

MATERNAL ADAPTATION TO PARENTING A CHILD WITH ASTHMA

By

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ABSTRACT

The purpose of this study was to investigate the adaptation of mothers to parenting an asthmatic child. Involving three co-researchers, a case study design was used to explore their experience of this phenomenon. The co-researchers were selected on the basis of these criteria: their child had been diagnosed with asthma within the last five years; the child's asthma had been diagnosed as "moderate" to "severe"; although more than one child in the family may have been diagnosed as asthmatic, it was possible to isolate the process of maternal adaptation to the one child; the mother had reached a point of feeling adequate in the role of mothering the asthmatic child.

The participants were invited to create a lifeline of the experience, and to use this as a reference when describing the story of their adaptation. Upon completion of their narrative, questions were asked based on my pre-suppositions of the experience of adaptation, should these not have emerged previously during the interview. The narratives were audio-taped, transcribed, and analyzed for common emergent themes.

Validation interviews were conducted in order to confirm the emergent themes. An abstraction of one narrative, selected as representative of the three, was developed and validated by the co-researcher. This abstract portrayed the commonality of the process as well as the emergent themes.

The study confirmed the existence of a process of adaptation marked by three phases. The stories revealed a movement from inadequacy to adequacy. The initial phase was dominated by negativity reflecting the mothers' sense of overwhelming

impotence. The active middle phase, a phase of transition, was one in which the mothers increasingly became agents in the management of their child and their child's illness. This phase offered them opportunities to change their perception of themselves and their situation. The resolution of the middle phase placed the women in the final phase, where the themes of inadequacy found in the initial phase are opposed by the complementary positive themes of competency, strength and understanding. Underlying the themes contained within the three phases were ongoing themes which facilitated and provided a backdrop for this process.

This study confirms the significant impact that the presence of an asthmatic child has on the life of the mother. The findings reveal the need for understanding and support from those around her as she struggles to gain a measure of control in this experience.

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CHAPTER I

INTRODUCTION

Individuals with asthma, most especially with moderate to severe asthma, are forced to live with a potentially debilitating, and oft-times inconsistent illness. They must learn to adapt their thinking and behaviour, as well as their environment in many cases, in order to function optimally in their world. For children with asthma, however, an adult is needed to play a primary role in the management of this illness. For most children this adult is most often a parent and, as stated by Carpenter (1980) (as cited in Breslau, 1983), this parent is most often the mother. In this case, the adult is not just "dealing" with the disease, but is also in an intimate relationship with that child. The aim of this study is to explore how it is that mothers of asthmatic children become adequate to this task.

Some studies, such as that of Snadden and Brown (1992), have revealed a process or continuum whereby individuals have adapted to their experience with asthma. However, research has not attempted to describe the phenomenon of the adaptation of the mothers of asthmatic children, or the meaning of that experience in their lives. As the primary caregiver for the child, the mother's competence in and comfort with her role has an effect on the child's health and wellbeing. Within the discipline of counselling, and other helping professions, it would seem important to understand this experience of adaptation.

The literature reviewed for this study addressed the factors contributing to the stress experienced by the family of the asthmatic child. Literature studying the

relationships within the families of asthmatic children demonstrated the current beliefs in the medical community about this relationship's contribution to the asthmatic condition. The research offered, although minimally, descriptions of mothers' perception of self.

However, the experience of these women as they adjust to the role of mother of a chronically ill child has had little attention. It is anticipated that by listening to the "voice" of these women a clearer understanding of this process of adaptation and journey toward adequacy would emerge. It is hoped that exploration may encourage further research into this area. Insight into this adaptation may enable counsellors, pediatric allergists and general practitioners to help other women facing a similar experience.

Asthma: The Physical Condition

Asthma, the leading cause of chronic illness in children, is estimated to affect between 5 to 15% of this population at some point during their childhood (Behrman & Vaughan, 1983; Canny & Levison, 1993). The word "asthma" is of ancient Greek origin and means "panting" (Canny & Levison), however, there is no definition at this time which is commonly accepted throughout the medical world. What is agreed upon is the fact that asthma is a condition which alters the flow of air to and from the lungs. A main characteristic of asthma is the irritability or hyperactivity of the airways, causing the bronchial tubes to become narrowed and in some cases partially blocked (Behrman & Vaughan). Canny and Levison explain that the process of the narrowing occurs in two ways. First, the muscles in the wall of the tubes constrict and spasm. Second, the inner lining of the tubes swells and produces increased

amounts of a thick mucus which blocks the airways. This blockage in the airways produces the symptoms familiar with asthma: wheezing, coughing, shortness of breath and chest tightness. These episodes may last from a few hours to a few weeks in some children. It is common, according to Canny and Levison, for difficulties with breathing to affect such behaviours as exercise, sleep and speech.

The onset of asthma may occur at any age, however, 80% to 90% of children with asthma demonstrated their first symptoms in the first five years of life (Behrman & Vaughan, 1983). The course and severity of the condition are unpredictable (Behrman & Vaughan; Canny & Levison, 1993; Renne & Creer, 1985). The ambiguity of this condition can cause distress in parents and caregivers as they struggle to manage their child's health.

Renne and Creer (1985) note three main characteristics of the condition: intermittence, severity and reversability. The intermittence of attacks of asthma vary between children and also for the individual child. Children with extrinsic asthma triggered by seasonal allergens such as pollens and mold may experience symptoms for only certain periods of the year. Other extrinsic asthma sufferers, allergic to foods or animal danders, are able to exert some control over the environment and thus over their asthma. Over 50% of children with asthma are allergic to dust mites (Canny & Levison, 1993) and as such have a difficult time year round.

Children with intrinsic asthma (or non-allergic asthma) are affected by such triggers as viral infections, exercise and cold dry air. In most cases, according to Renne and Creer (1985) the etiology of the attacks is unknown. It has been suggested by Miklich et al., (1977), as cited in Renne and Creer (1985) that many asthma

sufferers have both types of asthma, and so may experience difficulties all year, increasing in severity on a seasonal basis. The intermittency of this condition can lead parents and children either to be on alert on a continuous basis, or to ignore the asthma outside of certain seasons. For some children, asthma will not be expressed unless the triggers have reached a certain threshold (Canny & Levison, 1993). It may take the parent much time and effort to discover specific allergens or combinations of allergens which produce the symptomology. Rolland (1987) notes three general forms of chronic illness, labelling asthma as a relapsing or episodic illness. This kind of illness alternates between periods of stability in which there are reduced or minimal levels of symptoms. These periods are punctuated by periods of more intense symptomology. Rolland comments that there is an uncertainty or ambiguity as to when and how intense an attack will be. A degree of flexibility is required within the family to deal with this type of situation. Rolland also notes that there can be a tremendous gap psychologically between the periods of calm and crisis, and that this in itself is a "particularly taxing feature unique to relapsing diseases" (p. 217). He describes the family as being in a constant "on-call state of preparedness" (p. 217), which interferes with the developmental goals of individual members of the family, as well as the family as a whole.

The severity of asthma also varies between children and within the child. An individual may lie along a continuum between those who only suffer with mild wheezing to those who are disabled by frequent acute attacks (Renne, & Creer, 1985). According to Canny and Levison (1993), 50% of children can be classified as having mild asthma, 40% as having moderate asthma, 5% as having severe asthma, and the

remaining 5% having coughing asthma. Renne and Creer suggest that the classification of severity of asthma be used only as a broad guideline, as the causes, symptoms and frequency of the condition are so varied.

The reversibility of the condition is considered by McFadden (1980) as cited by Renne and Creer (1985) as the primary differentiating characteristic of asthma. The bronchial tubes may return to normal either spontaneously or after sufficient treatment. Therefore, diagnosis often relies on the improvement of the symptoms after a course of treatment such as a bronchodilator. According to Renne and Creer, it is this factor which has contributed to the conflicting results of asthma research, as well as the frustration experienced by the parents and physicians as they attempt to diagnose and then to manage the condition.

CHAPTER II

REVIEW OF THE LITERATURE

Studies have suggested that the presence of a chronically ill child in the family is a stressful situation (Eiser, Eiser, Town & Tripp, 1991; Eiser & Havermans, 1992; Hamlett, Pellegrini & Katz, 1992). Asthma, a chronic illness which varies in severity and cause within and between sufferers, inflicts a state of continuous stress upon the parents and other family members (Schwam, 1987). Kazak (1989) notes that the balance of family relationships and roles are affected by the change within the one member. Early theories and studies have focussed primarily on the mother's role in the development of her child's asthmatic condition (Meijer, 1980) even referring to the existence of the "asthmatic mother" (Block, 1969; Block, Jennings, Harvey & Simpson, 1964). I have reviewed the early development of theories of asthma as well as current literature on the impact of chronic illness, asthma in particular, upon the family. Studies have primarily been of a correlational nature, examining the emotional and physical environment within which the mother and other family members exist. I have also examined a narrative study of the experience of adults with asthma.

Historical Trends

In order to understand the experience of a present-day mother of a child with asthma it is helpful to review the roots of the medical perspective on the illness. What beliefs permeating the approach to understanding and managing asthma today

are contributing to the mother's ability or inability to cope in her role? Where did these come from?

Emerging out of a psychoanalytic background in the 1940's, the work of French and Alexander (1941) (as cited in Renne & Creer, 1985) became the standard approach to the diagnosis and treatment of asthma. This view has strongly dominated the management of the illness since that time, contributing to the "generation of guilt in mothers of asthmatic youngsters" (Renne & Creer, 1985 p. 52). This study, upon reflection, was weak (Renne & Creer, 1985) and further empirical investigations have produced conflicting results (Gustafsson, Kjellman, Ludvigsson & Cederblad, 1987). French and Alexander's four suppositions about the condition of asthma have permeated the medical and psychiatric approach. These beliefs are: asthmatic sufferers have an infantile dependency upon their mothers which conflicts with other emotional needs; attacks of asthma are related to a suppressed cry for the mother; there is a unique asthmatic personality; psychotherapy, especially psychoanalysis will reduce or eliminate the asthmatic symptoms (Mattson, 1985; Renne & Creer, 1985).

In the last decade these beliefs have not been substantiated, with clinical workers noting that there appears to be no universal personality type in asthmatic individuals, and that the children that psychiatrists often see are a biased sample of patients with behavioural problems (Mattson, 1985). There has been a movement, within this field of research, from the psychoanalytic perspective to the family systems perspective, noting the circularity of the relationship between the asthmatic condition and the family.

An example of the work emerging from the psychoanalytic perspective is Meijer (1980). This article demonstrates that belief system which contributed to "mother-blaming". As stated by Altounyan (1974) in Schwam (1987) asthma has a social stigma for many people. He noted that it is considered a symptom of emotional inadequacy rather than an organic disease, and that either the individual with the asthma is choosing not to recover, or else the mother has contributed to the inadequacy of the individual. The Meijer (1980) article outlines a study of the feelings of mothers towards their asthmatic children. Meijer refers to past accusations of these parents having a "psychopathogenic influence on the asthma of their children" (Groen, 1976; Miller & Baruch, 1957; Sperling, 1968). He believes that when there is a conflict between the emotional needs of the child and that of the mother, the mother's needs take precedence. This is due, according to Meijer (1980), to the mother's "preoccupation with the need for personal satisfaction from a dependency relationship with the child." As the child matures, anxiety supposedly increases in the mother, with the child reacting to this anxiety. In the asthmatic child, it is presumed that the child gives up autonomy, which "arouses anger, frustration and guilt" (p. 34). These emotions are often associated with the process of the development of asthmatic symptoms, according to Meijer.

Meijer (1980) questions whether there are psychological factors involved related to the "representation of the child in the mother's mind" (p. 34). Is the asthmatic child mainly identified with positive or negative figures in the mother's early family life? Meijer used the Family Relation Test (Anthony & Bene, 1957), weak in both reliability and validity, to measure the feelings of the mothers of 60

asthmatic children about each member of her nuclear family. Feelings about herself were examined, as were beliefs about her asthmatic child's personality, looks, behaviour and attachment to mother. Meijer states that the mothers identified their asthmatic children more often with positive figures from childhood than did the mothers of nonasthmatic children. He believes that this finding indicates that overly intense warmth from a mother is linked with asthma. He states that his finding supports that a "balanced" warmth, however, is linked with non-asthma. Meijer comments that, although there was no significant difference between the two groups on the measure of attachment, the "type and quantity are different" (p. 39). He explains this by referring to a previous study (Meijer, 1978) which showed a significant difference between the two groups on the measure of dependency. This study had investigated the "conflictual attitudes" of the mothers towards their asthmatic children. He believes that these attitudes might exist because the mother, identifying with positive family figures, feels guilty and maintains a tight hold on the child. The child is kept dependent longer than is needed. The attachment, therefore, is equally strong in both groups, but when linked with dependency in the asthmatic group becomes unbalanced.

Meijer's (1980) discussion of his findings ask the reader to accept these previously listed psychoanalytic premises. From that position, Meijer then extrapolates from his results and uses his findings as support for the premise that asthma is "a psychosomatic symptom" which "acts as a substitute for psychological manifestations of inner stress" (p. 39) (ie. the smothering relationship with the mother), rather than a physical condition sometimes aggravated by emotional or

physical stress. For Meijer, the mother has greatly contributed to the asthmatic state of the child through her separation anxiety and the child's reaction to it (p.38). As a correlational study, however, the findings do not reveal causes, only relationships. As such, the study further indicates, if only weakly, the circularity of the family relationships rather than support the belief that the mother is the root cause of the child's health difficulties.

Emerging from the same theoretical roots as Meijer, Byrne and Murrell (1976) developed a study to examine the self-perceptions of mothers of asthmatic children. They hypothesized that identifiable patterns of self-description would differentiate the mothers of asthmatic children from the mothers of non-asthmatic children, given the premise that mothers of asthmatic children "communicate excessive concern to their children in the form of anxiety and over-protective maternal behaviour" (p. 179). Byrne and Murrell affirm their support of Minuchin et al. (1975) in the belief that asthma is a psychosomatic illness, which is exacerbated by the "overprotectiveness" of their mothers.

Byrne and Murrell (1976) compared the responses to the Gough and Heilbrun Checklist (1965) of 65 mothers of school-age children with asthma and 100 mothers of school-age children without any chronic illness. This checklist contains 300 self-descriptive adjectives in its original form. This list, however, was pared down to 70 items chosen by 10 "clinically experienced psychologists and psychiatrists" (p. 179). These items were deemed to be the adjectives which most clearly, in their opinion, reflected an individual experiencing stress. As well, items were included which reflected, also in their opinion, maternal qualities. The participants decided whether

the adjective applied to themselves or not. They were also given the opportunity to evaluate to what degree the adjective was applicable.

