

## From Their Own Response: Experiences of Korean Children with Chronic Illness and Their Families

Park, Eun-Sook<sup>1</sup> · Oh, Won-Oak<sup>2</sup> · Suk, Min-Hyun<sup>3</sup> · Yoon, Young-Mi<sup>4</sup>

<sup>1</sup>Professor, College of Nursing, Korea University, Seoul

<sup>2</sup>Associate Professor, Department of Nursing, Dongguk University, Gyeongju

<sup>3</sup>Associate Professor, Department of Nursing, College of Health Science, CHA University, Pocheon

<sup>4</sup>Professor, Department of Nursing, Seoil College, Seoul, Korea

**Purpose:** This study was done to better understand how sick children and their families define chronic illness; what behaviors they used for managing chronic illness; and how they perceived the socio-cultural context of Korea. **Methods:** This study was a secondary analysis of qualitative studies. Articles on children with a chronic illness and their families located in electronic databases were selected for review. Twenty one qualitative studies were reviewed. Qualitative studies that had used an analysis tool, the Family Management Style Framework were reviewed. **Results:** Children with chronic illness and their families tended to accept illness as a negative outcome and thought that they were deprived of the context of normality. In the traditional Korean family style, parents-in-law demand absolute obedience from their daughter-in-law, leading to a conflict between the two parties, which, in turn, may have negatively affected their perceptions of chronic illness. Western and oriental medical treatments were used, and participants sought an array of folk remedies. **Conclusion:** Culturally specific findings can help to better understand the difficulties faced by children with a chronic illness and their families and can provide invaluable input into the development of culturally appropriate and sensitive nursing interventions.

**Key words:** Children, Chronic disease, Life experience

### INTRODUCTION

A health care system and a flexible mutual relationship with health care provider are essential for children with a chronic illness and their families to successfully adapt to their situation. In cases involving a child with a chronic illness, nurses provide a broad range of expertise as health manager, assistants and counselors in addition to their nursing care. Therefore, nurses need to understand the experiences of children with a chronic illness and their families to help them sustain a family life and meet their daily needs.

The growing incidence of chronic illness among children is a social concern (Allen & Vessey, 2004). In the United States (US), 31% of children under age 18 have reported to suffer from at least

one illness, which indicates an increase in the number of children with a long-term illness or physical disability that affects their daily lives (Melnyk & Feinstein, 2001). Children with a chronic illness must deal with physical and emotional issues as they become physically inactive and undergo various treatments and examinations related to their illness. Consequently, their parents face uncertainty over the physical and psychological development of their children who are experiencing fluctuations in their symptoms over the course of their illness (Sharkey, 1995). Taking care of a chronically ill child can be a source of tension and strife for family members (Hockenbery-Eaton, Wilson, & Winkelstein, 2005).

This study aimed to understand how chronically ill children and their families in Korea deal with daily life and respond to the chronic illness. This study used the Family Management Style Fra-

\*This work was supported by the Nursing research institute grant of Korea University.

Address reprint requests to: Oh, Won-Oak

Department of Nursing, Dongguk University, 707 Seokjang-dong, Gyeongju 780-714, Korea  
Tel: 82-54-770-2619 Fax: 82-54-770-2616 E-mail: ohwo@dongguk.ac.kr

Received: July 15, 2009 Revision received: October 6, 2009 Accepted: October 12, 2009

mework (FMSF) as an analysis tool. Because most qualitative studies of chronic illness have focused on a specific topic or concept, these have rarely been provided a comprehensive understanding of how the family as a unit incorporates the demands of the child illness into family life. Knafl and Deatrick (1990) suggested the FMSF and to identify key aspects to explain how the family as a unit responded to childhood illness. This framework has been provided evidences of its usefulness by other researches (Knafl & Deatrick, 2003).

A secondary analysis of qualitative studies was conducted. Because secondary analysis is an effective method for answering new research questions and procuring scientific outcomes (Yi, 2004), this study attempted to analyze the other qualitative studies related to chronic illness of children by using this method. Culturally-specific findings can help to better understand the difficulties faced by children with a chronic illness and their families in Korea and can provide valuable input into the development of culturally appropriate and sensitive nursing interventions.

