Exploring the Health-Related Quality of Life Among Children With Moderate Asthma

Li-Chi Chiang

ABSTRACT: Asthma is one of the most common chronic diseases, impacting more than 10% of children in Taiwan. The recurrent signs and symptoms and complexity of disease management impact the life quality of children with asthma. The purpose of this study was to describe the content and dimensions of health-related quality of life (HRQOL) among children with moderate asthma by descriptive qualitative research based on in-depth interviews. Eleven children, aged 6-12 years, and their mothers from two medical centers in central Taiwan were interviewed and tape recorded. The transcripts were analyzed using content analysis. Six themes relevant to the children's QOL with asthma were identified: (1) physical disturbances of signs/symptoms, (2) limitations of activity, (3) emotional distress, (4) discord in parent-child relationships, (5) restrictions in school social life and (6) daily inconvenience of managing the disease. These findings highlight the ways in which the overall quality of life of children is impacted by asthma including the physiological and psychosocial domains. The breadth of these findings may lead to greater insights into the nursing care of children with asthma.

Key Words: health-related quality of life, children with asthma.

Introduction

Asthma is the most common chronic childhood disease in Taiwan. The prevalence of asthma has risen in recent years. A longitudinal study indicated that the prevalence of school-age asthma children increased eight times during the past 20 years in Taiwan (Lu & Hsieh, 1988). More critically, both asthma morbidity and mortality are increasing. The percentage of severe asthma also increased from 8% to 20% in one recent hospital-based study (Kao, See, Wu, & Huang, 2001). The abrupt and recurrent asthma signs/symptoms and the complexity of disease management threatened the overall life quality of children with moderate and severe asthma (Butz, et al., 2004). Based on the results from recent studies, this chronic condition can affect children's physical health, emotional health, social activities, and school achievement (Chiang, Huang, & Lu, 1999; Forero, Bauman, Young, Booth, & Nutbeam, 1996; Perrin, MacLean, & Perrin, 1989, Mishoe et al., 1998). In Taiwan, Chiang et al. (1999)

found that asthmatic school-age children have 40%higher absenteeism rates, more than 50% feel limited in terms of exercise, and 13% strongly dislike school. Children aged 6-12 face many social and developmental tasks. According to Erickson (1963), school-aged children are attempting to master the relationships with their peers and other social groups. Good asthma control could increase their self-confidence, but the repeated episodes also limit their activities and jeopardize children's achievement on these developmental tasks. Current medical treatments and health care efforts not only emphasize the control of symptoms, but also increase the quality of life for children. Understanding the experiences of children with asthma is considered an important basis for proper nursing interventions. However, most studies about the content and dimensions of quality of life (QOL), which are based on studies in western countries, might not be appropriate for children with asthma in Taiwan. Different health and cultural beliefs of Taiwanese people might affect different dimensions of the life of children with

RN, PhD, Associate Professor, School of Nursing, Graduate Institute of Nursing, China Medical University. **Received:** October 8, 2004 **Revised:** January 10, 2005 **Accepted:** January 24, 2005 Address correspondence to: Li-Chi Chiang, No. 91, Hsueh-Shih Rd., Taichung 40402, Taiwan, ROC. Tel: 886(4)2205-3366 ext. 3510; Fax: 886(4)2205-3748; E-mail: lichi514@mail.cmu.edu.tw

asthma. The purpose of this study was to examine the experiences affecting the life quality of children with moderate asthma from children's and their parents' perspectives.

