The Stress of Caring for Children With Asthma: A Qualitative Study of Primary Caregivers

Sue-Hsien Chen¹ • Jing-Long Huang² • Kuo-Wei Yeh³ • Yun-Fang Tsai⁴*

¹PhD, RN, Director, Department of Nursing, Chang Gung Memorial Hospital at Keelung, and Assistant Professor, Department of Nursing, Chang Gung University of Science and Technology • ²MD, Vice Superintendent, Chang Gung Memorial Hospital at Linkou, and Professor, Chang Gung University • ³MD, Director, Division of Allergy, Asthma, and Rheumatology, Department of Pediatrics, Chang Gung Memorial Hospital at Linkou, and Associate Professor, Chang Gung University • ⁴PhD, RN, Professor and Chair, School of Nursing, College of Medicine, Chang Gung University, and Consultant, Department of Nursing, Chang Gung Memorial Hospital at Keelung.

ABSTRACT

Background: Asthma is one of the most common chronic diseases in children. The unpredictability, frequency, and health risks associated with acute asthma attacks have a profound impact on the daily lives of affected children and their families. Understanding the experiences of primary caregivers may help nurses provide better care to children with asthma.

Purpose: This study explores the experience of primary caregivers in providing care to children with asthma.

Methods: The study used exploratory and descriptive research methods and collected data using a qualitative research interview approach. Seventeen primary caregivers of children with asthma who visited the allergy clinics of two medical centers and one regional hospital in northern Taiwan participated in the study. An interview guide with a semistructured questionnaire was used, and verbatim transcripts of the audiotape-recorded interviews were analyzed using content analysis.

Results: The findings are described in three themes covering 10 categories. These themes and categories include feelings of uncertainty during illness (disease as perception related, lack of information), feelings of chaos and instability (worry, fear, frustration, helplessness, physical distress), and social tension and family conflict (disorientation of daily activity and burden of care, economic burden, family tensions and disagreements).

Conclusions: Negative experiences with asthma care and the unpredictability of the disease outcomes impair the ability of caregivers to adapt successfully to their caregiving role and encourage perceptions that they cannot cope with this illness. Better understanding the caregiver experience may assist healthcare providers to better target support to these caregivers so that they are better able to care for children with asthma.

Key Words: primary caregiver, caring experience, asthma, child.

Introduction

Asthma is one of the most common chronic diseases in children. The gradual increase in the incidence of asthma-related morbidity and mortality in children over the last 2 decades is of great concern to healthcare providers (Akinbami, Moorman, Garbe, & Sondik, 2009). Asthma is the most prevalent chronic illness, which may significantly impact children and present challenges to their families (Englund, Rydstrom, & Norberg, 2001). The unpredictability, frequency, and severity of asthma attacks impact the daily lives of the families of asthmatic children profoundly (Cheng, Chen, Liou, Wang, & Mu, 2010). Caregivers of children with chronic illness often experience fear and feelings of uncertainty with regard to managing the disease because of frequent visits to the emergency room (Wood et al., 2007). A condition with an unstable course, such as the remission-recurrence cycle of asthma, symptoms is more stressful than a condition that remains constant for a long period (Chen et al., 2006; Wright, 2007). Thus, caregivers may experience frustration and depression over their lack of control over the declining health of their patient.

Parenting a chronically ill child is a challenge (Coffey, 2006; Mu, Wu, Wu, & Liu, 2008). Some parents of children with chronic illnesses seek information about their child’s condition...
and have a desire to learn the facts about the child’s illness (Kaugars, Klinnert, & Bender, 2004; Kieckhefer & Ratcliffe, 2000). Parental or caregiver understanding of the disease process, appropriate use of medications, and preventive measures are important for effective management, especially in young children (Chen et al., 2004; Chiang, Wen, Tien, & Huang, 2012; Kaugars et al., 2004; Liu et al., 2010). In clinical visits, we showed that caregivers of children of asthma are limited in their daily activities as a result of their caregiving duties. Previous studies reported that the primary caregivers of children with asthma are limited in their own normal daily activities and experience anxieties and emotional stresses as a result of their child’s asthma (Butz et al., 2005; Guevara, Wolf, Grum, & Clark, 2003; Juniper et al., 1996; Mansour, Lanphear, & DeWitt, 2000). In addition, uncontrolled asthma can be a source of increased disagreement and conflict among family members (Kaugars et al., 2004). The absence of adequate support systems may generate an imbalance in the caregiver’s responsibilities and may negatively influence the willingness of caregivers to seek follow-up asthma care (Plantin & Daneback, 2009). Those primary caregivers who are not well prepared to provide ongoing care often become the victim of the disease (Jerrett & Costello, 1996). This study hopes to offer better suggestions for asthma care under the presumption that greater awareness of the experience of primary caregivers will facilitate healthcare providers providing targeted assistance to caregivers based on their situation-appropriate needs.

