

UNIVERSITY OF THE WESTERN CAPE

FACULTY OF COMMUNITY AND HEALTH SCIENCES

RESEARCH REPORT

**TITLE: CAREGIVERS' EXPERIENCES WITH IMPLEMENTING
ASTHMA MANAGEMENT GUIDELINES FOR CHILDREN WHO
ATTEND A HOSPITAL IN THE WESTERN CAPE**

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ABSTRACT

Asthma education aims to reduce exacerbations by helping the patient or the caregivers to recognize early warning signs and act accordingly. However, a number of studies have indicated that childhood asthma morbidity is still rising. The goal of this research study is to explore the caregivers' experiences of implementing the asthma education guidelines. The question to be answered by this research is: "How do caregivers experience the implementation of the guidelines for preventing an asthma attack?"

Caregivers attending the asthma clinic at Red Cross War Memorial Children Hospital, Rondebosch were the study population who participated in this qualitative study. Purposive sampling was applied for recruiting participants to the study. A semi-structured, open-ended interview schedule was used to collect data from individuals during semi-structured, in-depth interviews. The data was analyzed according to the guidelines of Creswell (2009). The results showed that care-givers found the education programme useful. They also reported that the education programme were offered at their level and was easy to understand. Care-givers indicated that the programme should continue because they learnt everytime they attended and found that the practical demonstrations were particularly useful.

DECLARATION

I declared that “*Caregivers’ experiences with implementing asthma management guidelines for children who attend a hospital in the Western Cape*” is my own work; that it has not been submitted for any other degree or examination in any other university, and that all the resources I have used or quoted have been indicated and acknowledged by complete references.

Name: Gabieba van Rhyu

Date:.....

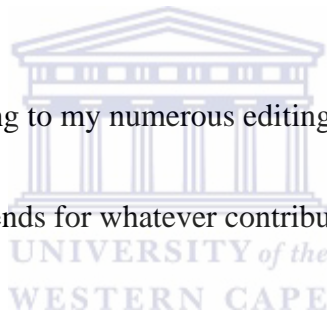
Signed:.....



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TO ALL OF YOU I EXPRESS MY SINCERE GRATITUDE.

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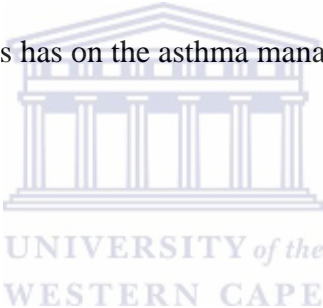


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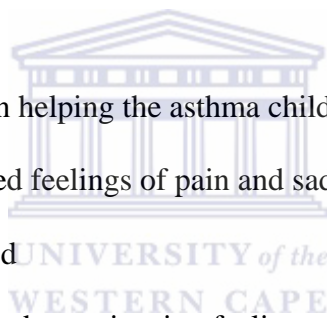
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LIST OF ABBREVIATIONS

ABBREVIATION MEANING

ABC	Asthma Basic for Children
GINA	Global Initiative National Asthma
HBM	Health belief Model
NAEP	National Asthma Education Program
NHBLI	National Health Blood and Lung Institute
WHO	World Health Organisation



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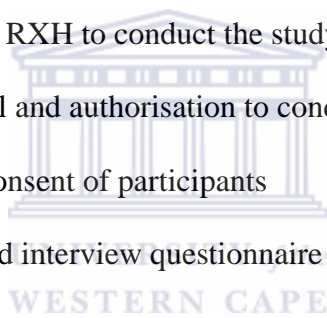
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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Asthma is a chronic inflammatory lung disease which is associated with airway hyper-responsiveness and tissue remodelling of the airway structure, and the physiological dysfunction of the lung characterised by breathlessness, wheeze and a variable airflow obstruction. The lung airways narrow and there is an increase of airways responsiveness due to a variety of stimuli. Asthma symptoms can, however, be controlled and can also be prevented (Murdoch & Lloyd, 2010). This means that the airflow limitation is reversible with the appropriate asthma treatment.

The burden of the asthma affects the patient (the child), their families, and the society in which they live, in terms of loss of work and school days, loss of income, impaired quality of life, hospitalisation, medical costs and mortality (Motala, Green, Manjra, Potter&Zar, 2009). Patient education has been described as an essential component of asthma management with clinical guidelines providing the basis for both the clinical management and asthma education (Pinnock, Fletcher, Holmes, Keely, Leyson, Price, Russell, Versnel &Wagstaff, 2010).

The prevalence of asthma is high in Cape Town and childhood asthma is a common disease (Green, 2007). Despite the available useful asthma therapies and management strategies, asthma morbidity remains a problem (Green, 2007).

According to Kurnat and Moore (1999), the health care provider needs to have the knowledge of the caregivers' perception, their needs, their concerns and their coping strategies.

However, caregivers need to be educated and supported, because caring for the asthma child is challenging and caregivers have to adapt and cope in different ways to manage their asthma children (Barton, Sulaiman, Clarke, & Abramson, 2005).

This chapter orientates the reader to the study background, the research problem, aims and objectives, the significance of the study, a summary of the research methodology and ethical considerations for the study.

1.2 BACKGROUND AND CONTEXTUAL INFORMATION

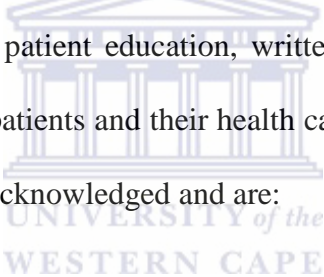
According to Braman (2006), there has been a particular sharp increase in the global prevalence, morbidity, mortality, and economic burden associated with childhood asthma over the last 40 years. Approximately 300 million people worldwide currently have asthma, and its prevalence increases by 50% every decade. Ten percent (10%) of the North American population has asthma. Asthma is under-diagnosed and under-treated, although the use of inhaled corticosteroids has made a positive impact on outcomes. The increasing number of hospitalisations for asthma – mostly children – reflects an increase in severe asthma, poor disease management, and poverty. Worldwide, approximately 180 000 deaths annually are attributable to asthma, although overall mortality rates have fallen since the 1980s. Most asthma deaths occur in those ≥ 45 years old and are largely preventable, frequently being related to inadequate long-term medical care or delays in obtaining medical help during the last attack.

According to the Global Burden Asthma Report (GINA,2007), asthma affects 300 million people worldwide and the burden of asthma disease on government, health care systems, families, and patients is still increasing worldwide. The report also indicates that it is the most common chronic childhood disease. Around 10% of South Africans have asthma, and the incidence of asthma has doubled in the past 20 years (Health 24, 2009). Asthma is also the

eighth leading contributor to the burden of disease in South Africa and is the second most important chronic disease after HIV/AIDS (Mash, Rhode, Pather, Ainslie, Irusen, Bheeki&Mayers, 2009).

In 1989, the Global Initiative for Asthma (GINA) programme was initiated in an effort to raise awareness amongst public health and government officials, health care workers, and the general public that the incidence of asthma was on the increase. The GINA programme recommends a management program based on the best available scientific evidence to provide effective medical care for asthma, tailored to local health care systems and resources.

As part of its commitment to reducing the global burden of asthma, GINA has outlined a six-point patient management plan to address that childhood asthma is one of the greatest challenges. The plan focuses on patient education, written medication plans, and ongoing communication and review with patients and their health care providers. The GINA goals for asthma treatment are universally acknowledged and are:

- 
- a) To achieve control of asthma symptoms
 - b) To maintain activity levels, including exercise
 - c) To prevent asthma exacerbations
 - d) To avoid adverse effects from asthma medications
 - e) To prevent asthma mortality.

Despite considerable knowledge with regard to the pathologic basis of asthma, the ongoing increases in asthma prevalence, and subsequent increases in morbidity and mortality, cannot yet be explained. In addition, the GINA goals of asthma management are not being achieved, with considerable under-diagnosis and under-appropriate or inappropriate treatment

presenting. A significant proportion of patients receive only basic care and are not able to benefit from therapeutic advancements. For the majority of the population of the world, asthma is a low public health priority. The diversity of health care systems worldwide and large variations in access to care require that asthma management guidelines be tailored to local needs. More cooperation is imperative between health care officials involved in asthma care, including medical staff at primary and secondary levels of care in order to develop individualized asthma management programs that will work at a local level.

Global Initiative for Asthma (2007) found that South Africa has the world's fourth highest asthma death rate among five- to 35-year-olds. Almost three-quarters of all the deaths occurred away from hospitals. It is clear that a need exists to educate South Africans about the recognition, prevention and treatment of asthma (Zar, 2004).

Asthma is also the most common chronic childhood condition and has a significant impact on the children and their families (Trollvik & Severinsson, 2005; Zwarensten, Bheekie, Lombard, Swinger, Elrich, Eccles, Sladden, Pather, Grimshaw, & Oxman 2007). Asthma can affect children throughout their lives. Day-to-day care-giving requirements, the complexities of the disease management activities and family dynamics, alone or collectively, may influence long-term health outcomes (Brown, Turk, Dale & Bousquet, 2007). Asthma has a significant impact on the wellbeing of caregivers and is associated with such things as uncertainty, emotional stress and an increase in financial demands and a change of lifestyle (Trollvik & Severinsson, 2004).

Asthma is common amongst relatively poor communities where the rates are highest and there is a great need for asthma education (Zwarensten, et al, 2007). Although asthma is not curable, it can be controlled. Persistent asthma symptoms can be reduced by the daily use of

preventative medication, as recommended by the asthma national guidelines (Halterman Lorrie, Sidora, Kitzman, & McMullen, 2001).

A study by Moosa and Henley (2007) of parental knowledge of childhood asthma indicated that parents/caregivers lack confidence to manage the acute asthma of their children and a need for asthma education was identified.

The National Heart, Lung and Blood Institute in the United States (NHLBI) of the National Institute of Health has established guidelines for the diagnosis and management of asthma (NHLBI, 1997). These guidelines include goals for asthma management, as well as the following key components for achieving control of asthma:

- a) regular assessment and the monitoring of symptoms;
- b) appropriate pharmacologic therapy;
- c) control of triggers and patient (asthma) education, and
- d) partnership with the families (NHLBI, 1997).

The aim of asthma education is to reduce exacerbation, because the caregivers will be able to recognise the early warning signs of asthma and act accordingly. This leads to decreased disruption of the family, reduces exposures to the side effects from repeated courses of oral corticosteroids, reduces absenteeism from school and work and leads to the empowerment of the caregiver (Brown & Levin, 2005).

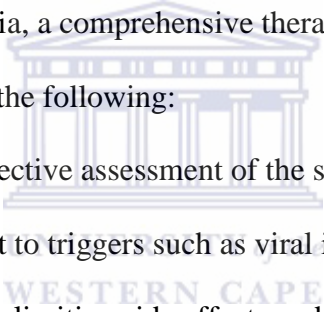
The South African Guidelines for the management of chronic asthma in children was updated in 2009. This guideline is also used and followed by the Western Cape Provincial hospitals/clinics. The recommendations are that the practitioners, (nurses and medical doctors) should strive to achieve the best possible therapy for each patient through the

motivation and education of caregivers and to ensure that all patients have access to appropriate medication.

The goal of asthma therapy is to control the child's asthma, so that the child is able to lead a normal, physically active life (Motala, Green, Manjra, Potter & Zar, 2009).

The criteria for a such a life are: to be completely free of asthma symptoms – i.e. coughing, wheezing and breathlessness; to attend school regularly and participate in school activities; to grow and develop normally as a child; to minimise the number of asthma attacks and avoid hospitalisation; and to avoid and minimise medication-related side effects (Motala, Green, Manjra, Potter & Zar, 2009).

To meet the aforementioned criteria, a comprehensive therapeutic approach must be followed. This approach includes the following:

- 
- a) Early diagnosis and an objective assessment of the severity of the attacks.
 - b) Control of the environment to triggers such as viral infections and allergens.
 - c) Optimal use of medication, limiting side effects and costs by using the most appropriate delivery systems (inhalers).
 - d) Follow-ups and regular clinical and quality-of-life evaluations.
 - e) Patients and caregivers receive asthma education.

According to McCarthy, Hansen, Herbert, Wong, Brimac & Zelman, 2002) asthma education has a significant impact on children and their families, as well as the health care system, resulting in a reduction of quality of the life and an increase in health care costs. Asthma education does form an integral part of the management of asthma in children and it enables the parents/caregivers to get a better understanding of their child's condition (Zwarensten, et al., 2007). However, the action that caregivers take may be affected by their understanding of

the asthma management and their concerns about medication prescribed (Peterson-Sweeney & Mc Mullen, 2003). According to Lalloo, Ainslie, Wong, Abdoll-Gaffar, Irusen, Mash, Feldsman, O'Brien & Jack, (2007), optimal management for a chronic disease like asthma requires active participation of patients. To achieve this, caregivers require education about asthma. The asthma child depends on the caregiver to make a positive decision regarding its health.

Asthma education and the guidelines do not only minimise the functional and emotional impact of asthma on children and their families, but it could also help the child and the caregiver to manage the asthma effectively with the aim to decrease the disruption and integrate the asthma management into their lifestyle (Kaugers & Klinnert, 2004). Such amelioration is necessary because caring for an asthma child is challenging and families have to adapt and cope with these challenges in different ways (Barton, et al, 2005).

The aforementioned suggests that asthma care and management needs an on-going partnership between the health care provider and health care user for optimal treatment to take place. However, for this partnership to work, caregivers and the health care provider need to have a common understanding of the nature of asthma.

The researcher is a qualified nurse at Vanguard Community Health Centre and has observed that at least twenty acute cases of asthma children are treated on a monthly basis at the paediatric clinic.

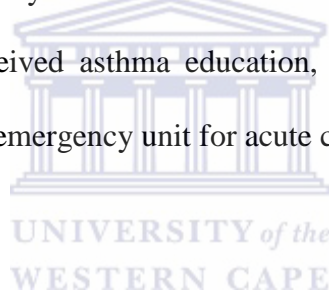
The setting for the study was Red Cross Memorial War Children's Hospital, a known children's hospital and a tertiary learning institution, situated in Rondebosch, Cape Town. This hospital serves the entire Western Cape, and receives referrals from the Vanguard Community Health Centre. At the asthma clinic in Red Cross Memorial War Children's Hospital all eighty (80) asthmatic children booked per week are seen by health care

providers. The asthma clinic is open from Monday to Friday from 7h00-16h00. During weekends the emergency unit (trauma) is open, if the need arises for acute care services.

Despite the fact that caregivers were educated about asthma, asthma children still attend the paediatric unit for emergency care and their asthma control seems to be relatively poor. The morbidity rate is still increasing and no study was done to explore the experiences of the caregivers with the implementation of the asthma education guidelines.

1.3 PROBLEM STATEMENT

Despite the availability of effective treatment, and although caregivers attend the clinic and are given education in preventative behaviour based on the education guidelines, children's asthma is not under control. Monthly statistics at the research setting show that approximately seventy-five (75) caregivers received asthma education, whereby thirty(30) of them tend bring their asthmatic child to the emergency unit for acute care and management.



1.4 RESEARCH QUESTION

What are the caregivers' experiences of the guidelines, presented by the health care workers, in assisting them to manage their child's asthma?

1.5 AIM AND OBJECTIVES OF THE STUDY

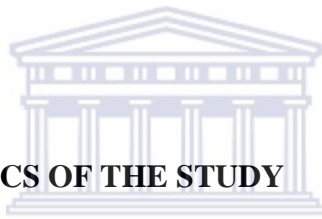
The aim of the study was to explore and describe the caregivers' experiences of managing their asthmatic child, and to establish whether the implementation of the asthma education guidelines assisted them in managing their child's asthma.

The objectives were to explore:

1. The challenges and fears of care-givers regarding living with, and helping the young asthmatic child when symptoms first appear.
2. The participants' views on the user-friendliness of the guidelines in helping the child.
3. The participants' understanding of the expectations of them as caregivers.

1.6 SUMMARY OF RESEARCH METHODOLOGY

The nature of the research question points to the selection of the qualitative research approach. The participants were purposively sampled and a semi-structured open-ended interview schedule was used to collect the data. Data was analysed by using audio tapes, transcribed the transcripts, formulating it into themes and the theme analysis was done inductively.



1.7 SUMMARY OF THE ETHICS OF THE STUDY

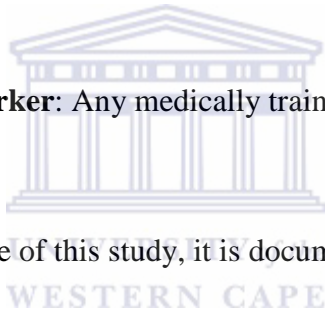
All consented participants were informed of the purpose of the study. Confidentiality, anonymity and the right to withdraw at any stage of the interview were explained to them. The study was approved and permission from the relevant authorities was granted for the study to be conducted.

1.8 THE SIGNIFICANCE OF THE STUDY

The aim of asthma education is to reduce the morbidity rate and to increase the caregivers' knowledge of asthma. Learning from caregivers about their experiences of the implementation of the educational guidelines for prevention of an acute asthma attack of the young child is crucial for improving preventative strategies and education guidelines. The outcome of the research may contribute to the knowledge base of the nursing profession in this field of practice.

1.9 OPERATIONAL DEFINITIONS OF KEY TERMS

- **Asthma:** A chronic inflammatory disease of the lungs.
- **Education programme:** For the purpose of this study, it is a programme designed to educate caregivers to manage their asthma child(ren).
- **Nurse(ing):** The nurse focuses on the care of the individuals and the community so that they attain, maintain or recover optimal health.
- **Child(ren):** For the purpose of this study, it is an individual less than 7 years of age.
- **Parent/caregiver:** For the purpose of this study it is an adult that cares for the asthma child.
- **Health care provider/worker:** Any medically trained person, who provides care to the asthma child.
- **Guideline:** For the purpose of this study, it is document or a guide used by the trained person to teach the caregiver.



1.8 OUTLINE OF THE THESIS

The dissertation is arranged into five chapters.

Chapter 1: Introduces the study and provides a background statement, the aim and objectives of the study, the significance of the study, its problem statement, the orientation to the research methods as well as the design and operational definitions.

Chapter 2: Focuses on the theoretical framework and the review of the relevant literature.

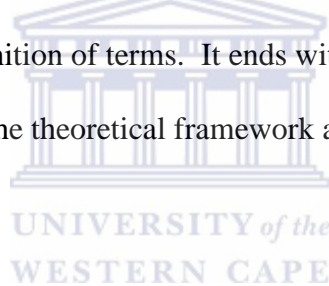
Chapter 3: Clarifies the research methodology, namely, the design of the study, the study sample, data collection, data analysis, reliability and validity, content validity and ethical considerations and limitations of the study.

Chapter 4: Explains the methods used for data analysis, presents the findings and describes an interpretation of results.

Chapter 5: Contains the summary of findings, recommendations and conclusion.

1.9 CONCLUSION

This chapter gives a description of the problem being studied, the aim and objectives of the study, an introduction to the literature review, an orientation to the research methods, the ethical considerations, and a definition of terms. It ends with an outline of the study. The next chapter is a presentation of the theoretical framework and the literature review.



CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Brink, van der Walt & van Rensburg (2006) suggests that the specific aim of the literature review depends on the role of the researcher. He/she can use the review to acquire knowledge on the topic or to critique existing practices; to develop research-based protocols and intervention; to develop a theory of conceptual framework; or to develop policy statements, curricula or practice guidelines. According to Creswell (2009) when conducting qualitative research, literature should be used inductively when the study is exploratory. Therefore, the decision on whether literature and theoretical perspectives should be presented before or after data analysis depends on the strategy of enquiry.

In this chapter, I firstly present the overarching patient-centred model as the conceptual framework for the study. A summary of related theories that offer explanations or a rationale for asthma education, implicitly or explicitly, are also discussed. The selected theories are: self-determination theory; the health belief model; social cognitive theory and the family-centred model.

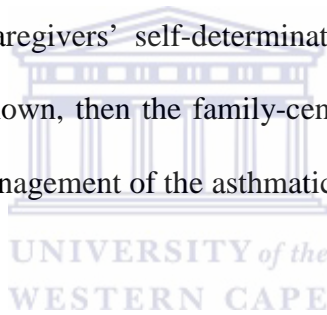
The literature under review was retrieved from websites such as EBSCO host, Science direct, Pubmed and Google Scholar. Literature showed that little has been written on the experiences of caregivers who have implemented asthma education. Only international research studies were found.

2.2 THEORETICAL FRAMEWORK

Patient-centred theory is the conceptual framework for this study, but other related theories: self-determination; social cognitive; health belief model and family centered theories are inter-related with the patient-centred theory.

Firstly, the caregivers' willingness to learn and change needs to be assessed. We therefore look at self-determination theory. If the caregivers are self-determined and are ready for changes, the health belief model describes the process for their belief system. The caregivers with the asthmatic child form part of an environment and a social group. Social cognitive theory is used to describe the caregivers' readiness and ability to learn.

When the components of the caregivers' self-determination, health beliefs and ability to learn/change are assessed and known, then the family-centred theory will describe how the family plays a vital role in the management of the asthmatic child.



