

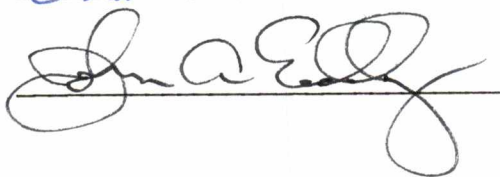
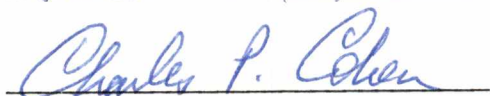
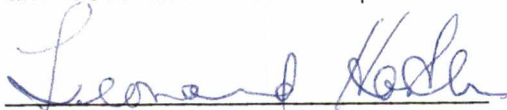
To the Graduate Council:

I am submitting herewith a dissertation written by John F. Duffy, Jr. entitled "Asthma: A Phenomenological Evaluation of Family and Child Perspectives." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Psychology.



Howard R. Pollio, Ph.D., Major Professor

We have read this dissertation
and recommend its acceptance:



Accepted for the Council:



Vice Chancellor
Graduate Studies and Research

ASTHMA: A PHENOMENOLOGICAL EVALUATION
OF FAMILY AND CHILD PERSPECTIVES

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P.37

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

John F. Duffy, Jr.

December 1981

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To my Family

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I would like to thank the Chairman of my Doctoral Committee, Dr. Howard Pollio, for his untiring enthusiasm and support not only during the work on this project, but also throughout my years of graduate study. Appreciation is also expressed to my Committee members. Dr. Len Handler, with his ability to get to the heart of matters, has helped me grow emotionally. Dr. Charlie Cohen, through his sharp questioning combined with genuine warmth, has stimulated me to conceptualize in different and rewarding ways. Dr. John Eaddy, by his unflagging interest and knowledgeable input, has helped me become more well-rounded in my understanding of asthma.

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ABSTRACT

In this study, families and children were interviewed about their thoughts, feelings, and actions regarding illness when the child was considered the identified patient. The purpose of the study was to develop a picture of family functioning and perceptions, with particular regard to asthma. Interviews were based upon an eleven question format for families and a fifteen question format for children. Questions were open-ended and designed solely to elicit information.

Two groups of families with latency aged children (identified patient) were interviewed. One group of nine families had a child with severe asthma. Determination of severity was indicated by the use of steroid medications for control of symptoms. An equal number of Control families, matched by age and sex of child, were interviewed using the same questionnaires. Children were interviewed separately, followed by the whole family interview. All families were volunteers, natural, intact, and without psychiatric histories. Interviews were tape recorded, transcribed, and analyzed for individual verbalization rates, individual family content, and group family and child content.

Results indicated that Asthma parents were more verbal, expressed greater feelings of responsibility, emphasized mastery, and expressed less empathy than did Control parents, with regard to child-illness situations. Asthma fathers were significantly more verbal than Control fathers during interviews, while mothers were similar across groups in their verbal production rates. Asthma families appeared to maintain more rigid parent-child boundaries than did Control

families. Asthma children indicated greater reliance upon external sources of help, and expressed less feelings of responsibility and empathy in illness-related issues than did Control children. The roles of medication and activity restrictions were highlighted by the Asthma group.

Methodological concerns were addressed. Results and clinical implications were discussed.

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CHAPTER I

ILLNESS AND ASTHMA AS AN ILLNESS

1. APPROACHES TO UNDERSTANDING ILLNESS

Socio-cultural Considerations of Illness

We are all ill from time to time; it is a part of living for all of us. As such, illness is experienced by a specific person, within a specific context, and has repercussions and meanings in work-related, family-related, and self-related areas. Illness cannot be described solely as a consequence of extrinsic factors intruding on our lives but must instead be viewed as an event that is inextricably interwoven within the very fabric of our experiences.

Although the general view of illness prevalent in Western society is that it is something that happens to people, Sigerist (1943) has noted that the experience and nature of illness has influenced, and has been influenced by, all of the major human institutions including law, religion, philosophy, literature, and medicine. The disposition taken by an individual toward illness has been also influenced by religious, philosophical, educational and socio-economic conditions. There is, thus, a complex relationship between person, illness, and society.

According to Sigerist (1943), different historical periods have viewed illness in many different ways. For civilizations of the Old Testament illness was viewed as punishment for sins; for the classical Greek civilizations it was viewed as a sign of inferiority; while for early Christianity it was viewed as a cross to be borne and valued as

suffering which would ultimately lead to purification and attainment of the state of grace. In certain primitive tribes, the causes of disease are not considered and the criteria for diagnosis are all social. Once unable to work and be productive the ill person simply becomes an outcast and is dealt with accordingly. In other tribes, the sick are viewed as guiltless victims of enemies or spirits and therefore receive strong social support. Understanding illness thus requires an appreciation of both its social and historical contexts.

Simons and Pardes (1977), in a more recent article, have emphasized the need to understand cultural and ethnic differences in a person's perceptions, beliefs and attitudes toward illness and that being aware of such differences paves the way for more effective intervention and treatment. Jelliffe (1956) long ago maintained that if medical treatment is to be successful it must recognize and take into account beliefs, attitudes, and customs because exclusively physiological approaches to health are both illogical and short-sighted. A more effective approach to treatment must address the contexts and meanings of illness. Even within contemporary American society there are clear cultural differences in an individual's identification and response to illness. Mechanic (1972), for example, observed that Jews and Italians respond to illness with much attendant emotionalism, Anglo-Saxon Protestants respond stoically, and Irish Americans broadly deny the experiences or effects of illness.

Illness thus emerges as a social as well as a biological phenomenon. Recognition of this fact enhances our ability to understand and approach the treatment of illnesses in more meaningful ways. King

(1972), for example, noted that illness and treatment are currently understood in terms of a mixture of historical and technological underpinnings that can be classed into three broad approaches: (1) primitive medicine which understands illness in terms of magic, spirits, and charms; (2) folk medicine which is based on traditions, staying close to nature, and utilizing concepts of natural balances; (3) scientific medicine which values rational study and identification of agents and processes. One need not stretch the imagination to recognize the barriers which arise when one of these approaches is attempted outside of its area of recognition and acceptance.

In contemporary Western civilization the medical approach has applied rational, scientific methods in its attempt to understand and treat disease. The dominant model is a biomedical one based upon the reductionist (and dualistic) notion that disease can be understood as a deviation from normative, measureable biological variables (Engel, 1977). This scientific method, which has sought to understand phenomena by scrutinizing increasingly smaller units of matter, has been extremely successful in treating illness. As knowledge of natural phenomena has increased, so too has enthusiasm for this model. The isolation of bacteria, viruses, toxic agents, as well as the observation and experimentation with physiological processes have increasingly enhanced our ability to limit the transmission of many diseases. This model has been so successful that Engel (1977) believes that what was at one time a scientific model has now achieved the status of a dogma whose limitations are sometimes overlooked. Data which do not fit it are discarded or held in abeyance with the belief that eventually they

will be understood within this framework. What was once a strategy is now a policy paradoxically limiting the advancement in understanding and treatment of disease.

What is often excluded from rational, reductionist approaches to illness are the so-called psychological and social components of disease. Efforts to take these aspects into account have often been biased in one of two ways, each of which maintains the separation of disease (body) from "other factors" (mind). One of these approaches, which has modeled the reductionistic approach so characteristic of medicine, attempts to identify and isolate specific psychological or sociological elements predisposing a person to disease. The focus here is on etiology and causation, parallel to the biomedical approach. A second approach has examined various psychological or sociological aspects as outcomes or post-hoc consequences of biomedically defined illnesses. A number of years ago, Barker, et al. (1953) wrote of the social psychological consequences of physical disability and more recent attention has been given to the psychological stresses and adjustments of persons with heart diseases and cancers. In both cases, the concept of illness has remained a narrowly defined and separate one. Adherence to such a view leads to an artificial separation between what Mechanic (1977) has defined as illness ("objective symptoms and their interrelations") and illness behavior ("perceptions, thoughts, feelings . . . affecting personal and social meanings of symptoms").

Delimiting areas of scientific investigations into various components may allow for greater control of variables and thereby permit more focused observations. As such observations become more delimited

and their contexts come to serve only as subsidiary or background factors, it is too easy to overlook or disregard the value of the ground in defining what is central or figural. Because laboratory investigations and the methods of the physical sciences are more advanced and have a more productive history than the social sciences, there has been a tendency to devalue or ignore factors other than biomedical in dealing with illness. As a result, much useful data has been overlooked, and a more comprehensive understanding of illness has yet to be achieved.

Within this context, Engel (1977) has described six problem areas that are not adequately taken into account by the dominant biomedical model:

1. The experiencing and reporting of biomedical abnormality requires consideration of psychological, social, and behavioral variables. The variability in the expression and/or experience of illness reflects more than quantitative variations in biochemical process.

2. The clinical data of illness need to be related to specific biomedical processes, yet there has been a striking neglect in developing a scientifically rational approach to behavioral and psychological data. Achieving reliability in interviewing and analyzing the meanings of patients' reports in psychological, social, cultural, anatomical, and physiological terms has not been given sufficient attention.

3. The susceptibility to, time of onset, severity, and courses of diseases are not due solely to somatic factors but may interact with psychophysiologic responses brought on by other prior or concurrent life stresses.

4. The person's decision to view him or herself as ill, or whether others view him or her as ill, is influenced by psychological and social factors.

5. The restoration of biochemical normality does not necessarily restore the patient to health.

6. The interaction between patient and physician influences the outcome of treatment.

Discussing the important effects of psychological influences on illness, Mechanic (1977) pointed out that people try to assess the meanings of their illnesses and that coping strategies are then devised based on such assessments. Taking into account the patient's understanding of his or her illness and the coping strategies which are then employed are important aspects of treatment. Mechanic (1977) and Engel (1977) both suggested that these may influence the medical outcome of the illness as much as biological considerations alone.

Sontag (1978a), in her vociferous attempt to view disease as solely a biological process, has described how illness has pervasive meanings for people and how these meanings are reflected in language, self-concepts, perceptions, and attitudes. By trying to separate the concept of disease from the person and personal meaning, she sought to lessen the potentially negative impact of certain illness metaphors. She also showed, however, how embedded and complex concepts of illness really are. In 1978(b) she wrote, "Nothing is more punitive than to give a disease a meaning." While it is unfortunate that certain illnesses have become encumbered with punitive and dreadful notions, the reality is that illnesses do acquire meanings.

A number of writers (Cannon, 1932; Engel, 1953; Groddeck, 1949; Shontz, 1975) have espoused a more unitary view of health and illness. Rather than describe disease as maladaptation or malfunction, it can also be regarded as the most adaptive measure available at a particular time to permit continued functioning of the person. Being ill need not be seen as something "bad" or "wrong" but can be considered as one 'way of being' within the range of possible 'ways of being' in relation to others and to one's view of one's self.

Modern medical approaches typically focus on illnesses rather than on people who are ill. Illness, however, may be viewed as an interactive process cutting across physiological, personal, social, and environmental levels. Shontz (1975), noting that being ill meant different things to different people, pointed out the necessity of understanding all aspects of a patient's life that were affected by illness in order to understand the meaning of it for that person. Groddeck (1949) further asserted that illness was not an entity but a way of self-expression and that a unitary approach to the person was needed to understand the meaning of an illness. He believed cause-effect approaches were faulty in this regard, and that approaching patients with such a fragmentary focus could be misguided and incomplete. Considering the human being as an integral and interactive part of the environment, Engel (1953) felt that separating people into functions (or parts) would eventually produce an unsuitable approach toward understanding human beings when ill or even when healthy.

Other writers have also attempted to conceptualize and define illness within a social framework. Parsons (1958) considered illness

as a socially institutionalized role and characterized it as reflected by a general disturbance in the capacity of a person to perform normally expected tasks. Furthermore, such an incapacity must be viewed by the person as beyond his or her power to overcome and therefore beyond his or her responsibility. Viewed in this light, illness became a legitimate basis for exemption from normal tasks, upon condition that the person viewed it as undesirable and accepted an obligation to get well.

What constitutes a "legitimate" sick role, however, has been debatable; a person's own judgements about him or herself sometimes no longer are considered sufficient or valid. Goldstein and Dommermuth (1961) pointed out that there has been continued difficulty in defining the sick role as evidenced by the amount of time and energy spent by others in determining whether a person is "really" sick or not. Doctors, relatives, and now lawyers and insurance companies define and evaluate symptoms in order to determine who is sick and who is not. Being ill is a complex social engagement.

Noting that people can only learn about illness while immersed in their own social systems, e.g., family and friends, Pratt (1956) and Wadsworth, et al. (1971) pointed out that the patient-physician relationship is only one of many different interpersonal relationships contributing to a person's understanding and definition of illness. Furthermore, social forces, habits, attitudes, and priorities in one's life all influence the behavior of the person, whether he or she is, or is not, ill (Koos, 1954). While people can be considered as the recipients (or objects) of such forces, one's state of health not only affects one's life, but also the lives of others. Being ill or healthy

is a reciprocal process which always occurs within a specific social system.

One's family represents a primary social system in which one is involved. Family and home relationships, therefore should be considered when attempting to understand the health and/or behavior of any one member. The family's influence on the target patient's perceptions, practices, values, attitudes, and beliefs does have an impact on medical efforts to help the patient. The family is a reference group which provides the context within which a patient utilizes medical diagnosis and carries out his or her actions (Mabrey, 1970).

Compared to our knowledge of health and health care on a larger sociological basis, relatively little is known about the family as a basic unit of health. Some of the effects of illness within the family have been written about by Barker, et al. (1953), Prugh, et al. (1953), and Anthony (1970), all of whom stressed the importance of looking at the patient's and the family's reactions to illness. Illness in the home alters routine; when one person is ill, others react, and the patient in turn reverberates to the family's response. Anthony (1970) noted that when a parent was seriously ill, there were intra-familial changes in dominance, roles, and routines. While being ill almost invariably stressed the family system, the stress varied with: (1) the degree of adequacy of the family system; (2) the nature and severity of the illness; (3) the way in which the family viewed the illness; (4) the patient's view of him or herself; and (5) available resources (Koos, 1954).

An interesting study which addressed the occurrences of illnesses in families was done by Kellner (1963) who kept records of family members' visits to a clinic for illness. Of the 356 families recorded, physical illness and minor emotional disturbances of members of the same family either coincided or closely followed each other in 60 cases. In other words, when one family member became physically ill, another reported some emotional disturbance within the same general time frame. Kellner interpreted these findings as suggesting that some form of interaction between members of the same family had occurred.

Other writers also have emphasized a family orientation. After focusing on the mother-child dyad within the family, Mechanic (1965) found such an approach insufficient in scope to help understand a child's attitudes about illness. On the assumption that mother and child attitudes would correlate in some fashion, he devised a questionnaire to compare mothers' attitudes about life, health and stress with their children's responses relevant to health and illness (willingness to report symptoms, view of own health, when contacting a doctor was seen as necessary). He found that children's attention to symptoms was minimally related to their mothers' attitudes and behaviors. He concluded that factors other than mother's attention to symptoms influenced the child's attention and suggested viewing the family as an ongoing social field as a potentially useful way of understanding more about illness.

Looking at illness from a family interaction point of view has been a much neglected area. Weakland (1977) noted that the vast

majority of pertinent research has been concerned with an individualistic, or at most dyadic, e.g., mother-child, orientation to the psychological aspects of disease. Concurrently, most research has looked at etiological factors in disease. Weakland has suggested that it might be better to look at the disease course itself since how a problem starts is often less important than what causes it to persist and expand.

Once a family member is ill, the illness follows a course which may be determined or shaped by a variety of factors. Important among these are the internal processes which give each family its own unique personality. Rackel (1977) pointed out that different families have their own attitudes and beliefs about what is to be defined as illness and what constitute appropriate reactions to it. In some families, illness may be accepted as a routine part of life. In others, illness may be an enemy to be fought against. Each family, however, reacts in its own way and the course of an illness, including recovery, can be aided or hindered by family atmosphere. Each family, too, is a blending of the varieties and ranges of conceptualizations, experiences, and beliefs derived from families of origin for each of the parents. The working out, or not working out, of these factors leads to the creation of a unique family style within each family unit.

Most studies of illness, however, are not oriented toward families. The usual approach has been to study the smallest possible units in order to render data more manageable; consequently, the literature which addresses illness is based primarily on an analysis of individuals and their varying perceptions of illness.

Individual Perceptions of Illness

A number of writers have contributed clinical observations and impressions about individual reactions to illness. Blumenfield (1977) and Bloom (1963) claimed that although illness has a clinical unity composed of signs and symptoms, the meaning of illness varies from patient to patient. To understand the meanings of an illness for a specific person it is important to explore the patient's thoughts about it, to learn which illnesses have occurred in the family, and to know how the patient responded to other family members when they were similarly ill. Bloom further believed that patients' fantasies about illness would be consistent with their own psychological makeup and past relationships.

Children have been considered to be more frightened and prone to view illness as a punishment for misdeeds. Beverly (1936) claimed that 90% of the children she saw in her medical practice believed they became ill because they had been bad. Langford (1948), in talking specifically about childhood illnesses, noted that the felt experience of strangeness, incomprehensibility and irritability when ill was an indication of a reduced ability to cope as one usually does. Accompanying these phenomena is a reduced interest in broader scope activities and a preoccupation with more immediate physical concerns. How children and parents handle these changes varied according to individual and family dynamics.

Regardless of individual differences, however, there seem to be four outstanding psychological consequences of being ill. These were described by Barker, et al. (1953) as: (1) a reduced scope of the

personal world; (2) egocentricity; (3) an increased focus on the body and bodily changes; and (4) regressive behavior characterized by apathy, insecurity, selfishness, narrowed interests, and hypochondriasis.

In addition to these consequences, the course of being ill can be divided into three time periods, with the experience of illness different in each one (Lederer, 1952). The first is a transition period in which the person moves from health toward illness. This stage is experienced by most persons as an awareness of undesirable or unpleasant sensations. There is a corresponding reduction of stamina and a decrease in the ability to perform usual routine actions. During this stage, many people respond with apprehension and anxiety, as they would in any other unpleasant situation. The disruption in one's ability to carry out ordinary life activities is considered frustrating and anxiety provoking. The experience of anxiety elicits whatever characteristic ways the person usually responds to any anxiety arousing situation. Thus, one may observe reactions ranging from aggressiveness (manifested by irritability) to passivity (manifested by compliance or by adoption of a pitiable posture). For some, the anticipated care and release from responsibility may be appealing; for others it may be interpreted as a sign of weakness and generate guilt and shame.

The second period of illness occurs when the person has accepted a view of him or herself as ill and abandons any pretenses of health. At this point, the person temporarily withdraws from daily activities and focuses on the problem of getting well. A preoccupation with symptoms and illness replaces the usual concerns of life. Responsibilities for decisions are relegated to other significant persons in the person's

life, while the patient becomes more involved with satisfying the simpler needs of rest, food, physical comfort and relief of bodily tensions. These tasks preoccupy the person, while concern for social roles are of lesser concern. The world becomes simpler, more childish and more constricted.

The third and last period involves convalescence and it is at this time that the patient relinquishes the newly entered sick role and begins to move back into the broader world of everyday activity. This phase is characterized by giving up dependent, egocentric behavior with a concurrent expansion of interests. It is as if the person is re-entering the world again and there is a lesser preoccupation with the self as an isolated unit. For some, this period is experienced as invigorating and heartily welcomed; for others it is approached reluctantly and encouragement is needed from those around.

Some writers have tried to determine the meaning of illness by ascertaining psychological and social conditions which preceded the onset of the illness. From this perspective illness has been conceptualized as a consequence of certain stressors. Mutter and Schleifer (1969) hypothesized that the onset of illness in a child was related to the child's ability to cope with changes in his or her psychological and social environment. To evaluate this hypothesis, they interviewed frequently ill and healthy children and their families and concluded that ill children generally sustained greater losses and related more poorly with their parents. The authors also claimed that there was less cohesiveness in frequently ill families and that the mothers of such children seemed to function less adequately. The

authors felt that the quantity and character of psychological and social settings were significant factors in the development of illnesses in these families.

Despert (1944) attempted to correlate emotional factors with susceptibility to colds in young children but her results were inconclusive. She found that the highest rate of absences from school was seen in: (1) children from broken homes; (2) children with emotional stresses; and (3) children free from such stresses. Conversely there were some children with emotional problems who had few colds. Clearly there was no neat pattern of correlation.

