exchanged during the medical interview and how active certain patients are during the conversation (Street, 1990), thus, potential education and income differences were explored related to illness uncertainty, relational uncertainty, and patient self-advocacy.

**Number of Visits.** An independent sample $t$-test was conducted to investigate if a difference exists between new-visit and return-visit parents. The $t$-test revealed that new-visit parents ($M = 2.45, SD = 0.65$) did significantly differ from return-visit parents ($M = 2.05, SD = 0.54$) on Illness Uncertainty ($t = 3.52, df = 50, p < .05$) indicating that parents who have visited specialists multiple times are able to assign more meaning to the illness and have more cues to predict outcomes of the illness than first-time visitors who have not developed a reliable cognitive schema in order to make sense of the illness. Although new-visit parents ($M = 1.93, SD = 0.58$) did not significantly differ from return-visit parents ($M =1.74, SD = 0.52$) on Relational Uncertainty ($t = 1.27, df = 50, p < .05, n.s$). Finally, new-visit parents ($M = 3.47, SD = 0.35$) did not differ significantly from return-
visit parents ($M=3.37$, $SD=0.41$) on Patient Self-Advocacy ($t=0.88$, $df=50$, $p<.05$, n.s.).

**Education Level.** An independent sample $t$-test revealed that participants who had not completed college ($M=2.29$, $SD=0.67$) and participants who had a college degree ($M=2.28$, $SD=0.66$) did not significantly differ on Illness Uncertainty ($t=0.83$, $df=52$, $p<.05$, n.s.). Also, participants who had not completed college ($M=1.80$, $SD=0.51$) and participants with a college degree ($M=1.84$, $SD=0.57$) did not significantly differ on Relational Uncertainty ($t=0.80$, $df=52$, $p<.05$, n.s.) indicating that education level for this sample was not a distinguishing factor for perceptions of uncertainty about communicating with the doctor, the child’s illness, or how the illness will progress. However, participants who had not completed college ($M=3.21$, $SD=0.40$) and participants with a college degree ($M=3.55$, $SD=0.33$) did significantly differ on Patient Self-Advocacy ($t=-3.30$, $df=52$, $p<.05$). This difference was further explored for each construct of Patient Self-Advocacy and the major significant difference between participants who had not completed college ($M=3.62$, $SD=0.55$) and those with a college degree ($M=4.04$, $SD=0.58$) was on the PSAS Interpersonal Assertiveness subscale ($t=-2.68$, $df=52$, $p<.05$). This relationship suggests that more educated patients report being more willing to engage in active communication and decision-making with physicians, which may be due to a better understanding of the decision making process, medical terminology, and the condition itself.

**Income Level.** A one-way analysis of variance (ANOVA) with Fisher-LSD post-hoc tests were conducted to investigate if differences exist between income levels and
reported uncertainty and self-advocacy. The ANOVA revealed there was no significant
difference among parents based on income [below $30,000 \((M = 2.21, SD = 0.73)\),
between $31,000 and $75,000 \((M = 2.4, SD = 0.63)\), and above $76,000 \((M = 2.17, SD =
0.63)\)] for Illness Uncertainty \((F = 0.95, df = 2/51, p < .05, n.s.)\) suggesting that although
income level may influence the physician-patient information exchange process (Street,
1990), it potentially has less of an influence on parents’ uncertainty about their child’s
condition. Additionally, no significant difference was found among parents based on
income [below $30,000 \((M = 1.71, SD = 0.44)\), between $31,000 and $75,000 \((M = 1.90,
SD = 0.48)\), and above $76,000 \((M = 1.81, SD = 0.67)\)] on Relational Uncertainty \((F =
0.53, df = 2/51, p < .05, n.s.)\) indicating that regardless of income, parents in this sample
were relatively comfortable talking with physicians. For the PSAS, although no
significant difference was found across all parents based on income [below $30,000 \((M =
3.25, SD = 0.54)\), between $31,000 and $75,000 \((M = 3.39, SD = 0.35)\), and above
$76,000 \((M = 3.53, SD = 0.29)\) \((F = 2.09, df = 2/51, p < .05, n.s.)\)], the Fisher-LSD post-
hoc tests did reveal that a significant difference exists between parents in the low income
group (below $30,000) and parents in the high income group (above $76,000). An
additional independent samples \(t\)-test was run to confirm this difference, and a significant
difference was found between low-income parents \((M = 3.29, SD = 0.48)\) and high-
income parents \((M = 3.5, SD = 0.29)\) on the Patient Self-Advocacy Scale \((t = -1.95, df =
50, p < .05)\). This suggests that lower-income parents were less likely to become more
educated, use assertive communication with physicians, and engage in mindful non-
adherence. Higher-income parents may have more resources to become educated, which
can influence assertive communication, but they also have the resources to engage in non-adherence because when they reject treatment or suggestions from physicians they are able to seek treatment elsewhere, travel to other clinics, or request different medication.