2.2.1 The patient - centered model as conceptual framework

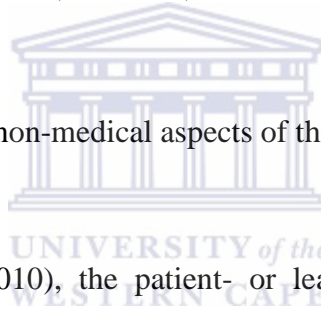
Dexter & Walsh (1995:183) defines the patient-centred approach as being “based on the belief that the patient is the important person in the relationship and that he/she has the resources and ability to help him/herself given the opportunity to do so.”

Speechly, Rimmer and Hodson, (1992) outlines a patient-centred model which stresses that a partnership needs to be created between the patient and the health care professional. The health care professional brings an expert knowledge base and, hopefully, long-term support. The patient brings the experiences of the chronic disease (in this case, asthma) that have been gained over the long term.

Together, these players can implement a plan of care and continue to evaluate it. One of the key features of the patient-centered model is that it suggests that the health care provider enters the patient's world and see the illness through the patient's eyes (Brown, Weston, & Stewart, 1989).

Groll, de Maeserner, Whitfield and Molink (1990) confirms other components of patient-centeredness:

- a) taking the patient and his/her problems ideas and expectations seriously
- b) involving the patient in decisions;
- c) giving patient information (education) to enable patients to take responsibility for their own health; and
- d) feeling responsible for non-medical aspects of the presented problem.



According to Pinnock, et al (2010), the patient- or learner-centred approach to asthma education may be useful in reducing re-admission to the emergency department, which suggests that re-admission is influenced by the extent to which the health care providers educated their patients. However, professionals must ask the caregivers to tell them what their understanding of asthma is; their fears and challenges with the asthma education guidelines; their understanding of the asthma treatment prescribed; the impact of asthma on the family function and what their expectations of the health care provider are. For the management of children's asthma, it is important to involve parents in the educational process. Some studies showed that asthma education had a significant impact on children and their families and the health care system resulting in increasing the quality of the life and decreasing health care costs (McCarthy, Hansen, Herbert, Wong, Brimac&Zelman, 2002).

The patient-centred approach to health care in the case of asthma involves sharing the asthma disease between the caregiver and the health care provider in an attempt to decrease the morbidity rate of asthma at the primary care level. The key focus is not only to make the caregiver an expert, but to integrate the management of the child's asthma into the family cycle. The goal of patient-centeredness is to form a partnership with the caregiver and the health provider, and to allow the caregiver to express his/her individual problems, fears, and frustrations with having to cope with the asthma disease. Patient-centred care of an asthmatic child is a preventative care model involving regular asthma education to be given the caregivers so that the asthma education can be integrated into the patient's care (Bauman, Fardy & Harris, 2003).

2.2.2 Self-determination and Patient-centeredness

The word 'self-determine' suggests self-motivation and an internal desire to learn and be prepared to make the necessary changes. In the case of caregivers, this means making a personal voluntary decision to change and to apply the asthma educational skills at home.

An awareness of the self-determination theory has also been associated with patient-centred education. Self-determination theory focuses on the degree to which an individual's behaviour is self-motivated and self-determined. It acknowledges the right of a patient to be involved in decision-making concerning personal and family related health matters (Deci & Ryan, 2002). While this extensive theory within the context of motivation is beyond the scope of this thesis, it is important for the health care provider to consider the psychological and social factors in decision-making so as to provide effective health care to patients and their families (Deci & Ryan, 1985). The following summary is presented to indicate the interrelatedness of patient-centeredness and concepts of self-determination in asthma education.

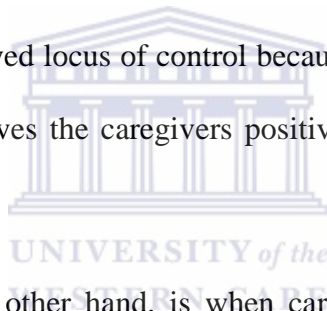
Williams, Frankel, Campbell and Deci (2000) support the notion that self-determination should go hand in hand with patient-centeredness. They argue that when health care professionals' relationships with their patients are more patient-centred than physician-centred, patients are likely to display higher satisfaction, better adherence to prescriptions, better physical and psychological health and will be more likely to maintain behaviour change. In implementing and integrating the principles of patient self-determination, physicians should consider psychological and social factors in providing effective health care education to patients and their families.

Children's health and wellbeing are affected by lifestyle factors and behaviours controlled by the caregivers, such as smoking, dust, pollens and physical activity. Therefore, the health care of asthmatic children, especially very young ones, depends on the adherence to and implementation of the asthma education guidelines by their caregivers. This means giving the prescribed medication to the child to prevent an asthma attack and limiting their exposure to asthma triggers.

Deci and Ryan (2002) suggest that these behavioural mediators of health outcomes must be recognised and that health care professionals should attend to the caregivers' experiences and motivation to learn so that the caregivers can maintain this behaviour, recognising that they need time to internalise the value and skills for change and then experience self-determination. Respecting patient's self-determination is associated with autonomy, competency, and relatedness. Deci and Ryan (2002) postulate that all human beings (in this study, the health care worker) regardless of culture and developmental level, have some basic psychological needs, and that these needs for autonomy, for competence, for relatedness can be easily frustrated as well as easily supported by social environments.

Autonomy refers to the patient's, or in the case of small children, the caregiver's motivation of self-regulation of health related issues, such as eliminating or limiting exposure to asthma triggers (e.g. smoking; dust) and giving the asthmatic child prescribed medication. Unfortunately, patients/caregivers more often engage in health related behaviour change or regulation only by means of controlled motivation. A form of controlled motivation is external regulation. Externally regulated behaviour is the least autonomous behaviour as it is performed because of external demand or possible reward (de Charms, 1968). Such actions can be seen to have an externally perceived locus of control whereby the caregivers would act on external rewards to avoid punishment and comply with social pressure.

While introjections are internally driven, Deci and Ryan (2002) suggest that introjected behaviour is an externally perceived locus of control because they aren't perceived as part of self. The health care provider gives the caregivers positive feedback and appraisal, if their child asthma is controlled.



Autonomous motivation, on the other hand, is when caregivers realise the importance of implementation and adherence to the asthma education guidelines and the health care provider then highlights the importance of change without using pressure. This is called integrated regulation (Deci & Ryan, 2002).

The concept of competency in self-determination refers to the caregiver's confidence to implement the required behavior change and to the health care provider's provision of relevant positive feedback to them. This sense of competency is affiliated with autonomy. Patients/caregivers are willing to change and to learn the asthma education and at the same time become competent to manage their asthmatic child (Markland, Ryan, Tobin & Rollick, 2005).

Relatedness is the process through which the caregiver is open to new education and complies with the asthma education guidelines. Respect, understanding and being cared for are important for this internalization of relatedness to occur.

Parent-centred practice and education and self-determination theory also imply that caregivers will be prepared for preventative treatment plans, including obtaining and administering the medication (Haltermann, Borelli, Conn, Tremblay & Blaakman, 2010).

Therefore, the actions caregivers take may be affected by their understanding of the asthma management and their concerns about medication prescribed (Peterson-Sweeney & McMullen, 2003). Caregivers' preventative actions thus may depend on the communication between the health professional and the caregivers. Inaccurate perception of the severity of asthma is believed to be a major reason for delays in treatment, which, in turn, increases the morbidity and mortality rate (Wong & Wong, 2001).

2.2.3 Health Belief Model (HBM)

The Health Belief Model (HBM) is the most used model for understanding, explaining and predicting human belief health behaviour. The HBM is a psychological model which was developed in the 1950s by the psychologist, Rosenstock (1974). The HBM integrates psychological theories of goal setting, decision-making and social learning. It postulates that health seeking behaviour is influenced by a person's perception of a threat by a health problem and by the value associated with the action aimed at reducing the threat (Pilot & Hungler 1999).

Assumptions of the Health Belief Model (HBM)

The HBM has several assumptions related to one taking a health related action. The HBM is based on the understanding that a person will take a health related action if he/she

- has a positive expectation that by taking a recommended action, he/she will avoid a negative condition
- believes he/she can successfully take a recommended health action
- feels that a negative health condition can be avoided (Becker, Radoski & Rosenstock, 1978).

Beliefs are thoughts that underlie the behaviour the individual engages in and which subsequently affects their health outcome (Bandura, 1986). The HBM is a specific model which suggests that health behaviour is a result of a set of core beliefs which predicts much behaviour (Rosenstock, 1974). Childhood asthma and the belief that the caregiver has the ability to perform behaviour that is beneficial to asthma (self-efficacy) have been associated with clinical outcome and the reduction of asthma morbidity (Bursch, Schwankosky, Gilbert & Zeiger, 1999). Positive beliefs of caregivers were associated with better child health and fewer asthma symptoms (Wade, Holden, Lynn, Mitchell & Ewart, 2000).

The Health Belief Model (Janz and Becker, 1984; Rosenstock, 1974) proposes that, in order for caregivers to perform a recommended health behavior, the caregivers' must first believe that their asthmatic child is at risk of having an asthma attack. In other words, the caregiver must first see the negative health outcome. At the same time, the caregiver must believe the benefits of following the asthma education guidelines, that they will minimize the asthma symptoms.

The health action the caregivers take depends on their perception of the asthma education and the threat of asthma, consisting of both the level of personal susceptibility to asthma and the condition and the degree of the severity of the consequences which might result from contracting the condition; the health action's potential benefits or efficacy in preventing or reducing susceptibility or severity; and physical, psychological, financial, and other barriers or costs related to initiating or continuing the advocated behavior (Becker, Radius & Rosenstock, 1978). Although various socio-economic and socio-demographic factors can influence the caregivers' behaviour, these variables are viewed to indirectly affect compliance to the asthma education.

The perceived barriers the caregivers may experience are: to follow the prescription of the asthma medication, to administer the medication to their asthmatic child, to access this medication at the health facility and to implement the asthma education guidelines at home. However, if caregivers improve their knowledge, and consequently have the capabilities to intervene in health behaviours to increase adherence to the asthma education guidelines, the asthma symptoms will be minimized/absent, and the factors that influence compliance with the treatment will then not always be effective (Rosenstock, Strecher & Becker, 1978).

Therefore, the action caregivers take may be affected by their understanding of the asthma management and their concerns about the medication prescribed (Pettersen-Sweetney & McMullen, 2003).

However, the understanding of parental perception about asthma may depend on the communication between the health professional and the client's caregivers. Inaccurate perception of the severity of asthma is believed to be a major reason for delays in treatment which, in turn, increases the morbidity and mortality rates related to asthma (Wong & Wong, 2001).

2.2.4 Social Cognitive Theory

This theory describes the interaction between individuals (caregivers) and their environment (home) and the human capacity to learn (Bandura, 1986). It describes how caregivers understand asthma education as enabling them to implement it at home to help their asthmatic child. This includes a behaviour change of the caregiver, because new behaviour is a product of an individual learning through observation and presentation, of their perception of their environment, and of physical and intellectual capacities (Bandura, 1987).

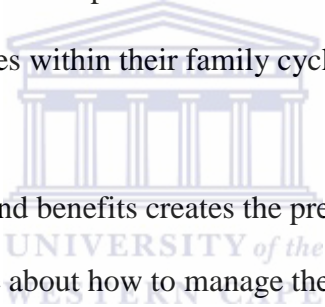
Social Cognitive Theory is relevant to health communication theory in that it deals with cognitive and emotional aspects and the understanding for behavioural change. It explains how people acquire and maintain certain behavioural patterns, whilst also providing the basis for intervention strategies. It also evaluates the behavioural change in terms of its dependence on the environment, and provides a framework for designing, implementing and evaluating programmes (Benight & Bandura, 2004).

Environment refers to the factors that can affect a person's behaviour. In this sense, environment refers to social and physical environments. Social environments include family members, friends and colleagues, while physical environments could refer to the size of a room, the ambient temperature or the availability of certain foods. Environment and situation provide the framework for understanding human behaviour (Parraga, 1990). The situation refers to the cognitive or mental representations of the environment that may affect a person's behaviour. In this instance, the situation is a person's perception of the asthma education program, time, physical features and activity (Glanz, Rimer & Lewis, 2002).

These three factors, environment, people and behaviour – are constantly influencing each other. The environment provides models for behaviour, and observational learning occurs

when a person watches the actions of another person and the reinforcements that the person receives (Bandura, 1997). The concept of behaviour can thus be viewed in many ways and behavioural capability means that if a caregiver has to perform a behaviour he/she must know what the behaviour is and have the skills or knowledge to perform it.

Social cognitive theory also specifies a core set of determinants. The core determinants include knowledge of health risks, the benefits of the asthma education, and the perceived self-efficacy that caregivers can exercise control over their child's asthma symptoms. The outcome expectations are for the child to be asthma symptom-free and to live a normal child life. Other determinants are the health goals caregivers set for themselves, the concrete plans and strategies for realizing them, and the perceived facilitators and social and structural impediments to make these changes within their family cycle.



Knowledge of asthma education and benefits creates the pre-condition for change. If the caregivers lack asthma knowledge about how to manage their child's asthma, it does affect the asthma management of their child negatively and the caregivers have little reason to implement the asthma education at home. That is why asthma education knowledge is needed to prevent the asthmatic child from having unnecessary asthma attacks. Beliefs of personal efficacy play a central role in personal change. If caregivers acknowledge the importance of asthma education, they will change their beliefs and behaviour.

Health behaviour is also affected by the outcomes and the caregiver's expectations when implementing the asthma education guidelines. The outcomes take on several forms. Physical outcome includes a pleasure effect in which the asthmatic child experiences less or no asthma symptoms. The behaviour is regulated by social reactions e.g. social approval or disapproval. This behaviour is produced by the caregivers' interpersonal relationship with the

health care providers. A third set of outcomes concerns the positive and negative self-evaluative reactions to one's health behaviour and health status. The caregivers will do things that give them self-satisfaction and self-worth in how to manage their child's asthma and prevent triggers that stimulate an asthma attack. The motivation is enhanced by teaching the caregivers how to manage their asthmatic child. Personal goals are rooted in the value system, and provide further self-incentives and educate the caregivers. Long-term goals for personal change encourage and motivate the caregivers to implement the asthma education guidelines at home (Bandura, 1986).

Caregivers are expected to change their behaviour through their asthma education guidelines and apply it at their homes. However, this depends on the caregivers' self-efficacy abilities, which will be determined by their experience, their emotional status and the social modelling (show the caregivers other like themselves can do it) they were exposed to (Bandura, 1986).

Theoretical guidelines from these models suggest that patients need to be empowered by learning skills to enhance their competencies for self-help situations. The information for action required can, for example, be taught by role-plays through either demonstration of a task or dialogue with the educator. Caregivers' are rewarded for the correct action and encouraged to assimilate further information into understanding to achieve competency in the skill. The asthma educator may, for example, outline the steps involved in using the metered inhaler and may ask the caregiver to role-play using the placebo inhaler. The health care provider must strive to identify the issues that the caregivers face every day, thereby acknowledging their uniqueness as a caregiver and an individual (Bandura, 1986).

These actions and behaviours of the health care providers include shared control of the consultation that is contextually relevant to the caregiver and joint decision-making on the interventions to focus on holistic health management, rather than a dependency on the health

professional's decision making. The power of decision making is with both the caregiver and the health professional and acknowledges the caregivers' expertise about their asthmatic child's condition. This shared responsibility can only operate when there is a mutual regard for each other's perspectives and a positive relationship exists between patient and health care provider (Sumsion, 1999).

2.2.5 Family-centred assessment and intervention model

A family is a specific group of people that may be made up of partners, children, parents, aunts, uncles, cousins and grandparents, and the child forms part of a family unit. Therefore, the child must be treated in conjunction with a family or a family member. The asthma education given to the caregiver will be taken home to form part of the family function.

The Family-Centred Care model is an adopted philosophy for paediatric care (Lewandowski & Tesler, 2003). The core definition of the Family-Centred Model is that it is accepted that there is a relationship between families and the health care provider and in this relationship the families are full partners in the provision of care of their children. Families value and expect to have a relationship of partnership with the health care provider (Harrison, 2010).

When providing family-centred care, the health care practitioner incorporates and applies the caregivers' knowledge into health care for the family, because the family is constantly in the lives of children and children are affected by those whom they are living with. It is assumed that the family that is involved with the child's care will provide a higher quality of care.

Cavallari and Dixon (1988) postulate that Family-Centred Care provides the health care provider with a framework for paediatric care and the goal is to provide support and promote physical health and emotional and psychological development that occurs within the family context.

The aforementioned theoretical perspectives imply that it is important to adhere to principles of a family-centred assessment and intervention model (Dunst, Trivette & Deal, 1994). Family-centeredness implies empowerment of the parents /caregivers to increase their competency and ability to mobilize resources. In this model, empowerment is defined as “a parent/caregiver’s ability to meet the needs and achieve aspirates in a way that promote a clear sense of intra family mastery and control over important aspects of family function” (Dunst, Trivette & Deal, 1998). This model consists of four components: family needs and aspirates; family strengths and capabilities; social support and resources; and professional help giving-behaviour.

The model suggest that families are empowered when their needs and aspirates are identified rather than professionally identified strengths and capabilities are built upon; social groups are mobilized to meet needs and professional helping is done in a spirit of partnership and respect. When families are empowered, they feel a sense of control and mastery over their situation as opposed to relying on the professionals to meet their needs (Dunst & Trivette, 1996).

Family-centred care means placing the needs of the child within the context of its family and community, and devising a dynamic model of care in collaboration with the child and its family. Children living with chronic diseases present complex problems, and there is a great need to recognise a structured system of care in the medical model for both child health-care providers and the families. Family-centred care is being increasingly viewed as best practice in child health-care settings (MacKearn, Thurston & Scott, 2005). According to these authors the following are the six key elements of family-centered care:-

- Recognizing the family as central to and/or the constant in the child's life, and the child's primary source of strength and support;

- acknowledging the uniqueness and diversity of children and families;
- acknowledging that parents bring expertise to both the individual care-giving level and the systems level;
- recognizing that family-centred care is competency enhancing rather than weakness focused;
- encouraging the development of true collaborative relationships between families and health-care providers; and
- facilitating family-to-family support and networking, and providing services that provide emotional and financial support to meet the needs of families (MacKean, Thurston & Scott, 2005).

A family is an interrelated system that experiences a ripple effect of the child's asthma exacerbations and in order to establish a partnership in asthma care with a family, it is necessary for the clinician to examine the effects of asthma on each family, tailor management needs around what is known about the family and set appropriate goals for change to improve asthma management and family functioning (Grineski, 2008).

Regular asthma education and evaluation of the caregivers' knowledge and understanding about childhood asthma should be performed in order to achieve effective management of the patient (Prapphal, Laasunthara & Sritippayawan, 2007).

Warman (2000) recommends an ongoing partnership and communication between the health care provider, the patient and the family for optimal treatment to take place. For this partnership to work, patients/families and health care provider must have a common understanding of the nature of asthma, its treatment, goals, the role in medication, and self-

management practice. However, if the caregivers' concern about the medication prescribed is understood, it will be possible to affect adherence.

A successful asthma education intervention is one that allows the child and their family to become confident and more effective in controlling their asthma. With children, there are three players involved in the coaching process: the child, the caregivers and the educator (Osman & Calder, 2004).

Having an asthmatic child may lead to difficulties managing behaviour or to emotional problems in the caregivers and psychological stress may exacerbate vulnerability to asthma symptoms. That is why caregivers need to know how to manage their asthmatic child calmly, authoritatively when their child shows symptoms of asthma and may need professional guidelines on the way to do this (Calam, Gregg & Simpson, 2003). In this context, the health care professional plays such a vital role in helping the caregivers understand asthma education and successfully implement it at home. The practice of family-centered care thus involves training and educating the caregivers of asthmatic children and to take responsibility for their child's asthma care, and self-manage that relationship.

Therefore, treatment guides not only enable families to effectively manage asthma, they also aim to decrease the disruption of family life by asthma and integrate asthma management into their lives (Kaugers&Klennert, 2004).

All the aforementioned models are interlinked and enhance the asthma education given to the caregivers. It is quite clear that the caregiver and the health care provider must build up a good relationship and improve the quality of life of the asthmatic child.

The effective management of paediatric asthma involves the successful integration of multiple systems of care, including the family system, the health care system, and the care

settings outside the family such as the day-centers or the school (McQuaid, Walders, Kopel, Fritz, 2005).

2.3 OTHER RELATED STUDIES

2.3.1 Experiences of caring for the asthmatic child

Barton, et al (2005) did a study of parent experiences of caring for their asthmatic child. The Australian parents/caregivers were given a questionnaire to complete. The data show how the caregivers identify, classify and experience their children's respiratory symptoms. Caregivers had anxiety about their children's health, lack of knowledge about the asthma disease, fear of the child dying, uncertainty about management and prognosis, as well the physical and financial responsibility of caring for an asthmatic child. The children's families had to integrate the asthma into their family life.

