



Family Adaptation to Chronic Childhood Illnesses

A systematic literature review

Degree Programme in Nursing
Bachelor of Health Care
Final Project
6.11.2008

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Degree Programme in		Degree	
Nursing		Bachelor of Nursing	
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Title			
Family Adaptation to Chronic Childhood Illness			
Type of Work	Date	Pages	
Final Project	Autumn 2008	21 + 2 appendices	
<p>ABSTRACT</p> <p>Asthma is a most common long-term disease in Finland among children. Families who have children with chronic illness such as asthma often experience difficulties in adaptation to the illness. Asthma, the attacks, the triggers and medication can be difficult to deal with for both the children and their parents. Successful family adaptation to chronic illness needs nursing interventions which can be applied to the individual families.</p> <p>The purpose of this Final Thesis is to examine the nurse's role when assisting families with children suffering from a chronic illness, what are the challenges to and needs of families with children who have chronic illnesses and how does a better understanding of the concept of empowerment positively influence health promotion and adaptation in families with chronic illness. Through this investigation of the literature pertinent to these areas we hope to show how they are intertwined with one another.</p> <p>The method of this study is a literature review. We have tried to convey to the reader what knowledge and ideas have been established on our topic before. We used the already existing knowledge to find answers to our research questions and seek information to support the aim of our paper. Electronic data bases were used to search for the relevant articles.</p> <p>Findings indicated that there is a need for a systematic tool to be in place for nurses so they would be able to acquire a systematic view of the overall coping abilities of families of children with asthma. We found that identification of the challenges and needs of families with children suffering from a chronic illness enables the families to better identify the resources available to them in order to facilitate positive adaptation to their child's illness. Empowered parents cope better with stresses associated with chronic illness. There is a need for more collaborative nursing intervention in these families' lives to help them better understand and identify coping strategies which will allow them to gain control over their children's illness and their family life.</p>			
Keywords			
empowering parents, asthma education, asthma in children, parents and coping,			

Degree Programme in		Degree	
Hoitotyö		Sairaanhoitaja AMK	
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Cathriona King-Sutinen ja Pia Wahlström			
Title			
Perheen Sopeutuminen Lapsuusajan Krooniseen Sairauteen			
Type of Work	Date	Pages	
Opinnäytetyö	Syky 2008	21 + 2 liitettä	
ABSTRACT			
<p>Asthma on yleisin pitkäaikainen lasten sairaus Suomessa. Perheet joilla on kroonisesti sairaita lapsia kuten asthmaattikkoja usein kohtaavat vaikeuksia sopeutua sairauteen. Asthman, kohtauksien, tekijöiden sairauden laukaisemiseen sekä lääkityksen kohtaaminen voi tuottaa vaikeuksia niin lapsille itselleen kuin heidän vanhemmilleenkin. Onnistunut perheen sopeutuminen krooniseen sairauteen tarvitsee sairaanhoidollisia menetelmiä jotka voidaan toteuttaa yksittäisille perheille.</p> <p>Tämän opinnäytetyön tarkoitus on tutkia sairaanhoitajan roolia kroonisesti sairaiden lasten sekä heidän perheiden hoitotyössä, mitkä ovat heidän haasteensa ja tarpeensa ja kuinka paremmin ymmärrettynä voimaantumisen käsite voi positiivisesti vaikuttaa terveyden edistämiseen sekä kroonisesti sairaiden lasten perheiden sopeutumiseen. Tähän opinnäytetyöhön käytetyillä tutkimuksilla tästä aiheesta pyrimme näyttämään kuinka nämä käsitteet ovat liittäytyneet toisiinsa.</p> <p>Tämä opinnäytetyö on kirjallisuuskatsaus. Olemme yrittäneet välittää lukijalle julkistettua jo tutkittua tietoa ja ideoita tästä aiheesta. Käytimme jo olemassaolevaa tietoa löytääksemme vastauksia tutkimuskysymyksiimme sekä tietoa joka tukisi opinnäytetyömme tarkoitusta. Artikkelit tähän opinnäytetyöhön ovat löytyneet sähköisesti elektronisista tietokannoista.</p> <p>Tutkimustulokset osoittavat että sairaanhoitajat tarvitsisivat yhdenmukaisen käytännön työvälineen jotta asthmaattisten lapsien perheiden sopeutumista kokonaisuutena voitaisiin mitata järjestelmällisesti. Kroonisesti sairaiden lapsien perheiden haasteiden ja tarpeiden tunnistaminen auttaa heitä löytämään olemassaolevia voimavaroja jotka auttavat heidän sopeutumiseensa sairauteen. Voimaantuneet vanhemmat sopeutuvat paremmin sairauden tuomiin rasituksiin. Nämä perheet tarvitsevat yhteistyökykyisempää sairaanhoidollista menetelmää jotta he voisivat paremmin ymmärtää ja tunnistaa sopeutumiskeinot jotka edesauttavat heitä hallitsemaan lastensa sairauden ja perhe-elämän.</p>			
Keywords			
voimaantuminen,voimaantuneet vanhemmat,asthma koulutus,lasten asthma			

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1. INTRODUCTION

In a family, caring for a child should be an enriching and rewarding experience. Families who have children with chronic illness such as asthma often experience helplessness, uncertainty and unwellness of being because of difficulties in adaptation to chronic illness (Brazil & Krueger 2000). Critical periods in the life of the chronically ill children, when they become ill or when the illness presents problems are especially difficult on the children and their families. The lack of adaptation tools or realization of resources at these times leads to emotional, behavioral and social problems for these families as a whole (Klennert et al. 2000, Bender et al. 2000, Svavardottir et al. 2000, Hentinen & Kyngas 1998). When the family trying to cope with the stressors involved in adapting to chronic illness, lack the understanding of the resources and tools needed for successful adaptation to their child's illness, it may reflect on the families' adjustment capabilities and how they perceive their child's illness (Klennert et al.2000).

