

# Experiences of the relationship between adolescents with asthma and their parents

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## FOREWORD

This dissertation is presented in article format in accordance with the guidelines set out in the **Manual for Postgraduate Studies, 2010 of the North-West University**. The technical editing was done according to the guidelines and requirements set out in Chapter Two of the Manual. The Harvard referencing style was used in Sections A and C, whereas Section B followed the APA referencing style.

The article will be submitted to the *Qualitative Health Research Journal*. The guidelines for the submission to the journal are attached in Addendum 6.

## DECLARATION

I, Marike J. Rossouw, declare herewith that the dissertation entitled:

**Experiences of the relationship between adolescents with asthma and their parents,** which I herewith submit to the North-West University: Potchefstroom Campus is my own work and that all references used or quoted were indicated and acknowledged.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

M. J. Rossouw

Editor's confirmation, signature and contact details

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## **SUMMARY**

**KEY TERMS: adolescents; asthma; chronic illness; family; intergenerational relationships; parents**

This study focuses on the experiences of the relationship between adolescents with asthma and their parents. Even though asthma has been described as the most common chronic illness in adolescence, very little research has been undertaken on the combined impact of asthma on the parent-adolescent relationship. The goal of this study was to explore and describe how adolescents with asthma and their parents experience their relationships with each other. The research was conducted from a qualitative research approach and followed a case study design. This allowed the researcher to develop an understanding of the meaning that the participants gave to their life experiences. A total of four families consisting of one adolescent and two parents each was purposefully selected and obtained with the assistance of a medical practitioner specialising in pulmonary disease in Bloemfontein. The adolescents had to be between the ages of 14 and 18, formally diagnosed with asthma by a medical practitioner and currently be taking medication prescribed by the relevant practitioner. In addition they had to be living with both of their biological parents in the same household. The qualitative data were gathered in the form of individual reflective journals, semistructured group interviews and unstructured individual interviews. The researcher's objective was to understand and interpret the meanings the participants gave to their own experiences, which were further done through field notes, member checking, and drawings participants made in the reflective journals. The interviews were audio-recorded and transcribed by the researcher. Thematic data analysis was used to transform the journal entries and transcribe data into meaningful information. The drawings made in the journals were analysed with the assistance of participants, thus a shared analysis. The Constant Comparative method was used to identify themes related to the research question from the researcher's field notes. The principles and strategies for ensuring the trustworthiness of the data were done through crystallisation. The findings of the study revealed that adolescents and their parents experienced mixed emotions in terms of asthma and the impact asthma had on their relationships. The adolescents' and parents' beliefs concerning the topics of the research were often contradictory. It was evident that they experience specific and often contrasting roles and responsibilities regarding the management of asthma in the parent-adolescent relationship, and most families had to make significant adjustments in their family lifestyle and relationships as a result of the adolescents' asthma.



# **SECTION A**

## **PART 1: ORIENTATION OF STUDY**

### **1. INTRODUCTION**

The article format was followed for this dissertation, as outlined in the A rules of the North-West University. In part 1 of Section A an overview of the research problem and methodology is given, followed by trustworthiness and ethical aspects applicable to the study. Part 1 provides an orientation towards the study and outlines the detailed research process that was followed. In part 2 of Section A an integrated literature review is provided. Section B consists of an article in which the actual data of the research are discussed. This section had to adhere to the guidelines of the Qualitative Health Research Journal to which the article will be submitted for possible publication. Lastly, in Section C an evaluation, recommendations and conclusion are presented regarding the comprehensive research process that was followed.

### **2. ORIENTATION AND PROBLEM STATEMENT**

Current estimates put the prevalence of asthma internationally between 234 and 300 million (WHO, 2011; GINA, 2012), and this might increase by an additional 100 million by 2025, according to Cruz (2007:15). According to a study by Elzouki *et al.* (2011:1373) over a twelve-month period, South Africa is one of nine countries with the highest prevalence of asthma symptoms. South Africa's asthma-related death rate is the fourth highest globally among five to thirty-five year olds, according to a recent report by the Global Initiative for Asthma (GINA, 2012). Of the estimated 3,9 million South Africans with asthma, 1,5% succumbs to the illness every year. They (GINA, 2012) report that Southern Africa's asthma prevalence is higher than in any other area on the continent, with more than 20% of school children across the region suffering from the illness. Asthma does not discriminate - persons of all ages and ethnic backgrounds suffer from the disease (Plottel, 2011:8). However, according to the World Health Organisation (2011), "asthma is the most common chronic disease among children". Specifically, asthma presents more frequently in adolescents (Fisher

& Lerner, 2004:124; Plottel, 2011:8). It should also be noted that the prevalence in adolescents has increased in recent years (Lawrence *et al.* 2009:71; Plottel, 2011:8; Taylor, 2003:348) and it is more common in the adolescent female population (Goldman & Hatch, 2000:724; Plottel, 2011:8).

Considering the prevalence amongst adolescents, in addition for this study the researcher had to consider that adolescents also face a critical period of identity formation which Erik Erikson (1968) defined as a “stable, coherent, and integrated sense of self” (Wytenbach, 2008:1). Moreover, the adolescence phase in many respects overshadows any other period of the lifespan with regard to the development of the self (Sigelman & Rider, 2011:357). This challenging developmental phase may however add to adolescents’ existing burden of a chronic illness such as asthma. Adolescence marks an increasing need of the adolescent for autonomy in the family system, a desire for independence (Brown *et al.*, 2006:505). This can be in direct conflict with the dependency they still have upon their caregivers for their asthma management, and may cause friction in the family, along with risk behaviour that adolescents tend to engage in which may further compromise their health (Naimi & Apter, 2010:201). Adolescence thus poses many challenges for adolescents with asthma and their families, and in addition these challenges might impact their interpersonal interactions, in particular the parent-adolescent relationship.

The challenges faced by parents caring for adolescents with asthma are evident during the strain on the relationship that often takes place between parent/caregiver and the adolescent. According to Lamanna and Riedmann (2006:453) the care proves to be a significant stressor for the parental caregivers. Vila *et al.* (2003:326) were able to confirm these findings in studies of parents and asthmatic adolescents. They found that the quality of life of both adolescents with asthma and their parents is impacted by emotional and behavioural challenges. They also found that self-esteem, as well as anxiety, in these adolescents were linked to the management of the impact asthma had on themselves and their parents.

While there has been numerous research on the impact of adolescents’ asthma on their parents/caregivers (Brannon & Feist, 2010; Lamanna & Riedmann, 2006; Sawyer *et al.*, 2005; Taylor, 2003; Vila *et al.*, 2003), the researcher had difficulty in finding research on the combined impact on adolescents with asthma and their parents, focusing on their relationships. Kaugars *et al.* (2003:476) highlight the importance of future research focusing on the psychological and psychosocial (for instance relationships in a family) aspects of

asthma. The exploration of the relationship between adolescents with asthma and their parents is thus of vital importance. The concept of ‘familism’ refers to a social pattern in which the family unit and relationships (for instance between adolescents and parents) are more important than individual interests (Mooney *et al.*, 2011:17; Lamanna & Riedmann, 2006:19). Fisher and Weihs (2000:293) support this concept, and propose that a family-focused approach should replace the traditional patient-focused perspective in considering the relational context in which chronic disease management takes place. The focus of existing research literature regarding adolescents with asthma and their parents is mainly on the individual and not in the context of their relationships.

Erik Erikson’s theory of social development was consulted to find an explanation for the way in which the adolescent phase influences adolescents’ development in a social context (in their families for example). Erikson argued that adolescents face the task of identity and role confusion (Friedman, 2000:85). Jean Piaget’s theory of cognitive development aided the researcher in understanding how the development of specific thought processes during the adolescent phase influences the parent-adolescent relationship. According to his theory adolescents are in the transition phase between concrete operational thinking and formal operational thoughts (Garcia, 2013:23). The Family Systems theory was also consulted in exploring the manner in which the family functions as a system and also in its external environment (Hazell, 2006:18). In addition the ABCX Family Crisis model was helpful in understanding how individuals behave and use available resources to cope with stressful situations like adolescents’ asthma in the family (Williams & Williams, 2005:2).

Based on the above review of the literature and additional reading that were done by the researcher, it is evident that adolescents with asthma and their parents experience altering and often encumbered relationships with each other. The adolescence developmental phase, along with emotional stress due to the caregiver role the parents often have to fulfil, contribute to these strained relationships (Lamanna & Riedman, 2006:453). Additional financial, social and emotional stressors might also add to the strain on the relationship between adolescents with asthma and their parents (Vila *et al.*, 2003:237). The implications of adolescents’ asthma might thus have a detrimental effect on the parent-adolescent relationship.

From the problem formulation the following research question was formulated: How do adolescents with asthma and their parents experience their relationships with each other?

### **3. RESEARCH AIM**

The aim (Eve, 2008:21) of this research was to explore and describe how adolescents with asthma and their parents experience their relationships with each other.

### **4. CONCEPT DEFINITIONS**

The following concepts surface in the integrated literature review in part 2 of Section A. They are defined below to enable the reader to develop an understanding and comprehension of terminology that are used in the literature review:

#### **4.1 Chronic illness**

Although literature does not provide a consistent definition of chronic illness, current themes include the following: According to Martin (2007:2086) chronic illness refers to the experience of a long-term health or bodily disturbance, and how individuals cope with the disruption. It may affect physical, emotional, intellectual, vocational, social or spiritual functioning (Mosby, 2009:72). Chronic illness seldom resolves spontaneously, and is generally not cured by medication or prevented by a vaccine. In addition it can be life-threatening (Goodman *et al.*, 2013:126). Martin (2007:2086) describes chronic illness as follows: “It is an experience of intrusive bodily or mental unwelcome unpleasant sensations.” In the context of this study the focus is on adolescents’ asthma, a chronic illness, and how it affects the relationships between adolescents and their parents.

#### **4.2 Psychosomatic illness**

Numerous theorists (Barrett, 2010:180; French & Alexander 1941:215; Minuchin *et al.*, 1978; Weiner & Freedheim, 2003:10) describe asthma as a psychosomatic illness. When an illness is psychosomatic, it involves both the mind and body. A psychosomatic illness can be defined as a physical disease that is thought to be caused, or made worse, by mental and emotional factors. Additionally this is more likely to happen when an individual’s immune system is compromised due to stress (Ware, 2004:168).