However, the caregivers had little knowledge of coping strategies and, when the child presented with the first asthma symptoms; they felt overwhelmed by emotion and their loss of control of the management of their asthmatic child.

Caregivers reported a greater sense of confidence in their management of the asthma as their child grew older, as the asthmatic child would communicate more effectively about how they felt. Caregivers were able to take on more of the responsibility for their child's asthma management. One interesting manifestation was that some caregivers were reluctant to let their children overnight at friends' homes because they felt uncomfortable about their child being away from them. They were particular uncomfortable about giving their child preventive medication for asthma when the child was symptom-free and they feared that their children would become dependent on or immune or tolerant to the medication, and this resulted in a failure to comply with the medication prescribed (Barton, et al., 2005).

In Norway, a study was done to describe parents' experiences of living with a child suffering from asthma. The findings showed that caregivers expressed feelings of uncertainty, helplessness and guilt; that they needed support and help from the health care professionals to adapt to everyday life and develop coping strategies. The caregivers have to live with uncertainty in their daily lives and these feelings were strong at the onset of their child's asthma, but re-occurred every time the child had an asthma attack.

Caregivers also use the try-out strategy to help and manage their child's asthma. The study also emphasizes the importance of mutual dialogue and good relationship between the caregivers and the health care provider to enable the caregiver to develop a competency in caring for their asthmatic child (Trollvik&Severinsson, 2005).

In the rural area of Alabama, a study was done to describe the experiences of rural families in caring for children with asthma. The knowledge concerning the triggers of asthma was not a problem, but the caregivers were unable to pay for special equipment and the furnishing of their homes as recommended by the asthma education. The family members could not adjust by stop smoking, even though they knew the implications of smoking (Barrett, Gallien, Dunkin & Ryan, 2001).

2.3.2 Self-management plans for asthma

Smith, Bosnic-Anticevich, Mitchell, Saini, Krass and Armour, (2006) has done a study in the Sidney community; the community pharmacists were trained and applied the self-management model of illness. This study concluded that the asthma self-management model of illness provide the patients with range of self-management skills and improved the clinical and psychological indicators of asthma. The aim of the study was to maintain a good, supportive relationship between the pharmacist and the asthma patients.

2.3.3 Parental perception of asthma

Peterson-Sweetney (2003) conducted a study to explore the parental perception of their child's asthma. The findings of this study were that caregivers want health care providers to respect and value their knowledge about their child and how they as caregivers manage asthma on a daily basis. They acknowledge that they are learning to care for their asthmatic child and that they value knowledge about asthma but did acknowledge that there is a gap in asthma knowledge. Some caregivers would seek information from other sources, whilst others caregivers accept it as appropriate to have limited knowledge about asthma.

Caregivers also want health care providers to listen to them and give them advice to improve the child's asthma care. Caregivers had to collaborate with the health care providers in their child's asthma management as well as in on-going asthma education (Peterson-Sweetney, 2003). Caregivers also expressed their concerns about the adverse effects of anti-inflammatory medication, but acknowledged the importance of the control of asthma symptoms.

Studies have been done in community childhood asthma and the findings are that childhood asthma management is substantial under treatment but that there is a need to increase the awareness of the chronic nature of asthma and the need to follow the treatment prescribed in asthma treatment guidelines (Maziak, Mutius, Beimfohr, Hirsch, Leupold, Keil & Weiland, 2002).

2.3.4 Health care service for the asthmatic child

Specifically related to health care, children in poor families often suffer because of financial difficulties caused by low income, transportation barriers due to no health insurance, and cultural and language barriers (Grineski, 2008).

Caregivers identified five barriers to care: the lack of insurance, cost of service, transportation, treatment delays and language/communication. This suggests that parents will be able to cope better with their children's asthma if they could take advantage of available resources. By maintaining and improving easy-to-use services, caregivers are encouraged to continue to seek assistance for their asthmatic children when needed. When caregivers did not take advantage of available services, it was because of their fear, pride, a desire to be self-sufficient, time constraints, scheduling conflicts, transportation, and language/communication barriers (Grineski, 2008).

2.3.5 Caregivers' health literacy level and asthma

Wood, Price, Dake, Telljohann and Khuder (2010), conducted a study to determine the effect a caregivers' level of health literacy and self-efficacy has on their child's asthma control. The findings of this study confirmed that improvement of caregivers' self-efficacy levels and health literacy has a positive effect on the child's asthma outcomes.

2.3.6 Various method of asthma education

A Columbian researcher, Findley (2011) developed the Asthma Basic Care (ABC) Program, which provided multiple opportunities for caregivers to learn about asthma signs and triggers in the asthmatic child. This multi-level intervention promoted caregivers' participation by offering them flexible workshop scheduling; and by adding a provider-education component to improve communication between caregivers and nurses.

In this study, the caregivers reported that, after participating in the program, 89% found it easier to talk to their doctor, and 80% said they were confident in their ability to manage their child's asthma. In the group without parent training, only 31% had taken at least one step

toward reducing triggers, 49% reported that talking to their child's doctor was easier, and 49% expressed confidence in managing their child's asthma.

This strategy strengthened the communication skills of caregivers and their asthmatic child's health and suggests that the health care provider contributed to the changes in their caregivers' asthma management behaviours through improved confidence and improved asthma control.

Warschburger, Busch, Bauer, Kiosz, Stachow and Petermann (2002) ran an educational program with caregivers and found that short-term patient-centred patient education program increased knowledge and the health status of asthmatic children. The self-management asthma plans led to positive results regarding knowledge and morbidity.

Another study was done in Norway to evaluate the effectiveness of various methods of asthma education for parents. The results revealed three themes: sharing of experiences; accepting the illness; and partnership building. The caregivers expressed feelings of satisfaction and increased their understanding through meeting other caregivers in the group. By talking to other caregivers they recognised and confirmed their own experiences and learnt to handle their asthmatic child adequately. The coping and try-out strategy made them aware to try out more and gain more confidence. The importance of a partnership between the caregiver and the health care provider was identified (Trollvik&Severinsson, 2005).

Valerio, Cabana, White, Heidmann, Brown and Bratton (2006) conducted a focus group study on Medical-Aid caregivers on their understanding of asthma. This study showed that caregivers frequently felt that they are unable to control and manages all circumstances of asthma and that caregivers with a low self-efficacy level may not be able to act or trust their capabilities for dealing with and caring for their asthmatic child. It was suggested that

caregivers require on-going asthma education, with the emphasis on the support and development of caregivers' confidence regarding their asthma self-management skills.

Watson, Gillespie, Thomas, Filuk, McColm, Piwniuk and Becker (2009) conducted a study on small-group interactive educational programmes for asthmatic children and their caregivers. The results were effective and showed significantly reduced need for hospital-based emergencies services. The quality of life of the asthmatic child and caregivers also improved.

2.3.7 Caregivers' health belief of asthma

In Hong Kong a study was conducted by Wong and Wong (2001) to determine caregivers' knowledge and beliefs of asthma. Many caregivers did not understand the pathology of asthma and there were misconceptions regarding the asthma management. The study concluded that it is important to know the caregivers' beliefs and knowledge of asthma care, because those influence the preventative measures of asthma control.

Regular asthma education and evaluation of the caregivers' knowledge and understanding of childhood asthma, is however important to achieved effective asthma management of the asthmatic child (Prapphal, Laosunthara, Deerojanawong&Scitippayawan, 2007).

2.3.8 The effect of family dynamics has on the asthma management

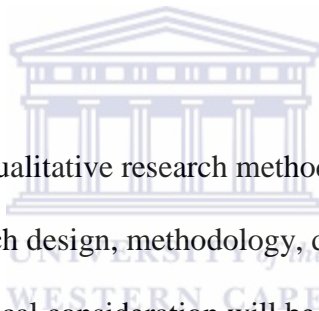
Kaugers, et al (2004) conducted a study on the influence of family on asthma care and the findings show that family conflict and distress as well as poor adherence to treatment worsen the asthma and the asthma outcomes. Family organisation, racial, and ethnic group also influence the asthma outcome depending on the family behaviours.

Fiese, Winter, Anbar, Howell and Poltrock, (2008) conducted a study to determine whether family routine and family climate are a burden for the mother-child interaction and for asthma care. The findings were that caregivers perceived the daily asthma management as chores and would engage less in supportive interaction with the asthmatic child. Coupled with poor adherence, these negative interactions would result in greater anxiety levels and lower the quality of life of the asthmatic child.

2.4 CONCLUSION

This chapter provided an introduction to the theoretical framework for an asthma education study and other related studies. The literature also addresses the lack of research done in South Africa.

The next chapter focuses on the qualitative research methodology adopted to perform the study. A description of the research design, methodology, data collection methods, data analysis, content validity, and ethical consideration will be outlined.



CHAPTER 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

Research methodology involves forms of data collection; analysis and interpretation that researchers propose for their studies (Creswell, 2009). In chapter two the theoretical framework and literature review of the study were presented. In this chapter, the process and methods used to conduct the study are explained.

3.2 RESEARCH APPROACH

The nature of the research question in this study points to the selection of the qualitative research approach. Creswell (2009) defines qualitative research as “an enquiry approach useful for exploring and understanding a central phenomenon. The researcher asks the participants broad, general questions and collects a detailed view in the form of words, and analyses this information for a description and themes. Then the researcher interprets the meaning of the information on personal reflections and the past research”.

According to Brink, van der Walt and van Rensburg (2006) a qualitative research approach includes methods that focus on qualitative aspects of meaning, experience and understanding and the study of human experience from a viewpoint of the research participants in the context in which action takes place.

Qualitative data is well suited for identifying the meaning that people place on events, processes and the structure of their lives. Their experiences and knowledge become clear and can be placed in context within the social world around them (Patton, 1990).

Patton (2002) recommends that health care providers should go beyond the quantitative evaluation of guidelines engaged in healing and prevention, since the best source and form of information are clients' stories. There is a richness there that numbers alone cannot capture. The first question of the data collection may elicit information relevant for phenomenological analysis, but the ultimate goal of the study is more in line with qualitative guideline (programme) evaluation.

The researcher wanted to explore the caregivers' experiences and understanding when implementing the asthma education guidelines at home. The caregivers' experiences are important as they are used to determine what changes or adjustments can be made to make the asthma education guidelines user-friendly.

3.3 RESEARCH DESIGN

Qualitative research is done in natural settings. According to Creswell (2009), it means exploring and understanding the meaning individuals/groups ascribe to a social or human problem.

A descriptive, exploratory and contextual design was used, since the researcher needed to explore and then describe the caregivers' experiences with implementing the asthma education guidelines from Red Cross Memorial War Children's Hospital, Rondebosch.

In this study, caregivers were allowed to express themselves in their own vernacular to give the most appropriate response.

Exploratory studies aim to provide a causal explanation of the phenomenon and are designed as open and flexible investigations. It adopts an inductive approach as the researcher makes a series of particular observations, and attempts to patch these together to form a more general,

but speculative hypotheses (Terre Blanche, Durrhein& Painter, 2006).The goals of explorative studies are therefore to create a general mental picture of the conditions and generate new ideas, conjectures; the feasibility of the research and develop techniques for measuring and locating future data (Neuman, 2010).

This design typically occurs when the researcher examines a new interest or when the subject of the study is relatively new. It is also a design used to investigate a persistent phenomenon in this case, the question of why caregivers often bring their asthmatic child back for acute service or care despite having received education on how to manage the asthmatic child at home (Babbie&Mouton, 2010).

Exploratory studies are done for three reasons: to satisfy researcher curiosity and desire for a better understanding; to test the feasibility of undertaking a more extensive study and to develop the methods to be employed in a subsequent study (Babbie&Mouton, 2010).

An exploratory-descriptive study design was chosen because the researcher wanted to explore the experiences of the caregivers with the implementation of the asthma education guidelines. This design was the most appropriate, because it was the first time that this topic was investigated at Red Cross Memorial War Children's Hospital, Rondebosch.

Furthermore, this design was used because the researcher wanted to explore this topic in order to know enough to be able to design and execute a second extensive study. It allowed the researcher to become familiar with the basic facts of why caregivers continue to bring their asthmatic child in for acute services (Neuman, 2010).

The use of an exploratory-descriptive design in this study enabled the researcher to provide a detailed and highly accurate picture of a situation, social setting and its relationship. This

entailed the description of the experiences of the caregivers with the implementation of the asthma education guidelines. The exploratory part was used to develop techniques for measuring and understanding participants' experiences in order to provide more client-friendly asthma education (Neuman, 2010).

3.4 PILOT STUDY

The pilot study was conducted to ascertain the feasibility of the main study and to highlight any problems or issues which may arise during the actual study (Burns & Grove 2010). This was also done to ensure the validity of the questionnaire and to remove complications and difficulties (Brink, van der Walt & van Rensburg, 2006).

The participants in the pilot study were also asked about the clarity, level of difficulty and appropriateness of the questions. The initial questionnaire was used in the pilot study, for which 20 caregivers were purposively selected. These participants were caregivers who attended the Vanguard Community Health Centre's asthma clinic. The pilot study suggested that more questions be asked regarding the experiences of the caregivers with regards to helping their asthmatic child.

3.5 COMMUNITY ENTRY TO CONDUCT THE STUDY

The researcher requested permission from the medical superintendent of children's hospital (see Addendum B), as well as the professional nurse in charge of the clinic. The researcher chose to do the study at a hospital that was unknown to her, in order to gather sufficient, rich information, uninfluenced by courtesy bias.

3.6 RESEARCH SETTING

The study was conducted at Red Cross Memorial War Children's Hospital in Rondebosch, Cape Town. This was the most suitable setting because the institution is a known children's hospital. This institution provides a comprehensive service to all children.

All caregivers with asthmatic children received asthma education as part of the initial visit and assessment of the asthma management. The asthma education was given by the health care providers, which include the nurse and the doctor. The asthma education provided is as stipulated in the asthma education guidelines of 2009 (Motala, Green, Manjra, Potter & Zar, 2009).

3.7 TARGET POPULATION

The study population included all caregivers with asthmatic children younger than seven years of age, who attended Red Cross Memorial War Children's Hospital in Rondebosch, Cape Town. The study population is the entire group of people that is of interest to the researcher, and who meets the criteria for inclusion. All caregivers who received education about the asthma guidelines of 2009 were included) in the research study (Babbie&Mouton, 2010). For this study, the caregiver included any adult who cared for an asthmatic child younger than seven years of age. Those who did not attend the asthma education programme (asthma education guidelines of 2009), were excluded from the study.

3.8 SAMPLING

Sampling refers to the researcher's process of selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest (Brink, van der Walt & van Rensburg, 2006).

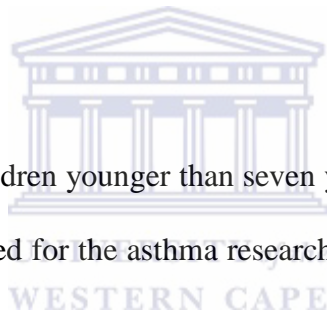
3.8.1 Sampling Method

A non-probability purposive sampling was used in this study. Creswell (2009) defines purposive sampling as the purposeful selection of participants for the study to establish rapport with the participants who can provide relevant and rich data. The advantage of the purposive sampling is that it allows the researcher to select a sample based on knowledge of the phenomena being studied (Brink, et al, 2006). The disadvantage is the potential for bias based on the fact that the sample may not represent the population, and only limited generalizations of the results can therefore be made (Brink, et al, 2006).

Caregivers who attended the Asthma Clinic of Red Cross Memorial Children Hospital in Rondebosch with (an) asthmatic child(ren) were purposefully sampled.

3.8.2 Sampling process

All caregivers with asthmatic children younger than seven years of age and who had received the asthma education were selected for the asthma research study. The caregivers voluntarily participated in the study.



3.8.3 Sample Size

Qualitative studies tend to use small samples in order to enable the researcher to investigate the situation in depth. Brink, et al (2006), suggests that a few subjects should be selected for a qualitative study because many subjects could complicate the data analysis.

The sample size for this study was eighteen (18) caregivers of asthmatic children younger than 7 years of age who had been educated on the asthma guidelines, but whose children keep coming back for acute asthma care and treatment, were selected for the semi-structured interviews. By the time the 18th caregiver was interviewed data saturation was reached. No new information was forthcoming from the interview.

3.9 DATA COLLECTION

Data collection is the precise systematic gathering of information relevant to the specific research objectives or questions (Burns & Grove, 2010). The data collection was done from July to October 2012, in the asthma consultation room of the Red Cross Memorial Children Hospital in Rondebosch.

3.9.1 Data collection method

Semi-structured interviews were used in the study. Face-to-face individual interviews were done to obtain information on the caregivers' experience with implementing the asthma education guidelines. In semi-structured interviews the interviewer asked a limited number of specific questions and probed for additional information to obtain the necessary depth of information (Brink, et al, 2006). Additional field notes were used to capture non-verbal responses and any information that would add richness to the data. It was anticipated that these notes would be used in discussing the findings. The interviews were conducted in a consultation room of the asthma clinic by the researcher. The interviews are useful in ascertaining values, preferences, interest, tasks, attitudes, beliefs and experiences. According to Babbie & Mouton (2001) the interview guide is a data collection instrument from which one person (the interviewer) poses questions to another (the respondent).

The advantages of conducting semi-structured, face-to-face interviews, as suggested by Patton (1990) were that:

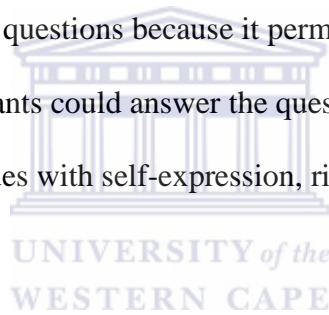
- The researcher had the opportunity to probe in order to get more, rich information;
- A number of different people could be interviewed;
- Systematic and comprehensive information could be obtained;

The interaction could be kept focused allowing for individual perspectives and experiences to emerge in order to gather high-quality data.

3.9.2 Data collection tool

A semi-structured interview guide was developed to meet the objectives of the study. The reason for using the interview guide was to ensure that information obtained from the eighteen caregivers regarding their experiences with implementing the asthma education guidelines covers the same material for each participant during the interviews and addressed the objectives of the research study. This semi-structured interview guide also allowed the interviewer an opportunity to probe when the information of the respondents was inadequate. The schedule included open-ended questions to obtain valuable information from the respondents (see Addendum A).

The researcher chose open-ended questions because it permitted unlimited numbers of possible answers and the participants could answer the question asked in detail. It permitted adequate answers to complex issues with self-expression, richness and detail (Neuman, 2010).



The asthma education guideline for management of chronic asthma in children (Motala, et al., 2009) was used as a tool for setting up these questions relating to asthma. The questionnaire was compiled from general asthma education questions and linked with questions of the caregivers' experience with implementing the asthma education guidelines.

The interviewer collected data about the caregivers' experiences/fears and challenges regarding their implementation of the asthma education guidelines. The questions asked were exploratory in nature and required descriptive responses from participants.

3.10 DATA ANALYSIS

Qualitative data analysis involves the integration and synthesis of narrative non-numeric data that are reduced to categories and themes with the aid of a coding procedure (Brink, et al, 2006). The data analysis in qualitative research is non-numerical, usually in the form of written words or videotapes/audiotapes. The analysis of data therefore involves an examination of words (Brink, et al, 2006). The audiotape recordings were transcribed and a thematic analysis was done inductively.

After each individual interview, the tapes were played back to the participants, who confirmed that the interview had been recorded fully and effectively. The transcriptions were done after the interviews by an independent transcriber. The tape recordings were transcribed verbatim and some were later translated from Afrikaans into English by an independent language practitioner.



To ensure anonymity, the real the names of the respondents were not used in the transcribed interviews. The data collected were kept in a secure location. Each interview was transcribed on a separate sheet; numbered according to the interview and all relevant data e.g. date, time of interview and code names were included.

The following guidelines as stipulated in Creswell (2009) were followed for the inductive analyses of the data, which was done by the researcher:

- Reading through all transcripts, in order to get a sense of the whole, and then jotting down first impressions/ideas/concepts in the margin of the text. Through this process, the researcher also considered the field notes and observations.
- Getting back to the transcripts and organizing the data by means of coding and sorting the images into themes and sub-themes of a chronicle. To understand the

participant's perceptions and experiences of reality, the analysis moved beyond content analysis, (what was said) to also note the structure and format of each "story" (how it was said). The way in which the experiences and perceptions are conveyed; their interpretations and reflections of the sequence of events and the expressions used to portrait the illness experiences helped the researcher to get insight into participants' views.

- Central generic themes (storylines) that emerged were identified and reported on Creswell (2009).

Creation of categories

Overlapping coding and the uncoded text:

Among the commonly assumed rules that underlie qualitative coding is that one segment of text may be coded into more than one category, and a considerable amount of the text may not be assigned to any category, as much of the text may not be relevant to the research objectives.

Continuing revision and refinement of category system:

Within each category, a search was conducted for subtopics, including contradictory points of view and new insights. Appropriate quotes were selected that convey the core theme or essence of a category (Thomas, 2003). The outcome of the process was seven themes which, virtue of the data analysis process emerged from the entire data set.