Clinical nursing has goals in promoting health especially in situations which represent a challenge to families. It has been showed that traditional approaches in nursing to supporting patients and their families may not represent the best tools for adaptation to chronic illnesses (Funnell & Anderson 2004). Other approaches show that successful adaptation to chronic illness in families is due to increased knowledge which leads to better coping and feelings of control over the illness. Through modification of behavior, increased understanding of resources and support systems, families with children who suffer from a chronic illness can overcome the difficulties and improve overall health promotion in the family (McQuaid et al.2005, Svavarsdottir & Raynes 2003, Bender et al. 2000, Klennert et al.2000, Svavarsdottir et al. 2000).

Among chronic illnesses we concentrated on asthma as it is the most common long-term disease amongst children in Finland. Asthma has increased in prevalence over the last 20 years among children up to the age of 15 years, the hardest hit age group being the under 5 year olds (Duodecim 2000). Asthma, the attacks, the triggers and medication can be difficult and sometimes frightening to deal with for both the children and their parents.

The needs of the families when adapting to chronic illness are very often difficult to assess from a health carer's position. Implemented tools which would assist the nurse in speedy assessment of the needs of a given family are scarce. Successful family adaptation to chronic illness needs nursing interventions which can be applied to the needs of individual families. Education and attainment of knowledge for these families leads to mastery over the disease. These tools, knowledge and collaboration with the health care professional are vital when aiming for positive outcomes on the overall wellbeing of the family (McMullen et al. 2007, McQuaid et al. 2005, Brazil & Krueger 2002).

The concept of empowerment is used widely in the context of nursing. A nurse's understanding of the concept of empowerment has association with positive impacts on health and the quality of client-oriented nursing which lead to overall positive effects on families gaining a sense of control over the child's illness. Through analysis of the concept of empowerment and understanding the ramifications of empowerment on the families, we gain a better understanding of how empowerment can influence the successful adaptation of families to their child's chronic illness and to their attainment of education and knowledge. A better understanding of empowerment can lead to proper health practices, to mastery over the disease and to positive experiences for families through successful adaptation.

The purpose of this literature review is to examine the nurse's role when assisting families with children suffering from a chronic illness and to examine the challenges and needs of families with children who have chronic illnesses and how a better understanding of the concept of empowerment positively influences health promotion and adaptation in families with chronic illness. Through this investigation of the literature pertinent to these areas we hope to show how these are intertwined with one another. Through a thorough and extensive exploration of their dimensions we will bring the nurse or health care professional a better understanding of the critical areas which need to be focused on when interacting with families of children who suffer from asthma but also with families who have children who suffer from chronic illnesses.

2. THEORETICAL FRAMEWORK

2.1 Asthma and children

2.1.1 Asthma as an illness and asthma medications

Asthma is a chronic inflammatory disorder of the airways. It is characterized by an obstruction of airflow, which can be completely or partially reversed with or without specific therapy.

The typical symptoms of asthma in young children are:

- Coughing, particularly at night and after exercise
- Wheezing or whistling noise in the chest
- Getting short of breath. Perhaps the child does not run around as often as usual, or needs to be carried more.

(Asthma Society of Ireland 2006, Sterling, Y & El-Dahr, J. 2006)

Asthma can be difficult to diagnose in children as it usually reveals itself with a variety of symptoms. “Procedures such as spirometry and other traditional objective measures of pulmonary function are difficult or impossible to perform in very young children. Thus, diagnosis often deprives from clinical judgment, symptoms assessment and treatment outcomes.” (Sterling, Y & El-Dahr, J. 2006:29.)

Once the child has been given a differential diagnosis, the child is usually recommended a complement of medications to manage the disease. Inhaled corticosteroids (ICS) are the first choice for controlled medication in all age groups and at all levels of asthma severity. The corticosteroids (Pulmicort, Astra) when administered are effective in reducing airway inflammation, hence reducing oedema and secretions of mucus into the airways. Additionally, long lasting beta2 agonists (Salmeterol, Formoterol) added to existing corticosteroid therapy can be used for control of nocturnal asthma-mild to moderate asthma management. Together these medicines relieve asthma symptoms by relaxing smooth muscle that have tightened around the airways and acting as anti-inflammatory by reducing, reversing and preventing swelling in the airways which reduce symptoms and prevent episodes from occurring(Conboy-Ellis 2006).

This section has, so far, mentioned the clinical picture of the disease and its management only. However, when speaking of asthma and children, focusing on the clinical side of the disease is not enough. To paint an adequate picture of asthma as a childhood disease and to describe asthma and children, we must look at the impact the asthma has on the child other than just purely from a clinical perspective.

2.1.2 Asthma effects on children and families

According to several articles, the impact of having asthma on children's lives is negative. "...although emotional and behavioral problems are not increased, school adaptation and peer interactions may be somewhat inhibited, particularly in children who demonstrate greater airway obstruction and school absence related to their asthma" (Bender et al. 2000:710). However, it is important that the psychological impact and the social implications the children's asthma can have on them must also be considered. Often pediatricians may intervene when there is a noted "increased illness severity, impaired physical and social activity, and frequent interaction with the health care system" (Bender et al. 2000:711). All these signs may be a cry for help on the part of the child and may mean that they are not psychologically dealing with the impact of the illness. Without intervention at this point, the child may slip further into the cycle of worsening symptoms, impaired social activities, social isolation and psychopathological dysfunction.