While informative in their own specific ways, these etiologically oriented studies take a cause-effect approach and implicitly divide time into "before" and "after." Also, by singling out pre-selected areas of inquiry they seem prematurely to narrow the focus of investigation and consequently to limit the significance and utility of the information received. More general, open-ended, broader scoped inquiries would seem to be more productive in generating a wider range of information. This, in turn, would enhance our overall understanding of illnesses in the lives of people.

Apparently few writers have gone directly to people and talked with them about illness to hear what they had to say. Bauman (1961), who asked people to define criteria for health, noted that most health studies dealt with attitudes toward health and illness while failing to ask people what their concepts of health were. She found that neither chronically ill, low income patients, nor medical students described health as a unidimensional concept. The main criteria listed

by both groups were: (1) a general feeling of well-being; (2) an absence of symptoms of illness; (3) descriptions of what a healthy person can do. There was, however, a difference in emphasis between the two groups. Feeling states and concerns with physical activities were stressed more by patients, while physical symptoms were emphasized more by medical students.

In a different study, Apple (1960) sought to determine how people defined illness. He read vignettes which incorporated varying degrees of three pre-selected factors (time of onset of symptoms, ambiguity of symptoms, interference with activities) to each of sixty people. He found that interference with usual activities and recent onset of symptoms were primary factors in the definition of illness, while the degree of ambiguity of the symptoms was found to be not significant.

Direct interviewing of people, particularly ill persons, about their own understanding and experiences of illness has not often been reported. Lefebvre (1977) interviewed cancer patients and their spouses and reported that being ill was a complex state involving disturbances in sleep, eating, sexual, and recreational behaviors as well as affecting significant persons in the patient's life. Wadsworth, et al. (1971) interviewed ill persons with complaints ranging from digestive and respiratory difficulties to tiredness, nervousness, and headaches. Such individuals tended to cite environmental factors as the reason for their problems ten times more often than did their doctors who were inclined to cite physiological factors. Both researches found that ill people experienced illnesses as multifacted and intertwined with personal, social and environmental conditions and evaluations.

The most relevant study related to this issue was done by Herzlich in the late 1960's and published in 1973, entitled Health and Illness. Eighty people in France (twenty-four describing themselves as presently ill) were interviewed about health and illness. Interviewing sought to generate data concerned with: (1) notions of health and illness and their interrelations; (2) ideas concerning the causes of illness and health; (3) relationship between these concepts and personal values; (4) evaluations of the ways in which the incidence of illness was perceived to affect social participation.

People generally contrasted themselves with the environment around them. The individual was seen as naturally healthy, but impinged upon by the unhealthiness of the world, particularly by the pressures of city life (85% lived in Paris; 15% in a village). People, when ill, characterized themselves as essentially passive; their activity was that of resisting noxious stimuli from the environment. The pressures of life were seen as eroding the individual's naturally healthy condition thus rendering him/her susceptible to attack by pathological agents. The issues of constraint and subjugation to undesirable life conditions were directly tied in with notions of health and illness.

Inherent in the notion of an "unhealthy world," two-thirds of the people interviewed cited toxicity as the cause of illness, while one-half cited germs. Toxicity referred to a process which happens over time and is slow and cumulative. Germs were seen as an "all or none" event. Illness was objectified as an intruder and its presence perceived in the conditions of life even when there was no manifestation

of illness in the person. Illness and health were contrasted, and were seen as in conflict with illness seen as a threat to the integrity of health. Because people identified more with being healthy Herzlich proposed that rather than feeling guilty for having become ill, guilt may stem from having lost one's health.

Polar characterizations of health and illness are over simplifications because within each condition there were numerous qualifications and shadings. Health was experienced both as a presence of freedom, of well-being, and of resistance as well as an absence of illness and an unawareness of one's body. Illness was referred to in a number of distinct forms such as fatal ones, common ones, childhood ones, and chronic ones. Intermediate states were also mentioned in which persons felt they could not categorize themselves as either healthy or ill.

The idea of illness being defined by a set of criteria which holds true for all people is untenable in the face of the qualifications given by the interviewees. Severity, pain, and temporal criteria all served to distinguish between different types of illnesses and Herzlich indicated that

. . . this pseudoclassification of illnesses is to arrange their characteristics not in any absolute sense but in terms of the ways in which the individual is involved with them
 . . . we noted how greatly they (the nature of the attributes used and recognized as significant) differ from medical and organic classifications.

The distinctions made by the people attest to the personal and individual involvement in each person's experience and understanding of illness.

The experience of illness was not reducible to physical aspects but included the expressed need to pay special attention to oneself

(possibly by going to a doctor) and to reduce one's activities. Recognizing a need or desire to slow down was seen as one of the first steps in signalling the onset of illness. Going to a doctor served to identify and name the illness thereby helping to organize the ambiguity involved in an altered feeling state. While the doctor played the role of constituting what was and was not considered part of the illness, it was personal inactivity which gave meaning to the physical symptom.

"In fact, as long as one's activity is unhampered, physical phenomena are perceived but not thought of as illness, while the sense of being ill arises only when everyday activity becomes difficult." Inactivity was regarded as a more important aspect of the illness experience than pain primarily because it was more closely linked with the experience of being isolated from other people. Inactivity thus mediated between the physical and psychosocial aspects of illness.

People fell into one of three groups in assigning meaning to illness. For some, it was seen as destructive; for others illness was a liberator; and for some it was regarded as an occupation. Those who viewed themselves as normally quite active and involved with society tended to consider illness as destructive. The essential aspect of illness--inactivity--meant a deprivation through desocialization. These people viewed the loss of their healthy social role as being imposed or inflicted upon them and felt that their ties to other people were severed through being ill. They experienced loneliness, depersonalization, and alienation; nothing about illness was seen as favorable. Power, for them became a major issue, as there was ambivalence between denying illness (omnipotence) and accepting it (impotence).

Behavior ranged from rejecting the illness role to passivity. Rejection was exhibited by remaining active, refusing to seek out a doctor, and by a reluctance to take medicines or let others know they were ill. Passivity resulted from a perceived failure of denial and the patient then let others take care of him or her, having given up trying to do it alone. Passivity was also a way of not taking part in the illness and turning oneself into an object claiming that it really wasn't he or she who was ill.

For those who experienced illness as a liberator, inactivity meant a release from the burdens of life. It allowed the person to participate in another world, an unreal and even an exciting one. This "time-out" allowed for pursuits of different activities, e.g., reading, enjoying solitude, and/or feelings of power through the special attention received. Such individuals did not hold up health and participation in society as ideals; they asserted themselves as distinct from the norms. Illness gave them the opportunity to "be themselves" and to enrich themselves through increased awareness and reflection.

When illness was perceived as an occupation, the job was to fight, to become engaged in an active struggle. Being released from normal social responsibilities was seen as positive because it allowed more time and energy to be devoted to the battle and social inactivity allowed for this new kind of activity. While fearing illness, such individuals accepted it as a reality and felt powerful enough to do battle with it. With them, the physical manifestations of illness played a more prominent role in defining illness. They went to doctors,

took medicines, and worked cooperatively with others to regain health. Relations with others were not seen as seriously disrupted and illness remained a socialized situation.

Through these interviews, Herzlich has presented evidence that illness means different things to different people. It is a multifaceted experience, calling into play a wide range of values, beliefs, and actions. Illness is not conceived solely, nor even primarily, in terms of the corporeal body; rather one's perceptions and behaviors are vital factors in defining the experience. Herzlich concludes that, "experience takes meaning at both the physical and psychosocial levels, in terms of the relations of the individual to society."

No investigation of this type with an American population has been published to date. One can wonder if similar results would be found, given the strong bond between individuals and society which so many writers have emphasized regarding illness. Paris is not Knoxville, but investigations such as Herzlich's provide stimulating material and demonstrate a fruitful approach to learning more about how people do experience illness.

In 1975, interviews concerning the personal meaning of health and illness were conducted by the present author and two colleagues (William A. MacGillivray and John R. Adams) with elementary school children from low and middle income areas in Knoxville. Analysis of the data produced by eleven children indicated that they generally knew they were sick because of physical symptoms or complaints. Emphasis was given to the body in designating oneself as ill, with changes in activity level not being a determining factor. When asked,

however, as to what they disliked about being sick, physical pain and discomfort were less often mentioned than restrictions on activities. Being ill was seen as a cutting off of oneself from the world. Exposure to bad weather and eating foods were seen as the primary causes of sickness, with germs rarely being mentioned. It seems obvious that activity level, physical symptoms, and contact with other people were all factors which helped to define the experience of illness.

These results suggest some cross cultural and cross age similarities of perceptions and descriptions of illness. Samples of American children as well as French adults emphasized environmental elements as primary factors in the genesis of illness. Both groups also indicated that restricted ability to engage in activities was a most important aspect of illness. Pain and discomfort, while sometimes valuable in recognition of the onset of illness, were of lesser importance in the overall experience of illness than these other factors.

Being ill, thus, involves much of a person's life and understanding illness requires that attention be given to a wide range of factors. This calls for a more comprehensive orientation toward understanding and treatment of illnesses. The field of psychosomatic medicine has attempted to fill this role.

Toward A Psychosomatic Approach to Illness

Kessler (1966), Prugh (1963), and Weiner (1977) regard psychosomatic medicine as an approach, rather than a speciality within medicine. The scope of this approach includes both physiological and psychological techniques for studying illness and care planning. It also emphasizes that persons, not cells and organs, have diseases and that

the human, social, and cultural environments must be considered when studying illness. This conceptual approach recognizes the inter-relatedness of human beings and their environments and the inherent unity and interaction of physiological, psychological and social factors in the onset and maintenance of disease.

Kessler (1966) cautioned against making the assumption that since an ailment could be psychogenic, that it was psychogenic. She divided psychosomatic conceptualizations into two broad approaches: specific and nonspecific. Specificity approaches have looked at personality types and internal conflicts as etiologic in the development of psychosomatic disorders. Nonspecificity approaches have considered stress in general as the etiologic factor. There is disagreement within this latter approach regarding whether physiological responses are or are not biological regressions to earlier physiological functioning. The trend in recent years has been to view psychosomatic disorders within nonspecific stress models, with disorders representing adaptive attempts to maintain organismic integrity under stress.

In recent years, there has been a marked increase of interest in non-physiological parameters and concomitants of physical illnesses thereby encouraging some workers in health related fields to maintain that all illnesses must be viewed from a psychosomatic approach. While such claims merit recognition and consideration, historically there have been certain illnesses which have consistently been viewed as psychosomatic. Because of the frequent observance of the as-yet not well understood interplay of physiological and psychological components in the onset and maintenance of illness, these illnesses have received

attention from both medical and psychological workers and a significant amount of research has been undertaken.

Asthma is a prime example of a disease which has generally been viewed as psychosomatic because of the variety of triggering stimuli which have been observed to initiate, sustain, and terminate the manifestation of symptoms. Variations in environmental conditions, activity levels, emotional states, and dietary practices have all been cited as factors in the initiation of asthma attacks. The degree of interplay among these factors is unclear, but asthma is generally considered to be an illness strongly influenced by physical as well as psychological conditions. Research into physiological and psychological components of asthma will be summarized here in order to elucidate the main approaches which have been taken in efforts to understand and treat the problems.

II. ASTHMA AS AN ILLNESS

Pathophysiology of Asthma

Criep (1976) reported that from 2-5% of the population have been estimated to have asthma. As much as 25% of elementary school absenteeism has been reported as due to asthmatic illness. The somatic symptoms which characterize the disorder consist of repeated periodic episodes of sudden wheezing which occur usually in conjunction with shortness of breath (dyspnea) and cough. These symptoms in asthma are due to obstruction of the respiratory flow, and the pathophysiology stems from obstructive changes in the bronchial airways. These changes consist of: (1) contractive spasms of the bronchial

smooth muscles; (2) increased secretion and thickening of the consistency of mucus; (3) edema of the respiratory mucous membrane (Allergy Foundation of America and American Thoracic Society, 1973; Cropp, 1975; Vaughan, 1973).

All of these increase the resistance to the flow of air. While the obstruction occurs during both inspiration and expiration, it is during expiration that the condition is more pronounced. This is because as the lung empties, the airways normally tend to close thus increasing resistance to the air flow. What usually happens during expiration is that the alveolar pressure surrounding the bronchioles is greater than the pressure in the lumen of the bronchioles causing the bronchioles to collapse. With the added obstructions which cause a narrowing of the airways, there is an increased pressure drop in them thereby decreasing forced expiratory flow rates. This closure means increased time is needed to expel air and also accounts for the wheezing which occurs. Increased efforts to expire only accentuate closure of the airways (Criepp, 1976; Permutt, 1973; Wood, 1973).

Levison, et al. (1974) report that more recent interest has turned to the problems in the peripheral airways rather than focusing on the constriction in the larger ones. While bronchospasm is one of the causes of asthma, the more critical lesion concerns the increase of trapped gas in the lungs. As the severity of the asthma attack increases, the airways close at increasingly higher lung volumes. The mechanism of the closure is still poorly understood, but bronchoconstriction alone doesn't explain it sufficiently. Possibly, the mucosal edema and increased flow of mucus physically block many of the small airways.

Airway obstruction also causes a reduction in vital capacity which is defined as the total amount of air which can be forcibly exhaled after maximum inspiration (Pinkerton, 1967). Because the narrowed airways close prematurely during forced expiration, there is an increase in the amount of air trapped in the lung after expiration (increased residual volume). This causes the asthmatic to breathe with inflated lungs which leads to increased inspiratory efforts to inflate the lungs. The overinflation of the lung results in an increased metabolic rate because of the increased resistance to blood flow through the lung because the vessels of an inflated lung resist blood flow more than a normal one. This accounts for the pulmonary hypertension which may be present in acute asthma. This overinflation leads to increased efforts to breathe and the sensation of dyspnea (Allergy Foundation of America and American Thoracic Society, 1973; Williams, 1973).

Airway obstruction is not uniform and in those areas which are completely obstructed, the alveoli overdistend resulting in an attenuation and closure of the capillaries. This leads to an increased resistance to blood flow. Those areas which are ventilated but non-perfused (no blood flow through) become dead space resulting in an increase of wasted ventilation, and thus an increase in the ventilatory requirements of the patient. In some other areas of the lung there may be diminished ventilation but no interruption of blood flow to the alveoli. These areas, more perfused than ventilated, will have reduced oxygen tension and the blood leaving the lung will cause a reduction of oxygen tension and oxygen saturation in the arteries.

This leads to the condition of hypoxemia or deficient oxygenation of the blood. Because of poor ventilation, carbon dioxide tension rises and the combination of the lowered arterial partial pressure of oxygen (hypoxia) and the raised level of carbon dioxide (hypercapnia) triggers an increase in ventilation. This diverts blood to better ventilated parts of the lung where more oxygen is available (Allergy Foundation of America and American Thoracic Society, 1973; Williams, 1973; Wood, 1973).

As airway obstruction becomes more severe, smaller airways become completely obstructed by mucus plugs, and small segments of atelectasis, or lung collapse, may result (Wood, 1973). Hogg (1974) believes the major cause of the obstruction is smooth muscle spasm, since the onset and termination of the attack can occur so quickly. It is unlikely that edema or increased flow of mucus into the airways can occur and stop so quickly. Shira (1973) reports that as the severity of the attack increases, edema and the inspissated (thickened) mucus are the dominant pathological conditions. However, the mechanisms which initiate bronchoconstriction are unclear, as are the mechanisms for the abnormalities in the distribution of inspired gases and of pulmonary blood flow. Criepp (1976) explains that mucus is secreted by the glands in the bronchial wall and that under normal conditions water is evaporated from these bronchial secretions. In asthma, the narrowing of the tracheobronchial tree creates humidity deficit which then renders the mucus sticky and inspissated, thus interfering with its drainage. Ciliary function becomes impeded so the mucus stagnates causing further obstruction.

Compliance is a measure of the elastic recoil of the lung. The lower the elastic recoil, the greater the compliance. With air trapped in the lung at the end of expiration, there is an increase in the elastic tension on the airway walls, hence less elastic recoil of the lung. Total lung capacity is increased during the asthma attack. Total lung capacity is the lung volume at which the maximum inspiratory pressures which can be generated by the chest wall is entirely dissipated across the lungs. This increase in total lung capacity is the result of a loss of elastic lung recoil, increased outward recoil of the chest, and the increased strength of the inspiratory muscle contractions. Since the lungs are overexpanded, more pressure is required to inhale a given volume of air, so the asthmatic has to work harder to inspire not only because of the airway obstruction but also because of his stretched lung. He or she needs about forty times as much oxygen as usual in order to move one ml. of air in and out of his lungs due to the lowered elastic recoil of the lungs and the poorly supported bronchioles (Criepp, 1976; Peress, 1976; Wood, 1973).

How the lungs and chest wall alter their elastic properties so quickly is not understood (Peress, 1976). Complete understanding of the airway closure mechanisms is not yet achieved (Levison, et al., 1974). The mechanisms for the uneven blood flow and distribution of gases are not understood (Shira, 1973). The interrelationships between the three components (bronchoconstriction, edema, and mucus plugs) are not understood, either (Williams, 1973).

Pinkerton (1967) says that asthmatics have a labile bronchial system; that is, it responds (constricts and dilates) to many stimuli.

In 1973, he wrote that the instability of the system probably stems from an immuno-physiological substrate. Based on this vulnerability, many things can activate bronchospasm, including inhaled allergens, bronchial infections, prolonged exercise, situational stress, and emotional changes.

The Search for Psychological Etiology of Asthma

The study of emotional factors in disease traditionally has been carried out by investigators from a psychodynamic orientation. Franz Alexander's (1950) observations reflect the general conceptual understanding most widely adhered to in explaining the psychological conditions and emotional states which may precipitate asthma attacks. Noting that emotions influenced normal breathing functions, he reasoned that almost any sudden emotional stimulus could be the precipitating emotional factor in asthma.

With asthmatics, it has been postulated that there is a central conflict which revolves around an excessive unresolved dependency on the mother (Chen & Cobb, 1960; Knapp, 1969; Lieberman, et al., 1959). With this repressed dependency conflict as the core, anger at the mother and the consequent fear of rejection are seen to be the essential emotional components, with asthma acting as a repressed cry of anxiety or rage (French, 1939). This dependency takes the form of a wish to be protected or encompassed by the mother; therefore everything that threatens to separate the child from the mother can precipitate an attack. The separation referred to may be either physical or emotional.

Excessive dependency conflict is seen as arising from a history of maternal rejection. The child responds to rejection and fear of separation by increased insecurity. Since crying behavior frustrates the mother and causes further rejection, asthma then symbolizes a repressed cry. Alexander (1950) noted that adult asthmatics often reported difficulty in crying and that attacks sometimes ceased if the asthmatic vented his feelings by crying. Confessing was also reported to decrease the frequency and severity of attacks. The interpretation of this was that confession established a dependent attachment to the therapist which had previously been disturbed by the patient's guilt feelings over anger and his expectations of rejection.

Generally, the mother has been seen as conveying a hostile, rejecting feeling to the child. Mirsky, et al., (1955), working with psychosomatically ill hospitalized children and their mothers, declared that these mothers were unable to give reliable accounts of early child care of their children. The authors concluded that these children were "consistently exposed" to inadequate mothering in the first year of life. Coolidge (1956) claimed that mothers of asthmatic children never severed their ties with their own mothers and therefore never felt themselves to be whole persons on their own. They then fused with their unborn children and, following birth, unconsciously fostered the development of asthma in the children through rejection of the child's individuality. In the face of such rejection, the children's dependency wishes were frustrated and hence, became stronger; the child also became enraged because of the lack of need gratification. These feelings were then repressed, and received expression through

the asthma attack. Controlling and punishing the mother were also considered to be secondary effects of the attacks (Saul & Delano, 1963).

Other writers have focused on the relationship between both parents and child to explain the development of asthma (Gerrard, 1948; Miller & Baruch, 1948, 1967; Pinkerton, 1967; Rees, 1963). The parent-child relationship was characterized as generally unsatisfactory because of the parents' own conflicts about dependency. The parents' handling of such conflicts varied and was reflected in how they then related to their child. Some parents were seen as overprotective and smothering as compensation for their guilt feelings over their hostility toward their child. The overprotective interactions resulted in a lack of a sense of independence and autonomy for the child, which created a heightened dependence upon the parents. The child thus felt him or herself to be weak, vulnerable, and insecure.

Other parents were described as openly critical, rejecting, and perfectionistic. These factors were seen as increasing the child's fear that he or she was unloved, resulting in a great hunger for affection as well as creating strong feelings of anger for not having received love. Because of the child's sense of insecurity, he or she would then "bottle up" feelings since any direct display would cause further rejection. Asthma then became a way of both relieving tension and of achieving closeness.