The mothers of the children with asthma were selected from three sources: a group from a society for mothers of asthmatic children; mothers of asthmatic children consulting a private chest physician; mothers of asthmatic children consulting a general practitioner. The mothers of the non-asthmatic children were obtained from school mothers' clubs. The children did not appear to be matched as to age or gender. The ratio of male to female children was 1.6:1 in the asthma group, and 1.9:1 in the non-asthma group.

Byrne and Murrell (1976) stated that their findings indicated a strong qualitative difference between the two groups, saying that "the cluster of items derived from ratings of mothers of non-asthmatic children lacked the obsessional and overprotective quality of the cluster of items derived from ratings of mothers of asthmatic children" (p.182).

Note must be made of the strong possibility of bias within this study.

Adjectives chosen by the mothers of asthmatic children as being most representative of themselves included: tidy, reliable and capable. On the other hand, adjectives chosen by the mothers of non-asthmatic children included: patient, soft-hearted, persevering. It is interesting to note that Byrne and Murrell draw attention to other adjectives, such as "calm" and "kind" within their analysis of the results. These adjectives actually rated substantially lower than other adjectives such as "persevering" and "self-denying". These latter adjectives, it may be supposed, do not as readily reflect the lack of obsessional over-concern Byrne and Murrell wish to

display. The validity of the interpretation of these adjectives is also in question. The adjectives chosen by the mothers of the children with asthma could equally reflect the self-perception of qualities of strength developed and deemed important through the on-going process of tending a chronically ill child. An opportunity for the mothers to express themselves in more detail would have increased the value of this study. There was also no indication of how long the children had had asthma, a factor which could affect the responses of the mothers. Without the presence of other chronic illness control groups it is difficult to support the hypothesis of the researchers.

In examining the literature it becomes apparent what a large impact the psychanalytic perspective has had on the view of asthma. It has been seen as a deficiency within the individual, or as a deficiency within the individual's mother. It has been seen to play a role in the structure of the family, meeting certain "needs" and maintaining the status quo of certain relationships. In response to Minuchin, Rosman and Baker's (1978) Psychosomatic Families, Coyne and Anderson (1988) comment that, rather than the child meeting the parent's "needs" by having diabetic crises which evoke certain strong emotions in the family, perhaps "a high degree of involvement is sometimes unavoidable, as parents struggle with unpredictable short-term illness crises, all the while continuing to carry out multiple daily treatment requirements." (p.119). They suggest that beyond the psychosomatic family model the family must be viewed within context. While dealing with disease within a family member, while dealing with the health care system, the family is responding

to ongoing threat and ambiguity. Like diabetes, asthma is an ambiguous and chronic illness producing continual stress in a family (Schwam, 1987).

Stressors associated with Asthma

Many studies have investigated the impact of a chronically ill child on the family. As Schwam (1987) noted, the parents of the asthmatic child face ongoing stress as they cope with the management of their child's chronic illness. Using primarily correlational studies to investigate the stressors and coping patterns of the families, many similarities and differences between specific diseases have been found. Some research has studied chronic illnesses apart from asthma, others have combined asthma with other chronic illnesses, and a few have reviewed the difficulties of asthma on its own. I will review a selection of these various perspectives, given that there is a paucity of work dealing with asthma alone.

Eiser and Havermans (1992) studied the coping process of mothers and fathers of chronically ill children. Two hundred and forty-five questionnaires were returned from the mothers and fathers of chronically ill children between the ages of 4 to 14. Using an unidentified scale measuring social and family difficulties, and the Coping Health Inventory for Parents, the researchers concluded that support and information regarding the illness were regarded by the parents as important factors in reducing stress across all illnesses. This finding, however, may be biased by the selection of families through self-help groups. The findings suggested that parents of children diagnosed with epilepsy and asthma experienced a level of difficulty second only to that of the parents of children with leukemia. Eiser and Havermans note that this high level of stress may be due to the "uncertainty or unpredictability" (p. 255) of the

illnesses. The coping patterns described in this study appeared to be linked to the specific disease and length of time of diagnosis. There was also an indication that the patterns used by the mothers differed somewhat from that of the fathers in the study. Increased level of autonomy, social support and information-sharing were listed as most important as coping factors for the mothers. It was noted, however, that a need for a high level of social support and information-sharing diminished over time. Eiser and Havermans postulate two reasons for this finding: the women feel more competent over a period of time, or they may still desire the support but find it withdrawn by others. Fathers rated autonomy as an important factor in their coping pattern, but were not as needful in the area of social support. As Eiser and Havermans note, this study suggests further exploration is needed into the coping mechanisms used by parents in relation to specific chronic diseases, as each disease carries with it its own limitations and difficulties. Further investigation of the validity of the questionnaire used to measure family difficulty and the Coping Health Inventory for Parents is necessary to support the credibility of this study. As Eiser (1990) states, however, chronic disease, asthma included, appears to have a positive relationship with increased levels of difficulty for the child in academic and social settings. Eiser (1990) also notes the negative effects this has on maternal mental health and family functioning.

Creer, Marion and Creer (1983) developed their Asthma Problem Behaviour Checklist. Used as a screening device for detecting maladaptive behaviours or nonperformed adaptive behaviours of the children with asthma, Creer et al. (1983) questioned the parents of 44 male and 29 female asthmatic children. The findings of

Creer et al. suggested areas of concern for either mothers or fathers as they cared for their child. These were: frustration over the lack of knowledge and efficiency on the part of teachers and school personnel in dealing with asthma; withdrawal from community activities due to concern over the child's health; feelings of general overprotectiveness of the child and concern as to the effect that had on the child; difficulties at work (particularly for single mothers) due to frequency of absences to care for child; feelings of resentment because of the perceived effects on the family of the child with asthma. On the positive side, this study suggested that the majority of parents rarely disagreed about how to manage an attack and that the responsibility was shared. The validity and reliability of this checklist has not been tested which weakens this study. This study identified some of the innumerable stresses that act upon the parents of children with asthma. As a guideline for helpers of families of asthmatic children, this test could be useful in pinpointing specific areas of concern for further exploration.

Peri, Molinari, and Taverna (1991) did a comparative study of 84 parents of 42 preadolescent children with atopic symptoms (asthma, bronchitis or hay fever) and 376 parents of 188 preadolescent children who were not subject to either atopic problems or other serious illness. Creer, Marion, and Creer's (1980) Asthma Problem Behaviour Checklist was modified to reflect Italian culture. Peri et al. (1991) reported that the families of the asthmatic children were characterized by higher levels of anxiety related to the presence of the disease. This finding was based on the elevated reported level of panic response by the parents of atopic children when faced with illness (27% positive response from parents of normal children as

compared with 65% positive response from parents of atopic children). Peri et al. argued that "increase in panic in these families depends on the tensions aroused by an atopic-type disease which, in turn, creates problems not only because of its chronic nature but also because it may lead to disturbances in the the whole family organization" (p. 96).

Similar to the findings by Creer, Marion, and Creer (1983), Peri, Molinari, and Taverna (1991) found that a high percentage of parents felt competent in managing their child's illness, and shared the responsibility equitably between both parents. However, unlike the findings of Creer et al. (1983), the Peri et al. (1991) study showed increased frequency of disagreement over how to intervene. A replication of the study, including a larger group of atopic symptomatic children and their parents, as well as identification of the length of time since diagnosis, may contribute to the validity of this study.

Hamlett, Pelegrini, and Katz (1992) also investigated the impact of specific childhood chronic illness on the family. Thirty mothers of 6- to 14-year old children with asthma or diabetes, and 30 mothers of healthy children were asked to participate in a structured interview and given a scale to measure family functioning. Three months later, the mothers completed a questionnaire to assess the level of stress experienced by their child in the previous 12 months. The children in both groups were matched for gender and age. In the chronic illness group, the participants had been diagnosed with asthma or diabetes for at least one year. Socioeconomic status was also matched. Hamlett et al. (1992) found a strong relationship between increased internalized, anxious behaviours by the child (eg.

worry, low self-esteem), asthma, and inadequate social support as reported by the mother. As Hamlett et al. note, this relationship indicates the role that social support plays in the life of the mother of a chronically ill child (from both a practical and emotional perspective). The researchers explain the effects of childhood chronic illness on the family as a unique process reflecting the child and his or her family interactions, as opposed to generalized and static. These findings suggest the circularity of the family experience of the presence of a chronically ill child as a "chronic stressor that may affect, or even potentially disrupt, mastery of normal developmental tasks of childhood as well as the balance of relationships within family systems" (p.44). It should be noted that this study, as with that of Eiser and Havermans (1992), revealed the need for further studies focussed on the specific illness. The findings suggested some differences between the impact of asthma, as opposed to diabetes, upon the family.

In one of the few studies evaluating asthma alone and its effects on the parents, Staudenmayer (1981) supported the beliefs of Creer, et al. (1983), Eiser and Havermans (1992) and Hamlett, et al. (1992) that the family also is affected by the chronic illness present in one member. He notes that these parents are often under uncommon stress. A sample of 159 mothers and 70 fathers participated in the research. The volunteers were taken from three subsamples of parents who had brought their children to the following institutional services: the inpatient service at the National Jewish Hospital and Research Center/National Asthma Center (NJH); the outpatient service of NJH; private practice.

Staudenmayer's (1981) study was undertaken to explore two objectives. The first was to develop an instrument which would evaluate the "parental psychosocial factors associated with childhood asthma" (p.627). The second objective was to explore the relationship between the anxiety of parents of asthmatic children related to the disease, and the amount and intensity of medical intervention deemed necessary to control the disease.

A 97-item questionnaire was administered to each of the parents. Using a five-point scale to answer the questions, the participants described the level to which they experienced the identified feelings. After a test-retest check for reliability, using 36 parents, within one month, 12 items were rejected. The remaining items were analyzed using cluster analysis. The clusters resulting from the analysis were similar between the mothers and the fathers, although there were sufficient differences found when reviewing specific items within the clusters. Staudenmayer (1981) found that many mothers reported feeling physically overwhelmed by the amount of care required for their child, in comparison to the reports of the fathers. This finding is supported in other studies (Breslau, 1983; Creer, et al. 1983). In a study of women's use of time and care of disabled children by Breslau (1983) it was suggested that these mothers experience more intense stress both physically and emotionally. Mothers typically are the primary caretakers of chronically ill children according to Carpenter (1980) (as cited in Breslau, 1983). (This finding is in opposition to that of Creer, Marion and Creer, (1983) whose respondents claimed that responsibilities were shared on a relatively equal basis.) Many daily routines are often disrupted by the additional hours spent in medical visits and in regular home care. Breslau (1983) notes that the

mother of a disabled child spends on average 30 hours a year escorting her child to medical appointments.

The parents also reported feeling distressed that the family focus seemed to be around the child's asthma attacks. Both mothers and fathers reported feeling emotionally isolated.

Staudenmayer postulated that increased parental anxiety would be directly related to the level of debilitation. Using three subsamples as a method of measuring this level of debilitation (eg. the children requiring inpatient care had the most severe level of debilitation; the children in private care had the least severe level of debilitation). Staudenmayer suggested that this relationship did indeed exist. A substantial number of the parents of the children in private care expressed a reduced level of distress, resentment and feelings of unfulfillment, as compared with the parents of children in the inpatient sample. This correlational study only shows a relationship between these two factors. It is also highly likely that there is an effect of the personal attention of the medical practitioner on the feelings of the parents which may instill a greater feeling of confidence and reduced level of distress.

Other findings of this study suggested that mothers experience more intense levels of distress in their role as parents of an asthmatic child than do fathers. In order to strengthen these findings, a replication of the study with a more evenly balanced number of men and women in each sample would be necessary. It is vital that the researchers also operationalize their measurement of the debilitation of the child more accurately, and not rely on the indirect measurement of which type of

institutional care they are receiving. This aspect of the study was confusing when reading the article.

Mothers and fathers in various studies have expressed their concern about their involvement in the medical management of their child's illness (Creer, et al., 1983; Donnelly, Donnelly, & Thong, 1987). Donnelly, et al. (1987) noted in their study that over 80% of a group of parents of asthmatic children were concerned about giving medication over long periods of time, and over 30% were of the opinion that "children's bodies are too small to cope with medications" (p. 434).

Creer, et al.'s (1983) study of asthmatic children and problem behaviours as perceived by their parents note the concerns expressed by parents over the physical and behavioural changes in their children after taking medications. These included observations of mild jitteriness to intense and sudden expressions of anger and aggression.

Wilson (1993) comments on the fears of parents that asthma medication may be addictive, and often confuse corticosteroids with anabolic steroids, such as those sometimes used by athletes to promote muscle growth. There is often concern by parents about the longterm use of these medications and future side effects. Schwam (1987) notes that many parents in his clinical practice were worried by such questions as: "Is this medication interfering with my child's growth?" (p. 49). At least one study (Hauspie, Susanne, & Alexander, 1977) has suggested that growth may slow down during the use of corticosteroid medication, but that individuals will catch up in their growth after completing puberty.

Many studies have found that financial worries are common among parents of chronically ill children (Creer, Marion, & Creer, 1983; Marion, Creer, & Reynolds, 1985). Nocon and Booth (1989) and Schwam (1987) have commented on the expenses of prescriptions, lost pay through absence from work, and extra items needed for the asthma sufferer, such as air cleaners or certain types of bedlinen.

It is clear from the literature that many stressful factors are impinging upon the mother as she attempts to manage her child's asthma. The literature reviewed here, however, has shown the stressors in a fragmented manner, shedding little light on the holistic experience of the mother.

Interpersonal Relationships within the Family

Sabbeth and Leventhal's (1983) review of the literature suggests that the impact of the presence of chronic childhood illness on a marriage is often "strong and often negative" (p.762). The literature covered by this article did not include the presence of the asthmatic condition, however several interesting observations and questions were raised by Sabbeth and Leventhal (1983). The literature reviewed suggested that divorce in families of chronically ill children is not significantly different from the frequency of divorce in control families (Gath, 1977; Martin, 1975). It was noted, however, that marital stress appears to be more prevalent in the families of the chronically ill child (Silbert, Newburger & Fyler, 1982; Tew, Payne and Laurence, 1974). Sabbeth and Leventhal commented that many would find these results surprising, assuming that the increased stress would be positively related to a higher divorce rate. They posited a question for further investigation, asking whether marital distress, as defined by the researchers, strengthens or weakens a marital relationship.

They suggest that the distress reported may have an adaptive function, as the parents express their feelings and concerns to each other in their efforts to manage parenting a chronically ill child. The findings of Donnelly, Donnelly, and Thong (1987), suggested that many parents of asthmatic children felt that their marriage had strengthened through the challenge of parenting their asthmatic child. As mentioned earlier, Creer, Marion, and Creer (1983) found that many parents were in agreement over ways in which to respond to asthmatic attacks. Contradicting this finding, as also mentioned earlier, was the report in the study of Peri, Molinari, and Taverna (1991) that there was substantial disagreement between parents about management of the attack. Schwam (1987) presents the notion that in many couples two different coping styles may be in use. He advocates tolerance for each other's style, stating that through this tolerance each individual may provide balance for the couple as a unit. "The parent who tends to use minimization can be a calm, supportive person who puts fears in a different perspective. The parent seeking relevant information can learn techniques to assist in the treatment. This allows parents...to feel some degree of control over the illness process" (p. 51).