To elicit the concerns of caregivers, this qualitative study investigated the experiences of caregivers living with children who experience asthma. Understanding caregivers’ concerns and perceptions during current asthma care is expected to help asthma educators ensure that integrated programs address the needs of the entire asthma-affected family.

Methods

We conducted a qualitative study that used individual, in-depth, semistructured interviews with primary caregivers of young patients with asthma to elicit and elucidate their caregiving experiences.

Sample and Recruitment

A primary caregiver of a child with asthma is defined as an individual providing unpaid asthma-related assistance and care. All of the children in this study experienced persistent asthma, with severity assessed using the Global Initiative for Asthma guidelines (Bousquet et al., 2007). The study group included 17 primary caregivers who visited the allergy clinics of two medical centers and one regional hospital located in northern Taiwan. The primary caregiver was eligible for the study if the child (a) was between 5 and 11 years old, (b) had been diagnosed with asthma ≥1 year before the study, and (c) had no other uncontrolled chronic health problems. Purposive sampling was used to recruit the primary caregivers. To protect the identity of the participants, the researchers used the letters A–Q for participant-identification purposes. Interviews were conducted in private locations that were acceptable to the participants.

An exploratory and descriptive study design and a qualitative research interview were used. In-depth interviews elicited information on the asthma care experiences of participants. Semistructured interview guidelines were formulated after discussions with respiratory therapists, staff nurses, a pediatric allergist, and a pulmonary case manager. Before collecting the data, a pilot study was performed to confirm the appropriateness of the interview guidelines.

Each interview started by questioning the participants about their asthma care experiences. The interview guide with open-ended questions has been established to address the experience of asthma care (Butz et al., 2005; Mansour et al., 2000; Snadden & Brown, 1992). This approach elicits detailed and significant responses while allowing caregivers to talk freely about what really matters to them. The four topics/questions in the interview guide include (a) the child’s disease (e.g., “How did you know the child had the disease?”), (b) the impact of the disease on their lives (e.g., “How does your asthmatic child affect your everyday life?”), (c) the affliction from asthma care (e.g., “Please share your experience of asthma care”), and (d) coping mechanisms (e.g., “Does anything help to change your feelings about asthma care?”). The participants were encouraged to talk about their asthma-related caring experiences at the beginning of this study. Through the interview guide-directed process, we encouraged the participants to comprehensively describe their current experiences with asthma care. The data set was considered saturated when further data collection yielded no new insights.

Before commencing the interview, the researcher explained the study, obtained consent or assent, and spoke with the participants. Written information describing the purpose and process of the study, including a detailed overview of participants’ rights and the protection of their identities, was provided to participants during the recruitment process. A personal information sheet that requested family demographic information and geographic information was completed for each participant. In addition, information was obtained regarding the age of the child at the onset of symptoms and at diagnosis, medications taken, hospital admissions, and emergency room visits. The institutional review board at our hospital approved this study, and informed consent was obtained from both the participants and the recipients of care. One in-depth audiotape-recorded interview lasting between 30 and 40 minutes was conducted for each participant. All audiotape records were transcribed verbatim within 24–48 hours, and transcripts were analyzed using content analysis. Each written transcript was compared with the corresponding audiotape records for accuracy, and any errors in transcription were corrected.

