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Living face to face with breathlessness

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Living Face to Face with Breathlessness:
An Interpretive Study of Low Income Families' Management Practices in Latino and African-American Infants and Toddlers with Severe Persistent Asthma

by

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DISSERTATION

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[redacted]

The Lord God formed Man from the dust of the earth. God blew into his nostrils the breath of life, and Man became a living being.

Genesis 2:7

Dedicated to

my children, Cortney and Forrest,

and

my sister, Ellen Trace

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ABSTRACT

Face to Face with Breathlessness: An Interpretive Study of Low Income Families' Management Practices of Infants and Toddlers with Severe Persistent Asthma

by

Karel Koenig

Despite new understanding of disease pathology, and new, more effective medicines and delivery systems, asthma morbidity continues to rise among infants and toddlers, especially in low income and ethnically diverse families. Long-held, widespread belief persists that home management failure explains high rates of morbidity. However, the experience, understandings, and caregiving skills of parents are largely unexamined. This interpretive investigation examined how low income Latino and African-American parents of children hospitalized for asthma or reactive airway disease understood and managed asthma in their 12 month to 4 year-old children with severe persistent asthma. Eleven families participated in three home interviews that focused on narratives of care, and from two to five home observations of family interaction during a 3 to 5 month period.

Families coped with caregiving responsibility, family stressors, and multiple daily hassles related to poverty. Although asthma immersed parents and children in world defining fear, parents relied less on professional providers than on themselves in making assessments and taking steps to access care.

Four distinct patterns of self-agency for managing asthma were found. Parents with *determined self-agency* managed asthma with the goal of self-sufficiency. Feeling overwhelmed when symptoms flared into crisis, parents practicing *discontinuous self-agency* relinquished care to professionals. Parents who practiced *flexible self-agency* devised varied strategies to treat crises and access care, while sharing responsibility with professionals whom they did not fully trust. Two single mothers practiced *self-agency disrupted* by more critical life concerns. Asthma management was important only during, and immediately following, crisis.

Frightened for their child's life during severe breathing crisis, parents experienced hospital management as additionally traumatizing for their child. Since most felt their daily management practices were disrespected and misunderstood by crisis care providers, parents dreaded future hospitalizations and worked to avoid emergency visits.

Findings point to a need for professionals to join with parents to improve asthma care. National Institutes Guidelines regarding early treatment and referral for specialist care were not followed for children in this study.

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CHAPTER 1

Asthma Morbidity in Infants and Toddlers

The Problem of Asthma Morbidity in Children Under Four Years Old

In the United States, children who are live in poverty and are younger than four years old are hospitalized for asthma more often than any other age group (Wissow, Gittelsohn, Szklo, Starfield & Mussman, 1988; Gergen & Weiss, 1990). Asthma in this age group is associated more often with upper respiratory infection than in other age groups (Morgan & Martinez, 1992; Cypcar, Stark & Lemanske, 1992). However, reasons for the high rate of hospitalization and the reasons why parents seek emergency care are not well researched. A statewide Maryland study associated poverty and African-American race with higher hospitalization rates due to asthma in children aged 1 to 19, an association either partially or entirely explained by poverty alone (Wissow et al., 1988). In Fresno County, California, where this study was carried out, children are 46% Latino, 14% Asian, 6% African American, and 0.7% Native American, comprising a population of 67% from racial 'minorities'. Children in Fresno County are also poorer than children in 55 of California's other 57 counties (Children Now, 1998). Moreover, national statistics indicate that mortality from asthma in Fresno County among five to 34 year olds are among highest in the nation ($P<.0025$) (Weiss & Wagener, 1990). No national statistics are available on hospitalization and mortality due to asthma among Latino children who live in poverty and are under five years old.

Specific environmental factors play a role in the exacerbation of asthma and are thought to explain some of the association of asthma morbidity and mortality with ethnicity, poverty, and living in Western urban societies (Lang & Polansky, 1994; Platts-Mills & Carter, 1997). Dust mites, cats, and cockroaches have all been found to trigger asthma (Rosensteich et al., 1997). The association of maternal cigarette smoking with wheezing, respiratory symptoms, lower respiratory tract illness, and hospitalization in exposed infants is also well documented (Morgan & Martinez, 1992; Ernst, Demissie, Joseph, Locher & Becklake, 1995). It is suspected that increased numbers of emergency room visits and deaths from lung and heart diseases are due to high levels of airborne micro-particles (less than 1/25,000 of an inch). These come from a variety of sources including coal-fired power plants, auto exhaust, wood burning stoves, and fertilizers. Fresno, California, is rated as having the third worst rate of particulate pollution in the United States by the Natural Resources Defense Council (*The Fresno Bee*, 1996). Little is directly known about how poor air quality might impact asthma management. Specifically, although several studies have looked at overall parental attitudes toward school aged children with asthma (see below, p. 21), no studies address the effects of increasing symptomatic episodes in infants and toddlers on parenting practices and attitudes or on parents asthma caring practices.

The economic impact on health care systems due to childhood asthma is great. In the United States during the five year period, 1983 - 1987, children under 18 years accounted for 34.6% of hospital admissions due to asthma and 24% of the $1 billion cost (Weiss, Gergen, & Hodgson, 1992). Children's emergency visits for asthma were 47.8% of total visits for asthma while a total of

$330.4 million was spent on the inpatient hospital and emergency care of children with asthma (Weiss et. al., 1992). Hospitalizations of children under four years old due to asthma continued to increase from 1992 to 1995 at Valley Children's Hospital, Fresno, California, amounting to from 49.5% to 52% of all admissions and length of stay due to asthma among children under 20 years old (San Joaquin Valley Health Consortium, 1996).

The availability of new, improved medications and in-home nebulizers has greatly improved management of asthma in the last 15 to 20 years. In addition, a better understanding of the crucial role of airway inflammation in asthma has led to improved management through wide use of steroid therapy. That hospitalizations have increased in all age groups, and especially in children under four years, despite the development of improved therapies frustrates researchers and providers alike (Bloomberg & Strunk, 1992; Stein, Canny, Bohn, Reisman & Levison, 1989). Preventing symptoms, addressing crises early and at home should theoretically reduce the need for emergency services and hospitalization.

Researchers have focused on the need to alter parental management practices in order to remedy asthma morbidity among children under 5 (Wilson, Mitchell & Rolnick, 1993). This emphasis reflects the assumption that emergency room use and hospitalization are the markers of asthma severity. Hospitalization and the need for emergency services are seen as a failure of management marked by underuse of inhaled and oral steroids, and failure to rely on written management guidelines when they are given (Friday, Khine, Lin & Cliguiri, 1997; Lieu et al., 1997; Warman, Silver, McCourt & Stein, 1999). Recent studies have emphasized the important role of caregivers, both specialists and primary care providers, and the inadequacies of health care system services for children with asthma who live in poverty (Friday, Khine, Lin & Cliguiri, 1997; Warman, Silver, McCourt & Stein, 1999).

Updated Guidelines for the Diagnosis and Management of Asthma (National Institutes of Health (NIH), 1997) spell out more than did the original guidelines (NIH, 1991) the components of asthma education and home management. Emphasis includes the need for providers to: establish and maintain a partnership with patients; address patients' fears; understand their current use of medications; elicit information about particular triggers and how to control them; discuss quality of life; learn about problems encountered with medication use; and work to re-educate about the proper use of inhalers. In addition, friendly, direct, and reassuring communication in the patient's primary language is emphasized as are attention to cultural beliefs and guidance regarding alternative health care practices. Nevertheless, no specific guidelines are given for the education of parents of children under four years who cannot cooperate in their own symptom identification and medication administration, and whose symptoms manifest differently than do those of adults. In addition, although in a pilot study of this project about the experience of living with asthma in children under four with severe persistent asthma, all parents described that they most dreaded the hospitalization of their children, the impact of prior experiences of hospitalization on the assessment and management of asthma crisis is not considered in the literature or in NIH guidelines.

Asthma Symptoms and their Management

Asthma is reversible airway inflammation, obstruction, and hyperresponsiveness dependent on genetic predisposition and triggered by infectious agents, allergens, irritants, and/or emotional stressors (Mrazek, 1992; United States Department of Health and Human Services {HHS}, 1991). Asthma is invisible, unpredictable, and crisis prone (Becker et al., 1993). A feeling of panic typically accompanies the inability to breathe adequately (Mrazek, Anderson & Strunk, 1982). School-aged children describe feeling nervous, angry, scared, and afraid of dying (Carrieri, Kieckhefer, Janson-Bjerklie & Souza, 1991). In children five years old and younger, the experience of difficult breathing, often with persistent coughing, is usually triggered by infection, accompanied by fever and congestion (Behrman et al., 1992; Wilson et al., 1993). Several oral and/or inhaled medications in combined regimens can prevent wheeze and cough (Stempel & Szefler, 1992).

Illness severity in asthma covers a wide range of symptoms, management issues and outcome risks. In its mildest form, asthma symptoms are little more than an easily managed infrequent nuisance, and the risk for adverse sequelae is low. Children are defined as having severe persistent asthma when they: 1) require continuous medications; 2) experience frequent episodes of distress; and 3) are at risk for chronically compromised lung function, limitation of activity, severe episodic distress, hospitalization, and death (Gutstadt et al., 1989; HHS, 1997; Behrman, et al., 1992; Bloomberg & Strunk, 1992; Weiss et al., 1992; Stempel & Szefler, 1992). Progression of symptoms, increasingly compromised pulmonary function, and hospitalizations define short-term asthmatic crisis (MacLean, Perrin, Gortmaker & Pierre, 1992; Perrin, MacLean & Perrin, 1989).

Since it is in the home and often during the night when episodes of dyspnea are likely to occur, parents are on the frontline of everyday, routine management of childhood asthma (Stempel & Szefler, 1992). Whether or not they do well carries significant consequences for the child's immediate health and his/her longevity (Creer, Stein, Rappaport & Lewis, 1992; Stempel & Szefler, 1992; Wilson et al., 1993). Besides medications, protection from precipitant causes such as infection, strenuous exercise, heightened emotions, and allergens, comprise the daily management necessary to control symptoms (Creer et al., 1992; HHS, 1991, HHS 1997).

Parents must decide, often without the help of immediately available professional advice, when to employ formal health care directives to avoid triggers, assess crises, and manage night routines. Parents define the parameters of exposure to known allergens and infections when children are young. Decisions about whether or not there are pets or smokers in the home, or contact with other children who may have infectious illnesses are made by parents (Stempel & Szefler, 1992). In addition, since anxiety exacerbates the feeling of breathlessness and leads to a vicious cycle of escalating illness, parental management includes remaining calm in crisis and calming the child (Staudenmeyer, 1982; HHS, 1991; Wee Wheezers, American Lung Association, 1996).

When home medications are not alleviating symptoms, parents decide when, and whether to access help. Failure to recognize impending crises and failure to appropriately treat increasing breathlessness accounts for most morbidity and mortality (Stempel & Szefler, 1992). Accessing care unnecessarily or the failure to access care appropriately also increases the cost of caring for children with asthma (Bloomberg & Strunk, 1992; Strunk, 1989; Stempel & Szefler, 1992). Even with more recent studies that ascribe some responsibility for failures in asthma care to providers and the health care system, the widespread belief that parents can prevent unnecessary morbidity and mortality by early recognition of distress, effective initial management of crises, and appropriate access of emergency care remains (Lieu et al., 1997; Stempel & Redding, 1992; Wilson et al., 1993).

The expectation that parents should be able to assess symptom severity is crucial to established ways of managing symptoms. However, even physicians have difficulty assessing symptom severity without the aide of measures of pulmonary function or blood oxygen saturation (Stein, et al., 1989; Stempel & Redding, 1992). Older children and adults can verbalize their distress and are able to cooperate with in-home peak flow testing of pulmonary function. The peak flow meter is a simple hand-held device. Three breaths of maximum exertion provide an objective measure of pulmonary status. Children under the age of 6 are not usually able to mange the device effectively enough to provide adequate assessment of pulmonary status (Yoss & McMullins, 1995). Even with peak flow monitoring, good control of symptoms may not be achieved and severely distressed breathing may not be accurately assessed (Shimm & Williams, 1980; Janson-Bjerklie, Ferketich & Benner, 1993). A pilot study of 6 to 18 year old children with moderate to severe asthma found that a significant number of parents and children did not perceive compromised breathing until peak flow levels were less than 50% of normal (Yoss & McMullins, 1995). Management guidelines call for alternative management strategies to begin when peak flow levels are 80% of normal (HHS, 1991; HHS 1997).

In infants and toddlers the early markers of distress are more subtle and/or non-specific: decreased activity; increased work of breathing; tachypnea; and cough (Stempel & Redding, 1992). Severe distress is marked by nasal flaring, intercostal and subcostal retractions, neck straining, and inflated chest (Wee Wheezers, 1996). There are no clear criteria for just what clinical signs and symptoms short of severe distress signal the need for emergency care and whether or not these may differ among children. In addition, since children under 4 years old cannot cooperate very well with peak flow meter testing, how symptoms correlate with levels of pulmonary function is not known. Literature attributes to parents the failure of effectively assessing distress and appropriately initiating responses (Wilson et al., 1993).

Summary With home management for asthma as the focal point in the crisis of care of young children with asthma, providers, asthma educators, and researchers struggle for effective ways to enhance symptom control and reduce the need for hospitalization. Parents clearly function in various ways in the translation of management demands into everyday caring practices. This study seeks to discover the background understandings and practices which underlie and organize how parents evaluate symptoms, assess severity, manage compromised breathing in young children, and take the step of accessing emergency care that could result in hospitalization. The children of interest are those with the most severe symptoms and the greatest risk for immediate poor outcomes.

Management Programs

Many clinicians and researchers have created and tested the effectiveness of asthma management programs designed to improve symptom management. In this section I will review some of those programs and discuss their success in helping the families and children who live with asthma.

Ninety-two children, ages not specified, with mild, moderate, and severe asthma completed an education program with their parents (Hinde-Alexander & Cropp, 1984). Severity was scored according to potency and frequency of medications, number of wheezing episodes, number of hospital admissions and emergency visits, and number of school absences in last 12 months. SES was not discussed. In a six week program, participants were taught warning signs of asthma, triggers, preventative treatment, and what to do in the event of an acute attack. Knowledge of asthma among parents and children significantly improved after the program over pre-program knowledge. Children were also included in an activity program of games, swimming, calisthenics, and relaxation training. After three months, parents' and children's attitudes toward asthma improved significantly. Each month, for one year, eight variables were measured. At the end of one year children had significantly increased activity levels, and significantly decreased health care visits and school absences. There were no significant decreases in the need for medications, or emergency or hospital visits. In addition, there were no significant increases in school activities (Hindi-Alexander & Cropp, 1984).

Since there were no control groups the effectiveness of the educational and activity components of the intervention cannot be assessed. It is disappointing that the program had no significant effect on hospitalizations or frequency of emergency care and that disease severity was not reassessed at the end of the study period. Nevertheless, the significant findings post-intervention and at one year indicate that improved manageability of asthma resulted.

A group of 19 children with mild to severe asthma, aged 6-14, were matched with a control group by sex, age, severity of disease (criteria were not given), and season of worst asthma. The children and their parents participated in a four week asthma education program (Whitman, West, Brough & Welch, 1985). Parents (or children) in both groups kept daily medication and symptom diaries, and parents assessed symptom severity weekly. After three months children in both groups, asthma and control, showed a significant decrease in number of acute episodes. The study group's knowledge of asthma and management and management skills improved significantly after the study. This difference was maintained after three months. Criteria by which parents assessed symptom severity were not given. As part of the same investigation Whitman et al. (1985) studied the effects of a three week educational intervention with 21 children with asthma aged 2 to 5 years. After three months, episodes of acute asthma had decreased significantly in the preschoolers. Knowledge and skills were not tested nor was there a control group. SES was not reported for either study. Parents did not assess that severity decreased significantly in older or younger children with asthma or in controls (Whitman et al., 1985). Overall, the results of this study confirm the value of keeping a daily log with or without educational intervention. Objective measures of pulmonary function in the older children would have enhanced the findings. However, in 1985, peak flow meters were not in widespread use.

Another study that evaluated a program designed to promote improved self management of asthma involved 18 children, aged 8 to 12, and their parents (Tal, Gil-Spielberg, Antonovsky, Tal & Moaz, 1990). An aged matched control group continued regular care at the clinic from which they and the study participants were recruited. The theoretical premise underlying the study was that asthma management depends on interactive cooperation between the family and health care providers rather than on the traditional notion that successful management follows from strict compliance to management directives. Six weekly sessions combined education and family communication skills training. Both parents participated. Evaluation interviews with parents and children to obtain data on medications, hospitalizations, school absences, who takes responsibility for daily care, who makes decisions about school absences, and how often the child remembered to take medications were held at baseline, three months, and 12 months. The significant findings include that both parents and children reported taking more responsibility for asthma care even after one year. Reliable reports from families and from hospital records about numbers of hospitalizations and emergency visits could not be obtained. Thus, an assessment of study participation on those important variables could not be shown (Tal et al., 1990).

This study emphasized family communication, specifically about asthma and its management with the goal of increasing child self care. Significant findings support the efficacy of the intervention on this account. Uniquenesses of the research plan were that: 1) both parents participated with the child in an intervention which emphasized family communication; 2) family and 'medical' systems were seen to interact in mutually respectful ways to achieve optimum care; and 3) professionals and the family designed a plan for decision making during acute asthma episodes. In this study conducted in Israel, SES and ethnic background were not reported and single parent families did not participate. It is, thereby, not directly applicable to more ethnically and sociologically diverse populations.

Ninety-five children, 47 in a study group and 28 in the control group, who had a mean age 9.5 years, were compared after a year long asthma management intervention (Hughes, McLeod, Garner & Goldbloom, 1991). Asthma severity at intake was assessed by frequency of asthma crises. Clinical assessments and individualized management programs were set up along with extensive education from a nurse coordinator about prevention and management strategies for study group children. Children then attended the clinic at three month intervals during which the physician and nurse coordinator provided individualized instruction for management. The nurse coordinator made a home visit once in each six month interval during the first year for the purpose of assessing the home environment and educating the family about environmental triggers. Controls were similarly assessed and given management instruction at the first visit. They continued to attend the clinic throughout the study period but did not necessarily see the same physician. They had no further visits with the nurse coordinator. Four criteria of asthma severity, lung function, school attendance, emergency care, and hospitalization, were assessed for all children at three month intervals until 12 months and again 12 months later. The study took place in Nova Scotia. No SES was reported (Hughes et al, 1991).

After one year children participating in the intervention took more responsibility for asthma. However, since management was assessed by their parents, this result may be skewed by social desirability. Peak expiratory flow was significantly improved in treatment group children at the 12 month assessment but the effect was not sustained to the follow up one year later. Numbers of hospitalizations and length of hospitalization were not significantly different.

The intervention did not result in many significant changes. Especially disappointing to the authors were the following findings: 1) no reduction in exposure to second hand smoke or pets in the home during the study; 2) no change in the number of post intervention visits by study children; 3) no change in numbers of asthma crises; and 4) no significant differences between study and control children at the 12 month post-intervention follow-up on any of the four severity criteria (Hughes et al., 1991). The major differences in this study and the study by Tal et al. (1990), were that despite individualized care no family interventions took place and the intervention was designed to distribute information. There was no stated importance of understanding the families circumstances and input. In addition, care was not designed to facilitate communication among family members or between providers and the children or their families. Nurse interventions were for assessment of the home environment and educational intervention.

In the Netherlands, a multidisciplinary education protocol for physicians and parents of children from birth to 4 years old was developed from a parental educational needs assessment of preschoolers who have asthma. The protocol was tested in a six month study with follow up at 1 year (Mesters, Meertens, Kok & Parcel, 1994). General practitioners (GPs) provided the protocol for parents, n=33 who were compared to controls, n=30 who received initial evaluation then the protocol six months later, and controls, n=18, who did not participate in the intervention. Researchers stated that participating parents had mostly middle or low levels of education. Ethnicity and income levels were not given. There were no significant demographic differences between study families and controls.

The treatment group had significantly more knowledge about asthma, level of self-efficacy expectations, and frequency of performing self-management behaviors (for instance, taking medicines as scheduled) than the first control group as measured at six months. In addition, protocol group parents indicated significantly more interest in asthma self-management at six months. Significance on both knowledge and self management measures was not sustained at 12 month follow up, however. Numbers of non-emergency and emergency visits decreased significantly more in the treatment group than in the second control group at the 12 month follow up. A decrease in hospital admissions did not reach significance in comparison with the second control group. Asthma severity as assessed by the GPs (who were not blinded to the study groups) decreased significantly in treatment group children compared to the second control group (Mesters et al., 1994).

This study of preschoolers with asthma and their parents is important primarily due to the fact that protocols were established according to needs assessment from the parents. Results showed significant differences on several management parameters and in the directly related use of medical services. The study would have been improved by assessing severity according to a standard set of physiologic criteria. Follow up past 12 months would also have been valuable. Since the children are young, effects of early management self-efficacy on later illness parameters would be very valuable. No discussion was given about how self management was conceived for very young children or whether management behaviors were only for the parents. Neither was there a stated concern for how parental management practices were or were not accommodated to promote self-efficacy and self-esteem in the child.

<u>Summary</u> The management interventions reviewed above all demonstrated at least significant short term improvement in knowledge of asthma when it was measured. In addition, the studies showed significant improvement in severity,

attitudes toward asthma, self management skills, activity levels, and numbers of acute episodes. However, results are not consistent across studies. Not all variables were measured in every study, nor were similar variables measured by the same criteria. Most importantly, the assessment of severity and self management were confounded by lack of objective measures and impartiality of those making the assessments.

In addition, most significant parameters did not hold up over the long term. Exceptions are increased activity level, decreased school absences (Hinde-Alexander & Cropp, 1984), increased child self responsibility for management (Tal et al., 1990), and decreases in numbers of emergency and non-emergency visits in preschoolers (Mesters et al., 1994). Interestingly, in addition to education about asthma and asthma management, these studies all included an interpersonal aspect of intervention: activities (Hinde-Alexander & Cropp, 1984); family communication (Tal et al., 1990); and involvement of the patient's physician in the intervention (Mesters et al., 1994). Additionally, one intervention developed its materials with the input of parents (Mesters et al., 1994) and another emphasized the mutual influence of family and medical system (Tal et al., 1990). However, the effects of none of these personal communication and relationship characteristics was assessed. Therefore, several issues stand out when these studies are taken as a whole. First, whether parental input and participation, or the professional support that the interventions provided, contributed to short term outcomes, or made the difference in long term outcomes cannot be assessed. Second, many of the significant associations may have resulted in part due to improvement in symptoms that would have taken place over time with or without intervention. Such an effect could contribute to increases in children's activity levels and in decreases in school absences. Decreases in acute episodes in children 2 to 5 and in their emergency and non emergency care visits also might be due to natural improvement of symptoms overtime. Two other observations are relevant. First, most interventions do not include children under four years old. Second, the two investigations in which young children participated did not show significant decreases in hospitalizations as a result of planned intervention. Thus, although knowledge of asthma and management skills is an essential component of interventions, just what effective management programs for families and children with asthma also require is not established, especially when children are younger than 4.

Nursing Research

In studying the viewpoint of parents whose children under 4 years live with chronic illness, nurse researchers have found that illness management is complex rather than straightforward, and evolutionary rather than fixed (Cohen, 1995; Deatrick, Knafl & Walsh, 1988; Knafl & Deatrick; 1986; Knafl & Deatrick, 1987).

Ray & Ritchie (1993) studied 29 families of chronically ill children from 3 months to 16 years where parents provided continuous, daily medical-technical care. Parents reported that in managing the burden of daily care, strengthening their family relationships was more helpful than consulting with health professionals. Among children hospitalized with disabilities nurses used grounded theory to discover how parents felt themselves "[e]merging as the disabled child's 'central person' " (Perkins, 1993, p. 2). Gradual increments in knowledge and involvement led parents to the role of highly skilled caregivers and the self-acknowledged "essential link, bringing together all others involved" in their children's care (p. 7).

Nurse researchers have also found that effective caregiving and management result when parents' ability to recognize symptoms in their children is valued by professional caregivers and forms the basis of intervention. In a study of acutely ill infants nurses found that parents' sensitivity to illness clues was valuable in the care of infants (Selekman & Malloy, 1995). They warned against discounting the credibility of parents' assessments when parents are uneducated, anxious, communicate poorly, or hold unfamiliar cultural beliefs.

A similar attitude toward parents' experiences with children's asthma was the basis for a nurse-managed hospital intervention. In the study of asthma in children under 5 years, nurse researchers in Scotland developed an in-patient asthma teaching intervention around an individualized discussion with parents of the events leading to the asthma crisis that precipitated hospitalization. Symptoms parents recalled as their child's crisis developed formed the background of education regarding management of subsequent crises. Children were from 2 to 14 years with 41.7% under age 5. During the 2 to 14 months following intervention, children in all age groups whose parents had participated experienced significantly reduced re-admission for asthma crisis compared to controls (Madge, McColl & Paton, 1997). Since randomization was carefully planned and reported in detail, the important risk of selection bias was reduced. All participants admitted for asthma were chosen on a random basis but only on Mondays and Fridays when the asthma nurse was available. However, children in the intervention and treatment groups matched with each other and with all children admitted for their first asthma admission during the study year on the basis of age, length of hospital stay, number of previous admissions, median days of follow up and treatment modalities. In addition, although these Scottish authors do not include specific ethnicity or income statistics, all three groups matched on "deprivation score," a score that the authors indicate was based on postal code.

Nurses have also reported the experience of parents in living with asthma in their older children. Consistent with the findings that when provided written management plans, parents of children with asthma do not think to use them in crisis, and that in hypothetical experimental situations parents would *not* refer to written plans in crisis (Warman et al., 1999), Kast (1999) found that formal educational information about asthma was disregarded by the mother of a 10 year old boy with mild-persistent asthma. His mother, who was hindered by poor reading and math skills, felt overwhelmed by the detailed management plan given her and worried that inhaled steroids might harm his vision. Kast modified her education to provide simple, concise instructions and to address James' mother's concern about the possible dangers of inhaled steroids. As a result James had experienced a period of nearly one year of improved symptoms. Kast stated "every patient does not need to know all we know about asthma." (p. 6).

Horner (1997) used grounded theory to describe the enormous influence of the prediagnostic period on mothers of school-aged children with asthma. Although the age of all children in the prediagnosis period is not identified, some children were between 30 and 60 months when diagnosed with asthma. Ethnicity, sex, and poverty level were not reported. Mothers described feeling frightened, helpless, and frustrated as they cared for recurrent episodes of illness that seemed never to end. In addition, sleepless nights wearied mothers as they watched their children struggle to breathe. Parents found that when physicians did not identify their child's symptoms as asthma and did not provide instructions about symptom relief that proved effective, mothers sought relief through chiropractic care, over-the-counter medications, and home remedies. Horner reports that the 12 mothers in this study found relief from the high uncertainty of the prediagnosis period when diagnosis brought the change of a more effective treatment plan.

Two nurse investigators used grounded theory in a study of 2 to 13 year old children with asthma, mean age 6.9 years with 30 families participating (Jerrett & Costello, 1996). Ethnicity, sex, poverty level, and asthma severity were not identified. The nurses found that parents' first encounters with symptoms left them uncertain and vulnerable. As they became more experienced and involved in seeking solutions for symptom control parents learned to modify their management intervention. Eventually asthma management became integrated into family life even though uncertainty about recurrence and the possibility of threats to parents' sense of control over the illness persisted. Without elaborating, the authors point out that parents could move successfully to the place of feeling in control of asthma due to a supportive and accessible health care system.

Summary These nurse conducted studies all contribute to the literature by emphasizing the importance of the parents' perspective when children under 4 years old are chronically ill. Whether it was studying the influence of family factors, designing an intervention from the starting place of a family's experience, modifying an intervention to account for a family's special needs, exploring the experience of living with an undiagnosed chronic illness, or explaining the family experience of controlling symptoms, each researcher told the story of illness management on the background assumption that successful illness outcomes depend on understanding what parents already do. Those studies of parents of children with asthma describe an experience that is confusing, frightening, tremendously stressful, and lonely, especially during the early stages of illness onset.

In studies of children 4 and under with severe persistent asthma, just how to reverse high morbidity remains obscure. However, two characteristics of asthma caregiving in children stand out as likely important to consider in planning better strategies for the management of infants and toddlers with asthma. First, besides the delivery of knowledge about asthma, adapting interventions to individual parent and family needs has shown positive results. Second, studies find that parents who have experience and knowledge about their children's asthma rarely follow professional prescribed management instructions. Third, parents described that caring for their children with asthma was a lonely and emotional caregiving burden. Finally, social circumstances, personal resources, and understandings of medications all influence parents' ways of following professionally prescribed management instructions.

Research in children younger than 2 years, who live in poverty and whose ethnicity may leave them socially disadvantaged, is extremely limited. It is noteworthy that children under two years with severe persistent asthma have almost always been studied as part of a larger group of children whose ages range from 2-13 years. Specifically, families found to be most at risk of having their children admitted to the hospital for asthma, that is, ethnically diverse, low income families with children under 4 years of age, have not been investigated.

Families share with professionals the goal of promoting and facilitating optimal well being of infants and toddlers with severe persistent asthma. In addition, families are intimately aware of daily demands asthma makes on them and their children. Thus, they are uniquely positioned to understand the distinctions that make living with asthma successful or problematic. Although some research, and especially that conducted by nurses, has seriously and empathically considered parents' perspectives, much of the literature leads one to view their perspective with some suspicion as family functioning has historically been associated with asthma morbidity.

Perceptions of Children with Asthma and Their Families

Both parents and providers take up the understanding of asthma as an illness within a shared cultural milieu of personal, social, and medical meanings (Kleinman, 1988). This study is based on two assumptions. First, in addition to understanding asthma as a disease defined by pathophysiological processes, living with and managing asthma involves understanding the meanings ascribed to it. Second, in investigating the experience of families whose children have asthma, it is necessary to consider how the professional medical community perceives asthma. Since the two perspectives, that is, of families and of professionals, are different, each will impact asthma management in distinct ways. These distinctions are expected to have overarching and ongoing importance for the families who are dependent on professionals for education, medical management, emergency services, and hospital care. In this section, I will discuss the meanings attributed to children with asthma and their parents as documented in western medical literature. A review of the literature finds that the perceptions of children with asthma, their parents, and the families of children with asthma have long been negative and laden with descriptions of emotional pathology.

Children with Asthma Historically, asthma in childhood has been viewed as a condition that evolves within psychologically disturbed relationships. Children were assumed to have fixed personality traits: overanxiety; lack of self-confidence; and a deep-seated dependency on their mothers. Historically the stigma of having asthma was carried in the terms "asthmatic children" and "asthmatics," terms that will be avoided in this project since they not only connote stigma but also leave persons with asthma primarily defined by their illness.

An early comparison study of children with asthma and children with cardiac disease found that in both groups some children exhibit similar psychological symptoms, and suggested that protracted illness especially in early childhood may account for dependency, anxiety, and low self-esteem (Neuhaus, 1967). In comparing children with asthma to children with cystic fibrosis and children who were not ill, Williams (1975) found that in an experimental situation, children with asthma performed significantly less well compared to other children if their mothers were not present and involved. Williams concluded that in the extreme maladjustment associated with heightened severity of symptoms, children exhibited "regressive dependency, ... a desire in the child to re-establish a close physical union with the mother, similar to that which existed prior to birth, physically protected, enclosed, with *complete passive* dependence." (p. 199). [Italics are mine.]

One study associated children's difficult temperament with asthma. Although temperament is usually considered a stable biological trait which characterizes each individual, many differences exist in definitions of temperament. The question of whether or not temperament is immutable is an especially complex one on which theorists have varying opinions (Goldsmith et al., 1987). They generally agree that temperament is not a set of specific behaviors but an underlying pattern or tendency to behave in characteristic ways. In addition, theorists consider temperament, though not entirely immutable, to be founded in individual biological differences which are characteristic of each individual and continuous throughout the life of that individual (Goldsmith et al., 1987).

Parents of 3 to 7 year olds with moderate and mild asthma, n=12, identified significantly more difficult "temperaments" in their children with asthma than in healthy children or children with cystic fibrosis (Kim, Ferrara & Chess, 1980). Parents perceived children with asthma as being less adaptive, having lower intensity of reaction, "lower mood value," and lower persistence. The authors acknowledged the unanswered question of whether or not child characteristics precede or follow diagnosis with asthma. Yet labeling the significant child behaviors as "temperamental characteristics" implies the association of asthma in childhood with established behavioral patterns, negatively defined. Further, the notion of illness specific temperament infers that such negative behaviors can be found in any child with asthma.

The implication persists that asthma in childhood and characteristically maladjusted behaviors are inextricably bound. Carson and Schauer (1992) describe other difficult behaviors documented in the literature as associated with childhood asthma: immaturity, lack of self-confidence, restlessness, overanxiousness, bossiness, timidity, sadness and withdrawal, impulsiveness and lack of anger control, critical attitudes toward others, stubbornness and insistence on having their own way. Their own recent work of midwestern Caucasian children aged 8-13 with asthma, 75% of whose parents were middle to high income, confirms the association between asthma and undesirable behaviors as perceived by their parents. Compared to normed samples of healthy children, the children with asthma, n=41, were assessed by their mothers as less adaptable, less acceptable, less reinforcing to the mother, and more demanding and moody on the Parenting Stress Index (PSI) and the Mother-Child Relationship Evaluation (MCRE) (Carson & Schauer, 1992).

<u>Parents of Children with Asthma</u> Mothers of 8 to 13 year old children with asthma studied by Carson and Schauer (1992) were found to be rejecting overprotective, and overindulgent. According to several recent correlational studies, relationships between parents and their children with asthma are conflicted. German mothers and fathers had more critical attitudes and more negative communications with their school aged children with asthma than did parents of healthy controls (Hermanns, Florin, Dietrich, Rieger & Hahlweg, 1989; Schobinger, Florin, Zimmer, Lindemann & Winter, 1992).

In a prospective Norwegian study, Askildsen, Watten, & Faleide (1993) studied the attitudes of parents of 161 never symptomatic six month old children at immunological risk for allergy (criteria referenced). When the children were 7 to 9 years old those who developed asthma were compared to the others. The investigators concluded that the mothers of children who developed asthma exhibited a "marked tendency to regulate, 'shape' and even invade the child" and that this tendency was a "subtle, preconscious strategy aiming at making the child dependent on them," but that it might also "reflect a strong personal motivation to protect and care for their child based on perceived needs of the child" (p.96).

One study records a more positive profile of parents of children with asthma. While concluding that asthma brought more everyday stress to parents of 37 children aged 3 to 5 with asthma, a study in England found the parents' discipline strategies did not differ from those of the parents of healthy controls (Eiser, Eiser, Town & Tripp, 1991). These parents reported ratings not significantly different from controls regarding their children's enjoyment of life and their interactions with other children.

Families and Children with Asthma Many studies of families of school aged children have found associations between family dysfunction and asthma morbidity, severity of symptoms, and death (Gustafsson, Kjellman, Ludvigsson & Cederblad, 1987; Strunk, Fukhuhara, LaBreque & Mrazek, 1988; Mascia, 1989; Strunk, 1989). In 1988 Boxer, Carson, and Miller reported that clinical psychologists and social workers assessed that 48% of children with asthma suffered parental neglect of their medical, physical, and emotional needs. The researchers described the effectiveness of long term hospitalization of school aged children with severe asthma, an intervention designed primarily to allow children to adapt to asthma in an environment not influenced by their parents. The need for routine and emergency medical care and hospitalizations in the year following the intervention were reduced (Strunk et al., 1989; Boxer et al., 1988).

A 3 month period of hospitalization for medical management and behavioral education of school aged children showed that, by involving parents and hospitalizing children, knowledge driven management behaviors in children improved. Parents of the hospitalized children participated in monthly parent education sessions with weekly reinforcement prior to and following children's weekend home visits (Brazil, McLean, Abbey & Musselman, 1997). After hospitalization the children had positive attitudes toward self-management behaviors. In addition, their knowledge of asthma and self-management behaviors were significantly correlated. As part of the study, children in a 3 week outpatient day camp program, that provided the same content but in which parents were not involved, showed a less positive correlation between asthma knowledge and management behaviors. In addition, their attitudes toward asthma management and management behaviors were negative. Thus, the involvement of parents combined with the opportunity for children to practice their management behaviors in a medically protective environment produced a positive outcome. Long term retention of the changes was not studied.

Many studies have been designed on the theoretical background put forth by Minuchin and colleagues (1975) who described four transactional characteristics of family function that were believed to characterize psychological dysfunction in families and lead to the exacerbation of symptoms in children with asthma. According to Minuchin these "psychosomatic families" are enmeshed, overprotective, rigid, and avoid conflict resolution leaving unsolved problems to be expressed again and again as increased symptomatic crises of breathlessness in asthma or elevation of blood sugar in diabetes (Minuchin et al., 1975).

Minuchin's thinking provided the basis for several studies about families of children have asthma. Olson (1989) incorporated some of Minuchin's concepts in developing the Circumplex Theory of family functioning, a Clinical Rating Scale (CRS), and questionnaire, the Family Adaptability and Cohesion Evaluation Scales (FACES) (Gustafsson, Kjellman, Ludvigsson & Cederblad, 1987; Donnelly, 1994). On this scale family adaptability and cohesion are rated on continua of low to high adaptability (chaotic or rigid) or cohesion (disengaged or enmeshed). The model is curvilinear since either extreme of either dimension is dysfunctional. Optimal family functioning occurs when adaptability and cohesion are balanced or in midrange. (Olson, 1989). Researchers reported significant associations between asthma and family dysfunction (Baron, Veilleux & Lamarre, 1992; Gustafsson, Kjellman, Ludvigsson & Cederblad, 1987). They also reported successful psychotherapeutic interventions designed to reverse family dysfunction as defined on the Minuchin model (Gustafsson, Kjellman & Cederblad, 1986;).

On the other hand, one study of children with asthma aged 9-15 , showed that high cohesion and defined structure defined families whose interdependent relationships led to better symptom control (Meijer, Griffioen, van Nierop & Oppenheimer, 1995). In addition, Donnelly (1994) a nurse researcher studied family hardiness, stressors, and functioning in families of young children (aged 1 to 5 years) where children had asthma. Using one instrument based on the Minuchin model and another to measure family hardiness and family stress, she found a significant positive relationship between balanced families and family hardiness in children with asthma. Furthermore, family hardiness levels were similar to those reported in "nonclinical" families. It is implied that families where children have asthma are not different from families where children are not ill in family hardiness, stress due to life change, and overall functioning.

The theoretical basis of Minuchin's work and its use as a model for the care of families of children with chronic illness has been challenged in a model laid out by Wood (1993). She proposed the construct of biopsychosocial response to illness that defines individual as well as family responsiveness to illness. However, this theoretical model has not been used to evaluate children with asthma. As a consequence, the body of research with significant findings regarding the emotional health of children, parents, and families in which children have asthma continues to carry the overtones of pathology as based on Minuchin's model of the "psychosomatic family."

Summary Studies over several decades attribute many negative personality traits to children with asthma. Specifically, children are 'too dependent' especially on their mothers, lack self-confidence, and are critical and demanding. Mothers are found to participate in this disturbed relationship by being overprotective, controlling, and critical of their child. Fathers of children with asthma, too, when studied were found more critical. Parents assessed parenting as stressful when children have asthma. Yet, studies of parental stress do not consider the parenting practices and child behaviors specifically resulting from or necessitated by asthma symptoms and their management.

Whether the conclusions of these studies apply to all children with asthma is questionable. Samples do not represent children from ethnically diverse, migrating, or low income families, with known increased risk of hospitalization and mortality due to asthma (Perrin et al., 1989; Weiss & Wagener, 1990). Neither do they represent children in urban areas where poverty and racial minority are associated with increased rates of hospitalization (Perrin et al., 1989; Wissow et al., 1988).

Overall the literature finds that families whose children are in need of the most intensive care for asthma have significantly more dysfunction, as defined on the Minuchin model, than children with diabetes, children with cystic fibrosis, and children who do not have asthma. Asthma severely out of control is associated with neglect as well.

Whether asthma causes family dysfunction or the other way around is not established. Two recent studies have tried to establish a cause and effect link between parenting attitudes and behavioral practices in childhood with the development of asthma. Mrazek (1992) studied 150 families at high genetic risk for asthma from pregnancy until the second year of the child's life. The sample were 92% Caucasian and the majority middle class per the Hollingshead SES scale. The investigation was not controlled for cigarette exposure nor for parity of the mother. In addition, interviews with the mother assessed paternal as well as maternal coping. At age three weeks mothers were interviewed about the perceived stress of parenting and their ability to cope while the interviewer made informal observations of the mother's parenting skills. Analysis revealed a positive correlation between parenting stressors, maternal coping, and the development of asthma defined as recurrent wheezing episodes with at least one not related to respiratory infection. While asthma correlated positively with negative parental stress and coping, infectious wheezing did not (Mrazek, 1992).

Most family researchers do not address the question of the direction of effect between asthma severity and family dysfunction. However, hospitalization of children with asthma in order to attain management goals seemed based on the belief that family influence was negative in children with severe persistent asthma, and that severing and modifying family management patterns by teaching better models of behavior would reduce asthma severity. The Minuchin model and the therapeutic interventions Minuchin designed as a result posit a similar direction of influence. Woods' model, on the other hand, seems clearly based on a belief that family and illness effects are circular.

Most studies show that families clearly influence the expression of asthma and its manageability. What is not clear are the qualities of family functioning that enhance the manageability of asthma. Especially lacking are studies of families from various ethnic groups and income levels where children are younger than four or five years. Only one family study looked specifically at family qualities in young children with asthma. The sample was not controlled for severity of illness, neither was the sample ethnically diverse. In addition, more than half the study participants had attended college while only 15% had not finished high school (Donnally, 1994).

Conclusion

Reasons for the increasing prevalence of asthma are not known. Increased morbidity is not thought to be due to changed diagnostic criteria (Gergen & Weiss, 1990). Moreover, there are no conclusive data about whether or not severity is increasing. As a result, rising asthma morbidity, as measured by hospitalization and use of emergency services, is seen as a failure to manage symptoms effectively and prevent exacerbation (Gergen & Weiss, 1990; Stein et al., 1989).

Although results of management interventions demonstrate success on some measures, taken as a whole they have failed to change the tide of increasing asthma morbidity in children under 4 years. All asthma management studies presume and do not refute that knowledge of asthma and asthma management successfully taught will lead to improved control of symptoms, even though there is evidence that knowledge of the disease and clearly spelled out plans for management are of less importance to parents and children than they are to professionals. Moreover, the effects of interventions are difficult to compare, especially since levels of severity and controllability of the illness share similar expression. Furthermore, in every investigation of management program effectiveness, salient contextual characteristics, such as family communication and professional cooperation and support play a role. However, the influence and quality of communication, cooperation, and support components cannot be effectively compared across studies since they differ between interventions, receive different emphases, and have not been measured.

Studies of children of all ages with asthma, their families, and management programs lack balanced ethnic and income level representation. In addition, research has led to few findings about children less than 4 years and has focused very little on children under 2 years. Studies also fail to make developmentally sensitive inquiries into the impact of the illness, nor are interventions designed with the developmental needs of infants and toddlers in mind. Since professionals and researchers attribute many negative traits to children with asthma, their parents, and their families as a whole and since professionals agree about the importance of promoting self management and self-esteem in older children, lack of attention to the early effects of asthma and its management on children and parents is surprising.

To summarize, families whose infants and toddlers have severe persistent asthma live within an experience that is poorly understood. Furthermore, several aspects of the problem are especially disheartening. First, the literature provides epidemiolgical evidence of increasing morbidity and hospitalization due to asthma among these children. Second, numerous studies demonstrate largely failed efforts to impart definitive knowledge about the disease, its management and effective prevention practices to parents. Moreover, where management intervention studies have demonstrated success, only rarely do results stand up for 12 months, and none have been measured beyond that period. In addition, ethnically diverse children under 4 years who live in poverty suffer most asthma morbidity, yet they, and their families, are the least studied.

The literature, thus, points out that the clues to effectively meeting the needs of families of infants and toddlers with asthma have been especially unavailable to professionals. Although parents of infants and toddlers with asthma are presumably also unclear about how to control symptoms and prevent hospitalization, it is they who have first hand, intimate understandings about the managing crisis wheeze and cough. In addition, asthma has been shown to have a pervasive influence on children and their parents, on the relationships between them, and on whole families. Moreover, following professional intervention, it is parents who integrate professional support and management directives into daily practices. Thus, I chose to investigate asthma management in infants and toddlers who live in poverty and are Latino or African-American from the perspective of the families of children with the illness.

In this study I will examine how parents, live in poverty and are either Latino or African-American, integrate, over time, the demands of illness management into caring for their 12 month to 4 year old child with severe asthma. Specifically, I will describe parents' understandings of asthma and asthma management skills. In addition, I will describe parenting practices particularly in light of: 1) the demands of asthma management established for the individual child; 2) prior experiences of crisis which led to the child's need for hospitalization and emergency care; 3) current understandings of how to respond in the event of crisis; 4) the simultaneous need to provide for asthma management, healthy development of the child, and the care of all family members; and 5) social and economic influences affecting asthma management.

CHAPTER 2

The Perspective of Attachment Theory

Introduction

Families' own circumstances, abilities, resources, and ways of taking on the caring of their children with asthma are a relatively little understood, but likely, powerful influence on the course of illness management. Living with a tenuous ability to breathe well, is a breath by breath circumstance, carried out in a social environment, constituted and shaped for the child by his/her family. In order to understand the experience of families from the perspective of their various concerns, I sought a theoretical lens from which I could better appreciate the organizing needs of the child in relationship to the organizing concerns of the family.

Many theoretical perspectives serve as background for this investigation, including, interpretive phenomenology, family systems theory, the circumplex theory of family functioning, child development theory, and attachment theory. I have chosen attachment theory as one lens to present in detail in this chapter. A discussion of interpretive phenomenology, the overall theoretical perspective of this investigation, will follow in Chapter 3.

Attachment theory affords a perspective on the affective relationships between infants and toddlers and their personal social environments. The value of this focus in infants and toddlers with severe persistent asthma and their families is important on two accounts. First, the emotional health of children and of their parents and the quality of the relationships between parents and children have historically been considered an important aspect of the illness. Second, the experience of acute asthma crisis and its hospital management are emotionally stressful events for children and their parents that likely shape the meaning of living with asthma in lasting ways.

The purpose of this chapter is, first, to present attachment theory with emphasis on the significance of secure attachment for healthy growth and development. Second, I will review the literature regarding attachment and chronic illness in young children with attention to implications of that research for children with severe asthma. Then, a discussion follows of the parental role in the security of attachment when children have asthma. Finally, several specific aspects of asthma, that may impact healthy emotional development in children with severe persistent asthma and their families, are discussed in light of attachment theory.

Attachment Theory

Historical Development

Convinced of the importance of real life events in the development of child psychology, John Bowlby, joined by Mary Ainsworth (Ainsworth & Bowlby, 1991), studied reunions of infants and young children with their mothers. When children were hospitalized in impersonal institutions, separation would progress to despair and detachment. Separation brought crying protest and frequent looking out for the mother to return. Despair followed with the children exhibiting monotonous crying, diminished activity, and quiet withdrawal, which some nurse caregivers, thought to be indicators of diminished distress. If the mother did not return, the child eventually began to accept care, food, and toys offered by the nurses. Sometimes the children even smiled and initiated social action. Though it appeared that the children were recovering from separation, such was not the case. Detached emotionally, the children exhibited listless turning away from the mother, seeming to have lost all interest in her if she returned to visit. If the child were to stay institutionalized for a long period with care provided by a series of care givers, she would become attached to each in turn and suffer repeated loss. Committing herself less and less to succeeding mother-figures, the child would eventually stop altogether taking the risk of becoming attached to anyone. Instead, showing passionate desire only for food or toys, she would not show feelings toward parents at their visits, and, though cheerful and apparently well-adapted, "appears no longer to care for anyone" (Bowlby, 1969/1982, p. 28). Detachment served as a defensive system of behaviors in the face of painful anxiety, separation, and loss (Bowlby, 1969/1982; Bowlby, 1980). Bowlby (1960) further noticed that separation and protest occurred for children with previously unimpaired relationships with their mothers. Thus, the quality of attachment lies not in the behavior per se but in how readily it can or cannot be reversed. The well-known Strange Situation, a laboratory procedure, was later developed to evaluate in detail the reactions of children to a brief separation and reunion with their mothers (Ainsworth, Blehar, Waters & Wall, 1978).

Distinguishing concepts Attachment is an affectional bond characterized by reciprocal emotional expression which clues mother and child and any observer into the affective quality of the relationship. By the latter part of the first year, a securely attached child will cry in protest at separation from the mother, or other primary attachment figure. For convenience 'mother' will be used to designate the primary attachment figure in the discussion which follows. In practice, the primary 'attachment figure' can be either parent, or another person, related or not related by blood, whom the child recognizes as preferred caregiver when she is fearful or anxious.

Ainsworth Blehar, Waters, and Wall (1978) found mothers of securely attached infants to be significantly more sensitive to infant signals, responsive to infants crying, and affectionate during body contact than were mothers of insecurely attached infants. When distressed, the securely attached child puts all interest in exploring the world on hold. She can only cry, sometimes sobbing, completely absorbed in her distress. On reunion with her mother, she will smile, exhibit joy, and seek physical contact then return to being interested in the environment around her. Thus, the nature of the affectional bond is elaborated in a range of emotional responses. Crying is neither good nor bad, nor consistently appropriate nor inappropriate across situations (Stroufe & Waters, 1977). Likewise, a child actively engaged in the surrounding environment usually signals the child's feeling of security. However, a child feeling profound loss, may behave similarly. Detached and lacking interest in the mother, the child may also engage actively in the environment (Bowlby, 1958).

Attachment is also an affectional tie to a particular individual (Ainsworth, 1989). Infants and young children make strong affectional bonds to particular others, usually in a clear order and usually with the mother being preferred over others. Thus, attachment differs from a generalized notion of undifferentiated dependency. According to social learning theory, children are in a state or stage in which they exhibit dependent behaviors which serve to solicit others to meet their needs. As long as needs are met the child will develop to independence. The notion that attachment to , separation from, and/or loss of a particular individual can be so profound as to interfere with healthy development distinguishes attachment theory and the concept of an attachment relationship from classic thinking about dependency.

Attachment behaviors constitute a system which is a primary and instinctual response to fear. The instinctive drives for eating and sexual attraction do not supersede the instinctual desire to establish an interpersonal tie with one caregiving individual (Ainsworth, 1969; Bowlby, 1977a). Classic theories of dependency, notably social learning theory, posit that the infant is dependent on the mother (or any other) in order to be fed and have other basic physiological needs met. Within this view, the instinct to be close to the mother serves only a secondary and transient function in the child's development to independent adulthood (Ainsworth, 1969). By contrast, Bowlby (1977b) sees that healthy social and emotional development necessitate sensitive, responsive care from a particular care giver.

Attachment also differs from the psychoanalytic position that the infant's relationship to the mother is explained as a primary sexual drive. Oral in nature during infancy, the sexual drive is believed exhibited in the infant's desire for the mother's breast. The changing objects of sexual desire, that when frustrated is repressed into the unconscious, define the various stages of human psychological development, oral, anal, and genital. The infant's care giver serves primarily as the object for satisfaction of the orally expressed sexual drive (Ainsworth, 1969).

Attachment behaviors are an instinctive response to fear which is at first manifest in protest when proximity to the caregiver is perceived to be in jeopardy. Though the child seeks proximity to mother in order to be protected from physical danger, the attachment figure is the child's protector, not only from physically threatening situations, but also when she feels separation from, or loss of the caregiver herself. Evolved from, and closely related to, animal responses when predators threaten, human infants' instinctual responses include sucking, smiling, clinging, crying, and following. First elicited at birth, these responses reach their peak between 18 to 30 months during episodes of the child's separation from the mother. Thus fear of physically dangerous circumstances translates to anxiety in the face of anticipated or realized separation from the protector (Bowlby, 1977a). Contrary to the notion that anxiety due to separation or loss is neurotic, Bowlby (1977a) believes attachment behaviors to be biological (and, therefore, instinctual) responses some of which are observed in animals as well humans. Typically, darkness, loud noises and other sudden large changes in stimulus level, sudden movement, and for humans strange or novel things and strange people instinctually elicit alarm.

The attachment bond forms within a unique interactional, dynamic, and evolving behavioral system. In infancy, the caregiver's sensitive responsiveness and availability complement the infant's sucking, smiling, clinging, crying, and following. The infant gradually internalizes the security of the attachment bond on the adventure away from the mother's close proximity. A positive internalized working model of attachment is re-inforced periodically by returning to the mother for comfort. During early infancy, periods of separation are brief, at first beginning with barely a glance away from the mother while being held in her arms. Gradually the periods of separation become greater as the infant learns that by crying, smiling, or moving toward the mother, she has some control in the attachment relationship (Main, Kaplan & Cassidy, 1985).

Language, cognitive development, and mobility allow the developing child to maintain the bond in new ways (Ainsworth, 1989). Behaviors that maintain the bond change allowing the unique bond to endure overtime and despite distance (Bowlby, 1977a). Although specific interpersonal attachment behaviors on the part of the person attached and the attachment figure evolve in an unfolding relationship and new significant attachments form in adolescence and adulthood, the affectional bond to the original attachment figure is not abandoned. It remains the core experience for secure attachment throughout life. Mary Ainsworth writes:

> I define an "affectional bond" as a relatively long-enduring tie in which the partner is important as a unique individual and is interchangeable with none other. In an affectional bond, there is a desire to maintain closeness to the partner. In older children and adults, that closeness may to some extent be sustained over time and distance and during absences, but nevertheless there is at least an intermittent desire to reestablish proximity and interaction, and pleasure - often - joy upon reunion. Inexplicable separation tends to cause distress, and permanent loss would cause grief. (1989, p. 711)

Attachment differs from dependency (Bowlby, 1977a). Dependency behaviors, carry the connotation of being childish and inappropriate after certain normative stages. Dependency behaviors are general ways of behaving which are manifest in many relationships. Dependency solicits the care of infants and children from older more mature individuals but must be given up in order for an individual to achieve independence (and maturity). Attachment is also unlike a primary sexual drive which must be repressed or transform itself into socially appropriate mature behavior. In contrast, when securely attached, a child becomes increasingly secure, develops healthy self esteem, and can capably explore, discover, and be a creative participant in her social and physical environment (Stroufe & Waters, 1977). Maturity does not exclude secure attachment to a particular individual or individuals nor does it preclude protest, despair, and grief due to separation or loss in later life (Bowlby, 1977a; Ainsworth, 1989).

Attachment behaviors cannot be quantitatively measured in the sense that children or other people are a little or a lot attached (Main, 1995). Specific behaviors considered in isolation do not determine the quality of the attachment. Just as crying, clinging, and following are not always indications of insecure (or secure attachment) so the amount of any of these or any other specific behavioral indicators do not alone describe the quality of attachment. Instead, specific behaviors on the part of the child, caregiver response, and the reciprocal child responses comprise a complex system of behaviors that define attachment. The quality of the system is evaluated according to how well it functions to promote the child's feeling of security (Stroufe & Waters, 1977).

The Strange Situation Since it has been widely used to assess the quality of maternal infant attachment, Mary Ainsworth's structured laboratory procedure is presented here to familiarize the reader with references to its use in the literature review which follows. Originally designed for 12 month olds, this observational procedure is used in the study of children up to 24 months. Parents and infants/children are observed behind a one way mirror as they spend brief periods in a laboratory room usually furnished with two chairs, some reading material for the adults, and toys for the child. The children's behaviors are recorded (now usually video recorded) during two brief separations from and reunions with the parent. Ainsworth established the following Strange

Situation classifications in a sample of infants and their mothers in Baltimore. Approximately 72 hours of home observations per infant confirmed the original three classifications and provided descriptions of maternal behaviors for each classification (Main & Solomon, 1990; Ainsworth et al., 1978).

Secure (Group B). The infant may cry or otherwise exhibit signs of distress during separation episodes. On reunion the child seeks physical proximity to the parent and then returns to play. During home observations secure infant behaviors are associated with mother's sensitivity to the infants signals and communications (Ainsworth et al., 1978; Main 1991).

Insecure-avoidant (Group A). Exhibiting very little or no distress on separation, the infant "actively ignores and avoids her [the parent] on her reunion." (Main, 1991, p. 140) Mothers in this group were found to be insensitive to infant signals and specifically reject attachment behaviors (Ainsworth et al., 1978).

Insecure-ambivalent (Group C). "The infant is distressed and highly focused on the parent, but cannot be settled by the parent on reunion." (Main, 1991, p. 140) These infants often expressed anger and sought contact in quick succession and generally failed to return to play (Main, 1991). Ainsworth and colleagues (1978) found these behaviors associated with insensitive and unpredictable maternal responsiveness.

Main (1991) and Main and Solomon (1990) in review of unclassifiable maternal-infant Strange Situation video tapes have identified a fourth qualitatively different group of behaviors, Insecure-disorganized/disoriented (Group D), in which infants exhibit unusual interruptions in organized behaviors when they are in the presence of their mothers. In preliminary data these behaviors seem to be associated with children whose mothers are frightened and/or frightening.

Summary The attachment behavioral system thus functions to protect the infant, allowing safe and creative exploration of the environment. It is an instinctual response, biologically founded and specifically adapted in the human infant for protection from physical dangers as well as anticipated or actual separation from the specific primary care giver. Attachment evolves within a relationship and its quality (successful development of a secure sense of self) endures throughout life. When attachment is insecure, disruptions in development are evident in infancy and early childhood as well as into adult life (Bowlby, 1977b; Lieberman & Pawl, 1990).

Attachment and Chronic Childhood illness

Two groups of researchers have studied attachment relationships in children with chronic physical illness. Children with asthma, however, have not been studied. Many others have conducted studies of children who, or whose mothers, suffer psychopathology. This section reviews the major findings of those that investigate children with chronic physical illness. Special attention is paid to implications for attachment relationships when children have severe asthma in early childhood.

Congenital Heart Disease and Attachment In a study of 42 infants with congenital heart disease (CHD) of varying severity, ranging from those who needed successive surgeries, were cyanotic, and who had congestive heart failure and/or cardiomegaly, to those with benign disease, infants with CHD were found to be significantly less securely attached than healthy controls as assessed by the Strange Situation. In addition, among infants with CHD those securely attached had improved, with respect to CHD, gradually since birth. However, since disease improvement and formation of attachment relationships were taking place simultaneously the direction of this trend could not be determined. Although numbers were too small to analyze statistically, diagnostic groups with more severe conditions, ventral septal defect and tetralogy of Fallot, were groups with larger numbers of insecurely attached infants. These were also children who had had surgery, the most severe having had surgery before 1 year (Goldberg, Simmons, Newman, Campbell & Fowler, 1991).

Although CHD and asthma differ in major respects, poorly controlled asthma and CHD similarly leave infants and young children with chronically compromised energy. In addition, especially when children with CHD need surgery and have more severe disease, the demands on their mothers and the potential for family disruption are increased. Nevertheless, the findings in the cardiac study do not directly apply to young children hospitalized with severe persistent asthma for numerous reasons. First, asthma is expected to be manageable and compatible with 'normal' development (Strunk, 1989; Schulz, Dye, Jolicoeur, Cafferty & Watson, 1994), while CHD has recognized life-long and limiting effects. Second, even severe asthma does not require surgery. Recovery or improvement during hospitalization usually begins from the time of admission. Third, nothing in the experience of severe asthma or its treatment compares with the physical trauma and pain of chest surgery suffered by children requiring surgery for CHD. Fourth, hospitalizations due to asthma are unplanned and crisis mediated while those due to CHD are mostly anticipated. Taking into account these differences, it is noteworthy that this study of children with CHD does find that insecure maternal/child attachment as evaluated by the Strange Situation is found in children with chronic illness under 18 months.

Cystic Fibrosis and Attachment A group of infants with cystic fibrosis (CF) aged between 12 and 18 months were compared to a group of 23 infants free of chronic illness and were found not to have significantly more insecure attachments. However, insecure infants with CF had lower weight and lower weight-height percentiles and had earlier dates of diagnosis than the securely attached infants with CF. Other indicators of disease severity (fat malabsorption and lung function) were not associated with security of attachment. Parents of both groups completed the Toddler Temperament Survey, a 97 item scale yielding information on specific dimensions of temperament as well as over-all categories of easy, slow-to-warm, or difficult temperament. No differences were found between the groups. The authors concluded that the mother-infant attachment relationship seemed resilient to the effects of the diagnosis of chronic illness since rates of insecurity among infants with CF were not significantly from controls. They warned, however, of the possibility that severe CF in early life may disrupt attachment since insecurely attached infants with CF had lower weight for height and earlier dates of diagnosis than did securely attached infants with CF (Fischer-Fay, Goldberg, Simmons & Levison, 1988).

