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Supporting self-care of chronically ill children

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Thesis Abstract:

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The topic of the thesis is supporting self-care of chronically ill children. Children have limited knowledge about their health and are mostly dependent on their families and other personnel for support.

The goals of the thesis are to identify the needs of chronically ill children and assist them on how they can support themselves; and to provide basic guidelines to families and nurses to support the self-care of chronically ill children.

The thesis was written using literature review method of research. The inductive approach of content analysis was used to analyze the data in an attempt to answer the research questions; What functional support do chronically ill children need from nurses and their families? How can the self-care of chronically ill children be promoted?

The results showed that support from the nurses, family, and other people was viewed as very important to children with chronic illness. Support, shared-management, and self-care were three concepts that came up from the results.

In conclusion, self-care was seen as a continuous process led by the nurse, but the family assumed many responsibilities. Self-believe and motivation was seen to be a key to successful self-care.

Keywords: support, self-care, chronic illness and child.

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Abbreviations

ENB	Evidence-based nursing
WHO	World health organization
MOSA AH	Ministry Of Social Affairs and Health (Finland)
CINAHL	Cumulative index to nursing and allied health literature
USA	United States of America

1 INTRODUCTION

Chronic diseases of childhood are likely to have implications for the psychosocial well-being of children, as well as their families (Barlow & Ellard 2006). The reason for choosing the topic is that, some children are infected by a chronic disease that usually affects them for many years or throughout their life time. Since such children are helpless at an early age, the thesis intends to find out how nurses and family can support these children to help themselves. Cavallo et al (2009) argues that it is important to help parents understand their child's medical situation and health, especially those whose children have more severe mobility dysfunction and make supporting easy.

Nurses are the health professionals who spend much time with clients, both adult and children. In Finland, families pay at least nine visits to a child health clinic. These visits are scheduled for the first year of a child's life to monitor the well-being of the child and the parents. This is followed by a total of at least six check-ups scheduled first at six-monthly and then at yearly intervals for all families. Three of the appointments are more extensive medical examinations. (Ministry Of Social Affairs And Health (MOSA AH) 2013). Chronically ill children and children who need some kind of support are best cared for by those with pediatric expertise and professionals (Sloand et al. 2002). The World Health Organization (WHO) outlines in primary health care code of implementation that there should be a better health care for all. It is therefore important for the healthcare workers and the families of chronically ill children to understand how to give these children adequate support, when the need arises (WHO, 8.10.2013).

A 2001 National Survey in the USA showed that 13% of children lived with special health care needs (Kieckhefer et al, 2009). The prevalence of childhood disability was estimated to be ranging from 5.8% in the United States to 9.8% in Finland in the year 2003 (Barlow & Ellard, 2006). The current number of children who need special health needs in the USA was around 18% as in 2004, and Kieckhefer et al believes these numbers keeps increasing yearly (Kieckhefer et al, 2009). As the number of children with special health care needs increases, the amount of money and time needed to support these children also increases. This explains why Neff

(2006) stressed on the fact that about 50% of all child health care expenses goes to support those children with some kind of chronic illness (Kieckhefer et al 2009).

According to Barlow & Ellard (2006), any disease which is medically diagnosed which shows little change or slow progression and last for 6 months or longer is a chronic disease. Gultekin & Baran (2007) argue that, chronic illnesses may include deviations from established norms and result in permanent disability. A disability is however considered as a restriction or lack of ability to perform an activity within the range that is considered normal for every human being. These two have comparatively different definitions but are related in some ways. The two distinctive definitions are often lost when prevalence figures are compiled, using them interchangeably. However, they emphasize that chronic diseases are not always activity limiting (Barlow & Ellard, 2006).

The aim of nurses in health care is to provide support. However, nurses should provide individualized care that respects and honors the families' perspectives, encourages open sharing of helpful next steps, and support the development of collaborative plans. The nurse should focus on providing care centered on the family, collaborate with the family, support both the child and family in stress management, and empower them through education and training. In designing family-centered support and education programs, the nurse should view the child's desires and knowledge as important as that of his/her parents. (Kieckhefer et al, 2009).

Family is the first and basic support provider for the chronically ill child. The burden of caring for children who has a chronic disease generally falls upon parents (Barlow & Ellard 2006). The family should accept the child, be understanding and provide encouragement to the child. Hopia et al (2004) believes that families need to understand the specific nature of their child's disease including diagnosis, prognosis, and the care plan. Berntsson et al (2007) says that it is important for the parents to trust their child, seeing their capacity to manage different situations. They also believed that the prerequisites for a child to feel good were a good relationship with their parents and their parent's capacity to support their needs.

This thesis targets chronically ill children themselves as a group that has much influence of self-care. This is because when the child grows up, they could get some knowledge about their self-care and how to function well without being much of a liability to others. According to Orem (1991) “Infants and those children in early childhood require care from others because they are in the early stages of development physically, psychologically, and psychosocially”, even when the child’s wellbeing is not distorted by any form of illness. In consideration to Orem’s article, this thesis view infants to early childhood before the age of 6 years as completely dependent on others such as parents, therefore the authors consider it normal for the child to be supported by families.

2 SUPPORTING SELF-CARE OF CHRONICALLY ILL CHILDREN

This thesis recognizes any person of either sex within the ages of 6 years to 17 years as a child. The reason for choosing this age group (6-17years) is that, children within this age are mostly dependent on their families and society. They have limited knowledge about their health issues. The thesis therefore seeks to find ways children with chronic illnesses could be supported. The factors that restrict nurses and families for rightly supporting chronically ill children will be assessed. In this way nurses, families and the society at large can support the chronically ill children appropriately.

Karl and Waqar (2000) in their research indicated that all parents found caring stressful and demanding, but accept that they had to cope with the situation for the sake of the child's wellbeing. The thesis therefore intends to assist families and nurses to identify the type of help they can offer to these children with some chronic illness. In this light, nurses, especially those in children's ward and the families of chronically ill children can refer to this thesis when supporting chronically ill children.

Evidence-based nursing (EBN) methods should be the baseline for nursing care for chronically ill children. According to Scott and McSherry (2008), the concept of EBN is still much unsophisticated as a scientific construct that leads to the problems associated with its use and misuse.

Nurses usually come into contact with children who have some kind of chronic illness. According to Sloand et al (2002), while some nurses may be concerned about some of the difficulties and challenges of working in a humanitarian crisis, they will also encounter uplifting and joyful times when caring for children. Interaction with health care team is very important as it helps children to accept their illness. Taylor et al (2008) further argued that children believed that from the many people who provided support, the most important was from their nurses. They further explained that children viewed health professionals as most supportive if they offered flexible treatment plans and the children knew they would not give up on them.

According to Taylor et al (2008) parents are the allies in helping children with their disease and are important in guiding even during treatment. Chronic illness in a child produces stress for both the child with the illness and his or her family (Mussatto 2006). As time goes on children with special health needs must become partners in the management of their illness. Because most of the care of chronic illness takes place at home, parents assume significant responsibility to start and support the child's role in parent-child shared management (Kieckhefer et al, 2009). They further argue that it is important for families of chronically ill children to be fully aware of the health condition of their children at all times, whether mild, moderate or severe. As children grows up, they start to understand their treatment and could take control of their own treatment, develop routines that best suits their situation, as they know what is best for them (Taylor et al 2008).