Few studies have investigated the effect on the siblings of the presence of an asthmatic child within the family. Disruption in family relationships are straining for other members of the family unit. There are conflicting studies reporting the perceptions of the feelings of the physically healthy brothers and sisters of sick children. Parents may worry that the siblings are not given their due in terms of attention and patience (Leventhal, Leventhal, and Van Nguyen, 1985). In contrast, Donnelly, et al. (1987) found evidence that parents perceived a drawing closer of the

family because of the presence of the member with asthma. A weak study by Lavigne and Ryan (1978) suggested that siblings of children with chronic illnesses seem more likely to be withdrawn and irritable than children in families without chronically ill children.

Further studies could provide a deeper understanding of the processes at work within the family of an asthmatic child. In turn, this understanding could provide greater assistance to these families as they face their extraordinary challenges.

The Experience of Asthma

In order to further explore the maternal experience of adapting to their child with asthma an examination of qualitative research is necessary. Qualitative analyses of the experience of asthma, either for the individual or the family, are scanty at best. The study by Snadden and Brown (1992) provided an interesting opportunity for seven adults with asthma to tell their stories. Snadden and Brown used an interpretive research method. The techniques used were immersion and crystallization in order to explore the emotions, feelings and meaning of this experience from initial diagnosis to acceptance. The purpose of the study was to examine the "concept of stigma in asthma and the illness experience of a group of asthma sufferers" (p. 1352). Snadden and Brown sent attitudinal questionnaires to all non-aboriginal native asthmatics within the ages of 18 to 60 within a rural family practice in Ontario. The patients had all used asthma medication within the last two years, according to the local pharmacy records. The six respondees, from an initial sample of 34, were identified as having the most intense feelings of stigma or pessimism. Snadden and Brown included one participant from an initial pilot

interview, which then brought the participant number to seven, including two males and five females.

The interview was semi-structured, consisting of open-ended questions. The questions focussed on sensory descriptions, areas of knowledge, experience and behaviour, opinions, values and feelings as outlined by Patton (1990). It appeared that of the seven participants, two were not in a state of acceptance of the condition. There was a range of frequency of attacks, frequency and amount of medication used, and length of time since diagnosis. The participants were located along a continuum describing their status as being "asthma in control" to "asthma controlled" (Snadden and Brown, 1992, p.1357). Several themes emerged along this continuum. These were: diagnosis and labelling; fear; knowledge; self-awareness; control; mentoring and acceptance. Diagnosis "gave meaning to confusing and perplexing symptoms" (p. 1354). Fear was present at the onset of each attack for all participants. However, it was noted that the participants who felt more accepting of their asthma were more easily able to control the sense of fear. Acceptance of the condition appeared to be inversely related to feelings of anger and loss of self-esteem after the diagnosis. Snadden and Brown suggest that a feeling of acceptance requires an acceptance of the limitations of their condition in conjunction with a "resolution of the anger" (p. 1354). This anger was related to the loss of control over self and freedom. The anger was also linked to intense feelings of frustration. The participants who felt the least in control of their asthma reported strong feelings of anger and low self-esteem. One participant commented that one aspect of feeling in control was the ability to be aware of and identify signals from your body. Another spoke of the need for initial

acceptance of the need for adjustment in order to reduce the anger and frustration felt by individuals with asthma. There is a sense of circularity in the reports of these subjects. It is not clear what the relationship is between anger and adjustment. It would appear that these two aspects of the process work together within the individual, rather than one "requiring" the other as previously stated by Snadden and Brown. This would be an interesting area for future research, and could be very helpful for individuals with chronic illness.

The themes of self-awareness, knowledge and experience were strongly demonstrated in the stories of the participants. Snadden and Brown (1992) comment that the integration of these aspects were facilitated in the participants by the presence of mentors. This mentoring ranged from support groups, physicians, and other asthma sufferers. Through reading, meetings with various health care professionals, and personal experience, the participants gained knowledge and increased their feelings of competence in managing their condition. The participants noted their increased awareness of physical limitations (eg. tiredness, restrictions on certain foods or physical activities). There was also an awareness of the impact of these restrictions and limitations on other family members. It was commented by one participant that it was essential to have the support and understanding of family and employers when coping with the aftermath of a severe asthmatic attack.

The findings of this study are important in evaluating the impact of asthma on the whole person. Snadden and Brown (1992) note that the findings support those of Nocon and Booth (1990) in relation to the profound effect asthma can have on the lifestyles of its sufferers. Snadden and Brown attempted to increase the reliability of

the study by bracketing out previous biases towards pessimism and stigma. The interviews were tape-recorded and transcribed. Field notes were also used. The validity of this study was supported by the variation in the age, severity of symptoms, and length of time since diagnosis. A more equal gender mix would have added to the validity of the study. The themes emerging from this study may add to the understanding and knowledge of the experience of the mother of a child with this condition. Such factors deemed important to the adult asthmatic, as mentoring, have been revealed in previously mentioned studies (Creer, Marion, & Creer, 1983; Eiser & Havermans, 1992) as important to parents of asthmatic and other chronically ill children.

Limitations in the Current Literature

The examination of the literature on a mother's experience of parenting an asthmatic child attempted to illustrate the historical trends in the medical and psychiatric approach, as well as the more current studies of the factors impinging on her world. The literature revealed many stressful aspects, including concerns about medications (Creer, Marion, & Creer, 1983; Donnelly, Donnelly, & Thong, 1987; Wilson, 1993), concerns about family relationships (Creer, Marion, & Creer, 1983; Donnelly, Donnelly, & Thong, 1987; Staudenmayer, 1981), feeling isolated and in need of support (Breslau, 1983; Creer, Marion, & Creer, 1983; Hamlett, Pelegrini, & Katz, 1992).

The literature revealed little or nothing about the experience of mothering a child with asthma. Byrne and Murrell (1976) attempted to explore this world by asking mothers to describe themselves and their behaviours, but this study was

extremely biased. Based upon the premise that mothers of asthmatic children were somehow different in their personality, with strong psychoanalytic overtones, this study further contributed to the negative view of these women.

Through the narrative work of Snadden and Brown (1992) it becomes clear that there is room to explore the meaning of the experience of mothering an asthmatic child, "looking at the condition and its problems as a whole, rather than as a sum of its parts". By increasing the understanding of the mother, we may also add to the understanding of the child and thereby assist them both.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore the process of adaptation to mothering an asthmatic child. What were the series of experiences as women became transformed through this adaptation? To understand this experience a phenomenological perspective was taken on three case studies. Yin (1981) describes the critical features of the case study as an empirical enquiry which "investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (p. 23). Rosenwald (1988) states that case study designs "emphasize connections and reversals of meaning rather than causes, functions, or class attributes" (p.261). Van Manen (1990) comments that "Phenomenological research is the description of the experiential meanings we live as we live them" (p. 11). Phenomenological research helps to express the intensity and complexity of these meanings in life experience (Van Manen).

In this research, I conducted two sets of interviews with the participants. During the initial interview, the participant was invited to describe her transformation. I took the three initial interviews and through a process of analysis noted and compared the emergent themes which developed from these stories. The second interview took place after all three initial interviews had been completed. At this second interview, the participant was able to review the common themes drawn from the three stories, and to validate or change any themes according to their experience.

Each participant was either interviewed in my home or their own. Using a tape-recorder, each interview was recorded in its entirety. A field diary was employed for notes recording emotions expressed through facial expressions and other physical behaviours.

Presuppositions and Expectations

"The first task is to explicate one's presuppositions about the phenomenon in question in order to prepare oneself for research" (Cochran & Claspell, 1987). Having personal experience of the process of adaptation to mothering an asthmatic child, it became especially important to have examined the beliefs that I carried into my research. In review, I was aware of the many strong feelings which emerged during this process. Among those feelings, frustration stands out as the primary emotion. This frustration was aimed at myself (for being unable to prevent the attacks due to lack of understanding and experience), at my child (for her inability to more clearly express her difficulties), and to several of my medical supports (for their seeming lack of compassion and understanding of our situation). Other strong emotions were anger, which was often coupled with the frustration, and a sense of isolation from other families because of my daughter's compromised health. The causes and symptoms of asthma are often misunderstood by the general public, which also lent to my feelings of isolation. It is still viewed by many as a somewhat psychosomatic illness. There was often a feeling of guilt, as I would analyze what I might have done better, or what I must have done in my pregnancy or when she was a baby to cause this illness. Family relationships were often strained, and parenting styles became somewhat polarized, as we attempted to adapt to our new situation. At times, I felt

very burdened as I struggled with my lack of knowledge and the ambiguity of the illness itself. These feelings I experienced are also to be found in the reports of parents in several studies on asthma and other chronic illnesses (Breslau, 1983; Creer, Marion, & Creer, 1983; Donnelly, Donnelly, and Thong, 1987; Hamlett, Pelegri, & Katz, 1992; Staudenmayer, 1981). However, as the time went on, through experience, reading, consulting with medical professionals of various disciplines, conversing with other parents of asthmatic children, and changing our environment and methods of dealing with the asthma, I grew into a position which felt more balanced and secure. The narrative work of Snadden and Brown (1992) also speaks of this process of adaptation from the perspective of adult asthma sufferers. With increased awareness of these predispositions through self-examination and research of the literature, I carried these predispositions into my research. When these issues did not arise during the telling of the participant's story, I employed these presuppositions as "a basis for questioning" (Cochran & Claspell, 1987).

Participants

Three women were selected to participate in this study. They were recruited through word of mouth to friends and acquaintances within the local school district. Upon contacting myself, the potential co-researchers received an explanation of the type of interview involved in the study and a decision was made as to the individual's fit with the criteria for the study. Participants in the study met the following criteria: the child had been diagnosed with asthma within the last five years; asthma had been diagnosed as "moderate" to "severe"; although more than one child in the family may have been diagnosed as asthmatic, it was possible to isolate

the process of maternal adaptation to one child; the mother had reached a point of feeling able to manage in relation to the child's condition and her new role; the mother was open to discussing and exploring feelings and the experience of the adaptation.

After a decision had been made as to the appropriateness of the volunteer for the study, an appointment was made for the first meeting. I then mailed a consent form to the participant prior to this first meeting.

Procedure

The First Interview. At the outset of the first interview I focused on developing a relationship of trust and rapport. Before signing the consent form, I answered any questions of the participant regarding the study.

I invited the participant to create a lifeline of the experience from the first stages of awareness of the child's compromised health to a point of maternal adaptation to the situation. Using the lifeline as a reference, the participant was asked to describe this process of adaptation. In order to clarify or elaborate details of the participant's story such open-ended questions as "What does that mean for you?" and "Could you tell me more about that?" were used. Egan (1986) states that such open-ended questions, or probes, may assist the client or participant to "define their problems more concretely in terms of specific experience, behaviours and feelings" (p. 141). I also employed such basic counselling skills as active listening and empathy to encourage the elaboration and extension of the details of the narrative.

Upon the completion of the participant's narrative, questions were asked based on my presuppositions of the experience of adaptation. These questions were:

1. Can you describe the role, if any, that the feelings of anger played in your experience of this process?
2. Can you describe the role, if any, that the feelings of frustration played in your experience of this process?
3. What effect did the presence of an asthmatic child have on your marriage?
4. What effect did the presence of an asthmatic child have on your family as a whole?
5. In what way has this experience changed you?
6. What impact did your relationship with your medical caregiver(s) have on the experience of the process?
7. Has this experience had an impact on how you view your asthmatic child?

Each interview was taped and transcribed. The emergent themes arising from the three interviews were examined, and one story was selected as most representative of the three.

The Validation Interview. The emergent themes determined from examination of the narratives of the three co-researchers were distributed to each of the participants approximately one week before the second interview. The participants were asked to read and reflect upon the themes. As well, one co-researcher received a copy of her abstracted narrative for validation.

The purpose of this second interview was to have the participants validate the emergent themes discovered during analyses of the protocols. The analysis procedure was explained to each participant and each theme was examined one by one. The participants were asked if the themes felt true or not true in the light of

their experience. They were asked to suggest any changes which might increase the accuracy and meaning found in this story. They were also asked if any aspect of importance had been left out. These validation interviews ensured that the participant's experience was understood by the researcher and that all changes and clarifications were noted. This procedure was also followed in the case of the abstracted narrative.

Procedure for Analysis

Following the method of analysis outlined by Colaizzi (1978), my initial step was to search for themes within the transcripts of the stories of the three participants. The transcripts of the initial interviews were read several times in order to increase familiarity with each participant's experience and expression of meaning. For each transcript, significant phrases or sentences pertaining to the experience were flagged by underlining in the transcript. A note was then made on an index card of the phrase or sentence. From these statements meanings were derived and noted at the top of each index card. Further derivation of meanings, from obvious to implied, were done. Care was taken not to stray from the true statement as expressed by the participant. These meanings were also noted on the index cards.

At this stage, each protocol contained a number of cards. Each card noted the meaning and the identified statement. These cards were laid out and sorted in groups with similar meanings, and clusters of themes were identified. Van Manen (1990) views the exploration of the common theme as the vehicle by which the researcher captures the phenomenon to be understood. For Van Manen, exposing the themes through "insightful invention" aids the researcher in making "sense" of the

experience. Finally, a theme title was developed to identify each cluster. I then wrote the name of each participant on a card, creating columns under each name, by placing cards naming the identified theme titles under each participant's name who expressed that theme. In this manner, I was able to identify themes common to all participants.

Upon completion of this analysis I selected one narrative from the three to represent the common emergent themes. This narrative was then abstracted in a chronological fashion, in order to more clearly depict the themes, details, structure and meaning of the maternal experience of becoming adequate to parenting an asthmatic child.

The research supervisor of this study and one other committee member were of assistance in the refinement of the emergent themes. As well, they examined all phases of the research for coherence and credibility.

The refined themes appeared to reveal the following structure. Four categories of themes emerged. Three of these categories reflected the three phases of the process: an emotionally overwhelming beginning; a turning point or peak of emotion leading into an active middle; and an ongoing reversible ending. The fourth category contained those themes which were revealed as ongoing and pervading throughout the process, supporting the process of transformation and adaptation. Quotations were employed to illustrate the emergent themes.

CHAPTER IV

RESULTS

In this chapter I list and describe the themes which emerged from the narratives of the three mothers of asthmatic children. Quotations which support these themes are noted. The findings are encapsulated in the chart following. (See Figure I.) An abstract of one narrative is presented and discussed.