Literature Review

Maintaining normal development and good quality of life has become the treatment goal for childhood asthma during the past decade (Pederson, 1997). Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns (World Health Organization, 1995). This definition revealed that quality of life was a complex and broad-ranging concept. The issues and debates surrounding the definition and assessment of quality of life have been discussed in chronic illness (Eiser & Morse, 2000; Guyatt, Jaeschke, Feeny, & Patrick, 1996) and in childhood asthmatic conditions (Bender, 1996; Eiser & Morse, 2000; Guyatt et al., 1996; Karen, 1999). Ferrans and Powers (1985) viewed QOL as a multidimensional construct with four domains: health and functioning, psychological-spiritual, social and economic, and family. Health-related quality of life (HRQOL) has been described as those aspects of quality of life that relate specifically to a person's health (Karen, 1999). This concept was identified as a subset or component of overall quality of life that is determined primarily by the person's health, and can be influenced by clinical intervention (Wilson & Cleary, 1995). In public health and in medicine, the concept of health-related quality of life refers to a person or group's perceived physical and mental health over time. Tracking health-related quality of life in different populations can identify subgroups with poor physical or mental health and can help guide policies or interventions to improve their health. There were two kinds of HRQOL: generic HRQOL, used to compare QOL across disease groups, and disease-specific HRQOL, appropriate particularly for chronic disease (Guyatt et al., n. d.). Wilson and Cleary (1995) proposed a health-related QOL conceptual outcome model including biological and physiological variables, symptom status, functional status, general health perceptions, characteristics of the individual, characteristics of the environment, and overall quality of life. The current literature shows little cross-cultural consensus regarding a definition of this multifaceted concept. Farquhar (1995) has suggested that this lack of consensus is due to the

multidisciplinary use of the QOL concept. Different values, beliefs, and perceptions of people with different diseases and cultural backgrounds have recently led to the rapid development of various measures of disease-specific QOL (Guyatt et al., 1996).

A review of the literature revealed that the ways in which children's perceptions of life are impacted by asthma are not well reported. The literature about the assessment of life experiences of childhood asthma reveals different life domains. Juniper's Pediatric Asthma Quality of Life (PAQOL) (Juniper et al., 1996) covers three domains: symptoms, emotional function, and activity limitations. Creer, Stein, Rappaport, and Lewis (1992) describe the life activities of childhood with physical activity and emotional behaviors. Ie Coq, Boeke, Bezemer, Bruil, and van Eijk (2000) developed a "How Are You" questionnaire for parents' reporting, including physical activities, social activity, and self-management. The qualitative studies about the illness experiences of asthmatic children also showed various findings. Wilderson (2002) reported that 24 of 31 children aged 7-12 perceived that their physical activity was limited. The most common symptoms mentioned were difficulty in breathing, citing wheezing, shortness of breath, tiredness, or headache. Yoos and McMullen (1996) interviewed 28 children aged 6-18 years old, and identified five themes: "I can't", "restrictions", "symptoms and treatments", "death", and "adaptation". Besides the feeling of physical symptoms from asthma, children with asthma felt that their lives were different from those of their peers, always feeling "I can't". They not only felt restrictions of life, but also worried about death and searched for adaptation. Rydstrom, Englund, and Sandman (1999) interviewed 14 children aged 6-16 years old with asthma, and revealed that the children strived to live normal lives. Some emotional feelings were reported, such as being deprived, guilty, lonely, anxious, and fearful. Santati, Ratinhorn, and Christian (2003) interviewed 10 parents and 11 asthmatic children in Thailand and identified six phases of the experiences in asthma attack prevention as searching out, seeking help, trying out and making change, dealing with change, never giving up, and finding ways to take control. The authors indicated that the children's quality of life has to be improved by suitable nursing intervention. To explore the specific content and dimensions of life quality affected by asthma among school-age children in Taiwan was important.

Methods

Design and Participants

This study used a descriptive qualitative approach. In-depth interviews were conducted at two medical centers with the permission in Taichung County of central Taiwan. A recruitment flyer was posted in the pediatric clinics, and clinic doctors referred children and parents to the researcher. Inclusion criteria for participants were: (1) children diagnosed with asthma at least one year earlier and using daily medications for asthma management; (2) between the ages of 6 and 12; and (3) no other major chronic conditions. The researcher telephoned the parents, explained the details of the study, and answered questions about informed consent documents. An effort was made to create a diverse sample in terms of residence (urban versus rural) and socioeconomic status. Eleven families (6 boys, 5 girls) agreed to be interviewed. In all cases, the children's asthma was considered moderate by an experiencing pediatric doctor according to national guidelines (Department of Health, the Executive Yuan, 2002). Mild and severe asthma were not included, for the reasons that the life impact of mild asthma may not be obvious and children with severe asthma have been treated into the moderate grade at the outpatient department. Before each interview, parents signed consent forms. All interviews were conducted with the children and their mothers during December 2002 and April 2003.