Cystic fibrosis differs from severe asthma in early childhood on several dimensions. First, CF worsens progressively leading to early death. Symptoms in children with severe asthma may improve or resolve with age. No studies specifically look at death in infancy and early childhood due to asthma. However, a study of 8 to 18 year olds identified psychological factors as more prominent in children who later died of asthma (Strunk, Mrazek, Fuhrmann &

LaBreque, 1985). In CF death is associated with physiological factors, usually irreversible blockage of the lung by thick mucoid secretions.

Second, although asthma like CF may involve chronically compromised lung function, extreme variability characterizes the ability to breathe among infants and children with severe asthma. Breathing effectiveness in any child may range from nearly normal to severely compromised. In addition, unlike in CF, asthma crises may occur suddenly and unexpectedly causing parents to fear that their children may stop breathing and die (Mrazek, 1986). In CF, reduced ability to breathe develops more gradually and progression to early death is universal. Thus, parents of children with asthma live with tremendous immediate uncertainty, while for parents of children with CF the outcome is certain and grim. In CF uncertainty lies in the long term. In severe asthma, demands for accurate and rapid assessment and action are greater although the long term prognosis is good.

Despite these differences, the finding of potential for disruption in attachment relationships among children with CF could translate to children with asthma. Children with severe asthma like children with CF live with daily treatment regimens, frequently if not chronically compromised breathing, and restricted physical activity.

<u>Preterm Infants, Down Syndrome, Developmentally Delayed Preschoolers and Attachment</u> Investigations of preterm infants (studied at one year corrected age) and developmentally delayed preschoolers (ages 2 and 4 years, 6 months) reported by Goldberg (1988) concluded that these childhood conditions do not necessarily interfere with secure attachment. Levels of secure attachment did not differ from those of normal healthy children.

Preterm Infants A study was conducted of 56 preterm infants in the first year of life from the Hospital for Sick Children in Toronto. Infants were demographically representative of the preterm infants in the neonatal unit. More specific ethnic or socioeconomic status (SES) information is referenced but not included in the published report. The distribution of attachment patterns did not differ statistically from normative data. In a counterintuitive finding from the same study, preterm infants in the fully secure group had experienced a greater number of neonatal complications than others. (Goldberg, 1988).

Although many premature infants later develop asthma, the data are not directly translatable to young children with severe asthma. Premature infants are a heterogeneous group in terms of their physical capacities. Many have other chronic conditions which complicate their development and the nature of their care. Many develop normally without asthma or other breathing problems, while many live with life-long physical and/or mental handicaps.

Developmentally Delayed Children A study of 11 developmentally delayed children in the Strange Situation showed that they, like preterm infants, did not differ from the normative attachment sample (Goldberg, 1988). Forty of these children had Down syndrome. Others, n=29, had neurological diagnoses, and 40 others delays of unknown etiology. Their median age was higher than the median ages of those children in the later Down syndrome studies reported above. No difficulty in classifying children with Down syndrome was discussed (Vaughn, et al., 1994). No differences were found between diagnostic groups (Goldberg, 1988).

Children with severe asthma usually differ from developmentally delayed children on the important dimension of visibility/invisibility. In a study of the correlates of chronic illness in children, children with normal appearance had mothers who were less satisfied with care, their families reported greater impact of the illness on the family, and their mothers had more psychiatric symptoms than when children did *not* appear normal (Jessop & Stein, 1985). Since asthma is invisible and the expectation is that development will be normal, these findings point to more risk for insecurity of attachment in children with severe asthma, than among developmentally delayed children whose delays are clearly evident.

The Parental Role in the Security of Attachment When Children have Asthma

In addition to the many studies that have found associations between problematic child and parental behaviors, some researchers, informed by attachment theory but not specifically designing studies around it, have found that parental psychological functioning may provoke asthma symptom onset in infants under 2 years old (Mrazek, Klinnert, Mrazek & Macey, 1991). Others have found that parental influence causes frequent exacerbations of symptom severity in older children (Boxer, Carson & Miller, 1988; Strunk Fukuhara, LaBreque & Mrazek, 1989). However, most studies that have found associations between problematic parent/child relationships and asthma have been unable to identify the direction of the influence of one on the other (Gustafsson, Kjellman & Cederblad, 1986).

Attachment theorists have also been interested in the effects of chronic illness on the relationship between parents and children and, conversely, the influence of problematic maternal behaviors on the security of parent/child relationships. Ainsworth takes the position that the mother plays a more important role than the child in shaping the quality of the attachment relationship (vanIjzendoorn, Goldberg, Kroonenberg & Frenkel, 1992). A meta-analysis of 34 studies using the

Strange Situation compared problem populations and normal populations to show that the quality of maternal infant attachment was significantly poorer where mothers had problems than when children were identified as ill. The authors acknowledged that classifying studies as either child problem or maternal problem was very difficult (vanIjzendoorn et al., 1992).

The meta-analysis considered fourteen studies of problematic mothering: maltreating mothers, mothers with mental illness, and adolescent mothers. The 19 study populations with identified child problems were: preterm infants, (n=229); deaf children, (n=41); physical handicap, (n= 36); children with Downs Syndrome, (n=58); autism, (n=15); cystic fibrosis, (n=42); and congenital heart disease, (n=44). Maternal infant attachment in these populations did not deviate in the expected proportion of secure attachment to insecure attachment as assessed in the original Strange Situation studies (vanIjzendoorn, et al,, 1992).

By extension, these findings about studies of attachment theory would support the position that parental dysfunction triggers asthma severity or may even be the cause of asthma onset in infants. Further, it would negate consideration of how asthma and its treatment affect attachment relationships. However, the meta-analysis, while affirming the importance of the maternal role in atachment security when children are seriously ill, did not identify studies about children with asthma. Thus, closer examination of illness effects when children have asthma is relevant.

From common sense and clinical experience, it is evident that parenting an infant or young child with severe asthma differs in many respects from caring for a child of similar age who does not have serious health problems or who has health problems of a different character. At least two perspectives regarding asthma and attachment are of interest. First, how well mothers (parents) respond to the emotional needs of children challenged by severe persistent asthma remains to be studied. In addition, a clearer view is needed of how the demands of asthma management may threaten, strengthen, or otherwise impact relationships between parents and children.

Severe Asthma in Young Children and Implications for Attachment Quality

Several aspects of severe asthma in young children point to the need for more thorough investigation into the ways attachment behaviors are evoked when infants and toddlers have serious asthma. In this section I will discuss how the attachment perspective will likely increase understanding of various aspects of the illness: breathlessness, uncertainty, hospitalization, and attributions of dependency. The section begins with a discussion of general considerations for the emotional well being of children who are ill.

Being Ill How illness in early childhood affects a child's instinctive attachment behaviors is little known. Anna Freud (1952) described numerous ways that acute illness in early childhood elicits behavioral changes in mother and child, and changes in the parenting environment, even when a child is not hospitalized. Though her work is not about attachment, it confirms the intuitive notion that a child may feel insecure after a severe acute illness. Freud writes that when children were ill, mothers reported disruptions in relationships: children might become either more clinging or more detached; sibling relationships changed. Children who had been ill might regress to bed wetting and soiling, and more infantile feeding behaviors. In addition, they often experienced sleep disturbances and had mood swings or temper tantrums. Children's sensitivity and lasting memories of similar painful experiences varied remarkably. Freud attributed this variability to different psychic interpretations of pain rather than to pain's bodily sensation (1952).

A thorough review of studies about the experience of illness and pain in early childhood and infancy cannot be undertaken here. However, Freud's work holds significance for the study of young children with severe asthma. First, in as much as in severe asthma, crisis is an acute exacerbation in the context of chronic physiological challenge, the work points out that illness brings special circumstances that can interfere, if even temporarily, with development and the crucial family relationships of early childhood. Second, painful and/or frightening procedures and restricted activity are regularly imposed on young children with severe asthma during a time when preoccupation with injury to their bodies and the desire to practice motor skills and assert autonomy define development (Freud, 1952; Erikson, 1963).

Breathlessness The universal subjective experience of asthma crisis is the sensation of breathlessness that, in severe asthma, occurs frequently and is frightening. Adults and older children report that acute fear or panic often accompany the inability to "catch one's breath" (Quinn, 1988). Although infants and toddlers cannot reveal the extent of the emotional distress they experience during breathlessness, it is likely that they may be even more fearful than older children and adults since they have neither the cognitive ability to 'interpret' their distress nor the physical ability to attempt to resolve it. In addition, fear and breathlessness occur in a mutually escalating circular relationship.

Since attachment theory indicates that instinctive response to the fear of breathlessness causes an infant to seek the proximity of her mother or other caregiver, crying, calling, and the desire to keep parents close would be considered a 'natural' reaction to acutely compromised breathing. Furthermore, the expectation for secure attachment is that the caregiver will be able to provide relief in the face of fear. Since proximity alone does not guarantee ease of breathing when a child has severe asthma, theoretically and intuitively, the stage is set for high risk of insecure attachment both because a mother may be unable to meet her child's physiological need and because she may feel she cannot provide adequate protection for her child's frightening situation. In addition, parents' ability to respond sensitively to children's needs may be blunted since parents likely feel frightened themselves. Moreover, since fear is emotionally contagious, children's fear may escalate in response. Yet, how parents' fears may influence a crisis situation that is frightening to a child and how parents' fears may affect their sensitivity and responsiveness to their children are not well studied.

Parents may wish to distance themselves from their child during painful hospital procedures. Presumably there are a whole range of parents' responses to their own fears which could affect the quality of their care. Just because parents feel fearful may not mean that they respond to their children in ways which promote insecurity. However, Main and Morgan (1995) have discussed the likely association between attachment figures who are frightened as well as those who are frightening and the most insecure expressions of attachment, the disorganized/disoriented category.

<u>Uncertainty</u> Jessop and Stein (1985) in a study of children under age 11 with chronic illnesses found a significant association between the need to watch for changes in the child's status (i. e. uncertainty) and the variety and flexibility of the mother's emotional responses. Severe persistent asthma is highly uncertain

in many ways. First, crises are frequent and may occur suddenly and unexpectedly. Second, although prevention is a major component of management, asthma exacerbations remain unpredictable. For example, at times a windy day may trigger a crisis; at times it may not. In addition, asthma may accompany other physical illness or emotional states such as gastroenteritis and temper tantrums. At times symptoms may be easily recognizable as asthma at times they may not. Moreover, asthma severity is, in many instances, difficult to assess even by physicians and other professionals familiar with asthma crises (Stein, Canny, Bohn, Reisman & Levison, 1989; Sudhakar, 1999). Finally, whether and just when to access emergency care carries uncertainties even for parents who are experienced caregivers. By definition severe asthma involves the frequent use of emergency services, an indication of high levels of ongoing uncertainty. Two cultural expectations likely compound the uncertainties parents feel when their infants and toddlers have severe persistent asthma. First, since good management is expected to prevent crises, parents are presumed to hold significant responsibility for inability to control symptoms. Second, the widespread stigma that asthma comes from emotional instability or is "all in a person's head" (Becker et al., 1993) adds to the perceived consequences of management failure.

Hospitalization Robertson (1963) and others found, that when parents could visit only on a restricted basis, children exhibited disrupted relationships and regressive behaviors following hospitalization. These post-hospitalization behaviors were evident even though during hospitalization children had seemed "well adjusted" (Bowlby, Robertson & Rosenbluth, 1952; Robertson, 1958, 1963).

As a result, literature from the Tavistock Clinic, site of Bowlby's research, urged allowing mothers to stay at their children's bedsides (Robertson, 1958, 1963; MacCarthy, Lindsay & Morris, 1962). The call became familiar in the United States where parents gained the privilege of staying with their children on obstetric and pediatric wards. Nurses encouraged attention to maternal child attachment in hospitals which resisted abandoning traditional routines, in intensive care units, in the special circumstances of prematurity, for infants born with birth defects, and if infants died (Schraeder, 1980, Jenkins & Westhus, 1981; Paukert, 1982).

Children with severe asthma usually experience several hospitalizations. All are precipitated by breathlessness and characterized by the frightening experiences of pain, trauma and separation. With repeated hospitalization the memory of these adverse circumstances are revived for children and parents. Thus, though acutely aware of their inability to effect improved breathing in their child, seeking hospital care carries intense ambiguity for many parents.

Attributions of Dependency The origins of so called 'dependency' problems, or regression to developmentally earlier behaviors, have not been studied among children with asthma. However, since severe asthma and its management clearly impact the earliest paternal/child relationships and since attributions of unhealthy dependency among children with asthma are deeply engrained in thinking about childhood asthma (Williams, 1975), a closer look at the significance severe persistent asthma holds for infants, toddlers and their parents seems appropriate. From the perspective of attachment theory children who are frightened by breathlessness and hospitalization may be exhibiting appropriate reactions to their situations. In this regard, attachment theory stands in dramatic contrast to traditional thinking about the emotional responses of children with asthma and their parents.

The basic theoretical assumptions of secure maternal/infant relationships are relevant in understanding the experience and management of asthma crises, the use of emergency services, and the experience of hospitalization as experiences likely to elicit intense but appropriate emotional responses rather than behaviors indicative of age inappropriate dependency. Emergency care and the hospital management of asthma crises both include painful or frightening procedures, and involve parent/child separation during periods when both parents and children feel emotionally stressed. By providing a framework for understanding infants' and very young children's responses to fear, a perspective informed by attachment theory allows an empathic way of studying the child's experience of crisis and hospitalization even though the child cannot verbalize that experience. While offering a perspective on the child's experience and response to fear, attachment theory also allows a perspective on parents' fears and the influence being afraid has on parental responses to daily management, crisis assessment and intervention, and hospitalization.

Moreover, in lieu of examining asthma in early childhood for indicators of pathological dependency, attachment theory affords a look at the threats to security posed by the illness and its management beyond infancy and early childhood. Most children with asthma develop symptoms before the age of three, and the youngest children, with the most severe disease, are likely to have symptoms that persist into adolescence (Mrazek, Anderson & Strunk, 1982). Likewise, the need for secure attachment begins in infancy and continues throughout life. Thus, the attachment perspective may provide a beginning understanding of how patterns of parent/child relationships in children with asthma are relevant as children grow.

Summary Some researchers found that the quality of the maternal/child attachment relationship was influenced most of all by mothers. Others found that children who are chronically ill may or may not be more insecurely attached to their parents. However, taken together current research leaves many unanswered questions about the quality of relationships between children who are chronically ill and their parents. Asthma in early childhood has not been specifically studied in relation to attachment. Research does suggest that early onset of illness, hospitalization, weakened physical state, and low visibility of illness are associated with insecurity of attachment in children with chronic illness. Moreover, severe childhood illness, the experience of breathlessness, the ongoing uncertainties of asthma, repeated experiences of trauma, fear, and separation due to hospitalization, and social attributions of unhealthy dependency all have implications for the quality of parental/child attachment when children have severe persistent asthma.

Conclusion

Among children with severe persistent asthma, the influence of maternal (parental)/child relationships on patterns of severity, remission, and the long term health of children are not well understood. Likewise, the impact of the illness on security of maternal (parental)/child relationships has not been specifically examined. Since poverty and minority ethnic status are not addressed in the attachment research of chronically ill children, their impact on early attachment relationships complicated by asthma is not known. As a consequence, clinicians are left without a clear theoretical premise to provide emotionally and developmentally sensitive professional management for children at highest risk of morbidity due to asthma.

Although these questions have not been specifically addressed, the perspective of attachment theory holds potential for understanding how management protocols and treatment procedures can be modified for the sake of the emotional well-being of parents and children. The need for such a perspective is supported by the unstated premise of all the studies reviewed here and in Chapter 1 that the health of parental/child relationships among children with asthma is as much an important and desirable outcome as is the remission of physical illness.

Thus, the perspective of attachment theory is taken in order: 1) to learn about asthma, its treatment, and management as an integrated experience of emotional importance; and 2) to describe the interplay of the demands of the illness, its management, and optimal emotional development in the practical everyday experience of low income, ethnically diverse families whose infants and toddlers have severe persistent asthma.

CHAPTER 3

Methodology

Introduction

The methodological and practical challenge of this study was to gain access to a world about which little is known, the experience of Latino and African-American families living in poverty when infants and toddlers have severe persistent asthma. The challenge was greater since I am personally inexperienced with asthma, Caucasian, socially privileged, professionally educated and experienced, and, therefore, distinctly "other" in relationship to the families who participated in this study, and their experience of living with asthma. Interpretive phenomenology as proposed by Heidegger and explicated by Dreyfus is the method used in this study (Heidegger, 1927/1962; Dreyfus, 1993). The method has been employed in the study of problems of health and illness by nurses Benner, Chesla, Smithbattle, and Weiss, as well as many others (Benner, 1994; Chesla, 1988, Smithbattle, 1994, Weiss, 1996). I chose interpretive phenomenology as the method best suited to the investigation of a largely unknown world of experience because an interpretive phenomenologist must: be continually engaged with the participant in her world; interpret the whole phenomenon as well as its various aspects; and aim for discovery of the phenomenon.

<u>Engaging with the Participant</u> First, interpretive phenomenology obliges the researcher to be continually engaged in the experience of the participants beginning with the choice of design and continuing through to interpretation of

data. Being engaged in the process requires the researcher to acknowledge her own biases, join the participants in discovery of the phenomenon, and maintain an empathic interpretive perspective. The interpretive researcher aims to be true to the experience of the participants, i.e. the phenomenon, during all phases of the investigation. She recognizes that quality research demands recognition of, and sensitivity to her own taken for granted way of viewing herself, others, and her investigation (Addison, 1989). In natural sciences, as opposed to human sciences, the resesarcher aims to free herself of biases and work within the framework of a theoretical projection (Dreyfus, 1993). The interpretive phenomenologist, on the other hand, holds that human endeavors take place on a background of interpretation of which the investigator cannot and would not want to be completely free. Addison (1989) states:

> The interpretive tradition emphasizes that there is no detached, privileged standpoint from which one objectively record "reality." I must recognize that I already work within an interpretive framework or paradigm, am predisposed to looking for certain aspects and away from others in the situation, and have a taken-for-granted way of doing research, of being a researcher, and of interacting with the participants involved. (p. 54)

Thus, the interpretive phenomenologist believes she cannot adopt an interpretive-free research perspective. Instead, the possibility of commonly held understandings between participant and researcher, and the possibility of dialogue and understanding are the starting points for discovery. A more full discussion follows. See Entering the Circle of Understanding, p. 70.

Interpreting the Whole Phenomenon and its Various Aspects Interpretive phenomenology involves interpretation of all levels of the phenomenon: the whole as well as its various aspects. Phenomenon are interpreted for the ways they are uniquely relevant in a particular personal and family context and also the ways in which they are meaningfully interconnected as part of a whole historical and social context of shared human practices (Heidegger, 1927/1962; Dreyfus, 1984). The interpretive researcher continually returns from the whole to the parts and back again in the development of interpretation (Benner, 1994).

Due to the coexistent demand to view the broad scope and the details, interpretive phenomenology helps the interpretive nurse researcher find a way to consider human response to illness with all the nuances, ambiguities, and disorganization that occur in lived, skilled activity with things and others (Chesla, 1995; Dreyfus, 1995). Since all contribute to a valid interpretation, findings reflect the complex reality of everyday lives and in doing so make better sense of the phenomenon than was previously available. Accessing a family's experience of asthma in their young child means considering the individual situations of all participant parents and children in their commonalities and differences. In addition, offering an interpretation requires considering how common and different concerns show up across various aspects of daily living with asthma, including assessing and responding to the child's breathing crises, avoiding environmental triggers and restricting activities, and managing daily treatment regimens. Moreover, interpretations, if well done, let the phenomenon show up better than either uninterpreted descriptions of phenomenon or generalizable theories that link decontextualized data. I will return to a discussion of how this may be so later in this chapter.

Discovering the Phenomenon The interpretive phenomenologist aims to discover the phenomenon. Since asthma management in young children is given very limited attention in the literature, I judged that a method designed to discover would be most appropriate. In contrast to interpretive phenomenology, rational-empirical methods aim to provide explanations that will predict future outcomes (Packer & Addison, 1989a). Interpretation has no formal predictive goal. Instead, the interpretive phenomenologist remains concerned with making practical sense of the phenomenon in context.

Discovery begins between researcher and participant in a shared world. From this shared and mutually engaged stance, the interpreter seeks to make sense of the participant's world on its own terms (Benner, 1994a). The shared understanding of researcher and participant may be minimal at first. Nevertheless, the interpretive researcher begins the process of discovery engaged with the participant. In this investigation, among the commonly held background of concerns of researcher and participant were the illness, the requirements for its management, and the demands of parenting .

The interpretive method of discovery is a circular process that begins in self-interpretive narratives of events as they unfold and continue to unfold for the participant. As new narratives are elaborated, the researcher returns to make better sense of the original ones in light of new narration. Thus the interpretation evolves overtime through a process of expanding discovery and understanding (Packer & Addison, 1989b; Dreyfus, 1993).

The Interpretive Method

Introduction In all interpretive projects, but especially when investigator and participants operate in very different personal and cultural worlds, one must ask how the interpretive researcher has a legitimate right to offer a valid interpretation of the participant's world. The following discussion is about how interpretive phenomenology seeks access to understanding lived experience, and about the claims made for legitimacy of this interpretive tradition.

Philosophical Tradition that Guides the Method

Role of Interpretation My understanding of interpretive phenomenology follows from the methodological tradition and work of Martin Heidegger, Hubert Dreyfus, Patricia Benner, Catherine Chesla and Max VanManen, (Benner, 1994a, Chesla, 1994; Dreyfus, 1993; Heidegger, 1927,1962; VanManen, 1990). Interpretive, or hermeneutic, phenomenology relies on the claim that self-interpretation defines our being human. Heidegger says our *Being* is an issue for us (Heidegger 1927/1962). We are concerned with who we are. What matters to people, both individually and collectively, directs the variety of ways we carry out our activity (managing asthma, for instance), and the ways we prioritize and integrate complex concerns. In these activities we live out our self-interpretation, or in other words, we define our being.

Shared Practical Worlds of Understanding Dreyfus holds that the way we understand is practical rather than theoretical or cognitive. We understand ourselves and are self-defined in the practical world of everyday skills, habits, and practices (Dreyfus, 1985; Benner, 1994a). Situated in meaningful worlds, on the background of taken for granted practical concerns some ways of acting (the ways we manage asthma, for example) show up for us as possible while other ways do not show up. For example, as a mother I find myself sharing history and an intimate relationship with my two adult children, a circumstance that affords me opportunities to relate to them and engage in activities with them with an ease and familiarity that I do not share with any other people. With friends I may feel easy and familiar in ways that I do not with my children. In each case, I share with others many common understandings that do not have to be verbalized, in fact, that cannot be adequately verbalized.

These taken-for-granted background understandings underlie the various contexts of our lives. They shape the ways we conduct our practical everyday activities by making possible for us a range of meaningful personal, social, and historical practices. The taken-for-granted background of our world also makes some possibilities unavailable. For example, living in various areas of the United States I have been able to learn to prepare various ethnic foods, including flour tortillas, a possibility unavailable to my Swedish great-grandmother who never left her small town in southern Sweden. However, I am not able to cook tortillas from scratch in the same way as can my good friend who grew up preparing tortillas alongside her Mexican mother. She is practically skilled in mixing the ingredients together in just the right consistency, even without a receipe, and with her mind on other things. In addition, when her children, now adults, arrive for a visit, she makes tortillas at times that help recall memories of cherished family events, accented by the warm smell of freshly cooking tortillas. All of this she does with little attention to planning. Her skill is shaped by her childhood memories, her early learned physical dexterity in the preparation of tortillas, her familiarity with the proper proportion of ingredients, and her long practice of providing tortillas first for her mother, father, and siblings, and then later for her own husband and children. Even though I may learn to make tortillas, the skill and meaning she conveys to her family in making them is not available to me.

The Hidden Background Though taken-for-granted and familiar, and in that sense understood, by those living in it, background concerns cannot be made entirely clear or spelled out to myself or to others (Heidegger, 1927,1962; Dreyfus, 1993; Benner, 1994a; Dreyfus, 1994). For example, I cannot explain how my adult children and I know each other so well. Though profoundly familiar to me, the experience is too pervasive for me to articulate fully either to myself, my children, or to anyone else (Heidegger, 1927,1962: Dreyfus, 1993,1994). Even if I were to make a detailed and thorough description of my experience of being a mother, that description could not capture the way it really is for me to be a mother.

However, others not directly involved in my experience may have an understanding of it in as much as some aspects of that experience are familiar to them (Dreyfus, 1993). Any understanding others can have of my experience would come from their experience of a similar relationship, for example. Perhaps, in speaking to a father, I may describe how my children I know each other so well that after an absence of several months communication comes easily. I would describe, for instance, how participating in shared activities, such as preparing a big family meal, flows smoothly, while we engage in conversations about other topics. He may have had similar experiences with family members or close friends, and on that background, have some understanding of my experience.

The Shared Understanding of What it is to Be More basically, all humans share the experience of being human. We all have the "know-how" it takes to carry on our everyday lives, even though we cannot give an adequate account of this "know-how," that is, we cannot articulate it in a way that would make sense to some other kind of being (Heidegger, 1927/1962; Dreyfus, 1993, & Dreyfus, 1994). However, though we cannot be clear about it, we nevertheless begin the interpretation of human experience on the basis of a shared familiar and taken for granted, understanding about how to carry on our everyday habits, skills, and practices. These habits, skills, and practices are taken up from the worlds of beliefs and practices available to us, worlds shaped by the families, cultures, societies, and historical eras in which we find ourselves.

<u>Interpretation and the Role of the Interpreter</u> In order to speak to the question of legitimacy of the interpretation of "one" by an "other," the distinction between understanding the meaningful background that makes sense of daily coping activities and interpreting that meaningful background is important.

Understanding is the way we just know how to go about carrying on practical coping activities, day by day and in the various circumstances of our lives. Interpretation means being able to see and articulate that background "as" something, i.e. being able to talk and write about what meaningful concerns organize and hold various coping activities together (Dreyfus, 1996). The interpretation of a person intimately engaged in coping, for instance, Lena, will likely not be the same as the interpretation of another interested, empathetic person, say Elizabeth, who listens to Lena's account of living with her child with asthma. As Lena tells Elizabeth how she copes with situations that frighten her, Elizabeth may interpret that Lena is skillful in her coping. However, Lena may not think she is skillful at all because coping skillfully with her child's severe asthma is so familiar to her. According to Dreyfus, in interpretive research, the researcher, though not in the participant's world can see that world in a way the participant cannot.

> Understanding is this very basic coping level which the participant has "got" and you [the interpretive researcher] haven't "got" (you don't have their understanding, you do have your own, but not theirs). But, interpretation is this other level where you are able to articulate it and see it "as "something. That's when you've "got" something they haven't "got." And that's why ... it's illuminating to them. ... It isn't some kind of inferior, second hand thing that you do, namely interpret them, because you unfortunately can't be them. ... They've got understanding. That means, in every situation they just automatically know how to cope. And you've got interpretation. You see what organizes and hold all these various situations and copings together. (Dreyfus, 1996, audio-recorded interview, p. 7)

Next, it is important to address the question of who the interpreter is and where she derives legitimacy for her perspective. Post modern qualitative researchers struggle with the issue of one "Self" claiming a valid interpretation of an "Other." Fine argues that struggling with the hyphen between self (the researcher) and other (the participant) necessarily involves understanding and dealing with issues of authority, power, and advantage, and requires looking both ways from the between space connecting Self and Other , i.e. at the hyphen. Valid consideration of these issues is not easy and must be undertaken openly (Fine, 1994). A discussion of the specific aspects of my experience and motivations for undertaking this research project, and the claims of the validity of interpretive findings will be addressed later in this chapter.

Interpretive phenomenology is premised on the understanding that no interpretation by one self of an other self or selves would be possible on any level except for a given shared understanding of the experience of being human. That is the only legitimate claim of the interpretive researcher. All other claims for the superiority of one interpretation over another are themselves open to interpretation. The interpretive assumption is that neither the world of the self nor that of the other can be spelled out completely (Benner, 1994a; Plager, 1994).

> No claims can be made that the other will be understood completely because human beings and world are not objects and cannot be frozen in time or explicated fully. Furthermore, the interpreter can never escape his or her own taken-for-granted background or stance that creates the possibility of an interpretive foreground. (Benner, 1994)

In contrast to the rational-empirical researcher, who would structure her research on a proven and testable theoretical base, the interpretive phenomenologist begins by setting forth her interpretive perspective as clearly as she is able. She engages or joins with the study participants where her world of experience meets theirs, and proceeds with the aim of gaining a fuller understanding of the world of an "other," knowing that she too exists in an interpretive circle beyond her complete understanding and beyond her ability to interpret with authoritative clarity.

Entering the Circle of Understanding

We understand what it means to be human in the practical world of everday activity (Heidegger, 1927/1962). Since the practices available to us come from a socially contructed world, it is this world of socially understood and constructed concerns that mutually engages researcher and participant. Likewise, an interpretive account is based on a culturally understood sensibility that the interpretation brings to the human experience investigated (Heidegger, 1927/1962; Dreyfus, 1994; Chesla, 1991). Interpretation is not subjective and isolated because meaning is not private. "Meaning is always in a particular context and based upon a background of shared cultural practices." (Addison, 1989).

The distinction between socially constructed meaning and subjectivity is illuminated by the following example. Although everything about how I interpret myself is particular, there is nothing subjective, that is, private, in how I interpret myself or others. It is contradictory to suggest that I could go about in the world revealing meaning which could not be shared. Private experience is like having a headache, according to Dreyfus (1994). I may have a headache, my headache, and I can never share my headache with you. Likewise, feelings are private. However, the meaning my headache or my feelings have for me makes sense only in the context of the world of public shared significance. My way of being as an interpreter is not private or subjective either. Interpreting families in the situation of caring for asthma crises in a young child, must make publicly understood sense of particular family experiences.

Defined in a socially constructed world, an interpretive researcher brings to her investigation a unique perspective or way of understanding herself as researcher, and understanding the world of the participants. Heidegger terms this the *Forestructure of Interpretation* (1927/1962).

The Threefold Interpretive Forestructure of Interpretation According to Heidegger, we must enter the interpretive circle in the "right way". This means acknowledging one's interpretive forestructure and the necessarily circular process of interpretation (Heidegger, 1927/1962; Dreyfus, 1993). The forestructure is three-fold: fore-having; fore-sight; fore-conception (Heidegger 1927/1962). The quality and relevance of interpretation are shaped by the depth, skill, and integrity with which the researcher lays out and continually keeps before her the forestructure of understanding. For, without laying out as clearly as possible the forestructure of one's interest in an investigation, the researcher is in danger of providing an interpretation that merely projects onto the phenomenon presuppositions brought to the project in the first place (Addison, 1989; Weiss, 1996). Before discussing the particular fore-structure I bring to this investigation, I will give an overview of its three distinct aspects using general examples and descriptors.

Fore-having is what I, as researcher, bring to the project in the first place. The various aspects of my fore-having include the very most basic aspects of myself, for instance that I am living, breathing, a woman, a mother, able to read and write, and that I have a healthy body. All of these are ways that I am defined or define myself make possible my pursuit of this project. In addition, my professional, social, ethnic, geographical, and historical situatedness in late 20th century American culture is a given part of my fore-having. Although rational-empiricists consider a researcher's fore-having to be the seat of bias, and therefore, rife with elements that interfere with effective research, in interpretive phenomenology, the fore-having is necessary. Since interpretation is circular, *"we understand in terms of what we already know."* (Packer & Addison, 1989) Without a personal, social, and historical context there would be no interpretation at all.

Fore-sight is the aspect of interpretation that affords me a perspective on what to interpret and how to approach it. My particular fore-sight in undertaking this project comes out of my being a mother, my nursing practice, and my study of interpretive phenomenology in nursing research. Together they solicit me to seek a better interpretive understanding of how families care for young children with persistent severe asthma.

Fore-conception includes the expectations I already have about the results of my inquiry, and what will count for me as relevant interpretive findings (Dreyfus, 1993; Weiss, 1996). My fore-conception is informed by previous investigations of the problem, that is, the review of literature of childhood asthma. In addition, I anticipate that parents' concerns for their children, though similar in some ways, will shape distinct asthma management practices and, further, that understanding the distinctions will carry relevance for professional nursing practice.

Laying Out the Particulars of My Fore-Structure

As a mother, a nurse, and as a student of research and scholarship, I have multiple concerns that influence and impact one another. Each of these contributes to this interpretive project, especially as they are experiences paralleled in the experience of the study participants.

First, caring for my own children when they were young was the most significant, satisfying, and difficult time of my life. Its significance came because intellectually and emotionally I knew that in being a mother I was about very important work. In addition, caring for my children when they were young was profoundly satisfying and engaging in a way that called upon me to respond with every aspect of my being. Furthermore, the passion to do well was all encompassing for me. However, caring for my children when they were young was hard work. Although married, I carried most household responsibilities, worked part-time to support my family, and often had no companionship in the tasks of parenting. I found, like other mothers, that little children are not easy. Their endless energy, intense emotional investment in every minute, their fierce pursuit of independence, their equally impassioned need for security, and the constant interplay of these opposing needs was a challenge not matched in my experience. I wondered how it might have been had my children been ill, or my social situation more compromised.

Second, as a nurse practitioner with clinical experience in primary care, I see opposing forces at work in the management of chronic illness. Modern technology has given us sophisticated knowledge, medicines, and treatment procedures designed to cure disease. In this climate, chronic illness that by definition cannot be cured, becomes more visible due to the successful "cure" of many acute illnesses. Yet, the traditional biomedical approach gives little recognition to the importance of the meaning of illness and suffering, issues of huge concern to families who live with chronic illness (See Kleinman, 1989).

In the practice of modern medicine when cure is not possible, providers turn to managing illness. However, the notion of managing illness often falls short as a principle for caring for people with chronic illness in that it brings up notions of success and failure. We can barely think or talk about "good illness management" without the contrasting notions of management failure or illness mismanagement. Thus, people who are chronically ill often carry the stigma of failure when their symptoms are not controlled. Especially in asthma, and like it, diabetes and hypertension, where symptoms are presumed controllable and expectations for performance and life functioning are the same as for those without chronic illness, failure to control symptoms is often viewed by patient, provider, and society as just that, *failure*.

My experience of caring for people who have chronic disease convinces me that the challenge of managing illness in daily life is a significant one. Further, I am convinced that the voices of people and families who live with chronic illness are not adequately heard and taken into account. As a result, in a system of incredible biomedical and technological advances, people with chronic illness find themselves alone, frustrated, and vulnerable.

My practice experience has shown me that good answers to the question of how living with illness works and how it does not work come from people who live with the contingencies of chronic disease on a day to day basis, since it is they who are intimately aware of the fine points of symptom expression, response, and control or lack of control. Moreover, for all of us, our health makes possible our future and shapes the world of our everyday living, while chronic illness, that by definition defies cure, reminds us that disease, suffering, and fear also carry meaning that shapes the human condition. Accordingly, the voices of people who live with chronic illness in themselves and their family members are the vulnerable human voices of us all.

Third, as a researcher and a scholar, I have come to understand the value and validity of unarticulated perspectives and the importance of interpretation in every area of research in a way that I did not understand before. Especially influenced by Packer and Addison's work Entering the Circle (1989), my study of interpretive phenomenology, the influence of my professors, and the support of my colleagues, I have learned to listen to the silent spaces and unexpressed concerns that guide human practices. In undertaking this investigation, I believe that families in which infants and toddlers have serious asthma is one of those spaces. The willingness with which participants, faculty, and supporting institutions have contributed to this study, as well as its findings, have confirmed that there is much unknown and much misconstrued about the management of serious asthma in very young children.

Interpretive Data

Narratives and Observations Narratives of families' experience with asthma are the primary data of this study. Narratives of specific events and situations provide practical interpretive accounts rather than generalized abstract explanations that might be gleaned from identifying isolated factors in asthma management. Since events of asthma crisis come together in a unique interpretative way for each person involved, and individual stories reveal how the teller makes sense of these events, the researcher seeks narrative data. Narrative descriptions can be powerful, because emotions, sensations of sight and smell, and recollection of physical settings are recalled when events and situations are relived in their telling (Chesla, 1994; VanManen, 1990). In the process of recalling and recounting real events, feelings, and meanings, and the participant's world of experience come to light for the interpretive listener, and sometimes for the participant as well.

Hearing the participant's account, the researcher returns to her own experience to understand what she hears. Although the account may confirm the researcher's forestructure of understanding, most often the researcher must accommodate her perspective to that of the participant and reach out for an elaborated account. The process thus opens up the phenomenon as narrator and the researcher come to share understandings about the participants' experiences. Incongruities or areas of incomplete understanding are retained and are included in the interpretive analysis (Benner, 1994).

Observations give the researcher the opportunity to appreciate the practical context of the stories participants tell. For example, stories of how children are held during administering of treatments come alive when, as researcher, I see how giving and receiving treatments actually takes place. Home observations further situate the family in their interactions together and in their shared space. When a family talks about keeping their child indoors to avoid her playing in a dusty yard, I see that the yard is entirely dust except for a large tree and that finding a place to play on grass, or even in a paved area, would be impossible. When I hear a mother tell me that her child is not afraid of strangers (even though she "hates" doctors) and I see how the child, cautious at first, becomes comfortable enough with me to climb on my lap and give me a kiss, the mother's evaluation is reinforced.

Design of the Study

Research Aims At the beginning of this study my research aims were:

1) To describe parents' understandings of asthma and asthma management skills.

2) To describe parenting practices particularly in light of:

   a) the demands of asthma management established for the individual child.

   b) prior experiences of crisis which led to the child's need for hospitalization and emergency care.

   c) current understandings of how to respond in the event of crisis.

   d) the simultaneous need to provide for asthma management, healthy development of the child, and the care of all family members.

e) social and economic influences affecting asthma management.

Family Demographic Descriptors
Table 1

Family	Ethnicity	Age/c*	Age/p	#chldrn @home /ages	Marital Status #extended family in home	Income yr	House /Apt #rooms **	Work/Sch m f
D1	Latino	15m	m/28 f/28	4 11y,10y,6y	married	<15,000	3	m/no f/40hr:w
D2	African-American	13m	m/21	1	single	<15,000	1	m/no
D3	Latino	37m	20	1	single with extended family in home/5	<15,000	4	m/10h:w 10h:sch
D4	African-American	18m	22	2 3y4mo	single with live-in friend	<15,000	3	m/40h:w 6h:sch
D5	Latino	37m	m/20 f/25	1	married with extended family in home/4	<15,000	4	m/no f/40h
D6	Latino	19m	31	6/3**** 7y,6y	single	<15,000	2	m/no
D7	Latino	33m	m/19 f/19	1	common-law marriage	<15,000	3	m/6h:sch f/<12h:w
D8	Latino	18m	19	1	single with extended family in home/5	<15,000	4	m/no
D9	Latino	14m	27	6/4*** 8y,5y,3y	single with live-in friend	<15,000	3	m/no
D10	Latino	27m	25	4 8y,4y,3y	single	<15,000	3	m/no
D11	m/Latino f/African-American	28m	37 38	2	married	15,000-25,000		m/40h:w f/40h:w

* Child's age at first interview
** Excluding kitchen, dining area, and bathroom
*** Total number of mother's children/ Number of children living in the home

The Study Participants

Eleven families were recruited by identifying Latino and African-American children between 12 months and 4 years of age who had been hospitalized due to asthma or reactive airway disease at Valley Children's Hospital in Fresno, California in the months from November 1996 to April 1997. All study participants were either Latino or African-American and English speaking. The children had been diagnosed with either reactive airway disease or asthma for at least 6 months. Children whose illness management was complicated by other chronic illnesses and/or disability were excluded from the study.

Letters were sent to request the family's participation. Each contained a reply letter and stamped, addressed envelope. Families who did not respond were telephoned after two weeks to follow up and answer questions they may have had about the study. Participants who did respond were called upon receipt of the reply and were enrolled in the study if they met criteria, and if after further description of the study, they wanted to participate. Data regarding the numbers of recruitment letters sent and reasons for non-inclusion are found in Appendix A.

Sample Characteristics

Ethnicity Eight families were Latino, two were African-American and in one family the father was African-American and the mother Latina.

Marital Status of Parents and Family Constellations In three families the parents were married. In one family the parents lived in a common-law relationship. Seven mothers were single. In three families, the parents lived with the maternal grandmother of the child and other extended family members.

One mother had a live-in boyfriend about whom she told me at the end of the second interview. One mother had a live in boyfriend, who was not the father of her children, and who spoke only Spanish. Each of these men was well known to the child in the study and participated in his care by being with the child in the hospital when the mother left for a few hours to care for herself or other children. One father was Spanish speaking and did not participate in the interviews. According to the mother he did not care for their daughter when she needed medicines or was ill.

Ages of the Parents Only three parents were older than 30. Ten of the eleven families had been first time parents as teenagers.

Sex and Ages of the Children Six children were girls and five were boys. At the time of the first interview, six children ranged in age from 14 to 24 months and five children were between 27 and 37 months.

Family Size and Birth Order of Child with Asthma All children with asthma were either last born or the only children of their mothers. One father had an older child who lived out of the household more than half of the time. Two mothers had children other than the child in the study in foster care. In ten households children other than the child with asthma lived in the family at least part of the time. One mother lived alone with her child and another adult when the interviews began and then moved into a household with one other adult and four other children. Two families had four children of their own in the household and one had three. The largest total number of children in any household was five.

Ages of Children at First Diagnosis By the parents' reports seven children were first diagnosed with asthma at the age of 2 to 3 months. Two children were diagnosed at age 7 to 8 months, one at 12 months, and one at 21 months.

Number of Hospitalizations By parents' reports five children were hospitalized two times due to asthma, five were hospitalized from 4 to 6 times, and one mother reported her son was hospitalized 10 times.

Interviews

Each family was interviewed three times. A grant enabled families to be paid $25 for each interview. Two families granted a fourth unreimbursed interview. Observations were not reimbursed. For one family the interview period extended to five months. All other families' interviews were begun and completed within three or four months. One child's father participated in the final interview alone when the mother chose not to. Otherwise, when both parents lived in the home, spoke English, and particpated in the care of the child's asthma, both were interviewed on all three occasions.

Interviews took place in the family's home and lasted between 1 1/2 and 2 hours. Children were usually present and often interrupted their parents. Parents showed respect for the interviewer attending to children in ways that facilitated continued conversation although sometimes disruption was unavoidable. The planned two hour interview length was sometimes too long. Children became demanding, and as a result, parents were often able to concentrate less toward the end of the interviews.

The first interview included explaining the nature of the study and its format, and obtaining consent. Parents completed a demographic data form and were asked to provide information so that a family genogram could be constructed.

The first interview was conducted according to an interview guide adapted by Chesla (1991) from the work of Kleinman, Eisenberg and Good (1978) and modified for this study (Appendix B). The intent was to allow the parents to describe how they understood 'the problem of asthma' before narratives of situations and events regarding management were elicited. The second and third interviews were designed as semi-structured interviews that would elicit parents' narratives about recent stressful incidents that had arisen in the caring for and parenting of their child with asthma. This coping interview has been widely used by nurses, including use in the study of adults coping with dyspnea (Janson-Bjerklie, Ferketich & Benner, 1993) (Appendix C). Parents were also asked about any good that had come from their experience of living with their child's asthma. Finally, parents were asked to comment on the impact of the study on their lives in general and in relation to asthma specifically.

Several families seemed most comfortable during the second interview. At the first interview, families took a little time to become accustomed to me and the nature of the investigation. Some expected they would be asked short answers to closed ended questions. Two families expected my direct intervention either with illness management or with the health care system on their behalf. By the time of the second interview all families seemed familiar with the nature of my interest in their situations and seemed at ease with our conversations. Expecting their openness to continue through the third interview I was surprised that, in at least four families, during the third interview participants' elaborated less on their experiences than they had in the earlier interviews. All these families had expressed surprise at the beginning of the third interview or at the end of the second that only one subsequent interview would take place. In retrospect I would plan this study with four or five interviews of one and one-half hours length to extend over a period of four to five months. The shorter interview is a more realistic format for families with young children. The greater number of interviews should allow for more gradual closure in conversations that elicit difficult memories and strong feelings.

Interviews were audio-recorded and transcribed. Editing for clarity was necessary as the transcriber was asked to include all extraneous comments, e.g. "ums," "ahs," "you knows," and verbatim pronunciation and grammar. Editing included listening to each interview word for word, correcting transcription errors, adding parenthetical comments about tone or extraneous sounds or explanations of interruptions when the taping was discontinued. For instance, if the parent were interrupted by a phone call, by someone at the door, or by the need to leave the interview to care for her children, and the tape recorder was turned off, this was noted. In addition, during editing of portions of the text used in the discussion of paradigm cases and exemplars for this thesis, I removed extraneous comments in order to make the text more readable.

In practice, the interviews were not neatly structured. Parents sometimes began narratives unsolicited. Two mothers when asked about parenting talked extensively about their relationships with their own parents and with the fathers of their children. Each set of family interviews flowed according to the concerns that the families brought to the research process. All included stories of the experience of asthma but all were uniquely constructed and framed by other situations significant to the families' self-understandings.

For all parents asthma crises with or without hospitalization were events that represented breakdown in the usual taken for granted background of day to day family life. All parents were prompted to interpret and provide detailed accounts of the practical aspects of these situations. Parents were asked about the differences between post and pre-hospitalization caring in order to better interpret the contrast between everyday non-crisis illness management and parenting prior to and following hospitalization. In addition, parents were asked to tell stories that illuminated the differences in caring from earlier infancy to the present in order to provide contrasts that reflected the influence of growth and development on asthma management. When there seemed to be incongruities from one portion of the narrative to another, parents were asked about these differences in order to understand better the underlying concerns that shaped the differences (Wright & Leahy, 1994; Benner, 1994a).

Each interview was begun with greeting and conversation about the child's asthma and the parents' health and well-being. Children were usually present during the interviews, often interrupting and needing parents' attention. These events sometimes became ways to engage parents in conversations about the differences between parenting when the child was ill and when she/he was not. Extended family members sometimes moved in and out the interview situation. On occasion a family asked me to share a meal with them which I did. Observational information was interwoven into subsequent interviews as a way to provide continuity between interviews and observations.

Observations

Between the first and second interviews and the second and third interviews, each family agreed to be observed twice in their home. Observation periods were arranged at different times of the day when possible. Early morning and late afternoon or early evening observations were made whenever possible in order to give perspective on the important times of early morning, and late afternoon and evening family routines. As a researcher, my preference was to be as much in the background as possible. However, parents would often engage me in dialogue about asthma and parenting during the observation periods. In addition, they asked and we talked briefly about my work and family.

Children over two years of age were given a set of eight crayons and a tablet of paper and encouraged to draw about asthma or whatever they called their trouble breathing. These drawings and the way parents interacted with their children as they drew were noted as observational data. In addition, four of the five children over two years were offered a girl doll with either brown or black skin color, depending on their own ethnicity, with which to play during the interviews and observations.

Field Notes

As soon after each interview and observation period as possible, I wrote interpretive and observational notes about the parents' neighborhood and access to it, proximity to the hospital, the lay out and interior ambiance of the apartment or house inside and out, the way parents and children were dressed, the nature of their greeting to me, the child's level of comfort with me and how this changed over the course of the interviews. Conversations between me and participants, and among participants and others present that were not tape recorded during observations were noted in detail. I noted especially the ease of the child's breathing, the parents' physical proximity to the children, their physical contact, the tone and content of their messages to the children, and the children's demands of the parents and responses to them. I also made observational notes about parents prevention practices and how the setting contributed to more or less successful prevention habits.

<u>Interpretation of Data</u>

Nature of the Data and Its Interpretation

Narrative accounts of practical situations and events give access to practical worlds (Benner, 1994a). Narratives answer questions such as: How did a situation begin? What did you see and hear? What happened next? How did you feel? How did you respond? How did others feel and respond? What happened after that? How did the situation end, resolve, or change? Instead of applying external concepts, criteria, or themes drawn from the experience of others onto the narrative data, phenomenological interpretation involves making comparisons "about the issues and clearings created in contrasting practical lived worlds." (Benner, 1994a, p. 112) Distinctions discovered, i.e. commonalities, distinctions, and incongruities, generate a dialogue that originates within the narrative text.

<u>Levels of interpretation</u> Interpretation of experiential data takes place on many levels. Taylor (1989a) argues that all language serves to make the implicit explicit in two ways: language depicts and represents; and language constitutes the situations, feelings, and ideas about which it communicates meaning. Thus, a mother with an intuitive way of understanding her daughter's suffering brings her understanding to a new level when she articulates it. Her story becomes a representation of the way she interprets that experience for herself. Furthermore, the articulation, being new for her, contributes to her understanding of her daughter's suffering and to the understanding of the listener (or reader) but is not equivalent to her unexpressed experience of the suffering. "No thematic

formulation can completely unlock the deep meaning, the full mystery, the enigmatic aspects of the experiential meaning of a notion." (Van Manen, 1990, p. 88)

In addition, the thematic or interpretive account a mother gives to herself and others reshapes the experience, giving salience to some aspects and backgrounding others, aiding her memory, and providing contrast and background to her interpretation of other times when her daughter suffers. Moreover, her account is unique and would not be equivalent to an account by others, for instance, the father or grandmother, intimately involved during the same events.

The researcher's interpretive account adds an additional layer, a two dimensional layer, to the interpretation. First, interpretation of the experience broadens the account by comparing the experiences of particular families to that of others. Second, the researcher deepens the account by taking an empathic but necessarily less involved interpretive view or stance of the world opened up to her by the family. Further, due to the constitutive nature of language the researcher's account will also shape the way parents' and children's experiences are understood by those interested in the account.

Moreover, an interpretive researcher herself shapes the way the experience of a child's suffering, for instance, is understood. First, she reflects the families' stories back to them for clarification, allowing them to see (hear) another perspective of their account. She asks probing questions to elaborate the account as well. Furthermore, since the researcher is in most cases the only person to listen in close detail as parents talk about their experiences with asthma, parents often process the experience differently after the interviews than before. One father in this study explicitly stated that on the basis of the interviews he reflected on his role as a father more, and became more communicative and less authoritarian in interacting with his four sons.

Interpretive Process Interpretation in this study was on going during all phases of data gathering and analysis. Interpretation began in the context of the interview, continued immediately afterward in the writing of field notes, and was on-going after each text was transcribed. Throughout the period of interviews, observations, and writing of the interpretive text interpretation has been a process within and among families. As interviews were simultaneously gathered and being interpreted, the processes of data collection and interpretation became interwoven. Previous interviews and their interpretation, informed subsequent interviews within, between, and among families. Interpretations that compare one family to another began as soon as interviews were available from multiple families.

Articulating the Interpretation Three processes were employed to articulate the interpretation of this investigation: paradigm cases; thematic analysis; and exemplars.

Paradigm cases Paradigm cases stand out as particularly focused and evident styles of practical concern. At first the strength of the paradigm showed in an unarticulated sense of connection between the narrative text, observations of the family environment, and ways of acting and speaking, for instance, points of emphasis in the dialogue. Gradually, by listening to interviews and rereading field notes, and by contrasting the proposed paradigm case with data from other families, the paradigm evolved into an articulated interpretation (Chesla, 1988; Benner, 1994; Weiss, 1996). Often incongruities were attended to by seeking elaboration in subsequent interviews. Sometimes incongruities could not be resolved, or could not be discussed again with the participant. Sometimes possible ways to reconcile incongruities remained unsubstantiated and were or were not noted in the written interpretation depending on their significance to meanings articulated in the paradigm.

Thematic Analysis When a clear style of management seemed to be held in common by two or more families, yet no one family alone stood out as a paradigm of the general style, the texts were read and interpreted according to themes that emerged in the dialogue. The process of thematic analysis proceeded by reading each case as a whole, to search for specific themes, and in detail, to determine if the theme was supported on all levels by the text. These processes were woven together by going from whole to theme to detail and over again varying the process order according to the interpretive leads brought up in various rereadings. Observational data was reviewed in order to further support the thematic analysis. Next, themes were compared and contrasted with other cases that had each been thematically analyzed according to the same process. Finally, the themes developed were contrasted with families thought to practice differing management styles in order to sharpen the interpretive findings of each. Rather than a cognitive structural framework, the texts themselves, and thematic similarities and differences guided the process. In this way the interpretation attempted to stay close to the informants' experiences and language.

Thematic analysis did not always proceed smoothly. Occasionally gaps in understanding could not be filled in. In one case an initial interpretation was dropped entirely in rereading and relistening to the interviews multiple times.

Reviewing the data did not clarify the interpretation. In its place an interpretation developed that was more consistent with the text both as a whole and in its detail.

Exemplars The written interpretation is developed from and presented through exemplars, short portions of narrative extracted from the interview texts that stood out as clear expressions of parents' underlying concerns. Exemplars supported a paradigmic or thematic interpretation. Many exemplars are included in the written interpretation in order to show how the dialogue fills out the interpretation and guides the way background concerns flow or relate to one another. The details of the exemplar, the mood or attitude of the participant, the juxtaposition of word choice, the sequence of events, thoughts and feelings, and the repetition of salient themes add depth to the interpretive account. Exemplars also allow the reader into the world of the participant by putting her/him into direct dialogue with the text. Only the investigator has a more intimate view of the participant's world.

Evaluating an Interpretive Account

No consensus exists about the most appropriate method to evaluate an interpretive account. Since traditional rational-empiricist criteria, i.e. internal validity, external validity, reliability, and objectivity, do not fit an interpretive account, several other evaluation processes have been suggested. Packer and Addison (1989) discuss four approaches to the evaluation of an interpretive account: coherence within the account; external evidence; seeking consensus among various groups; and the implications for practice. None is, however, without difficulty. The following discussion of these four aspects of evaluation is based on Packer and Addison's discussion.

Coherence Where an empirical account seeks internal validity, an interpretive account strives for coherence. The interpretation of the text as a whole should be consistent, intelligible, believable, and should be held up by a detailed reading of the text (Packer & Addison, 1989; Weiss, 1996). In addition, a good interpretive account depends on attention to seeming incongruities that can derail one interpretation in favor of another. Packer and Addison argue, however, that finding an interpretive account intelligible, even when all counter evidence is considered, is a valuable criterion, but not thoroughly reliable in the empirical sense. According to Taylor (1985b) individuals may disagree on whether an account makes good sense since that depends on the kind of sense one understands.

External Evidence Using external evidence, i.e. evidence that does not come from the text itself such as the participants' evaluation of the interpretation may counter "the possibility that the investigator is offering only a confirmation of his or her preconceptions." (Weiss, 1996, p. 70) Relying on the participants' evaluation of the interpretation, however, has both practical and theoretical problems. Practically, the participant may find the interpretation disturbing, or judgmental. For instance, in this study some mothers were found to give up the skillful ways they previously cared for their children with asthma during the hospital management of asthma crisis. Knowing this, a participant who vested authority in the researcher, might believe she has done something wrong in the care of her child or that she had displeased the researcher. On the other hand, she may disagree with the interpretation and feel that the researcher has betrayed her trust. Theoretically, the participant's evaluation of the account cannot provide a non-objective standard for the evaluation of an interpretive account. Where researcher and participant disagree one is still left with the problem of evaluating the account from some interpretive viewpoint.

Consensus Seeking consensus among interpretive researchers about the validity of an account could be thought of as analogous to inter-rater reliability in empirical research. Consensus of those familiar with a topic would show that the interpretation makes sense. In the case of directly competing interpretations, Packer and Addison (1989) and Taylor, (1985a:1979) hold that evaluations of validity are "better" in as much as they provide a better account than competing interpretations. Taylor elaborated. "The superiority of one position over another will thus consist in this, that from the more adequate position one can understand one's own stand and that of one's opponent, but not the other way around." (Taylor 1979, p. 67, as cited in Packer and Addison, 1989, p. 285)

However, the variety of perspectives on care of young children with severe persistent asthma could certainly lead to a wide array of opinions among and within interested groups of asthma experts and researchers, nurse and physician clinicians, and health policy researchers. For example, some might disagree about the validity of this work if, even though for a majority, its validity were convincingly established. Thus, the question of whether a work holds validity and should or should not be rejected, either all together or in part, is not really addressed by an effort to seek consensus among researchers.

Implications for Practice An interpretive account can be evaluated according to its implications for practice. "A true interpretation is one that uncovers an answer to the concern motivating the inquiry ... and it should have the power to change practice." (Packer & Addison, 1989, p. 289) Since the motivation for an interpretive account is a practical concern, the uncovering or discovering that occurs in the interpretation should "free" practice from formality and misconceived assumptions, and transform practice through improved understanding. Of course, the relationship may not be direct. A plausible interpretation may or may not have an immediate or lasting effect. Interpretive work may spur additional descriptive work or intervention, or related empirical research. On the other hand, an interpretive account may be taken up so eagerly as to "become a slogan and no longer be felt a moving description" or it may "become mere 'assertion'- a hollow claim" when divorced from the contextual understandings from which it emerged. (Packer & Addison, 1989, p. 289). Moreover, interpretive accounts may be valid, yet dismissed or not taken up at all in formal practice if rival political and economic concerns are deemed more pressing. In another scenario, interpretive accounts may be taken up in the practice of individuals or small groups and remain an anonymous and more or less inconsequential influence on practice.

The validation of an interpretive account is necessarily elusive. In other words, it is not surprising that no firm criteria or methods can be found on which to base the validation. Dreyfus (1985) argues that striving for empirical certainty in the human sciences, that is, seeking a comprehensive framework to explain human activity, really proposes that all seriously meaningful differences be reduced to quantifiable, predictable representations, that is, nihilism. Moreover, since no account can be free of human interpretation, not only would a serious researcher want to avoid eliminating meaningful differences, she/he would be not be able to do so. The understanding of how to engage in the practical activity of being is so much a part of us that we cannot get clear enough about it to explicate it, test it, and use experimental methods to predict how it will work out in future human activity and interaction.

Re-Entering the Hermeneutic Circle

For a rational-empirical researcher who seeks a true representation of phenomenon, the inability to establish firm criteria on which to evaluate an interpretive account is world shaking. Moreover, acknowledging the existence of various interwoven levels of interpretation within an interpretation increases the sense of ungroundedness, and, according to the schemes of rational-empirical science, destroys validity.

In contrast, the interpretive evaluation of an interpretive account is a process that begins in the work of preparing the account. In this study, on-going evaluation of and critique were sought during all stages of the investigation from advisors, colleagues, parents of children with asthma who were not in the study, and from professionals expert in the care of children with asthma. With formal presentation (defense) of this study, the process of interpretation continues in the practical and theoretical critique it engenders, and in whatever ways it may shape the practices it describes. This account itself thus becomes part of the interpretive circle in which others (professionals and non-professionals alike) involved in the care of young children with severe persistent asthma will find more or less value for asthma care practices and research. Interpretation within this milieu of practice and understanding interplays in a continuous process of evaluation and modification of practice. According to Heidegger there is no interpretive end point. The bottom line criterion for evaluating an interpretation is the phenomenon. The evaluative question is "Does the interpretation make sense of the phenomenon?"

[You] have to finally refer back to your own experience and check it in your experience and if it checks with your experience you accept the interpretation and if it doesn't you don't. No amount of sytematicness [sic] will get you to accept it if it doesn't fit your experience. And if it does fit your experience you don't have to say well I'll accept it until a more complete interpretation comes along. It just bottoms out in your experience. (transcription of Dreyfus' audio-recorded lecture on Being and Time, May 25, 1994)

CHAPTER 4

Families' Social Context

Introduction

The purpose of this chapter is to describe various aspects of the social context of the families' lives, as they affected everyday living in general and living with asthma in particular. With the exception of one family where the mother and father both worked full time in institutional jobs that brought them benefits but combined income of less than $25,000 per year, the families in this study were disadvantaged by extreme poverty and by being ethnically diverse. The appendix contains a chart giving information regarding family income, members of household, number of rooms in the household, number of family members, and the hours the mother and father spent away from home either at school or at work.