2.1 Support

Support can be described as to sustain, hold up, or maintain in a desired position or condition, as in physically supporting the abdominal muscles with a scultetus binder or emotionally supporting a client under stress (Anderson, 2002). A scultetus binder is made of a flexible maKaulal with double thick center PAD and five (5) strips on each side of pad. Support in this thesis means any form of assistance in the form of physical, psychological, empowerment, educational and economic that helps to cope with the challenges imposed by chronic illnesses on children.

According to Hopia et al (2004) systematic family nursing is one of the strategies that can be used by nurses to promote family health during hospitalization. This method can begin first by promoting the health of the entire family, which means understanding every member's situation in relating to supporting the family. Other strategies are selective family nursing and situational-specific family nursing. These strategies support families of chronically ill children, either when used singularly or adopted together.

Creating environment which supports children to gain independence and self-confidence will enable the children to manage their illness by themselves. Hence

supportive environment should be encouraged during hospitalization of chronically ill children, and when at home with families and friends to enable them manage their condition as much as possible. (Kirk et al 2012.).

According to Venning et al (2008) psychological support for chronically ill children enables the child to accept his/her disease and focus on other strengths. The nurse and family can enhance sense of self, minimize the impact of experience of illness, promote positive impact of illness, helps them accept with the ongoing situation, and support with the future coping. On the overall, this concept will give the children sense of hope. The child's experience of chronic disease can have a major impact on his or her mental health status, if not well supported. Mental health problems predominantly stem from the subjective experience of chronic disease rather than the physical reality (excluding those chronic diseases that result in mental degeneration etc.). Thus, mental support is of great importance to both sufferer and caretaker (Venning et al, 2008).

Families of the chronically ill children suffer some financial difficulties during the whole time of support process. MOSAAH (2013) confirms that "The special care allowance compensate for the parents' loss of income during time spent caring for the child or taking him or her to hospital appointment". This kind of compensation shows the final support needed to be given to the families of those going through chronic illness experience. Nelf (2006) argues that "hospital and outpatient costs associated with care of these children accounts for over 50% of all child health care expenses" p. 101 (Kieckhefer et al, 2009)

2.2 Self-care

Self-care "is the practice of activities individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (Orem 1991). Self-care is also a personal care accomplished without technical assistance, such as eating, washing, dressing, using the phone, and attending to one's own elimination, appearance, and hygiene. The goal of rehabilitation medicine is maximal personal self-care (Anderson, 2002).

Self-care has a process, purpose, order and if it is carried out efficiently, it adds experience in a specific way to a person's structural integrity, functioning ability and development. This is the more reason why, undermining a person's health condition, everything necessary should be done to include self-care as part of therapeutic objectives (Orem, 1991). Again, Bertz et al (1994) claimed that self-care can be seen as an intended activity, personal, and ongoing benefits to one's own health and well-being. Taking into consideration Orem's model (1991) self-care can be referred to as acquired behavior similar to beliefs, habits, and practices within a person's cultural group (Bertz et al 1994).

Self-responsibility for a person's health is an important responsibility to include in nursing practice with children and families. Children are educated on being responsible for their condition of health and how to adapt to the unusual disease condition. In the same way, parents should be counselled and motivated in self-responsibility such that parents can model positive health behavior to their children. Children emulate many of their parent's healthy behavior and practices, hence nursing interventions on how children can self-care for themselves should include the parents. Self-care should also allow the person in a diseased condition to carry-out their task, of medical management, undertaking normal daily roles and emotional impact should be understood and managed (Kirk S. et al 2012).

2.3 Child and chronic illness

According to Orem (1991) "Infants and children require care from others because they are in the early stages of development physically, psychologically, and psychosocially." even when the children's wellbeing is not distorted by any form of illness. Therefore it is considered normal for the child to be supported by families. Hence, this review looks at supporting chronically ill children within the ages of 6-17years. This is because at this stage of life they should begin to act independently of families, except they are deterred by any form of chronic illness.

Chronic illness is any disorder that persists over a long period and affects physical functioning (Anderson, 2002). Miller (2000) refers to chronic illness as "an altered

health state that will not be cured by a simple surgical process or short course of medical therapy”.

Chronic illness presents an unusual demand on the sufferers and their families. In general, the effects of the illness can be divided into two groups. The child with a chronic illness will experience impaired functioning in more than one part of the body. They usually have multiple impairments in their body, mind and spirit. The other generalization is that the illness-related demand on the individual and its effects cannot be completely eliminated. Chronic illness is the irreversible presence, accumulation, or latency of disease states or impairment that involve the total human environment for supportive care and self-care, maintenance of function and prevention of further disability (Miller, 2000).

There are several obligations to the child with chronic illness as well as his or her family. The child will have to endure close medical attention regarding symptoms, response to therapy and conformity. They must acquire a knowledge of self and therapy so that self-monitoring is feasible. The family is supposed to learn and refine skills for every day monitoring and management. All these efforts must be directed toward keeping the problem contained and in remission while in the same time moderating anxiety over the possible future outcome of the disease condition (Miller, 2000).

3 GOALS AND PURPOSE OF THE THESIS

3.1 Goals

The goals of this thesis are to identify the needs of chronically ill children and how they can support themselves. Another goal is to provide basic guidelines to families and nurses to support the self-care of chronically ill children.

3.2 Purpose and research questions

The purpose of this thesis is to find ways to reduce the stress the child, families and nurses go through in order to help chronically ill children. For this purpose, questions such as what is the family's perception of stress, either physical or emotional or psychological will be asked. Also an assessment about the chronically ill children's personal abilities will be made to know what they can do by themselves. Knowing the strength of the children could then guide nurses and the families on how to help the children and in the same way motivate the children to be as independent as possible.

Research question of this thesis are:

What functional support do chronically ill children need from nurses and their families?

How can the self-care of chronically ill children be promoted?

4 IMPLEMENTATION OF THE THESIS

4.1 Literature review

The data collection method used for this thesis was a literature review. Aveyard (2010) describes literature review as a comprehensive study and interpretation of literatures by other authors or self that addresses a specific topic and gives way for a new article or area of investigation. Literature review is an objective, thorough summary and critical analysis of the relevant available research and non-research literature on a particular topic being studied. Furthermore, a systematic review should detail the time frame within which the literature was selected, as well as the methods used to evaluate and synthesize findings of the studies in question (Cronin P. et al 2007).

4.1.1 Data collecting process

Data was collected from published research papers in English language. Database's of CINAHL with full-text, and EBSCO host were used and some relevant books and other online sources were also employed during the search. The articles were chosen from the period of 2003 – 2014. Systematic literature review was the method used for evaluating, synthesizing findings and to answer the research question. Systematic literature review can be defined as a critical appraisal and analysis undertaken according to a fixed plan or system or method (Gough et al 2012).