## METHODS

### Design

This study used a secondary analysis of qualitative studies to better understand the experiences of children with a chronic illness and their families in Korea by reviewing published qualitative studies that had used an analysis tool, the FMSF (Knafl & Deatrick, 1990). Even though FMSF was developed long time ago, this is accepted as a useful framework among research areas of chronic illness and family (Figure 1).

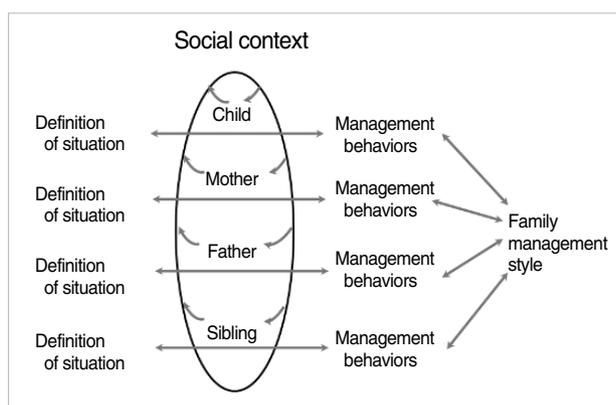


Figure 1. Model of the Family Management Style Framework.

Secondary analysis poses a limitation in many cases because it is based on data derived from questions posed in previous studies (Szabo & Strang, 1997); therefore, bias from the analyst can be incorporated into the results because we cannot observe the original interviews or determine supporting information for understanding the original studies (Thorne, 1994). Despite these limitations, a secondary analysis can be an effective way to produce new findings that would be impossible to formulate with the small sample size in qualitative studies and to verify the reactive questions established in original studies. Additionally, secondary analysis does not place a burden on participants who are physically or mentally ill because participants are not required to be involved in the study (Thorne, 1994).

### Sample

Since the 1970s, nursing health care studies involving children have been conducted in Korea, and qualitative studies began to be released in 1993. Articles on children with a chronic illness and their family were searched in electronic databases of the National Assembly Library from 1993 to August 2008. At first, qualitative researches was searched and then entered key words such as 'chronic illness', 'chronic disease', or 'specific chronic disease name as asthma, cancer et al.'. Seven major journals, including the Korean Society of Nursing Science, were selected for review because they were nursing science-related academic societies. Articles were searched by the table of contents. A total of 221 studies were retrieved. Of the 221 retrieved studies, 26 were qualitative studies. Of these qualitative studies, five were excluded from review due to topics that were inconsistent with the purpose of this study or only contained summarized raw data. This resulted in 21 studies for review (Appendix).

Among the 21 studies, six used a phenomenologic approach while 3 used a grounded theory approach and 3 used an ethnography. The other eight studies used a qualitative content analysis and only one article used an interpretative approach. The chronic diseases addressed in these studies included pediatric cancers, cerebral palsy, and asthma. Interviews were conducted with children with a chronic illness, siblings, mothers, and other family members. The majority of studies included data from mothers (57%). The main research topics included the particular illness, parental experiences with sick children and illness, uncertain-

ties, burdens, feelings of hopelessness, and family characteristics.

### Data analysis

The FMSF was applied to family responses in the original 21 studies. The experiences of children with a chronic illness and their families can vary depending on the sociocultural context. This framework is used to explain for differences in social and culture-specific experiences. In this study, researchers selected the FMSF as inclusion criteria for review because this framework was considered to be an overarching construct that encompasses a variety of specific management styles (Knafl & Deatrick, 1990). The FMSF is a working model developed by Knafl and Deatrick (1990). In this model, issues involving children with a chronic illness and their families are explained by three components: a definition of the situation, the management behaviors, and the sociocultural context (Knafl & Deatrick, 1990).

Definition of the situation is defined as the subjective meaning family members attributed to important elements of their situation. Management behaviors are defined as efforts directed toward caring for the illness and adapting family life to illness-related demands. Sociocultural context is defined as factors that shape how the family defined and managed the situation. For example, how a family responds to a chronic illness varies. The responses are based on each family members' attitude regarding the situation facing them; the consequences of the behavior for each family member; and how those consequences influenced his or her definition of the situation. This mutual effect can be perceived as a distinct sociocultural phenomena.