In qualitative research, credibility is the criterion of validity used to establish the trustworthiness of the data. The principal investigator in this study was trained on qualitative interview techniques and has worked at the asthma department of a
children’s hospital for 18 years. To ensure data credibility, a comfortable and private setting was used for each interview to ensure an interactive atmosphere during the discussion and prolonged engagement with the data, and peer debriefings were conducted. The process involved a review of methods, procedures, and conclusions by the researcher and three impartial peers who were experts in the study subject or methods.

Data Analysis
All interviews were transcribed verbatim. Transcripts were first open coded word-by-word and line-by-line. The interview text was then read to understand independently each of the participants’ descriptions, which were then compared and discussed with respect to the aim of each research question. The texts were then split into meaning units that appeared to share the same content and then sorted into the categories that were inspired by the units. Each author carefully cross-checked his or her analysis with that of the other team researchers to ensure the accuracy of the emerging categories. Finally, the complete data set was categorized, and relationships among the categories were used to conceptualize the data into themes.

Results
Characteristics of Participants
Seventeen primary caregivers of children with asthma were recruited and enrolled as participants. The mean age of participants was 40.9 ± 13.88 years (70.6% mothers, 5.9% fathers, 23.5% grandmothers). Among these, seven had a high school education, and 11 respondents were currently employed. The mean age of their children with asthma was 6.65 ± 1.77 years (mode = 6 years). The asthmatic condition was rated “severe” in 35.3% of the children and “moderately severe” in the remaining 64.7% of the children. Other participant characteristics are described in Table 1.

Analysis of the raw interview data yielded multiple themes. The themes that formed the backdrop for participant experiences included (a) feelings of uncertainty during illness, (b) feelings of chaos and instability, and (c) social tension and family conflict (Figure 1).

Feelings of Uncertainty During Illness
The variable and unpredictable nature of asthma may cause considerable uncertainty. This theme expressed the feelings of uncertainty perceived by participants in caring for their children with asthma and was based on two factors.

Category 1: Disease as perception related
Many primary caregivers expressed difficulties with accepting the asthma diagnosis, even after a postdiagnosis severity assessment had been conducted. Several said, “I was very vague in my understanding of asthma” and “It’s just a cough, I thought.” In addition, some said, “Most physicians had neither the opportunity nor the free time to tell us about asthma.” Furthermore, several primary caregivers doubted the validity of the asthma diagnosis and believed the symptoms were because of a cold.

A lot of times, it’s very difficult because I didn’t really have much of an understanding about asthma, of what it actually is…. Is it just a cough, or is it a true attack?…. Most physicians had neither the opportunity nor the free time to tell us about asthma. I did not understand the cause of asthma, you know. (A)

He was having recurring throat infections, and we really did not know at the time if it had anything to do with allergies. (B)

Category 2: Lack of information
Participants expressed that they needed accurate and complete information about the disease and its treatment. In this study, the participants also tended to underestimate both their children’s need for information and their children’s reactions to the situation. Many participants expressed that insufficient knowledge and experience made them unsure about what was best for their children. Furthermore, information that should have been provided by the healthcare team was absent or incomplete. Some primary caregivers may not have been given access to basic asthma medications or care.

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>5.9</td>
</tr>
<tr>
<td>Mother</td>
<td>12</td>
<td>70.6</td>
</tr>
<tr>
<td>Grandmother</td>
<td>4</td>
<td>23.5</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12</td>
<td>70.6</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>29.4</td>
</tr>
<tr>
<td>Severity of asthma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate persistent</td>
<td>11</td>
<td>64.7</td>
</tr>
<tr>
<td>Severe persistent</td>
<td>6</td>
<td>35.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of the primary caregivers (years)</td>
<td>40.9</td>
<td>13.88</td>
<td>26-67</td>
</tr>
<tr>
<td>Age of asthmatic child (years)</td>
<td>6.65</td>
<td>1.77</td>
<td>3-10</td>
</tr>
<tr>
<td>Length of illness (years)</td>
<td>1.57</td>
<td>0.60</td>
<td>1-2.6</td>
</tr>
</tbody>
</table>

Note. The mode for the age of asthmatic child (years) is 6.
Is she wheezing; do I hear a high-pitched whistle sound?... I am concerned that my son’s coughing may be a symptom of asthma. (I)