Geographic, Economic Context

Urban Fresno is a city built of various tracts of homes and apartments that sprawl out from an economically depressed downtown. Before 1960 the city was contained within a few square miles around a railroad depot. It now stretches more than 8 miles north and several miles south of the railroad. Fresno, the city, is the commercial and political center of Fresno County which begins in the foothills of the Sierra Nevada mountains on the east and reaches to the rolling hills where the Coastal mountains begin on the west. Most of the county lies in California's Central Valley, a flat landscape of orchards, grape and cotton ranches, and fruit and vegetable fields that depend on irrigation for all water supply. Fresno days are extremely hot and dusty in summer, and foggy, gray, and chilly damp or rainy in winter. Fresno County's orchards, ranches, and farm lands produce more profitable crops than do farms or orchards in any other county in the United States. Most crops, such as tree fruits, and berries, beans, tomatoes, and nuts require long hours of intense, but seasonal, manual labor. The majority of farm laborers are Mexican. Some are permanent residents, while others migrate on a temporary basis. Estimated California county population statistics are that Latinos from all countries comprise over 38% of the population, while African-Americans are approximately 5% of the total. Latino children comprise 46% and African-Americans 7% of the population under 18 years (Children Now, 1998). Other minority groups who live in Fresno in significant numbers are South-East Asians , Japanese-Americans, Chinese-Americans, and Armenians. The Caucasian population includes many descendents of those who migrated from the drought plagued Oklahoma dust bowl in the 1930's. Unemployment in Fresno county in July 1999 was a typical 12.8% (San Francisco Chronicle, Sept 1, 1999).

All but one family in this study lived within the cities of Fresno or Clovis, a small city contiguous with Fresno. Urban neighborhoods where the families lived were all built since 1950. Four families lived in houses, two of those with extended family and one in the rented room of a house. The rest lived in apartments. One family lived 30 miles from Fresno in a rural town where the center of the economy was planting, harvesting, and packing tree fruit, grapes, and nuts. The extended family of mother, father, daughter and maternal grandparents shared a 3 bedroom house on a treeless lot in a recently built tract development.

Poverty and Housing

Six of the nine families in this study with incomes less than $15,000 per year, who lived in the city of Fresno, lived in apartments in the poorest white or integrated (African-American and others) neighborhoods. The three others were: Tonya, a 21 year old African-American mother who had no permanent housing; Maria, a 20 year old Mexican-American mother who shared a house with her extended family; and Freddie and Lucy, whose apartment was in a middle class neighborhood. I will discuss each in turn and then present a composite of the living conditions of the others.

When we met, Tonya and her 14 month old daughter lived in a rented room where Tonya cleaned house for a demanding and critical aunt of the baby's uninvolved father. During the three months of our interviews, Tonya moved two times, within her African-American neighborhood, a region of the city of Fresno separated from other parts of the city by Highway 99, the main freeway between Sacramento and Los Angeles. For 30 years, with all urban-suburban growth occurring north and east of the highway, the neighborhood has been virtually ignored by the majority community except in its reputation as a dangerous haven for crime and illegal drugs.

Maria, who was the only English speaking adult in her household lived in a three bedroom house with spacious living room and tree shaded yard that was located less than 1/2 block from land cleared for a freeway extension. Her four generation family included three adults and five children ranging from 2 months to 7 years.

Lucy and Freddie, both 28, with their four sons, Eduardo, 14 months old with asthma, and three sons 11, 10, and 6 years old, lived in a two bedroom apartment on the edge of a tract of middle class houses. Their apartment, like the house Maria and her family lived in, was within 1/2 block of the site of new freeway construction. It was clean and neat, and sparsely furnished. Their small living area (kitchen, dining area and living room) had one large window. Eduardo shared a room with his parents where he slept in a crib. Cardboard boxes stacked on their sides with open fronts served in lieu of dressers for storing clothes. Although Eduardo's father Freddie had held a steady job for 7 years, the family had no car and no phone. Freddie made necessary calls from work. Lucy, his wife, relied on a pay phone about 40 yards away from their apartment to make emergency and other out going calls.

More typically, the apartments of families in the study were in poorer neighborhoods. Although parents kept their apartments neat, dusty yards, poorly or not recently painted facades, doors, and interiors, poor ventilation, and old shag carpet compromised the quality of living space.

Two families who lived in apartments had severe problems with cockroaches that hid in and beneath furniture, behind pictures on the walls, and ran freely across the floors. Both mothers complained that they were unable to control the insects which are known to trigger allergic asthmatic reactions (Rosensteich et al., 1997). Landlords and neighbors did not cooperate in eradication efforts according to the parents. Pesticides applied to one apartment in a complex would send the roaches retreating to adjacent unsprayed apartments. When pesticide effects had worn off in the treated apartment roaches would return.

Parents in this study expressed some concern with the safety of their neighborhoods but usually not of the immediate yard outside their doors. In one family the mother was concerned that her 6 year old son had to walk home along an alley after he got off his school bus every afternoon. Since her other son, the youngest, had to stay indoors in order to prevent asthma crisis, she could not go to meet the school bus. One mother let her preschool sons, including the 2 year old with asthma, play within the grounds of her apartment complex if they were accompanied by her teenaged brother. When the children went to a nearby playground she accompanied them.

Stability of Family Living Arrangements

Two years after the interviews ended only two families were still living in the same location. Two families moved during the interview period and have moved again since. Furthermore, family constellations changed for four families during the interview period. One mother lost custody of her children because of drug abuse. In one family, the maternal grandfather, maternal aunt, and cousin of the child with asthma moved out of the household. As a result, the 18 month old with asthma, her mother, the mother's 16 year old brother, and the maternal grandmother moved from their rented house to an apartment. When the teenager got into a fight on the apartment property, the family was forced to move again. In another family, a 30 year old maternal aunt, who was physically abused by her husband, moved in with her daughter to share the home where the child with asthma, her mother and father, and the maternal grandparents lived. In the fourth family, the mother of the child with asthma called the police to say that her son's father was selling drugs. As a result the father was jailed. The mother got a job and a different apartment for herself and her four sons.

Medical Care

All but one family relied on free medical care. The family where both parents worked was insured. One family had Medi-Cal coverage with an out-patient share of cost that they could not meet. Consequently, they did not keep their son's appointments with the pediatric pulmonologist, relying instead on free clinic care and a family doctor not familiar with the management of asthma in infants.

Transportation

Most of the families in this study had one car that was used primarily by the parents who worked. Mothers were most often left to rely on walking (including crossing six lane city roads and intersections), public transportation, and rides from extended family who did not live in the household in order to shop for groceries, visit family and friends, to keep scheduled medical appointments, or go to the hospital in an emergency. Often travelling meant changing buses to get to school, clinic, or hospital. One mother stated she chose her apartment location specifically in order to be within walking distance of the children's hospital. The hospital has since built a new rural campus and moved more than seven miles away. Several 24 hour walk in clinics remain near the original location. Although most families had not chosen residences specifically to be near the hospital, at the time of this study, six of the eleven families lived within two miles of the hospital.

Telephones

Communication with the study families was by telephone to their home except for one family who had no telephone. In this case, I arranged or changed appointments with the father by the telephone at his workplace. No families had answering machines. Two mothers carried pagers in order to be easily available to family members who cared for their children while they worked. Telephones were occasionally out of order which put scheduling and confirming appointments temporarily on hold.

Appointments for interviews were often changed and were sometimes broken. Families routinely had to deal with shifting work schedules, and adult education classes in addition to family demands. Moreover, during this study, there were family deaths, a family injury in a drive by shooting, emergency attention to credit problems, and the need to report and manage a visit by county workers for child abuse of a niece by her mother. Despite these difficulties, most interviews and observations were completed within 4 months. In one family, the interview and observation period lasted for six months. All families completed all three interviews, although in one family the mother who had initiated the interview process declined to participate with her husband in the third interview. He stated she felt she had said too many negative things about the hospital, nurses, and doctors and that the interviews upset her.

Television

In most families, television seemed to provide diversion and access to the culture beyond the worlds of their daily activity. All families except one had television, and television programs were a constant presence. In two families the television was deliberately turned off during our interviews. In one family the television played in the living room while we interviewed in the kitchen. In the other seven families with television, programs played throughout our interviews even though in many cases no one was watching. Some parents strained to talk and listen to each other and to me over the noise of television programs to which they did not listen, or listened intermittently. I sometimes requested that the volume be turned down in order to be able to record our conversation.

One mother said she played television day and night and that her children could not sleep without it. When I arrived at their home one morning at 8 am for an observation, the children with their aunt were asleep on the living room floor with the television on. During several evening observations parents in several families watched television with their children. Children sometimes watched favorite videos. Parents watched game shows, sit coms, soap operas, talk shows, and sports.

Family Constellations and the Role of Extended Families

Most of the parents in this study had taken on their parental role as teenagers (10 of 12 mothers and 3 of 4 fathers) and all parents carried primary responsibility for parenting and managing asthma. In the four families where both parents lived with the child with asthma, three fathers assisted in asthma management. One was not involved. Four single mothers lived alone with their children. One married couple and two single mothers lived with extended family. Two mothers had live-in boyfriends who were not fathers of any of their children. Of the six families with more than one child, four mothers had children by more than one father. Two fathers of children were in jail. The other fathers who did not live in the home had rare or no contact with their children.

Eight of the eleven families depended on regular (more than once weekly) support from extended family. One mother described the bond between herself and her mother, grandmother, cousins, brother, and sister-in-law. *Ruby: "I'd be; Oh! I'd die. I would be really stressed out them."* D4.1 p. 25. *" ....they [other family members] feel the pain I'm feeling."* D4.2 p. 19. For another mother, whose own mother depended on her financial and emotional support, proximity and availability of extended family only added responsibilities to the demands of parenting and managing asthma.

Two mothers occasionally needed to depend on family members with whom they had conflicted relationships. One married couple relied at times on extended family most of whom lived out of town. Other parents told stories of current and past family conflict. Following an argument with his mother at age 5, one father had run away from home never to return. One mother had attempted suicide after an argument with her father whom she felt would not listen to her.

Smoking, Alcohol and Drugs

Three of the sixteen study parents were smokers. All these smoked outside the home. Only one parent had altered his smoking behavior due to the child's asthma. Although he had never smoked in the home, he told how after diagnosis he made sure that the smoke from his cigarettes did not blow inside. The other parents' smoking or non-smoking habits were established before the diagnosis of asthma.

Questions were not asked about alcohol or drug abuse unless the topics were brought up by study participants. Nevertheless, some parents volunteered information about both. In one family drinking binges led the father of the child with asthma to be verbally abusive. However, the mother felt relieved that at the time of the interviews that the father had stopped drinking and had stopped the verbal abuse. She also related that her own father, with whom the young family lived, told the younger man he would be expelled from the home if the drinking or verbal abuse continued.

Two families were directly affected by drug abuse. One mother herself had abused cocaine for 10 years, had been "clean" for a little over a year, and then returned to cocaine as our interviews ended. For a more detailed discussion see Chapter 6. Another mother's husband, and father of the last of her four children, had abused and sold drugs. He was jailed, and at the time the interviews concluded, was released to join the family.

Violence

Parents told stories of physical, sexual, and emotional abuse in childhood. Two mothers spoke of regular sexual abuse by step fathers that lasted for several years. One mother told of the verbal and physical abuse she and her siblings were subjected to by their father after their mother whom he had physically abused committed suicide. Two mothers had abused their own children and were separated from at least some of them. See Chapter 6 for more details.

The Law

In addition, to the two families in which the fathers of the child with asthma were in jail, one mother's younger brother was in jail. Another mother's boyfriend was in jail for a few days during our interviews. The same mother, Ruby, revealed to me during our last visit that she was on parole and had been wearing an ankle bracelet for five months. She had been accused, she said, by another woman of pulling a gun on her. After six days in jail and her mother posted $1000 bail, she pled guilty, and was convicted. Ruby claimed she was innocent but did not have time to fight for herself in court.

> Ruby: So I was going to Court on it and missing days and days at work, and I lost my job. So I just went ahead and took a deal and this is my deal to be on this thing for six months. ... instead of having to go to jail.
> Int: So you were convicted? ...
> Ruby: Yeah.

> Int: You have a record then, for pulling a gun on somebody?
> Ruby: And I didn't do it. ... I swear, I didn't do it. I did not do it. I would not do that. And I don't have time to be going to Court and fighting the system. D4.3 pp. 19-20.

With her ankle bracelet Ruby's every move was monitored. For instance, she could only do laundry during certain hours and only a certain number of times a week.

Jobs and School

Eight of the fifteen parents in this study worked, six full time. Of these, four where mothers and had primary responsibility for caring for their child with asthma. Two single mothers who had always worked in the past said they would still be working except for the need to be always available to their children. Three mothers who also worked went to school, one to earn a GED, and two to post high school business programs. Two parents in the study were functionally illiterate. One was a single mother who could not read medication labels or nebulizer instructions. Even though her son's pediatrician, who knew she was illiterate, had explained these things to her in detail, she was not sure she had remembered accurately and asked for my help. One father relied on his wife to read medication labels, appointment cards, and equipment instructions to him.

Consciously Reforming Lives

Several young families in this study struggled against the difficult social circumstances in which they found themselves. All held out hopes for new lives. One teenaged couple talked about how they had "messed up" in high school by not graduating and by being friends with people they did not respect. Both were committed to being responsible parents, which included being available to provide daily parenting, to manage asthma successfully, and to see their daughter graduate from high school. The father who was illiterate had worked occasional odd jobs until he and his wife began working as joint managers of their apartment complex. The mother collected rent and managed complaints. He did emergency repairs, and cleaned, painted, and refinished between renters.

Another family took their sons' education seriously, expecting their school assignments to be completed and their grades to be "C" or above. Every week the father took special time to talk to each of his sons, in turn, about their school experiences. Freddie said he wanted his sons to be above average and not like the "majority."

> Freddie: I says, I go, [to his oldest son] ... "If the majority of the people are good, Luis, we wouldn't be having the problems we're having now." ... "So it's the minority that's going to be in the right and it's going to hurt sometimes, if you want to be in the right." D1.3 p. 15.

The single mother of 4 sons under age 6, whose husband was in jail for selling and using drugs, found a conservative church community that taught a life style exclusive of tobacco, drug, and alcohol use. Together she and her sons enjoyed the church's worship and social activities. Although this mother still kept contact with her husband, she was determined that he would not come back into her life until he found help through personal reform and a relationship to her church community.

<u>Conclusion</u>

The demands asthma and its management made on the families in this study complicated lives already burdened. Parents lived with violence, jail, poverty, poor access to efficient transportation, and stressed interpersonal relationships. In addition, many parents suffered the personal torment of having been inflicted with emotional, physical, sexual, and drug abuse during childhood or adolescence. Although young, several parents had made personal commitments to improve their lives by reversing what they judged were past mistakes.

The social environment required that parents balance asthma and other life demands mostly on their own. When the support of extended family was available to them, their lives were usually made easier, although in one family extended family members compounded the burden.

For all but one of the study families, poor living conditions and poor transportation especially aggravated the management of asthma. First, families who lived in apartments infested with cockroaches usually had no choice but to live with them. Second despite the fact that asthma crises could make trips to the emergency room necessary day or night, the only public transportation available to them around the clock was by ambulance. Moreover, even during the day, few families lived in areas with direct bus service to the children's hospital.

Employers gave no special consideration to mothers or fathers when children were ill. On the contrary, three of the four mothers who worked full time and two who worked, or had worked, part time were threatened with loss of their jobs when they left or called asking to stay home when their children were experiencing increased symptoms.

Asked if anything good had come from the experience of living with asthma most parents were emphatic that nothing good had come from the illness. However, one mother said asthma made her and her husband feel more responsible. Freddie, father or four sons, explained that his interest in all his sons had improved as a result of the youngest's asthma.

Freddie: When you get one in the hospital, you may not like to think it, but you can't help but think it, you don't know if you'll ever lose him. So that makes you want to just say "Hey." You want to know what's going on with the other guys too. You never know when they might have to go in the hospital. So even though I'm impatient sometimes, I take the time to talk to these guys and find out what's going on with them. D1.3 p. 10.

Family Demographic Descriptors
Table 2

Family	Ethnicity	Age/c	Age/p	Age/dx	#hosp	#chldrn in home	Marital Status	Income/yr	Names of Mother Father Chilld/(sex) **
D1	Latino	15m	m/28 f/28	3m	3	4	married	<15,000	Lucy Freddie Eduardo/(m)
D2	African-American	13m	m/21	3m	5***	1	single	<15,000	Tonya Jasmine/(f)
D3	Latino	37m	20	2m	2	1	single with extended family in home	<15,000	Maria Susanna/(f)
D4	African-American	18m	22	2m	2	2	single with live-in friend	<15,000	Ruby Reggie/(m)
D5	Latino	37m	m/20 f/25	1yr	2	1	married with extended family in home	<15,000	Elena Melissa/(f)
D6	Latino	19m	31	19m	3-5	6/3****	single	<15,000	Margarita Peter/(m)
D7	Latino	33m	m/19 f/19	7m	2	1	common-law marriage	<15,000	Lara Javier Carolina/(f)
D8	Latino	18m	20	2m	6	1	single with extended family in home	<15,000	Anna Araceli/(f)
D9	Latino	14m	27	2m	10	6/4****	single with live-in friend	<15,000	Vicki Travis/(m)
D10	Latino	27m	25	3m	4	4	single	<15,000	Abby Isaac/(m)
D11	m/Latino f/African-American	28m	37 38	21m	1	2	married	15,000-25,000	Corrine Jimmy Bette/(f)

* Child's age at first interview

** Names used in dissertation text, not actual names

*** Jasmine had had 2 hospitalizations at the beginning of these interviews, three months later she had been hospitalized three more times.

**** Total number of mother's children/ Number of children living in the home

CHAPTER 5

Discovering Asthma

When infants in this study first experienced a crisis of difficult breathing, cough and wheezing, all parents felt distressed by their child's escalating struggle to breathe. In subsequent days and months their own accustomed routines of eating, sleeping, and bathing fell away. All felt caught up in frightening circumstances over which, at best, they had tenuous control. By the time parents had sought emergency care numerous times and children had been hospitalized, parents longed for the ultimate reprieve for their child and themselves, that their children would outgrow crisis breathing.

Since symptoms begin insidiously, usually with a benign 'cold', a runny nose and maybe a cough, parents found themselves dealing with asthma before they could reflect on what was happening.

> Freddie: We just went with the flow. ... We do it because we had to do it because he's our son, he's sick and we have to deal with it period. And we have kids to take care of and we have to do it period. It's like you have to go to work. You don't think about it. ... You don't think about why. You just do it. D1.3 p. 41.

Parents coped with recurrent and escalating crises of difficult breathing by seeking care from providers in doctor's offices, clinics, and hospital emergency rooms. Most still assumed they were dealing with isolated episodes of compromised breathing that accompanied the inevitable "cold's" common in infancy and early childhood. Coming to learn that recurrent, often precipitous and life threatening symptoms signaled an incurable chronic illness, changed for all parents the way they understood their child's sickness.

In this chapter, I will discuss the ways three young families came to discover that the sickness they saw in their child was life threatening, on-going, and in the background of every day living even when their child had no evident symptoms. This discovery of asthma's significance sometimes came prior to diagnosis, sometimes with the diagnosis, and sometimes much later. In all cases identifying asthma as an chronic illness with intermittent flares solidified many aspects of parents' previous experience with asthma and was a turning point in the development of parents' relationship to the illness and their role in managing it. Interpretations of each family will include, how parents saw and assessed symptoms of sickness in their child, parents' experiences with seeking provider care, what parents understood about living with chronic illnesses in themselves and others, and parents' affective reactions to their child's breathlessness.

For all parents, discovering their child had asthma was more than knowing facts about asthma, and more than knowing about physiological, scientific, and therapeutic processes. Instead, discovering one's child had asthma meant finding oneself within a threatening and largely unknown world.

> Lara: You have to have it or your kid has to have it or someone very close to you that you love more than anything in the world before you could realize what asthma is. I thought asthma was just, oh you can't breathe. You know, you have a hard time breathing [for example] when they run. It's not even like that, it's, you can't breathe. *You cannot breathe.* D7.3 p. 22.

Asthma, the illness, carried personal meaning for most parents before symptoms began. For some, past experience with asthma was intimate. One mother had asthma herself. Another mother had witnessed a frightening crisis in her young cousin when she was a child and experienced the death of an uncle from asthma during these interviews. For other parents, nieces, a sister, and grandparents had less severe asthma. Although of varying levels of significance, these experiences came to the foreground when parents recognized that their children had asthma. A minority of study participants associated asthma only with the experience of their own child with asthma.

With the diagnosis given and accepted parents were reminded of what they already understood about asthma in others and from the media. In addition, the significance of their child having asthma came from already manifested experiences with their child's recurrent exacerbations of wheezing and cough. All parents had seen their children struggle to breathe. Now these episodes were recognized as part of an on-going state of illness.

For some families, the child's illness was recognized by parents and providers as asthma and named asthma very early. For others, only after one or more hospitalizations and numerous emergency visits was the illness identified by providers (and then accepted by parents) as chronic and needing prevention. One family, greatly distressed at not knowing why their son had been so severely and frequently ill for a year, still felt a measure of relief in being able to know finally that they were dealing with a known illness that demanded preventive response. One mother unhappily anticipated her daughter would be, like herself, always at risk of frequent crises.

Not surprisingly, from distinctly shaped background experiences, each family's understanding of asthma was unique. One mother "knew" she was seeing asthma in her child from the onset of the first symptoms. Another was disbelieving, and one family found themselves up against a menacing unknown about which they had only distanced understandings.

In discovering asthma some parents began to access health care in a new way. The two families, of the three discussed in this chapter, who had known asthma less intimately before their children's diagnoses, became much more assertive in accessing care. A third mother, who knew asthma as life threatening in other family members accessed care after the diagnosis much as she had before. It was later, when her son had a severe crisis in which she felt his pleading helplessness and feared for his life, that her way of accessing care radically changed.

Three participant families will be described in detail here. They are chosen for the for the distinct ways asthma showed up for them from the onset of the first symptoms until the time of our interviews: Anna, who knew from the onset of Araceli's symptoms that she was seeing asthma; Lucy and Freddie, who agonized for a year over what Eduardo's diagnosis might be; and Ruby, who, learned Reggie's diagnosis early, but did not discover its full import until nearly one year later. These families are also chosen for the richness of the data about discovering asthma that they provided during the interviews and participant observations. Two mothers were single mothers, one Latina and one African-American. In the other family the parents were married: the father, Latino; the mother, Latina and American Indian.

Anna and Araceli

From Onset to Diagnosis Of the 11 families who participated in this study, only Anna, who herself had been hospitalized with asthma as a child, suspected that 15 month old Araceli might have asthma when the first symptoms began. Anna understood how asthma felt from her own experience. Feeling breathless was scary and made her feel dependent on the help of others. Araceli's illness recalled for her a desire to be supported by the watchfulness of others, especially professionals. At first she felt panic when left in a busy hospital to deal with Araceli's crisis alone. Later she learned to calm herself. Thus, for Anna, recognizing asthma in her child came easily, but dealing with the emotions that diagnosis of asthma triggered in herself was not easy. Anna described what she noticed about Araceli's first crisis.

> Anna: It's like after that, she was, just kept getting sick and then they diagnosed her, they said it was asthma. ... But I noticed it, like all the symptoms like I would get, like she would have wheezing, she would have coughing like her sides would pull in and you know I just, just could tell the way she felt, because like that's the way I get too when I get real bad. D8.1 pp. 1.2.

How Araceli, 15 months old, felt as she wheezed, coughed, and used intercostal muscles to breathe was clear to Anna from the beginning. She had experienced the symptoms herself. For Anna, asthma meant her daughter would be in and out of the hospital with episodic crises becoming less frequent but no less severe as she grew.

Asthma hurt, made breathing hard, and left Anna feeling helplessly weak. Her understanding about how asthma feels, provided a link to knowing asthma in Araceli. In Araceli's crisis Anna could feel the symptoms she saw. She could distinguish between the characteristic cough that meant Araceli's breathing was constricted and a cough not associated with constriction, "*a regular cough.*" From her own experience Anna knew that a constricted cough felt tight, hurt in her back, and was accompanied by thick mucous and a struggle to get her breath. At times asthma left Anna so weak she could not walk.

Anna's capacity to read asthma in others was evident prior to her daughter's birth. Before Araceli was born, Anna could sense her nephew, Steven's, distress when his mother, her sister, could not.

> Anna: ... [S]he [Anna's sister] don't have asthma so she don't know how it feels. And she wouldn't take him to the, "Oh he's not that bad. He'll get better. His medicine will kick-in." And I was like, "No, take him to the hospital. I mean, I know, listen to me I know the way it feels." You know, cause he would get real bad. He had real bad asthma. And she, and every time I made her take him, they kept him. He was real bad. D8.1 p. 9.

As with herself and Araceli, *"knowing"* asthma in her nephew turned on understanding how symptoms feel which signaled for Anna the severity of Steven's symptoms. What Anna assessed about how an asthma crisis felt determined, for her, the need to seek emergency care. The appropriateness of Anna's assessments were validated. When she *"made"* her sister take Steven to the hospital for asthma, he was hospitalized.

When pressed for more information about how she assessed her ability to "know" asthma, Anna elaborated.

> Int: How can you recognize when somebody has asthma when a lot of other people don't?
> Anna: I don't know, I just. I don't know I guess I just know it. ... Well, I mean I probably could be wrong you know, but I mean if I see someone like me, to me, I don't even have to look at her stomach, when she's having trouble breathing, I'll just know like, oh she's having trouble breathing. Just like when she breathes fast; when she's like (pause). ... Like when I can tell too, is when she has to breathe harder. She's working to breathe. D8.1 p. 34
> Anna: And a lot of times it's just, I can tell too by just the cough. She just starts coughing and coughing and like I can tell it hurts her cause when she would cough she would start crying. Every time she would cough she would cry. She wouldn't stop coughing. She looked her, her lips were getting dark, like purple. D8.1 p. 34.

Although she hesitated to identify with certainty signs that help her recognize asthma, Anna's experienced awareness of Araceli in crisis was a developed and skillful assessment practice. Rapid difficult breathing, which Anna sensed even without looking for retractions, was one sure sign of Araceli's troubled breathing. Crisis was also linked to cough and Araceli's pained cry. Anna had seen how when these symptoms became more intense Araceli's lips became dark purple .

From the beginning, Anna knew she was seeing asthma.

> Anna: ... I thought I hope she don't get it, but I knew right away because you know, I had it. D8.1 p. 2.

<u>The Story of Diagnosis</u> Although, at first, her physicians did not diagnose Araceli as having asthma, Anna did not doubt the meaning of her symptoms. At age 2 months and after a "whole month" of Araceli's being in and out of the hospital emergency room for respiratory crises, Anna helped a doctor establish the diagnosis:

> Anna: ... Like the reason why they diagnosed her with asthma because they said, cause I would tell them well maybe it's asthma. And they said, yeah maybe it is cause the same like symptoms and all that so. Like I probably wouldn't know if I looked at her and she was sick and I wouldn't know what was wrong with her if I didn't have it and ... D8.1 p. 3.

Timid and deferential as she told Araceli's doctor that the diagnosis must be asthma, Anna held to her underlying belief that she knew when she was seeing asthma better than others did. With the diagnosis finally given, Anna's skill in assessing asthma's symptoms and her early sense of their significance was affirmed. In addition, her understanding of Araceli's illness was now explicitly informed, first by her own life long experiences with asthma, second by what she heard, saw, and knew about asthma in Araceli and in others, and third by her own appropriate prediagnosis management of Araceli's crises.

Beyond Diagnosis to the Present At the time these interviews began, Anna had multiple takes on what asthma meant. Physiologically, asthma felt tight, Anna understood, because air cannot easily get out of her lungs. She told how as the work of breathing increased through bronchioles narrowed by swelling and mucus, the chest wall pulls in with every breath. Anna watched for Araceli's chest wall pulling in, knowing it meant crisis and the need for emergency care.

Possible Death from Asthma Most important to Anna, asthma was frightening. She had learned from the media and from her mother that people die and may die suddenly from asthma. Anna was learning that asthma kills many people.

> Anna: Before I was like I didn't think asthma was that serious you know. But it's serious and I mean a lot of people have just died from that. I mean like even now that I hear more kids die from asthma. It's like you know, "Take asthma seriously." ... But a lot of people die from asthma. I guess cause I don't know a lot of people who have died from asthma, but a lot of people do die from asthma. D8.2 p. 35.

> Anna: ... when I hear stuff like that I think, dang I've got to take care of myself you know. D8.2 p.36.

Anna knew that asthma held the frightening possibility of sudden death. She related the story of a 12 year old boy who despite feeling hot and sweaty ran in cool air, then just fell, and died. Asthma is *"bad,"* (Anna's word) and very different from episodic disease or from disease where a precipitant cause is clear. Anna suspected the boy who died must not have known he was sick. She found in his story a message to take care of herself, a message which began in knowing asthma. Knowing not only meant feeling asthma, but also, for Anna, not ignoring what she felt.

Weakness and Sensitivity Anna had grown up in the experience of her own asthma. Her illness, which had not remitted completely, had most recently required emergency care 4 years prior to her interviews with me. As a result, in conversation about Araceli's asthma, Anna often related her personal understanding of asthma. When sick with asthma, Anna felt fearful and unsure of what crisis might lie waiting, and worried that she would not get better.

> Anna: Like I'm like, gosh am I going to get better and you know? I'm just real worried.
> I: So sometimes you worry you won't get better, huh?
> Anna: Uh huh. It takes long to get better and stuff like that. I can't do things cause I'm sick. D8.2 p. 30.

For Anna, asthma meant being vulnerable to protracted weakness. The scare and worry and weakness hung on. Anna paid attention to the fear she felt as she struggled to breathe even when she may not have wanted to. The distress of shortness of breath and coughing could not be hidden or ignored. In high school three years earlier, Anna found that although she tried, she could not tolerate her friend's cigarette smoke. Reluctantly, and risking rejection, Anna told her friend not to smoke. For Anna, admitting weakness to her teenage friends was less risky than subjecting herself to the possibility of wheeze and cough.

In addition, to taking her own asthma seriously, Anna also took Araceli's asthma seriously.

> Anna: You know she could be doing fine and then she just gets sick. She'll just all of a sudden she'll just start coughing and coughing and just all of a sudden.
> I: You haven't really figured out what it might be that comes before hand that makes the cough come?
> Anna: It probably, it probably is that she has weak lungs or I don't know. They said that that could be it. They said she has sensitive lungs and she can get sick like that, real fast.
> I: How is it for you not knowing what's going to happen with her?

> Anna: I don't know I just try to go day by day. When she's sick I mean I get scared. I get scared because I know the way it is and I know how it feels when I get real sick and I just, I always take care of her real good when she gets sick. D8.1 pp. 5-6.

Anna understood that for Araceli as well as for herself asthma could come on suddenly, a characteristic of the illness that was described to her by professional providers as having sensitive lungs. The triggers that precipitated and the signs that gave evidence of lung sensitivity were not always straight forward. For instance, although cough in an atmosphere of cigarette smoke accompanied a sensation of tight breathing for Anna, she knew that cough did not mean asthma in all circumstances. Thus, she understood that, despite being able to assign direct cause and effect in some instances, she could not always do so and needed to pay careful attention to the signs and symptoms of tight breathing on an incident by incident basis. Anna described that paying careful attention to such complex sets of possible triggers and probable signs was the practice of taking "real good" care of Araceli, for Anna knew that critically compromised breathing could develop quickly.

Crisis as Helplessness From the time she first suspected Araceli had asthma, Anna's experiences with helplessness during asthma crises were well established. During Araceli's crises the same feelings re-emerged. Thus, discovering asthma meant for Anna the rediscovery of her own helplessness, a helplessness especially acute when she was alone as she struggled to breathe.

The mutually spiraling relationship between breathlessness and fear could leave Anna feeling helpless, i.e. physically weak, unable to think, emotionally paralyzed, and unable to 'do' anything, both in her own crises and when Araceli was very sick.

> Anna: But there's, you know there's been a lot of times that oh I'll just start crying cause I thought you know, she would get so bad, and I thought she was just going to stop breathing. And I [got] scared. D8.1 p. 10.

Anna was most frightened when she was alone.

> Anna: I mean seeing like my daughter sick ... I just think, I hope nothing happens to her. I just start thinking like, oh what if this happened and I just start crying and, but that's usually when I'm by myself [and] she's sick and I don't have nobody there with me. ... It's like, cause I just thinking stupid things. Like oh my gosh, I'll just think about like if she stops breathing. Oh God what am I going to do and stuff like that. D8.2 p. 23.

Being brought to helplessness by asthma, Anna had learned that knowing what to do during crisis in herself or others was an essential part of understanding the significance of asthma. Unlike other families in this study for whom asthma was unfamiliar or understood as something other family members would manage, Anna knew, from the time of her first suspicion that Araceli had asthma, that experiencing and responding to crises in an appropriate manner were inextricably linked. Often, Anna would cry when she did not know what to do and when there was no one else to rely on for help. She found comfort in the company of others (nurses, Araceli's father, her sister, her grandmother) who would help her in her crisis or who would help her help her daughter when Araceli was in crises.

Two unexpected episodes of constricted breathing helped Anna learn that fear made breathlessness worse. On one occasion she was without her inhaler but did not know it. Thinking she had her inhaler helped her control the fear that came with impending constriction. On another occasion, the relationship between escalating fear and breathlessness became even clearer to Anna. As she walked the four blocks home from school one day, her chest began to feel tighter and tighter and her whole body felt weaker and weaker. Her inhaler, she realized, was in her grandmother's car.

> Anna: I was at home and then I was calling my grandma everywhere seeing if I could find her. I didn't have nothing at home. Inhalers or nothing. So I was just sitting at the kitchen table and I was just like trying to sit still and then I just felt like I was going to stop breathing. I just couldn't breathe. And I just started crying and I was crying and crying and then I just walked into the living room and I was crying to my sister. She was sitting in the living room on the phone and I walked in and she looked at me and she just hung up and called the ambulance. You know she got scared. ... After I stopped crying I was like it didn't bother me any more. And the ambulance came and I was just fine. D8.2 p. 29.

Anna's fear and breathlessness escalated to weakness, panic, and helplessness during her quiet, solitary struggle to restore normal breathing. With no one else aware of or concerned for her situation, Anna was panicking. As her sister's concern began, and with the ambulance called, Anna calmed. Although she may have anticipated that medical intervention would eventually reverse her stressed breathing, Anna was able gather the strength to overcome her panicked breathlessness only with the help of her sister before medical help arrived.

With her daughter in crisis Anna felt similarly panicked when alone.

> Anna: I mean I always just think the worst things sometimes. I just think the worst things and I don't think, "Well if this happens then I'm going to do this." I just, cause I get panicky like I just get scared and I don't know what to do, like when she gets real bad. D8.2 p. 23.

> Anna: I just don't know what to do. It's just like when I get panicky, it's like everything's just blanks out of my head. So that's not good.D8.2 p. 26.

As when she did not know what to do to care for herself in her own breathlessness, Araceli's breathlessness frightened Anna and overwhelmed her sense about what was an appropriate response. She thought the worst, panicked, and felt helplessly empty headed. Again, paralleling her own crises, Anna felt worse when she was alone facing Araceli's crises. For Anna that was often.

> Anna: There's nobody never there with me hardly. It's just like I'm always by myself. ... If someone's there, like if her dad was there I wouldn't get panicky, because I know he's there with me. And he's going to help me if anything happens.D8.3 p. 8.

> Anna: I get all panicky and he just gets like, "Calm down you know when you get like that, you just make it worse." D8.2 p. 26.

When she was alone, Anna had to overcome her panic.

> Anna: I get panicky but then just for awhile. I mean just for a little bit. Get panicky. But then after, I calm down because I'm no good being all panicky. It doesn't do no good. D8.3 p. 8.

Although Anna was most calmed in her own crises by assurance of help from others, she learned that she could calm herself and be of assistance to Araceli in her asthma crises. Calming herself required that Anna override her initial, and familiar response of panicking in the face of breathlessness. Thus, Anna's intimate knowledge of asthma made it necessary to overcome a deep seated tendency to panic that she may not have been able to manage in Araceli had she not had the experience of successfully coming through feelings of panic herself.

The Search for a Helpful Explanation In crisis, Anna gave highest priority to finding an appropriate response so that she could restore her own or Araceli's normal breathing. Searching for the reason she and Araceli had asthma paled in importance . However, Anna did search. When she thought about why she and Araceli had asthma, Anna was, at bottom, perplexed.

> Anna: I don't even know. I don't even know why people get asthma. I don't know. ... I don't know why. Like I think once, I don't even know what asthma is. I mean I know what happens, like when she's having an asthma attack. I know how she gets when she you know, how she feels and stuff, but I mean I don't know what it is. I don't know why people have it. D8.1 p. 27.

> Anna: I just think, "Well, why would she get sick?" I mean sometimes, she don't go outside. She just stays home, but she'll get sick. And it's like guy [an expression like "gosh"], when she doesn't even go outside I mean I don't know why she gets sick. D8.1 p. 15.

Whether Anna knew of a genetic predisposition for asthma or thought asthma might be contagious is not clear. When she was pregnant she asked her doctor about the chances of Araceli having asthma. Her doctor assured her that, although many members of a family might have asthma, asthma is not "catching". Anna thought then that Araceli might be born without asthma.

> Anna: ... I mean they told me, "You know you could have your baby and you know she could be normal. She won't even get asthma." But you know, some people do and some people don't. But she got it. D8.1 p. 28.

Disappointed by Araceli's illness but without self blame, Anna continued the search for a reason that would give her a handle on preventing Araceli's symptoms.

> Anna: Because I'm just, [don't] want her to get sick. You know I'll do anything just you know to prevent her from getting sick you know. But sometimes she just gets sick anyways. I mean if it's cold I take her and cover everything and have her covered up real good all the time and she just gets sick. D8.2 p. 32

Resignation Anna remained helpless to find even tenuous control over asthma's insidious invasion. She was instead as resigned to the vagaries of Araceli's asthma crises as she was to her own.

Although Anna would *"do anything"* to spare Araceli's being sick, she believed that the severity of Araceli's asthma was largely out of her control. Araceli had been hospitalized seven times before the age of 15 months.

> Anna: It's bad. I mean for her being small, I'm like God I mean she gets sick, all the time. She gets real bad, like you know. I mean some of them in

> the hospital they say, you know, she has severe asthma. They told me you know she's real bad. And for being so small and being in the hospital that many times, being admitted that many times, all the time they tell me like when they see her, I tell them, God you know, she's small and she's been in here all that time you know. D8.1 p. 37.

Anna responded skillfully to Araceli's repeated crises but always without hope for anything except survival. Repeated hospitalizations had not changed the course of Araceli's illness. Feeling unable to challenge asthma's persistent and unremitting course, Anna felt resigned to Araceli's crisis filled life with asthma.

After a long hiatus in her own symptoms and three months since Araceli's last crisis, Anna thought of the future.

> Anna: Well you know what? Now I have, don't, I haven't used my inhaler for a long time. It's not bothering me. So hopefully it's going away you know. Cause I haven't used it in a long time.
> Int: Has it interfered in the past with what you want to do with your life?
> Anna: No. No. I mean I would get shortness of breath I would just have to do my inhaler, but no it's not. [Anna does not complete the sentence.]
> Int: What about Araceli's asthma? Is what happens with that going to make a difference in what happens with your life in the next couple of years?
> Anna: No, it won't stop me from doing anything. But it would probably be hard cause you know I'm going to have to do her medicine or hopefully it'll be, she'll grow out of it. D8.3 p. 21.

> Int: [I]s there anything you can do to make a difference with the asthma or is it something that just kind of happens and you're kind of standing there watching and you have to take care of her when it happens?
> Anna: Uh uh. It's just when it happens, it happens. And I just have to deal with it. Take care of it, take care of her, give her her medicine and .... D8.3 p.22.

Anna anticipated that the future would bring more crises for Araceli and for herself. Her attempts to discover a reason for asthma that provided control over symptoms and clues about her future with asthma had not led anywhere. Anna did not expect them to. Instead, she could only hope that asthma would remit as Araceli grew.

Summary The process of discovering Araceli's asthma had led Anna to a pervasive resignation. Asthma was not a challenge but a mantel, a part of Anna that had also become part of Araceli. Anna had known asthma well since it pervaded her body. Asthma crisis was only the worst encounter within an uncontrollable experience that demanded she overcome panic and enlist the help of others. Although professional providers responded to Araceli's first breathing crises as if they were acute, episodic, resolving, temporarily scary, and preventable, Anna knew they were not, and responded by seeking emergency care as soon as she thought Araceli's difficult breathing became painful, a sure sign of her belief that, without intervention, symptoms would not resolve. Even before diagnosis Anna knew that asthma was on-going, always hidden beneath the surface of daily life, and required appropriate response to bring symptoms to resolution. The diagnosis confirmed what she knew but did not want to believe, that Araceli, too, would always be threatened with a potential for troubled breathing that could erupt without warning into frightening episodes of life threatening proportion. Moreover, discovery of asthma found Anna wholeheartedly engaged in the project of taking care of herself and Araceli. Anna knew that she must forever be ready to ameliorate compromised breathing on a daily (hour by hour, minute by minute) basis and advocate for Araceli. She skillfully assessed asthma's flares, sought help without hesitation and was sure about the appropriateness of what she was doing.

However, as sure as Anna seemed in her knowing about and caring for asthma, she was also tentative and hesitant in her speech and, often, in her thinking. In the interview portions presented above I have edited out "you know"', or "like you know" numerous times for clarity. Anna would often qualify a strong statement by using an opposite in the same the sentence. For example, *"I always just think the worst things sometimes." D8.2 p. 23.* Anna's thoughts would often trail off and when asked to elaborate on previous ideas she would sometimes forget what she had told me.

In addition, Anna showed great deference toward professionals. First, Anna could only timidly suggest to doctors that Araceli could have asthma. (See reference to D8.1 p. 3.) Second, Anna told how she surprised herself when a male nurse questioned her knowledge of asthma. She confided that she had not appreciated the extent of her own knowledge.

Though Anna responded to her situation with a skill which her family and professionals verify, for Anna, crisis was an overwhelming emotional experience of fear and helplessness. All that Anna understood about how asthma looks, about what is appropriate to do, about how effective her efforts would be, and about what the future would hold, was shaped by the experience of crisis. Feeling alone and fearing death, Anna sensed that without others to calm her, and advocate for her, she could not adequately and appropriately respond to reverse breathing crises. Instead, she felt helpless. Nevertheless, Anna found she could overcome the emotional storm that shut off her ability to think when Araceli was in crisis. She could calm herself and calm Araceli as well. Still very frightened and unsure Anna found small comfort in this tenuous skill.

Lucy, Freddie, and Eduardo

From Onset to Diagnosis Lucy and Freddie, unlike Anna, did not know they were seeing asthma in 14 month old Eduardo until he was given the diagnosis by the pediatric pulmonologist during his third hospitalization just prior to our first interview. Discovering asthma was for them a journey of isolation and uncertainty. From the hindsight of diagnosis they judged that they and professionals had managed Eduardo's asthma poorly. Since they always felt responsibility for optimizing Eduardo's well being, the diagnosis led them to review past events and blame themselves for past missed observations. Although their review was now aided by a diagnosis that contextualized and gave meaning to past confusing symptoms, they nevertheless felt guilty for misjudging the significance of Eduardo's symptoms and angry at the health care providers for failing to make an earlier diagnosis. Besides Eduardo, Lucy and Freddie, both 28, had three older sons, ages 11, 9, and 6 years.

At age 3 months Eduardo's first symptoms were neither unusual nor alarming.

> Lucy: He was sick for about week and then . . .
> Freddie: We thought it was the common cold.
> Lucy: Yeah.
> Freddie: Nothing more. D1.1 p. 8.

Then Eduardo's breathing changed. Unlike Anna who knew what she was seeing when Araceli first had difficulty breathing, Lucy and Freddie looked back and realized they had *"no idea"* of the meaning of 3 month old Eduardo's first symptoms. While Anna did not hesitate to seek help at the emergency room, Lucy and Freddie first waited overnight to take Eduardo to the clinic he usually attended.

> Freddie: And his breathing was tight.
> Lucy: It was real shallow. He was barely breathing at all.
> Freddie: ... It was kind of like a (father makes short hard sounds), like that . ...
> Lucy: Cause we didn't know.

> Freddie: We had no idea that's what he had.
> Lucy: We didn't know what it was. And we thought well I'll make it easier. So I took him to the doctor and the doctor gave him antibiotics, and he didn't give him albuterol or anything like that. They just gave him antibiotics and a decongestant. D1.1 p. 6.

Eduardo's breathing did not improve in the next 24 hours. In fact, it got worse. Still Lucy and Freddie waited as they weighed what to do. Self-supporting, without medical insurance, and low income, they pondered the wisdom of seeking emergency hospital care. Such an option not only carried financial risks but also was not part of their doctor's plan for Eduardo's care. They chose to follow the doctor's instructions literally, thinking that if they took Eduardo back to the doctor too early, they would be criticized for not giving the prescribed antibiotics time enough to work.

> Lucy: We didn't know what asthma was.
> Freddie: Until the night before we took him to the hospital his breathing was so tight that it was scary. D1.1 p. 8.
> Lucy: And we were both thinking if we were, trying to decide if we should take him to the hospital, because we didn't have any insurance. At the time we didn't have any insurance and we were trying to decide if we should take him, or are they going to say, "You didn't try the medicine. Well, why didn't you try the medicine and then take him in?"
> Freddie: They did give us that problem when we took him.
> Lucy: So we decided the next day to take him in. And they took him in right away though. ... He went from the doctor to the hospital. D1.1 pp. 6-8.

Looking back Lucy and Freddie believe they should not have waited.

> Lucy: If we would have known, we would have taken him in sooner, but we waited too long to take him in.
> Freddie: Yeah. ... Well, we felt bad when we found out that that's what he had and we were just blaming ourselves like, guy we should have took him in. You know, it's our fault.
> Lucy: And when he got as bad as he did we would ...
> Freddie: And that's what they told us at the hospital that we should have brought him in sooner it wouldn't have been as bad. But ... so that's kind of just made us feel bad. D1.1 p. 8.

Lucy and Freddie shared deep feelings of guilt and blame about the events of Eduardo's first crisis. Unfortunately, hospital providers who told them they should have sought care for Eduardo sooner reinforced these feelings. As Lucy and Freddie tried to assess what would have made a difference and where the responsibility lay, each evaluated the situation a little differently. Freddie assumed that the blame for not seeking care earlier lay squarely in themselves. Lucy felt the blame deeply but also held the doctors partly responsible. She and Freddie were doing as the doctors had told them, and Eduardo had not been given medication to reverse reactive airway constriction. It seemed not only that Lucy and Freddie, but also the doctors, did not realize the seriousness of Eduardo's situation.

<u>The Story of Diagnosis</u> Even after the first hospitalization, which they would recall as the time when Eduardo was most ill, Lucy and Freddie continued to wonder what his illness was. Asthma was not definitively diagnosed until Eduardo's first visit from the pediatric pulmonologist during a hospitalization 9 months later. In the meantime Eduardo had been to the clinic doctors many, many times for distressed breathing.

> Lucy: No they [only] treated him very recently for his asthma. And then when we ... and all these times he's been in the hospital he's been to the doctor all in between then.
> Freddie: I mean his medical chart at the at the clinic is about that thick. [Demonstrates about two inches with his fingers]...
> Lucy: And all these times he's been in the hospital three times and in between all these times he's been back to the clinic so many times. ... I mean it's .. just he's been sick. He's had the asthma and everything. He just didn't go to the hospital for it. I have so many little albuterols. (laughs) D1.1 p. 8.

Freddie recalled his relative naivete about the illness at the time medications were first prescribed. From the vantage point of greater skill and experience with the disease he recalled his earlier lack of understanding with some fearfulness.

> Freddie: I had, I had no understanding of... when we, when he was first prescribed albuterol, the very first prescription of albuterol, I just thought when you gave it to him he's going to be fine and that's that. I had no idea, that he needed... I just assume when you take medicine that's that, you're better . But I had no idea that it was something y'd have to take ... every three hours, every four hours. D1.3 p. 4.

That Eduardo's respiratory symptoms had an underlying chronic cause did not occur to Freddie (nor Lucy) at first. During Eduardo's second hospitalization at age six months, he was prescribed *"a long term"* medication (an inhaled steroid). However, on discharge he was given enough to last for a month. When it ran out clinic doctors refused a refill. In the interim, they had treated Eduardo's numerous crises as isolated episodic events. While doctors who saw Eduardo at the children's hospital said Eduardo had asthma, clinic doctors did not. Since Eduardo's symptoms seemed to be resolved after hospital discharge, Lucy and Freddie assumed, at first, that he had recovered completely from unrelated episodes of sickness. However, Eduardo's crises recurred frequently. Both parents, but especially Lucy who spent all her days and nights with Eduardo, felt uninformed. That no answers about Eduardo's sickness were forthcoming frustrated her. Both parents felt helpless to avert recurrent crises.

Lucy told what an earlier diagnosis of asthma would have meant.

> Lucy: Well if they [the doctors] think, I mean if it's asthma say it's asthma. Don't say that we don't want to say it's asthma. If it's asthma say it's asthma, don't just treat it. ... If you got one doctor saying it's not asthma, you got another doctor saying "we don't like to say it's asthma until he's 2 years old." ... [S]ome of the doctors at [the children's hospital are] saying, "Yeah he has asthma." So I go back to the clinic. Well this doctor says he has asthma. ... That's what frustrated us the most, that nobody wanted to say it was asthma. ...
>
> Int: If you had known it was asthma?

Lucy: If they had told us it was asthma, okay we know what's wrong with him. He has asthma. ... We would have looked up into it more. We would have asked more questions about it? We would have read up more on it.

Freddie: Right, but ...

Lucy: We wouldn't have been getting third hand advice from other people. We would have found out for ourselves. We wouldn't have been taking advice from people here and people there. We would have found out everything on our own. ...

Int: [Y]ou were all trying to guess it? Maybe what it really was..?

Lucy: Yeah that's what we were doing. If we would have known it was asthma we would have went and read up on it. We would have did all the things that we are doing now [to prevent symptoms]. Now we just barely started doing .

Freddie: We're trying. ...

Lucy: He's a year old already. Yeah it's been about 9 months. And if we would have known sooner, we would have, got on the ball.D1.1 pp. 49-50.

Lucy and Freddie believed that knowing Eduardo's diagnosis earlier would have made a big difference. Instead they felt confused by the lack of agreement between hospital and clinic doctors.

<u>Beyond Diagnosis to the Present</u> With the diagnosis finally given by the pediatric pulmonologist, Lucy and Freddie were less bewildered about their circumstance. Their understanding of asthma had become constituted by several practices and beliefs.

<u>*Advocating with More Assuredness*</u> Lucy was still frustrated because clinic doctors would not give Eduardo inhaled steroids on a regular basis. However, they needed to rely less on advice they got from other people about Eduardo's symptoms, and instead, became Eduardo's advocates. The understanding that she was dealing with asthma confirmed for Lucy that she could determine what Eduardo needed. When clinic physicians whom she viewed as recalcitrant and unknowledgeable refused to prescribe medications, Lucy began to persist in requesting them. Freddie stood in agreement with her.

Following Prevention Advice Following the diagnosis Lucy and Freddie had been instructed about asthma prevention. As a result they began to "do things" to try to prevent Eduardo's symptoms. This topic will be treated at length later. However, presented here is an example of how life changing these preventive practices were.

Since Eduardo's visit with the pediatric pulmonologist, Lucy and Freddie took up, at his advice, the practice of trying to keep Eduardo in environments of even temperature. As a result, they kept Eduardo confined indoors almost all the time. At the times of these interviews, Eduardo, a very active child, seemed quickly frustrated in his indoor environment. Both parents poignantly described how even as a 7 or 8 month old infant Eduardo could be comforted from crying by their taking him outdoors. At 14 months he often stood looking out a low window. On those few temperate days when Lucy did take Eduardo out she noticed his complete fascination with the experience.

> Lucy: ... He even like ... the leaves in the gutter, he's just totally amazed by it. He'll go over there and he'll just sit, squat and he'll just look at an ant go by, cause he doesn't hardly ever see them. And he'll look at the leaves the different colors and cats, dogs, he just ... he's amazed by them cause he hardly ever sees them and he's just like he trips, he trips out on everything the trees and the wind. He could just look at it and and especially the leaves on the ground in the gutter. D1.1 pp. 43-44.

Managing the Unknown and Unexpected: Accusation, Blame, and Anger The certainty of diagnosis supported Lucy and Freddie's belief that Eduardo's many crises were due to illness, and were not entirely in their control. In addition, the diagnosis validated their efforts to obtain inhaled steroids and a referral to the pediatric pulmonologist from Eduardo's clinic doctor.

Feeling Accused, Taking Blame Instead of accepting blame when they felt accused of doing something wrong, they were hurt and angry.

> Freddie: It's like you're treated as, "What are you doing wrong for him to be having these attacks." That's the attitude that I get.
> Int: Everywhere?
> Freddie: So far. I mean, well, I mean I don't want to say everywhere, I mean well the clinic and the hospital. Are you giving him his medication right, as prescribed. Well, of course, I am. But just sometimes when they don't get well, and I know for a fact sometimes it don't work because my nieces [who also have asthma] still do that. They take their medication as prescribed and sometimes their attack is so bad that they have to get admitted. D1. 1 p. 53.

> Freddie: It makes us feel bad because he's going to the doctor all these times. People are looking at us like we don't know what we're doing. But if you could see we have three other children and we've never had any medical problems with them. So I mean, it's not like, it's just confusing. It's hard. But people look at us like, they look at us like "Do these parents even know what their doing?" Type of attitude. And if they only knew ...
> Int: ... It sounds like ... they just expect that if you're good parents that he's not going to be sick. Is that what you're saying?
> Freddie: Yeah, that's what it seems like. It makes my wife cry. It made her cry. Not any more. She used to it, but it makes her feel like she's not a good mother. If they only knew we have three other boys, there's nothing wrong with them. ... D1.1 p. 27.

Greater experience with Eduardo confirmed for Lucy and Freddie what they had heard from Freddie's sister and brother-in-law about their adolescent daughter's experience with asthma, that symptoms were not always controllable even with daily medications. The diagnosis allowed Lucy and Freddie to accept that exacerbations do occur in the usual course of the disease. However, as much as the diagnosis validated Lucy and Freddie's experience and sanctioned seeking care without guilt, they also felt accused and socially stigmatized. Especially hurtful was the accusation of not being good parents. Lucy and Freddie took pride in their children and their close family. The older boys were respectful, always close to home, helpful to each other and to their parents, loving toward

Eduardo, and good students at school. Freddie wanted to tell those who accused them of poor parenting, *"If they only knew..."*

Blame came often. Freddie told me of the emergency visit that resulted in Eduardo's first hospitalization.

> Int: So when you go to the hospital the feeling is, "Boy, you've done something wrong." By you showing up here it means you've done something wrong?
> Freddie: Yeah, that's the feeling and I don't think that should be the proper feeling, because they're infants. They're infants and they still feel, and they look at you like, "Well the infant is in the care of the parents therefore what are you doing wrong?" I don't think it should be like that. But yet, they're more apt to take care of a teenager and not say anything about the parents, because the teenager can defend themselves. ... I know a child can't defend themselves, but I don't think we've done any, I mean, we still deep down take a lot of blame for him being in January [first hospitalization]. Sometimes we do. We still feel bad to this day. I'll never forget those 10 days [the 10 days Eduardo was hospitalized]. This part was the hardest 10 days I've ever been through. I still kind of blame myself for that, but I refuse to say it's my fault the other two times. I'll take the blame for January, but the other two times, I refuse to take that blame, because I've been giving it to him and so has my wife as prescribed. When you can't help it, you can't help it, and you just go in. D1.1 pp. 53-54.

During the most recent hospitalization Freddie again felt blamed.

> Freddie: ... I mean in the hospital they made me feel like I was ignorant. Before he was released this last time around, the doctor said ... the nurse, she said, "He needs to take the [inhaled steroid] and albuterol." I said yeah okay, ... And then she says, "Well, do you know how to give it to him?" I said, "Yes through that chamber." So the way she was going about it was, "So, do you know what you're doing?" ... "This was his third time here. Do you know what you're doing?" I said "Yes I know what I'm doing." "Well how do you do it? Explain it to me?" I said, "It's two puffs. It's five to seven breaths and then another puff. And then it's [inhaled steroid] and the same. She says, "Well I'm going to bring a dummy in here and I'm going to bring you a chamber and you show me." And I said, "Okay." So I showed her how I was doing it and she says, "Oh, okay." It made me feel like I didn't know what I was doing and that's why he was in the hospital that third time. Cause her attitude was, "Well he's been here too many times, do you know what you're doing?" D1.1 p. 25.

Lucy and Freddie felt defensive since, even though they followed their doctors' management instructions, Eduardo's symptoms recurred and escalated. At clinic visits and when hospitalizations were necessary, they felt and continued to feel accused of neglecting Eduardo, that is, that they were either ignorant of how to control his symptoms, should have done it better, or should have brought him for emergency care sooner.

Impeded Access to Specialist Care Eduardo's first evaluation by the pediatric pulmonologist came during his third hospitalization. Lucy and Freddie had tried to obtain specialist care much earlier. Lucy's mother who worked in the billing department at the clinic Eduardo attended offered to pay privately for a visit to the pediatric pulmonologist between Eduardo's second and third hospitalizations.

> Freddie: Well, we tell them [the doctors at the clinic], "Hey, he's already been in the hospital they already told us that he needs this kind of medication and he has more clinical visits than you can imagine. And we want to get to the bottom of this." And their, and his attitude was "who are you to tell me type." And when my mother-in-law says, "Hey, just refer us to a specialist we're getting tired of this, just refer the specialist I'll pay for it." And no he refused. D1.1 p. 53.

Once sure of the diagnosis, Lucy and Freddie were angry at those who provided inadequate management plans, incomplete, inaccurate diagnoses, and impeded their access to specialty care. Frustrated by being unable to change the pattern of crisis, they felt inappropriately prepared to care for Eduardo.

Despite the many aspects of care they could not control and about which they felt unfairly blamed and angry, Lucy and Freddie felt profoundly responsible for Eduardo's suffering. Freddie, especially, continued to assume blame for Eduardo becoming so extremely ill prior to his 10-day-long first hospitalization.

However, in the process of discovering that Eduardo was battling asthma, Lucy and Freddie learned seek hospital care without guilt when Eduardo's breathing crises did not improve steadily. Despite the humiliation of feeling blamed by hospital providers, there were times they felt they must take him to the emergency room. Before seeking emergency care, they did, however, exercise judgment and weigh other circumstances in addition to considering the severity of Eduardo's symptoms. Whether their practices involved unnecessary risk is not clear as will be discussed in more detail in Chapter 6.

<u>Fear of Death</u> With the diagnosis, Lucy and Freddie gained a perspective that helped make sense of their experience with Eduardo's sickness. However, the definitive diagnosis, asthma, also increased their anxiety by bringing incontrovertible confirmation of Lucy's and Freddie's worst fear: that Eduardo could die in breathing crisis.

Lucy and Freddie had seen how symptoms made Eduardo barely able to breathe.

> Lucy: Oh yeah. He won't lay down by himself. And we don't like to lay him there you never know when he's going to stop [breathing] so we hold him. D1.1, p. 12.

Death and asthma were closely linked for Lucy and Freddie in the memory of one of their high school classmates who died of asthma.

> Lucy: We went to school with a guy in high school and he died of ...
> Freddie: Right.
> Lucy: asthma attack.
> Freddie: My wife and I went to school with a guy, named Tony and he had asthma and he went out to ... he went out somewhere to a drive-in movie or somewhere he had forgotten his medication, left it at home. He had an asthma attack and he died.
> Lucy: He died.
> Freddie: He was in the 9th grade. And if anything...
> Lucy: That's...

Freddie: That's the kind of stuff that gets my mind.
Lucy: The stuff that nothing but bad goes through your head. You think of the future, nothing, what good is going to come out of this.
Freddie: A simple thing like taking the medication would have saved that Tony's life.
Lucy: Yeah.
Freddie: You remember , don't you?
Lucy: Yeah. D1.1 p. 34.

Lucy and Freddie realized that Eduardo's asthma put him at risk for dying not only during times of clearly discernable crisis but even when he might appear to be functioning normally. Moreover, they believed this risk of unexpected sudden death might always hang over Eduardo.

Understanding Eduardo's Experience Lucy and Freddie were clearly concerned about Eduardo's well-being. They felt frightened and called to relieve his suffering, but unlike Anna they could not rely on clues about how asthma must feel in making decisions about what course of action they should take.

Lucy: He just looks so sad like he's looking at us like, "Do something" or ... he looks confused and scared. He's real scared.
Freddie: As far as what they are they're going through I don't even know what they're going through. We've had the doctors try to explain it to us where the lungs ...
Lucy: They just close up.
Freddie: Yeah.
Lucy: They say that they just close up.
Freddie: I couldn't even guess how that feels.
Lucy: Yeah. It probably hurts. I don't know. Because he just looks at us like he's asking us to do something for him, he's gotten real sick at times. I mean real sick. D1.1 p. 10.

