Family members' perceptions of having a child with asthma in Japan

by

Masako Ono, R.N. , B. S. N.

A Thesis

Presented to
Oregon Health Sciences University
School of Nursing
In partial fulfillment of
the requirements for the degree of
Master of Science

May, 1992

APPROVED:

[redacted]

Marie Scott Brown, Ph.D. , Professor, Thesis Advisor

[redacted]

Sheila Kodadek, R. N. , Ph.D. , Associate Professor, First Reader and Department Chairperson of Family Nursing

[redacted]

Pam Hellings, R.N. , Ph. D. ,P. N. P. , Associate Professor, Second Reader

Acknowledgements

I gratefully acknowledge my thesis committee for making this study possible. My thesis advisor, Marie Scott Brown, has been a constant support behind this thesis. Her large-hearted attitude eased my nervous and impending feeling and helped to go forward. Also her anthropological insight stimulated my cultural awareness. I also would like to thank Pam Hellings, who was my academic advisor and one of thesis committee members, for her support during three years. I also would like to thank Sheila Kodadek, who gave me the prolonged knowledge regarding the chronically ill children and their families.

In addition, I would like to gratefully thank Ms. Noriko Katada, who is associate professor at St. Luke's Nursing College in Japan. She gave me a great insight and support for data collection and data analysis in Japan. Without her enormous support and encouragement, I could not have completed this thesis.

For the completion of this study, I am most indebted to the families who were willing to share their lives with me by participating in this study. They willingly gave of their time and themselves by telling their stories and welcoming me into their homes.

Furthermore, I would like to thank Dr. Junko Hirooka to provide the information and willingly allow me to attend her clinic to upgrade my knowledge and share her experience.

To my most struggling part, English, I would like to thank Arvilla Claussen to devoted her time to help my Japanese English to more like

English.

Finally, my friends both in Japan and America and my family have kept me hanging here by supporting emotionally and financially. Especially, I am so grateful that my friend, Kazuko Kamiizumi, and my brother, Masao Ono, helped my first using Japanese word processor to transcribe the interview again and again.

Abstract

Title: Family members' perceptions of having a child with asthma in Japan.

Author: Masako Ono, RN. , BS.

Approved: [redacted]

Marie Scott Brown, Ph. D. , Thesis Advisor.

The purpose of this study was to explore the family members' experience of having an asthmatic child. Family members included in this study were fathers, mothers, siblings, and the school age child with asthma at the allergy clinic in the general hospital in metropolitan area. All were interviewed one time except one child. A total of 26 family members in six families who had a child with asthma were each interviewed separately. Three major experiences were identified from the interview data: 1) The individual family members' experience of making decisions regarding changes in their family lifestyle, 2) Responsibility for managing the child's asthma, and 3) Variations in family adaptations to their child with asthma. These data were then analyzed and compared with the data available from the literature published in the United States and Canada and Japan and suggestions were made to explain both similarities and differences between the experiences of families in different cultures but with similar health concerns. This will hopefully be the beginning of a clearer understanding of family members' experience when the family has a asthmatic child.

Table of Contents

CHAPTER PAGE

List of Tables

TABLES PAGE

CHAPTER I

INTRODUCTION

Recently, as people's living styles have been changed and medical technology and treatment have developed, the number of chronically ill children has increased in our society. Even though this increase in numbers may not represent an increase in percentage, still conservative estimates are that 10 to 20 % of children in America experience some long-term illness (Stein & Jessop, 1984, cited in Perrin & MacLean, 1988). Both the numbers and percentage of this population are significant to nursing practice. Actually, although the incidence of new cases of chronically ill children has not changed, the survival rate for many conditions has increased (Baba, 1990; Patterson, 1988). Appropriately, the attention to this area in nursing research has also increased.

In Japan, as in the United States, the number of chronically ill children has increased (Baba, 1990). Similarly, the number of children with asthma has increased yearly (Baba, 1988); presently asthma represents almost half of all chronic illness diagnosed in Japanese children (Akasaka, Nezu, Suzuki, Mitsubayashi, Maruki, & Maeda, 1982).

In both Japan and the United States, the experience of the chronically ill child and his/her family has been studied from several perspectives; including the chronically ill child him/herself, parents, mainly mothers, and more recently, siblings of the chronically ill child and fathers. The current trend in research is toward emphasizing the family perspective rather than individual family members' perspectives. However, even though family research has been emphasized, data still come primarily from one person's perspective, usually that of the mother. Therefore, we do not know much about the other family members' perceptions of the experience of having a chronically ill child, and we do not know how those different perceptions can be viewed together for a truly family perspective. To understand these lived experiences from different perspectives would help nurses and other health professionals assess the families of chronically ill children and identify potential problems and interventions for such families.

The purpose of this study is to explore the Japanese family experience of having a chronically ill child with the diagnosis of asthma from the perspective of each individual family member.

CHAPTER II

REVIEW OF THE LITERATURE

Generally, most of the literature on the impact on the family of a child with a chronic illness has focused on mothers or relationships between mothers and their chronically ill children (Sabbeth, 1984). Some of the reasons for this focus on mothers include the following: 1) mothers are assumed to be most influential with their children, 2) they bring their children to the clinic more often than fathers, and 3) they are more likely to participate in parent groups (Sabbeth, 1984).

The impact of having a chronically ill child on mothers has been described in several ways. For example, the stages that mothers are assumed to pass through prior to and following the diagnosis of a serious illness have been described, including shock or disbelief, anger and resentment, self-blame, and later sadness and acceptance (Sabbeth, 1984).

Early studies in the United States frequently were derived from a psychoanalytic framework. They often described the impact of chronic illness as the incidence of psychological problems in the family. Many authors (e.g., Walker, Thomas, & Russell, 1971) have noted depression among the mothers of children with a chronic illness such as spina bifida. Sabbeth (1984) pointed out one frequent problem. It was that overprotective behavior may be the result of the mother's anger toward her ill child, and her secret wish to be rid of the child. However, these studies lacked controls; later studies which did not use the psychoanalytic framework have failed to confirm these early results.

Little is known about the impact of chronically ill children on fathers. Apley (1967, cited in Sabbeth, 1984) noted that fathers of children with a congenital heart defect were less unsatisfied in relationships with their children than mothers (42% vs. 68%). Sabbeth (1984) assumed that the physical absence of the father, such as long hours working outside the home, might facilitate emotional withdrawal and the avoidance of intense anger, disappointment, or sorrow. Furthermore, Sabbeth (1984) assumed that the father's sense of isolation might result from the societal stereotype which prohibit men from expressing their feelings or demonstrating their vulnerability. However, the facts and influencing factors are still unclear.

Different experiences between mothers and fathers also have been reported. For example, Damrosch and Perry (1989) found that mothers of children with Down syndrome experienced "chronic sorrow" more frequently than fathers did. Many studies have looked at divorce and/or marital distress as an indicator of the impact of chronically ill child on the parents' marriage. Sabbeth and Leventhal (1984) reviewed the literature on marital adjustment relative to having a chronically ill child and found no significant differences in divorce rate between parents with chronically ill children and those with healthy children. However, in some studies (e.g., Lansky et al., 1978, cited in Sabbeth & Leventhal, 1984) marital distress was experienced more by parents of chronically ill children than by parents of healthy children. In contrast, Sabbeth (1984) found that parents of chronically ill children tended to become closer, but the term "closeness" was not well defined.

There are many studies on the impact of the chronic illness on the child him or herself. Perrin and MacLean (1988) reported that the rate of behavioral problems is twice that of the able-bodied population. However, Tavormina et al. (1976, cited in Perrin & MacLean, 1988) have found little incidence of overt psychopathology among children with chronic illness. This discrepancy might be explained by the use of biased samples, since the population used in most of the studies was receiving high-quality services and more behavioral problems were detected (Perrin & MacLean, 1988). Among school-aged children, school attendance /school absence may be a better predictor of the effect of chronic illness on the child. Some studies have reported lower academic performance (Patterson, 1988), increased occurrence of depression, and lower self esteem among chronically ill children (Weitzman, 1984).

Most of the findings concerning siblings were obtained from their parents (Sabbeth, 1984). These findings described siblings' feelings and thoughts of embarrassment, guilt about their embarrassment, and resentment. There is a question whether siblings of chronically ill children are at risk for developing psychosocial problems (Sabbeth, 1984). Several studies (e.g., Taylor, 1980) report that they are, but findings differ in some diseases, such as spina bifida which showed higher maladjustment (Tew, cited in Sabbeth, 1984) and nephrotic syndrome which showed that the child with nephrotic syndrome did not have more abnormal behaviors than control group (Vance, cited in Sabbeth, 1984). These other findings (e.g., Lavigne & Ryan, cited in McKeever, 1983) suggest that the severity or visibility of the illness might influence the adjustment process of siblings.

Furthermore, recently, there is an on-going study (Deatrick & Knafl, 1990; Knafl & Deatrick, 1990) which is conceptualizing family response to chronic childhood illness. In their study, they are trying to conceptualize family management style through individual family member's interviews.

The Family with an Asthmatic Child

The research on families with an asthmatic child has been addressed in several ways: family management style (e.g., Deatrick & Knafl, 1990; Knafl & Deatrick, 1990); management programs (Alexander, Younger, Cohen, & Crawford, 1988); educational programs (e.g., Feldman, 1987); anxiety (e.g., Staudenmayer, 1981); perceptions and attitude toward asthma and its treatment (Donnelly, Donnelly, & Thong, 1987); and specific children's characteristics and mother-child relationships (e.g., Caroselli-Karinja, 1990; Khampalikit, 1983) in the United States. Similar to other studies on families with chronically ill children, most have studied the phenomenon from the mother's perspective. Studies in the late 1970s and early 1980s indicated that the family's or mother's experience of having an asthmatic child usually includes burden, fear (Khampalikit, 1983; Reddihough, Landau, Julie

Jones, & Richards, 1977; Staudenmayer, 1981), and the parents had negative perceptions, including the perception that their children were more dependent than other children. These results are currently being questioned, however. During this time, asthma was widely considered to be a psychosomatic disorder (Hobbs, Perrin, & Ireys, 1985). This theory however has been changed in the past 10 years, and environmental factors, such as allergens and stress, are currently considered more influential in its etiology (Garrison & McQuiston, 1989). More recently, biochemical imbalances in the autonomic nervous system have also been considered an etiology of asthma (Garrison & McQuiston, 1989; Hobbs et al. , 1985), although this is still unproven hypothesis (Garrison & McQuiston, 1989).