These results provide further evidence of the multilayered uncertainties experienced by parents of children with HVMs. Not only does uncertainty stem from the medical diagnosis, but also factors such as income, education, desire to be assertive, locus of responsibility, and perceptions about the relationship with the physician add more links to the chaining of uncertainties. Furthermore, the quantitative results indicate that parents have varied expectations about the medical interview and how to manage their child’s health care. This suggests that parental uncertainty must be assessed person by person when healthcare providers are interacting with parents.

While the quantitative results reveal interesting findings about the self-reported uncertainty, complex forms of health locus of control, and the factors that influence patient self-advocacy, these results are only one piece of the interwoven uncertainties associated with a complex illness. The triangulation of the participant-observations, open-ended responses, and quantitative results will be discussed in the following section.

DISCUSSION

This study employed both participant observation and a survey approach to explore uncertainty of parents of children with hemangiomas and vascular malformations. The 13-months of observation confirmed much of the literature on uncertainty and physician-patient communication, but it also highlights dilemmas unique
to an orphan condition, like HVMs. Observations revealed the interwoven problematic integrations that occur because the condition is not well-known in the medical field. Patients with HVMs are at a higher risk of misdiagnosis, have more difficulty finding specialists, and receive inconsistent information. These challenges illustrate that the potential for more information to increase uncertainty is high (Brashers et al., 2000) and the struggle parents face in assigning meaning to the condition (Mishel, 1988) and developing a cognitive schema to make decisions about their child’s treatment (Babrow et al., 1998). These dilemmas suggest that more emphasis should be placed on information-verifying and checking of understanding for those dealing with unknown conditions. The process of information verifying could provide more decision-making cues to participants. Additionally, information verifying – especially summarizing information, restating information, and checking understanding – is often something parents are more comfortable with than asking questions (Harrington et al., 2004), especially when they are receiving inconsistent information and may not understand the information enough to even develop questions.

These chain-like uncertainties were also illustrated in the open-ended responses provided by parents. Parents reported uncertainty about the future, potential surgery and treatment options, other health risks associated with the HVM, their child’s pain, and the psychological implications of a physical deformity. These interwoven concerns illustrate that illness uncertainty is frequently a combination of medical, social, and personal uncertainties (Brashers et al., 2006) that together characterize the illness experience for the parents.
The survey open-ended responses also illustrated the way in which information influences uncertainty. For these parents, the information they were receiving was often conflicting, inconsistent, or incomplete. Information that does not provide discrete outcomes can increase uncertainty and influence the coping process (Brashers et al., 2000). However, information seeking may be the only feasible option for parents of children with HVMs as avoiding information about their child’s health, and about a condition that is complex, may not be a rational choice for these parents. Parents, however, need to better understand the process of communicatively managing uncertainty as more information may decrease, maintain, or increase their uncertainty (Brashers et al., 2000).