Procedure and Analysis

Children and parents were interviewed together in a quiet place in the hospitals or in the interview room at the researcher's school before their doctor's appointments. The researcher conducted the interviews using a guide that was developed consonant with the literature (Berg, 1998) and previous work (Chiang, Huang, & Chao, 2001). Questions moved from the general (about everyday activities and the child's feelings about the disease) to the specific (depending on the individual's life). For example, some general questions were: "What are your (your child's) everyday activities?" "How has asthma affected your (your child's) life?" "What's your (your child's) feeling about this condition?" Each session was conducted in a friendly, relax, and warm rapport situation. After a brief introduction of the researcher, the first interview was conducted with the children to ask about their life experience, especially peer relationships and school life. Most children with asthma can understand and express their major concerns about the disease of asthma and their experience. Some children were shy and quiet; the researcher used colorful pictures in asthma teaching books to guide children to dialogue with the researcher. The interviews with children lasted between 20 and 30 minutes. Then the mothers were interviewed for about 60-120 minutes. During this period, the children may give some explanation of his/her feelings and perceptions to clarify, or played with the pencil gift and read the asthma teaching book. All parents gave permission to tape record the interviews.

To formulate a narrative description of the parents' and children's perceptions of life with asthma, content analysis (Berg, 1998) was performed on verbatim transcripts. Words and phrases associated with a healthy life or quality of life were highlighted and used to develop a coding list. Synonymous and repetitive codes were grouped together to create an analytical guide. With the assistance of two pediatric nursing experts, the researcher used a double-coding technique to check and confirm themes and categories (Berg, 1998); the agreement rate ranged from 80 to 85%. This process was repeated until saturation of themes was achieved.

Trustworthiness

For qualitative studies, reliability and validity are measured in terms of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility, or internal validity, is measured in terms of data authenticity. The researcher's interview skills stemmed from her 18 years experience working with children, and 10 years caring for children with asthma. Participants were recruited from the natural setting as much as possible to ensure credible data. Transferability, or external validity, entails the faithful documentation of the feelings, thoughts, and experiences expressed by study participants. To ensure transferability, the researcher reviewed the transcripts several times to re-identify the thoughts, feelings, and reflections expressed during the interviews. To ensure dependability, i.e., internal reliability and consistency, the researcher conducted all interviews to sustain the same attitude toward the questions and refocus the discussion back to the topic when the conversation was distracted. Data were recorded and closely managed the transcription process as completed by a single research assistant. During the analysis of the transcripts, an audit trail

was used to record the analysis process. To maintain a high level of confirmability, the transcripts were discussed with two participating mothers to ensure that the description accurately reflected their life.

Results

Six themes were identified: (1) physical disturbances from signs/symptoms, (2) limitations of activity, (3) emotional distress, (4) discord in parent-child relationships, (5) restrictions on school social life, and (6) daily inconvenience of managing the disease. The themes, definitions, and characteristics are listed in Table 1.

Physical Disturbances from Signs/Symptoms

Physical disturbances from daytime signs/symptoms

The participating children had to deal with recurrent symptoms that included coughing, wheezing, shortness of breath, tightness in the chest, and dysphasia. One mother said, "*It never ends. I can always feel the distress in his chest and hear his coughing. I sometimes think he will*

Definition and Characteristics of Identified Themes

never get well." Another said, "Once the weather starts getting cold, her shortness of breath begins."

Sleep disturbances from nocturnal signs/symptoms

Asthma exerts a strong negative influence on sleep quantity and quality. In the words of one mother, "*My* son always has asthma attacks in the middle of the night." Another mother reported the same problem, "*My* child always coughs in the night; neither one of us can sleep."

Limitations of Activity

Limitations of play

Play activities can be limited by actual signs and symptoms of asthma or by the fear of triggering an asthmatic episode. As one mother admitted, "We always stay at home and don't like to go outside. If we go outside when the weather is windy, he starts coughing again." The mothers of children with asthma sometimes feel as though they must give up their social lives. A nineyear-old child complained, "My mother won't allow me

Table 1.