Themes Emerging from Narratives

All of the stories of the three co-researchers displayed similar themes, although the intensity of certain themes varied with the individual. The themes clearly demonstrated the process that the women experienced, and appeared to naturally fall into phases reflecting the chronology of the adaptation of the mother to mothering the asthmatic child. These phases I identified as the "Beginning", "Middle" and "Ongoing End". As well, it was clear that certain themes were ongoing throughout the process of adaptation. The shared themes revealed the commonality of the experience of the co-researchers with regard to their feelings, thoughts and behaviours around their child.

List of Themes Emerging from Narratives

A. Beginning

1. Frustration

Frustration, one of the dominant feelings expressed by the mothers grew out of reaction to several different situations. The feeling of frustration was primarily incited by a reaction to the lack of support by medical caregivers, and more specifically by a

Figure 1. List of Themes Emerging from Narratives of Mothers of Asthmatic Children

| | |
|---|-------------------------------------|
| <u>Beginning</u> | |
| Frustration | |
| Helpless Fear | |
| Anger | |
| Isolation | |
| Self-Doubt | |
| Being "Out of Sync" with Child | |
| Seeing the Child as Different from Others | |
| | <u>Ongoing and Pervading Themes</u> |
| <u>Middle</u> | |
| Determination | Uncertainty |
| Seeing the Child as the | Love |
| Same as Others | Responsibility |
| Networking | Alarm for Family |
| Seeking Information | Supports for Mother |
| Experiencing "Trial and Error" | Hindrances for Mother |
| in Managing the Asthma | The Task of Medicating |
| | Concerns regarding |
| | Medications |
| | Venting Emotions |
| | Balancing Family and |
| | Sibling Concerns |
| <u>Ongoing End</u> | Being an Advocate for |
| | the Asthmatic Child |
| Developing a Healthy Respect | |
| for the Asthma | |
| Trusting Self | |
| Attunement to the Child: Learning | |
| to Recognize the Signs | |

reaction to feeling "unheard". "So then you have to try battling with authority, the people that know, the professions." This sense of being "unheard" was seen in two types of situations. The first situation was when the mothers were initially trying to explain how ill their children were to unbelieving medical professionals. Before a diagnosis of asthma, there was a strong suspicion by the mothers of the severity of the symptoms their child was demonstrating. The search to find a medical ear to

listen and understand their concerns became an overwhelmingly frustrating experience.

... that they wouldn't listen to me... That they didn't believe me, that I thought my child was sick. You know, (laughing), I was beginning to feel like I was nuts, I did!!... But I knew I wasn't. Having gone (to the doctor) in the past and being told that there's nothing wrong.

I said, "You know, he needs steroids or something. He's asthmatic. He's not..." But they would never... no one would say, "Yes, he is asthmatic." Nobody would say that.

And so... there's a certain... almost loyalty that you feel towards these doctors, because they've done so much for you, and you've relied on them so heavily. And yet, in this instance, it's like, "You screwed up! You're wrong! There is something wrong! And you're not seeing it!" or whatever... I was disappointed ...

The second situation was when the mothers were attempting to question or follow up on medication or other treatment being given to the child. Frustration again appeared as their opinions and observations about the relationship between their child and certain medications were dismissed.

I was asking that kind of question and just..."Who are you?" (laughing) "Who rattled your cage?"

Nobody took it seriously.

Because they would just give him some Ventolin, and like I say, a prescription for some syrup which I know is not going to help. But you can't argue with the doctors. They know (laughing).

And, to finally meet with this... the implication that, "Well, it's really just him. He doesn't know how to behave. It's not the medication." But I... that's what was implied. That was when he said... words to the effect of, "Was he like this before he started the medication?" That comment...

Frustration was described as being at "breaking point", "just at the end of my rope", and having "had enough". It was seen as a "barrier" which "breaks you down" especially in the area of self-confidence.

Because, obviously, if you were a good parent you would know what the problem was, and you would be able to tell people what it was, and they would instantly know!... But you're not, because nobody believes you...It's a vicious circle.

2. Helpless Fear

A sense of helpless fear was most noticeable, but not exclusively so, in the earlier stages of the experience of parenting an asthmatic child. One mother first experienced fear when her doctor mentioned the possibility of her child having asthma.

The fear of... that I'm going to start with... the asthma being mentioned.

Okay? That shook me rigid.

Later on, fear is mentioned in relation to the child's experience of his or her asthma or the reactions to the prescribed medications within a short time after the diagnosis. As asthma varies within and across individuals, and as such, there are no strict guidelines for management of the illness, the mothers were fearful of their lack of competence in this area.

If I don't take him to the doctor in time he might die! I mean, that's extreme, I know that's extreme. But I taught a little boy who died because he didn't get to his medication quick enough. He was in the house, on his own, and he didn't get his Ventolin. He died!

So then you're not just frightened because they have this thing, but you're frightened because you don't seem...well... I know you can't

cure it, but you can't control it because the control (the medication) is so wrong for him.

I felt scared... and very worried about him. Scared that I was going to lose him. (after a severe reaction to a medication)

Fear was often expressed by the mothers as playing a part in the development of a "hyper-attentive" attitude towards the children during the early stages of the condition. They became vigilant in their observation of their children, fearful that they might miss an important symptom or sign, although at this stage they were still unsure as to what they were actually looking for.

(Fear) probably made me over-anxious. Made me watch him. Made me presume he was worse than he was.

And once he was nearly back to hospital. I hadn't spotted it because he kept getting ill and colds and stuff... and I think that must have frightened me so much that I got quite, almost neurotic about it...And I would...I wrote it on the calendar. I tried to be meticulous about, "I noticed this change... I noticed that change...I started the Ventolin today." I would log all the things so that if anybody asked me I could say, "There! There's the pattern. It's all noted."

3. Anger

Anger became a very powerful emotion as the frustration with themselves and the medical system peaked. Like the feeling of frustration, anger was originally directed both inward and outward. It was, however, aimed at specific targets. Expecting some relief from medical caregivers, such as the Emergency Department at Children's or a pediatric specialist, and still not receiving it, the anger exploded from the women.

Well, in that first year I was getting very angry. Really angry. I was angry at the physicians in the Emergency Department at Children's Hospital... And by the end of it I was just furious with all of them, because they don't listen... They weren't listening to me. And why should I have to drag my baby in four and five days in a row, sometimes twice a day. I'm exhausted. The kid is really sick, you know. They weren't helping anybody. I was really mad.

Anger that I wasn't believed (by the pediatrician)... Yeah, that was when the anger really got me, because I knew my kid.

The anger was turned inward upon themselves, as well, as they felt that they were letting their child down, by being unable to determine what was wrong and how to help them.

That was a conscious thing (anger). I was so frustrated. I was so angry.

And not at the child, but at why I couldn't, as a parent, figure out what was wrong with my child, and help him.

4. Isolation

A sense of emotional isolation, of being alone in this experience, was present. The isolation was felt in differing arenas of life for the different mothers, both inside and outside the home. The mother who had had asthma from birth, and had parents who had asthma themselves, was also fortunate to have a very supportive extended family. Her experience of isolation in relation to her child's asthma was somewhat more limited than the other mothers in the study, and most clearly expressed by her experience with the staff of the Emergency Department of Children's Hospital. This was time when she felt singled out and alone in her fear and pain for her child.

I felt that they just put me off and said, "Let's just let her sit there for a while." Like I said, "She's a new mum with a new baby and the baby's not that sick..." I can hear them whispering (laughing) in the corner, "She's back again."

Isolation was expressed by two of the mothers in their telling of the need for support from peers and community.

... So that there was more... more support for families. Because families must feel isolated. I felt isolated dealing with that... that need is not met. And it should be met because it's a child's life. And a mum shouldn't have to worry about that, I don't think.

You know, I don't go sort of thinking, "Gosh, I wonder where I could find someone with asthma?" But, you know, in some respects, you almost should, you know... It's very very helpful.

Strangely enough, I used to take comfort from going up and down Tenth Avenue and seeing people doing the studies like yours. You know, they'd have a notice on a coffee shop window saying, "Do you have a child that fits this category?"... I found that comforting because I thought, "Gee. At least somebody's investigating it and they fill it in years to come, so other people don't have to go through this... don't have to have a person looking at them as if they're mad."

The isolation existed even within the family unit, where one woman told of her feeling of isolation in relation to her worried husband when attempting to manage their child's asthma.

...so I didn't feel I had a very calm level-headed husband to talk to...so there was even more isolation.

I'll not cause him tension, but it confirms my isolation.

For one of the mothers, an example of isolation was reflected in the need for her to personally research asthma in order to begin coping with her child's condition.

But the groundwork was done by myself reading about asthma. I think that... that's back to the isolation thing. You're on your own!

5. Self-Doubt

In attempting to manage and cope with the asthmatic condition of their children, the mothers went through many phases of self-doubt. The conflict within themselves as to their competence in dealing with this illness was present especially in the face of lack of support from some medical caregivers. There was a sense of constant self-observation and self-evaluation, as they sought to understand what was needed from them. Their lack of experience led to many unsuccessful attempts at management, which reinforced their belief that they were inadequate for the situation.

...at the same time (as trying to deal with the condition) you're feeling,

"Oh, no! I wonder what I'm doing!!!

And it's all hard going... and learning. And not feeling that you're learning properly. Because if you were, the situation would be under control.

But it's a constant search. And you're constantly looking for, you know, little loopholes. "What have I done, what have I not done?... Am I, you know, vacuuming too frequently, too infrequently?... A duvet cover on the bed..."

Then you've got a very... befuddled area of - for myself - wondering what's going on?... Am I dealing with it properly? I don't like what's happening. Losing control... because I could see things were going wrong.

Watching him, questioning myself, and wondering.

There are so many things that can cause a cough - if that's the trigger you're looking for - there are so many things... and I don't have medical ears. I don't know what to listen for. And you can misinterpret it.

6. Being "Out of Sync" with Child

The feeling of being "out of sync" with their child and the child's condition was prominent during the earlier stages of the illness. It was as though there was a lack of connection in some way between the messages or signs their

child's behaviour and body were giving out, and the mother's reception and understanding of those signs. With asthma, due to its variability, it is important to be able to recognize these individual patterns and signs in order to be able to anticipate or cope with an oncoming crisis or difficulty, according to the mothers. The development of this ability is a function of experience and effort. At first there appears to be little competence in differentiating between subtle changes in mood, physical capabilities and behaviour as caused by asthma.

Between (the ages of) five and a half and seven it was complete hit and miss. There was no confidence there at all.

Sometimes it was a wet bark; sometimes it was a dry bark. And I learned to see that there were those differences, but at the beginning... it was just a cough. I hadn't a clue. (the asthmatic condition) was more severe at the beginning because I didn't know the signs, so it would get really set in and dangerous.

One mother looked back and compared her initial responses to impending asthma attacks to her reactions in the present. Initially she would not recognize or gauge the signs correctly and would often leave a visit to the emergency until her son was very ill, or alternately, rush in, distraught, not knowing how to cope on her own.

So when we go to the hospital now, it's not a real emergency. You know, he's not deathly ill like when he was a baby...

(after successfully recognizing and coping with an impending asthma attack in the present)... even a year ago, if I thought he was having an asthma attack I would be at the hospital right away, you know!

7. Seeing the Child as Different from Others

It appeared that mingled with the feeling of relief at finally having a diagnosis from the doctor, came the realization that this child was different from most others around him. There came the realization that the child needed more attention, and perhaps a different kind, from the parents. Just how different the child was would be determined over time. Some of the expressions of the mothers were around the child's different physical needs and capabilities.

The first sign that I had that he was asthmatic was when he was born he had the driest skin I've ever seen... He had a layer of skin peel off him, and since then he's had excema... it goes with asthma.

Inside you want to say, "Oh, but it's really cruel. Oh, what a terrible problem he has."...But like yesterday at the track meet, he came off one run and I looked at him and thought, "Oh, he really is running out of puff. Oh, the poor wee soul. Oh, no."

At first I thought, "That's it! He's in cotton wool for the rest of his life!
(laughing) He'll never play soccer! Oh, no!"

Other concerns referred to the mothers' perceptions of their children as expressing different behaviours and personality styles, (for example, most mothers believed that their sick children had more difficulty dealing with stress than their well siblings, especially when struggling through an asthmatic period). With this new perception of the child as "different" came the confusion for the mothers over the "roots" of this being "different". Within the natural variation of personality types within a family, how much of this child's differentness was a product of the asthma, and how much was a naturally occurring expression of personality?

It's also, not only is there a huge difference in personality, but I think that the illness also accentuates that.

And you want to blame it (difficulty for the child when dealing with stress) on the asthma. I feel that... sometimes I guess you could use it for an excuse if it made life easier.

B. Middle

1. Determination

The feeling of determination became an overwhelming emotion appearing to arise out of the mother's initial feelings of anger and frustration. It seemed that the

feeling of anger most especially acted as a catalyst for movement into a more active role in the management of their children's condition. There was a strong motivation to rise above their frustration and fear and gain competence.

What I did was, I was so mad... what I did was... my mother-in-law goes to the same doctor's office I do. And she had been friends with the nurses there for 25 years. I phoned my mother-in-law and said, "I'm desperate. S. is so sick, and I haven't..." Like I would sit there for sometimes three hours before somebody would come and talk to me... I think they thought I was a paranoid mother or something... I said, "Get on the phone to... and get her to do something. I need somebody to help me."

So, I walked out of there... left cheerfully and smiled at the doctor (pediatrician), "You're right. Bye bye... I won't be back. I am going to deal with this come hell or high water. We'll survive..." but that anger thing, I guess, spurred me through and gave me the determination to get over that... so it helped me in a way. It was sheer bloodymindedness.

...and then just saying, "Well, I'm just going to be bloodyminded. And I'm bloodywell going to find out what's up with this kid..."

One mother articulated the path of this change in focus when she said, "(Anger changed into) more motivation and conviction that there was something wrong and that we've got to get to the bottom of it..."

2. Seeing the Child as the Same as Others

The ability to see the asthmatic child as similar to other children seemed to happen over a period of time, as upon initial diagnosis of asthma, they had been struck with how this illness would single out their child. Instead of a generalized view of their child as different, the notion that asthma may only affect certain areas of their child's life was developing. This new perception was a great relief to these mothers. However, this change did not come without some conscious effort on their part as they had grown to realize that movement toward normalizing the child was psychologically and emotionally healthy for the child and the family. As the mothers' confidence in their ability to cope increased, they seemed to find within their relationship with their children a broader experience of life.

I worry a little bit more about him than the other ones and whatnot.

But now that he's older and I see he's doing well and he's playing all the sports and everything... he's not favoured or treated special or anything... It's a relief to see him doing so well.

