The Experience of Puerto Rican Families Who Bring Their Children to the Emergency Department for Asthma Care

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University of Connecticut 2006

The aim of the study was to describe the experience of Puerto Rican families who brought their child to the emergency department (ED) for asthma care.

Asthma is the most common chronic pediatric disease, affecting 6.3 million children in the United States and accounting for 728,000 visits to the ED in the year 2000. Black and Hispanic children are frequent visitors; however Puerto Rican children use the services most often. The volume, patterns and populations of children who use the ED for asthma care have been extensively studied, although to date there are no known studies that have explored the ED experience for asthma care inductively from the perspective of Puerto Rican families. Understanding the experience of these families may shed light on why and how they utilize the ED for asthma care.

Using a qualitative method, the researcher conducted an in depth exploration of the ED experience. A hermeneutic phenomenological approach combined the use of descriptive and interpretive methods to explore the essence of the ED visit. English and Spanish speaking participants were recruited from an urban asthma clinic in the Northeast. Interviews were taped, transcribed and
reviewed with each participant. In addition, a multidisciplinary panel reviewed the results to avoid bias and selective inattention.

Rich quotes about the toll asthma has taken on the families emerged during the analysis. Ten themes including “In awe of asthma” and “The folklore of asthma in Puerto Rican families” provided insight into the experience of families as they sought care for their child. Field notes from direct observation in the ED, clinic and neighborhoods enhanced the text.

The results illuminated the impact of asthma on the Puerto Rican families participating in the study. The interviews provided insight into the human experience associated with the published statistics about ED use in this population.
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Dedication

Thank you to all the families who shared their experiences. Your willingness to speak openly helped me “see”. This new insight will guide my practice and hopefully the practice of other health care providers.

To Sue Martel M.S.N. (1958-2004), my dear friend, we made the journey through BSN and MS together. I know you were with me on this last leg of the trip. I miss you.
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CHAPTER ONE: INTRODUCTION

Asthma is the most common chronic pediatric disease, affecting 6.3 million children in the United States (US) and accounting for 728,000 visits to emergency departments (ED) for asthma care in the year 2000 (American Academy of Allergy Asthma and Immunology, 2003). Black and Hispanic children use the ED for asthma care more than other ethnic groups in the US; however the greatest use is by Puerto Rican children (Boudreaux, Emond, Clark, Camargo, 2003; Katten et al, 1997; Ortega, Gergan, Paltiel, Bauchner, Belanger & Leaderer, 2002). Researchers have examined numerous variables including socio-economic status (SES), geography, insurance status and physiologic status of the child, including asthma severity and lung function, in an effort to explain the frequent ED use by this population. Repeatedly, the outcomes show that children of Puerto Rican descent use the ED more, even when controlling for all the aforementioned factors.

The volume, patterns and populations of all children who use the ED for asthma care have been extensively studied (Battleman et al, 2001; Christakis, Mells, Koepnsell, Zimmerman, & Connell, 2001; Ford et al, 2001; Homa, Mannino, Lara, 2000; Katten et al, 1997; Lara et al, 2003; Ledogar, Penchaszadeh, Garden, Acosta, 2000; Young & Kellerman, 1996). To date, however, there are no known studies that have explored the ED experience for asthma care inductively from the perspective of Puerto Rican families. Little is known about why these
children and their families use the services in such large numbers. Why do Puerto Rican children access services at a disproportionately higher rate than other children their age? How do Puerto Rican families make the decision to bring their children to the ED for care? What is the experience of care in the ED for a Puerto Rican family? A phenomenological study of Puerto Rican family members’ experiences accessing asthma care in the ED can begin to provide some answers to these questions and perhaps guide culturally sensitive interventions for children with asthma and their family. The family member makes the decision on where and when to access care for his/her child; therefore interviews with parents and caregivers may give insight into the decision making process and the phenomena of the use of the ED for asthma care.

The aim of this study was to describe the lived experience of Puerto Rican families when they brought their child to the ED for asthma care. Using van Manen’s hermeneutic phenomenological approach, the researcher interviewed families, asking them to share the details of their visit(s) to the ED. The goal of the inquiry was to explore the essence of the experience and provide a vivid account of the life world of the participants. “Lived experience is the starting point and end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of its essence, in such a way that the effect of the text is at once a reflexive re-living” (van Manen, 1990, p.38). The use of a hermeneutic phenomenological approach provided Puerto Rican family...
members with an opportunity to describe the ED experience in their own words.

The experience for these families was influenced by many factors, some of which may have been directly related to their ethnic background. It is commonly believed that the Puerto Rican population is unique among the Hispanics in the United States. They often live in two different cultures, migrating from the island to the mainland, thus operating in two societies, one Anglo dominant and the other their native land. How these attributes influence the life world of Puerto Rican families when they used the ED for asthma care has not been studied to date.

An in depth understanding of the ED experience could guide culturally sensitive interventions for asthma care. Cultural influences have been shown to influence health-seeking behavior. Walsh et al used the term “unpacking cultural factors” (Walsh, Katz, & Sechrest, 2002, p. 1129) to describe the process of looking beyond a simple ethnic/race designation to depict a population. Inquiring about beliefs, attitudes and influences of the individual's environment provides more insight than a simple broad ethnic designation. In Walsh's study, cultural beliefs and attitudes were more highly correlated with favorable diabetes management outcomes than ethnicity alone.

In addition to unpacking cultural influences, the researcher must commit to the phenomena. "Even minor phenomenological research projects require that we not simply raise a question and possibly soon
drop it again, but rather that we ‘live’ this question, that we ‘become’ this question” (van Manen, 1990, p. 43). During the course of the study, the researcher spent time in the clinic and neighborhood the families called home. Hours were logged in the clinic and ED as well as periods of time spent observing in the ED waiting room at various times of the day. Field notes from these sessions were intertwined with the interview transcripts and a folktale to create a vivid text that shows the reader compelling and insightful descriptions of the ED experience as the families lived it.

The clinician as reader is challenged to stay vigilant to the lived experience of children and families and avoid viewing the world strictly through surveys, graphs and tables. Descriptions of lived meaning in a phenomenological text can enhance the nurse’s awareness of the patient experience. Ontological inquiry brings the clinician into the life world of the families. Plato stated “it is impossible to heal the body without knowing something about the soul, indeed without knowing something about the nature of the whole” (van Manen, 1997, p. 319).

The following text is an attempt to capture the essence of the lived experience for the study participants. Each family had a story to tell. Those stories and field notes are the building material used to create the final text. The text emerged from the writing and rewriting, from the pieces merging into the whole, from the spirit of the families. Perhaps this example of human science will help health care providers get closer
to the life world of the Puerto Rican children and their families as they use the ED for asthma care.

The following chapters include the philosophical underpinnings of hermeneutic phenomenology and the qualitative method used to conduct the study. Current studies on asthma, use of the ED, culture and spirituality, as well as parenting a child with asthma, are included in the review of literature. In addition, more specifically quantitative studies on the use of the ED by Puerto Rican families are incorporated. To date, there are no qualitative studies looking at the use of the ED for asthma care by Puerto Rican families. The methods chapter provides the step by step process used to collect data as well as attention to human subjects consideration and methodological rigor.

In summary, children of Puerto Rican descent are using the ED for asthma care at a disproportionately high rate compared to their white and black peers. This phenomenon is well documented in the quantitative literature; however, at the time of this study there were no known qualitative studies looking at these phenomena.
CHAPTER TWO: PHILOSOPHICAL UNDERPINNING

This chapter provides insight into the philosophical underpinnings of the method used in the study. Hermeneutic Phenomenology is a human science approach to research, grounded in philosophy and psychology. It is both a philosophy and a method. van Manen's approach to phenomenology combines the best thinking of the scholars who espoused human science. However, he states that the work of those Dutch and German scholars had a "marked unconcern with methods and epistemology. Students of outstanding scholars such as [named students] were meant to learn the process by osmosis or apprenticeship, which the Germans called "Bildung"(van Manen, 1990, p.7). van Manen talks of his interest in human sciences beginning in the 1960s while studying pedagogy in the Netherlands. His orientation to teacher education was influenced by the German Dilthey-Nohl school and the Utrecht School which was of Dutch origin. He self-proclaims his work is a blending of those traditions. The chapter begins with a review of the major contributions to the development of phenomenology.

Dating back to religious scholars in the 1700s, including Immanuel Kant, phenomenological inquiry focused on description and meaning of an experience. It was born as a critique of positivism. Hermeneutics comes from the name of the Greek god, Hermes. As the messenger to the god Zeus, Hermes interpreted his messages to the people. As the method evolved, the focus on rigor and comparison with natural science began.
Wilhelm Dilthey (1833-1911), a positivist thinker, who was moving away from positivism, is credited with making the distinction between Human Science and Natural Science (Palmer, 1999). The difference, in simple terms, is that natural science focuses on things and human science focuses on persons. He further clarified this division by saying that the difference is that natural science explains and human science understands. He felt strongly that all experience must be related back to the consciousness from which it arises and that impressions of the world are conditioned by the sense organs. He believed that each “thing” was defined by the beholder of the “thing” and had meaning only in the content of the objectivity of the person who holds the “thing” in their possession or consciousness. As a result, the world is framed through the eyes of each individual, through the eyes of the person experiencing it. In his deviation from positivism, he declared there are no causal explanations and life is understood through description. Philosophy, as Dilthey describes it, analyzes and does not create. If we use a modern example, Dilthey saw life in sound bites as experienced by each individual and when the sound bites are spliced, reality is created.

The belief that information cannot be obtained without understanding helped to frame the human science paradigm. Dilthey, however, came in conflict with his own philosophy when he set his focus on developing a rigorous, objective natural science-like method to collect data for human science research. Despite this effort to mimic natural
science on some level, he remained steadfast on the need to examine how humans live in the world. He believed that nature can be explained but human life must be understood. The understanding of the human experience is the basis for phenomenology.

The German influence on phenomenology had its roots with Edmund Husserl (1889-1976). He was a central figure in the movement who also had the desire to develop a rigorous humanistic science. Husserl reflected relativism (anything can be true but truth is relative). His belief was that phenomenology was a priori, meaning that conclusions arose from what had already been decided. The lived experience that came before shaped the experience and decided the conclusion. His view was that truth already existed even if no one conceived the truth. He stated that “…sciences of matter of fact and experiential science are equivalent concepts” (Husserl, 1982, p.16) He argued that as the human science researcher enters into the project; he/she should do so without any “pre-given philosophical standpoint”. He contended the findings of phenomenological inquiry are “actual beginnings”. Husserl believed that the researcher entered the process being aware of his or her individual ego, which was put aside for the inquiry. In the process the researcher was clear about what he or she brought to the study in the form of knowledge and preconceived notions. Putting aside this taken-for-granted natural attitude, one could then embrace a phenomenologically reflective attitude and enter the study free of outside influence. Husserl
stated: “In our fundamental findings we have presupposed nothing, not even the concept of philosophy, and thus we shall also proceed in the future” (Husserl, 1982, p.36). This process was described as bracketing.

Husserl (1982) discussed bracketing as one way human science could mirror natural science in his general introduction to pure phenomenology. He spoke of “parenthesizing every objectivity” (p.60). If the researcher completely shuts out any judgment he/she leaves the natural attitude and can be “free of theories” and see the experience as it clearly shows itself. He went on to speak of entering a “new region”. The researcher opens him/herself to the essence of the lived experience (p.6).

Husserl was originally a mathematician and this background was influential in the development of the concepts of extracting essences from what the consciousness had produced. The use of essences was a systematic, logical way to extract information from the account of the lived experience, moving phenomenology to an eidetic science.

Throughout his written work, Husserl justified human science on a par with natural science but often found himself in some conflict on the fine line about how science is influenced. He stated: “There is no science of matters of fact which were, if fully developed as a science (sic), could be pure of eidetic cognitions and therefore could be independent of the formal or the material eidetic sciences” (p. 17)

Husserl often spoke about the “thing” which later would be embellished by his student Martin Heidegger. “The perceived physical
thing can exist without being perceived, without even being potentially intended to; and it can exist without changing. The perception itself however is what it is in the continuous flux of consciousness and is itself a continuous flux; continually the perceptual 'Now' changes into the enduring consciousness of the 'Just Past' and simultaneously a new 'Now' lights up” (Husserl, 1982, p. 87).

When the researcher turns to the “thing”, he or she is seized by it and the turning becomes a valuing act. However, one cannot reflect on an experience while living it. The experience does not have to be “real”; it can be in the imagination or in one’s memory; how the participant sees it. Husserl stated that the lived experience was not easily accessible and often taken for granted. The task of really “seeing” what is around us requires phenomenological study.

Phenomenology took on a new dimension with the influence of Martin Heidegger (1889-1976). As discussed, he was a student of Husserl who took a different path; he proposed interpretation as part of phenomenological inquiry. He parted from Cartesian subject/object duality and understanding achieved just by being in the world. His belief about truth was that it only existed in the context of someone to conceive it, which was in contrast to his teacher. In order to illuminate the contrast we can use an example of a simple rock. For Husserl this rock exists no matter if anyone conceives of the rock or acknowledges its presence. For Heidegger, the rock only exists when someone describes it as a rock and
brings it to expression, being with it in the world. Heidegger strays from a priori knowledge and focuses on the lived experience. In his book *Being and Time* (1953), he wrote about returning to the "things" to start the inquiry. "It is the 'things' themselves, from the depths of their silence, that it [phenomenological inquiry] wishes to bring to expression." The researcher "must begin with the phenomena, 'The Things', while the study of theories is secondary" (Heidegger, 1962, p. 3). He believed the 'things' of the world speak for themselves.

Heidegger also focused on human existence from an ontological perspective where one looks at the world from the standpoint of being in the world. This human existence or simply being is what he called Dasein. He spoke of being authentic by seeing oneself in relation to the world. Those who are unauthentic, are ambiguous and live their lives based on daily routine, following the crowd. Dasein is a critical concept in his Phenomenologic inquiry, as it places the researcher in the life world of the participants.

Heidegger dedicated his book to his teacher; however he parted from him both philosophically and politically. Philosophically, Heidegger did not believe a researcher could enter into phenomenological inquiry without preconceived notions and completely free of bias. He did not believe one could completely bracket his or her thoughts. Politically, World War two split Husserl, a Jew, and Heidegger who took up arms with the Nazis. It is said that Heidegger turned his back on his teacher at a time
when he was persecuted for his religious beliefs. At the end of the war Heidegger was banned from Germany for his participation in the Nazi regime. He took up residence in France and influenced the French phenomenologist.

The question and book title; *What is phenomenology?* was asked and answered by French philosopher Maurice Merleau-Ponty. Also rejecting the Cartesian mind/body duality, he stated, “It is philosophy intent upon being an exact science, but it is also an account of space time and the world 'as lived' (Merleau-Ponty, 1956, p.59). He proposed that phenomenology allowed for deeper understanding of everyday life experiences. “A genuine conversation gives me access to thoughts that I did not know myself capable of, that I was not capable of…” (Merleau-Ponty, 1968, p. 13). The accounts of specific times and events of the “lived experience” are the result of Merleau-Ponty’s contributions to the method.

van Manen developed the process of researching lived experience by providing a frame-work from which to proceed in human science research. This framework is built on the philosophic base described in the preceding paragraphs. In the text the philosophy is translated to a method, however due to the nature of the method the researcher is prompted to revisit the philosophical roots while using it. Hermeneutics as a philosophy requires the researcher to question Cartesian duality, identify their ego
and bracket it as they enter the life world of the participant to obtain the interviews.