Theme	Definition	Characteristics
Physical disturbances from signs/symptoms	Physical disturbances caused by recurrent signs/symptoms, and effects on daytime activities and sleeping	 Physical disturbances from daytime signs/symptoms Sleep disturbances from nocturnal signs/symptoms
Limitations of activity	Activity limited due to concerns over potential asthma attacks	Limitations of playExercise limitations
Emotional distress	Depressed feelings or emotional reactions of children with asthma as perceived by children or observed by parents	 Depression Unstable temper Anxiety Fear of asthma attacks
Discord in parent-child relationships	Arguments and other contentious interactions	 Parent-child friction Conflicts between discipline and protection Issues related to asthma control
Restrictions on school social life	Inability to participate in interactions and personal relationships at school	 Comparisons with others Reduced peer interactions Worries about school performance
Daily inconvenience in managing the disease	Regular life interrupted by complex control and management	 Frequent medical visits Abstinence from certain foods or toys Pain associated with getting shots or drawing blood Bothersome medications

to go outside and play with my friends. She is afraid that I will get an asthma attack. I cannot participate in many activities."

Exercise limitations

Several children reported that they were excused from participating in physical education classes because of the fear that even moderate exercise might cause an asthma attack. At least one child said that she felt relieved to be able to rest while others played basketball or other games:

That's beneficial to me — I don't need to run! I hate running. When I'm running, I feel a shortness of breath similar to an asthma attack . . . Even if it's harmful for my health, I think asthma is good for me in some ways; it excuses me from physical education classes.

While it may be a misconception that children with asthma should not participate in any exercise whatsoever, it is an idea that found general acceptance among all of the mothers and children interviewed.

Emotional Distress

Depression

Because of their chronic health condition, several children described themselves with such terms as "*miserable*" and "*pitiful*." One said, "*I have such bad luck; I am such a pitiable and fragile child*."

Unstable temper

Because of their fluctuating emotions, children with asthma are known for having temper tantrums and for severe mood swings. Many mothers said that it was difficult to nurture their bad-tempered children. For example, a mother told me that one time in school her daughter was being punished by a teacher, "She was crying and crying, and then she had a major asthma attack. She simply cannot control her temper." Another mother complained that her son "shouts and screams during the playtime. He is incorrigible; nobody can control his emotions."

Anxiety

This emotion can result from worry over the eventual outcome of the disease or for no specific reason. One child was worried that the medication "*won't let me grow as tall* as my friends." Another child reported feeling anxious about "whether asthma will influence my personal future and physical appearance."

Fear of asthma attacks

Some children and parents reported living in constant fear of an attack. One young boy illustrates his experience, "I was running and running while I was in a physical education class, then I started having difficulty breathing. It was terrible. I hate that class, and I am afraid of getting another attack in that situation.

Discord in Parent-Child Relationships

Parent-child friction

Contentious relationships between children and mothers frequently resulted from arguments over how best to avoid or manage asthma attacks. In one mother's words, "I can't always handle his problem, and he always does things in his own way. When I told him to take his medication, he got angry." Her son responded, "Don't bother me; I know everything I need to know about my disease."

Conflicts between discipline and protection

The young interviewees frequently complained that their mothers controlled many aspects of their lives. Parents of children with asthma must be very precise about food, toys, and physical activities. Asthma therefore exists as a major issue and beyond the usual friction that occurs within most families, such as the usual advice about studying hard and not wasting time on trivial matters and games. A typical comment from a mother was, "*I* do my best to control my child's disease, but I don't get any cooperation."

Issues related to asthma control

In order to control their children's asthma, many parents felt that they had no choice but to enforce a long list of rules — an obvious source of friction. Several children made such complaints as "My mother won't let me go outside by myself. She always controls my life" and "Sometimes I forget to take my medicine, and Mommy criticizes me!" One mother reported, "I can't let the condition get worse. It's very difficult to control this disease, so I can't take the risk. I hope my child can follow all the rules which are good for him."