And now, I'm back to seeing him as a child who participates in every way, the same as everybody else... but that will always be there... I have to just see him, treat him like everyone else.

But you want to protect them from life, don't you? But you have to say, "No. I'm not going to do that."

And every mum worries about this (health of their children) all their life. When I'm thinking about this, I think, "Now shut up! He's old enough. Leave him alone!" (laughing) If he gets married I won't say to his wife, "Are you making sure he takes his medication?"

... he has certain gifts in certain areas, and I do it with any child, you try to offer them the ability to pursue these.

3. Networking

The action of networking often appeared to be in reaction to the stress and isolation that the women felt around their asthmatic child. The two non-asthmatic mothers actively sought out friends, agencies, and medical caregivers in order to find support.

I'm much more able to cope. I have a network of people who support me and listen to me. My GP understands where things are, what's

happening. Dr. C., the allergist, understands what's happening and is working with us and I. with the asthma.

Another thing that I found helpful in treating the asthma and coping with the asthma is talking to other mothers who have children with asthma! Because it is imperative to have a network where we support each other. And nonjudgmentally support each other, and share information.

The mother who was asthmatic herself did not state that she had networked in this way, but had looked to her extended family and pediatrician for support. However she did mention that she wished to make use of the local health agencies by attending their workshops on asthma and the management of asthma in children. She also stated that she felt she would be more involved with other mothers of asthmatic children as her son starts to attend the public school system next year.

4. Seeking information

Strengthened in their determination to play a more active role in their child's life with asthma, many sources of information were sought out by the mothers. Knowledgeable friends were consulted, pertinent literature was researched, associations such as the Asthma and Allergy Association were requested for the latest information, and doctors, pharmacists and other medical caregivers were questioned.

We saw a pediatrician who is one of the top in his field. And we were also sent to see a pediatric allergist, Dr. C. I was lucky then, because in that time I met a woman who is allergic to an awful lot of stuff, and she gave me the address of the Asthma and Allergy Association, and said, "If you don't want to do it... join... don't. I'll give you all my stuff." So I read all sorts of things, and they were really helpful.

One mother related that during an emergency she had often sought information and advice from a more experienced friend in order to be fully prepared for whatever questions the doctor may need to ask in order to assist her to deal with the situation.

So when I have a real problem, my first line of defence is to call this friend and to say - especially if it's something that is a new territory that I haven't crossed before, and I know that she probably has - and I will call and say, "What do I need to know, what information do I need to have?"

5. Experiencing "Trial and Error" in Managing the Asthma

The women's accounts showed that because asthma so often fluctuates in its effect on the individual, the mother of the asthmatic child is left on the front lines learning to monitor the symptoms and alter the medication accordingly. The experience of "trial and error" required close observation, patience, and a willingness on the part of the mother to play a role in determining the causes, symptoms and

relievers of the asthma symptoms. One mother expressed her desire for more support in this area because it became so confusing for her as a non-medical individual.

... although you really would like to have the perfect amount (of medication) - but you can't go back to the doctor every three days and say, "See, see... how am I doing?" (laughing)... maybe they could have an Asthma Clinic, and you could - especially for newly diagnosed asthmatics, who have to monitor and change their medication - that you could go in and they could listen to the chest and say, "Well, you know, it sounds real good. Sounds just fine." Or, "It's not clear enough. You need to either continue at this level or up it a bit." Because I think that education is lacking. And the parents are the forefront of the asthma... It was a trial and error.

The balancing act between "parenting" and "doctoring", as one mother put it, became more difficult during periods of manipulation of medications and environment. The women commented that when doctors find that new medications they try with the child have negative effects, the mother plays a part in being one of the first to notice and have to deal with the effects of these medications.

...he had some kind of a reaction to the drug they put him on... very agitated, and very hyper, and... couldn't sleep, wouldn't sleep... So I took him home (under direction of the pediatrician) and was up with him most of the night.

On Christmas morning he just went nuts, and he started destroying his room. Throwing his head against the wall, throwing his stuff around his room... So we were in the hospital all day with him Christmas Day. And they didn't know what it was. It was the Beclomethasone that the doctor gave me...so they sedated him...and he was asleep for about seven hours... And then he woke up and he was my little boy again... So they don't give it to him anymore.

Then we were discharged with very little explanation of what asthma was, how to treat it, the reactions of the medication in his body, how his body might react to it. And from five and a half when it started until he was about six and a half, I then had to battle with his pediatrician to have him taken off steroids because of the effects it had on him. So I could see that he needed some, but he needed a different kind or it needed to be administered differently because he didn't... he stopped sleeping. He's never been a good sleeper, but he virtually went without sleep... But thankfully, that extreme reaction to the Ventolin has passed with T. now, and the Salbutamol does not sit so badly with his system. So, I don't have the problem that I did.

C. Ongoing End

1. Developing a Healthy Respect for Asthma

As the mothers continued to develop their confidence in themselves and their ability to read the signs of impending problems, they also realized that their

children's health could still be compromised should they let their guard down. Beginning to understand the nature of this condition, they learned that asthma is never fully under control. They expressed a vigilant respect when dealing with their children's asthma.

I don't think it leaves me ever. I'm always watching him.... but as he takes on new experiences I wonder how his little body will react to them... that's what preys on me.

Oh, it's all okay. We're fine now. But knowing that he will come off the medication; he will start again; I may miss some triggers, etc. I'm always ready to face the fact that I have to start again.

I don't feel it now (fear and frustration)... not now... I may do. You're always open to... things change. So, watch it! Don't get too comfortable!

One mother's comments about her use of certain medical aids as an element of her management programme reflect the serious, wary approach she has toward her child's illness. These aids, used every day, are a part of her and her child's life.

...ideally, you want to start to treat it before you get the flare up... which is why things like a stethoscope and a Peak Flow Meter are really the first hand

things... You do that over a protracted period of time and you can see when things are going to start going wrong before they actually start... Get in control.

2. Trusting Self

Learning to self-trust in decision-making around their children's asthma was a very important development in the mother's ability to manage the condition. Recognizing the value of their experience and intuitive understanding of their children, there was a renewed sense of trust in the contribution they could make to their children's wellbeing.

I just tell people that they know their child best. Take their time; be really sure about what they're saying, and trust their own judgment.

I've had to learn to trust my instincts over someone else's "professional" opinion, because I know him better. I know what he's capable of better than anyone else.

... he was really sick. So I took them both to the doctor and he was basically... my doctor said he had bronchitis... it was more than bronchitis, I thought, because it was really... you know, you can tell just by picking him up and putting him... putting his chest to your ear,

or his back to your ear, you can hear him wheezing and gurgling...and with the excema and everything.

3. Attunement to the Child: Learning to Recognize the Signs

Learning to recognize the signs of oncoming difficulties with their children seemed to be an important part of the management of the condition. The recognition of the signs or patterns of symptoms peculiar to the child was both conscious and unconscious in the mother. Two of the mothers volunteered the phrase "being in tune" with their child.

And how much I will... how much medication I'll give him will depend on how he is, how upset he seems... how anxious. Just by experience.

I try to deal with I. with much more compassion and less critical... a less critical eye. And very in tune with his physical being.

... and I can tell you when the tree pollen is bad by I. I don't know why but I can!

... I figured out, in as much as I can, that it's seasonal. And I figured out that there is a relationship with grass.

I think because I'm asthmatic myself, so I'm sort of in tune with him... now I take him before he's really bad... I can see the signs.

It was more severe at the beginning because I didn't know the signs, so it would get really set in and dangerous. Whereas, now I see it, and can control it a bit better.

I also watch for emotional reactions. You know, if something happens, and he cries, that's another little signal that something's not right. I haven't seen that one for a while.

... I'd been back to the doctor's so many times, and had her saying, "Now, this is what you do. Are you doing this?" It had happened so many times that I guess it was almost in my nature now. I did it instinctively.

D. Ongoing and Pervading Themes

1. Uncertainty

This feeling is strongly tied into the nature of asthma, and therefore remained an underlying and unsettling theme throughout the process. Uncertainty was evident around all aspects of the condition, from the variability of the symptoms depending upon the season or weather conditions, to the effects of medications. It was as though the one aspect of asthma that was certain was its uncertainty.

It's not... I don't feel that... I don't feel as if I have a key with which I can lock it and say. "Right. That's it. It's all locked; it's safe... you wait for it to come. A new thing to trigger it off."

Unless it now is going to take another turn. Who knows?

But, I wouldn't say that I'm completely confident, because he can still pull a weird one.

I think that one of the problems with it is that it is a little bit of a hidden thing...but ideally, you want to start to treat it before you get the flare up...

You're battling this unknown disease. This thing you can't see.

But I don't mind because I think I have a rather tenuous hold on the situation. Ha! (laughing)... yeah, yeah well! You know, you never know, do you?

But knowing that he will come off the medication; he will start again; I may miss some new triggers, etc. I'm always ready to face the fact that I have to start again... Not on edge, but just... watching. Yes. It

doesn't bother me as much. Says me, clutching my hands! (laughing)

Squeezing my knuckles!

Uncertainty was also found around the ability of the medication to control symptoms of asthma, and then, due to some unknown reasons, stop working.

(on Intal) He didn't have an asthma attack for a whole year! I couldn't believe it! (he was then taken into Emergency due to a severe asthmatic attack)

2. Love

The expression of love and tenderness by the mothers in the study was primarily implicit. The sense of caring responsibility was clear in the description of concern for aspects of the child's emotional and physical pain which may be influenced by the mother.

Because it was still T. and I. If I missed it he was the one that would suffer.

Try to keep cheerful. Not show the child that you're worried.

The feeling of love was also expressed through emotional descriptions of a desire to protect their child.

And until you have your first asthma attack... anything you have with a child is a first, whether it's a broken leg... whatever... it's a first! And it's your kid! And you adore them, and they're there, in pain... when it's your own little one there, you're maybe not thinking as clearly or as logically as you need to think, because your emotions are so tied up.

But you want to protect them from life, don't you? You don't want bad things to happen to them... And you just want to give them a big hug and say, "It's okay, honey..."

He was so tiny, and I felt so connected to him. So close to him.

3. Responsibility

The mothers' expression of responsibility reflected a belief that they were the ones in charge as the front line workers, rather than the doctors or other medical caregivers. Unfortunately, in the early stages this sense of responsibility was accompanied by a feeling of inadequacy or powerlessness in the face of the medical establishment and the illness itself: responsibility without authority.

Here was your child... their life depends on you!... But now I'm

Number One. If I don't take him to the doctor in time he might die!

But then it really frightened me because you know it's going to happen, and it's up to you to stop it happening. (an asthma attack)

If I missed it he was the one that would suffer. So, I was increasing my knowledge, but I still felt that I was the one that called the shots. And if I missed it he suffered. Not me!

... feeling that you are so central to the management... wanting to do your best, but your best isn't good enough because it's not well-matched yet.

And the parents are the forefront of the asthma... because unless we pick up that there is a problem, it goes unnoticed.

For two of the mothers the sense of being the one in charge within the family when dealing with the asthmatic condition of their children was strongly expressed. Reasons behind this varied from the mothers being the parent who was working inside the home, and therefore more available to the child, to the father actually being unwilling to take on a share of the responsibility for management.

But he (the husband) knows that I'll take care of it.

4. Alarm for Family

The theme of concerns about the effect of the presence of an asthmatic child within their family was prominent within the stories. The effects were found on three levels: the individual; the individual and another member of the family; the family unit as a whole. In one family, the oldest sibling would become very upset when the asthmatic child was having an attack. Jealous, in the eyes of his mother, of the attention paid to his brother, he became angry with his parents.

I think the older boy, my oldest son, because we only had the two for a while, I think sometimes he feels because we were going to the hospital a lot and everything, I think he felt sort of left out sometimes... but he knew S.... everybody was worried about S...

I guess he's just jealous... or maybe he's just sick of it!... Everybody's worried about S...

He (the sibling) doesn't get angry at his brother... he gets angry at me or his dad.

In another family, the concerns were around the effects on both of the other siblings. Although they seemed patient and accommodating, there was a worry that they were being short-changed in terms of time and attention from their parents.

It's stressful. It's stressful, because there is a lot of attention given to the asthmatic child... And so it's a matter of budgeting time... It has to come from somewhere. So, it comes a bit from the other two. And, it's not intentional. But I think they feel it at times.

There is a stress and adjustment. And so I think the older one has grown up a little bit faster than he needs to.

The concern about their own interactions with the family was expressed openly. The stress of coping with the ups and downs of an asthmatic child during this process of adaptation had taken its toll on their patience and peace of mind.

They had a worried mother in charge... It makes you less patient, more concerned, more watchful.

But mainly it's the lack of patience, short-temperedness ... this is with the younger one... You've got different things on your mind and you are trying to focus.

It's hard when you've got other ones at home.

... because it... you're battling this... you're battling this unknown disease. This thing you can't see. But it's making a big mess of the family... it's upsetting the dynamics of everybody.

5. Supports for Mother

Expressions of appreciation for the support that was shown them as the mothers tried to learn and cope with their children's condition were common. This support was both emotional and informational. Many found their primary source of support coming from a particular medical caregiver. Messages of reassurance and reinforcement, a willingness to follow up concerns and provide information, and just simple listening were the most valued forms of support mentioned.

But, thankfully, I had it easier with my family doctor...She just took over. Which was super. But, had she not been so amenable it could have been very frightening.

And that was when I went to the family doctor. Seeking reassurance ...
And she'd give me reassurance...And she gave me a plan...

If she (the pediatrician) hadn't been willing to see me all the time and reinforce what I was doing... tell me what the next step should be (if

there needed to be a next step)... I couldn't have done it... she was always there.

I have a very good, very down-to-earth GP... She doesn't slough you off and say, "Call me in the morning." And then, she's also not above saying either, "I made a mistake," or "This didn't work".

And she (GP) was great and she listened.

He (pediatric allergist) would listen... but then asks intelligent questions after listening to us... It was wonderful! Someone that believes you! And is doing something about it! Also he's not stuck on things... "Well, if this isn't working we have to find something that will work better."

He (pediatric allergist) was on our side, in our corner. We were fighting the same thing. We weren't fighting each other.

One mother found a great deal of support from her son's teacher. The teacher was aware of the constructive role that she could play in assisting with the management of her student's asthma, and notified the mother of any signs of impending difficulty.

It was very good with his teacher in Grade One. She was very tuned in to him as a person, and so she could see the signs of when things were starting to go a bit peculiar.

One mother stressed that her relationship with her husband was one of her strongest sources of support. The comfort of having another with whom to share her worries and fears was indispensable.

Fortunately, though, I'll say this, is that my husband and I have a good marriage and we work together really well as a team... I don't know how we would have coped if that wasn't the situation. I mean, I can't imagine being in a shaky marriage or having multiple other problems in that relationship, and deal with a child that we have at home.