Creswell (2009) suggests that verification, in the context of qualitative research, is "a process that occurs throughout the data collection, analysis and report writing of a study."

Creswell (2009) lists several data verification methods and suggest that at least two of these methods should be used in a study.

The researcher engaged in the following procedures for data verification:

- *Rich, thick description* – this includes describing the setting and participants. Patton (2002) alludes to the fact that phenomena can only be understood within the context in which they are studied, findings cannot be generalized from one context to another and the data represents simply another construction to be taken into account in the move toward planning. However, presenting thick descriptions will help the reader to make decisions regarding transferability.
- *Member checks* were done by reflecting and checking with participants at intervals and at the end of the interview around the researcher's understanding of their perceptions and stories.
- *Peer reviewing and debriefing* provided an external check of the research process. The supervisor did spot checks on recorded interviews and transcriptions and moderated the data-analysis process to reach consensus on the interpretation of the data.
- *Clarifying research bias*. Since the researcher has been working in this field for 24 years, she had to consciously step out of her role as a professional nurse working in this area and take on the role of researcher, and reflect on prior knowledge of negative experiences that could bias the data-collection and data-analysis.

3.11 ACADEMIC RIGOR

Qualitative validity is based on determining whether the findings are accurate from the standpoint of the researcher, the participants, or the readers of the account (Creswell, 2009).

3.11.1 Internal validity

Internal validity has to do with subjects' selection, and it determines the extent to which effects detected by the study is a true reflection of the reality (Burns & Grove, 2010). It prevents false negative responses therefore caregivers were excluded as subjects if they did not attend the asthma education as stipulated in the guideline of 2009. The exclusion was done to prevent them from influencing the responses of caregivers with the implementation of the asthma education guidelines. Instrumentation influence was prevented by the fact that answers were self-reported by the respondents. The environment was controlled and the interviews were done in a closed consultation room to prevent contact between the subjects, so as to ensure minimal threat to the validity of the data.

Validity is concerned with the accuracy and truthfulness of the scientific findings; to determine the extent to which conclusions effectively represents the empirical reality and whether the constructs devised by the researcher represent or measure the categories of the human experience that occur (Brink, et al, 2006). Qualitative methods focus on the qualitative aspects of meaning: on the experiences, the viewpoint and the understanding of the human experience of the participants in the context in which the action has taken place (Brink, et al, 2006).

3.11.2 Trustworthiness

Babbie and Mouton (2004) refer to trustworthiness as the concept which ensures neutrality in qualitative research designs. Trustworthiness requires that the researcher employs strategies of credibility, dependability and conformability:

- (i) The use of semi-structured interviewing techniques, tape recordings of the interviews and verbatim transcriptions increased the accuracy of the descriptions

of participants' experiences and therefore increased the credibility of the findings (Streubert& Carpenter 2010).

- (ii) Dependability relates to the reliability of data over time and different conditions and refers to the detail and information provided by the study to allow others to replicate the methods of the researcher and reach the same conclusions (Streubert& Carpenter 2010). Dependability was established with the interviews which involved maintaining and preserving all transcripts, notes, audiotapes, notes, etc.
- (iii) Conformability of a study establishes that “data, findings and interpretation are clearly linked” and the participants along with other research professionals support and agree with the researcher’s interpretation of the findings. The researcher uses the criteria as a guide to ensure trustworthiness of the study (Streubert& Carpenter 2010). Conformability will be determined by linking the data to their sources.

According to Babbie and Mouton (2004), the framework for trustworthiness consists of three main criteria: truthfulness, applicability and neutrality.

- (i) Truthfulness was ensured by:
- the use of audio-recording of interviews to ensure that the researcher did not forget or misinterpret the participants’ words;
 - writing field notes directly after each interview to ensure that no significant observations would be forgotten or missed;

- reporting the participants' own words to indicate the range and variety of responses to each question asked;
 - continuing with data collection until data saturation was obtained; and
 - consulting with the study supervisors to review the process and the findings
- (ii) Applicability was achieved through rich description, whereby the research process, the characteristics of the participants and the context are supplied to allow readers to determine to which extent the circumstances are similar to their own context.
- (iii) Neutrality implies that an inquiry that is free of bias or is separated from the researcher's perspectives, background, position, or conditioning circumstances. When a researcher or the research is said to be neutral, the inquiry is also implied to be trustworthy and legitimate. Neutrality is a term that is often attached to research to demonstrate that it provides an objective and unbiased view of the object under study (Streubert & Carpenter 2010). The researcher therefore chose to the study at Red Cross Memorial Children's Hospital to remain neutral and to prevent any bias.

3.11.3 Reliability

The researcher took limited notes during the interviews, observed the non-verbal responses and recorded the discussions. The researcher then reflected and compared all the information gathered to ensure equivalence of data. The instruments were also pilot-tested before use in the main study.

3.12 ETHICAL ISSUES

3.12.1 Authorisation to conduct the study

Permission to conduct the study was obtained from:

- The Ethical Committee of the Faculty of Community and Health Sciences, UWC
- The Management of the Nursing Division of the selected tertiary hospital.
- The participants (the caregivers of asthmatic children).

3.12.2 Voluntary participation

The researcher is responsible for conducting the research in an ethical manner, which means that human rights are protected e.g. the participants were informed that participation was voluntary and that they had the right to withdraw without any adverse consequences.

3.12.3 Risks and benefits

To maintain respect and human dignity, the researcher ensured that the research questions were not more intrusive than they needed to be (Brink, et al, 2006). The participants were informed that there were no known risks associated with their participation in the study. They were also informed that while there were no financial benefits in participating, their contribution will help to improve the asthma education programme which will benefit their child and all other asthmatic children in future.

3.12.4 Informed consent

The participants were explained the purpose of the study and they were given time to read information and the consent document, and were given a chance to ask questions before they committed themselves. (See Addendum B)

For the purpose of the principle of beneficence, the participants were informed that participation had no monetary benefits, but that they would benefit by using the opportunity to make a positive contribution through participation in the study to long-term implications on asthma education guidelines and asthma management.

3.12.5 Confidentiality and Anonymity

All participants were reassured that their information shared will be kept confidential and that anonymity will be maintained. The researcher protected the participants by not using their real names at any stage of the research process. No individual who participated in this study will be identified in the publication that may develop from the study findings. The researcher reassured the participants of her adherence to the confidentiality principle and that no personal information will be revealed in reports or publications which may emerge from the study. All study-related health information was kept strictly confidential and was not accessible to unauthorised parties. However, general information about the study may be available on request.

The participants had the right to withdraw or terminate their participation at any stage of the research study (Brink, et al, 2006).



3.13 CONCLUSION

This chapter provided a detailed description of the research design, methodology, validity, reliability, trustworthiness, and ethical considerations.

The next chapter gives a detailed description of the findings of this study, and also explores the main trends and patterns of the study. It continues to summarise and discuss the main result which emerged from the data collected.

CHAPTER 4

RESULTS AND DISCUSSION

4.1 INTRODUCTION

In this chapter, the researcher describes the findings of this study, explores the main trends and patterns, summarises, and discusses the main findings that emerged from the data collected.

The discussion which follows the presentation of the findings is based on the central themes and sub-themes that emerged from the data collected in accordance with the patient-centred theoretical framework which was selected for the study. The patient-centred theoretical framework is the central theory for the discussing of the findings; however the discussion also refers to other related theories which explain implicitly or explicitly the rationale for the asthma education program and which supports the patient-centred theory. Findings of literature relating to these themes are used in an integrated discussion for a better understanding of the subject researched.

For the purpose of the study a semi-structured interview guide was compiled for the individual interviews. The open-ended questions were verbally posed to facilitate free flowing responses. The following questions guided the interviews:

- Tell me about your experience with helping your asthmatic child?
- Tell me about your challenges and fears relating to helping your asthmatic child?
- How did the asthma education/guidelines that were given to you by the nurse or doctor help you to help your child?
- How did you experience the way the nurse spoke to you and explained the asthma guidelines?

The findings and discussion will be presented as follows:

4.2 DEMOGRAPHIC INFORMATION OF PARTICIPANTS

Participants were purposely chosen to represent the caregivers of asthmatic children attending the Red Cross Memorial War Children’s Hospital in Rondebosch, Cape Town. Relevant demographics data were documented (Table 1), and represents a general profile of the study participants and enabled the researcher to identify the precipitating or contributing factors of all the problems that the caregivers may experience.

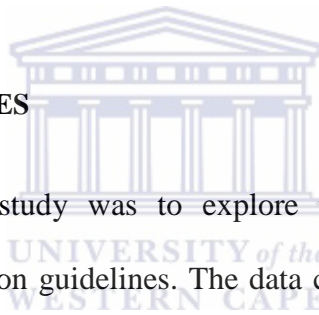
Table 1: Demographic information of participants

Characteristic variable	Number of participants (n = 18)
Age	
21-25 years	3
26-30 years	8
31-35 years	3
36-40 years	1
41-45years	3
Marital status	
Married	5
Single	13
Educational level	
Primary school	3
Incomplete Secondary school	12
Matric completed	3
Occupation	
Housewife	12

Employed	6
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Almost all the caregivers were the asthmatic children’s biological mothers.

The majority of the participants (8) were in the age group of 26-30 years. However, the age did not have a direct bearing on the analysis, but is an indication of the participants’ level of maturity. Twelve (12) of the participants were unemployed, single and had incomplete school education. This was significant as participants may experience financial difficulties and or difficulty in understanding the asthma education programme due to their level of education or literacy, which may, in turn, have a negative impact on the management of the child’s asthma.



4.3 CAREGIVER’S EXPERIENCES

One of the objectives of the study was to explore the caregivers’ experiences with implementing the asthma education guidelines. The data collected was reduced to seven (7) themes through the data analysis process. The identified themes and their sub-themes are presented in Table 2. Links are made with the theories which underpin these central themes.

Table 2: Caregiver’s experiences of implementing the asthma education guidelines

Themes	Subthemes	Theoretical framework
1. Asthma education had a positive effect on the management and care which caregivers provided for their child who had	1.1 Caregivers verbalised that they found the asthma education useful. 1.2 Individual educational session with caregivers made the asthma education easier to understand.	Theme 1 is underpinned by the main theory adopted for this study viz. the patient-centred theory, and is further

<p>asthma.</p>	<p>1.3 The practical demonstrations helped the caregivers effectively manage the asthmatic child.</p> <p>1.4 The asthma education helped and improved the asthma care and management.</p> <p>1.5 The simplified comprehensive education session promoted the caregiver's willingness to learn more.</p> <p>1.6 Caregivers understood the need to make changes / adjustments at home to reduce the asthma exacerbations.</p> <p>1.7 Caregivers were prepared to teach all involved in asthma care at home.</p> <p>1.8 A friendly learning environment promoted learning.</p>	<p>supported by the theories of self-determination, social cognition and the family-centred theory.</p>
<p>2. The need for regular, continuous asthma education still exists.</p>	<p>2.1 Difficult to understand the medical terms used by the health care provider.</p> <p>2.2 To enhance communication between the caregivers and health care provider to eliminate confusion and to form a partnership in asthma care.</p> <p>2.3 The importance of the shaking of the asthma inhaler device.</p>	<p>The central theory in theme 2 is the patient-centred theory which is supported by the social cognitive and the self-determination theories.</p>

	<p>2.4 Incorrect use of the inhaler device had a negative effect on the asthmatic child and it increases the asthma morbidity rate.</p> <p>2.5 The importance of the caregivers understanding the physiology of the asthma condition.</p> <p>2.6 Regular asthma education and inhaler device technique checks are important.</p> <p>2.7 The irregular use of the asthma inhaler device had a negative effect on the asthma care.</p>	
<p>3. Difficulties were experienced with the asthma care and management.</p>	<p>3.1 Caregivers experience financial difficulties.</p> <p>3.2 According to the demographic data collected, most of the caregivers were single, unemployed and these factors may lead to poor asthma care and management.</p> <p>3.3 Asthma management and care must be given to staff at the day centers (e.g. school, crèches).</p>	<p>In theme 3 the main theory is the patient-centred theory and is supported by the family-centred theories.</p>
<p>4. Overwhelming emotions interfered with</p>	<p>4.1 Caregivers experienced anxieties about helping the asthmatic child.</p>	<p>Theme 4 is underpinned by the patient-centred</p>

<p>performing the prescribed interventions</p>	<p>4.2 Caregivers' emotions had a negative effect on the asthma management.</p> <p>4.3 Caregivers expressed experiencing feelings of helplessness when their child has an asthma attack.</p> <p>4.4 Guilt feelings when helping the asthmatic child had a negative effect on the asthma care.</p> <p>4.5 Caregivers expressed experiencing feelings of pain and sadness associated with helping their asthmatic child.</p> <p>4.6 Caregivers expressed experiencing feelings of fear when helping their asthmatic child.</p>	<p>theory and is supported by the Health Belief Model.</p>
<p>5. Caregivers displayed overprotective behavior.</p>	<p>5.1 Caregivers' fears and behaviour hampered the asthmatic child from living a normal life.</p> <p>5.2 Caregivers verbalised fears of separation from their asthmatic child.</p>	<p>In Theme 5 the central theory is the patient-centred theory and is supported by the family-centred theory and Health Belief Model.</p>
<p>6. Positive effect of family support and family</p>	<p>6.1 Shared asthma care reduces anxieties within the family and makes</p>	<p>Patient-centredness is the main theory in</p>

involvement.	asthma care easier. 6.2 Shared asthma care leads to shared responsibility. 6.3 Poor family involvement leads to an increase in anxiety.	theme 6 and is supported by self-determination; family centred theories.
7. Caregivers need to develop coping skills through support / social groups.	7.1 Caregivers need copings skills to manage their asthmatic child effectively. 7.2 The need for a social or support group for caregivers to be able to learn from each other.	Theme 7 is underpinned by the patient-centred theory and is supported by the self-determination theories and the family-centred theory.

The participants expressed a largely positive experience with the asthma education and found it very useful. The participants were prepared to make the necessary changes at home to prevent future asthma exacerbations. The participants also verbalised their fears and challenges when helping their asthmatic child.

The following is a detailed discussion of the identified themes with regard to the caregivers' experiences with implementing the asthma education guidelines.

Theme 1: Asthma education has a positive effect on asthma management and care

The Global Initiative for Asthma (GINA, 2002) described that the aim of asthma education is to provide the caregivers with suitable, adequate information and training so that the child can keep well. It is important to develop educational programs to support caregivers with children suffering from asthma.

Subtheme 1.1 Caregivers verbalised that they found the asthma education useful

By implication, the patient-centred theory proposes that health care providers must educate caregivers through information sharing, and involve them in the decision-making around the care of the asthmatic child. In addition, Plaut (2005), suggest that asthma education is a continuous process and that caregivers need asthma tools and techniques to continue their learning and to improve their ability to manage their asthmatic child's condition.

The value of the patient-centred approach is attested by the participants' reports that they found the education program interesting and useful. Some of them reported that "It [asthma education] was very useful, and the nurse did elaborate why we must use the pumps." and "I did understand it and it was good." and "The asthma education was useful for me, because the more I can learn about asthma the better it would be for me, I would say every time I learn more and more and he [the asthmatic child] got better and better."

Caregivers verbalised that they found the asthma education useful and noticed an improvement in their asthmatic child's condition.

"It was [asthma education] useful, and when I give him a pump as I was told, he gets better, and I know now what to do." Another participant reported that she learnt new information with the asthma education. "It was [asthma education] useful, because I learned stuff I never knew before; they showed me the right way how to use the pumps, and the preventer and so on." Willingness to learn is one of the key elements of the self-determination theory, and the extent to which caregivers are open to new information is the extent to which they will become competent to manage the asthmatic child (Markland, Ryan, Tobin & Rollick, 2005). Even when asthma management was known to the caregiver, they verbalised that they still learnt from the asthma education, as suggested by this comment: "For me that knows asthma, I still learn."

The patient-centred theory highlights the fact that patients are the important persons in the health care/professional relationship and should be given the resources (education) to help him/herself (Dexter & Walsh, 1995). By giving caregivers the information (asthma education), they will take responsibility for their asthmatic child's health (Groll, 1990).

Subtheme 1.2 Individual educational sessions with caregivers made the asthma education easier to understand

When they were asked if the educational session was conducted one-on-one or in a group, the researcher noted that the participants' body language and their facial expressions indicated appreciation. All participants reported that they received individual education session from the health care provider.

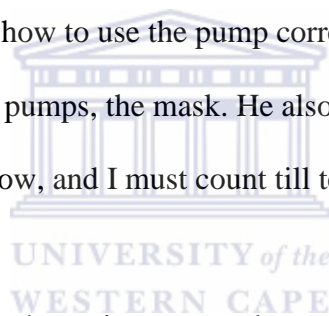
According to Zepeda, Varela and Morales (2004) the individual caregiver's education programme is as strong as the social context in which they are embedded. One participant said that "It [the asthma education program] was meaningful [educational] and I feel it helped me a lot and the more they can teach me, the better I understand and with that knowledge I may help not only him [the asthmatic child], but somebody else that also has asthma."

Another participant said: "The way they explain [asthma education] wasn't difficult, I immediately understand [understood]."

The participants also verbalised that the practical demonstration helped them to understand how to effectively manage their child at home. They referred, for example, to the correct positioning of the asthmatic child when using the inhaler device. This participant explained how this was done: "Like how I must use the pumps [asthma inhaler device], it was not too complicated, and I could quickly learn and make adjustments." Another caregiver mentioned that "They will show you what to do and then you have to show them what you do." This is done for the nurse to establish whether the caregiver understood and is able to perform the

activity or technique. The patient-centred theory supports this, because the caregivers and the health care provider must share in the asthma management; they must form a partnership and together they make the asthma care effective (Pinnock, et al., 2010).

The participants reported that the health care provider demonstrated to them how to use the inhaler device correctly. The following statements illustrate this: “Yes, they did, and they would ask me to show them how I use the pumps at home. “The doctor will ask, have you done this and please show me, and then I have to show her what I did.” “They will show me and ask my son to practice it.” “They teach you how to use the pump correctly and how to inhale.” “Yes, and I even practice how to use the pumps.” “They will show me and ask my son to practice it. They teach you how to use the pump correctly and how to inhale.” “Yes, doctor showed me how to use the pumps, the mask. He also checks if I do it right.” “How to use the pump and how he must blow, and I must count till ten.”



These statements are supported by the patient-centredness theory, confirming that the sharing of the asthma disease between caregivers and health care providers is important. In this regard, the social cognitive theory points out that there is an interaction between individuals (caregivers) and their environment (home/ asthma staff) and the human capacity to learn (Bandura, 1986). The caregivers’ knowledge of asthma will enable them to manage their asthmatic child. This include behaviour changes of the caregivers, because a new behaviour is a product of an individual learning through observation and a presentation of the perception of the environment, and physical and intellectual capacities (Bandura,1986).

Subtheme 1.3 Practical demonstrations helped the caregivers effectively manage the asthmatic child

Participants reported how they were given the opportunity to practice the asthma inhaler device: “They [nurses and doctors] would ask me to show them how I would use the pumps at home. The doctor will ask have you done this and please show me, and then I have to show her what I did.” “They will show me and ask my son to practice it. They teach you how to use the pump correctly and how to inhale.” “I was with my son and I did it in front of them, and they showed me how to use the pumps on him.” These reports indicate that the caregiver’s skills and confidence were being developed. This is in line with a study done by Kallstrom (2004), which revealed that caregivers often struggle when trying to put the asthma knowledge into action and often require the health care provider to help them. It is acknowledged that the demonstration of medication administration is an important tool and it is entirely possible that the caregiver has a less than perfect administration technique with the metered dose inhaler or nebulizer. Patient-centred care, which is a preventative care model – does stipulate that regular asthma education gives the caregivers the opportunity to practice and prevent any unnecessary asthma exacerbations (Bauman, Fardy & Harris, 2003).

Subtheme 1.4 The asthma education helped and improved the asthma care and management

This participant verbalised that she understood the asthma education and could teach other family members at home: “If I didn’t understand any word I would ask them and they will explain it in lame [simplified] terms, because if I don’t understand [how to use the asthma inhaler device] I would not be able to teach the others at home. That is why I must understand.” The family-centred theory supports this statement, because an asthmatic child’s family is central to asthma care/management (Harrison, 2010). One of the participants

acknowledged that she was taught how to use asthma inhaler correctly and saw an improvement in her child's condition: "I did understand it [how to use the asthma inhaler], but in the beginning it was a bit difficult and I did everything as I was told, like how to give the pumps and his treatments [medication]. And every time when I came it went better and better. I would say every month I learnt more and more." The self-determination theory emphasises that the health care provider must ensure that caregivers know how to use the asthma inhaler device, and motivate them to comply/adhere to the prescribed medication (Deci& Ryan, 2002).

These participants' responses confirm that the optimal management of childhood asthma requires the active participation of caregivers. Parent education is directed towards the provision of specific knowledge and skills to caregivers with the objective of enhancing a child's health and asthma care. It also enhances the parent-child interaction when implementing the asthma education guidelines (Zepeda, Varela& Morales, 2004).