Twenty one studies were carefully reviewed for their findings. Text was extracted that reflected the participants' experiences. In the studies that had used a grounded theory approach, we found that the abstraction of concepts and categories used by the researchers to be quite diverse. Therefore, researchers decided to not use the identified concepts and categories for our study. Researchers underwent a process that included re-reading, re-reviewing, and re-discussing the truncated text that were extracted from the studies in order to define the main concepts. The definitions of the main concepts were compared against the original text, reviewed, and categorized.

## FINDINGS

The FMSF with the three major components resulted in 30 different concepts and 9 categories (Table 1).

### Definition of the situation

Three categories were created to capture the following concepts related to "a definition of situation": the meaning of chronic illness, the attitude of a child with a chronic illness, and perception of the situation involving a chronic illness.

### The meaning of chronic illness

Children and their family members tended to accept chronic illness as "an incurable disease that must be coped with", "a type of fate", and "punishment". Participants thought they should cope with a chronic illness during life while taking time and enduring difficulties. Some of the participants regarded a chronic illness as fate, citing sinister signs in their conception. Others believed that they were being punished for wrongdoings committed in a previous life.

### The attitude of a child with a chronic illness

Participants described their child with a chronic illness as "a weak child who would not grow normally", "a source of worry", "my karma", and "the connecting string between family members". Chronically ill children were seen as weak children who could not grow normally because of a spate of sicknesses and subsequent growth retardation, and their violent, inattentive behaviors combined with impulsiveness and stubbornness became a source of worry for family members. These children were regarded as a burden, a cross to bear, or karma that could not change. However, these children were also seen as connecting family members together even during a crisis.

### Perception of the situation involving a chronic illness

The situation involving a chronic illness was perceived in terms of "suffering", "running down everyday life", "endless tunnel", and "deprived of the context of normality", and "it is like walking on thin ice". Suffering, one of the most common experiences, resulted in not only physical weakness and sluggishness but also psychological setbacks, such as despair and sadness. Given their expres-

**Table 1.** Experience in Korean Family of Children with Chronic Illness

Domain	Categories	Concepts
Definition of the situation	The meaning of chronic illness	An incurable disease that must be coped with A type of fate punishment
	The attitude of a child with a chronic illness	A weak child who would not grow normally A source of worry, my karma The connecting string between family members
	Perception of the situation involving a chronic illness	Suffering Running down everyday life Endless tunnel Deprived of the context of normality It is like walking on thin ice
Management	The attitude and behaviors of illness management	Compliance with treatment Therapeutic limitation Balance maintenance Improving empowerment
	The parental attitudes and behaviors	Closeness between mother and child The priority of a sick child
	The response to the situation	It's up to God Accept it as part of life Conceal it Express my true feelings
Sociocultural context	The social response to chronic illness	Stigma
	Traditional family style and relationship	Belief based on shamanism Dominant control of parents-in-law Importance of having a son to continue the family line
	Health care environment	A combination of Western and Oriental treatments The use of folk remedies Limited insurance coverage and coverage period A lack of a social support system

sion of “it is like walking on thin ice”, anxiety was prominent as participants were always concerned about the treatment, prognosis, and future of their children and the child’s possible death.

When a child was chronically ill and financial resources were limited, fatigue and desperation led family members to have a feeling akin to “walking on thin ice”. Participants found that they could not afford to do anything for themselves in their daily lives. Once they lost confidence with the treatment or became disappointed when symptoms did not improve, the participants became uneasy, despairing, desperate, and hopeless as if they were standing in an endless tunnel. Because of the perception that they differed from those in mainstream society, the participants had a feeling of being deprived of the context of normality.

### Management behaviors

Children and their families engaged in various behaviors for the treatment of disease. Three categories were created to capture the following concepts: the attitude toward treatment and

consequent behaviors, the parental attitudes and behaviors, and the response to the situation.