Recently in Japan a multicausal theory on the origin of asthma has been accepted. This is characterized by the combination of heredity (or genetic predisposition), allergic factors, psychological characteristics, and infectious processes (Uchimi, Amamiya, & Torii, 1980; Caroselli-Karinja, 1990). However, it is still believed that parents and asthmatic children are more anxious than children without asthma and that parents tend to be overprotective. The asthmatic child is stigmatized by being labeled "dependent, uncooperative, and less adaptable to society/social life" (Uchimi et al., 1980). Nursing parent-child assessments and interventions have been based on these assumptions. Some specific clinical problems have been described as 1) families providing developmentally inappropriate environments, or 2) families using psychologically unhealthy childrearing techniques such as being overprotective, anxious, or spoiling or rejecting of the child (e.g., Uchimi et al., 1980). Children in such families were reported to be overly dependent and very anxious about asthma attacks. In some studies, the psychological influence is more related to the severity of the disease (Shibutani, Toyoshima, & Takaki, 1986; Tsay, Mukoyama, Matsui, Iwasaki, & Hashimoto, 1981). In these case studies, excessive restrictions of physical activities in home and school and parents' tendency to obey the child were reported (Uchimi et al., 1980).

Several Japanese studies on parent-child education/ programs focused on the parent-child relationship (e.g., Osugi, 1982). The effect of the parents' characteristics and attitudes toward their children was stressed and concern about the asthmatic children's refusal to attend school was noted (Tsay et al., 1981; Takashima, 1990). The school life of the asthmatic child was influenced by problems, such as restricted physical activities, fewer opportunities to attend field trips, being picked on, and increased school absence (Nishikawa, Masaki, Kajita, Tomita, Shirai, Nagakura, Iikura, Seo, Sugimoto, & Saito, 1981; Takashima, 1990). There are few Japanese studies of the siblings or fathers of children with asthma.

In summary, both Japanese and American studies indicate that family members differ in their perceptions of having a chronically ill child/sibling and the illness has a different impact on each of them. More research is needed to clarify these differences and to understand the perceptions of the family as a whole toward their experiences of having a child with a chronic illness.

Research Question

What is the individual family members' experience of having a child with asthma in the family in Japan?

CHAPTER III

METHODS

Design

This was an exploratory descriptive study designed to describe the experiences of the individual members of a Japanese family in which there was a child with asthma.

Informants

The target population was composed of Japanese families of asthmatic children in elementary school, ages 7 to 12 years. The informants were obtained from the allergy clinic of a pediatric outpatient clinic in a general hospital, in a metropolitan area in Tokyo, Japan. Actual informants were members of six families of children with asthma. The method used to select the informants was purposive. The criteria for the sample were the following:

1) The family consisted of a mother, a father, a child with asthma who was in an elementary school (age 7 to 12 years), and at least one sibling age 7 to 18 years old,

2) the family had no more than one chronically ill child,

3) the diagnosis of asthma had been made by the pediatrician at the allergy clinic in the hospital, and

4) the child with asthma was followed by the outpatient clinic.

Data Collection

Prior to data collection, this study was examined by the Oregon Health Sciences University Human Subjects Review Committee to assure the protection of all subjects. In Japan, the study was examined by the Nurse Supervisor Committee in the hospital from which the informants were obtained.

The data collection method used was a semi-structured interview. The interviews were conducted by the investigator using an interview guide (Appendix A-1, 2). This interview guide had been developed for this study by the investigator and was derived from a literature review and by discussion with experts in the field. The interview guide was translated from English to Japanese and both the English and Japanese versions of the interview guide were reviewed by both a Japanese and American panel of experts.

Procedure

The families who met the criteria were chosen by the investigator and a physician in the pediatric outpatient clinic through a review of patients' charts. These families were invited to participate in the study at the outpatient clinic by the investigator. At this time they received an explanatory letter with a separate page which was to be mailed back indicating whether the family did or did not wish to be part of the study (Appendix B-1, 2). They were invited to take the explanatory letter home to use in explaining the study to the other family members. If all family members agreed to participate, they sent the reply postcard back indicating their willingness. Then the investigator made an appointment by phone with the family for a home visit. The investigator continued contacting families until she got six families. The clinic staff (nurses, doctors, a clerk) were not informed which families were participating in the study in order to keep the families' confidentiality. All family members were interviewed separately. The protection of the confidentiality of each family member's information was emphasized to each person. The interviews were audio tape recorded. The interviews were assigned a code number and the names associated with the codes were locked away so that the confidentiality of data could be protected.

Analysis Strategies

The interviews were transcribed by the investigator to facilitate the qualitative analysis. It had originally been planned that the transcription would be translated into English by the investigator and reviewed by a bilingual translator. However three problems were encountered with this plan: 1) It was extremely expensive financially 2) the time necessary for this step was not available and 3) many nuances of meaning which were evident in the Japanese script were lost in the translation process. So, instead of translating each interview into English first and doing the analysis in English, the analysis was done directly from the Japanese transcript. Data obtained from the interviews were analyzed first by topical coding based on the questionnaire, and then by conceptual coding. After conceptual coding was complete, patterns of relationships between concepts were sought. Such relationships were sought within each interview, among interviews of the same family, among parallel roles of each family (e.g., among all the father respondents, and all the mother respondents).

CHAPTER IV

RESULTS

The results of the study will be described in two parts. The first part of the results section will include those results which describe the demographic variables of the informants; the second part of the results section will discuss the findings of the analysis of the content of the interviews.

Demographic Data

Six families were interviewed based on the criteria. First, a pilot interview was done with the first family. The researcher planned to include this first interview in the final data only if it was decided by the researcher and her supervisor that it was complete and appropriate. It was decided, after careful review, to include this family in the final analysis. Also during the interviews, one family was identified who did not meet the criteria because the child's sibling had also recently had a light asthma attack. Nonetheless, the judgement was made that since this family met all the other criteria, data from this family would be kept. Consequently the resulting sample size was six families. (General demographic data is provided in Table 1 and Table 2).

In these six families, the average age of the fathers was 43.8 years (with a range of 40-48 years); the average age of the mothers was 40.7 years (with a range of 38-42 years); the average age of the children with asthma was 10.3 years (with a range of 8-12 years); the average age of the siblings in the study was 10.5 years (with a range of 7-14

Table 1

Demographic Data (parent)

	Father	Mother
N (total=12)	6	6
Mean age	43.8	40.7
(range)	(40 - 48)	(38 - 42)
Average education	13.3	12.3
(range)	(12 - 16)	(12 - 15)
Work outside home	6	5
Annual Income	6.5-15 million Yen (about $ 50,000-115,000)	

Table 2

Demographic Data (child)

	Asthmatic child	Siblings
N (total = 14)	6	8
Girls	4	5
Boys	2	3
Mean age in years	10.3	10.5
(range)	(8 -12)	(7 -14)
Onset of disease		
age in years	3.3	
(range)	(1-6)	
Duration (years)	7	
(range)	(5-9)	
Severity of Asthma		
Light	1	
Mild	4	
Severe	1	

years). The average number of siblings in the study was 1.3 (with a range of 1-2).

Two fathers worked in a "fish market," a large fish wholesale market near Tokyo Bay. Their job started early in the morning, around 3 a.m. , and ended by early afternoon. This characteristic was considered important, because asthma attacks tend to happen more frequently at night. Three of the fathers ran businesses by themselves. One ran a restaurant and two ran wholesale outlets; one was for daily necessities, one for fish. The remaining two fathers were employees; one was an engineer and one was a salesman.

Three mothers were employed by their husbands. Their work schedule was more flexible than that of the fathers and they worked less time than did the fathers; more of their time was consumed in domestic chores. One mother worked as a full time nurse in a nursing home. One mother worked in a hospital as a clinical laboratory technician full time. One mother was a full time housewife.

The father's average length of education was 13.3 years with a range of 12 to 16 years (In Japan, a compulsory education is 9 years, elementary school and junior high school). The mothers' average education was 12.3 years with a range of 12 to 15.

The income of all the families was in the middle to upper middle income bracket. According to recent Japanese statistics (Health and Welfare Statistics Association, 1992), the average income in one family was about 6 million yen (about $ 48,000) per year, and the informants' income ranged from 6.5-15 million yen (about $50,000 -$115,000) per year.

Four families owned their own homes. The amount of space in each home varied widely; none of the homes had a garden. The investigator visited five of the six homes; the sixth home was not visited by the investigator, but the family described to her changes which they had made in their home because of their child's asthma. Two families had their workplace on the first floor and lived on the second and/or third floor. Two families lived in an apartment; each apartment had at least four rooms including a dining room and kitchen. Three of the families lived with grandmothers and one also lived with a cousin.

No families expressed a particular religious preference nor did they note religious beliefs which influenced their experience.

The time of disease onset for the children ranged from 1 to 6 years old, the average being 3.3 years. The duration of having asthma ranged from 5 to 9 years, the mean being 7 years. The average number of admissions to the hospital was 8.7, ranging from 0 to 25.

The severity of the disease was determined by the pediatric allergy specialist at the allergy clinic for this study. This pediatrician stated that it was difficult to say objectively how severe each case of asthma was because of the ambiguity of the ways this disease can be classified. However, based on her experience and on the treatment, she described these children's conditions as ranging from light to severe. According to this doctor, children with one light, four mild and one severe condition were included in the sample.

Because the District Office officially recognized that the asthma of the children of five of the families was caused by pollution, those families were awarded government financial assistance. One family did not receive this type of financial support because they lived out of the designated area. This family, however, had health insurance which covered 70 % of the cost of treatment for the child's asthma.

Content of the Interviews

The interviews with the members of six families in which an asthmatic child lived revealed that their perceptions of living with an asthmatic child involved three major experiences: 1) the individual family members' experience of making decisions regarding changes in family lifestyle, 2) responsibility for managing the child's asthma, and 3) variations in the family adaptation to life with a child with asthma.

The Individual Family Members' Experience of Making Decisions Regarding Changes in Family Lifestyle

One commonly cited theme derived from the analysis of the interviews was the theme of the experience of a family lifestyle which changed dramatically because of living with a child with asthma.