Only one mother interviewed had immediate family living in the city. She has found them immensely helpful during emergency situations.

He (older brother) had to go to his aunt's on Christmas Day. I felt so bad...

Such groups as the Asthma and Allergy Association provided background support through workshops and available brochures. These kinds of groups helped to normalize the situation and provided practical information for the management of asthma.

...getting that thing from the Asthma and Allergy Association. It was all so sensible and level-headed. It considered things that I felt the pediatrician would not consider. So that helped... that and taught me enough to make me feel comfortable. I found the advice consistent.

Friends with asthmatic children were a great comfort, providing opportunities to compare notes and reassure each other.

So when I have a real problem, my first line of defence is to call this friend and to say... especially if it's something that is new territory that I haven't crossed before, and I know that she probably has... and I will call and say, "What do I need to know, what information do I need to have?"

6. Hindrances for Mother

As the mothers attempted to cope with the responsibility of managing their children's asthma, hindrances and lack of support emerged from various sources. Each mother found at least one area or individual in the medical system which, whether actively or passively, became a hindrance in her ability to learn or cope with the child's condition. One aspect of this feeling was expressed as not being heard, or a feeling of being dismissed.

And when we walked out of that office we were shattered. Not because we were hoping that he (pediatrician) would find something horrible with our child, but because he basically didn't listen to what we were saying... looked only at the physical presence in front of him... I was feeling that he was giving us mainly, sort of like lip-service...

I was fuming! One that I wasn't even being listened to. You know, they (staff at Children's Hospital) wouldn't even listen to me and the wouldn't even look at the baby. Which really made me mad.

One mother commented on the effects of trying to learn about the medications her son needed to take while dealing with an unsympathetic teacher.

The beginning of kindergarten... the stress at school started... there was stress at school and (he was) in trouble with the teacher... it was so bad that year. With the first teacher, when I. was in kindergarten, it wasn't good at all.

Although many spouses may have wanted to be supportive of their wives during this process, two of the mothers commented on finding the actual level of support as somewhat lacking. In some cases, the mothers found themselves having to deal with their husband's difficulties in dealing with the condition, as much as dealing with their child's problems.

It's hard on C. but not so much... He did all the worrying but didn't have to do the coping... Because it's my job, because I'm home. He's not here, so I'm the one that has to do it.

But he overreacts sometimes... He's a little nervous about it.

There was a common feeling that there is not enough ongoing support and training available to parents of asthmatic children outside of the personal physician, who may or may not be readily accessible.

In a perfect world I wish you could go to someone, maybe at the Public Health thing... and you could - especially for newly-diagnosed asthmatics who have to monitor and change their medication - that you could go in and they could listen to the chest and... feedback... how to monitor... Because I think that education is lacking.

7. The Task of Medicating

The administration and management of medication was an important task, which may involve a wide range of medications, and several appliances for administration. As well, it is necessary to be knowledgeable about the purposes, general effects, and interactions of the drugs that are being administered. This task, therefore, may require a good deal of time and attention on the part of the person medicating the child, depending on the needs of that child at that time.

And that's when she (pediatrician) suggested we buy the Nebulizer for home. And she put him on daily doses of Ventolin and arranged for him to get tested for allergies... And he was on a daily dose of Ventolin for ages, like three times a day. There was this little, tiny baby with this mask on.

So what we do now is, if he gets a cold we start Ventolin, and we do a low dose of that right through the cold. And then I keep it up for two weeks, roughly. I just watch him.

For instance, when I. was on his Nebulizer, say three times a day, he's got fifteen minutes to kill three times a day... He normally has his medication while sitting at the kitchen counter, and I am there.

8. Concerns regarding Medications

Concerns regarding the amounts and types of medications that are given to their child to prevent or control the symptoms of asthma were prevalent. A balance was continually being sought between overmedicating and subjecting the child's body to excessive chemicals, and undermedicating and letting the asthma damage the child's system. The medications mentioned ranged from the use of over-the-counter antihistamines to corticosteroids such as Pulmicort.

So he takes Seldane, which I don't like him on... Not at all.

You see, the Intal's not very strong. I don't want to give him anything too strong, you know, if he doesn't have to have it... It's quite safe, which I like. The Pulmacort is real steroid, and I don't want to give him it when he's that little, you know, if I don't have to.

It's like Cortisone, but it's given to kids. I was so devastated. Anyway, he had some kind of reaction to the drug they put him on... He's walking around in circles. He wasn't coherent... he wasn't responding to us or anything... On Christmas morning he just went nuts...throwing his head against the wall... really destructive!

The medicine was a real big thing and it still is to some extent. Because you don't want to give kids way too much steroids... you don't want to overmedicate, but undermedicating is almost more dangerous than overmedicating - although you really would like to have the perfect amount.

... there was a problem... I mean, I was really worried that I wasn't medicating enough...

Then we were discharged with very little explanation of what asthma was; how to treat it; the reactions of the medications in his body, and how his body might react to it. And from about five and a half when it

started until he was about six and a half I then had to battle with his pediatrician to have him taken off steroids because of the effects it had on him... he stopped sleeping... he had no interest in eating and was just as high as a kite - eyes all bloodshot, and had a look in his eyes as if he just was not with us - constantly.

9. Venting Emotions

This theme represents a process characterized by strong emotions, with different emotions dominating different phases. Venting emotions, whether to husbands, friends or doctors was a common behaviour. As the mothers became more experienced with the support systems around them they were more able to find a listening ear, and to feel more free to express some of the more intense and negative feelings within themselves. Venting these emotions helped to put life in perspective, as well as releasing the stress and strain of the situation they were in. This was also a sign to others that their empathy and support were in great need at that time.

It was nice when I told him (husband) the story about the pediatrician. He was angry too!

And that was when I went to the family doctor... Seeking reassurance. Saying, "Look. This has happened."

He was really not well, and you're going through this big cafuffle trying to figure out why his health is so poor... When I got home I phoned B. (a friend) right away. I remember that. Saying, "You just won't believe this."

And then he (GP) couldn't believe that I hadn't been looked at or anything (in Children's Hospital Emergency), so he... that's when he got J. (pediatrician) involved - J.H. - ... and then I told her how furious I was, and then she said, "Well, never come in off the street again..."

10. Balancing Family and Sibling Concerns

Playing an important role in balancing the management of their asthmatic child's condition with the needs of the rest of the family, the mothers felt very much that they were the organizational and emotional hub of the family. It was felt that with the added responsibility of learning to manage their asthmatic child's life, the family system was becoming strained. In trying to cope with the other members of the family, they were beginning to feel overloaded and occasionally inadequate for the job.

It (seeking information regarding asthma management) takes up a lot of time doing that kind of inquiry, a lot of time on the phone. So you don't have the time for family.

He (brother) gets angry at me and his dad... Maybe I should sit down and talk about it with him, but, usually at the time I'm too busy, or whatever, or on my way to the hospital... you're in turmoil. So I guess he's just a little bit ticked that S.'s getting all the attention...

We, as a family unit, we handle the house ourselves, including the grounds and everything else. And so, it's a matter of budgeting time, and it's not that we don't spend time with the kids, because we do, but a lot of it would be more... group things... But to give twenty minutes of undivided attention to someone, three times a day, the same person... It has to come from somewhere. So, it comes a bit from the other two...

Attempting to enlist the help of the husband was mentioned as one method of balancing out the tasks involved in managing their child's asthma.

I try, when he's (husband) not at work and he's off, I try to get him to do the things with the doctor... it's a definite determined effort to make him go to the doctor (with child).

One mother expressed the difficulties in balancing her own needs, however minimal they might be, with the needs of the rest of the family as they cope with their asthmatic member.

With I. it's even more challenging. Because, of course, you need to get out. You're a person, you have a life - or you may have had a life, or maybe you're looking for a new one! - but (laughing) you are in a state of needing to have a break. Especially if it's been a really stressful time... And so one of the things that we've done is, over very stressful periods of time when the asthma is bad, one of us will go out and one of us will stay home. Which is not great for the couple, but it is great for half of the couple.

11. Being an Advocate for Asthmatic Child

Playing the role of advocate for their children, in the face of misunderstanding or ignorance by another was strongly pervasive. The predominant situations for this behaviour were when dealing with those in authority, such as doctors or teachers. Although not easy for the mothers, the concern (and sometimes fear) for their child's health and emotional wellbeing gave them the strength to stand up and fight to be heard.

And then, I think it was a few days between pediatrician and Dr. C, and we basically went back to N. (GP) and said, "Look, this guy says there is nothing wrong and we know there is." And fortunately the GP listened to us and recommended that we see the other guy.

It's not what you want to do, but I think that ideally, you've got to be able to communicate with the teacher and say, "Look, it's a really bad time now. I'm not giving him a holiday, per se, but we're going to do our work at home for a few days until we're on an even keel, and try and keep up with it...keep up with it that way."

So then you have to try battling with authority, and the people "that know", the professions. I found that difficult... I'm going to see the pediatrician and say, "Look. This is not working... something is wrong."

Commentary

The stories of the three mothers painted a picture of the process they had undergone in adapting to the mothering of an asthmatic child. Asked to describe their experience from the early stages of suspicion of unwellness in their child, to a place of greater comfort in the management and understanding of the condition of asthma, the co-researchers revealed a movement from inadequacy to adequacy, from incompetence to competence. This process can be seen as three phases of experience in the stories of the mothers: the overwhelming beginning phase, the active middle phase, and the ongoing end.

Twenty-six common themes emerged from examination of the three narratives. It was from the recognition of the interrelatedness of these themes that the three phases of the process became evident. Eleven of these emergent themes were ongoing, supporting the movement through the process of adaptation. There was a

complementarity between certain themes, with those emerging at the onset of the experience opposing the themes present at the close of the process. A helpless fear of asthma diminished and was replaced by a more positive and practical feeling of healthy respect for the condition. The self-doubt of the mothers became self-trust in their capability to make competent decisions around their children's illness. A feeling of being "in tune" with their child was a welcome change from the earlier feeling of being "out of sync".

The first phase began well before the diagnosis of asthma, and was one of overwhelming confusion and negativity. The feelings expressed were those of fearfulness, frustration, anger and emotional isolation. As well, there was a strong sense of self-doubt and being "out of sync" with their own child. At first the mothers were suspicious of an underlying cause for their child's ill health. Their frustration grew as they encountered dismissal from various medical caregivers. They were afraid of the possible diagnosis, and later were afraid when receiving the diagnosis of asthma. The feeling of emotional isolation and misunderstanding both before and after the diagnosis at this stage due to lack of understanding on the part of doctors, friends, relatives and the community, was apparent. As well, with the shock of the diagnosis of a potentially life-threatening chronic illness, there was the tendency to view the child as extremely different from others, and focus primarily on the ensuing inadequacies and inabilities.

The themes of helpless fear, frustration and anger were clearly instrumental in the movement from the first phase into the second. As fear and frustration with their inadequacy and the lack of support from the medical system grew, the mothers

became more and more angry. The anger eventually culminated in the birth of a strong determination to play a more active and controlling role in the management of their child's health. This marked the mothers' entry into the second or middle phase of the process.

This middle phase was dominated by themes of activity. Through these activities the mothers were to set the stage for the overthrow or diminishment of the original negative themes they had experienced. These would eventually be replaced with the positive themes which would dominate the final phase. Through networking the sense of isolation diminished. In seeking information and experiencing "trial and error" in the management of asthma, the feelings of fear and self-doubt were becoming transformed into those of respect for the illness, and self-trust. Within this phase came also a new way of seeing their child. Rather than focussing on the differentness of their asthmatic child, the mothers came to realize that recognizing the similarities with other children was also realistic and helpful for the child. This was only possible through the growing experience with the management of the asthma. The illness was still a dominant force in the lives of these women and their children, but was becoming somewhat less daunting as experience and hard work gave them a greater measure of control.

The third and end phase of the process was marked by a sense of adequacy to the situation; an increased feeling of competency and comfort in the management of their child's asthma. This is not a fixed achievement, due to the nature of asthma. As a changeable illness, so varied in its causes and effects among and within individuals, this phase recognizes the inevitable movement back and forward

between adequate and inadequate management. Although the actual control of the asthma may vary, at this stage of the process, the mothers felt that they were adequate to the challenge of repositioning themselves and their method of management. As stated before, it is as though they had become comfortable with their level of discomfort. The realistic respect for asthma, an increased trust they have in themselves, combined with a greater understanding of their children and their relationship with the illness, demonstrated their increased sense of adequacy in their role as mothers of asthmatic children.

Underlying this process were several ongoing themes which supported the movement from inadequacy to adequacy. These themes fell into three categories: themes of feeling; themes of action; themes of personal support. The themes of feeling either openly lent support to the process, or challenged the process by presenting ongoing stresses to be dealt with. The themes of love and responsibility were two of the positive and encouraging feelings expressed throughout the stories. The love of mother for child was implicitly expressed. It was also clear that a strong sense of responsibility, of being the primary person responsible for the health and well-being of the child, existed for the mother. This sense of being the "hub" of the family provided the backdrop for the movement from inadequacy to adequacy. If not her, then who? Who would take those steps necessary to protect her child's health? Working together these two themes supported the movement towards understanding and management of the illness.

Feelings of concern around asthma and the medications used in the management of the illness were also pervasive in the stories of these mothers.

Uncertainty, understandable given the nature of asthma, was perhaps the strongest of the ongoing themes expressed through the narratives. It was always there, as one mother was to say, "It never leaves me." It was a theme, in conjunction with the concerns about the effects of the medications on the body and behaviour of the child, which would creep in at times of stress and crisis and undermine the confidence of the mothers. Ongoing throughout the process was also the sense of concern or alarm for the effects the presence of this asthmatic child was having on the state of the family. Especially during times of crisis, all attention was focussed on the one individual, and from this other difficulties would emerge in the relationships and behaviours of other members.

Throughout the process many activities on the part of the mothers were apparent. Front-line administration and management of medication was perhaps the most obvious, requiring knowledge and, in some situations, a good deal of available time. This task will most probably remain an ongoing one until the children are able to take it upon themselves to manage their own medication. The knowledge gained through their experience will be a valuable gift to their children.

The role as advocate for their child supported the process in a most basic way. It first was noticeable in the ongoing search for a diagnosis for their child when the first signs of ill-health were observed by the mother. Strengthened by the determination during the middle phase of the process, this role became a vehicle whereby information and understanding could be given and received on behalf of the child. This theme will most probably continue as long as the parent is responsible for management of the asthma.

As a mother, many women find themselves in the position of balancing the needs of the individual within the family with the family itself. When a chronically ill child is present within the family, this presents a new twist on this role.

Demanding or requiring more or a different kind of attention, the asthmatic child shifts the balance of the family energy. First noticing these shifts, and then finding new methods to effectively deal with them, is an ongoing theme within a family of an asthmatic child. It is an essential part of the adaptation process.