The articles were selected on the bases of the topics, abstracts, result and conclusion. The search was limited to CINAHL and EBSCO host database because there were enough articles to get the required information for the completion of the written work. However, some additional internet sources that are trusted were also used. The keywords used to search for information were support, self-care, chronic illness, and child.

Support is to sustain, hold up, or maintain in a desired position or condition, as in physically supporting the abdominal muscles with a scultetus binder or emotionally supporting a client under stress. The assistance giving to this end, it could be physical support, emotional support, or life support. (Anderson, 2002)

Self-care is personal care accomplished without technical assistance, such as eating, washing, dressing, using the phone, and attending to one's own elimination, appearance, and hygiene. The goal of rehabilitation medicine is maximal personal self-care. (Anderson, 2002)

Chronic illness is any disorder that persists over a long period and affects physical functioning (Anderson, 2002). Miller (2000) refers to chronic illness as an altered health state that will not be cured by a simple surgical process or short course of medical therapy.

4.1.2 Inclusion and exclusion criteria

There are countless articles written about the topic of this thesis over the years. All these articles have relevant information for some particular time period, group of people in a location or country, or people suffering from some disease. Some of these articles were written in the era where science and technology was not fully developed. Even though they had very useful information in those times, the change in the way of life and technology has made their importance limited. There was the need to find a way to get articles which would contain information which is not so different than the current state of technology, treatment procedures and the health policies. An inclusion and exclusion criteria which would help the authors to get the best information for the thesis was developed to help reduce the number of articles to a manageable size which has the needed information and is up-to-date. The inclusion and exclusion criteria which the authors came up with are presented in table 1.

Table 1: Inclusion and exclusion criteria.

Inclusion	Exclusion
<ul style="list-style-type: none"> • Publish Literature • Articles with abstract 	<ul style="list-style-type: none"> • Unpublished literature • Articles with no abstract
<ul style="list-style-type: none"> • Free literature • Literature written in English language 	<ul style="list-style-type: none"> • Non free literature • Literature written in other languages apart from English
<ul style="list-style-type: none"> • Published in year 2003 or later • Peer reviewed articles 	<ul style="list-style-type: none"> • Publish before the year 2003 • Non peer reviewed
<ul style="list-style-type: none"> • Scientific articles 	<ul style="list-style-type: none"> • Nonscientific articles

Any article considered in the column of 'data search results' met the criteria for inclusion and exclusion. Articles written in Finnish and/or Swedish were excluded even though the literature review was done in Finland. The required articles used were current, not more than 11 years. Any part of an article that appears in this thesis that is older than 11 years must have been quoted or referred from a current source and deemed as up-to-date or applicable.

4.1.3 Data search results

The data search was done from two electronic data bases of EBSCO host and CINAHL with full text.

The search was very difficult due to the fact that using the key words and the linking words could not produce enough articles. Only three articles were found when the search words "support self-care* AND chronic illness* AND child" was used. With or without truncations, the search did not yield the required articles. A refined search with the following keywords 'support* AND self-care chronic illness

AND child' gave only one article. When the authors added the conjunction "of" to the search, one more article was found making it two articles in a whole. Using the search words support* AND *self-care* of *chronic illness* AND child* four articles were found.

At this point the authors were not sure of getting enough articles for the thesis, until they used 'support self-care of chronic illness AND child' as their search words. The number of articles that found was around 2,765 articles. The inclusion and exclusion criteria reduced it to the numbers shown in table 2. The number of articles were reduced by applying limits like full text articles, reading headings, by reading the abstract. After reading through the 34 articles, 11 were chosen and included in the final thesis.

The first search was done using EBSCO host data base. The search yielded the following results as presented in table 2.

Table 2: Data search from EBSCO host.

Source	Criteria	Number of articles chosen
EBSCO host	keywords: support self-care chronic illness and child	2,765
	articles with full text	796
	according to heading	110
	by reading abstract	34
	Full text read	11

A search from CINAHL with full text data base also provided the following results shown in table 3. The table shows how the inclusion and exclusion criteria were

used to get the required articles by cutting down the number of articles at each stage of the process.

Table 3: Data search from CINAHL

source	Criteria	number of articles chosen
CINAHL with full text	keywords: support self-care chronic illness and child	1,152
	according to heading	112
	reading of abstract	36
	reading full text	2

Data search in CINAHL with full text produced results similar to that of EBSCO host. Same articles were found from both data bases. Most of the articles that were found in EBSCO host were also in CHINAL. Only two new articles were found good for the purpose of the thesis. All together thirteen articles were used for this thesis.

4.2 Content analysis

The inductive approach of data analysis was used for the thesis. Data analyzing process of the thesis was undertaken by content analysis. Content analysis is a research technique for making replicable and valid inferences from already existing literature. Also, content analysis is a method of analyzing quantitative or qualitative data by using inductive or deductive way (Elo & Kyngäs, 2008). The aim of content analysis in the thesis is to detail and build a pattern in a concrete manner, that will enable indebt understanding of how to support and care for chronically ill children.

Content analysis is also generally recognized as a method of analyzing documents, which allows the researcher to test theoretical issues to enhance understanding of the data collected. It is possible also with the system of analysis to distil words into smaller content related categories. By this it is assumed that when classified into the same categories, words, phrase, and so on they still share the same meaning. Content analysis is a research methodology for creating replicable and valid inferences from data to their context, with the intention of providing knowledge, new understanding, a representation of facts and a practical guide to action .(Elo & Kyngäs, 2008).

As stated by Elo & Kyngäs (2008) inductive way of approach is used in the absent of not enough previous knowledge about the researched phenomena. It is recommended if the knowledge or idea is fragmented. The categories in this kind of approach are derived from the data in inductive content analysis.

Data analysis can be grouped into three main phases; preparation, organizing and reporting. The analysis of literature review is operationalized on the basis of previous knowledge about the topic or subject or phenomena. The key frame work of all content analysis is that the text is classified into smaller content categories (Elo & Kyngäs 2008). According to Graneheim and Lundman (2004) in the preparation phase, selecting unit of analysis such as words and themes is required. That is followed by sampling and making meaning to the data.

The organizing phase is the making of a meaning to the data collected and to recognize what is going on, the moment to put together the sense of the whole information and data gathered (Elo & Kyngä 2008). At this stage when reading the material and data the question should be: what is happening? Why? Who is telling? Where is this happening? In order to become totally submerged into the data this is the reason for reading through the written material many times (Polit & Beck, 2008).

4.2.1 4.2.1 Data analyzing process

This thesis is conducted using the content analysis principle and inductive approach in organizing the data and reporting the result. Open coding by using markers for highlighting, notes and headings were written down in the on a different sheet of paper to describe all aspect of the content while reading was going on. Then the articles were read all over again for better understanding. The information was then written in the way the authors understand and interpreted it. All headings were collected into coding sheets and categories were freely generated at this stage. At the end of organizing phase, categories were put together into groups and under headings.