In the interviews of all parents it was clear that they felt that at least some part of their lifestyle was changed because of living with a child with asthma. The specific parts of the family lifestyle which the parents cited as being changed (or at least being considered for change) were four: 1) the home environment (carpet, bed, pillow, etc.), 2) daily activity (cleaning), 3) habits (having a dog, smoking), and 4) jobs. Except one father, all mothers and fathers mentioned their home environmental changes and the cleaning issues. Two fathers discussed the fact that even though it would be better for their child with asthma if they moved to an area with cleaner air, this was simply not possible because of their jobs which could not be changed. One father mentioned his smoking and one mother mentioned her dog. There were a number of interviews which spoke of the influence that living with a child with asthma had on their daily habits. For instance, one father mentioned that although he knew his smoking was bad for his child with asthma, he was unable to change this habit because he felt he needed it as an outlet to help manage his stress level, being, as he was, in a highly stressful job. Similarly one mother told the story of how, even though she knew that being around dogs was not good for her child's asthma, she decided to keep a dog in the house because she felt that the psychological importance of the dog to her, to the asthmatic child and to the rest of the family, outweighed the problem it caused related to the asthma.

In the contrast to the parent interviews, the interviews of the children cited fewer categories of things perceived as changing because of the asthma. Two asthmatic children did mention a few of the environmental changes, such as carpet removal, and remodeling the house. No siblings mentioned any lifestyle changes.

It was clear from the interviews that making the decision about what to change and how to change it to make the best adaptation for the child with asthma and the rest of the family was a serious struggle for every family. In this process, five factors were identified which appeared to influence the family members' decision to change or not change their lifestyle. These five factors were the following: 1) the parents' evaluation of the severity of the child's condition 2) the parents' belief in a " Window of opportunity" for cure of the asthma 3) the parents' uncertainty of the cause of the asthma attacks 4) the parents' sources of information about the disease 5) the parents' experience of conflicting values regarding making asthma-related changes.

The Parents' Evaluation of the Severity of the Child's Condition

Three fathers specifically mentioned that their child's asthma was not severe enough for them to change jobs. One father said that it was really no obstacle in his life; nothing to affect or interfere with his life. Another father said that even if his daughter became allergic to soba and if he owned a soba restaurant and if his daughter asked him to change his job, still, he might not do it unless it was very serious. Another father similarly said that he had never thought of changing his job since the disease was not that serious.

In contrast to some fathers, one mother said: "Because of having her, I couldn't go to work...All the time, if she had an attack, once or twice a month, and if I worked full time, then it might cause trouble for the people at work. Because I would have to take days off." (Appendix C-1). This mother started to work two years ago. At that time she chose the job of being a part time visiting nurse which was convenient for her because of the flexible time schedule. Because of this and other considerations, this mother later took a full time job closer to her house.

In this study, the parents' perceptions of severity of the child's asthma was very similar to the doctor's evaluation of severity. For example, one father said his child's asthma was not severe enough to change his job. The doctor classified this child as mild.

The Parents' Belief in a " Window of opportunity" for Cure of the Asthma

The second subcategory under this theme dealt not with the severity of the disease, but rather with the question of whether the disease was permanent, chronic, short or long term, or even whether there might be a " window of opportunity," i.e., a certain short period of the time during which, if the proper things were done, a cure for life might be achieved, but after which, if the proper things had not been done, the child would continue to be asthmatic.

As an example of this struggle to understand whether the illness would be short or long term was one father said that: " At first I thought that time could cure my child's asthma. Now I have come to doubt this. Now I realize that it can continue into adulthood, and that makes me wonder if it may just last through her entire life...But maybe if we could cure it during this time of her childhood, we could prevent this. I feel it might be possible if we do something during these childhood years. This is one of the reasons that we built a new house." (Appendix C-2). The mother of the same child, however, said that she thought that her daughter's lungs were weak and that this weakness would probably last for her entire lifetime.

The Parents' Uncertainty of the Cause of the Asthma Attacks

Many parents were struggling with uncertainty about what caused the child's asthma attacks.

For example, one father said, " My wife asked me to ask my father to take the carpet off. If we knew for sure that taking the wool carpet off would cure A's asthma, then, we would take it off." (Appendix C-3). This father's struggle about whether the carpet was really the cause of the asthma even created a quarrel with his own father. Because his own father had put the carpet in just four years ago when they built the house, it was difficult to approach him to ask him to remove it. Nonetheless, because this father, though uncertain, thought that the carpet might be the cause of the asthma, he did indeed approach his father, asking him to remove it, knowing that it might cause hard feelings, but at last the grandfather gave in and did take the carpet away.

One mother was struggling about whether she should keep the dog in the house. The reason she said that she was uncertain about what to do was she believed that the dog was just one of the many items which were assumed to be bad to the child's health or to cause the asthma attacks. After struggling with the idea, her decision was to continue to have the dog.

Another mother expressed doubt about her efforts to prevent an attack by cleaning because of the school environment. She cleaned her house meticulously, but in the school there was much dust in the corridor.

doctor told them to change, she did not know how much they could do, but some of them, if they were important, of course they would have done it. She thought that if they could do them all, it would be better. But it was impossible. She did try to clean the house diligently by using a vacuum cleaner.

Other information sources about the disease were books, mass media, such as TV or newspaper, public lectures, friends, and relatives. For the fathers, the information source was often their wives. Those information sources also somehow influenced their decision to change their lifestyles, in both good ways and bad ways. One mother and one father from the same family said that they thought their son was more dependent. This father said that even though he was not familiar enough with other children to compare his child, he felt like this. Both of them said separately that they were not sure if their partner thought the same way as they. They read in the newspaper a long time ago that an asthmatic child lacked self-reliance (*iraishin ga tsuyoi*). So they were wondering if their son might be such a child, or if "the lack of self-reliance" might be just one of his characteristics. The father only knew that he made his son dependent "*amaesaseta* " because he had asthma. The mother felt the child's asthma might be her fault after reading the article which said that the mother was the origin of asthma or responsible for the asthma.

The Parents' Experience of Conflicting Values Regarding Making Asthma-related Changes

Some things seemed to be so much a part of the family's lifestyle that they were hard to change and the family had to face conflicting values relating to whether they were or were not willing to make a given change in their lifestyle. For example, one father said that he had a difficult time trying to quit smoking. He used to smoke, and when his child had asthma, he tried to quit because it was bad for both his child and his own health too. Actually he was able to quit smoking for about one month, but then he started smoking again. Now when he wants to smoke at home, he smokes on the veranda. He explained that he needs to smoke because it relieves his feelings of tension from the stress at work.

One mother explained why she continued to keep a dog in the house even though she realized it was one cause of her child's asthma attacks. At first, she described several changes that the family did make: to an all-wood floor except one tatami room; to beds instead of futons; to the pillow with plastic tube instead of feather or buckwheat chaff; to use of cotton blankets. It was clear from her description that the family was willing to make many changes, but then, she said " Whatever we could change, we changed. Only...We have a dog...Elder sister likes it very much and I like it too, and it has been with us for our whole lives...So, even though we knew that my child has asthma, we kept the dog, and when he died we replaced him with a new one." (Appendix C-4). She explained how a dog was an important part of her and her family's life. In her struggle to decide whether or not to keep the dog, she tried to weigh the advantages and disadvantages of the dog to her child's health and of the other family values such as their psychological attachment to the dog. In the end, she decided to keep the dog.

Another value which heavily influenced decisions about family lifestyle was the value placed on the parents' jobs, particularly the father's. One mother and father from the same family explained that they could not do anything about changing their lifestyle because of their job. They owned and ran a restaurant.

And a final value seen in the interviews to conflict with the decision about making asthma-related changes was the value of convenience. In the interview of one father, he described that he had become exceedingly aware of cleanliness in the house. In fact they had become so careful about cleaning the old house which it became apparent was impossible to keep dust-free, that they decided to build a new house specifically to accommodate the needs of the asthmatic child. However as they began to build the new house they realized they would need to compromise. Although they originally had planned to have all wooden flooring, they soon realized that this would severely limit the space. (In tatami style, when sleeping at night, people spread futon and in the daytime they put the futon in the closet. This meant that the family could use the space more effectively. If they kept all wooden floors and beds, it would mean that the beds could not be rolled up during the day the way a futon could. Because the house was small to begin with, this would result in much less space for the family to move around in since the fixed bed would take up considerably more floor space than the futon which should be rolled up into a small bundle in the corner of the room during the day. Since this would make it very inconvenient for both the parents and the other child, they finally decided to compromise and have the first floor flooring of wood, but the remaining floors tatami.

Responsibility for Managing the Child's Asthma

Another theme of the family experience of having an asthmatic child was the responsibility for the illness management. There were two main aspects of this theme: Whose responsibility was illness management and transfer of responsibility for illness management.

Whose Responsibility

It was clear from the interviews that all fathers expected their wives to manage most aspects of their child's asthma, including medication, going to see the doctor, school activities, communication with the doctors and the school teachers, and so on. When talking about the responsibility, some of the fathers used the word " *makaseru* " which means that they would leave the responsibility to someone else, in this case to the mother. Although all fathers participated in the management of the child illness, especially when the child had an attack, most of the management was the responsibility of the mother.

Some of the examples of fathers participating in the illness management are the following: One father said that he did understand a great deal about his child's illness, even though he did not know about all the medicine his daughter took. However, he said that since his wife often forgot medication for his daughter, he used to ask his daughter if she took the medicine in the morning, just in case that was a morning on which the mother had not reminded the daughter. His role also included talking with the doctor about his daughter's condition when she was hospitalized or was in the emergency room because of her asthma attacks.

Another father told about his experience with a school principal. His daughter was supposed to participate in the field trip (*kougaijisshu*) in another prefecture for two nights when she was in the fifth grade. Although the classroom teacher was not concerned much about this, the school principal was afraid that she might have an asthma attack at night and asked one of the parents to accompany their daughter during that practice. Then the father went to the school principal with the medical certificate and discussed whether his daughter could go without a parent. The school principal explained that they did not know how to treat her when she had an asthma attack, even though both the school doctor and the school nurse would accompany the class on this outing. At that time, the father realized that the school principal was frightened that something might happen to his daughter and he did not want the school to be responsible for any problems in this regard. At this point the father became very firm with the principal telling him that he would not hold the school responsible for any problems resulting from an asthma attack during this field trip; he himself would assume such responsibility, but he did insist that his daughter be allowed to accompany her classmates without having a parent present. Finally, the father convinced the school principal who, after checking with the child's physician, did allow his daughter to participate in the experience. The father said that the school teachers were just interested in their salaries, "*salary men teacher*."