#### **4.3 Psychosocial stressors**

Psychosocial stressors are described as having a negative impact on the parents/caregivers of adolescents with asthma. According to Lazarus (1966:167), psychosocial stressors can be

defined as “aversive/demanding conditions that tax or exceed the behavioural resources of the organism”. More simply put, psychosocial stress results when individuals perceive threats in their lives (real or imagined) and in addition believe they lack the required resources to cope with it successfully (Kamarck, 2012:126).

#### **4.4 Adolescence**

Despite the fact that there is much debate and deliberation on the definition of adolescence, the World Health Organisation (WHO) provides a comprehensive definition. According to WHO (2013) adolescence can be seen as “the period in human growth and development that occurs after childhood and before adulthood, from ages 10-19”. Besides physical and sexual maturation, this developmental phase also marks adolescents’ progression toward social and economic independence, establishment of an identity, the development of skills needed to embody adult relationships and roles, as well as the capacity for abstract reasoning (WHO, 2013). In the context of this research, adolescents with asthma between the ages of 14 and 18 were included as population, and the researcher took the unique challenges adolescents face in adolescence into consideration.

#### **4.5 Relationships**

The adolescents’ asthma was explored in the context of the relationship between adolescents and their parents. Intergenerational relationships can be defined as “the chains of relationships across generations”, between parents and children (Bengtson *et al.*, 2002:567).

### **5. THEORETICAL FRAMEWORKS**

The following theoretical frameworks formed the basis from which the study was approached:

#### **5.1 Erik Erikson’s theory of psychosocial development**

Erik Erikson’s (1902-1994) theory of psychosocial development is a well-known theory of personality in psychology. Erikson believed that personality develops over time and in a series of stages. His theory of psychosocial development focuses on the impact of social experience on individuals across their entire lifespan (Welchman, 2000:12). One of the main elements in Erikson’s theory is the ego identity, which he described as individuals’ conscious

sense of self that develops through social interaction (Friedman, 2000:78). In addition to ego identity, Erikson argued that a sense of competence motivates individuals' behaviours and actions. In each stage of Erikson's theory the individual must become competent in a specific area of life (Norton, 1994:56). According to Erikson people experience a conflict or crisis during each stage that results in either growth or stagnation of development. Erikson maintained that adolescents between the ages of 12 and 18 face the life stage crisis of identity versus role confusion. They thus have to establish an identity or remain confused about the role they have to play later in life. If they successfully complete this task, they move on to the intimacy versus isolation stage in young adulthood (Friedman, 2000:85; Norton, 1994:64; Welchman, 2000:41). The adolescents in this research study are thus experiencing the life stage conflict of identity and role confusion, which was taken into consideration by the researcher.

## **5.2 Jean Piaget's theory of cognitive development**

According to psychologist Jean Piaget (1896-1980), children progress through four key stages of cognitive/intellectual development marked by shifts in how they perceive and understand the world (Modgil & Modgil, 2013:15). Piaget described children as 'little scientists', who are actively trying to explore and make sense of their environment. By observing his own children, Piaget developed a cognitive development stage theory that includes four distinct stages: the sensorimotor stage (birth to age two), the preoperational stage (two to seven years), the concrete operational stage (ages seven to eleven years) and the formal operational stage which starts in adolescence and continues into adulthood (Garcia, 2013:23; Modgil & Modgil, 2013:18). In the context of the research study, adolescents are in the process of moving from concrete operational thinking to formal operational thinking. This has an impact on how they experience and perceive their asthma and relationships with their parents.

## **5.3 The Family Systems theory**

Dr Murray Bowen (1913-1990) developed the Family Systems theory in the early 1950s. The framework emerged from the General Systems theory, and suggests that individuals cannot be fully understood in isolation from one another, but rather as a part of their family, as the family is an emotional entity. The family is a system of interconnected and interdependent individuals, which cannot be understood when separated from the system (Hazell, 2006:18).

This theory was used as framework, as it explores how the family members function as a system in its environment.

#### **5.4 The ABCX Family Crisis model**

The ABCX Family Crisis model, presented by Reuben Hill in 1949, has over time been adapted and developed further. According to Williams and Williams (2005:2), it is a comprehensive approach to the variety of variables involved in understanding how families respond to, and cope with stress and crises. According to the model stress is an inevitable and normal part of family life, disrupting the balance and equilibrium of family functioning. Not only does each family member have a unique perception of the stressor, but so does the family as a whole. The family subsequently copes with the stressor and crisis by attempting to maintain equilibrium. According to McCubbin and McCubbin (1991:20) it is a dynamic model as it emphasises that all three components (stressors, resources and perception) are continually in interaction with each other. The ABCX model was consulted to comprehend better how families cope with a crisis situation like asthma in the context of the family.

### **6. LITERATURE REVIEW**

The following themes were investigated in the literature review: asthma; adolescent development; chronic disease; family; intergenerational relationships; parents; parents as caregivers; Erickson's psychosocial development theory; Piaget's theory of cognitive developmental theory; the Family Systems theoretical framework and the ABCX Family Crisis model.

The body of literature under initial review consisted of journals, newspaper articles, dissertations and books. Search engines included Google Books and Google Scholar, as well as the North-West University databases. Medical research reports and social surveys and statistics were also consulted.

## **7. RESEARCH METHODOLOGY**

### **7.1 Research approach and design**

A qualitative research approach was used where the researcher attempted to collect rich descriptive data regarding the relationship between adolescents with asthma and their parents, with the intention of developing an understanding of what was being observed and studied (Delport *et al.*, 2011:297; Frost, 2011:146). According to Richardson and Saks (2013:326) the qualitative research approach is ideal to facilitate a deep understanding of the experience of chronic illness in the context of individuals and families, whereas the quantitative research approach fails to do this. They (2013:326) are of the opinion that qualitative research methods are especially useful in new fields of research where experiences of individuals and families are of concern, providing rich descriptions of what it is like to experience illness.

For the purposes of this research a case study design was conducted, which according to Yin (2012:3) involves (among others) research on individual people in order to describe, analyse and interpret a particular phenomenon. According to Yin (2012:131), a multiple case study covers the research focus more intensely and thus results in a stronger case study. It strives toward a holistic understanding of how the specific population (adolescents and their parents) interact with each other in a specific situation (adolescents' asthma), and how they experience it (relationships) (Nieuwenhuis, 2007:75). The case study was an appropriate design for this research as the researcher attempted to explore the meaning that the participants gave to their life experiences (Fouché & Schurink, 2011:320) regarding asthma, and specifically in the parent-adolescent relationship. It ensured a deep understanding of the dynamics of the research topic (Nieuwenhuis, 2007:75) as the researcher developed a comprehension of the participants' interaction as a family, how family members experience their relationships, and the experience of the adolescent's asthma in the family.

This study also entailed applied research with an explorative and descriptive nature (Bhattacharyya, 2009:14). Explorative research is used to improve the understanding of the research problem that has been identified (Schumacher, 2008:19). According to Hall (2008:19) descriptive research focuses on 'how' (how do adolescents with asthma and their parents experience their relationships with each other?), 'what' or 'who' rather than 'why' questions.



## 7.2 Population

The population of this research study included adolescents with asthma and their parents. Lerner and Steinberg's (2009:619) definition of middle to late adolescence ages (14-18) was used as criteria for the adolescent population. The researcher worked towards data saturation, not choosing a specific number of applicants with whom to do interviews (Pitney & Parker, 2009:44). Four families which consisted of twelve participants in total took part in the study.

The purposive sampling method (Teddlie & Tashakorri, 2009:179) was used, leading to rich information collected from the small case study. The population was obtained through a medical practitioner in Bloemfontein specialising in pulmonary disease.

The specific inclusion criteria of the sample consisted of:

Adolescent criteria:

- Adolescents (aged 14 – 18) who had formally been diagnosed with asthma by a medical practitioner (longer than a year before). The researcher was of the opinion that not enough information would have been generated otherwise.
- The adolescents had to currently be on medication prescribed by their relevant medical practitioner. Adolescents who were diagnosed with asthma in early childhood can go into remission during adolescence not experiencing any symptoms, or with no need to take medication (Levy *et al.*, 2006:245). Asthma would therefore not continuously have had an impact on their relationships with their parents.
- The adolescents had to live with both parents since the study focused particularly on the relationships in two-parent families. In the researcher's opinion this ensured rich and in-depth data concerning the relationships between the adolescents and their parents.
- Adolescents had to be available to attend a group interview session together with their parents, as well as an individual interview. In addition they were required to keep a reflective journal from the first meeting until the date of the individual interview.

#### Parent criteria:

- Both parents had to be from the same household since the study particularly focused on the relationships in two-parent families.
- The parents had to be the adolescents' biological parents. The researcher was of the opinion that unnecessary variables might occur otherwise.
- The adolescents' parents had to be available to attend one group interview session together with the adolescent, as well as an individual interview. In addition they were required to each keep a reflective journal from the first meeting until the date of the individual interviews.

#### **7.3 Research procedure**

- The researcher made contact with a medical practitioner, informed him about the research proposal and discussed data collection plans, techniques and research value.
- Ethical clearance was obtained from the North-West University: NWU-00060-12-A1.
- After an agreement had been signed with the practitioner, he contacted parents of adolescent patients who qualified for the research criteria.
- The details of adolescents and their parents who were willing to participate in the study were communicated to the researcher.
- A literature study was conducted.
- Appointments were made with the participants for an initial meeting.
- Informed written and oral assent were obtained from adolescents under the age of 18, and consent was obtained from the parents during the initial meeting with the parents and adolescents (see addendum 3). Their involvement in the research process and the content of the reflective journals were discussed with the participants.
- The participants' residences were used as venues where interviews were held. Relevant times and dates were organised and communicated to all participants.
- The data were gathered through individual reflective journals, semistructured group interviews, unstructured individual interviews, and drawings made in the journals.
- The data were transcribed, analysed and described.
- The findings are discussed in Section B.

## 7.4 Data collection methods

### 7.4.1 Individual reflective journals

According to Waterman (2013:155), individual reflective journals can be used in the context of health research in order to gain an understanding of the participant's personal views and emotions regarding chronic illness. The adolescents and parents were asked at the initial meeting to keep individual reflective journals. These documents are described by Lankshear and Knobel (2004:225) as research products created by research participants. It enabled the researcher to collect data written from the point of view of the participants, allowing insight into their thoughts and emotions. The participants were required to make a drawing in the journals about how asthma affected their relationships with a description of the drawing. In addition they had to make daily entries from the initial meeting until the date of the individual interviews regarding the challenges and positive aspects of the relationship, as well as their individual thoughts and emotions.