The research article by Svavarsdottir et al (2000) attempted to identify the most time-consuming and difficult care-giving demands experienced by mothers and fathers of young children with asthma. The results of this cross-sectional research design were that "the most time-consuming care-giving task identified by mothers of young children with asthma was providing emotional support. Other time-consuming care-giving tasks were managing discipline and behavioral problems of the child with asthma, giving developmental support for the child, handling an asthma episode...other difficult care-giving tasks experienced by mothers were getting up at night to care for the child."(Svavarsdottir et al 2000:352.) As can be deduced from the results of the above research article, the impact of asthma on a child's life is enormous and often quite negative, with emotional, behavioral, and physical disruption to their lives.

Children who are coping with chronic asthma do adjust but very often with difficulties to their situation. The adjustment to their illness often has an impact on the ability to regulate emotions. The process of a child being able to regulate his or her emotions in a correct way requires that the child has developed an array of healthy emotions and is able to access them when transitioning between emotional states. Children who suffer from emotional regulation dysfunction may display anxiety, depression, outbursts, and disruption of their internal equilibrium as well as difficulties in the parent-child relationship. "For parents who experience increased anxiety and stress related to the child's illness, coping becomes evident and may be directed at the reduction or elimination of anxiety, achievement of additional resources, ongoing management of family tension, and shaping family members appraisal" (Svavarsdottir & Rayens 2005:388).

The effects of the parents' sense of coherence, well-being and the family's overall hardiness have a profound effect on the emotional regulation of the children who suffer from a chronic condition. Results indicate that strengthening family hardiness is an important goal, since hardiness may help families adapt over time to chronic illness, thus strengthening their children's ability to better cope emotionally and psychologically (Svavarsdottir et al 2000).

Asthma prevalence, morbidity and mortality are on the increase world wide. The exact reasons for this are unknown. However, it is fair to say that increasing environmental pollution, lack of access to medical care, lack of correct diagnostic techniques and lack of adherence to treatment could be quoted as influencing the increases in cases.

Asthma is the most common chronic childhood disease. It also is the primary cause of school absences and responsible for majority of pediatric admissions to emergency departments and hospitals. From a child's point of view asthma can be daunting disease to adjust to. Many children live with the frustration of having their asthma interfere with their normal daily activities and disrupt their social interaction with their peers. Children need education in how to respond to their symptoms from their health care provider and support and understanding from their own families (Fisher 2001).

When we consider children and asthma, we must realize that even though they are resilient to many stressor events, the burden of having a disease such as asthma can

have a clearly measurable effect on their lives. Some recent studies have suggested a link with greater asthma severity and increased adjustment problems in children coupled with more difficulties in the mother child relationship. The patterns observed are consistent with reports of high levels of psychiatric disorders among adolescents with very severe asthma (Klennert et al. 2000).

In the light of such reports we must as nurses and health care professionals understand that children learn from their interactions with family members. The quality of interfamilial coping is a critical component of the chronically ill child's ability to negotiate the stressful demands of managing their illness, socialization with physically healthy peers, and functioning effectively at school (Brazil & Krueger. 2002).

According to the majority of the articles reviewed here, possibly the most important factor for the child successfully coping with their asthma was how their family adjusted to the disease.

2.1.3 Family adaptation

Throughout the literature that describes family coping or, as it is referred to at times, family adjustment, to their child's illness, we have identified certain factors during the writing of this literature review which inevitably influence whether a family is able to gain a sense of control over their child's illness. The most influential factors were economic, educational/knowledge, support/resource availability and internal stresses. Due to the limited financial resources, economically challenged families lack the basic ability to manage the asthma because of inadequate access to proper health care, medications, asthma knowledge and social support (McQuaid et al. 2005, Bender et al.2000, McMullen et al.2007, Brazil & Kruger 2002)

2.1.4 Empowerment

Over the past decades the concept of empowerment has been more widely used than ever before in nursing literature and as a result the concept itself has evolved into a well established and recognized theoretical approach in a wide range of disciplines (Kuokkanen & Leino-Kilpi 2000). Empowerment, according to the literature reviewed can be defined as a process or mechanism by which an individual or a group of people gain mastery over their affairs and issues by which one can discover and develop the

inherent capacity to be responsible for one's own life, a vision that guides each encounter (Funnell & Anderson 2004). Empowerment also represents a process of:

- becoming empowered or empowering oneself
- an outcome - being empowered
- an intervention - empowering others

Most of the definitions suggest that empowerment involves a shift in the transfer of power (Homan-Helenius 2005).

Throughout the literature, several concept analyses of empowerment were identified. Antecedents, defining attributes and consequences of empowerment were present in a lot of the reviewed literature. Some differences were also as identified in the literature. However, more common components were identified throughout the literature than differences. Common antecedents were identified as collaboration between the health care professional and the patient, joint trust and respect, equality in the status, and commitment to process (Funnell & Anderson 2004, Houston & Cowley 2002, Kuokkanen & Leino-Kilpi 2000, Leyshon 2000).

Defining attributes common to many articles included self management, feeling in control of the disease, recognition of the clients' autonomy, client freedom to make choices which lead to positive or negative outcomes and to accept responsibility for those actions and collaborative decision making. The consequences of empowerment for the client were found to be a sense of control over the disease and life, positive self image and positive outlook for the future.

Traditionally, the health care professional's training was based on a medical model of care, a paternalistic approach where the health care professional was the one in control of the situation, the provider of information, diagnosis, treatments and in control of the outcome of the experience of the patient. This approach left the client in a passive, receiving, and powerless position which, more often than not, led to shortcomings in compliance with the achievement of goals (Funnell & Anderson 2004). From a philosophical and psychological stance, the concept of empowerment used as empowered patient education is the most desired shift in the relationship between the health care professional and client. This collaborative approach allows the empowerment model of care, "chronic care model", to lead the way forward to mutual decision making and the overall encouragement to gain autonomy over one's illness and

life. This approach has been tested and found highly effective according to the literature (Funnell & Anderson 2004, Homan-Helenius 2005).