### The attitude and behaviors of illness management

The attitude of participants to the illness management was characterized as “compliance with treatment”, “therapeutic limitation”, “balance maintenance”, and “improving empowerment”. Although some participants had trouble complying with the treatment suggested by health care providers, most participants showed good compliance with medical treatment regimens or instructions and accepted the inconvenience associated with the treatment such as limited physical activities. Participants helped their children maintain physical and physiological balance through exercise and a balanced diet and improved their children’s abilities by stimulating independence and self-esteem.

### The parental attitudes and behaviors

Given the slowed growth rate in chronically ill children, there

were diverse forms of parenting attitudes and behaviors. The most prominent parental attitudes were “closeness between mother and child” and “the priority of a sick child”. In many families, the mother took responsibility for taking care of a chronically sick child; unconditional maternal love easily over-indulged sick children.

#### The response to the situation

Participants had different attitudes toward the situation involving chronic illness by saying “it’s up to God”, “accept it as part of life”, “conceal it”, and “express my true feelings”. When participants viewed a chronic illness as a kind of fate, they relied on God. Some participants accepted the illness by showing a positive attitude, while others hid the fact that their child suffered from a chronic illness. There were several participants who expressed their anger and negative attitude by using profanities.

#### Sociocultural context

Social and cultural factors, including the social response to chronic illness and the health care system, influenced the way participants responded to a chronic illness. Attributes related to the sociocultural context were classified into three categories: the social response to chronic illness, traditional family style and relationship, and health care environment.

#### The social response to chronic illness

Participants expressed a social “stigma” attached to chronic illness because a chronic illness is deemed as a punishment, an abnormal condition, or an infectious disease in society. Participants thought that they were discriminated against and not treated equally or fairly. Also, “shamanism” was influential in shaping the social attitude toward chronic illness in Korea. Many people thought the incidence and treatment of chronic diseases occurred by supernatural power. This notion is related to the view that the incidence of chronic disease is God’s will (“sky” in shamanism) or a punishment, and participants sometimes sought shamanic healing from witches.

#### Traditional family style and relationship

The traditional family style and relationship was also an important factor in influencing the way participants responded to chronic illness in Korea. Participants described the characteristics of

their family style and relationship as “dominant control of parents-in-law” and “importance of having a son to continue the family line”. Under the influence of Confucianism, parents-in-law demand absolute obedience from their daughter-in-law, leading to conflict between the two parties, which in turn negatively affected their response to chronic illness. A chronic illness occurring in the oldest son of a family is deemed as a heavy burden of guilt, emphasizing the importance of continuing the family line.

#### Health care environment

The “health care environment” for the management of chronic illness was characterized as “a combination of Western and Oriental treatments”, “the use of folk remedies”, “limited insurance coverage and coverage period”, and a “lack of a social support system”. Korea has a health system in which both Western and Oriental medical treatments are used, and participants sought an array of folk remedies. Participants also pointed out a structural inadequacy of the health care system by citing limited coverage and coverage periods for chronic diseases and the lack of a social support system.

## DISCUSSION

This study was intended to help better understand how sick children and their families feel about chronic illness, what behaviors they take for the management of illness, and how they perceive the sociocultural context.

This study revealed that children with a chronic illness and their families tended to accept the illness as fate, karma, and punishment. This fatalism was likely to be rooted in the cause and effect beliefs of traditional folklore. Family members regarded their sick children as weak or as a source of worry. This finding is consistent with those of Knafl, Brietmayer, Gallo, and Zoeller (1996) who found that families with chronically ill children regarded their sick children as a problem or tragedy. In the same study, children with a chronic illness were also viewed as a part of ordinary existence. This type of view was not observed in our study. Thus, Korean families with a chronically ill child had a more negative attitude than their counterparts in Western countries, signifying the need for an approach focusing on the normal consequences of chronic illness rather than abnormal consequences.

The most common experience of children with a chronic illness and their families was “suffering” as the circumstance and situation facing them. Suffering is a unique and subjective experience and is a feeling composed of sorrow, depression, despair, desperation, guilt, diffidence, hopelessness, uneasiness, and anger (Kang, 1996).