### 7.4.2 Drawings in journals

A visual data gathering method (drawings) (Roos, 2009:3; Theron *et al.*, 2011:20) was used for data collection. The participants were asked to make a drawing of how asthma affected their relationships and write about it in their journals. These drawings were not interpreted, but merely used to gain a richer understanding of the participant's views, feelings and beliefs on how asthma affects their relationships. The drawings were also used to initiate conversation between the researcher and participants during the individual interviews. The following procedure was used (Theron *et al.*, 2011:22-30):

Steps	Application to study
Step 1: A reassuring invitation	The participants were repeatedly reassured that the focus of the drawings would be on the content and not the quality. This reassurance was also included in the letter of information, consent form and again when the instructions for the drawing were given (Theron <i>et al.</i> , 2011:28).
Step 2: A choice of drawing tools	The researcher provided a variety of colouring pencils and drawing tools during

	the initial meeting which they could use to make drawings in the journals and keep with them.
Step 3: A leisurely pace	The participants were instructed to make the drawing in their own time. It was suggested that they sit comfortably and take their time in visualising and drawing. The participants were given a specific prompt to visualise how asthma affects their relationships, and then draw what comes to mind. Giving a “specific prompt provides structure and contributes to richer data generation”, according to Theron <i>et al.</i> (2011:28).
Step 4: A shared analysis	During the individual interviews the participants were asked to share their understanding of the drawing with the researcher. This shared analysis, according to Theron <i>et al.</i> (2011:28), provides a richer understanding to the researcher.
Step 5: A civic dissemination	The participants were informed that the drawings would be used for data collection, analysed and stored at the Centre for Child, Youth and Family studies for the prescribed length of time. Their permission was obtained in this matter.

#### 7.4.3 Semistructured group interviews

In addition to the reflective journals the researcher used semistructured group interviews as a data collection method (Nieuwenhuis, 2007:87) with both adolescents and parents, which required them to answer predetermined questions, set up by the researcher. The interview schedule (see addendum 5) was tested with consulting experts, and by doing a literature review. It was adjusted accordingly and the relevant questions were included in the final interview schedule. This proved to be an ideal data collection method for this research study as it allowed the researcher to gain a detailed picture of the participants’ beliefs about the

topic of the research (Greeff, 2011:351-353). The interviews were audio-recorded at participants' residences and the interviews lasted approximately one hour each.

According to Cohen *et al.* (2011:433), group interviews can produce different results from individual interviews with the same participants about the same topics. Participants may not be completely honest in front of each other, especially when discussing relationships. They (2011:433) report that individuals greatly value the opportunity for one-to-one conversation and that individual interviews work particularly well with adolescents when sensitive matters such as relationships and family issues are discussed. It is for these reasons that the researcher conducted unstructured individual interviews in addition to the semistructured group interviews.

#### 7.4.4 Unstructured individual interviews

According to Low (2013:88), unstructured and semistructured interviews are ideal data gathering methods in understanding the experiences of individuals and families with chronic illness. Unstructured individual interviews were conducted with all the participants after the group interviews had been completed and the researcher had retrieved the individual reflective journals. This method was used in order to gain additional in-depth information in an informal conversational manner (Greeff, 2011:348), allowing the researcher to ask 'how' and 'why' questions from the participant's perspective of subjective experience (Low, 2013:88). The researcher studied the participants' reflective journals before the commencing of the individual interviews, and used the drawings and daily entries to initiate conversation. The interviews were audio-recorded at participants' residences. The interviews lasted approximately half an hour each, and no follow-up sessions were necessary.

#### 7.4.5 Field notes

According to Greeff (2011:359) "field notes are a written account of the things that the researcher hears, sees, experiences and thinks about" in the course of the research. These notes were taken by the researcher in stages starting with initial words and phrases and then progressing to notes of an elaborated and detailed nature (Babbie, 2007:311). The field notes made by the researcher throughout the research process consisted of the following four categories (Flick, 2009:434-435; Richardson, 1994:527):

- Observational notes which covered perceptions of the research.

- Methodological notes which included methods and frameworks that were applied to the situation.
- Theoretical notes about the grounded theory that other researchers described.
- Personal notes which included the researcher’s own observations, experiences, biases, emotions etc.

## 7.5 Data analysis

The strategy for this study was inductive which, according to Nestor and Schutt (2012:43), entails that the researcher “first examines the data and then derives a theory to explain the patterns shown in the data”. The inductive strategy involves a process of coding the data collected without an attempt by the researcher to fit it into a pre-existing coding frame, or adapt it to analytic preconceptions, according to Braun and Clarke (2006:83). The case record for this research consisted of and was analysed in the following way:

### 7.5.1 Individual reflective journals, semistructured group interviews and unstructured individual interviews

Thematic Analysis (Braun & Clarke, 2006:77-101; Whittaker, 2012:94-101) was used. According to Braun and Clarke, (2006:79), “thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data.” Thematic Analysis can be seen as a flexible method that provides a rich, detailed and complex account of the data collected (Braun & Clarke, 2006:81).

Overview of the non-linear process of phases and how it was applied (Braun & Clarke, 2006:87):

<b>Phases</b>	<b>Description of the process followed</b>
Phase 1: Familiarising of researcher with the data	The researcher transcribed, read and re-read the data, and noted down initial ideas.
Phase 2: Generating initial codes	Interesting features were coded in a systematic fashion across the entire data set, collating data relevant to each code.
Phase 3: Searching for themes	Codes were collated into potential themes, and relevant data gathered to each potential theme.
Phase 4:	The researcher checked if the themes worked

Reviewing themes	in relation to the coded extracts and the entire data set, and generated a thematic ‘map’ of the analysis.
Phase 5: Defining and naming themes	The researcher conducted an ongoing analysis to refine the specifics of each theme, and the overall story the analysis told, generating clear definitions and names for each theme.

### 7.5.2 Drawings in journals

A Shared Analysis (Theron *et al.*, 2011:26) was used to analyse the visual data (drawings). The drawings were used to initiate conversation during the unstructured individual interviews between the researcher and participants about how asthma has affected their relationships. The participants were asked to describe and clarify the drawings they had created. The researcher attempted to identify themes and patterns emerging from the drawings and descriptions from participants. The participants were then consulted regarding the emergent findings (Theron *et al.*, 2011:26).

### 7.5.3 Field notes

The field notes were used in support to the other methods of analysis. The Constant Comparative method (Marks & Yardley, 2004:78; Michie & Abraham, 2004:159) was used to analyse the researcher’s field notes. This entailed finding major themes through the development of codes. The researcher regularly read through the notes looking for themes that are related to the research question. These themes were then given a code name and analysed. The following phases of the Constant Comparative method were used (Marks & Yardley, 2004: 76-78):

Phase 1: Initial establishment of theory and themes	A wide range of detailed themes and theories were established by studying the field notes and using ongoing comparison.
Phase 2: Elaborating more abstract themes	The themes and theories were confirmed and developed to a more abstract level by elaborating the scope of categories established in phase 1. Major themes were identified.

Phase 3: Analyze themes and verify an integrated theory	The core theory emerging through the categories of the field notes were established and code names were developed for major themes identified in phase 2. The field notes were then analyzed.
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## 8. TRUSTWORTHINESS

According to Lincoln and Guba (1985:43) the trustworthiness of a research study is of paramount importance in evaluating its worth. This involves establishing the study's credibility, transferability, dependability and confirmability. According to Merriam (1998:125) credibility deals with the following question: "How congruent are the findings with reality?" Credibility is one of the most important factors in establishing trustworthiness (Lincoln & Guba, 1985:69). The following provisions were made by the researcher to ensure credibility and promote confidence that the topic of research had been accurately recorded (Shenton, 2004:73): The researcher made use of appropriate, well-recognised research methods; an early familiarity of the culture of the participants was developed; crystallisation was achieved; both semistructured group interviews and unstructured individual interviews were conducted as a way to ensure honesty in participants; interactive questioning was used in data collection dialogues; supervision sessions were held between the researcher and the researcher's supervisor; member checks of data collected were done and interpretations/theories formed; previous research findings were examined to determine the degree to which the research results are congruent with those of previous studies; and an in-depth description of the literature was given.

Transferability involves the applicability of the research findings to another context (Wise, 2011:1). According to Shenton (2004:69), it is impossible to claim that the findings and conclusions of research are applicable to other situations and/or populations, since the findings of a qualitative research approach are only relevant to "a small number of particular environments and individuals." Lincoln and Guba (1985:83) argue that the researcher has a responsibility to ensure that sufficient contextual information concerning the fieldwork sites is provided to enable the reader of the research to make comparisons. The researcher can therefore not make transferability inferences since he or she only knows the 'sending context' (Shenton, 2004:70). The researcher subsequently made no claims in respect of the study's



transferability, but provided sufficient contextual information about the study and the methodology used.

In order to attain dependability in the research, the research methodology was reported in detail, enabling future researchers to repeat the research, though not necessarily for the purpose of gaining the same results. The research design might thus be viewed as a 'prototype model'. Overlapping data gathering methods (individual reflective journals, semistructured group interviews, unstructured individual interviews, drawings in journals and field notes) were conducted to ensure further dependability. In addition an in-depth discussion of the research process was given allowing readers to access the extent to which appropriate research practices had been followed (Shenton, 2004:71).

According to Shenton (2004:72), confirmability can be seen as "the qualitative researcher's comparable concern to objectivity". The researcher ensured as far as possible that the research findings reflected the experiences and opinions of the participants, rather than that of the researcher. The following steps were taken by the researcher to ensure confirmability (Shenton, 2004:73): Crystallisation was used to reduce the effect of the researcher's biases; admissions were made of the researcher's beliefs and assumptions; the researcher recognised the potential shortcomings in the research methods and their potential effects; and an in-depth methodology description was given in order to allow the integrity of the research results to be scrutinised.

Trustworthiness included crystallisation (Nieuwenhuis, 2007:81, Richardson 2000:959) as a substitute for triangulation in this study. This was achieved through the use of various data gathering methods (individual reflective journals, semistructured group interviews, unstructured individual interviews, drawings in journals, supportive field notes) and data analysis techniques (inductive strategy, Thematic Analysis, Shared Analysis and the Constant Comparative method), as well as the patterns that emerged through the interpreted understanding of the phenomenon studied, according to Nieuwenhuis (2007:81). He is of the opinion that crystallisation provides the researcher with a complex and deep understanding of the research.