Closely tied to the need to find balance within the family unit is the need for the mother to vent emotions that have been stirred up during this ongoing process. Immersed in the learning experience, feeling caught between a sick child and sometimes seemingly unsympathetic world, needed by other members of her family, there needs to be a time for her own expression.

The final ongoing themes in the stories of these women were that of support and hindrance as they journeyed to a place of adequacy as mothers of an asthmatic child. The hindrances were both passive and active. The most common sources of obstruction were found in the medical system, where the sense of being dismissed or unheard was often experienced. Other "authority" figures played a part in hindrances experienced in this process. A passive hindrance was the feeling that greater ease of access to information and practical, hands-on guidance would have been of tremendous value. It was these ongoing hindrances which were the basis for the movement from frustration into anger, and finally determination to become a stronger and more active role.

Hand in hand with the recognition of the hindrances experienced throughout the process was the expression of appreciation toward the sources of emotional and practical support. Whether they were sought out, or were offered freely, these sources listened, assisted, and informed the mothers during times of calm and crisis. These sources ranged from family members who looked after siblings during rush visits to the hospital, teachers who patiently worked with the mother to assist the asthmatic child, and specialists who "listened" and then worked diligently to assist the mother with a plan of action.

Having teased out the interrelated themes of the three narratives, the story of a mother of an asthmatic child and her journey toward adequacy in her role becomes richer. We are more clearly able to see the interweaving of the themes throughout the process. Taking the narrative of "Ann", I have created an abstract of her story, in order to reveal these interweavings and to provide a context in which to understand the process she experienced.

Ann's Story of the Adaptation to Mothering an Asthmatic Child

Ann, a mother of a nine year old boy with moderate asthma, was eager to participate in this study. It pleased her to be able to tell her story and possibly lend support in some manner to other mothers going through this experience.

... I used to take comfort from going up and down Tenth Avenue and seeing people doing the studies like yours. You know, they'd have a notice on a coffee shop window saying, "Do you have a child that fits this category? Would you be willing to talk to us or consider a different way of medication if you haven't been taking cortocosteroids

for however long?" I found that comforting because I thought, "Gee. At least somebody's trying to find out."... But having done it (having a child with asthma), at least... at least you can talk to other people that are asking all these questions. So you're being of some use.

Ann is a homemaker. Before taking on this role fulltime, she was in the education field. She is married with two young boys. In her story of adapting to mothering an asthmatic child, she was describing the process she went through with her oldest boy, T., who is now nine. Since making initial contact with Ann her youngest son has been diagnosed with asthma as well. However, it was decided that we continue as co-researchers in this study, as Ann was very clear about the boundaries between the two experiences.

Three Years Old. Ann's story began when T. was three years old. T. was continually having colds and sore throats. These "ongoing" problems combined with a "cough that wouldn't go away" were causing Ann to be concerned about his health. When she would take him in to the doctor "there would be nothing wrong". She grew to recognize the cough, a distinctive bark, and wondered if he needed a stronger medication than the one recommended by the doctor (Dimetapp, a cough medicine). Being a recent immigrant to Canada, with no family here to rely on, Ann felt her only source of help was the doctor. However, she was beginning to feel "guilty" for making so many appointments with the doctor for what appeared to be so minor. "It was awful. I just hated going in. And the first thing I did was apologize for taking up her time, 'But he had the cough again, and could you listen to him?'"

T. was becoming more and more unhealthy. Ann recalls at some point during that year the doctor listening to his chest "and mentioning a touch of bronchitis. And the very next time we went back she mentioned 'asthmatic, slightly asthmatic'". No further steps were taken by the doctor at this time. Ann was becoming increasingly frustrated as T.'s condition became increasingly worse. By this time, T. was now having recurring bouts of tonsillitis, as well as his other problems.

Five and a Half to Seven Years Old. T. had entered kindergarten and it was felt by his doctor that the tonsillitis was so frequent and so severe that it was starting to affect his day-to-day life. It was decided that he would have his tonsils and adenoids removed. After the surgery T. continued to bleed and was kept in the hospital for observation. When he recovered the next day he was permitted to go home. He had lost a lot of blood and "he was just wiped". After five days he had "a really, really bad asthma attack". Frightened, Ann took him in to the doctor. She feels that it was then that the doctor diagnosed T.'s condition as asthmatic, but did not reveal this to Ann at that time. Ann was instructed to return home with T. and monitor his breathing. The doctor phoned back within an hour and a half, questioning Ann as to the status of T.'s breathing, called back half an hour later, and instructed her to take T. into Children's Emergency. T. was put into an Isolation Ward incase he might have a virus.

And that (the virus) may have triggered the asthma. Now, since then we have confirmed now that any cold or... just a common or garden cold... or a virus can trigger asthma for T.. That's what does it. So, hence, when he was ill he kept having that cough... It was a cycle that

did not really break until that time, and then all the doctor's little mutterings about "asthma" had finally set in and they were ready to start treating it.

Ann recalls thinking that "the small seed that had been planted in my brain when he was three has taken root now. It's not going to go away." It was a shock.

Kept in the hospital for couple of days, T. was given "strong oral steroids and Ventolin very very frequently." However, when he was released Ann was not given any explanation of his condition, what medications were available to treat it, and how his body might react to those medications. This information was to become more and more important to Ann and T. as time went on. Ann looks back on this time as the beginning of the process she was to go through as she learned to cope and manage T.'s asthmatic condition. She was frightened of her own "inadequacy" in the face of this sometimes life-threatening condition. Ann likened it to bringing home a baby from the hospital, knowing very little about how to care for it, and yet without the "joyful reward" of that situation.

Ann was referred to a pediatrician upon the diagnosis of asthma. T. was placed on steroids in order to reduce the inflammation in his hyperreactive airways. Although T. was no longer suffering from tonsillitis, his health continued to deteriorate. Ann was beginning to believe that the steroids themselves were causing this deterioration.

And from five and a half when it started until he was about six and a half, I then had to battle with his pediatrician to have him taken off steroids because of the effects it had on him. So I could see that he

needed some, but he needed a different kind or it needed to be administered differently...

T. had virtually stopped sleeping. His eyes were bloodshot and his appetite was severely reduced. Ann felt as if he was not "with" them. His eyes even had a different "look" in them. It was frightening.

Ann remembers meeting a woman who had many allergies and mentioning her hunch about T.'s problem with his steroid medication. Through this woman she learned of the Asthma and Allergy Association and was encouraged to contact them for information. The woman also offered to lend her any information she had on the topic. Ann found this material very helpful and it supported her notion that T. may have an allergy to his medication. Feeling some relief Ann was motivated to return to her pediatrician armed with this supporting evidence. She thought, "I'm not losing my marbles. I'm right. There is a connection between this medicine and how T.'s acting."

Unfortunately, the pediatrician did not agree with Ann, and would not consider investigating the situation. Ann became further frustrated with this doctor when he asked her, "Was he like this before he started on the medicine?" He did not believe her. He did not trust her judgement. Ann's reaction was one of anger. She kept that feeling to herself, but vowed she would not return to the pediatrician and instead returned to the care of T.'s G.P.. "He'd said, 'Well, okay. You can take him off the Beclovent and I'll see you here in two weeks. You'll be back!'. "

Ann remembers this time as one full of questions. She had questions for the doctors. She also had questions for herself. "What's going on? How's this affecting my son? Is it going to stay with us? Am I dealing with it properly?"

She felt as if she was losing control. The conflicting feelings she had were overwhelming. She worried about not being able to recognize signs, and therefore risking her son's health by not administering medications appropriately. On the other hand she was very concerned about the effects the prescribed medications were having on T.'s body and behaviour. She felt isolated and responsible.

It's not easy to learn by experience when your child is ill. That's what got me! I felt completely and utterly helpless. Here was your child... their life depends on you!...he's reacted to the medications, so we stop it all... but now, I'm Number One. If I don't take him to the doctor in time, he might die!

The anger elicited in Ann by the pediatrician, Ann believes, played an important role in her motivation to learn more about T.'s condition and how to manage it. She believes that it spurred her on in her search for answers. She calls it a "turning point". She still was questioning her own ability to manage, but was determined to do her best without the pediatrician. She was encouraged by a friend who is a doctor, who agreed that the steroids were worth investigating as a problem for T..

Ann felt validated upon returning to the G.P. who listened and agreed that steroids could be at the root of T.'s unusual behaviour. This decision to try and

manage the asthma without steroids took place about nine months after T. was first put on them by the pediatrician. From this point, until about the age of 7, T.'s symptoms seemed to level out. At least he was not getting worse. "So, between the two of us, from the age of six and a half, that bit there (indicating Lifeline), it was still really awful because we were trying to figure out how to get a handle on it."

Ann gave an example of the difficulties she faced at that time. T. was fighting off frequent colds, and his cough was becoming quite noticeable. Ann was not yet able to distinguish the symptoms well and missed the signs of an impending asthma attack. Taking him into Emergency, T. was prescribed very strong liquid steroids. He was sent home and Ann administered the medication there.

But it took three days for him to really settle down. Of course, in the meantime, he went really peculiar because he was on the strongest... I think that must have frightened me so much that I got quite, almost neurotic about it. Watching him, questioning myself, and wondering.

Ann became, what she thought of, as overly attentive to many details of T.'s life. Every possible trigger for his asthma was noted and monitored. She vacuumed and dusted more frequently; she didn't want him outside if the grass around him was being cut; she worried about him playing soccer. Life for Ann became full of tension, fear and worry. She felt more isolated. Her feelings of responsibility grew, and she started a log on the calendar.

I tried to be meticulous about, "I noticed this change... I noticed that change... I started the Ventolin today..." I would log all the things so

that it anybody... if anything went wrong, and anybody asked me I could say, "There. There's the pattern. It's all noted."

The support of the doctor was crucial to Ann's ability to cope with the management of T.'s asthma. "If she hadn't been willing to see me all the time and reinforce what I was doing, tell me what the next step should be (if there needed to be a next step), I couldn't have done it."

Another major source of support at that time was a good friend whose child was also diagnosed as asthmatic. As well as providing emotional support, this friend also was helpful in providing information and comparing notes.

Ann received a measure of support from her relationship with her husband. Within their relationship, however, she still feels the major weight of the responsibility to manage T.'s condition. This, she feels, increases her sense of isolation. Although he worries about his son, she worries and copes with the situation. He has never really had to learn to recognize the signs, and is not sure about amounts of medication to be administered. "Because I'm home. He's not here, so I'm the one that has to do it."

It was during this time that Ann did most of her investigation into the effects of the various asthma medications available for T.. As with most medications, here are both generic and original brands of asthma medication. Salbutamol is the generic form of Ventolin. Beclomethasone is the generic form of Beclovent. (The generic forms of many drugs are what are recommended and required by the British Columbia government medical plan as they are relatively inexpensive compared to the brand names.) T. was exhibiting different reactions to the different forms of the

drugs he was given, having become very ill using the Salbutamol. Through discussions with a pharmacist and reading on her own she was to discover that different drugs had different propellants, and it was possible that the propellants could be causing T. to have unusual reactions to the medication. He could be allergic to it. This appeared to be the case with the Salbutamol.

Feeling that the pediatrician would not believe her, as he had not believed her when she was concerned about T.'s reaction to the steroid medications, Ann took her new information to her G.P.. Again she was listened to, and felt understood. However, "...the groundwork was done by myself reading about asthma... that's back to the isolation thing. You're on your own!"

Seven to Eight Years Old. Remembering back, Ann recalls the year between seven and eight years of age as a much easier time for T., and so, for herself as well. "But I did see him becoming more healthy, and with that less of a juggling act with the asthma."

T. appeared to be able to fight infections more easily, and therefore was not having as many asthma attacks. Ann, through experience, was also becoming more aware of the signs of impending problems and was better able to avoid triggers or cope with the attacks themselves. For Ann, the situation was not "hit or miss" as it had been for her in the years previous. She was now beginning to feel more in control and confident in her ability to manage T.'s condition. "And at age seven I began to know... to think, 'Now I'm getting it.' And seven to eight was much better, I remember... I was happy."

Ann's comfort and confidence was soon shaken, however, with what she refers to as a "wake-up call". Taking his increasing good health, and her ability to spot trouble signs, for granted, she ignored a cough he developed that summer. She was not concerned, thinking that this was not part of the pattern that she had noted on her calendar. T. had never had problems in the summer before with asthma. As a consequence, the problem developed into a serious asthmatic episode. As Ann states, she had let her "guard down". This was something she has not permitted herself to do again.

Eight Years Old to Present. Between the age of eight and the present day, T.'s health has improved dramatically. Ann describes his health as having plateaued at a higher level than she can recall since he was a baby. With this has come increased comfort for Ann. She feels that she is coping well, and describes herself as "coasting along. "She is always aware, however, that triggers and reactions can change. "But I wouldn't say that I'm completely confident, because he can still pull a weird one."

The conflicting emotions Ann expresses reflect the confusing nature of the condition itself. It is as if she has become comfortable with her level of discomfort, as well as with her real ability to cope. T.'s asthma is changing with time. He has developed an increasing number of allergies. As well, he is now involved in a greater number of sports which, while improving his overall health, can cause him difficulties with his breathing (especially during particular times of the year eg. extreme cold, or pollen season.) Ann is often placed in a position where she must cover up her emotions and fearfulness for her son, in order to let him challenge

himself and become more independent. This is not unlike most parents, but is somewhat more difficult for the parent of a chronically ill child.

On the positive side, with time, T. has become more able to identify symptoms himself. This is partially due to the effort of Ann. Working with T. she has encouraged him to express his feelings, both emotional and physical, in his own words. This has made a great contribution to the increased level of comfort Ann has felt over the last year.

Ann expressed concern with the effects that the experience of managing the asthmatic condition of a child has had on her relationship with her family. She believes that she has been more worried, more short-tempered, and less patient than she would otherwise have been. On the positive side, Ann is more aware that "life is precious. Not to be taken for granted. Naturally with that, how precious good health is. And it's made me accept responsibility."

Ann has learned to balance her attentiveness to T.'s condition with her encouragement of his development and independence. It was painful, hard work, even for a determined, "bloodyminded" woman such as herself. She knows that this situation will not soon go away, but for the time being she is coping. "And now, I'm back to seeing him as a child who participates in every way, the same as everybody else. He's just like everybody else, but... and that will always be there."

Interpretive Comments

As a co-researcher in this study, Ann was forthcoming, with a blend of both humour and seriousness. An intelligent, educated woman, it became obvious through the interview that she had considered her feelings about and reactions to her

son and his illness many times throughout the process. Without much prompting, Ann was able to "flesh-out" key points (as she saw them) in her story, providing a strong sense of the links between her feelings, actions, and the backdrop of her life as a wife and mother.