While there is a certain fittingness to the symbolism of asthma symptoms which accords nicely with descriptions of asthmatics' parents, the accuracy of such depictions has been seriously questioned by a number of researchers. Criticism has centered on issues of parent

personality patterns and on the difficulty one is likely to have separating current factors from predisposing ones. Poonawala (1973) reported conflicting results from studies of asthmatic personalities and the parents of asthmatics. Some studies have concluded that there are no differences at all between the parents of asthmatics and non-asthmatics. For example, Fitzelle (1959) found no significant differences in personality profiles or child rearing attitudes between parents of asthmatic and non-asthmatic children. He also reported no significant differences between the parents of children with mild vs. severe asthma. Jones, et al. (1976), using MMPI profiles, stated that no single personality style was unique to asthma and concluded that it would be premature to impose a unifying theory on asthmatics.

The most telling criticism of psychiatric research on asthma has been leveled at the "cause-effect" approach. Weblin (1963) claimed that no sound studies exist where "before and after" effects relating to asthma have been examined. He suggested that asthma attacks could be seen as a way of reuniting parents when there was overt parental hostility. Here, too, the presence of purported parental hostility is assumed a pre-condition for the onset of asthma symptoms. Weiss (1973) and McNichol, et al. (1973) went as far as to indicate that knowledge of emotional disturbances and their prevalence in children, as well as accurate pictures of the histories of these children, was very limited. Studies comparing asthmatic with non-asthmatic individuals have overlooked the fact that psychologically all asthmatics are not alike.

Are emotional factors causes or effects of asthma? Are they specific for asthma? Specificity theories assume that the conditions for developing asthma exist before the onset of the somatic symptoms; however the secondary effects of the condition have yet to be untangled from the primary ones. In fact, unless one conducted longitudinal studies of children and families before and after the onset of asthma, separating out pre- and post-asthma factors appears to be an uncertain endeavor. Consequently it seems that, both physiologically and psychologically, there is only limited knowledge about the etiology of the asthma condition.

Toward A Family View of Asthma

A number of writers (Moos, 1973; Prugh, 1963; Weiner, 1977) have criticized research endeavors which seek to discover specific etiological factors in the onset of psychosomatic disorders. These authors emphasized that, while illness arises from many factors, being ill also generates a variety of possible responses within the patient's family. While pathogenic emotions, unconscious conflicts, parental attitudes, and the like may be factors in psychosomatic illness, they are not sufficient conditions for the development of such illness. A cause-effect approach is too limited a conceptual model and often obscures appreciation of the influence of simultaneous, ongoing relationships within the family.

Psychosomatic researchers have also been faulted for making unfounded assumptions and for maintaining unscientific attitudes. Mendelson, et al. (1956) were particularly sharp in their criticisms

of researchers who approached problems as devout believers invested in proving issues rather than learning about them. Use of biased population and data samples, equation of phenomenological descriptions with etiological information, and use of analogical reasoning about "regression" were produced as examples of this situation. Kaplan and Kaplan (1959) also cautioned that establishing a causal relationship between any psychological factors and physical illness was an assumption. They noted that, although psychological and physical systems involve different levels of description, use different semantics, and require different methods of inquiry, research literature often inappropriately equates concepts derived from different realms.

Over thirty years ago, Richardson (1945) cautioned that looking for and finding particular conflicts or personality patterns in individuals did not warrant claiming causality. He noted that other people with similar conflicts or personalities did not have psychosomatic disorders. He suggested looking at the patient as part of a family system and thereby viewing illness as an integral aspect of family living rather than an entity of its own. Ackerman (1958) and Haley (1962) also decried omitting considerations of contemporary life environments in attempts to understand illness and proposed shifting the focus from the individual to family relationships.

Meissner (1964, 1966, 1977) noted that the focus of much research related to psychosomatic illness concerned factors in the family such as overprotection-rejection, parental pathology, conflict, and parent-child interactions. Reasoning that the family provided a context within which to understand psychosomatic disorders, he suggested looking at a more

"primitive" level of emotional involvement in which fusion of family emotionality was considered independent of individual emotionality. He also suggested that paying particular attention to the patterns of involvement and interactions within the family might lead to better understanding of psychosomatic disorders.

While Meissner made the transition from the individual to the family, he still maintained a cause-effect orientation. With specific regard to asthma, Grolnich (1972) pointed out that assuming a causal relationship between any aspect of the family system (e.g., roles, affects) and asthma was premature and unfounded. He noted that it is difficult to evaluate the etiological significance of events which also are common in control groups.

The transition from an individual to a family level and from a cause-effect approach to a system orientation was completed by Minuchin (1974) and Minuchin, et al. (1977, 1978). Specifically, Minuchin has criticized the linear model of disease which maintains that life stresses influence emotions which then lead to bodily responses which then culminate in illnesses. He has also questioned the validity of attempts to establish a one-to-one correlation between unconscious psychodynamics and physiological responses. These essentially stimulus-response approaches are criticized for ignoring the capacities of individuals as acting and reacting members of family systems as well as for their lack of appreciation of the influences family members have upon each other. The interdependence of the parts of the system, with behavior both causative and caused, means that influences occur at many points and levels. Accurate understanding of any aspect of the system requires consideration of the nature of the system as a whole.

Few researchers prior to Minuchin have attended to contextual familial issues. Titchner, et al. (1960), in doing a family oriented case study of ulcerative colitis, sought to consider each person or relationship as a part of the family field. While attending particularly to the mother-child relationship, these researchers concluded the significant issues were how "she (mother) acts in the particular relationship with the particular child in a particular period--all within the context of the whole family's dynamic patterns." In other words they felt that knowing the personalities and underlying psychological conflicts of various family members did not provide an accurate understanding of how one person's relations with another influenced the other. Dubo, et al. (1961) conducted extensive laboratory work and interviews with 71 families with asthmatic children referred by allergists. Mindful of not confusing etiology with reactions, they evaluated information in light of total family tone and relationship qualities. Comparing the extreme ends of family adjustment groups, they found no relationships between family situation and asthma situation, i.e., age of onset, severity, and response to treatment. They also found no characteristic personality profile among the children interviewed, but did find that those with the most positive family relationships were the most "adjusted."

Noting that the psychiatric groups which usually form the focus of research display high levels of anxiety and fears of suffocation and death, these authors found their population to be less similarly troubled. The major factor in lowering anxiety was reported to be the availability of medication. The most commonly expressed feeling was

frustration with asthma for its interference in personal goals and social life. They concluded that the family situation affected both the adjustment of the asthmatic child to the illness and the degree to which the illness imposed limitations upon the child.

Such studies suggest that both individual psychological experiences as well as interpersonal transactions need to be studied to achieve a more holistic and accurate view of illness. As Weakland (1977) noted, so little is known about factors influencing any disease, studies should be exploratory, flexible, and guided by general principles. It is along these lines that the present research proceeds.

The purpose of the present research is to elicit information about the meanings of asthma from both parent and child points of view. The assumptions underlying this research are: (1) illness has meanings for the person who is ill; (2) illness has meanings within the context which it occurs; and (3) one way of ascertaining these meanings is through interview data. As Weakland also suggested, the interviews address: (1) the family's conception of illness; (2) how it is presently a "problem" for the patient and family members in daily life; (3) how the patient and family attempt to handle the "problem."

While most related research has been concerned with the etiology of illness, this research concurs with Whitehorn's (1947) emphasis on the value of distinguishing between meanings and causes. Whitehorn believed that the mutual understanding of meanings could be more important than specific etiologic hypotheses in terms of their practical value for treatment. The results of the present interviews will provide descriptions of the meanings of an illness for the children and

their families. Analysis of such meanings will provide a basis for discussion of the implications such research has for treatment and for future directions in more general studies of illness.

CHAPTER II

PROCEDURES USED TO INTERVIEW FAMILIES AND THEIR CHILDREN

I. INTRODUCTION

The purpose of this study is to describe perceptions of illness by families and children where the child is the identified patient. The data to be presented was derived from two sets of open-ended interviews with one set of questions used for interviewing families and another for interviewing children. All questions were generated by the author.

The Family Questionnaire was devised to elicit information regarding thoughts, behaviors, and feelings related to illness. Most questions concerned issues related to the child's illness; a few, however, pertained directly to the parents. The questions used in the Family Questionnaire were pilot tested with a small group of families and suggestions from these families were incorporated in the final questionnaire used. The Family Questionnaire is presented in Appendix A. The Children's Questionnaire was designed to generate information about the children's feelings, thoughts, and actions pertaining to their own illnesses. It also sought to obtain information about their perception of family members when they (the children) were ill. Most of the questions for the Children's Questionnaire were pilot tested for relevance and comprehensibility with a large group of elementary school age children. The Children's Questionnaire is presented in Appendix B.

II. SUBJECTS

Eighteen families, divided into two groups of nine each, were involved in the study. All families met the following three criteria for inclusion in the study: (1) having an intact family, that is, the family unit consisted of the natural parents and their natural children, with there being no history of divorce or separations within that family unit; (2) the presence of a child age 6-12, who was to be considered the identified patient; and (3) the absence of a psychiatric history for family members.

In addition to these criteria, nine families had a child (identified patient) who suffered from asthma. Since asthma exists in varying degrees and may at times be confused with other bronchio-pulmonary disorders, a uniform criterion was used to ensure the accurate identification of patient-children. All asthmatic children had been or were currently using some kind of steroid medication for occasional symptom arrest. Eight of the nine children were referred by their pediatrician or allergist. The ninth child was contacted through a more informal word-of-mouth system. A sample of the letter to physicians is included in Appendix C.

The letters were followed by telephone calls and appointments were arranged to meet with physicians to explain the nature of the study. In all cases, physicians elected to contact appropriate families to enlist their participation. All contacted families agreed to participate. The author was then given the names and addresses of the families and a letter and response form were then sent to them (Appendix D). When the signed response form was returned, the author called

the family by telephone and explained the purpose and nature of the study, answered questions, and arranged a date and time to meet with the family.

The other nine families were chosen because their child was considered by them to be in good health and had no history of serious illnesses. Another criterion for inclusion was that they had a child whose age in years matched the age of a child in the Asthma group. "Control" families were found through a less formal method than was used in securing Asthma families. Flyers, requesting volunteers, were posted in apartment buildings and at shopping centers in lower-middle to middle class areas of Knoxville. Another recruitment procedure was simply through word-of-mouth.

Some of these families called the author to inquire about the study. Families who did not meet all three criteria were thanked for their interest, and excluded. In a few instances, one parent called expressing interest in participation and then later called back, informing the author that the spouse was unwilling to participate. Reasons ranged from lack of time to having been involved in a research project in the past and having been displeased with the manner in which it was conducted. These persons, too, were thanked for their interest, and excluded. In other instances the author was given the names and phone numbers of neighbors or friends of friends or co-workers. In all cases, the nature of the study was initially conveyed by word-of-mouth to the families who then expressed an interest in further information. At that point, the author called them and appropriate arrangements were then made. All eligible families contacted in this manner agreed to participate.

All families were volunteers. All families were white, generally middle class with, in most cases, both parents employed. They all lived within a 60 mile radius of Knoxville, Tennessee, thereby including both rural and urban representation. All children were judged by the author to be of Average range or above in intelligence based on their verbal productions and reported academic achievement. In each of the two groups of nine, herein referred to as the Asthma group and the Control group, there were three children age 6, two children age 7, and two children age 9. The Asthma group had two 11 year-olds while the Control group had one 11 year-old and one 12 year-old. All but one child had at least one sibling. Appendix E presents the age, sex, and sibling characteristics of the children. Table E-1 displays the number of children. Appendix F presents the interviewer's general impressions of the interactive styles of each child interviewed. No predominant features were noted for either Asthma or Control children. The rationale for choosing latency age children was that they were old enough to be verbally competent and young enough to be unaffected by adolescent issues and body changes.

No effort was made to control for current medicine use nor for length of history of symptoms within the Asthma group. As it turned out, all children in this group had developed symptoms within the first few years of life. Except for one child, all were currently taking a variety of medications on a daily basis for their prophylactic benefits.

III. PROCEDURES

The source of data for this study was provided by interviews conducted with the children and their families. All interviews were conducted at the homes of the families, except for one which was conducted at an outpatient medical clinic. The locations were chosen by the families for their expressed convenience. Consistency in interviewing was maintained by following the interview schedule closely, with all questions being asked in sequence except for those instances where deviation served to maintain the flow of communication.

The purpose of the study was explained to the interviewees and they were encouraged to ask questions and express concerns at any time they wished. Both parents were then requested to read and sign the permission form (Appendix G). In all instances, the child was interviewed first and separately from the family. The rationale given to parents was that the child would not be influenced in his or her responses by responses of other family members. It was also reasoned that this allowed for less distraction and a better opportunity for rapport to develop between interviewer and child.

Following this, the interviewer and child joined the rest of the family and the second set of questions was directed to the family as a whole. At the outset, all family members were encouraged to speak; in actuality, parents did most of the speaking while children listened or played. Although responding was left open to each person's initiative, there were two questions to which both parents were directly encouraged to respond. Those questions were exceptions because they

called for responses which were not oriented toward the child, but rather focused on the parents. The questions were, "How do you feel about being ill yourself?" and, "How would you define illness?"

While the interviews adhered to clearly structured sets of questions, a more informal, friendly, conversational tone was attempted and effected. All families appeared interested and talked freely and easily. The total time for each set of interviews ranged from a little over one-half hour to nearly two hours. Following the questions, the interviewer attempted to summarize what he believed he had heard, and gave each family the opportunity to amplify or clarify.

All interviews were conducted by the author and were recorded on cassette tape. These recordings were later transcribed and categorized for analysis.

IV. DATA ANALYSIS

All eighteen audio cassette recordings were transcribed. Each transcription was composed of a Child interview section and a Family interview section. Transcriptions were then analyzed in three different ways.

First, frequency counts were made for speech acts by mothers, fathers, children (identified patients), and siblings. Any utterance or verbal response by an individual family member was considered a speech act. The range, mean, and standard deviation were calculated for each group of respondents. The mean percent of total speech acts produced by each family member was also calculated.

Next, each question was analyzed individually by the author. Responses produced by all eighteen children to each question were listed verbatim on paper. Each response was then transferred to an index card, and the back of the card was coded to indicate whether it was from the Asthma or Control group. This resulted in fifteen piles of index cards, one for each question asked of the children.

Listing responses produced by families was somewhat more complicated. The following procedure was adopted as a means of calculating frequency of response. If more than one family member gave the same response to a single question, it was counted as a single response. If responses were judged to be different or in disagreement, each response was counted as a separate entity. Exceptions to this rule were for the questions, "How would you define illness?" and "How do you feel about being ill yourself?" Every response to these questions was counted separately. Responses produced by all eighteen families to each question were listed verbatim on paper. Each response was then transferred to an index card, and coded on the back. This generated eleven piles of index cards, one for each question asked of families.

Responses to each of the twenty-six questions were then categorized in order to try to make the data more comprehensible. This was accomplished by having two independent raters sort cards for each question into groups of similar responses. One rater was the author; the other was a woman with a Master of Science (M.S.) degree in Child and Family Studies. No predetermined categories were given. Each rater sorted cards and composed categories without knowledge of the other rater's groupings.

A comparison of cards within groupings for each question revealed a very high degree of agreement between raters. Interrater reliability for cards sorted into categories ranged from .88 to 1.00 with a mean of .95 for responses produced by children and from .84 to 1.00 with a mean of .94 for responses produced by families. The categories derived and used for analyses were those in which there was either complete agreement between raters or in which there were only minor discrepancies in terminology. In some instances, categories were combined where the essential meaning of each category was similar. For example, the categories "have to take medicine" and "have to go to the doctor" were combined into "need for medical treatment." In those instances where there was some disagreement as to which category a response belonged, a third independent rater (a male Ed.D. candidate in School Psychology) was presented with both responses and category options and requested to make a forced choice decision.

With responses categorized on the basis of this procedure, the data were then analyzed quantitatively. The number and pattern of response categories given by all families and children were recorded according to question. The number and percent of overlap of different category patterns were also recorded by question.

The number of Asthma families giving a response in each category was recorded by question. This was compared to responses given by Control families to the same question. The pattern of response categories for each family was also recorded and compared. This afforded not only a picture of how many families in each group gave a certain type of response, but also produced a representation of what each individual family said.

Finally, most Asthma families raised some issues and made points above and beyond information requested by the questionnaire. The author read through these transcriptions and noted those which stood out for him. These themes were then listed and the number of Asthma families who expressed them was recorded. A brief synopsis of the author's notes on each family is presented in Appendix H.

An analysis of themes by Control families was not conducted. Control families simply responded to the formal questions and engaged in cordial conversation afterwards. A number expressed that they were sorry they didn't have "too much interesting to say" about illness since it was not something they had ever thought about.

CHAPTER III

RESULTS

I. INTERVIEW BEHAVIOR

Length of Interviews

All interviews were conducted in the same manner. The length of time involved in interviewing varied considerably and ranged from approximately thirty minutes to nearly two hours. A uniform way of measuring the differences in the lengths of the interviews is to count the number of transcribed pages for each interview. The length of the average Asthma family interview was approximately 21 pages, with a range of 14 to 26 pages. The average Control family interview was approximately 10.5 pages, with a range of 7 to 14 pages. Clearly Asthma families had much more to say than Control families. In fact, much of the difference between the length of the two interviews was due to the fact that a majority of the Asthma families spoke freely of concerns not specifically addressed in the formal questionnaire. These concerns will be discussed in a later section (Thematic Analysis of Concerns Expressed by Asthma Families).

Frequency of Response for Individual Family Members

Another measure of interview behavior is provided by the number of times each family member spoke during the interview. Frequency counts were made of speech acts for each family member. Any utterance or verbal response by a family member was considered a countable response.

Tables I-1 and J-1 in the Appendix present the number and percent of total speech acts given by each person in each Asthma and Control family. The mean number of speech acts for Asthma mothers was 93.67 (range = 52-132); for Control mothers it was 41.00 (range = 21-69). The mean number of speech acts for Asthma fathers was 84.00 (range = 39-166) while for Control fathers it was 25.78 (range = 7-40). The mean number of speech acts for Asthma children was 7.44 (range = 0-27); for Control children it was 14.22 (range = 0-42). The mean number of speech acts for siblings in each Asthma family was 8.58 (range = 0-68); for all siblings in each Control family it was 22.00 (range = 0-93).

On the average, Asthma mothers produced more than twice as many speech acts as did Control mothers during the course of the interview. Asthma fathers made more than three times as many speech acts as did Control fathers during the interview. These data are consistent with the finding that Asthma family interviews were, on the average, twice as long as Control interviews. It suggests that the longer Asthma interviews were due to the notably higher frequency of Asthma parents' speech acts. Not only did Asthma parents speak more often than Control parents, but Asthma fathers contributed proportionately more to the interview than did Control fathers.

In contrast to their parents, Asthma children spoke only about one-half as often as did Control children. Asthma siblings also spoke less than did their Control counterparts, speaking on the average just over one-third as often. Thus, while Asthma children and siblings spoke considerably less than Control children and siblings, their parents, especially their fathers, more than made up for the lowered

frequency--particularly since Asthma family interviews were, on the average, twice as long as Control interviews.

Also of note is the range of speech acts given by each member in both groups. While Control mothers and fathers had ranges of 40 and 33 respectively, Asthma mothers and fathers had ranges of 80 and 127 respectively. The difference in range between the two groups of mothers is proportional to the frequency difference between them, that is, approximately 2:1. The degree of range difference between Asthma and Control fathers is approximately 4:1, whereas the mean frequency of speech acts difference is slightly more than 3:1. This indicates that while Asthma fathers averaged more contributions than Control fathers, there was a greater degree of variability among the Asthma fathers.

While the Asthma children had a range of 0-27 speech acts, only two of the children produced more than ten speech acts. In the Control children group with a range of 0-42, four children spoke more than ten times. Thus, while there was variability in both groups, the Asthma children in general were more uniform in their lower response level.

The same trend holds true for the Asthma siblings. While their response frequency rate ranged from 0-68, in six of the nine families the number of speech acts was less than 5. When dividing number of speech acts by the number of siblings per family, in the Control group only three of the eight families with siblings had speech acts with a frequency of less than 5. Again, we can note the trend toward greater uniformity within the Asthma group.