This was not true of all families, however. In another family, for instance, it was the mother rather than the father who would bring her son to the hospital both for his regular health checks and for emergencies. She explained that because her husband worked in the fish market and had to get up very early in the morning she felt that waking him up to take the child to the hospital at night would interfere with his job; besides, she added that she believed that she was better able to explain the child's condition to the doctor or nurses than the father.

Another aspect of who took responsibility for the child's asthma arose when the child was at school. One mother said that she did not expect the school teacher to treat her child when she had an asthma attack in school and asked the teacher to call the mother. On the other hand, there was another mother who said that the school nurse did take care of her child when she had an asthma attack, though the mother qualified this by saying that the nurse was not always able to do this if she was very busy, and consequently the mother requested that the nurse call the mother if necessary (in Japan, by law, each public school has a full time school nurse).

In only one family was a sibling cited as taking responsibility for the asthma. This was a thirteen year-old sister who said that when the mother was not at home, she asked her sister who had asthma if she took the medicine and if she had not taken it, this sister would make sure that she would take it. This particular sister was the one sibling who had herself had light asthma attack one year ago, and consequently was somewhat familiar with the disease.

One father said that at the attack the parent could not do anything, but depended on the doctor.

Transfer of Responsibility for Illness Management

Another important issue around responsibility for managing the child's asthma was the transfer of responsibility from mother to child. This transfer of responsibility for illness management seemed to be seen most clearly in two areas: The child's interface with the school system and the child's interface with the health care system.

In the data, illness management included medical care (medication, visiting the doctor periodically), treatment of asthma attack (including both initial treatment such as drinking water, or taking medication, and later transfer such as visiting the doctor or emergency room), and daily life management (the environment and others, health promotion and maintenance behavior).

In the area of medical care, both taking medications and visiting the doctor were included. In most families, this transfer of responsibility was suggested originally by the doctor but actually carried out by the mother.

herself and her disease.

When one mother was describing her experience with transferring the responsibility for the medication from herself to her daughter, she described how she had been originally very nervous about the responsibility even herself and used to write down all the medicines she took, but when the doctor finally told her that it was time to teach her daughter how to take this responsibility, she was relieved. Since the daughter was in good condition at that time, she did give the responsibility to her child. She was careful not to keep asking the child whether she had really taken her medicine since she felt this might cause the girl to become less responsible. Even though the mother knew the daughter was a little nervous, she felt it was good for her. In this same family, however, the father and grandmother, who were also nervous about whether the child would assume the responsibility appropriately, used to ask the child if she had taken the medication each time. Finally the doctor told them that all this questioning was too much for the child, that she was sick and tired of hearing these question and should be trusted to take on the responsibility without such constant interference. After this warning from the doctor, they stopped asking her about her medicine.

Another mother with a 12 year-old asthmatic child explained how and why she transferred the responsibility of the child's illness management from herself to the child. The mother used to manage the medicine, carefully counting the number of pills and checking to see if the daughter had taken all of them. However after meeting the doctor, she changed her way of dealing with the child. She started to think that if the child had no "*jikaku*" (self-awareness), she would never be cured. So she gave the responsibility to her child, but still she was worried about whether or not her child was doing it correctly. She was afraid that her child might not be responsible about her medications; consequently the mother still checked the medicine in secret.

In regard to transferring to the child the responsibility for treating an asthma attack, two types of information emerged from the data: 1) initial treatment such as drinking water and medication, and 2) later medical treatment such as visiting the doctor or emergency room. For instance, when children had an attack in school and needed treatment such as drinking water, cupping, or abdominal breathing, they were able to handle these treatments by themselves even as early as 8 years old and the parents recognized their child's ability to deal with such situations on their own.

The mother of an eight year old child said that the child became able to self-treat because of being taught repeatedly by the doctors and the nurses during several hospitalizations. She was also learning by herself, through her experience, which treatments to use and how each eased her symptoms.

In the school system, mothers of two 8 year old children and two 12 year old children told the teachers in the school that when the child had an asthma attack or any other problems with the disease in school, they should let the child make a decision (*makasete*) if she/he would go to the class or not; this is especially true in the physical education class.

At the time of attack, the mother, and sometimes both parents, evaluated the severity of the child's condition and decided whether the child should go to the hospital or not. One father of a 12 year-old child said that the child was able to understand when she needed to go to the hospital by herself and recently she decided and asked the parents to take her to the hospital, which was not the parents' decision. This child explained that she knew when she had to go to the hospital.

Another mother of a 12 year old child said that the child did not ask her parents to take her to the hospital by herself because she was a patient child, and could wait for or postpone treatment for a few hours. The mother tried to take her child to the hospital before 12 a.m. or after about 5 a. m. because the mother felt she was sorry for the medical staff even though the medical staff said she could come whenever a severe attack occurred. Contrary to the mother, the father in the same family tried to bring the child to the hospital whenever she had difficult breathing. The mother admitted this discrepancy. This child thought she could manage her attack and wanted the mother to leave her alone, but her mother usually woke her up when the coughing or wheezing started. The child explained that her mother told her that she disliked hearing the sound of wheezing or coughing, so she woke her daughter up.

In the area of the daily life management, for example, one 12 year-old child explained how she managed her illness in her life in school and other places. Because she found that contact with animals triggered her asthma attacks, she voluntarily chose the responsibility of working on the class newspaper rather than caring for the class animal. In addition she tried to do things to increase her physical strength, such as ensemble (club activity), swimming, and footbase (a kind of baseball for girls). She did all these things hoping that they might cure her illness, but she is gradually realizing that doing these things may not cure her asthma. Her mother said that her daughter lacked "*jikaku* " (self-awareness) because she often forgot to take her medication. Her father also described this child as lacking "*jikaku* " (self-awareness) even though she was active in school and other places, because she did not follow his advice about various things such as going to bed early in order to avoid fatigue.

One mother explained that when her 12 year-old son entered junior high school she would become worried because this level of education is known in Japan to be extraordinarily difficult since the student must study so hard to pass the entrance examination. Although she had, for years, tried to help her son make his own decisions regarding his asthma, she felt that this attempt had not yet been totally successful. But now she realized that it was becoming imperative that he become responsible for his own care, so she was becoming more and more firm in her expectations of him. She was making it clear to him that she did in fact expect him to make responsible decisions. The father in this family felt that his wife was overly concerned about whether their son would be able to take on the responsibility of his disease appropriately.

He felt that, even though the child had not yet demonstrated such responsibility, he would achieve it naturally as he grew older.

Variations in the Family Adaptation to Life with a Child with Asthma

The last theme derived from the interviews is the theme of how the family members varied in their adaptation to life with a child with asthma. Such variation was seen both within and among families.

One adaptation found in the data was the restricting of the child's activities, or of family's activities. The amount of such restriction differed greatly among families. For instance, some mothers and fathers expressed their fear about causing attacks if they allowed the child to stay over night or travel to other places, and that's why they could not allow the child to do that. Some families tried to limit the restrictions for the sibling by allowing the brother and sister to travel with one of the parents while the other stayed with the asthmatic child. In this case, usually the mother and the affected child stayed at home. One father said that when the child asked to go somewhere with her sister and grandmother, he just said " no" because it would cause trouble with other people and even these people did not want to take her because if something had happened they were in trouble. Only if she was with the parents could she go anywhere.

Within one family, the father explained that when the asthmatic child's condition worsened, he was no longer able to pay enough attention to the younger sibling, and the family situation deteriorated to the point where the father described it as "hell." He often wondered why this had happened to him and thought that if he had not married his wife, he would never have had to suffer like this. He thought this because there was no asthma on his side of the family but there was on his wife's side. It was so bad that he could not even think about the younger child and it even created problems between his wife and his parents. All he could think of to say to the younger child was " be patient." He felt this way of adapting was harmful to the younger sister even though the sister herself never told the investigator about these effects on her. The mother of this family said that the disease was so severe (a few years ago) that it had dramatically affected her life, especially her family relationships. She said that: "It was changed. Totally changed. I myself was changed. Completely different ...Serving my father-in-law and mother-in-law...I was reluctant. That was understandable, wasn't it? Because they were not my own parents. I cried many times. But it was...After A became ill with asthma and that condition continued, and she had many repeated hospitalizations, and I felt it was very hard to part with her; because of all these things, I thought that I could change myself, my feelings, if it was for her, and I tried to do my best and did it. I was able to be changed. I tried not to care about all those demands from my mother-in-law. It should be alright if I endured it." (Appendix C-5). After this family met the doctor who is still their doctor now and the child was hospitalized for one month, the child had dramatically decreased the number of attacks and had no hospitalizations for one year. Following the advice of the doctor, the family allowed the child to go outside. With no hospitalizations for about one year, even though there might have been light attacks, the family really got to feeling safe. The father said that the family's life has totally changed since that time.

However, most families found various ways to lead less restrictive lives as the children grew up and illness improved. One mother of eight year old child controlled her child to stay overnight in friends' house when the child was young. However, as the child grew up, the child demanded eagerly to join activities with her friends and the mother could not keep her inside of the house anymore. Therefore, the mother allowed the child to stay overnight during limited days and keep calling at friend's house and asked the friend's parents if she was alright. One another parents of eight year old child said they allowed the child to go travel only if the parents accompanied with her. These two families allowed the rest of family members' travel even though the child could not join them. One father of 12 year old child said that when the child was young and the attack was frequently occurred, the whole family could not go travel anywhere and even near the house they limited the time in outside or the place for the child. They started to travel after the child condition was stable and got some security feeling about the travel. Although there was one mother who, from the very beginning, tried hard to treat her child as normal so that he would not think of himself as seriously ill, most families, at least at first, allowed their children "*amaesaseta,* " that is, they allowed their children to be dependent on them and they were very protective toward them. However, later on, most families changed their attitude toward their children and began expecting them to be more independent and to take more responsibility for themselves. Two father said that they also treated their children as normal because they were told to do so by the doctor.

The response to the attack was somewhat similar among family members of the affected children. When they realized that their child was having an attack, most of the parents described their first feeling / thought as "*mataka* " (oh, not again!). At the same time they felt pity for the child and thought that they wanted to take the place of the child if possible. The asthmatic children also explained about their attack experiences. One 12 year old child said that he wanted his family to understand his difficulty with an attack, because his mother used to tell him "*urusaiwane*" (do not bother me!) and seemed not to express empathy for him. Actually this mother agreed that she had not been very empathic to the child. This boy assumed that his friends also thought about his attack in the same way as his mother. He was annoyed about having these symptoms and he tried not to bother his classmates when he slept with them in the same room on overnight school travels.