Restrictions on School Social Life

Comparisons with others

When children with asthma compare themselves to healthy children, they are quick to notice and react to their differences. A typical response from the children was "*I* am very weak physically. If one of my classmates gets a cold, I know that I will catch it. So my mother always lets me stay home when she knows that colds and the flu are going around. . . I don't like being so fragile that I can't have the same life as my friends."

Reduced peer interactions

Interaction between children with asthma and their peers are impacted in several ways. One girl was afraid of teasing from her male classmates if they knew she had asthma. One mother said of her son, "*He just doesn't know how to interact with others because he has few opportunities to play with friends.*" Children can become isolated because of their fear of an asthma attack. A mother shared this observation: "When most children were playing happily, my daughter was sitting aside because she felt some uncomfortable signs of an impending attack."

Worries about school performance

The potential effects of asthma on academic success can be divided into physical and intellectual categories. One mother was concerned about the possibility that the disease and the regular use of an inhaler would "have bad effects on the development of my child's brain." Another mother acknowledged that her son "is very fragile physically, therefore he must study hard to get a university degree for a job that needs intelligence, not physical strength." A common complaint among all Taiwanese parents is the stress associated with getting their children into good schools at every level. One mother said, "He is too weak to do physical labor. I hope he will have a white-collar job."

Daily Inconvenience of Managing the Disease

This theme was expressed by both mothers and children when the chronic condition created inconvenience in their everyday life. Their stories illustrate how the complex mix of disease-control methods ensured the children's health, but also inconvenienced their lives in many ways.

Frequent medical visits

A standard life for a child with asthma involves commuting between school, home, and a hospital or clinics. In most families these visits are given top priority, despite their inconvenience. One mother described her son's routine this way: "*His father drives us to the hospital, even when he is exhausted after a full day of work. We must visit the doctor not only to get a prescription for medication, but also to examine my child's condition.*"

Abstinence from certain foods or toys

All of the participating families had lists of items that were strictly restrained to control the disease. One culturally bound restriction that was mentioned by the majority of mothers was drinking ice water, which Taiwanese strongly believe is bad because it conflicts with the natural warmth of the human body. Junk foods were ranked high on the restricted list of many interviewees, for instance, carbonated beverages, chocolate, hamburgers, and other fast foods. One mother's typical comment is: "My child cannot eat melons [e.g., watermelon or honeydew melons], because these kinds of vegetables are recognized as 'cool foods' that cause further damage to a weak trachea." Several children complained about food allergies, primarily to eggs, milk, and seafood. One mother complained, "It is very difficult to prepare proper foods for my son." Toys that some of the participating children could not play with included stuffed or fur-covered toys. Pets were banned because of their tendency to trigger asthma attacks.

Pain associated with getting shots or drawing blood

Almost all of the interviewed children complained about the invasive procedures they had to endure at hospital/clinics, mostly getting injections, but sometimes having blood drawn on a regular (e.g., twice-monthly) basis. One eight-year-old girl stated succinctly, "*I hate going to the hospital. They always give me a shot.*"

Bothersome medications

The most common complaint came from childrenhaving to put up with complex medication regimens on a daily basis or having to take unpleasant medicines. One boy said that the drugs he took (especially traditional Chinese medicines) were very bitter. An older boy said, "I hate using the inhaler every day. I can eat medicine but not inhale it." None of the children seemed to fully comprehend the details of their medication routines.

Discussion

Domains of HRQOL

The findings include six domains of HRQOL of children with moderate asthma: physical signs/symptoms, activity, emotional, family relationship, school social life, and daily life. These domains are in accord with Ferrans and Powers' (1985) definition of QOL as a multidimensional evaluation of an individual's illness experience in the context of culture and personal values. In this view, QOL primarily represents a subjective sense of well-being that encompasses physical, emotional, family relationship, and social dimensions.