Percentage Analysis of Individual Family Member Responses

Asthma parents thus spoke more often than Control parents and Asthma children and siblings spoke less than Control children and siblings. Calculating the percentage of responses given by different family members yields a clearer picture of participation rates. Table 1 presents the mean percent and standard deviation of speech acts given by different family members during the interview.

As can be seen from this table, nearly 92% of speech acts in Asthma families were produced by parents, whereas 70% of speech acts in Control families were produced by parents. Clearly Asthma interviews were more dominated by parents. Not only did these parents have a lot to say, as indicated by the number of speech acts, but most of what was said during the interview was said by them. The Asthma children and siblings spoke not only less frequently than Control children and siblings, but the average percent of their speech acts was also very small (8.34%). In Control families, children and siblings accounted for 32.31% of all speech acts, indicating a more equal spread of responding. Asthma parents took more control and responsibility for responding, whereas the Control parents were less dominant in the interviews.

A simple 2×4 analysis of variance was performed on these data in order to determine if there were significant differences among variables. Results indicated a significant difference between Family Members, $F_{3,63} = 48.46$; $p < .001$, and a significant interaction between the variables of Family Members and Asthma and Control groups, $F_{3,63} = 6.91$; $p < .001$. No significant overall difference, however, was found between Asthma and Control groups, $F_{1,63} = .06$; $p > .10$.

TABLE 1
 MEAN PERCENT AND STANDARD DEVIATION OF SPEECH ACTS
 BY DIFFERENT FAMILY MEMBERS DURING INTERVIEW

Family Group	Respondent							
	Mother		Father		Child		Siblings ^a	
	$\bar{x}$	s.d.	$\bar{x}$	s.d.	$\bar{x}$	s.d.	$\bar{x}$	s.d.
Asthma	49.33	7.10	42.44	12.76	3.67	2.62	4.67	9.06
Control	41.78	12.41	28.00	11.59	12.56	11.24	19.75	16.38
difference	7.55		14.44		-8.89		-15.08	
t-value	1.47		2.44*		2.34*		2.37*	

^aper family

* $p < .05$

Because of the significant interaction obtained on the basis of analysis of variance results, t-tests were done to determine the significance of the difference between means produced by various members of the families. As can be seen in Table 1, there were significant differences ($p < .05$) between the means of fathers, children, and siblings. There was, however, no significant difference between the means of the mothers.

From these data it can be seen that Asthma fathers spoke proportionately more than Control fathers, while Asthma and Control mothers spoke essentially the same percentage of times. Asthma children and their siblings spoke proportionately less than their Control counterparts during the interview. In both groups, the mothers spoke most often, thus carving out their role as hostess/spokesperson; the big difference, however, was in how often the rest of the family spoke. Asthma fathers spoke almost as much as their wives, while their children remained relatively silent. In Control families, when the mother wasn't talking, there was a more equal sharing of speech time between father, target child and siblings, with the father speaking slightly more than the others.

II. RESPONSES TO FORMAL QUESTIONNAIRE

Family Data

All families were asked the same eleven questions and responses to each question were categorized according to the procedure described previously. Table 2 presents the number and pattern of response categories given by members of both family groups to each question. The

TABLE 2

NUMBER AND PATTERN OF RESPONSE CATEGORIES FOR ASTHMA AND CONTROL FAMILIES BY QUESTION

Dependent Variables	Questions										
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11
Number of different categories	4	5	10	7	2	6	5	6	9	4	9
Number of possible category patterns*	15	31	1023	127	3	63	31	63	511	15	511
Number of different category patterns	3	8	7	7	2	7	5	5	6	4	8
Asthma group											
Control group	6	5	7	5	1	9	5	5	7	6	6
Total number of different category patterns used by Asthma and Control groups	7	13	14	11	2	11	9	8	11	7	13
Number of overlapping category patterns between Asthma and Control groups	2	0	0	1	1	5	1	2	2	3	1
% overlap	.29	.00	.00	.09	.50	.45	.11	.25	.18	.43	.08

*Calculated according to formula $N = 2^n - 1$, where n = number of different categories.

number of different response categories generated for each question ranged from 2 (for Question 5) to 10 (for Question 3). In other words, some questions generated fairly uniform responses while others evoked a larger variety of answers. Given the response categories for each question, the number of possible ways a family could have answered the question is shown in Row 2. For example, the responses to Question 1, "How can you tell when (child) is becoming ill," fell into 4 content groups and each family gave at least one response belonging to one content group.

It is possible though to combine the 4 groups of responses into 15 different combinations of content groups, and these combinations will be referred to as category patterns. Rows 3 and 4 indicate the number of different category patterns actually used by Asthma and then Control families. The responses of all Asthma families to Question 1 fell into 3 different category patterns. The responses of all Control families fell into 6 category patterns. This indicates that there was more similarity among answers given by Asthma families than there was for answers given by Control families. Hence, Asthma families are more uniform in how they decide when their child is sick. While there were 3 category patterns given by Asthma families, and 6 by Control, Row 5 indicates that there was a total of 7 different category patterns generated by all of the families (i.e., including all Asthma and Control families) out of the possible 9 category patterns which could have been generated. This indicates an overlap of 2 category patterns between the Asthma and Control families; hence there is a $2/7$ or 29% agreement in criteria used to determine when children are ill.

Looking across Row 3 for all 11 questions, Asthma families were most similar to each other in their responses (range 2-4) to Questions 1, 5, and 10, they were moderately similar in their responses (range 5-6) for Questions 7, 8, and 9, and least similar in responses (range 7-9) to Questions 2, 3, 4, 6, and 11. For Control families, there was a high degree of similarity in response patterns only to Question 5. Moderate similarity between families was found for Questions 1, 2, 4, 7, 8, 10, and 11. Least similarity in response pattern was found for Questions 3, 6, and 9.

Asthma families were more homogeneous in response patterns in comparison to the Control families on four questions (1, 6, 9, and 10) whereas Control families were more homogeneous on four different questions (2, 4, 5, and 11). On three questions (3, 7, and 8) each group of families responded with an identical number of response patterns.

In response to most questions, the nine families responded differently from other families in their respective groups. While there was a high degree of similarity among Asthma families on three questions and greater dissimilarity among them on five questions, the Control group was highly similar on only one question and was more dissimilar on three questions. Thus, while each group's frequency of homogeneity was equal, i.e. four, the degree of similarity and dissimilarity differed. Asthma families were both more similar and more dissimilar to one another, while Control families were overall less extreme in their variations.

Looking at the degree of similarities between Asthma and Control groups in their respective response patterns, the percentage of

overlap falls into three groups. High overlap between groups (.40-.50) occurs on Questions 5, 6, and 10; moderate overlap (.18-.29) on Questions 1, 8, and 9; and low overlap (.00-.11) on Questions 2, 3, 4, 7, and 11. These results indicate that not only were the two groups highly or moderately similar among themselves in their response patterns to Questions 5 and 10, but they were also quite similar to one another in exactly how they answered. On Question 6, the similarity between groups was greater than the similarity within them. The degree of similarity between groups suggests that Questions 5, 6, and 10 do not discriminate between groups. Questions 2, 7, and 11, on the other hand, are better overall discriminators because at least one of the groups is similar to itself and minimally similar to the other. On other questions, where there is low overlap between the groups, there is generally low overlap within them also, therefore diminishing the between-group discriminatory value of the questions.

Thus, for eight of the eleven questions there was either high inter- and intra-group similarity or low inter- and intra-group similarity in response patterns. This pattern of results suggests that these questions would not be useful in differentiating Asthma from Control families. Three questions (2, 7, and 11) would seem better suited to discriminate between groups based on the variations of response patterns obtained. It must be noted, however, that although these questions may discriminate between groups better than the other questions, there remains too large a variation of patterns within each group to allow for any semblance of prediction.

A Pearson product moment correlation was calculated between the number of different categories produced with the total number of different category patterns obtained and yielded a significant positive correlation ($r = .75$; $p < .01$). When the same measure was computed between the number of different categories produced with percent of overlapping category patterns between groups, $r = -.59$ ($p < .05$) indicating a significant negative correlation. In correlating the total number of different category patterns with percent overlap, a significant negative correlation ($r = -.71$; $p < .01$) was also found. Hence, the greater the number of categories produced as answers to a question, the larger the total number of different category patterns given; and the larger either of these values, the less likelihood was there in overlap of answers. The crucial factor in determining the degree of similarity between groups was simply the number of response categories generated by the groups.

Child Data

An identical format to that used in regard to the Family data will be followed in presenting the number and pattern of response categories appearing in the answers produced by child respondents (see Table 3). The children answered a different set of questions and produced between 2 and 7 response categories. Asthma children were either highly (range 2-4) or moderately (range 5-6) similar to each other in their responses to all of the questions. Row 3 indicates those questions to which their response patterns were highly similar (Questions 1, 3, 4, 6, 9, 10, 11, 12, and 14). They were moderately similar to each other in response patterns to Questions 2, 5, 7, 8, 13, and 15.

TABLE 3

NUMBER AND PATTERN OF RESPONSE CATEGORIES FOR ASTHMA AND CONTROL CHILDREN BY QUESTION

Dependent Variables	Questions														
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15
Number of different categories	2	5	3	3	5	3	4	5	5	4	4	3	5	3	7
Number of possible category patterns*	3	31	7	7	31	7	15	31	31	15	15	7	31	7	127
Number of different category patterns	2	6	4	2	6	3	6	5	4	3	3	2	6	3	6
Asthma group															
Control group	2	5	3	4	2	2	5	7	6	2	3	6	5	3	4
Total number of different category patterns used by Asthma and Control groups	2	8	4	4	6	3	8	9	6	4	5	6	10	3	9
Number of overlapping category patterns between Asthma and Control groups	2	3	3	2	2	2	3	3	4	1	1	2	1	3	1
% overlap	1.00	.38	.75	.50	.33	.67	.38	.33	.67	.25	.20	.33	.10	1.00	.11

*Calculated according to formula $N = 2^n - 1$, where n = number of different categories

There was also a good deal of similarity among Control children in their response patterns as indicated in Row 4. Questions 1, 3, 4, 5, 6, 10, 11, 14, and 15 yielded high similarity (range 2-4). Moderate similarity (range 5-6) across response patterns was found for Questions 2, 7, 9, 12, and 13. Only Question 8 generated low similarity (range 7-9) among the response categories derived from answers produced by Control children.

Looking at Rows 3 and 4, Asthma children were more similar among themselves in response patterns than were the Control children on four questions (4, 8, 9, 12). Conversely, Control children were more similar among themselves in response patterns than were the Asthma children on eight questions (2, 3, 5, 6, 7, 10, 13, and 15). Answers produced by each group were coded into an identical number of patterns on three questions (1, 11, 14).

For the most part, questions tended to generate the same degree of similarity of response patterns across Asthma and Control children. The exceptions were Question 5 (high similarity for Control and moderate similarity for Asthma), Question 8 (moderate similarity for Asthma and low similarity for Control), Question 9 (high similarity for Asthma and moderate similarity for Control), Question 12 (high similarity for Asthma and moderate similarity for Control) and Question 15 (moderate similarity for Asthma and high similarity for Control). Even with these differences, however, the range in number of response categories produced by both groups was greater than 2 on only two questions (5 and 12). Hence, children in each group generated approximately the same number of response categories for 13 of the 15 questions.

This analysis suggests that not only were the children in each group similar to one another but that there was a significant similarity across groups. From calculating the total number of different category patterns used by the Asthma and Control children, the percentage of pattern overlap for each question was derived. There was a high percentage of overlap (.67-1.00) for Questions 1, 3, 6, 9, and 14, a moderate degree of overlap (.20-.50) for Questions 2, 4, 5, 7, 8, 10, 11, and 12, and a low degree of overlap (.00-.19) for Questions 13 and 15. Thus, while these last two questions were the best discriminators between the two groups, their discriminatory value is weak due to the degree of similarity/dissimilarity of response patterns given by each group to these questions.

A Pearson product moment correlation, computed between the number of different categories produced and the total number of different category patterns obtained, yielded a significant positive correlation ($r = .74$; $p < .01$). There was a negative correlation ($r = -.65$; $p < .05$) between the number of different categories produced and percent of overlapping category patterns between groups and a negative correlation ($r = -.69$; $p < .01$) between the total number of different category patterns and the percent of category pattern overlap. Again, as with responses produced by families, the trend was the same: the greater the number of categories of answers to a question, the larger the total number of different category patterns given; and the larger either of those, the less the likelihood of any overlap. Thus the number of response categories generated by both groups of families was the main factor in determining the degree of similarity or dissimilarity between

groups. Since there was only one question that generated more than five response categories, it follows that there would be a generally higher degree of similarity between the Asthma and Control groups of children.

III. CONTENT ANALYSIS OF RESPONSES TO EACH QUESTION

Family Data

Tables 4 through 55 present the content of responses produced and the types of patterns formed by this content for all eleven questions responded to by both family groups. The following analysis will proceed first by stating the question and then by discussing similarities and dissimilarities in the content of responses produced by Asthma and Control families. Family, rather than Child, interviews will be considered first.

QUESTION 1: How can you tell when (child) is becoming ill?

Table 4 indicates that nearly all of the Control families cited a mood or behavior change, usually irritability or tiredness, as the major way in which they could tell their child was ill. Only half as many Asthma families cited this criterion as an indicator of illness. For nearly all of the Asthma families, an observed physical symptom such as wheezing, coughing, or congestion was the signal to them that their child was becoming ill. Only half as many Control families as Asthma families reported physical symptoms as the way in which they recognized the onset of illness. In fact, more than half of the Control parents reported that their child would tell them that he/she was

TABLE 4
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 1

Category		Family Group	
Letter	Content of Category	Asthma	Control
a.	Observed mood or behavior change	4	8
b.	Observed physical symptom	8	4
c.	Child tells us	1	5
d.	Unaware	0	1
Total Different Responses		13	18

sick, in contrast to only one Asthma family which cited this criteria. In all cases it was the mother who was told about the sickness. In one of the Control families, the child reported that he felt sometimes even other family members couldn't recognize when he was ill.

The response category patterns produced by both types of families (see Table 5) indicate that not only did nearly all of the Asthma families say recognition of a physical symptom was the way in which they recognized the onset of illness; the majority of them (5/9) cited only this factor (category b) and no other. One-third of the Asthma families reported mood or behavior change as well as physical symptoms (category ab) as their major signals. Only one Asthma family did not cite physical symptoms, but relied on a combination of observed mood or behavior change as well as on their child's specifically telling them. All Asthma families' responses fell into one of three patterns, indicating a generally uniform way in which illness was recognized: the overriding factor in all cases was an observed physical symptom. Even for the three families who relied on an observed mood or behavior change, an observed physical symptom was always also part of the deciding symptom complex.

Control families, in contrast, were more varied in the ways in which they recognized illness in their children. Although nearly all families responded with an observed mood or behavior change, only 2 cited that as the only way in which they recognized their child was ill (category a). The most common response (which occurred one-third of the time) was that in addition to a mood or behavior change, their child also told them he or she was feeling ill (category ac). For

TABLE 5
CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 1

Family Group	Category Letter*					
	a	b	ab	ac	bc	abc
Asthma	0	5	3	1	0	0
Control	2	0	1	3	1	1

*Each letter in this table refers to content, as coded by letter, presented in Table 4 (p. 63).

these families, there was no single factor which signalled the onset of illness. More often than not, it was two or three factors, the specific combinations of which varied.

In both groups, parents took the responsibility of observing something with their children. For Asthma parents, most often a physical symptom was observed; for Control parents most often a mood or behavior change was observed. With Control families, however, the child also took more responsibility for letting his or her parents know he or she was sick. It can be seen then that Asthma families are more uniform in how they recognize illness, i.e. by observing a physical symptom. Control families focus less on physical symptoms and more on mood and behavior changes. Children in Control families also take more responsibility for informing parents when they are sick.

QUESTION 2: How does (child)'s being ill affect the family?

Sixteen responses produced by Asthma families referred to effects on the family in contrast to seven such responses by Control families (see Table 6). Not only was there a higher frequency of such responses, there was a higher proportion (16/20:7/13) of them given by the Asthma families. Clearly for this group of Asthma families, their child's being ill affected the whole family.

Seven Asthma families volunteered that their child's being ill interfered with vacations and trip planning, social occasions, or routine scheduling plans. Only 1 Control family mentioned such an effect, while 6 (or two out of three) Control families claimed their child's illness had little or no effect on family functioning. Although 4

TABLE 6
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 2

Category		Family Group	
Letter	Content of Category	Asthma	Control
a.	Little or none	4	6
b.	Changes routine/restricts planning	7	1
c.	Creates tension	4	3
d.	Focus more on child/less on siblings	2	3
e.	Financially	3	0
Total Different Responses		20	13

Asthma families claimed little or no effect, all qualified that answer by naming at least one effect it did have. Three Control families gave an unqualified "little or no effect" answer.

Asthma and Control groups were similar in acknowledging affective change due to the child's illness. Responses such as "we all get a little bit upset," "it makes me nervous," and "it makes me feel bad because I know he feels bad" were typical of responses produced by both groups.

Two Asthma and 3 Control families felt that paying less attention to other children in the family was at least an occasional hazard. None of the Control families, however, mentioned finances in response to this question although three Asthma fathers said that the asthma treatments had a noticeable impact on the family financial situation.

The patterns of responses produced by families (see Table 7) indicate that two-thirds of the Control families said that their child's being ill had either little or no effect on the family (category a) with the exception that some of them paid more attention to the sick child and less to his/her siblings. (Note patterns a, ad, and abc). This is markedly different from Asthma families, two-thirds of whom cited at least changes in routine and restrictions in planning (category b), with most of those talking of additional effects as well. (Note patterns b, ab, bc, be, abe, bcd, bde). While Asthma families were less uniform in the exact nature of their answers, there was high agreement regarding the effects on routines and plans. They spoke of a hesitancy to make plans, to visit people, or take trips because of the unpredictability of asthma symptoms. Many spoke of tailoring vacations

TABLE 7

CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 2

Family Group	Category Letter*											
	a	b	c	d	ab	ac	ad	bc	be	abc	abe	bcd
Asthma	0	1	0	0	1	2	0	1	1	0	1	1
Control	3	0	2	1	0	0	2	0	0	1	0	0

*Each letter in this table refers to content, as coded by letter, presented in Table 6 (p. 67).

around seasonal conditions or continually being alert to stimuli in the environment which could trigger attacks. Despite this, four of the Asthma families did say that they were so accustomed to those things, that it was "just a part of the routine" thereby minimizing the impact of the changes. Clearly, however, Asthma families were aware of, and acknowledged changes in, the family according to their child's condition.

QUESTION 3: Why do you think (child) becomes ill?

Both groups of families gave a wide variety of responses (ten categories) to this question, with interesting differences between Asthma and Control family responses (see Table 8). Every Asthma family cited allergens as a factor in asthma attacks and over one-half of them believed the inclination was inherited. In sharp contrast to this belief of an internal predisposition, 7 Control families cited the transmission of germs from others as the reason for illness. Three of the Control families also cited improper health care, such as lack of sleep or disregard for proper clothing in inclement weather, as a significant factor. For Control families, illness was something that happened to, or was brought on by, the specific actions of a basically healthy person.

An approximately equal minority of families in each group cited excitement or exhaustion as a precondition for illness. The notion of the letting down or wearing down of one's natural resistance was conveyed by both groups. For the Asthma group, breathing changes during excitement were seen as contributing to occasional asthma attacks.

TABLE 8
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 3

Category		Family Group	
Letter	Content of Category	Asthma	Control
a.	Allergens	9	2
b.	Germs from others	0	7
c.	Inherited	5	0
d.	Excitement/exhaustion	2	3
e.	Weather change	2	1
f.	Improper health care	0	3
g.	Unpredictable	2	0
h.	Denies psychological etiology	2	0
i.	Body chemistry/functioning	1	1
j.	Denial; joke	0	2
Total Different Responses		23	19

While emotions were mentioned as significant by two Asthma families, two other families volunteered specifically that they believed asthma attacks were not a reflection of a psychological or emotional problem within their children. When asked by the interviewer why they had mentioned this at all, one family said that it was "an old wife's tale" they had heard years ago. The other family said they had utilized the services of an allergist for a while who told them that asthma was a completely psychological problem and parents were essentially responsible for the development of conflicts leading to asthma attacks. These parents reported they felt harassed as well as increasingly alarmed as their child's symptoms worsened due to the physician's cessation of allergy medication for the child. They of course changed to another physician's care.