One younger sibling (seven years old) said that during the time the parents and the affected child were in the hospital at night he stayed at home alone and he was scared being alone because he believed that there was a ghost in the second floor. He was hoping the rest of the family would come back soon.

Another aspect of helping the siblings to adapt to the illness situation was that during the asthma attack the siblings were excluded from the immediate situation. Some siblings voluntarily left the home in order to reduce potential contributions to the attack (e.g., dust from playing in the house). Other siblings were asked by the mother to leave, to go play outside.

In summary, the experiences of the family members of having an asthmatic child were centered around the family adaptation. The changing family lifestyle, illness management and variations of adaptation were considered as parts of the whole family adaptation.

Most of the parents said that whatever they could do they did, but admitted that there were limitations for the family in changing their lifestyle. Also, most of the parents said that they believed their child would outgrow asthma as he/she got more physical strength, usually by the time of puberty or adolescent.

It appeared that there were some gender differences between the parents in how they experienced having a child with asthma. around their experiences. The impact on the fathers seemed in general to be less than on the mothers. The fathers tended to spend more time wondering about the origin of the asthma, about the most effective treatment, and about the severity of the child's condition or about whether improvement was occurring. They were disappointed that despite their efforts the child's asthma was not cured.

On the other hand, the mothers tended to have more stress physically and emotionally and more concern about the relationships with the child than the father. The mothers were closer to the child than the father physically and emotionally. The fathers took a more supportive role surrounding the family. The siblings tended to be excluded, especially at the time of an asthmatic attack.

Besides the main experiences, what was the most difficult for the family members was described as having them sleep disturbed by an attack, and causing a sudden disruption of the family's daily life rhythm. Even the siblings complained about this and the parents said that it effected their performance at work.

CHAPTER V

DISCUSSION

The purpose of this study was to explore the experiences of family members living in a family which has a child with asthma. However for the purpose of the Master's Research Project (MRP), the discussion will be restricted to data obtained from the parents, later the data obtained from the children will be discussed in future work. This chapter will discuss the findings from the study. After the discussion, the limitations of the study will be described. Then, implications from this study for nursing practice will be described. Finally, there will be suggestions for possible future nursing research in this area.

Discussion in Findings from the Data

There were several important insights derived from the findings of the interviews. The insights chosen to be highlighted in this discussion section are not only the typical findings in the data but also specifically those which can be compared between Japan and America.

Changing Family Lifestyle

Among the family's experiences about changing their lifestyle, how mothers and fathers differed from each other in their experience as a result of their child's having asthma were found out. One difference between mothers and fathers in the Japanese families was the specific parts of their lives which were disrupted and the extent to which their lives were disrupted. The specific ways in which their lives were affected seemed to differ somewhat. For instance, although both mentioned the excessive cleaning that was necessary and the expense involved in obtaining equipment such as a special vacuum cleaner, it was the mother who actually did the cleaning and kept struggling with its effectiveness. Most fathers mentioned the importance of their job in regard to making or not making changes related to the child's asthma; only one mother mentioned her job in this context. These examples seemed to reflect gender specific roles in the family, and will be discussed later. However, the fathers' experiences of not having their lives much affected or disrupted seemed to be supported by their wives' devotion to child care. In this study, smoking appeared to be an issue primarily for the fathers while pets seemed to be more important to the mother. On the other hand, most of the mothers mentioned the home life changes and the emotional changes in her family relations while only one father did so.

In the experience of the family's decision making about changing their lifestyle in this study, five factors were derived as the most important factors which influenced the decision making process.

A number of families mentioned the importance of the job, particularly the father's job, in relation to the child's asthma. In their accounts, because of the father's job it would be impossible for the family to accommodate totally to the child's asthma. On the contrary to the results, both in Japan and the United States, some similarities were reported regarding the father's job and moving. A Japanese study by Yamamoto, Seya, Watanabe, Takano, Uchida, & Inoue (1988) found out that 7.4 % of the fathers of severely handicapped children (total was 122) changed their jobs and 31.1 % of the families moved to another places when the children were diagnosed as handicapped. However, the reasons for the changes were not delineated clearly in the paper. Another study of fathers of children with cerebral palsy in Japan also noted that one of 12 fathers changed his job because of his child's illness and six fathers (50 %) arranged their jobs to be close to a good doctor. Anderson (1981), a study in the United States, found that an entire family moved to another location, necessitating the father's change of job, in order to seek treatment for the child with leukemia.

At last, even if the parents, especially the fathers, changed their jobs, the child's asthma might not be cured. Usually, it is difficult to specify the cause of asthma, and also it is believed that there are several causes of asthma. On the other hand, like leukemia, if the treatment was done only in certain places, the father might change his job to seek treatment because there might be no other perceived choice for this family.

These results suggest that fathers' decisions about changing lifestyle might be influenced in part by how the father perceives and evaluates the child's disease, and its severity, or disease specific factors, including the need for special treatment or medical facilities near the family's home. In such sense, it can be said that if the father of asthmatic child thought the asthma was severe enough and might have been influenced by the environment, such as jobs or living places (industrial area etc.), he might change his job and move to another place.

When or if a father decides to change or arrange his job to respond to asthma might be influenced also by the culture in Japan. Even though men's attitudes toward their jobs have been changing, the man's job is still central to his life, and consequently to his family's life. Not only is it a means of financial support, but it in some ways can be seen as the major focus of his energies. He owes loyalty to his work. He works many hours. His work relationships are almost as strong as his family relationships. And he is expected to remain at the same workplace until he retires. Changing jobs is quite unusual in Japan and a middle aged man who seeks new employment is likely to be looked at askance. The prospective employer may well wonder if such as person has something wrong with his work skills or his ability to get along with people. It would be likely that the man would have difficulty even finding a new job. However, American society is currently very mobile. Few people remain in the same job their entire life. In fact, in certain occupations, it is the expected norm for workers to seek promotion by changing employers. Because of this job mobility it is not uncommon for the middle aged men to look for and find new jobs. In addition to the issue of mobility is the issue of job centrality. Although for some high level business executives jobs are the highest priority in their lives, this is not the cultural expectation for all men. It is not unusual for many families to view the man's job as a way to support the family financially, but no more than that.

Another finding of this study, which was identified as one of conflicting values, is the parents' habits as related to the child's asthma. The specific habits mentioned in literature from both Japan and the United States, and also in the interviews of this study are smoking and the keeping of pets. In one Japanese study (Uchimi, et. al., 1980), they conducted a survey with 50 families of asthmatic children and found out that 70 % of these families had someone who smoked within the family. A study by Donnelly et al., (1987) in the United States concluded that a pet was easy to give up but smoking was not. There certainly was some evidence from the present study that smoking was very difficult to give up, and frequently the father in the family continued to smoke even though it is well known to families of asthmatic children that smoking can precipitate problems for the child. One father did discuss his smoking and was unable to give it up. Two other fathers did not mention their smoking, but the researcher noticed a cigarette pack on the table in one home and in the other home, she met the husband smoking on the back as she left. Smoking did not occur in one family, but it is not known if smoking occurred in the remaining families. So it does seem that a parent's giving up a habit of smoking to improve their child's health is similarly difficult for both American and Japanese families.

As to the other idea expressed by Donnelly et al., (1987) that a pet was easy to give up, this was certainly not validated by the one family in this study who kept replacing their dog even though they knew that this was not good for the child's asthma, they did, however, believe that it was good for the child's emotional development. According to a Japanese study by Uchimi et al., (1980), 34 % of the 50 families with asthmatic children had pets, such as cats, dogs, rabbits, and birds. It is difficult to reach a certain conclusion with such a small sample, however, both pets and smoking are difficult for some people to give up.

Furthermore, even though the factors which influenced the decision making process varied from family to family and among the family members, one important factor appeared to be how the family perceived their situation, including the severity of the disease and uncertainty regarding the cause of asthma and asthma attacks. The family member's values suggested by choices around jobs, smoking behavior or pets might be influenced by their perceived situation. Mild asthma may not impact the fathers' jobs because of the belief that the illness is not severe enough to change a job or the change will not result in cure or improvement. If they think or believe that the child's asthma will be cured due to their lifestyle changes, then they would do so. Or on the contrary to that, the perceived situation might be influenced by the family members' value. For example, the person might value a pet so highly that he/she might convince him/herself that the disease is not severe enough to give up the pet, or the uncertainty of the causality of the disease might become the excuse for keeping the pet. Those kinds of interpretations seemed to be operative especially when the family members did not change their lifestyle in some parts. They might suspect that their unchanged lifestyles might result in adverse effects on their child's asthma, but more than that they might need to keep their valued lifestyle. Their guilt feeling toward the child might facilitate such interpretations which might ease their guilt feeling.

Finally, it is important for the family to have the correct knowledge about the disease to improve or change the family's health behavior or lifestyle, but health care professionals must also be aware of the need to carefully assess the family's perceived situation and the factors influencing their perceptions to improve or change the family's health behavior or lifestyle.

Responsibility for Illness Management

Probably the typical difference between how the mothers' and fathers' lives were influenced by this experience was the issue of responsibility for the child. Interestingly this, in many ways, was quite similar to what is reported in the American literature.

The Japanese fathers, much like the fathers in the United States, expected their wives to shoulder most of the responsibility of the child's illness management. Some fathers in the study used the word "*makaseru* " for this situation. This means that with or without agreement, one person gives his/her authority and responsibility to the other person. Usually this word implies a trust to the other person. Not only the father, but also the mother in Japan think about "child care" as a mother's job even when both parents work equally. The father's role tended to be as a "helper" or "support " to the mother. Most of the fathers took some responsibility in certain aspects of the disease such as reminding and monitoring the child of medication, instructing the child and driving the child to the hospital. One father said that his wife was the expert and whatever she "ordered" him to do, he would just follow this order. Another father said he was kind of a "messenger boy" between the mother and the doctor or nurses in the hospital. When his wife needed his help such as driving the child to the hospital at night he would do so. This is not so different from what has been shown in many studies in the United States literature (Anderson & Elfert, 1989; Jackson & Vessey, 1992; Turk & Kerns, 1985). These studies also indicate that it is usually the mother who is expected by both the mother and the father to assume the major responsibility for illness management. Another reason which might be considered about the woman as a caregiver is that it may be even though the guilt and blame feelings are common in the parents of chronically ill children, the woman felt more guilty and responsible for the child with chronic illness because the mother brought the child to the world (Anderson & Elfert, 1989).