In summary, phenomenology evolved from a religious base in the 1700s to modern day. The major contributors to the method began with Edmund Husserl who believed the human science researcher was an outside observer, bracketing him/her from the process of data collection and analysis. Martin Heidegger, the student of Husserl, proposed interpretation as part of the Phenomenologic process. The French influence of Merleau-Ponty and others brought phenomenology into the modern times. van Manen's hermeneutic phenomenology was heavily influenced by the Dutch and German schools of thought. His focus was on the creation of the written text as the vehicle to convey the findings of the Phenomenologic inquiry.
CHAPTER THREE: REVIEW OF LITERATURE

Introduction

The following chapter is the review of literature. The chapter is divided into three sections. Section one addresses asthma from several perspectives. The initial discussion is a review of asthma statistics which includes an overview of the morbidity and mortality of asthma in the US and more specifically in Connecticut. This is followed by a description of asthma care and use of the Emergency Department (ED). The use of the ED services by Hispanic Puerto Ricans for asthma care is discussed, offering some hypotheses on the reasons for that frequent use.

Section two is an overview of culture and spirituality as related to Puerto Rico and its citizens. This section examines the literature on culture in relation to health care decision making and the use of folk medicine.

Section three examines qualitative and quantitative studies on parenting children with chronic illness and more specifically children with asthma.

Asthma Statistics

The magnitude of asthma is best defined by the statistics mentioned in the introduction of this paper: Asthma is the most common chronic pediatric disease, affecting 6.3 million children in the United States and accounting for 728,000 visits to emergency departments (ED) for asthma care in the year 2000 (American Academy of Allergy &
Immunology, 2003). This section will look at asthma and more specifically ED use for asthma care.

The American Lung Association states in a fact sheet on their web site that of the 6.3 million children with asthma in the US, 4 million suffered from an asthma attack in 2003. In 2002 there were 4,000 deaths from asthma (all ages). Asthma is the third leading cause of hospitalization for children under 15 years of age (American Lung Association, 2005).

It is clear asthma morbidity and mortality are significant in the US and so is the financial impact on direct health care costs, which is estimated at about $11.5 billion dollars. In addition to the direct cost, there are indirect costs of asthma. Each one of the estimated 12.8 million missed school days is a potential missed day of work for a parent. The additional cost of prescription drugs for asthma is estimated at $5 billion dollars, placing indirect costs at an estimated additional 4.6 billion dollars a year (American Lung Association, 2005).

These remarkable statistics have brought asthma care to the national spotlight. In 1998 the President's task force on Environmental Safety Risk to Children declared asthma a national epidemic (Lessard, 2004). Because of its impact on health in the US, improvement in asthma care and emergency department use have become objectives of Healthy People 2010 (US Department of Health and Human Services, 2005).

On the local level in Hartford, Connecticut (CT), asthma is also pervasive. In a report posted on the Healthy Hartford, CT website, 15% of
the adults in Hartford were reported as having asthma. The statistics, which were broken down by race/ethnicity, revealed that 50% of the Hispanic households reported a member of the household with asthma. More households in poverty reported asthma, with 44% asthma incidence versus 25% for higher income households in Hartford.

In the spring of 2004, Hartford was rated the tenth worst city for asthma in the country by the Asthma and Allergy Foundation of America (AAFA) (Asthma and Allergy Foundation of America, 2004). The cities were ranked based on 15 individual factors that included asthma morbidity and mortality, air quality, smoking laws, as well as medical factors including number of prescriptions and asthma specialists per capita. AAFA goes on to say that 8.7% of school children in Hartford have asthma overall. In a further breakdown of the Hartford school statistics, 7.8% in elementary school, 10.2% in middle school and 9.4% of high school students were reported to have asthma (Asthma Allergy Foundation America, 2004). From these reports it is clear that asthma is a national as well as a local (Connecticut) epidemic.

Asthma Care

Asthma care has been well described in the literature. The National Heart Lung and Blood Institute (NHLBI) initiated guidelines for the care of asthma in the early 1980s (National Heart, Lung and Blood Institute, 2005). These guidelines were based on expert opinion and were widely disseminated in the health care arena. The guidelines were updated in the
late 1990s to reflect changes in practice and the addition of new medications. The intent of the guidelines was to help providers and patients manage this complex, chronic illness. The routine management of the illness has been aimed at keeping asthma sufferers active in daily life and helping them avoid trips to the ED for care.

Emergency Department Use for Asthma Care

There is a robust collection of quantitative studies on use of the ED for asthma care. The following section examines ED use by children with asthma. All the studies in this section are quantitative analyses of patterns of ED use. There are no known qualitative studies on this topic. The large numbers of children using the ED is thought to be a reflection of uncontrolled asthma.

This section also examined several other variables including environment, beliefs about health and ethnic origin are examined. The Latino/Hispanic designation used in many of the studies is very broad and includes many different groups including Mexicans and Puerto Ricans as well as numerous other Spanish speaking countries. Each of these subgroups of Hispanics is unique, not only in culture, but also in geographic location of their residence in the United States. Figure 1 shows the geographic distribution of Hispanics in the US.
Lara et al (2003) examined Emergency Department use for asthma care in a Latino inner city population in Los Angeles. Using a bilingual patient survey and retrospective chart reviews, she had a sample of 234 children who had used the ED, 69% of whom were Latino. Outcome measures included acute need for services based on objective physiologic measures, extent to which the child experienced barriers to primary care before the ED visit, and the importance caregivers assigned to the worsening symptoms. Based on the survey that inquired about the caregivers perception of need My child's symptoms are getting worse, 96% of the caregivers stated they came to the ED because the child's symptoms were worse. This study correlated physiologic measures with parent perceptions in one subset of Latinos. They discussed the fact that parents bring their children to the ED for real symptom as perceived by the parents. The participants were bilingual and the sample was fairly large; however the findings are not necessarily transferable to all Latinos. Given the geographic location of the study and the geographic distribution of
Puerto Ricans in the US it is most likely most of the participants were not Puerto Rican.

Ford et al (2001) examined patterns of emergency department use by adults for asthma in Harlem. The population was predominantly African American; however, he referenced Hispanics (9% of the study population) as high users of the health care system for asthma. He stated that ED use is a reflection of asthma management failure and that these visits can be avoided. He attributed poverty and access issues as reasons for the increased ED utilization. He does recognize that poverty is shared by all members of the target community, and therefore there may be other factors influencing ED use. He pointed out that there was a slight relationship between mental health status and internal locus of control and ED use. The participants with depression and those who did not feel in control of their health were likely to be frequent users (OR 1.1 and 1.5 respectively) of the ED. He made no mention on how the participants perceived their symptoms in this study.

Christiansen et al (1996) studied 998 fourth grade students with asthma in San Diego. The majority of the children were Mexican-American living in an impoverished area of San Diego. In this study the Hispanic children (all subgroups including Puerto Ricans) missed more school, used the ED more and were less likely to have insurance coverage compared to their white and black classmates. This information is congruent with the National Health and Nutrition Examination Survey
(NHANES) assigning the highest prevalence for asthma to Puerto Ricans 11.2% in the 6 month to 11 year old age group compared to Mexican Americans at 2.7%.

Boudreaux et al (2003) and colleagues examined racial/ethnic patterns in the use of the ED for asthma care in New Jersey. The sample was 1095 children with 62% African Americans and 23% Puerto Ricans. These two groups had a higher incidence of ED use in the past year, despite no difference from the rest of the sample in asthma severity, hospitalization length or post discharge outcomes. The black and Hispanic children were from households with lower socioeconomic status (SES) and were less likely to have insurance; however they were as likely to have a primary care provider (PCP) as the other children in the study. Although the black and Hispanic children had more severe asthma as evidenced by past history, they presented to the ED with disease equal in severity to their white counterparts. This study examined the influences that drive ED use. Is it a greater physiologic need or are other factors, such as SES, more influential? McConnochie et al (1999), questioned whether a higher incidence of hospitalization may be warranted in some cases, specifically in lower SES. Their review of 2028 records of children hospitalized for asthma in Rochester NY, age 1 mo to 19 years old, found that inner city males were more likely to be hospitalized for asthma. He proposes that the higher incidence of hospitalization among this population is because of more severe disease and not based on SES. He
feels the admissions are not over utilization but greater need based on clinical criteria.

The variables of SES and race/ethnicity influence on ED use for asthma care are described in the discussion that follows. The hypothesis presented is that lower SES and certain racial and ethnic backgrounds are a proxy for poor health. Morales, Lara, Valdez and Escarce, (2002) discuss the problems with data about Hispanics. As an ethnic/racial group, Hispanics have often been mislabeled and miscounted in both US Census and other data used by researchers. They are included as a homogeneous group yet when the sub groups are broken out in data analysis each one (e.g. Mexican Americans, Puerto Ricans, Cubans) has very distinct patterns of health and illness. This makes it difficult to compare some studies if the Hispanic subgroups are not clearly identified.

There were several articles that examined ED use through the lens of SES and continuity of care with primary care. Christakis et al (2001) looked at 46,000 pediatric patients enrolled into a group health HMO. They examined the use of the emergency department and the relationship to continuity of care. Participants were stratified according to Medicaid coverage, which can be a proxy for SES. They found that decreased continuity of care was associated with more frequent ED use. In addition the children covered by Medicaid were more likely to use the ED for care.

Liu et al (2001) examined health care utilization and sociodemographic information from the records of 2927 patients 12 years
and older who were enrolled in three health plans. Over one half resided in the Northeast. The demographics revealed that Hispanics made up a large percentage of the severe asthma patients in the study. The odds ratio of severe asthma if one was Hispanic was 1.74 followed by African Americans at 1.54 indicating that the Hispanic participants are at greatest risk for asthma.

Amre, Infant-Rivera, Gautrin & Malo (2002) described SES and utilization of services, most specifically ED use and hospitalization in children who had universal access to health care in Canada, thus removing the financial barriers often encountered in studies in the states. They found that SES did not influence ED use but did have an impact on hospitalization. Children who were in the lower SES bracket were more likely to be hospitalized.

Lieu et al (2002) followed a cohort of children in a Northeast region who had asthma and were in managed Medicaid. They used the American Academy of Pediatrics (AAP) Children’s Health Survey for Asthma to measure parent reported asthma status. In addition they looked at the statistics from the HMO records to assess asthma status and some other variables. There were 313 self identified Latino children of whom 137 were Puerto Rican. The Puerto Rican children had lower parent reported AAP scores compared with other Latino children. They also had lower emotional and activity scores. Overall the study reinforced the notion that
Black and Hispanic children in the Managed Medicaid population had a lower asthma status than white children.

Ortega et al (2002) surveyed 897 children (93% of the Hispanic children were Puerto Rican) with active asthma that were screened at Connecticut hospitals. The objective was to develop and test an asthma severity scale. The results showed that the score on the severity scale was uniform across the black, white and Hispanic children; however the ED utilization by the Puerto Rican children was statistically significantly greater than the White or Black children.

In another study that looked at the site of care and how that impacted medication use, Ortega et al (2003) again demonstrated that, despite an identical asthma severity score, black and Hispanic children had more urgent visits for asthma. Ortega and colleagues also explored the use of services by insurance status of children with asthma. He found that race and ethnicity did not modify the relationship between insurance status and health care use. He suggested further studies look at maternal attitudes and beliefs about asthma.

Another variable examined in an attempt to analyze ED use was environment. Ledogar et al (2000) studied inhabitants of a large housing unit in Brooklyn. The population of the building was made up of 3015 people in 946 households. The ethnic breakdown was 46% Dominican, 42% Puerto Rican, 6% other Latino and 6% other. The results showed that 5.3% of the combined Dominicans and other Latinos had asthma,
while 13.2% of the Puerto Ricans had asthma. The results were not explained by housing, household size, use of home remedies, educational attainment or education. This raised the question of the role of genetics in asthma for this population.

Several authors examined asthma morbidity and mortality and found similar findings. Carr, Zeitel & Weiss (1992) and colleagues examined data on asthma deaths and hospitalizations in New York for people 0-34 years old. They discovered that Blacks and Hispanics were 3 to 5.5 times more likely than whites to be hospitalized or die from asthma. They also noted that geographically the Blacks and Hispanics lived in the poorest neighborhoods. In another study looking at morbidity in children already identified as low income, foreign born Hispanics had significantly more ED visits than whites or blacks although they used less controller medications and reported less illness severity. Because this study was done in the West it is likely fewer of the participants were Puerto Rican (Klinnert, Price, Lieu & Robinson, 2003).

Homa, Mannio and Lara (2000) specifically examined Hispanic subgroup mortality in the 1990s. The three groups examined were of Mexican, Puerto Rican and Cuban heritage. They found that from 1990 - 1995 national and regional mortality for Puerto Ricans were higher than other Hispanic subgroups and, more specifically, higher in the Northeast. This helps to substantiate the importance of looking at Hispanics who are not put in subgroups by geographic regions. Based on their research
findings they concluded that not all Hispanics are at increased risk for death. They went on to say that differences in health beliefs and acculturation between Hispanic subgroups are important to consider. The researchers briefly discuss genetic predisposition, which is another avenue for research. They stressed looking beyond disease severity, physiology and access to care, to the participants' beliefs about asthma, management of the disease, and use of folk remedies as some variables that may contribute to the findings.

There is an emerging body of literature examining genetic variation and physiologic response to asthma in the Hispanic population. Gonzales et al (2004) compared 684 Puerto Rican and Mexican study participants' response to bronchodilator therapy. The measure of response was change in FEV1. The authors concluded that the Puerto Ricans with asthma had more severe disease and less responsiveness to the bronchodilator therapy. In collaboration with Brigham and Woman's Hospital in Boston, Connecticut Children's Medical Center (CCMC) and the University of Connecticut (UCONN) researchers allergy tested 791 children living in Hartford, 312 or over one third (39%) were Puerto Rican. The results showed that Puerto Rican children with asthma were three times more likely to be allergic to cockroaches and twice as likely to be allergic to weed mix as white children with asthma. This is an area ripe for further investigation (Burchard et al, 2004).
Cultural Influence

Cultural influences have been shown to impact health-seeking behavior. Walsh, Katz, and Sechrest (2002) use the term “unpacking cultural factors” to describe the process of “looking beyond a simple ethnic/racial designation to describe a population” (p.1129). They go on to say that “Inquiring about beliefs, attitudes and influences of the individual’s environment provides more insight than a simple broad ethnic designation” (p.1129). In their study, cultural beliefs and attitudes were more highly correlated with favorable diabetes management outcomes than ethnicity alone.

The definitions of culture for the purposes of this project are as follows: a) Oxford Dictionary (1980): “the customary beliefs, social forms and material traits of a racial, religious or social group” (p.208) and b) Huff and Klein (1999) who are social scientists: “Culture in any group or subpopulation can exist as a total or partial system of interrelationships of human behavior guided and influenced by the organization and the products of that behavior” (p.3).