Lucy: He just gets really panicky.
He gets real panicky and scared like, like a look like real scared.
Freddie: If he was having it now he clings. He would cling onto us.
Lucy: Like he's confused. Like he's confused like he doesn't know what's happening.
I: How was that for you the first time you saw that?
Lucy: It was scary man. I just cried. I didn't know what to do. It was sad. I didn't know what to do. (pause) D1.1 p. 18.

Although doctors said that Eduardo's lungs close up during an asthma crisis, Lucy and Freddie did not know how that translated into distress for Eduardo, nor did they find that knowing what to do was evident until many months later. Freddie could only surmise that lungs closing up must be painful. Unlike Anna who took early action in seeking care and in getting a physician to diagnose asthma because she heard signs of lung constriction and understood the pain Araceli suffered, Lucy and Freddie responded to the signs of Eduardo's signs of distress without any understanding of his bodily experience. Instead of feeling asthma, Lucy and Freddie saw asthma's fearsomeness on Eduardo's face and in his behaviors. As they watched his struggle to breathe, they saw him looking confused, frightened, sad, and reaching out to cling to them. Lucy felt him call out to her to "Do something!" His plea left her deeply moved and feeling helpless in not knowing what to do.

Summary For this family, the course of discovering asthma was a long and continuing one. At first, Lucy and Freddie were not worrying about Eduardo's symptoms. They had 3 older sons and were familiar with upper respiratory infections. None of their other sons had been severely ill. None had been hospitalized for any reason. Even 9 months later, they remained bewildered, assuming blame for not knowing what they should have done when Eduardo's respiratory symptoms first flared. For Lucy and Freddie, the search for a definition to help organize their experience and to give them a handle on how to manage Eduardo's illness better was excruciatingly slow. When it came there was no relief from the fear that Eduardo could die from his illness. In addition, even with the diagnosis they continued to feel at the mercy of a capricious illness, caught between doctors who did not agree, limited by their novice level familiarity with asthma, and financially too vulnerable to continue the expert care they valued. The last is discussed in Chapter 6.

Ruby, Reggie, and Tony, along with Franklin and extended family

At two months old Reggie's wheeze and congestion led Ruby to take him to a hospital emergency room where he was treated and diagnosed with asthma. At the time Ruby already knew very well the frightening circumstance of severe asthma crisis and the potentially life long threat asthma poses. A few years previously she had witnessed a young cousin's dramatic, near death, asthma crisis. Moreover, Ruby's middle aged uncle was surviving asthma only by continuous home oxygen therapy. Despite this family background of asthma, at first, Ruby did not feel the significance Reggie's diagnosis would come to hold for her. Unlike Anna who, at first symptoms, built her understanding of Araceli's illness on her own experience with asthma, Ruby's understanding evolved over a period of 13 months. Typically, Reggie developed distressed night breathing that often escalted to asthma crisis. His symptoms would ameliorate only after repeated emergency visits where he was diagnosed with recurrent ear infections and associated asthma crisis. When at 15 months old Reggie experienced his worst crisis and second hospitalization, the terrified expression on his face remained vivid in Ruby's mind and dramatically changed her outlook and understanding about asthma.

Ruby, was a 22 year old African American mother of two sons, Tony and Reggie who at the time of the first interview were 39 months, and 17 months old. Ruby held a new full time job as a security guard at a local fruit packing plant where she supervised the orderly incoming registration of produce trucks. She carried a pager on which, if necessary, she could always be reached by her family.

Ruby lived with her sons and a boyfriend, Franklin, who declined to be interviewed for this study. Franklin, who was not biological father to either of the boys, cared for them at times by himself, especially in the early mornings when Ruby left for work. Afterward, when Franklin went to work, he took the children to Ruby's maternal grandmother or to her cousin. Both Tony and Reggie were diagnosed with asthma at about the same time. However, only Reggie had been hospitalized for asthma.

Onset to Diagnosis Reggie first became ill while Ruby was at work and he was in the care of her grandmother and cousin.

> Ruby: I didn't know it was asthma. ... He was over at my grandmother's and I believe she called me at work. And I was working at an inventory job then, so I was back and forth out of town to San Jose and different places. And she paged me I was in San Jose [approximately two hours from home]. And she said something's wrong with Reggie, he doesn't want to eat. So I told my supervisor, you know, I needed to go home, something was wrong with my child. So when I came home, my cousin had already took him to the hospital. So they had told my cousin he was asthmatic and his throat was sore that's why he wouldn't eat anything. So I'm like, you know he's not asthmatic. He's never had any breathing problems. D4.1 p. 6.

Having left home with him apparently healthy, Ruby did not believe the diagnosis. Denying he had asthma, she wanted to believe that he had only a sore throat. Not wanting to eat had been, after all, the first sign of Reggie's distress, Ruby reasoned. The next week when Ruby was at home with Reggie she saw for herself Reggie's *"hard stomach"* and heard his wheezing. An emergency visit confirmed the diagnosis as asthma. This time Ruby believed what she heard.

Story of Diagnosis For Ruby, there was reason to deny the diagnosis. As a child Ruby had learned how asthma set off panic in her family.

> Ruby: I'm like, cause it's, to me it's scary because I had a cousin who had asthma. And he would have an asthma attack and everybody would be running around the house when I was a little girl. We all stayed in grandmother's house and everybody would be running around the house looking for his pumps and to me it, it was really scary. I'm thinking, "What if he [Reggie] has an asthma attack and dies in his sleep or I don't hear him wheezing and I can't help him" ... D4.1 p. 5.

Although she did not have asthma herself, Ruby learned early what happened when someone in her family had asthma. Parents and grandparents responsible for protecting children would drop everything in order to respond to crisis. Unlike Anna who felt asthma's fearful grip in her chest, and for whom asthma was an isolating and individualizing experience, asthma scared Ruby and brought to mind her whole family's panicked scurrying to rescue a young cousin from breathlessness. In Ruby's family, when you did not have asthma yourself, you were responsible for those who did. Thus, hearing "asthma", Ruby recalled the fear brought by crisis and, in addition, wondered what she could do if she were alone at night when Reggie had a crisis. What, she wondered, would happen if she were not vigilant as she slept.

Asthma can be controlled or prevented Even though she was familiar with asthma in many other family members, at first Ruby, like Lucy and Freddie, thought medicine could stop or prevent asthma completely.

> Int: When he was first sick and you had to go to the hospital ...
> Ruby: Back then I thought they could just stop it completely. ... I thought they could stop it completely or find out what was causing it so I could keep it away from him. D4.3 p. 28.

However, Reggie, like the other children described thus far, was either in the doctor's office or the emergency room with an episode of wheezing every month until his hospitalization at 15 months. Each time he would be given a short course of medications. Episodic treatment lasted for a year.

Ruby believed modern medicine could determine the cause or causes of asthma. She recalled how her cousin's frightening crisis was thought subsequently to have been triggered by an allergy to grass. She suspected Reggie may have had allergic triggers for his asthma as well. Since he was younger than the usual age of first testing for allergies, 3 or 4 years, Reggie had not been tested. Ruby was left feeling frustrated that Reggie should continue to suffer when simply avoiding offending allergens might help. Unable to prevent his frequently recurrent crises, she felt out of control. In this first year of illness, Ruby felt she could do little except remain vigilant for signs of crisis onset. She also realized that Reggie's situation was likely chronic, despite the fact that physicians treated him at emergency visits as if his episodes of sickness were separate and unrelated.

Beyond Diagnosis to the Present Meanwhile asthma was manifesting itself more clearly for Ruby in the many ways it changed Reggie.

Signs of Distress Attentive to Reggie's everyday moods, appetite, and the subtle signs of breathing distress, Ruby became skilled in assessing his state of health.

Mood and Inactivity From the time he was only a few months old, Reggie gave early behavioral clues that crisis might be imminent.

> Ruby: I could figure out when he would have an attack before his attack would get too crucial. ... I could tell by his attitude. His attitude would totally change. He is a very happy friendly baby. If he just sat there, (to child) Yes baby. If he just sat there and he didn't want to be bothered, he didn't want to be played with, he was going to have an attack.
> Int: You knew when he was really little. When he was like 3 or 4 months?

> Ruby: When he was like 3 or 4 months. Even then cause he was a very happy baby. Very happy. D4.1 p. 11.

Ruby learned how to read the severity of Reggie's symptoms in the change of his affect from happy to uninterested. As Reggie got older the behavioral signs of his mood had changed but the contrast continued.

> Ruby: [L]et me see, if Reggie's happy he's running through here, playing, tearing up things. He's a regular 18 month old. If he's not feeling good he's going to lay around, he's going to lay in the bed. If you touch him he's going to, "No, stop." He don't want to be touched, then I know. But when he was younger, littler I could just tell cause he would just lay around and sleep all day. D4.1 p. 11.

As Reggie developed into a toddler who reveled in his mobility and ability to assert his will, asthma crisis brought a dramatic decrease in activity and an aversion to close contact.

Lack of Appetite Ruby noticed other behavioral signs.

> Ruby: [H]e has very good eating habits. If he didn't eat, there was really something wrong. Cause he has very good eating habits. He wouldn't eat at all. He wouldn't even take a bottle. He'd probably just hold it in his mouth, but if you go look at it in 30 minutes, he's still on the same amount of liquid that it was when you gave it to him.
> So it was scary because he would have, when he would go to the hospital he would have, probably mostly, well twice, he had to have an IV, because he had gotten dehydrated cause he wouldn't eat or anything. D4.1 p.12.

In a crisis Reggie did not eat "at all" which was frightening because as an infant, Ruby recognized he could become quickly dehydrated.

Lost Voice and Scary Scream Ruby noticed Reggie's voice and vocalizations.

> Ruby: He cannot talk if he's having an asthma attack. It's like aak (demonstrates), in every, he's gasping in between every word. He cannot talk. He will scream, but he can't talk. ... [I]t sounds terrible. It's a scary-like scream. It's scary for me too if he gets really bad. It's scary for me too.
> Int: What are you afraid of most?
> Ruby: Him not breathing at all no more. Him just not breathing at all. D 4.1 p. 17.

Reggie, who at 16 months said only a few words and did not speak in sentences, could not *"talk"* during a crisis. Instead he screamed, a frightening scream that made Ruby fear he would stop breathing. In this terrible scream Ruby heard a unique signal of potential disaster.

By the time of Reggie's second hospitalization for asthma, Ruby had incorporated into her evaluation of Reggie's breathing several behavioral signs that indicated to her, not only Reggie's distress, but also the severity of his situation.

In the following dialogue she told how she came to set her own standards for when to give Reggie treatments and when to take him to the hospital.

> Int: Did they tell you when you need to come to the hospital?
> Ruby: When I can see his ribs.
> Int: Okay. But I thought that's when you were supposed to start the albuterol?
> Ruby: That's when I'm suppose to start the albuterol. I'm suppose to give him, when I could see his ribs I'm suppose to give him at least 4 treatments at home and if he's still wheezing really bad then I'm suppose to take him to the hospital.
> Int: I see.
> Ruby: But I never do that. I get scared and I take him straight to the hospital. I'll skip the treatments and I'll just take him to the hospital.
> Int: If you see his ribs.
> Ruby: If I see his ribs. But I figure given him one at night prevents even the fact of seeing his ribs. ... He's scaring me when I can see his ribs. Cause he's like gasping by then.
> Int: So not only can you see his ribs, but he...
> Ruby: he's gasping. ...
> Int: Anything else? That goes on with him that you recognize?
> Ruby: If he's having an attack besides those ribs and no. Well, this last time he was clutching his chest like, I guess his chest was hurting trying to work his lungs so hard to get air [and] His eyes. His eyes get really brown. ... His eyes get brown [and] his face turns red, he gets really flushed. D4.1 pp. 14-16.

Ruby's skill in assessing Reggie's situation had become well developed by the time of his most serious crisis. Ignoring the plan an emergency room doctor gave her, Ruby did not hesitate to act on what she had learned by observation were evident signals of crisis. When Ruby saw Reggie's ribs she headed off to the emergency room.

In summarizing Reggie's first year with asthma, Ruby told me:

> Ruby: .. Now I see that they can't [stop asthma]. They can, but they haven't applied theirselves to do it. But I guess, I think they figure he'll grow out of it. Which don't bet my child's life on what you think. Don't bet my child's life, when you thinking he'll grow out of it. Assure me he'll grow out of it. They can't do that.
> D4.3 p. 28.

With the diagnosis made, Ruby felt providers had ignored what she knew, but did not pay much attention to at first: that asthma is on-going even when no symptoms can be identified. Furthermore, she felt providers had failed to search diligently for the cause of Reggie's crises. Ruby wanted to know what caused symptoms so that she could prevent them. However, she did not sense that any preventative help would come from traditional health care providers. She felt let down, and determined both to protect and to advocate for Reggie.

<u>Fear of Death</u> What scared Ruby most about Reggie's asthma was that he could die. Her fear was linked inextricably to her sense of needing to respond rapidly to his distress.

> Int: What are you most afraid of?
> Ruby: Him not breathing at all no more. Him just not breathing at all, so.
> Int: Does that come from what you knew about asthma before or what you see with Reggie?
> Ruby: I think it comes from what I knew about asthma before. From the way all the adults in the house were panicking trying to get the pump for the cousin like it was, you had to have it now his life was threatened by this. And I think that's what where the fear of him dying comes from. Cause I thought then my cousin was going to die. You know if he didn't get this pump now. So. D4.1 p. 17.

Fear was a generalized response Ruby had to crisis in a close relative. She had the same reaction to her aunt's asthma.

> Int: What kinds of things have you heard from other people about asthma, when you start talking around. Cause you said you were asking questions.
> Ruby: Yeah, well I asked my auntie. My auntie, I don't how long she's been asthmatic, but my mother always makes this joke that she should be in a plastic bubble. Because she can't be around cigarettes. She can't be around anything. Nothing. So, and then I've seen her have an attack as an older woman. So it scares me is what an asthma attack can do to her as an older woman as to what it can do to my baby. ... She's the same way my cousin was. It's her son, who is the one had the asthma attack. She's clutching her chest and she can't breathe and then she's shaking her pump you know, trying, oh it is, it is a terrible thought. And then the adults they know how to inhale it and how long to hold it. A child doesn't know that. D4.1 25

Ruby noticed the same chest clutching reaction in her aunt as she did in Reggie. She saw that asthma crises occurred as rapidly and caused as much distress and fear in older people who know what is happening as they did in Reggie. The comparison made Ruby feel Reggie's vulnerability even more since her aunt's terrible distress highlighted for her how much more distress there must be for a child.

When Ruby's uncle died from asthma during the months of our interviews, she felt death from asthma come very close to home.

> Ruby: It is terrible. I had the uncle who had real bad asthma, who just passed. And seeing him, well seeing him pass with asthma didn't put a better feeling on me about asthma. ... He had an oxygen machine that he carried around with him and one at home. And his attack just finally got really really bad and he was trying to tell my mom, but he couldn't get any air. So she's a nurse. She threw him to the ground giving him CPR. ... 911 couldn't get in. They were stuck outside for like 10 minutes. [So while a cousin] went to let them in, he stopped breathing. ... [H]e was on the oxygen when he stopped breathing. So it's real devastating to my mom because... she felt like she failed, but she did all she could do. ... It's terrible. ... So it was was kind of hard on the family 'cause then I'm like, dang they really do die of asthma. ... But I look at, it's put on me now, it is really, I was already paranoid. I am really paranoid now. D4.3 p. 4.

For Ruby the fear of death became too clear in the lives of those around her. Asthma's devastating effect on adults capable of helping themselves during crisis, magnified the sense of responsibility she felt to Reggie. Asthma frightened Ruby and, in addition, just as her mother felt she failed Ruby's uncle, Ruby feared she could fail Reggie.

> Ruby: He's laying there [in Ruby's arms], and he's, but he's like, it's the look of confusion on his face, like is, do somebody know that I'm in distress, is somebody going to help me? D4.1 p. 27.

In his bewildered gaze Ruby felt Reggie beg for her to help.

> Ruby: I know that he put his trust in me. That's what you know, for him to be a little guy, it is not much he can be thinking, but when he grabs this and I'm holding him and talking to him and he grabs my hair, I know that he knows everything's going to be all right. That's why I feel if one day he stops breathing, I'm going to feel like I failed Reggie, cause he trusts me. ... He trusts me to get him to the hospital, to give him his treatment or whatever it is to help him breathe better. ... Helping him feel better. ... Yep, that's my baby I have to be the one responsible. D4.1 p.29.

In Reggie's pleading Ruby felt a profound call to assume primary responsibility for his well-being. Failing Reggie would be as devastating to her as his death from asthma. Following, in Chapter 6, is a discussion of how Ruby's heightened sense of responsibility led her to practice day and night vigilance in order to be available to rescue Reggie from asthma crisis.

<u>Asthma's Place Among Life's Other Stresses</u> The numerous stresses in Ruby's life besides asthma included: being a single mother; working full time because she did not want to be on welfare; losing that job, where she was recognized as doing a difficult job well, due to plant closure; assuming another less interesting and part-time telemarketing job; living with a boyfriend who was with her most of the time but who was expecting a child by another woman;

helping this same boyfriend recover after being seriously wounded from a drive-by shooting during the time our interviews took place; being on 6 month's probation, monitored by ankle bracelet for the conviction of pulling a gun on another woman (a crime she denied); experiencing her mother's illness due to HIV infection and her father's illness due to cirrhosis of the liver; and attending school in the evenings twice a week to learn computer skills.

Despite all these other stresses, many related to and all complicated by poverty, Ruby identified asthma as the biggest stress in her life.

> Rudy: Yeah, it's hard because I have an asthmatic child, my mom's HIV positive, my dad has cirrhosis of the liver and it's just... oh God, I just take it day by day.
> Int: ... You said you weren't [had not been] working for awhile.
> Ruby: Oh God no. I was, I just went back to work in December. ... I had been off since, I had been unemployed since July, but I had to get back to work because the bills are closing in on me. D4.2 p. 25.

> Ruby: I have to go to work to pay the bills, because AFDC gives me next to nothing. So I have to go to work to pay the bills, but I have to be there for Reggie if he has an attack so. If I don't go to work, I'll lose the car, lose the apartment. So it's like, I don't you know, it's a split ... it's crazy.
> Int: So you're torn?
> Ruby: Yeah. I have to go, I have to pay these bills and get clothes on their back and food on the table and I have to go to work. So. That's the only other stress I have besides his asthma. D 4.1 p. 24.

Ruby was left feeling torn between wanting to support herself and her children and wanting to attend Reggie closely.

> Ruby: [Asthma is] a big problem to me all through the day. Even if I'm not around Reggie. Whoever has Reggie, I'm going to, I'm calling them constantly to make sure he's all right. I feel comfortable when he's with Franklin. Well, I feel comfortable when he's with grandma too, but grandma's a little older and she doesn't really understand a lot. Franklin, doesn't understand either, but Franklin knows what to do if this happens or that happens or if that happens. Franklin's, he watches so he kind of knows what to do. D4.2 p. 4.

> Int: Without the support [you get] from your grandma and your boyfriend. That would be very difficult.

> Ruby: I'd be; Oh! I'd die. I would be really stressed out then. D4.2 p.p. 24-25.

For Ruby, Reggie's asthma was the most important stress of all because leaving Reggie and going to work pulled her from opposing directions and left her feeling *"crazy"*. She needed her job, even though it prevented her from keeping close watch over Reggie. As a result, she continued working, while she remained vigilant and responsible for the quality of Reggie's breathing at all times, even if others were caring for him. She felt gratefully dependent on the care her grandmother and Franklin were able to provide. Among all the social burdens of Ruby's life, she felt asthma held the most potential for unanticipated disaster since Reggie's life, she believed, hung in the balance. She talked about her relationship to asthma.

> Ruby: Yeah [asthma is the most difficult stress in my life] ... I don't know if I think the asthma expects a lot of me or if I expect of me. ... I don't know if I expect a lot of me cause of the asthma or what is it. I think the asthma expects a lot of me, I don't know. I don't know. I know Reggie's bad, that's why his asthma don't go away cause he gets a treatment. ... If he gets a treatment he just run and play and then it'll flare asthma back up and he'll need another treatment. D 4.3 p. 26.

Although her thoughts were not well worked out (we were constantly interrupted during this conversation), Ruby understood that worry about Reggie's asthma focused much of her life. Whether she focused unnecessarily Ruby was not sure. On an everyday level, asthma clearly required vigilant attention to the detail and context of Reggie's illness. Ruby found that dealing with asthma was not always straight forward. As was true for other parents in this study, Ruby learned that, for reasons she did not understand, breathing treatments provided only temporary symptom relief. In addition, she could not be sure if Reggie's being active was a positive or negative indicator of his well being. Moreover, asthma's chronic uncertainty was so pervasive that, despite making herself always available to respond to Reggie's symptoms, Ruby had not been able to reverse the trend of frequent crisis episodes and emergency visits. Meanwhile, as a young mother, she strove to provide adequate financial support for her family of three by working and going to school.

Knowing about asthma Acquiring more facts about asthma was not of concern to Ruby even though accepting asthma's ups and downs frustrated her. Ruby did not, however, take up the project of meticulously reordering her home environment in the hope of avoiding unidentified allergens. In contrast, two other families in this study practiced fastidious prevention in the belief that it would alter asthma's course. Ruby, instead, hoped for a decisive way to prevent Reggie the pain of difficult breathing. Her questions about asthma primarily concerned how to assess a crisis and how to respond appropriately.

> Ruby: So the things I've asked about asthma is: How crucial is it? How long does he have to get to the hospital? When would I know when an attack is coming? That's how I know about the ribs. I asked the doctors that. And they say to keep him away from cigarette smoke, but I don't smoke cigarettes. D4.1 p.25.

In addition, Ruby had no desire to understand the physiology of asthma. Unlike, Anna and Lucy and Freddie, and other parents in the study, Ruby did not have an explanation for what might be happening inside Reggie as he struggled to breathe.

> Ruby: Let me see. I don't have no understanding about asthma. I just know the things that I'm supposed to do to stop my son's asthma attacks and getting too crucial. I understand that it's a breathing disorder and I know the things that I'm supposed to do to stop it from happening. D4.1 p. 13

Ruby did not wish to attend to the details of physiology and ordered management unless she could see definitive results. Until then, she was most interested in being able to skillfully assess and respond to Reggie's symptoms. She had low tolerance for partially effective or subtly effective prevention and treatment techniques. Ruby, like Lucy and Freddie, wanted to find out what she could do to prevent reactive airway constriction and crises from asthma. However, unlike the others Ruby was not interested in the fine print. Thinking the cause of Reggie's asthma was unknowable, and the triggers were too complex for her to identify on her own, Ruby assumed a reactive stance toward asthma. In this she was similar to Anna who took up living with asthma as a response to an inevitable and unconquerable threat. However, unlike Anna, Ruby believed there must be an alternative, a way to change Reggie's situation. Convinced, most likely, by the experience of her cousin, Ruby often stated that she wanted Reggie tested for allergies. If she knew the triggers, Ruby thought, she could make sure that Reggie avoided crises.

Summary Ruby experienced asthma as a terrible weight that threatened Reggie with death. For her, the link between death and asthma were never far from consciousness. Ruby had experienced asthma across her own life from childhood and into motherhood as a young adult. Moreover, besides her intimate knowledge of Reggie's frightening and on-going crises, Ruby had seen how asthma affected close members of various ages in her extended family. Yet, despite her life long experience with asthma, when Reggie first became ill, Ruby was not prepared for the stress asthma would bring. During a year of Reggie's moderately severe crises and episodic emergency care, Ruby became more and more frustrated at being unable to find an identified trigger or triggers that if targeted could prevent Reggie's symptoms. As a result, she felt frustrated at being forced to deal with the contingencies of asthma as they arose.

Although at first Ruby denied to herself that Reggie had asthma, she soon accepted the diagnosis. However, like Lucy and Freddie, it was only after about a year later and numerous moderate crises, that one serious crisis and hospitalization transformed Ruby's understanding of asthma. At that point, Ruby realized that asthma was serious and did not go away. In addition, over the course of Reggie's life with asthma Ruby developed nuanced, and more and more sophisticated skills in assessing Reggie's circumstances. Attending carefully to Reggie's difficult breathing through crisis after crisis, Ruby discovered numerous markers for crisis severity. Most of these she had picked up entirely on her own.

Thoroughly frightened by the thought of losing her child, Ruby took on the responsibility of preventing Reggie's death from asthma with fierce personal commitment. Stressed in many life circumstances with which more socially and economically privileged mothers did not have to cope, Ruby, nevertheless, put asthma at the top of the list of her life's stressors. As a result, she maintained day and night vigilance for signs of Reggie's distressed breathing despite a daily life filled with an excruciating number of demands and unknowns. Ruby could not figure out when asthma, which always carried the threat of death, might show up, and she did not know when or if it would go away. Since she felt a minute by minute responsibility for Reggie's ability to breathe, she would come to his aid when he was ill even if she had to give up work. She headed to the emergency room for help when she sensed crisis. In her caring for Reggie, she did not worry about losing her job or whether or not she would meet with approval when she got to the emergency room. She went when she felt she must.

Discussion

For these parents nothing was clear cut or systematic about taking the first steps in dealing with asthma. Even diagnosis did not reveal a clear plan about how best to cope. Usually, asthma surprised children and parents. The meaning the illness would hold for them became evident only gradually even when they knew the diagnosis early. At the time of diagnosis, most parents denied it could be, felt bewildered, or were angry or sad. The impact of time spent not knowing the nature of their child's illness left some parents estranged and clueless, and others out of control of the illness. However, from the beginning of symptom onset, all began developing their own skills and beliefs about their child's sickness that had become incorporated into their understanding of asthma by the time the diagnosis was finally established.

Without consciously setting out to do so, all these parents took on distinct roles in response to the demands of asthma even if overwhelmed by what was happening. Somewhere in the process of discovering asthma, either with the diagnosis, or at the time of the most serious crisis, asthma acquired deep meaning for Anna, Lucy and Freddie, and Ruby. Knowing their child had asthma flooded these parents with their own background understandings and experience of asthma, chronic illness, hospitalization, suffering, and death. Primarily parents felt frightened. For the families discussed here, asthma brought up feelings of loneliness, rejection, frustration, sadness, and stress as well. Anna, although she had some understanding of her ability to recognize and act when she saw symptoms escalate to crisis proportions, felt especially hopeless to change asthma's course. She was resigned to meeting the demands asthma dictated. Lucy and Freddie felt angry at others, self-critical, bewildered, alienated from appropriate health care, and determined to do better in helping Eduardo. Ruby, unable to stop Reggie's crises herself, wished for and expected better answers from the health care system. She hoped for a cure but believed it would come through a medical breakthrough that would allow her to identify the triggers of Reggie's asthma. In her singular focus, she did not perceive or act upon other prevention measures. Thus she waited, frustrated and stressed but, nevertheless, always vigilant to protect Reggie from distress and herself from failing him or losing him.

For all these parents, the present was so all-occupying that thoughts about the future were largely unformulated and general. Their hope was that their child would grow out of asthma. They feared that, when away from the parents, a crisis with life threatening potential could occur and their child might not have inhalers at hand or adults in close enough proximity to avert the crisis. They worried that running and being active might provoke crises.

Conclusion

In all these families discovering asthma was similar: immersion in world defining fear which evoked pain in parents as well as children. All the parents were motivated to give their best energies to active caring for and protection of their child. Yet, the process of discovering asthma was complex and highly individual. Parents learned about asthma from their direct experience of recognizing and managing early symptoms, accessing care, and from the advice of others. These three families counted the care and advice of providers as centrally important. Yet, they all relied less on doctors and other providers than on themselves in making assessments and taking steps to access care, and they all shared the fear that their child might die. In different ways, all believed in and came to understand the importance of their own agency in preventing crises, and in relieving their child's suffering.

CHAPTER 6

Introduction

In this chapter I will discuss four qualitatively distinct ways that parents manage their child's asthma on a daily basis. Since daily management flows uninterrupted into crisis management and accessing hospital care, I will show how routine daily management and care in crisis are linked and are mutually defining. The relative importance asthma management plays in life's daily context is variable. First, asthma management fits into each family's daily life along with numerous other life concerns. Second, due to intermittent exacerbations of crisis breathing in children with persistent asthma, parents' styles of asthma management take on fluid and flexible rather than fixed or rigid form. Moreover, the management styles explicated here overlap each other in some aspects, change overtime, and reshape themselves as the experience of asthma continues, and family circumstances evolve.

Four distinctive management styles were manifest by the eleven families in this study:

Determined Self-Agency: Managing with the goal of self sufficiency.

Discontinuous Self-Agency: Managing illness that is largely beyond one's control.

Flexible Self-Agency: Managing with flexibility and sharing responsibility.

Disrupted Self-Agency: Managing asthma in lives disrupted by other concerns.

These four styles will be presented in two ways. In the discussion of Determined Self Agency, I will present a paradigm case with exemplars from other families presented to elaborate on the interpretive analysis. In discussion of the other three management styles, the salient aspects of the style will be illustrated through the interpretative analysis of characteristic themes with exemplars drawn from various families practicing that particular style of management. In both instances, the goal of the analysis is to present distinctions between styles by demonstrating similar and/or contrasting family practices.

Determined Self-Agency: Managing with the goal of self-sufficiency

Paradigm Case

Fear and Vigilance

Ruby, who was presented in Chapter 5, was a 22 year old African-American single mother whose fear of asthma ran deep. If 18 month old Reggie would die from asthma, she felt she would have failed him. Her sense of unique personal responsibility for Reggie's well-being knew no bounds. Ruby wanted to be with Reggie when he was ill. It never crossed her mind to leave him alone when he was hospitalized. *"I was not going to leave him there by himself. ... [I]f I go home, my baby's going with me." D4.2 pp. 11-12.* If being with him during a crisis meant leaving work, Ruby would do so. Since his asthma was likely to flare during the night, she insisted on working days.

> Ruby: I work days, because if he's sleeping and he has an asthma attack anybody else you know they panic. So, I, I don't work nights. I don't let him be alone at night. [T]hey panic.
> But I've missed days [of]work, ... because if he's real sick I won't go to work. There's nothing they can tell me to make me come to work if he's that bad. D4.1 p. 2.

Although Ruby had help in caring for Reggie from her maternal grandmother, her boyfriend, her cousin, and her sister-in-law any one of whom might take care of Reggie in their homes while Ruby worked or to give her a rest, Ruby did not relinquish her personal commitment to assessing Reggie's health and making the decisions regarding his care. Her cousin, grandmother and boyfriend all deferred to Ruby when Reggie's asthma exacerbated.

> Ruby: ... I have, I have quite a bit of help, but if he gets too drastic everybody's like, "No don't bring him back until he's better." They, they're scared you know. ... Cause Sunday, as a matter of fact I took him to the hospital Sunday. He was at my sister-in-law's house and she called me. She was almost in tears. She was like, "Please come and take him to the hospital." Cause he was breathing so hard, you could just see his ribs you know. D4.1 p. 3.

Reggie's "attacks" came on fast and frightened the whole family. Accordingly, Ruby remained personally attuned to Reggie's earliest signs of cough and wheeze in order to prevent crises from becoming severe. Professionals, she thought, should help answer the pressing questions about crisis. *"How crucial is it? How long does he have to get to the hospital? When would I know when an attack is coming?" D4.1 p. 25.* At my first visit to Ruby when Reggie was just 16 months old, she told about how preventing attacks became incorporated into everyday activities.

> Ruby: Well, because it's everyday I can never forget, it's like I have to tie a ribbon to my finger. Reggie has to have his medicine 3 times a day. To me, he has to have this treatment once a night and I have to watch him around every, if he goes in the room and plays with [his 3 year old brother], I have to be in the door way watching what's going on. ... I watch him.
> Int: What are you afraid might happen?
> Ruby: I'm afraid he would have an attack, just have an attack and Tony's a little boy [Ruby's older son who is 3 1/2 years old] he doesn't know. ... And I mean I don't just stand there watching the whole time, I'm in and out of there. I'm in and out of there. Cause I'm afraid he'll have an attack and I'll be doing something else, like cleaning up or, and when I'm cleaning or wherever I'm cleaning at, this highchair, it's following me around the house. He's in it.
> Int: So these attacks come on pretty fast. ...
> Ruby: Within 5 minutes time. ... They're there and bad.
> Int: He can be feeling good and then 5 minutes later?

> Ruby: And then all of a sudden he's gasping. He's gasping. And then they told me at the hospital to watch for a runny nose, but he doesn't always get a runny nose when he's having an attack. D4.1 p. 19.

Ruby's fear of asthma led to minute by minute vigilance. Her challenge felt formidable. Convinced that Reggie's breathing could deteriorate without warning, she kept Reggie close and watched his breathing. It is as if in the metaphor of the high chair Ruby demonstrated her determination to take control of Reggie's illness. If asthma were going to show up, she would not be caught off guard.

Days were continuous hard work, "I think it's difficult when the kids have asthma like Reggie does because somebody always need to be there. You can never blink your eye." D4.1 p. 17. After the hard days, nights gave no rest.

> Ruby: I'm thinking, "What if he has an asthma attack and dies in his sleep or I don't hear him wheezing and I can't help him", but I, I'm a very light sleeper now. I use to could just, I would sleep hard I couldn't hear anything in my sleep. But now I'm a very light sleeper. Cause I always want to hear. D4.1 p. 5.

Changing Treatment Patterns

Parents practicing determined self-agency altered the timing and dosing of medications in order to achieve symptom control. Their underlying concern was to prevent asthma from showing up without warning. After Reggie's most recent hospitalization, Ruby brought home specific instructions: to complete a three day course of oral steroid and a ten day course of antibiotics; to give inhaled steroid by metered dose inhaler three times a day; and to give nebulized albuterol if Reggie's breathing became so difficult that she could see his ribs. Ruby modified the plan, especially at night.

> Ruby: At night if he's having an attack, he tries, he sleeps pretty good through anything. So if he sleeps... I give him a treatment anyway in his sleep. ... [A]t night, I don't know if it's the cold air or what it is, it seems to, I don't know at night he just gets really bad. His nose is all clogged up and his chest is rattling and he asleep and he's snoring and I'll give him a treatment anyway. And he'll calm down for about 30-45 minutes and then it's right back to the same noises. D4.1 p. 20.

Not waiting until she could "see his ribs," Ruby gave the nebulized albuterol whenever Reggie sounded noisy or congested at night. That practice helped him breathe better, but only temporarily, and did not ease Ruby's intensely fearful vigilance. After a year of frequent trips to the emergency room, Ruby welcomed receiving inhaled steroid.

> Ruby: They would give me albuterol for the aerochamber, for the nebulizer, but they never told me to do it everyday. Nobody never specified to me for him not to have an attack, I need to do this everyday. So I would only do it until the attack was gone. So then when I went to the hospital [Reggie's hospitalization at age 14 months], they gave me the inhaled steroid which is to be used everyday. Which they should have done that last year some time. You know nobody never did that. D4.1 p. 9.

Although happy to have the hope of better control over symptoms, Ruby felt let down that she had spent so many months with only albuterol to treat Reggie's symptoms and with no clear instructions about giving it on asymptomatic days to prevent crisis. Ruby felt very unsupported, but vindicated in her judgment, that symptom prevention was a crucial part of management. In fact, as will be discussed below, she initiated practices for preventing symptoms long before professionals acknowledged its importance.

Within two months, after being given a prescription for an inhaled steroid at hospital discharge, Reggie was experiencing fewer episodes of labored breathing. As a result, Ruby stopped giving the inhaled steroid. However, his runny nose and his milder wheezing episodes did not cease. During those two months, Reggie had also had one more emergency visit. Although the emergency room doctor wanted to hospitalize him, Ruby talked the doctor into letting her take Reggie home.

Later, six months after hospitalization, Reggie continued to have a runny nose on most days and had experienced an additional emergency visit. He had also had a few milder episodes of wheezing and/or chest congestion. As Reggie's night time symptoms ameliorated, Ruby felt differently about night time vigilance.

> Int: What about [how you paid] real close attention to Reggie's breathing at night?
>
> Ruby: Well that's changed a lot, because Reggie's not having as many attacks as he used to have and if he's having them, he's not having them that much at night. It usually starts in the day and then that night, yeah I'm watching, but like I get up and sit up and watch his chest or touch his back. But I'll still touch his back. When he's in the bed there I'll still do that. But I don't think that's just a fact because of the asthma. Because I touch all kids' backs. I watched my brother's baby over the weekend. His baby's about six months. Franklin's baby [by another woman] is about a month and a half. And I touch those kids backs too. ... I touch all children's back, I don't think that's just the asthma.
>
> Int: You were doing something special about paying attention to Reggie at night though, weren't you?
>
> Ruby: Yeah. I used to, Oh God, I used to drive myself crazy. I don't know how I got up and went to work. ... I don't think I had to watch him, at first either. I think it was just in *my* [Ruby's emphasis] mind. ... Now I'm sure of myself that I won't let nothing happen to him. ... I know that when I have to get up, ... I'm going to get up. D4.3 p. 23.

At the time of this last interview, Ruby was less concerned about Reggie's asthma flaring at night for at least two reasons. First, she was sure, as it was by now a long established habit, that she would wake if his breathing became troubled during the night. She she would even wake when his breathing was normal just to reach out and check his back. Second, his symptoms had ameliorated and Ruby had become better able to anticipate and monitor symptom flares. However, since Reggie continued to experience episodic crises that she could not prevent or reverse, Ruby did not feel she had control over Reggie's asthma.

The Search for More Effective Management Practices

As unpredictable as Reggie's asthma was, and as much as Ruby felt confused about how to change that, she did not relinquish her desire to find a way to prevent Reggie's crises. Her basic view was that allergies must trigger his asthma. She was also frustrated that physicians did not pick up on her desire to have Reggie tested for allergies, dismissing her concerns because he was *"too young."* Ruby was not told that the earliest age that for allergy testing is 3 or 4 years.

Doctors had discussed other probable triggers of asthma. However, through her own reasoned cause and effect observations, Ruby had already ruled out several other triggers.

> Ruby: And they say to keep him away from cigarette smoke, but I don't smoke cigarettes. ... And the incense, the incense the kids bought me ... I had thought it was these incense. But it's not these incense cause my grandmother doesn't light them and he had an attack in my grandmothers. My sister-in-law doesn't light them and he had an attack there. And if I light them here, 9 times out of 10 he won't have an attack here. .. So I was thinking cause she said cigarettes that it could be the smoke. ... But it's not these incense. I don't smoke cigarettes so I don't know what it is. D4.1 pp. 25-26.

Ruby also ruled out dogs as a possible allergic trigger.

> Int: Have you figured out some of the things that might trigger his asthma?
> Ruby: I have not. I have not figured it out. Cause it's like, I had a theory that it was a dog, because my grandmother has dogs. But he stayed at grandma's house for about 12 days out of the month of November, of no, not of November, of December. No attack. And then he comes here the next day and has an asthma attack. I don't know what it is. ... I don't know. D 4.1 p. 23.

In addition, Ruby wondered whether she had overdressed or underdressed Reggie. He had been 10 months old at the beginning of the previous summer and was just learning to walk. Despite living in Fresno which often reaches temperatures greater than 100 degrees in the summer and is regularly over 90 from May to mid-September, Ruby's maternal grandmother liked Ruby to dress Reggie warmly in summer. Franklin, her live-in boyfriend, on the other hand, thought Ruby put too many clothes on Reggie during the summer.

> Ruby: Cause in the summer [Reggie] gets hot and we don't, grandma likes to keep him all covered up you know so he doesn't get sick. ... I don't know if it's getting hot or getting cold. I don't know if it's getting hot that makes him sick or me not letting him get ... him get cold, cause I cover him up too much. I don't want his chest to get cold, I don't want this, I don't want that. Well, usually Reggie has on house shoes, socks, something covering his legs. His legs are always covered even in the summer time. And last summer he was a real little thing and Franklin kept telling me that baby's too hot. You have him on too much clothes. He have him on too much clothes, you have him on too much this, you have him on too much that. D4.2 pp. 27-28.

Receiving conflicting advice from her beloved grandmother and her boyfriend, Ruby felt confused about the issue of how to dress Reggie in the summer. Putting this unsolved issue aside, Ruby took hope that in the upcoming summer Reggie could be spared crises. These interviews concluded before Ruby had to decide how to dress Reggie in warm weather. She was convinced that Reggie needed protection from unseen allergens in the outside air such as pollens or grass.

Ruby's concerns about allergy protection were based on watching a family member in asthma crisis when she was 6 or 7 years old. The connection between frightening asthma crisis and allergy exposure became indelibly imprinted in her experience.

> Int: What do you remember most? ...
> Ruby: The running around. That's what I remember most. ... The running around and the coughing. ...
> Int: So do you remember what was going on with everybody when they were running around?
> Ruby: They were looking for that inhaler. That was the main thing that I remember. They were looking for that inhaler, but, ... my grandmother had a allergy test done on him. So they basically knew what to keep him away from which was grass. ... And he had come home from school that day, and at school he had been in grass. Not only just playing ball, but literally rolling around in the grass and so forth then... I'm thinking he's going to die, you know I was a little girl. I'm thinking, "Oh my God, is he going to die?" Cause he's sitting there, he can't really walk, he tried to take a step, he's grabbing onto the stuff and trying to breathe. And he was a little boy his self, he was about 10 or 11. D4.1 pp. 5-6.

For Ruby, the frightening prospect that her cousin could have died rested in the information that he had been exposed to an avoidable allergen known to trigger his asthma. Knowing and, thereby, being able to avoid specific triggers carried significance for Ruby. She believed an allergen must be somewhere in Reggie's environment, most likely, outdoors.

General allergen avoidance mattered less to Ruby. Her household was neat, the children's rooms, dining room, and living room were newly, tastefully, and inexpensively decorated. In addition, Ruby took pride in Tony's and Reggie's clothes being clean and looking good on them. Nevertheless, Ruby paid little attention to daily dust management. Her dining room table gathered dust as it sat always set for a special dinner party with goblets, several plates at each setting, with napkins and candles all color coordinated.

Instead of general prevention measures, Ruby tried to identify the offending allergen herself, and failing that, to follow the other treatment suggestions. First, confirming her conviction that knowable and specific allergens must trigger Reggie's asthma, Ruby found that when Reggie would go outside, *"He'd get a runny nose instantly. ... I think he's allergic to something in the air." D4.2 p. 28.* In addition, after finding that inhaled steroid did not solve the problem of Reggie's nearly chronic runny nose, Ruby found new hope in an alternative management strategy. By calling and taking advice from a group she called the "asthma connection" for which I could not find a listed phone number in Fresno, Ruby began giving Reggie two generic-over-the counter medicines, one diphenhydramine and the other a decongestant and antihistamine combination.

Since Ruby had previously noticed the tell-tale first sign of a "cold" occurred prior to the onset of a crisis, she thought one or both of these medicines might make it possible for Reggie to play outside during the summer without risking asthma crisis. So, in addition to the nebulized albuterol, which she usually gave Reggie before bedtime, Ruby began giving Reggie the decongestant antihistamine at night as well. When he had no congestion during the first several days following this regimen, Ruby stopped giving the nebulized albuterol and Reggie continued to be congestion free.

For more than a week, she saw definitive results from over-the-counter treatment and hoped she would be proven right. However, to her disappointment, Ruby found that Reggie's runny nose recurred. As a result, she stopped giving the medicines and gave up her hope of having found in them a long term solution to Reggie's problem.

Professionals, Ruby thought, may have missed the subtleties of Reggie's situation and forgotten to control his runny nose.

> Ruby: [I]f he's going to go outside, it's like, if I'm going to take him outside then I'll give him a half of teaspoon in the day time also, you know.
> Int: ... What do you think that does?
> Ruby: I don't know, I don't know. I think probably stops his nose from running in his chest from being congested, cause if you notice every time you came over here, Reggie's had a runny nose.
> Int: Yes.
> Ruby: So his nose isn't running. I don't know if all along I just needed the medicine to stop his nose from running, to stop the attacks from coming on, because the doctor never prescribed anything for his nose running. He's always prescribed stuff for his asthma. Maybe he looks past the runny nose which could be the problem which could trigger off the chest congestion, which could trigger off the asthma. I figure if I could stop the nose from running, then I could stop the chest from getting congested, then I could stop the asthma from triggering. D4.2 pp. 27-28.

Ruby's intuitive understanding that Reggie's runny nose triggered chest congestion and asthma was correct. Ruby's concern, however, went unrecognized and unanswered by everyone except herself.

Assuming Primary Agency

Ruby's sense of being more personally responsible to Reggie than his doctors or nurses did not diminish, even when over the counter medicines proved ineffective. She felt responsible for Reggie and his well being on every occasion and in every situation, even when doctors and nurses "tied" him down with a blanket so that he could be suctioned. At first, Ruby could only to stand beside his bed with nothing to do except watch.

> Ruby: And with my son, them tying him like that, they didn't feel how I felt about it. To them it was a job, but to me it's personal. You know that's my baby you're tying like that and I didn't like it. D4.2 p. 19.

However, despite times during Reggie's hospitalization when Ruby could not participate in his care, she found herself continually vigilant. During his crisis, Ruby was especially claimed by Reggie's plight.

> Ruby: I feel like I'm already letting him down because I let the attack get too far, which I can't do nothing to stop it. If it wants to go there, it's going to go there. I feel like I'm letting him down once the attack gets too far ... I wished I could take it. I would take his sickness to myself if I could. I would be sick and let him be fine. D4.1 pp. 37-38.

Although Ruby may have had profound doubts about whether she or asthma would win control of Reggie's situation, Ruby never doubted that her involvement in Reggie's illness was complete. It was as if the asthma were her own. In fact, she would have preferred it that way.

With asthma no one, except Reggie, had more at stake than Ruby.

> Ruby: He trusts me to get him to the hospital, to give him his treatment or whatever it is to help him breathe better. ... That's my baby. I have to be the one responsible. ... So it's on me to tell the doctors what I think needs to be done for my, you know my child's health. D4.1 pp. 29-30.

Ruby felt sure of her special sensitivity to Reggie's needs and equally sure of the crucial nature of her agency in assuring his well-being. In the 14 months of Reggie's illness, since no method had emerged effective against asthma's capricious patterns, Ruby's anxiety mounted.

> Int: You're surprised that ... he keeps, he continues having a attacks.
> Ruby: Yeah, that's what getting me, that it's continuous. Now I thought it would be over with by now, but I guess. Not over with, but this they would some how be able to help me control it. And I'm not getting that. I'm not getting that at all. You guys don't understand what I go through. Nobody... Other parents might understand. I don't know if the doctors really understand or not, but its... ... I want to figure it out. I wish I had them machines to do the testing. I'd figure it out myself. An allergy test or something. D4.3 p. 29.

Because there had been no answers to reverse Reggie's unrelenting symptoms, Ruby felt let down. She was surprised and frustrated with what she viewed as a failure of modern medicine. Ruby wanted better answers but felt she could not rely fully on professional caregivers whom she thought did not understand how difficult and scary asthma was to live with. In her opinion, they offered only the barest management guidelines, leaving her as a parent to live with the unremitting uncertainty of Reggie's asthma. Despite these frustrations, managing Reggie's asthma was a challenge from which Ruby never shrunk. Nor did she hand over her primary role to anyone else. She allowed others to help. Indeed, she sought help from family and professional experts, but she remained always watchful and caring about Reggie, always thinking about how to help him, and always in charge.

Furthermore, Ruby felt that doctors did not appreciate her knowledgeable attention to Reggie's asthma.

> Int: You told me before the doctors don't seem to trust that you know what to do about the asthma.
> Ruby: That's why I think they want to hospitalize him every time he goes, because they figure if I keep bringing him to the hospital, then I must not know. You know, which I do know, but I feel like the hospital can do a little more than I can. See if they have all those machines and all that stuff, you know.
> Int: So they don't, they don't really know how much you know about asthma?
> Ruby: No, they don't. They think I'm just another young kid coming in there with an asthmatic child. But I've been, I've been paying attention. D4.2 p. 37.

Ruby brought Reggie to the hospital knowing that she understood his asthma well, believing that he would benefit from professional and technical care, and wanting reassurance because she feared Reggie might die in asthma crisis. Instead of feeling that providers respected her knowledge and caregiving, she believed that just by bringing Reggie for emergency care, she was perceived as young, inexperienced, and unfamiliar with Reggie's asthma.

> Ruby: But I feel like the hospital, I feel like the people at the hospital know a little more what they're doing than I do. And I feel like if he's going

> to, if he's going to barely die they're the ones that can save his life. The hospital's the one. D4.1 p. 32.
>
> Ruby: Sometimes I do know the things and I don't have to take Reggie to the hospital, but I have to have that second reassurance from the hospital that he's okay. D4.1 p. 36.

As committed as Ruby was never to abandon her caring of Reggie, Ruby was also clear that she needed the hospital. Although she did not hesitate to tell caregivers if she thought they were doing something wrong, she actively absorbed the caregiving practices that she could use at home.

> Ruby: When [Reggie] stayed two nights in the hospital it was me and my cousin. I think I left her two hours, came home showered and changed and I went back up there with my cousin. ... I want to know what they're going to do. I want to see what they're doing. I want to see because it, I feel like, if they're going to do something different I want to be there to see. So if I have to do it at home, I'll know what to do. So I like, when, if he's staying in the hospital, I like to be there myself. I don't want nobody to tell me what they did, I want to see it. If I have to do it at home, I can do it myself. D4.1 p. 33.

Ruby learned by seeing skills in practice. She also learned by asking questions.

> Ruby: I'm the type of person that asks a lot of questions. And I want to know what's coming next ... as soon as they finish something else, I would ask them, "What are you guys going to do next time you come in?" So nothing was really too surprising to me. D4.2 p. 10.

During emergency room visits and hospitalization, Ruby asked many questions of the respiratory therapists as they were giving Reggie's treatments. The following dialogue illustrates how Ruby could easily be stereotyped as an angry and meddling mother who was automatically reactive and disrespectful of authority. Having learned that albuterol is given without dilution in the nebulized treatments at the hospital, Ruby later gave instructions to a respiratory therapist who did not seem to know the proper amount of medication to give.

> Ruby: So when I went to the hospital Sunday, well I, you know I watched them, as they do the things, I caught on. So when I went to the hospital Sunday, aw the respiratory therapist was giving him a treatment, what he gave him, oh he just put straight albuterol, no saline water. I told him, That's only supposed to be 30 puffs." And he, he was like, "No you're supposed to finish off the treatment." So we were having a little dispute there. And I told him, "I don't want you to give him a treatment." Call in the doctor and ask him how long you suppose to, if it's just albuterol, I know it's only suppose to be 30 breaths. Cause they don't want, the don't give it to him that long like that. And I don't want him doing something and nobody else been doing it ... and I didn't want him to give him all that albuterol like that. Just straight.
>
> Int: So what did the respiratory therapist say?
>
> Ruby: So he went and talked to another respiratory therapist, which told him it was only suppose to be 30 puffs. So I guess he was kind of new, he didn't really know, but see I knew. D4.1 pp. 10-11.

Ruby's heightened attentiveness to Reggie's situation served not only the of learning new skills and routines but confirmed for Ruby that she carried primary agency in managing Reggie's asthma. In intervening so that Reggie would receive the accurate dose of albuterol, Ruby learned that she was accurate about critical aspects of hospital crisis management and that her challenge to the novice respiratory therapist had been justified. Ruby also realized unhappily that she could not depend without reservation on the care given by professionals. Instead, in order to assure Reggie's well-being, she must remain alert and assert herself to assure that hospital management proceeded correctly.

Ruby's important role in assuring Reggie's well-being was further strengthened during breathing treatments. Reggie felt much more relaxed when Ruby held him and let him help hold the tube of the nebulizer. In the following narrative Ruby tells how she felt it was important to extend herself to assume responsibility for being attuned to Reggie's overall hospital experience.

> Ruby: I think if you keep on the same pattern, or keep your child on the same pattern, then they get pretty much used to the system and if though you keep letting this person do this, this person do that then it changes for

> the child and the child's getting confused and they're not wanting to do it, because the whole thing gets confusing to them. And they don't want to cooperate with you or with the nurse or with whoever. You have to make sure everything's going to work for the nurse, it's going to work for you, and it's going to work for the child.
> Int: So you're constantly trying to [compare the care of different providers and determine what is best for Reggie]?
> Ruby: Yeah. It's terrible. D4.2 pp. 30-31.

Reggie's hospitalization demanded "terrible" work and no relief for Ruby from the work of asthma management. The hospital experience, only confirmed for her the importance of her own agency in all arenas and at all times. Previously she had felt ultimate responsibility whether she was at home with Reggie, or at work while he stayed with others. During this hospitalization, Ruby realized that her need to attend to Reggie carried on even during the management and amelioration of his immediate crisis, and extended to every detail of his hospital care. In fact, as things proceeded, Ruby's responsibility took on a new quality. She evaluated all that she saw and learned about hospital procedures in order to prepare herself for doing similar procedures at home. Even as the medical treatments Reggie endured (intravenous fluid administration [IV's], suctioning, and nebulized medications) improved his breathing, concern for Reggie's level of personal distress always remained central to Ruby's thinking and feeling about the hospital experience. Besides enduring Reggie's suffering as if it were her own, Ruby appreciated how Reggie would need to cooperate with asthma management in order for it to be truly effective.

Agency as Advocating

In the months that followed Reggie's second and very frightening hospitalization at age 14 months, Ruby saw a fundamental distinction between her role and that of professionals.

> Ruby: I have more time to sit there and monitor the things that go on with Reggie. Which in the hospital they don't, because they have other patients they have to take care of and so forth. But me I'm just focused on one this child, so I can focus on him fully. Nobody else just him. So yeah there's a difference. But I don't fault them for that difference. They're doing their job. This, it's my lifestyle. So I can't really fault them for that. D 4.1 p. 41.

> Ruby: To them it was a job, but to me it's personal. D4.2 p. 19.

Being completely immersed in and focused on the care of her one child made all the difference in being able to appreciate the general impact of asthma and to recognize the significance to Reggie of its nuanced presentations. Ruby believed that no amount of training could give professionals the same understanding as her own, because she gave her life to the project of helping Reggie survive asthma.

At the same time, Ruby believed the doctors could collaborate more with her in managing Reggie's care.

> Ruby: What I would really, really like from a doctor, I don't like running my kids to the hospital all the time when I know exactly what they need to get better. I would to be able to call that doctor and see if that doctor could call up for a prescription. Not saying that I would call everyday, every two weeks, every three for the same prescription, abusing you know the license of the woman or man or abusing the situation. Just when I know it's critical... Just to what I know is critical. They can call in the prescription for me. You understand?
> Int: So it sounds like you'd like a little more cooperation.
> Ruby: Yeah. Yeah, I would. ... *That's what I would like. For them to understand that I know what I'm talking about as well as they know what they're talking about.* Cause I'm living this nightmare. D4.2 p. 39.

To interpret this exemplar narrowly, would be to say that doctors seemed to stand in the way of Ruby getting the medicines she wanted for Reggie during crisis. However, Ruby was concerned with more than medicines on demand. Ruby was convinced that her intimate and unique perspective on Reggie's asthma legitimized her role as a partner in caregiving. She wished doctors would respect her skillful ability to evaluate of Reggie's condition. In return she would give professionals respect.

Thus, there was no question of wanting to usurp the role of professional providers. However, Ruby was misunderstood on one occasion that proved crucial in shaping her attitude toward hospital care. Two months after Reggie's hospitalization at 14 months, Ruby defied an emergency doctor's wishes by insisting Reggie not be hospitalized.

> Ruby: It was a man doctor and he's telling me that my son needs to be hospitalized. And I'm telling him that well ... I told him that my son's went home worse than that and when he stayed in the hospital he was worse than that. Cause he wasn't really really bad when he went, but he was bad, but he wasn't as bad when they kept him. He's telling me, no, he needs to stay in the hospital, because he's not breathing like this and he's not breathing like that. And I told him, "Well you give me some antibiotics and you give me some [steroid] syrup, and if he's not breathing better then I'll bring him back. But if he's breathing better, then we're going to stay home." I felt like at that time that doctor didn't trust my opinion about my child, like I didn't know what I was talking about as far as him having asthma. ... He said that they, if he wanted Reggie to stay he could make him stay ... and if I wouldn't let him stay that he could call the CPS [Child Protective Services] on me. So I told him, "Well I feel like, if you look back in my son's records, you could see every time he's been here, I've been here with him. So if you feel like you want to call CPS, if I take him a leave out of here, you do that. Cause I'm telling you, I'm telling you what prescriptions that my son needs. On a Sunday, I can't go to his doctor and get them. So I'm coming to the hospital. It's a Sunday. So you call, you do that. You call CPS and you tell her that I came here and told you what medicines my son needed and you didn't want to give him to me. And we'll see if CPS takes my child or if they want to take your doctor's license." ..
> Int: And then what happened?
> Ruby: He wrote out the prescriptions and let me go home. D4.2 pp. 37-38.

Ruby recalled that Reggie had been more ill at past emergency room visits. On several of those occasions, he had been sent home with prescribed steroids and antibiotics. Ruby knew hospitalization would bring her no relief from vigilance, and would contribute to her feeling less in control. In addition, if Reggie were hospitalized she would feel responsible for how well others cared for Reggie. She also had learned what hospitalization would offer compared to what she could do for Reggie at home. Feeling threatened and disrespected, Ruby confronted the emergency room doctor to demand that Reggie be released. The encounter escalated into mutual threats. Not intimidated, Ruby maintained her protective stance. Later, she reflected.

> Ruby: That doctor was really trying to keep him Sunday. He was. He really was. Well, I didn't let him stay though. Sometimes I wonder if I, you know what if I don't let him stay and he gets home and he dies or something. But I know that if he gets to breathing real bad, I'm going to take him back to the hospital and tell them, "Yeah you can keep him. I made a mistake." I'm not afraid to tell them that I made a mistake. D4.1 p. 36

Ruby knew she had taken a risk for Reggie and for herself. Now she would be the only one responsible that he did not die. In order to assure Reggie's survival, she might have to humiliate herself and admit that she had been mistaken. Although fearful, Ruby was convinced that she could do at home all that could be done in the hospital.

> Ruby: ... [W]hat I seen him do last time was nothing more... I thought they were going to do something different in the hospital than what I'd do if I took him home, at that time and they didn't. So this time I knew there wasn't, they wasn't going to do nothing different from the last time. Nothing different from what I do at home. D4.1 p. 33.

Ruby took Reggie home to her mother's house to be near her mother's oxygen tank in case his breathing deteriorated. After a day of nebulized breathing treatments, oral prednisone and antibiotics, Reggie's breathing had improved enough that Ruby went to work the next morning. When she returned in the afternoon, *"he was fine... I feel confident that once he has albuterol for the nebulizer and the [steroid] syrup then he'll be fine. He'll be fine." D4.1 p. 36.*

In addition to taking into account all of her own reasons for not wanting Reggie to be hospitalized, Ruby had made an assessment of the emergency room physician's knowledge of asthma management.

> Ruby: I felt like that he felt, that he didn't really know what he was talking about. Cause if he knew what he was talking about, he would have kept on arguing me down. He would have kept on telling me and kept on telling me. I felt like he wasn't too sure of himself anyway. Cause like that lady, now that lady doctor, [Ruby is referring to Reggie's hospitalization at 14 months] I kept telling her I didn't want Reggie to stay. She kept telling me, "No." He definitely had to stay. He definitely had to stay. So I feel like she knew what she was talking about, she was sure of herself. He didn't seem too sure of himself, if he just let me go on with that. He wasn't too sure of himself.
> Int: Well, how does that feel when you want to depend on the hospital, and you feel that they're not as sure about this as you are?
> Ruby: He hasn't been back. So..
> Int: At the time how was it?
> Ruby: Well it was, I was happy I was able to show this doctor, that he didn't really know what he was talking about, but then again I was upset because he didn't know what he was talking about and he's trying to tell me that he could have been hospitalizing my son for absolutely no reason. D4.2 p. 38.

Competing successfully with the doctor was a double edged sword. On the one hand, Ruby's knowledge about how to manage Reggie's crisis was not disputed and his care was left completely to her. On the other, her sense of trust in the availability of professional support and her desire to rely on professionals withered. Although by her defiant attitude, some might not have thought so, Ruby's stance belied an underlying faith in the efficacy of medical care. She did not question that the hospital had something to offer Reggie. However, on her assessment, Reggie's crisis was not severe enough to warrant hospitalization and the doctor had not shown her that he had more to offer than she already knew.