He has always suffered from bronchitis, but I was never told that he had asthma. Health teams never provided information on asthma attack care. (O)

I don’t believe in the medication, and then I think about side effects.... I don’t know anything about asthma, and I have many questions that I’d like answers to. (K)

**Feelings of Chaos and Instability**

Childhood illness often places a highly stressful burden of care on the primary caregiver. Many participants in this study appeared disturbed by the emotional and psychological pressures of clinical care, with these pressures driven by worry, fear, frustration, and helplessness. They expressed fear that their child might die during a nocturnal asthma attack. Nocturnal asthma attacks led to poor sleep quality and disrupted activity patterns in participants. Disruption of daily family life was further reported in terms of how much of a hassle it was for participants to change plans or respond to the shifting nature of family routines. The effects in terms of emotional and physical distress on those who care for children with asthma are analyzed below.

**Category 1: Worry**

Many participants expressed concern about their ability to problem solve and about the impact of the side effects of asthma (e.g., reactions to drugs, rejection of medication, and the impact of the disease on normal childhood learning).

I’m worried that the asthma could affect my child’s future.... I feel that her condition is stable and has improved, but the medicine might damage her body. I have often said that she should stop taking this medication. (C)

I’m worried constantly about her health. Last night she woke up with a stuffy nose, and my heart sank into my stomach (my brain realizes this is an exaggerated reaction, but my nerves don’t). (M)
Category 2: Fear
Some participants expressed concerns about their child not being able to breathe properly. They described their fears that their child would die during an asthma attack. These feelings were very intense at the onset of their child’s illness, and participants expressed that these feelings would recur whenever the child became seriously ill.

I’ve always been afraid when I see that my child is ill with an asthma attack. I’m afraid I won’t discover his symptoms soon enough. (Q)

It was terrible. I felt like this every time he has an acute asthma attack…. I remember those times as nightmares. The first time he had an asthma attack it really frightened me and put me at a loss as to what I should do. I get a pain in my stomach when I think about it. I try to forget it. (K)

Category 3: Frustration
The inability to accurately detect symptoms may enhance the caregiver’s frustration, especially in the context of uncertainty about the illness. These participants reported, “I don’t know what we’ll do.” They expressed being painfully aware of their responsibilities to take care of their sick children. Their inability to control the symptoms of the disease often resulted in feelings of sadness, anxiety, frustration, and powerlessness.

I am frustrated with the asthma attacks, and if my child has to eliminate the persistent cough and wheeze, I don’t know what we’ll do. I know that doesn’t make sense, but denial seems to be the only solution I can come up with at the moment, I am so depressed. (H)

Why can’t he be a normal life? The pediatrician is saying that…crying and temper tantrums may trigger an asthma attack…. sometime he is crying and fussing, I tried the “controlled crying” but I am losing my patience. (A)

Maybe the emotions of anger and frustration go hand in hand. This also leads me to feel guilty for not having more patience…. If I had cleaned the house properly, he would not have become ill. (D, I)

Category 4: Helplessness
Throughout their interviews, most of the participants expressed feeling helpless, expressed as an inability to solve problems, achieve goals, or mobilize energy on one’s own behalf. Those participants who were less able to control the illness and/or their child’s behavior may experience more intense feelings of anxiety and helplessness. They feel unable to provide what their children with asthma require in an emergency and do not know how to help.

Sometimes he is fine, but sometimes he has an attack, in which case we have no means of handling it. (C)

There was no one who could tell me about this and I had to figure out everything by talking with other asthma patients in order to deal with the asthma attacks. I felt helpless. (L)

We lived in a polluted industrial area, and, although leaving that neighborhood won’t be easy, I can’t think of a better way to work around this situation. (E)

Category 5: Physical distress
Many participants reported spending most of their time and energy engaged in asthma care and, because of the unpredictability of the disease, keeping a watchful eye over their children. As the illness progressed, the participants experienced increased levels of distress with a greater adverse impact on their own health and daily lives. The participants reported physical distress, which refers to the consequences of a failure by the individual to respond appropriately to a physical threat.