Hispanic culture and health care have been studied with regard to health promotion, HIV/AIDS and diabetes. Many of these studies describe major attributes of the Hispanic culture and its influence on health-seeking behaviors. Hispanics were described as: more fatalistic (fatalismo); having a strong religious influence in decision-making which could cause the family to relinquish much control to God; using Western medicine as a last
resort behind self-care, help from family and friends, and folk medicine; not likely to have access barriers due to insurance coverage; seeking trust (confianza) with their health care provider (HCP); and considering personalized care (personalismo) to be critical in the relationship with the HCP. Acculturation, shown to play a role in how much influence the aforementioned cultural beliefs have on health-seeking behavior, is addressed in many of these studies as a contributing factor (Duggleby, 2003; Larkey, Hecht, Miller & Alatorre, 2001; van Servellen, Chang, Lombardi, 2002; Walsh et al, 2002)). More specific information about Puerto Rico and Puerto Rican culture follows.

Puerto Rico

Puerto Rico’s main island and satellites cover 2,000,000 acres of land. It lies between the Atlantic Ocean and the Caribbean Sea. Approximately three-fourths of the island is mountainous with elevations up to 4,400 feet. The climate is temperate at the coast and there is little variation in the mountains with mean temperatures 73.4 in the winter and 78.9 in the summer.

The population of Puerto Rico is a rich blend of Indian, Black and White cultures. The earliest inhabitants were believed to migrate from Florida to Cuba and on to Puerto Rico. The Taino (Indian) culture evolved on the island. They called the island Borquen, island of strong men. The Indian heritage is still present even after years of Spanish influence. Over the years Columbus, Ponce De Leon and others came to the island to visit
and some stayed. Some of the visitors and conquerors mistreated and subjugated the native Indians who fought but lost battles to the white men. Over time African slaves were brought to the island as the Indians died out. The integration of Spaniards, Indians and Africans created the rich Puerto Rican culture we know today. This mix is evident in all aspects of the culture (Galucci, 1987).

**Puerto Ricans in the US**

In the US, the Hispanic population is the fastest growing minority with over 35.3 million (12.5%) residing in the US, excluding illegal immigrants. According to the US Census 2002, 8.6% of the US population is Puerto Rican. This group is the third largest Hispanic subgroup following Mexican Americans at 66.9% and Central and South Americans at 14.3%. This is the number of Puerto Ricans on the mainland United States as Puerto Ricans living in Puerto Rico are also US citizens. Geographic distribution of Hispanics is concentrated in certain parts of the country. (see figure 1). Mexicans reside primarily in the West (54%) and the South (34%) while 58% of Puerto Ricans live in the Northeast. Nearly one half of all Hispanics lived in a metropolitan area and Puerto Ricans were the most likely to live in this setting. Hispanics are more likely to live in poverty with Puerto Ricans the most likely of the subgroups to live below poverty level (Ramirez & de la Cruz, 2002).

Despite the numbers of Hispanics in the US, there is limited data on their health patterns and needs. Zambrana and Carter Pokras (2001)
examined the available health data for this group and concluded that data
collection at the national level must be refined to look at all of the
subgroups of Hispanics. In addition, they suggest a renewed national
focus on this fast growing minority, which would include appropriate
instruments for research that are sensitive to ethnic differences. The
American Academy of Pediatrics Latino Consortium has called for a focus
on the health of Hispanic children that includes development of validated
instruments and inclusion in studies. The consensus statement was
reviewed by Flores, Fuentes, Barbot, Carter-Pokras, Claudio, Lara et al in
a 2002 journal article (2002).

Puerto Ricans have the highest asthma mortality rates in the US,
among Hispanic subgroups and non-Hispanic Blacks and Whites.
Mortality rates were higher for those Puerto Ricans in the 0-4 year old age
group and those of all ages living in the Northeast (American Lung
Association, 2003). The Hispanic Health and Nutrition Examination Survey
(HHANES) reported lifetime asthma prevalence at 20.1% for Puerto Rican
children compared with 4.5% Mexican-Americans, 8.8% Cubans, 6.4%
non-Hispanic whites and 9.8% in non-Hispanic Blacks (Homa et al, 2002).

It is commonly believed that the Puerto Rican population is unique
among the Hispanics in the United States. They often live in two different
cultures, migrating from the island to the mainland, thus operating in two
societies, one Anglo-dominant and the other their native land. Rene
Marques, one of Puerto Rico’s most important contemporary playwrights
wrote about this dilemma in his work *The Oxcart*. He stated that the 
Puerto Rican "exists in a schizophrenic society. Puerto Ricans have two 
languages, two citizenships, two basic philosophies of life, two flags, two 
anthems, and two loyalties. It is very hard for human beings to deal with all 
this ambivalence" (Marques, 1969). Inquiry about how these attributes 
influence the decision by Puerto Rican families to use the ED for asthma 
care has not been studied.

*Spirituality and Herbal Medicine*

Puerto Rican culture as mentioned is rich in religious influences. 
The majority of Puerto Ricans are Catholic; however Protestant 
Evangelicals and more recently the Pentecostal movement are included 
as predominant religious influences. Religious beliefs are thought to 
influence Puerto Rican's approach to health and illness. Folk remedies are 
discussed as an integral part of the Puerto Rican culture. In addition there 
is a strong devotion to certain saints. The saying Si Dios quiere (if God 
wants) reflects the belief that God's will prevails. Puerto Ricans are 
believed to use prayer as a coping mechanism to deal with illness or 
death. Patron saints and rosary beads are used to protect and drive away 
evil (Juarbe, 2004).

The overarching themes of spirituality, which could include various 
religous practices and prayer, are a significant component of alternative 
therapy portrayed in literature. Prayer has typically been viewed in the 
biomedical world as obstructionist to prescribed medical care. A group of
researchers Barnes, Plotlikniff & Pendleton (2000) examined spirituality from the perspective of the child, caregiver and provider. In their research on how spirituality is defined and employed by families in times of illness is most relevant for this review. Families are noted to recruit spirituality to help them make sense of illness and ultimately find meaning for that illness. In addition, spirituality, as it was broadly defined in the article, can be a coping mechanism during times of stress. It is commonly thought that religious therapies and practices can become barriers to more conventional medical care (Huff & Kline, 1999). Pachter et al (2002) reported in a cross cultural study of Hispanics which included Mexicans, Guatemalans, Mexican Americans and Puerto Ricans that prayer was not identified as a treatment for asthma by the participants from Connecticut, whom were mostly Puerto Rican families.

Non-traditional home remedies were mentioned in several articles on asthma care. One study specifically asked if home remedies were used. A group of 1511 individuals were contacted and asked questions about traditional healing. African Americans were the most likely to say they would treat their child with home remedies (29%), followed by Whites (21%), and Hispanics (17%) (Roy, Torrez & Conklin Dale, 2004).

**Parenting the Child with Asthma**

The literature review revealed several quantitative studies and few qualitative studies on parenting child with asthma. The studies found in an extensive search of several data bases are described here. In a grounded
theory study, Rydstrom, Englund, Segesten & Rasmussen (2004) examined the impact of asthma on the family. Seventeen mothers were selected by the asthma nurse. The mothers were chosen as messengers for the family. It was also hypothesized by the author that the mother was more relationship oriented. This definition of “relationship orientation” was not clearly delineated in the article, nor was it clear if fathers were not invited to participate or not interested. The use of one family member to speak for all the remaining members was used by this author to include more members in the process.

In the results the authors discussed how the disease takes on “commander of the family” (Rydstrom, 2004, p. 89) They went on to say that asthma is a constant factor in family relations, but that the influence waxes and wanes with disease flare ups. Mothers in the study shared that they always had fear of the death of their child from an asthma attack. In addition, fear, uncertainty and being governed by the illness were also discussed. Families were hyper vigilant to the need to jump to action when an asthma attack hit.

Several authors described the fear felt by families, particularly mothers, when an asthma attack began (Donnelly, Donnelly, & Thong, 1987; Koenig, Chesla & Jebbedt, 2003; Kurnat & Moore, 1999; Rydstrom, 2004). These studies pointed out the apprehension felt by families when the child with asthma became ill. The articles discussed family stressors,
including rigid medication schedules, constant changes of plans to accommodate the illness and marital stress between parents.

Donnelly et al (1987) used questionnaires to assess parental attitudes toward asthma. The questionnaire contained 77 questions and some demographic information. The 128 families who participated were randomly selected from a list of children with asthma who were admitted for their asthma. Overall the parents were pessimistic about the impact of asthma on the child and the family. There was ambivalence about giving medications and the side effects of those medications. This may have biased the sample due to the fact that asthma is usually severe when it requires hospitalization for the child. The second concern with the results was the worry that families exhibited the "courtesy factor" which is the tendency to provide answers that are non-controversial. Overall the results of the study were difficult to interpret due to the way the questions were presented to the families. The answers tended to be related more to the way the questions were worded. For example, questions posed in the positive elicited positive responses and the same for negatively worded questions. There was no information in the article on the development and analysis of the questionnaire prior to the study, which further weakened the results.

Konig et al (2003) studied parents perspectives of the management of asthma of children admitted to the hospital. The study used interpretive phenomenology and attachment theory. The sample included only infants
and toddlers thus narrowing the focus and limiting the generalizability of the results. The authors cited Benner’s (1994) interpretive phenomenology as the method used for the study. There were 11 families interviewed for the study. Parents shared feelings of fear and how they struggled to deal with their own fear and remain present for their child. Fear was mentioned tangentially in regards to the decision to seek care. The main focus of the interview was on the experience of the hospitalization.

Kurnat et al (1999), in a small (14 subjects) unpublished study used Hymovich's Parent Perception Inventory to elicit specific parent concerns about their child's asthma. The author did not share any information about the instrument's reliability, validity or factor analysis. The concerns on the inventory were related to asthma management, medications, child care, and family relationships. The questions did not include any about fear or emergency department use. Due to the small sample and limited information on the instrument, this study does not contribute much to the body of knowledge on parenting a child with asthma. Nor does it lend support to the results in this study.

Fear was mentioned in one study about how families described asthma (Yoos, Kitzman, McMullen, Arcoleo & Anson, 2005). The children in the study talk of the fear they felt when the wheezing begins. This fear was noticed by the parents who responded by trying to speak to health care professionals in order to get help for their child. The article described
a disconnect between the languages of the parent and the health care provider during this conversation.

Coffey (2006), in a recent meta-synthesis, reviewed 11 qualitative studies of parenting children with chronic illness. One of the themes found in the studies was “living with worry”. Parents talked of worrying about the present and the future. One mother revealed how worried she got at night when her child was sick and the dilemma she had over placing a call to the doctor in the middle of the night. Another said, “You expect the worst, something is going to happen” (p52).

There were other qualitative studies that described parenting the child with asthma. Peterson-Sweeney, McMullen, Yoos & Kitzman (2003) interviewed 18 mothers using semi-structured questions. The aim of the study was to ask parents about medication use. The results focused on management of asthma but did not shed any light on parental feelings about asthma.

Maternal fear was evaluated in a study of forty children with asthma recruited from the outpatient department of a Canadian Hospital (Gupta, Guiffre & Crawford, 2001). The researchers compared anxiety and fear of parents and children diagnosed with asthma with those diagnosed with congenital heart disease. They used questionnaires and interviews to gather data. They found that maternal anxiety was an important factor to consider when planning treatment for children with asthma. Children with anxious mothers, even in the absence of any personal mental health
issues, had more fear about medical procedures. The children with asthma had more fear of medical procedures than those with congenital heart defects.

One study examined maternal mental health in relationship to medication adherence and response to asthma attacks (Ortega, McQuaid, Canino, Ramirez, Fritz, & Klein, 2003). The authors concluded, from the sample of 1,891 children living in Puerto Rico, that the mental health of the mother did not seem to impact the incidence of asthma attacks or hospitalization. They did, however; suggest further research into the Puerto Rican families’ perception of asthma.

In summary, asthma is reaching epidemic proportions in the United States (US) and children who are Black and Hispanic are more likely to suffer the most from the disease. Puerto Ricans, who are unique among the Hispanics in the US because they are US citizens and often migrate between the mainland and the island, use the ED for asthma care more frequently than their Black, White and fellow Hispanic peers. Several factors have been examined to determine their influence on ED use, including SES, insurance coverage and disease severity. To date there are no qualitative studies that examine the experience of using the ED by the families of Puerto Rican children with asthma. Finally, parenting a child with chronic illness, specifically asthma, was examined with a focus on fear felt by parents during episodes. The lack of qualitative studies on this topic necessitates further human science studies.
CHAPTER FOUR: METHODOLOGY

Introduction

The following section provides a road map for the process of phenomenological inquiry that resulted in the creation of the phenomenological text in Chapter Five. Part One of this section includes the aim of the study, research question and a definition of hermeneutic phenomenology used to produce the phenomenological text. Part two, outlines the steps taken to gain access to the sample, the sample followed by the demographics of the population. Part three the procedure, presents the step by step process of conducting the interviews, including gaining access, the personnel involved and the challenges of obtaining the data. Part Four is the data analysis presents the process used to analyze the data according to the hermeneutic phenomenological method. The process incorporates the use of art, literature and field notes to enhance the text. Rigor and Human Subject considerations are addressed in the final part of the chapter.

Aim of the Study

The aim of the study was to describe the essence of the experience of Puerto Rican families when they took their child (ren) to the ED for asthma care.

Research Question

What is the lived experience of Puerto Rican families who take their children to the ED for asthma care?
Hermeneutic Phenomenology Defined

A hermeneutic phenomenological approach was chosen for this project to allow the researcher to explore the meaning of the experience for the Puerto Rican family when taking their child to the ED for asthma care. The process of qualitative study illuminates an experience through individual voices of the participants. The writings from the inquiry guide the reader to both read and experience the text. Field notes, close observation and detailed descriptions of the interview process strengthen the findings.

A hermeneutic phenomenological approach combines descriptive and interpretive methods to explore the essence of an experience. The methodological structure of hermeneutic phenomenological inquiry, as presented by van Manen (1990), includes six research activities which are discussed at length in the data analysis section. While using this method, the researcher is reminded that there is dynamic interplay among the activities. Creativity and flexibility are encouraged as part of the method. van Manen (1990) states “A good phenomenological text has the effect of making us suddenly “see” something in a manner that enriches our understanding of everyday life experiences” (p. 345). He goes on to say; “So the expectation is not to arrive at a recipe, a foolproof set of techniques and know-how’s that are guaranteed to produce repeatable scientific result” (van Manen, 1997, p. 316).

The method is simple, clear and emphasizes the writing and rewriting of the text to illuminate the lived experience of the participants.
“Hermeneutic phenomenology is how socially and historically conditioned individuals interpret their world within their given context” (Polit & Beck, 2004, p. 249).

Max van Manen (1990) states: it [hermeneutic phenomenology] is a “project of someone; a real person, who, in the context of particular individual, social and historical life circumstances sets out to make sense of a certain aspect of human existence” (p. 12). Hermeneutics describes how one interprets life by using the text to analyze the data, writing and rewriting the text and including expert opinion. The method allows for incorporation of literature, poetry and art to enhance the reflective process.