Empowerment is not a new concept. However, it is an ever evolving one. Much of the literature is descriptive and theory-based, as many concepts emerging out of nursing science are at this moment. To ensure correct advancement of this concept it must lend itself to further measurement and testing to allow its application over a wider base where it would be most usefully engaged.

2.1.5 Empowered client education

Since empowerment is a large concept, it is wise to concentrate on the concerns of empowered client education separately. Bearing in mind that successful client education can not be created without the influence of empowerment.

Client education is an important part of the health care professional's profession. To be successful, education of the client requires collaboration, exchange of information, mutual respect and trust. Approaches to client education strategies within the empowerment philosophy incorporate interactive teaching strategies designed to involve patients in problem solving and addressing cultural and psychological needs (Huston & Cowley 2002, Funnell & Anderson 2004, McCarthy et al. 2002).

3. RESEARCH QUESTIONS AND PURPOSE

With the increase in numbers of child sufferers of asthma, nurses are facing more challenges in successfully educating families to adapt to their child's illness. Traditional educational approaches alone are no longer adequate for dealing with the current situation. Literature supports the need for a marriage of both traditional and collaborative approaches by nurses in educating families to adapt to chronic illnesses. Our purpose is to investigate the nurse's role in assisting families of children with chronic illnesses.

The information gathered and examined in this literature review will focus on answering the questions:

- What is the nurse's role when assisting families with children suffering from a chronic illness?
- What are the challenges to and needs of families with children who have chronic illnesses?
- How does a better understanding of the concept of empowerment positively influence health promotion and adaptation in families coping with chronic illness?

4. METHODOLOGY

4.1 Method of analysis

This paper is a literature review. We have tried to convey to the reader what knowledge and ideas have been established on our topic before. We have analyzed already existing knowledge and have looked for strengths and weaknesses in them. We used this knowledge to find answers to our research questions and to seek information to support the aim of our paper.

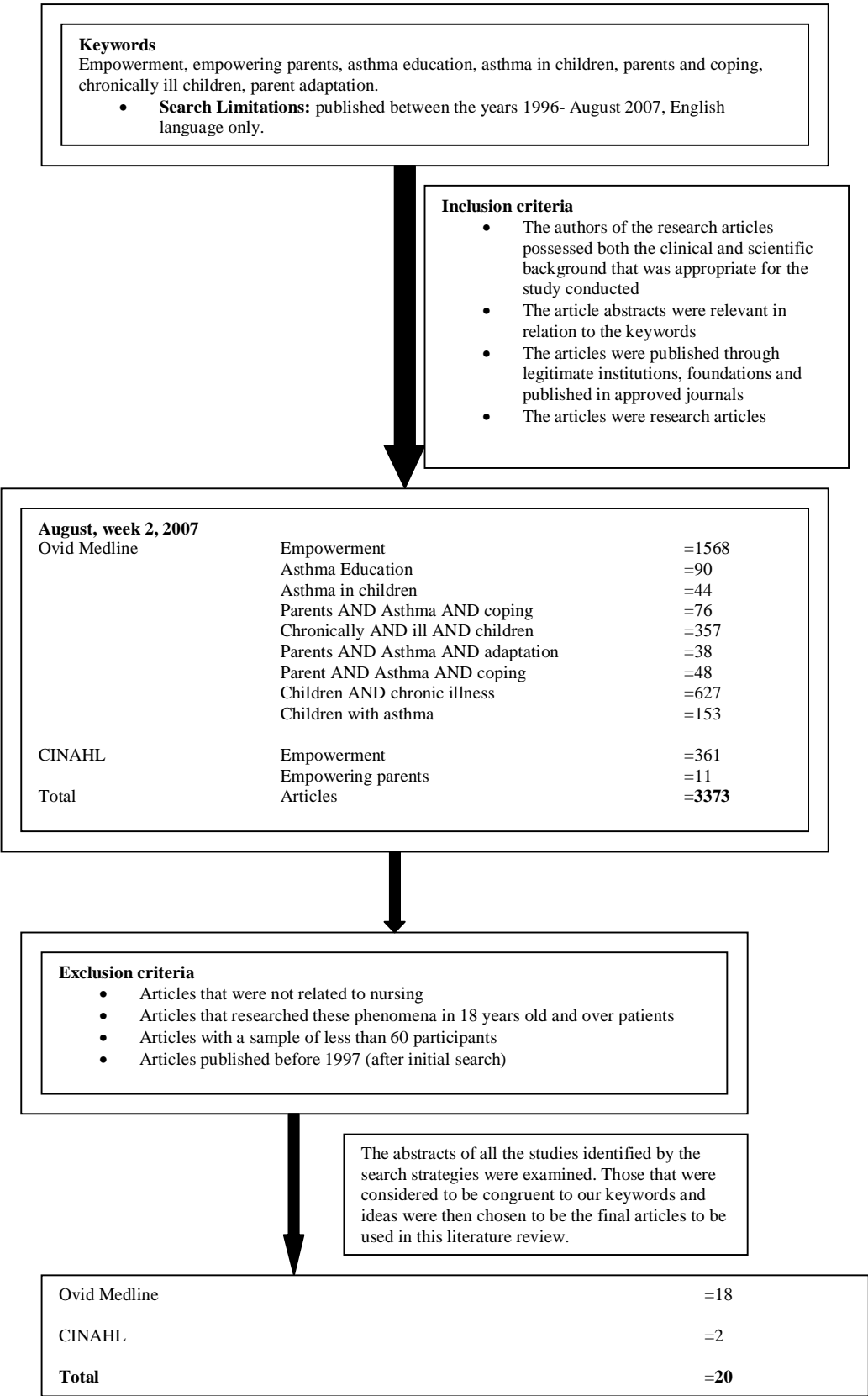
We have followed the guidelines according to Nursing Research Conduct, Critique & Utilization. 4th Edition, by Nancy Burns and Susan Grove.