The category patterns presented in Table 9 indicate many individual family differences in the exact nature of responses. Beyond saying that allergies and an inherited predisposition were at the root of the asthma, no other major factors were mentioned by Asthma families. One-third of Control families mentioned germs only while the rest were diverse in their answers, although seven of these families included "germs" as at least a causative component. No Asthma or Control families responded identically, except to other families within their respective groups. (Note that 3 Control families gave a b only response, while 2 Asthma families gave ac, and 2 gave acd.)

TABLE 9
CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 3

Family Group	Category Letter*													
	b	ac	ae	ag	ah	bf	di	abj	acd	acg	adf	bfi	ae hi	bde j
Asthma	0	2	1	1	1	0	0	0	2	1	0	0	1	0
Control	3	0	0	0	0	1	1	1	0	0	1	1	0	1

*Each letter in this table refers to content, as coded by letter, presented in Table 8 (p. 71).

QUESTION 4: What do you do to help (child) when he (or she) is ill?

Nearly all of the families in both groups said they gave medicines to their children when he/she was ill, and most mentioned that they would call a doctor if the severity or persistence of symptoms warranted it. The high degree of similarity between groups ended with that response. Almost all Control families emphasized attending to the child's comfort by such things as providing special foods, "petting" or "babying" the child, giving "lots of love," "fluffing pillows," and so on. Only one-third of the Asthma families mentioned doing such things. Instead, other than giving medicine, the next most common action taken by Asthma families was to limit the child's activities as a primary way of helping their child. While Control families reported "giving" more, Asthma families reported "taking away" more.

Four of the Asthma families referred to emotional components in treating the illness, i.e. categories d and e. Two of them talked about the frustrations involved when medications and preventive measures did not work. Two others emphasized the importance of keeping calm primarily as a way of reassuring the child that everything would be alright. Both families expressed the opinion that they felt their own reactions had significant impact on their children and, therefore, they felt responsible for not exacerbating the child's symptoms. Only 1 Control parent mentioned an emotional component and caused her frustration in trying to get her children to rest when ill. One family in each group felt it was important to let the child sleep as a way of recuperation and 1 Control family felt that the child was capable of either taking care of himself or letting the family know what was needed (see Table 10).

TABLE 10
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 4

Category Letter	Content of Category	Family Group	
		Asthma	Control
a.	Give/get medical oriented help	8	7
b.	Give extra personal comfort/attention	3	8
c.	Limit his/her activities	5	0
d.	Get frustrated in attempts to help	2	1
e.	Keep calm to keep down anxiety	2	0
f.	Let sleep	1	1
g.	Let child rely on self	0	1
Total Different Responses		21	18

The category patterns presented in Table 11 show that the most frequent answer, given by one-third of the Asthma families, was giving medicines and limiting activities, i.e. categories a and c. Two-thirds of Control families gave the combination of medical plus personal attention (i.e. categories a and b) as their response to the question. While the intentions of both groups were the same, some of the actions taken were of a different nature. It should be noted, though, that when the two Asthma families talked of keeping calm to minimize the child's anxiety they were also addressing the issue of child comfort.

For Asthma families, treatment seems to be more rigid and potentially more tense whereas for Control families medical treatment is combined with a more relaxed, nurturant atmosphere. There were, however, significant variations in how Asthma families talked of their treatment efforts.

QUESTION 5: How would you describe (child)'s general health?

Eight of the Asthma families described their child as healthy or "just like any normal child." All nine Control families said their child was healthy (see Table 12). This, of course, was one of the criteria for qualification as a Control family. Only 1 of the Asthma families said their child "gets sick a lot" and they attributed it to an overall low resistance level which they saw as interrelated with the predisposition toward asthma. A number of Asthma families prefaced their answer with qualifications such as "other than this problem" or "unless he's having an attack." Clearly, having severe asthma did not mean for these families that their children were sickly. They perceived their children as basically healthy and treated them accordingly.

TABLE 11

CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 4

Family Group	Category Letter*									
	a	b	e	ab	ac	ag	bf	abf	abd	acd
Asthma	1	0	1	0	3	0	0	1	1	1
Control	0	1	0	5	0	1	1	0	1	0

*Each letter in this table refers to content, as coded by letter, presented in Table 10 (p. 75).

TABLE 12
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 5

Category		Family Group	
Letter	Content of Category	Asthma	Control
a.	Good/normal/healthy	8	9
b.	Gets sick a lot	1	0
Total Different Responses		9	9

An examination of Table 13, which shows that 8 Asthma and 9 Control families responded in category a, also suggests this interpretation.

QUESTION 6: How do you feel about being ill yourself?

This question was directed toward both parents in all families and the overwhelming response from most of them was their dislike for being ill. Their reasons and what they did about it varied somewhat, but there was also much similarity in response between groups. (See Table 14.) Two-thirds of all families had at least one member who did not like being ill primarily because it interfered with activities, disrupted routines or kept them from engaging in anticipated activities. In a similar vein, 5 Asthma and 4 Control families had members who did not like being ill, but who accepted and treated it, generally with hopes that they would quickly be over it. A number of these individuals, particularly fathers, said that they used to fight being ill, i.e. ignore it or work on through it, but that they had changed over the years and now treated illness sensibly and rapidly so as to be through with it as quickly as possible. Five Asthma and three Control fathers expressed a strong dislike for being ill and an intolerance of it in themselves. They chose to keep active and working, fighting off illness, and seeing it as a kind of battle which they were determined to win.

Mothers, more than fathers, in both groups said they did not like illness because it interfered with their activities. Asthma fathers more than mothers, and Control fathers only, said they pushed on through illness. More Asthma fathers than mothers, and a nearly

TABLE 13
CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 5

Family Group	Category Letter*	
	a	b
Asthma	8	1
Control	9	0

*Each letter in this table refers to content, as coded by letter, presented in Table 12 (p. 78).

TABLE 14
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 6

Category Letter	Content of Category	Family Group	
		Asthma	Control
a.	Don't like because it interferes with activities	6	6
b.	Dont like, but accept and treat	5	4
c.	Don't like--just keep on going	5	3
d.	Rather me than the children	1	1
e.	Feel guilty	0	1
f.	Other/vague/concrete	3	2
Total Different Responses		20	17

equal number of Control fathers and mothers, said they accepted and appropriately treated illness in themselves even though they did not like it. One of the Control mothers expressed a sense of guilt when she became ill. She took it as a sign that she had neglected to care properly for herself. One parent in each group responded in a protective, empathic manner, saying he or she would rather be sick than see his or her children sick. He or she felt a better sense of control over the illness if it was with him or her, and expressed that he or she did not like the feeling of helplessness they experienced when children were not feeling well.

Three Asthma and 2 Control families had a member whose response was judged to be vague, concrete, or idiosyncratic. Responses such as "just sick," "don't know how to answer that because we don't get sick much and it's not serious anyway," and "I complain about it" were typical of answers in that category.

The category patterns presented in Table 15 indicate that there were more identical answers between than within groups. Five families matched completely across groups in their responses. (Note categories a, b, ac, ab, bcf.) Within the Asthma group there were two sets of families which matched, and none matched within the Control group. These results are particularly interesting when one raises the question of how parental attitude toward illness may affect their children's attitudes or actual health behavior, and vice versa. The indications here are that Asthma parents and Control parents are very similar to one another in their own attitudes about being sick. The parents are similar not only as couples, but also when matched by sex across groups.

TABLE 15

CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 6

Family Group	Category Letter*									
	a	b	f	ac	ab	bc	be	abd	abf	bcd
Asthma	1	1	0	2	1	0	0	0	1	1
Control	1	1	1	1	1	1	1	1	0	0

*Each letter in this table refers to content, as coded by letter, presented in Table 14 (p. 81).

This question drew more similarities between groups (except for Question 5, which concerned parent's characterizations of their children's general health) than any other question. This question was also different in that it focused on the parents themselves rather than on the children or on the family. Parent responses indicate that while Asthma and Control groups respond differently from one another in dealing with their children (which is highly related to the nature of the differences between the children's health patterns), they are very similar when dealing with themselves.

QUESTION 7: What precautions do you think are important to take for (child) to avoid becoming ill?

As can be seen in Table 16, every Asthma family emphasized avoidance of situations and protection from allergic stimuli as precautions to avoid illness. Only 2 Control families mentioned such measures. Instead, all Control families considered observance of basic good health practices, such as balanced diet, proper attire, and sufficient rest as the main precautionary measures necessary for maintenance of good health. Only 1 Asthma family mentioned this factor. Four Asthma families also expressed that the use of medicines was considered an important precautionary measure while only 1 of the Controls mentioned this.

Clearly, Asthma families felt the need to take actions which are over and above the normal routines involved in staying healthy. Additionally, these actions are not of the type which strive to "get more of a good thing" such as jogging or other currently popular exercises.

TABLE 16
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 7

Category Letter	Content of Category	Family Group	
		Asthma	Control
a.	Avoid situations; protect from . . .	9	2
b.	Observe basic good health practices	1	9
c.	Medicine	4	1
d.	Common sense	1	2
e.	Trust child's judgement	1	1
Total Different Responses		16	15

The precautions mentioned are of the nature of warding off harmful influences which attack the basic state of health. For Control families staying healthy is not mostly a matter of doing anything special; it is routine. The 2 Control families who spoke of protecting their child were both referring to a need to avoid others who were ill and capable of spreading germs.

While a minority of families in both groups felt that the use of common sense and the child's own judgement were important, the overall thrust of the answers indicated that parents feel it is their own responsibility to ensure the health of their children.

The category patterns presented in Table 17 also reflect clear differences between the families. Seven of the nine Asthma families responded with the protection and/or medicine theme. Even those who mentioned common sense, trusting the child's judgement, or good health practices, also mentioned protection and avoidance as important. Six Control families made no mention of engaging in unusual or extra measures to ensure health. Even the three who mentioned avoidance or medicine also emphasized basic good health practices.

These response patterns indicate that parents see it as their responsibility to help keep their children healthy and that Asthma parents have to take a more active and controlling role in comparison to Control parents. The nature of the actions taken by Asthma families also tended to be of a defensive nature in order to ensure continued health.

TABLE 17
CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 7

Family Group	Category Letter*								
	a	b	ab	ac	ae	bc	bd	be	acd
Asthma	3	0	1	3	1	0	0	0	1
Control	0	3	2	0	0	1	2	1	0

*Each letter in this table refers to content, as coded by letter, presented in Table 16 (p. 85).

QUESTION 8: What do you think (child)'s attitude is about being sick?

One-third of the Asthma families said their child did not like being ill because it interfered with activities such as playing and going to school. More than two-thirds of the Control families also gave such a response (see Table 18). Two-thirds of the Asthma families emphasized the stoicism, "maturity," and acceptance their children displayed in the face of the asthma whereas not one Control family noted that their child was not bothered by being ill. Those Control parents who did not note that their child disliked being ill said that their child hated it or became upset by it. Three of the Control families remarked that while their children hated being ill, they did like the extra attention and special treatment which came along with it. There was almost a playfulness in how they spoke of the child's secondary benefits, which related to the fact that the parents had already spoken about the extra personal attention and comfort they gave to their children when ill. Only 1 Asthma family felt their child enjoyed secondary gains while disliking the illness. As may be recalled, fewer than half of the Asthma families spoke of giving special personal attention and comfort as a reaction to their child's becoming ill. Accordingly, few Asthma families saw their children as achieving secondary gains from their illnesses.

The patterns of response categories presented in Table 19 elucidate the points already made. While there was some similarity across groups, particularly in recognition of the dislike for illness because of its impact on activities (i.e., category a), the majority of responses by Control families belonged to this category. It is also

TABLE 18
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 8

Category Letter	Content of Category	Family Group	
		Asthma	Control
a.	Doesn't like because it interferes with activities	3	7
b.	Doesn't complain/accepts it well/ isn't bothered	6	0
c.	Hates the illness, but likes the secondary gain	1	3
d.	Hates it/gets upset	1	2
e.	Feels badly and angry, but acts maturely ("gets it out")	2	0
f.	Likes the attention	0	1
Total Different Responses		13	13

TABLE 19
CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 8

Family Group	Category Letter*							
	a	b	c	ac	ad	be	abd	cdf
Asthma	2	3	1	0	0	2	1	0
Control	5	0	1	1	1	0	0	1

*Each letter in this table refers to content, as coded by letter, presented in Table 18 (p. 89).

interesting to note that half of the Asthma families who said their child did not complain or accepted illness well, i.e., category b, also acknowledged negative effects, i.e., categories d and e. Hence it can be seen that the majority of Asthma families (6 of 9) acknowledged that their children did not like or were upset by being ill. Conversely, there was complete denial of negative effects in three of the Asthma families, in contrast to Controls and the rest of the Asthma group. While most families in both groups recognized negative feelings their children have about illness, there was a strong emphasis either on overcoming or mastering such feelings in the Asthma families.

QUESTION 9: How would you define illness?

This was a broad question and, as such, generated a wide range (9 categories) of responses (see Table 20). The most common response given by families of both groups was that being ill meant not being able to carry out responsibilities. Seven families in each group used inactivity as the main criterion for illness. Four Control families said they defined illness for themselves by the presence of a physical pain or problem, whereas only 1 Asthma family used this criterion. Three Asthma families said that illness was "just a part of living." In contrast, 2 Control families viewed illness as something to be fought against and not given in to. Both of these responses were given by the fathers who said they tried to work on through their illnesses.

One family in each group expressed that for them illness was necessarily something major which was stigmatizing. Accordingly, the

TABLE 20
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 9

Category		Family Group	
Letter	Content of Category	Asthma	Control
a.	Inability or lack of desire to perform responsibilities	7	7
b.	Physical symptom or focus	1	4
c.	Just a part of living	3	0
d.	Something you don't give in to	0	2
e.	Stigma; something major	1	1
f.	Vague; too general	1	1
g.	Result of personal action/inaction	0	1
h.	An annoyance	1	0
i.	Don't know/hard to say	0	1
Total Different Responses		14	17

Asthma family objected to the word "illness" being used as a synonym for asthma. They felt that asthma did not interfere substantially with the ability to perform activities and on that basis did not consider it as an illness. One Asthma family simply expressed that illness was an annoyance and 1 Control family said they just did not know how they would define illness. One Control family did say they felt illness was the result of not staying busy enough, which then allowed a person either to focus upon or develop physical symptoms.

While there are similarities across groups, the category patterns also indicate variations (see Table 21). Three Asthma families in comparison to just 1 Control family used inability to carry out activities as their sole criterion. Although four Control families talked of physical symptoms, they all did so in conjunction with other categories of answers. The 1 Asthma family who focused on physical symptoms gave that as its sole criteria. In general, while both groups emphasized the performance criteria, they differed in whether they accepted it as part of living or saw it as something physical to be fought against.

QUESTION 10: How do you treat (child) differently when he (or she) is well rather than ill?

There was a tape error during one of the Control family interviews while they were responding to this question. While part of their answer was recorded on tape (and categorized as "expect more from child"), an unknown quantity was lost. Given the nature of their recorded response, it is unlikely that what was lost would have had

TABLE 21

CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 9

Family Group	Category Letter*										
	a	b	h	ab	ac	ad	ae	af	bg	bi	acf
Asthma	3	1	1	0	2	0	1	0	0	0	1
Control	1	0	0	2	0	2	1	1	1	1	0

*Each letter in this table refers to content, as coded by letter, presented in Table 20 (p. 92).

any significant impact on the general balance of the total responses produced by this question.

An interesting note is that almost every family at first heard this question as "How do you treat (child) differently when he is sick rather than well?" This most likely was due to the emphasis of the other questions on sickness than on wellness.

Of the four categories of responses, the Asthma and Control groups had identical representation for two of them (see Table 22). A little more than half of both said that when their child was well they attended less to his/her symptoms via medicines or comfort. Two families in each group remarked that there were fewer restrictions placed on their children when they were well. Although families were similar in their frequency of this response, it seems significant that only 2 Asthma families noted the decrease in restrictions since 5 Asthma families previously had spoken of activity restriction as a means of helping their children when ill.

Five Asthma families claimed that there was little or no difference in their treatment of their child, regardless of illness or health. Only 2 Control families claimed such. Also, none of the Asthma families said they expected more from their child, while 3 Control families mentioned this. The impression given by responses of the Asthma families is that they do not expect any less from their children when they are ill. As may be recalled, only a minority of Asthma families spoke of giving personal comfort and attention to their children when ill, in contrast to 8 out of 9 Control families who had spoken of this as the usual family strategy.

TABLE 22
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 10

Category		Family Group	
Letter	Content of Category	Asthma	Control
a.	Focus less on child with meds and attention	5	5
b.	Little or no difference	5	2
c.	Fewer restrictions	2	2
d.	Expect more from child	0	3
(e)	Other (tape error)	-	(1)
Total Different Responses		12	(13) 12

The patterns produced in response to Question 10 (see Table 23) indicate a relatively high degree overlap between groups in the way they responded to the question. What stands out most, however, is that 4 Asthma families gave only the response of "little or no difference." This represents complete denial with no qualifications of the type given by the 2 Control families, and further substantiates the impression that with the Asthma families the emphasis seemed to be on mastery of difficulties rather than on providing extra comfort as was the case for Control families.

QUESTION 11: How would things be different if (child) never got sick?

In contrast to the previous question which focused on the child, this one was more open-ended and elicited a wider variety of responses. The majority of Asthma families addressed family-focused differences, in contrast to child-focused ones. Most Control families were hard pressed to come up with responses. Control families prefaced their responses with something like, "Well, he (or she) gets sick so seldom that it's really hard to say," or "Well, we really haven't had much cause to think about it." What they almost unanimously indicated was that illness was such a negligible part of their lives that they just did not think about it. Four of 7 Control families who responded in the "nothing/hard to say" category (see Table 24), did so without qualification. Of the other three, one made a joke about getting more done around the house (an allusion to their treating their child specially when ill?), one said they wouldn't have to pay for occasional medical bills, and one said it would probably create a problem for them. For

TABLE 23
CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 10

Family Group	Category Letter*						
	a	b	c	d	ab	ac	ad
Asthma	2	4	0	0	1	2	0
Control	1	0	1	2	2	1	1

*Each letter in this table refers to content, as coded by letter, presented in Table 22 (p. 96).

TABLE 24
NUMBER OF FAMILIES RESPONDING PER RESPONSE CATEGORY
TO QUESTION 11

Category Letter	Content of Category	Family Group	
		Asthma	Control
a.	Nothing/hard to say	1	7
b.	Financially better off	4	2
c.	Family would be less cautious; more spontaneous	5	0
d.	Fewer limitations on child	4	1
e.	It would be a relief (emotional)	2	0
f.	Child wouldn't get sick or need medicines	2	0
g.	Child would get less special attention	1	0
h.	It would create a problem	0	1
i.	Other	1	1
Total Different Responses		20	12

that family, occasional illness was seen as a legitimate way to slow down an otherwise hectic life-style ('We'd run ourselves to death; that's the only time we stop to rest').

Asthma families gave a wider variety of responses generally referring to family effects or child effects. Five of the families spoke of how they could travel more, be less concerned with allergic stimuli, and do things more spontaneously. None of the Controls presented this as a problem area. Four of those 5 Asthma families referred to improved finances or emotional relief on themselves as additional changes if the child were never ill. Four Asthma families said there would be fewer restrictions on the child if the child were never sick. On the previous question, which directly inquired about their treatment of their children when ill and well, only 2 families noted restrictions as a factor. Restrictions are apparently felt to be an overall family issue rather than strictly a child-oriented one.

The category patterns presented in Table 25 show that five Asthma families cited between two and five changes which would occur if their child were never ill. When disregarding the disclaimer about no changes coming about, it is clear that Control families could think of at most only one change which would come about if their child were never ill. This comparison is an indication of the impact of asthma on Asthma families in contrast to the effect of other illnesses on Control families. While Asthma families cite a number of changes, the most frequent being in the areas of finances, spontaneity, and limitations, the patterns indicate many individual differences across families. This result would seem to highlight the fact that while asthma has impact on all the families, the number and degree of issues varies for each.

TABLE 25

CATEGORY PATTERNS GIVEN BY FAMILIES TO QUESTION 11

Family Group	Category Letter*										
	a	b	c	d	g	ab	ah	ai	bc	ce	bde
Asthma	0	0	2	1	1	0	0	0	1	1	1
Control	4	1	0	1	0	1	1	1	0	0	0

*Each letter in this table refers to content, as coded by letter, presented in Table 24 (p. 99).

Child Data

To determine the presence of age-related differences in responses, Asthma and Control children were divided into two groups. Responses given by 6-8 year olds were compared with those given by 9-12 year olds. No significant differences were obtained except on Question 15 for the Asthma group and Question 7 for the Control group. Those exceptions will be taken into account in the sections addressing those questions.