This study's results reveal that the contents and domains of HRQOL for the children with asthma studied are similar to those of the nine existing instruments for measuring HRQOL for childhood asthma. The disturbance of daily life, disturbance of sleep patterns, physical disturbance from signs/symptoms and physical activity limitations were congruent with most of the other QOL instruments. Physical disturbance, physical activity limitation, and emotional distress were consistent with the PAQOL of Juniper et al. (1996). The daily inconvenience domain extended the avoidance of environmental exposures in the Asthma QOL of Gibson, Henry, Vimpani, and Halliday (1995). The present study's findings also include parent-child relationships and school social life, which is consistent with the Children's Health Survey for Asthma (Olsen & Asmussen, 1999) and the HAY (Ie Coq, Boeke, et al., 2000; Ie Coq, Colland, Boeke, Bezemer, & van Eijk, 2000). The results illustrate that QOL was a multidimensional concept including six dimensions, although some of them were consistent with some existing QOL, the dimensions and contents developed by this study are more comprehensive, including the physical, psychological, and social dimensions. The results should sensitize nurses who are assessing QOL in children with asthma to the impact of this disease on their lives. Providing interventions responsive to their individual needs and concerns is necessary.

Diversity of Disease Management

Caring for a child with a chronic disease such as asthma requires cooperation from the child and parents to

follow the directions of health care providers. Many issues interfere with their daily life, such as taking medication every day, enduring the pain of invasive procedures, and frequent visits to the hospital. Furthermore, Chinese parents believe that children with asthma have a genetic defect that weakens the "qi" of the lungs, spleen and kidneys. They believe that external evil forces will upset the bodily balance of "qi." In order to maintain the balance of "yin" and "yang" forces, children with asthma are often forbidden to eat certain foods (Tam, 2002). This special diet increases the complexity of managing the disease and the level of inconvenience in Taiwanese families.

Psychosocial Developmental Tasks

The results indicate that school-age children are acutely aware of differences between themselves and other children, especially in terms of reduced peer interactions and worries about school performance. Ladebauche (1997) discussed how the fear of being labeled as different and a need for privacy might prevent school-age children from discussing their asthma with others. The fear of being labeled different is particularly acute for Asian children because of the cultural emphasis on belonging to a group. Important selfconcepts are established during childhood, and a chronic disease such as asthma may interrupt these processes. Children also need to develop a sense of industry and capability to bolster their self-confidence. Some of the children interviewed stated that they found it difficult to concentrate on reading or studying because of their asthma. In Taiwan the expectations for children's performance in school serve as a powerful motivating force in most families, and school performance is a major focus of concern.

Proxy Assessment of HRQOL

In some circumstances, as in the case of individuals who can't subjectively analyze their situation, a proxy assessment from a caregiver may be an important resource. Although children and parents often have different perspectives of impact of treatment and QOL, parents are normally able to make reasonably accurate judgments for their chronic children. The study revealed greater agreement between parents and children in their assessments of disease-specific QOL (Eiser & Morse, 2001; Jokovic, Locker, & Guyatt, 2004). The researcher's goal was to integrate the two perspectives, based on her belief that even school-age children are capable of a basic understanding of how asthma affects their lives in terms of physical health and the need for treatment and monitoring. This understanding puts them in positions of negotiating with their mothers on how best to respond to the disease.

Limitations

Efforts made to ensure the trustworthiness of this study's findings strengthen the investigation, and this findings provide two different perspectives to assess asthma-related QOL. However, the limitations of this study are that the sample included only school-age children with moderate asthma under treatment in pediatric clinics, excluding other children with mild and severe asthma, or noncompliant children, and those whose parents visited different hospitals. Additional follow-up interviews over a longer period may reveal different perspectives at different developmental stages. Further effort is needed to develop a culturally adaptive, reliable, and valid instrument to measure HRQOL for children with asthma.

Conclusion

Children with asthma experience significant physical, psychosocial, and emotional disturbances in their everyday life. Questionnaires that fail to fully assess the important consequences of asthma will most likely fail to accurately measure HRQOL. Meeting this goal may require multiple measures that address the concerns of patients and those who are most likely to be affected on a secondary level (usually family members). This study provides six domains for constructing an instrument that measures aspects of life most appropriate to HRQOL in Taiwanese asthmatic children. Accurate assessments of the influences of asthma on the lives of children and their parents are required to promote more effective nursing interventions and to improve the potential for positive treatment outcomes.