Similar ideas were grouped under every corresponding heading as sub-category. The main idea from the sub-categories was used to form the generic categories and main categories. An example of the data analysis process used in the thesis is shown in table 4. The table shows how ideas were grouped into various categories using the nurse as the main category.

Table 4: The nursing support

sub-category	generic category	main category
<ul style="list-style-type: none"> -honour family's perspective -encourage open sharing -collaborative planning 	Family centred nursing	Nursing support
<ul style="list-style-type: none"> -physical and psychosocial health. - well-being -reliable source for medical support -health care interventions 	Health promotion	
<ul style="list-style-type: none"> -partnership with family -understanding the family -planning about care of child together 	Collaboration	
<ul style="list-style-type: none"> - identifying stress -coping with stress -information about illness -support 	Stress management	

5 RESULT

The importance of supporting a child with chronic illness cannot be over emphasized. This is because normal children without any chronic disorder begin to act independently of families at some point in time. However, when they are faced with some kind of disease that limits their abilities, they rely on the family to make up for the things they cannot do by themselves. Support also involves the families and nurses as caregivers and how the coping with illness is being handled (Berntsson et al, 2007).

A 2001 National Survey in the USA showed that 13% of children lived with special health care needs. They further say the current number of children who need special health needs in the USA was around 18% as in 2004, and they believe these numbers keeps increasing yearly. As the number of children with special health care needs increases, the amount of money and time needed to support these children also increases (Kieckhefer et al, 2009).

Barlow & Ellard (2006) believe childhood chronic disease may have implication for the psychosocial well-being of the children and their families as well. Therefore, it is important for professionals like nurses to collaborate and support families of chronically ill child in their ongoing daily management of the children (Berntsson et al, 2007). According to Kieckhefer et al (2009), even though the outpatient cost of children with chronic illness is very high, the more important concern of parents was the non-monetary cost of providing ongoing daily management of their condition. In view of this, the family as well as the children needs some kind of financial assistance. In Finland for example, there is a provision for special allowance to compensate parents for their loss of income during time spent caring for the chronically ill child (MOSAACH, 2013).

The results indicated that, support for chronically ill children was provided by nurses, family, by the children themselves, and sometimes by other professionals and friends. The nurse plays a role in guiding adolescents and their families towards adulthood and independence self-care by helping them identify and use their strengths and resources for the achievement of future goals (Berntsson et al 2007). The Maternal and Child Health Bureau (2005) acknowledges that parents

are the most constant and important care providers of their children (Kieckhefer et al, 2009).

The results have been grouped into different main categories as follows, nursing support, family support, supporting self and support from other people. The main categories have been further divided into generic categories.

5.1 Nursing support

Among the health care professionals, nurses are usually the first professional who takes contact to patients, receiving patients, and monitoring patient's conditions regularly, interpreting and carrying out doctors' orders, and discharging patients. In this respect nurse practitioners must offer families professional support and encouragement to discuss fears and feelings openly in an effort to assist families in adapting to their child's diagnosis of a chronic illness (Goble, 2004).

Nursing support covers a broad spectrum of activities which is directed towards the child and his/her family. These nursing activities have been grouped under different headings as the generic categories from the main category nursing support. The generic categories for nursing support includes family centered nursing, health promotion, collaboration, stress management and empowerment.

5.1.1 Family centered nursing

Kieckhefer et al (2009) suggests that nurses should provide individualized care that respects and honors the families' perspectives, encourages open sharing of the helpful next steps, and supports the development of collaborative plans. Thus, when caring for children with chronic illness, the nursing support should not be focused only on the illness but on the family as well. Especially, when designing family-centered support and education programs, the nurse should view the child's desires and knowledge as important as that of his/her parents. Also, Mussatto (2006) explains that in caring for families and children with chronic conditions like congenital cardiac malformation, attention should not only be on physical health

but also on the psychosocial health of the family. This family-centered support will give the nurse an insight into the family situation, and subsequently design an appropriate support program for them (Hopia et al 2004). It is important for the nurse to know that chronic illness in children produces stress to the family. She further suggested that nurses must be perceptive and empathetic to the stress of chronic illness to the family (Mussatto, 2006).

5.1.2 Health promotion

The main aim of nursing should be health promotion. Hopia et al (2004) believes that the aim of all nurses is to promote health. However, they argue that nurses' actions in promoting family health are random and dependent on the strategies of individual nurses. From their research, Gultekin & Baran (2007) explained that parents of chronically ill children need to be aware of the possible abnormal reactions and behavior of their children so that they can accept support from health professionals. Nurse should advise parents of the signs and symptoms, effects, and how to help their children. Therefore, nursing staff needs to know the family's current situation, what the child's illness means to the family, and how the family has coped with other stressful situations previously. Nursing support can be directed towards the family or the child him/herself in the case of older children. The nurse therefore needs knowledge about the family's background, history, and coping skills in order to determine how to provide support (Hopia et al 2004).

5.1.3 Collaboration

Family-nurse relationship should be very effective when it comes to supporting chronically ill children. Effective collaboration between nurses and the family of children with chronic illness leads to better understanding and provision of needed support for the child. In this respect parents of children with a chronic illness should be seen by nurses as a valuable resource in understanding and managing the illness. Knafel & Zoeller (2000) however states that nurses should assess the confidence and practical competence of the parents of chronically ill children

regularly. Competent families should be given the chance to participate in their child's care (Hopia et al 2004). Sloper & Lightfoot (2003) however argue that, despite the increase in consultation initiatives within health services, the case for children's participation in user involvement is notably missing (Hopia et al 2004).

5.1.4 Stress management

Also, nursing support is aimed at stress management of both parents and the chronically ill child. Childhood chronic disease may have implications on the psychosocial well-being of families and children (Barlow & Ellard 2006). Hopia et al (2004) indicated that, it is stressful for a family when their child who has a chronic illness is admitted to the hospital, but nurses have the opportunity to promote the family's health while the child is hospitalized.

Figure 1. explains factors that influence stress and coping, and the adaptation process of families with a chronically ill child to experience well-being and quality of life.