QUESTION 1: When do you say you're sick?

The first question, serving as an opener for the formal questionnaire, elicited generally brief responses, if any (see Table 26). Fully one-third of all the children either did not answer, or were vague ("Sometimes I am and sometimes I'm not"), or were concrete ("When I get sick"). All of those who answered gave responses indicating physical symptoms as the major signal for awareness of illness.

Table 27 also displays that 4 Asthma and 2 Control children were unable to respond clearly to the question. Evidently, it presented at least some difficulty to children in both groups, but the degree of difference between groups is such that no interpretations ought to be made.

QUESTION 2: Tell me as much as you can about what it's like to be sick.

Again, there were no large differences between groups, and a moderate degree of similarity in how they answered this question (see Table 28). The most common description of being ill focused on physical aspects. More children in each group spoke only of physical

TABLE 26
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 1

Category Letter	Content of Category	Child Group	
		Asthma	Control
a.	Physical Symptom	5	7
b.	No response/vague/concrete	4	2
Total Different Responses		9	9

TABLE 27
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 1

Child Group	Category Letter*	
	a	b
Asthma	5	4
Control	7	2

*Each letter in this table refers to content, as coded by letter, presented in Table 26 (p. 103).

TABLE 28
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 2

Category		Child Group	
Letter	Content of Category	Asthma	Control
a.	Physical emphasis	5	7
b.	Negative affect	2	2
c.	Social isolation/restriction	2	3
d.	No response/vague	2	0
e.	Denial	0	1
Total Different Responses		11	13

symptoms than spoke of any other single event or combination of events. In addition to this physical emphasis, a smaller number of children in each group talked of having to stay in bed or of not getting to play with friends or to go outside when ill. Two children in each group also talked of feelings associated with their illnesses; frustration and worry were mentioned by Asthma children while anger and worry were mentioned by Control children. Two Asthma children remained vague or did not answer this question as well as the first one. One of the Control children said he was no different when sick than when healthy so there was nothing to tell about it.

Clearly, more than any other factor the physical emphasis was primary for both groups. Again, there was less mention of it by children in the Asthma group. All one can state with certainty is that Asthma children did not talk as often about their physical symptoms as did Control children. For approximately one-half of the children in each group, the negative feelings or social restrictions were also primary (see Table 29). Overall, there were no outstanding differences in category patterns between the groups.

QUESTION 3: How do the others in your family know when you are sick?

Table 30 shows that, again, 2 Asthma children were vague or gave no response. It should be noted that it was not always the same children who gave these responses. One can state that in comparison to the Control group, some Asthma children were more frequently vague in their answers to questions. Or, put another way, one receives more vague answers from some Asthma children than from all Control children.

TABLE 29
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 2

Child Group	Category Letter*							
	a	b	c	d	e	ab	ac	bc
Asthma	3	1	1	2	0	1	1	0
Control	4	0	0	0	1	1	2	1

*Each letter in this table refers to content, as coded by letter, presented in Table 28 (p. 105).

TABLE 30
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 3

Category Letter	Content of Category	Child Group	
		Asthma	Control
a.	Behaviors or symptoms	6	7
b.	I tell them	2	6
c.	No response/vague	2	0
Total Different Responses		10	13

Codable responses to this question indicated that family members recognized the child's sickness in one of two ways: either they could tell by the child's symptoms or behaviors or the child verbally brought it to the family's attention. Two-thirds of the Asthma children said their parents could tell through observation. Slightly more than two-thirds of the Control children believed the same. A major difference was that only 2 Asthma children said they themselves told their parents they were ill, whereas two-thirds of the Controls did so. In other words, Control children sometimes take more direct responsibility for notifying their parents. This suggests that parents of Control children may not be aware of illnesses until they are told by their children. It furthermore suggests that at times, Control children's symptoms were too ambiguous to interpret as illness. In any case, Asthma children feel, or at least report experiencing, less responsibility or need to tell their parents they are ill. For the most part their parents can tell and assume the responsibility for noticing their child's symptoms or behaviors. This corresponds with the impressions given by the parents themselves in their interviews, both in the amount of talking they did and in what they said.

The category patterns (see Table 31) indicate only 1 Asthma and 2 Control children took sole responsibility for alerting the family about his or her illness. For 5 Asthma children, the parents took the responsibility, and 3 Control children's parents did so. The biggest contrast was in the shared responsibility (ab) response. Only one Asthma child responded in this manner whereas four Control children reported this more flexible condition. This indicates that Control

TABLE 31
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 3

Child Group	Category Letter*			
	a	b	c	ab
Asthma	5	1	2	1
Control	3	2	0	4

*Each letter in this table refers to content, as coded by letter, presented in Table 30 (p. 108).

children and parents share responsibility for recognition of illness whereas Asthma parents assume most of the responsibility.

QUESTION 4: When you're sick, what do the other people in your family do?

Again, there were two major categories into which nearly all responses fell (see Table 32). There was a large difference between how Asthma and Control children responded. Every Asthma child referred to the use of medicines and/or to calling a physician as the family's method of helping when the child was ill. Slightly under one-half of the Control children gave such a response. Six Control children referred to extra care and attention they received when ill. Responses such as "they keep me in bed," "they let me lie on the couch" and "they help me get around" are representative of these answers. Four Asthma children gave such responses. Their emphasis on medicine over personal care reflects accurately parental perceptions of how they handle the asthma condition. The one Control child who previously had denied that being ill was really any different from being healthy said that his family did little different when he was ill.

The category patterns (see Table 33) further elucidate the nature of the responses. Of the 9 Asthma children who referred to the use of medically oriented treatment, 5 mentioned only this as the family response to illness. For 4 Asthma children, the use of more personal supportive efforts was mentioned in conjunction with the response of giving medicine. Four Control children referred only to their families' efforts to help care for or attend to them, while an

TABLE 32
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 4

Category		Child Group	
Letter	Content of Category	Asthma	Control
a.	Utilize medicine/physician	9	4
b.	Help care for/attend to	4	6
c.	Nothing different	0	1
Total Different Responses		13	11

TABLE 33
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 4

Child Group	Category Letter*			
	a	b	c	ab
Asthma	5	0	0	4
Control	2	4	1	2

*Each letter in this table refers to content, as coded by letter, presented in Table 32 (p. 112).

additional 2 children referred to that in conjunction with giving medicine. Only two Control children gave solely the medicine/physician response in contrast to 5 for the Asthma group. Clearly, for the Asthma group the use of medicine is seen as primary, with personal comfort being secondary in importance. None of the Asthma children referred to supportive personal attention as the only family response to his/her illness. For most Control children, medicine was not mentioned and general help and attention were given as the main responses to child illness.

QUESTION 5: When you're sick, how does it change what you usually do?

Although there was a wider range of responses by children in the Asthma group (see Table 34), the majority of children in both groups said that being sick led to a reduced or restricted activity level. Having to stay in bed or not being able to play were the most common responses. For Control children, restricted activity was the only clear response given, with 7 children giving it. Two children in the Control group were unable to respond to the question clearly. While 7 Asthma children also mentioned restricted activity, 4 also gave a different or an additional response ranging from "can't breathe" to "have to drink a lot of juice and take medicine" to "doesn't change much." Only one Asthma child was unable to answer the question.

The category patterns in Table 35 display the ways in which the children answered. Asthma children noted changes in addition to restricted activity levels, whereas Control children did not. This indicates that for some Asthma children being ill means more than just

TABLE 34
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 5

Category Letter	Content of Category	Child Group	
		Asthma	Control
a.	Restricts activity	7	7
b.	Must take in substances	2	0
c.	Physical symptom focus	1	0
d.	Denial	1	0
e.	No response/vague	1	2
Total Different Responses		12	9

TABLE 35
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 5

Child Group	Category Letter*					
	a	b	e	ab	ac	ad
Asthma	4	1	1	1	1	1
Control	7	0	2	0	0	0

*Each letter in this table refers to content, as coded by letter, presented in Table 34 (p. 115).

social restrictions. For them, being ill involves additional bodily concerns.

QUESTION 6: How do you feel inside when you're sick?

This question did not elicit the types of feeling responses expected. Almost all given responses referred to physical feelings rather than "emotional" feelings (see Table 36). It is common for children to have difficulty identifying and verbally expressing emotions when conflictual issues are at hand.

Of the 3 responses which addressed emotions, 2 were given by Asthma children. One said that the sound of her wheezing "kinda drives me crazy . . . makes me feel bad." The other said that when he was wheezing it was "like a little man (in my chest) yelling that I can't breathe." The 1 Control child said he felt "mentally tense and frustrated" and "at fault." Other than the vague responses by 2 Asthma children, all remaining responses referred to physical feelings such as feeling tired or in some kind of pain. All 9 Control children gave such responses while 7 Asthma children did so.

The category patterns displayed in Table 37 indicate that when affective states were mentioned they were always in conjunction with a physical symptom focus. This further indicates the emphasis on physical feelings evoked by this question.

QUESTION 7: What do you do when you are sick?

Table 38 shows that more than twice as many Control as Asthma children gave a rest/relax response, yielding a higher proportion

TABLE 36
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 6

Category		Child Group	
		Asthma	Control
Letter	Content of Category		
a.	Physical symptom focus; don't feel good	7	9
b.	Unpleasant affective state	2	1
c.	No response/vague	2	0
Total Different Responses		11	10

TABLE 37
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 6

Child Group	Category Letter*		
	a	c	ab
Asthma	5	2	2
Control	8	0	1

*Each letter in this table refers to content, as coded by letter, presented in Table 36 (p. 118).

TABLE 38
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 7

Category Letter		Child Group	
		Asthma	Control
a.	Rest/relax	3	7
b.	Medicine related	5	5
c.	Seek/get help from others	4	3
d.	Help self	1	1
Total Different Responses		13	16

(7/16) of their answers in that category in comparison to the Asthma group's (3/13). For children in the Control group, there was a greater emphasis on sleeping, reading, or watching television. Although both groups gave a similar number of responses in other categories, a higher proportion of Asthma responses fell into them. The emphasis was on use of medicines and the reliance on their parents for help. Both groups reported use of those measures, although the Control group relied more heavily on rest and relaxation. The older (9-12 year olds) Control children gave this response more than the younger (6-8 year olds) children who relied more on medicines. One child in each group reported helping himself ("get my mind on trying to breathe" and "just take care of myself").

An analysis of category patterns (see Table 39) further emphasizes these differences. Two children in each group referred only to rest or relaxation. Five more of the Controls spoke of rest and relaxation as well as either using medicines or getting help from others. Only 1 other Asthma child gave such a response. Instead, 5 Asthma children mentioned medicine and/or help from others, with no reference to relaxing. Only 1 Control child answered that way.

Asthma children relied more heavily on something/someone external for help. There was more of an expressed dependence upon something other than oneself as well as one's having less internal, personal control. For Control children the implication was that by taking it easy and letting things run their course, with some external help, all would turn out well.

TABLE 39
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 7

Child Group	Category Letter*							
	a	b	c	ab	ac	bc	bd	abc
Asthma	2	2	2	0	0	1	1	1
Control	2	0	0	3	2	1	1	0

*Each letter in this table refers to content, as coded by letter, presented in Table 38 (p. 120).

QUESTION 8: What do you think about when you are sick?

Responses to this question (see Table 40) indicated that nearly half of the children in each group said they thought about play or school activities they were missing while ill. Four Asthma children gave broad, general responses to the question. Typical of such responses was "about getting better" without being able to elaborate further. Two Control children gave such responses. The largest difference between groups was in their report of dismaying or worrisome thoughts. Only 1 Asthma child reported thinking "about how quickly it happened; how a minute ago I was fine." In contrast, 4 Control children reported such thoughts as "worry about if my brothers and sisters are going to get sick, too," "sometimes I stop my thoughts because I get angry about being sick" or "think about I hope I don't get worse." Only 1 Asthma and 2 Control children reported thinking about getting to a source of help, and only 1 each thought of physical symptoms.

The category patterns (Table 41) show more uniformity in responses among children in the Asthma group than among children in the Control group. Seven of nine wished either to be well or to be active whereas only 3 Control children gave these responses. For the Asthma group, it seems that they mainly thought about getting the illness over with so they might become socially active again. Although other indications have been that Asthma children rely heavily on others for help and that their symptoms can be quite severe, their responses to Question 8 indicate that their thoughts do not center on those issues. There was more variation within the Control group, with less of an emphasis on "getting it over and done with."

TABLE 40
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 8

Category		Child Group	
Letter	Content of Category	Asthma	Control
a.	Social/active	4	4
b.	No response/general/broad	4	2
c.	Unpleasant/worry/dismay	1	4
d.	Getting help	1	2
e.	Physical concern	1	1
Total Different Responses		11	13

TABLE 41
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 8

Child Group	Category Letter*								
	a	b	d	e	ab	ac	bc	cd	ce
Asthma	3	3	1	0	1	0	0	0	1
Control	2	1	1	1	0	2	1	1	0

*Each letter in this table refers to content, as coded by letter, presented in Table 40 (p. 124).

QUESTION 9: What's your reaction when you realize you are getting sick?

The word "reaction" was used in this question because it was judged to be neutral and therefore left open the types of responses possible. The most popular response dealt with physical symptoms or reactions (see Table 42). Four Asthma and 3 Control children described the onset of symptoms as their reaction. Two Asthma and 4 Control children said they rested or slowed down when they realized they were becoming ill. Frequency of response across the two groups was quite similar for all categories. Two Asthma and 1 Control children sought out others for help. One or 2 children in each group were vague in their responses. One Control child said he got angry when he realized he was getting sick because to him it was a sign of failure not to stay healthy.

The category patterns displayed in Table 43 also show similarities between the groups in responses made by individuals. The largest difference between them was that nearly one-half (4) Asthma children gave only the physical symptom response in comparison to only 1 Control child doing this. Thus, for this group of Asthma children, the word "reaction" led to thoughts of physical symptoms more singularly than for Control children. Otherwise, the types of reactions reported by children in both groups were similar, while varying across individuals. In fact, Control children were more similar to Asthma children than to each other.

TABLE 42
 NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
 TO QUESTION 9

Category Letter	Content of Category	Child Group	
		Asthma	Control
a.	Physical symptom/reaction	4	3
b.	Rest/slow down	2	4
c.	Rely on others for help	2	1
d.	No response/vague	1	2
e.	Negative affect	0	1
Total Different Responses		9	11

TABLE 43
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 9

Child Group	Category Letter*					ab
	a	b	c	d	e	
Asthma	4	2	2	1	0	0
Control	1	2	1	2	1	2

*Each letter in this table refers to content, as coded by letter, presented in Table 42 (p. 127).

QUESTION 10: How do you feel about other people who get sick?

The two groups differed in the frequency of their expressions of empathy for others who were ill (see Table 44). Every Control child said he or she felt sorry for ill others. One of the six year olds said that although he felt sorry for them, sometimes, he didn't "when they hit me and I hit back." The Asthma group was not as uniformly empathic. The majority of them gave an empathic response ("want to help them" or "feel bad for them because it's not fun to be sick"), and one even said "other people look at sick people and think they're going to die" indicating a sense of anxious empathy. There was, however, a higher frequency (3) of no responses to this question than to any other.

The category patterns (Table 45) indicate that there were no overlaps in categories. Since responses occurred only in separate categories, this further substantiates the information yielded by Table 44.

QUESTION 11: How do you think the others in your family feel about you when you are sick?

Responses to this question correspond closely to those produced in response to the previous one. Eight of the nine Control children said their parents tried to help them or felt badly for them because they loved them (see Table 46). One even added his parents did so due to worry that he might go to the hospital. Only 4 Asthma children responded with "they try to help me" or "I guess they hope I get better."

TABLE 44
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 10

Category Letter	Content of Category	Child Group	
		Asthma	Control
a.	Empathic/caring	5	8
b.	No response	3	0
c.	Mixed	0	1
d.	Fearful of loss	1	0
Total Different Responses		9	9

TABLE 45
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 10

Child Group	Category Letter*			
	a	b	c	d
Asthma	5	3	0	1
Control	8	0	1	0

*Each letter in this table refers to content, as coded by letter, presented in Table 44 (p. 130).

TABLE 46
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 11

Category		Child Group	
Letter	Content of Category	Asthma	Control
a.	Empathic/concerned	4	8
b.	No response/irrelevant	4	0
c.	Worried/scared	1	1
d.	Don't know	0	1
Total Different Responses		9	10

One child went further saying "they feel like something might happen to me and I might have to go to the hospital and they get scared." The remaining 4 Asthma children gave either no response or an apparently irrelevant one such as "have an earache or face gets red." (Mindful that this response was given by a distractible six year old, one could wonder about a disguised communication regarding parent's frustration or impatience.)

The category patterns (Table 47) fall nearly identical to the category content frequencies, showing that most Control children are aware of empathy from their families, while about one-half of the Asthma children are. One Control child felt puzzled by the question, saying that he was so seldom ill that he really had no idea how his parents felt about his being ill.

QUESTION 12: What's nice about being sick?

Two-thirds of the Asthma children could think of nothing at all that was nice about being sick (see Table 48). The other one-third said getting to watch T.V., getting presents, and receiving special attention were nice things about being sick. Fewer (4) Control children said nothing was nice about being ill and more (5) said it was nice to receive help or special privileges. Additionally, 4 Control children said that getting out of going to school was a benefit of sickness. Not one Asthma child felt that way.

On the whole, Control children saw more positive consequences associated with illnesses than did Asthma children. In terms of potential secondary gain from illness, Control children would apparently be more susceptible than would Asthma children.

TABLE 47
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 11

Child Group	Category Letter*				
	a	b	c	d	ac
Asthma	4	4	1	0	0
Control	7	0	0	1	1

*Each letter in this table refers to content, as coded by letter, presented in Table 46 (p. 132).

TABLE 48
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 12

Category		Child Group	
Letter	Content of Category	Asthma	Control
a.	Nothing	6	4
b.	Get help/treated nice, special	3	5
c.	No school	0	4
Total Different Responses		9	13

The category patterns presented in Table 49 indicated a good deal of uniformity in the way in which children in the Asthma group responded. They either found nothing nice about being ill or liked the special attention. Because 4 Control children answered this with "no school," the response range for them was extended and responses, accordingly, varied more. Of particular interest is that only 2 Control children said that illness had absolutely nothing nice about. This stands in contrast to 6 Asthma children claiming such. Again, secondary gain would not seem as likely a factor with the Asthma children as it might be for children in the Control group.

QUESTION 13: What's not nice about being sick?

Response frequencies were similar across groups in most categories (see Table 50). Two-thirds of the children in each group said they did not like being confined or missing out on activities. This was the most frequently mentioned dislike. The next most disliked thing about being ill was the physical aspect such as difficulty breathing, having stomachaches or headaches, etc. This was mentioned by 4 Control children and 2 Asthma children. What was disliked by Asthma children more often was the medicine or the need to go to a physician or hospital for injections. Five Asthma children said this, whereas the medicine issue was not brought up by Control children at all. It was this factor which constituted the major difference between the groups on this question. Two Asthma children and 1 Control child mentioned the worry or irritability as an unpleasantness about illness. One Control child gave a response which may have fit into the affective response category, but was too vague to code.

TABLE 49
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 12

Child Group	Category Letter*					
	a	b	c	ab	ac	bc
Asthma	6	3	0	0	0	0
Control	2	2	1	1	1	2

*Each letter in this table refers to content, as coded by letter, presented in Table 48 (p. 135).

TABLE 50
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 13

Category Letter	Content of Category	Child Group	
		Asthma	Control
a.	Confinement/interferes with activities	6	6
b.	Physical aspects	2	4
c.	Treatment/medicine	5	0
d.	Negative affective response or atmosphere	2	1
e.	If you don't get help (medicine)	0	1
Total Different Responses		15	12

What was primary for the majority of both groups was the dislike of confinement. Almost as significant for Asthma children was the dislike of medical treatments. Thus, while they had already indicated a strong reliance upon medicines and physicians there was also an aversion to them. This ambivalence about treatment is something Asthma children have to cope with much more than Control children do.

The category patterns (Table 51) show that one-third of the children in each group mentioned only the dislike of confinement. Control children emphasized dislike of physical symptoms more than did Asthma children, whereas Asthma children disliked the medical measures required to treat the physical symptoms. Other than those general trends, responses were comprised of individual variations.

QUESTION 14: How are you different when you are well rather than sick?