The GINA guideline (2002) also emphasizes the importance of effective communication between health care providers and the caregivers because it reduces morbidity and is a central point to parental/caregivers' education if you aim for shared responsibility of the asthma care. The asthma education guidelines of 2009 also propose that parental asthma education is one of the main principles for the management of childhood asthma (Motala, et al, 2009).

The goals of the National Asthma Education and Prevention Program (NAEPP, 1989), which health care providers should meet, are:

- to raise awareness of patients/caregivers, health professionals, and the public that asthma is a serious chronic disease

- to ensure the recognition of the symptoms of asthma by patients/caregivers, families, and the public and the appropriate diagnosis by health professionals and
- to ensure effective control of asthma by encouraging a partnership among patients/caregivers, physicians, and other health professionals through modern treatment and education programs.

Similarly, the Expert Panel Report of the National Heart, Lung and Blood Institute (NHLBI, 1997) recommended that the focus of asthma education should be on:

- the basic facts about asthma;
- the purpose of medication;
- the technique in the use of inhaler, spacer and holding chamber; self-monitoring;
- environmental control measures when and how to take rescue actions;
- joint development of treatment goals with caregivers and family;
- written daily self-management plan and an action plan for exacerbations;
- encouraging adherence by promoting open communication; adapting, reviewing and adjusting plans as needed and
- emphasis on the goals and outcomes.

Health care providers must therefore be aware that asthma education is the key to effective asthma treatment, not only for the patient but for everyone involved in the patient's life (NHLBI, 1997). To accomplish these programme goals, health care providers must ensure that caregivers understand the presence of the asthma signs and symptoms, since the need for emergency acute asthma care is usually due to an inadequate treatment programme or an incomplete understanding of asthma (NHLBI, 1997). .

Subtheme 1.5 The simplified comprehensive education session promoted the caregiver's willingness to learn more

One participant reported: “The [medical] terms they use were fine [understandable], but they [nurses/doctors] were specific, everything they tell to you, they bring it to your level of understanding.”

Some participants' verbalised feelings of enjoyment: “Their attitude was very nice and I had to go twice for the education due to changing of the pumps and any question I had they would explain to me.” Zepeda, Varela and Morales (2004) support this statement, stating that caregivers who receive a more intensive intervention have greater benefits. It is important that individual asthma education programmes meet the parents' needs, build the strengths of the caregivers and promote parental empowerment and self-confidence.

Another participant reported: “The thing I like the most is the way they explain the whole asthma education and the practical part of it.” This supports the idea that partnership is an important goal of patient-centredness and that continuous communication leads to positive reward for both the caregivers and the health care provider (Bauman, Fardy & Harris, 2003).

A Columbian researcher, Sally Findley (2011), provided the ABC (Asthma Basics for Children) Program which suggests multiple opportunities for caregivers to learn about asthma signs and triggers in the asthmatic child. This multi-level intervention promoted caregivers' participation by offering them flexible workshop scheduling, and added a provider-education component to improve communication between caregivers and nurses. After participating in the programme, caregiver reports indicated that 89% found it easier to talk to their doctor and 80% said they were confident in their ability to manage their child's asthma. In the group which did not participate in the programme, only 31% had taken at least one step toward

reducing triggers; 49% reported that talking to their child's doctor was easier and 49% expressed confidence in managing their child's asthma.

This strategy strengthens the communication skills of caregivers and improves the asthmatic child's health while the health care provider has contributed to the changes in their asthma management behaviours, improved confidence, and improved asthma control.

The effective management of asthma requires the development of a partnership between the caregivers and the healthcare provider. The aim of this partnership is to enable the caregivers to gain the knowledge, confidence and skills in the management of the asthma. The partnership is formed and strengthened as caregivers and their healthcare provider discuss and agree on the goals of treatment, develop a personalised, written self-management action plan including self-monitoring, and periodically review the asthmatic child's treatment and level of asthma control. The follow-up consultations should also include checking adherence/compliance to the medication plan and recommendations for reducing exposure to risk factors (Bateman, Hurd, Barnes, Bousquet, Drazeni, Gerald, Gibson, Ohta, Byrne, Pedersen, Pizzchini, Sullivan, Wenzel & Zar, 2008). This is supported by the following participants' reports:

The participants reported that, to clear up misunderstandings, they asked questions: "You know all the people are different and if I don't understand I will ask." "I would tell her I don't understand, please explain. They were very friendly, calm and collected."

Another participant verbalised how she appreciated the clarification to questions she asked: "No, they explain each and every word to me." "Yes, I always ask questions, that's why I always say Red Cross Hospital (asthma staff) is a very good hospital."

These statements are in line with a study done by Bryant-Stephen and Li (2004), that contends that asthma education is not only about acquiring knowledge, but also involves the ability to retain the knowledge learned for effective daily application.

The two-way communication process was displayed during the asthma education session. The participants reported how they were allowed to communicate freely: “It wasn’t so that they would tell you listen and you must just listen.” The other participant reported not feeling intimidated at all: “It was not as if they were dictating to you.” “It was okay, if I didn’t understand any word I would have asked them and they would have explained it to me.” This is in line with a study, conducted by Trollvik and Severinsson (2005) which found that it is important for the caregivers to know the process of understanding the child’s disease and make sure that the parents are active asking questions about the asthma, because insight and attitudes is not learned by the one-way conversation.

Self-determination theory goes hand in hand with patient-centredness (Williams, Frankel, Campbell & Deci, 2000), and it stipulates that a caregiver’s behaviour will determine his/her willingness to learn and determine their adherence to asthma education guidelines (Deci & Ryan, 2002). Social cognitive theory stipulates that caregivers will be able to exercise asthma control if they have knowledge of health risks and the benefits of the asthma education.

Through this, the principle of self-efficacy will be achieved (Bandura, 1986).

Optimal asthma management can be achieved by educating the caregivers and their families to make lifestyle changes and adhere to drug therapy for long periods even when the asthmatic child is symptom-free. However, any parental misconceptions should be addressed by adequate education, which is essential for better asthma control (Zaraket, Al-Tannir, Abdulhak, Shatila & Lababidi, 2011).

Subtheme 1.6 Caregivers understood the need to make changes / adjustments at home to reduce the asthma exacerbations

After the participants received the asthma education, they reported that they made the necessary changes at home to reduce the asthma exacerbations.

The following statements reflect how the participants make the necessary adjustments at home: The participants reported how they got rid of their pets at home:

"The cat we gave it away, we did have a hamster and she got sick, we got rid of it." "They say the cats dogs not allowed." The self-determination theory refers to the caregivers self-regulation of the asthma condition, when they eliminate or limit the exposure to asthma triggers e.g. smoking, dust, warm blooded animals, and give the asthma child prescribed medication (Ryan &Deci, 2002).

Even the asthmatic child's eating habits were adjusted, to prevent unnecessary allergies: "She must not eat a lot of luxuries." "For example the big bompies [ice lollies in a plastic wrapping], she's not allowed to eat it because it triggers her allergies, actually not only the asthma she got bad allergies."

Participants were prepared to do regular cleaning at home. "I had the carpets and I had to take all the carpets out and now I only got ceramic tiles in my place. The mattress to be put in the sun, but in winter it is a bit hard. Change bedding regularly, change bedding and mop the floors."

Another participant realised the importance of removing triggers at home: "Yes, kind of like when they said I must remove things at home, which I didn't do before e.g. vacuum the mattress."

These changes was also suggested by Bateman, et al. (2008), because an asthma exacerbations may be caused by a variety of factors, sometimes referred to as “triggers”, including allergens, viral infections, pollutants and drugs. Reducing an asthma child’s exposure to some of these categories of risk factors (e.g. smoking cessation, reducing exposure to second-hand smoke, reducing or eliminating exposure to occupational agents known to cause symptoms and avoiding foods/additives/drugs known to cause symptoms) improves the control of asthma and reduces medication needs. Therefore, medications to maintain asthma control have an important role because asthmatic children are often less sensitive to these risk factors when their asthma is under good control. Caregivers should be encouraged by the health care provider to implement environmental control measures, such as avoiding exposure to tobacco smoke in the home or car, dust control, and having no warm-blooded pets in the home (NHLBI, 2003).

The patient-centred model emphasizes the importance of a partnership between patient and the health care professional (Speechly, Rimver and Hodson, 1992).

Subtheme 1.7 Caregivers were prepared to teach all involved in asthma care at home

Participants’ family members were prepared to make changes as illustrated in the following statements: “My husband needs to smoke outside.” “I would say the smoking, because my brother smokes.” This in line with Gauderman’s study, conducted in 2006, that concluded that unhealthy environmental factors (i.e., air pollution, smoking) increase childhood asthma morbidity, and it is imperative to identify factors that may protect asthmatic children from asthma triggers. Most caregivers adopted indoor environmental changes in their households to avoid an asthma episode or symptoms, and this awareness was attributed to physician care and education made available to caregivers (Valerio, Cabana, White, Heidmann, Brown& Bratton, 2006).

The family-centred theory stipulates that family involvement is the primary source of strength and support in the asthma care and management (MacKean, Thurston & Scott, 2005).

In this regard, some participants reported they experienced difficulty to implement these changes at home: “Oh, the dogs and cats, it is my neighbours’ dogs and the fence is open and we cannot stop the dogs from coming into our yard.” “We got these huge plants inside and I’ve heard that they are not good for him, but I can’t throw them away because they are not mine.” Although caregivers have learned methods to prevent the environmental triggers, they continued to experience situations that were beyond their control, like neighbours’ dogs (Valerio, et al, 2006).

When getting the history of the asthmatic child, factors in the home or external environment that precipitate symptoms of asthma must be identified. Knowledge of these triggers forms a very important component of asthma treatment and management. (O’Pray, 2007).

According to social cognitive theory, the environmental factors (at home) do plays a role in the caregivers decision-making and may have a positive or negative effect on a person’s behaviour (Benight&Bandura, 2004).

Asthma is a medical condition defined by the National Heart, Lung and Blood Institute (1997) as an inflammation that narrows the airway and results in wheezing, coughing and difficulty breathing. Inflamed airways are the cause of sensitivity to breathing in irritants like pollen or chemical-based cleaners. The inflammation is characterized by hyper-responsive airways that narrow easily when triggered by a stimulus. The airway lining swells from the inflammation and mucus becomes thick and sticky. The inflammation and subsequent narrowing and swelling of the airways result in symptoms which keep on recurring. Symptoms of asthma are just the tip of the iceberg. Airway inflammation is the underlying cause of asthma symptoms (Green, 2004).

Not all the asthmatic children have the same triggers, which is why it is so important for teachers, parents and children to know what their triggers are and how to avoid them (Green, 2007).

One of the primary goals in the management of asthma is to minimize or prevent the risk of future exacerbations and, by preventing an exacerbation, reduce the social and financial burden of asthma (Jackson, 2011).

The parent-centred practice and the self-determination theory also imply that caregivers must be prepared for the preventative treatment plans, including obtaining and administering the asthma medication. (Haltermann, Borelli, Conn, Tremblay & Blaakman, 2010).

According to National Ag Safety Database (2004) caregivers should be aware of the unique triggers that are present at their homes e.g. wood smoke, fertilizers, pollen from crops and weeds, and chemicals, as well as areas high in mould such as feed and storage facilities.

Caregivers should be prepared to take the steps to avoid exposing asthmatic children to these unique triggers by:-

- learning what triggers attacks for your child
- avoiding triggers that bring on attacks, such as cigarette smoke, diesel exhaust and fertilizers
- limiting work and play outside when air pollution and pollen levels are high
- keeping asthmatic children away from farm areas high in mould irritants– storage areas, feed mixing work areas, hay, etc.
- not using a wood-burning stove, kerosene heater, or fireplace, if possible.

An understanding and avoidance of the triggers of asthma (e.g. exercise, viral respiratory infections, irritants, allergens, some drugs and chemicals, and cold air) may allow the

asthmatic child to live a normal life while reducing medicine intake. Therefore, a comprehensive asthma education should describe possible triggers and explain to the caregiver how to avoid or prevent them (Plaut, 2005).

According to the United Nation Education Scientific and Cultural Organisation (UNESCO, 2003), a “learning-friendly” environment means placing the caregivers firmly at the centre of the learning process. A learning-friendly environment is one in which caregivers benefit not only from learning by themselves, but also from the learning of others whose needs are also taken into consideration. A learning-friendly environment empowers them to learn, use and adapt to new asthma management and education methods. Caregivers can also learn to how to deal better with their asthmatic child at home by using techniques that the health care provider taught them in the asthma education.

1.5 A friendly learning environment promoted learning.



Subtheme 1.8 A friendly learning environment promoted learning

Participants expressed that the health care provider provided a friendly learning environment for them to learn and make the understanding of the asthma education easy for them. The following statements are the reflections of the positive attitude of the health care providers: “They were friendly, and nice, and that is what I need and when his lungs collapse, they help me.” “Their attitude was very nice.” Yes, well the doctor she gets is a very good doctor. They are very nice and all the other doctors are okay.”

“Doctor will always explain everything to you. They are they are nice, they always treat him nice.”

This is in line with the NHLIBI (1995) recommendations, that the asthma education must be brief and simple and a few key points should be emphasized, e.g. patient education, and should include simple explanations of the asthma condition, should raise

expectations of a normal, active life but should also point out that asthma episodes can be fatal if the disease is not kept under control.

Partnership and a good understanding between the caregivers and the health care provider are also the core functions of the patient-centred theory, because asthma care is long-term, requiring on-going treatment support (Speechly, et al., 1992).

The following statements reflect how simplified the education was and how it improved the participants' understanding of asthma:

“The way they explained it was very good.” “It was okay, if I didn't understand any word I would have asked them and they will explain it to me. I ask them to put it in lame [simplified] terms, because if I don't understand I would not be able to teach the others at home. That why I must I understand.” “They are very helpful and talk in the manner that you would understand, and it was not difficult for me grasp, what they were saying.” “They were always been supportive and would explain every little detail to me.” The asthma outcomes improved when the health care providers were taught to provide simple messages combined with basic communication and counselling strategies. This was important not merely to educate caregivers, but also to discover and address their specific concerns and confirm that they do share common goals and to tailor the management plan to the caregivers of asthmatic children (Trollvik&Severinsson, 2005).

Social cognitive theory supports these statements. If caregivers have sufficient knowledge of the asthma management /education, they will be able to help their asthmatic child effectively (Bandura, 1986).

The health care provider can empower caregivers and their families with the knowledge, skills, and confidence and teach caregivers how to control their child's asthma. The way the

health care provider communicates with the caregivers and families will influence how well they follow the treatment plan. No matter where health care providers interact with caregivers, the four Rs—reach agreement, rehearse, repeat, reinforce—are the basis for patient self-management education and should occur at all points of asthma education. (Trollvik&Severinsson, 2005).

The participants verbalised that they valued the asthma education and that the process was simplified and they were eager to search for more asthma information by networking. The following statement illustrates it: “Yes, the asthma education helps, but I took a step further to learn more and find things out for myself.” Well, they gave me all the information, but I had to take an extra step to go learn more, in order to help my child better.”

“Yes, I did and wanted to help my child. I went also to do research on the internet.”

The self-determination theory emphasizes the importance of being self-determined and self-motivated to learn; and to adhering to the prescribed guidelines/medication. The behaviour change and willingness to learn more will ensure that the asthmatic child will be managed effectively (Deci& Ryan, 2002).

A participant saw the asthma education as an opportunity to help others: “It was useful [asthma education] and I feel it helped me a lot and the more they can teach me the better, and with that knowledge I may help not only him, but also somebody else that has asthma.”

These willing to learn more statements are signs of self-determination, as describe in the self-determination theory (Deci& Ryan, 2002).

A participant declared that she will share asthma information with everybody involved in the asthmatic child’s care and management: “At the crèche the teachers know how to use the pump. Yes, whenever I hear there is a new teacher will go and show them how to use the

pump.” “I will ask them to put it in lame [simplified] terms, because if I don’t understand I will not be able to teach the others at home. That is why I must I understand.” This statement is in line with a study conducted by Trollvik and Severinsson (2005) that shows that it is imperative for caregivers to share all information about their child's asthma condition with family members, parents of friend, teachers, and anyone who may be caring for the child. Caregivers and the child care providers should work together to provide feedback to health care providers. Shared asthma care is one of the principles of family-centred theory, because the child must be treated in conjunction with the family (Dunst&Trivette, 1994).

Theme 2: The need for regular, continuous asthma education still exists

Regular asthma education and evaluation of the caregivers’ knowledge and understanding about childhood asthma should be performed in order to achieve effective management of the patient (Prapphal, Laosunthara,Deerojanawong&Sritippayawan, 2007).

However, the process of asthma management occurs on a continuum that is experiential and developmental for mothers and children, and it directly reflect how the family defines the situation they are seeking control. Given this understanding, health care professional need to provide advice that acknowledges the family’s own perspective about what it means to be in control of the child’s asthma. When this lacks congruence with the health care provider’s definition of asthma control, the family’s expectations need to be addressed effectively to gain adherence to preventive care measures (Buford, 2004).

Subtheme 2.1 Difficult to understand the medical terms used by the health care provider

Health literacy is the ability to read, understand, and act on health care information. Healthy People 2010 define health literacy as “the degree to which individuals have the capacity to

obtain, process, and understand basic health information and services needed to make appropriate health decisions.” A significant impact will be achieved if these management plans are followed and adhered to. Primary health care is also known as first contact with the clients/patients, therefore proper sufficient asthma education can have a positive effect on the morbidity rate of asthma. Therefore, if the level of a caregivers’ knowledge about asthma is unsatisfactory or misconceptions are identified, it implies that there is a need for more regular asthma education.

Participants’ reported that they [health care providers] used medical terms they did not understand: One participant reported: “I didn’t understand the medical terms they used.” Another participant said: “The language [terms] they used was too high.” Whilst other participants reported that these misunderstandings were cleared by asking questions. “I will ask her and she will explain to me.” “Yes, when they used the medical terms, I would think what are they saying now and I will ask questions.” “I didn’t understand any word I” “I will ask her and she will explain to me.” “Yes, when they used use the medical terms, I would think what are they saying now and I will ask questions.” “If I didn’t understand any word I would have asked them [health care provider] and they will explain it to me.” Even the language used by the health care provider caused misconceptions, as reported by a participant. “When they use their own language, and I didn’t understand, I would ask them to explain to me, and put it in lame [simplified] terms.”

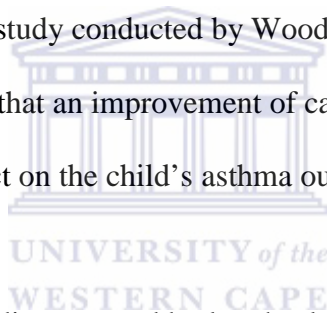
Whereas another participant verbalised no language problem: “I want to know what they are saying, it was in my language, but just now and then there were medical words they use.”

Social cognitive theory does stipulate that each person is an individual, and that their ability to learn depends on their cognitive ability (Bandura, 1986). However, if the caregivers don’t

understand the rationale of the asthma management, poor asthma knowledge may lead to poor compliance to the asthma medication regimen (Wong & Wong, 2001).

A study conducted by Flores (2006) also confirms that, when caregivers are confronted with language barriers, their asthmatic children are exposed to an increased risk of re-visiting the emergency room, and a higher risk of being hospitalised.

Low health literacy levels are a widespread problem which does affect people of all social classes and low income populations (Wolf, Gazmararian &, Baker, 2005). These low health literacy skills are due to a lack of educational opportunity, learning difficulties, or cognitive decline which is increased in older adults (Rogers, Wallace & Weiss, 2006). This view is corroborated by the findings of a study conducted by Wood, Price, Dake, Telljohann and Khuder (2010), which confirmed that an improvement of caregivers' self-efficacy level and health literacy has a positive effect on the child's asthma outcomes.



The confusions and misunderstandings caused by low health literacy levels can be avoided by:

- Giving caregivers information before their appointment to inform them what will take place
- Using less jargon during the consultation
- Asking caregivers questions during the current consultation about details that they might have changed, e.g. Tell me how you use your asthmatic child's asthma inhaler device at home.
- Drawing or giving caregivers some written key words to take home,
- Using pamphlets or pictures to reinforce any key messages caregivers need to remember (Roberts, Ghiassi, Martyn, 2008).

Lara, Rosenbaum, Rachelefsky, Nicholas, Nicholas, Morton, Emont, Branch, Genovese, Vaiana, Smith, Wheeler, Platts-Mills, Clark, Lurie and Weiss (2002) stated that no health condition more than asthma illustrates the extent to which successful control and prevention of illness depends on the existence of a joint enterprise between public health and the individual medical care. The quality and accessibility of the intervention depend on the multi-faceted approach that requires an active involvement of the health care provider and others affecting the lives of the children. This shows that an effective, individualised caregiver-nurse partnership is particularly important for instituting and maintaining efficient asthma management (Papi, Haughney, Virchow, Roche, Palkonen, Price, 2011).