In taking control, Ruby knew that being responsible for treating Reggie at home meant assuming the risk that he might get worse or even die. Although she was unsure at first, the correctness of Ruby's assessment of Reggie's crisis and the way to manage it was borne out by what followed. As she states so simply, *"He hasn't been back. So...."* *D4.2 p. 38.*

Ruby elaborates.

> Ruby: Reggie hasn't been to the hospital since the last time I told you I took him and they wanted to keep him. I kind of stopped depending on the hospital, because I know now that their main, to me their main goal is to hospitalize him to make him better. And I don't think he needs to hospitalizing him most of the time. D4.2 p. 35.

Feeling misunderstood when she arrived for emergency care and not wanting to subject Reggie to hospitalization, Ruby preferred to step up her efforts to prevent symptoms through the use of over the counter antihistamines and decongestants. In addition, Ruby has been open to other possibilities for management.

> Int: And you're trying the new doctor as well?
> Ruby: Yeah, Dr. C.
> Int: Do you ever hear about other things that people try to help asthma be better.
> Ruby: Well this one girl told me that when her kids have an asthma attack she gives them popsicles. I don't know what that's for. I don't know, I never tried that. (to child) You drank it all gone. And he's a real smart child, I hate to see him tied down to a pump the rest of his life. Cause he's a really active kid. He's only 18 months and he drinks out of that cup just really good. You know? D4.2 p. 35.

Always looking for an effective answer, one with a plausible explanation, Ruby will consider that popsicles might help in a crisis. However, she remained skeptical. Meanwhile during the last months of our interviews and visits Ruby found a new doctor for Reggie. Several months later, Reggie had found a new cooperative relationship with Dr. C who listened to her, and accepted emergency appointments. A year later Reggie had not been back to the emergency room for asthma crisis.

Summary Informed by fear for Reggie's life, ever vigilant, always learning, and always adjusting her managing practices, Ruby sought clearly defined causes of asthma crisis and clearly demonstrable results from medical and behavioral regimens. Although Ruby did not give meticulous attention to customary prevention recommendations, prevention and control were always on her mind.

Aware that it could stop Reggie's breathing altogether, Ruby was thoroughly respectful of asthma. She had seen in her family that asthma can make people always dependent on inhalers. Worse, she had seen that asthma can lead to an old age of almost complete incapacitation and sudden death.

Ruby expected that modern medical care should have answers about how to control and prevent asthma. Struggling to control many other areas of her life, Ruby felt more out of control in relation to asthma than any of the others. Determined not to fail Reggie, she became ever more convinced of her primary agency in the management of Reggie's asthma. During the period of these interviews and observations, Reggie did not have regular professional asthma management except in crisis. Ruby often felt no respect from caregivers whom she judged to be less experienced about asthma than she. As a result, Ruby's sense of personal accountability and her determination to find effective help for Reggie grew stronger as she became more experienced. At considerable risk to herself and Reggie, Ruby always retained the claim of primary responsibility for his care. Though she would defy authority to defend this responsibility, Ruby's concern was not merely reactive defiance of conventional authority and traditional recommendations for asthma management. Ruby was always in search of both effective relief of Reggie's immediate distress, and long term permanent control of his symptoms.

Themes of Determined Self-Agency

In the following section, I will discuss two themes that characterize the families who practiced asthma management in the style of determined self-agency, wanting appropriate medicines at the onset of crisis, and taking management risks.

Wanting Appropriate Medicines at the Onset of Crisis

Although it was not true at first, by the time of the most serious of their 13 month old son, Eduardo's, asthma crises, Lucy and Freddie, both 28, like Ruby, felt they had sufficient experience with asthma to assess their son's needs. They also felt competent to manage crisis in its early stage, in order to prevent worsening symptoms. However, they felt deprived of easy access to the medicines necessary for crisis management.

Freddie, father of 14 month old Eduardo, talked about how having the tools for asthma management made all the difference. Eduardo had first been hospitalized at age 3 months.

> Freddie: If I can treat him here, then I'll do it. I always, always thought, I wouldn't be able to do it. Being able to take care of him. Especially knowing that he went in another two times after the first time. I thought, 'Man' are we ever going to be able to treat him here? But aw.
>
> Int: What turned that around for you, that now you feel a lot more confident...?
>
> Freddie: Well, we've got, everything that we've got now to treat him with, we didn't have all at once to begin with when he was first released. ...

> Finally, this 3rd time around [Eduardo's third hospitalization], we got introduced to this Dr. R, and he.... that's when we were told he needed the [inhaled steroid] you know long term. Well, we told him, you know, we have a problem with that. We can't get that through his normal physician. But um, it all depended on who we saw at the clinic also. Certain doctors would prescribe others wouldn't. And then another thing we found out we needed eventually was a breathing machine. Which we never had. So, with those two medications along with the breathing machine, now that we have it all at once, and now that we've got the clinic to finally prescribe that to us ... I mean had we known all this stuff from the beginning, there's no doubt in my mind, my wife and I would have prevented him from going to the hospital those two times. D1.3 pp. 5-6.

During the first 7 months of Eduardo' periodic crises, Lucy and Freddie had no reliable access to long term or crisis medications unless they sought emergency care. Even then the medicines given on discharge from the emergency room lasted only through the crisis and for a week or 10 days afterward.

Lucy and Freddie, like Ruby, felt angry that the health care system itself obstructed their access to appropriate medicines for controlling symptoms and managing crises. During the third hospitalization the pediatric pulmonologist was the first provider to prescribe inhaled steroids for Eduardo to help prevent attacks. During hospitalization, Reggie, too, had seen the pediatric pulmonologist who encouraged regular appointments. These would have given both families regular access to inhaled steroids. However, neither family kept regular appointments. Ruby simply forgot. Lucy and Freddie distinctly appreciated the specialist's care but could only afford to see him once. He had encouraged them to keep using the "long term" medication (inhaled steroid), but Lucy and Freddie could not obtain the medication, even when they asked, from their primary care physician at the clinic where, for Eduardo and his brothers, care was free.

What distinguishes the experience of the two families described here from other families in the sample is not the manner in which medicines were prescribed or available to them. The experience of not receiving medicines to give on symptom free days to prevent crisis was not unique to these parents. For the first several months, often up to a year, children in this study were given medicines to treat episodic symptoms only. In addition, although other parents realized in some cases that the medicines they were given were not preventing recurring asthma crises, only Lucy and Freddie, and Ruby felt that their inability to manage asthma successfully was due to not being able to obtain appropriate medicines at the appropriate time.

Taking Management Risks

All parents interviewed for this study wanted very much to avoid the possibility that their child might be hospitalized. Like Freddie, many had a strongly articulated aversion to the child's hospitalization . *Freddie: "I would do everything I could to avoid going to the hospital." D1.3 p. 5.* However, Ruby, and Lucy and Freddie in their determined self-agency came to take crisis management steps they identified as risky. In their ambivalence for seeking crisis care, Lucy and Freddie decided to wait several hours before seeking crisis care for Eduardo. However, in doing so they disregarded their own judgment that he needed immediate care. In addition, they were bothered by the thought that at the time of his third emergency visit, he had been sicker than they thought.

> Lucy: The last time he was sick we almost took him in. We almost took him in cause he was sick. We almost took him, but,... during Christmas, we almost took him in. ...
> Freddie: Cause his breathing was tight.

Lucy: He was tight. And he was, he probably, we probably should have taken him. We should have. And we had a few people come and just you know people with asthma, we had just people come and look at him. You know look at him, not like they're doctors or anything, but you know come and tell us what they thought. Half of them said, "Take him in." The other half said, "Wait." Because we knew once we got the [steroid inhaler], we were hoping that once we got the [steroid inhaler] that you know, that it would clear him up, pretty much because you know the [steroid inhaler] you know, shrinks the, you know, the swelling and we knew that's what it was.
...
Lucy: It was Christmas Day we were going to take him in. The next day the clinic was going to be opened. And if we could avoid that hospital as much as possible then we'll wait. ... I think we were just pretty much trying to talk ourselves out of not taking him. ... because we, sometimes when we take in to the clinic, and he's real, they tell us it's not as bad as it sounds you know, it's not as bad as it seems. He sounds pretty bad and aw, she gave us the [steroid inhaler] and ... he didn't just clear up just like that you know...
Freddie: It took a day or two. ...
Int: When you were thinking about taking him to the hospital, what were the things that told you, you should take him in? That you probably should take him?
Freddie: Well, for me he was fussy and his breathing was tight. ...
Lucy: He didn't eat for two days. He didn't want a bottle. He was crying all night long. ...
Freddie: We just didn't want to take him in, honestly. We didn't want to take him in. D 1.2 pp. 16-17.

Lucy: We've never taken him when they've haven't kept him.
Freddie: Right. ...
Lucy: So that's what we were thinking you know over Christmas, if we took they were going to keep him. They probably would have. I think so. I think they would have kept him. D1.2 p. 15-16..

Holding onto the possibility that Eduardo was less ill than he seemed, Lucy and Freddie clearly knew that a minimum he needed an inhaled steroid that they knew they would receive at the emergency room or, if they waited until morning at the clinic. They weighed various considerations. Even given inhaled steroids, Eduardo would not feel better immediately. With medicine on that day or the next he would still need several days to get better. In addition, hospitalization would mean more distress for Eduardo. Friends familiar with asthma gave mixed assessments about whether to seek emergency care.

None of these factors pointed clearly to either the need for immediate crisis care nor sanctioned Lucy and Freddie's desire to avoid the hospital. As a result, although Eduardo had signs of significant distress, Lucy and Freddie waited. The next morning he was doing better when they took him to his primary care physician where he received the inhaled steroid.

As Ruby had, Lucy and Freddie avoided the hospital precisely because they thought Eduardo *would* be hospitalized. The thought that professional providers would judge Eduardo so ill that he needed hospitalization did not motivate Lucy and Freddie to seek emergency care. To the contrary, the thought of likely hospitalization increased their willingness to take the risk of waiting.

As the experience of attending to asthma in their child had led Ruby, and Lucy and Freddie to trust their own capabilities they learned simultaneously to distrust most professional health care. Angry and frightened, and sensing the importance of their own agency, these parents became "lone ranger" advocates for their children. Instead of finding themselves in cooperative relationships with health care providers, they had developed a practice of seeking supportive professional care only reluctantly and with specific and preconceived ideas of the particular management needed.

Discontinuous Self-Agency: Managing illness largely beyond one's control

Three of the single mothers who participated in this study, Maria, Anna, both 20 years old, and Tonya, 21, with daughters 37 months, 16 months, and 12 months respectively, practiced a management style characterized by discontinuity in self-agency and resignation to the power of asthma. During those times when her child suffered most from asthma, each mother felt temporarily compelled to relinquish caring in a way characterized by feelings of inadequacy and defeat. Anna felt alone, panicked, and helpless during Araceli's asthma crises. Maria became a bystander, unable to think clearly or act on Susanna's behalf. Tonya left the hospital room while Jasmine's crisis was being managed, unable to cope otherwise.

In this section I will first present two exemplars of Tonya's and Maria's discontinuous caregiving during the apex of crisis in the hospital. Maria's will be discussed in detail with background themes presented to fill out the exemplar. In the second section, I will discuss the three mothers' daily management of asthma, specifically the understanding and use of medicines and the mothers' beliefs and practices regarding symptom prevention.

Subsequently, associated management themes will be discussed which also show discontinuity in these mothers' sense of effectiveness in the management of asthma: first, in assessing the severity of symptoms and the need for hospital care; and second when giving care in the hospital as crisis ameliorates. Finally, the mothers' overall attitude toward their daughters' asthma will conclude this chapter.

Discontinuity in Caregiving During Hospital Crisis Management

Tonya Tonya recalled finding out that Jasmine would be hospitalized for the first time. Tonya, who had asthma herself and knew the pain of restricted breathing, learned to hold back her tears when she saw Tonya in crisis.

> Tonya I don't show it when I'm sitting in there with her, cause I try and be strong so she won't see me cry. ...
>
> When I first took her for the first time, I cried and my friend, her dad's cousin was like, "you can't be crying in front of Jasmine. You got to be strong." I'm like, "It's easy for you to say I can't, but you guys don't have to go out here to [hospital] at least once or twice a month behind asthma" I said. It frustrates me a lot and I just kind of got used to it.

> Int: What's the most frustrating part of it...?
> Tonya: With her wheezing and everything and then I know she's not feeling too good. Then she gets to doing this to her chest and everything and so. [Pats her chest.] D2.2 pp. 6-7.

Tonya's primary concern, like that of all the parents in this study, was for Jasmin's suffering. From the beginning Tonya felt she was following asthma to the emergency room. Able to control only her desire to cry, Tonya told about the numerous emergency visits that left her frightened and unsupported.

> Tonya: Usually when I'd have to take her I'd sit there and cry. But now it's like at least I know she's in better hands you know, and the doctor is doing what he can, to prevent it from happening, worser, so...
> Int: And you're crying because you know she's really struggling to breathe.
> Tonya: Yeah, then she's real, she's struggling to breathe and everything and kind of like hurts me and I'm like, oh my mom's always telling me, "Don't you know asthma kills babies?" I'm like. I know that, that's why I'm always taking her to the hospital so she can do better. D2.2 p. 12.

Relieved that Jasmine was in the hands of physicians who knew about asthma, and who she thought could prevent it, Tonya, nevertheless, continued to feel Jasmine's pain and was afraid, but did not show her feelings. Even though her mother's comments about babies dying from asthma escalated her fear, Tonya persevered, taking the advice of those who had told her to "be strong," Unable to prevent or reverse Jasmine's crisis breathing, and implicitly admonished by her mother to hand over Jasmine's care to professionals, Tonya learned to take Jasmine to the hospital "always."

<u>Maria</u> Maria describes hospital management of Susanna's crisis.

> Maria: I can't protect her from it, I can't. But the doctor's gonna come and give her a shot or if the doctor's going to come and not give her a shot. If the doctor's gonna come and put IV in her and she's scared if the doctor's gonna come and check her or anything I can't you know, pull her away from them [sic] and

> protect her from her feeling scared. Because I know it's going to make her feel better, but I'm not sure she knows.
> Int: Are there ways that you try to do that? To help...
> Maria: Comfort her. Just, tell her no owee. That's what she understands. "No owee" I'll tell her, "No owee baby, no owee." And she'll understand it's not going to hurt her. But if she's going to get her IV in her or I can't tell her "No owee" because you know, she's, it's going to hurt her. So. D3.1 pp. 33-35.

Maria felt stunned to the point of not thinking clearly when Susanna was hospitalized. Feeling overwhelmed and inadequate to prevent Susanna's pain or calm her fears, Maria was unable to reconcile two conflicting concerns. On the one hand, she wanted to pull Susanna from the physicians and nurses. Then, however, there would be no relief for Susanna's asthma. On the other hand, leaving Susanna in the care of providers meant no relief for Susanna from pain or fear. Foremost in Maria's thinking was how to find a way to comfort Susanna. However, the painful procedures had to be endured. Maria could do nothing to change that. Furthermore, she felt unable to communicate to Susanna what she knew. Crisis care severed the connection of caring that Maria felt toward Susanna.

<u>*Contextual Background*</u> With this first experience of inpatient hospital care of Susanna for asthma, Maria's caregiving role had shifted dramatically. Maria was primarily responsible for Susanna's care, until the hospitalization when, she felt to unable to contribute at all to the resolution of Susanna's severe crisis. On a day to day basis for nearly three years, whether she had been at home, at work or with friends, Maria had been primary caregiving parent for Susanna and had been directing the daily management of her asthma. She had taken Susanna to the nursery at the high school where she attended class to earn her diploma. She willingly stayed home from social events when Susanna was ill, and returned

home quickly from work or junior college whenever Susanna's asthma flared. Her mother and grandmother counted on Maria to take primary responsibility for managing Susanna's asthma and Maria took on this role seriously. *"[N]obody would know how to take care of her but me like when it comes to asthma." D3.2 p. 29.* Maria sometimes solicited the opinion of her mother and grandmother about when to access emergency care. However, she was always and ultimately responsible for Susanna's well being. *"I'm, it all depends on me what to do with her." D3.2 p. 21.* Maria felt critically accountable for properly responding to Susanna's crises. Without her effective and appropriately timed response, *"What would happen to Susanna?"* she wondered. D3.1 p.34.

Thematic Background In this section I will discuss how, in general, crisis management and, in particular, hospital management of Susanna's asthma left Maria frightened and confused, and her caregiving interrupted.

Comforting and Giving Up Comforting Maria knew the vulnerability that asthma had brought Susanna since infancy, when she had first needed emergency care for the illness. Now at age 3, difficult, ineffective crisis breathing compromised her play, her appetite, and her ability to talk. When sick, she would seek Maria's comfort in ways she did not need to when she breathed well. Maria also knew that asthma and its management frightened Susanna. As shown just above, at Susanna's first crisis requiring hospitalization at 34 months, Maria, who never left Susanna's bedside, was fully aware of the pain and discomfort Susanna felt. She watched knowing that Susanna's fear came not just from the forced intrusions of the immediate crisis situation, though these were acute and previously unknown to both Susanna and Maria. *"There was just so much new things for both of us. D3.2 p. 39."* Susanna's fear came also from her long history of visits to the emergency room where, since infancy, hospital professionals who were strangers examined her , gave painful injections, and restrained her to give breathing treatments.

Maria anticipated that staying overnight in the hospital would be difficult for Susanna as well.

> Maria: I was just I had so much on my mind, ... to have Susanna stay somewhere else where she wasn't used to. Cause she's never ... as a matter of fact, I had to sleep on the bottom they had the chairs. ... I had to sleep, and she's used to sleeping with me. ... And she had the bed up on the, on the top, her crib and she I guess she wasn't allowed to sleep with me and that was like a, and I had to stay up and I was falling asleep. And I, she was next to me, she fell asleep and sometimes I would dose off and the nurse would tell me, "Well, you have to put her on the bed." I'd go put her on the bed, she'd wake up and she'd want to be with me so I put her down. And I have to stay up until she falls asleep, then I'll fall asleep again, so it was like a routine. D3.2 pp. 39-40.

Until this hospitalization, Susanna had slept every night in the same bed with Maria. Maria, who never left Susanna with anyone else or anywhere else at night, worried that sleeping in the hospital bed would exacerbate Susanna's fear and discomfort. In fact, what Maria worried about occurred. In the hospital, Susanna would sleep only in Maria's arms.

Maria's worry for Susanna was also a worry for herself. Susanna's hospitalization stunned Maria, she had managed Susanna's asthma for nearly three years. Although crises had frequently required emergency care, Maria thought that, even though she could not reverse crises, she could judge their severity. As will be discussed in the following section, Susanna's first hospitalization shocked Maria into reconsidering some of her accustomed ways of practicing asthma care.

Maria had previous experience with the threat asthma posed to her ability to comfort Susanna. Sometimes there was no way to comfort Susanna and still meet the demands of asthma management. Maria recalled an emergency visit early in the course of Susanna's illness.

> Maria: When she was about may be 10 months maybe, 9 months, about a year. This was when, this, I think as a matter of fact it was her second time getting her treatment. But she put up a fuss. We had to pin her down and she cried and cried. Her face was red, red. Finally she just fell asleep. I couldn't do nothing about it. I was calm, you know trying to make her feel better, but I couldn't do nothing. The doctor, I had to hold her back, her little arms, she's just screaming, she's sweating, her face is red, her eyes are red and she's, and finally she just fell asleep. ... So I had to sit there and put the medicine when she was asleep. ... All you can do is just wipe the, wipe her face up. D3.2 p. 16.

Maria described poignantly the all out struggle asthma was for Susanna and her own equally poignant sense of inadequacy in the face of Susanna's suffering. As she held Susanna, Maria stayed deliberately calm as a way to help calm Susanna. However, Susanna's struggling did not stop and Maria felt helpless to do anything except clean the secretions and tears off her face.

Even at home, Maria found that causing Susanna's emotional discomfort during breathing treatments was impossible to avoid. Although the treatments are not painful, Maria needed to restrain Susanna in order to give inhaled albuterol.

> Maria: And when she was little ... I wouldn't want to give it to her, because she struggles so much. ... D3.2 p. 38.

> Maria: Well ... in the beginning. She was like barely a baby. I'd have my brother help me. My older brother. He'd come and visit and I'd say, "Hold her down." Cause he's a lot stronger cause. I said, "She might be small, but she can wiggle and move and..." So I'd have to have him hold her down, hold her hands back and put it on her face. Until she gives up and she has to sit there and cry and just take it. D3.2 p. 40.

The conflict between Maria's desires and the demands of asthma were so great that she would often defer the giving of breathing treatments to her stronger, older brother. Without his welcomed help, Maria felt no choice but to give up trying to comfort Susanna in favor of successfully managing the illness. Sometimes Maria would resolve this conflict by omitting or delaying Susanna's breathing treatments altogether. *"Sometimes I would feel so bad to give it to her, that I maybe skip." D3.2 p. 38.*

Being Set Aside by Crisis Not only was Susanna's survival at stake in asthma crisis, so, also, was Maria's ability to help relieve Susanna's suffering.

> Maria: Well, it makes me feel bad that I can't do more to help her. That I have to take her to the hospital. Cause she does not like going to the hospital. She doesn't like the doctors. So it makes me feel bad that I can't do more. I can't help her out with you know, her breathing. I can't give her anything to make her feel better. D3.1 p. 22.

For Maria, feelings of defeat were clearly tied to what she wanted to do but could not do for Susanna. During hospital crisis management Maria had lost her usual ways of comforting Susanna. She could not hold Susanna or reassure her that the frightening treatments would not hurt. Moreover, there was nothing Maria could give or do to resolve the breathing crisis.

While hospital doctors, nurses, and respiratory therapists took over Susanna's care, Maria could only step aside, watching and listening as Susanna cried and struggled. What mattered to Maria was not just that Susanna be comforted and her crisis be resolved but that she, Maria, be instrumental in providing for Susanna's emotional and physical comfort. In the situation of hospital crisis, Maria no longer felt authority, control, or influence.

Maria's need for emergency assistance in Susanna's crisis stood as a mark of defeat, a negative judgment on her ability to care. In this regard Maria was no different from Ruby. However, because she felt cut off from Susanna's physical and emotional reach, Maria did not view emergency care as an extension of her own ability to care for Susanna and manage asthma. The contrast with Ruby is dramatic. Ruby viewed emergency care as way to get Reggie's needs met and a way to save her from failing him. When she felt her role usurped by professional providers she defiantly assumed care on her own. As will become more evident in subsequent discussions, both strategies, that is, either being overwhelmed and giving up care entirely to others, or feeling usurped and taking over care entirely by oneself, carried risk for the successful management of asthma.

Losing Confidence Despite feeling defeated in needing to seek emergency care for Susanna, Maria had developed a certain level of confidence about being able to determine when Susanna needed to go to the emergency room. Then, after nearly three years of living with asthma, Maria was surprised that an emergency visit resulted in Susanna's first hospitalization.

> Maria: Sometimes she's worse and like I said sometimes she's worse than other times. Sometimes you could barely see her kind of move her stomach in and sometimes she'll like (she demonstrates breathing), like she can't, [she has] to take a deep breath. Or she can't even talk without being able to just pause and take an deep breath.
> Int: What was it about the last time that made you think she really wasn't all that sick? ...
> Maria: She wasn't breathing as hard. She wasn't struggling to breathe as much as I've seen her. ... Like I can see, I can still see her stomach, her struggling a little bit more with her stomach. But I, like I said I seen her worse. That's why I was really surprised. Because I had seen her worse. D3.2 p. 35.

Maria was familiar with Susanna's symptoms and had trusted that she knew how severe Susanna's crisis was.

> Maria: ... I gave her the inhaler. Nothing was working, so I decided just to take her in. Usually when I take her in, they would give her stronger medicine and she would be okay. And I guess this time that I took her in, it was wasn't working. Her oxygen was low and they were giving her medicine after medicine and the doctor decided just to her leave in. And that was just her first time. I was surprised that she could actually ... she didn't look so sick. I seen her worse. I've seen her worse than that. She never was hospitalized. Usually her medicine would kick in. This time I was surprised that she even stayed and she wasn't as sick I'd seen her before. D3.1 p. 5.

The doctor's decision to hospitalize Susanna, dealt a critical blow to Maria's belief in her own ability to assess the severity of Susanna's symptoms during crisis. As the one upon whom Susanna and her family relied to know about Susanna's asthma and how to care for it, Maria worried what might have happened if she had waited longer to take Susanna to the hospital. Susanna's hospitalization further dismayed Maria for she had failed to recognize the severity of Susanna's situation. Stunned but not defeated, she felt resolved to continue meeting the challenges asthma posed. However, just how to go about doing that was not clear to Maria.

Maria felt powerless to continue her caregiver role as asthma management shifted from care centered primarily at home to crisis hospitalization. Unable to reconcile the need for resolution of Susanna's suffering with her own desire to continue as primary caregiver, Maria also was acutely aware of Susanna's struggle. Feeling inadequate and defeated, Maria, and like her, Tonya, and Anna relinquished caregiving to professional providers at the height of crisis.

Disconnection between Understanding and Use of Medicines

Tonya, Maria, and Anna experienced a disconnection between their understanding of the medicines they were giving to control symptoms and the use of these medicines for management of asthma. Tonya told about one of six medicines she was giving Jasmine after her fourth hospitalization in the previous 3 months.

> Tonya: Um, that one they were giving her that in the hospital for her to like, see if she has any reflexes on throwing up. So they just told me to give this. And I told them that she don't ever throw up. So, they just told me to just keep giving it to her to see if she has any reflexes on throwing up. ... They just, all babies they give this to to see if they have any reflexes on throwing, throwing up their food that much. And I told them she don't never throw up her food. So they told me just keep giving this to her. D2.3 pp. 12-13.

Without understanding, in fact, doubting that Jasmine's symptoms warranted a medicine to treat "throwing" up Tonya complied. She did so solely on the authority of the physicians and not because she understood how the medicine should work or because she could see results when she gave it.

When they had to give several medicines to their daughters, these mothers could not distinguish clearly among them.

> Int: Do you know what goes on inside of her when she's having trouble breathing?
> Anna: Well, I guess like, she, her, I don't know her bronchials I guess. I don't know they get like swollen and like they get swollen, like say these are her lungs right? And like she's just breathing normal and you know she's breathing good, but then they get swollen and so the hole where the air goes through, it gets smaller, and like less air can go in and that's when her oxygen gets low and gets all the mucus in it and it's just, that's what makes it hard to breathe and stuff. Her lungs just like tighten up.
> Int: So they can't get enough air?
> Anna: Yeah. They don't get enough air.
> Int: Do you know what the different medicines do to help Araceli get that better?
> Anna: No there's a lot of them. I don't really know but I know they make you get better. Like I know like the, when I do the nebulizer it helps her breathe better and that... what are these here called? The bottom ones, the yellow ones?
> Int: The [brand name of non-steroid anti-inflammatory medicine]?
> Anna: [Brand name of non-steroid anti-inflammatory medicine.] Those I guess they help open, take the swelling you know. These (albuterol) like, I don't know, like opens her bronchials up and help her breathe better. And the steroid syrup I guess just, I guess loosens her lungs up too. I don't know. D8.1 p. 27.

Anna could not clearly differentiate the effects of the three medicines she was giving Araceli either in terms of their mode or duration of action. She learned that swelling, tightening, and congestion are all physiologic processes which define asthma and she had a rudimentary understanding the general ways in which medicines effect which physiological change. However, Anna stopped short of making the connection between how what she knew informed the use of the medicines. *"I don't really know but I know they make you get better."*

For Maria who had been using the same medicines to treat Susanna's asthma for nearly three years, the differences among them were similarly blurred.

Maria lumped together and summed up her understanding of the actions of each one of the medicines she gave Susanna. They all are, she said, *"to clear her breathing."* In contrast to her generalized notion of medicine effects, Maria elaborated finely detailed characteristics of Susanna's breathing. She described the presence or absence, and level of intensity of wheezing, cough, abdominal breathing, retractions, and congestion as evidence of whether Susanna's breathing was easy or hard, good or bad. Thus, Maria had learned to make a whole range of distinctive evaluations about Susanna's breathing and the severity or lack severity of her symptoms. Since she understood the medicines to have only the general function of clearing breathing, Maria also found only an imprecise, tenuous connection between the nuanced symptoms she noticed and the way the medicines she gave Susanna might head off a crisis. Maria's most clear justification for giving the medicines the way she did in the way she did was simply stated, *"[The] doctors give us medicine, 'Here, this will make you feel better:' We take their word for it."*

The significance of this disconnection can be seen by contrasting how Ruby understands and uses medicines for Reggie.

> Int: And you, you really don't have any idea what might be going on inside [his chest]?
> Ruby: Nope. None. ...
> Int: Do you have any idea what's the difference between these medicines, how they work differently? How the [inhaled steroid] really helps him and ...
> Ruby: Oh, the [inhaled steroid], they explained to me, ... is to keep the attack from coming on and the [inhaled] albuterol is to treat the attack if it happens to come on. .. That's all I know. D4.1 p. 24.

Ruby could not describe any internal physiological changes due to asthma and could not by extension describe specific physiological effects of the medicines. However, unlike Tonya, Maria, and Anna, Ruby understood that the actions of inhaled steroids and inhaled albuterol are different. Ruby, like Lucy and Freddie, understood the difference in these medicines in terms of their purpose. The inhaled steroid was to be used even on routine days and was to prevent attacks. The inhaled albuterol was to be used to reverse crises. As a result, Ruby (and Lucy and Freddie alike) used the medicines differently and expected different results from each. Since they expected to see distinct types of outcomes, that is, prevention of onset or reversal of crisis, they made assessments about the value of the medicines in specific situations.

For example, after a few months Ruby noticed that Reggie was not wheezing at all. She reasoned, therefore, that he must not need the inhaled steroid and stopped giving it to him. He continued to do well. As another example, Lucy and Freddie wanted to take control of Eduardo's asthma. During the winter when Eduardo was having frequent breathing crises for which he received only inhaled albuterol, Lucy and Freddie asked for inhaled steroid. They became angry when Eduardo's primary care physician would not prescribe it.

Maria, by contrast, not only gave medicines because they were ordered and without a sense of how the medicines might be used to effect a change in Susanna's illness, she also could not recognize any connection between an improved winter with Susanna's asthma and anything she might have done to bring that about.

Following Susanna's two hospitalizations the previous fall, Maria had been more consistent in giving Susanna inhaled steroid. During that winter, Susanna had fewer "colds" (almost always the precursor of her asthma crises) and fewer episodes of compromised breathing.

> Maria: [M]y mother actually noticed that she wasn't getting sick, she's told me. She said maybe it's because of the flu shot, I'm not sure. D3.2 p. 29.
> Int: [W]hen you don't give her the [inhaled steroid], [do] you notice that ... she had trouble breathing more often?
> Maria: Well, um, when I don't give it to her, when I don't give it to her like, I can tell she gets ... more sick. The reason why, I'm thinking too maybe, the reason why she hasn't been sick is because I've been giving to her more frequently. ... And um, maybe that's the reason why she's not getting sick as much as she was before. ... Cause before I would skip around maybe sometimes or you know. D3.2 pp. 32-33.

That there might be a connection between Susanna's fewer crisis in the winter of our interviews and the inhaled steroid occurred to Maria as a possibility, but only after some consideration. She also considered that Susanna's flu vaccination might be the primary reason for her better health that winter. It is possible that there was no connection between Susanna taking inhaled steroid and having fewer asthma crises.

Perhaps, having had the flu vaccine did prevent a severe infection induced crisis. What is very clear is that Maria had no sense that in giving the inhaled steroid she might have been making a difference. We see this in two ways. First, as mentioned, Maria believed she had only limited control over Susanna's asthma. Second, she did not attempt to make inhaled steroid always available for Susanna. The doctors would prescribe only enough to last a short time (several weeks) after hospitalization. Maria did not receive inhaled steroid from Susanna's primary care physician. By comparison, Ruby, and Lucy and Freddie, argued with providers in their effort to have inhaled steroid always available to them even though, like Maria, they had no firm knowledge of the physiological effects of inhaled steroid. However, Ruby, Lucy and Freddie all believed inhaled steroid provided them an effective way to decrease the frequency of crises.

An example further illustrates the style of medicine use that Anna and Maria shared.

> Anna: .... from the last time they prescribed [oral steroid] for me when she was in the hospital. They gave me a lot. I mean she only takes that for like three days or five days, but there's, I still have like some left. So I just, like if I see if she's getting sick, then I'll give her some.
> Int: I see. You give it to her twice a day?
> Anna: No, once a day. ....
> I: And so that's what he told you to do?
> Anna: Uh huh.
> Int: Does he tell you how long to give it?
> Anna: Just for like either three days or five days that's it. Not more than five days. ... Or she'll take it today and won't take it tomorrow or take it the next day, like..
> Int: How do you know which way to give it? Every second day or five days in a row?
> Anna: Well I'll call him or I'll call him or, if see, if she's not real sick, I'll give it to her like every other day. But if like she's real bad, I'll give it to her just everyday. ...
> Int: Does he ask you to call him if you have to give her the [oral steroid], if she gets sick?
> Anna: No, I just call him and ask him. D8.2 pp. 8-9.

Even the pre-approval of a physician and good evidence of a medicine's efficacy, in this case an oral steroid, did not prompt Anna to adjust Araceli's medication regimen on her own. Fortunately, she had access to a physician willing to help her step by step each time she called even though he had previously instructed her about how to give the oral steroid should a crisis arise.

Maria's sense of having minimal and inconsistent influence over the course of Susanna's illness also showed several months following Susanna's hospitalizations when she had run out of medicine and experienced a crisis. Maria, for reasons that were unclear, did not follow through with the pediatric pulmonologist who had first prescribed inhaled steroid and nebulized albuterol. In addition, she had never been given these medicines by Susanna's primary care physician. Unable to manage the crisis on her own, Maria took Susanna to the emergency room.

> Maria: I took her into the, I ran out of her medicine, her medication, so I couldn't give her anything and she was getting worse and worse. So I decided just to take her and they did those same things they always do. Give her, her medication, her inhaler. Yeah. They do the same thing all the time. D3.3 p. 1.

Although she needed medications for Susanna, Maria, unlike Ruby, did not go to the emergency room to obtain medicines or instructions for care. Her purpose was to seek care which she believed would resolve a crisis that she did not expect to be able to resolve on her own. Thus, familiar emergency routines became a part of the repertoire of asthma management that Maria counted on but did not try to appropriate as part of her own management practices. In this way she was entirely different from Ruby.

Maria explained her management style.

> Maria: I, the first year is when I've noticed is when I've actually noticed when I have to take her. Or I noticed when she starts breathing hard, take her in. But throughout the years I've been given more medications to help it a little bit better. ....
> Int: You're trying to manage more at home?
> Maria: Uh huh. I try, before I would notice her, her first year I would notice her breathing hard. I would take her. Don't even try giving her no medication, just take her. .. This year I've tried giving her medications and if that doesn't work then take her. ... Usually it doesn't work. D3.1 pp. 35-36.

At the beginning of Susanna's illness, Maria did not feel that during crisis she was able to care for her at home. At the time of this interview, nearly three years later, Maria had a different way of managing Susanna's symptoms at home but she still had no confidence that what she could do would make a difference. Maria's sense of herself as Susanna's caregiver in crisis was limited to routine medication administration, a practice that Maria believed held little hope for effective result.

Thus, hospital emergency care became an indispensable component of Maria's management plan.

> Maria: if she doesn't get any better you just take her to the hospital. And I know that whenever I take her to the hospital, she always gets better, regardless. She's always going to get better. So I guess now as she's getting older, I'm understanding more about whatever happens, she's always going to get better. ... So that's what maybe doesn't make it so scary as much as it used to be. ... Because I know that I just take her in and bring her back and she's going to be okay again. D3.3 p. 12.

When Susanna experienced a crisis, Maria counted on Susanna's crises always resolving at the hospital emergency room. In this regard, Maria had a much different relationship to the hospital than did Ruby, even though both used the hospital emergency room as the source of primary care. Unlike Maria, Ruby believed her home management of Reggie's crises made a difference. If/when it

did not she took Reggie to the emergency room. In seeking emergency care, she never stopped believing that she could give better care to Reggie than he would receive in the hospital. Taking asthma management into her own hands, Ruby never completely trusted the care of Reggie to others.

Maria, like the other parents in this study, feared asthma. She worried that Susanna might die from asthma and thought that Susanna's asthma crises were becoming more severe. Just prior to these interviews Susanna had experienced her first two hospitalizations. In the two years following the conclusion of these interviews, Susanna has been hospitalized two more times for asthma. Although fearful, Maria downplayed her fear of asthma, a fear assuaged not because she understood asthma any better, nor because she understood better ways to ameliorate Susanna's crises, but because she had become accustomed Susanna's numerous crises always resolving. Unlike parents who practiced other management styles, whose fear that their children might die from asthma never diminished and who never failed to recognize that they were afraid, Maria believed that she did not need to be frightened. *" So that's what maybe doesn't make it so scary as much as it used to be. ... Because I know that I just take her in and bring her back and she's going to be okay again."*

Maria's narrative illustrates her disconnected agency in two ways. First, there was a disconnection between her giving of medication to Susanna and improvement/lack of improvement of Susanna's breathing. Second, there was a disconnection between Maria's care of Susanna at home and the care Susanna received in the hospital. Maria knew that Susanna received the same medication at home and in the hospital but that in the hospital she got better while at home she did not. Nevertheless, she believed that Susanna's getting better was somehow a result of how the medicines worked. In this way, what happened in the hospital was beyond Maria's understanding. Hospital management was, however, a mystery that Maria respected and depended on.

To summarize, regarding their styles of medicine management for asthma, Maria and Ruby exhibited distinct understandings of and expectations of asthma medication efficacy that paralleled their distinct understandings and expectations for emergency care. Because Ruby was able to see a connection between the medicines she gave and the quality of Reggie's breathing she actively absorbed the nuances of hospital management, appropriated them, and, defying professional advice, took action on Reggie's behalf. At home and in relationship to professional health care providers, Ruby always held an uncompromising belief in her own indispensability regarding all areas of asthma management. On the other hand, Maria's understanding of the effect of the medicines she gave Susanna was not formulated in a way that allowed her to see specific and distinct results from their use. She gave medicines out of the knowledge that she had been told to do so. Her agency was, thus, reduced to rule following.

Discontinuity between Prevention Practices and Their Impact on Symptoms

Tonya, Maria, and Anna held little hope for changing the course of the asthma by preventing exposure to asthma triggers. However, all attended to the details of prevention with various levels of mindfulness. Tonya who at the first of these interviews felt that Jasmine's asthma was becoming less critical kept a neat household for herself, Jasmine, and the woman in whose house she lived (an aunt of Jasmine's mostly absent father). Allergic to dust herself, Tonya recalls sneezing and wheezing if she was exposed. However, when asked on several occasions if there was anything she could do to prevent Jasmines' asthma, Tonya noted that she avoids taking Jasmine outside on rainy, cold, or windy days. She made no mention of preventing Jasmine's exposure to dust.

Tonya recognized that Jasmine began to wheeze when she was playing vigorously with her young cousins who occasionally came to visit.

> Int: [H]ow was it when you were taking care of [your young cousins as a teenager]?
> Tonya: [T]he other kids you could just let them rip and run and may be they get tired and go to sleep. But her, if she plays too hard, her asthma acts up. So I keep an eye on her especially with her asthma and stuff. D2.1 p. 8.

But Tonya did not intervene.

> Int: So there are times when you stop her from playing hard?
> Tonya: Actually, she will stop herself. When her asthma acts up she goes and sits down. She will sit there and laugh and talk with the kids and stuff, but she won't get up and go run with them. D2.1 p. 8.

I saw Tonya's casual attitude toward prevention during one visit when she had to clean the household where she lived. As Tonya swept the carpet with a broom, Jasmine and I were in close proximity. Although the dust raised did not immediately trigger Jasmine's symptoms, Tonya showed no concern that it might or that a delayed reaction might occur. Her stated concern about cleaning was to keep the house, where she sublet a room from Jasmin's paternal great-aunt, very clean in order to maintain her right to live there with Jasmin.

Anna, on the other hand, paid detailed attention to preventing possible triggers. She or her mother asked smokers who came to the house to smoke outside. Moreover, when she noticed one day that Araceli started to wheeze when the neighbors mowed the lawn, Anna concluded that Araceli was allergic to grass. Anna avoided putting perfume on herself and using baby powder on

Araceli. She noticed that Araceli's symptoms had improved since the family moved from a house with mold in a damp bathroom.

For some allergens Anna noticed a direct relationship with Araceli's constricted cough.

> Int: And the dust. What do you do about that dust?
> Anna: Well, we couldn't vacuum and it was like an old vacuum. You could see dust coming out too, I went with my mom and got a new vacuum. We vacuum all the time. Don't sweep. Like sweeping, ... if we [hadn't] vacuumed, I'd just get the broom and just sweep my room and you could see all that stuff in the air. ... I'll always be dusting you know. Or even, even like the blankets, like the quilts, not like this [one] but there's like smoother quilts that we have. Maybe they're thick blankets.
> Int: How do you know that it's the blanket, for instance?
> Anna: Cause she'll start coughing and all that like ... one or two times I noticed it and well she had this one blanket, it was like a real thick one, like different materials. ... I mean she would just cough, I would put her to sleep with it in the day. It's like the smooth blankets you know, the feathers and all that stuff. That'll all get to her. Me too, this [gets to] me too. D8.1 pp.37-38.

Unlike Tonya, Anna directed her thinking to things in the environment that might trigger Araceli's asthma. Her house and later the apartment to which she moved was free of mold, and as always, was neat and dusted. When others in the household, including her young nephew, were ill, Anna kept Araceli away from his coughing and washed Araceli's hands frequently. Maria's household was also very neat and clean. However, keeping a dust free environment for the prevention of Susanna's symptoms was not part of Maria's stated notion of prevention. Necessary prevention practices, according to Maria, were to avoid Susanna's close contact with her young brothers and sisters if they had acute "colds" and to keep Susanna indoors during cold or windy weather.

In the winter, even on milder days, Anna always took warm clothes for Araceli when she left the house. In the summer Anna avoided being in air conditioning with Araceli since she knew that coming out of the summer heat into very cool air conditioning made her wheeze herself.

> Anna: Because ... I'll do anything just you know to prevent her from getting sick you know. But sometimes she just gets sick anyways. I mean if it's cold I take her and cover everything and have her covered up real good all the time and she just gets sick. D8.2 p. 33.
> Anna: I just think, well, why would she get sick. I mean sometimes, I mean, she don't go outside. She just stays home, but she'll get sick. And it's like guy, when she doesn't even go outside, I don't know why she gets sick. D8.1 p. 15.

For as much as she wished to prevent Araceli's symptoms and for all her concern about eliminating and avoiding environmental triggers, Anna found little effect on the course of asthma as a consequence of her efforts. However, because she noticed general effects on her own and Araceli's asthma after some exposures, i.e. mold, mowed lawns, and specific effects in others, i.e. dust, smoke, and cold, Anna persisted with a program of moderate prevention practices.

In this group of three mothers the approach, effort, and reliance on prevention measures to impact asthma reflected an overall low level sense of self-agency in the face of the illness. These mothers' styles of prevention varied. Tonya and Maria made little effort to control environmental factors, while Anna made a more conscious effort. However, all three thought only minimal effect on the illness could be achieved by strict attention to prevention guidelines.

Crisis: Signal of Impending Caregiving Limit

Tonya, Maria, and Anna were unable to see a relationship between their crisis home management skills and progression or reversal of their daughters' symptoms. Instead, when distinct indicators signaled crisis, these mothers' effective role in the control of symptoms ended, heralding an inevitable need for crisis care. For Maria the 'red flag' symptom was Susanna's spitting up mucous. For Anna, Araceli's suffering meant the need for emergency care as discussed in Chapter 5. For Tonya, characteristic wheezing signaled a crisis which she could not reverse.

However, despite well recognized signals, these mothers weighed other conflicting situational concerns in determining just when to seek emergency care, for example, time of day and the child's fear of emergency care,. Anna timed emergency visits to avoid nighttime exacerbation of symptoms.

At first, she waited through the night even though she knew she would be unable to reverse Araceli's symptoms on her own.

> Anna: Like, we don't have a car either. ... So it's like, and so most of the time I have to wait till the morning, you know. And I'll just keep giving her her treatments. I mean if I think she's real sick, I can't sleep. I mean I'll lay down and doze off a little bit, but I can't sleep you know through the night. I'm just always giving her treatments until the morning comes and I'll take her to the doctor. D8.1 p. 31.

In the morning, when Araceli's symptoms would often have improved, she would take her by bus to the children's hospital where she would either be admitted or remain in emergency care for most of the day. Subsequently, the experience of worrying through the night led Anna to seek emergency care at the early signals of crisis.

Maria's concern was Susanna's fear of emergency care.

> Maria: She's scared of doctors. When she's sick, I'll tell her "We'll take you to the doctor." And she'll understand. ... I try, before I take her in, I make sure I've given her everything that I can. Then if I see nothing's working you know, I have to take her. Cause eventually I'm going to have to end up taking her anyway. D3. 1 pp. 24-25.

Instead of seeking early emergency care, Maria continued to try home interventions even though she believed emergency intervention would be inevitable.

> Maria: Well actually actually, I , the first year is when I've noticed is when I've actually noticed when I have to take her. Or I noticed when she starts breathing hard, take her in. But throughout the years I've been given more medications to help it a little bit better. ... before I would notice her, her first year I would notice her breathing hard. I would take her. Don't even try giving her no medication, just take her. This year I've tried giving her medications and if that doesn't work then take her. Usually it doesn't work. D3.1 pp. 34-35.

As her familiarity with Susanna's asthma crises grew Maria gave medicines longer at home before taking Susanna to the emergency room. She had, however, almost no confidence that her efforts to relieve Susanna's distressed breathing would negate the need for emergency care.

Interestingly, although Anna and Maria similarly confronted a limit point in asthma crisis beyond which their control over asthma ended, their differing concerns led to vastly divergent relationships to emergency care. Anna, after experience, hastened more quickly to the hospital where she usually waited for many hours with Araceli in the emergency department. On the other hand, after experience, Maria waited longer at home. She could usually see neck retractions along with rib retractions and labored abdominal breathing when she took Susanna for emergency care. Susanna would receive immediate attention. *"When I, usually every time I go they take her in [and] they put her down as urgent." D3.1 p. 25.*

Just why Maria waited until Susanna's crisis was critical before seeking emergency care is not clear. Two concerns likely contributed. As noted, Maria wanted very much to minimize Susanna's discomfort. In addition, Maria had seen that Susanna's crises all followed similar patterns and that with emergency care she always "got better". Whether Maria waited to see even worse symptoms before assessing that Susanna needed immediate crisis care is not known. Maria mentioned that she had never seen Susanna "turning blue", a symptom , she had been warned, would signal the need for emergency care.

Maria, Anna, and Tonya were all knowledgeable about the distinctive symptoms of their daughters' progressive asthma crises. In this, they were similar to Ruby, and Lucy and Freddie who had all become skilled interpreters of the particular mosaic of symptoms that meant crisis for their child. However, one set of families, those practicing determined self-agency, were mobilized by the symptoms of escalating asthma crisis to seek better control of what was happening to their sons. They understood seeking hospital care as an extension of their own management practices. By contrast, the other three mothers, were led by the crisis to give up control even as they went through prescribed management steps.

Blunting Management Practices During Hospitalization

In this section I will discuss how during their daughter's hospitalization, Tonya, Maria, and Anna each put aside accustomed ways of intervening to ameliorate her child's symptoms during breathing treatments. These mothers, like parents in ten of the eleven families in this study, gave close attention to their children during hospitalization. Each was by the bedside of her child night and day with only short breaks to shower and dress in clean clothes. Yet, the style of these three mothers contrasts dramatically with that of Ruby, and Lucy and Freddie for whom hospitalization was like a course in asthma management and who, once familiar with hospital practices, held providers accountable.

Tonya and Maria are presented as contrasting exemplars of the style of management in which parents hand over caregiving to professionals during crisis and hospitalization. Tonya, unafraid to intervene in Jasmine's care at first, withdrew from caregiving and from knowledge about asthma during the course of this study. In that three month period Jasmine was hospitalized three times. Maria, stunned by Susanna's first hospitalization after nearly three years of crisis emergency room visits, only gradually came to assert her caregiving skills on Susanna's behalf in the hospital setting.

Tonya Beginning the first time Jasmine was hospitalized, Tonya understood the advantages of hospital management only in general terms. Differences between hospital management and home management remained a mystery to her. Tonya did not know specifically what the doctors did to help Jasmine calm down and breathe better in the hospital. *"But they just told me, they gave her some stronger medicine to work with the albuterol." D2.2 p. 2.* Unlike Ruby who had mastered the details and felt she understood all the important aspects of hospital management, Tonya recalled only the general notion that in the hospital Jasmine received stronger medicine. It did not occur to Tonya that she might have been able to manage Jasmine's crisis without hospital intervention.

Tonya believed that hospitalization would bring certain relief for Jasmine's crisis. However, relief always came at the expense of Jasmine's pain and her struggle to be free of forced breathing treatments, IV insertions, and suctioning. Tonya felt extreme discomfort at Jasmine's pain and crying, and cried herself. At first, when Tonya thought that caregivers where sometimes rougher with Jasmine than they needed to be, she intervened. *"[W]hen they're trying to give her a breathing treatment, it's like they're so rough with it. They, I try to tell them the right* *way that she'll really take it if they do the way that I show them to do it." D2.2 p. 20.* However, Tonya grew to tolerate Jasmine's pain and crying in order to go along with hospital procedures. *"There's nothing I can change about it. Just do what the doctor tells me to do." D2.3 p. 20.*

Tonya allowed that Jasmine would be better taken care of in the hospital despite her frustrations with "rough" caregivers. "I felt a lot better with her being in there cause the doctors know how to really calm her down better than I do." D2.2 p. 20. Tonya's concern for Jasmine's physical pain and emotional distress in the hands of unnecessarily rough providers took back stage to her need to find relief for Jasmine's asthma crisis. She feared that Jasmine could die. Giving up her own agency was the only way she knew to insure Jasmine's survival.

At home Tonya was skilled at eliciting Jasmine's cooperation with taking medicines and receiving breathing treatments. After intervening with the "rough" hospital providers, felt she had earned respect for her skill. *"And they go, "We've been doing this for so many years," and like yeah but not all kids are all alike. Mine is different. So finally I show them how to do it and they're amazed that she doesn't be grouchy and fussy." D2.2 p. 20.* However, unlike with breathing treatments, during painful and frightening IV insertion and suctioning procedures, Tonya could not relieve Jasmine's suffering. Even though she felt extremely discomforted by Jasmine's suffering, she endured without intervening. At times Tonya felt so frustrated that she would leave Jasmine's bedside.

> Tonya [W]hen I leave out the room, I just hate to see her hollering and screaming and it's like if she holler and scream, she like looks at me like, a kind of "help me" look. D2.2 p. 24.
>
> Tonya: I keep [my frustrations (Tonya's word)] inside. When I'm sitting in with her I do, but I go outside and get some air. ... I feel a lot better once I go outside and get air and everything. Um, she sits there and takes the

> breathing treatments and everything. The only part I didn't like, when they had to put the IV in her and she was really fighting. And then she has to, [she's] calling me and I have to, then I have to go outside.
> Int: You had to go outside?
> Tonya: Yeah, when she wanted me to hold her. And she's fighting the doctors while they're trying to put the IV in. ... I just sit [outside] and I just wait and then if I think they're done I go back in and sit with her and hold her. D2.2 pp. 7-8.

Unable to tolerate her own frustrations Tonya found relief only by separating herself from Jasmine's pleas for rescue. Leaving the room helped her put out of mind the impossible situation of seeing Jasmine suffer and feeling unable to do anything about it.

Tonya continued her narrative:

> Int: What happens when you come back after they put the IV in?
> Tonya: Oh ... she's sitting there looking at it like, or she holds it and rocks like this with it. ... She calms down. I try to like give her at least what 5 minutes or so to calm down before I go back in there. And I go back in there and she's usually she's sitting there looking at [the IV] or she has her bottle going back to sleep. I know she's been exhausted from fighting it, crying so much.
> Int: Is somebody there with her then or do they leave her alone after they put the IV in?
> Tonya: Oh no, they sit there with her. And wait till I come back in then they finish off what they're doing.
> Int: Have you ever walked in when she is crying.
> Tonya: Yeah, she looks at me and I just pick her up and she goes right to sleep. D 2.2 p. 16.

The question of why Tonya abandoned the assertive stance she demonstrated about the management of Jasmin's breathing treatments when Jasmin was suctioned and received IV's, cannot be answered definitively. Likely, she felt more confident about intervening during breathing treatments with which she had experience than during others that were out of the realm of her experience and were not only frightening, but were also painful for Jasmin. Nevertheless, the contrast in her stance is dramatic. In addition, this incongruity and the shift in her management and parenting practices over the course of these interviews were clear.

Prior to Jasmine's frequent hospitalizations in the winter of 1996-1997, Tonya said she felt confident that she could manage Jasmine's symptoms. She also felt competent in seeking hospital care, doing so even when her mother or others did not think it necessary. Repeated hospitalizations with aggressive treatments began transforming Tonya's confidence in her own ability to meet Jasmine's needs. As management became complicated with more medications and by more frequent crisis interventions, Tonya ceased to understand how specific aspects of management led Jasmine to *"do better"*. She could only see that medicines, procedures, and provider care did help. After four hospitalizations Tonya saw a patterned regularity in the treatments provided her daughter and became accustomed to being able to do little to impact on asthma's unexpected flares without going to the hospital.

> Tonya: And they told me she was going to stay for a couple of days, it's not like I was upset about it or anything, cause I knew everything. She goes in there. She stays for a couple of days for her to get used to the medicine.
> Int: Did you learn any new things about asthma while you in the hospital with her?
> Tonya: No not really. What everything they were telling me I already knew about. ... They just gave her her treatments and suctioned her and everything. That's all. It was about the same as the last time. D2.3 p. 20.

Instead of wanting to know why Jasmine had frequent crises or what she could do on her own to prevent or treat them, Tonya became familiar and less upset with hospital crisis procedures and incorporated hospital stays into her routine for crisis management. Hospital management gave Tonya relative relief, but remained disconnected from the care practices she carried out at home. As a result, they were not situations from which she felt she could learn and improve her own skills.

According to Tonya, Jasmine became accustomed to hospitalization as well.

> Tonya: Well, when they was giving her a treatment, she wasn't crying or nothing, she was sitting there taking her breathing treatments. The only part she cried at is when they had to suctioned her out. But she didn't cry too much with that either. She just laid there and just went ahead and let them go ahead and do it. D2.3 p. 4.

By the time of her third hospitalization in six weeks, Jasmine who was 16 months old had learned, her mother thought, to submit to routine but painful procedures. Previously Jasmine had cried and struggled against the restraint of providers. Now she endured passively. Although the reasons for Jasmin's change in behavior are not clear, from the perspective of attachment theory, Tonya's own practice of ignoring her emotions and turning away from Jasmin's suffering so as not to interfere with the technical demands of crisis management likely played a role.

The implications that Tonya's leaving when Jasmine was frightened and in pain may have for the quality of the relationship between mother and child cannot be determined. However, Bowlby's work on attachment is highly informative. According to Bowlby, Ainsworth and Main, the attachment bond between mother and child serves specifically to protect the child in crises. A child indicates her (or his) fear and solicits her mother's protection by crying and seeking proximity in the face of actual or anticipated danger. The mother's attunement to the child elicits in the mother a protective response. Her desire is to draw her child close and ward off the danger. When a mother's actions assuage her child's fear the attachment bond is deemed secure. Secure attachment is believed to be central to successful emotional development throughout life. Attachment is, furthermore, a particular relationship between a mother (or other consistent caregiver) and her child. As was discussed in Chapter 3, no one satisfies the child's need for emotional security as does the one familiar caregiver.

Tonya wanted very much to protect Jasmine from the suffering not only of hospital procedures but also of painful, distressed breathing. Unfortunately, she felt compelled to leave <u>especially</u> <u>when</u> and <u>because</u> Jasmine called out to her. When she felt Jasmine's need for her as most acute and as a result felt most helpless to make a difference for Jasmine, she chose to leave, thinking that both she and Jasmine would be calmed by the separation.

The ability of a child to be comforted by returning to her mother after an emotionally traumatic separation is a hallmark of secure attachment. After the IV procedure was complete, Tonya found Jasmine exhausted but still eager to be held as she fell asleep. Her narrative shows that although stressed and thwarted in their respective needs to be protected and to protect, Jasmine sought and was comforted by Tonya on reunion, the sign of a secure maternal/infant relationship. It is evident that during crisis management of Jasmin's asthma, critical events that could challenge the quality of attachment were occurring. Significantly, the critical nature of these events was appreciated neither by Tonya nor by hospital providers. See chapter 7 for further discussion.

<u>Maria</u> In contrast to Tonya but also exemplary of discontinuous agency, Maria refrained from intervening in hospital crisis management until several days into her daughter Susanna's hospitalization. When she finally intervened she felt reconnected to her own skillful practice of providing comfort for 34

month old Susanna during breathing treatments in the emergency room and during home crisis management.

In the early hours of Susanna's hospitalization, Maria had felt helpless to relieve Susanna's fear as hospital staff restrained her during breathing treatments. Resuming a more active role, allowed Maria to reflect that holding Susanna made a difference.

> Maria: Yeah. I think she liked it better when I hold her or when I'm with her and doing it or when she's doing it [holding the nebulizer tube]. ...
> Int: And she was sitting in your lap?.
> Maria: Yeah. Because I think there's a couple of incidents when I did it for her and she wasn't really complaining. Other times they came in and did it themselves and she was, that she was complaining about, ... Cause she felt safer if I did it for her. D3.2 p. 18.

Maria learned that in the hospital, as she had at home, Susanna preferred sitting on her lap and holding the nebulizing machine tube herself. As Susanna's hospital stay extended, Maria regularly held Susanna during breathing treatments. The satisfaction Maria felt in being able to comfort Susanna re-established Maria's sense of efficacy as Susanna's caregiver. In retrospect she believed Susanna had been very fearful during earlier hospital crisis management.

> Maria: They um, most of the time they did, they well, the times that they did [the breathing treatments], she would cry and then most of the time when I did it, well I did it like twice, it dawned to me well she doesn't cry when I give it to her. ... And then I give it to her. But most of the time she'd cry and I you know, I'm thinking, "Why, why is she crying? She's used to this. Maybe she's scared." And then I think of the two times that I gave it to her and she was okay with it. And she was holding it. And it was a lot better. 3.2 p. 40.

Maria's narrative gives no hint of her long experience with frequent emergency visits for crisis care. Instead she tells a story of new and frightening circumstances for herself and her daughter, on the one hand, and an inability to respond effectively, on the other hand. As the course of hospitalization proceeded, Maria had become slightly more assertive about her ability to comfort and care for Susanna during hospital procedures.

In the highly charged situation of crisis hospitalization, parents in this study responded in dramatically different ways despite two common aspects of their caring. First, they shared a belief in the centrality of their own important role in the relief of their children's suffering and fear. Second, all also knew that their responses to asthma crisis were crucial for resolution of symptoms and their child's well-being. However, the limits of their ability to stay involved in the care of their children during hospitalization differed sharply. In the pattern of discontinuous agency, Maria was immobilized and distanced by her concerns for Susanna's reaction to the strange hospital environment and the thought that she might have entirely missed the seriousness of Susanna's situation.

In contrast, parents who practiced in the style of determined and flexible self-agency found possibilities for action, even in the face of life-threatening deteriorations in their child's condition. For example, despite the efforts of hospital staff to restrain her son during treatments, Ruby insisted on holding his hand for comfort. She maintained her place at his bedside out of concern that Reggie would feel abandoned if she left him with strangers.

> Ruby: I cried a couple of times to see the things that they do to him, but I never want to leave, ... I would really be letting him down, if I just left him and he couldn't see and he knew no one and he's there all alone. ... I wouldn't want him to be alone. I wouldn't want him to be alone. So I wouldn't leave him. D4.2 pp.38-39.

Concern about abandoning Jasmine to the care of others in crisis did not show up for Tonya. Concern about being emotionally available to Susanna did not show up for Maria. Rather, Tonya and Maria followed the lead of hospital personnel in carrying out technical care. During crisis, not only did each give up hands on care, as did all other parents in this study, Tonya and Maria set aside their own sense of self agency. Each submerged her expression of emotions and deferred her caregiving to professionals out of bewilderment, fear, and suffering.

Comparing this management style with Ruby's demonstrates important differences in the stances the two groups of mothers took vis-à-vis hospital care. Ruby felt terrible pain at seeing Reggie endure and struggle against IV insertions, suctioning, and breathing treatments. She feared Reggie might die and stayed in the background during procedures with which she was unfamiliar. However, during traumatic procedures she felt Reggie's suffering, her anger rose, and she remained determined never to give up the sense that she knew what was best for Reggie.