There may be some subtle differences hidden within this similarity, however. The mother's life is more independent in the United State. In Japan, even if the child has no chronic illness, the mother's life is more centered around the family and child (Fujimi, 1989). The value that Americans place on individualism is getting noticed but still not fully common in Japan and consequently the mother's need to express herself in ways other than through her child is not as valued in Japan as in the United States, even when the child does not have a chronic illness.

Since even the mother with a child without a chronic illness is expected to center her entire life around her family and children, this expectation may not be so different from the mother of a child with asthma. In the United States, however, where the prevailing norm in families with children who do not have chronic illness is more likely to be that the mother is more independent, the enforced lack of independence resulting from the heavy responsibility for the child with asthma may be even more difficult to cope with since it so violates American values of individualism.

Another consideration about the responsibility for the illness management was the issue of transfer of responsibility from the mother to the child. The bottom line of this transfer is the child's development, cognitively, socially and emotionally. How, when, and why the mother transfers her responsibility is also influenced by how the mother perceives the child's disease, how the mother evaluates the child's ability to pursue the responsibility, and how the mother evaluates her child's characteristics which might influence how well the child pursues the responsibility for the illness management. When the mother wanted to discontinue the medication in the near future, she might not be active to teach her child about the medicine, such as its name or effect, and also not interested in self-management for the child's illness, except the most necessary ones, such as when to take the medication and the first treatment like drinking water and abdominal breathing.

Variances of Family Adaptation

Another area for discussion is the area of the restrictions experienced by the family and the child as a result of the asthma. According to the family accounts, these restrictions might be influenced by the parents' anxiety about the asthma attack itself and also about the unpredictability of the attack. This seemed to be more related to the parents' perception of the severity of the disease. The meaning of the severity is more related to the number of attacks which the child had. This can be seen as the disease controlling the family life. This restriction seems to loosen as the child grew up and the illness course improved. The child's development forced the parents to allow the child to be more independent and to expand his/her social life activities.

Such restrictions appear to be common in both cultures. Vavasseur (as cited in Thomas, 1990) listed such restrictions experienced in families in the United States who have child care options and finances. Although all the Japanese families also discussed the restrictions they experienced in their family life as a result of the child's asthma, the specific types of restrictions varied somewhat from those described in American families. Like the issues of the father's work, the explanation for such differences frequently appeared to be deeply embedded in the culture. Families in both cultures experienced restrictions related to travel. However, the reasons for these restrictions seemed slightly different. For the families in both Japan and the United States, the restriction occurred frequently because travel would make it impossible to care for the child properly. In Anderson's work (1981), for instance, the factor of the anxiety related to the disease of diabetics was cited as a reason for keeping the child near the home. Although these were also mentioned in Japan, the families more often mentioned that they could not travel because of the hardship this would impose on the other people. The Japanese value of "*meiwaku*" i. e., the reluctance of people to endanger personal relations by "causing trouble" was an important one in this regard.

Childcare options were found to be importantly restricted in the American family with a child with chronic illness (Vavasseur as cited in Thomas, 1990), but this was seldom mentioned in Japanese families. In Japan, unlike the United States, the parents seldom leave their child in the care of baby-sitters or other persons not in the immediate family. The idea of the husband and wife going out to dinner and leaving the child with a baby-sitter is not common in Japan even for children without chronic disease. Consequently the difference in child care between families with children who have asthma and those with children who do not have asthma is not strikingly different.

The last restriction mentioned by Vavasseur is that of finances. This also appeared to be different in Japan. Although many American families appear to be severely restricted financially when their child has a chronic illness, the families in this study did not report such problems. Whether this is because of the general economic differences between the two countries, because of the type of insurance coverage available in

Japan, or because of the official governmental financial support to certain asthmatic children as described earlier, is uncertain.

Again because of the small sample size, it is difficult to be certain that these differences between findings are real differences between the experiences of Japanese and American families or only artifacts of the sample size. Nonetheless, they are suggestive or important cross-cultural comparisons that should be incorporated into future studies.

Methodological Issue

Most of the work investigating what the experience of Japanese family members is when one child in the family has asthma has been done in the United States. One of the major contributions of the present work is that, in contrast, the data was gathered in Japan. Because this is one of the unique strengths of the present study, the discussion also will address in-depth the cross-cultural applicability of the research methodology.

The research method used was qualitative. This is a method becoming more popular in recent years in nursing research in the United States. In that county it is finding great applicability in investigating phenomenon in a way that quantitative approaches were unable to. It provides a way to explore the lived experience of clients in various setting. There are a number of data collection methods and designs, all of which are qualitative in nature, currently being used in the United States. Grounded theory, intensive interviewing, phenomenological investigation, and inductive inquiry are all qualitative attempts at gathering and analyzing data in such a way as to learn more about the real experience of people with whom nursing deals. The present study was an adaptation of such methods to the Japanese situation. In the process of using such methods in Japan several things have become clear. One issue that may have highlighted cross-cultural differences was the use of the interview. Interviews have been very successful in research in nursing in the United States and are considered an excellent way to elicit in-depth data about people's experience. However, communication is a culturally conditioned phenomenon and it is clear that communication in Japan is different than it is in the United States. Children in Japan are socialized differently than in the United States. They are not taught to be assertive and to express themselves verbally in the clear succinct way that American children are. Rather they learn a communication process that is deeply embedded in the context. It is often not considered appropriate to express one's emotions directly and verbally. The Japanese child learns the fine nuances of communication---some of which are verbal, but much of which are indirect, and many of which are nonverbal. These kinds of communication do not lend themselves well to the direct questions and analytic techniques developed so far in the United States for this kind of research. Therefore, when the interview is conducted to Japanese, the interviewer must be aware of these features/limitations and be sensitive to the context during the interview. To prove the validity of the data from the interview, the multiple examiner might be helpful to reach the agreement of the interpretation of the interview data.

In addition to the general communication pattern which is different than that of the United States, the cultural notion of what topic can be discussed and with whom they can be discussed and by whom they can be discussed are also at variance from United States norms. The idea of discussing the marriage relationship or sexual life, for instance, elicit considerable embarrassment. The issue of saving face and protecting family privacy are also important in this regard. The fact that the interviewer is not part of the family may mean that it is culturally inappropriate to divulge certain kinds of family information to him/her. For these reasons, face-to-face interviews may be inappropriate at least for some type of information and written data collection methods might be more effective.

Also the translation process was one of the important considerations from a cross-cultural perspectives. Because the original interviews were done in Japanese and needed, for this study, to be translated into English, a number of problems arose. The process of recording and transcribing such interviews are well known to be time-consuming projects, but when after transcribing, they must be translated, the task becomes almost insurmountable without considerable resources. Part of the issue is simply time and resources, part is expertise and part is the subjectivity of the translation process. Because so much of a culture's communication is do deeply embedded in language and individual's thinking processes are so heavily influenced by their language, there arises in all cultures fine nuances and shared understandings which simply have no counterparts in other languages. Terms such as "*jikaku* ", "*makasera* " and "*amaeru*" are simply not translatable. The connotation of such words is rich and culture bound and English has no analogous concept.

It can be seen then, that the both the research methodology and the specific findings of this study are rich not only in their own right, but because they are part of a small but growing attempt in the field of nursing research to compare and contrast the experience of families in different cultures struggling with similar health issues.

Limitations

The limitations of this study emanate from two primary sources: The use of interviews to gather data and the restriction of the information to the immediate family of the child with asthma.

Because the study gathered data through interviews, it was possible to get in-depth information from the subjects. This was a rich advantage to this data collection method. However, there are also some disadvantages. The first disadvantage is that since interviews are very expensive in terms of time, energy and money, it was necessary, as it often is when using interviews, to use a small sample size; only six families were included. Similarly, because of the large amount of resources required to use the interview method of data collection, it was not possible to do more than one interview with any one person. Consequently, it was not possible to go back to clarify meanings with the interviews. Nor was it possible to compare all aspects of the family members' experience since it frequently happened that a particular experience was only mentioned in one of the later interviews and there was no way to know whether those individuals interviewed earlier had also had such an experience. This limited the researcher's ability to compare and contrast experiences between families or between specific members of families and sometimes even between members of the same family. Other limitations which should be considered related to the technique of collecting data by interview are age and cultural limitations. Young children are not always as facile at using this method of describing their experience, particularly to an interviewer whom they have not learned to know and trust over time. Social desirability is likely to be a very serious threat to the accuracy of a report from a young interviewed by an adult whom they may well identify as an authority figure of some kind.

There also may be a cultural disadvantage to using the interview technique. Although such methods of data collection are becoming more common and respected in the United State, the experience of researchers using such interviews may be different in Japan than in the United State. The cultural norms for expressing oneself, for whom it is appropriate to express oneself to and what issues are appropriate to discuss with someone outside the family as well as who in the family is considered the appropriate spokesperson are quite different than in the United State. All these limitations to the use of interviews for collecting data must be considered when reading this study even though the researcher felt that the richness of the data far outweighed such disadvantages.

Another limitation to be kept in mind is that the family members interviewed were only the immediate family members, i. e., mother, father, and children. Neither grandparents nor other relatives were interviewed. Particularly in Japan, such extended family members may be very important in influencing the experience of all concerned. For instance, of the families in this study, three of the six families lived with their grandmother. Frequently these extended family members are important sources of emotional and/or instrumental support, or the source of stress. Such members of the extended family may give serious problems with anxiety or guilt and may be the ones who deal with the child and the asthma attacks when the parents are not home. Currently this situation is occurring more frequently because of the trend toward having both parents working, and these parents tend to ask their parents, especially grandmother, to take care of their children during daytime. Health care givers might benefit greatly from understanding their experience in more depth and might be able to provide much more effective care to the family as a whole. However, because of resource limitations, it was not possible to include them in this study and this must be considered a limitation.