Acknowledgments

This research was supported by grants from China Medical University (No. CMC-91-NS11) and the National Science Council (NSC-92-2314-B039-019), Taiwan, Republic of China.

References

Bender, B. G. (1996). Measurement of quality of life in pediatric asthma clinical trials. *Annals of Allergy Asthma Immunology*, 77, 438-445.

- Berg, B. L. (1998). *Qualitative research methods for the social sciences*. Boston: Allyn and Bacon.
- Butz, A. M., Riekert, K. A., Eggleston, P., Winkelstein, M., Thompson, R. E., & Rand, C. (2004). Factors associated with preventive asthma care in inner-city children. *Clinical Pediatrics*, 43(8), 709-719.
- Chiang, L. C., Huang, J. L., & Chao, S. Y. (2001). Developing a scale of self-management behaviors of parents with asthmatic children in Taiwan through triangulation method. *Journal of Nursing Research*, 9(1), 87-97.
- Chiang, L. C., Huang, J. L., & Lu, C. M. (1999). Study of predisposing factors and self-management behaviors of school-age children with asthma and the impact of summer asthma camp. *Journal of Nursing Research*, 7(4), 307-320.
- Creer, T. L., Stein, R. E., Rappaport, L., & Lewis, C. (1992). Behavioral consequences of illness: Childhood asthma as a model. *Pediatrics*, *90*, 808-815.
- Department of Health, The Executive Yuan (2002). *Guidelines for asthma diagnosis and treatment*. Taipei: Author.
- Eiser, C., & Morse, R. (2000). A review of measures of quality of life for children with chronic illness. *Archive of Disease in Children, 84*, 205-211.
- Eiser, C., & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research, 10*, 347-357.
- Erickson, E. H. (1963). *Childhood and society* (2nd ed.). New York: W.W. Norton & Company.
- Farquhar, M. (1995). Definitions of quality of life. *Journal of* Advanced Nursing, 22, 502-508.
- Ferrans, C. E., & Power, M. J. (1985). Quality of life index: Development and psychometric properties. *Advances in Nursing Science*, 8(1), 15-24.
- Forero, R., Bauman, A., Young, L., Booth, M., & Nutbeam, D. (1996). Asthma, health behaviors, social adjustment, and psychosomatic symptoms in adolescence. *Journal* of Asthma, 33(3), 157-164.
- Gibson, P. G., Henry, R. L., Vimpani, G. V., & Halliday, J. (1995). Asthma knowledge, attitudes, and quality of life in adolescents. *Archives of Disease in Childhood*, 73(4), 321-326.
- Guyatt, G. H., Jaeschke, R., Feeny, D. H., & Patrick, D. L. (1996). Measurements in clinical trials: Choosing the right approach. In B. Spilker (Ed.), *Quality of life and pharmacoeconomics in clinical trials* (pp. 41-48). Philadelphia: Lippincott-Raven.

- Guyatt, G. H., Naylor, C. D., Juniper, E., Heyland, D. K., Jaeschke, R., & Cook, D. J. (n. d.). *How to use articles about health-related quality of life measurements*. Retrieved Dec 1, 2004, from: http://www.cche.net/ usersguides/life.asp
- Ie Coq, E. M., Boeke, A. J. P., Bezemer, P. D., Bruil, J., & van Eijk, J. Th. M. (2000). Clinimetric properties of a parent report on their offspring's quality of life. *Journal* of Clinical Epidemiology, 53, 139-146.
- Ie Coq, E. M, Colland, V. T., Boeke, A. J. P, Bezemer, P. D., & van Eijk, J. Th. M. (2000). Reproducibility, construct validity, and responsiveness of the "How are you?" (HAY), a self-report quality of life questionnaire for children with asthma. *Journal of Asthma*, 37(1), 43-58.
- Jokovic, A., Locker, D., & Guyatt, G. (2004). How well do parents know their children? Implications for proxy reporting of child health-related quality of life. *Quality of Life Research, 13*, 10297-1307.
- Juniper, E. F., Guyatt, G. H., Feeny, D. H., Ferrie, P. J., Griffith, L. E., & Townsend, M. (1996). Measuring quality of life in children with asthma. *Quality of Life Research*, 5, 35-46.
- Kao, C. C., See, L. C., Wu, C. J., & Huang, J. L. (2001). Time trend and seasonal variations in hospital admission for childhood asthma in a medical center of Taiwan from 1990 to 1998. *Asian Pacific Journal of Allergy Immunology, 34*, 211-214.
- Karen, S. (1999). Description of health-related quality of life conceptual model. *Outcome Management for Nursing Practice*, 3(2), 78-82.
- Ladebauche, P. (1997). Managing asthma: A growth and development approach. *Pediatric Nursing*, 23(1), 37-44.
- Lincoln, P., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lu, K. H., & Hsieh, K. S. (1988). The changing of allergy disease during past decade in Taipei. Acta Paediatrica Sinica, 29(2), 104-109.