Subtheme 2.2 To enhance communication between the caregivers and health care provider to eliminate confusion and to form a partnership in asthma care

Asthma education should be an integral part of all interactions between health care provider and the caregivers, and is relevant to the asthmatic child of all ages. All individual caregivers require certain core information and skills, but most education must be personalised and given to the person in a number of steps. Social and psychological support may also be required to maintain positive behavioural change with the caregivers (Bateman, et al., 2008).

This view is confirmed by participants who suggested that they would appreciate if the health care provider would communicate with them more frequently:

“More talks will help because some parents are shy and they may ask more questions in a group.” “Give more education for us.”

Continuous, communication and sharing of information are the key elements of the patient-centred theory, and leads to the building-up of a good partnership between the caregivers and health care provider (Bauman, Fardy & Harris, 2003).

According to the National Heart, Lung, and Blood Institute (1997), clinical practice guidelines strongly recommend that health providers should educate caregivers of asthmatic children on self-management. According to asthma education guidelines, parental asthma education is one of the main principles for the management of childhood asthma (Motala, et al., 2009).

A participant supports this, saying: “To communicate to the moms more and to keep them on their feet [make caregivers aware of all the asthma changes] with the changes of asthma.”

The Global Initiative for Asthma (GINA, 2002), in respect of asthma education, aims to provide the caregivers with suitable, adequate information and training so that the asthmatic child can be well-cared for. This aim is in line with the view that it is important to develop educational programs to support caregivers of children suffering from asthma.

One participant felt that frequent educational asthma talks are helpful to caregivers: “The [asthma] education and to communicate more to the moms, what to do. “

The positive beliefs of caregivers were associated with better child health and a fewer asthma symptoms (Wade, Holden, Lynn, Mitchell&Ewart, 2000).

The GINA guideline (2002) also emphasizes the importance of effective communication between health care providers and the caregivers, as this reduces morbidity and is a central point to parental/caregivers’ education when the aim is shared responsibility of the asthmatic child’s care.

Subtheme 2.3 The importance of the caregivers understanding the physiology of the asthma condition

However, the caregivers need to understand the underlying inflammatory mechanisms of asthma and the safety of anti-inflammatory therapy; the importance of adhering to regular inhaled corticosteroid therapy; the importance of preventing exacerbations; the importance of

regular check-ups of the child's asthma which include assessment of lung function; and the right to have a written action plan to use when the asthma becomes uncontrollable or to help maintain optimal control (Gustafsson, Watson, Davis & Rabe, 2006).

In this regard, Zedan, Ezz, Regal, Osman and Fouda, (2010) point out that caregivers' understanding of disease pathology and its management have been associated with greater adherence to the preventative regimen and decreased unscheduled medical visits or hospitalisations.

In the case of an acute asthma attack, contraction of smooth muscle occurs. Hypertrophy of bronchial muscle and then the asthma becomes chronic, and it tends to reduce the size of the bronchial lumen even if the bronchial muscle is relaxed. The underlying mucosa becomes oedematous and is infiltrated by a variety of inflammatory cells. The mast cells, macrophages and leucocytes, in particular eosinophils, are evident in increased numbers both in the mucosa and lying free in the fluid in the bronchi and alveoli. An abundant secretion of mucus occurs, and mucus is abnormally viscous and difficult to cough up. The abundant tenacious, mucosal oedema and spasm of bronchial muscle all contribute to the reduction in the expiratory flow rate which characterizes an acute asthma attack. (D'Arcy & McElnay, 1989).

Asthma is characterized by narrowing of the bronchi caused by:

- swelling of the mucosa;
- an increased amount of sticky mucus or secretions lying in the airways produced by the mucus glands. The swelling and increased secretions are called inflammation; and
- muscles that go into spasm. Spasm occurs only when there is inflammation.

When the bronchi become too narrow or partially obstructed from inflammation and spasm, the typical symptoms of asthma will develop (D'Arcy & McElnay, 1989).

The participants were asked to give a basic explanation of their understanding of what asthma is, and most of them could only basically define what asthma is. They were unable to say what happens to the lungs and why the asthmatic child presents with these symptoms.

The following statements reflect the participants' poor perception of asthma pathophysiology] theory:

“Asthma is when you child’s chest gets tight; she can’t breathe and I think it is the allergies that brings it on.” “He struggles to breathe.”

“It is allergens, the lungs swell up and get smaller, and the child starts to cough.”

“She’s short of breath; coughing and her chest make a noise.”

“Well, it the chest gets tight due to the swelling of the lungs, and then the child starts to cough and have difficulty to breathe.”

“I will make a noise, a wheeze then I know her chest is tight, and normally when her chest is tight her whole chest pulls up. And her on top when her chest is very tight then you can put your finger here in (trachea area), then I will h give her the reliever and let her relax and then and count tell fever and give another puff and if she don’t get better I take her to the hospital.”

“They cough, can’t breathe, lungs swell [bronchioles dilating].”

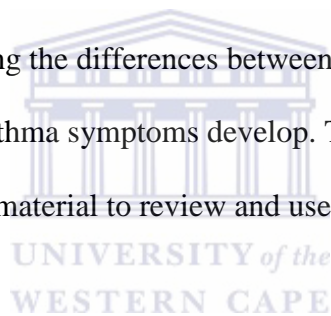
“Yes, I did he would just say he has an infection and his lungs is a bit damage, and some part of the lungs can’t be prepared.”

“He struggle to breath, lungs doesn’t work properly.”

“His chest is tight and he has heavy breathing.”

The patient-centred theory suggests that the health care provider must ask the caregivers question, to determine their level of understanding of the asthma education, because a poor understanding will have a negative impact on their asthma management at home (Pinnock, et al., 2010). A study done supported the theory that it is important to know the caregivers' beliefs and knowledge of asthma care, because it influences the preventative measure of the asthma control (Wong & Wong, 2001).

Asthma education is thus very important. Asthma disease management approaches vary and if the caregivers have the adequate knowledge they will manage their asthmatic child effectively (Brown & Green, 2005). But educating the caregivers cannot be achieved in one encounter; it should be done each time the child is seen for asthma management. Teaching the caregivers begins by explaining the differences between the functioning of normal airways and what occurs when asthma symptoms develop. This information can be given verbally or by supplying reading material to review and use at home (O'Pray, 2007).



Subtheme 2.4 Incorrect use of the inhaler device had a negative effect on the asthmatic child and it increases the asthma morbidity rate

The correct inhaler technique is fundamental for the effective inhaled therapy. Applying the incorrect inhaler technique can impact drug delivery to the lungs and compromise bronchodilation in the short term and asthma control in the long term, depending on the drug.

Evidence from a preliminary study suggests that repeating instructions on inhaler technique improves the client's adherence to therapy and asthma outcomes. The key challenge for nursing practice is the training of caregivers of the asthmatic children the correct inhaler technique (Papi, Haughney, Virchow, Roche, Palkonen & Price, 2011). Participants reported how the health care provider taught them the correct use of the asthma inhaler device:

“I learned stuff I never knew before; they show me the right way how to use the pumps, and the preventer and so on.”

“I did everything they told me to do and how to give the pumps and his treatments [medication use].” Giving new information and readiness to learn are the concepts defined in the patient-centred- and self-determination theory (Williams, et al., 2000).

The other participants reported that their asthma inhaler technique was corrected: “Before I did not use the pump correctly, but now we know; they have always been supportive and would explain every little detail to me”. “Yes, the doctor showed me how to use the pumps, the mask. He also checks if I do it right.”

Another participant acknowledged how the correct use of the asthma inhaler device improved her asthmatic child’s condition. “When I gave him the pump as I was told, he [asthmatic child] gets better”. The caregivers are motivated to learn and realise the importance of implementation and adherence to the asthma education guidelines without being pressurised by the health care provider to change. This is called integrated regulation of the patient-centredness (Deci& Ryan, 2002).

The participants were ask to demonstrate how they use their asthmatic child’s inhaler device and then they realised the sequence of the use of the inhaler device was incorrect and the health care provider taught the correct technique.

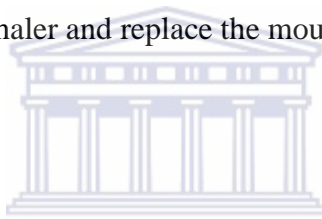
The National Asthma Council in Australia proposes basic steps for using the inhaler:

Getting ready

1. First assemble your Spacer by lining the notch of the one half with the slot of the other half. Then, push the two parts firmly together.
2. Remove the mouth piece cover from the inhaler and check that the mouth piece is clean.

3. Shake the inhaler well.
4. Fit the inhaler into the slot opposite the mouth piece.
5. Hold the Spacer as shown .Breathe out slowly.
6. Close your lips firmly around the mouthpiece as shown, do not bite.
7. Press the inhaler to release a dose medicine into the chamber. Then, breathe in steadily through your mouth.
8. Remove the Spacer from your mouth and hold your breath for 10 seconds, or for as long as you're comfortable. Breathe out slowly.
9. If a second dose is required keep the inhaler upright and wait for a minute. Then repeat steps 3-8.
10. After use, remove the inhaler and replace the mouth piece cover

(National Asthma Council, 2008).



This caregiver acknowledges her poor control of the asthma inhaler device use. “You must shake the asthma pump you give one puff and she must inhale it only two puffs, and then I count till 10. She’s so fast and then takes another one that’s why I didn’t let her do it herself anymore.”

These following statements illustrate that the caregivers have a good perception of how to use the asthma inhaler device, but their techniques are incorrect. All of them didn’t connect the asthma inhaler with the mask. “In the morning I give the Budeflam, give 2 puffs and we count till ten. But if her chest is tight she will be on my lap and I will give her the asthma pump.”

“I let him stand then he must breath out, I then put the mask and spacer together and put it around his mouth and give him one puff and then count till ten and then he must inhale and then I give him another puff.”

“The budeflam I use morning and night, that is the preventer, and when her chest is tight I will give her the asthavent pump, and her allergy tablet at night. Shake the pump, put it into the spacer and the mask over the nose, give a puff, count till 30 and give the next one again.”

“I shake the pump, give a puff then I count till 10 and give another puff. The Budeflam is the preventer, and I give to him morning and night.” This is line with a study conducted by Kaugars, Klinnert and Bender (2004), because asthma is a chronic disorder that requires daily monitoring and administration of controller therapies for effective treatment, and it was suggested that caregivers must have the ability to manage and cope with chronic stressors that could potentially protect the asthmatic children from the risks associated with asthma.

The following participants did not mention the shaking of the asthma inhaler device, which is an important action, as it is through that action that the medicine is sufficiently delivered to the lungs: “Well they tell me she got asthma and I must give the pumps. I must put the mask in front of the pump with the spacer attached and then give her a puff and then count till 10 and give another puff. I will take the mask and put it in front on the spacer and shake the pump and attached it to the spacer, give her a puff and then count till ten and then give her another puff and ask her to breath in.” However, Wilson (2003) emphases that the asthma medication is generally delivered directly to the lung by specialised inhaler devices and the caregivers need to learn how to use devices/inhaler technique effectively (e.g. by shaking the inhaler prior to use).

According to literature, the level of caregivers’ knowledge concerning the asthma condition had no significant effect on compliance to drug therapy (asthma inhaler device).The caregivers should be educated about the asthmatic child’s inhaler device therapy including how the inhalers act and why you must shake the inhalers that they can make logical

decisions regarding their treatment, since the use of medicinal drugs is not founded on medication knowledge alone but also on lay reasoning and logic (Lumme-Sandt, Hervonen, & Jylha, 2000).

These following statements are in line with the correct use of the asthma inhaler device, and these steps taken will ensure less asthma exacerbations:

“First you have to shake the pumps and attached on the spacer and let breathe in and give a puff and the inhale it then count till ten.”

“I first shake the pump, and connect it to the spacer give him a puff and count till ten, give him another puff and then he must breathe in. I will give him 5 puffs every 15 minutes until his chest cleared up.”

“Put the spacer and the mask together, shake the pump, give a puff, shake the pump again, given another puff and count till 10 at a time. I will give him 2 puffs of budeflam twice a day and one puff of serevent twice a day, which are his preventers, and one puff of the asthavent/ventolin when his chest is tight.”

“Shake pump, give a puff, count till 5. And give another puff, he must breathe in, and then again for 3 times. He sat on my lap and shakes the pump, spray, count till 5 and spray again.”

“I shake it, put the spacer on with the mask, give her one puff, count till 10 and give another puff.”

Social cognitive theory recommends these methods of practical demonstrations and suggests role playing as an important component of skills acquisition and to ensure the correct use of the techniques/skills at home (Bandura, 1986).

Subtheme 2.5 The importance of the shaking of the asthma inhaler device

Regular asthma education and evaluation of the caregivers' knowledge and understanding of childhood asthma should be performed, in order to achieve effective management of the patients/asthmatic children. To improve the knowledge of asthma amongst caregivers, the baseline of the knowledge must first be disclosed (Prapphal, Laosunthara, Deerojanawong&Sritippayawan, 2007).

When the participants were asked why they shake the inhaler device, most of the caregivers didn't why they shake the inhaler device, only that they were told to do so.

The participants reported the following: "No, they did not tell us why we must shake the pumps." "I don't know."

Other participants had a vague idea of why they had to shake the asthma inhaler device, and reported the following: "Because the medication divides, so the medication can mix, and the medication will come out better."

Some of the participants didn't reply to the question asked.

The effective supply of medication and appropriate prescribing is worth nothing if the actual delivery of the medication to the lungs is poor. That is why health care providers must educate the caregivers on how to use their asthmatic child's delivery devices. Even local studies have confirmed poor inhaler techniques among caregivers with asthmatic children and this contributes to poor deposition of medication and poor control (Mash, et al., 2009).

Subtheme 2.6 Regular asthma education and inhaler device technique checks are important

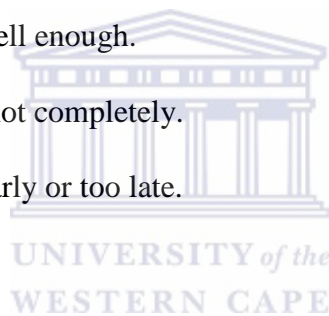
The aspects of disease management that are important to asthma include knowledge of the disease, its treatment, and the effective use of different therapies. Healthcare providers play a

crucial role in empowering caregivers with the necessary skills and knowledge to manage their child's asthma (Franks, Burton & Simpson, 2005).

However, it is imperative for the health care provider to assess the caregivers' perception and the child's asthma control on each visit, because regular, continuous asthma assessment enhanced both health care provider and caregivers' understanding of the asthma control (Carrlton, Thompson, wan, Conboy-Ellis &Coates, 2010).

The common mistakes with the use of the asthma inhalers devices are:-

- Not shaking the inhaler well enough.
- Breathing out too fast or not completely.
- Pressing the inhaler too early or too late.
- Breathing in too fast.
- Using an empty inhaler



An asthma inhaler device must be checked to see if there is still medicine in it. This can be done by shaking the inhaler. If there is still medicine in it you will hear it (National Asthma Council Australia 2008).

Therefore, must the inhaler technique be rechecked and education given on a regular basis, to the correct technique, as inhaler technique deteriorates again after education. The inhaler technique education is best delivered by verbal instructions and physical demonstration of the technique by a skilled health care provider, either face to face or by video. Through demonstrating the steps can also help overcome language barriers (National Asthma Council Australia, 2008).

Subtheme 2.7 The irregular use of the asthma inhaler device had a negative effect on the asthma care

A participant verbalised/acknowledged that she once forgets to give her child prescribed medication: “Yes, I forget once.” Literature confirms that forgetfulness is the major reason for non-adherence (Sladder, Reddel&Bosnic-Anticevich, 2002).

The compliance to medication is one of the important key elements of patient-centredness and self-determination theory. The caregivers’ willingness to change and to comply is important for the asthma management (Haltermann, et al., 2010). It is a challenge for health care providers to motivate caregivers’ to give preventive medication when the asthmatic child is asymptomatic (Anarella, Roohan&Balistreri, 2004).

Participants reported that if they don’t give their asthmatic children’s inhaler device, then her child will get sick. “No otherwise he will get sick.” This statement is in line with the health belief model, when the caregivers realise the importance of giving the prescribed medication and that the asthma exacerbations has a negative effect on the child’s health (Becker, Radius, Rosenstock, 1978).

Non-adherence can takes many forms; caregivers fail to attend appointments; fail to follow prescriptions; miss doses of medication; or fail to use their inhalation device correctly. The incorrect use of an asthma device may be accidental. Sub-optimal adherence has been shown to result in poor asthma control, an increased risk of hospital admission, and increase asthma morbidity (Burgess, Sly &Devadason, 2011).

However, non-compliance is a major obstacle to the effective delivery of health care. The World Health Organisation (2006) estimated that only about 50% of patients with chronic diseases living in developed countries do follow the recommended treatments. The low rates of adherence to asthma management and treatments are thought to contribute substantially to

the human and economic burden. The major barriers to compliance are thought to include the complexity of modern medication regimens, poor "health literacy" and a lack of comprehension of treatment benefits, the occurrence of un-discussed side effects, the cost of prescription medicine, and poor communication or lack of trust between the caregivers and the health-care provider.

Theme 3: Difficulties experienced with the asthma care and management

Caring for the asthmatic child does not only involve all the regular parenting tasks, but also tasks such as filling prescriptions, paying careful attention to household cleaning and avoiding environmental triggers, and remembering to take medications. The aspect in asthma and of itself may not be burdensome, it is the tedious and repetitive aspects of management that can be burdensome and set the stage for a negative emotional climate (Fischer & Weihs, 2000).

However, children and their families must live with asthma and deal with the consequences of asthma on a daily basis. Family emotional climate and parent-child relatedness may also contribute to asthma paediatric severity (Wood et al., 2006).

Subtheme 3.1 Caregivers experience financial difficulties

Caregivers of asthmatic children face a special challenge in protecting and promoting their children's health (Lovell, 2008). Caregivers with asthmatic children may experience financial strain and this can affect the family (Sorgen, 2010).

A participant verbalised that she experienced financial difficulty in trying to attend the monthly follow-up appointments: "Oh, financially it is a problem, because I am not working at the moment, and he had to come to the doctor a lot, and when he [asthmatic child] comes to see the doctor it is a lot of petrol money and I did talk to the doctor before. At times I can't

make the appointment, because my husband is the only one working and financially it is tight [difficult]. I am his mother now and I feel I have to look after him. And I phoned to say I can't come due to money problem. She does understand me and give me two months' supply of his medication. Man, actually doctor wants to see him every month and I will listen what she says today. And I will discuss our finances." The patient-centred theory does stipulate that asthma care is a shared responsibility and the caregiver must share his/her difficulties (financial problems), that may hamper the asthmatic child wellness (Pinnock, et al., 2010).

Winthrop (2005) also confirms that unemployment and financial stress has an overall negative economic impact on the family of the asthmatic child care. Other literature sources confirmed that the cost of effective precautionary interventions is important to consider, but it does affect the low income family negatively and caregivers find the maintenance of this preventative measure difficult and cost-effective (Wu & Takaro, 2007).

The rest of the participants didn't experience financial difficulties, because they received financial support from their families.

Family income is strongly associated with the asthmatic children's health. However, numerous studies have indicated that deterioration in finances or a job loss may be due to the child's chronic illness (Montgomery, Oliver, Reisner, & Fallat, 2002).

Subtheme 3.2 According to the demographic data collected, most of the caregivers were single, unemployed and these factors may lead to poor asthma care and management

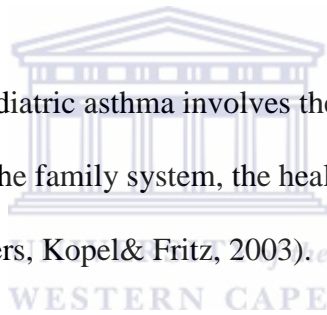
According to the participants demographics, twelve (12) of the eighteen (18) were single and unemployed, and this might be factors contributing to poor asthma care and management.

The low household incomes and limited finances can result in increased caregiver risk for negative outcomes, particularly the out-of-pocket costs for the child's asthma care.

Caregivers who are unemployed or have low incomes may experience more distress, because they may have fewer resources to meet asthma care needs and demands. Overall, financial concerns cause particular distress for caregivers during long-term asthma treatment, as their resources become depleted, whereas higher income families, with better financial resources to purchase the asthma care needs, might not become as distressed or burdened as those caregivers with limited finance. The caregivers' financial burden and depressive symptoms commonly has a most negative outcome on asthma care (Reinhard, Given, Petlick& Bemis, 2003).

Subtheme 3.3 Asthma management and care must be given to staff at the day centers (e.g. school, crèches).

The effective management of paediatric asthma involves the successful integration of multiple care systems, including the family system, the health care system, day care centres and the schools (McQuaid, Walders, Kopel& Fritz, 2003).



The school or crèche principal must involve his staff in developing a school asthma management program. An effective program requires a co-operative effort that involves students, parents or guardians, teachers, school staff, and physicians. Many members of the school staff can play a role in maintaining the school's asthma management program, but the principal or school nurse are the most appropriated people to initiate and implement this program (NHLBI, 2003).