Being Resigned to Asthma

The three mothers who practiced asthma management in the style of Resigned Self-Agency, as Tonya said many times *"just got used to it [asthma and its demands]." D2.3 p. 24.*. At our second interview, following Jasmine's second hospitalization Tonya informed me:

> Tonya: I just take, I just take it day by day. It's not like I'm going, it's not like, okay this day she's going to go to the hospital and that day, I just take it one day at a time. D2.3 p.15.

For these mothers, asthma set its own agenda. Tonya lived day by day not knowing which days would bring crisis and the necessity for a trip to the hospital. Moreover, asthma was never out of her consciousness.

> Tonya: I just sit and wait for asthma to happen, it's not like I know when it's going to happen and now that she's diagnosed with it, I just do everything I can to prevent her from having too many asthma attacks. D2.3 p. 16.

Asthma was in control and arrived like an unwelcome, unannounced guest. Tonya did everything she could do to prevent Jasmine *"from having too many asthma attacks."* Yet, she ran out of methods she considered effective and was left passively waiting for the inevitable.

> Tonya: It's just that I just, I just got used, got used to her asthma and everything. That's all I can do is just get used to it if she has it. I have to deal with it the best way that I can. I can't, constant, I can't always be scared about her asthma cause it's not going to make it any easier. D2.3 p. 24.

Finally, living with asthma meant accommodating to the supremacy of the illness and Tonya did so willingly. She could not let up on her vigilance because asthma frightened her.

> Tonya: When her asthma acts up, sometimes I be thinking that it's not going to get any better it's going to get worse. And my grandfather, he just died by asthma and emphysema and everything. ... I try not to think like that. I think positive about it, but I sometimes I think like that. D2.2 pp.4-5.

Trying to put aside her fear of Jasmine's possible death from asthma, Tonya, nevertheless, resigned herself to asthma's vagaries. Knowing that Jasmine had always improved when she, Tonya, did as the doctors told her, Tonya had ceased seeking new understandings of asthma or discovering new management practices. Recurring and frightening in every instance, asthma was always more than Tonya could get a handle on.

Out of her long experience with asthma Anna talked similarly.

> Anna: [Y]ou know since I've had asthma and since she's had asthma, I've learned a lot more about asthma. ... So you know it's like I'm used to it already. It's like I'm used to it. It's like nothing that I don't understand about asthma you know. I'm used to it. D8.1 p. 8.

Asthma demanded accommodation and Anna complied. Asthma, as we saw in Chapter 1, colored her past, present, and future. Anna resigned herself to meeting the manifestations of asthma with no expectation that her relationship to asthma would ever be any different. For Anna, and Tonya and Maria as well, hope for reprieve lay only in the prospect that their daughters would outgrow asthma. They did not expect to be able to reverse asthma's insidious and capricious hold.

Flexible Agency: Managing with Flexibility and Sharing Responsibility

Introduction

Four families practiced a style of flexible self-agency in managing their daughters' and son's asthma. The four were diverse in age, ethnicity, education, family configuration, and economic status. Lara and Javier, 19 year old Latino parents of 34 month old Carolina lived alone with their daughter. Elena, a 20 year old Latino mother of 37 month old Melissa, lived with her daughter, parents, and non-English speaking husband in her parents' home. Abby was a 25 year old single Latina mother of four sons, aged 6, 5, and 4 years, and 27 month old, Isaac had asthma. Corrine and Jimmy, 37 years and 38 years old were parents of a 9 year old son and 27 month old Bette who had asthma. Corrine was Latina and Jimmy African-American.

Five themes characterized the practice style of these four families. These themes follow from two crucial and interconnected self-understandings that defined parents who practiced asthma management in the style of flexible self-agency. First, even from the first signs of distressed breathing, these parents' felt confident and uniquely able to recognize the level of their child's distress. Second, the parents in this group always believed that their child's well-being hinged on their own proper response to asthma. As a result even though they were at times unsure what that response could be, these parents found ways to stay involved and maintain their commitment to their primary caregiving role.

The five themes that characterize management behaviors in this group of parents are: 1) Centrality of parents' intuitive and cognitive recognition of their child's distress; 2) Active variation of strategies to relieve asthma; 3) Parents' meticulous attention to standard prevention practices; 4) Desire for collaborative relationships with professional providers; and 5) Asthma's undiminished fearsomeness.

Theme #1: Centrality of Parents' Cognitive and Intuitive Recognition of the Child's Distress

Above all considerations of the effects of asthma on her life, Abby felt how much Issac suffered.

> Abby: [W]hy does my baby have to have asthma and suffer like this you know go through all of this. I mean it's, it's sad. It makes me sad. ... It's hard to see kids sick like that. It's not fair for little kids to suffer and be sick like that all the time. Asthma to me is something bad really, cause I've never had any sickness like that in any of my kids. D10. 2, p. 9.

Although parents who managed asthma in the styles of determined and discontinuous self-agency were also keenly tuned in and responsive to their children's suffering, in both groups parents had additional agendas that shaped the manner in which they acted on the distress they saw in their children. Ruby, for instance, who felt determined at all costs not to fail Reggie, anticipated beforehand the likely outcome of each emergency visit. Likewise, each time Anna saw Araceli suffering from a hopelessly escalating crisis she mobilized her response in a pattern as predictable as Ruby's. Instead of feeling determined to take control, however, Anna felt destined to give in to the higher power of asthma.

In contrast, Abby, and the other parents who managed in the style of flexible agency, were able to respond to their children's suffering with more flexible strategies, and with better reliance on their own intuition about the relative level of that distress. Flexibility of style began in the careful witness they bore to signs of their child's emotional and physical distress. Whereas Anna had noticed the differences in cough that indicated Araceli asthma had flared, Lara recognized Carolina's asthma in several familiar symptoms that showed up with distinctive characteristics. At the time of her birth at 32-24 weeks gestation, Carolina's abdominal breathing was described to Lara as immature respiratory function. During Carolina's first breathing crisis, abdominal movements signaled more than reversion to an earlier way of breathing. Lara noticed Carolina's tremendous effort to breathe. She also remembered noticing asthma's distinctive cough during the first crisis. Only asthma's mild wheeze was unfamiliar to her. A weak cry alarmed Lara as well.

> Lara: She [was] just laying there crying, I mean she was a cry baby. Oh God, she was a cry baby when she was a baby and when she would get real sick she would just cry, but like a weak cry. Not wanting to cry, so weak that she didn't even want to cry. So it's like, that's not her. D7.1 p. 10.

Since Lara knew the usual vigor of Carolina's demanding cry, she heard the feeble cry as signal of unusual difficulty. She was able to describe the critical wheeze, cry, cough, and abdominal breathing that identified restricted breathing, on the basis of her flexible attunement to Carolina's weakness and distress. Moreover, Lara attributed her recognition that Carolina needed help to an intuitive evaluation of Carolina's situation.

> Lara: [A] lot of things you know when you're a mother, just like mother's instinct. That's really true what they say, mother's instinct. You just kind of know, you know when they're about to catch their cold, you know when they got the cold, you know when, you know what medicines to give them. D7.1 p. 10.

Not only did Lara attribute her ability to make and interpret physical signs to intuition, she also claimed that motherhood made her intuition unique. For Lara the demand to find relief for Carolina flowed inextricably from her own privileged intuition of Lara's suffering. During the first recognition of a breathing crisis, Lara was motivated to seek help.

> Lara: ... I just felt like, just concerned so I took her in. I just, I didn't know what was wrong at first. I wanted to get medicine for it. I didn't want her to be suffering like that with having to inhale real deeply you know. So I just, I didn't know how to feel, I just took her in. D7.1 p. 8.

Lara also appraised Carolina's needs and devised a management strategy to reverse her compromised breathing.

> Lara: I was just like, just shocked like, "God you know it's taking her that much to breathe. She needs to go in. She needs help." When you're putting that much effort in to trying to breathe, you should, you're going to need oxygen. I didn't know what was wrong with her. D7.1 p.9.

Even at first, Lara's response to Carolina's asthma crisis took on the added dimension of mindful and active advocacy. Thus, sensitive observation to the physical signs of Carolina's crisis, feeling uniquely compelled to respond on Carolina's behalf, and suppositions about what professional intervention should entail all flowed from Lara's deeply felt concern for Carolina.

Corrine and Jimmy were thrust into trusting their own intuitive responses, and believing in their indispensable part in asthma caring, when nine month old Bette's first crisis developed without warning into a life-threatening situation.

> Corrine: And the baby sitter had said that she took a nap, but when she woke up that she was kind of lethargic. She was kind of limp. She wasn't running a temperature, but she just didn't look right and for me to get over there right away. Otherwise she was going to call 911. She said because... [S]he was really worried. She was really worried. Well I worked down on [city location about 4-5 miles from the baby sitter] and the baby sitter is over here. So I got in the car and as I drove up, she was getting ready to take her without me. ... Bette was just, her eyes were rolling. Her eyes were not, kind of were back. She was real limp. She was just like she wanted to sleep, like she couldn't, I don't know. She scared me. So the baby sitter left the kids at the day care with her daughter which helps her too and she came with me and she held her. And as I drove, which is just past [city street], as I drove from the baby sitter's house I was hitting her. I was kind of hitting her, not hitting, hitting her, hitting her to make her stay awake. Because she was like in a state where she just wanted to sleep. She couldn't keep her eyes open. ...
> Jimmy: It surprised me. It shocked me. Man.
> Corrine: [We had] no warning. D11.1 pp. 5-6.

Corrine and Jimmy had been totally unprepared for this grave crisis. Nevertheless, Corrine was instantly caught up in Bette's situation. Totally unfamiliar with what was happening, her only worry was that she might not get Bette to the hospital soon enough.

Jimmy, also arrived at the hospital from work. Together he and Corrine told about how they felt in the first few hours of Bette's hospitalization.

> Jimmy: Yeah, when I went to the hospital. Yeah. I was just trying to be patient. Nervous.
> Corrine: It's an ugly feeling.
> Jimmy: I was just, I don't know. I was numb. Yeah, I was scared. ... I was afraid. I didn't know what was going on. ... [W]hen I got there she was already hooked up to everything.
> Corrine: She was already hooked up and everything.
> Jimmy: And she was just laying on the bed. She wanted me to hug her and and keep her, you know, stand by her and stuff like that. D11.1 p. 8.

Arriving at the hospital Jimmy first saw Bette as she lay in bed with an IV in her arm and oxygen flowing through her nose. Scared, nervous, and essentially helpless to alter Bette's situation, Jimmy was, nevertheless, able to contribute to Bette's well-being just by being with her and responding to her requests for hugs.

Elena was another mother in the group of parents who practiced flexible self-agency. Elena's story was also a story of confidence in her capacity to meet whatever challenge asthma might present. However, while the others had easy access to emergency care, Elena who lived in rural Fresno County did not.

Like Lara and Javier, Elena saw 3 year old Melissa suffering as she struggled to breathe.

> Elena: What hurts me is like seeing her that she can't breathe, that she's like suffering to breathe. When I couldn't [do anything] I was just sometimes, it's like "Oh God, help!" ... I get like so sad like and I can't do nothing about it. I wish [I could] do something. Or to give her something that [it] would go away . But... D5.1 p. 28.

Feeling helpless to change Melissa's situation, Elena felt deeply sad. Yet, she found effective ways to respond.

Elena's mother became sad as well.

> Elena: Seeing her like that when she gets sick. You know that's hard too. Seeing her when she gets sick. ... I feel ugly, and I feel sad. I feel sad like. I wish I could do something so she won't have that again or ... Like my mom, whenever she sees her that she's sick, sometimes she starts crying because she gets sad that a - ah that she's going to be in the hospital all this stuff that they do to her and yeah it's hard. So it's hard. D5.1 p. 27.

In her extended family, Elena carried responsibility for finding the way to resolve Melissa's crisis. She wished to avoid hospitalization. Although asthma was hard because of Melissa's struggle to breathe, it was made worse by traumatic hospital procedures. Emergency care was a choice of last resort. At the first sign of crisis extended family members in the home began to dread the prospect of emergency care. Crises that began or lasted into the night brought the biggest challenge.

> Elena: I see her suffer and all the things that she goes through. So that's why I just want to help her here. So she won't have to go there. ... I want to help her. When I could see her [that] she has a cough and she's like (demonstrates loud breathing) and I start like hearing like. I go oh my gosh she's going to get sick. Everybody in the house is saying, "Oh she's starting getting sick. We're going to have to take her to the hospital." You know, just start getting worried. So, that's why I try to give her the medicine. I put her vapor here and her feets with the sock and the...[shows a jar of vapor rub and points to her chest] ... it says that that will help her like just breathe too.
> Int: Because you don't want her to go to the hospital.
> Elena: I see what happens [at the hospital] and I feel bad.
> Int: And you saw some of the same things this time that you saw before. Like her neck going in and trouble with her ribs. Did you see that on Saturday night?
> Elena: No I just saw her like here [points to her neck]. ... When I see her that it's here [indicates her neck] and [indicates her ribs] that's another thing when I want to take her to the doctor. ...[C]ause that's when she's really, really suffering and she can like (she demonstrates breathing).
> Int: And that's what her breathing sounds like?
> Elena: Yeah. D5.2 pp. 13-14.

Like the other parents who practiced flexible self-agency, Elena paid careful attention to Melissa's physical symptoms. When Elena saw supraclavicular but not intercostal retractions, she decided Melissa was not yet *"really, really suffering"*. She chose to depend on her own capacity to comfort Melissa, keep her warm, and attempt to relieve her constricted breathing with prescription and nonprescription medicines. All this was done in order to avoid a trip to the hospital. Lara continued to observe Melissa carefully to discern if the symptoms she saw meant severe distress that she could not manage on her own. Unlike Ruby, and Lucy and Freddie, Elena felt confident that what she could help Melissa even without the benefits of professional care. Unlike Maria, Elena believed that she might be able to prevent hospitalization.

Yet, caring for Melissa at home was not without risk, as Melissa did not have a local physician to advise her. At the emergency room of the local hospital no personnel were competent to insert an intravenous catheter (IV) in Melissa's small veins. An earlier crisis had resulted in delays while IV insertion was attempted and while waiting for the ambulance that transported Melissa to the children's hospital 25 miles away. In addition, since three working adults in the family household shared one car, accessing emergency care caused serious disruptions in family routines. While to Elena these contingencies justified taking the risks of home management of crisis, they also magnified that risk. Eighteen months following the conclusion of these interviews, Elena had successfully reversed Melissa's distressed breathing at home on several occasions and she had not been rehospitalized.

Thus the situations and outcomes of crisis in families who practiced flexible agency varied greatly. However, despite asthma's frightening uncertainties, the parents who managed in the style of flexible self-agency felt certain that their child's well-being hinged on their own appropriate practices in responding to its challenges.

Theme #2: Parents Chose Varied Strategies to Relieve Asthma Distress

Parents practicing flexible self-agency characteristically gave close attention to varied details of their child's crisis. In response they adopted management responses distinctive to their interpretation of the child's situation. Lara and Javier were exemplary. They devised a plan for crisis care centered on attention to Carolina's distress. When the plan proved ineffective they revised the plan and their actions reinforced for them the importance of their primary agency in Carolina's asthma care.

Lara and Javier found themselves without clear guidelines for appropriate action when Carolina's symptoms flared. They had been given no crisis management plan. Carolina's pediatrician would prescribe over the counter combination antihistamine/decongestant for the cough and congestion that Lara and Javier identified as early signs of crisis. However, the medicine did not relieve Carolina's symptoms. As a result, Lara and Javier stopped seeking the pediatrician's care and searched for effective care elsewhere. First, they took up the strategy of seeking help for early crisis at the walk-in clinic operated by the children's hospital where they were told that a decongestant should be given instead of the antihistamine/decongestant combination over-the-counter drug. However, based on past experience, they decided the decongestant would not be effective in reversing Carolina's cough and congestion, so they adopted another approach.

> Lara: If it's totally to where we know that it's bad, we'll take her to the emergency room, [children's hospital] emergency. Basically all we try to do is we catch her runny nose and we try to get medicine before it gets worse, and they [walk in clinic providers] don't give us the kind of medicine that she needs. It's always [over the counter antihistamine and decongestant]. So we'll just give her, her inhalers [left over from previous emergency visits] ourselves. We just give her inhalers before it gets worse. D7.1 pp21-22.

Although not entirely certain that what they were doing was ideal, Lara and Javier continually rejected treatments they thought were ineffective. Instead, they adopted strategies that seemed to make a difference. In the process Lara and Javier remained actively attuned to asthma and learned to recognize the qualities that distinguished common symptoms as signals of asthma while they waited to find whether home management would resolve Carolina's crisis.

> Lara: [W]e'll know if she's catching a cold, when she'll cough at night. Not now, but in the winter. That's how we know. Those coughs. And another thing we learned, is those coughs are asthma attacks. ... We thought that cough was a cough. A cough is a cold you know. For us people cough as a cold, but for asthmatics, a cough is an asthma attack. Especially during her sleep or during nap. D7.1 pp. 35.

Lara and Javier basically found no good or effective help anywhere, and thus, reverted to self-care practices until they felt there was a crisis requiring hospitalization.

> Lara: [I]f she's already coughing and stuff and breathing hard then, we take her to the emergency. That's how we make our decisions by her, what's wrong with her. We try to get her in before it's, it's too late. We try to get medicine before it's too much worse .... D7.1 pp. 35.

Over the 30 months of Carolina's crises, Lara and Javier had developed more and more finely detailed observations of the symptoms that marked significant crisis, cough, congestion, wheeze, abdominal breathing, decreased appetite, and low energy. As a result, they based their decisions on where to access emergency care according to the severity of Carolina's symptoms.

Prior to Carolina's most serious hospitalization, obtaining professional care took considerable persistence and shifting of strategies. Since Carolina had a fever, little energy, and slept a lot, Lara and Javier judged she was in serious crisis. They decided to seek care at the emergency room.

> Lara: They said, 'She's was fine.' Whatever, they sent us home. ... That night she was, she wasn't doing good, she was running up a fever constantly. And we were, there is something wrong with her. I don't care. I know the difference. There's something wrong with her. D7.1 pp. 35-36.

> Lara: The next morning we, they sent us home really late so we all slept. ... [When we woke up] Carolina was like (she demonstrates breathing, loud tight gasping). And we were like, no, no, something is wrong with her. So we took her to [walk-in clinic] and we thought maybe they'll do something different for her. And they did. They put her on an oxygen tank and shipped us to [children's hospital] in an ambulance. D7.2 p. 17.

Sensing that Carolina's unremitting fever and very labored respirations indicated serious crisis, despite emergency room providers telling them otherwise, these parents persisted in their search for a provider who would respond in a way that addressed their concerns. Their perseverance, sense of urgency, and confidence in their own assessment of Carolina's crisis even led them to seek care at a clinic they usually considered only for low level crisis care.

The prompt decision by the staff in the walk-in clinic to send them to the hospital and Carolina's 8 day hospitalization, supported Lara and Javier's astute earlier decision to seek crisis care at the children' hospital emergency room. Thus, the experience reinforced in both parents the crucial importance of their ability to evaluate Carolina's needs, to continue actively responding to crisis, and to advocate for her even when professionals minimized the severity of Carolina's illness and the level of Lara and Javier's concern.

Elena, like Lara and Javier, learned how to access care that suited Elena's needs at the local rural clinic even though she found that in more severe crises clinic providers were not skilled enough to care for Elena. Corrine used her judgment to assure that Bette would remain hospitalized when the physicians suggested that Corrine could take her home. Abby guided the care of physicians whom she thought had a less keen sense of Isaac's condition than she did. In all these examples, parents developed strategies to obtain, in their view, the best available care for their children even though in choosing these strategies they did not feel assured that an optimum outcome was guaranteed.

Theme #3: Belief in the Importance of Meticulous Attention to Prevention

Two mothers who practiced flexible self-agency are exemplary among all study participants for their continuous and detailed attention to keeping their homes allergen free.

> Corrine: I try to do as much as I can at home. My window sills, I go through maybe every three weeks, I [bleach] or I sterilize all my windows. And I clean all the mold off the windows in my rooms. And I really have to go through the house and really clean. Really good. And I try to do it as often as I can, but it's real hectic because it takes all day to get things because we talk mold, dust, anything could trigger it. But she's done so well, I don't know if it's because of the summer and that there's not, I don't know. The blooms are out and I've really watched her with the trees blooming and I thought that that would really get her. D11.1 p. 1.

Prevention was a matter of trying to eliminate or avoid common environmental allergens, mold, dust, and pollens without knowing for sure that these affect Bette's asthma. Nevertheless Corrine cleaned house with meticulous care that would take a whole day out of her highly scheduled and very busy life. Regardless of her efforts, Corrine could not seem to prevent the "colds" that came with change of weather and seemed to precipitate Bette's asthma. Corrine continued her housekeeping practices, however, despite having no clear evidence of their impact on Bette's symptoms.

Corrine wanted to avoid using steroids for Bette on a regular basis. *"I really tried to keep Bette away from the steroid part and I try to do as much as I can at home." D11.1 p.1.* She weighed the pros and cons of allergy therapy, environmental control of allergens, and daily albuterol therapy.

> Corrine: ... I really thought about taking her to an allergist, just to find out what she was allergic to, but I haven't done it. And then I thought to myself,

> if I were to take her to an allergist, what is the difference? Me giving her a steroid, [or] albuterol, but she doesn't take a steroid, [so just giving her] albuterol, giving her this stuff for her asthma treatment when I could go to an allergist and give her allergy shots. Would that keep the asthma from going away? ... And I threw it at my doctor. He goes, "Man you've been thinking, huh?" ... I said, you know I'm going to find out, where are the pros and cons? What is worst? Giving her injection of an allergy injection all the time or giving her albuterol? Will the allergies, I mean that's basically from what my understanding is, is it's something in your house that's giving off an allergy reaction. ... So when they schooled us at the hospital, plus people that you talk to, you hear. Hey, you have mold and stuff. So every few weeks I get all my mini blinds and everything goes to the top and especially in the winter. Not so much in the summer. I didn't have to do it for a good two months. But in the winter when the house sweats, you got steam going, you get that mold on your windows. I can go through and I have Jimmy take her to the park, get her out of the house. ... When I'm going to do a lot of cob webs and a lot of off the fireplace and all that kind of stuff, I try to keep her out of the house. So...
> Int: Do notice that makes a difference for her? ...
> Corrine: You know what, I don't know. I have hardwood floors and vacuuming it still, all that dust gets up and sweeping and doing all of that with the floors. So I just have him take her outside and let the dust calm back down, cause you're not going to get all of it. But I don't know.
> Int: So you really do think through this stuff a lot, don't you?
> Corrine: I do, I try to, I mean I, I'm trying to avoid going back to the hospital. I don't want to do that any more. I'm trying to avoid having to give her this albuterol everyday. You know she may need it and that's just something I have to deal with. But I'm trying to do as much as I can to keep her away from it. Cause you know all that stuff is not good for them. I mean, it helps them, but to me any kind of medicine ... that you have to take everyday ... That's my opinion. D11.1 pp. 40-42.

Corrine thought carefully about how she might prevent Bette's symptoms. Primarily, she wanted to avoid both hospitalization and the need for Bette to receive medications on a regular basis. As hard as she had to work to maintain a dust and mold free environment for Bette, the alternative options for living with asthma were less acceptable. If Bette's symptoms persisted, Corrine anticipated she would need continuous daily medications, an unhealthy option in Corrine's judgment. An alternative might be that frequent allergy injections were necessary. However, they offered hope for amelioration of symptoms, but no guarantee of a cure. Prevention Corrine believed held more potential for controlling asthma.

Lara and Javier felt similar importance in keeping a clean home.

> Lara: So basically what we learned too, is dust does, you have to be dust free. I mean that's what we try to be. I mean if you look on the window sills, we don't have dust or on my lamps, I mean we don't; we dust all the time. And when we do do it she has to be in her room or when I vacuum or he vacuums cause he cleans her room and he dusts, he brings her out here and shut the door. Because bedrooms carry a lot of dust. D7.1 pp.11-12.

Like Corrine, Lara and Javier kept Carolina away from the dust that cleaning raised as well. However, for them meticulous cleaning was part of a larger strategy of prevention.

> Lara: Basically raising a kid with asthma is, I mean, she's normal as like a normal kid. She developed good, she's smart, she's real smart, but as in raising a kid with asthma, a tid [tiny], a little bit different because you have to be very clean. You can't treat her like a normal kid in the winter. "You want to go with me empty the garbage" and you just have her jacket and shoes. No not with her, you have a beanie, a jacket, a blanket. You don't, we do not want her getting sick. If she's sick, it's like, "Oh man, here it comes, her asthma acts up." The cool, the heater during the winter. We want the house very warm because of her. If her hands are cold we're like, "All right turn on the heater." Keep it on or set it at a temperature to where she's going to stay warm in here. I mean it's a little bit difficult, I mean as to being awareness. Or like having her around certain people that, "Can you please not smoke or can you blow your smoke the other way?" Or, "Don't touch her if you have dirty hands." Or if a kid's sick, "Please don't let your kid touch her, I'm not trying to sound rude but she's a very sick child with asthma. And I don't want her catching a cold from your kid and then getting sick." So we try to keep her away from kids with germs or kids with runny noses. ... Those kind of kids that are normal without asthma, it's easier for their mothers they just blow the nose or wipe their boogers or give them their medicine or whatever, but it's like us, we end up stuck with a kid that can't breathe because of that mucus. D7.1 pp. 20-21.

Managing the symptoms was a matter of *"awareness"* for these 19 year old parents. Taking up vigorous prevention strategies involved social assertiveness as well. Before moving into their own apartment they asked the landlord for a new cooler pad. They told relatives and friends that Carolina could not be exposed to smoke or children with colds. Lara and Javier persisted their protective and preventive practices knowing that other parents and relatives might not understand. Children with asthma had some needs that other children did not, they believed. As Lara explained, whenever she saw it, she would clear mucus from Carolina's nose. Mucus was not a simple matter for Carolina. Early nasal discharge might become a full blown asthma crisis within two days. Other mothers, Lara said, did not have to attend so carefully to slight colds.

Javier who occasionally smoked cigarettes explained the strategy for preventing Carolina's exposure to cigarette smoke.

> Javier: I always have to wash my hands. When I go outside and smoke a cigarette, all the time [I remember] to wash my hands when I touch her or pick her up. ...
> Int: And you've noticed that the smoke makes a difference.
> Javier: Yeah, that's what the doctor said. ... So I had to stop doing that.
> Lara: Well, he's always smoked outside though. I don't like the smell of cigarettes.
> D7.1 p. 11.

Even though it had previously been his practice, after Carolina's hospitalization and the couple's consultation with the pediatric pulmonologist, Javier found new legitimacy for only smoking outside. Avoiding others who smoked was more complex.

> Lara: Just last weekend, no the weekend before, me and her went to his aunt's house and they smoke. They smoke cigarettes and I didn't want her to be there because they smoke cigarettes. And they smoke in their house and we were watching TV and they were smoking, and I asked them to open the doors and windows and they did. And I gave her inhalers, but she was like, "Stop already." She told them like that. And so I took her into his cousin's room where nobody smoked or nothing. So me and her just stayed in there the whole time. Cause in that room there's no smoke.
> Int: How long were you there? ...
> Lara: Maybe about 2 hours.
> Int: How was she when she when she got home?

Javier: Fine.
Lara: Just fine. D7.1 pp. 11-12.

Lara's protection of Carolina meant a few hours of social isolation, and Lara and Carolina made no subsequent visits to Javier's aunt. As a result,Lara and Javier carefully supervised Carolina's contact with other children. She played outdoors with neighbors when they did not have runny noses or coughs. Her half sister lived with the family for several days every other week if she was not ill. In addition, Carolina played and was in close contact with cousins when they visited a few times a year from out of town.

> Lara: Not really. We don't really want, I mean it's not that we don't want her around kids, it's just that you know kids have a lot of germs and with her asthma we get scared of her getting sick. So it's like "Don't touch her. Don't." So nobody never comes over that much. But I mean she does play with her cousins [who lived in Los Angeles and Oregon].
> Javier: When they're not sick.
> Lara: When they're not sick. D7.1 p. 3.

Other parents restricted their children's outdoor play on windy days.

> Elena: Most of the time we have to be inside here and it hurts me because my niece, she goes out and plays with kids when they come here. And she wants to go and if the day, it's too cold, I don't want to let her go out. And then she starts crying and I'll say in a way. It's hard. D5.1 p. 26.

Restricting Melissa's social contacts was not easy.

> Elena: Yeah and I feel bad when these days are windy and she wants to cry and cry. She wants to go out. The air, you know it has too much pollen and that's what the doctor told me too, that it could be the air. When I see that it's sunny and it's not too much windy. I just let her go out. I let her go out all the day.
> Int: ... [W]hen she's inside all day instead of outside in the wind, have you seen that make a difference in her breathing?
> Elena: Yeah, when [there's] too much wind and it looks like it's going to rain, she's outside and she starts coughing. And she comes in she starts coughing a lot. So that's why I go, no that's, it's bad for her. D5.2 pp.14-15.

Although Lara and Javier, and Elena appreciated and encouraged their daughters' play with other young children, their belief that prevention practices would help reduce symptoms and prevent crisis took precedence. The challenges and hardships entailed did not deter them from being actively engaged in eliminating possible household allergens and preventing their daughters' exposure to other known triggers. Elena summarizes her motivations for trying to prevent symptoms.

> Elena: ... [T]he first time that she got that ... I didn't know more things. Now I know how to prevent. If I see her like that and if I don't I want her to go to the hospital and I have to give her the medicine and try, don't take her [out] that much, like when there's too much wind. Just take care, take more care of her. D5.1 p. 28.

In diligently insisting that Melissa not play outside on windy days Elena found a way, in addition to giving medications, to respond to asthma. She believed in the efficacy of these practices and that what she had learned to do was a way of taking care of Melissa that would forestall future hospitalizations.

Theme #4: Interactive, Collaborative Relationships with Professional Caregivers

Parents who practiced flexible self-agency experienced the most interactive relationships with caregivers of all parents in the study. In this section I will discuss in detail three families and the nature of their relationships with providers during hospital crisis events. The families share three similar defining qualities that are noteworthy for the dissimilar ways they show up in each family.

First, Corrine and Jimmy, Abby, and Lara and Javier, were similar in being able to claim a level of certainty in assessing their children's needs. Second, all these parents remained reliant on and valued the intervention of health care providers. Third, when these parents perceived that providers had made or would make misjudgments in the care of their children, all maintained collaborative management relationships with professionals, nevertheless.

These parents' familiarity with asthma in their child varied from novice, Corrine and Jimmy, to very familiar with asthma's presentation, Abby, to being up against a new asthma phenomenon after many years of experience with asthma, Lara and Javier. As a result, the level of shared decision making between providers and each family, and the amount of direction these parents gave hospital providers varied.

One mother, Abby, told physicians how to manage her son's emergency room crisis, and felt a strained relationship with the pediatric pulmonologist on whom she wanted to rely. One mother, Corrine, shrunk from assuming responsibility for crisis management feeling she needed to depend more on the professional expertise of her daughter's physician. Another mother, Lara, made a significant intervention on behalf of their daughter even though she felt confused about hospital procedures.

Despite playing effective and pivotal roles in their children's emergency management these parents at times felt confused and uncertain about asthma's severity, what was required of them, and how to relate to providers. Nevertheless, these times of confusion did not divert them from believing in their own value in the management of their child's asthma. Nor did they turn away from seeking collaborative relationships with providers.

Abby Abby, who spoke up to suggest hospital management strategies for her infant son Issac, was sometimes rebuffed, but remained determined to be heard and to cooperate with providers as well. Over Isaac's 15 month life, Abby had developed a level of confidence about when to take Issac to the hospital.

> Abby: I can tell, I can tell, pretty much every time I knew that something was wrong with him, I was always right all the time. Maybe once or twice I was wrong and they'd send him home, but hardly ever am I wrong. Practically every time [he'd be hospitalized] unless it was just for an ear infection or something. You know mainly every time I take him in for his asthma and his wheezing, usually they admit him. Most of the time. 75 percent of the time. D10.1 p. 26.

By listening to Isaac's breathing, "looking at him," and "feeling" his congestion as she held him, Abby had learned subtle distinctions that indicated asthma crisis severity. His most severe crisis unfolded just before his first birthday.

> Abby: His asthma started acting up and as it was he wasn't, I knew he was getting sick because he didn't have any energy. He would just lay there. And he wasn't eating as much and I can tell just by him at night his breathing.... I'd give him his treatments ... He would just breathe really really scary. It would scare me... And then he started running a little temp, a low grade fever. So I was like well I wonder if I, gosh, I started hearing him, I was talking to a friend of mine and I was like. I've got to take him to the hospital, but I know they're going to admit him. That's my first thought. I know they're going to admit him. Then I'll get ready, "Should I take a bag? ... Should I pack a bag for myself already?" 'Cause usually I'm always right. They always end up admitting him. You know because a baby, they say if they have 104 temperature it's really bad. To have a low grade fever it's still really bad. 'Cause you can have pneumonia and have both, a low grade fever or a high grade fever. And it wasn't, his fever wasn't very high, but I could just tell something was wrong with him other ... 'Cause he was just, he looked sick. And I just got...
> Int: How many days had he been sick?
> Abby: Well, the longest I'll go is like not even two days. 'Cause usually I'll try to keep his temp down, take him a bath... D10.2 p.14.

Abby's thoughtful attention to the details of Isaac's illness convinced her that he needed care that only the hospital emergency room or hospitalization could provide. She dreaded the prospect.

> Abby: I mean so, I sat here and I was just like I don't want to go. I don't want to go to that place. You know my stomach was in a knot. And I was like "come on Issac, get ready to go to the doctor." You know, I knew instantly as soon as I walked in. D10.2 p 14.

As viscerally onerous as a trip to the hospital felt, Abby deliberated, packed her own bag, and told 12 month old Issac where they were going. As she walked into the emergency room, Abby felt certain Issac would be hospitalized. She encouraged providers to give him x-rays.

> Abby: I tell them to take x-rays of him, because there's a lot of times where they sent him home and thought he was okay. [Then] I take him back and he has to be admitted to the hospital because he had something you know. Oh he just has bronchitis, he's okay and sent him home. Then all night long he had trouble breathing and I took him back to [children's hospital] and it ends up he has pneumonia and they have to admit him for four days. So... D10 pp. 11-12.

Abby had long experience of appropriately accessing emergency care for Issac. His resulting hospitalizations reinforced for her the prudence of her crisis management practices and her pivotal role in Isaac's care both at home and in the emergency room.

Emergency room procedures also challenged Abby's confidence, however.

> Abby: They took his oxypulse, or whatever...
> Int: The pulse oxymeter they put that on his finger?
> Abby: Yeah. It was like 90/92, 93. And that wasn't too good to them. They don't like that. And that's what scares me is because he could be home and I wouldn't notice and what if his oxygen was like 90 or 91. How am I going to know that kind of stuff? And that's really bad because they don't like the thought that it gets down that low and they automatically put him on oxygen. How am I going to know [when] it gets down that low?
> Int: So that number is really important to you?
> Abby: Yeah, to me because it is to them. As soon as that machine starts going off they come. I mean it scares me. D. 10. 2 pp. 14-15.

Hospital personnel responded more to pulse oxymeter readings than they did to Isaac's breath sounds, appearance, or anything Abby could tell them about the signs that he was severely ill. Noticing providers' rapid responses to pulse oxymeter readings, Abby questioned her own ability to assess the severity of Isaac's crises. She worried about how she was going to know when the oxygen in his blood was low. Her question remained unanswered.

Her confidence somewhat shaken at not being able to read the severity of Isaac's crisis as well as could the pulse oxymeter, Abby was, nevertheless, undaunted in her conviction that she must be the one to initiate appropriate actions on Isaac's behalf in a crisis. Learning as much as she could was a priority.

> Abby: I mean it's, [thinking about what I could do] just drove me nuts. It was like, it drove me nuts thinking about it all the time. It's like God. ... I would always sit there and while the therapist was giving him treatments. I would sit there a lot of the times and just talk to them. And why is he like, why is it, why, I would always ask him questions constantly. ... Look if you get tired of me asking you questions you can tell me to stop. And they're like no no, it's okay. I was always just wanting to learn something from what happened or why are you guys going to do this or just learn things so that I would know. D10.2 p. 20.

At the same time Abby was disappointed by lack of attention the pediatric pulmonologist gave to the details of Isaac's situation.

> Int: Is there anything ... you would have wanted from [the specialist] had he come to visit you in the hospital?
> Abby: Well, it's that they never knew, I would go to the appointment and I was like, well Issac was in the hospital a couple of weeks ago. "Oh, well we didn't know that." I'm like, "What do you mean? He's your patient. Shouldn't you guys know these kind of things or come and check up on him or ... I mean that's what you guys specialize in is asthma. Or respiratory. [So] that you guys should know know exactly what's going on and be able to talk to me about it [and] tell me why it's happening." And it's like they never, they should be able to know his history: when last time he was sick and how he got sick and just why he got sick. ... So maybe if he knew what was going on and he knew he was in the hospital for this certain reason and he knew that he had pneumonia he'd be able to explain it to me more. "Well this is probably why it happened." Or, "This is ... you need to do this better." But I never got any of that kind of stuff. D10.2 pp. 19-20.

Since she felt very much alone, unsupported, and without a long range understanding of asthma management, Abby dreaded the possibility of future crises. However, she fully accepted responsibility for managing Isaac's asthma with all its contingencies.

Abby had hoped for closer attention from the pediatric pulmonologist so that she could view Isaac's ongoing experience with asthma in a larger context. She wanted to learn what had precipitated Isaac's frequent exacerbations in order to understand, manage and prevent them more effectively.

Corrine and Jimmy Corrine and Jimmy, who were new to asthma when Bette's first crisis was upon them, felt uncomfortable when her physician asked them to decide whether to hospitalize her. His offer tempted them to take her home, where she would be more comfortable. Despite this, they held to their sense of the severity of Bette's situation and their need to depend on professional care. The high level of intervention needed to bring resolution to Bette's crisis reinforced the appropriateness of their concern.

Unlike the other study families who knew the children's hospital only from the perspective of being patients or family members of patients, Corrine worked for the hospital and was an acquaintance of the emergency room physician. He made clear to her that hospitalization would mean increased distress for Bette, and that as an alternative, Corrine and Jimmy could treat her at home. What motivated the physician to take this position is unclear. Perhaps, he sensed Corrine's fatigue, or perhaps, as Corrine feared he misjudged how ill Bette was.

> Corrine: What do we do? Do we admit her or do we play this game about coming back and forth. ... So the choice was, okay do we come home and then go back and sit in there for another 4 hours and go through this all over again just for them to say, Well you know I think you should admit her again?" And so the choice for me and Jimmy to make was just to admit her.

> But why go through this and make her go through it again. And let's kick this now and it's already been two days and nobody's had any sleep. She hasn't even slept that well. "Let's get her going and lets take care of it." He said, "That's all I needed to know." D11.2 pp. 18-19.

Since Corrine was exhausted, and because she and Jimmy, who was at home with their 9 year old son, worried that Bette would need to return to the emergency room, they decided she should be hospitalized. However, the discussion between Corrine and Bette's physician had not addressed Corrine's deeper concern, that she wanted professional guidance in a situation that was for her confusing and unfamiliar.

> Corrine: I didn't want to come home, not that I didn't want to come home with the burden [but] because it's a problem that she has, but I didn't know enough about it. See, I felt more comfortable if I was there with the help and with the knowledge of these other people that knew what they were doing. ... We'd been back to the ER 3 times already. D11. 2 pp. 19-20.

For Corrine, Bette's very frightening and unresolved asthma crisis was a burden because of its unfamiliarity. Corrine did not know asthma, was frightened by Bette's sudden severe crisis and unresolving symptoms, and had no explanation for Bette's dramatic respiratory compromise. If Bette were hospitalized Corrine would have a professional partner in her vigilance and be supported by someone with knowledge beyond hers in making asthma management decisions.

In retrospect Corrine weighed the pros and cons of the decision to hospitalize Bette. Bringing Bette home would make her less frightened.

> Corrine: I wanted to bring her home because I didn't want her to have to go be terrified. [At the children's hospital], they make it, they try to make it the best, relaxed. They [don't] want the kids ... to be afraid of going back. But I knew they were going to have to poke her .... D11.2 pp. 20-21.

At home Bette could be spared the distress of additional hospital procedures. However, Corrine worried that coming home might be detrimental.

> Corrine: When you're at home with them you feel so sorry for them that when they cry and you're trying to give them a treatment that you let them take as much as you can take and then you let them rest. Where at the hospital, they don't do that. They know what they have to have. They know what's going to make them a lot better and a lot faster. D11.2 p. 20.

Bette's need for comfort and rest would make Corrine less inclined to be aggressive in giving Bette unwanted but necessary breathing treatments. Corrine also considered that Bette's recovery might take much longer without suctioning and IV medication.

> Corrine: [It] would have probably made it a little bit easier. ... To bring her home. But I felt that I wanted her well quick. Because she had suffered already for two or three days. ... [B]ecause they intravenously have her steroid in her and they're just constantly suctioning her so she could breathe and that muscle could open up in her lungs and I mean stuff that we couldn't do here. We couldn't do that here at home. I could have brought her home and it could have taken us three weeks for her to get well, when it took her five [days]. ... D11.3 p. 38.

The course of Bette's hospitalization supported Corrine's belief that Bette's recovery had been quicker in the hospital. In retrospect, Corrine reviewed how at home she could not give intravenous steroids or perform naso-tracheal suctioning in order to assure that Bette's suffering would not be prolonged.

Only by Corrine's persistence had Bette been hospitalized.

> Corrine: And I told [the doctor] well what do you think? That's what I told him? And I said, "I'd like your opinion." And he said, "Well, you know what? I'm going to give you my opinion, I'm going to let you know, you can go home, but if you have to come back, we have to go through all this all over again before we can have a reason to admit her. All over." So every time we went back to the ER, they had to go through giving her the aerosol treatment, they had to give her oxygen, they had to check her SATS [blood oxygen saturation]. They had to go through that step, which the ER has to do in order to have a reason to admit her. D11. pp. 18-19.

Corrine puzzled over why the doctor might have suggested she and Jimmy take Bette home, and why he seemed more concerned about the inconvenience of frequent return visits to the emergency room than about symptom outcome. Sensing her own uncertainty about asthma management Corrine pressed the physician.

> Corrine: There's still a question mark there. Why could I have brought her home and treated her to get her well, but then they had to do all that stuff in the hospital to her? And then when the respiratory therapist came, they have to tell the doctors how she's doing after they suction her. And she needed it three times. So I don't know if maybe he looked back on all that when she first came in, on her SATS, how they couldn't get her SATS up. I mean maybe he looked back at all of that and thought, "Well, God they've been back in the ER twice. Maybe this baby does really need all this stuff." D11.3 pp. 37-40.

The idea that at first the doctor may not have known the severity of Bette's situation made Corrine uncomfortable. She was equally uncomfortable with the idea that the doctor might have allowed Bette to be treated at home knowing that she was very ill and would benefit from hospital care. Corrine puzzled at length over why the physician had ordered the frequent tracheal suctioning that he knew Bette would not get at home. Repeatedly, after Corrine's efforts to explain it away, the question of why she needed to press the physician for advice about hospitalization still troubled her. She had not wanted decisions for Bette's care to be entirely hers and she felt she had come dangerously close to prolonging Bette's crisis.

The physician's offer that Corrine and Jimmy could care for Bette at home was appealing but also made Corrine uneasy. She hoped for a cooperative but not equal relationship with the physician. She sought his judgment and the perspective of his expertise in the evaluation and management of asthma.

Corrine, like the other parents who practiced flexible self-agency, continued to work with medical providers and rely on their advice. As the hospitalization unfolded Corrine remained actively attuned to the details of hospital management procedures despite vague underlying doubts about the physician's judgment.

Lara and Javier Lara and Javier also desired to cooperate in a supportive relationship with professional providers. As I presented earlier in this chapter, they continually adapted professional management strategies that in their judgment best suited Carolina's needs. This discussion will show that despite feeling accused of being negligent or incompetent parents, they kept hoping to find caregivers who valued their skillful attention to Carolina's asthma and would aid them in her care. They remained fully attentive and involved in hospital management practices, continued to intercede on Carolina's behalf during hospitalization, and worked in collaboration with hospital professional and non-professional personnel. The events that surrounded a decision to do bronchoscopy for Carolina are exemplary.

Carolina's second hospitalization severely strained the relationship between Lara and Javier and professional providers in general and with the physician who managed Carolina's hospital admission in particular.

> Lara: I was kind of upset at [children's hospital]. ... They got down on me and Javier like, "Why didn't you guys bring her in here. Why did you take her to [walk-in clinic]?" And so I got mad right back. That was their making me upset, they tried to make us sound like unfit parents because we're teenagers. We know what's wrong with our child, we know when she needs to be tooken in. We know what's wrong with her. We know when to give her her medicine. We know what environment to have and what environment not to have you know. And so I got upset. I said, "I brung her into the emergency over there last night and you guys sent us home." ... I showed them the paper. ... I showed them the paper. Like you know how they give you the yellow, I showed it to them. I said, right here. And I

> threw it down on the table and I shut my eyes. ... I was angry. They, I mean cause they came down on us. That hurt. I mean, I'm not a unfit parent. I don't feel that way at least. They made it sound like, "Why didn't you bring her in sooner?"
> Int: How did you feel about that Javier? ... I don't know. I wasn't really right there. D7.2 pp. 17-19.

Lara wanted to be respected for her expertise and intimate familiarity with asthma. Having tried for nearly 24 hours with to get effective help for Carolina, the physician's question left Lara feeling offended, angered, and immediately defensive of her and Javier's role as parents, and their skilled familiarity with asthma. However, while her confidence in her uniquely specialized ability to care for Carolina never flagged, Lara continued to seek a mutual and cooperative relationship with Carolina's physicians. In fact, even though their interchange had been contentious, the physician's concern matched, and thereby, substantiated Lara's concern.

Lara's level of involvement in Carolina's asthma management significantly shaped the decisions that preceded Carolina's scheduled bronchoscopy.

> Lara: [Carolina was] so critical, so critical. I mean that bronchoscopy scared the Holy, out of me.
> Javier: Yeah.
> Int: You knew what bronchoscopies were?
> Javier: No, they just stick a tube down to your lung and ...
> Lara: With a camera. Well they explained it to us. Of course they have to.
> Int: What was the part of it that scared you?
> Javier: That the lung collapses.
> Lara: Yeah, about the lung collapsing, that it could collapse.
> Javier: Yeah.
> Lara: What scares you the most is that surgery paper you have to sign, if they die they're not in fault. That was like, should I get, should she do it? I don't want her to die. I'm not out trying to sue anybody, but I don't want her to die you know. D7.3 pp. 13-14.

Despite their fear that they might lose Carolina, Lara and Javier, cooperated with preparation for her bronchoscopy. With the procedure planned for a Monday, Carolina had not been suctioned for the whole weekend before.

> Lara: ...They were about to give her a bronchoscopy. They were about to give her one and God heard my prayers or something, cause one day the next respiratory treatment lady had came in in the morning, right before they were going to give her the bronchoscopy, and she goes, "Have they suctioned her for the week-end?" and I go, "No." And she was like, "God, she needs to be suctioned." And my mom and all them, like, "No just let them do the bronchoscopy. She's going to have to have that, she leave her." And I was, "No. If that's going to help you guys be quiet. You're not the parents. [The respiratory therapist said] I just want to get out some mucus and stuff. And I was like, if it's not going to harm, nothing to do with the bronchoscopy, then, yeah, I want it done. And so she suctioned her and after she suctioned her, her oxygen, it went all the way to 98 by herself. And she goes, "Let me try taking out the nostril thing." The oxygen? [I asked.] Aw, she goes, "Let me try taking them off and see how she does." And usually right when we take them off she'll drop. I mean, she'll drop big time. They've tried it a couple times when she's in there. Cause that's the longest time she's ever been admitted was 8 days. And she tried taking it off and it stood up to 98 by itself for like 5 minutes. And I was like "Whoa." And it stood like that. She said, "I'm going to come back in and check on her in about 10 minutes." She goes, "But if it does drop within that time, come out and tell me and I'll come put it back on or whatever." And I was like, "Okay." And it stood like that, it stood like that for an hour. It stood like that the whole day, the whole night and the next day they let her come home. So that's all she needed. She needed to be suctioned and they didn't do it within the whole week-end. That's what she needed. D7.1 pp. 15-16.

Attentive to every phase of Carolina's care and always concerned for what would work to Carolina's benefit, Lara developed an intricate knowledge of how pulse oxymetry is used to assess and direct the treatment of respiratory crisis. She was attuned to the input of others as well, and participated in the management of Carolina's crisis even in the hospital. Lara acknowledged the fortuitous intervention of the respiratory therapist and then asserted her will over her mother's in the decision to allow Carolina to be suctioned. Restoration of Carolina's normal breathing resulted from mutual assessment and decision making on the part of Lara and the respiratory therapist, and validated Lara's interventions.

However, Lara worried that her assertiveness may have had detrimental effects.

> Lara: I didn't know [she needed to be suctioned]. [The] lung specialist R, came to see her. And he told them to do a ... it was a different chamber, it was like, it, it pumped against her face like, pressed real hard like that, back and forth. And it was, he said it was shooting the medicine straight to the lungs [and] making her [cough] and what happened then was [that] I thought that's why they weren't suctioning her. I thought that's why they weren't suctioning her, because of the new machine he put her on. [But I found] out you can still suction and use the machine. I didn't know that. I mean, I do ask a lot of questions while I'm there, like "What does this machine do? What's it for? What medicine you put in it? How frequently?" I ask, we ask all those questions, but I didn't know they can still be suctioned. I thought he was giving her [the mask and not suctioning her], because I kept telling him. Can you please not suction her every two hours. I says, "She's getting wore out getting woken up every 2 hours." I said, "Her nose is bleeding constantly out of nowhere." I said, "The inside of her nose is getting dried out." And I asked them "Can you not suction her as much." ...
> Int: And you think that's why they stopped over that week-end?
> Lara: I thought, I thought, that's what I thought. But when she came in on Monday, that respiratory treatment lady, she was like, "They haven't suctioned her?" And I was like, "No." She did and sure enough her oxygen went up. D7.1 pp. 16-17.

As well as feeling tremendous relief that bronchoscopy was not necessary Lara felt personally responsible that Carolina had not been suctioned for more than 48 hours. She had unquestionably played a key role in Carolina's crisis management and was not sure she had performed optimally. Being assertive on behalf of Carolina put Lara at risk of self blame even when professionals were clearly guiding the process. Lara deliberated in detail about the interface between breathing treatments delivered by mask and the need for periodic suctioning, a dead end as events would later clarify. Lara believed that if she had asked the right question, Carolina might not have suffered prolonged breathing distress and low blood oxygen saturation.

Theme #5: Asthma's Undiminished Fearsomeness

The parents who practiced flexible self agency never grew accustomed to the contingencies inherent in living with and managing asthma. Instead, living with asthma was a continuous struggle of adjusting to capricious symptoms, whose significance was not always evident. In addition, they felt compelled to respond appropriately in every new instance. In contrast, parents who practiced determined or continuous self-agency developed well-defined stances for identifying and responding to crises. Although asthma had presented itself in familiar patterns to parents who practiced flexible self-agency, and all parents felt themselves experienced in meeting its demands, they knew that in the future asthma could show a different, and possibly more fearsome face. As for most parents in this study, Abby felt asthma's scariness from the very beginning.

> Abby: ... [H]e would like he would be grunting for air sometimes. Like (she demonstrates gasping and grunting and then holding his breath), yeah and for a long period of time he would like (she demonstrates) and then ... hold it and then that's I jumped up out of bed and I grabbed him and took him to the hospital. That scared me. Cause he'd be like grunting and hold it like, (she demonstrates breathing) I could hear it. I could hear the way it was. It didn't sound good at all. ... That's when I just barely started to know all about this stuff. ... There was just a lot of times that he was just really really bad. Really really bad. D10.1 p. 23.

In retrospect Abby understood how little she had known about asthma at first. Unlike parents in the other groups, Abby continued to fear what asthma could bring even much later. After she had correctly suggested that Issac had pneumonia and needed chest x-rays, she worried if she could properly assess the severity of symptoms.

> Abby: I'm afraid that [Isaac's] going to stop breathing or [he could be] just not getting enough oxygen and we're not knowing about it ... *It's like, what if he, he has a massive asthma attack and stops breathing or I don't know what happens when that happens that's the only thing I'm scared about is him. Just, the breathing, that's what scares me about it.* You never know. Like I was staying in the hospital and here he is falling asleep and then he drops really low, his oxygen it drops very very low. And I'm like what, I wouldn't, if he was at home I wouldn't have been able to notice that at all. How would I have known that he was losing oxygen. I couldn't tell when that happened. ... I wouldn't have noticed that if I had been at home. D10.1 p. 22.

Abby thought the future could hold at least two frightening scenarios. In sudden crisis Issac might just stop breathing. Alternatively, even when symptoms seem milder, Issac might not maintain good oxygenation. In both cases, Abby's concern was that asthma could kill Issac and she wouldmiss the opportunity to respond appropriately.

By contrast, Anna and Maria, in turn, told about their relationships with asthma after long experience in dealing with crises.

> Anna: It's just when it happens, it happens. And I just have to deal with it. Take care of it, take care of her, give her her medicine and... [her voice trailed off and became inaudible on the recording]. D8.3 p. 21.

> Maria: And then she starts, you can see her, she starts breathing, you can see her veins from her neck.
> Int: Oh, so she really struggles to breathe.
> Maria: Yeah. A lot. When she talks she can, can't even hold a whole sentence because she has got to take a deep breath.
> Int: How are you through all this? ...
> Maria: Well, it's been so long, already I'm used to it. So. I know more about it. D3.1 p. 7

Abby's underlying worry about asthma also came up whenever Issac caught a cold.

> Abby: Asthma to me is something bad really, cause I've never had any sickness like that in any of my kids. For him to catch a cold and then get all this wheezing and then the congestion in his chest, I mean I guess asthma has affected his respiratory, I mean of course it does. But I'm saying if he gets a cold, I instantly get nervous because I think, oh God he's getting a cold

> now. His asthma's going to act up, cause the winter time it gets worse for him. ... And that's when I get paranoid. D10.2 pp. 9-10.

Abby always feared asthma for how sick Issac could become but also for the way it challenged her to respond.

> Abby: ... Like now it's like I try to catch it before he even, that point [severe crisis] even comes to him. But see it's like I said, I never know that he has pneumonia though. Because as soon as he gets a cold he'll be sick for two days and then he catches pneumonia. He gets it so fast. ... So I always, I never catch it soon enough. Never. D10.2 p. 21.
>
> Abby: And I don't know why, what causes him to get pneumonia. I don't, it's like when he gets a cold, and he starts to get that runny nose, I get really paranoid that he's going to get pneumonia. Instantly I'm like, oh God. D10. p. 29.

Asthma never left Abby feeling defeated but neither did she feel any sense of having control over its capricious way of showing up. Any sign of illness, whether respiratory or not, put Abby on high alert for asthma. On one occasion, in the summer just before our last interview, Issac had a fever of 104. In the previous 2 days his brothers had been ill with stomach flu, nausea and vomiting. Abby cared for them without seeking professional care. Abby's response to Isaac's sickness was entirely different.

> Abby: So now it's just if he gets, if I even, like yesterday or on Friday. I was wondering I've got to take him to the hospital. I've got to take him to the hospital.
> Int: Friday when he had a fever [and no difficulty breathing]?
> Abby: Yeah. I was ready. ... I was ready to take him to the hospital. And stuff, but my baby sitter, her husband was like, "No, just go to church and then if he's like that afterwards then we'll take him to the hospital." When we got home he fell asleep and the next day he was already better. *So but in my mind I was already thinking, I got to take him to the hospital, I got to take him to the hospital. I don't want him to get dehydrated. I don't want him to get an IV. I don't want... I was already getting, freaking myself out, but I just let it go this time and he was fine. He was fine.* D10.2 pp.21-22.

Abby lived with knowledge born of experience that Issac might develop pneumonia within a few days of beginning of cold. Even when his illness was not respiratory, and could be explained by contact with his brothers who were ill, Abby was primarily informed by the experience of Isaac's respiratory illnesses escalating into cough, wheezing, and congestion that she would be unable to prevent from becoming a full blown asthma crisis. In the events she recalled above, Isaac's vulnerability and her responsibility in the face of asthma's never ending uncertainty, moved Abby to prepare for a visit to the emergency room. Only the reassurance and assistance of trusted neighbors prevented the trip.

Thus, Abby's relationship to asthma evolved, through an on-going process of learning and responding to complex matrices of symptoms, and appropriate treatments and diagnostic procedures. Yet, even after several years' experience, Abby worried about the limits of her knowledge and skills. At times Abby's response to Isaac's illnesses proved brilliantly effective, while at other times Abby's fear of asthma inappropriately skewed her judgment about the severity of Isaac's less significant illnesses. Always in the background asthma loomed, threatening to overcome Issac, and undermine Abby's ability to care for him. Abby continued to be concerned that in the future asthma could impose unexpected demands and that her practices might require ongoing adjustment.

Self-Agency in Asthma Management Disrupted by Other Life Concerns

The Illness

For two families in the study, care of asthma was mostly overridden by other overwhelming life concerns. The illness was uppermost in parents' minds primarily during crisis and its immediate resolution. In remission, their concerns diminished dramatically. Overall, asthma drew the attention of these single mothers in two important ways. First, asthma was a very difficult aspect of an already very difficult life.

> Vicki: It's just another thing. It's just another one of problems in my life. It's, there's something else on the add-on. Do you know what I mean? Because it's like, my life's always been hard, [and] it's [asthma is] something else. ... Sometimes it gets frustrating and I start thinking, you know all this is happening to me when, oh my son's in the hospital I'm thinking, this has happened to me, this has happened to me, and this has happened to me. Now look what's happening to me now, my son's in the hospital. And everything I tried to do good, it seems like it's going worse for me. I'll think that. And I'll think, now what do I do, I mean to get away from the situation. ... I see the bad things. I see all the bad things. So it's like you know, I try to just take it a day at a time. That's it, a day at a time and see what happens. But it's nothing easy, it's hard. It's hard. D9.2 pp. 50-51.

Second, although both mothers continually put concentrated effort into being strong for their children, asthma crisis brought feelings of terrible weakness. Keenly attuned to Peter's agonized suffering, Margarita felt completely helpless during his worst crisis. Her story of Peter's worst crisis is exemplary.

> Margarita: I imagine it's pretty bad for him, because I mean, put yourself in his shoes, I mean. Or for me to put myself in those shoes. Imagine trying to gasp for air? The wheezing. Be wheezing all over the place, I mean. ... He looked like a grayish purple color. Like, like, more like a powder white but with purple in it? And that was like, you know he couldn't breathe if he was that color. I mean you just by looking at him, his eyes were watery, he was coughing a lot. It runny, he had runny nose. He was, he was pretty sick. He was crying I guess cause he couldn't gasp for his air you know. He couldn't. But he was, he was, he was coughing every, every, every two seconds he was coughing. ... [H]e was, he was looking in my face. ... [T]he way he looked at me like he wanted me to help him. [Margarita laughs as she tells this.] I felt so helpless cause I couldn't, all I could do was call the ambulance for him. You know the ambulance. And when they did, they said, "No this baby's very sick. We have to take him by ambulance." So that's when they kept, and the doctor said if we send him home he might collapse on you or something or you know or something could happen to him. So they kept him there. D6.1 pp. 8-9.

In this section, I will first present description of these mothers' difficult lives. Second, I will discuss the three central life concerns that shaped their management of asthma.

Vicki, 27 years old, and Margarita, 31 years old, were both physically and emotionally abused in childhood, and had abused their own children. Both struggled to provide better lives for their children.

<u>Life Concerns</u>

<u>Vicki</u> Living with a drug dealer who was the father of several of her children, Vicki had abused crack cocaine for 10 years until two years prior to these interviews. When her mother, who cared for Vicki's five older children, reported her to child protective service authorities, Vicki began a process of recovery. Her 13 month old son, Travis, conceived while she was on crack, was born when she had been "clean" and had been in a treatment program for about 6 months. Unlike her five previous births, Travis' was the first labor and delivery she ever felt. A photograph of Vicki at 18 years old showed a profile of her attractive, slender nose. Now, the nose lay wide and flat on her round face due, she told, me to sniffing crack.