In following Ann through the story of her adaptation to mothering her asthmatic son, a flow or movement of themes from negative to positive, from inadequacy to adequacy, is revealed. The initial experience is one of overwhelming negativity and lack of control as she experiences such feelings as anger, fear and frustration. For Ann, the feelings of frustration with the illness, certain caregivers and her own lack of understanding of the condition developed into a feeling of anger. Ann sees the peaking of this anger, and the accompanying frustration and fear, as the "turning point" for a movement into a place of increased motivation and determination to increase her knowledge and her capability to manage T.'s illness. Ann had decided to take more control.

With this newly found determination came new behaviours, experiences and perceptions. Ann began to network, seek out information and take on a more active management role on the "front line". She began to feel less fear, and to see her son as more similar to other children rather than dissimilar.

Continuing to move towards a more positive place, Ann appears to be more confident of her abilities and more "in tune" with her son and his illness. With her greater knowledge of asthma she has moved from a feeling of helpless fear, to a healthy respect for the condition. There is a greater sense of balance between Ann and the asthmatic condition of her son. She is more able to control the situation

through her increased understanding of her son, knowledge of the illness itself and support of certain medical caregivers. She knows that asthma is a confusing and inconsistent adversary, but she is well armed.

CHAPTER V

DISCUSSION

Statement of Findings

Examining the stories of the three co-researchers, twenty-six common themes emerged. Fifteen of these fell into three phases in a process which carried the mothers from a place of inadequacy to that of adequacy in managing their child's asthma. Underlying this process were eleven of the twenty-six themes. These were ongoing and pervading, supporting the movement towards competency.

Limitations

It is not possible, on the basis of this study, to generalize the findings to a population, given a sample size of three individuals. Although an effort was made to clearly state my views and experiences, as well as to contain their influence within the interviews, it is possible that these may have affected the results in an unseen way.

Another limitation may be related to the co-researchers' participation in the study. Although appearing comfortable with myself and eager to share their stories, they may have chosen not to express particular aspects of their experience. Certain themes may have a richer background than may be possible to determine from the individual story as it is presently articulated. For example, could certain themes be more generalized than had been stated? Although attempting to minimize this limitation by including only those participants whose experience had taken place in

the last five years, the effect of inadequate recall of the experience could have affected the findings.

Implications for Theory

The main contribution of this study is the provision of an initial holistic understanding of the development of mothers in relation to their asthmatic children. A clear description of a process by which mothers of asthmatic children come to a place of greater comfort, adequacy and control in managing their child's illness is revealed. In general, this study extended the understanding of this experience. Given the paucity of evidence in this area, the present study confirms the scattered findings of previous work, while providing new insights. The discussion following will deal with the relevant literature and to what extent this study confirmed, disconfirmed or extended the earlier related work.

The themes emerging from this study clustered into four groups. A set of ongoing and pervading themes provided a backdrop to the three phases of the process. The themes were woven together in an interrelated manner which moved the mother through the process of adaptation.

The beginning phase is one of overwhelmingly negative feelings, dominated by frustration, fear and anger. Snadden and Brown (1992) acknowledge the emergence and interrelationship of these themes in the early stages of adjustment to a chronic illness. In the present study, the combination of the three of these themes was instrumental in the movement from the initial phase to a more active middle phase. The themes of fear and frustration appear to increase and at a specific "turning point" explode into anger. It is this anger which propels the mother into the

second phase with a strong determination to take more control of her child and the asthmatic condition. This is the first movement toward a greater sense of adequacy. Other themes contributing to the overall sense of discomfort and inadequacy are a sense of isolation (also noted in the findings of Staudenmayer, 1981), self-doubt, seeing the child as different from other children, and feeling "out of sync" with the child.

The second phase reveals a transition between inadequacy and adequacy. This is an active phase dominated by increasing knowledge and experience. There is a burst of new-found determination. Through networking, emotional needs were met and the sense of isolation diminished. Information-seeking was a dominant activity. The emergence of these themes supports the findings of Eiser and Havermans (1992) and Snadden and Brown (1992) which suggested that the parents of asthmatic children and adults with asthma considered these activities as critical to the coping process.

Experiencing the "trial and error" of managing such a condition as asthma was a strong aspect of this phase. Although a challenge, the mothers' experience with the uncertainties as a front-line worker assisted in their movement towards adequacy and adaptation. As Schwamm (1987) states, "Feelings of mastery can replace helplessness."

Throughout this process, certain ongoing themes were interwoven in the process of adaptation. Due to the nature of the condition, uncertainty was pervasive throughout. In the initial state of little knowledge and experience, this uncertainty contributed to the level of fear and frustration felt by the mothers. However, as they

moved through the process, the uncertainty was reflected to a lesser degree in a healthy respect of the condition.

Confirming the findings of Staudenmayer (1981) a stressful sense of responsibility weighed on the mothers. As primary caretakers they often received minimal support from others, including their spouses. This finding in the present study does not support Creer, Marion and Creer (1983) and Peri, Molinari and Taverna (1991) who suggested that for the majority of families the responsibility was shared relatively equitably between the parents. The theme of responsibility provided a strong impetus in the movement toward competence.

Concerns around the impact of the presence of the asthmatic child in the family were enduring. This theme, along with the attempt to balance family and sibling concerns with that of the asthmatic child added to an already stressful situation. The presence of these themes confirmed the findings of Leventhal, Leventhal and VanNgyen (1985) which suggested that parents are concerned about the possible lack of attention and patience given to siblings of asthmatic children.

Ongoing use of a support system provided relief for the women in the study. This support system gave the mothers a safe place to vent their emotions and to feel heard and understood. This support system was often a source of information as well. Hindrances and lack of support, however, were also present throughout the experience. Reinforcing the findings of Creer, Marion and Creer (1983), the present study revealed a concern with the lack of support and understanding from several sources such as the child's teacher. Other sources noted were family members, medical caregivers and various significant people in the child's life.

The administration and management of medication was a continual task. Sometimes time-consuming (Breslau, 1987) it was also a source of worry. The physical and behavioural reactions of their child after taking certain medications was a strong concern for the mothers in the present study, as was the concern over the unseen long-term effects of corticosteroids. These emergent themes are consistent with the findings of Creer, Marion and Creer (1983), Donnelly, Donnelly and Thong (1987) and Wilson (1993).

The role of advocate for the child was embraced by these women during the initial stage and grew throughout the process. In the face of misunderstanding or ignorance by another the mothers determinedly pushed for greater control and more information about their situation. This theme was strongly interconnected to the process of adaptation and development of adequacy.

Throughout this study the ongoing presence of a loving concern for the child was clear, whether explicit or implicit. This theme, like the other themes identified, was integrally related with the others. Each contributed to the process as a whole.

The final phase finds the women in a place of greater comfort in their role. They had a sense of adequacy and competence which was not present in the initial phase. This ending is not a fixed state, but rather a flexible phase from which the mothers may enter and exit depending upon the state of their child's asthma. Having once attained that level of adequacy, it is however less daunting to return to a stage of questioning and learning in order to regain a measure of control once again. At this phase the mothers have attained a healthy respect for the asthma, where once there was a helpless fear. There is increased self-trust and a sense of attunement to

their own child's particular health difficulties. A sense of adequacy, a greater comfort in their role, has emerged for these women as they deal with the tremendous challenge of caring for an asthmatic child.

Implications for Practice

The process and themes emerging from this study have provided a map which the mother or therapist may employ in facilitating the mother's movement from inadequacy, through adaptation, to adequacy as a mother of an asthmatic child. Seeing her situation reflected in this map will help to normalize her experience and perhaps assist in an easier movement through the process.

It is possible that the sense of fear and isolation may diminish greatly knowing that there is a common path that is followed by mothers of children with this condition. This common path involves employing certain behaviours and attitudes in order to attain a greater sense of adequacy. By encouraging the mother to actively network she will increase the size of her support system. On the other hand, recognizing that there will always be those that are unsupportive or actively hindering to the child's wellbeing, a mother can attempt to be proactive. Obstacles can be avoided or discarded (eg. unsupportive medical caregivers) more readily. Important individuals in the child's life can be educated and informed (eg. teachers, members of the family, friends) early on in the process. The awareness of the reality of the experience, both good and bad, helpful and hindering, may help to diminish the anger felt during the beginning phase of the process.

A proactive position may be able to be taken in regards to the effects that the presence of the asthmatic child has on the family. Enlisting the support of extended

family members or friends of the family, she may be able to more easily balance the emotional and physical aspects of running a family with a chronically ill child. Being aware of the potential frustrations, a mother may pass more easily into the middle phase of the process, becoming more of an agent in her role. Being aware of the ongoing inherent uncertainty of the illness may also ease the movement into this phase. By becoming increasingly active in seeking information she will become more knowledgeable about the condition of asthma, and thereby have greater ability to manage her child's illness. This more active role allows the mother to develop increased self-trust and a heightened attunement to her child's particular triggers and symptoms. An awareness that other mothers have been able to move into a place of balancing the special needs and characteristics of the asthmatic child with the common ones of the general population may be very comforting.

Use by the Individual. The process and themes revealed through this study may be used by the mother who is in the early stages of adaptation to mothering an asthmatic child. As stated, the awareness of this process may facilitate understanding of her own experience of the conditions as well as normalizing her feelings. The study reveals patterns of feelings and behaviours that assist the mother in overcoming obstacles in her path toward adequacy.

Use by the Therapist. With the incidence of asthma on the rise, the numbers of clients entering therapy with the added stress of a child with chronic asthma will also increase. This study provides a description for the therapist of the process that mothers experience during the adaptation to their situation. Reflection on this process and the emergent themes may provide clarity and understanding of the client

with these difficulties. The therapist is encouraged to ask questions of him or herself that will reveal the movement or changes taking place in the client's experience. Such questions may include: Where is the client in this process? In the overwhelming beginning phase or the active middle? What obstacles are present which may impede this journey toward competency? The study implies that an integration of certain common themes, whether pervasive or stage dominant, is an important aspect of the process toward adaptation and adequacy. The therapist, in considering this implication, may take on the role of facilitator for the client. The therapist, being only one source of support and guidance, may encourage relationships with other sources (eg. specialists, local health agencies, other mothers of asthmatic children) thereby enabling the client to proceed more successfully through this experience.

The therapeutic setting for this relationship may be either one on one, or within a group setting. The individual counselling provides a setting in which to explore the adaptive process within the context of the mother's total life experience. The group setting, on the other hand, may offer the mother an opportunity to both normalize her process, and to interact with others in a similar position, an integral component of the process itself.

Implications for Future Research

This qualitative study has contributed to the understanding of the maternal experience of caring for a child with asthma. Replications of this study could expand, refine or alter the present findings.

It may be useful in suggesting other areas for further research in this area. Survey studies would permit information-gathering across a wide range of participants. Another use of the survey approach would be to investigate the effects of group intervention using the process model as a basis for discussion. An exploration of the differences in this process across cultural and ethnic groups would be interesting, especially in the light of the tremendous growth of heterogeneity within North America.

Summary

The purpose of this study was to investigate the adaptation of mothers to parenting an asthmatic child. Involving three co-researchers, a case study design was used to explore their experience of this phenomenon. The co-researchers were selected on the basis of these criteria: their child had been diagnosed with asthma within the last five years; the child's asthma had been diagnosed as "moderate" to "severe"; although more than one child in the family may have been diagnosed as asthmatic, it was possible to isolate the process of maternal adaptation to the one child; the mother has reached a point of feeling adequate in the role of mothering the asthmatic child.

The participants were invited to create a lifeline of the experience, and to use this as a reference when describing the story of their adaptation. Upon completion of their narrative, questions were asked based on my pre-suppositions of the experience of adaptation, should these not have emerged previously during the interview. The narratives were audio-taped, transcribed, and analyzed for common emergent themes.

Validation interviews were conducted in order to confirm the emergent themes. An abstraction of one narrative, selected as representative of the three, was developed and validated by the co-researcher. This abstract portrayed the commonality of the process as well as the emergent themes.

The study confirmed the existence of a process of adaptation, marked by three phases. The stories revealed a movement from inadequacy to adequacy. The initial stage was dominated by negativity reflecting the mothers' sense of overwhelming impotence. The active middle stage, a phase of transition, was one in which the mothers increasingly became agents in the management of their child and their child's illness. This phase offered them opportunities to change their perception of themselves and their situation. The resolution of the middle stage placed the women in the final stage, where the themes of inadequacy found in the initial stage are opposed by the complementary positive themes of competency, strength and understanding. Underlying the themes contained within the three phases were ongoing themes which facilitated and provided a backdrop for this process.

This study confirms the significant impact that the presence of an asthmatic child has on the life of the mother. The findings reveal the need for understanding and support from those around her as she struggles to gain a measure of control in this experience.

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APPENDIX A

CONSENT FORM

Project Title

Maternal Adaptation to Parenting a Child with Asthma

Investigators

This project is supervised by Dr. Larry Cochran (telephone number 822-5259). It is being carried out by Eileen Taylor as a thesis requirement for a Master of Arts degree in Counselling Psychology.

Purpose of the Study

The purpose of this research project is to explore the process of adaptation of mothers of children with asthma. The researchers are interested in the maternal perspective on coping with and caring for a child whose health is compromised by an asthmatic condition.

Procedures

Participants will be asked to describe their experience as a mother of an asthmatic child. This description will cover the time from the first stages of awareness of the child's compromised health to a point at which they felt more competent in managing the child's condition and her own new role. This initial interview will last approximately two hours and will be audio-taped. Should the investigator feel that further exploration of certain ideas or emotions expressed by the participant would enrich the understanding of the experience, another interview may be requested of the participant.

Upon the investigator's completion of interviewing all the participants in the study, an analysis will be done to determine common themes arising from the data. From these common themes a common narrative will be developed. This narrative will be sent to each of the participants. A final interview will allow the participants to validate the common narrative or to note changes or clarifications.

All of the information collected will remain completely confidential and under no circumstances will participants be specifically or indirectly identified in the writing

up of the results of this study. Audiotapes, notes, field diaries, index cards, and any other research materials used during this study will be identified by a code number. The subject's name or other identifying information will not appear in or on research materials. The only individuals that will have access to the information will be the members of the research team.

A copy of the final narrative will be provided for each participant.

Your participation in this study is voluntary. You may refuse to participate or withdraw from participation at any time. You will have every opportunity to discuss any concerns about this project, or your experience as a participant, at any time before, during, or after any interview.

The interviewer is aware that sensitive issues may arise during the course of the interviews, and will therefore ensure that a level of comfort is reached before closing.

I acknowledge having read this and having received a copy of the consent form. I understand that should I have any questions or concerns I am free to contact Dr. Larry Cochran at the University of British Columbia at #822-5259, or Eileen Taylor at (phone number).

Date: _____

Participant's Signature: _____