Implications

In spite of these limitations, this study does provide a rich data base for not only clinical practice, but for research and theory development as well. It provides clinicians with in-depth knowledge of just how various family members experience their lives with the children with asthma. It is important as pediatric nurses and family nurses that we begin to understand more fully how illness in one family member affects the lives of all other family members. This study is certainly a good example of that happening. Although clinicians often deal only with the child suffering from the disease, such a study as this makes it clear that this is only a small part of the picture, and to do truly holistic care, the clinician needs to take into account many other aspects of the family life such as those described by the informants in this study. Issues such as whether to use tatami or wooden floors, whether to ask the siblings to leave when the child is having an attack, how to go about transferring the responsibility of the management of the illness to the child are all important issues for the family, as these families have clearly explained in their interviews, yet they are not issues with which the clinician has traditionally been involved. Hopefully this study will sensitize clinicians working with children with asthma not only to the needs of the child him/herself, but also to issues of the other family members.

Similarly, although this study has a number of limitations, it serves as a useful pilot study of the experience of Japanese family members living with a child with asthma. It is hoped that this will serve as a starting point for similar research in the future. Such research could expand this work in a number of directions. Certainly expansion of the research to families living with children with other chronic disease such as diabetes and rheumatoid arthritis should be studied. Other useful research in this area would include longitudinal work which would follow families from the time of diagnosis through the later stages of childhood. This would correct for the retrospective limitation of the present study.

Including family members from the extended families such as grandparents, aunts or uncles would also be a useful direction in which to expand this pilot study.

This study could also provide the groundwork for future research involving assessment and management strategies for the clinician working with such families. Assessment tools might be derived from the information given be these families and then researched as to their usefulness. Intervention techniques such as anticipatory guidance interventions based on the information shared by these families might also be constructed and tested empirically.

Finally, there are implications not only for the clinician and researcher, but for the theoretician as well. Analyzing these findings as they relate to family functioning theory should be very helpful to future theory development in this field.

Summary

The number of chronically ill children has been increasing both in the United State and Japan. In both countries, asthma is the most common disease and the number of this population has also been increasing.

The literature related to the chronically ill children and their families in the United States were reviewed and used as a base for this study. From this work an interview guide was derived to investigate systematically the experience of these families. This study was undertaken in order to get a beginning understanding of family members' experience of having an asthmatic child. Family members included in this study were fathers, mothers, siblings, and the child with asthma. All were interviewed one time except one child. A total of 26 family members in six families who had a child with asthma were each interviewed separately .

Three major experiences were identified from the interview data. 1) The individual family members' experience of making decisions regarding changes in their family lifestyle, 2) Responsibility for managing the child's asthma, and 3) Variations in family adaptations to their child with asthma.

These data were then analyzed and compared with the data available from the literature published in the United States and Canada and Japan and suggestions were made to explain both similarities and differences between the experiences of families in different cultures but with similar health concerns.

This will hopefully be the beginning of a clearer understanding of family members' experience when the family has a asthmatic child. This study also contribute to the chronic illness literature in general.

REFERENCES

Akasaka, T. , Nezu, S. , Suzuki, I. , Mitsubayashi, T. , Maruki, K. , & Maeda, K. (1982). Zensokuji no shinrigaku [Psychology of asthmatic child] . Shoni Naika, 14(2), 171-183.

Alexander, J. S. , Younger, R. E. , Cohen, R. M. , & Crawford, L. V. (1988). Effectiveness of a nurse-managed program for children with chronic asthma. Journal of Pediatric Nursing, 3 (5), 312-317.

Anderson, J. M. (1981). The social construction of illness experience: Families with a chronically-ill child. Journal of Advanced Nursing, 6, 427-434.

Anderson, J. M. , & Elfert, H. (1989). Managing chronic illness in the family: Woman as caretakers. Journal of Advanced Nursing, 14, 735-743.

Baba, K. (1990). Korekara no shoni iryo [Future child medicine] . The Japanese Journal of Nursing Science, 15(1), 57-63.

Baba, M. (1988). Kikanshi zensoku [Bronchial asthma] . In M. Hirayama, M. Ando, Y. Takano, K. Tamura, T. Nomura, M. Fukaya, S. Morigami, & Yuzuki (Eds.), Gendai Kodomo Daihyakka [Current Child Encyclopedia] (pp. 143-145). Tokyo: Chuo Hoki Publisher.

Caroselli-Karinja, M. F. (1990). Asthma and adaptation: Exploring the family system. Journal of Psychosocial Nursing, 28(4), 34-39.

Damrosch, S. P. , & Perry, L. A. (1989). Self-reported adjustment, chronic sorrow, and coping of parents of children with Down syndrome. Nursing Research, 38(1), 25-30.

Deatrick, J. A. , & Knafl, K. A. (1990). Management behaviors: Day-to-day adjustments to childhood chronic conditions. Journal of Pediatric Nursing, 5(1), 15-22.

Donnelly, J. E. , Donnelly, W. J. , & Thong, Y. H. (1987). Parental perceptions and attitudes toward asthma and its treatment: A controlled study. Social Science Medicine, 24(5), 431-437.

Feldman, C. H. (1987). Asthma education: General aspects of childhood programs. Journal of Allergy Clinical Immunology, 80(3), 494-497.

Fujimi, J. (1989). Kazoku seikatsu no raifu sutairu [Lifestyle in Family life]. Kango Kenkyu, 22(2), 126-136.

Garrison, W. T. , & McQuiston, S. (1989). Chronic illness during childhood and adolescence: Psychological Aspects. Newbury Park, California: SAGE.

Hirose, T. , & Ueda, R. (1989). Noseimahiji no juyo ni kansuru chosa: Chichioya o chushin toshite [The survey regarding to the acceptance of having an cerebral palsy child: fathers' case] [Abstract]. Proceedings of the 20th Annual Convention of the Shoni Kango, 91-93.

Hobbs, N. , Perrin, J. M. , & Ireys, H. T. (1985). Chronically ill children and their families. San Francisco: Jossey-Bass.

Jackson, P. L. , & Vessey, J. A. (1992). Primary care of the child with a chronic condition. St. Louis: Mosby Year Book.

Khampalikit, S. (1983). The interrelationships between the asthmatic child's dependency behavior, his perception of his illness, and his mother's perception of his illness. Maternal-Child Nursing Journal, 12(4), 221-297.

Knafl, K. A. , & Deatrick, J. A. (1990). Family management style: Concept analysis and development. Journal of Pediatric Nursing, 5(1), 4-14.

McKeever, P. (1983). Siblings of chronically ill children: A literature review with implications for research and practice. American Journal of Orthopsychiatrics, 53(2), 209-218.

Murphy, S. (1986). Family study and nursing research. IMAGE: Journal of Nursing Scholarship, 18(4), 170-174.

Nishikawa, K. , Masaki, T. , Kajita, T. , Tomita, U. , Shirai, Y. , Nagakura, T. , Iikura, Y. , Seo, K. , Sugimoto, & Saito, H. (1981). Gakudo zensokuji no gakko seikatsu jotai [The problems of school children with bronchial asthma] . Shoni Hoken Kenkyu, 40(3), 260-264.

Osugi, K. (1982). Zensokuji no ryoshin kyoiku: Kaunseringu o toriirete [Parent education in asthmatic child: Introduce counseling into parent education] . Shoni Kango, 5(13), 1721-1727.

Patterson, J. M. (1988). Chronic illness in children and the impact on families. In C. S. Chilman, E. W. Nunnally, & F. M. Cox (Eds.), Chronic illness and disability (pp. 69-107). Newbury Park: SAGE.

Perrin, J. M. , & MacLean, W. E. (1988). Children with chronic illness: The prevention of dysfunction. The Pediatric Clinics of North

America, 35(6), 1325-1337.

Reddihough, D. S. , Landau, L. , Johnes, H. J. , & Rikards, W. S. (1977). Family anxieties in childhood asthma. Austrian Pediatric Journal, 13, 295-298.

Sabbeth, B. (1984). Understanding the impact of chronic childhood illness on families. Pediatric Clinics of North America, 31(1), 47-57.

Sabbeth, B. F. , & Leventhal, J. M. (1984). Marital adjustment to chronic childhood illness: A critique of the literature. Pediatrics, 73(6), 762-768.

Shibutani, S. , Toyoshima, K. , & Takaki, S. (1986). Shoni kikanshi zensoku no shinriteki yoin to soreni taisuru kanji to ryoshin no ninshiki [Psychological factors of childhood asthma and asthmatic child's and his mother's perception to them] . Shonika Shinryo, 49(2), 243-248.

Staudenmayer, H. (1981). Parental anxiety and other psychosocial factors associated with childhood asthma. Journal of Chronic Disease, 34, 627-636.

Takashima, H. (1990). Bunka no hatten to arerugi shikkan [Culture development and allergy disease] . Shoni Hoken Kenkyu, 49(1), 3-10.

Taylor, S. C. (1980). The effect of chronic childhood illness upon well siblings. Maternal-Child Nursing Journal, 9, 109-116.

Thomas, C. (1990). Stressors experienced by families with children on peritoneal dialysis. Unpublished master's thesis, Oregon Health

Sciences University, Portland, OR.

Tsay, M. , Mukoyama, T. , Matsui, T. , & Iwasaki, E. (1981). Kikanshi Zensokuji ni mirareta tokokyohisho no jusan rei [Thirteen cases of school phobia in children with bronchial asthma] . Shoni Hoken Kenkyu, 40(5), 476-479.

Turk, D. C. , & Kerns, R. D. (Eds.). (1985). Health, illness, and families: A life-span perspective. New York: John Wiley & Sons.

Uchimi, M. , Amamiya, H. , & Torii, U. (1980). Zensokuji no kango: Yoiku kankyo to seishinteki antei no juyosei ni tsuite [Nursing in asthmatic child: Importance of nurturing environment and mental stability] . Shoni Kango, 3 (3), 257-265.

Walker, J . , Thomas, M . , & Russell, I. (1971). Spina bifida and the parents. Developmental medicine of Child Neurology, 13, 462-476.

Weitzman, M. (1984). School and Peer Relations. Pediatric Clinics of North America, 31(1), 59-69.

Yamamoto, K. , Seya, Y. , Watanabe, T. , Takano, S. , Uchida, T. , & Inoue, Y. (1988). Shogai shoni no chichioya so (sono 2) : Chichioya toshiteno ikikata to sono shinjo [Image of Father with an handicapped child (second report): The living way as a father and his mind] [Abstract] . Proceedings of Shoni Hoken Gakkai, 666-667.