The process of phenomenological understanding involves moving beyond the obvious. In figure two, the researcher, based on what she knew at the time, asked the question about why Puerto Rican families go to the ED for care. The figure represents her best thinking about the problem after reading the literature. The figure represents the original research question. Each box in the diagram is a domain of influence on use of the ED as hypothesized by the researcher and reviewed in the review of literature in Chapter 3. At this point she began her hermeneutic inquiry and the quest toward phenomenological understanding. Van Manen states that it [phenomenological understanding] is “distinctly existential, emotive, enactive, embodied, situational, and non-theoretic; a powerful phenomenological text thrives on a certain irrevocable tension
between what is unique and what is shared between the reflective and pre-reflective spheres of the life world. Without this tension, the qualitative research text tends to turn flat, shallow and boring because it loses the power to break through the taken for granted dimensions of every day life" (van Manen, 1997, p. 346). The phenomenological text in Chapter V breaks through the taken for granted presented in figure 2. This figure was created at the outset of the research study to organize the information from the literature that answered the original research question: Why do Puerto Rican children with asthma access care at the Emergency department in greater numbers? Each box was a heading created by the researcher to breakdown the studies in categories and shape the outline for the review of literature in Chapter 3. Many of the studies discussed hypotheses for ED use, and provided numbers of children who used services but none spoke of the meaning of using the ED for asthma care. This revelation moved the research study from a quantitative study to a qualitative study. The figure represents the pre-reflective thinking of the researcher prior to the qualitative study. The interviews and subsequent analysis of the transcripts moved the researcher from the pre-reflective in figure 2 to the reflective in the text of the paper. The writing of the text brought the researcher beyond the obvious to a place where she experienced the essence of the phenomena.
Figure 2 Pre-reflective Paradigm of the Study

**Question:** Why are Puerto Rican children with asthma accessing care at the Emergency Department in greater numbers?

**Systems Issue**
- Medical home
- Access/hours, geography
- Insurance coverage/copay/economic strain
- Transportation
- Wait Time
- Prescription coverage/samples

**Disease Severity**
- Classification/guidelines followed
- Physiologic/Clinical Presentation
- Parent's Perception
- Current Medications
- Comorbidity

**Cultural/Health Belief**
- Beliefs about care
- Health vs. disease mgt
- Value health
- Quality of Life
- Who makes health care decisions in the family?
- Parental assessment of illness
- Acculturation
- Folk Healing Practices
- Spirituality
- Avoidance
- Social Stigma

**Health Care Relationships**
- Relationship with PCP
- Relationship with ED/23 hour staff
- Cultural competence of care providers at each site
- Past experience (positive or negative)

**Environment**
- Tobacco smoke
- Housing
- Pets
- Cockroaches
- Chronic Community Stress

**Education**
- Literacy Level of Parents
- Language barriers
- Education provided to child and family

**Additional Variables to consider:**
- Age of the child
- Time of day of visit/initiation of 23 hour stay
- Seasonal variation
- Current quality of life
- Socioeconomic Status (SES)

**Gaining Access**

The researcher worked as a student intern with the Asthma Center beginning in the fall of 2003 through the summer of 2005. During that time, she accompanied staff during clinic appointments and visited the CCMC emergency department. She shadowed a nurse and physician while observing care of children with asthma. The observed clinic visits with families lasted approximately 30 minutes each. The ED visits were 8 hours
long, observing children arriving for care via ambulance or walk-ins. During this time the researcher, with family permission, made observations of the interactions between staff and family. The researcher also spent time in the emergency room waiting area on several different days at different times of day. At the completion of the observations, she compiled anonymous field notes about the setting and family interaction with the staff.

One entry in the field notes notebook described the demeanor of the mothers who patiently waited to be seen by the pulmonologist in the clinic. They were very respectful and polite. The researcher did the intake interview with the families while at the clinic. She noted how engaged they were during the conversation. The family members listened attentively as the pulmonary nurse gave them information about asthma.

The researcher spent time in all areas of the ED. The waiting area was bright and colorful with many chairs and some toys. All the signs in the ED and throughout the hospital were in both English and Spanish. The triage area was open and the nurses were readily available to greet families the days I visited the ED. The patient care area was a large, clean unit with small single patient rooms. Nursing staff and physicians worked closely together in the busy nurse’s station. The staff relied on translators to facilitate communication with the Spanish speaking families. At times, the translators did not arrive to the ED in a timely manner so the staff often attempted to speak Spanish with the family.
The neighborhood around the Children’s Hospital in Hartford is worn and crowded. The housing projects are in various states of disrepair and the streets are littered with trash. During the summer, the 90 degree temperature radiated from the pavement. The air was so thick and still outside the air conditioned buildings that it seemed to hang in the researchers lungs. The background noise and tail pipe emissions of cars and trucks were constant. The air quality on some summer days was poor. That was often evidenced by the respiratory status of the children in the ED and clinic.

Setting/ Sample

More than one in eight people living in the United States are of Hispanic origin. Of the 37.4 million Hispanics, Puerto Ricans living on the mainland United States comprise 8.6% of the total. The Northeast is home to 58% of this population. Puerto Ricans comprise 40% of the inhabitants of Hartford Connecticut (United States Census, 2002). A 2000 survey by the Hartford Health Department (www.healthy.hartford.gov/Ashtma/AsthConcern.htm) reported that 50% of Hispanic households had at least one family member with asthma. The site of the study, the Asthma Center, is a division of Connecticut Children’s Medical Center (CCMC) located in Hartford, Connecticut. In 2002, the ED at CCMC provided care to almost 2,000 children with asthma, and the Asthma Center enrolled approximately 10,000 families in
Easy Breathing®, an asthma identification and management program offered to all children in the greater Hartford area (personal communication, Michelle Cloutier, Fall 2003). The Asthma Center holds clinics three to four days a week at CCMC and several primary care offices in the greater Hartford area.

The purposive sample was recruited from the Puerto Rican families enrolled in the Easy Breathing® program in the greater Hartford, Connecticut area. Participants were referred to the Asthma Center from a recent ED visit, primary care provider (PCP) visit or an acute care inpatient stay. The child received an appointment for a clinic visit and was enrolled in the Easy Breathing program at that time. The families identified themselves as Puerto Rican on the Easy Breathing survey®. The study criteria required that each participant must be Hispanic Puerto Rican, a parent or legal guardian, 18 years of age or older, with a child 6 months through 18 years old diagnosed with asthma. A visit to the ED for asthma care in the past year was also necessary to enter the study.

Ten women agreed to be interviewed for the study. At the time of the interviews, several were accompanied by male family members who declined to be interviewed. One woman was a grandmother who was the legal caregiver of her grandchild. Their children ranged in age from 18 months to 14 years old. Three of the mothers and the grandmother were exclusively Spanish speaking. Four of the interviews were conducted in Spanish with a translator. The site of the interviews was usually in one of
the patient exam rooms in the asthma clinic; however two were done in conference rooms adjacent to the cafeteria. All the participants had brought their child to the ED in the past year. All but two mothers used the CCMC ED. Four of the mothers reported they did not have a primary care provider for their child. The demographics of the participants are listed in Table 1.
Table 1: Demographics of the Study Participants

<table>
<thead>
<tr>
<th>Language spoken at home</th>
<th>Child's Age</th>
<th>Visits to the ED past year</th>
<th>ED Location</th>
<th>PCP</th>
</tr>
</thead>
<tbody>
<tr>
<td>English and Spanish</td>
<td>2</td>
<td>4</td>
<td>CCMC</td>
<td>Y</td>
</tr>
<tr>
<td>English and Spanish</td>
<td>2.5</td>
<td>1</td>
<td>CCMC</td>
<td>N</td>
</tr>
<tr>
<td>Spanish</td>
<td>6</td>
<td>1</td>
<td>SF</td>
<td>Y</td>
</tr>
<tr>
<td>English</td>
<td>11</td>
<td>3</td>
<td>CCMC</td>
<td>Y</td>
</tr>
<tr>
<td>Spanish</td>
<td>14</td>
<td>1</td>
<td>SF</td>
<td>Y</td>
</tr>
<tr>
<td>Spanish</td>
<td>8</td>
<td>1</td>
<td>SF</td>
<td>N</td>
</tr>
<tr>
<td>English and Spanish</td>
<td>9.18mo</td>
<td>1</td>
<td>CCMC</td>
<td>Y</td>
</tr>
<tr>
<td>Spanish</td>
<td>5</td>
<td>1</td>
<td>SF</td>
<td>N</td>
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<tr>
<td>English</td>
<td>2</td>
<td>1</td>
<td>CCMC</td>
<td>N</td>
</tr>
</tbody>
</table>
Procedure

Interviews were conducted from March through August of 2005 following approval of the University of Connecticut and Connecticut Children’s Medical Center Institutional Review Boards. Originally, the researcher was to attend asthma clinic once a week and invite families with scheduled appointments, who met the study criteria to participate in the study. The clinic show rate is 40-60% despite routine personal phone calls from a bilingual Spanish speaking secretary the evening before clinic. Acknowledging the low show rate, the researcher was still optimistic this method would yield an adequate number of participants. After several weeks of attending clinic with a low yield of participants, the team of clinic nurse and researcher added another strategy to recruit families.

The clinic nurse reviewed records from all clinic days each week and identified any family who met study criteria. During the clinic visit she invited the family to participate and asked if they would accept a call from the researcher to set up an appointment for an interview. If the family agreed, their name was given to the researcher who called them to invite them to participate in the study and arrange an interview. When the researcher called families from an out-of-state phone number, they did not answer the phone or hung up. The first 6 calls yielded only one contact and an appointment for an interview. At this point in the study a bilingual
research assistant with a local phone number joined the team and began to make phone calls to schedule interviews.

The scheduled interviews yielded a low show rate of less than 40%. Many days no participants came for scheduled interviews despite reminder calls the morning of the interview. Most participants lived within blocks of the hospital and some had transportation arranged, yet did not show for the appointment. Two women came for interviews that did not meet study criteria and had to be turned away.

All interviews were conducted at CCMC. Families joined the researcher and research assistant for the audio taped session in a private area in the clinic. The researcher secured written consent in English or Spanish, depending on the participants' preference. The consent form was reviewed in detail with each participant. The research assistant was present for 8 of the 10 interviews to assist with any language barriers during the process. Demographic questions were completed (see Appendix A) and the interview began. Most participants had their children with them during the interview; however the children did not participate in the interview.

Interviews started with the research statement: "Tell me about your experience when you took your child to the ED. Please be as specific as you can and provide all the details." During the interview, probes for clarification were added as needed. The researcher used Professor van
Manen’s suggestion: “get very particular, detailed and concrete stories of events that happened on a particular day at a particular time.” (personal communication, 2003) Each interview lasted about 45 minutes, which included the consent process.

As the interviews proceeded, the probes became more focused, using the themes that emerged from the first six interviews. The interview always began with the original research statement and ended with an open ended question: “Is there anything else you would like to tell us about the experience?”

Four of the interviews were conducted with women who were exclusively Spanish speaking (one grandmother and three mothers). The research assistant was present with the researcher to interpret in all those interviews. The assistant was a bilingual MD/pediatrician from a South American country who was part of the nursing school at the time of the study. He was well versed in pediatric asthma care and in the goal of the study. He studied the research method prior to the interviews, and after each interview he and the researcher reviewed the process and content of the interview.

During the interpreted interviews, the researcher asked the questions, and they were repeated to the participant by the research assistant. He then stated the participant’s answer. In any case where direct translation was not possible, the assistant was careful to state that and say he was making an interpretive statement.
At the conclusion of the first interview, each participant was given a $10.00 gift certificate to a local department store. At the conclusion of the study, all participants were sent a second gift card after the researcher returned to them to interpret the text of the interview.

The tapes from the interview were transcribed by a professional medical typist. For the interviews conducted in Spanish with the research assistant translating, the typist only typed the English part of the interview. Once typed, the transcripts were hand delivered with the tape to the researcher. At that point they were placed in a secure locked location. A copy was sent to each participant and a second interview was scheduled.

The second interview was to clarify any part of the transcript and to seek additional meaning about the experience. These lasted less than 30 minutes. They were done over the phone, which was the preferred method expressed by the participants. The research assistant conducted the second interviews with the Spanish speaking participants.

Data Analysis

The data analysis, according to van Manen's method, includes six steps. These are listed below and will be embellished in the following paragraphs.

The steps as described by van Manen are as follows:

1. Turning to a phenomenon which seriously interests the researcher and commits them to the world
2. Investigating experience as we live it rather than as we
conceptualize it

3. Reflecting on the essential themes which characterize the phenomenon

4. Describing the phenomenon through the art of writing and rewriting

5. Maintaining a strong and oriented pedagogical relation to the phenomenon

6. Balancing the research context by considering parts and whole
   (van Manen, 1990, p. 30)

In step one, the researcher chooses a topic for which she had a great interest from years of clinical practice in pediatric asthma. The commitment to the phenomena required considerable use of time and resources given the distance from the researcher's home in rural Vermont. As described in the gaining access section, many hours were logged in the environment prior to the start of data collection. This allowed the researcher to truly commit to the phenomena.

Reading texts on care of Hispanic families and the history of Puerto Rico prepared the researcher intellectually for the study. However, spending time in the urban children's hospital observing care for the children with asthma and their families in different settings allowed her to enter into the life world. Time was spent in the neighborhood, recording field notes and photos of the area. This helped the researcher move from the intellectual plane to the place where the families lived.
Figure 3: The neighborhood

The picture in Figure 3 is a shot of one of the neighborhood streets. The photograph was taken from the car as the researcher was driving around the Hartford neighborhood.

Reflection on the conversations and life world of the families was a major part of the creation of the phenomenological text. The researcher drove 8 hours round trip to conduct the interviews. The travel was from a very rural location to an urban area. During that weekly transition each week between the two very different worlds, much time was spent in reflection on the interaction with the family, the hospital environment and
the surrounding neighborhood the family called home. This reflective time allowed the researcher to be primed to read the text and highlight the themes that presented themselves repetitively throughout the interview. The caution in this deep reflection is selective inattention and researcher bias, which was addressed by engaging in a hermeneutic discussion with colleagues. Collaborative assistance in analysis for a hermeneutic discussion was requested from the research assistant, Asthma Center staff, an anthropologist and Puerto Rican co-workers. The researcher and research assistant met before and after every interview to discuss the process and outcome of the interviews. Dr Lee Pachter, an anthropologist from St Francis Hospital in Hartford, met with the researcher to review the research proposal and method. In addition he offered his advice on working with Puerto Rican families. Finally, the researcher worked with several Puerto Rican co-workers. They offered their insight on their culture and how to approach families to ask for an interview. In addition they shared their own experience with asthma in their families. According to van Manen, the hermeneutic discussion is a way to test one’s work. The text is shared with others to bring out the strengths and test the meanings. This can be done formally or informally according to van Manen. The text was shared with Dr Cloutier and the research assistant when it was completed.

The transcripts were read multiple times to extract the themes and isolate key statements and phrases. van Manen discusses three
approaches to isolating thematic statements in his text *Researching Lived Experience* (1990). The three approaches include 1) the wholistic or sententious approach 2) the detailed or line by line approach 3) the selective or highlighting approach. This data analysis was done primarily by the third choice as she had used this approach in another study; however all three will be described here.

The wholistic approach looks at the text in its entirety and in order to formulate a statement that captures the essence of the phenomena. The detailed line by line approach looks at every single sentence to discern how that sentence contributes to the development of the phenomena in question. The selective / highlighting approach is done by listening to the tapes and reading the text several times, seeking essential statements or phrases that seems to contribute to the development of the phenomena. In choosing the third option, the researcher focused on the essential themes by listening to the conversations and reading the text several times to find the words that would capture the essence of the experience and contribute to a rich, descriptive text.