I have never slept well since my son’s first asthma attack. I often have mood swings, brain fog, dizziness, and ringing in my ears. I was afraid that he would not survive an attack. (C, G, P)

I have often had to care for [my] child’s illness during the night. Naturally, I didn’t get to sleep well, but at least I could care for her. (M)

I’m tired. I have no energy to do anything. I am completely exhausted because I have to care for the children. (F)

Social Tension and Family Conflict
A person experiences stress when he or she does not have the ability or resources to cope when confronted with an external stressor or when they worry about not having adequate abilities or resources. A chronic pediatric condition may increase stress and distress among family members, leading to tension in intrafamilial relationships. This conflict, actual or perceived, is caused by the opposition of needs, values, and interests, which results in disagreements and conflicts of interest. A comprehensive study of the impact of this conflict on the caregivers is discussed below.

Category 1: Disorientation of daily activity and burden of care
Most participants reported that managing a household while caring for a chronically sick patient may require the family to
readjust its habits. Participants indicated that the burden of care changed the daily activities of their families and caused disorientation. Most of the discord among family members occurred when the burden of care was not distributed equally.

In the beginning, I was very flustered and feared that he would have an attack. As a result, I woke up several times at night to check if he was all right. When he slept calmly and steadily, we felt reassured. Our lives have been impeded by his sickness. (F, H)

I don’t get any help from my family. They think that I can do it all by myself. What they don’t realize is that it has affected me both mentally and physically and the stress is sometimes unbearable. (P)

Category 2: Economic burden
In this study, participants reported facing economic hardship caused by the aggregate of expenditures on treatment (direct cost) and production and income losses (indirect cost). They described their related coping strategies and the consequences for their household’s finances.

The cost of medical treatments and procedures can be expensive, so we needed to start working part-time. (E)

We have spent a lot of money on her treatment; I cannot work because I need to take care of the children. (P, Q)

Installing devices such as air purifiers and dehumidifiers would be very expensive. I don’t think we can afford these expenses. (L)

Category 3: Family tensions and disagreements
Some participants reported that there were disagreements regarding the proper approach to patient care, care options, and the proper approach to handle a patient who refuses treatment. In addition, participants reported that other non-care-related disagreements between the caregiver and other family members often made the role of the caregiver more difficult.

We often had a lot of disagreement about the children’s medicine. My husband did not accept the use of steroids because of their side effects. In his own understanding, using steroids is a kind of drug addiction. And I was always blamed by my family about how I gave medication to the children. (Q)

...burst into crying because of the child’s discomfort.... I was hurt and irritated as well as angry. And, I was unable to communicate with my husband. I worried that he was not well, but somehow every time we had an argument, we would fight over his being sick. (I, P)

The doctor said that installing devices such as air purifiers and dehumidifiers can help improve indoor air quality at home. However, it will be costly. This problem caused our relationship to be full of tension and disagreements, so we stopped communicating with each other on this issue. (E, L)

Discussion
The findings of this study provide rich data on the experience of primary caregivers in looking after children with asthma. The difficulties with asthma care faced by participants caused feelings of uncertainty during illness, feelings of chaos and instability, and social tension and family conflicts.

Primary caregivers of children with asthma must live with regular uncertainty and must constantly monitor the breathing condition of their child and manage issues as they arise. The participants expressed the fear that they may not be able to adequately help their children during asthma attacks. Their experience of stress was related to the possibility of an acute asthma attack. Obviously, a major problem is telling the primary caregivers that they cannot control the condition or predict outcomes when their children have exacerbated asthma attacks. That uncertainty was one of the greatest stressors for the primary caregivers and the source of almost constant worry/concern.