4.2 Data collection

Internet databases were used to search for relevant articles. The databases that were searched included Ovid Medline, Pub Med, Cinahl, Medscape, Medic and Science Direct. Several University libraries in Finland were used including the Helsinki Polytechnic Stadia library. The basic search engines Yahoo and Google were also employed. The most useful of these databases for this paper were Ovid MEDLINE (Medical Literature Online) and Cinahl (Cumulative Index to Nursing and Allied Health Literature).

The articles chosen were published between the years 1996- August 2007. The search restrictions for these articles were set to Full text and English Language only. The keywords used in the search were empowerment, empowering parents, asthma education, asthma in children, parents and coping, chronically ill children, parent adaptation.

Table 1. The data collection process



4.3 Synthesis of results: successful familial adaptation to chronic childhood illness.

Through interest in the topic of family adaptation to chronic childhood illness and reviewing the literature, we compiled questions of interest to nurses. Through a systematic review of the literature, we began to answer our 3 questions. We found through this systematic review that the role of the nurse is to understand the following to allow for successful adaptation of families to chronic illness: Table 2

Table 2. The role of the nurse in successful adaptation of families to chronic illness

<u>Families' Needs</u>	<u>Nurses' Role</u>
Need for knowledge	Provide information about the disease
Need for understanding	Facilitate the families in understanding their of resources and support
Need for empowered collaborative partnership	Collaborative relationship with the family to allow successful mastery over the child's illness facilitated by empowered nurse education.

A successful synthesis of the above can lead to positive family adaptation to their child's illness.

The above suggestions do not provide an exhaustive account of the findings but represent themes of nursing interest which we believed to be useful.

5. FINDINGS

5.1 Need for knowledge: Nurses' role when assisting families with children suffering from chronic illness

Parents are the most sensitive to their child's illness and notice the psychological and physiological effects more definitely than the children themselves or the closest members of the social chain to the children such as their teachers. Both children and teachers saw few changes in the children's behaviors due to illness. However, the parent-child relationship was found to be strained and difficult. The suggestion coming forth was that the family is directly linked to how the child will cope with the illness (McQuaid et al. 2005, Bender et al. 2000).

The studies also showed that emotional regulation in children with asthma is altered. When children were assessed through parent report, through child interviews and through child participation in an emotional regulation paradigm, it was found that emotional regulation was not only influenced by intrinsic factors such as temperament but also by repeated interactions with caretakers. The manner in which caretakers modulate emotions for their young children and teach the regulation of emotional behavior played a major role in the children's own emotional regulation. The idea was supported by the fact that parents of children with asthma reported higher levels of over anxious symptoms for their children when compared to a control test groups, suggesting that this may be a reflection on the adjustment capabilities of the parents and how they perceive their child's illness (Klennert et al. 2000).

When reviewing the literature, it was found to be the general consensus that there is a need for a systematic tool to be in place for nurses and health care professionals, in order to facilitate them in acquiring a systematic view of the overall coping abilities of families of children with asthma. How the family integrates the management of asthma into the family system, or fails to do so have been shown to have implications for asthma outcomes (McQuaid et al. 2005).

One such tool which was found to be a valuable tool in assessing family-based asthma management was the Family Asthma Management System Scale (FAMSS). This scale assesses asthma management through clinical interviews. This scale is multifaceted yet systematic and yields results with good internal consistency. The difference with this and other assessments tools such as self-report instruments and objective assessments (to name but a few) is that they provide rather restricted findings and have limited a capacity to capture the complex range of behavior that characterizes asthma management and alone they do not provide any information regarding the context in which the medication is administered or adhered to (McQuaid et al. 2005).

However, a slightly modified FAMSS provides an assessment tool that allows for results that provide information on asthma knowledge, symptom assessment, family response to symptoms, child response to symptoms, environmental control, medication adherence, collaboration with health care providers and balanced integration. The challenge of family adjustment assistance in terms of the disease, requires a nurse or

health care professional that possesses a very clear picture of each individual family they deal with so as to best provide the necessary support.

5.2 Need for understanding: Challenges to and needs of families with children having chronic illnesses

National guidelines for asthma diagnosis and management have over the past twenty years called for effective partnerships to be built between health care professionals, their patients and their families in a bid to bring patients and their families into a more proactive position when addressing disease control. “How the family integrates the management of asthma into the family system, or fails to do so, has been shown to have implications for asthma outcomes” (McQuaid et al. 2005:492).

5.2.1 Economic/educational/knowledge factors of family adaptation

Results found from several different articles suggested that “economic challenges may result in the diminished capacity to optimally manage asthma as a family” (McQuaid et al. 2005:499). Furthermore, these economically challenged families had compromised family based management skills due to their “limited financial resources-resulting in restricted access to health care, medications and adequate housing” (McQuaid et al. 2005:499). The findings suggested that this “compromised family based asthma management skills may be an important mechanism underlying the propensity for diminished asthma outcomes among children from low socioeconomic status backgrounds in particular”(McQuaid et al. 2005:499). The research article by Bender et al (2000:711) found that “families that are challenged by such factors as economic instability or few social resources may perceive the child’s asthma as an enormous disruptive influence where as families with relative stability and support may have considerable resilience and report little adverse impact even in the presence of severe illness”.