The text in a hermeneutic research study is written and rewritten to continue to refine the description of the meanings of the experience for the families. To illuminate the phenomena, the researcher synthesized: a) in-depth review of the transcripts b) incorporation of field notes c) second interviews for interpretation of the dialogue generated. In addition the use of Puerto Rican literature, art and history was incorporated in the analysis.
Prior to the data analysis, the researcher had access to Professor Max van Manen, via email. She participated in his online class from September 2004 to January 2005. During that time she consulted with Professor van Manen on the study design and methodology. In addition she was a participant in a writing group of eight participants from all over the world. The group created written work generated by prompts from Professor van Manen. The assignments were then critiqued by her classmates and the professor. The writing laid the ground work for the creation of the phenomenological text in this study.

*Human Subjects Consideration*

The Institutional Review Board (IRB) at both the University of Connecticut (UCONN) and CCMC approved the proposal, (see Appendices B&C) interview questions and consent forms for the project, including modifications in recruitment of participants. The consents were translated into Spanish and back translated by a professional translator at the University of Massachusetts. (see Appendices D&E) In addition, there was a bilingual research assistant on hand to support all interactions with the families. Children were not directly involved in the study, but their asthma care was explored indirectly through the voices of their families.

The audio tapes were transcribed by a professional transcriptionist. The study was confidential; therefore, there was a master list of participants and tape numbers, in order to facilitate return to the participant for interpretation of the transcripts. The master list was kept in
a locked box. The tapes were not identified with any names and were kept in a secure place until the end of the study, at which time they will be destroyed. All interactions with the family were confidential. There were no known risks for families who participated in the study. There were no direct benefits; however families were offered a gift certificate in a nominal amount for participation. The researcher has participated in educational offerings on the conduct of responsible, ethical research including the University of Vermont and NIH tutorials on ethics in the conduct of research. (see Appendices F&G)

Methodologic Rigor

Rigor for the study was assessed using the qualitative evaluative criteria of credibility, fittingness and auditability (Beck, 1993). Credibility measures the vividness of the description of the phenomena. Readers and informants who have had the experience should recognize the researcher's description of the experience. The applicant kept detailed field notes, validated findings with informants and remained ever vigilant to the effect of the researcher on the text of the study. The use of a hermeneutic circle helped to avoid selection bias in data analysis. Fittingness is likened to external validity in quantitative research. The assessment of this concept includes assuring that the informants are typical for the population under study and are from a range of individuals experiencing the phenomena. The participants were randomly chosen from a group of families attending an asthma clinic. The ages of the
children ranged from 18 months to 14 years. Auditability includes the method of data collection such as a reliable tape recorder, clear transcripts and field notes for accurate recall. The researcher kept all the field notes in a note book, clearly marked with dates, times and places.

In addition, the processes of data collection were clearly described and consistent throughout the study. Finally, it is critical that another investigator could clearly follow the decision trail used by the researcher in the study. The major advisor confirmed the steps of the decision trail using the transcripts and note cards with the themes.

In summary, the method of inquiry for the study is presented step by step in this chapter. The recruitment for the study presented several challenges for the researcher and clinic staff. A Spanish speaking research assistant who is a credentialed MD pediatrician assisted in 8 of the 10 interviews acting as translator.
CHAPTER FIVE: THE PHENOMENOLOGICAL TEXT

Figure 4: "Loss of Manuel"

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Introduction

“Hartford is the 10th worst metropolitan area in the United States for asthmatics, according to a new report released today. The relatively dismal ranking among the top 100 ‘asthma capitals’ by the non profit group Asthma and Allergy Foundation of America did not surprise local asthma experts... However, the disease causes problems everywhere in the country and such studies help bring attention to the severity of the asthma epidemic, which has increased dramatically in recent years... “The problem is most acute in poor neighborhoods in cities such as Hartford. Asthma is poorly managed and controlled in the inner city’, said Dr.Bimalin Lahiri, chief of pulmonary and critical care medicine at St Francis Hospital and Medical Center.” (Hathaway, 2004)

This article from a Hartford, Connecticut newspaper describes the immense impact asthma has on Hartford and beyond. Asthma, in the pediatric population, has reached epidemic proportions nationally as reflected by these selected morbidity statistics: 641,242 ED visits in 2002 and 12.8 million missed school days in 2003. It also kills. In 2002, over 4,000 deaths (all ages) were attributed to asthma (American Lung Association, 2005). Children who are most affected by asthma are living in poverty in the inner cities. These same children are also more likely to be of Hispanic Puerto Rican and African American descent. These children, along with their families, suffer from asthma in far greater proportions than any other race or ethnic group.
The University of Connecticut and Connecticut Children’s Medical Center recently conducted a study confirming the aforementioned statistics. Approximately 8000 parents of children between 6 months and 18 years old who visited a primary care provider in the city of Hartford were asked to complete a survey. Of the children screened, 33% had asthma. The children who had the greatest incidence of asthma were the Hispanic Puerto Ricans and African Americans at 48% and 35% respectively (Cloutier, Hall, Wakefield & Balit, 2004).

The prevalence of asthma in the Puerto Rican community, as discussed here and in the review of literature far exceeds the general US population. The disease drives families to make numerous trips to the emergency department for care. Yet, according to the statistics, the disease is poorly controlled. What does control mean? Is it defined by purely physiologic measures? More importantly, what is the meaning of asthma to the Puerto Rican families who live with it every day?

Respiratory disease is a major part of Puerto Rican families’ life, and reference to asthma and death can even be found in the artwork and folktales passed on from generation to generation. The picture on page 58 “Loss of Manuel” was painted by a Puerto Rican artist who wrote of the anguish of the loss of a child in a flier accompanying the print. In addition, the following excerpts from a Puerto Rican folktale, translated into English, illuminate the suffering that respiratory illness brings a small child and his family.
Monsona Quintana's Purple Child

(El Nino Morado De Monsona Quintana)

Emilio S Belaval

Last night another was born. Monsona Quintana’s child was one of those purple babies so common in our mountains.... She was ready to do anything to save her little [baby]... She took off her new petticoats to make some good diapers, kept her eyes on the cradle and prayed to Santa Rita, patron of country children... Monsona Quintana pulled up the sleeves of hope to save her child from death. ...day after day a new herb was used ...hour after hour; the agonized shadows grew under the mother’s eyes... His mama walks him with fearful stride, with passionate rage... the medicine woman has no art to calm that cry.....

This folktale embodies the spirit of the phenomenological text that follows. According to van Manen, a phenomenological text helps us “see” what was not there before. He states that “Many readers have at one time or another been profoundly moved in the realization of being touched by human insight” (van Manen, 1997, p. 7). He goes on to say that phenomenological inquiry is a “deepening experience, an intensified awareness” (van Manen, 1997, p. 7) . The participants who shared their stories during the interviews provide the reader, with a glance at their world. This text, the product of a human science study, allows the reader to enter the life world of the participants during one point in time. It is by no means meant to do any more. van Manen (1997) is quick to remind us
that phenomenological texts do not “yield absolute truths”. They provide a “glimpse of the meaning of human existence” (p. 7). The following account of the lived experience of Puerto Rican families who bring their children to the ED for asthma care is meant to help the practitioner to “see” asthma with a phenomenological attitude and perhaps even feel an intensified awareness while reading the text.

Each of the themes in the folktale about Monsona Quintana’s *Purple Child* is mirrored in the six themes of the phenomenological text and listed in Table 2. The approach to human science research as described by van Manen (1990) includes “interpretive and narrative tasks” (p. 165). He offers suggestions for how to organize the text, including the thematic approach used here. The themes and titles presented here emerged during the interviews; several titles are the mothers’ own words.

Table 2: Folktale and Research Themes

<table>
<thead>
<tr>
<th>Folktale Theme</th>
<th>Research Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last night another was born. Monsona Quintana’s child was one of those purple babies so common in our mountains</td>
<td>Folklore of Asthma</td>
</tr>
<tr>
<td>She kept her eyes on the cradle</td>
<td>In Awe of Asthma</td>
</tr>
<tr>
<td>And prayed to Santa Rita</td>
<td>Praying to God, Si Dios quiere</td>
</tr>
<tr>
<td>She was ready to do anything to save her little baby</td>
<td>The Decision…Time to go</td>
</tr>
<tr>
<td>Monsona Quintana pulled up the sleeves of hope to save her child from death</td>
<td>The ED Environment: Concern and Cussing</td>
</tr>
<tr>
<td>Day after day a new herb was used, the medicine woman has no art to calm that cry</td>
<td>Culture and the Medicine Woman</td>
</tr>
</tbody>
</table>
The Folklore of Asthma

Asthma is part of the everyday life of the participants interviewed for the study. Each of the families spoke about the impact of asthma on their lives. Collectively, many of the participants diverted their gaze to the floor as they spoke of the extent of asthma in their family history. One shared, “Ok, I have five children and the fourteen year old has allergies, the eleven year old has asthma and the twins, the little boy, not the girl, have asthma....my mom passed away from asthma”. The tears welled up in her eyes as she spoke of her mother. She often accompanied her mother to the doctor’s office or emergency room for asthma care. Her aunt was also mentioned in passing; “she had twelve kids and they all had asthma.”

A mother of five children spoke of the vine of asthma that was woven throughout her family tree. She was somber when she shared her family history. It was a story heard over and over during the time of the interviews and clinic visits: “Down from my grandparents, down from my father, my brother, myself, my two daughters, my sister and my cousin. When I was younger I was hospitalized for asthma and my grandmother was also hospitalized with asthma too.”

One mother was more cavalier about the permeation of asthma in her lineage. She tossed her head as she spoke of her family members with the asthma diagnosis, as in acceptance of her fate: “Grandmother,
father, mother, me, sisters, yea the whole family, aunts, yeap, my great-grandmother died from that [asthma]."

During another interview, an adorable, innocent toddler, oblivious to the genetic link to his respiratory condition, roamed around the room as his mother spoke about the family medical history. She avoided speaking about her family, but was quick to say: “His father had asthma when he was a child and had family members very sick and who died from asthma.”

The one line answer from a mother: “Yeah there is a lot of asthma in my family” was the theme that was repeated in all 10 interviews. A Spanish speaking mother conveyed to the interpreter that her mother, living in Puerto Rico, was diagnosed with asthma. She looked away and then after a long pause, she continued the conversation. A Spanish speaking grandmother shared with the translator that “her mother in Puerto Rico had some respiratory problems and is already dead.”

One mother who agreed to an interview was accompanied by two of her three children at a clinic visit. As a health care worker she shared her experience with caring for children with asthma at work as well as her own asthma diagnosis. She went on to say:

“My son within the first three months of life, he was asthmatic. With my second one we found out when she was four years old. I was very sad because I was like Oh my gosh she does not have asthma
that's so good she is four years old. My little one who is four was diagnosed early."

Asthma permeated their lives and their conversations. The statistics came alive in the voices and facial expressions of each of the participants. They shared their history with the disease and their fear of asthma.

**In Awe of Asthma**

“Asthma kills”. A young mother spoke about her experience with an asthma death at the hospital where she worked. Repeatedly each participant spoke of someone in her life who succumbed to asthma. Speaking of her own mother and her struggle with asthma, one woman tried to ignore the tears that welled up in her eyes. Stoic in her delivery of the story, she told of the numerous trips made to the emergency room with her mother. Now she was bringing her own children in for asthma care: "And you know I get concerned, as I mentioned before, my mom passed away of an asthma attack...she had it badly."

Cousins, aunts, neighbors, many carry the asthma diagnosis in Hartford. Asthma is not to be ignored. It is a part of the heritage, part of everyday life. One mother stated: "I just get very afraid of asthma and how it has gone down to my children. I am just very concerned for them.” During a routine visit in the clinic another parent spoke of an infant niece who had just died from asthma. Her tone was calm and matter of fact.

One weekday morning in the ED, a preschool boy arrived by ambulance from school. He was working very hard to breathe and just
gazed down, avoiding all eye contact with the staff. His mom arrived in the
ED about 45 minutes later. She was young and had a wide-eyed gaze as
she entered the room. She slipped into a chair in the corner, avoiding the
bed as the nurses and doctor attended to her child. The nurses told me
she had been there before. She sat poised in her chair but did not
approach her child until everyone left the room. The researcher saw the
shock and fear that dominated her youthful face. Her facial expression
was one seen often by health care professionals.

The awe of asthma was clear in all the interviews: "It is scary
because you feel out of control. You feel like you are falling." This mother
used the word scary many times during the course of the conversation.
She spoke freely of the loss of control she felt when her child was in the
throes of an asthma attack. "Scary because I feel like OK, there is nothing
else I can do. It is out of my hands when it comes to breathing. You [are]
scared for them because you know asthma can kill." She went on to
explain how she too had asthma and was one day away from intubation
during her last hospitalization. She said again, "It was very scary."

Another young mother spoke about her experience in the
Emergency Department in terms of her fear of asthma: "It was a bad
experience of course because I am the mother so asthma is bad. I mean a
couple of weeks before a kid died [in the ED] of asthma. He was 18." After
she spoke, she looked down, got up and walked away from the table for a
moment to compose herself.
Repeatedly participants spoke of the flood of emotions they felt during their child's asthma attacks and subsequent trips to the ED: “I was mad and scared for him...it was just a mix of emotions. It was like I was mad scared and I did not really know what to do.” As they carried out the familiar routine of dealing with asthma, it appeared that the range of feelings, including fear, were always present: “…and it was scary because he wasn't breathing right and all he was doing was crying.” Another mother spoke about getting nervous and that feeling drove her actions although she felt she should know what to do: “I get nervous and I guess when I get nervous I don’t know what to do in some cases. I just try to do the best I can.” In her case the best she could do was to go to the ED where she could get help for her child. For some, the fear began at the first sign of wheezing: “When I hear wheezing and coughing I get concerned and like to bring him right away.” Vigilance around the child’s respiratory status was part of the life of many of the women:

“When I am sitting there [and] he’s next to me leaning on me and he’s not usually being himself, energetic and laughing and cracking jokes... I hear that wheezing and I do get concerned. You know I get concerned because I lost my mom of the same reason and it works on my mind.”

When many of the participants spoke about the severity of asthma, they moved to the edge of their seat and became more animated. In a serious moment, one mother looked down and stared into space. “Asthma
can kill, asthma can kill,” she repeated as she wiped a tear from her eye. When the asthma attack appeared, the level of concern rose exponentially for the families interviewed. As they spoke of seeking care for their child, the concern and fear was evident in their words and expressions: “I just pray to God that, you know, they’ll hurry up and see him soon.”

Praying to God, *Si Dios quiere*

The Hispanic Puerto Rican culture is steeped in Christianity. The roots of Catholicism are deeply imbedded in the foundation of Puerto Rican culture. The expression *Si Dios quiere*, if God wants, reflects the trust and confidence in the will of God, especially in times of illness. The literature, reviewed in chapter III refers to the influence of spirituality in everyday life in Puerto Rican communities. Many of the women interviewed turned to prayer as part of their asthma care routine. One mom spoke in a broken voice about what happens in the wee hours of the night when asthma hits: “With the asthma they wake up with a nightmare… Mommy, Mommy I’m scared… I rock with her and will start praying and she’ll relax and she’ll fall asleep.”