Surprisingly, the means on the Uncertainty in Illness Scale were low. There appears to be an inconsistency between parents reporting low illness uncertainty ($M = 2.27, SD = 0.66$) on the scale measures, as compared to the complex chains of uncertainties reported in the open-ended responses and identified in the participant-observations. This may suggest new validity questions about the Uncertainty in Illness Scale and the measurement of uncertainty among parents’ experiences dealing with an unknown condition like HVMs. It may be that the uncertainty is more complex and multilayered than current scales can accurately operationalize. This further underscores that qualitative research is needed to serve as a validity check on scales, and it is possible these uncertainty scales should not be used as a sole measure of parental uncertainty.

Another interesting finding from the survey results of the Disease-Specific Locus of Control Scale was the frequency of “mixed type” locus of control. Literature on locus
of control has focused on classifying individuals as possessing external, internal, or chance locus of control personality orientations. However, one study (Dahnke et al., 1994) recognized the co-occurrence of both external and chance dimensions of health. In that study, these individuals trusted their care to physicians, but because of the uncertainty of illness also recognized that good fortune or fate may also play a role in illness progression. What is unique in the current study is the high number of individuals who were classified as possessing both External Other and Internal dimensions of locus of control. This finding may be unique to parents who feel responsible for the care of their child, but also trust the HVM specialists to provide the best care necessary. This External Other/Internal mixed-type classification may reveal an additional source of uncertainty experienced by parents who struggle with accountability for their child’s health.

Theoretical Implications

The results of this study have several implications for the existing theories of uncertainty in illness. First, the interwoven uncertainties of an orphan illness suggest that Problematic Integration theory (Babrow, 1992) may best explain the cognitive uncertainty processes that parents experience and how these influence communicative coping. The ambiguous and ambivalent dilemmas reported by parents in this study may force parents to constantly reappraise their illness uncertainty because certain dilemmas challenge their existing beliefs and values about being a good parent and caring for their child. Additionally, the PI concept of chaining uncertainties captures the complexity of uncertainty for parents of children with HVM. Uncertainty is not a single, isolated phenomenon, but is influenced by other, sometimes competing uncertainties. These
dilemmas not only produce their own uncertainty, but may trigger a new set of dilemmas that impact the coping process and the uncertainty management process of the parents and children.

The Communicative Management of Uncertainty Theory (Brashers et al., 2000) also offers valuable insight into the communicative and information seeking processes of parents of children with HVMs. The unknown nature of the HVM condition and the inconsistency of information available to parents and health care professionals indicate that more information frequently leads to more uncertainty by increasing the number of potential outcomes. While the alternative to seeking information is avoiding information, it may be important for the theory to examine the implications of avoiding information by parents. It may be possible that parents would not choose to avoid information about their child’s condition because of the social implications—it may seem irresponsible for a parent to avoid information about their child’s condition because of their own uncertainty. Additionally, it may imply that coping with the uncertainty relies more heavily on other strategies such as emotion management, rather than information management (Hogan & Brashers, 2009). Further study examining parents’ uncertainty management processes may reveal a process that is unique to parents and illness that are highly complex and relatively unknown.

Finally, the current study also has highlighted ways to expand Mishel’s (1988) model of illness uncertainty. The model currently includes four types of illness uncertainty: 1) ambiguity concerning the state of the illness, 2) complexity regarding treatment and the system of care, 3) lack of information about the diagnosis and
seriousness of the illness, and 4) unpredictability of the course of the disease and prognosis. The results of this study indicate that uncertainty stemming from social stigma associated with illness may also be frequent with illness experiences. When stigmatization is anticipated by the parents (or patient) it could produce anxiety or social isolation for fear of social disqualification. Additionally, the unique uncertainty parents experience because they are not the one experiencing the pain may be another source of illness uncertainty. When parents are unable to determine how much pain their child is in or struggle deciding whether or not to put their child through surgery, it can cause a removed type of uncertainty resulting from a lack of cues used to manage uncertainty. Both areas of uncertainty were expressed in the current study and may be a useful expansion of the current Uncertainty in Illness Theory.