- Mishoe, S. C., Baker, R. R., Poole, S., Harrell, L. M., Arant, C. B., & Rupp, N. T. (1998). Development of an instrument to assess stress levels and quality of life in children with asthma. *Journal of Asthma*, 35, 553-563.
- Olsen, L. M., & Asmussen, L. (1999). Current methods in measuring health-related quality of life in children with asthma. In K. B. Weiss, A. S. Buist, & S. D. Sullivan (Eds.), *Social and economic impacts of asthma* (pp. 99-126). New York: Marcel Dekker.
- Pederson, S. (1997). What are the goals of treating pediatric asthma? *Pediatric Pulmonology Supplement*, 15, 13-16.
- Perrin, J. M., MacLean, W. E., & Perrin, E. C. (1989). Parental perceptions of health status and psychologic adjustment of children with asthma. *Pediatrics*, *83*(1), 26-30.
- Rydstrom, I., Englund, A. D., & Sandman, P. (1999). Being a child with asthma. *Pediatric Nursing*, 25(6), 589-595.
- Santati, S., Ratinhorn, A., & Christian, B. (2003). Parents' experiences in asthma attacking prevention: Struggling to take control. *Thai Journal of Nursing Research*, 7(3), 186-198.
- Tam, A. (2002). Western medicine in the eastern mind: A need for integration (commentary). Archive of Disease in Children, 87(4), 289-290.
- World Health Organization. (1995). The World Health Organization Quality of Life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science Medicine*, 41, 1403-1409.
- Wilkerson, R. R. (2002). Younger and older children had different experiences of asthma and its management. *Evidence-Based Nursing*, 5(4), 123.
- Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life: A conceptual model of patient outcomes. *Journal of the American Medical Association*, 273(1), 59-65.
- Yoos, H. L., & McMullen, A. (1996). Illness narrative of children with asthma. *Pediatric Nursing*, 22(4), 285-290.



探討中度氣喘兒童之健康相關生活品質

蔣立琦

- 摘要: 氣喘是台灣最常見的兒童慢性疾病之一,影響台灣超過10%之兒童。氣喘反覆的症狀/徵候以及複雜的疾病管理衝擊氣喘兒童的生活品質。本研究目的主要是透過深度訪談,以描述性質性研究方法,描述中度氣喘兒童健康相關生活品質的構面及內容。研究者訪談中部地區兩所醫學中心的11位6-12歲的氣喘兒童以及其母親,將訪談資料進行內容分析,共確認六項氣喘兒童健康相關生活品質的主題:(1)身體症狀/徵候之障礙;(2)活動之限制;(3)情緒壓抑;(4)親子關係不和睦;(5)學校社交生活受限;以及(6)疾病管理造成生活不便。這些發現綜觀氣喘對兒童生活品質影響之層面,包括身體、心理、社會領域,本研究結果將可以引導護理人員對氣喘兒童之健康相關生活品質具有較完整之考量。
- 關鍵詞: 健康相關生活品質、氣喘兒童。

中國醫藥大學護理學系所副教授 受文日期:93年10月8日 修改日期:94年1月10日 接受刊載:94年1月24日 通訊作者地址:蔣立琦 40402台中市學士路91號