Findings suggest that asthma knowledge and family and child response to their illness were positively associated with parental knowledge. One research suggested (when using convergent validity to assess its results) that “parental performance on a standard measure of asthma knowledge was positively correlated with FAMSS (Family Asthma Management System Scale) subscales of asthma knowledge, family response to

symptoms, collaboration with physical and the overall summary score” (McQuaid et al. 2005:498) .

Research which examined and documented parent perceptions of the education they received from their child’s health care professional on the subject of asthma found that areas of the NAEPP(National Asthma Education and Prevention Program) Expert panel’s advice (that was deemed critical for effective disease management) were not fully discussed by the health care professionals with parents.

Areas such as how to use a metered dose inhaler, how to manage an asthma attack and the effects of passive smoke exposure on triggering attacks were frequently covered. However, it was found that less than 50% of the time equally important issues such as how to build a collaborative relationship between the health care professional and the parents, parental knowledge of the child’s feelings about asthma, asthma management skills and written care plans by parents for home management were discussed. Other areas such as asthma medication education received from the child’s health care provider fell short of the recommendations the NAEPP Expert Panel deemed critical for effective disease management. A reported overall score of 61% suggests that almost 40% of content considered to be critical in helping parents manage their child’s asthma was reported not to have been fully discussed, despite the child having had several visits to the health care provider in the prior year. These findings reflect a considerable gap when the premise of appropriate parental early intervention is based on knowledge of the causes, triggers and treatment of asthma (Mc Mullen et al. 2007).

5.2.2 Support/resource factors of family adaptation

The findings into support/resource availability to the families found that healthy relationship with their social support system has an influence on successful family adaptation to their children’s asthma. Access to resources (social, economic, and cognitive) was found to facilitate coping. “Research on the mediating influence of social support for specific stressor events has indicated that social support makes individuals less vulnerable to crisis” (Brazil & Krueger 2002:172). According to the study of Brazil and Krueger (2002:172) “social support is valuable resource to parent care givers...Parents should be encouraged to develop their own strengths and resources to prevent potential problems resulting from the demands of the care giving”.

In Bender et al. (2000) a stepwise regression was used to assess which factors predicted the child's psychological adjustment when measured by the questionnaire Child Behavior Check List (CBCL). This questionnaire measures the parent-reported evaluation of behavioral and emotional problems, social competence and school competence. The analysis of the questionnaire found that the measure of the family's network of social support outside the immediate family was the strongest contributor to the model with a partial R² of 0.116, which means that 16.6% of the variability in the CBCL total score was explained by social support after all the other variables in the model were selected and accounted for. This finding clearly indicates the importance of the family's support availability as perceived by the family.

One research used open questionnaires to provide parents with an opportunity to describe their problems in caring for the ill child. The results suggested (when analyzing adaptation to other variables using cross tabulation) that with the subject of parental adaptation and the influence of social support upon it more than half of the families who did not have conflict appeared to receive abundant emotional support, while half of the families who had many conflicts appeared to receive poor emotional support.

Furthermore, it was concluded in the same study that parents with poor adaptation felt that they received poor emotional and instrumental support from their relatives as well as poor support from health care staff. Of the many possible moderating factors that affected adaptation, social relationships and support are most influential for mothers of children with chronic disease (Hentinen & Kyngas 1998).

5.2.3 Internal stressors of family adaptation

Families who have chronically ill children meet a lot of internal stress. In previous studies examining this area, families were found to encounter more negative verbal behaviors, more communication issues and had issues with internalizing conflicts. Parents and care givers of these ill children found themselves in a difficult position as they must manage their child's illness and have knowledge about treatments. They also have the responsibility for the emotional, physical and developmental well being of the child.

Families with children who suffer from asthma encounter behavioral issues with their children that often their healthier counterparts do not. Children with asthma also

experience more nighttime disturbances due to the nature of the disease and as side effects to their medicines. Much of the time and energy of these parents is taken by caring for these children. Both mothers and fathers experience that the most time-consuming task is providing emotional and developmental support for their children. Other difficult caregiving tasks experienced by both parents was handling an asthma episode followed by managing discipline and behavioral problems, giving developmental support for the child, providing emotional support for their spouse or partner, and structuring or planning activities for the family (Svavarsdottir et al. 2000).

Due to the stress incurred and the fatigue reported by the parent's different areas of their lives were reported to be effected. Mothers seemed to be the parents who find it difficult to manage their own well-being, manage work or school responsibilities, and manage the care for the young children with asthma at the same time. The fathers reported providing emotional support for their spouses or partner as both a time-consuming and difficult caregiving task (Svavarsdottir et al. 2000). The families of chronically ill children face many challenges related to their family life therefore it is important to be aware of how these overwhelming pressures can lead to family tension and stress.

The study by Klinnert et al. (2002) found that parents of children with asthma reported higher levels of overanxious symptoms for their children than parents of controls who participated. This may, in fact, be a reflection on the adjustment capabilities of parents and how they perceive their children's illness. Again, it may be inferred from such findings that parents of such children need better education and support mechanisms to truly deal with the stressor events when dealing with chronic asthma. This support could also lead to the parents being able to fully recognize and use resources available to them.