Member checking was done to verify the researchers' interpretation of what had been observed with the adolescents and parents after the individual semistructured interviews had

been conducted (Niewenhuis, 2007:86). The principles and strategies used for enhancing the rigour of the data through crystallisation (Ellingson, 2009:10-14) are discussed in the table below:

<b>Principles</b>	<b>Strategies</b>	<b>Application to research</b>
Deepened complex interpretations	1. Data collection	Individual reflective journals, group semistructured interviews, individual unstructured interviews, and drawings were used to collect data. Supportive field notes and member checking were also conducted.
	2. Member checking and drawing techniques	The researcher relied on the participants to clarify their descriptions during the individual semistructured interviews, as well as the drawings for the researcher to gain a rich understanding.
Analyses	1. Multiple methods	The strategy for the study was inductive (Nestor & Schutt, 2012:43), and Thematic Analysis was used to analyse the journals and interviews (Braun & Clarke, 2006:77). A Shared Analysis (Theron <i>et al.</i> , 2011:26) was used in analysing the drawings and the Constant Comparative method (Marks & Yardley, 2004:78) in analysing the researcher's

		field notes.
	2. Rich, detailed descriptions	The researcher provided a rich, detailed description of the research findings.
	3. Paradigms	Paradigms were used to explain the themes and patterns, as well as contrasting findings that emerged from the data.
Genres of representation	1. Multiple texts	Data were collected as representations of multiple expressions, which included writing and conversations.
Researcher reflections	1. Reflexivity	The researcher kept field notes to record and be aware of her own ideas, emotions, observations, assumptions, biases and experiences of the research.

## 9. ETHICAL CONSIDERATIONS

As human participants were involved in this research process, the ethical behaviour of the researcher was of vital importance. Appropriate ethical and professional behaviour during the research process are described by formal codes of conduct, outlining acceptable and unacceptable practices (Babbie, 2010:78). The following ethical steps were taken by the researcher to ensure the participants' well-being at all times during the research process:

- The researcher obtained institutional approval, and the approved protocol was followed carefully (Elmes *et al.*, 2011:86). Ethical clearance was obtained under the project: Developing sustainable support to enhance quality of life and well-being for children, youth and families in South Africa: a transdisciplinary approach. The ethics number is NWU-00060-12-A1.
- Meaningful research was done that will contribute to the understanding of the relationship between adolescents with asthma and their parents (Goodwin, 2009:62).
- The researcher avoided harm by staying true to the research process and not exploiting the emotional vulnerability of the participants. According to Babbie (2010:75) harm might be of an emotional, and/or physical nature.
- The researcher aimed to preserve and protect the respect and dignity of the participants at all times (Allen, 2008:288). Participants were not forced to do anything against their will.
- The researcher attained informed consent and assent from all the participants before starting to employ any data collection methods, and informed them of all aspects involved in the study (Elmes *et al.*, 2009:84, Goodwin, 2009:62).
- It was explained to all participants that the research was voluntary, and that they could quit the study at any time without consequences (Allen, 2008:288, Goodwin, 2009:62).
- The data gathered were handled as strictly confidential and the participants' names and details remained anonymous. Confidentiality was discussed with all participants. Data that could potentially lead to the identification of participants were not reported. Participants' private residences were used as venues where data were gathered, and this ensured anonymity from outsiders. They also had the right not to answer questions at any stage of the research process if they did not wish to do so (Goodwin, 2009:62).
- The researcher audio-recorded the participants' voices during the individual and group interviews. Consent was attained from the participants beforehand (Elmes *et al.*, 2011:86).

- The researcher did not make use of any deception (Elmes *et al.*, 2011:86) at any time during the research process and this was also mentioned to the participants. They were informed of all factors regarding the research study at all times.
- The participants were ensured that if emotional needs should arise during the research process, the researcher would make appropriate referrals to professionals.
- Participants were informed that there would be no remuneration involved (Emanuel, 2008:312), but snacks and beverages were available at the interview sessions for the participants' enjoyment and comfort.
- The completed research dissertation and the data gathered will be stored at the Centre for Child, Youth and Family Studies (North-West University) in Wellington for the prescribed length of time.

## **10. CHOICE AND STRUCTURE OF RESEARCH ARTICLE**

The dissertation follows the article format as prescribed by the North-West University. The dissertation consists of the following sections:

Section A

Part I: Orientation to the research (Harvard referencing style)

Part II: Literature review (Harvard referencing style)

Section B: Article (APA referencing style): Experiences of asthma in adolescence relating to the parent-child relationship

Section C: Evaluation, recommendations and conclusion (Harvard referencing style)

Section D: Addenda

The Qualitative Health Research Journal (international and interdisciplinary) has been identified as a possible journal for submission (see addendum 6).

## **11. CONCLUSION**

In part 1 of this section A an overview of the research problem and methodology was given, as well as the ethical aspects that had been addressed. This formed part of a general orientation of the study. An integrated literature review will follow in part 2 of section A.

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# **SECTION A**

## **PART 2: LITERATURE REVIEW**

### **1. INTRODUCTION**

Asthma is the most common chronic disease among adolescents (Mannino, 2002:122; Naimi & Apter, 2010:201). It not only significantly affects the adolescent with asthma, but also the entire family, and in particular the relationship between the parents and adolescent. In the words of Taylor (2003:372): “Individuals do not develop chronic diseases; families do.” In part two of this section an integrated literature review is presented that provides a general background of the theoretical concepts and frameworks that feature in the research. Topics that will be addressed include the following: Orientation toward asthma with regard to adolescents and their families; aspects of adolescent development; the intergenerational relationships between parents and adolescents; and the impact of asthma on the parents and extended family of adolescents. In addition the Family Systems theoretical framework, Erik Erikson’s theory of psychosocial development, Jean Piaget’s cognitive development theory and the ABCX Family Crisis model that served as frameworks for this study, will be discussed.

### **2. ASTHMA**

Asthma is defined as a “common reactive airway disease characterized by acute constriction of the bronchial tubes in the lung” (Fisher & Lerner, 2004:72). When individuals experience asthma symptoms their airways swell and overproduce mucous. This usually happens spontaneously when individuals are exposed to allergens, viruses and bacteria. These symptoms can also occur after exercise (Friedman, 2008:1).

Asthma, like many other diseases, has a medical as well as social dimension, which are intertwined. Individuals with asthma are affected on a daily basis in many different areas of their lives, be it schooling, employment, social interaction, physical activities, personal relationships or emotional well-being (Andrew & Booth, 1991:39; Harvey & Kostas, 2010:184). The extent of the impact asthma has on individuals’ lives varies greatly from

person to person according to their unique circumstances. According to Falvo (2005:1) the level of impact is dependent on the individuals' pre-illness personality, severity of the illness, the meaning individuals attach to the illness, the individuals' current life circumstances, and the availability of family and social support. Harvey and Kostas (2010:183) add to this by stating that asthma not only significantly affects the individual patients' lives, but also that of their friends, family, colleagues and the community.

The family can be seen as a social network that not only gives family members their identity but in addition provides strong psychological bonds (Falvo, 2013:22). The family of individuals with a chronic disease fulfils an important role. In addition to support in general, family members often act as caregivers, especially parents of children and adolescents. They provide physical, emotional and financial support. They rarely have any training, often do it without recognition or support, and hardly ever receive financial aid. Individuals living with chronic illness are often solely dependent on family caregivers (Goldberg & Rickler, 2011:41).

While persons of all ages suffer from asthma (Plottel, 2011:8), certain age groups and the accompanying developmental stage make the implications of the disease more challenging (Gjonaj *et al.*, 2001:688). According to de Benedictis and Bush (2007:687), adolescents with asthma are worlds apart from children and adults with regard to their needs and problems related to asthma. These problems might include denial of symptoms, a careless attitude, non-adherence to asthma medication and a poor relationship between adolescents and their families (de Benedictis & Bush, 2007:688). While young children are completely dependent upon their parents for all of their asthma care (Harvey & Kostas, 2010:186), and adults are capable of managing their own chronic illness effectively, adolescents find themselves somewhere in the middle (Boltin, 2001:151).

This complicated and often perplexing situation can be attributed to the unique and challenging developmental phase they find themselves in, which may increase demands and strain on both the adolescent with asthma and their families (Brown *et al.*, 2006:506; O'Donohue & Tolle, 2009:4). Adolescents have to face numerous developmental tasks and challenges during the adolescent phase.

### 3. ADOLESCENT DEVELOPMENT

Adolescence can be seen as an often difficult transitioning period into adulthood, associated with unique developmental challenges (Brown *et al.*, 2006:505). This might include internal distress, strained relationships, the creation of an own identity, and difficulty in navigating new social roles to name but a few (O'Donohue & Tolle, 2009:3). Adolescents undergo changes at a rapid rate affecting their physiological, psychological, cognitive and psychosocial developmental systems (Boltin, 2001:151). Additionally, these changes take place in reaction to their environment, and different social systems. Development in adolescence occurs in a reciprocal exchange between adolescents and their context which include the individuals, their family, friends, community and culture (O'Donohue & Tolle, 2009:7).

Erik Erikson (1968) argued that individuals face eight psychosocial stages, also known as crises during their lifetime. Each crisis occurs at a specific time determined by the biological maturation and the accompanying social demands they experience. In order to move on to the next stage, individuals first have to successfully resolve the present life crisis they find themselves in (Shaffer & Kipp, 2010:44). Erikson argued strongly that adolescents between the ages of 12 and 20 experience the psychosocial conflict between identity and role confusion. During this life crisis they have to establish basic social and occupational identities, or else they will stay confused about the appropriate roles they should embody as adults (Shaffer & Kipp, 2010:45). Upon successful completion of the identity versus role confusion stage, adolescents will move on to the next life crisis which consists of intimacy and isolation during young adulthood (Kroger, 2013:55; Shaffer & Kipp, 2010:45).

According to Sigelman, Rider (2011:495) and Smetana (2011:21), achieving autonomy is another key developmental task during adolescence which often results in parents relinquishing more control to the adolescent. Erikson (1968) described this gained sense of autonomy by the adolescent as the larger task of establishing an identity separate from the adolescent's parents. Erikson's theory also suggests that identity does not first emerge during adolescence, as many believe, but develops over time and is that part of the self-concept that contributes significantly to an overall sense of self (Elder *et al.*, 2009:22; Kroger, 2013:83). Establishing an identity might however prove a significant challenge for adolescents, as asthma adds another layer to their quest for identity development. Adolescents can for

instance either define themselves as an asthmatic, or a person with a chronic illness (O'Donohue & Tolle, 2009:11).