Limitations

It is important to recognize the limitations of this study. During the participant-observation, the majority of the time was spent observing physicians and families interact. While this provided valuable insight into physician-patient communication, it may have been too narrow of a focus. There may have been potential benefits in observing families interacting with other health care professionals, including the social worker and nurses. Broadening the scope from physician-patient communication to other healthcare provider-patient communication could reveal more about the entire healthcare experience at a HVM clinic.

Another limitation was the clinic environment where the consent was obtained and surveys were distributed. The process was complicated by several factors associated
with the process of visiting the clinic. Some parents arrived late and had very little time to complete the survey; others agreed to participate, but were often preoccupied taking care of a young child or completing paperwork needed by the hospital. The process of distributing and receiving completed questionnaires may have been more fluid if informed consent was obtained prior to the parents arriving at the clinic and they were aware of their participation prior, instead of being asked to participate and given the questionnaire on such short notice.

CONCLUSION

The findings of this study highlight the interwoven uncertainties posed by “orphan” illnesses and how they influence the parents’ ability to assign meaning to the illness experience. These complexities also suggest that existing measurement scales may not be able to accurately measure the multilayered and complicated nature of the uncertainty experienced by parents. Qualitative research should also be used to test the validity of the scales and provide a deeper analysis of uncertainty. Additionally, the study suggests that existing theories on illness uncertainty could be expanded to include the unique uncertainty of “orphan” illnesses and the distinctive characteristics of parental uncertainty – characterized by a lack of cues needed to make health related decisions.

The results of this study provide support for continuing research on illness uncertainty. Future research on parental uncertainty may reveal unique uncertainties that may broaden the current research on patient uncertainty and provide a broader perspective of illness uncertainty in families. Additionally, because the physician is still a preferred source of information for managing uncertainty in illness, future research may
look at communication skills training that improves patient and parent communication
during the medical interview to increase information verifying (restating information,
summarizing information, and checking understanding) and potentially improve the
ability to manage uncertainty.
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*Patient Education and Counseling, 52*, 7-16.


Questionnaire

Thank you for agreeing to participate in this study. Your feedback is very important to this research and provides great insight into doctor-patient communication. Please respond to each item to the best of your ability. Be as open and honest as possible to ensure the most accurate results. When you have completed the survey, you can return it to the registration desk.

Using the scale below, please indicate to what extent you agree with the following statements about your child’s medical condition and your health care experiences. Write the number in the blank provided.

1 = Strongly Disagree
2 = Disagree
3 = Neutral
4 = Agree
5 = Strongly Agree

1. I do not know what is wrong with my child.
2. I have a lot of questions without answers about my child’s condition.
3. I am unsure if my child’s illness is getting better or worse.
4. It is unclear how bad my child’s pain will be.
5. Because of the unpredictability of my child’s illness, I cannot plan for the future.
6. I do not know how I should manage my child’s situation.
7. It is not clear what is going to happen to my child.
8. I can generally predict how my child’s illness will go.
9. I do not know what the diagnosis will be for my child.
10. I am not sure how to behave when talking to the doctor.
11. I do not know for what I should ask the doctor.
12. I am concerned that the doctor may not give me all of the information I want.
13. I do not know how to get the right information about my child’s illness from the doctor.
14. I am not sure if I can have a good relationship with the doctor.
15. I am worried about how to talk with the doctor.
16. I am not sure whether I should ask the doctor all of the questions I have.
17. I am nervous about seeing the doctor.
18. I know what questions to ask when I see the doctor.
19. I believe it is important for people [people with hemangiomas or vascular malformations] to learn as much as they can about their illness and treatments.
20. I actively seek out information on my child’s illness.
21. I am more educated about my child’s health than most US citizens.
22. I have full knowledge of the health problems of people like my child [people with hemangiomas or vascular malformations]
23. I do not get what I need from my child’s physician because I am not assertive enough.
24. I am more assertive about my child’s health care needs than most US citizens.
25. I frequently make suggestions to my physician about my child’s health care needs.
26. If my physician prescribes my child something I do not understand or agree with, I question it.
27. Sometimes there are good reasons not to follow the advice of a physician.
28. Sometimes I think I have a better grasp of what my child needs medically than my doctor does.
29. If my child is given a treatment by my physician that I do not agree with, I am likely not to take it.
30. I do not always have my child do what my physician or health care worker has asked him/her to do.
31. Health professionals are primarily responsible for seeing that my child’s condition improves.
32. Following doctors’ orders to the letter is the best way to keep my child’s condition from getting worse.
33. The type of help I receive from other people pretty much determines how quickly my child’s condition is going to improve.
34. In order for my child’s condition to improve, I have to depend on many other people to see that the right things happen.