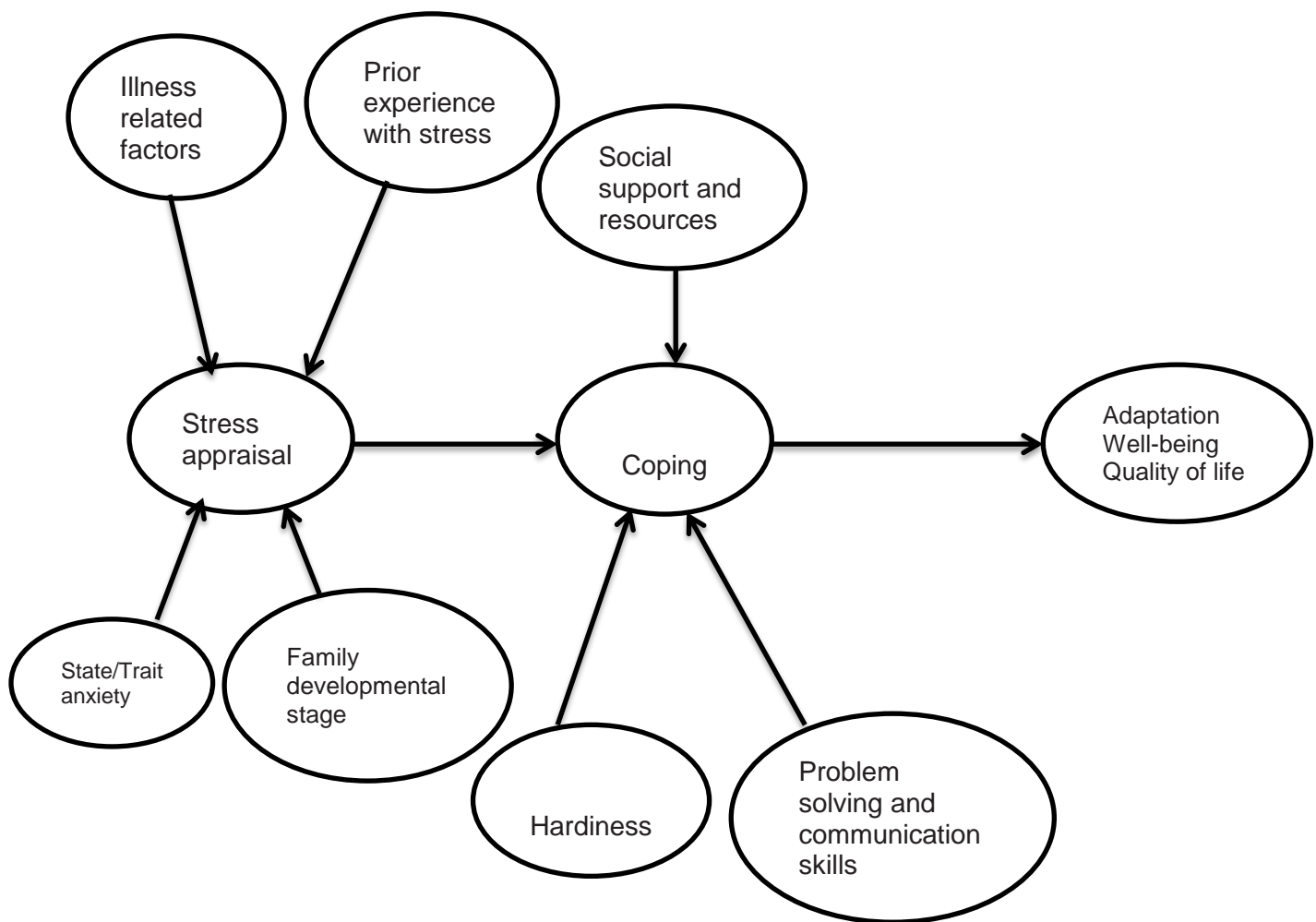


Figure 1: Adaptation by the family to chronic illness in their child. (Adapted from Mussatto, 2006)

Families undergo stressful situations when they have to take care of a chronically ill child. Chronic illness in a child produces stress for both the child and his/her family, but nurses have an opportunity to influence how these children and their families interpret and adapt to these challenges (Mussatto, 2006). Krenitsky-Korn (2011) noted that a person's adaptation constantly changes. The child and family's initial perception of the stressor will have a considerable impact on their ability to adapt. For example, families that have successfully coped with challenges and stress in the past may find strength in their demonstrated ability to adapt based on their past experience. Thus, the more stress a family has had in the past, the easier it is for them to cope and adapt to future stress (Mussatto, 2006).

5.1.5 Empowerment

Nurses can empower families and their children with chronic illness by educating and training them about the disease. Even though Mussatto (2006) found that children and families are naturally resilient, she indicated that in order to adapt successfully, there must be ongoing support and understanding to the family's situation. When considering children with asthma, Krenitsky-Korn (2011) was with the view that school nurses play a supportive role for students with asthma through promotion of wellness, by helping to achieve adequate asthma control through self-management skills. Kieckhefer et al (2009) was with the view that as parents and children with variety of chronic illnesses move through various phases of managing the disorder, it is essential for the nurse to understand the parental desire for knowledge, and should provide support by establishing a starting point for the management of the disorder.

5.2 Family support

The family can support the child by accepting the responsibility for caring, understanding and encouraging the child with a chronic illness.

5.2.1 Responsibility for caring

Family is the first and basic support provider for the chronically ill child. The burden of caring for children who has a chronic disease generally depends on parents (Barlow & Ellard 2006). Also Kieckhefer et al (2009) argues that parents assume significant responsibility in starting and supporting the child's role in disorder management, because most of the care of chronic illnesses takes place in the home. After the initial stress the family faces, it is important for them to also provide adequate support for their child. Accepting the child's condition is an aspect of the family support. A child's chronic illness affects the family's relationship with the child. The associated need for care, possible problems with self/family-esteem, and social interaction however forces the family to reassess how the whole family will function. (Hopia et al, 2004)

5.2.2 Understanding

Also, the families understanding of their child's illness and need for care helps them to cope and provide the needed support for the child. Hopia et al (2009) believes that families need to understand the specific nature of their child's disease including diagnosis, prognosis and the care plan. According to Perry & Toole (2000) the school-based programs that focused on increasing the parent's knowledge of asthma resulted in decrease in absenteeism (Krenitsky-Korn 2011). The absenteeism usually results from asthma attacks and allergies. Bartholomew et al (2006) was with the view that actively involving parents in asthma education has enhanced the impact of those programs (Kieckhefer et al 2009). The family's understanding of the child's condition will help them to balance the child's healthcare needs with those of other family members, thus deeper understanding of the chronic illness eases stress and help to provide the needed support (Barlow & Ellard 2006).

5.2.3 Encouragement

Another aspect of family support is encouraging and trusting the abilities of children with chronic illness. In order not to be over protective, it is important for the parents to trust their child, seeing their capacity to manage different situations. For example, a girl appreciated that her mother has always forced her to try something once before she helped her, to see what she could manage. "She has always found a way for me to manage everything myself. The only thing I need help with now is perhaps a push to help me get on the tram or reach something really high (girl 19 years)". (Berntsson et al 2007).

Kieckhefer et al (2009) agrees with Berntsson et al (2007) on the view that encouraging and trusting the abilities of the chronically ill child is an essential support the family can give. Parent's view about their child's abilities and the trust they have in their children is illustrated in Table 5.

Table 5. Means and standard deviations for the shared management overall score, subscales and individual questions (source: Kieckhefer et al, 2009).