This developmental stage can be especially trying for adolescents with a chronic disease such as asthma (O'Donohue & Tolle, 2009:3), who even under normal circumstances, live in an ever-changing world with many threats to their well-being (Boltin, 2001:151). Adolescents with asthma not only face the same developmental challenges as their healthy peers, but carry the added burden of the illness. This may frequently be in conflict with the typical developmental tasks of adolescents (Brown *et al.*, 2006:506; Hendry *et al.*, 1995:112; O'Donohue & Tolle, 2009:3). An example of this is the clash between the dependency adolescents have on their parents regarding medication adherence, social stigma, poor coping skills, etcetera, and their increased developmental need for autonomy and developing an identity separate from their parents (Naimi & Apter, 2010:207; O'Donohue & Tolle, 2009:3; Sheppard & Grö hn, 2004:59; Sigelman & Rider, 2011:495).

Additionally, adolescents with a chronic illness may not only find it difficult to establish an identity, but also to be able to consolidate a mature identity/personality (O'Donohue & Tolle, 2009:11). This can be due to the specific developmental risks that adolescents with chronic illness face, such as the prolonged dependence that adolescents often have on parents and others. This in turn can either cause them to become compliant and childlike, or non-compliant and rebellious (Neinstein, 2008:1057). Adolescents often use regression due to an inability to cope with chronic illness such as asthma (Falvo, 2005:5). Regression refers to adolescents reverting to an earlier stage of development, for example childhood or early adolescence. As a result they become more dependent, behave more passively, or respond more emotionally than would normally be expected at their developmental level. The return to an earlier stage of development may also have a therapeutic or positive effect on adolescents in the early stages of chronic illness, especially if treatment of the condition requires rest and inactivity. However, when adolescents persist in a regressive mode, it can be detrimental to their ability to adjust and attain independence which will allow them to function optimally (Falvo, 2005:5).

According to Naimi and Apter (2010:207), adolescents' increased need for autonomy and independence might cause them to perceive their caregiver or parents' input and concern as irritating and nagging. This may result in adolescents avoiding to take their medication, creating conflict in the family (Penza-Clyve *et al.*, 2004:191). According to Naimi and Apter



(2010:207), a gained sense of autonomy might enable adolescents to manage themselves and their disease effectively.

The characteristics of chronic illness coupled with the developmental tasks adolescents face, might place significant psychosocial stressors on affected individuals and their families (Brown *et al.*, 2006:505; Williams *et al.*, 2002:831). The most significant psychosocial factor associated with adolescent asthma is stress placed on the affected adolescents and, their family, and/or the interactions between adolescents and their family members (Egan, 2010:6; Sawyer *et al.*, 2001:1110; Wood, *et al.*, 2007:549). Adolescents' stressors are primarily centred on their asthma symptoms, and thus they affect their emotional well-being (Egan, 2010:7). This in turn also raises the stress levels of the family and affects their well-being negatively, described by Egan (2010:7) as interactive stressors. According to Neinstein (2008:1057), the psychosocial stressors that are most likely to be dysfunctional in adolescents with chronic disease are achieving independence and the stability of family relationships.

According to O'Donohue and Tolle (2009:3), individuals with asthma in the adolescent phase need to take more responsibility in managing their chronic disease (Levesque, 2012:103). Disease management can be seen as an essential component of asthma care which is influenced by adolescents' growing need for independence, increasing maturity and engagement in health risk behaviours (Naimi & Apter, 2010:201). According to Gjonaj *et al.* (2001:688), adolescents with asthma are developmentally inclined to deny the severity and chronic nature of their asthma and may choose to ignore symptoms. They may experience anger as a result of having a chronic disease, and believe they can ignore symptoms without consequences. Risky behaviour such as smoking, which is common during adolescence, add to the challenge of adolescents taking successful control over their chronic illness (Boltin, 2001:151; Gjonaj *et al.*, 2001:688; O'Donohue & Tolle, 2009:3; Robertson & South, 2007:139).

The cognitive and behavioural skills required to successfully manage a disease such as asthma, may include self-control, planning and problem solving. These skills can be beyond the capacity of adolescence (O'Donohue & Tolle, 2009:3). According to Piaget (2007:89) concrete thinking, which is oriented in the present, occurs during early to middle adolescence. Concrete thinkers are not able to think abstractly and find it difficult to understand the consequences of their behaviour, engaging in risky behaviour and not taking their medication correctly, for example (Boltin, 2001:151). Egocentrism often occurs during this stage,

initiating personal self-consciousness (Shaffir & Kipp, 2010:176). Elkind and Bowen (1979:40) called this the imaginary audience, where adolescents are convinced that others in their environment are as preoccupied with their behaviour and feelings as they are themselves (Shaffir & Kipp, 2010:176). According to Piaget (2007:187) this error in thinking is often outgrown by adolescents as they develop formal-operational skills (Shaffir & Kipp, 2010:176).

Formal-operational thinking develops during late adolescence, and with it hypothetico-deductive reasoning, which enables the adolescent to think hypothetically (Boltin, 2001:151; Piaget, 2007:190). This ability to think abstractly allows the adolescent to anticipate the future and to make challenging personal decisions by weighing various courses of actions, not only for themselves, but also involving others (Boltin, 2001:151; Shaffir & Kipp, 2010:276). In addition formal-operational thinking enables the adolescent to form a stable identity, and to understand other people's perspectives and behaviour, thus growing their social skills.

On the negative side, however, this newly found ability also enables adolescents to imagine hypothetical alternatives to present realities, and this may cause them to question and criticise their parents' authority, for example. These perceived logical inconsistencies and 'flaws' in the real world might cause them to become confused, frustrated, and even rebellious towards their parents and others (Shaffer & Kipp, 2010:273-276). Piaget (2007:102) viewed this idealistic fascination with how the world is supposed to be, as a result of the adolescent's newly acquired abilities of abstract reasoning. He (Piaget, 2007:103) stated that formal operational thinking can be seen as the primary cause of the 'generation gap' between parents and adolescents.

#### **4. INTERGENERATIONAL RELATIONSHIPS**

The parent-child relationship changes during adolescence. This can be attributed not only to the generation gap as mentioned above (Piaget, 2007:103), but also to less time spent together and an increase in conflict between family members and the adolescent (Sigelman & Rider, 2011:495; Sheppard & Grö hn, 2004:59; Smetana, 2011:24:37). Parents often experience the period of adolescence as more challenging than other stages in their child's life (Grolnick, 2013:89; Steinberg, 2001:6).

According to Steinberg (2001:5) mothers, fathers and adolescents experience their interactions with each other in very different ways, which in turn could cause conflict. This could be attributed to the different perspectives the parents and adolescent bring to the relationship, the adolescents' search for autonomy and parental regulation (Sheppard & Grö hn, 2004:59). Adolescents generally recover quicker from parent-teenager conflicts. Steinberg's (2001:5) research indicated that the day-to-day conflict between parents and adolescents over mundane matters are often perceived by the teenager as trivial, while it proves to be a significant stressor for parents. Steinberg (2001:7) is of the opinion that this increase of conflict in the parent-adolescent relationship can also be attributed to the challenging psychological nature of the adolescent's developmental stage and midlife stage of the parents, which tend to happen simultaneously.

In the context of a chronic illness, such as asthma, family relationships can be both a source of support and a stressor, particularly for the adolescent (O'Donohue & Tolle, 2009:50; Wolfe & Mash, 2006:509). O'Donohue and Tolle (2009:3) add to this by stating that the quality of family relationships serves either as protective or as risk factors to the adolescent's ability to cope effectively with chronic illness. Protective factors include effective coping, stress management and adjustment in the family relationships, whereas neglect and abuse (be it physical, sexual or emotional) can be seen as risk factors which result in adolescents' decreased ability to cope effectively with asthma.

According to Brandt (2001:213-214), benevolent overreaction can be seen as another risk factor, resulting in decreased self-esteem, poor self-control and a lack of initiative in adolescents (Cava, 1979:87; Falvo, 2013:17; O'Donohue & Tolle, 2009:52). Benevolent overreaction can be defined as a recurring pathologic behaviour shown by families of a child or adolescent with a chronic disease, such as asthma. It occurs as a result of parents' natural, protective behaviour, and consists of a cluster of parental tendencies including overprotection, overindulgence and permissiveness (Brandt, 2001:214; O'Donohue & Tolle, 2009:52). According to O'Donohue and Tolle (2009:52), high levels of parental overprotection could result in family conflict, which might be highly detrimental to the chronically ill adolescent. This might cause additional stress to be placed on the adolescent, resulting in a decreased ability to cope effectively (Barakat & Kazak, 1999:78; Drotar, 2006:36; O'Donohue & Tolle, 2009:52).

Families caught in this harmful benevolent overreaction cycle are often unable to encourage their child to act independently, and tend to focus on their child's challenges as a result of the chronic illness. The family becomes focused on the adolescents' illness and the need for caregiving, which could make it difficult for adolescents to reach their psychological and developmental milestones. This in turn might result in adolescents developing separation anxiety, which typically occurs in very young children (Brandt, 2001:214; Herbert, 2005:168). This fear of separation can occur throughout adolescence and into adulthood (Brandt, 2001:214).

Early psychoanalysts French and Alexander (1941:212) were of the opinion that separation anxiety occurs mainly between the child or adolescent with asthma and the mother. This can be attributed to the perceived psychosomatic nature of asthma which causes a psychological conflict of dependency in adolescents with asthma (French & Alexander, 1941:212; Kradin, 2013:104). This psychosomatic condition results in the adolescent reflecting an unconscious dependency on the mother, triggered by separation anxiety (Kradin, 2013:104). According to Kradin (2013:104) it was suggested metaphorically by French and Alexander (1941) that asthma serves as adolescents' unconscious desire to "have the last word" in their struggle for autonomy, the difficulty in breathing being a symbolic expression of dependency (Barrett, 2010:180; Coffman & Levenson, 2011:442). These psychological conflicts thus enable and maintain the asthma, and subsequently the dependent relationship between mother and child (Barrett, 2010:180; French & Alexander 1941:215, Minuchin *et al.*, 1978; Weiner & Freedheim, 2003:103). Parental styles are another concept that might have an influence on the relationship between adolescent and parents.