When participants were asked about any concerns about the asthma education they verbalised the need for all day care centres (schools) to be educated about asthma.

The participants reported that the day care centres do not have enough knowledge of the asthma care and management.

The following statements illustrated caregivers concerns: “The school is not educated properly to deal with her and to help the parents” “He was in the crèche for 3years and I took him out because he had too much of infections.”

However, the family-centred theory support these statements, because the asthmatic child forms part of a family or a society, and the integration of the child’s care will lead to a well and symptom-free asthmatic child (Dunst, Trivette&Deal, 1988).

Another participant reported how her asthmatic child had to take her asthma injection and the school educator just observed: “She just told me mommy I think I am fine and I think I need that injection now. Her teacher told me, she knew exactly what to do and how to use her pumps and told me that she took her own medication and that she counted till ten and the teacher was actually shocked to see how she can take her own medication.” The National Lung Institute, (2009) recommends that the school educators and staff must work together with caregivers, asthmatic children, and health care providers to minimize risk and to provide a healthy and safe educational environment, because a good health and safety are prerequisites to academic achievement.

In the United States asthma is a leading chronic illness among children and cause of school absenteeism. That is why teachers, day care providers, and educators can help children manage their asthma. The Centres for Disease Control and Prevention (CDC), government and the non-government resources for school personnel planning or maintaining an asthma management program was established. (The National Lung Institute, 2009).

Theme 4: Overwhelming emotions interfered with performing the prescribed interventions

According to literature, having an asthmatic child may lead to difficulties managing behaviour or to emotional problems in the caregiver/parent. Psychological stress may exacerbate vulnerability to asthma symptoms. That is why caregivers/parents need to know how to manage their asthmatic child calmly authoritatively and may need professional guidelines on the way to do this when their child showing symptoms of asthma (Calam, Gregg & Simpson, 2003).

Subtheme 4.1 Caregivers experienced anxieties about helping the asthmatic child.

A participant reported how the health care worker advised her to be calm: “What the doctor told me is to relax, give the asthma pump, and medication when she can’t breathe, I stress and I don’t like it.” “I try to stay calm and help me by giving him the pumps.”

These overwhelming emotions do interfere with performing the prescribed interventions of the asthma management. The health belief model emphasizes the importance of belief and that a positive expectation can avoid negative health conditions (Becker, et al., 1978).

Caregivers do question their ability to help their asthmatic child, because the chronic illness of asthma has the ability to transform the lives of the individual and the caregivers. This transformation process is associated with a process of chronic grief, related to loss of the image of a healthy child, loss of independence, altered social patterns, to changing roles of family members and social networks. This also involves the replacement of pleasurable and productive activities with medical regimes and monitoring systems and the loss of the perceived normal future leads to a state of grieving and powerlessness (Maltby, Kristjanson & Coleman, 2003).

The participants verbalised that they become anxious while helping their asthmatic child when the child has asthma exacerbations. The following statements illustrate how the asthma exacerbations emotionally affected the caregivers: “Well it is hard and for me I am giving the pumps and why doesn’t it help him.” While other participants will burst into tears: “I wanted to burst into tears.” “I feel bad, and I cry.” “I just burst into tears.”

Some of the participants verbalised feelings of uncertainties:

“For me it was for how long he was going to have asthma as asthma is a very danger disease and you never know when it is gonna[going to] happen again.” The participant reported being extra cautious: “I also walk around with his pumps for just in case. I feel bad, and I cry.” This is in line with a study conducted by Barton, Sulaiman, Clarke, and Abramson (2005) which confirms that the caregivers’ had little ideas of coping strategies and when the child presents with the first asthma symptoms, they felt overwhelmed by emotions and lost control of the management of their asthmatic child. Even the health belief model stipulates that the positive health beliefs of caregivers are associated with better child health and a fewer asthma symptoms (Wade, Holden, Lynn, Mitchell & Ewart, 2000).

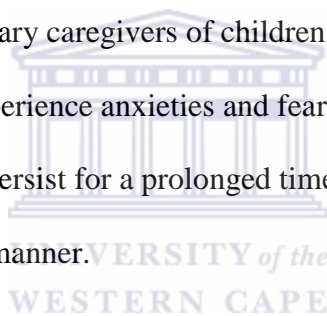
Fear – that feeling you get when you are worried that something bad is going to happen – is an unpleasant emotion or thought. It is the unfounded fear that is within you that is undermining your confidence, and jeopardizing all your real hopes of success. Caregivers fear that their asthmatic child’s condition will be the very worst because they expect the worst to happen, and this fear can almost immobilise some caregivers (Mc Gill & Smith, 2003).

Subtheme 4.2 Caregivers’ emotions had a negative effect on the asthma management

According to the Asthma Care Centre (Castillo, 2006), stress from fear, anger, work or home-related problems can have a significant impact on worsening asthmatic symptoms. In some

rare cases, a psychological illness can somehow be an underlying cause or trigger for recurrent asthmatic symptoms. Severe asthma has an impact on your work, school, family and leisure activities to such an extent that it significantly changes your quality of life. Not only can asthma education increase the knowledge of the caregivers and family but it will also decrease their anxiety (Kallstrom 2004). Some caregivers develop a long-term stress reaction than can destroy healthy primary judgment of the situation (Lazarus & Folkman, 1987).

The participants reported that they experience anxieties when helping their asthmatic child at home. "I'm nervous and I panic and I don't know what is gonna [going to] happen to him." My fears and I know it is fatal. I wouldn't like to get worse." This is in line with a study done by Juniper (2003). The primary caregivers of children with asthma are limited in daily normal daily activities and do experience anxieties and fears due to child's illness, but when feelings of guilt and uncertainty persist for a prolonged time, the parents react to the child's asthma situation in a destructive manner.

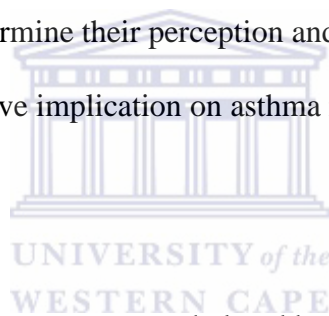


Even though participants experienced these fears, some of them still have hope for their asthmatic child to outgrow the asthma: "My one fear is and I pray that she out grows it. And if she doesn't outgrow it, it will be then on her, because when she gets older and want to take part in sport and that might be a problem. Just hope the severity of asthma will get less [which means less asthma exacerbation]." Literature does confirm these statements that the caregivers of children with asthma have numerous fears and concerns and that caregivers tend to overestimate their child's asthma control and underestimate the asthma's severity, and that this may be related to parental perception of symptoms. Parents' attitudes and beliefs about their child's health influence the use of medication and health care services (Gustafsson, Watson, Davis & Rabe, 2006).

Some participants reported that their fears predicted the worse to happen [the asthmatic child may die]:

“Fear that he may die.” “I may lose him and he may die and that is the worst.” “I don’t lose him when I am not around.” “I thought I am gonna [going to] lose her, and she was very small then. I thought she not gonna [going to] make it.” Literature does confirm this, that the mothers/caregivers’ with high level of depression symptoms show less confidence in their own ability to manage their child’s asthma, as well as a decrease in the asthmatic child’s adherence to the asthma medication regimen (Bartlett, et al., 2004).

The non-verbal data in the transcripts describes their expressions and hand gestures as being anxious and frustrated and sad at times. The health belief model does point out that the health actions of the caregivers will determine their perception and beliefs of the asthma education, and may have a positive or negative implication on asthma management (Becker, et al., 1978).



The participants verbalised that they were overwhelmed by their emotions, which made it difficult for them to help their asthmatic children, as illustrated by the following statements: “It is actually sad; because it is like that I couldn’t take properly care of her.” This is in line with a study conducted by Sales (2008) that found that maternal coping plays an important role in the psychological wellbeing and quality of life of asthmatic children.

Subtheme 4.3 Caregivers expressed experiencing feelings of helplessness when their child has an asthma attack

A study conducted by Trollvik and Severinsson, (2004) described parents/caregivers experiences in four main themes. These are feelings of uncertainty, helplessness and guilt; the need for support and help from health care professionals; adaptations to everyday life;

and development of coping strategies. Parents with subtle forms of guilt can be less open about their guilt because they are embarrassed about those feelings.

Participants verbalised and reflected the point made in the literature in statements such as the following: “I feel helpless and panic.” “I feel useless, and because you feel powerless and even if you try and you can see that things not working.” “I feel useless that moment and everybody is panicking and they didn’t what to do.” “I feel helpless, there’s nothing I can do for her.” “I’m nervous and I panic and I don’t know what going to happen to him. I cried and panic and didn’t know what to do.”

Participants reported trying to stay calm, but that it was difficult for them to do so: “But I learn to stay calm, because a mom’s emotions affect your child and then they get miserable.”

The caregivers often verbalised feelings of nervousness, frustration, anxiety, fear, or anger concerning their child’s asthma. This is in line with a study done by Bartlett, Krishnan, Riekert, Butz, Malveaux and Rand (2004) that caregivers with asthmatic children with high levels of depressive symptoms had a harder time dealing with their asthmatic child and reported that their child’s asthma had a significant impact on their daily lives. They felt helpless about their child’s asthma symptoms, had less confidence in the medication regimens prescribed, and had more difficulty communicating with the health care provider.

Participants reported and confirmed these feeling as described in the literature – feelings of sadness, pain and nervousness – when they have to help their child who is having an asthma exacerbation: “Like I said it is not a nice feeling to see your child suffer and would take his pain any time and he has a lot to live for.”

“I am so nervous, and because I myself had bad asthma and I feel hurt when it happens to him.” “For me I’m not nervous, I just felt heartbroken and I’m stressing, and feel sad.” A review of literature on the topic confirmed the prevalence of statements, that the fear and anxiety become present, and it varies in degrees, from the first asthma attack on, even a

single sneeze or runny nose can send the asthma caregiver into a panic.

Because caregivers do not fully know how to control or prevent symptoms, they feel frighteningly insecure. Besides fear and anxiety, the asthma caregiver may experience guilt. Thus, well-managed asthma is the key to overcoming the fear and confusion that this illness causes the caregivers (Fleming-Carroll, 2004).

Subtheme 4.4 Guilt feelings when helping the asthmatic child had a negative effect on the asthma care

Some participants' reported feelings of guilt when helping their asthmatic child. They confirmed this statement by reporting: "Oh, it is a mother's duty. I just have to do it. At times I just cry." "I don't wish this on my worst enemy, because it 'is not a good sight to see. It was a frightening experience in that you can't help your own child, you got the pumps and it is not helping her." This is in line with a study done by Shalowitz, Mijanovich, Berry, Clark-Kauffman, Quinn and Perez (2006), that caregivers of asthmatic children are shown to have more depressive symptoms (sadness, pain and anxiety) than mothers of well children. Significantly, maternal depression has been associated with increased asthma morbidity and decreased asthma medication adherence (Brown et al., 2006).

Caregivers with high levels of depressive symptoms reported incorrect use of inhalers, less understanding of the purpose of the medications, inconsistent use of medications, more difficulty administering medications, less confidence treating acute asthma symptoms, and were more likely to forget their child's asthma medications (Bartlett et al., 2004).

Therefore, the asthma health care provider working with depressed caregivers must alter their asthma management with an increased follow up through phone calls and regular visits to provide and reinforce asthma education. Education on depression should also be provided, and periodic depression screening should be performed. This will enhance the asthma

management plan for the child and treatment for the caregiver (Pak & Allen, 2012).

Subtheme 4.5 Caregivers expressed experiencing feelings of pain and sadness associated with helping their asthmatic child

The participants verbalised that they find it difficult to control their fears and emotions, which cause them not to manage their child effectively at home.

Some participants panic but refuse help from others. The following statement illustrates this::

“I was stressed, panicked and didn’t want to give my child to someone else.” Other participants panic and don’t know how to manage the asthmatic child effectively:

“There are times when he coughs and his chest gets tight, then the pump does help him and I will give him his tablets. And sometimes nothing helps him and then I feel frustrated, because I can’t help him [asthmatic child]. Then I am very nervous than ever, I don’t know what may happen to him. You hear so a lot of things about asthma and that’s why I must use the nearest day hospital or clinic, and when it comes to that time then it is really tough for me.”

Literature does confirm these statements in which caregivers express low self-efficacy in the execution of asthma management and treatment of their child’s symptoms. The caregiver’s emotions appear to play an important role in the delivery of asthma care. The point is that the situation could be positively affected by a supportive relationship with the health care provider (Valerio, et al., 2006).

Another participant reported the inability to manage their child’s asthma exacerbation alone:

“Especially when I am alone, but when his dad is there then I am calm, because he [dad] knows what to do.”

“Anything may happen and I may lose him. I do stress a lot when his chest gets tight, and I don’t know what lies ahead for me.”

During asthma exacerbation, participants reported that even waiting at the acute care service

appeared to be long: “I feel upset and there was a time that I cried with him, because he couldn’t breathe and the nurses took long to help him.” However, a study by Valerio, Cabana, White, Heidmann, Brown and Bratton (2006) confirms that, if caregivers frequently felt unable to control and manage all circumstances of asthma, caregivers with a low self-efficacy level may not be able to act or trust their capabilities for dealing and caring for their asthmatic child. It was suggested that caregivers require on-going asthma education, with the emphasis on supporting them and developing their confidence regarding their asthma self-management skills.

Subtheme 4.6 Caregivers expressed experiencing feelings of fear when helping their asthmatic child

Some participants even expressed feeling out of control: “I felt helpless, and I didn’t know what to do, I was scared. I felt like I am losing my head.” “I thought I am going to lose my child and I get so angry when her chest starts because I can’t see myself going through this pain again, sitting at hospital and my anger is my way of dealing with something.”

However, all these negative beliefs, fears and behaviours caregivers engage in will subsequently have a negative effect on their asthmatic child’s health outcome (Bandura, 1986). The health belief model stipulates that caregivers must first believe that their asthmatic child is at risk of having an asthma attack, and then the caregiver will see the negative health outcome. At the same time, the caregiver must believe in the benefits of following the asthma education guidelines, that it will minimize their child’s asthma symptoms. Beliefs of personal efficacy play a central role in personal change (Janz & Becker, 1984; Rosenstock, 1974).

Understanding this is crucial, as caregivers are the key link between health care providers and the asthmatic child in that they provide information of their child’s asthma symptoms upon which physicians make their decisions regarding the child’s asthma management and need for

treatment.

Therefore, there is a need for healthcare professionals to emphasize the chronic nature of asthma, but also to negotiate strategies with caregivers to optimise the use of asthma medication, with due consideration being given to caregivers' fears, frustrations and health beliefs (Barton, et al., 2005).

Theme 5: Caregivers displayed overprotective behaviour

An overprotective parenting approach is likely to develop in families with chronically ill children, as asthma management requires intensive medical care, which consequently places a considerable physical, psychological, and social demand on the individuals and families involved (Holmbeck, Coakley, Hommeyer, Shapera & Westhoven, 2002). Parental overprotection has been more recently defined as a level of maternal or paternal protection that is excessive, taking into account the developmental level and abilities of the child and can be regarded as a specific pattern of behaviours whose function is to ensure the safety of the asthmatic child. This usually occurs as a result of the caregivers trying to make sure the child follows the asthma treatment regimen (Holmbeck et al., 2002).

Subtheme 5.1 Caregivers' fears and behaviour hampered the asthmatic child from living a normal life

The emotional responses are the parents' feelings about their child's illness – such as the concern about being overprotective – as well as their feelings about their own lives – such as being bothered because the child's asthma interferes with family relationships (Reichenberg & Broberg, 2005).

Participants expressed fears and would not allow their asthmatic child to play alone with their friends. Participants tried to justify the fear by saying, "... you must remember he's

impulsive and has no sense of danger, that's why I must be strict." Some even try to confirm their reasons by stating that he [the asthmatic child] likes to play alone and "I watch him when he plays."

One participant would not allow her asthmatic child to play at the neighbour's house:

"There are too many things I had to explain to them about his asthma and it is never ending." These interesting statements were supported by literature that showed that some caregivers were reluctant to let their children overnight at friends' homes, because they felt uncomfortable about their child being away from them (Barton, et al., 2005).

Subtheme 5.2 Caregivers verbalised fears of separation from their asthmatic child

Reflecting what is in the literature, participants verbalised their fears around not wanting their child to be away from them, and not being in favour of the asthmatic child sleeping over at a relative's place because, when the child slept over, they couldn't sleep and phoned the relative all the time, only to be told that the child is okay and that they should sleep and get some rest. The next day they get up early, only to find out that the child had slept well and was busy playing. Some of the participants were even prepared to watch and see their asthmatic child play with other kids.

Therefore, the health belief model stipulates that health seeking behaviours are influenced by a person's perception of a threat by a health problem and the value associated with the action aimed at reducing the threat. (Polit&Hungler, 1999).Therefore, before offering asthma education clinicians need to acknowledge and help reduce parental fears so that parents are able to take in new information. The focus of nursing education should include strategies for recognising and reducing parental fears before offering patients education and information. Community partnership can develop to involve interested parents in participating in parental support group (Berg, McConnell, Milam, Galvan, Kotlerman,

Thorne, Jones, Ferdman, Eggleston, Rand, Lewis, Peters & Richardson, 2007).

Theme 6: Positive effect of family support and family involvement

The family does play a vital role in effecting optimal asthma care management and adherence to the asthma treatment. Effective structuring of family routine also plays a role in providing, ensuring and reinforcing a nurturing climate that fosters effective problem-solving (Rhee, Belyea&Brasch, 2010).

Subtheme 6.1 Shared asthma care reduces anxieties within the family and makes asthma care easier

A well-functioning family is more effective in managing or coping with asthma in children and results in a favourable asthma outcome (Rhee, Belyea&Brasch, 2010).

Participants' behaviour supported this literature claim, showing that family involvement in the asthma care and management is an important component which reduced their anxiety levels. The following statement can serve as an illustration of this: "That her son knows how to use it[asthma inhaler device], he gave it to her [asthmatic child],and when she got sick at school, he took her home and looked after her."

Other participants' family members will share the asthma duties by stating; "When she [the asthmatic child] is in hospital my daughter will come and relieve me; my husband and my in laws help me at home; myself and my mother take turns to look after him.

The non-verbal transcript indicated the signs of relief participants felt when they been helped/assisted at home with the asthmatic child. Participants displayed feelings of relief when they had been supported by a family member. The family-centred model explains these statements, by pointing out that the asthmatic child forms part of a family, and when

families are empowered, they feel a sense of control and mastery over their situation, and any form of family support strengthens this sense of control (Dunst&Trivette, 1996).

According to Brazil & Krueger (2002), the effects of childhood asthma is concentrated in the family home and successful family functioning impacts of the asthma management.

The higher the level of family support and involvement the greater the asthma control and quality of life of the asthmatic child, because a family with favourable psychological attributes will be more likely to manifest a well-controlled asthmatic child (Rhee, Belyea&Brasch, 2010).

Subtheme 6.2 Shared asthma care leads to shared responsibility

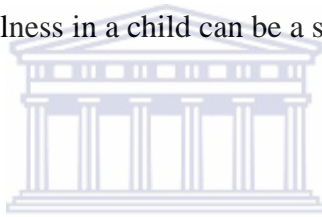
Participants verbalised that they share the asthma care with the other family members, and that it made the task of caring for the asthmatic child, as well as life in general, easier at home and that it also reduced their anxiety levels. The following statements illustrate this:

When the participants were occupied, the other family members will take over and the other participant's: "My dad will help me by giving her [asthmatic child's] the pumps [inhaler device]." "Like my dad is quite good."

The shared family cause a sense of assurance of no worry as reported by the following participants: "Like I said I don't have a problem with the people at home, they knew what to do and what pumps to give to her. "If they with their granny and my sister, I don't need to worry.

Participants were even enlightened by the availability of family members: "My mom will always come help me." "Yes, they tell me sit mommy, we will help you, and they give him medicine." "When I am busy, my mom will take over the cooking and I will see to them and, if my mom is alone, my dad will administer the medication to them." This is in line with a study done by McQuaid, Walders, Kopel, Fritz and Klinnert (2005), which showed that a better asthma management in terms of a better integration of asthma into the family's

daily life, is linked to a more timely response to symptoms, which have all have been associated with decreased asthma morbidity in children. Family cohesiveness has a positive impact on health outcomes and asthma care, and can be more influential than other forms of social support in improving the asthmatic child's health. Even in the case of a small family, such as a single-parent family, asthma outcomes are better when family cohesiveness is high (Mangan, Gerald, Wittich, 2007). Family-centred-care thus involves sharing the asthma care within in the family, on the understanding that the family is the asthmatic child's primary source of strength and support (MacKean, Thurston & Scott, 2005). While parents are responsible for their asthmatic child and cherish the management of the condition, they are simultaneously dependent on others when their child becomes sick as the diagnosis of serious illness in a child can be a shattering experience (Shilling & Young, 2009).