Several months prior to these interviews, Vicki moved with Travis to a two bedroom, one bath apartment in a poorly maintained apartment complex where residents shared a dirt courtyard. According to Vicki, her neighbors were drug dealers. Two daughters, 2 years and 10 years, were living permanently with Vicki's mother. Three other children, girls 8 years and 5 years, and a 3 year old son, all under court custody, had been returned to live with Vicki and Travis only 30 days before these interviews began. Vicki was visited regularly by social

workers and had frequent court dates to determine if she were capable of reclaiming the custody of these three children.

Margarita Margarita lived with three of her eight children. Three lived with their father in the same town as Margarita. However, she rarely saw them. A 12 year old son, the oldest, and a 5 year old son were in the custody of Margarita's older sister. Besides 18 month old Peter her youngest child who had asthma, a daughter 7 and a son 6 years old lived with Margarita.

Margarita was not forthcoming about the exact circumstances that led to removal of her two sons from her home. However, she implied she had been physically abusive, saying she "had lost it". On another occasion Margarita also said she been neglectful by leaving her older children alone while she "partied." Margarita had a twin sister, Patti, who lived with a 3 year old daughter in an apartment about 50 feet from Margarita's back door. Patti had a history of physically abusing her daughter since infancy when she would, according to Margarita, bang her head against the infant's. Child protective service (CPS) authorities had long term involvement with Patti. Early in the course of my interviews with Margarita, Patti's daughter came to Margarita's apartment with bruises and cuts on her face. Margarita called CPS, and as a result, police and CPS authorities arrived at Margarita's apartment and put the child in foster care.

Margarita talked at length about her desire to provide her children with a happy childhood. Her own childhood had been very difficult. Especially tragic was the death of her mother. Overdosed on sleeping pills, Margarita's mother collapsed and died in the family living room as Margarita, aged 5, begged her mother to wake up. Subsequently Margarita and the eight of her ten siblings still living at home were subjected to regular physical and emotional abuse by their father.

Margarita could not write, and could read only a few words. She was unable to understand the instructions on Peter's prescription medicines and nebulizer. During the first of my visits, she asked me to confirm that she understood the schedule for giving the medicines and that she was assembling the nebulizer properly. Margarita wished that the nurse who had come to her home to visit her and Peter several months earlier could come again.

> Margarita: And there was a health nurse coming out as a matter a fact his name was D. ... And he would come over and he'd get Peter and he'll said, "Oh honey. What's wrong with you." and everything. You know he was real nice and everything. He checked on his heart, and he'd check his weight. How much he was growing. You know and that's the kind of help I really do need for somebody to come out and do that. D6.1 pp. 42-43.

Maintaining Control

Margarita and Vicki told of the strenuous and continuous effort they put into maintaining control over their own behavior and emotions.

Margarita Margarita explained her motivation.

> Margarita: I know it's wrong for me to hit on my kids, because my dad did that to me. And I, and I started thinking well I don't want to do that to my kids. Do you know what I'm saying? I was, I went through that, I don't want my kids to go through that either. That's a sad thing right there. To abuse on your kids. D6.2 p. 15.

In addition to refraining from physical abuse, Margarita wanted very much to be emotionally "strong" for her children. However, she found dealing with fear and sadness extremely difficult. Afraid and feeling helpless during the height of Peter's worst crisis, Margarita remembered how she had smiled inappropriately at the time. She laughed in the retelling as well. See the dialogue above on page

2, D6.1 pp.8-9. Laughing and smiling was, according to Margarita, her common response to sad topics of conversation.

She cried in telling me the story of her family. Then, self-conscious, she explained her discomfort with being "emotional."

> Margarita: I guess I gotta keep strong for my kids.... You know I try to be strong for them.
> Louisa: I love mom.
> Margarita: I love you too mija. I try to be strong for them, myself for them. That's where it comes, that's what keeps me strong, my kids. ...
> Int: ...Was there a time when that really came clear for you and you thought, "Yep, I'm strong."
> Margarita: Try to put things behind, that's all I can tell you. I mean try to put things behind. Try to do it for them you know. Be strong for them. So I don't want them to see me emotional like this cause that hurts them and stuff like that. ... So I try to be you know as strong as I can. Like Superman, you could say. D6.2 p. 13.

Not crying was a way for Margarita to be strong for her children. Louisa, her 7 year old, came in from playing on two occasions during our interviews to ask if her mother was crying. Margarita avoided some subjects I asked her about, calling them too emotional. Her crying, Margarita said, would make her children feel sad.

Vicki On her own, and for the first time, parenting her children sober, Vicki was struggling to manage four children, three under the age of 5. Although she was under close scrutiny by Fresno County Child Protective Services and the County Court, what Vicki said about her effort to control her life was tremendously painful to hear. Vicki said about talking to her children, *"I yell at them a lot."* From my observation, she was easily frustrated and not skilled at involving her children in activities they enjoyed. She would tell them to play outside in the dirt courtyard. The small space was treeless. There were no toys, only cement stairways to other apartments. A mud puddle had been created when a hose that watered the dry grass in front of the apartment complex had leaked at its connection to the faucet.

> Vicki: I yell at them a lot. I have a bad habit of yelling at them. And before I used to have real foul language. I used to cuss at them a lot. I did. I'm not going to say I didn't. I used to cuss at them really bad. For them being kids, I mean I used to curse at them. And now to the point to where I took parenting, took all these other classes. Do you know what I mean? And I went through rehab and I went through things to learn to calm down, take time out for myself. If I get too frustrated with them, I'll take time out. ... lock myself in my room, cause I know I'll get to the point I'll want to just hit them. Keep hitting them and it's not going be do me no good to keep hitting them. D9.2 p.26.

Even on routine days Vicki's tenuous hold on mothering worried her. She put immense effort into not becoming angry or violent with her children. Physically abused in childhood, Vicki told me how flashbacks of her abuse flooded her memory as she dealt with her own children. Vicki requested psychotherapy for herself. In order to establish her reliable interest, the Fresno County Adult Outpatient Mental Health Clinic would see her if she showed up for three intake interviews before beginning therapy. Vicki made the first appointment, but failed the others.

Since her older children had moved in with her Vicki wondered if Travis' asthma had exacerbated as a result of her increased stress, Travis having to share her attention, and him hearing her "yelling" at the other children.

> Vicki: Now it's been three months ... that I've had them. Getting kind of used to them now. Travis's getting used to them too. He's got more people to play with now it's not just him no more. ... Cause he's used to being the only one since he was little. Now he sees that his brothers and sisters are there. He don't like it that much. And that's why the first time I thought too may be he was getting sick... .. Now it's not on him no more it's on all of them. He's not the only one. ... [And] I thought maybe because of all the noise, stress, and me yelling. And then him thinking that I'm yelling at him. D9.2 p.2.

Managing Symptoms

The Hassle of Controlling Symptoms Vicki found that asthma management required trying to deal with unpredictable episodes of wheezing and cough. She struggled especially when Travis' had symptoms at night.

> Vicki: I have to be up all day. The sleep that I get at night, I need it, for the kids. Do you know what I mean? I mean he's not the only one I got, that's what I mean. The other ones are, they're strong. They're up all day. They don't take naps. They're up constantly up and down. So it's like I have to be behind them constantly, watching out for them, feeding them and you know. D9.2 pp. 36-37.

Vicki needed the physical and emotional stamina to meet the various daily needs of all of her children. Since she could not do well on interrupted sleep, nighttime strategies were designed to ensure that Travis sleep well rather than to determine if his distress was due to asthma. In order to avoid waking Travis up unnecessarily at night, Vicki would not give treatments if Travis were sleeping. On the other hand, if he seemed restless, Vicki gave medication even when she was not sure that Travis' breathing was stressed.

Managing Amidst Suspicion and Mistrust

Vicki and Margarita felt suspicious and suspected, mistrustful and mistrusted. They walked a tightrope stretched between their private struggles for control of disturbing emotions and behavior, and a life under the public scrutiny of social service systems and the county courts. Crisis prone asthma raised intimate havoc in their already chaotic lives.

Vicki Vicki, especially, felt suspicion and suspected at nearly every turn. All aspects of her life were constituted by the demands of the court. She knew that if she failed to keep dental and medical appointments for her children, and if her two school age children did not attend in school regularly she would not be

given their custody. Travis' most recent asthma crisis and five day hospitalization left Vicki teetering between failure and success in the eyes of county authorities. With Travis in the hospital and the other children at home, Vicki needed help, but had none. Her mother and sisters, alienated by Vicki's long drug habit, did not offer their assistance when Travis was sick.

> Vicki: I knew that that's the way they [her mother and sisters] were, but still it kind of made me upset and I started crying cause I was like God, why can't somebody be there for me. Just this time right now that I need somebody. D9.2 p. 16.

In being forced to choose between being with Travis in the hospital or with her other children at home, Vicki felt abandoned and vulnerable. During Travis' previous crises, she had lived alone with Travis in the drug treatment program facility. Whether Travis was well or ill she could be with him night and day. This time, Vicki tried bringing her older children with her to visit Travis in the hospital. However, she lacked the parental control or influence to manage the visit satisfactorily. *"They [the children] run through the hospital. I have to run after them."D9.2 p. 16.* At one visit with all the children, she was told by nurses that her children could not be allowed to run through the hospital. After that, Vicki stayed at home during the day and visited Travis in the evening when her boyfriend was home from work. She would returned home late in the evening, to sleep in order to be with her children in the morning when her boyfriend left for work. Providers criticized Vicki.

> Vicki: Yeah, I didn't manage to spend that much time with him [Travis in the hospital], that's why I got in trouble, because they said I wasn't spending enough time with him. They thought I was abandoning him. ... The doctor had told me ... that he'd never seen me. As many times as he'd been in there, he'd never seen me. So he had to call social services on me, he told me because I was not being a responsible mother, like I was suppose to. I was supposed to be there with the baby and spend more time with him. And like

> I explained to him, it's impossible, I told him I got three other kids at home. I got to send to school and stuff. ... And I don't have no, I have family, but not somebody that will say, okay, well I'll help you out. Do you know what I mean? Leave them with me for a couple of hours, go. Nobody. None of my family would even take time out to do that for me. D9.2 pp. 15-16.

The hospital social worker arranged for volunteers to spent time with Travis during his hospitalization. Thus, Vicki endured feeling abandoned by her family, torn by the demands of asthma crisis, and criticized by Travis' physician whom she knew belonged to the network of authorities who controlled her future. Worse, she felt miserable leaving Travis alone overnight in the hospital.

> Vicki: I think he was in there five days. Five days, yeah he was in there. I would get up in the middle of the night and I just wouldn't sleep right. I guess I would feel him crying. I could hear him crying for me. And then I would get up and I would walk to the crib and my [boyfriend] would tell me, "What are you doing? What are you doing? The baby's not here." I guess it'd be in my sleep, he'd go, "Come on lay back down." And then I'd start crying, because then I'd look at the crib and then I was like, my son's crying. He's crying, I know he needs me right now. I can feel him crying. I hear him. So I called the hospital in the middle of the night. And they would tell me, "No, he's sound asleep." So I thought okay, well I'd go back to bed for a little bit. But then I had really restless nights. Cause I would hear them. You could hear, you could feel your kid. Do you know what I mean? Crying. You could feel that. You could feel the hurt they hurt. Just like they could feel your hurt. You know when they hurt. When they hurt, when you hurt. D9.2 p. 18.

Vicki felt that her family and Travis's physician viewed her every action with suspicion. Moreover, she felt caught in an impossible parenting dilemma, but without a choice, she carried on unsupported, except by her boyfriend. Asthma had only heightened the anxiety that pervaded Vicki's personal and family life.

<u>Margarita</u> Margarita's life was infused with relationships of mistrust. Besides her early family history of disturbed relationships, her estrangement from three of her children, her infrequent contact with two others, and her confrontation with her twin sister, Margarita experienced a major rift, during the

period of our interviews, with an older dependable sister who was the legal guardian of two of her children. *"When I need something, she'll help me out or something or she'll take me to the doctor's appointments and stuff like that." D6.1 p. 2.* Following an argument over whether Margarita should wear a borrowed ring, they did not talk for several weeks.

As in her relationship to her sister, Margarita depended heavily on professional expertise and an accommodating hospital environment for help with Peter's asthma management. However, as with her sister, Margarita was profoundly angered by hospital professionals. On the one hand and in contrast to her own low self-confidence, functional illiteracy, and the profound emotional challenge she felt when Peter suffered a crisis, Margarita's expectations of professional care and her need to depend on staff were high. She trusted their knowledge and expertise, and felt supported in their caring.

> Margarita: [T]hey're real good there [at the hospital]. I like the nurses and everything. They're nice and everybody knows Peter. When I take him over there, like for x-rays, they take x-rays of his lungs, to see if he doesn't have any leumonia from the last time. .. And they say, "Oh hi, Peter." All the nurses knows him already and they'll start touching his hands and everything. D6.1 p. 7.

On the other hand, she felt let down, condescended to, accused of mismanaging Peter's symptoms, and mistrustful he would be well cared for in the hospital. Several hospital experiences were negative. First, at the time of admission for his worst crisis Margarita was frightened by Peter's suffering and did not know how to help. However, in the hospital she was blamed for the severity of his crisis.

> Margarita: Like this last time he this, this doctor right there at [hospital] he was mean to me. Not a doctor, but I mean a nurse, but he was, he was a guy. And he was kind of mean, he goes, "Well your baby's wheezing and

> everything, because well, you don't control it honey in time." Like you know he kind of like raised his voice up at me. ... I said, "That's mean. I mean I bring my baby so you guys can help him and this is what you tell me." And then he starts yelling at me I mean like trying to raise his voice up on me. As it is you're upset and then for them to tell you something like that? ... And I go well in the first place, this is why I brought my son over here so you guys can help him. I said, and he goes, "Well I'm just telling you maybe if you would've controlled it on time, *mom*" [Margarita's emphasis] and he kind of like raised his voice up on me. "If you would have controlled it on time, that would have not happened." To the baby, he goes, "Poor little baby." And he was like, rubbing his hair and everything.
>
> Int: Oh, so he was nice to Peter and not nice to you.
>
> Margarita: He was, yeah he was, I didn't want him to be nice nice to me, but I mean, but him yelling like that to me? ... I mean as it is you're broken hearted by taking your baby like that and then... I told one of the doctors and one of the doctors talked to him. ... I'm not trying to be mean or anything, but I mean that's not right for them... you go there so they can help you, not so they can lecture you. D6.1 p. 11.

Margarita had come to the hospital desperately fearful for her son. Instead of the help she hoped for, she felt accused and suspected of being uncaring, incapable, and neglecting. Her deference in speaking up after the incident described above belied the depth of insult to her empathy for Peter's suffering, the action she had taken on his behalf, and her disillusionment at being blamed for his circumstance.

During Peter's nearly week-long hospitalization, Margarita's anger was triggered again. She spent the days and two nights out of three in the hospital. One morning she had come back to the hospital to find scratches on Peter's leg.

> Margarita: Like, this last time when my baby was in the hospital, there was a lady, you know how they give him treatments, the nurses? ... Okay, when, when I left, I left my baby in charge to them, well I took off home. Cause I had to go home and shower and change and eat, cause there they don't give you any food, you have to buy your own food and stuff. And when I went home... ... when I went back, it was on a, okay Friday I took off, then Saturday morning I went back and I noticed my baby has scratches right here.
>
> Int: Scratches on his leg?
>
> Margarita: On his leg. Big old lash, lashes of scratches. I guess where they hold him down, cause he kicks a lot and everything. And I, I told the

> doctors, I told one of the nurses there, the head nurse of staff, I told her, "What happened to my baby. How come he's like this?" And then you could tell, it hurted him a lot, because when I was changing his diaper, well I would put lotion on him. Cause I have that habit of putting baby lotion on him. ... He would just toss and turn. And you could see where there were like this, and they looked like grown-up's nails.
>
> Int: Finger nail scratches.
>
> Margarita: Finger nails, yeah. And they, he was like, you could tell where somebody tried to hold him tight. And they and like, cause the baby does move. You know what I'm saying? Cause he, I mean nobody likes for somebody to stick a big pipe down their throat or down their nose. Their going to jump around and everything like that. ... I told them, and then the nurse looked at me she goes, "Well honey, I don't know what happened." And I go, "You guys are nurses. You guys should have patience for this, for these kind of things, I mean. Why you guys let this happen to my baby." What happened to him, I was all upset, I was saying all kinds of stuff. ... And I go, "I want to talk to the head nurse. Your head nurse." Not the one I was talking to, but another one. The supervisor. And so I talked to the supervisor and they said that they were going to find out who was it. And they don't know who it is. Up to this up to today, they don't know who did that. ... But I think that's rude. You know, because the next time I'm not going to, I'm not going to be able to um, um, trust in them because of the baby. You know what I'm saying? Or leave him there by himself. I'm not going to trust those nurses up there. I'm going to keep right there. I'm going to stay right there on his side. D6.1 pp. 12-13.

The episode left Margarita questioning not only the nurses reliability but also her own.

> Margarita: ... For them to do that to my son, scratch him like that. I don't know if they did that or not, but I'm under the expression they did. (nervous laugh) Because I mean who else is going to scratch him? I'm so sure, I don't think the people right next door to him, that you know like the roommates next door? ... The little babies and stuff and the mother's. I don't think their going to go up and scratch the baby. You know what I'm saying? ... I mean, it had to have been a nurse. That's that's my expression, I mean. ... It was hard for me. It was hard and I don't think that was nice at all, what they did to me. What they did to the baby.D6.1 p. 13.

With no one owning responsibility for the scratches on Peter's leg, Margarita wondered if she might have accused the nurses falsely but decided she had not. Further, Margarita wished for better more attentive nursing care. She especially wished the nurses could pick up Peter when he cried. Crying made his wheezing worse. At home, after giving medicines, Margarita's first way of managing a crisis was to hold Peter to her chest while, as she rhythmically thumped his back, he was temporarily calmed.

> Margarita: One of the nurses one time told me, cause I told her, "Can you please pick him up if he's crying?" I told him, cause one time I walked in the baby was crying and his face was all red and everything, cause they had let him cry for a long time. The nurse goes, "You know what honey, we can't be picking up the baby each time he cries, cause we got other kids to attend too." So, you know then, one time I come over and I see him all scratched up like that. So that's why I don't even trust them any more. And that's a crying shame you can't even trust the nurses around there. D6.2 p. 37.

For Margarita, this issue too, that is, whether the nurses would hold Peter, was an issue of mistrust verses trust, rather than an issue of conflicting expectations and competing needs. Margarita expected Peter to be given lots of tender loving care to assuage his fears. The nurses could not comfort Peter at every turn and still give necessary treatments to all their patients.

Other parents, Lucy, Ruby, Lara, and Abby, for example, expressed as Margarita did, conflicting attitudes toward hospital staff. They talked of being watchful during hospitalization in order to insure that their children received the best care and attention possible. All had misunderstandings with nursing staff. None, however, was left as helpless, confused, and full of self-doubt as Margarita in the wake of negative encounters and experiences. Lucy, Ruby, Lara, and Abby responded in ways that left them feeling stronger and more in control of what to do when future crises occurred as was discussed in earlier sections of this chapter.

Disrupted Day by Day Management

Vicki understood that with asthma airways became inflamed and constricted, however, her understanding of the different actions of Travis's various medications (oral, nebulized, and inhaled through aerochamber) was confused, changing from one time to another during the study. Vicki suctioned Travis with a bulb syringe when he seemed congested and percussed his chest to loosen his phlegm. Travis had a new supportive pediatrician who saw him regularly and would talk to Vicki when she called.

> Vicki: He's an excellent, excellent doctor. ...[H]e's helped me cope with this. He's helped me deal with the situation. ... He's helped me deal with the situation that I have when the baby's sick. He'll take it step by step with me and explain to me how what I can do or you know how he can ease my mind from thinking so much about it. D9.1 p. 8.

Yet, asthma management was difficult.

> Vicki: The hardest part for me is, when he doesn't, he doesn't want anything. He doesn't want to eat. He doesn't want to do anything when the asthma really starts to hit him, he doesn't want to eat. He doesn't want to do anything. He just wants to be feisty. He just wants to be crying and he wants to be held. And I understand that and that's okay, but sometimes I can't do it cause I got other ones too. I got things I got to tend to. And he wants to be the only one. He's been the only one for a long time, since he's been born. So now it's, now the other kids are in the home and now he's, it's kind of hard for him to cope with that cause it's always just been him. D9.1 p. 14.

> Vicki: The hardest thing about him is just the restless part. When he doesn't sleep and he doesn't want to eat anything. That's the hardest part, when he just cries and cries. He don't want anything. You could suction him out and that's only hard. That's the only thing I don't like dealing with. Is him being irritable. D9.1 p. 17.

Vicki suffered most from Travis' asthma because it precluded order and calm in her daily life. Asthma made Travis irritable and restless. She knew he suffered and wanted to calm him but often did not know what to do. At times when Travis was inconsolable but well, Vicki was able to leave him alone to cry.

However, when he was ill, she realized that leaving him to cry made his symptoms worse.

Margarita had minimal understanding of asthma management. Although, she gave medicines in the way she was told, she felt confused at almost every turn. Peter had a cold for three days prior to his worst crisis.

> Margarita: He had it only for three days. Just for three days. And I didn't think anything of it cause I had some medicine there, but it was still good and it was, it was his name on there. And it was albuterol, but it seems when I gave him that he got, I don't know he just got out of control even more. ... And that's what I told the doctor. and the doctor said that didn't cause it, what caused it was that he had a flu. That he was already, the virus was going on and ... it was just that he was already sick. That's what it was.
> Int: How long was he really having trouble breathing?
> Margarita: He just, just that day, he just, he just started all of a sudden. ... I was laying down with him, on the bed and it was in summer too. And I, I was, we were all laying down watching TV in our bedroom. And all of sudden I hear he's, he's, he's sleeping, he wakes up, I guess cause he couldn't gasp for his air and he started wheeze, and I heard it and I mean he was just wheezing all over the place. He turned purple on me, just in a few minutes. D6.1 p. 6.

In retrospect, Margarita felt unsure that she had acted appropriately in giving Peter albuterol, even though these had been his pediatrician's instructions. The limits of her ability to trust others and to learn contributed to the confusion Margarita felt around asthma, and the stakes were high.

> Margarita: I only know that's it's very dangerous if you don't control it and you can pass on and you could die from it, if you don't control it. ... Especially on babies. Their lungs, their lungs ain't that big like ours. D6.1 p. 20.

With almost no warning asthma could disrupt life, and plunge Margarita into feelings of helplessness. She recalled Peter's most recent hospitalization.

> Margarita: He said one of his lungs had leumonia. He had leumonia on his right lung. And he was having a hard time breathing cause of that. So that's emotional. That's why I keep a close eye on him, because of all of

> that that I've been through too. ... I didn't know he was that sick. Cause like I told you he was, he was wheezing, he was wheezing a lot, but he wasn't, not like the first time when he really got sick. ... You could barely hear the wheezing. And that's what I don't understand and then they pronounced him that he had asthma. And I got real upset and got so upset I couldn't even talk to the doctor. ... He could have passed, if I would have left him here at the house, the doctor said, or maybe two more days, he would have died on me. D6.1 pp. 35-36.

With asthma Margarita was caught up with a very dangerous illness over which she felt minimal influence. Confusion met Margarita at almost every turn in asthma management. She had been confused about the meaning of symptoms, confused about the use of the medicines, and confused about what she needed to do to prevent crisis and escalating illness. Peter's asthma left Margarita speechless and flooded with emotions. *"I didn't know what to do, I mean it was like... how can I tell you? I was helpless. I couldn't do anything to him. ... So that's helpless right there. You feel helpless." D6.1 p. 34; D6.2 p. 18.*

Understanding Prevention

Vicki did not place faith in prevention. Except to avoid Travis's exposure to cold, she found only little connection between avoidance of triggers and the onset of symptoms. On several occasions when I asked if there was anything she could do to diminish the frequency of Travis' symptoms, Vicki would shift the conversation to talk about how she gave medicines at illness onset. Thus, Vicki admitted to no deliberate prevention practices, even though she said she had read that dust and smoke could trigger symptoms. Vicki also reported that she smoked on occasion, but only outside. Her home seemed neat and swept on the occasions that I visited. However, Vicki freely allowed Travis to play outside in the dirt with his older brother and sisters. This practice also gave Vicki a few moments to herself inside the apartment whose large kitchen window was open onto the area where the children played. When asked about effective ways to prevent asthma, or if there was anything she could do about it Vicki said, *"You know, to tell you the truth, I don't notice anything. It just comes all of a sudden." D9.1 p. 29.*

Margarita, by contrast, believed, as she had learned from professionals, that asthma prevention required keeping Peter out of the cold and away from smoke. She saw the problems with smoking first hand. On one occasion her brother was smoking when he came for a visit. When he lit a second cigarette, Peter started to cough so Margarita insisted her brother stop.

When Margarita discovered that something like smoking caused Peter to wheeze she avoided the trigger. Triggers she noticed included perfumes, hair sprays, and burning food in the kitchen. *"He'll kind of like want to throw up and cough and stuff when he's around perfume and stuff like that. So actually that's why I don't put any perfume on or sprays in the house." D6.1 p. 19.*

Both mothers, but especially Margarita, kept themselves, their children and their small apartments neat and clean. However, whether they were motivated to do so by my visit, or by asthma, or for some other reason was not clear. Margarita cleaned and rearranged the furniture in her living room on a regular basis. Vicki said she swept her floor every day. On days when her children played outside she sometimes bathed them twice. Most disconcertingly, Vicki had to wage a continuous battle against cockroaches. Although cockroaches shared apartments with many families in this study, Vicki's living space was the most infested. Several hung out behind each picture on Vicki's living room walls. Eventually Vicki took the pictures down. The couch, Vicki said, was their haven. She hoped to move to an apartment without roaches. Before moving she would throw the couch away so as not to risk taking them along. Cockroaches walked across the kitchen floor only several feet away from the couch where we sat and talked. In addition, Vicki suspected that a recent bite on Travis' arm had been from a cockroach.

The Role of Researcher and the County System of Social Services

Vicki and Margarita were familiar and involved with the system of social services in Fresno County. Both perceived my visits as part of a system of services which could be helpful but was also threatening. Vicki risked losing her children depending on the judgement of the courts about her suitableness to parent them. She was very agreeable and presented herself as cooperative and not threatened. However, I could not determine the degree to which Vicki trusted the interview and observation procedures of this study. It is possible she worried that to refuse the interviews, drop out, or be uncooperative would jeopardize her standing with child protective authorities. Perhaps, she thought cooperation would be to her advantage. Perhaps she was motivated to participate by the $25 fee paid for each interview. It is impossible to know.

Margarita's constant concern with making a good impression and the parallel concern that I was not fully trustworthy most certainly limited the quality of our interviews. On one occasion I brought her family some brownies. Later, she ate one, felt sick and worried that I might have laced them with drugs. As a result, she did not eat the others. Margarita was openly confused that I had not come to help her understand and care for Peter's asthma. In addition, she was always wary of the tape recorder. Several times she got into a sensitive discussion of her feelings only to interrupt herself to ask me if the tape recorder was still on. When I said it was, she would usually continue talking. Only on one occasion did she request that I turn the tape recorder off. When I did so she continued her narrative by repeating a vulgar epithet that her sister had flung at her in anger. Despite the indications of mistrust, Margarita was very open with me about the very painful experiences of her childhood and about the funeral of a friend who had committed suicide during the course of our interviews. During the observation periods, Margarita would talk continuously about her life even though I never asked her to do so.

Discussion

Margarita and Vicki attended to their sons' asthma almost exclusively only during crises. Otherwise, their concern for asthma was pushed to the background by other more pressing family concerns. Asthma never failed to hold salience for these mothers who both felt their sons' suffering deeply, and feared that asthma might cost Peter and Travis their lives. Nevertheless, their concerns about the illness, did little to shape Margarita and Vicki's daily parenting and caregiving practices, and were not discernable as clear patterns of management practice.

Asthma crises were remembered as times that severely disrupted the tenuous hold each of these mothers had over her own life and the life of her family. While each mother attested to and demonstrated her desire to provide a better life for all her children including her son with asthma, attaining this goal was a continuous uphill battle. For Vicki, especially, the struggle held more failures than successes. For her children the pain of her continually shifting ability to parent them must have been almost intolerable. Within 3 months after my last visit with Vicki, she had returned to drugs, and re-entered a drug treatment program. For both mothers, emotional distress from the memories of their own childhood abuse arose to interfere with efforts to discipline their children lovingly and effectively. Family members sometimes helped in small ways but were also estranged. Both mothers were alone especially in times of asthma crisis.

Vicki and Margarita had learned the importance of cooperating with the court system and the world of human service agencies, including the health care system. These agencies held commanding influence over their lives and the future of their families. Both mothers depended on, but simultaneously mistrusted that system. As a result, these interviews, although cooperative, were infused with guarded responses.

Margarita and Vicki gave a picture of clearly compromised asthma management and parenting skills. The poignancy of their situations lay, however, not in their deficiencies, but in the enormous obstacles inherent in their striving to be good mothers, to manage asthma adequately, and to prevent the suffering of all their children.

Chapter Summary

Characteristic management practices of parents in these four groups arise from parents' differing understandings of their own relationship to their child's asthma and their differing suppositions about how to manage it. Those with determined self-agency believed that in order to survive asthma their children depended solely on them. Crisis brought a heightened fear of failing the child, a correspondingly heightened sense of responsibility, and profound feelings of self-blame or anger when management was less than optimal. During hospital management of crisis parents actively absorbed management procedures and knowledge about the use of medicines in order to learn how to manage crises without hospitalization. These parents expressed open mistrust of providers, maintained scrupulous hospital vigilance over provider practices, and devoted themselves to managing crises at home whenever possible. Finally, despite poverty, and lives filled with other difficult demands, they defined asthma as the biggest stress in their lives.

In contrast, parents practicing in the style of discontinuous self-agency felt overcome by their own fears during their children's asthma crises. These parents felt helpless during hospital crisis and entirely dependent on professional caregivers. Unable to think, unable to communicate their support to their child, and unable to find an effective role for themselves during hospitalization, they learned to tolerate their children's discomfort and suffering. These parents rarely critiqued providers. Without understanding differences among medications, parents in this group followed medical instructions closely. Even when given the encouragement by their physicians to be more aggressive in giving medications on their own if crisis seemed pending, they requested physician consultation before doing so. Understanding medications and employing recommended prevention practices held little hope for relief from asthma. The parents in this group typically responded to asthma crisis in their children by noting its signs, and staving it off as long as they could, with little hope of resolving the symptoms. Subsequently, feeling self-defeated, they left home to seek emergency care. There, even though like all but one family in this study, they never left the child's side, management was entirely given over to hospital providers. They all claimed they *"got used"* to asthma and expected frequent, and possibly worse, crises to continue. Two of these mothers minimized their significant worries about asthma's continuing threats although they clearly recognized the prospect of future crises, sensed deficiencies in their knowledge, or felt self-doubt undermine their confidence in accustomed management strategies.

In contrast, parents who practiced flexible self-agency always held to their own central role in management, depended on professional care, and maintained a sense of responsibility for outcome. While never getting firm control over asthma's fearsomeness and varied presentations, they were never completely overwhelmed by asthma. Instead, these parents struggled with the variable demands asthma and professional management posed. In response they adjusted management strategies according to the contingencies of each situation. Although parents practicing flexible self-agency absorbed knowledge from hospital experience, provider encounters, pharmacists, and from family and friends, what they learned remained in a background arsenal to be called on if needed. Families in the other groups, by contrast, developed less flexible patterns of assessing symptoms and responding to crises. In contrast, parents with flexible self-agency felt depth and strength in their own capacities for effective asthma management. Stress due to asthma waxed and waned for these families, depending on the presence or absence of severe symptoms. However, prevention practices played a central role in routine asthma care even when symptoms were not evident. As much as they trusted their own abilities and counted on the effectiveness of their own responses, these families also counted on collaborative professional help. Asthma remained for them neither something they felt control over nor something to which they became accustomed. Living with asthma was thus an evolving circumstance with an open-ended future. For parents in other groups asthma crises took on a predictable face. In response they established fixed patterns of practice designed to control and manage crises. When children were asymptomatic, these practices were largely abandoned.

For the two mothers for whom asthma management was disrupted by other life concerns, response to asthma was limited to meeting the demands of crises. Prevention and routine management were not issues for these mothers in the face of larger issues of their own behavioral control and the parenting of their large vulnerable families. The more complex concerns which informed their behaviors did not come through in their interviews.

CHAPTER 7

Parents' Accounts of Children's Acute Asthma Crisis and Its Management

The Problem

Acute asthma crisis in infants and toddlers demands immediate attention to clearing and opening airways, assuring adequate oxygenation, and initiating treatment of underlying causes of airway distress such as infection and inflammation. Comforting children and allaying parents' fears are necessarily of secondary concern. However, meeting children's physical needs, does not address the critical emotional needs of children and their parents when symptoms are acute. Hospital crisis was for, all parents in this study, the hardest part of living with the illness. Management procedures for acute asthma crises were defining emotional events of high intensity that focused the difficulty of living with asthma by affecting parents' relationship to their child, the illness, children's responses to management, and parents' subsequent asthma management practices.

The long standing belief that children with asthma grow to be overly-dependent on their mothers and their mothers over-protective of them (Williams, 1975), however unfairly stereotypic, indicates the significance of affective as well as physiological aspects of acute asthma crisis. However, the typical western biomedical approach is to minimize the importance of emotions and the meanings of illness events. "Soft" professional attention, that is, attention to psychological and socially significant aspects of illness, rather than the physiological and technical, is considered less relevant and not cost effective (Kleinman, 1988). In addition, there exists within western medicine a widely held underlying assumption that all suffering stems from biomedical factors. In this view identifying disease pathology, finding the cause, and delivering the biological / technical cure eliminates the need to attend to illness meaning (Foucault, 1973).

The purpose of this chapter is to focus on parents' narratives of their children's and their own experiences during hospital management of asthma crisis. Emotionally, hospital crisis management is a story of pain, abandonment and separation, and fear of death, all emotional situations of great import especially for infants and very young children and their parents. According to attachment theory, all of these experiences are central to the understanding of children's emotional needs and parents' responses. As a result, in this investigation, interpretation of the parents' perspective is informed by attachment theory as proposed and practiced by John Bowlby in the psychotherapeutic treatment of children and their parents (Bowlby, 1958; Ainsworth, 1992). Two important concepts from attachment theory bear the most immediate relevance for this investigation. First, according to attachment theory, the most salient dynamic of every young child's emotional experience and the basis for the interactional and affectional relationship between parent and child is that, *when frightened, children seek the protection of a particular parent or caregiver.* The quality of protection felt by the child over time becomes the basis for emotional well-being and the development of a secure sense of self. Second, attachment theory includes the premise that *both the need for and the desire for protection from fear, whether real or imagined, continues throughout life* (Ainsworth, 1989). Studies show that parents who are afraid are in need of protection in order to feel secure themselves and in order to provide optimally responsive caring for their children (Main & Morgan, 1995).

Original studies of attachment were done by observing the interactions between children and their mothers. However, infants are known to form primary attachment bonds with other individuals who are not their mothers (Ainsworth, 1989). In addition, Main, Kaplan, & Cassidy (1985) found that fathers and mothers form separately unique emotional bonds with their children. Comparisons between the bonds of mothers and children, and fathers and children have not been extensively studied, however. In this chapter "mother" will be used when discussing the primary attachment relationship between infants and adults for efficiency and smoothness of description.

Attachment theory, by focusing attention on frightening experiences and the need frightened children and adults have for protection, allows a valuable perspective for assessing current practices. On that basis, attachment theory can inform practitioners who care for infants and toddlers with asthma whether management of crisis promotes or impedes parents' protection of their children and provides parents support in their parenting role.

Introduction

Parents identified naso-tracheal suctioning as the most traumatic, frightening, and distressful aspect of hospitalization for their children and also for themselves. Since airway secretions often reaccumulate quickly to clog airways, suctioning was sometimes repeated as much as every two to three hours in the first hours and days of asthma crisis. With repeated hospitalizations, the procedure became routine but no less terrorizing for children in this study.

Despite strong negative feelings, parents also viewed suctioning as a tremendous advantage of hospitalization since effective opening of clogged airways could not be accomplished at home with the use of a bulb syringe. After hospital suctioning, on the other hand, breathing improved dramatically.

Most parents also had extremely negative feelings about breathing treatments delivered under restraint and the pain of intravenous catheter (IV) insertion, especially when several unsuccessful attempts preceded successful insertion of the catheter. However, neither IV insertion nor breathing treatments seemed to parents as onerous as naso-tracheal suctioning.

Parents told about their children being "panicked" and "terrified." They were "scared" that their children might die from breathlessness and they, the parents, usually cried. In acute asthma crisis, parents felt challenged to provide relief for their children in a situation beyond their control. They felt vulnerable, unable to cope on their own, and in need of guidance.

In this chapter, I will consider both children's and parents' experience in discussing how parents perceive their children's fear, crying, and efforts to solicit the parents. The parents' own fear, anger, response to their child's suffering, and responses to the medical crisis will be reviewed. A discussion follows of how the interpretive findings inform our understanding of professional caregiving for children and their parents during hospital management of asthma crisis.

Childrens' Fear

Precisely when a child's fear of breathlessness is most acute, crisis management dictates that she endure intimate bodily restraint by strangers, and procedures that are painful, intrusive, and would be frightening even if breathing were normal. Parents describe how their children are terrified during suctioning and fight to exhaustion.

One mother, unfamiliar with asthma, described how she recognized the severity of her 3 month old son's first episode of distressed breathing by the fear on his face.

> Lucy: He just gets really panicky. He gets real panicky and scared like, like a look like real scared. ... Like he's confused. Like he's confused like he doesn't know what's happening. D1.1 p. 18.

Fear escalates with the pain and intrusion of air space brought by the insertion of a suction catheter.

> Corrine: I mean they're scared, they're, they're... I cried the first time. It was hard just to see that she was terrified and you know it hurts. For them to stick something down your nose and she was just terrified. D11.1 p. 11.

Acutely attuned to the terror 21 month old Bette felt, Corrine cried.

Several parents believed their children felt most frightened by being restrained. Abby, mother of Isaac whose last hospitalization was at age 23 months, recalled:

> Int: He cries [during suctioning]?
> Abby: Oh yeah. Well, because they have to tie, put his arms down and tie him up with the blankets and you can imagine sticking a tube up your nose. I mean no one, he just, they said it doesn't really hurt, it's a little uncomfortable, but usually they draw blood from him all the time you know. It's terrible. D10. 1 pp. 14-15.

Not quite convinced that suctioning did not hurt, Abby described how Isaac most hated being tied down.

> Abby: I don't think that it's painful when they do it [the suctioning], it's uncomfortable, when they do something like that, but it just scares them and they cry cause they don't like it. ... I don't think it's painful, I think it's really

> uncomfortable but I don't think it's pain, painful. It's just for a little baby to have to be tied down it's really, for one it's going to piss them off. I'm sorry but.. They're going to be like... That's what makes them go nuts I think. And then to have a tube stuck up their nose and stuff. ... So yeah just for one to have them tied them down is just, they automatically start screaming and crying you know. D10.2 p. 12.

Jimmy and Corrine agree that restraint is most terrifying for their daughter Bette who was 21 months at the time of her hospitalization:

> Jimmy: Well she doesn't like to be like strapped down. Probably no kids like that.
> Corrine: Confined.
> Jimmy: You confine her she snaps. D11.1 p.14.

Freddie and Lucy recalled that Eduardo's fear of hospital procedures was linked to restraint.

> Freddie: Well see you know, when he was in the hospital for those three times, they suctioned him. There's a tube that they stick down their nose and I think that really traumatizes.
> Lucy: Yeah because they put him in a little papoose and they restrain them and then when they do the x-rays, they you know, they held them down like that. I think that that really ...
> Freddie: And he was only three ... yeah he was only three months.
> Lucy: And I think that messed him ... D1. p. 32.

Increased Fear and Protest with Succeeding Suctioning Procedures

Memory Most parents found that for their children fear intensified when reinforced by the memory of prior hospitalizations. Lucy and Freddie told how Eduardo learned his fear of clinics, hospitals, and doctors from the experience of hospitalization beginning at age three months. At the time of these interviews Eduardo was 15 months old.

> Lucy: He doesn't like going to the doctor. ...
> Freddie: He knows where he's at. He's smart.
> Lucy: Cause you got to go through one door and then you got to go through another set of doors. ... We went through one set of doors, and he

> just went wild. he tried to throw himself back and he knew. He won't let them weigh him, take his temperature.D1.2 p. 13.

Lucy and Freddie described the power of Eduardo's feelings and the strength and duration of his protest.

> Freddie: And he can tell a doctor and a nurse.
> Lucy: And I'll tell them when I take him to the clinic, "When is he going to be seen?" Because they'll stick you in the room and they make you go in there. And I'll tell them always in the waiting room. When you're ready to really really see him, call him.
> Freddie: Yeah.
> Lucy: Because I'm not going to sit in that room and listen to him cry for a half hour. D1.1. 32.

Maturation Most parents found that their children became less tolerant of suctioning and other hospital procedures as they grew older. Especially after 8 or 9 months of age, infants anticipated procedures when respiratory therapists, nurses, and doctors woke them or walked into their hospital rooms. During the procedures they struggled more. Parents told stories of how advancing physical and emotional development along with memory of prior procedures made subsequent suctioning, IV placement, and restraint for breathing treatments more of an ordeal. Their stories confirm the significant shifts in cognitive, physical, and emotional development that occur after 6 to 8 months of age.

An infant at this stage first learns that objects have permanence (Cole & Cole, 1989) and can distinguish between familiar figures (Ainsworth, Behar, Waters, & Wall, 1978). For the first time, her mother (or other significant attachment figure) exists in a continuum across time and space even when absent (Ainsworth, Behar, Waters, & Wall, 1978). In this developmental period, an infant will also demonstrate ability to achieve intended goals (Cole & Cole, 1989) and can employ more advanced motor behaviors in addition to signaling behaviors in order to attain those goals (Ainsworth, Behar, Waters, & Wall, 1978). According to attachment theory, these cognitive and physical abilities afford an infant in distress the ability to solicit her preferred attachment figure above all others. Several parents in this study found that after 6 to 8 months their infants protested the sight of individuals associated with forced and intrusive treatments more angrily than they had in early infancy. In the narratives that follow, parents tell that their children protested more and more vehemently as their efforts to find relief from forced procedures and restraint were completely frustrated. Later I will discuss in detail how infants in this study solicited and found comfort in the proximity of their parents during and after suctioning and forced breathing treatments.

In acute asthma crisis for the first time and hospitalized for the first time, 21 month old Bette learned quickly what would happen as providers awoke her from much needed sleep and prepared to suction her. Her mother, Corrine, tried to anticipate Bette's fear.

> Corrine: I mean [suctioning] was the ugly part. ... And you know why, the hard part was to be waking up scared. ... [B]ecause she knew they were going to suction her lungs. And she hated it. And I mean she was so strong. So strong and they had to hold her down...
>
> Int: [S]he was a little more calm and you could hold her the first time?
>
> Corrine: Right. I was holding her and I was talking to her and I had to have my body on top of her, because if I didn't hold her they were going to strap her down. See, and they ... would have confine her, strap her down. Just like they did with the IV. Well, she freaked out when they did that [with the IV], because they had her totally velcroed in. I mean she was not going to move. And she totally lost it. So I knew that if I didn't hold her down and try to let her relax, for her to let them do that, they were going to have to strap her down. ... "And I thought, oh forget this. No way." So I'd comfort her and I'd talk to her and I'd rub her head and she'd let them do it the first time. She didn't like it at all.
>
> Well, the second time that they did it she freaked. She said, forget this. That's when they had to have two of the people come in. And the man, the young kid or guy or whatever couldn't even hardly hold her down. So they strapped her down that other time. ... She was really mad. She was really

> mad. She cried, it was a hurt cry that she had. She was hurt, her feelings were.
>
> [F]inally she didn't want it anymore. The second and third time. ... She was crying at the top of her lungs. ... She was mad. She was upset. She was crying. She didn't want to be held down. She didn't want that tube down her nose. ... She was trying to strain and get away from them. Well then they told me they would strap her head down. And I thought, oh God. So I'm in the background the second and third time just trying to calm her down, but not holding her because the second time I helped them hold her, thinking that she would let them do it. But all the whole time she's moving her head now. She knows what they're going to do. She knows that that little tube's going down there to do and she was trying to get it to come out of her nose. Trying to pull it out... It was awful. D11.2 pp. 21-25.

Bette struggled against suctioning from the moment she awoke until the procedure was over. Even when only Bette's head was unrestrained, Corrine saw her make efforts to remove the catheter from her nose. Corrine could not bear to see Bette's desperate fight. She felt herself beginning to cry and left the room.

Although the escalating intensity of Bette's and Isaac's struggling against repeated crisis procedures was evident, some children protested little. They were, nevertheless, still afraid. At sixteen months, Jasmine struggled less than during earlier hospitalizations. In the three month period beginning when she was thirteen months old Jasmine was hospitalized four times in asthma crisis. Her mother, Tonya, told how frightened Jasmine had been during the first of these hospitalizations. By the fourth crisis, Jasmine's reaction to IV insertion and other procedures had changed.

> Tonya: [At first] I [was] not used to seeing babies get IV's stuck in them. ... And I [was] not used to her crying the way she was, but now when... They take her, they have to take all babies that they give IV's to in a different room. ... So they, they don't ever have no problems or no trouble getting the IV in. ... She went ahead and went with them. She didn't cry or nothing. She cried when they put the IV in cause it hurts, but ... Other than, she didn't cry. When she came back, she was like, they gave her a breathing treatment and her medicine and just she went straight to sleep. D2.3 p. 9.

Jasmine endured restraint, IV insertion, breathing treatments and separation from her mother with little protest. Although Jasmine's seeming tolerance of hospital procedures might be seen by some to be indication of positive adjustment, it is likely a signal of increasing distress. The first attachment studies were conducted by Robertson in 1958 when hospitalizations were longer and parents were permitted to visit only infrequently. Infants from 12 to 24 months were found to protest inconsolably at first while looking "eagerly towards any sight or sound which might prove to be his missing mother." (Bowlby, 1969/1982) If she did not come the infant would then appear hopeless and exhibit signs of despair marked by decreased protest and quiet acceptance of the situation.

> The active physical movements diminish or come to an end, and he may cry monotonously or intermittently. He is withdrawn and inactive, makes no demands on people in the environment, and appears to be in a state of deep mourning. This is a quiet stage, and sometimes, clearly erroneously, is presumed to indicate a diminution of distress. (Bowlby 1969/1982, p. 27)

Tonya elaborated on Jasmine's reaction.

> Tonya: [S]he's used to it now. Now when they suction or give her breathing treatment ... she doesn't really cry. *She hates when they do it,* but she just lays there and just takes it so they can go ahead and get done with it. D2.3 p. 10.

Tonya sensed that Jasmine "hated" hospital procedures even though she protested very little.

Javier, father of 33 month old Carolina, told how she cried and tried to talk as suctioning began and then, like Jasmine, endured suctioning.

> Javier: I was scared, but it's going to help her though so I just stayed there. A long as she's getting better.
> Int: And when you look at her what's happening with her when she's being suctioned?
> Javier: She's crying. ... It's okay. It hurts, but okay. ... like the day before we're getting out she'll just stay there. Don't do nothing. Just let the doctor do, what she, what the doctor has to do.
> Int: So it's worse when she first goes in?
> Javier: Uh huh. But then she gets used to it. And she don't cry. She don't do nothing. She just stays there. All stiff. All scared. She just looks straight up. D7.1 p. 14

Being "used to it" meant outward tolerance of suctioning, a tolerance marked by lack of protest but not by inner calm. Carolina's body stiffened. Her gaze was fixed and impersonal. In addition, Tonya's and Javier's feelings and reactions paralleled those of their children. Each kept her/his own fears and distaste of suctioning under tight control and endured without complaint.

Parents' Interpretations of Crying

When children breathe well crying is a signal of distress and/or protest. When children breathe normally adequacy of respiratory function usually goes on unnoticed by children and parents alike. Even with crying, breathing is taken for granted and is out of conscious awareness. When very young children have asthma, crying is no less a signal of emotional distress and protest. However, the parents in this study became acutely tuned to the physiological dimensions of breathing as well as the meaning of their children's crying. Physiologically compromised breathing increased children's fear and crying, and increased the work of breathing, thereby increasing the child's need and desire to cry. For these reasons, crying was physiologically detrimental. Yet, crying temporarily improved the delivery of inhaled medications by improving air exchange and was, therefore, promoted at times by professionals. Parents found these biomedical considerations crucial as they were important for the prevention and resolution of asthma crisis. However, since they transformed crying from a pure signal of emotional expression to a signal with significance for illness and treatment of symptoms, parents found responding to their children's crisis crying problematical. Three dimensions of salience for parents will be discussed here: the reciprocal association between wheezing and crying; the relationship between crying and the delivery of inhaled medications; and the primacy of crying as a signal of distress.

<u>Reciprocal Association between Wheezing and Crying</u> Parents found that their children's crying carried differing messages. On the one hand, wheezing made children cry and signaled the child's growing desperation to breathe. The opposite was also true: crying caused wheezing.

In her 19 month old son, Peter, Margarita saw both aspects of the association.

> Int: What do you think crying does to him when he has asthma? Is that good or does it make it worse?
> Margarita: It's bad, because it makes him wheeze more. ... It makes him get upset more. It makes him wheeze more. Cause I notice when ... he's sick and he's wheezing, he'll just yell, when he gets upset, he'll wheeze more. It'll make him wheeze more. D6.2 p. 37.

Furthermore, Margarita noticed that crying escalated wheezing.

Anna noticed that crying seemed to cause 14 month old Araceli to wheeze even when she was not ill.

> Anna: Like cause like she'll just, like say, well if she was sick right now, her asthma was bothering her, we'll be asleep, she'll get up and cry and like crying makes it worse for her to breathe so, and she'll just keep crying, crying, crying until I just, sometimes, sometimes when she's not sick, but she keeps crying and crying, I just get up and give her a treatment. D8.1 p. 22.

Despite contrary professional counsel as to the benefits of crying, Anna discovered that Araceli's crying was sometimes harmful and warranted treatment to relieve respiratory distress.

Crying and the Delivery of Inhaled Medications Since normative clinical practice operates on the assumption that crying benefits the delivery of inhaled medication, respiratory therapists encouraged, and pediatric pulmonologists confirmed, the desirability of children crying during breathing treatments, especially during management of crisis. Anna told about 18 month old Araceli's experience.

> Anna: [W]hen her asthma's bothering her and she cries it makes it harder for her to breathe, I think. But like if she's crying and I'm doing a treatment on her and she's crying, it's better for her, cause she breathes [the medicine] in and she breathes it deeper. Even over there like at the hospital she always cries, but it's better for her to cry, cause the medicine goes in deeper to her lungs.
> Int: They told you that it's better for her to cry and breathe deep?
> Anna: Yeah, it's better for her to cry once they do the [breathing treatment]. And cough like, and then when she cries too, she coughs, starts coughing you know coughs all that stuff up.
> Int: And when you're not giving her a treatment and she's crying, is it the crying that brings on the asthma? Or the asthma that brings on the crying?
> Anna: Maybe the crying that brings on the asthma, because when she starts crying and then she'll cry and she'll just like cry for a long time until she takes a deep breath. And she gets all red and all sweaty and she starts coughing and she won't stop coughing. D8.2 p. 17.

Despite feeling that crying exacerbated symptoms and could even cause them, some parents believed, as Anna did, the professional advice that crying aided in the effective inhalation of medicine during breathing treatments. When Araceli cried at home during breathing treatments Anna felt it was *"better."*

On the other hand, some parents were uncomfortable with the advice that crying made breathing treatments more effective. Corrine was the only mother to talk of *encouraging* her child to cry in order to increase the efficacy of at home breathing treatments. Nevertheless, she, too, remained ambivalent. She told of giving 28 month old Bette breathing treatments.

> Corrine: Sometimes I let her cry, I make her cry. Because when she'll cry she'll go [she demonstrates a long deep inspiration]. You know how they cry and they take that deep breath, well then that makes her take it in easier. See, that helps me a little bit more when she's cries, because she's blowing out and sucking in with the cry and she gets more of the mist. And that seems to help her a little bit more. *I hate to see her cry, but I mean if that's what's going to ... I have to ... she's got to do that.* .... [S]he's frustrated with it. But being that she gets more of it, it seems to put it in her lungs a lot faster. D11.2 pp. 10-11.

Deeper inhalations of medication caused Bette to cough up secretions and then absorb the inhaled medication even more effectively. Afterward, Bette's body relaxed, her breathing slowed down, and she stopped crying. However, administration of inhaled medications was an ordeal that took twenty to twenty-five minutes.

> Corrine: I think [the inhalation treatment] scares her. ... I think she cries when I have to scold her and she has to sit down and she has to take it.
> Jimmy: Uh huh.
> Corrine: That's when she starts to cry. Because she gets mad. She doesn't want to do it and she has to do it. And what happens is she gets off and she gets on the chair and she gets up and then finally she gets frustrated and I have to tell her that she's got to do it. ... Off and on and off and on and then we'll say okay well sit in the chair if she wants to do it by herself. So I mean we have to go through that, she doesn't like it.
> Jimmy: And she takes it off and then it's your turn. ...
> Corrine: God, it takes me about 25 minutes. ... When she doesn't want to do it, it takes a long time. Because of course she turns the machine off and she turns it on. She pulls the plug out. You know we go through this ordeal with her. D11.2 p. 11.

The necessity of overriding Bette's thorough resistance to the breathing treatment left her underlying fear and anger unabated. No attempts were made to evaluate the temperamental differences of children in this study. As a result, just how Bette's temperament shaped the delivery of breathing treatments is not known. However, appropriate to her developmental stage and consistent with the side effects of albuterol, Bette's resistance to the procedure and Corrine's efforts to cajole her into sitting still increased. Sitting still in one place for 15 minutes or longer is not in the repertoire of a 2 year old whose activity level is not significantly compromised by symptoms. Moreover, Corrine noticed as did many other parents that inhaled albuterol made Bette more active. As a result, despite the almost immediate relief of Bette's wheezing, Corrine did not find Bette anymore willing to cooperate as the treatment proceeded.

Freddie's delivery of breathing treatments for his 15 month old son evolved during the course of our interviews. He anticipated that Eduardo's, struggle against breathing treatments now might pose dangers in the future when Eduardo would be older and responsible for monitoring asthma on his own. Freddie came to believe that Eduardo's comfort and cooperation with the demands of asthma management was crucial. With his wife, Lucy, Freddie, as discussed in Chapter 5, recalled the recent experience of a teenage niece with asthma. The niece's failure to use medication as prescribed and in a timely manner led to an unanticipated and frightening asthma crisis during an out of town school field trip. The teenager's parents were now much more uneasy about their daughter being away from home. In addition, Freddie and Lucy remembered that a high school classmate had died from asthma 10 years before from failure to take bronchodilators as prescribed. They worried that as an adolescent Eduardo might not want to take his medicines and also that he might feel stigmatized by needing to carry and use an inhaler in front of his peers. In response to his worries about the future Freddie decided that Eduardo must learn to cooperate with breathing treatments now.

> Freddie: Before yes [we had to force Eduardo to take breathing treatments]. Definitely. Definitely. He wouldn't let you give him that treatment. ... And see when they fight the treatment, they don't get as much in it. ... And that's hard too. You know he needs to take it, and you can really tell that they need to be in a relaxed mode. ... to take in this medication. And it was hard, because knowing he'd fight you, holding his breath [you knew] a lot of the treatment is being a waste. ... It's shooting out the other end of the tube if he's not taking it in. Holding his breath, fighting it, kicking, wouldn't keep his face down. You can't hold him too tight where you hurt him. So it's, it was hard. D 1.3 p. 29.

Besides the long range consequences he hoped for, Freddie noticed that the medicine seemed to work better when Eduardo was relaxed. Moreover, when Eduardo cooperated with treatments he needed them less often.

> Freddie: But now, the difference too is we had to give him more treatments in the past. ... So we would do it like every 3 hours the treatment. As opposed to like this, this last time ... he took it and I tell you when he took it, it's like he really didn't need a treatment in four hours, but we gave it to him any ways you know. Have to be safe. But [because of] how he took it the first time around, by the time he needed his next treatment, he still sounded good. You could hear a little wheezing or a little rattle, but he sounded good. Compared to the past, where even after you gave it to him once, he sounded like he needed it the next 15 minutes. D1.3 pp.29-30.

Ruby found it difficult to tolerate hospital procedures that made 18 month old Reggie cry. At home she taught him to cooperate with breathing treatments and take deeper breaths by coughing rather than crying.

> Ruby: I'll tell Reggie to cough or whatever and he'll cough. And I think that when he coughs the medicine gets down better than him just hollering and crying and screaming upsetting hisself. That's what I think he's doing when he's crying. Upsetting hisself. So I tells him to cough and he coughs. D4.2 p. 15.

Some parents believed that crying during the administration of inhaled medicine was effective. Others found that when their child could cooperate with treatments, medication was more effective. Parents understood that effective inhalation of beta blockers could bring dramatic relief of symptoms. However, parents did not know how best to achieve optimum results from inhalation therapy. Current national guidelines for asthma management do not discuss the issue (National Institute of Health Guidelines, 1997). Professionals endorse crying as a method for increasing air exchange but acknowledge that crisis management may not be a good model for at home practice. Just how much fear reduces, or relaxation enhances, medication effectiveness is unknown.

Parents understood that crying and asthma are interrelated in complex ways. They were especially familiar with the circular and mutually escalating relationship between crying, constricted breathing, and fear. Although they cooperated with and saw effective results from traumatic suctioning and forced breathing treatments, the parents in this study always remained attuned to their children's fear, suffering, and anger. Even Tonya whose acceptance of hospital asthma management was more fatalistic did not forget that Jasmine *"hated"* traumatic intrusions.

Soliciting the Parents and Being Comforted

According to attachment theory, beginning in the first year of life children in fearful situations cry out to signal their particular parent(s) or parent figure for help. Parents in this study told how their children, when frightened by the desperate hunger for air, felt more comfortable being held. During hospital crisis procedures when children could not be held and parents stood at the bedside, even touching their children, children's fear and their attempts to reach out for their parents became more impassioned. Parents' saw that in their suffering, struggling, confusion, and anger, their children pled passionately and often futilely for them to provide protection and relief.

Abby told how Isaac's aversion to suctioning increased with successive hospitalizations. At 23 months his appeal that Abby extricate him from the restraint imposed by professionals was especially fervent.

> Int: And he's looking at you?
> Abby: Yeeeees. Directly at me and he's crying, "Mama, mama, mama." D10.2 p. 2.
> Abby: He looks at me with big eyeballs, looking at me like... [I say.] It's okay honey, it's okay honey, now don't cry. Don't cry." He goes, "mama" he looks at me and I try to calm him down and it's okay, it's okay. I thought maybe he'd get used to it after awhile. You know kids would get used to it and say, okay this, but he absolutely hated it. He did not like it.
> Int: How is he when it's over?
> Abby: He's tired. Falls asleep sometimes. He's just, he's laying there and he's crying and he's like all sweaty and he tightens his whole body up and as soon as they're done he comes to me. He jumps on me. He usually falls asleep most of the time ... in my arms. He falls asleep cause he's tired. And then he can breathe much better.... His chest is more clear and he could breathe a lot better and then. D10.2 p. 6.

At 23 months Isaac engaged Abby in the poignancy of his plight. Since at this, his eighth or ninth hospitalization, Isaac was now familiar with suctioning, Abby had not expected his intense fear and anger. Her efforts to reassure him did not calm him. The ordeal was onerous, one that took all Isaac's physical and emotional strength. When the end of the procedure brought relief, he finally found the solace and protection he sought in Abby's arms.

After the suctioning Bette was just as exhausted but not as quickly comforted as Isaac.

> Corrine: But she was mad at me... Yeah, [after suctioning] I would pick her up to hold her and tell her I'm sorry I know it hurts. And she would kind of like now she does, she gets down and she tries to hit me. You know, but

> then she didn't want me to really cuddle her and hold her. She kind of like, like she wanted me to but she didn't want me to.
> Int: You're making a motion with your shoulder like she's pulling her body away?
> Corrine: Yeah, yeah. She's kind of pulling me away or she didn't want me, she wanted to be on my lap, but she didn't want me to hug her and hold her like a baby you know like she, which she would after she wasn't mad anymore. So once she settled down and I gave her some water and we gave her some juice and I talked to her and I rubbed her head and then I could get her in my arms and would just wrap my arms around her and give her a kiss, she would let me do it. See but immediately following she didn't want anything to do with it. She wanted to be on my lap, but she didn't want me to cuddle her and hug her. To me that told me she was mad. ... She wanted to let me know she was upset. Yeah, she was really upset. D11.2. p. 24.