Parenting styles can be defined as "a set of attitudes, goals and parenting practices that create an emotional environment through which the child and parent interact" (Darling & Steinberg, 1993:495; Friedman, 2008:7). Numerous research studies (Alderfer *et al.*, 2003:283; Brown *et al.*, 2006:509; O'Donohue & Tolle 2009:3; Sheppard & Grö hn, 2004:59; Steinberg, 2001:8; Zeller & Modi, 2008:28) show that an authoritative parenting style (characterised by warmth, monitoring of activities, involvement, control that is firm yet flexible, constant discipline that is not harsh and psychological autonomy granting) is a strong predictor of enhanced treatment adherence and effective adjustment in adolescents with chronic disease. In contrast, authoritarian or permissive parenting practices are associated with negative outcomes in terms of behaviour and social competence in children and adolescents (Kotchick

& Forehand, 2002:258; Zeller & Modi, 2008:28). The authoritarian parenting style is characterised by high and coercive control, low warmth and harsh discipline. In contrast permissive parenting lacks warmth, monitoring, discipline and control (Zeller & Modi, 2008:28). Parents practicing an authoritative parenting style as discussed above thus have a positive effect on not only the adolescent's ability to cope effectively with asthma, but also on the parent-child relationship (Alderfer *et al.*, 2003:283; Brown *et al.*, 2006:509; O'Donohue & Tolle 2009:3; Sheppard & Grö hn, 2004:59; Steinberg, 2001:8).

According to Brandt (2001:214) there are typical behavioural tendencies displayed by adolescents with a chronic disease and their parents. This includes parents' proneness to deny their child's behavioural problems, weak disciplinary action, inconsistent discipline and setting limits poorly. As a result the adolescent has few age-appropriate friends, with parents performing activities for the adolescent that they are capable of performing themselves, for example finishing the adolescent's sentences or answering for them. This might cause adolescents to seem immature for their age, as few demands are made by their parents. In addition parents also tend to ignore incidents of antisocial and hostile behaviour displayed by the adolescent, for example cursing (Brandt, 2001:214).

Hockenberry and Wilson (2013:541) report that mothers and fathers tend to adjust, cope, and handle their child's chronic illness differently, regardless of the child's age. Mothers are often the primary caregiver, increasing their risk of developing social isolation, psychological stress and fatigue (Coffey, 2006:51). Fathers tend to use problem-oriented coping strategies, which include gathering information, exploring options, and weighing choices (Hockenberry & Wilson, 2013:541). A Swedish research study showed that mothers and fathers also manage their uncertainty regarding asthma in different ways. It was found that mothers mostly act in a protecting manner and express feelings of sadness, while fathers, in contrast, act in a liberating way and express feelings of acceptance (Devore, 2006:1).

A study done by Srinivasa *et al.* (2006:123), found that the mother-adolescent relationship tends to be stronger than the father-adolescent relationship. They attribute this finding to woman generally taking on most of the responsibility for child rearing, and being more closely involved in their children's lives than men. This enables them to develop strong reciprocal relationships with their children. They (2006:124) also found that adolescents' psychosocial functioning and ability to adapt to challenging situations, like asthma, tend to be

most effective when the adolescents have strong relations with both parents. They report that if the adolescent does not have strong relationships with both parents, a healthy father-mother relationship alone will not contribute to successful adolescent adjustment. In addition, adolescents who have strong relationships with both parents rarely have behavioural problems, regardless of whether the parents have a strong relationship with each other (Srinivasa *et al.*, 2006:124). Family connectedness thus seems of vital importance to the well-being of adolescents (Neinstein, 2008:1057).

## **5. IMPACT OF ASTHMA ON THE PARENTS AND FAMILY OF ADOLESCENTS**

Chronic illness proves to be a challenge and often burden, not only to the affected individual, but also to the individual's family (Naimi & Apter, 2010:207). According to Vila *et al.* (2003:327) the impact on the family of adolescents suffering from asthma, and in particular their parents, can be severe. A sudden, unexpected diagnosis of chronic illness might lead to diverse emotional reactions (Falvo, 2005:6). Subconscious grief surfaces when parents start to suspect a problem in their child's health and well-being (Brandt, 2001:212). When these suspicions are confirmed and the diagnosis is made, the parents might experience intense grief. Parents must grieve the loss of their perceived 'perfect child' (Berger, 2008:82; Brandt, 2001:211). The distress and sorrow felt by parents are not linear, and they must move through the five stages of grief (consisting of denial, anger, bargaining, depression and acceptance) before they can fully acknowledge their child's diagnosis (Berger, 2008:82; Falvo, 2013:23; Kübler-Ross & Kessler, 2005:7). According to Brandt (2001:212), grief has no end point for families of chronically ill children and adolescents.

During the stage of grief, feelings of shock, disbelief and numbness might also surface, which could result in denial of the diagnosis or the extent of its seriousness (Falvo, 2005:6). According to Brandt (2001:213), denial is a normal reaction often used by families of chronically ill individuals as a defence mechanism to cope with their grief. (Devore, 2006:1, Falvo, 2005:6). Adolescents with asthma and their families might also perceive the diagnosis of asthma to be a threat, they might fear the unpredictability of the illness, and as a result experience anxiety (Falvo, 2005:7).

Anger can surface during the grieving process - a possible result of family members' blaming others for the illness, or even themselves which leads to guilt (Falvo, 2005:7). An example of

this is harmful practices or habits in the household such as smoking or pets, and the family member perceiving it as a contributing factor or cause of asthma in the adolescent. In addition adolescents might feel that their asthma places a burden on the family, and experience guilt as a result (Falvo, 2005:8). Anger could also manifest as a result of frustration, due to the family realising how serious the situation is, and experiencing feelings of helplessness (Falvo, 2005:7). If parents and family members do not find appropriate outlets for their anger, it can be 'turned inward' leading to depression (Brandt, 2001:212). Caregivers in particular have been found to be at an increased risk for distress, anxiety and depression (Brandt, 2001:213; Rosenthal *et al.*, 2009:186; Shewchuk & Elliot, 2000:555). Accompanying feelings might include helplessness, hopelessness, apathy, dejection and discouragement (Falvo, 2005:7). Studies show that parents find it difficult to handle their own and their child's emotions simultaneously. Additionally, they also find speaking about the adolescent's illness challenging, whether it is to the adolescent, to other family members or to the outside world (Brandt, 2001:212).

Social, emotional, physical and financial strains are often placed on the family members of adolescents with asthma (Brandt, 2001:213; Rosenthal *et al.*, 2009:186; Shewchuk & Elliot, 2000:555). Parents might experience increased levels of stress and anxiety because of a lack of knowledge about asthma, fear that their child might die, and additional anxiety about their child's health on a daily basis (Brandt, 2001:213; Jarret & Costello 1996:305; Naimi & Apter, 2010:207). According to Falvo (2005:7), the life-threatening nature of an illness contributes to parents' fear and anxiety, not only because of a potential loss of function, but also potentially loss of life. This strain is evident in an observation by an asthma specialist: "In no disease does the parent so often undergo the fear their child is dying" (Travis, 1976:165).

Family members are often so concerned for the individual's health that it drastically affects their daily lives (Falvo, 2013:23; Vila *et al.*, 2003:327), including freedom of movement and association with others. Asthma, especially in its severe forms, is known to negatively impact the quality of life of affected adolescents and their families (Taylor, 2003:349; Vila *et al.*, 2003:320). Families must adapt, adjust and often change their roles both as a family unit and among individual family members as a result of the affected individual's chronic illness. In turn, the way in which families react and adapt to the disease will influence the adolescents' adjustment as well (Falvo, 2013:23).

By extension, the relationship between the affected adolescent and caregivers can deteriorate (Taylor, 2003:374). The parents, who often fulfil the role of primary caregivers, face the task of providing support and care, and having to offer the solutions and adjustments required by the chronically ill adolescent in order to find meaning in the experience of illness and to re-establish quality of life. Asthma places an increased strain on parental time and energy (Kurnat & Moore, 1999:289; Naimi & Apter, 2010:207) and might result in caregivers becoming fatigued due to the additional responsibilities (Falvo, 2013:23), or even experiencing burnout in extreme cases (Devore, 2006:1). This often leads to emotional stress for both parents as caregivers and for the affected adolescent (Brannon & Feist, 2010:270; Harvey & Kotses, 2010:221). These emotional burdens on family members might result in feelings of resentment, antagonism and frustration (Falvo, 2013:23).

Social support is seen as a powerful mediator of family adjustment to a stressful life event, such as asthma (Brandt, 2001:213). This might include parents sharing the responsibilities of care with other family members and friends, and is shown to generally result in significantly higher levels of family functioning. Maintaining meaningful social relationships outside the home are also important, not only to promote personal growth in family members, but also to decrease stress (Brandt, 2001:213). The family and their available social support can be seen as systems in which the adolescent and parents attempt to successfully manage and cope with the challenges of the illness.

## **6. THE FAMILY SYSTEMS THEORETICAL FRAMEWORK**

The Family Systems theoretical framework has increasingly been used by researchers to study family members' responses to chronic illness. The framework considers families to be systems due to the fact that family members interact with each other, exhibit coherent behaviours, and are interdependent on one another, the glue which holds them together (Chibucos *et al.*, 2005:279; McCubbin & Patterson, 1983:22; Morgaine, 2001:1). According to Chibucos *et al.* (2005:279), the Family Systems theory is concerned with two main aspects of families, the elements that exist in families as a system, and between families and their environment. The Family Systems theory consists of the following components (Morgaine, 2001:1-2):



- *Family systems have interrelated elements and structure:*

The individual members of a family are seen as the elements of the family system. Each element (family member) has its own unique characteristics, and is in a relationship with the other elements of the system (other family members) (Chibucos *et al.*, 2005:279). The reciprocal and dynamic relationships between the family members function interdependently (Clark, 2009:21). The sum total of these interrelationships between the family members creates a structure which consists of membership in the family and boundaries between the family and its environment (Morgaine, 2001:1).

- *Family systems interact in patterns:*

The interaction patterns between family members in the family system are predictable. The family's balance and equilibrium are maintained by these repetitive cycles of behaviour, and in addition it serves as a pointer to the family members of how they should function (Chibucos *et al.*, 2005:279; Morgaine, 2001:1). For example, the mother displaying concern and caregiving behaviour toward her adolescent son with asthma, will most likely repeat the behaviour, and it serves as an example to other family members of how to act in their interactions with him.