This was a difficult question to answer for some of the younger children in each group (see Table 52). Three Asthma and 2 Control children gave irrelevant answers or said they didn't understand the question. Responses which were relevant fell into two general categories: 6 Asthma and 7 Control children said they could play, help with chores, and enjoy other people more when they were well, with heaviest emphasis on being able to play. The other major category contained responses which dealt with feeling less tense, breathing easier, looking less pale, and generally just feeling better. These types of responses were given by 5 Asthma children in comparison to only 1 Control child. Asthma children focused more on their bodies than did the Control children. In response to this question, when

TABLE 51
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 13

Child Group	Category Letter*									
	a	b	c	e	ab	ac	ad	bd	abc	acd
Asthma	3	0	2	0	0	1	0	1	1	1
Control	3	2	0	1	2	0	1	0	0	0

*Each letter in this table refers to content, as coded by letter, presented in Table 50 (p. 138).

TABLE 52
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 14

Category Letter	Content of Category	Child Group	
		Asthma	Control
a.	Can be active and social	6	7
b.	Look and feel better	5	1
c.	Other/irrelevant	3	2
Total Different Responses		14	10

Asthma children drew a distinction between health and illness, it was not only in terms of social aspects but in terms of physical aspects as well.

The category patterns presented in Table 53 also bear out this impression. Of 7 Control children who mentioned being social and active, 6 mentioned only this category. Of 6 Asthma children who mentioned this category, only 1 mentioned just that alone. Five of these children combined it with the looking and feeling better response, i.e., category b.

QUESTION 15: How would things be different if you were never sick?

There were some clear differences in how each of the groups responded to this question. In general, the responses presented in Table 54 indicate that the question was more relevant for children in the Asthma group than in the Control group. Just over one-half of the Asthma children said they would be able to do more things, primarily to "play more" or they would have fewer restrictions such as "more things in my room." Only one Control child mentioned being able to play more if he were never sick. Alternately, 5 Control children responded in what was considered to be a vague or philosophical manner. They made statements such as, "it would feel funny because you do get sick sometimes" or "there must be a reason for sickness, some purpose to it" or "that question is weird." None of the Asthma children gave a response such as this. Two of them were unable to respond to the question, as were 2 of the Control children. Three Asthma children mentioned that they wouldn't have to go to the doctor, get I.V.'s, or

TABLE 53
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 14

Child Group	Category Letter*		
	a	c	ab
Asthma	1	3	5
Control	6	2	1

*Each letter in this table refers to content, as coded by letter, presented in Table 52 (p. 141).

TABLE 54
NUMBER OF CHILDREN RESPONDING PER RESPONSE CATEGORY
TO QUESTION 15

Category		Child Group	
Letter	Content of Category	Asthma	Control
a.	Be more active; fewer restrictions	5	1
b.	Vague/philosophical	0	5
c.	Don't know/no response	2	2
d.	Wouldn't have to do unpleasant things	3	1
e.	Physical symptom focus	1	1
f.	Enjoy more, worry less	1	0
g.	Would be deprived of attention	0	1
Total Different Responses		12	11

take medicines if they were never sick. One Control child said she 'wouldn't have to clean pans when I throw up' if she were never sick. One child in each group said he or she wouldn't have a physical symptom and 1 Asthma child talked of how she and the family could enjoy trips more and worry less if she were never ill. Only 1 child mentioned the loss of secondary gain, and that was a Control child.

The main difference between the groups was that Asthma children gave more specific responses to this question. For them, not being ill means being able to do more enjoyable things and not having to do some unpleasant things. For Control children, illness had little or no pervasive impact on their lives and their responses reflected this. They were more distant; they mused upon and were amused by the question.

The category patterns presented in Table 55 also lead to this conclusion. Seven of the Control children were philosophical, vague, or didn't respond. Another spoke only of the loss of secondary gain. Only 1 Control child talked about things "being better" if she were never sick. On the other hand, 7 Asthma children talked of one of more benefits they would have from being in perfect health. The older children (9-12 year olds) spoke of being able to do more while the younger ones (6-8 year olds) either gave no response or said they wouldn't have to do unpleasant things. Possibly, the older ones, having lived with the problem longer, felt more of an impediment upon their social activities due to their asthma.

TABLE 55
CATEGORY PATTERNS GIVEN BY CHILDREN TO QUESTION 15

Child Group	Category Letter*								
	a	b	c	d	g	ad	af	de	ade
Asthma	3	0	2	1	0	1	1	1	0
Control	0	5	2	0	1	0	0	0	1

*Each letter in this table refers to content, as coded by letter, presented in Table 54 (p. 144).

IV. THEMATIC ANALYSIS OF CONCERNS EXPRESSED BY ASTHMA FAMILIES

As noted previously, the interviews with Asthma families were longer than those with Control families primarily because of the ease with which these families volunteered information regarding feelings and concerns. Table 56 represents a synthesis of themes and issues expounded upon by the Asthma families. Appendix F presents a brief synopsis of themes by family.

The most common theme expressed by Asthma families was the strong sense of responsibility for helping the child. While this conclusion has already emerged from an analysis of the frequency and percentage of parental responses, 5 families spoke directly of this issue at length. Specifically, they spoke of the "second nature" quality to the precautions and plans in which they engaged. Assessment of seasonal and weather conditions, household dust, air conditions, and judgement of their own resourcefulness in successfully negotiating such things were quite prominent topics. They also talked of their need to watch or be tuned into their child, how to recognize and gauge signals which might indicate the onset of an attack. At the same time, there was an awareness that they did not want to stimulate the development of an attack by becoming anxious or "smothering" the child. They spoke as if they knew their children and their symptoms inside and out. Some felt that occasionally they were too restrictive; most felt they were not. They expressed they had learned much from the physicians, particularly regarding medicines and routine measures such as putting plastic over pillows, no rugs in the bedroom, vacuuming and dusting every day.

TABLE 56
THEMES EXPRESSED BY ASTHMA FAMILIES

Themes	Frequency
Strong sense of responsibility for helping the child	5
Worry over medicines and effects	4
Anxiety--coping--hope	4
Try to figure out causes	3
Denial of any difficulty	2
Surprised how many others have similar difficulties	2

As time passed and as the symptoms came and went and returned again, parents began to discriminate more accurately what worked for their child and what did not. They began to feel like experts, at least where their child was concerned. At the same time, they regarded the physician and hospital as their ultimate backup for support. One example of this was the family which used a humidifier on their physician's advice to help abate flare-ups in their child's symptoms. It began to seem to them that the symptoms worsened--but the doctor said it would help. The parents decided to disregard that advice based on their own judgement of the in vivo situation. Some time later, the physician told them he had subsequently learned that sometimes spores developed within the humidifier system to which some asthmatic children reacted with an exacerbation of symptoms.

These parents continually exercised such judgement. Some did so to the degree that they would often try to figure out the causes of an attack immediately following it. They would think of what they let the child do yesterday or today, what he or she came into contact with (dust, grass, animals, etc.), was he or she too excited or exhausted. They would try to figure out what possibly could have triggered the attack so they could add it to their storehouse of information concerning the constellations of factors present when other attacks had occurred. The timing of attacks was so variable, so unpredictable, that continual reassessment seemed necessary.

Underlying these concerns appeared to be the belief that they could, with enough work and time, "cover all the bases" and keep their child virtually symptom-free. Despite the fact that all children

continued to experience attacks, none of the parents interviewed expressed feelings of guilt or failure. Four of them did say they felt that way for the first year or two, when the child was younger and when firm diagnoses had not been made by their physicians. Some spoke of anxiety, lying awake at night listening for symptoms, and fear for their child's life. They agreed that their distress lessened when finally referred to allergists who either were familiar with such symptoms or who seemed capable and secure in their knowledge of what was happening.

This partnership between parent and allergist seemed to form a basis for parents to begin to feel competent and more relaxed. This permitted them to engage in coping efforts with the kind of resilience they demonstrated. Because their child was always growing, and medicines and dosages were being changed so often, there was always the element of change which meant that parents never really knew exactly what worked and what did not. One parent expressed that 'we're doing so much and he's been on so much medicine that who knows what is or is not helping.' Successfully coping meant being able to adhere to medicine schedules and restrictions, but then to be flexible enough to vary or attempt to discontinue those which might no longer be helpful. Those parents also spoke of the hope that with age and consequent physical and physiological changes their child would become symptom-free. There was guarded optimism; both aspects of which were apparent and acknowledged by these parents.

Two families emphasized that the asthma was no problem at all for them. One said they never talked about it; they went on the

assumption that all of them were handling it well. That was also the only family interviewed in which the child (a 9 year old boy) sobbed, and the mother expressed sharp dislike for the interviewer's use of the word "illness." It was also the only interview during which active restorative and soothing measures were taken by the interviewer. The other family expressing that asthma was no problem was one in which the father as a child had moved to Arizona and eventually back to Tennessee because of his asthma condition. In comparison to the disruptions this father's symptoms had had on his family, his son's condition and treatment were expressed as minimally problematic.

Two families recalled experiencing surprise and relief when they first learned so many other parents had similar difficulties. Physicians' waiting rooms and hospitals were places where such unexpected contacts happened. Parents reported that they felt supported and understood, in contrast to the usual feeling that people (especially relatives) did not really understand the necessities for alertness and caution.

The primary worry that nearly one-half of the parents expressed concerned the long term effects of the medicines used, particularly those containing steroids. They were keenly aware of the possibility that their children's growth could be affected negatively and that unknown side effects could develop. The use of these medicines was something they did with trepidation, but with confidence that such medicines were needed because all other efforts had fallen short. Once again, judgement, responsibility, and hope were key factors for these families.

CHAPTER IV

DISCUSSION

I. THE WORLD OF THE ASTHMA FAMILY

Family Results

The overall picture of the Asthma families which emerges is one in which there are clear similarities along with individual variations. Asthma families were more similar to each other in some responses and more dissimilar in other responses when compared to Control families. This, in part, may be due to their having had more to say than the Control families. There was no "typical" Asthma family, although there were enough similarities among them to encourage a generalized description.

The frequency and percentage of speech acts by family members, which indicated that Asthma parents committed over 90% compared to Control parents' rates of 70% of speech acts, suggest that there may be a more rigid delineation of boundaries between adults and children in Asthma families. Parents take charge while children are less assertive. Asthma fathers in particular are more active and involved, possibly responding to a recognition of a need for ancillary support of the mother in dealing with stressful situations. The asthmatic condition may serve to create or bolster a sense of parental cooperation and unity more than is seen in families without asthma. The additional support of the mother does not come, however, as a means of filling a void since, as indicated by their response rates, Asthma mothers are

involved as much as Control mothers. The data indicate that the two groups of mothers are more similar to each other than any other match between pairs of respondents. That Asthma fathers may be more dominant than Control fathers in other life situations is a possibility which merits future inquiry.

The image of the cold, hostile, demanding mother which has been depicted in some psychiatric literature (Gerrard, 1948; Miller & Baruch, 1948, 1967) is not substantiated here. The Asthma father, who has at times been characterized as emotionally absent, aloof, or overly harsh was also not found in the present population. In fact, most Asthma fathers were more involved with their children than Control fathers, at least where illness was concerned. Westley and Epstein (1969) noted that families in which the parents were supportive of each other seemed to have psychologically healthy children and family relationships. Centrality of the relationship between parents was the major determinant of the health of their children. By this criterion, these Asthma families studied appear to be healthy.

The primary issue which comes to the fore in these findings is that of control. The control issue, as indicated by Asthma parents' responses to questions and which appeared in their spontaneous themes, is manifested in a range of situations. It is this issue which may have contributed to the older theories (Coolidge, 1956; Gerrard, 1948; Rees, 1963) regarding "unresolved dependency conflicts" in the parents. It is easy to understand how the two issues, i.e., control and dependency, could be mistakenly confused because they can also be reflected by each other. This can be seen by looking at an interpersonal

relationship in which control issues are manifest and dependency issues are latent. A lucid example is when in psychotherapy a patient is judged to be attempting control of the interview by use of such tactics as talking too much about "irrelevant" material, not talking, changing topics, etc. These efforts to control are often interpreted as efforts to avoid dependency and closeness because of underlying conflicts surrounding such issues.

In this same vein, it appears that the control (and the need felt for it) expressed by Asthma parents may have been interpreted as reflective of unresolved dependency conflicts which then created the asthmatic condition as the child's means of coping with his or her subsequent dependency conflicts. What emerges from the present interview data, however, is the realization that the nature of asthma attacks and the complexity of the attendant syndromes necessitate that control become a primary issue. One seeks to gain or maintain control when the lack or loss of it is at issue. From these family interviews, it is apparent that such a threat is an ever-present possibility. It is also evident that not only is the achievement of control a significant issue for these Asthma families, but so is the ability to be flexible regarding medications and routines. The control is not a rigid one; it is one which requires sensitivity to nuances in the environment and in their children.

Asthma families are faced with a number of paradoxes. They talked of how difficult it is to control and even, at times, to identify factors which stimulate asthma attacks. They also cite inherited predispositions toward allergies in their children. The

struggle is to control what ultimately cannot be completely controlled. It is really a management issue--not a power one. Asthma parents are also faced with the presence of a chronic, unpredictable, condition which has enormous impact upon family activities and functioning. At the same time, because of the long-term nature of the condition, they learn to accommodate to it which then creates a new and different norm for functioning. What might be judged by others as a major problem is felt by Asthma families to be only an inconvenience or even just a part of living. Part of their accommodation involves the development of a "future orientation"--they know they can cope in the present because they have hope that the future will bring relief.

Once again, the nature of asthma--its chronic, yet sporadic appearance--would seem to account for Asthma parents defining their children as healthy and for their not viewing asthma as they would other "illnesses." The movement through the three stages of illness as described by Lederer (1952) does not seem appropriate for children with asthma. It also seems that while the threat of asthma attacks pervasively influences (controls) family activities and planning, the asthma condition and its attendant symptoms are isolated by the families and seen as separate from the way their children "really are." This tactic of isolating can be seen as one way of containing a problem so as to make it manageable and thereby prevent its possible overburdening of the whole family life. It also permits families to continue functioning at a high level because they can see themselves as essentially healthy. It furthermore permits the family to blame the asthma and not the child for any inconveniences experienced. This becomes

important for the families not to blame the child just as it is helpful for the child not to experience him or herself as blameworthy. It is the asthma, not them, that is to blame.

Of course, the asthmatic condition and the child are related and treating the asthma preeminently means treating the child. Asthma families described themselves as "taking away" in contrast to Controls "giving" more when their children were ill. One reason for the difference may be the nature of the illness involved. Asthma attacks often occur quickly and unpredictably and swift action is called for. With successful treatment measures, the symptoms subside rapidly and there is seldom much time to pamper the child. Providing comfort and special attention may be subsumed under the actions of providing medical attention. The parents' focus on giving medical attention rather than providing comfort may be interpreted as subtle rejection of their child's feelings. While this interpretation is plausible, the situation which Asthma parents address is akin to an emergency. In asthma, it is the medicine above all else that brings relief. The illnesses Control families spoke of were generally minor infectious disorders which lasted a few days, and whose symptoms did not rapidly remit in response to ardent administration of medication.

Another reason Asthma parents may have described themselves as less nurturing during treatment may concern their attempt to deny their child's dislike of illness. This raises the question of whether Asthma children mind being ill as much as Control children do or if their parents' perceptions may be somewhat distorted. It also raises the question of the need for Asthma parents to minimize the difficulties "being

ill" may have on their children. Such a possibility is given credence by the parents' emphasis on their child's ability to handle things "maturely."

One can also wonder about the course of development of this attitude, since asthma can be such a frightening illness and also because the asthma had been present for many years. The denial of anger may be an adaptive compromise--one which has an underlying recognition that illness is naturally upsetting, but which also stresses (and is relieved by) the ability to be able to weather the storm. Asthma parents characterize their children as similar to themselves: capable of overcoming adversities and of negotiating obstacles with a minimum of psychological disruption. The message to all is: we can make it.

It is also of interest that while nearly all of the Asthma families used physical symptoms as the means by which they recognized illness in their children, there was only slight mention of physical symptom factors when they defined illness more generally. This may suggest that asthma is considered as something different from illness, or at least as a kind of illness unlike more general illnesses. Parsons (1958) characterized illness as a legitimate way to take time out from responsibilities and Control families did indeed say they expected less from their children when their children were ill. Asthma families, however, tried to convey that even though their child had severe asthma, and even though they necessarily needed to focus more on medicines and restrictions, they really tried not to treat their child differently. The implication is that the child is not special by virtue of his condition, that special allowances are not made for him or her, and that

the child is "as healthy as any normal child." In their pursuit of normalcy, however, the Asthma families seem more normal than normal. That is, they acknowledge fewer feelings and behaviors which could potentially be considered as illness-related weaknesses or faults.

One final note on the Asthma families is that of all eleven questions asked there was only one on which the Asthma and Control families were more similar across groups than within them. The question was "How do you feel about being ill yourself?" As their responses indicated, Asthma and Control parents expressed their feelings about being ill in nearly identical terms. Their descriptions of their reactions to (and reasons for) their dislike of being ill were also very similar. No distinctions between Asthma and Control parents were found with regard to this issue. This indicates that, with this group of families, parents' feelings regarding their own illnesses seems to have had no influence on the development or maintenance of asthma or illness. If and how it may interact with other variables remains unknown. What it does indicate is that there appears to be no simple direct correlation between parents' attitudes and illness. This is congruent with the findings of Mechanic (1965) and Titchner, et al. (1960) who concluded that the relationship between illness and the family system was a complex one.

Children's Results

The children were demographically similar across groups in many ways: birth orders, by chance, were similar across groups; three children in each group were the youngest, one Asthma and two Controls were the middle, and five Asthma and three Controls were the oldest siblings

in their families. One Control child was an only child. Appendix D presents a brief impression of each child. There were no trends among groups or age ranges in the children's manner or abilities to express themselves. Generalizations cannot be made about Asthma children on these bases of age or sibling position.

A few differences between Asthma and Control children did emerge, however, in terms of their experiences of illness. Although Asthma children had the more chronic physical symptoms, fewer of them mentioned such symptoms in their descriptions of illness. On the basis of this result it is possible to assume the use of denial as a means of handling conflictual feelings aroused by asthma. On the other hand, these data might be taken to suggest that asthma for these children is not synonymous with "sick" although those who did talk of symptoms were describing asthmatic symptoms.

In this regard it is also important to note that their parents seemed to separate asthma from illness conceived more broadly. When describing their reactions to being sick Asthma children focused more on physical symptoms than did Controls. Feelings when ill also were described as physical by the majority of children in both groups. It appears that although there may have been an initial reluctance by Asthma children to talk of physical symptoms, that reluctance disappeared as the interviews proceeded. In fact, in response to one of the final questions, Asthma children spoke of improved physical appearance and feelings as an anticipated consequence of "perfect health." The initial downplaying of the physical aspects may thus reflect an adaptive stance by these children to function well in spite of the reality of their physical problems.

The importance of physical activity and play as a ground against which illness is defined was highlighted by both groups. The enforced social restrictions when ill was the most disliked aspect of being ill by children in both groups. Asthmatic children, however, also expressed dislike for medical treatments, yet stated a desire to get well as quickly as possible. While these children indicated a strong reliance upon medicines (and physicians) for relief from symptoms, there was also an aversion to them.

This ambivalence about treatment is something Asthma children have to cope with much more often than Control children. The intrusion of medical treatment into their ongoing lives is a long-term actuality and one which Asthma children must accept for their successful negotiation of the illness. Asthma children become the objects of actions by others (i.e., parents and medical personnel) and are rendered dependent in that respect. Accordingly, they report that they have little responsibility in telling their parents when they are ill. Even though their symptoms can be quite severe, Asthma children did not express excessive concern about finding help. The old image (Alexander, 1950; Miller & Baruch, 1948, 1967) of the asthmatic child as being excessively anxious or fearful did not emerge from the present interviews. Possibly the state of knowledge currently achieved regarding medical treatment has allowed these children to know that they will get help and that symptoms will abate.

In contrast to the descriptions provided by Asthma children, Control children expressed more worrisome thoughts about being ill. This may have been because Asthma children were more accustomed to

getting ill and recovering, lending a predictability to their continuing health/sickness/health situation. It would be a distortion to describe the Asthma children as unemotional or stilted in their affective lives as their interactive styles and verbal expressions do not support such a description. Nearly half of the Asthma children, however, did not express empathy regarding other people who were ill. One wonders if the less frequent expression of empathy reflects less experience of empathy. If so, why might this be the case? Given the other responses by families and children, it may be that, due to the nature of the asthma experiences, required treatment seems to be "task oriented" rather than "sympathetically personal." For these children emphasis has been on coping with, and overcoming, adversity, not on feeling sorry for oneself or one's child. This set of experiences may carry over to the child's attitudes about others who are ill. Nearly half of the Asthma children were unable to say how their parents felt about their (the child's) being ill. One wonders why they were unable to recognize their parents' feelings. Possibly the parents place so much emphasis on mastery and action that their underlying empathy is obscured. It is also possible that the children feel self-conscious about their difficulties and then they either correctly or incorrectly assess parents' feelings about their situation.