Participants described their feelings as despair, uncertainty, desperation, and sadness in this study. This finding is consistent with the adversity facing participants who care for a child with a progressive illness during the complex chronic phase (Gravelle, 1997). Participants were faced with chronic uncertainty and compared their life to an endless tunnel or walking on thin ice. This kind of uncertainty can be explained by two different points of view. First, uncertainty is associated with a fatalistic view that the occurrence of a chronic disease in their children was predetermined. They believe that they can do nothing to change their destiny. Second, families caring for a chronically ill child appear to be faced with uncertainty. Oh (1999) suggested that families caring for children with cancer experienced uncertainty; however, the levels of uncertainty changed over the course of the illness, and nursing interventions were required to help them reduce or relieve the uncertainty. It may be possible to help families caring for chronically ill children to reduce the level of uncertainty through nursing interventions.

Participants also thought that they were deprived of the context of normality because they were ignored in society. This negative thought is related to the social stigma that they feel. A stigma refers to something bad or unusual about a person, and stigmatization is the process by which a society bestows its own negative meaning on the behaviors, signs, or attitudes of an individual (Joachim & Acorn, 2000). Stigmatizing chronic illness would have a negative impact on sick children and their families who try to cope with their difficult situation (Joachim & Acorn, 2000). The Korean culture has traditionally been unreceptive to inherited chronic illnesses, viewing these conditions with a sense of disgrace. Given this traditional background, families with chronically ill children are faced with a more negative social response than their counterparts in Western countries; therefore, support programs should be designed to ameliorate understanding of children with chronic illnesses and their families.

Management behaviors, a component of the FMSF, were con-

ceptualized as the management of illness, parental attitudes, and parental behaviors to the situation. Most participants complied with the requirements or restraints of the treatment regimen. Restraints placed on children, such as limited diet or physical activity, can take their toll. When the ultimate purpose of treatment is to help the children grow normally (Wong, Hockenbery-Eaton, Wilson, Winkelstein, & Schwartz, 2001), it is necessary to examine how children with a chronic illness respond to restraints placed on them and to propose ideas to reduce the number of restraints for medical management.

Participants showed a diversity of parental attitudes. However a close relationship between the mother and child, and the priority of the sick child were the most prominent phenomenon of the overall parental attitude. The closeness between a mother and sick child was attributable to mothers being the primary care providers of their sick children among the family members; the role of fathers and mothers is clearly divided in Korean families. Thus, they may have different experiences in taking care of a child with a chronic illness, although this was not found in the present study. Pelchat, Lefebvre, and Perreault (2003) reported in their study of caring for disabled children that the father's expectations were attuned to the outer world; the actual day-to-day tasks related to the child's care were not the father's priority. The mothers were less demanding, and their expectations were more self-focused.

Also, another reason is that the majority of studies included data from mothers (57%) in this study. Further studies are needed to determine how the roles of fathers and mothers are altered when one of their children has a chronic illness and further examine how their roles differ. As mentioned earlier, participants also became apathetic toward their sick child and abandoned their usual parenting philosophy to put priority on the care or the demands of their sick child. This type of attitude is interpreted as a problem faced by families taking care of sick children. Mothers with disabled children experience a struggle with the past and the present, and must simultaneously deal with their own and their child's issues and feelings. However, being overprotective and having a relenting attitude will result in over-indulging sick children and hinder their developmental growth (Park, 1993; Wong et al., 2001). Parental support should be provided in a way that promotes physical and psychological aspects of sick children.

Participants responded to their situation differently by stating, “it’s up to God”, “I try to hide the fact that I have a child with chronic illness”, “I express my feelings”, or “I accept it as part of my life”. The attitude expressed as “it’s up to God” was associated with religion, which is a main source of psychological support for families caring for chronically ill children. Nursing care combined with a religious approach would be more beneficial. The attitude expressed as “I accept it as part of my life” was meant to be positive in regard to the situation, and those having that attitude have tried to cope with all the difficulties and inconveniences caused by sick children in their daily lives. This attitude was perceived in terms of normalization progress in many studies of families caring for chronically ill children (Shephard & Mahon, 2000), with normalization being the process, state, style, or philosophical approach attempted to meet social standards by behaving and thinking as if the children were healthy (Morse, Wilson, & Penrod, 2000). Given the results of numerous studies that children with a chronic illness and their families are ultimately interested in normalization, further studies are needed to determine the factors influencing normalization efforts.