Persistent themes in the interviews were prayer and spirituality. Invoking the help of God when dealing with asthma was mentioned by several participants; however, they seemed reticent to discuss religion and God in any depth. Several referred to using prayer during the ED experience.
The stress of a sick child with asthma seemed to bring on prayer. "I pray like there is no tomorrow at night. Oh God help me...I just pray because I [am] scared" was a comment by one mother as she spoke about the experience of caring for her child who was wheezing and very ill. A Spanish speaking mom's comments were relayed by the translator, "she thinks that to be praying or asking for help to God helped her child with asthma." Another mother who was very reserved and timid during the interview shared that "...she prays for her family, especially her son." An additional comment by a Spanish speaking grandmother was that "when God send disease for our children he knows why he did it." This comment may reflect the notion of fatalism discussed in the previous chapter on Puerto Rican culture. Another mother relayed to the translator that "religion is very important in her life..." It is clear that religion and prayer played a significant role in the lives of several of the women in the study. However none of them said that they used prayer as a treatment that would delay medical care for asthma.

As stated earlier, Christianity has a strong presence in Puerto Rican culture. This mother spoke openly of her reliance on her religion during times of stress:

"Oh well we're Catholic. We Catholics and I believe miracles do happen and I can say my son being a miracle and it was a very difficult pregnancy with him." This mother spoke in great detail about her devotion to a Mexican saint during her pregnancy and
today. “So I will read the bible every day to him, I will talk to him about him [her son] and I made a promise... I will name my child after you.”

These comments reflected the deeper connection with a higher power this mother felt. She was the only one who was willing to go into detail about her faith, despite attempts by the interviewer to encourage more dialogue on the topic with all of the participants.

Of note, two of the younger mothers stated that religion was not important in their life. The comment that “some people use that as an excuse” was delivered with great resolve and may have been a reflection of a woman acculturated to her current environment and less bound to tradition.

In the face of the numerous accounts in the literature about spirituality and faith coming in conflict with biomedical culture, it was interesting that none of the women interviewed said that faith altered their decision to seek traditional health care. The mothers did say however that faith supported them in the stressful time as they made decisions about going to the ED.

The Decision.... Time to go

The quantitative literature is replete with statistics about how many Hispanic Puerto Rican children utilize ED services for asthma care. There are many hypotheses created about why they go to the ED, including those cited in the complex diagram in Figure 1. Why do these families go
to the ED? The following inquiry was posed to each participant who was interviewed: Please think of a time you brought your child to the ED. Please think of specific details. The following paragraphs may shed light on “why now is the time to go?”

Every one who was asked these questions responded by talking about her child’s wheezing, coughing and shortness of breath as the reason for going to the ED. One mom pulled at her own shirt as she spoke: “Wheezing, retracting, [and] pulling at his chest. I remember one time he completely stopped breathing. His face turned completely purple.” The symptoms of asthma drove these women to make the decision to go to the ED. The wheezing was the trigger for most of the participants to prompt them to head to the ED. This mother shared: “I felt uncomfortable because he would start wheezing at home and [I] just rushed him in.”

Asthma management involves attention to symptoms and timely intervention with appropriate medications. Many of the mothers spoke of a written “sick plan” they used when their child had wheezing or coughing, however when that sick plan was not working, appropriately, they were quick to bring them to the ED: “He starts coughing...wheezing and coughing. I give him a treatment at home. When I see that wheezing continues and that he continues to cough and this is not working for him [he was brought to the ED].”
The idea that asthma control at home is the first step in management was well understood by most of the mothers who were interviewed. One stated: “If I can control it in my house, fine. If I can’t I bring them to the Emergency Room.” An additional comment by another mother reinforced this sentiment: “Usually what I try to do is not bring them to the ED.”

The mother of five spoke of home management. She was a calm woman, taking time for an interview while all her children played in the waiting room with their dad. Her voice was steady as she spoke of the last time she came to the ED:

“We were at home. She [the child] came home from school and was coughing a lot. Why are [you] coughing so much? I gave her the machine (nebulizer) to see if it was going to be ok but after that she
kept coughing and coughing so I decided to take her here (CCMC) So we came.”

Not all parents were as methodical in their approach to treatment or the use of a sick plan; however they all knew that wheezing and coughing are symptoms not to be ignored: “I felt uncomfortable because he would start wheezing at home and just rushed him in.” This mother was the one of only two who spoke of trying to contact her primary care provider first. “If it is at night and they take a while to call back....if he is really bad I just rush him in without calling.” Two of the Spanish speaking mothers stated that they saw the symptoms in their children and brought them to the hospital because they knew that was where their child would get the best care. They felt there were “lots of services” at the hospital emergency room compared to the clinic.

The ED Environment: Concern and Cussing

The ED space is large, open and welcoming in the eyes of the observer there to watch others, but how is it perceived by the families who go there to access care for their child? One mother commented about the fact that the waiting area was comfortable and there were lots of chairs, there was a large sofa. When they arrive in the ED, families are greeted by bilingual staff and asked to wait their turn to be called back to a room for care. This is the superficial picture we would see as the observer, but what did the families who use the space for emergencies experience? How did they feel about that experience? The range of emotions
expressed by the participants about their ED experience ranged from comments about loving care by the ED staff: “...the hospital workers are very good for the children... [they give care] with a lot of love” to frank disdain when a mother shared that the ED staff knew her well “cause I cuss everybody out.”

Once the women discussed the decision to go to the ED, the interviewer requested that they remember a specific time they were in the ED with their child. They were asked to be specific and remember sights, sounds and even smells when they were there. Not all mothers were able to embellish their accounts of the trip to the ED with vivid comments but quite a few were able to speak about how they felt when at the ED. Several also spoke about being advocates for their child as the moments ticked away in the ED waiting room.

In addition to the fear of the disease discussed earlier, the Emergency Department environment added a level of apprehension for some of the women, especially one who was exclusively Spanish speaking. She said she felt a little scared of the surroundings, going on to say there were lots of kids, lots of fathers and lots of mothers and she did not speak English. The volume of people in the waiting room was also mentioned by a mother; “I gotta say this. The last time I went to the ED, it was packed. When I mean packed, I mean packed.” Another Spanish speaking mother shared that the last time she came to the Emergency Room there were a lot of people waiting: “There were a lot of people in
Noise levels were something some mothers also discussed. Two mothers stated: “There were kids crying” and another said “There was noise. Over there in the waiting [room], yeah lots of noise ...”

“Yes it is a scary sight. I know there are great doctors and they take care of him right away but it can get scary.” This sentiment was echoed throughout the interviews. The women spoke of the waiting and the worry that their child would not be seen promptly. Another mother spoke of being afraid but having some support helped her as she waited:

"...so it was really scary. Thanks God at that moment his dad was there with me and my mom was there with me so it was like I wasn’t alone. I had support right there with me, but yes it was scary. I mean if I would have been there by myself, without them I wouldn’t know what to do.”

Most could remember without hesitation how long they waited and how they felt and acted during the wait. The overall wait time was easily recalled in most interviews like this account: “They had me in the ED for like 3 hours before they saw me in the back and then I was waiting in the back for another half hour until a doc came to see her, then another 20 minutes till another could come see her. I left there at 4 o’clock in the morning and I got here at 8 am."

Vivid recollection of time was relayed in wait time for not only their child but others in the waiting room:
“The baby was like not even 2... she got hit in her head ... a real big cut...they had her waiting there...I had to go back there and cuss them out for her...I see that baby just bleeding and bleeding...

[The mom said] I'll wait, yours needs help more.”

This mom then lowered her voice and said “long waits, lots of long waits.”

The uncertainty of the wait time seemed to add stress; “you know, just the waiting and how soon they’re going to get here [in the room in the ED] to give him the treatment. If there are other emergencies more serious than my son then I have to wait.”

During the long waits some mothers spoke to the triage nurse to advocate for their child:

“You know a couple of times I have gotten up and I’ve approached the nurse or whoever is at the window...and I say, you know my son is wheezing a lot. I am getting a little concerned how much longer it is going to be because he really needs a treatment.”

The communication with the staff was often very direct: “I tell them he has had two treatments back to back within fifteen minutes and he's not breathing and they take me in right away.” Being direct with the nurse was the style of one mom: “You know what, sounding worse, is getting worse” was all she had to say in her strong tone of voice. As the participants spoke of the wait, equity in choosing who is seen was a concern: “…treat everybody the same. Not some better than others or not
you know treat the person with like attitude cause he's been here more times than others.”

One more mother spoke of her time in the ED: “We wait our turn and everything and they took me and sent me into a room... They take you in the room and so it was like this room right here they lay down [child's name] in the bed and they told me the doctor will be with you soon and that was a long time.”

In the spirit of simpatia (being nice), the Hispanic tendency to avoid conflict in social and personal encounters, one Spanish speaking grandmother said she waited patiently, she did not ask anyone to get the patient promptly, she just waited.

**Culture and the medicine woman**

“What appears to be taking place...Is a growing movement of young Puerto Ricans back and forth between the island and the United States. They come back looking for a job, but rarely find one. They have been reminded in the United States that they were Puerto Rican, but here they are told that they speak Spanish with an “English” accent that you are not really one of us. The young Puerto Rican may well ask himself not only “Where am I going?” but “Who am I?” (AW Maldonado, *The Nation*, March 16, 1964)

Puerto Ricans distinguish themselves from other Hispanics in several ways, including the fact that they are United States citizens, freely moving from the island to the mainland. This excerpt from the Nation
clearly outlines this distinction. Due to the free movement in and out of two different worlds, acculturation takes on a new meaning for this population of Hispanics. One of the accepted measures of acculturation is the language spoken at home. The families in the study were asked this question at the time of the interviews. Of the ten families, four spoke only Spanish at home, three spoke only English and the remaining three spoke both English and Spanish. In the conversations during the first interviews, several mothers offered information about their travel to Puerto Rico in relation to how it affected their child’s asthma. Seven of the mothers and the grandmother had taken their children to Puerto Rico recently. The two younger mothers said they had not been to Puerto Rico. The travel to the island may be indicative of the level of acculturation and adherence to traditional values and folk healing.

The literature on cultural competence, as discussed in the review of literature on culture, states clearly that Hispanics frequently use folk healing and herbs and defer medical care in favor of these traditional treatments. Huff and Kline (1999) say that Hispanic Puerto Ricans favor curanderismo, the use of a local healer who is religious in nature. Sobadoras (female healers) are popular in Puerto Rico (Joyce & Villanueva, 2000). They are medicine woman who combine listening skills and massage to assist the patient. What healing traditions did the families in the study hold dear and how much did they embrace the medical model versus folk healing when seeking care for their child? All the participants in...
the study were asked to talk about the use of traditional healing in regard to treating their child for asthma.

The first mother interviewed talked about her great grandmother: "...she used to always be creative with ginger (jengibre) and made tea out of ginger and some other green leaves from Puerto Rico." She went on to say that she never used any of those remedies with her own children. One mother said she used ginger for herself but not her children:

"The only thing that I use and it seems to help me because I'm asthmatic is ginger root tea and we have been doing it since I could remember. You can just buy the root crush it and smash it and put it to boil. We took like a spoon or two".

Another mother, who was Spanish speaking, acknowledged that she "did not trust the herb medicine". She had some experience with a tea she was using in Puerto Rico called Manzanilla (chamomile).

A mother of five said she had heard about ginger root but said: "but I never, not me, take it and not my daughters."

Huff and Kline (1999) stated that often Hispanic families who use folk healing are reluctant to tell the practitioner about this practice (p. 191). Several mothers interviewed said they did not use herbs. One of the Spanish speaking moms told the translator that her relations still believe in herbs but that she thinks the doctor has the cure. Two of the other women who discussed use of herbs denied their use and deferred to the doctor:
"just the medicines the doctors give him." It is impossible to determine if the mothers were holding true to the notion that it is not advisable to speak of folk healing with the health care professional. This is an area needing further research.

Finally, there is one more anecdote to that completes the Phenomenologic text. This interaction was a turning point in the study which had been plagued with obstacles including patients’ disconnected phones, missed appointments, and the language barrier. The researcher had seriously considered ending the study but one mother halted that idea with one simple encounter. This mom was a petite Spanish speaking woman. She sat in the chair as she politely answered all the questions relayed from the researcher by the translator. As the interview was coming to a close, she was asked the final question the researcher had asked in every interview: “Is there anything else you wanted to tell us?” She turned to the researcher and said: “God Bless you for doing this. Thank you for asking because no one ever asks us.” She turned away and avoided eye contact for a split second. That was helpful because the researcher needed to wipe a tear away from her eye.

Van Manen (1990) reminds us that: “...All interpretive phenomenology is cognizant of the realization that no interpretation is ever complete, no explication of meaning is ever final and no insight is beyond challenge” (p. 7). This phenomenological study has given a glimpse of the lived experience of the ten families while using the ED for asthma care. It
also offered an opportunity for the reader to have an intensified awareness of the life world of the families.
CHAPTER SIX: DISCUSSION

Summary of Research Findings

As stated earlier, the phenomenological text is written to help the reader “see” what they may have missed viewing the world through the lens of natural attitude. As we enter in the final chapter and discussion of the text it is imperative that we acknowledge van Manen’s thoughts on the role of the text. He states:” The phenomenologist does not present the reader with a conclusive argument or with a determinate set of ideas, essences or insights. Instead he or she aims to be allusive by orienting the reader reflectively to that region of lived experience where the phenomenon dwells in recognizable form”. (van Manen, 2002, p. 238)

Theme one, The Folklore of Asthma described the prevalence of asthma in the participants’ family history and beyond. The interviews revealed that asthma was a part of the everyday life of the participants. The illness was pervasive in the families, neighborhood and beyond. The words of the families made the statistics come alive and resonate with the reader.

Theme two: In Awe of Asthma was named as such because the interviews revealed a fear and respect of asthma. Many of the women spoke of their fear of asthma and the emotions they felt when their child had an asthma attack.
The stress experienced during an asthma episode was seen in the facial expressions and heard in the powerful words of the women who were interviewed.

Theme three: Praying to God, Si Dios quiere reflects the influence of faith and religion on asthma care. The literature suggests that Hispani families turn to spiritual interventions in lieu of biomedical care. Several of the women spoke of the role their Christian faith played in helping them deal with stress. However, none of the women stated that they chose spiritual interventions over traditional biomedical care during their child's asthma attack.

Theme four: The Decision... Time to go evolved as compilation of all the anecdotes about how the families perceived their lived experience up to the time they arrived at the ED for care. Each of the women clearly described the physical signs their child exhibited during the asthma episodes. These signs were seen as the trigger for the women to bring their child to the ED for care. Two of the participants spoke of the ED as a place with lots of services for their child which prompted them to go there for care.

The title for Theme five was a direct quote from one of the mothers. The theme reflected the experience of the women once they arrived at the ED for care. They all had some vivid recollection of the event. Some women were able to speak of the sights and sounds and others could just verbalize the emotions they felt at the time. The comments included how
crowded and noisy the waiting room was during their wait. Others spoke of the interaction with the staff in both positive and negative emotions.