Table 2.
Means and Standard Deviations for the Shared Management Overall Score, Subscales, and Individual Questions

	<i>n</i>	Mean	Standard Deviation
Parent Desires	128	3.5	1.2
3. I believe that by the time my child is a teen she/he will be able to manage her/his chronic illness well with support by parents and health care providers.	129	3.7	1.4
5. I see my child gradually increasing his/her own illness care.	129	3.5	1.4
6. I want my child to take on more responsibility for the care of his/her chronic illness.	128	3.3	1.4
Current Knowledge	127	3.1	1.0
1. I can identify several things my child can do to help manage his/her chronic illness now or in the near future.	129	3.2	1.4
4. I have a long-term plan for slowly transferring responsibility for chronic illness care to my child.	128	2.6	1.3
9. I know when my child is communicating that things are going well or badly with their chronic condition.	128	3.3	1.4
12. I know when my child is doing well and is ready to add the next small step in self-care responsibilities.	127	3.1	1.3
Current Actions	127	3.1	1.2
2. I allow/encourage my child to take an active role in helping with day-to-day management of his/her chronic illness.	129	3.5	1.3
7. In the past 4 weeks I have involved my child in actively managing his/her chronic illness.	128	2.9	1.4
8. I support my child in communicating directly with his/her health care provider about his/her chronic illness treatment and/or its results.	128	3.1	1.4
11. My child has started to/initiates an increase in self-care responsibility.	127	3.0	1.4
Overall Shared Management Score	127	3.2	1.0

Note: Numbers preceding each question reflect the order in which the items appeared in the questionnaire. Analyses reported in this table did not include item 10, which read, "If my child tries to help with managing his/her chronic illness and things go badly, I get discouraged and feel like I don't know what to do next."

According to the response to the questions used by Kieckhefer et al (2009), parents had some trust in their children and allowed them to participate actively in managing their own care. This motivated the children to actively participate in the care. Trust is therefore seen as an important element of self-care.

5.3 Supporting self

Even though nurse and the family of chronically ill children provide support for the child with a chronic disease, the child must be ready to take part in the caring process. The can support him/herself by gaining some knowledge about own disease, accepting the illness as natural part of life, having a self-believe and being motivated to do things by self.

5.3.1 Knowledge about own disease

Children with some kind of chronic illness or disability may have to live with it for the rest of their lives. For this reason, Berntsson et al (2007) believes children need to have some knowledge about their body's needs and reactions, and how they can be interpreted, to help them cope with the stress associated with their illness. According to Gultekin & Baran (2007), it is important to provide children with information regarding their illness. Kaul (2011) believes that self-management is the key to the long-range personal and academic success of children in the care of chronic illnesses like asthma. Knowledge about self-management may be gained from training or formal education. Research indicated that only 21% of his sample size (81 African American children) had participated in any formal asthma education program.

The research of Gultekin & Baran (2007) showed that children who knew much about their disease exhibited more positive self-concepts. Evans (2013) indicated there is an increased need for knowledge and skill competencies in the domain of assessment and intervention planning for children with chronic illness and disabilities. Being knowledgeable about one illness gives an insight on how that child views him/herself. In spite of having a serious illness, children who had knowledge about their illness were able to hold back fear and anxiety if they understood how the problem could be handled (Berntsson et al 2007).

5.3.2 Accepting illness as natural part of life

One important thing that can support the self-care of children according to Berntsson et al (2007) is a feeling of acceptance of the illness or disability as a natural part of one's life. Mussatto (2006) believes that a successful adaptation can be manifested by a psychological functioning such as self-acceptance. According to Evans (2004), children with chronic illnesses such as asthma, diabetes, and congenital heart diseases face complex challenges in developing a sense of self-worth. Berntsson et al (2007) indicates that children who have a chronic disease or children who may see themselves as different in some way have poorer self-esteem. This was exhibited in their research as one participant expressed a certain feeling of powerlessness, while another did not seem to have accepted his situation. In addition, Evans (2004) argues that the emotional distress, cognitive, and socio-behavioral outcomes of chronically ill children may not be influenced by the severity of their limitation but rather the child's perception of him/herself as a worthwhile person.

5.3.3 Self-believe or self-assertive

Children with chronic illness are limited in what they can do, but they may not be limited in all other aspects of life. There is a feeling of personal growth and self-believe if adolescent's ability and capacity were shown respect, involvement and trust. Other factors that affects self-believe include focus on strength, and being motivated to try and do things by self (Berntsson et al, 2007).

5.3.3.1 Focus on strength

According to Berntsson et al (2007), when children have knowledge of their bodily reactions and physiology, it gives them practical knowledge on how to manage the situations that occur in conjunction with possible deviation. Self-believe helps children to practice their own self-care. Evans (2004) explains that, a child may see himself or herself as limited in one sphere but a master in another area. Thus, self-believe makes chronically ill children not to concentrate on only their

limitations, but rather more focused on their strengths. Some children with chronic illness believe that one learns a lot when living with a disability and that, a disability can have some advantages. Furthermore, some children with chronic illness feels they have developed their creativity because of the disease and that they did not find their limits restricted (Berntsson et al, 2007).

5.3.3.2 Personal growth

Children experienced personal growth when their ability and capacity were shown respect, and they were involved and trusted (Berntsson et al, 2007). According to Kieckhefer et al (2009), the child's responsibility for the management of his or her chronic illness typically increases with age. Gultekin & Baran (2007) also found that children with a chronic illness exhibits more positive self-concept with increase in age. Ayala et al (2006) found that, the desire to assist with self-care is strong in children in late middle school (Kieckhefer et al, 2009). Children's perception about their personal competence influences their behavior, actions, motivation, and perseverance in self-management positively (Kaul, 2011).

Personal growth is a process that takes a lot of time (Kieckhefer et al, 2009). This time helps children to develop their personal skills for the future. Berntsson et al (2007) explained that to feel good, the chronically ill children felt their knowledge was important. It also gave them more opportunity to handle the different situations that their illness brought with it. For asthmatic patients, the process of development, coping, and adapting to their condition is shown in figure 2 below. The process can also be true for other chronic illnesses.