35. Regarding my child’s condition I should only do what the doctor tells me to do.

36. If my child’s condition worsens, it is my own behavior which determines how soon he/she feels better again.

37. I feel quite directly responsible for my child’s condition getting better or worse.

38. Whatever goes wrong regarding my child’s condition is pretty much my own doing.

39. The main thing that affects my child’s condition is what I myself do.

40. If my child’s condition takes a turn for the worse, it is most likely because I have not taken proper care of him/her.

41. I tend to give myself the credit when my child’s condition improves and the blame when it gets worse.

42. I’m the one with the main responsibility for what happens to my child’s condition.

43. No matter what I do or anyone else does, if my child’s condition is going to get worse, it will get worse.

44. Most things that affect my child’s condition happen to him/her by chance.

45. Luck plays a big part in determining how my child’s condition varies from day to day.

46. Whatever improvement occurs in my child’s condition is largely a matter of good fortune.

47. If my child’s condition worsens, it’s largely a matter of fate or happenstance.

48. As far as my child’s condition is concerned, whatever will be will be.

Please continue on to the next page to respond to the open-ended portion of the survey.
The next questions, please respond openly and honestly about your feelings. The more thorough you are in your responses the more accurate the results of this study will be. Please use the additional sheets of paper and/or the back of this survey for additional response space.

49. Explain any anxiety, uncertainty, questions, or concerns you have about your child’s illness.
50. How do you seek the answers to your questions or deal with your anxiety or uncertainty about your child’s illness? Do you call your physician, research on the Internet, talk with your pediatrician, etc.? Explain how you educate yourself and your child:
51. How knowledgeable do you feel about your child’s condition? Do you feel capable of explaining the actual condition, treatment options, and future progression of your child’s hemangioma or vascular malformation to your family, friends, pediatrician, etc.?

Please continue on to the next page to respond to the demographic portion of this survey.
Demographics

52. How many times have you visited the Cincinnati Children’s Hospital Medical Center Hemangioma and Vascular Malformation Clinic?
   1 = This is our first visit  3 = 6 – 10 times
   2 = 2 – 5 times   4 = More than 10 times

53. Child’s Age.

54. Child’s Sex:  1 = Male   2 = Female

55. Your Age in Years.

56. Your Sex:   1 = Male   2 = Female

57. Your relationship to patient:
   1 = Mother   4 = Grandfather
   2 = Father   5 = Aunt/Uncle
   3 = Grandmother   6 = Other Legal Guardian

58. Child’s condition (diagnosis as of today’s date):
   1 = Arteriovenous Malformation   5 = Vascular Malformation
   2 = Capillary Malformation       6 = Venous Malformation
   3 = Combined Vascular Malformation   7 = Hemangioma
   4 = Lymphatic Malformation       8 = Unsure

   9 = Other (please describe):

59. Highest level of education you have completed:
   1 = Some High School   4 = College Graduate
   2 = High School Graduate   5 = Some Graduate School
   3 = Some College   6 = Graduate Degree

60. Yearly household income:
   1 = $15,000 or below   4 = $51,000 - $75,000
   2 = $16,000 - $30,000   5 = $76,000 - $100,000
   3 = $31,000 - $50,000   6 = $100,000 or above

Thank you for your participation!