The final theme, Culture and the Medicine Woman, addressed cultural influences on asthma care. Contrary to the suggestions in the literature that herbal medicine may be used in lieu of traditional biomedical care, none of the women stated they used folk medicine to treat their child. Several of the women admitted knowledge of various folk remedies but clearly stated they did not use them for their children.

The findings shared in the phenomenological text have some parallels with the current literature; however the most significant finding from the researcher's point of view was the pervasive nature of asthma morbidity and mortality in the family history, which possibly escalated the level of fear felt by the participants when their child became ill.

*Relationship of Findings to Current Literature*

Asthma is the most common pediatric chronic illness in US, affecting 6.3 million children in the United States. The burden of the disease is borne by Black and Hispanic children who live in poverty and urban settings. These children often present in Emergency Rooms for care. It is unclear why they use the ED so frequently, as they are often not found to have more severe asthma than their white peers. In the year 2000, there were 728,000 visits to the ED for care (American Academy of Allergy, Asthma and Immunology, 2003) a statistic some scholars use as a marker of a disease out of control.
Numerous quantitative studies, extensively reviewed in the Review of Literature chapter, have examined the patterns of ED use for asthma care. A variety of variables have been examined in hopes of gaining insight into the increased use of the ED by Puerto Rican children. Figure 1 is a compilation of many of the potential variables that factor in to the use of the ED for asthma care. The phenomenological text in the previous chapter provided some very different insights into the experience of families who go to the ED for asthma care.

Access and health insurance are often two reasons hypothesized for use of the ED for care. Numerous studies in the review of literature examined families with public assistance and their ED use (Boudreaux et al, 2003; Christakis et al, 2001). In a Canadian study, Amre (2002) studied ED use within the context of national health care which assures access for all citizens. Access to primary care providers was another variable in some of the studies hypothesized to drive families to the ED for care. When presented with the open ended research question, not one woman interviewed mentioned that they perceived problems with access to a primary care provider as the reason they went to the ED. Four of the ten participants did not have primary care for their child. However, several mothers with primary providers mentioned being in contact with that provider in the time leading up to the ED visits. In a recent study reviewed in Pediatric News, 251 parents, whose children seen in the ED for non-urgent illness, were asked about primary care access. The survey results
showed that 45% had contacted their primary care providers and that 73% of the parents were actually referred to the ED for care. Only 4% said they used the ED due to lack of a primary care provider (Kirn, 2004). None of the mothers interviewed mentioned lack of insurance as a reason they went to the ED.

The literature on Hispanic/Puerto Rican cultural competence emphasizes that spirituality is a pivotal part of the family value. In some instances, the devotion to prayer may delay treatment from a conventional health care provider. Several women in the study talked about prayer, but none ever said that prayer delayed care or interfered with the conventional medical practices used for their child's asthma care. They said that prayer was very important to them. One mother spoke of asking a saint for help in the care of her child with asthma, and in return she named her second child after that saint.

There are 4,000 asthma deaths per year in the United States, with deaths for Puerto Ricans highest among the Hispanics living on the mainland (American Lung Association, 2005). For the women in the study, the possibility of death from asthma was very real. Many parents were concerned about their child succumbing to death from asthma. Many of the participants talked about close family members who had died from asthma. Discussion about death was pervasive in the interviews.

Fear was insidious in the words and the eyes of the participants. Repeatedly, mothers in the study spoke of fear, being afraid and how
scary it was to watch their child wheeze. Many said as soon as they heard the wheezing they got concerned and moved to action. Two authors discussed fear tangentially as part of a larger assessment of ED use; however it appeared that parents perceptions of asthma severity were a factor in the decision to go to the ED for care (Lara et al, 2003; Lieu et al, 2002).

Use of herbal medicine has been documented in the literature as a barrier to conventional care. Several sources including Huff and Kline (1999) suggested that herbal medicines are frequently used by Puerto Ricans. Mothers in the study said they had heard of the use of herbal medications; however they did not use those preparations for their children. One mother did say she used ginger root for her own asthma but was clear she did not use it for her children. When considering this information, the reader must know that the literature suggests that Hispanics, in the spirit of *simpatico*, may not tell the health care practitioner they are using these substances because they do not want to be openly in conflict with conventional health care practices.

*Limitations/Difficulties in Conducting the Study*

The process of conducting a qualitative study is always challenging, even in the best of settings. The literature supports this notion. Beck and Kearney (1993) in their presentation cited several barriers that included safety concerns when the researcher is in an unfamiliar neighborhood. The neighborhoods of Hartford were very unfamiliar to the researcher who
traveled there from rural Vermont. This unfamiliarity limited the site of the interviews to the hospital building, which may have prevented many families from participating. Recruitment for the study was also limited to the families who made a visit to the asthma clinic after their ED visit.

The language barrier was a big consideration in the planning and execution of the study. Families were reluctant to even answer the phone when they saw the phone number was an out of state area code. Often when families answered, the researcher was not able to speak with the party due to language barriers. This was resolved when the bilingual research assistant joined the study.

No show patients were the biggest barrier to expanding the study beyond the 10 family members. The show rate at the asthma clinic is between 40 and 60 percent. Each family is called the night before the visit to remind them and some are called the day of the appointment. The show rate for the interviews was approximately 50%. Lacy et al (2004) examined the reasons for no shows in an urban setting. In her study 34 patients were interviewed and three major themes emerged as reasons for the no show: 1) personal fear of bad news or pain, perceived snubs by the health care system 2) long waits/perceived disrespect and 3) misunderstanding of the scheduling system. The researcher did not investigate why families did not show for the interview appointments; however the no show rate is consistent with other reported studies.
Once families agreed to interviews, it was often difficult to contact them to set up a time to meet at the hospital. One mother enthusiastically agreed to an interview while at clinic. She asked to be called to set up a time the following week. When she was called, her phone was disconnected and there was no forwarding number. This happened several times during participant recruitment.

Cultural differences must be considered as a barrier. This was addressed by the addition of a research assistant who was Hispanic. The research assistant was a pediatrician who was well versed in research and asthma care. He was very personable to the mothers. He also was very skilled at keeping a very fluid three way conversation moving along during the interview; however the participants were often reticent to embellish their answers. The Hispanic culture as relayed by Huff & Kline (1999) has a family structure with the father as protector and the mother in a sacrificing role. In discussions with Puerto Rican members of the hermeneutic circle (discussed in the earlier chapters) during the research process it became clear that the mother's role was to care for the children while the father made decisions related to finances and housing. This is further supported in a study by Galanti (2003) who discusses the role of the woman in the day to day care of the children, including decisions regarding their care. The fathers "make or must be consulted for the important decisions" (p. 183). Perhaps the males present at the time of the interviews did not participate due to lack of knowledge of their child's
asthma care. It is unclear if the use of a male interpreter altered the outcome of the interviews based on the traditional male-female relationships in the Hispanic culture.

The interviewees were all women which may have provided an one-dimensional perspective on the ED experience. As discussed earlier, on several occasions the women interviewed were accompanied by males who chose not to participate in the interview process. The over representation of females however, may not be a concern as Puerto Rican women are more likely to be the head of the household than their other Hispanic counterparts (Huff, 1999).

The challenge for the researcher was to become knowledgeable about the culture of the interviewees. As discussed in the gaining access section, this was done by spending time in the environment. In addition, extensive reading on Puerto Rican culture and health beliefs enabled the researcher to become more familiar with the culture. The University of Connecticut library has a robust set of holdings on Puerto Rico. The researcher read both historical information about the evolution of Puerto Rico from a sovereign state to a colony of the United States as well as references on Puerto Rican culture and folktales. Another strategy to enhance cultural competence was internet use through a monthly newsletter “Escape to Puerto Rico”. The newsletter, a lay publication, includes current news on Puerto Rico as well as articles and quizzes on history and culture. In an article about the challenges of cultural
competence, Roberta Waite (2005) states: “To be culturally competent, nurses must not only understand their own world views, but also those of their patients. They must avoid stereotyping and misapplication of scientific knowledge” (p. 32). Galanti (2003) goes on to say: “... the difference between a stereotype and a generalization lies not in the content but in the use of the information. A stereotype is an ending point; a generalization is a beginning point” (p. 180).

Another challenge in the study was the interview process. As a novice qualitative interviewer the researcher was challenged to choose words wisely during the interview. Ever vigilant to cultural sensitivity and the delicate balance of power between the professional/participant relationships the researcher proceeded with the process. The disparity in the educational level of the interviewers and interviewees was most likely great as only about 62% of Puerto Ricans in the United States complete High School (Huff, 1999). These challenges were magnified during the bilingual interviews as translation added to the communication challenges. After the first interview, the research assistant and researcher debriefed and made some modifications to use in future interviews including the restating of all questions and answers by the research assistant in English and Spanish.

The clinician as researcher phenomena tested the researcher during the interview process. Several authors have addressed this issue, which often leaves the researcher feeling helpless to the plight of the
participant. Johnson and Clarke (2003) discussed the frustration felt when the researcher is listening and not able to "do" anything. They go on to say: "I felt so pathetic...all I could give them was a leaflet...but I suppose that was something" (p. 429). Several times during interviews the researcher felt compelled to advise the families on care but refrained.

Another limitation in the study was funding. The researcher unsuccessfully applied for a federal grant to conduct the research. Since the project was unfunded, it limited the ability to add additional participants to the study. Considerable time and resources were spent to recruit families to participate in the study. Many 8 hour days passed without any families eligible for the study attending clinic. When families were eligible they often could not stay to participate in the interview on the day they attended clinic and were lost to follow up. Funding also limited the addition of research assistants/interpreters for the study. The research assistant who participated in the study did so as a volunteer. The cost of additional female interpreters was prohibitive and therefore may have influenced the outcome of the study.

Finally, the writing of the phenomenological text was another test for the researcher. Van Manen speaks often in his writings about the challenges of writing a phenomenological text, of choosing the right words to illuminate the lived experience. Writing in general is challenging as the author deals with the details of formatting and methods, and sometimes the words to not materialize on the screen. In qualitative writing the author
is charged with sharing the deep personal thoughts of the participants and creating a text that helps the reader “see” the phenomena at hand. Van Manen (2002) states: “Sometimes the writer simply does not know where to turn, what to do next. Indeed, at times it feels as if one is writing in the dark” (p. 7). The researcher emerged from the darkness to the light with the production of the text.

Future Research

The lived experience of families using the ED for asthma care was explored in this hermeneutic phenomenological study. The themes that emerged were somewhat different from what appears in the current literature. If we revisit the original paradigm of the study in Figure 1, it is clear these results just skim the surface. In Figure 5 the original Paradigm of the Study is revised to reveal the areas addressed by this phenomenological study. It is clear from the contrast of Figure 1 and 4 that there is much more work to do. Future research must be aimed at bridging this gap.
Figure 6: Paradigm of the Study Revisited

The current study could be continued to add more participants. The additional participants could include a broader base of families from other clinics in the city. These family members may add more insight or confirm that the original study had truly reached saturation. In recruiting additional families it would be important to address the absence of males as interviewees. The use of only one male research assistant may have influenced both recruitment and interview outcomes; therefore there should be consideration of more than one assistant.

Prior to this study, the researcher had drafted a questionnaire to address the original research question presented in Figure 1: Why do Puerto Rican children with asthma access care at the ED in greater numbers? The questionnaire (see Appendix H) was an attempt to address all the items in Figure 1. At the time of the development of the
questionnaire the researcher became concerned that perhaps the questions were not culturally sensitive. In addition there was a concern that perhaps the paradigm of the study did not address all the reasons families take their children to the ED for asthma care. The questionnaire development was put on hold. The researcher then turned the focus to the qualitative study to hear the words of the families who used the ED for asthma care for their child.

This questionnaire must be revisited in light of the new findings illuminated by the qualitative inquiry. The questionnaire can now incorporate the themes from the study to shape the questions. Support for the use of qualitative research as a foundation for development of questionnaires is well documented in the literature. Beck & Gable (2003) developed the landmark Post Partum Depression Scale (PDSS) based on the findings from phenomenological inquiries with post partum women. The scale items in the postpartum depression scale “were created from quotes of mothers who participated in Beck’s postpartum research” (p.297). The reliability and validity of the scale is strong because of the use of the mother’s words to develop the scale. The Crohbach alpha reliabilities for the scale range from .83-.94. Construct validity was examined using confirmatory factor analysis and comparison to other standardized measures including the Structured Clinical Interview for DSM-IV Axis I Disorders which further supported the strength of the scale.
Larkey et al (2001) also developed a survey using the results from qualitative research. She conducted focus groups with Hispanics to examine health seeking behavior. Using the results of the focus groups she went on to create and instrument to further analyze those behaviors with greater numbers of Hispanics. The alpha coefficients, though not as strong as the PDSS, ranged from .55-.74.

The draft scale developed prior to the phenomenological inquiry focused on access and relationships with health care providers. The 20 item scale had only one question about fear of asthma. It did ask about folk healing and spirituality; however the questions were poorly phrased in light of the findings from the Phenomenologic inquiry. The questionnaire must be rewritten and tested with Puerto Rican families. In addition the questionnaire should be translated and evaluated for semantic equivalence. When properly constructed and tested the revised questionnaire may be more culturally sensitive and relevant to the participants, therefore yielding valuable results for the clinicians who care for this population. The results from the questionnaire could inform practice for asthma education.

*Implications for Practice*

van Manen (1990) states:

“To do hermeneutic phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the life world, and yet to remain
aware that lived life is always more complex than any explication of meaning can reveal” (p. 18).

The aforementioned quotation prefaces this section so the reader realizes that the study results are but a snapshot in time to be considered in both future research and clinical practice. Morse (1997) states in her book that the findings from qualitative studies generate theory and that” theory is not reality, but a representation of reality”( p. 185).

The Puerto Rican families who participated in this study shared their great fear of asthma and wheezing. This information can guide practitioners to approach them with supportive caring when they arrive for care. During a hermeneutic discussion Dr Cloutier suggested we ask the family member who brings their child for asthma care to tell us what worries them the most. The education done for these families must be done with the recognition that when parents are stressed they will not absorb the information as readily. This may reinforce the need for close follow up and a repeat education session for the families.

The need for cultural sensitivity in the approach to care was reiterated by the study findings. The practitioner must be aware of the pervasiveness of asthma in this population; including the effect it has had on generations and what that means for the family for whom you are providing care. The cultural awareness also applies to recognizing the influences of prayer and herbal medicines on health practices. It appeared that neither of these interfered with the conventional health practices
however they were mentioned by families as part of their experience of asthma.

The accounts of the decision-making process prior to going to the ED were not congruent with the hypotheses presented in the current literature. As discussed in the preceding chapters, it was thought that families went to the ED because they did not have access to primary care, insurance or it was just more convenient to go to the ED. The families in the study shared reasons of fear and concern as the major reason to go to the ED. The practitioner, who was practicing under the assumptions just listed, may be challenged to make a paradigm shift when encountering this population in the future.

This hermeneutic phenomenological inquiry has shed some light on the experience of Puerto Rican families who bring their child to the ED for asthma care. This study is a beginning point for future research and by no means meant to drive practice changes. More research with this population is needed. To quote Morse (1997): “And if we did not have to create theory-if it already existed as an entity in the world- we would be unemployed. There would be no mystery, no interpretation, and no excitement to the puzzle of life” (p. 185). This text represents a piece of the puzzle of The Experience of Puerto Rican Families Who Bring Their Child to the Emergency Department for Asthma Care.
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Appendix A

Research Question and Demographic Questions
Research Statement

Tell me about your experience when you took your child to the Emergency Department (ED) for asthma care. Please be as specific as you can and provide all the details.