We found that social and cultural factors have an impact on the medical environment, family style and relationship, and social value. Boys were traditionally preferred over girls due to the importance of continuing the family line, putting more burden on mothers who are taking care of sick children. Deeply rooted in Confucianism, age equates to wisdom and reverence in the Korean society. In a family, a mother-in-law demands obedience of her daughter-in-law, blames the daughter-in-law for the chronic disease, and even interferes in family matters, including family nursing care for a sick child, which leads to family strife. The response of grandparents to chronic illness should also be investigated to develop nursing strategies for families in which the disease is inherited from the mother’s side. Developing a better understanding of how families with chronically ill children respond to the chronic illness will be important for reducing the uncertainty facing these families and increasing their resilience in caring for the sick child (Patterson, 2004).

## CONCLUSION

This study identified how Korean families caring for chronical-

ly ill children respond to their situation and found useful information suggesting the direction of further research. However, this was a secondary analysis of qualitative studies, which is not ideal for the overall purpose of the study; data originating from previous studies can be somewhat problematic. Additionally, it was difficult to collect sufficient information due to differences in the research methods used in this study and the original studies. While these limitations must be acknowledged, they do not invalidate this study.

This study provides evidence that a diverse range of strategies is required to address the emotional issues facing children with a chronic illness and their families. The most imminent need appears to be for an improvement in the social response to chronic illness to help families maintain a context of normality. The development of nursing strategies also seems to be important to help these families normalize their feelings and lives through promoting positive thinking and discouraging fatalistic negative responses. An investigation into the responses of children with chronic illnesses to the use of restraints for medical management and the associated outcomes would be desirable for developing better nursing techniques with the goal of promoting normal growth.

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## Appendix. The qualitative studies for analysis

No.	Author(s)	Publication year	Title	Research method
1	Park, E. S.	1993	A study on the attitudes of family with asthmatic children	Content analysis
2	Jung, M.	1994	Caring experiences of mothers with a schizophrenic child: An interpretive approach	Interpretive approach
3	Lee, W. J. et al.	1996	Lived experience of mothers who have child with cerebral palsy	Phenomenological method
4	Jang, H. S.	1997	Parenting experience of mothers of children with mental retardation	Content analysis
5	Cheon, N. Y.	1998	The experience of sibling if children with cancer	Content analysis
6	Lee, M. S.	1998	The lived experience of mothers mentally handicapped daughters having menarche at puberty	Content analysis
7	Choi, M. H.	1998	Caring experience of mothers of IDDM children	Grounded theory method
8	Park, E. S. et al.	1998	Maternal uncertainty in childhood chronic illness	Content analysis
9	Oh, W. O.	1999	Uncertainty experience in parents of children with cancer	Grounded theory method
10	Lee, M. K.	2000	Experiences of home-nursing by the mothers with mentally ill children	Grounded theory method
11	Oh, S. N.	2000	Illness experiences of children with juvenile rheumatoid arthritis	Content analysis
12	Oh, S. E.	2000	The lived experience of mothers of children with muscular dystrophy	Phenomenological method
13	Choi, H. J.	2000	Disease experiences of adolescents of patients with Diabetic Mellitus	Ethnographic methodology
14	Kim, S. L.	2001	Burden of mothers of children with CP	Phenomenological method
15	Jin, J. H.	2001	School reentry experience of childhood cancer early survival children	Content analysis
16	Lee, K. H.	2001	An Ethnography on Korean adolescents' substance abuse	Ethnographic methodology
17	Yun, M. S.	2001	The experience of the mothers about powerlessness of children with congenital Heart disease	Ethnographic methodology
18	Bak, K. S.	2001	The lived experience of mothers about rearing of school children with cerebral palsy	Phenomenological method
19	Lee, E. J.	2002	Experiences of mothers with cardiac disease children	Phenomenological method
20	Park, E. S. et al.	2006	Health behavior and perception of therapeutic restriction in chronically ill children and their parents	Content analysis
21	Na, H. K.	2006	Phenomenological study on the parenting stress in the mother of atopic child	Phenomenological method