Illness-related uncertainty has been regularly highlighted as a predictor of adjustment outcomes in parents of children with a chronic illness (Stewart & Mishel, 2000). This study found that the participants tended to underestimate both their children’s need for information and their children’s reactions to their illness. This finding is similar to the results of other studies (Jerrett & Costello, 1996; Kieckhefer & Ratcliffe, 2000). The lack of information about asthma and the unpredictability of its outcomes may impair the ability of caregivers to adapt, leading them to believe themselves incapable of coping with the illness. Previous reports have found that distress in caregivers is associated with a diminished ability to cope with caring for an asthmatic child and have subsequently identified distress as a marker for higher negative impact of a child’s illness on the family (Frankel & Wamboldt, 1998; Trollvik & Severinsson, 2004). At this point in the trajectory, the perceived uncertainty of a caregiver leads to care distress. There is a period of helpless emotional “floundering” for the caregiver when the child does not improve and has repeated illness episodes, which lead to family frustration (Wuest & Stern, 1991). Caregivers may be unable to handle asthma care adequately. Some studies have associated perceived uncertainty and unpredictability with emotional difficulties in individuals who experience a variety of chronic medical conditions (Cheng et al., 2010; Mishel, 1988). Caregivers have the additional responsibility of trying to support their child through a difficult time and thus feel inner distress. As the illness of their children progressed, participants in this study related that they experienced increased levels of
distress, which had a greater adverse impact on their health and daily life. Thus, they often reacted by restricting the daily activities of their children. This restriction ranged from simply avoiding triggers to placing limits on physical activity (e.g., not playing outside in an effort to avoid pollen). This finding is congruent with the findings of several other investigators (Wolf, Miller, & Chen, 2008; Wood et al., 2007). Placing faith or absolute trust in a healthcare provider may decrease the feeling of uncertainty in caregivers/parents, whereas perceiving discrepancies or ambiguity from healthcare professionals erodes trust and may increase uncertainty (Dellve, Reichenberg, & Hallberg, 2000). Uncertainty and unpredictability are integral components of asthma. Therefore, the potential contribution of healthcare professionals to the long-term emotional adjustment of caregivers warrants further consideration. Furthermore, it is important for healthcare professionals to discuss these feelings with caregivers and to be aware of this important issue.

The literature shows that family conflicts may hinder the effective management of asthma (Kaugars et al., 2004). Family conflicts generally arise because of a lack of communication, differing points of view regarding the illness, and the poor quality of family life attributable to the child’s asthma attacks (Kaugars et al., 2004). In some families, the stress felt by the primary caregiver also contributed to increased family conflicts and difficulty with asthma care. In this study, disagreements between family members regarding the distribution of asthma care responsibilities led to increased participant stress and family conflict. This finding is congruent with previous studies that reported that disagreements within families negatively impacted social relationships (Houseknecht & Hango, 2006). This study indicates that family conflicts frequently arise because of insufficient asthma-related information and inconsistencies in this information when given. The increasing uncertainty among caregivers may result from caregivers neglecting their own needs while caring for their patients. These findings concur with the findings of previous studies (Englund et al., 2001). Previous studies report that a lack of effective communication, an underutilization of resources, and the absence of adequate support systems may generate an imbalance in the responsibilities of caregivers (Moffat, Cleland, Van Der Molen, & Price, 2007). It seems that primary caregivers and their families do not possess adequate information and/or do not communicate effectively with medical staff regarding the adequate provision of care. According to the Global Initiative for Asthma, an ongoing partnership between healthcare professionals, the patient, and the patient’s family is important for successful asthma care (Paul, 2010). As a consequence, identifying these primary caregiving factors and following them up with information targeted at primary caregivers may promote a better understanding of asthma and more effective self-care. In summary, research and clinical work may be advanced with increasing asthma knowledge regarding which specific family characteristics predict adherence, as these may significantly affect asthma outcomes.

A lack of adequate resources may cause parenting stress and, in turn, cause ineffective caring behavior (Wade et al., 1997). The results of this study show that primary caregivers restrict the daily activities of their children to minimize the severity and long-term risk of disease-related symptoms. It is understandable for parents/caregivers to be concerned regarding their child’s asthma, particularly if they do not have access to all of the information necessary to effectively control the disease and prevent symptoms. In this study, caregiver stress may affect the ability of families to provide sufficient care for their asthmatic child. Providing constructive values and coping mechanisms to primary caregivers has been shown to facilitate their situational learning through discussion and reflection (Thompson et al., 1994). According to Gibson (1995), the process of critical reflection is a necessary part of the empowering process, which helps individuals take charge of a situation and develop a sense of personal power (Gibson, 1995). Using information to modify perceptions related to the seriousness of a disease may help parents control their feelings and help them cope with the predictable aspects of their child’s illness. The resultant enhanced empowerment and self-efficacy of the caregiver may significantly improve their participation in problem solving and healthy decision making (Wang, Dong, Gan, & Wang, 2007). Therefore, intervention strategies that enable primary caregivers to make decisions about goals, therapeutic options, and self-care behaviors and to assume responsibility for daily asthma care are effective in helping them care for their asthmatic children.