Demographic Questions

1) Your child's date of birth: ________________________________

2) How many times did you go to the Emergency Department for asthma care in the past year? ________________________________

3) Where did you go?
   ______CCMC/ Children's Hospital ______St Francis ______
   _______Other

4) Does your child have a doctor or nurse practitioner they see regularly?
   ____________yes ___________no

5) What language do you speak most at home? ________________________________
Appendix B

University of Connecticut IRB Approval
DATE: August 16, 2005
TO: Regina Cusson
School of Nursing, Unit 2026

Jean Coffey
Christine Malloy, 10.

FROM:
Protocol #H04-201: The Experience of Puerto Rican Families who Bring Their Children to the Emergency Department for Asthma Care

RE:

On August 16, 2005 the IRB granted re-approval of the above referenced research study under expedited review #7. The study is valid through September 8, 2006. Enclosed please find a validated consent form valid through September 8, 2006. Thank you for your continued commitment to human subjects protection.

The following applies to all research studies:

- Please forward a copy of any applicable grant application(s) to this office for review.
- All advertisements/flyers to be used in this study must be reviewed and approved by this office. Please forward all copies as appropriate.
- The consent process involves two required elements: 1) a discussion of the study by the person obtaining consent and the subject, and 2) an opportunity for the subject to read the consent form. BOTH elements must be present for an appropriate consent process to take place. Please note that it is never appropriate to forgo the discussion, even if the subject will then read the consent form. In addition, subjects must be given the opportunity to have the consent form read to them if they have difficulty reading. Please be sure to ask all subjects if they would like to read the consent form themselves or have it read to them.
- An approved, validated consent form (with the IRB’s stamp) must be used to consent each subject.

Assurance: This institution has an Assurance of Compliance on file with the Office for Human Research Protections (Federalwide Assurance No. FW A00007125, 7/07/2007).

Funding: None

Re-approval: This study must be re-approved by September 8, 2006. Please allow one month for re-approval.

Modifications: If you wish to change any aspect of this study, such as the procedures, the consent forms, or the investigators, please communicate your requested changes in writing to the IRB. The new procedure is not to be initiated until IRB approval has been given.

Please keep this memo with your copy of the approved protocol.

Attachment: Validated consent form(s)

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Appendix C

Connecticut Children's Medical Center IRB Approval
Institutional Review Board Continuing Approval Notification

PRINCIPAL INVESTIGATOR: Jean Coffey RN MS PNP
Asthma Center

TITLE: The Experience of Puerto Rican Families Who Bring Their Child to the Emergency Department for Asthma Care

CCMC IRB NUMBER: 04-044
REVIEW TYPE: Continuation, Expedited
OPPP Federal Reg Code: See 45CFR46.110(7)

ACTION OF THE IRB:
Approved for continuation on 8/8/05 by expedited review [see 45CFR 46.110(7)].

IRB APPROVAL VALID THRU: 7/31/2006
PROGRESS REPORT DUE: 6/30/2006

FUNDING AGENCY (as noted on the IRB application):

NOTE:
(1) It is the understanding of the Committee that this project will be terminated as of 7/31/2006 unless the investigator notifies the IRB that the study will continue and submits a written request for continuation as close to the progress report due date as possible. See Request Form for Continuation at g:\ccmcdoc\research\irb\applications or www.ccmckids.org/research/irb.

(2) As stated in your initial approval letter, unexpected and/or serious adverse events should be reported to the IRB Office immediately after their occurrence. Other adverse events may be summarized and reported at the time of a continuation request.

(3) It is necessary to inform the IRB in writing, for review and approval, of any modifications prior to their implementation.

Sarah Kiskaddon, JD Date
Vice-Chair, Institutional Review Board

All correspondence addressed to the IRB Office (4H) should reference your IRB # 04-044
CCMC's DHHS Federal-wide Assurance Number is: 00004706.

282 Washington Street Hartford, CT 06106 (860) 545-9000

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CONSENT FOR PARTICIPATION IN A RESEARCH PROJECT
University of Connecticut/Connecticut Children's Medical Center

Principal Investigator: Regina Cusson PhD APRN
Student: Jean Sheerin Coffey RN MS PNP
Major Advisor: Regina Cusson PhD APRN

Study Title: The Experience of Puerto Rican Families Who Bring Their Child to the Emergency Department for Asthma Care. (Interviews)

Invitation to Participate: You are invited to be a part of a research study. We want to know what brings Puerto Rican children with asthma to the emergency room for care.

Purpose: To explore the experience of Puerto Rican children with asthma and their families when they go to the emergency department for care.

Description of the Procedures: The study nurse will talk with you about your experience when you bring your child to the emergency room for asthma care. It will take about 45 minutes for the first interview and approximately 30 minutes for a follow up meeting. The study nurse will ask you questions about going to the emergency room with your child. She will say: “Tell me about your experience when you took your child to the emergency department (ED) for asthma care. Please be as specific as you can and provide all the details.” The nurse will also ask you to read some questions on a survey and tell her what you think about the questions. The interview will be audio taped and transcribed by a professional transcriptionist. If you agree the nurse will meet with you again and show you the written words from the interview. At the time of this meeting she will ask you if you want to say more or change anything from the first interview.

Risks and Inconveniences: The first interview will take about 45 minutes. The second meeting will be 30 minutes or less. There are no identified risks to participating in this study.

Benefits: There are no direct benefits to you when you participate in the study. You may be able to help nurses and doctors improve care for children with asthma

Economic Considerations: You do not have to pay any money to be in the study. You will get $10.00 for each interview and survey response.

Confidentiality: Your name will not be used in the study. The audio tape and the papers will be locked in my office. The audio tape will be destroyed at the end of the study. The University of Connecticut Institutional Review Board and the Office of Research Compliance may inspect the study records

Voluntary Participation: You do not have to be in this study if you do not want to. You can change your mind and drop out any time you like without any
penalty. If you have more questions or if you have a research-related problem you can call Jean Coffey or Dr. Regina Cusson at [redacted]. If you have any questions about your rights as a research subject, you may contact the University of Connecticut Institutional Review Board at [redacted] or the Connecticut Children's Medical Center Institutional Review Board at [redacted].

Authorization:
I _______________ give permission to audiotape this interview session and use the recording for the purposes of this study.

Please initial _______________

I have read this form and decided that I, _______________________________ will participate in the project described above, the general purposes, the particulars of involvement and possible hazards and inconveniences have been explained to my satisfaction. My signature also indicates that I have received a copy of this consent form.

Signature: __________________________________________________________
Relationship to child: ________________________________________________

Date:_______________________________________________________________

_______________________________________________________________

Signature of Primary Investigator  Date

_______________________________________________________________

Signature of the Person Obtaining Consent  Date
Appendix E

Informed Consent Spanish Version
CONSENTIMIENTO PARA PARTICIPAR EN UN PROYECTO DE INVESTIGACIÓN
University of Connecticut
Connecticut Children’s Medical Center (Centro Médico Infantil de Connecticut)

Investigadora principal: Regina Cusson PhD APRN
Estudiante: Jean Sheerin Coffey RN MS PNP
Consejera principal: Regina Cusson PhD APRN

Título del estudio: La experiencia de las familias puertorriqueñas que traen a sus niños a la sala de emergencias para que reciban atención médica para el asma. (Grupo muestra elegido)

Invitación para participar: Se lo invita a que participe en un estudio de investigación. Parte del estudio consiste en formar un grupo muestra elegido integrado por los padres de los niños que padecen asma y que se han dirigido a la sala de emergencias para recibir atención para el asma. Los grupos muestra elegidos son un grupo de personas que hablan con el coordinador del grupo, responden a preguntas específicas y cuentan sus experiencias.

El propósito del grupo muestra elegido es obtener información que ayudará a las enfermeras y a los médicos a comprender por qué los niños puertorriqueños que padecen asma se dirigen a la sala de emergencia para recibir atención médica.

Propósito: Investigar la experiencia de los niños puertorriqueños que padecen asma y de sus familias cuando se dirigen a la sala de emergencia para recibir atención médica.

Descripción de los procedimientos: Usted participará en un grupo muestra elegido con varias familias el cual será coordinado por una enfermera y un traductor. La reunión de grupo durará alrededor de una hora. La enfermera le hará preguntas sobre las experiencias que ha tenido cuando se dirige a la sala de emergencia con su niño. La enfermera también le pedirá que lea una encuesta con algunas preguntas y que le diga qué opina sobre las preguntas. El grupo muestra elegido será grabado. Un profesional de la transcripción escribirá las palabras en papel para que la enfermera las utilice con el fin de hacer un repaso de la reunión.

Riesgos e inconvenientes: El grupo muestra elegido le quitará aproximadamente una hora de su tiempo. No creemos que haya ningún riesgo derivado de su participación en este estudio.

Beneficios: Usted no tiene ningún beneficio directo por participar en este estudio. Sin embargo, usted puede ayudar a los médicos y a las enfermeras a mejorar la atención que reciben los niños que padecen asma.
Costes: Usted no tiene que pagar ninguna suma de dinero para participar en este estudio. Usted recibirá US$ 10,00 por participar en el grupo muestra elegido.

Confidencialidad: Su nombre no se utilizará en el estudio. La cinta y los papeles estarán bajo llave en mi oficina. Al finalizar el estudio la cinta será destruida. Se realizará una publicación con la información que se haya obtenido en el grupo pero no aparecerá ningún nombre o información que lo identifique. El Consejo de Revisión Institucional de la Universidad de Connecticut (The University of Connecticut Institutional Review Board) y la Oficina de Conformidad de las Investigaciones (Office of Research Compliance) pueden inspeccionar los registros del estudio.

Participación voluntaria: Usted no tiene que participar en el grupo muestra elegido si no lo desea. Usted puede cambiar de opinión y retirarse del estudio en cualquier momento sin que se le penalice por abandonar el grupo. Si tiene más preguntas o si tiene algún problema relacionado con la investigación, puede llamar a Jean Coffey o a la Dra. Regina Cusson al teléfono [número]. Si tiene alguna pregunta con respecto a sus derechos como sujeto de investigación, puede comunicarse con el El Consejo de Revisión Institucional de la Universidad de Connecticut (The University of Connecticut Institutional Review Board) al teléfono [número] o al Consejo de Revisión Institucional del Centro Médico Infantil de Connecticut (Connecticut Children’s Medical Center Institutional Review Board) al teléfono [número].

Autorización:

Yo____________________ autorizo ___________no autorizo a que se haga una grabación de esta entrevista y a que se utilice la grabación para los propósitos de este estudio.

Por favor, escriba su inicial__________

He leído este formulario y he decidido que yo____________________ participaré en el proyecto arriba descrito. Me han explicado claramente los propósitos generales, lo que implica mi participación en el estudio y los posibles riesgos e incomodidades. Mi firma también indica que he recibido una copia de este formulario de consentimiento.

Firma: ______________________________________________________________________

Relación con el niño: ____________________________________. ___________

Fecha: ______________________________________________________________________

Firma del investigador principal Fecha
Appendix F

University of Vermont Certificate of Education

In Protection of Human Subjects
June 2, 2003

Re: Education in the Protection of Human Subjects in Research

To Whom It May Concern:

Jean Coffey has completed an on-line tutorial entitled, The Protection of Human Subjects in Research. Topics include a history of the ethical guidelines and federal regulations governing research with human subjects; a description of the roles and responsibilities of the research investigators and other groups for protecting human subjects; the terms of the University of Vermont's Assurance with the Office for Human Research Protections, and the research categories that are governed by the regulations and by the Assurance; the different levels of IRB review, from research that is exempt from review to special considerations for vulnerable populations; protocol submission requirements; the elements of informed consent; and the conduct of research including the reporting of adverse events.

Sincerely,

[Signature]

Ruth Farrell, Director
Office of Sponsored Programs
Authorized Institutional Official
Appendix G

NIH Certificate of Education

In the Protection of Human Subjects
This certifies that [User] has completed the Human Subject Assurance online training, Module 2.

Tuesday, September 10, 2002

(Use your browser's "Print" button to print this certificate.)
Appendix H

Draft Questionnaire
Emergency Room Survey

1) Your Child's Age___________

2) Your Address__________________________

3) The language in which you read best _______Spanish _____ English

4) The language you speak most at home _______Spanish _____ English

5) Name of your insurance__________________________

Do you have to pay for your child's:

6) Care at the doctor's office Yes ___ No

7) Care at the emergency room Yes ___ No

9) How to you get to the doctor's office? ______ car ______ bus ______ taxi ______ walk

10) How long does it take you to get to the doctor's office?

____ 5min ______ 15 min ______ 30 min ___ > 30 min

11) When was your child's last visit to the doctor ________

12) How long did you wait to see the doctor? ___________

13) How to you get to the Emergency Room? ______ car ______ bus ______ taxi ______ walk

14) How long does it take you to get to the Emergency Department?

____ 5 min ______ 15 min ______ 30 min ___ > 30 min

15) When was your child's last visit to Emergency Department ________

16) How long did you wait to get care? ___________

You are:

_____ Mother ______ Father ______ Grandparent

_____ Other family ______ Babysitter ______ Other

Thank you for answering the questions.

PLEASE TURN OVER

Dear Parent,
Many children in our neighborhood are coming to the emergency department for their asthma care. The doctors and nurses at the Asthma Center want to understand why these children are coming to the emergency room for care. Please answer the questions as best you can. Your answers will be used to help improve care for children with asthma.

Please mark each answer with an X in the box next to the question.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5</td>
<td>X</td>
</tr>
</tbody>
</table>

**Sample**

My child has asthma

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*It is easy to:*

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Travel to the emergency department for asthma care</td>
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<tr>
<td>2. Talk to the staff at the emergency department</td>
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<tr>
<td>3. Talk to the staff at the doctor’s office</td>
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<tr>
<td>4. Get a translator at the emergency department</td>
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<tr>
<td>5. Recommend your doctor to other Puerto Rican families</td>
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<tr>
<td>6. Trust the doctor at the emergency department</td>
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<tr>
<td>7. Recommend the emergency department to other Puerto Rican families</td>
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<tr>
<td>8. Become frightened by my child’s asthma</td>
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<td>9. Have faith that God can make my child’s asthma better</td>
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<tr>
<td>10. Ask family for advice on how to care for my child’s asthma</td>
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<tr>
<td>11. Use folk healing to care for my child’s asthma</td>
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<td>12. Believe that asthma is my child’s fate</td>
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<td>13. Be embarrassed about my child’s asthma</td>
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<tr>
<td>14. Make the decisions about my child’s asthma care</td>
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<tr>
<td>15. Travel to the doctor’s office/clinic for asthma care</td>
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<tr>
<td>16. Remember a bad experience at your doctor’s office</td>
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<tr>
<td>17. Remember a good experience at your doctor’s office</td>
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<tr>
<td>18. Remember a bad experience at the emergency department</td>
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<tr>
<td>19. Remember a good experience at the emergency department</td>
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<tr>
<td>20. Trust the doctor in the clinic</td>
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