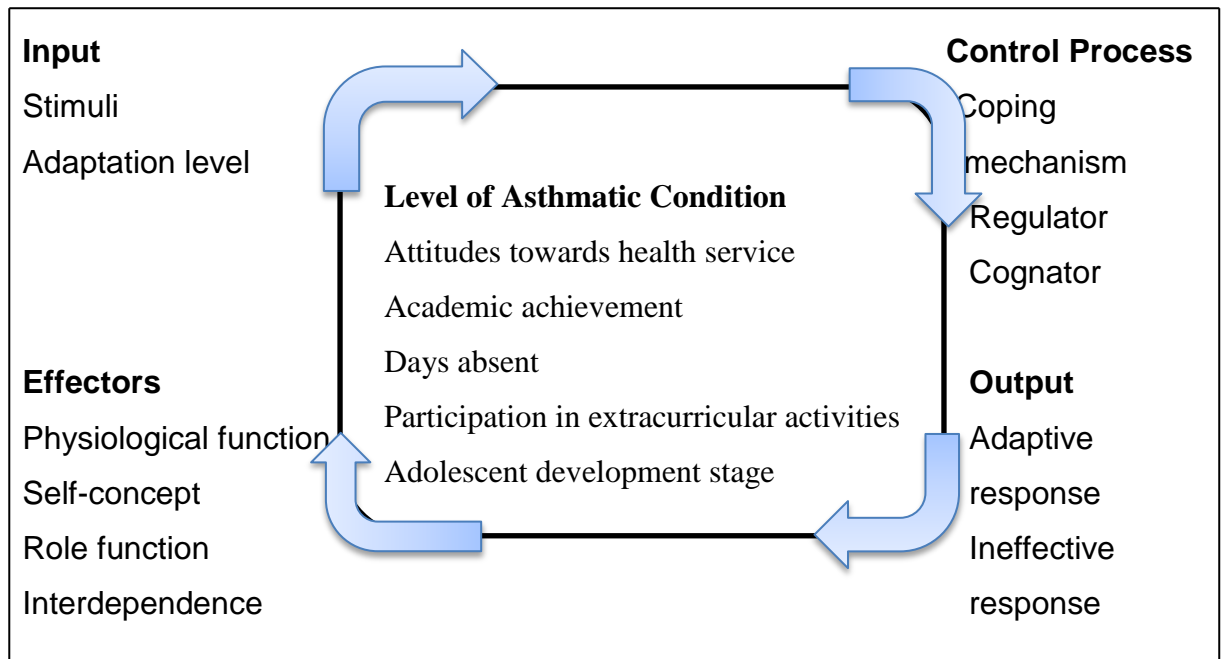


Figure 2: Adolescent development and chronic illness. (Source: Adapted from Krenitsky-Korn, 2011).

As a child goes through the process of coping, adapting and shared management, their knowledge about the chronic condition increases. Thus the child begins to see him/herself as capable (Krenitsky-Korn, 2011). According to Kieckhefer et al (2009), by late adolescence many teenage children manage all care, and in some case they attend clinic visits alone.

5.3.4 Motivation

It must be said that, no matter how much knowledge or self-believe a chronically ill child has he/she needs enough motivation for him/her to accept the idea of self-care. According to Berntsson et al (2007) chronically ill children believed nurses encouraged their progress and were pleased about that. This encouragement is enough motivation for the children to believe in their capabilities. Current research on self-management of chronic illness suggests that self-efficacy beliefs are a key motivational influence (Kaul, 2011). One kind of motivation to children with a disability in Finland is that the health care system provides assistive device to help them cope with their disability (MOSAAH 2013).

5.4 Support from other people

Support from other people like friends and professionals like teachers proved to be as much important as support from family and health professionals. In school age children, opinions and feedback from peers is central to the development of self-esteem (Evans, 2004). Berntsson et al (2007) describes the interaction between chronically ill children and their friends as implicit support. Support from peers was seen as different from that of parents in that the young person was accepted as the equal of healthy adolescents.

Teachers working with chronically ill children need to be more prepared to support these children's effort to manage their own conditions (Kaul, 2011). According to Peebles-Wilkins (2006), teachers should be given some in-service training so that they can support children with chronic illness. If school personnel are knowledgeable about asthma and are aware of how the child in their classroom is managing this disease, it will be easier for them to identify those children in need of help (Kaul, 2011). For example, Peebles-Wilkins (2006) encountered a boy who had a seizure while in music class. According to her the way the teacher dealt with the situation was marvelous, as the teacher prepared the other children, provided a supportive and safe environment, acceptance, and facilitated the boys return to the class after changing into new cloths.

5.5 Summary

The results from this thesis indicate that supporting self-care of chronically ill children is a continuous process. The process involves nurses, families, chronically ill children themselves, and teachers and peers. According to the thesis, the role of each of the people involved in supporting self-care of chronically ill children is shown in table 6 below. Table five present a summary of the finding in this literature review.

Table 6: Summary of findings

Sub-category	Generic category	Main category	Goal
-honour family's perspective -encourage open sharing -collaborative planning	Family centred nursing	Nursing support	Supporting self-care of chronically ill children
-physical and psychosocial health. - well-being -reliable source for medical support -health care interventions	Health promotion		
-partnership with family -understanding the family -panning about care of child together	Collaboration		
- identifying stress -coping with stress -information about illness -support	Stress management		
-basic support -parent-child management -leadership -social support	burden of caring		
-acceptance of the disease -consideration -respecting the child	understanding		
-show trust in the child -motivation to perform -good relationship -love and affection	encouragement		
-information -signs and symptoms -body's reaction to disease -triggers	knowledge about own disease	Supporting self	
-self acceptance -self-worth -self esteem -positive thinking	accepting illness as natural part of life		
-focus on strengths -personal growth	self-believe		
-encouragement from nurses -self-efficacy -availability of assistance	motivation		

Cont. Table 6: Summary of findings

Sub-category	Generic category	Main category	Goal
<ul style="list-style-type: none"> -acceptance as normal person -leisure with peers -motivation -positive feedback -quality time together 	equality between peers	Support from other people	Supporting self-care of chronically ill children
<ul style="list-style-type: none"> -creation of a safe environment -joy and recreation -inclusion in activities 	recognition		

6 DISCUSSION AND CONCLUSION

This thesis was aimed at supporting the self-care of children with chronic illnesses. This is a process which starts from the time the disease is diagnosed until the time when the goals of self-care is achieved.

6.1 Reflecting on the results

The results of the literature review shows that to achieve the basic goal of self-care, there should be effective cooperation between the nurse/school nurse, the family of the child, and the child with that condition. Teachers and friends (peers) also have a very important role in the process. From the results, three major areas of focus came up, support, shared-management, and self-care.

6.1.1 Support

Support was seen as the key element in the whole process. Both the family and the child with the chronic illness needed some support. Special support like transport and access to personal assistant are provided to children with disabilities and their families (MOSAAB 2013). However, support is usually aimed at promoting the child's self-care but each party has a different way of giving his or her support. According to the research by Berntsson et al (2007), children with chronic illness viewed the support from parents as mostly verbal, while that from peers meant acceptance, activities and source of joy and recreation. Nursing support was mostly directed towards the family and child with the chronic illness (Kieckhefer et al, 2009), and somehow towards teachers and peers (Kaul, 2011).

Nursing support can be directly to the chronically ill child, through the family to the child, or through teachers and peers to the child. The direction of nursing support is illustrated in figure 3 below.