Generally, then, while the children in both groups were similar in many ways, the main differences recovered through the present interviews concerned the areas of responsibility/control and empathy. Asthma children are dependent on others for help and learn not to worry that help may be inadequate. Empathy has a quality of shared feeling born

of recognition of the difficulties another is experiencing; since the emphasis in the Asthma group is on overcoming adversities rather than resonating with them, the expression of empathy is diminished. Control children, while also dependent upon others for help, experience greater personal responsibility for becoming ill and healthy. These children also more easily recognize empathic concern within themselves and others.

II. METHODOLOGICAL CONCERNS

The accuracy and utility of any research results depend upon the reliability and validity of the research design and methods. The open-ended questionnaires used were designed specifically for provoking responses regarding illness in general and asthma in particular, and their appropriateness for the collection of such data is clear. There may be other questions or open-ended formats, however, which could elicit different information relevant to understanding the experience of illness. The results of the present research are thus influenced by the range and nature of the questions asked. An effort to go beyond such limitations was made by acknowledging and discussing information received (i.e. family themes) not specifically generated by the questionnaires.

The type and number of participants in this study pose the strongest limitations on the generalizability of results. All families were white, middle class, Protestant, and native to Tennessee. As may be recalled, different cultural and social groups recognize and respond to illnesses in varying ways. Generalizing these results beyond such a

population may be unwarranted in light of variables which can affect the experience of illness. Since the sample size used in this study was small, results also need to be considered cautiously in that light.

All Asthma children had severe asthma, judged by the need for steroids. This factor is of particular importance since the definitive diagnosis of severe asthma and the resulting treatments strongly shaped family experiences and attitudes. In families with less severe asthma, there may be more room for ambiguity in interpretations and consequent actions.

Finally, all interviews were conducted by the author in an effort to ensure consistency in interviewing style. While present results emerged from the interviewees' rather than the interviewer's preconceptions, the author's presence and style surely has some effect on the families and may have influenced the results obtained. Having a stranger come into one's home is intrusive. Being asked questions about personal and family affairs is additionally intrusive. Such a method of gathering information may have influenced, to some degree, the information obtained. Families may have attempted to present themselves as healthy and well-functioning lest they be judged negatively. Children communicate more easily through indirect (game-playing) and non-verbal (drawing) expressive modes. Direct verbal interchange as used in this study provides limited access to children's thoughts and feelings. That the interviewer was a male is surely not without influence. For example, it is possible that Asthma fathers stepped forward as family protector and spoke more than might have been the case had the interview been conducted by a female and focused on less personal issues.

III. IMPLICATIONS FOR CLINICAL TREATMENT

These results have implications for clinical work with asthmatic families. The traditional stereotypes of the parents of asthmatics as rejecting of their children do not appear accurate. Present results serve to caution clinicians against conceptualizing family dynamics prior to substantial interaction with the families. Recalling that the families evaluated in this research were considered by themselves and others to be well-functioning, the findings regarding control and empathy must be interpreted in that light. An assumption that a high degree of parental responsibility with a lowered degree of expressed empathy is pathogenic in asthma, thus, may be unwarranted and inaccurate. For those families, it is a part of their adaptive functioning. What is healthy cannot be defined outside of its context and what is adaptive in one context may be maladaptive in another.

Belief that specific psychological conflicts or underlying personal dynamics lead to the development and expression of asthma appears to be a simplistic and unwarranted assumption. While emotional arousal is recognized by these families as a potential factor in the onset of asthma attacks, it is by no means the only or most significant such factor. Clinicians ought be aware of the inadequacy of such a conceptual approach to treatment.

The information obtained in these interviews suggest that the more important issue is how the family systems cope. Part of their coping processes involve their own attempts to observe and discover factors which stimulate asthma attacks. It seems that were problems to arise they would occur in areas involving family functioning. What

the clinician should expect to observe is an involved father, a strong parental coalition, an inquisitive and active approach by that coalition, and an openness and willingness to discuss relevant issues. Children will present as varied in their verbal expressive skills and emotional expressiveness. They will generally be trustingly dependent upon external sources of help (regarding their asthma), but otherwise engage in age appropriate activities.

When any of these factors are not observed, exploration of reasons for their absence would appear to be an appropriate and important therapeutic endeavor. Therapeutic goals should be defined as helping families to function as well as possible. This involves the formation of a capable parental coalition which experiences itself as competent in addressing issues surrounding asthma. It also involves the ability to help the child grow and develop a sense of independence and autonomy, while recognizing the appropriateness of occasional restrictive measures for control of the asthma symptoms. A potentially troublesome area for these families is parental denial of children's feelings about asthma. While Asthma parents emphasize maturity, their children express negative feelings and concerns about their appearances and health related to asthma. Some Asthma children also were unsure of their parents' feelings toward them when ill. Asthma parents may be reluctant to communicate empathy openly to their children because of concern that the children may use illness for undue secondary gains. Indications from this study are that such manipulation by the children seems unlikely.

Finally, these families had the best working relationships with medical personnel who respected their feelings and judgements. These

families valued their own competence to administer and monitor treatments at home. This involved not only following "doctor's orders" but adjusting them at times to suit different situations. Such actions should not immediately be considered as resistance to treatment, but rather as a reflection of the family's need for competence and control in light of a difficult situation.

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APPENDICES

APPENDIX A

FAMILY QUESTIONNAIRE

1. How can you tell when (child) is becoming ill?
2. How does (child)'s being ill affect the family?
3. Why do you think (child) becomes ill?
4. What do you do to help (child) when he (or she) is ill?
5. How would you describe (child)'s general health?
6. How do you feel about being ill yourself?
7. What precautions do you think are important to take for (child) to avoid becoming ill?
8. What do you think (child)'s attitude is about being sick?
9. How would you define illness?
10. How do you treat (child) differently when he (or she) is well rather than sick?
11. How would things be different if (child) never got sick?

APPENDIX B

CHILDREN'S QUESTIONNAIRE

1. When do you say you're sick?
2. Tell me as much as you can about what it's like to be sick.
3. How do others in your family know when you are sick?
4. When you're sick, what do other people in your family do?
5. When you're sick, how does it change what you usually do?
6. How do you feel inside when you're sick?
7. What do you do when you are sick?
8. What do you think about when you are sick?
9. What's your reaction when you realize you are getting sick?
10. How do you feel about other people who get sick?
11. How do you think the others in your family feel about you when you are sick?
12. What's nice about being sick?
13. What's not nice about being sick?
14. How are you different when you are well rather than sick?
15. How would things be different if you were never sick?

APPENDIX C

LETTER TO PHYSICIANS

January 29, 1980

Dear Dr. ,

I am presently seeking families to interview regarding their perceptions and attitudes about asthma. and have suggested I contact you as a potential referral source.

I am in need of six intact families which have a child, aged 6-12, whose asthmatic condition has required at least occasional treatment with steroid medication. I would like to interview the identified patient and the family for approximately one and one-half hours, at their convenience. My efforts are directed solely as information gathering, and are not experimental or treatment oriented.

If you have any such appropriate patients, I would be most appreciative of your help. I will be delighted to meet at your convenience to discuss more fully the parameters and processes of my investigation.

I will phone you in about one week in the hopes that we can arrange a time to meet. Thank you.

Very truly yours,

John F. Duffy,
Associate Psychologist
Regional Mental Health Center of Oak Ridge/
Morgan County Medical Center

cc

JFD/jlm

APPENDIX D

LETTER TO PARENTS AND ACCOMPANYING RESPONSE FORM

Dear Parents:

I am a Ph.D. candidate in the Department of Psychology at the University of Tennessee and am working on a project trying to learn about people's views of illness. Usually illnesses are treated as isolated events. Professionals usually don't ask people about what it is like being ill or what it means to them when they are ill. What I would like to do is talk to children and families about their ideas and feelings about illness.

This letter is to ask your permission to interview members of your family in my efforts to gather such information. What I propose to do is ask a standard set of questions to the family as a group and to a child/children individually. The interviews will be tape recorded and then coded by numbers in order to ensure strict confidentiality. If the results and discussion are to be published, the information will be sufficiently disguised so that recognition of specific families and family members will not be possible.

I expect the entire interviewing procedure to take about one and one-half hours. Participation in this project is completely voluntary and no one is under any obligation to start or complete it. Your selection as possible participants is due to the fact that you have school age children who have illnesses which require medical attention from time to time. Selection is in no way intended to imply that your family is unusual or problematic.

The interviews will be conducted at your convenience either at your home or at the University of Tennessee. At any time during our contact, I will answer any questions or discuss anything pertinent to our project involvement together. I take it as my serious professional obligation to safeguard against anything at all being disruptive about the interviews, and if concerns arise, do let me know.

Immediately following the interviews, I will summarize and try to reflect back to you what I've heard from you. As I share my perceptions, you will be able to clarify any possible misunderstandings on my part. Also, after I've interviewed all of the families in the project and looked at the information, I will be glad to meet with you again and share what I have learned.

Enclosed is a response form and a stamped envelope for your reply. If you decide to participate, I will follow up this letter with a phone call to arrange for an interview time.

Sincerely,

John F. Duffy
Department of Psychology
University of Tennessee
522-3371

JFD/ta
Enclosure

RESPONSE FORM

Mr. John Duffy:

_____ YES, we are willing to be interviewed.

_____ NO, we do not agree to be interviewed.

Reasons (optional):

Name: _____

Phone Number: _____

APPENDIX E

AGE OF CHILD AND (SIBLINGS)

Asthma Group

1. 6 year old male (w. 3 year old female)
2. 6 year old male (w. 5 year old female)
3. 6 year old female (w. 13 year old male)
4. 7 year old female (w. 9 year old male)
5. 7 year old male (w. 9 year old female and 14 year old female)
6. 9 year old male (w. 4 year old male)
7. 9 year old male (w. 4 year old male)
8. 11 year old male (w. 1 year old female and 9 year old female)
9. 11 year old female (w. 7 year old female, 13 year old female, and 17 year old male)

Control Group

1. 6 year old male (w. 5 year old male, 10 year old male, and 12 year old female)
2. 6 year old male (w. 12 year old female and 14 year old male)
3. 6 year old female (w. 8 year old female)
4. 7 year old female (w. 9 year old female)
5. 7 year old male (w. 4 year old female)
6. 9 year old male (w. 5 year old female and 6 year old male)
7. 9 year old male (w. 5 year old male, 17 year old female, and 20 year old female)
8. 12 year old male (w. 9 year old female)
9. 11 year old female

TABLE E-1

NUMBER OF CHILDREN INTERVIEWED PER AGE GROUP

Group	Ages							
	6	7	8	9	10	11	12	
Asthma	3	2	0	2	0	2	0	6 males 3 females
Control	3	2	0	2	0	1	1	6 males 3 females

APPENDIX F

Asthma Children

1. 6 year old male--distractible, tangential, immature speech and manner
2. 6 year old male--direct, honest, clear, to the point
3. 6 year old female--distractible, immature, hard to develop rapport
4. 7 year old female--sits and looks uptight, little responding
5. 7 year old male--clear, thorough, direct and open
6. 9 year old male--didn't answer much
7. 9 year old male--open, expressive, clear, addresses negative effects and fears
8. 11 year old male--cries, upset by talking of asthma, feels badly and inadequate, answers thoroughly
9. 11 year old female--verbal, pleasant, articulate

Control Children

1. 6 year old male--tangential, vague, blocked speech, cooperative but doesn't come across clearly
2. 6 year old male--speaks freely, but irrelevantly at times; doesn't understand some questions; distractible
3. 6 year old female--direct, pragmatic answers, not warm, but obedient and task oriented
4. 7 year old female--verbal, rambles, wants to please, fanciful flavor, answers thoroughly
5. 7 year old male--answers clearly, wants to do well, nervous giggles, afraid he might fail
6. 9 year old male--direct, clear, relevant, open, pleasant
7. 9 year old male--uncomfortable and distant, nervous giggles, answers brief and often vague
8. 12 year old male--verbal, dramatic, focuses on negative feelings and strong opinions
9. 11 year old female--articulate, direct, to the point

APPENDIX G

INFORMED CONSENT

Having been explained the purposes and procedures of this research project by Mr. John Duffy as part of his Ph.D. Dissertation, we hereby agree to our family being interviewed. We understand that our family members will be interviewed, and that such interviews will be tape recorded, transcribed, and then coded for confidentiality. Were any results to be published, we understand that information would be sufficiently disguised so that recognition of individuals or families would be impossible. We understand that any questions or concerns we have will be responded to at any time. We also understand that we are free to withdraw our consent and discontinue participation in this project at any time. We have been explained that our participation is completely voluntary, and agree that we are under no coercion to participate. We understand that the interviews are for the purposes of gathering information, and are not for the purposes of treatment or experimentation. We also understand that immediately following the interviews Mr. Duffy will summarize what he has learned from us and we can clarify any possible misunderstandings on his part. Finally, we understand that Mr. Duffy has agreed to meet with us, if we wish, to discuss what he has learned following the completion of the project.

APPENDIX H

BRIEF SYNOPSES OF IMPRESSIONS OF ASTHMA FAMILIES BY FAMILY

- 1A. Both parents open and informative; mother feels she has great influence on child's behavior and feelings--emphasis on keeping calm; mother recalls own asthma and anxiety as a child; observing, hoping, waiting for change; a sense of uncertainty about what exactly is helping and what isn't anymore, but a great sense of responsibility for providing emotional support and maintaining hope and optimism.
- 2A. Both parents verbal and cooperative with each other in responses. Father concerned about possible bad effects of meds. Both parents have puzzled about causes, timing of attacks, cure. Feel much responsibility for helping and being aware and need to reassure selves they're doing the best they can. Need to be flexible and cautious. Accurate empathy with child and sibling. Some over-compensation to not leave sib out of discussion.
- 3A. Father says little; sib speaks up for father and mother at times. Mother describes conflict with child over meds. No one seems to say good things about anyone else. Sib sarcastic re: child. Mother anticipates oppositional behavior from child. Mother had to be coerced by own M.D. to seek allergist for child. A constant process of listening and judging severity of symptoms. Concrete family--not ideational or psychological minded.
- 4A. Father very vocal on what an inconvenience it all is. Father is a "know-it-all" who had problems letting M.D.'s help early on. Also didn't want to impose on M.D.'s. Now they rely on them and admit they can't solve it on own. Frightening early on--you learn to cope over time and as child gets older. Just try and roll with the flow. Mother denies child feels badly; father recognizes some upset for child at times. Mother was surprised so many kids got allergy shots.
- 5A. Parents focus on puzzlement on causes and timing. Need to use own judgements a lot--no clear cut guidelines or sure fire things that are guaranteed. Process of learning and refining info about precautions and treatment. The only sure thing is meds and hospital. Talk of letting child grow and not smothering him. Each attack they sift through all the factors to try and figure out. A learning process over time. Mother feels faith in God has helped her.

- 6A. Parents verbal and cooperative with each other. Father most verbal and talks of own very severe asthma as child. Both worried over meds and effects. They seem to be very "matter-of-fact" about it all; feel it doesn't bother child; that he just accepts it. Parents feel competent to handle situation, and to act as a "partner" with M.D. re: advice.
- 7A. Parents verbal and cooperative with each other. Talk of anxiety first few years and how you learn to cope through efforts and trial and error. They've thought of emotional as well as physical causes at particular times. Mother feels it's important to reassure child and keep calm for his sake. Let him grow and be active as much as possible. Let him use own judgement now. Having allergist and meds has really helped. Mother surprised so many kids have allergies and get shots.
- 8A. Both downplay the impact or severity; strong denial component especially with mother. Both mother and father say "we" when talking of child. Both express concerns about the number of meds, but emphasize helpfulness. They seem to restrict him or remind him of precautions a lot. Mother bothered by word "sick." Seems to be a conflict over how much they should let go and let child be responsible at this point. They say they don't talk about or dwell on it and child doesn't either--just keep active. Mother wants family ministry to help as much as medicine. Mother and child both got more upset than anyone else I saw.
- 9A. Parents verbal and open. Talk of difficulties, but sense of support is evident. Parents see selves as responsible for "do's and don't's." Lots of focus on child. Concern about meds. Need to use their own judgement a lot. Scary at first; need to learn to live with it, and look to future with hope. They've taken her to many clinics. Seems to provide a focus for parents. None of the three sibs talked. Attitude of M.D.'s important.

APPENDIX I

TABLE 1-1

NUMBER OF SPEECH ACTS AND PERCENT OF TOTAL SPEECH
ACTS PER FAMILY GIVEN BY EACH PERSON
DURING ASTHMA FAMILY INTERVIEWS

Family Number	Mother		Father		Child		Sibling _{(N)*}	
1	103	(.55)	81	(.44)	1	(.01)	1 ₍₁₎	(.01)
2	132	(.44)	118	(.39)	27	(.09)	22 ₍₁₎	(.07)
3	132	(.53)	38	(.15)	9	(.04)	68 ₍₁₎	(.28)
4	101	(.39)	142	(.54)	11	(.04)	8 ₍₁₎	(.03)
5	52	(.55)	39	(.41)	4	(.04)	0 ₍₂₎	(.00)
6	104	(.39)	166	(.61)	0	(.00)	0 ₍₁₎	(.00)
7	60	(.49)	54	(.44)	5	(.04)	4 ₍₁₎	(.03)
8	64	(.52)	58	(.47)	2	(.02)	0 ₍₁₎	(.00)
9	95	(.58)	60	(.37)	8	(.05)	0 ₍₃₎	(.00)
$\bar{X}$ =	93.67	(.49)	84.00	(.42)	7.44	(.04)	8.58	(.05)

*Number of siblings old enough to speak

APPENDIX J

TABLE J-1

NUMBER OF SPEECH ACTS AND PERCENT OF TOTAL SPEECH
ACTS PER FAMILY GIVEN BY EACH PERSON
DURING CONTROL FAMILY INTERVIEWS

Family Number	Mother		Father		Child		Sibling _{(N)*}	
1	52	(.29)	24	(.14)	9	(.05)	93 ₍₃₎	(.52)
2	59	(.50)	40	(.34)	13	(.11)	5 ₍₂₎	(.04)
3	13	(.30)	19	(.44)	4	(.09)	7 ₍₁₎	(.16)
4	49	(.35)	33	(.23)	38	(.27)	21 ₍₁₎	(.15)
5	48	(.40)	31	(.26)	42	(.35)	0 ₍₁₎	(.00)
6	61	(.55)	18	(.16)	12	(.11)	19 ₍₂₎	(.17)
7	21	(.48)	7	(.16)	2	(.05)	14 ₍₃₎	(.32)
8	21	(.27)	32	(.41)	8	(.10)	17 ₍₁₎	(.22)
9	45	(.62)	28	(.38)	0	(.00)	--	--
$\bar{X}$ =	41.00	(.42)	25.78	(.28)	14.22	(.13)	22.00	(.20)
							12.50**	(11.29)

*Number of siblings old enough to speak

**Number per siblings in family

VITA

John F. Duffy, Jr. was born on December 13, 1949 in New York City and lived most of his formative years in Chatham, New Jersey. He attended Catholic elementary schools and graduated from Saint Peter's Preparatory School in Jersey City in 1967. He attended Seton Hall University in South Orange, graduating with a Bachelor of Arts degree in Psychology in 1971. From 1972-1973, he worked at Saint Dominic's Home, a child residential and treatment facility, in Blauvelt, New York. In 1973, he entered the School Psychology program in the Department of Psychology at The University of Tennessee, Knoxville. He transferred to the Clinical Psychology program in 1975 and proceeded to meet degree requirements of both programs. Practica and employment sites included the Knoxville City School System, Psychological Services Section, the Psychological Clinic at The University of Tennessee, Knoxville, and the Regional Mental Health Center of Oak Ridge. From 1977-1978, Mr. Duffy completed his clinical internship at the Texas Research Institute of Mental Sciences in the Texas Medical Center in Houston. He returned to Tennessee and has been employed with the Regional Mental Health Center of Oak Ridge since 1978.

He has one daughter, Bevin Eileen, who is six years old and in first grade.