APPENDIXCES

Appendix A-1

Interview Guide (English version)

A. Demographic data:
  1. Mother, father, child
  2. Sex: male, female
  3. Age (Grade):
  4. Occupation:
  5. Religious:
  6. Income:
  7. Level of education:
  8. Diagnosis:
  9. Onset of child illness:
  10. Treatment schedule and follow up schedule at out-patient clinic

B. To parents
  1. What does it mean to be the mother /father of a child with asthma ? (Tell me what it means to you personally)
    1) How does it change your life and/or your family life?
      (Probe for daily life,business life, relationship among /between family, physically, emotionally,financially)
    2) How does it change your attitude toward
      -disease
      -medical staff
      -health care system
      -school
    3) What happens when plans need to be changed because of the asthma?
      How do you feel about it?
      What does it mean?
    4) What have you gained personally (as a family) by the experience of caring for a child with asthma?
    5) What has been most difficult personally by the experience of caring for a child with asthma?

C. To children

The purpose of these question is to explore the meaning of having a sibling with asthma or having childhood asthma. Because of the potential range of age and development for these children is so broad, the following are only examples of how the investigator will approach the question of meaning.

1. What is it like to have a brother/sister who has asthma?
2. What do you think would be different if (person) did not have asthma?
    (Probe for understanding effect of having asthma or asthmatic brother/sister on school life academic achievement, physical activities, peer relationship)
3. How does it feel to you when your brother/sister has an asthma attack?
    (Probe for change plan, scare to death)
4. Have you ever thought you might get asthma?
    (Probe for understanding of etiology and scare of possibility to develop asthma)
5. How do you think your brother/sister get asthma?
    (Probe for understanding of etiology of asthma and possible guilt feeling)

Appendix A-2

Interview Guide (Japanese version)

インタビュー・ガイド

＜質問項目＞

１．一般項目

（１）父親、母親、兄弟、患児

（２）性別：男、女

（３）年齢（学年）

（４）職業

（５）宗教

（６）経済状況（収入）

（７）教育レベル

（８）診断

（９）発病時期

（10）外来での治療計画（薬物、受診間隔など）

２．両親へ

（１）あなたにとって、喘息のお子さんの父親／母親であることはどのような意味を持ってますか？

１）喘息のお子さんをもつことによって　あなたの生活あるいは家族の生活はどのように変わりましたか（変わりますか）？
＊日常生活、仕事、家族間・内での関係、身体的、精神的、経済的な変化

２）喘息のお子さんを持つことによって、あなたの喘息、医療スタッフ、医療システム、学校に対する態度は　どのように変わりましたか？

３）喘息のために　計画を変更しなくてはいけなくなったときどのようなことがおきますか？
（計画を変更しなくてはいけなくなったことについて　あなたはどのように感じますか？）

４）喘息のお子さんをもつことで、個人的になにか得るものがありましたか？

５）喘息のお子さんをもつことで、なにが一番個人的に大変でしたか？

３．お子様へ（子どもの年齢に幅があるため、以下の質問は多少変更されることがあります）

（１）喘息の兄弟をもつことは／喘息であることは　あなたにとってどのようなものですか？

（２）もしあなたの兄弟／あなたが　喘息でなかったらどのように違っていたと思いますか？
（学校生活、友人関係、身体活動など）

（３）あなたの兄弟／あなたに　喘息の発作がおきた時　どのようにかんじますか？

（４）あなたは　喘息になるかもしれないと思ったことがありますか？
（兄弟のみ）

（５）どのような理由で　あなたの兄弟／あなたは喘息になったと思いますか？

Appendix B-1

Invitation to the participation in the study (English version)

I am a graduate nursing student in Oregon Health Sciences University in the United States. This study is a requirement as a master's theses in graduate nursing program. This study is under supervision of faculties in Oregon Health Sciences University.

The purpose of this study is to explore the experiences of Japanese family who have a child with asthma.

Although participating in this study will not be of immediate benefit to you, the information you contribute may benefit other families of asthmatic children.

If your family (a father,a mother,siblings over 7 year olds, and a child with asthma) chooses to participate in the study, each of you will be interviewed separately. The interview will take approximately 15 minutes to one hour. The questions will include such things as "What does it mean to you having a asthmatic child?" "How does it change your life (daily life, business life, etc)?" These interviews will be audio-tape recorded. If you feel uncomfortable about any questions, you are free to refuse to answer these.

Your family's participation in this study is completely voluntary and you may withdraw from the study at any time without penalty or loss of benefits to which you are otherwise entitled. During the process of transcription, your name will be deleted and pseudonym will be substituted. Only the investigator and her research committee (Oregon Health Sciences University) and a Japanese nurse expert will have access to these transcriptions. The recorded tapes will be destroyed after the study. Neither your name nor your identity will be used in the theses.

Please explain to your children about the study, and do not force them to participate in the study.

If you prefer that the interview take place outside of your home, the transportation fee to the place of interview will be paid by the investigator. Otherwise, there are no costs associated with your participation.

If there are any questions about this study please feel free to ask the investigator any time. the investigator's address and telephone number are followed;

Masako Ono
c/o Ms. Kamiizumi
1-22-12 Kakinokizaka, Meguro-ku, Tokyo 152
03-3723-3272

If you decide whether agree to participate in this study or not, please send me back the reply postcard attached this letter by using stamped envelope. If you agree to participate in this study, the investigator will contact with you and discuss about the interview date and place.

Thank you very much for your cooperation.

July ,1991
Masako Ono

Reply letter (English version)

My family understands this study by the enclosed explanation letter and explanation by the investigator (Masako Ono).

As a result of each family member's decision; (please check either response)

My family agrees to participate in this study. (   )
My family does not agree to participate in this study. (   )

____
Signature(Father)

____
Signature(Mother)

____
Address

____

Telephone Number

Appendix B-2

Invitation to the participation in the study (Japanese version)

1991年7月19日

ご家族の皆様へ

研究参加へのお願い

私はオレゴン・ヘルス・サイエンス大学の看護学部修士課程在学中の学生です。この度、修士論文の一環として慢性疾患をもつお子様のご家族が実際に家庭で、また社会でどのようなことを経験なさっていらっしゃるのか理解するための研究を行うことになりました。この研究自体は、皆様に今、直接利益になることはないかもしれませんが、皆様のご協力は、今後、病院外来などでの個々のご家族にあった看護・指導に役立つものと思っており、ご家族の皆様の研究への参加をお願いする次第です。

研究方法としましては、ご家族の皆様一人ひとりにインタビュー（面談）をさせていただき、お話を伺いたいと思っております。インタビューにかかる時間は、およそ１５分から１時間を予定しております。このインタビューは、後の分析を確実にするために、テープに録音されます。ご家族の皆様のお名前は、論文の中で使われることはありません。又、録音されたテープは、研究終了後、消去されます。

この研究は、任意の参加に基づくものです。とりわけ、お子様のご意見も尊重したいと考えておりますので、ご家族の皆様でお話し合いの上、研究への参加を決めていただきたいと思っております。お忙しいところ恐れ入りますが、同封の用紙にご協力の有無をご記入のうえ、返信用封筒にてお返事をいただければ幸いです。尚、不明な点、ご質問などございましたら、下記のところまでご連絡ください。

〒152　東京都目黒区柿ノ木坂 1-22-12　パークハイム1-B
上泉和子 方
電話　03-3723-3272

本日はお忙しいところ、お時間をさいていただきありがとうございました。

オレゴン・ヘルス・サイエンス大学
看護学部大学院修士課程

Reply letter (Japanese version)

小野正子　殿

研究テーマ：日本における喘息児をもつ家族の認知について

私の家族は研究者（小野正子）より、この研究についての説明を受け、あるいは、研究への参加願いを読み、その内容を理解しました。家族全員で話し合いの結果、以下のような結論に達しました。

（　　）私の家族はこの研究に参加することに同意します。

（　　）私の家族はこの研究に参加することに同意できません。

ご署名（お父様）；＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

ご署名（お母様）；＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

ご住所；〒＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

☎＿＿＿＿-＿＿＿＿-＿＿＿＿

尚、研究に参加なさらない場合は、ご両親様どちらかのご署名のみで、住所・電話番号等のご記入は結構です。

Appendix C

Japanese Transcripts

1「あれがいるから　働きに出れなかったっていうのはありますね・・・始終ね、あれが喘息発作、一月に一回か二回起こせば、まず、常勤で働いたら、他の人に迷惑かけますよね。休まなきゃいけないっていうのは。」

2「やっぱりゆっくり時間をかけなくちゃいけないのかなって事で・・・その辺が今ちょっとどうなんだろうって疑問を思いかけて来たって部分があるんです。だいたい・・・それを引きずってきちゃうと、もうずっと治らないんじゃないかなっていうものがあるんですよね。要するに、ある時期にきちっと治しておかないと、引きずってずっと・・なっちゃうと、一生なおんない部分があるのかなって事で、やはり時期ですか、治さなきゃいけない時期・・・というものが、ある部分じゃここ一二年じゃないかという気もしてる。だから、今ちょうど小学校六年ですけど、ここ一二年でちゃんと治しとかないと、ちょっと治んなくなっちゃうかなっていう心配はあるんですよね。だからここんとこでちょっと。そういう意味で、ちょっと家も建て替えたっていう意味もある訳ですからね。」

3「家の女房が言うの。絨毯が・・・。直接おじいちゃんに言えないから。じゃあって俺が言うでしょう。・・・絨毯取ったら100%治るのかって。治るんだったら取るよ、誰だって。」

4「変えられるのは、だいたい変えたんじゃないかなと思うんですけどね。ただね、犬がいるでしょう。・・・上の子がね、犬がもう大好きで、私も好きで、ずっと居たんですよね、生活の中にね・・・だから、喘息ってわかってても、三匹目は飼ったんですよ。」

5「変わりました。まるっきり変わりました。私自身が変わったから。全然違う。・・・結局舅（姑）仕えっての・・・そういうのしたりすると、厭ですよね。自分の親と違うんだから。何回も涙こぼしたことありますよね。それが、結局Aちゃんが喘息になって、ああいう状態が続いて、入退院繰り返してる、ああいう状態続いて、後ろ髪引かれるみたいな、そういう思いして、そういうことによってね、Aのためだったら、私自身も気持ちを変えられると。私自身、じゃ、努力しようと変えたんですね。変えられたんですよ。ああ、おばあちゃんに対してもこうしてこうしようって、いちいち気にしないで。私自身我慢すればいいんだって。」