Bette's extreme anger did not dissolve immediately after suctioning was completed. Even though she could breathe much more easily and was once again in Corrine's arms, Bette's ambivalence was evident. Seeking comfort she wanted to be on Corrine's lap. Feeling angry and resistant she hit and pulled away. Calming down came gradually. First, Bette accepted juice, then Corrine's comforting words, and finally, her embrace and kiss.

Following her hospitalization, Bette would let out a dramatic and new kind of cry on separation from Corrine and Jimmy.

> Corrine: She wouldn't let neither one of us go. ... She didn't want anybody out of her sight. I couldn't even go from ... they'll have the door like this and there was a phone. ... [S]he was right by the nurses station because she was so bad that first couple of days you know they really had to watch her. I needed to get on the phone and call work and say, "Okay I'm still here." ... She freaked out. She wanted mom, mom. Where is mom? And [she'd] cry and cry like a scared, I mean it was just like frantic scare cry. ... And it's a weird, it's really a weird cry. D11.2 p. 23.

Separation from her parents, especially from Corrine, continued to be a traumatic event for 21 month old Bette once she came home from the hospital.

Sometimes on separation from her parents Bette would let out the same frantic and scared cry.

> Corrine: [J]ust lately me and my husband have started on Saturday evenings going out together by ourselves. Just in this last month. Being able to leave her. And it just kills us to hear her cry. It kills us. Since she has been in the hospital, it kills us to hear her cry. Because she doesn't hardly cry. She's not a real cry baby. ... And when we get to where we're going we call and then she's fine. ...
> Int: What is it about the crying that is so hard for you?
> Corrine: I think because she cried so much when she was in the hospital. It was a fear cry. It wasn't just a cry, cry. And I notice sometimes when she's cries, it's like a fear cry, *like don't leave me*, cry. ... [It's just] when we're going to be separated, when I'm going to be separated from her. And she wasn't like that before she went to the hospital. D11.1 pp. 44-46.

The depth of fear in Bette's cry reminded Corrine and Jimmy of Bette's hospital experience. They felt Bette's hurt. Besides the new quality and intensity of her cry, Bette seemed to cry more easily following hospitalization if she expected Corrine and/or Jimmy to be with her and they were not. For example, on afternoons when Corrine's mother would pick up Bette from the babysitter's house, Bette, who had expected Corrine, would cry during the whole trip by car to her grandmother's house. Prior to hospitalization, her first, she had not.

At 21 months Bette's ability to remember the permanence objects have through time and space had reached a whole new developmental level. After approximately 18 months infants begin to hold inner representations of absent objects or persons, imagine the absent figure, and their way of relating to that figure (Cole & Cole, 1989). From early infancy, an infant will prefer her mother in times of fear or perceived fear. In the second year, an infant will express intense distress if separated from her mother or if her efforts to solicit her mother's caring response are not effective. Strange environments and strange individuals are especially frightening in this stage of emotional development

(Ainsworth, Behar, Waters, & Wall, 1978). Bette's severe asthma crisis and hospitalization had come as her cognitive and emotional abilities took these dramatic developmental shifts. Corrine remembered Bette's unique and frightening cry on leaving home that Saturday night as the cry she had during hospitalization. The implication that Bette was recalling her separation from Corrine during the physical and emotional trauma of hospital procedures or that the separation reminded her of being separated from Corrine in the hospital cannot be verified. However, at 21 months, Bette was likely developmentally capable of recalling and connecting events in this way. Moreover, the intense fear Corrine sensed in Bette's cry is consistent with Bowlby's theory that an infant's primary attachment relationship is a life and death matter that will lead an infant who perceives it threatened to severe distress (Bowlby, 1969/1989).

Parents' Fear, Anger, and Response to Their Child's Suffering

All parents in this study were already frightened by their child's asthma crisis and, therefore, found hospitalization especially frightening. Most parents cried on seeing their children struggle against hospital procedures. Lucy described her fear and feeling of helplessness: *"It was scary man. I just cried. I didn't know what to do It was sad. I didn't know what to do. D1.1 p. 18.* For parents in this study hospitalization was unfamiliar. Only two had had prior personal experience with hospitalization during childhood, but neither event carried as much impact as their child's hospitalization during acute asthma crisis. All parents were unfamiliar with the hospital management of acute asthma crisis.

Parents who described themselves as never leaving their children's bedside during hospitalization either walked out of the room for a few minutes during suctioning or disengaged by "not looking" at what was going on before them. Parents felt scared, personally hurt, and angry. Abby, Lara, and Corrine are exemplary.

Abby told how she had developed many strategies to comfort 23 month old Isaac during hospitalization. However, at times with many professionals "working on him" every way Abby knew how to help failed. Then her own feelings of hurt and fear overwhelmed her.

> Abby: Like I try to pat on his back and... Oh I try to comfort him. I come up to him and I'll tell him, "It's okay" and I'll hold his hand or something or I'll lay my head on him or something cause I want to cry with him. But... ... Sometimes I walk out of the room because it's hard on me. It's hard to see him [struggle]. I mean when he's in the emergency room and he has all these, there's a respiratory therapist working on him and other people working on him. It's a lot. It's a lot on a mother to see their little baby go through something like that. Sometimes I have to walk out and ask someone else to stay with him, because it's too much for me. It hurts me, I think more than it hurts him sometimes. D10.2 p. 11. p. 2.

Abby willingly allowed Isaac to be suctioned because she could see clearly that he breathed better afterwards. However, sometimes she found that watching him struggle overwhelmed *her* so much that she left the room.

Lara, too, felt afraid and personally hurt when at 8 months old and first hospitalized for crisis Carolina was suctioned. *"I was scared. Scared because I don't like to see them put that long tube up her nose to suction out the boogers. I don't like to, that hurts my ... that just hurts me." D7.1 p. 14* Wanting to leave the room but feeling she could not, Lara avoided looking in Carolina's face. *"I had to just hold her down and turn my head." D7.1 p. 14.* Later when Carolina was hospitalized at 27 months her father, Javier, stayed with her during the suctioning and Lara left the room. Javier was frightened, too. "I was scared, but it's going to help her though so I just stayed there. As long as she's getting better." D7. 1. p. 14.

Corrine, like most parents, was particularly frightened when suctioning brought up blood..

> Corrine: And you could see the blood come out and that's just even more fear for me. So the second time I cried. I had to kind of had to walk out of the room because I told my husband, "I can't deal with this." D11.2 p. 12.

Seeing blood come up in suctioned secretions, Abby felt angry.

> Abby: Yeah, ... [some respiratory therapists] draw blood and you see all the blood coming out. I get angry. And so when they have to come in all the time, every three hours to suction him out, every four hours. Most of the time I would stay in the room, most of the time. So I would stay in there, but when he was, when he was really really sick I would just, I would leave the room because that's when they would have to suction him through his nose, down his mouth, they'd do that down his mouth and up his nose and they do all this stuff and it's like, I can't handle this man. It's like, it's like, oh, I get so worn out and tired. It's like. But I don't leave him for a minute. I mean I'll walk out and but I'll come right back in. D10. 2, p. 4.

Clearly conflicted about watching Isaac suffer and struggle, Abby became physically and emotionally exhausted by the frequent interruptions for deep suctioning. Unable to watch, she left the room.

Parents' Responses in the Experience of Crisis

Many parents felt several competing concerns during the hospital management of asthma crisis and told about grappling with how best to respond to their children. Worried that the child might be left alone among strangers when he or she was frightened, many parents spoke about their desire to stay close.

> Abby: I think he needs to feel that I'm there. I'm with him through this whole thing. ... I want him to know that I am there no matter what. I can't leave him, I need to see, it feels like it's my responsibility just to be there with him through this whole thing. D10.2 p. 5.

Abby's underlying concern was for Isaac to feel she had not abandoned him. Although she felt helpless to relieve Isaac's suffering and assuage his fear and anger, Abby also felt responsible for his well-being, both physical and emotional. She went on to say that during his hospital stay she wanted to *"know what they're doing with my kid." D10.2 p.5.* Moreover, she wanted Isaac's emotional needs to be met.

> Abby: I need to know that they're paying, that he can get attention. I need to know that they're, they're a lot of sick babies there. They can't just pay attention to him. He needs the attention I figure and he doesn't get it if I'm not there. ... There's times I'll walk in [after returning from being gone a few hours to take a shower and change clothes] and he's crying his head off and nobody's in there with him. I need to know that there's always going to be somebody there with him. D10.2 p.5.

Abby left Isaac's room during suctioning, nevertheless. In retrospect, she reasoned that with her out of sight Isaac might struggle less, might not identify her as perpetrator of the hated procedure, and might not see her cry.

> Abby: Well, sometimes I think when I'm there and he sees me, he cries more and wants me. And when I walk out of the room... ... There's a lot of times where if a kid's going to get a shot or get checked or something that they cry and cry more because their parents are there, but if you leave the room... Like the dentist, you can't be in the room with them, because they'll cry for you. As soon as you leave out of the room, the dentist will work on them and they won't cry for you. So I figure maybe if I leave the room...
>
> Also because it hurts me to see him to see him go through that. He doesn't see me and I don't want him to hate me for letting him go through something like that. So maybe I think, if I leave the room and cry out there. Yeah cry out there, that he won't get more upset. Because I'm standing right there, he's looking at me and he's struggling for me to hold him. So he's fighting more. And wants me so... ... [When I'm standing close] I guess that sometimes he wants me to pick him up and hold him. And I can't do that. D10. 2 pp. 1-12.

Even though she explained to herself that keeping Isaac calm might be better accomplished by leaving the room, Abby's desire to comfort Isaac and the responsibility she felt for maintaining her ability to do so trumped all other concerns. She feared that if Isaac saw her cry, her ability to comfort him would be undermined, for in crying, he would see her helpless. Moreover, she reasoned, standing by and sanctioning restraint and forced trauma might cause Isaac to reject her, and might spoil his trust in her ability to protect him. At least if she left the scene temporarily Isaac might divorce her from the terror thrust upon him and be willing to accept her protection when the procedure finished.

Corrine, like Abby, left Bette's bedside and room during suctioning. In retrospect, she considered why she had left, reassessed the situation, and decided she would do differently if she could.

> Corrine: I mean it's hard because you just, at that time you just do what you think because it's spontaneous. You have to do what you think is going to comfort your child. But then after you think about later, by that time it's too late. I mean how could you have... if it happens again then I'll know maybe to do something really different. Because I've already been through that, done it and it worked, but I still think I wouldn't leave her. I really don't think so.
> Int: And what you didn't want was for her to see you upset.
> Corrine: Right. That's the only thing, is to see me upset. And then that would probably scare her even more. But I think if I had to do it again, I would probably do it the same anyway. Even though I know that I don't want her to think that I'm the bad guy, but you're kind of stuck, it's like do you, don't you, do you, don't you. But you need to be there because they need to hear your voice to be comforted too. So I still think that I would do it. I still think that I would be there and I would still help them hold her down. Because I don't want her to be strapped down and feel claustrophobic. I have claustrophobia. To me I hate it. And I just think of me feeling that way, I don't want her to feel that way. D11.2 pp. 26-28.

Corrine, like Abby, had two concerns: Bette's comfort and well-being; and the preservation of her role as Bette's protector in the face of danger. Abby and Corrine both knew how effectively naso-tracheal suctioning would alleviate constricted, obstructed breathing due to asthma, yet each agonized for her child, sensed her child's terror, felt her child's poignant pleas for *her in particular* to intervene, felt helpless to respond, and cried herself. Both felt responsible and worried that their children would find them less strong, reliable, and trustworthy.

Discussion

In this study the most immediate and evident consequences of the failure to give more than cursory attention to the emotional needs of children and to the concerns of their parents was that children became more fearful and parents became more avoidant or angry when repeated procedures were necessary. Parents in this study felt their children's suffering during crisis and yearned to do something to relieve it. Their encounters with professionals during the hospitalization of their children most often left them feeling fearful of the suffering asthma and its treatment caused, embarrassed by their feelings of helplessness, and confused about what their response should be. Most dreaded future hospitalizations.

Attachment literature and professionals expert in the emotional development of children who were consulted during this study confirm the desirability of parents being with their children during traumatic hospital procedures whenever possible. All children, but especially children between 6 or 7 months and 3 years are developmentally sensitive to separation from their parents in times of crisis. Since this fear, the fear of abandonment, leaves a lasting impression and may alter a child's sense of security when feelings of abandonment are recurrent or ongoing, mothers and fathers should be supported and encouraged to be with their children during traumatic or frightening procedures.

Two families in this study spoke of the exceptionally *"good"* care given by professionals. Freddie and Lucy told about Eduardo's visit to, Dr. P, pediatric pulmonologist.

> Lucy: [W]hen we went to Dr. P ... it was good because when we went to see him he goes ... he knew just right away ... and *he just knew ... why he was afraid of doctors*. He goes, "He's been in the hospital too many times."
> Freddie: That was great to hear that.
> Lucy: That made us feel good, like he understood.
> Freddie: It sure did.
> Lucy: He didn't call my son a brat. He didn't say, "What's wrong with him?"
> Int: You hear some of that?
> Freddie: Yeah. (emphatically)
> Lucy: Yes. And he, Dr. P knew right away, ... He was sympathetic. He knew.
> Freddie: That was the first doctor that asked that my wife *and I can honestly say, he is caring*. Cause when he walked in ... cause he's scared of doctors.
> Lucy: He's really really scared.
> Freddie: So when he walked in Eduardo just clinged onto her. And his first remark was this kid has been in the hospital too many times. ... But that was great to hear that from him. The other doctors are like, This kid is spoiled type of deal. Dr. P let him play with his stethoscope everything, I thought that was real neat.
> Lucy: Most of the doctors no way.
> Freddie: Cause no doctors ever let him. He's scared of those things and when Dr. P let him hold it, he grabbed it and he was like "Oh" (laugh)
> Lucy: (laughs)
> Freddie: So he's comfortable with [the stethoscope] now. No other doctor ever did that.
> Lucy: Yeah. It was good when we went over there. D1.1 pp. 22-23.

Dr, P *"cared"* when he made Lucy and Freddie feel respected, understood, and validated in their concern for Eduardo instead of isolated, blamed, or rejected. In their previous encounters with clinic and hospital professionals Lucy and Freddie shared the impression that they and/or Eduardo were blamed, as if something were wrong with Eduardo or them. *Freddie: "I mean that* [Dr. P's *caring] was just amazing how, how all these times we've heard about the child's spoiled or what's wrong with the child." D1.1 p. 48.* Until this visit Eduardo had cried inconsolably in every circumstance having to do with doctors. In contrast, Dr. P seemed not only to accept Eduardo's fearful clinging to Lucy, but acknowledged that he understood how frightening hospitalization had been for Eduardo. Dr. P shared Lucy's and Freddie's empathetic concern for Eduardo's fear and calmed Eduardo's distress. Allowing Eduardo to play with his stethoscope seemed to lessen his fear. Eduardo, like his parents, relaxed for the first time in their experience with professionals.

The second exemplar is from Corrine. Bothered by the seeming lack of empathy of staff who woke Bette up frequently for suctioning when she had had almost no sleep in over 24 hours, Corrine questioned, but only to herself, the need for frequent suctioning. One provider changed Corrine's thinking.

> Corrine: There was one girl she was good. ... [S]he told me, "I've got to do it. And I've got to get that stuff out of there. Because if I don't do it, we're going to have to keep doing it over and over and over. So if we get it good and we do it good and we suction all that stuff out, we're not going to have to keep coming back and doing it [taking all the fluid out of her lungs]."
> Int: What made her good? ...
> Corrine: Because *I didn't know and no one else told me that.* Maybe that's why I thought she was good and she kept doing it. *She kept trying, doing it and doing it and doing it until she got it all out.* And maybe that made, they're all probably good, but maybe that's what made me feel she was [good]... because she told me. *She talked to me.* She said, "Look we got to do it, because if we don't, you know she's going to get more fluid, we're going to have to do it all over again. *And I know that it's hard for you."* ... and the times that she did she got lots of fluid out of there. I mean lots of fluid. There was a little blood, *she says, "You're going to see blood."* and I had already known that, but she got it out of there and she got all that gook out of there. And [Bette] slept so good after that. God she slept so good. D11.2 p. 26.

Corrine felt the provider, likely a respiratory therapist, gave good care in personally acknowledging and giving an explanation of what she was doing and why it had to be done. Corrine learned that, done well, suctioning would not need to be repeated as often. Hearing ahead of time that she could anticipate seeing blood in the secretions, Corrine was less frightened. Corrine also valued the therapist's empathetic recognition of her concern for Bette. Whether due to Corrine's calmer acceptance of the procedure, a different response from Bette, or the therapist's skill, this procedure seemed more effective than others had been. Afterwards, Bette slept well.

The above exemplars point out how effective and efficient care depends not only on technically good procedures but also on recognizing and addressing parents' fears, being aware of parents profound sensitivity to the suffering of their children, and their equally deep sense of responsibility to alleviate it. In addition, respecting parents' need to know what to expect during unfamiliar traumatic procedures calms their fears because they do not know what various signs such as blood stained mucous drainage mean. Optimal care would also include listening to parents talk about their feelings after difficult procedures are finished, and planning with parents ways to involve and support them in their caring for their children during future crisis procedures and at home management. Ideally, parents should experience hospital professionals as welcome partners who lend empathic aid and expertise in the management of their child's asthma crisis.

However, quality care is more than knowing and practicing the interpersonal and educational skills exemplified above. Two other considerations are critical. First, although short term "success", i.e. managing through the crisis is part, albeit the most dangerous and dramatic part, of living with asthma, long term implications for living with asthma flow from the experience of crisis care. The experience of crisis left clear memories of the emotional trauma parents and their children experienced. Hospital procedures, especially breathing treatments, were later remembered negatively by most parents and children in this study when the same treatments were given at home. The contradictions between hospital crisis management and ideal home management when children cooperate and participate are striking, as witnessed by Freddie's re-educating himself, Lucy, and Eduardo regarding breathing treatments.

Although, perhaps appropriate due to the need for efficient and effective relief of symptoms during crisis, forced treatments delivered with children restrained were seldom carried on as a long term practice at home. Children rebelled and parents avoided following through with home management plans. Parents received instruction in the techniques of successfully delivering breathing treatments but no developmentally based guidance on how to help children cooperate. It may be that delivery of treatments even during crisis needs to be modified so that from the beginning parents participate, and ways are explored to comfort children when they are extremely frightened by their critically compromised breathing and the strangeness of where they are and what is happening to them.

A second important consideration for quality care during acute asthma crisis is to attend to relief of suffering. Children's memory for perceived crisis situations especially after 6 months of age, illustrates the significance of hearing and addressing children's cries as markers of distress for which there will be memory. Although infants may never be able to verbalize it, parents found that children remember their experience nonetheless. Meeting parents' needs by encouraging their supportive engagement with their children could mean that parents and children alike discover ways to cope positively with their fears, and feel less anxious because they do not feel alone and unprotected during frightening episodes of acute illness and necessary traumatic hospital procedures.

CHAPTER 8

Implications

Introduction

The findings of this investigation challenge the widely held belief that parents either succeed or fail in managing asthma. All parents in this study struggled to manage asthma effectively, although their individual capabilities differed, as did the personal, family, and community resources that sustained them. Their stories evoke empathy for the challenges they faced and respect for the courage and effort they brought to coping with asthma. The findings also point out the deep gulf between the technology of disease management and the translation of medical/technical understanding of the disease into professional caregiving practices suitable for families with the constraints imposed by low income and social disadvantage. Before turning to specific practice recommendations, I will discuss wider issues of illness meaning that help define this gulf.

At least four important tensions involved in the delivery of professional care for infants and toddlers with asthma and their families come to light in the interpretive findings. They are characterized by opposing considerations that interplay to shape the course of routine and crisis asthma care: 1) immediate health care needs verses long-term needs; 2) long range developmental implications verses short term developmental effects; 3) universal standards for management verses plans suited to the particular needs of individual children and their families; 4) appropriate dependence and protection verses over-dependence and over-protection.

Immediate Health Care Needs verses Long Term Needs

In the current health care climate where delivery of clearly defined and delineated health care services is highly valued, the meaning of service events, just like the meaning of illness events, is de-emphasized in favor of providing technically efficient and effective care. During crisis, providers may view bringing a child through a life-threatening asthma episode as an event with a defined beginning and end. Parents, in this study, however, worried not only for the immediate survival of their child, they worried for the future. Their hope for a healthy outcome took place on a background of interwoven concerns, some specific and immediate, some general and largely unarticulated. As events unfolded, parents began shaping unique understandings and responses to their child's asthma and its management. They watched providers deliver care and decided either to leave care always to providers, to emulate provider care, to guide it, or to reject it.

The experience of being present during hospital procedures and management helped shape parents' ways of responding to future crises, their ideas for prevention, and the meaning of living with the illness. During more routine hospital care and in preparation for discharge, providers taught techniques of managing symptoms while parents listened not only to remember what they were told, but also to seek answers about the future. What does this illness mean? How did she get it? What will taking medications mean for my child in later childhood and adolescence? Will she forget or resist taking medications? Will she refuse to carry inhalers? Will she die from lack of timely reversal of symptoms? Will she need to depend on medications and/or oxygen continuously as an older adult? Opportunities to discuss questions such as these and explore with professionals the similarities and differences between hospital crisis care and routine management were extremely limited. As a result, parents usually determined for themselves, and with the help of family and friends, how aggressive to be in restraining children for the administration of medications. Most also modified routines when symptoms escalated but did so regardless of provider instructions. In addition, parents determined for themselves how to recognize the signals that heralded the need for emergency care. Some parents did not give medications as regularly due to their aversion of imposing unwanted treatments on children. In addition, parents had varying practices for determining when to access emergency care and varying expectations of the emergency care they sought. Despite all their individual and professionally unguided decision making, most parental management behaviors were not detrimental to the well-being of children, at least in the short run. However, whether parents made optimal decisions for the long term welfare of themselves and their children and for the prevention of future crises could not determined by this study.

The failure of professionals to address the meaning acute crises held for parents and to discuss parents' concerns for the long term effects of acute crises was evident. There are at least two immediate effects resulting from this failure. First, without professional input parents were unsure they had made optimal management decisions. Second, for most families, the relationship between themselves and providers became more strained with successive crisis events.

Through the interviews conducted for this study, parents indicated their need to talk about the profound impressions left by the experience of crisis from the earliest evidence of its onset through its resolution. Such dialogues are not typically a part of practice. However, during the progress from crisis onset to resolution, parents had taken many deliberate steps in response to their children's symptoms and suffering. In recounting the stories of events parents were able to recall in detail asthma crisis' impact on them and the way the actions they had taken impacted the illness. Validation of parents' impressions and supportive critique of their behaviors, could have helped providers join parents at the level of their worst fears and very deep sense of responsibility. In this light, parents' significant contributions in managing home environments, giving various medications, and choosing to access emergency care would be better understood. As a result supportive education could be better suited to individual family needs, and interventions to improve care could be more appropriately designed. In addition, parents would feel better understood and likely be more inclined to cooperate with professionals.

Long Range Developmental Implications verses Short Term Developmental Effects

Several developmentally related concerns arise from the crisis management practices described by parents in this study: 1) whether the intense emotional reaction to crisis management carries adverse long range consequences; 2) how to ease emotionally painful separation of parents and children during frightening, painful, and intrusive crisis procedures; and 3) how to bridge the gap of differing behavioral expectations, during crisis verses home management of asthma.

Intense Emotional Reaction to Crisis Management First, in the press of immediate crisis care primary consideration is given to the smooth accomplishment of procedures such as suctioning, breathing treatments, and IV placement. Children's pain, fear, intense dislike of physical restraint, and panic at separation from their parents are dealt with as encumbrances to effective crisis management. Although this study did not attempt to assess the consequences of children's experiences, parents reported the intense physical and emotional energy with which children responded to their experience. According to parents, children suffered agonizing physical pain, fought against their circumstance with enormous physical and emotional effort, and felt fiercely angry and stunned by their experience. In short, parents told that, in addition to the distress of having extensively compromised breathing, children felt emotionally and physically assaulted by the hospital management of severe asthma crisis.

According to parents in this study the most noxious aspects of hospital crisis management experience were pain, restraint, and separation from parents during distress. However, parents in this study felt as if their reactions to the suffering and cries for help they sensed in their children went mostly unappreciated by professional providers. In support of parents' intuitive assessments of the suffering of their children during asthma crisis, this investigation confirmed two conclusions reached in the research of responses to pain in infants and children under four years. First, general body movements, facial expressions and characteristics of cry are the best indicators of pain intensity in infants (McGrath, 1990).

Second, children up to age four respond to pain in various and complex ways dependent on situational and familial factors. According to McGrath (1990), "no one single behavior [body movement, facial expression, or cry] constitutes an unequivocal measure of an infant's pain" (p. 51). This statement echoes the position taken by Bowlby (1969a) and Ainsworth (Ainsworth, Blehar, Waters and Wall, 1978) who also found that behaviors indicating distress do not necessarily signal inappropriate emotional response. Although crying and fighting may be difficult for providers to cope with when management calls for IV placement, breathing treatments, or nasotracheal suctioning, they may be developmentally appropriate and healthy responses from infants and toddlers who are afraid and in pain. Therefore, the hospital management of asthma crisis should be conducted in the recognition that successfully restraining infants' physical struggling, and subduing their expressed emotions may be affectively detrimental even though these practices allow for quick completion of procedures.

Parents indicated that forced restraint increased the emotional and physical distress of their children. Conversely, when ways were found for parents to hold their children, children accepted hospital procedures more willingly. Although it may not be possible for children to be held at times of most acute distress, provider sensitivity to the important role of paternal protection in infancy and early childhood might lead to wider use of nestling children in parents' arms during most breathing treatments, IV placements, and even nasotracheal suctioning. Dialogue in the literature and among practitioners about the important issue of children's fear of and rebellion against restraint could lead to changes in practices procedures that would make restraint less necessary and, thus, less common.

The Pain of Separation The issues of children's fear, parents' reactions, and the separation of parents and children was most acute during hospitalization and management of acute crisis. For a more complete discussion see Chapter 7. The families in this study reported that the emotional trauma of illness was compounded when children were separated from their parents in times of distress. Although professionals were occasionally reported to offer parents the option of being present with their children, parents reported no consistent provider practice of encouraging the proximity of parents and their children during traumatic procedures. Moreover, during IV insertion, a procedure that often succeeded only after many attempts, parents reported and providers confirmed that children are intentionally removed from their parents' presence. Parents reported no supportive education about the experience of separation during the hospitalization of their children. In addition, they reported no opportunity to talk about their expectations and fears regarding hospitalization, discuss their feelings, or discuss and evaluate their behaviors during traumatic events. On the rare occasions when providers were reported as acknowledging parents' needs, parents reported that they and their children both felt less frightened. Moreover, when parents found themselves able to assist in comforting their children, they felt more able to conduct home management on the model of their hospital experiences.

<u>Differing Behavioral Expectations Demanded During Management</u> Hospital crisis management as described by the parents in this study could have been more sensitive to developmental needs of children. In older infants and toddlers, numerous important developmental changes are in progress. Children are beginning to develop a sense of self. They are striving to learn control over their own behaviors and, especially in the second year, they exhibit acute sensitivity to bodily intrusion. Moreover, during late infancy and in the second and third years of life, besides experiencing rapid physical growth and development children are learning their physical possibilities and limitations (Cole &Cole, 1989).

During asthma crisis, parents reported that children were developmentally violated on two fronts, first by the illness and then by treatment designed to alleviate it. The illness left them out of control, physically threatened, and physically limited by fatigue, lack of appetite, and lack of energy. Treatments forced each child to submit to bodily intrusions and endure pain against her will. These extremely frightening situations required children to relinquish all physical control. The impact they might have on a young child's sense of physical limits and bodily capacity deserve further study.

Moreover, at home parents were left with the challenges of administering breathing treatments that they and their children remembered as extremely loathsome. Most children were no more accepting of and cooperative with breathing treatments at home than in the hospital. One family proceeded with gentle but total restraint. In another, the mother spent 25 minutes several times a day trying to cajole her two year old to breathe nebulized medicine. Most parents gave up on nebulized treatments unless children's symptoms began escalating. Providers in many situations suggest that parents offer inhaled medicines via aerochamber instead of by nebulizer due to the relative ease and rapidity of medication delivery. Children object to aerochamber delivery as well, as it requires placing a mask over the nose and mouth. Aerochambers, however, deliver medication in only several deep breaths, a procedure that takes a minute or two.

Three important developmentally related questions arise from these medication delivery issues. First, are there as yet unexplored effects on the emotional development of children who are forced to submit to unwanted management routines on a long term basis? Second, are we as professionals doing all we can to create a developmentally appropriate management path as children move from fulminate crisis to routine situations when symptoms are mild or in remission? Is appropriate management designed with the aim of promoting healthy physical and emotional development as well as the remission of respiratory symptoms?

Family autonomy versus family dependency in the management of asthma in infants and toddlers

Parents had difficulty reconciling the question of how autonomous and how dependent to be in relationship to professionals and the system of health care services available to them. This interpretive study shows that most parents struggled hard to control asthma on their own but also desired to find reliable, accessible, and dependable professional providers to lead and support them. However, for most, managing asthma was a lonely experience that involved wandering a landscape riddled with risks, of which they were sometimes but not always aware. Risk lay in possible mismanagement either from delayed reliance on professional help during crisis, in taking up rote rather than engaged and reasoned home management of crisis, or from taking on full responsibility for medical events at the height of crisis. Most parents reports show they gave limited voice, even in retrospect, to their hurts, fears, and to the vicarious suffering they experienced as their children struggled. Instead, an aspect of managing asthma became learning how to manage the expectations of emergency providers and the advantages of some venues over others.

One part of parents' struggles around competence in asthma management was to endure assaults to their self-esteem. These were felt most directly in criticisms received from professional providers. This investigation did not include interpretation of providers' experience in relating to parents, therefore, it may well be that in at least some cases parents perceived criticism when it was not intended. According to parents' reports, however, some providers seemed to presume that asthma crises, even in very young children, are reversible without emergency care. In other words, providers assumed that the need to seek emergency services or have one's child hospitalized reflects a failure of management. As a result, on many occasions parents felt demeaned by provider comments and caught between irreconcilable provider expectations. On the one hand, providers sent parents home when they sought early emergency care, a circumstance which often led them to return only hours later with their child even more ill. On the other hand, providers criticized parents for poor illness management when the crises for which they sought emergency care were more advanced.

As discussed in Chapter 6, parents also experienced more subtle assaults on their self-esteem and sense of skillfulness as caregivers during the rush of hospital crisis management. Whether they determined to manage on their own, were inclined to hand over care to professionals, or allowed themselves to maintain flexible in response to circumstances, learning how to deal with the health care system was difficult and challenged parents' sense of self-worth. Many who gave up the techniques they knew for comforting and being close to their children or helping their children cooperate with procedures in order to allow the smooth flow of medical-technical procedures, later had second thoughts about the wisdom of doing so. In deference to procedural demands, many endured without comment, or with silent tears, agonizing separation from their children whom they could see were frightened, having great difficulty breathing, and who were suffering from restraint and painful procedures. Those who spoke out angrily retreated from reliance on hospital caregivers, physicians, respiratory therapists, and the providers who provided routine care. Whether angry or silent most felt isolated and alone. Those who were flexibly engaged in management maintained the best self esteem. However, none of these found or adopted collaborative relationships with physicians, advanced practice nurses, or other specialist care providers. In managing their children's asthma parents in three of these families continually worked within conflicted interpersonal provider relationships with the result that they relied heavily on their own judgment and know-how. As a result, they felt alone in bearing responsibility for the potential fatal consequence during crisis managed without or contrary to the input of providers.

In addition, some parents felt frightened and unsupported when they found themselves more skilled and knowledgeable than were the providers on whom they wanted to rely. One mother, Ruby, angrily claimed her competence over the insistence of Reggie's physician that he be hospitalized. Later she felt she found a collaborative relationship with a pediatrician who respected her views about the management of symptom flares. Another, Corrine, when handed authority by Bette's physician to decide whether Bette should be hospitalized, chose hospitalization. Although Ruby, in the first example, operated independently and, in the next example, Corrine sought a dependent relationship to the authority of physicians, neither mother desired complete self-sufficiency nor complete reliance on professionals. Ruby and Corrine each realized, however, that subsequent events had validated the action she had taken. While pleased with this validation, each was frightened to think that she had made a more sensible decision than did her child's physician. What, Corrine wondered, if Bette had come home with her? Would it have taken her three weeks to be able to breathe easily? What Ruby wondered if Reggie had been *"hospitalized for no reason?"* (D4.2 p. 38) Instead of bearing responsibility for management decisions on her own, Ruby and Corrine each desired a collaborative interdependence in relationship to her child's physician and other professionals in which she would find support, guidance, and respect.

Universal Standards for Management verses the Particular Needs of Individual Children and their Families

In developing and putting into practice guidelines for responsive care for families whose very young children have persistent asthma there are two important considerations: 1) meeting needs related to poverty and social disadvantage; and 2) the need for individually sensitive care plans and protocols.

Meeting Needs Related to Poverty and Social Disadvantage First, the families in this study, all low income and socially disadvantaged, experienced a gap between their daily lived worlds and the world of health care services on which they depended. There were many indicators of this gap. For example, families were unable to continue with specialist provider services due to expense, cumbersome transportation, responsibilities toward other children, and the need to meet the expectations of employers who demanded strict attendance at the job site. Several families could not meet the Medi-Cal co-payment required for specialist care. One mother was frustrated by Medi-Cal regulations that complicated continuous access to her son's prescription medications. Moreover, for all except one family in this study, other very difficult circumstances added caregiving responsibility and high level daily hassles to the obligations of parenting infants and toddlers and managing illness. Among these were: a drug abusing , drug dealing spouse; gun shot violence; alcohol abuse; spouse's inability to meet credit obligations; frequent relocation of family living space; crowded living space; living space shared with critical or unfriendly others; criminal probation of caregiving parent; jailed family members; dependent adult family members; and, in the extreme, sexual and physical abuse *of* the caregiving parent in childhood associated with caregiver drug abuse and child abuse *toward* siblings of the child with asthma.

Estrangement from the health care system showed up differently for families. Most parents reported angry exchanges between themselves and providers. Some parents felt too timid to offer providers their relevant knowledge of asthma and their familiarity with effective caregiving practices. Parents felt uncertain about provider support, often feeling rejection instead. Some parents mistrusted provider expertise. Finally, other contextual needs were poorly addressed. A mother who was illiterate felt confused about the giving of medicines and the operation of her son's nebulizer. Another mother, who had no help with the care of other children at home when her son was hospitalized, was rarely available to her hospitalized son. After several days, his physician complained about her lack of attention to his distress. As a result, volunteers were belatedly engaged to help comfort him in her absence.

Estrangement also showed up in that parents felt discriminated against by asthma care providers for being young and low income. Although parents in this study were not asked directly about feelings of discrimination, they volunteered stories about incidents that felt discriminatory. None mentioned feeling discriminated against due to ethnicity or race. It is very possible they were intimidated by my being Caucasian and did not feel comfortable talking about racial or ethnic discrimination. I was aware that racial consciousness was high. Both African-American families displayed pride in their heritage through the pictures, ceramics, and other decorative objects in their homes. In three Latino households the primary language was Spanish. One family showed me pictures of their large extended family who lived in Mexico. Another mother told me of the difficult transition she had when in school she was expected to speak English for the first time.

Families in this study lived within worlds where the experiences of poverty and social marginalization, through different in detail, were shared. In addition, parents differed in literacy levels, intelligence, education, ethnical customs and practices, experience in parenting, and stability of relationships. As a result, the effects on asthma management that were unique for each family were not determined by economic status and ethnicity alone.

<u>Need for Individually Sensitive Care Plans and Protocols</u> In general current NIH management protocols are insufficiently sensitive to the effects of social context on the management of asthma. In addition, no special mention is made of the needs of disadvantaged families. This study highlights that although well delineated protocols for the physiological management of asthma are the foundation of effective management, they do not address all the issues pertinent to the management of severe persistent asthma in very young disadvantaged children.

It is not surprising that despite advances in understandings of the pathophysiology of asthma, and the availability of new, useful, and easily delivered medications for daily management, that asthma morbidity continues to rise. The experience of families in this study highlights how issues of illness meaning contribute vast variation to the ways suggested protocols become manifest in daily practice. Furthermore, the gap parents feel between their understanding of asthma and its management and the way professionals understand and manage asthma is evident.

How to bridge the gap between individual family needs and standardized plans for asthma management would be a challenge even if health care system time and resources were unlimited and families were not encumbered by poverty and social disadvantage. Since many profound issues were interwoven and manifest the illness in complex ways for families in this study, findings show that families need highly individualized support. The most recent studies that have reported parents' failure to use written management plans confirm this conclusion. In addition, the finding that most providers do not give written management plans to low income, inner-city, African-American children, 2 to 6 years old, even though 80% of their parents read at seventh grade level or higher (Farber, Johnson & Beckerman, !998), may reflect provider recognition that a plan not specifically adapted to individual needs does not influence management.

Traditional scientific approaches would have us identify risk factors and, in systematic way, set out formulas that address them. However, a solution devoted solely to following rule based guidelines that focus on the disease rather than the illness in life context would have limited effectiveness for at least two reasons. First, effective management that relieves suffering as well as symptoms involves being responsive to specific contextual needs. Context includes individual emotional responses, individual and family expectations, and interpretation of illness and management events (Dunlop, 1994). The endeavor of devising general guidelines to fit all specific contexts thus seems an endless and probably impossible undertaking. Second, in positing general standards, the danger of holding the importance of standards above the importance of individuals, finding deficiency in individuals who fail to conform, and responding punitively is great (Foucault, 1979; Smithbattle, 1994). Furthermore, Hooper (1995) found that rule based protocols, employed as "gold standards," stifled expert nursing practice. Optimum management and genuine caring are not assured by adopting protocols even if they could be tailored to the varied social circumstances of individuals or families. Without involvement in the issues of meaning and interpretation that underlie visible characteristics there is no access to the concerns which, more than general management plans, shaped the asthma caring practices of families in this study. Thus answers to the question of how best to provide appropriate support must be appropriately individualized for all parents. Furthermore, in order for effective, sensitive caregiving to be put into practice, planning needs to take into consideration the current climate of restricted caregiving resources.

The difficulty with developing social context protocols for asthma management is evident from the findings of the previous chapters but is simplified in the specific example of Maria, mother of Susanna. Born in the United States to a Mexican immigrant mother who has never spoken English, Maria was capable, intelligent, a responsible mother, on the path of a community college education, and intent on developing a business career. Nevertheless, she was reticent in interpersonal relationships and diffident in dealing with authority. When Susanna was hospitalized Maria's compliant and uncomplaining manner could easily have been read as lack of intelligence, skill, or motivation. In fact, none was the case. Yet, until the hospitalization was nearly over, Maria did not speak up to involve herself in Susanna's care nor did she report that any providers encouraged her to do so. When Susanna left the hospital, Maria felt less skilled, more uncertain, and more frightened by asthma.

Maria's feeling on discharge might have been different. By first listening to Maria's experience of caregiving during Susanna's crisis, one could recognize her intelligence, and appreciate her high level of motivation to help Susanna. Moreover, in listening to her story one would understand the way she shared caregiving with her mother and grandmother when Susanna was well, even though she retained ultimate responsibility for asthma management even when she was away from home for school or work. Receiving an individualized plan developed on this background, Maria might, then, have left the hospital with management guidelines more suited to her needs, abilities, and circumstances, and more likely to prevent future crises. Moreover, she would likely have felt more capable and more confident of her role in Susanna's care. Instead, Maria was given only a skeletal plan, and no plan for follow up unless Susanna should experience another crisis.

Appropriate Dependence and Protection verses Over-Dependence and Over-Protection

Research contends that mothers are over protective and demanding and their children with asthma are overly dependent on them (Abidin, 1990; Askildsen, Watten, & Faleide, 1993; Hermanns, Florin, Dietrich, Rieger & Hahlweg, 1989; Schobinger, Florin, Zimmer, Lindemann & Winter, 1992; Williams, 1975). The findings in this study indicate that problematizing the many concerns of parents and the immediacy of their children's needs as maladjusted protection and unhealthy dependency is an oversimplification of the issues.

In this study, mothers were found to respond to their children's symptoms and cries for distress in ways that were designed to assure symptom relief. Each mother, and each father as well, chose the way she or he thought best among the possibilities available. Able to rely only on themselves to detect first signs of abnormal breathing some parents responded with hypervigilance. Ruby who talked most poignantly about being vigilant also voluntarily acknowledged that she probably did not need to sleep lightly for Reggie's sake. Waking up often and touching his back was something she did to assure *herself* that he was breathing normally. This mother's insight into the complex relationship she has with her son and his asthma overturns notions of pathological "overprotectiveness." Ruby acknowledges that both her son's asthma and her own emotions are cared for by her attentiveness to his night breathing. Her acknowledgement of these dual concerns gives the clinician two points of discussion about the appropriateness of Ruby decreasing her vigilance.

Parents needed assurance that their children's breathing would not deteriorate even when they could not listen to every breath. Especially in the early stages of the illness when parents were unfamiliar with abnormal breath sounds and when most children in this study were non-verbal infants, parents felt responsible to maintain continuous vigilance. Parents longed for children to indicate when breathing was difficult. Before children could talk, parents attended carefully to the signals children gave of distress, among these were: disinterest in active play; lack of appetite; chest rubbing; irritable crying; and clinging behaviors.

As children grew and their familiarity with asthma increased, parents modified their vigilance practices. Still, they took up the project of looking out for symptoms without any formal guidelines. Whether behaviors were appropriately suited to the illness, and to the age and developmental level of their children was left for them alone to determine. Parents felt relief from the responsibility of solo decision making when children communicated their distress by asking for inhalers or if, when offered, inhaled medications were accepted willingly. However, even for the older children in this study, those over 2 1/2 years, parents appropriately relied primarily on their own assessment of all illness indicators rather than on the child's initiative to guide their awareness of the manifestations of asthma and its severity.

Data that was not included in the interpretation of findings showed that parents believed asthma made special demands on their otherwise "normal" children. When children were ill parents interpreted clinging and crying as signs of suffering, but the same behaviors were viewed as manipulative or inappropriate when children were well. Of the many behaviors that parents interpreted differently depending on whether the child was ill or well, crying is exemplary and universal. Most parents reported they knew the difference between cries of distress due to compromised breathing, and crying unrelated to asthma.

Acute vigilance helped parents maintain control over capricious symptoms in a climate of inconsistent, and sometimes unfriendly, professional care, and ambiguity about when emergency care was appropriate. In addition, parents in this study carried on their own lives despite the demands of asthma. Rather than being overprotective, the parents were remarkable for managing asthma responsibly despite their youth and limited social, educational, and financial resources. Furthermore, they did so while assuming full responsibility for the care of their other children and, in some cases, of other family members.

Enhancing Delivery of Care and Improving Practice

In general, public awareness and public policies that reflect a commitment to illness prevention could help humanize the experience of living with asthma for families like the ones in this study. For example, a policy of refusing to house families on public assistance in roach infested apartments should be instituted for the prevention of asthma. In addition, free or compensated transportation for both specialist and emergency care should be available on demand to children with severe persistent asthma.

There are several suggestions for practice modification. First, the National Institutes of Health (NIH) Guidelines for the Diagnosis and Management of Asthma state that all children with two emergency visits for asthma crisis should be referred for specialist care. The children in this study, all of whom met this criterion, were either not referred for specialty care, or were referred much later. In addition, families' lives were constrained by several barriers to following through with specialist care. Specifically, these were: unreliable transportation; interrupted telephone service; child care, and responsibility for getting other children to medical appointments and/or to and from school; strict employer demands for attendance backed up by threats of job loss; and the policy of dropping children from eligibility for specialist care after several failed appointments.

NIH guidelines also state that children with two emergency visits for asthma should receive inhaled steroids to be used daily, even when they are asymptomatic, in order to prevent recurrent crises. No child in this study was treated according to these guidelines. Forums for concerted dialogue about NIH guidelines regarding specialist care and the use of inhaled steroids should be carried out with all primary care providers who care for infants and toddlers with asthma. The reasons for failure to follow NIH recommendations should be aired, and steps should be taken to correct the lack of early recognition and treatment of asthma.

Study findings indicate that joining parents in the effort to assure the well-being of their infants and toddlers with severe persistent asthma is as crucially important as the specific treatment modalities prescribed to improve care. Without on-going, respectful involvement from the providers and staff who carried out hospital management procedures parents felt increasingly isolated from professionals, and disbelieving of medical/technical explanations and expectations.

Educational interventions should be provided for emergency and hospital providers, both professional and non-professional, with three aims in mind. The first aim is to have providers appreciate the ambiguity and difficulty in home asthma management when children are very young and when families are economically and socially disadvantaged. Parents in this study arrived for emergency care having tried everything available to them to manage their children's asthma, but found providers who were condescending, rejecting, and blaming. Respectful care should include positive recognition of the parent's role in illness management. Although afraid and often confused, parents in this study were always profoundly concerned for the well-being of their children even when their lives were otherwise severely stressed. In addition, parents brought understandings about asthma, and familiarity with the responses of their children to asthma into every encounter with the professionals from whom they sought care. On that basis, genuine interest in parents' "know-how" should be fundamental to all interactions between providers and parents.

The second aim of staff education is that emergency and hospital providers gain an appreciation of the importance of the relationship between parents and children during infancy and toddlerhood, including how asthma crisis and management procedures affect the relationship between parent and child. Parents in this study reported that providers were not particularly supportive of parental proximity and involvement with children during hospital crisis management. Proximity of parent and child, and encouragement of the parent's supportive role should be the model for caregiving during every traumatic hospital event. New techniques for comforting and holding children should be discussed and practiced. Restraint should be minimized and infants' and toddlers' cooperation with nebulized breathing treatments should be maximized.

The third aim of provider education is that providers learn to shape care according to the meaning the illness has for families. To begin providers must assume an open stance toward families' experiences and find space in the practice for listening to parents' direct narratives. The approach of joining parents at the level of their concerns is essential for engaged practical reasoning with the individual or family in one's care. According to Benner (1989; 1994b) engaged practical reasoning makes expertise and caring in nursing practice distinct from the attempt to deliver context-free care, that is, care practiced according to set criteria but without consideration of issues of meaning. She discusses Taylor's (1985) example of the contrast between a contextually meaningful practice and a context-free behavior.

> A practice differs from discrete behaviours in that it is a culturally constituted, meaningful action. ... [For instance, there is a distinction between] the discrete behaviour of raising the arm and the culturally constructed public human action of raising the hand in a voting practice. A practice is located within a tradition and is continually being worked out in history and through the on-going development of the practice. A practice has a referential context of meanings, skills and equipment, and has the capacity to be worked out in contexts that allow actualization of the notions of good embedded in a practice. (Benner, 1994b, p. 137)

Thus, in respectfully acknowledging parents' skills and knowledge about the experience of living with their child's illness, providers can begin an engaged process of reasoning and expert care. Joining parents in this way involves remaining open to the detailed contextual contingencies that shape the process of illness management for individual families. On this background, and the background of her clinical expertise, the engaged caregiver can set priorities for caring with the aim of developing a collaborative strategy in which family members participate as much as they are interested and capable. The provider's expertise and "know how" can guide the process of engaged professional caregiving to a beneficial outcome. In this way, the process serves the parent and child by providing expert support and skilled response to symptoms, and also serves as a model for parents in the care of their children.

If, for instance, parents were queried about the non-verbal signals they read in their child during hospitalization and if their suggestions about comforting their child were solicited, two results might accrue. First, if parents' fears were acknowledged, their own level of comfort and calm would likely improve. If parents' suggestions for personalizing care proved valuable, their sense of confidence in being able to respond effectively on behalf of their children would be reinforced. In addition, with parents calm, children would likely feel less frightened and struggle less against procedures. In experiencing the cooperation of the other, parents and caregivers might together focus more effectively on the work of symptom management. The alternative, and the current practice reported by parents in this study, is that parents and providers feel alone as they struggle separately to maintain control over a frightening and unpredictable condition. The unfortunate irony is that each has a perspective that, if mutually communicated, could benefit the other.

The role of nurses in the care of infants and toddlers with asthma should be expanded in order to attend to issues of illness meaning and significance, and the ways these shape parent's care practices. First, families whose children have experienced severe crisis and/or hospitalization should receive periodic home visits by a network of public health nurses specializing in asthma care. At times of impending crisis this service would likely ease the burden and increase the effectiveness of parental caregiving, promote better understanding of daily illness management, emphasize the importance of following an individually designed written management plan, and prevent escalation of early symptoms to full blown crisis and hospitalization.

Second, hospital nurses specializing in the support of parents whose children are hospitalized should be available to parents to listen to their concerns, answer questions, support their participation in hospital illness management, and advise them about issues of on-going care in ways that promote illness management and optimum self-efficacy in parental caregiving. In order to facilitate an on-going dialogue about illness meaning and its influence in asthma management, a narrative history about the experience of illness onset, evolution, and management of crisis both at home and in the hospital should become part of the child's permanent record. Then, issues of long term management could be addressed in the context of the family's history with the child's illness and the meaning it holds for them. Narratives should include the experience of emergency and inpatient management of crises.

Recognition that parents as well as children need supportive care should be the basis for developing strategies that help parents emerge from the experience of hospitalization with a better understanding of asthma management, more confidence in their ability to effect the outcome of crisis, and less aversion to seeking emergency services. When the demands of immediate management do not allow for attention to parents' emotional needs, a later "debriefing" opportunity for parents could be considered as part of crisis follow up care as soon as breathing is stabilized and prior to hospital discharge. In this way, parents' experiences of emergency care and hospital management, and established practice styles can be considered when designing strategies for future management.

Finally, parents, and likely providers, would also benefit from open discussion of topics in asthma management about which the proper course of management is not clear. Two current ambiguous issues are: 1) whether or not crying during breathing treatments holds more benefit than risk in both the short and long term; and 2) the difficulty of assessing infants and young children in moderate distress from compromised breathing. The first has been discussed in Chapter 6.

Regarding the second, infants and toddlers in mild distress may have good reserve capacity for air exchange or they may have little reserve, even with similar, usually moderately elevated, rates of breathing. Thirty percent of these children go on to develop severe distress yet there is no known sign to distinguish them from children whose breathing will improve (Sudhakar, 1999). Oxygen blood saturation, that can be conveniently measured by a pulse oxymeter placed on a finger or toe, is the only non-invasive indicator considered accurate in measuring respiratory reserve in children with moderate distress. Providers themselves are unsure about how aggressive to be with therapy and whether or not to recommend hospitalization without the assistance of this measure. Discussion of how to assess illness severity when symptoms are moderate would help parents realize the ambiguity of the situation and feel less alone in being able to assess the level of their child's distress accurately. As a result, crisis would be less likely to undermine parents' ability to respond effectively to their child's distress. Several parents in this study mentioned that they thought they had learned how to read the level of severity of their children's symptoms. They went to the emergency room expecting to be sent home shortly with medicines to treat asthma. To their surprise, however, as a result of a pulse oxymeter reading, their child was hospitalized. This experience left parents disturbed by their misjudgment of distress severity. As a result, they took away the message that their developing confidence in managing the illness had been misguided. They worried that in succeeding crises they might not seek care in time. Asthma had become more fearsome and their ability to control it more tenuous.

To conclude, NIH guidelines need to be applied more consistently when infants and toddlers have severe persistent asthma. In addition, every aspect of the management of severe asthma in very young children should be built on a commitment to promote parents' sense of competence in asthma management and parenting, and to establish collaborative relationships between providers and parents in order to achieve that end. Since parents are on the frontline of symptom prevention, recognition, and assessment, development of an on-going learning experience for parents about asthma management should be based on provider respect and support, and dedicated to effective collaboration and shared responsibility between providers and parents.

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Appendix A

Sample Recruitment Summary Information

Letters Sent: 59

Response letters received: 7

No follow up to recruitment letter: total 8; no phone 4; study full 4

Phone diconnected: 2

Phone message left with mother, father or other person in household with no response after several attempts: 4

Did not meet criteria: 13

- no continuous medications: 4
- Spanish speaking only: 7
- wrong Dx: 1
- too old for study: 1

Refused participation: 3

Visits attempted no show: 3

Brief summary:

1) Visits scheduled on two separate occasions. One time postponed due to company in the home. New appointment rescheduled when I called one day ahead to confirm. Telephone call day prior to that app't: app't rescheduled to 2 days later. 8am day of app't: tc to father to confirm app't for 1pm. 1pm nephew only at home msg left with him. No further response from the family.

2) Mother returned response letter. App't set. Day prior I called to confirm. Phone answered by woman who said mother and son had moved and the day before and she did not know where they were or how to get a hold of them.

3) App't scheduled. No answer the morning prior to the 2pm app't. I went anyway; no answer at the door. A few hours later I called and woman who answered the phone said mother was afraid of someone and so had gone elsewhere. I called back one time after that, no answer. No further attempts to contact. This

mother had been very kind on the phone and very interested in talking to me and said I didn't have to pay her.

Failure to schedule interviews with interested family:

One father who had primary custody of his son and along with his wife took primary responsibility for asthma care was interested. The boy's mother sometimes cared for him for a day or two, Since the father worked two separate full time jobs, he, the step mother, and I found it impossible to set up convenient app'ts. We tried for a month.

Appendix B

Explanatory Model Interview

1. Before we get started talking about asthma, I am wondering if you will tell me a little bit about your family.

Probes: Who is in your family? (Ask about members, relationships, birth order)
Who of these people live in this house?
Are there others who have asthma?

2. Can you tell me what asthma is like in your child? When did you first notice it? What happened? What led up to it? What happened after that?

3. Is there a specific management plan established for your child?

a) What is your plan for routine days?
b) What is your plan for times of crisis?
c) Who worked out this plan with or for you?

4. People have different ideas about what asthma is in children. I'm interested in your understanding of asthma.

a. Will you describe, in your own words, what asthma is?

Probes: What does asthma look like in your child?
Is there something different about the way your child's body, or emotions work?
When do problems with wheezing, coughing, and breathing occur in your child?
What brings it on?
Are there clues that tell you these problems may develop?
And what do you call asthma in your family?

b. Can you describe the first things you noticed about your child that made you suspect there was a problem? Why do you think it started when it did?

c. What do you think might have caused these problems or differences?

d. How severe is your child's illness? What do you think the course of the illness might be?

e. How do you think asthma is for your child?

Probes: How does your child feel on a usual day?
During a crisis how do you think your child feels?
Does your child act differently toward you when breathing is difficult? Does he/she act differently towards others?

Are there ways your child talks or tries to talk about asthma?

Does your child seem to need you in different ways because he/she has asthma?

f. Is being a mother (or father) to your child different because your child has asthma? What are some of the ways mothering (fathering) is different?

Probes: On routine days?
In crises?

g. How has asthma changed the way you parent your child?

h. Is this different from the ways you parent your other children who do not have asthma? In what ways?

5. I would like with talk to you about any time in [name of child]'s life when you have been away from him [her] for an extended period of time. How do you think these have made a difference for your child? What differences have they made for you?

6. What are the chief problems that asthma has caused for your child?

7. What do you think what might happen in the future with [name of child]'s asthma? Is there anything you have heard about other children with asthma that you think about?

8. What are your hopes and desires for your child's future?

9. What is the best kind of care your child could receive for his/her illness?

Probes: Medications
Education
At home care
Emergency care
Family care
No treatment helpful? Any options?

Adapted from Kleinman, A., Eisenberg, L., and Good, B. (1978). Culture illness and care. Clinical lessons from anthropologic and cross cultural research. Annals of Internal Medicine, 88, 251-258.

Appendix C

Family Coping Interview

1. Can you talk briefly about what your child having asthma has been like for your child? What has it been like for you? What has it been like for the family?

2. I am interested in the kinds of things that happen in families when a child has severe asthma. Will you tell me about a time that in the last three months when [name of child]'s having asthma was particularly difficult for you, your child, or your family?

[Try to obtain a narrative and ask the following questions if they have not been addressed.]

a) How did you first notice the asthma?
What was happening with your child?
b) What did you think about it?
Probes: What did others [family members] think about it?
c) How did it make you feel? (Ask each family member)
d) Did it seem as if you needed to do something about it?
Probes: What did you think you needed to do?
Did it seem to you as if you could handle the difficulty?
e) What did the family [you, your child other family members] do first?.... next?
f) How did that all get worked out? (Who decided? Who agreed? Who disagreed?)
g) Were there other things that other family members did?
h) Did [the child]'s behavior or asthma change during this time?
i) How do you feel about what your family did to make [the difficulty] better?
Probe: If it happened again would you handle it in the same way or in a different way?
j) Do you have any thoughts about what led up to this difficulty?
Probes: Had anything like it happened before?
What did the family do at that time?
In what ways was that like this time?
In what ways was it different?
k) Was there anything different about [name of child]'s behavior or behavior toward you after this difficult time?
l) Was there anything different about [name of child]'s asthma after this difficult time?
m) Do you think there are different things you do as a mother (a father) because or what happened?
n) Are there differences in the way you and [name of child] get along together since this difficult time? What are these differences?
o) Do you think there were any changes in the child because of what happened? How is the child different?
p) Do you think there were any changes in the family because of what happened? What has changed the most? How is the family the same?

3. Can you think of another time in the last three months when [name of child]'s having asthma was particularly important for you, your child, or your family?

4. Will you tell me about a time when it was necessary to take [name of child] to the hospital in order to control a episode of difficult breathing?

[Try to obtain a narrative and ask the following questions if they have not been addressed.]

a) What did you notice first?
  What was happening with your child?
b) What did you think about it?
  Probes: What did others [family members] think about it?
c) How did it make you feel? (Ask each family member.)
d) When did it seem as if you needed to do something about it? (Ask each family member.)
e) What did the family [you, your child other family members] do first?.
  Probes: Who did that?
  Did others do something different?
  Did everyone agree about what needed to be done?
  Did some have other ideas?
f) Were there other things that other family members did?
g) Did [name of child]'s behavior in general or behavior toward you change during this time?
h) What was happening with [name of child]' asthma during this time?
i) How do you feel about what your family did?
  Probe: If it happened again would you do anything in the same way or in a different way?
j) Do you have any thoughts about what led up to this [important time, specific event]?
  Probes: Had anything like it happened before?
  What did the family do at that time?
  In what ways was that like this time?
  In what ways was it different?
k) Is there anything different about [name of child]'s behavior in general or behavior
  toward you because of the crisis that led to the emergency visit or hospitalization?
l) Is there anything different about [name of child]'s asthma because of what happened?
m) Do you think there are different things you do as a mother (a father) because of what happened?
n) Are the differences in the way you and [name of child] get along together since you made the trip to the emergency room/hospital? What are these differences?
o) Do you think there were any changes in the family because of what happened? What were these changes?

5. Will you tell me about what it was like during the time [name of child] was in the hospital?

a) How did [name of child] react to being in the hospital?
b) During that time how did the family manage?
d) How did you feel? (Ask each family member)

e) Do you have any thoughts about what led up to the hospitalization?
Probes: Had anything like it happened before?
What did the family do at that time?
In what ways was that like this time?
In what ways was it different?

6. Are there any differences in your child and family since the hospitalization? What are these differences?

7. Will you tell me about what it was like for your family on the first day or days when your child came home from the hospital?
   a) Was [name of child]'s behavior in general or behavior toward you different in those first few days? (Ask of all adult family members.)
   b) Were there ways that your behavior toward your child was different? (Ask of all adult family members?)
   c) Were there any ways that you felt differently about your child? (Ask of all adult family members)
   d) What were the ways that [name of child]'s asthma was different after the hospitalization?
   e) Did you feel differently about how to care for [name of child]'s asthma?

8. What kinds of things do you do so that [name of child] will not have trouble breathing?

Using a similar format, ask the following questions.

9. Will you tell about a time when your child had particularly difficult time with asthma during the night?

10. Will you tell me about a time when your child had wheezing, coughing, or difficulty breathing which you could not bring under control?

11. Has there been a situation involving your child's asthma which has been particularly warm, meaningful, or satisfying for your family, and has brought you closer together.

12. [Conclude the interviews with an overview discussion.] How has [name of child]'s having asthma changed your family? You as a mother/father? You as a couple [or in relationship to other family members]? Do you think you respond differently to [name of child with asthma] than to you children who do not? What is different about you and your family today than before [name of child] had asthma?

Modified for this study from an interview guide adapted by Chesla from the Coping Interview, Stress and Coping Project, R.S. Lazarus and J.B. Cohen, 1977.