Limitations of this study included the small sample size and the limited number of families that participated, which limits the generalizability of the findings. The scope of the study should be broadened to capture a broader range of patients with chronic asthma. Therefore, future research designs must consider the multiple factors that may contribute to the onset, manifestation, and morbidity of asthma. In addition, a better understanding of the etiology, pathogenesis, risk factors, and protective influences that affect asthma outcomes may improve preventive measures. There is a need for randomized studies on the effects of group empowerment programs. A future holistic approach to optimal asthma care should include both medical- and family-function parameters as well as an integration of the outcome measures regarding health-related well-being and quality of life and their impact on society and on healthcare costs.

Conclusions

This study associated uncertainty in caregivers with misinterpretations of disease-related information and unreasonable fears regarding the potential progression of asthma. Greater uncertainty in participants was positively associated with lack of perceived control over the care situation, which negatively affected the psychological adaptation of these caregivers. On the basis of these findings, the relationships among the aspects of psychological functioning and asthma outcomes
may be bidirectional. The findings of this study show that providing caregivers with appropriate and accurate information is necessary to promote their understanding of asthma and self-care efficacy. Enhanced empowerment and self-efficacy in primary caregivers should improve their capacity to problem solve and make healthy decisions. An understanding of the stressors of primary caregivers is important to facilitate the development of interventions that better address their need for better professional support during the disease management process. In addition, our findings also reveal that family conflict exacerbates tensions in intrafamilial relationships. This may affect the ability of families to provide sufficient care for their asthmatic child. Importantly, our study found that social tension and family conflicts may hinder the effective management of asthma.

Acknowledgments
This research was supported by CMRPG2800111, 2800112, and 2800113 from Chang Gung Memorial Hospital at Keelung.

References
(Coauthor work published in Chinese)


氣喘兒童的照護壓力：主照顧者之質性研究

陳淑賢1 黃璟隆2 莊國偉3 蔡芸芳4*

1基隆長庚醫院護理部主任，長庚科技大學護理系助理教授 2林口長庚醫院副院長，長庚大學教授 3林口長庚醫院兒科過敏氣喘风湿科主任，長庚大學副教授 4長庚大學護理學系教授兼任主任，基隆長庚醫院護理部顧問

背景 氣喘是兒童最常見的慢性病，由於急性氣喘會反覆、不定性的發作，隨時會危及生命，對於患童及其家庭的日常生活產生深遠的影響。瞭解主要照顧者的經驗，或許能提供患孩更好的照顧。

目的 本研究目的是探討氣喘兒童之主要照顧者氣喘照護經驗。

方法 採質性研究法，於臺灣北部的兩家醫學中心及一家區域醫院被診斷氣喘一年內的兒童之17位主照顧者（受訪者）為訪談對象，以半結構問卷之訪談指引收集資料，運用內容分析法進行資料分析。

結果 歸納出三個主題及十個類別：(1)生長延緩性感受（疾病認知、信息缺乏）、(2)混亂和不穩定感受（擔心、恐懼、沮喪、無助、身體不適）、以及(3)社會緊張和家庭衝突（生活失序和照顧負擔、經濟負擔、家庭關係緊張和分歧）。

結論／實務應用 負面的氣喘照護經驗和不可預測性的結果，照顧者適應似乎受影響，致使他們察覺到他們無法應付的疾病。經由訪談瞭解主照顧者經驗，我們希望能提供照顧者於應對氣喘兒更平順。

關鍵詞：主照顧者、照護經驗、氣喘、兒童。

接受刊載：103年6月23日
*通訊作者地址：蔡芸芳 33302桃園縣龜山鄉文化一路259號
電話：(03) 2118800－3204 E-mail: yftsai@mail.cgu.edu.tw