The study results by Klinnert et al. (2002) found several points of interest when looking at internal stress within the families of asthmatic children. The subjects were assessed through parental report, child interview and child participation in an emotional regulation paradigm. The information from these reports yielded that mothers (primary care givers) report higher levels of overall internalizing problems for their children with asthma than do mothers of healthy controls and that the parent report measure (CBLC) showed increased problems among children with asthma. From this it can be concluded that parents clearly have issues interacting with their ill children. The report also

identified the association between emotion dysregulation of the children and more frequent, poorly controlled asthma symptoms showing a relationship between psychological difficulties and greater asthma severity. This asthma severity was identified to be as a result of poor symptom control which is often linked to poor adherence with medication and poor asthma management in general. Poor adherence and asthma management for childhood asthma has been related to both child and family dysfunction. Overall family dysfunction is contributed to poor child emotional regulation, poor adherence to medicine regimens, and greater asthma severity.

5.3 Need for empowered collaborative partnership: Understanding of the concept of empowerment in relation to family adaptation

Several of the research findings indicate that parents with asthmatic children lack essential asthma knowledge. Research has indicated that not only knowledge of asthma is poor in general, but also severe shortcomings exist in the knowledge of medications and the symptoms of asthma attacks. The results of the pilot study by McCarthy et al. (2002) which was conducted on 57 families over a two year period and compared the effects of empowering and traditional approaches to asthma education. When these two different educational approaches were used, families that had received the empowering educational program (which consisted of interactive and responsively designed approaches which reinforced parental expertise, problem solving and collaborative relationships with the health care professionals), acquired an increased sense of self control and increased ability to make decisions and provide care for their children. Furthermore, the results from the study show that the traditional approach to educating such families (where the health care professional acts as the expert) no longer meets the complex variety of needs these families possess. The study, in fact, highlights the need for effective education which involves provision of information, focusing on the experience of living with asthma and enabling these clients and their families to develop the attributes and skills required to function as equal partners in the health care team, making informed choices about the health of the client and complete management of the disease on a daily basis.

To further support the above pilot study the research article published by McMullen et al (2007:43) documented “significant gaps in education, particularly in content areas of communication and development of a relationship between health care provided and patient/family. It also highlights demographic differences in education received”. In the

report parents of 228 children with asthma reported on the education they had received based on the recommendations of the NAEPP (National Asthma Education and Prevention Program). The researchers documented results according to which:

- 66% of the parents agreed that the overall proportion of the education was fully discussed
- 75% were educated about how to manage asthma attacks
- 81% were educated about how to administer medications and their effect
- 44% discussed goals of management
- 44% were provided with written guidelines for acute management

The education given to the parents differed significantly based on symptom severity and socio-demographic characteristics. For example, parents with children suffering from moderate to severe persistent symptoms reported receiving more education than those with mild symptoms. The report highlighted ineffective communication and collaborative relationships between parents and health care providers. “The differences in education reported have implications for pediatric nurses involved in asthma education and warrants further investigation” (McMullen et al. 2007:43).

6. ETHICAL CONSIDERATIONS AND RESEARCH LIMITATIONS

As the paper is a literature review the ethical considerations were that, the writers of this paper had to trust the validity of current information on this subject available for this paper, also that:

- The authors of the research articles possessed both the clinical and scientific background that was appropriate for the study conducted
- The articles were published through legitimate institutions, foundations and published in approved journals

Some research limitations were faced in this study. The most challenging limitations were that there were not enough research available specific to asthma and related to adaptation or empowered patient education. Many of the articles discussed these subjects in a broader context, not limiting themselves only on asthma but discussing all chronic illnesses. Another research limitation was that it was difficult to concentrate on any specific age group, since most research articles talked about children but not of the specific age of the children.

7. DISCUSSION

We found that the nurse when assisting families with children suffering from a chronic illness needs to have knowledge of the disease, the ability to identify adaptation dysfunction in families and the ability to support adaptation through empowered client education. The articles reviewed suggested that better knowledge about the disease of asthma, its symptoms and how management of the disease can all be attained in collaboration with the nurse or the health care professional and the family. These articles also suggest that the nurse's role in the proper adjustment of these families to their children's disease is crucial. Nurses should be aware of difficulties with the family relationships, economic stressors, what resources are available to the family and how much knowledge they have about the disease. In a collaborative way the nurse-family-relationship should lead to empowered parents feeling in control of the disease instead of feeling the disease has control over them.

We found that the identification of the challenges to and needs of families with children suffering from a chronic illness enables the families to better identify the resources available to them in order to facilitate positive adaptation to their child's illness. The suggestions in this study clearly show the precarious position these vulnerable families are in. It lends support to the notion that empowered parents cope better with stresses associated with chronic illness but also highlights the need for increased nursing intervention in these families' lives to help them better understand and identify coping strategies which will allow them to gain control over their children's illness and their family life.

A better understanding of the concept of empowerment by the nurse and the family allows for better overall health promotion within the family and positive outcomes through gaining mastery over their child's illness. The findings suggest that parents with asthmatic children do not receive an education based on the NAEPP recommendations which incorporates the ideas of empowerment client education into its guidelines. This type of inconsistency leads to issues with adherence to asthma management overall.

8. CONCLUSION

The research questions that we attempted to answer in fact led us to no concrete conclusions about the phenomenon of family adaptation to chronic childhood diseases. However, they led us to some interesting findings which are useful for nurses when attempting to assist families who are in crisis when trying to gain a sense of control over their child's illness. When answering the questions we found out:

A nurse must be an information provider, helping the families understand the child's illness

- The symptoms and causes
- The medications and interventions

A nurse must also be a facilitator in helping the families realize

- Their challenges
- Their resources
- The support available to them

A nurse must be an empowered educator

- To have the ability to educate the family through both traditional and collaborative approaches
- To empower the family through a combination of open communication, partnership and support

Overall, the study revealed some interesting findings, like those mentioned above. In addition, the review also indicated that further research into this area would be justified to evaluate how the parents feel about the empowered approach to adaptation. The parents' opinion of the nurse as a partner, the information dissemination techniques of the nurse, the support systems available to the families and their opinion on overall quality of care they are given would also be worthy of further examination. Furthermore the bulk of the literature available on the subject of empowerment focuses on the theoretical description of the concept. The need for more research into the

operationalization of the concept of empowerment is needed. This is especially vital for nursing as a whole as it would give extra validity to empowering interventions.