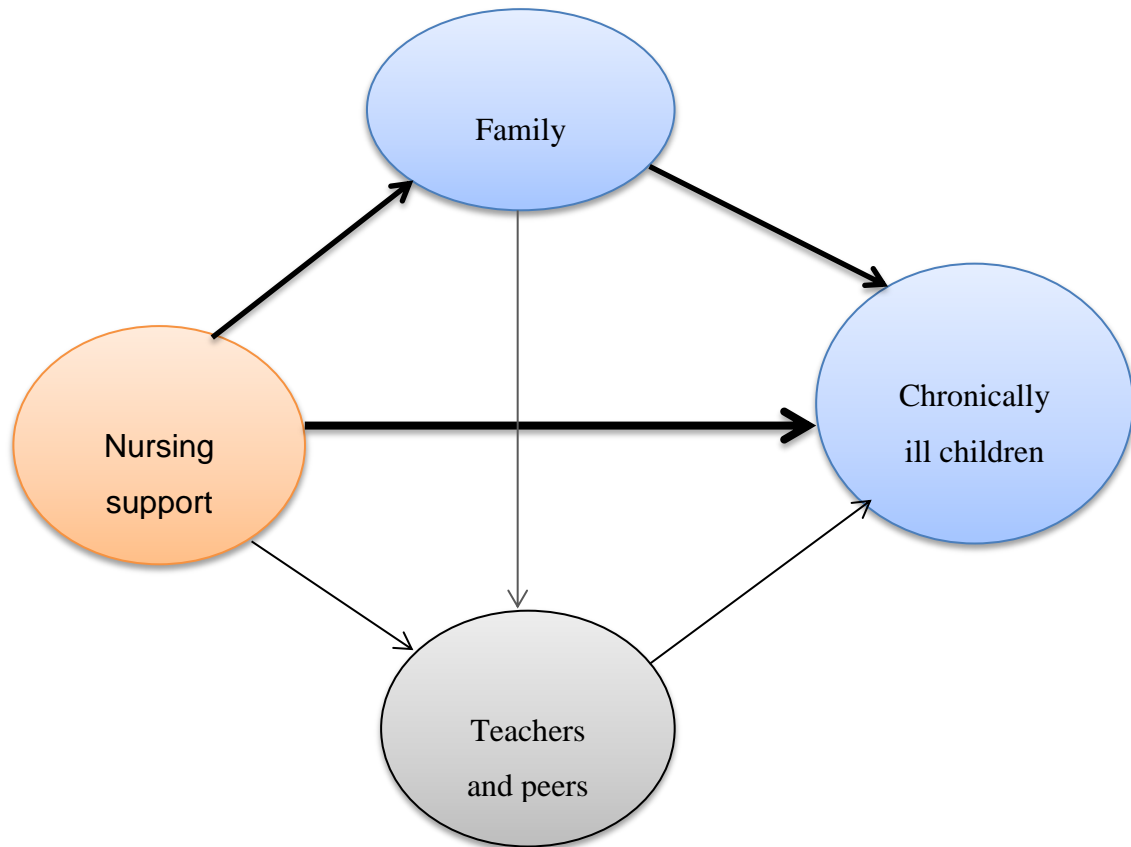


Fig 3: Process of nursing support for chronically ill children.

Callery (1997) and Lampinen (2002) argues that, paediatric nurses identify support for and pay attention to parents as an important part of their work. Thus, nursing support in paediatric hospitals for the child are mainly directed through the parents. They also believe that when parents are allowed to participate in the care of their hospitalized child, it supports and enhances their ability to cope with the stress associated with the illness (Hopia et al, 2004). The nurse's role is to guide children with chronic illness and their families towards independent self-care (Berntsson et al, 2007). According to Kaul (2011), school officials are encourage to work with health professionals in the school setting to help increase the child's level of self-efficacy related to asthma management.

6.1.2 Shared management

Kieckhefer et al (2009) argues that children with chronic illnesses needs to become partners in their care over time. Since most of the care of chronic illness takes place at the home, parents tends to be the partners to the child with a chronic condition. Even though Mussatto (2006) believes the family and child goes through a period of stress when the child is diagnosed with a chronic illness, Hopia et al (2004) argues that the family copes well with the stress if they are allowed to participate in the care of the child. According to Barlow & Ellard (2006), the emotional distress of families in their research was high when their child was diagnosed with cancer, but declined after one year. When the family overcomes the initial stress of the chronic illness, then they start the first process of shared management.

The family's desire for knowledge about the chronic disease and the current actions in support of parent-child shared management should be analyzed. This knowledge is the basis for an individualized care that respects and honors the family's perspectives, encourages open sharing of ideas, and the development of collaborative plans for parent-child shared management. Parents usually take the bigger tasks in the early stages of parent-child shared management. As their age increases, the child tends to assume more and more responsibilities in the shared management. However, if the impact of the chronic illness is too severe, they may be limited to few things otherwise age is the gauge to know when to include the child and when to give more roles of independent care to the child. (Kieckhefer et al, 2009).

A good relationship between parents and child ensures an effective shared management. Berntsson et al (2007) believes a good relationship between parents and child helps to make the child feel good. Feeling good in turn will encourage the child to participate in a parent-child shared management.

6.1.3 Self-care

Self-care of chronic illness is influenced by the person's knowledge about the illness, acceptance of the illness as part of natural life, self-believe, and motivation. Knowledge about the disease reduces fear and anxiety in the child. Knowledge about the body's physiology and how the disease affects it is very important for the child. It helps them to know how to react and to manage the situations that occur in conjunction with possible deviations. Also, knowledge about the illness helps the child to easily identify the signs and symptoms, thus treating it in the early stages. (Berntsson et al, 2007).

Before a successful self-care, the child must accept his/her chronic illness as part of his/her natural life. Failure to accept this means failure to practice self-care. When children with a chronic illness accept their condition as not being negotiable, they appear to be more resistant to the difficulties caused by the disease. For example, the chronically ill child may ask a question like so I am going to have to take this medication for the rest of my life? I don't notice it that much or it just seems natural. Not accepting the disease rather creates stress to the child. (Berntsson et al, 2007).

The more a person believes in his/herself, they are motivated to do things. Self-believe and motivation makes the chronically ill child feel self-competent and personal growth. Children experience self-development when their abilities and capabilities are shown respect (Berntsson et al, 2007).

6.2 Ethics and limitations

This thesis is not a primary research but a literature review. For a literature review it is not necessary to get the permission from the ethics committee and respondents of interviews and questionnaires. All articles and journals are peer reviewed. All articles used for this thesis meets the inclusion and exclusion criteria. Any direct text was put into a quotation marks and a reference given to that effect. All ideas copied from other sources were referred to the original source. Plagiarism is avoided in this thesis.

The thesis was limited to the support given to chronically ill children. Data search was limited to library data base in EBSCO host and CINAHL with full text. Most of books used are dated back to 1990 which renders the information not up-to-date because of the time interval and changes in technology and other factors like, government policies, culture, and environment.

6.3 Suggestions for further study

Current literature on the topic, supporting self-care of chronically ill children is based on only the perception of the chronically ill child. Even though it is good to know and understand the child's perception of their condition, it will also be important to know the opinion of the other personnel who assist with self-care.

Future researches could try to find the nurses' perception about supporting the self-care of a child with chronic illness and his/her family.

A research about how children view their peer with a chronic illness will enlighten the need for peer support

There is research about chronically ill children and their attitude towards school. However, there is no research about how school teacher perceive children with chronic illness, and the challenges teachers face when supporting them.

6.4 Conclusion

In conclusion, self-care was seen as a continuous process that demands a lot of effort. The process is led by the nurse. However, the major responsibility lies on the family because; most of the care takes place at home. Children spend ample time in school and playing with friends, thus support from teachers and peers is crucial. Acceptance by peer gives the chronically ill child a feeling of self-worth. Children with chronic illness themselves needs to be committed to the course of

self-care by acquiring knowledge about the disease, believing in one self as capable, and being motivated to try to do things.

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