- *Family systems have boundaries:*

The boundaries in a family can be seen as either opened or closed. An open boundary system allows external influences to penetrate, whereas closed boundary systems isolate its members and might seem secluded and confined. However, no family system is ever completely open or completely closed (Morgaine, 2001:1). For example, where some families will accept and welcome help from extended family and friends in caring for the adolescent with asthma, others will not and will continue to function in isolation.

- *Family systems function by the composition law:*

Every family system consisting of individual members forms an organic whole (Morgaine, 2001:1). According to Clark (2009:21) "the whole is more than the sum of its parts". The family unit is thus more important and significant than the individual family members.

- *Family systems use messages and rules to shape members:*

Messages and rules can be seen as repetitive, unwritten relationship agreements which prescribe and limit the family members' behaviour over time. They perform numerous functions which might include giving power, inducing guilt, controlling or limiting behaviours and they maintain themselves by reproducing. For example, parents regularly remind adolescents to be responsible and to always take their medication (McCubbin & Patterson, 1983:25; Morgaine, 2001:1).

- *Family systems have subsystems:*

Family systems consist out of small groups usually made up of two to three members. According to Morgaine (2001:1) the relationships between these members are known as 'subsystems', 'coalitions', or 'alliances'. Every subsystem has its own boundaries, rules, and unique characteristics. In addition, membership in subsystems might change over time (Chibucos, *et al.*, 2005:279; Morgaine, 2001:1). The relationship between mother, father and an adolescent with asthma can thus be seen as a unique subsystem in the family. It may for example be characterised by caregiving behaviour, conflict and concern, which will differ from the parents' relationship with another sibling or member of the family.

In the context of chronic illness, the Family Systems framework focuses on how families use adaptive behaviours and resources to cope with the stressors associated with the disease (Barakat & Kazak, 1999:334; Webb, 2009:21). When change, such as a diagnosis of asthma, occurs in one member of the family, inevitably the family system as a whole must change (Lamanna & Riedmann 2006:66, 449). According to Kazak (1989:28), the Family Systems theory emphasises how family members' attitudes and behaviours regarding the illness never exist in a static system, but rather mutually influence one another across and within contexts (Harvey & Kotses, 2010:217). According to Naimi and Apter (2010:206), the families' well-being and the adolescents' asthma reciprocally influence each other. Inevitable changes occur in the family system because of a chronic illness such as asthma. These might include (among others) the reorganisation of family roles, sibling relationships, and priority shifts in parental attention because of the tasks associated with the illness (Brown *et al.*, 2006:509; Shannon & Cusatis, 1996:31).

Weiner and Freedheim (2003:103) studied the way in which family dynamics in the family system affect asthma and vice versa. They are of the opinion that dysfunctional family

dynamics that exist in the family system could create and enable a ‘psychosomatic’ illness such as asthma (Barrett, 2010:180; French & Alexander 1941:215, Minuchin *et al.*, 1978; Weiner & Freedheim, 2003:10). These dysfunctional dynamics in the family might include rigidity, overprotectiveness, enmeshment, overindulgence, permissiveness and lack of conflict resolution (Brandt, 2001:213; Weiner & Freedheim, 2003:509). These traits thus have a reciprocal effect. It might for example influence the adolescents’ asthma negatively, increasing symptoms, which in turn creates tension in the family and between the parents, and has a negative effect on the relationship between the parents and the adolescent. The following is a detailed example of this phenomenon as described by Brandt (2001:214):

Dysfunctional dynamics in families with a chronically ill adolescent might result in the appearance of a recurrent destructive cycle in the adolescent-parent relationship and family system (Brandt, 2001:213; Weiner & Freedheim, 2003:509). This phenomenon could cause adolescents to become insecure, and to focus primarily on their asthma. In turn, this might result in parents experiencing guilt, shame and low self-esteem. These feelings might increase the parents’ behavioural tendencies of overprotection, indulgence and permissiveness. As a result, the adolescent is “deprived of new experiences, discipline, structure, and the frustration necessary to promote independence, self-control and initiative” (Brandt, 2001:214). Adolescents thus remain dependent on their parents, and seem developmentally immature for their age. In turn, parents might experience feelings of frustration, resentment, ambivalence, anger, and even hostility. These emotions either are hidden, resulting in passive-aggressiveness and self-sacrifice, or shown overtly in the form of aggression. The cycle starts anew by parents transferring these emotions and feelings to the adolescent, who then resumes feeling insecure and focusing on the asthma (Brandt, 2001:214).

According to the family systematic view, the effect of chronic illness in the family can also be positive and even productive. It can maintain homeostasis in the family by diffusing conflict (for example tension and arguing between the parents might prompt the adolescent to have an asthma attack, which distracts the parents from continuing the conflict) (Weiner & Freedheim, 2003:509). However, families are more likely to function effectively and adjust well to an adolescent’s chronic disease when they use coping strategies which are positive, effective, and healthy (Drotar, 2006:281; O’Donohue & Tolle, 2009:51).

While the Family Systems theory is able to adequately explain how the family functions as a system and with regard to its environment, the ABCX Family Crisis Model is helpful in

understanding how families cope with a specific stress and crisis situation like asthma in the family.

## **7. THE ABCX FAMILY CRISIS MODEL**

Because of the fact that asthma is seen as a stressor and crisis situation in the family system (Mandleco & Potts, 2012:65), the ABCX Family Crisis model is helpful in explaining and comprehending how families cope with and react to asthma. Each of the ABCX components of the model will be explained and applied to the context of the adolescent's asthma in the family.

### A – Stressors or demands:

The A component of the ABCX Family Crisis model consists of a variety of stressors/demands that place pressure on the family for change in the members' normal reaction patterns, like asthma. According to Schlesinger & Epstein (2010:302) "stressors or demands are events that vary along a number of dimensions". These dimensions of stressors consist of the following:

- Whether they are internal or external to the relationship (internal in the case of asthma, as interpersonal relationship dynamics between parents and adolescents are often affected).
- The suddenness of the onset (diagnosis of asthma).
- Whether they are predictable and expected (the degree to which symptoms are predictable and whether family members suspected that symptoms could be as a result of asthma).
- Their degree of ambiguity (uncertainty or decisiveness among family members).
- Their severity (symptoms of asthma).
- Their duration (asthma is a chronic, ongoing stressor).
- "The degree to which the family members choose to be exposed to the stressor" (whether family members choose to be directly involved in the management of asthma care and support, or not).
- How many family members are affected directly (for example adolescents with asthma and their parents as caregivers) (Boss, 2002:27; McCubbin & Patterson, 1983:9; Schlesinger & Epstein, 2010:302).

These dimensions of stressors largely determine how the family members will act in response to the stressor. When a stressor like asthma exists in the family, the members often have to make changes in important areas of their relationships. According to Schlesinger and Epstein (2010:302) these changes might occur in the family's goals, roles and established patterns of interacting with each other. McCubbin and Patterson (1983:21) are of the opinion that it is not the adolescent's asthma (stressor) itself that creates the need for change, but rather the challenges associated with it (for example the mother of the adolescent with asthma takes on the role of primary caregiver, and this results in added strain on her time, emotions, and finances. The parent-adolescent relationship might also deteriorate because of conflict about medicine adherence).

Additionally, if families have not found a resolution for earlier stressors and the implications it (prior strains) had, they might find it difficult to resolve current stressors successfully. For example, if the family experienced financial difficulty or strained relationships prior to the diagnosis of asthma, and it was left unresolved, the diagnosis and its associated stressors might prove a significant challenge. If the family can successfully manage a stressful situation before the next one occurs, they have a much better chance to remain resilient as a family. The family might however experience cumulative stressors if a stressor pile-up occurs, for instance simultaneous financial, relationship and social strains, which will negatively influence their ability to cope with asthma in the family (Williams & Williams, 2005:3-4).

## B – Resources

The family's ability to cope with asthma is also influenced by a variety of resources that may be available to them as individuals and as a family. According to Schlesinger and Epstein (2010:304) there are usually three major categories of resources available to individuals and families coping with stressors:

- *The personal resources of each individual*

Individual family members' health, education, intelligence, job skills, problem-solving skills, finances and psychological characteristics such as a sense of mastery and self-esteem are examples of personal resources (Boss, 2002:49; McCubbin & Patterson, 1983:26, Schlesinger & Epstein, 2010:304).

- *Resources of the family*

These resources are found in the family relationships. They include collaborative problem-solving skills, cohesiveness, effective communication skills, mutual support and the ability to adapt to altering relationship roles and patterns in an attempt to cope with stressors (Epstein & Baucom, 2002:346; Schlesinger & Epstein; 2010:204; Walsh, 1998:237).

- *Resources provided by the environment outside the family*

These may be obtained from relationships and contact with extended family, friends, neighbours and community organisations such as health care services, social service agencies, employers, schools and religious institutions. Knowledge gained through books and the internet can also be seen as an environmental resource. According to Schlesinger and Epstein (2010:304) forms of social support include “emotional support, validation, assistance in problem solving, financial aid” and practical support with tasks associated with care giving to the adolescent with asthma.

According to Schlesinger and Epstein (2010:304), effective coping not only depends on the availability of resources but also on the manner in which the family utilises these available resources. A shared belief by family members that the family is strong and capable to actively take control over the adolescents’ asthma can be seen as another resource within relationships that is a key component to resilience (Dattilio, 2009:37; McCubbin & McCubbin, 1991:57; Schwebel & Fine, 1994:26; Walsh, 1998:240).

#### C – Perceptions and appraisal of stressors:

The C component of the ABCX family crisis model involves the family members’ perception and appraisals, or evaluation, of asthma as a stressful life event occurring in their lives. According to Williams and Williams (2005:5), the family’s culture gives messages about the appropriate way to react to a crisis. Families then interpret these cultural messages in the same ways they interpret their own perspectives. Although individual family members might have varied opinions about the adolescents’ asthma, shared perceptions can be powerful and surpass variation in individual views (Schlesinger & Epstein, 2010:205). In addition this may lead to selective perceptions by the family (Epstein & Baucom, 2002:367), for example their resistance to acknowledging the true extent of severity of the adolescent’s asthma. According

to Schlesinger and Epstein (2010:205), family members tend to evaluate stressors or demands in terms of the threat it might pose to them. They also assess the degree to which they believe they have adequate and sufficient resources to cope with the stressors.