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Appendix 1

Quantitative studies examined in the literature review: Family adaptation to chronic childhood illnesses

Author/Title	Purpose	Method	Results
Anthony et al.2003, USA	To determine the extent to which parental perceptions of child vulnerability predict school and social adjustment in children with chronic illness	Quantitative Study 69 child-parent dyads were recruited.Parents: self-report of parental perception of child vulnerability.Children: completed measures of social adjustment	Increased parental perceptions of child vulnerability are related to increased social anxiety in children.Lower levels of parental education related to both increased perceptions of child vulnerability and increased school absences.
Bender et al. 2000, USA	To test hypotheses that the burden of childhood asthma compromises psychological adaptation and that the degree of compromise increases with disease severity	Quantitative Study Total of 1041 children aged 5 to 12 years were randomized to the trial after confirming their mild to moderate asthma. Questionnaires assessing anxiety,depression behavioral competence,social support and family functioning.	Psychological difficulty was not increased with asthmatic children. Psychological adaptation in the children was associated with the psychological adaptation of the families.
Brazil & Kruegel 2002, Canada	To examine patterns in adaptation among parents with an asthmatic child. Differences in adaption between mothers and fathers were examined	Quantitative study Nonexperimental,descriptive design, which parents participated in a one-point-in-time home interview. Participants had participated in a 3-month inpatient program.Family adaptation was measured. 84 parents participated.	Findings indicated that need for additional support for mothers in their role in caring for the chronically ill child is needed.
Hentinen & Kyngas 1998, Finland	To describe the adaptation of parents who have a child with a chronic condition and some factors connected to it	Quantitative Study Data collected by questionnaires from 189 parents of children with chronic condition.	Support from health care staff and the need to obtain more information were not connected to adaptation as clearly as emotional or instrumental support. Parents wished more support when the child was under nine years old.

Author/Title	Purpose	Method	Results
Hopia et al. 2004, Finland	Aim was to describe how nurses in a paediatric unit promote the health of families of children with chronic conditions during the children's hospitalization.	Quantitative Study Data was collected from two finnish hospitals in 2002 using group interviews. 40 nurses who worked with chronically ill children and their families participated.	Family care was based on three distinctive strategies. Nurses used systematic, selective or situation-specific strategy while promoting health. Findings indicate that the systematic way seems a useful strategy.
Klennert, et al. 2000, USA	Examine behavioral adjustment and emotion regulation among 6 year old children with asthma and a group of healthy controls.	Quantitative Study 81 children with asthma and 22 healthy controls. Emotional and behavioral functioning were assessed through parent report, child interview and child participation in an emotional regulation paradigm.	Maternal report revealed more internalizing and total behavior problems for children with asthma. Child interview and behavioral observations of emotion regulation yielded no difference between groups. Asthma severity was related to increased emotional difficulties by clinical interview and observation but not by maternal report.
McCarthy et al. 2002, Canada	To provide findings that have implications for asthma education and for the education of health professionals	Quantitative Study Sample of 57 families participated in a multi-session educational intervention. 29 empowering approach, 28 traditional approach. Data collection before and 6 months after intervention.	Significant differences were found regarding sense of control, ability to make decisions, ability to provide care for parents who participated in the empowering approach.
McMullen et al. 2007, USA	Describes asthma education received from the health care provider and evaluates differences in their report based on sociodemographic and disease characteristics.	Quantitative Study 228 parents of children with asthma were recruited from diverse clinical practice sites and asked to report the level education received in key content areas the National Asthma Education and Prevention Program identified as critical.	Gaps exist in education received overall, especially areas of developing a collaborative relationship between a parent and a health care provider.
McQuaid et al. 2005, USA	The objective was to to examine psychometric properties of the family asthma management system scale (FAMSS).	Quantitative Study FAMSS was given to 115 children with asthma and their care givers. 53 families participated.	FAMSS is a valuable tool to assess family-based asthma management.

Author/Title	Purpose	Method	Results
Svavarsdottir, et al. 2000, Iceland & USA	To identify the most time-consuming and difficult caregiving demands experienced by mothers and fathers of young children with asthma. To examine both direct and moderating relationship of individual SOC and FH with family and caregiving demands on parents' well-being.	Quantitative Study 76 families with children with asthma The resiliency Model of Family Stress Adjustment and Adaptation was the conceptual framework for the study.	Resiliency factors sense of coherence(SOC) and family hardiness(FH) and family demands had direct relationship to the well-being of parents of young children with asthma.
Svavarsdottir & Raynes 2003, Iceland & USA	To identify factors that influence American and Icelandic parents' health perceptions among families of infants or young children with asthma	Quantitative Study A cross-sectional research design of 76 American families and 103 Icelandic families with children with chronic asthma completed questionnaires.	American and Icelandic families differed in hardiness. In both countries differences were found in caregiving demands and health perceptions between mothers and fathers. Interventions emphasizing family and individual resiliency and strengths have the potential to affect parents' views of their children's health.
Svavarsdottir & Raynes 2005, Iceland & USA	The purpose is to assess whether there are cultural and gender differences in parents' general well-being, sense of coherence and perception of family hardiness and also to examine the effects of parents' sense of coherence and well-being on family hardiness.	Quantitative Study A cross sectional research sample design used a sample of 137 two-parent families. Questionnaires measured the sense of coherence on parents' well being and family hardiness.	Focused interventions for families with asthmatic children should be developed