Subtheme 6.3 Poor family involvement leads to an increase in anxiety

Other participants reported feeling stressed when their partner does not help with the asthma care and management, and fulfil his/her duties of care: "He doesn't just have the patience with her. Even when she is by him, he will forget even to give her medication. And I think it's for him too much and he's not interested, and he is there by us he will tell her to come to me for there medication. I told him that he must do his part."

Kaugers and Klinnert (2004) conducted a study that confirmed that the influence of family – in terms of the family being a source of conflict and distress – on asthma care, worsens the asthma, causes poor adherence to medication regimens and worsens the asthma outcomes. Childhood asthma is strongly affected by family factors, including the psychological functioning of the caregiver, the interactions between the caregiver and the

child, and the children's functioning. Some families may be particularly at risk for difficulties in managing asthma due to problems in their family social environment (Repetti, Taylor & Seeman, 2002).

However, the family-centred model emphasises that it is necessary for the health care provider to examine the effects of asthma on each family and tailor management needs around what is known about the family and set appropriate goals for change to improve asthma management and family functioning (Grineski, 2008).

The process of asthma management occurs on a continuum that is experiential and development for mothers and children, and directly reflects how the family defines the situation they are seeking control. Given this understanding, health care professionals need to provide advice that acknowledges the family's own perspective about what it means to be in control of the child's asthma. When the health care provider's advice lacks congruence with the family's definition of asthma control, the family's expectations need to be addressed effectively to gain adherence to preventive care measures (Buford, 2004).

Theme 7: Caregivers need to develop coping skills through support/social groups

Maternal coping plays a role in children's quality of life and psychological well-being in the family coping with childhood asthma. The health care provider must teach the caregivers how to cope with the daily issues of managing with the asthmatic child (Kaugers, Klinnert & Bender, 2004).

Subtheme 7.1 Caregivers need coping skills to manage their asthmatic child effectively

Even though the participants have received the asthma education, they verbalised feelings of panic and stress when helping their asthmatic child. This is an indication of poor coping abilities to managing the asthmatic child.

The family-centred care model recommends facilitating family-to-family support and networking, and providing services that provide emotional and financial support to meet the needs of families (MacKearn, Thurston & Scott, 2005).

Some participants reported that they were not coping, a reality that supported these claims found in the literature: “I was stressed, panicky and didn’t want to give my child to someone else.”, and the other participant: “I will get frustrated, because I struggle to give her the pump [asthma inhaler].”

Another participant even verbalised the inability to handle the asthmatic child alone: “Then I am very nervous than ever, I don’t know what may happen to him and that’s why I must use the nearest day hospital or clinic, so he can have oxygen and when it comes. It gets really tough for me, especially when I am alone.”

Paediatric asthma is a stressful condition for afflicted children – a reality borne out by literature – but it also creates a highly stressful situation for the caregivers of these children. The caregivers’ psychological functioning influences the child’s asthma, but weak psychological functioning of the caregivers is specifically associated with worse asthma outcomes in children (Kaugars, et al., 2004).

Some of the participants verbalised experiencing a feeling of no control when the asthmatic child had an exacerbation: “Anything may happen and I may lose him, I stress when his

chest gets tight, and I don't know what lies ahead for me.” “I feel upset and there was a time that I cried with him, because he couldn't breathe and the nurses took long to help him.” “I felt helpless, and I didn't know what to do, I was scared. I felt like I am losing my head.” “I thought I am going to lose my child or I am being punished for something [self blaming] and I get so angry when her chest starts because I can't see myself going through this pain again, sitting at hospital and my anger is my way of dealing with something.”

This is in line with a study conducted by Sorgen (2010) which suggested that caregivers who are having a tough time coping with their asthmatic child may find it helpful to join a support group where they can share their experiences with other caregivers in similar situations. In addition, Kaugars, Klinnert and Bender (2004) also suggested that caregivers' ability to manage or cope with chronic stressors could potentially not protect children from the risks associated with asthma. Caregivers who used more positive, approach-oriented coping strategies (e.g. active, cognitive, and social support) would have lower anxiety and could provide a higher quality of life for the asthmatic child. Conversely, caregivers who used more avoidance coping would have higher anxiety levels and decrease the quality of life of the asthmatic child.

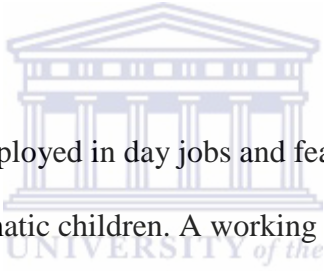
Subtheme 7.2 The need for a social or support group for caregivers to be able to learn from each other

A support group is a group of people with a similar problem or situation who try to work together to get through the hard times together and they and they support each other when the other needs help. A social/support group helps participants share their feelings and learn from other participants. A support group will be a place for them to ventilate their fears and anxieties. Participating in this group provided an important emotional resource. These mothers encouraged each other, validated feelings, and affirmed efforts in

mothering. They empathized with each other's hardships, with a level of understanding that only those who had gone through similar circumstances could provide (Sullivan, 2008).

Participants reported they experienced feelings of fears and panic when they had to help their asthmatic child, and this negative feeling had a negative impact on their asthma management:

The following statements illustrate the participants' feelings of fears: "My worst fear when she had a asthma attack the last time it was so bad, I thought I'm going to lose her, and was prepared to take over her place of suffering." "Whilst the other participant: "It feels like my life is standing still, it's tiring and you never know when it's going to happen."



Some of the participants are employed in day jobs and fear they would not be able to come in time to help their asthmatic children. A working participant shared her experience: "When I got home my asthmatic child couldn't breathe and she was crying. You know I panicked it was really bad, and she was lying in my arms and couldn't do anything. They [nurses] had to help me and they gave me some sugar water and they helped me because that time the pump didn't want to work, because I was using the wrong pump and the dad took her to hospital." This observation is in line with a study conducted by Farmer, Marien, Clark, Sherman and Selva (2004) which suggested that many caregivers may benefit from psychosocial interventions in primary care settings that will enhance their level of social support and promote a more positive appraisal of the impact the asthmatic child has on a family. Knowing that there are others going through similar circumstances can help to reduce feelings of isolation and build a sense of community (Sullivan, 2008).

However, both the patient-centred and self-determination theory highlighted the importance of the health care provider forming a partnership with the caregivers, allowing the caregivers to express their individual problems, fears and frustrations with having to cope with the asthma disease, but first taking psychological and social factors into consideration when providing asthma education to the caregivers (Deci& Ryan, 1985).

Caregivers of children with chronic health conditions were more likely to identify a need for contact with other families experiencing similar life situations for networking, discussion, and for support (Perrin, Lewkowics& Young, 2000).

The Parent of Asthmatic Children (PAC, 2006) support group meetings are designed for caregivers who have asthmatic children. The caregivers listen to a variety of guest speakers and are encouraged to talk to other caregivers with similar concerns and difficulties. Because caregivers with asthmatic children often face a number of challenges that can lead to anxiety, fear or conflict, it is important that they learn to overcome obstacles and challenges, and find ways to work with these in order to maintain a healthy and positive living environment.

PAC meetings help the caregivers accomplish this by offering them:

- Tips on coping and managing childhood asthma.
- Updates on emerging trends in research and treatment.
- Information on new services for asthma patients.
- Opportunities for families to network.

PAC meetings offer an excellent resource and support mechanism for those caregivers with asthmatic children and help them to manage their asthmatic child

and build a healthier atmosphere (Breathe California, 2006).

Higher levels of social support perceived by caregivers lead to more positive child health outcomes. With adequate professional and informal community supports, families may be able to access more resources and function more effectively, thereby promoting the asthmatic child's health and reducing overall family needs (Kazak , Prusak, Mc Sherry, Simms, Beele, Rourke, Alderfer& Lange, 2001).

Therefore, when health care providers provide the asthma education, they should screen the caregivers for depression. A positive screening would indicate a need to educate caregivers about the condition of depression and the impact it could have on the asthmatic child. Health care could then obtain permission to establish contact with a mental health care provider and initiate referral if the need should arise and then collaborate with the mental health care provider if necessary. The discussion of the positive screening should consist of education about depression and the negative effect on the asthma management (Martinez, 2006).

4.4. CONCLUSION

In this chapter, data collected during interviews were analyzed. Themes and sub-themes were identified that described the caregivers' experiences with implementing the asthma education guidelines. A review of literature and the theoretical framework was done to verify whether the findings supported what already known about the topic. The discussion reflected both positive and negative views of the caregivers' experiences and difficulties around the implementation of the education and management of their asthmatic child.

The next chapter summarizes the findings, provides recommendations that are revealed by the findings, and identifies the limitations of and conclusion to the study.



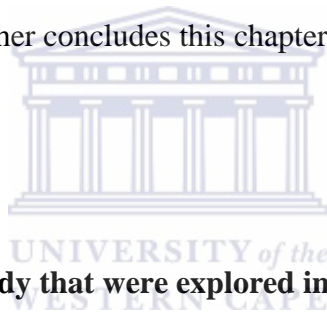
CHAPTER 5

SUMMARY OF RESULTS, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

5.1 INTRODUCTION

The previous chapter dealt with the presentation and discussion of the results and literature control. This chapter will summarise the results of the findings, make recommendations, and discuss the limitations of the study as experienced by the researcher and draw conclusions.

The recommendations are based on the findings and the notable information in the discussion chapter. The researcher concludes this chapter with a conclusive summary.



5.1.1 The objectives of the study that were explored included:

- Exploring the challenges and fears of caregivers living with, and helping young asthmatic children when the first symptoms appear.
- Exploring the participants' views on the user-friendliness of the guidelines (how easy or difficult to implement) for helping the child.
- Establishing participants' understanding of the expectations of them as caregivers.

5.1.2 Summary of the results

The results highlighted that asthma education had a positive effect on the management and care which caregivers provided for their asthmatic child; however,

difficulties with asthma care and management were experienced by some caregivers. Caregivers acknowledged the positive effect of family support and family involvement and the care of the asthmatic child. The need for regular, continuous asthma education still exists, including the need for regular practice and checks on the asthma inhaler technique. It was reported that overwhelming emotions and overprotective behaviour interfered with caregivers' ability to perform the prescribed interventions of the asthma management, confirming the need to develop coping skills through support/social groups.

5.2 RECOMMENDATIONS

The following are the recommendations, based on the findings of this study:

5.2.1 The need for a comprehensive, continuous asthma education programme:

- To ensure that caregivers understand, by offering the programme in simplified terms and in a language that the caregivers are able to understand.
- To exclude possible myths of asthma that may hamper the asthma management.
- To conduct regular checks of the asthma inhaler device technique through role-play and demonstrations of asthma management skills.
- To teach caregivers self-efficacy management and reduce asthma exacerbations.
- To give continuous asthma education at each follow up visit and while caregivers sit in the waiting area e.g. practical demonstration and videos

based on the premise that repetition serves as reinforcement.

- To ensure that the asthma education programme is more user-friendly for the caregivers, such as making it available in the patient's home language.
- To make the asthma education pamphlets available in the languages of the caregivers since language barriers may lead to misconceptions and poor adherence, thus increasing asthma morbidity.

5.2.2 Provide a social support group to:

- support caregivers who have emotional issues / difficulties around asthma management;
- assist caregivers with devising coping mechanisms and coping techniques;
- help dispel unwanted fears and guilt around asthma management from caregivers' minds;
- help caregivers deal with the process of change, adaptation and learning to cope with the asthmatic child's attacks;
- clarify misunderstandings / misconception around asthma care and management;
- allow caregivers to meet each and share their difficulties and experiences;
- facilitate the identification and referral of any caregiver who discloses feelings of depression; and

- give caregivers the opportunity to make suggestions on the asthma education programme.

5.2.3 To establish partnerships with:

- The caregivers through the use of effective communication so as to overcome barriers of asthma education
- Educators at the Day Centres and schools so that the caregivers don't need to stay absent from work to take care of their asthmatic child, because absences from work have financial implication or could lead to a job loss. The asthmatic child should not miss out unnecessarily on his / her daily activities at the centres / school.
- All health care facilities to improve asthma education through a variety of media. The childhood asthma education is not well known to the public, and the participants reported that, while other chronic disease will be discussed at other forums, childhood asthma is not.
- families of asthmatic children, because the family of the asthmatic child plays a vital role in his / her asthma care and management.

5.2.4 Recommendations for further research

Various issues arose from the research and a number of considerations for future research are recommended:

- This study was done at a tertiary level of care. Further research must be done at primary and secondary levels of care.
- Further research should be done to explore health care providers' perceptions

of and difficulties with the implementation of the asthma education guidelines at a facility.

5.3 Limitations of the study

Limited literature was found on this research topic and none were found in the South African context. This meant the researcher had limited information on which to confirm the findings of the study. It is therefore important that the findings of this study be published in both national and international journals.

In South Africa, race is frequently an indicator of economic status, (and thus similar socio-economic backgrounds) care should be exercised when seeking to generalise the finding of their interpretation, therefore cannot be generalised. This study was done at a tertiary institution, which may not reflect the real difficulties at primary or secondary care levels.

Lastly, the study focused on caregivers' experiences around the implementation of the asthma education guidelines and did not include the health care provider's experiences. In light of the understanding that education is a two way process, this is a significant limitation of the study.

5.4 Conclusion

The researcher was impressed to learn how caregivers found elements of the asthma education programme useful. The researcher identified that it is not easy for the caregivers to implement the asthma education guidelines due to their emotional issues and their understanding of asthma education and realises that this should be acknowledged by health care providers.

The asthma morbidity rate will decrease if the caregivers' knowledge of asthma care is improved, positive self-efficacy is developed, feelings of being overwhelmed are decreased, and emotional difficulties stabilised. Childhood asthma can be effectively managed through global asthma education, development of partnerships and by establishing social support groups for caregivers.



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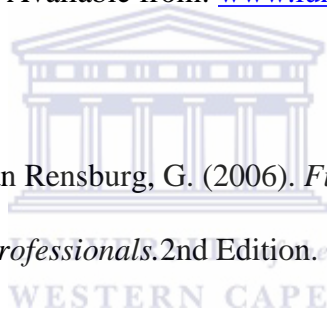
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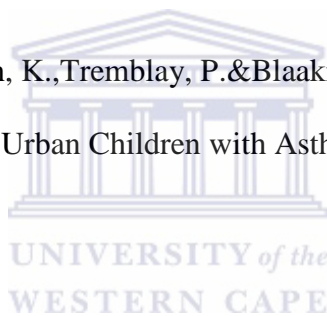
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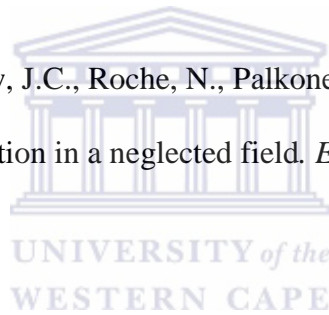
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APPENDICES

Appendix 1

Letter to Red Cross Hospital requesting permission to conduct interviews

Gabieba van Rhyn

No 10 21st Avenue

Elsies River

7490

March 2012

Dear Sir/Madam:

Re: Research Study: Caregivers experiences with implementing asthma education guidelines

I, Gabieba van Rhyn, hereby request permission to conduct research at your facility. Find attached documents of the approved proposal and ethical clearance by the Research Committee at the University of the Western Cape.

I would appreciate consideration of this request.

Thank you.

Yours sincerely,

Gabieba van Rhyn

Appendix 2

**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH
DEVELOPMENT**

Private Bag X17, Bellville 7535
South Africa
Telegraph: UNIBELL
Telephone: +27 21 959-2948/2949
Fax: +27 21 959-3170
Website: www.uwc.ac.za

15 June 2011

To Whom It May Concern

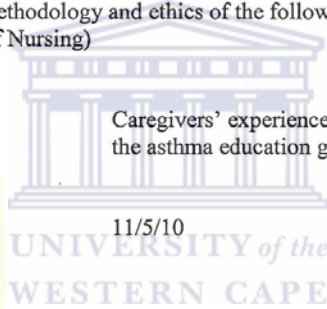
I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Ms G Petersen (School of Nursing)

Research Project: Caregivers' experiences of the implementation of the asthma education guidelines

Registration no: 11/5/10



*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*



**UNIVERSITY of the
WESTERN CAPE**

A place of quality, a place to grow, from hope to action through knowledge

Appendix 3



RED CROSS WAR MEMORIAL CHILDREN'S HOSPITAL

REFERENCE:

thomas.blake@pawc.gov.za

Date: 22 May 2012

MS G VAN RHYN

UWC

REQUEST TO DO RESEARCH

Dear Ms van Rhyn,

Your application to do research at the RCWMCH has been approved. I suggest you approach the Operational Manager in the Asthma Clinic for space to conduct your interviews.

Yours faithfully,

Tommy Blake

Dr. T.A. Blake

MANAGER MEDICAL SERVICES



UNIVERSITY of the
WESTERN CAPE

Appendix 4

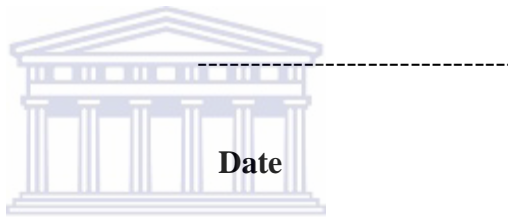
ADDENDUM B

LETTER OF CONSENT FOR INTERVIEW

I the undersigned fully understand the research aims, my rights and the role as participants in the study, as well as issues related to confidentiality.

I hereby express my willingness to participate in this study. I am aware of my rights to withdraw at any time. I also grant the researcher the permission to use the information obtained as part of the research project and to publish the findings as part of research report.

Caregiver's signature



Date

Thank-you for your co-operation and willingness to participate in this study.

Researcher's Contact Details

Gabieba van Rhyn

Study Coordinator's Name: Prof F. Daniels

University of the Western Cape

Private Bag X17, Bellville, 7535

Telephone no: (021) 959 2794

021) 959 2911

Appendix 5

ADDENDUM A

UNIVERSITY OF THE WESTERN CAPE

SCHOOL OF NURSING

SEM-STRUCTURED INTERVIEW

QUESTIONS	PROBES
1. What is the relationship with your asthmatic child?	
2. Are you employed?	
3. Does your child who suffers from asthma attend school/crèche?	If so what is your concerns or challenges regarding the fact that your child goes to school/crèche?
4. Who is the main caregiver of the asthmatic child?	
5. Who else is involved in the asthmatic child care?	How or to what extend are they involved? How did they learn what to do to when the child has an asthma attack? Who taught them?
6. Have you attend an asthma education programme at the clinic/	If so, were you in a group or were you alone with the nurse or doctor?
7. How useful was the information?	Explain?
8. Tell me your experience about the way the nurse explained the asthma guidelines	In terms of the language, level of communications, audio-visual material,

to you?	nurse attitude. What did you like most about the asthma education programme? What did you least like about the education programme?
9. What did you learn about asthma from the nurse?	Elaborate?
10. What is your experience of living and helping an asthmatic child? Tell me the story of from the beginning your experience up to this day?	How does it affect the family? Are the family members willing to help? What extra precautions you take to care for the child? How does it affect your routine, if at all? Are you able to leave your asthma child with someone if you need to go somewhere? If not, why not?
11. What are your fears about your child having this condition?	Give me examples of the times when you experience these fears? Elaborate?
12. What causes your child asthma attack?	What makes it worse?
13. What did the nurse or doctor teach you about managing your child's asthma attack?	Explore the understanding of the steps: how many puffs? Why must you shake the pump? How must the child breathe when you give the pump?
14. Do you give the medication as prescribed by the health care provider?	
15. Describe the occasions when you were	If so, what were the reasons?

unable to give your child his/her asthma education?	
16. How do you feel while helping your child who having asthma?	What goes through your mind?
17. What are your challenges and fears relating to helping the child when first asthma symptoms observed?	Explore the examples of incidence of challenges and fears.
18. Have you or the person who cares for your child always been able to successfully help your child when she /he have an asthma attack?	If not why were you unsuccessful? How did it make you feel? How did you manage the situation?
19. How often do you need to take your child to the emergency unit for help?	Why do you need to take your child to the clinic?
20. What questions would you like to ask about the asthma education?	
21. How can the staff improve the asthma education programme?	Explain?
22. What do you think nurses can do to ensure that caregivers use the guidelines as prescribed?	Explain?

Appendix 6

DECLARATION OF EDITORIAL PROFICIENCY

TO WHOM IT MAY CONCERN:

This serves to attest that I, Nigel van Ster, (*undersigned*) have subjected to editorial scrutiny a complete thesis submitted to me by Ms Gabieba van Rhyne, a student at the University of the Western Cape, said thesis being a study aimed at exploring the caregivers of asthmatic children's experiences around the implementation of asthma education guidelines. The question Ms van Rhyne's research aims to answer is "How do caregivers of asthmatic children experience the implementation of the guidelines for preventing an asthma attack?"

SIGNED:



**PROFESSIONAL
CAPACITY:**

UNIVERSITY of the
WESTERN CAPE
Senior Hansard Editor, Parliament of South Africa

DATE:

13 May 2013

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