When family members evaluate the stressful event of asthma as a challenge that can be managed through active effort, rather than as an uncontrollable event that must be accepted in a passive, fatalistic manner, the family is more likely to cope positively and effectively (Boss, 2002:12; McCubbin & McCubbin, 1991:86; Schlesinger & Epstein, 2010:206; Walsh, 1998:246). In the event of a stressful life crisis like asthma, families tend to weigh the demands inherent to the disease against their capabilities for meeting these demands (Schlesinger & Epstein, 2010:206). For example they might doubt their capacity to be caregivers to the affected adolescent, afford asthma medication, or cope with the disease on an emotional and social level.

When the family members perceive that the demands of asthma exceed the family's resources and coping abilities, tension and stress are experienced regardless of whether their perceptions are accurate. These subjective evaluations thus mediate individual family members' responses to asthma. According to Schlesinger and Epstein (2010:206) subjective cognitive factors play a significant role in how family members cope with demands in their relationships. Once a family has become destabilised and subsequently entered a crisis state, their evaluations of the situation are likely to affect their attempt to adapt and re-establish equilibrium.

#### X – The crisis state of disorganisation:

Families in general are able to cope effectively with demands for change posed by stressful life events such as asthma. They do this by utilising their resources and perceiving themselves as capable of successfully dealing with the adolescents' asthma. However, when the family's resources and appraisals do not reduce pressure from the stressor and the associated challenges, the family system's functioning and organisation become destabilised, leading to a crisis state of disorganisation (Schlesinger & Epstein, 2010:306).

In a crisis state the coping mechanisms families normally use to manage stressful situations successfully become immobilised or break down (McCubbin & McCubbin, 1991:95;

McKenry & Price, 2005:17). During this break-down the individual family members tend to experience a variety of affective, cognitive, psychological and behavioural symptoms that significantly differ from their typical ways of functioning (Greenstone & Levitan, 2009:91; Schlesinger & Epstein, 2010:306). These symptoms might include confusion, indecisiveness and a sense of helplessness. Accompanying emotional symptoms of a crisis state might include anxiety, irritability and depression. Social withdrawal, disrupted daily routines and overly depending on others for help can also occur (Schlesinger & Epstein, 2010:306).

In addition to these symptoms family members might experience, a crisis state might also affect the interpersonal relationship patterns in a family. Even though a state of disorganisation results in family members making changes in an attempt to restore equilibrium (changes in roles and development of new resources for example) (Schlesinger & Epstein, 2010:306-307), these changes might also result in the deterioration of relationships due to depression or alienation between family members as a result of the attempt. In contrast, a crisis state can also provide the family with an opportunity for growth and the achievement of a higher level of functioning as a result of the adolescent's asthma as a stressor.

All three of the components as discussed above (stressors, available resources and the family's perceptions) thus interact with each other in order to create the outcome of the crisis (Williams and Williams, 2005:6). For example, asthma and its accompanying financial and emotional stressors exist in the family. In response, the family mobilise their available resources which consist of intelligence, family cohesiveness, social support from extended family, information through health institutions, and financial support. They perceive their stressors to be manageable and their ability to cope with it sufficient. As a result the family does not reach a crisis state of disorganisation, and copes with the adolescent's asthma successfully. In contrast a family might potentially lack the resources required and experience cumulative stressors. As a result they enter a crisis state of disorganisation which is detrimental, not only to their ability to cope with the adolescent's asthma, but also to relationships in the family. The stressors, resources and perception of the event (A, B and C components), thus determine the outcome of the crisis (X) (McCubbin & McCubbin, 1991:62).



## **8. CONCLUSION**

Based on the above review of literature it is evident that asthma, a common chronic illness in the adolescent population, not only affects adolescents' own lives significantly, but also that of their families. In addition the adolescence developmental phase poses challenging tasks for adolescents, such as establishing an identity and achieving autonomy. Conflict can occur between parents and adolescents as a result of adolescents' need for autonomy, and their dependency on their parents as a result of asthma.

The caregiver role of parents coupled with the burdens and demands of asthma might result in psychosocial stressors (social, emotional, physical and financial) placed, not only on the adolescent, but also the family and parents in particular. This might have an impact on the parent-adolescent relationship. The Family Systems theory and the ABCX Family Crisis model were used to explain how families use various behaviours and resources to cope with and adapt to life stressors and crises such as asthma.

In Section B the analysed data and subsequent findings and results will be discussed in article format according to the prescribed guidelines of the Qualitative Health Research Journal.

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## **SECTION B**

### **ARTICLE**

Experiences of Asthma in Adolescence Relating to the Parent-Child Relationship

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#### **Bio**

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## **Abstract**

The aim of the research was to explore and describe the experiences of asthma in adolescence pertaining to the parent-adolescent relationship. A qualitative research design was used. Four families consisting of one adolescent and two parents each, thus twelve individuals in total from Bloemfontein in the Free State region (South Africa), were selected as participants. Qualitative data were collected by conducting semistructured group interviews, unstructured individual interviews and individual reflective journals. The data were thematically analyzed. The results showed that adolescents and their parents experienced ambivalent emotions regarding the adolescents' asthma, as well as contradictory views on the parent-adolescent relationship. They experienced specific roles in their relationships regarding the adolescents' asthma, and faced challenges unique to asthma as a chronic illness on a daily basis. Asthma in adolescence significantly influences the parent-child relationship although the participants' views on their experiences were often of a contradictory nature.

## **Keywords**

adolescents / youth; asthma; families, caregiving; illness and disease, chronic; relationships, parent-child

Asthma can be seen as a global public health phenomenon affecting individuals of all ages and backgrounds and their families (Kabra et al., 2010; Plottel, 2011). It is estimated that 300 million people suffer from asthma internationally and 250,000 premature annual deaths can be attributed to asthma according to the American Academy of Allergy Asthma and Immunology (AAAAI, 2013). The number of people with asthma internationally will increase by an excess of 100 million by the year 2025, as reported by the AAAAI. According to the Global Initiative for Asthma (GINA, 2012) an estimated 3.9 million South-Africans suffer from asthma and South Africa has “the fourth highest asthma death rate in the world among the ages of 5 to 35”. In addition, the most common chronic disease in children is asthma, with nearly 20 percent of South African adolescents reporting asthma symptoms. The asthma prevalence among adolescents in South Africa is on the increase (Zar & Lalloo, 2013).

The period of adolescence often has a negative impact on the parent-adolescent relationship (Brown et al., 2006). In addition to the normal developmental challenges, psychosocial stressors are placed on adolescents and their parents as a result of asthma. This can include emotional stress, difficulty in achieving independence from parents and instability of family relationships (Neinstein, 2008). The adolescent phase is characterized by the tasks of establishing an identity and gaining independence from parents (Erikson, 1968). While adolescents strive towards autonomy, the implications of living with a chronic disease such as asthma might result in prolonged dependence on their parents/caregivers (Neinstein, 2008). This in turn can cause conflict in the family relationships (Penza-Clyve et al., 2004).

The management of asthma takes place in the context of the parent-adolescent relationship, where the parents often fulfill the role of primary caregivers (Goldberg & Rickler, 2011). The quality of these intergenerational relationships largely determines the extent to which adolescents and their parents successfully cope with asthma (O’Donohue &

Tolle, 2009). In addition the parents of a chronically ill adolescent tend to cope with the situation in different ways, mothers behaving in a protective manner and fathers acting in liberating ways (Devore, 2006; Hockenberry & Wilson, 2013). According to Brandt (2001) and Weiner and Freedheim (2003), these parents also have a tendency to show certain behavioral traits including overprotection, rigidity, enmeshment, overindulgence and a permissive style of parenting. In contrast, an authoritative parenting style which includes warmth and psychological autonomy granting, contributes to adolescents effectively coping with asthma and the strengthening of the parent-adolescent relationship (O'Donohue & Tolle, 2009).

Chronic illness in the family has a profound impact on affected individuals and their parents in particular (Vila et al., 2003). The diagnosis of asthma in adolescents often causes parents to experience the non-linear five stages of grief, which consist of denial, anger, bargaining, depression and finally acceptance (Berger, 2008; Falvo, 2013; Kübler-Ross & Kessler, 2005). In addition, adolescents with asthma and their parents might experience feelings of helplessness, fear and anxiety as a result of unpredictable asthma symptoms and the ever-present threat of death (Brandt, 2001). The changes required in families coupled with the added emotional, physical, financial and social demands on parents/caregivers might result in strained parent-adolescent relationships (Falvo, 2005; Taylor, 2003).

Theoretical frameworks were utilized in comprehending how adolescents with asthma and their parents cope with chronic illness in the family relationships. The frameworks consisted of Erik Erikson's theory of social development, Jean Piaget's cognitive developmental theory, the Family Systems theory and the ABCX Family Crisis model.

Available research (Brannon & Feist, 2010; Lamanna & Riedman, 2006; Taylor, 2003) is focused on the individuals' experience of asthma and not on the relationships between individuals with asthma and their families. According to Mooney et al. (2011)

‘Familism’ implies that family relationships are more significant than individual interests. Fisher and Weihs (2000) add to this by stating that the social and relational context in which chronic illness takes place should be taken into consideration. The focus of chronic illness research should be on the family unit and not solely on the individual with a chronic disease such as asthma according to Fisher & Weihs (2000). The exploration of asthma in adolescence relating to the parent-child relationship is thus of vital importance and the following research question was asked: How do adolescents with asthma and their parents experience their relationships with each other?

### **Research Method and Design**

Qualitative research and the multiple case study design were used in this research study to develop an understanding of adolescents with asthma in the context of the parent-adolescent relationship (Delpont, Fouché & Shurink, 2011). According to Yin (2003) a multiple case study allows the researcher to explore differences and similarities between and within cases, and then to draw comparisons.

### **Research Context and Participants**

Participants included adolescents with asthma between the ages of 14 and 18 and their parents. The participants came from White Afrikaans speaking families, from a middle income class although these were not specific criteria for inclusion. The population was obtained through the assistance of a medical practitioner specializing in pulmonary disease. The purposive sampling method was used to collect detailed information from the small case study (Teddlie & Tashakorri, 2009). To qualify for participation in the research, the adolescents had to be formally diagnosed with asthma by a medical practitioner, and currently taking medication prescribed by the relevant practitioner. In addition adolescents had to be living with both of their biological parents in the same household.

## **Procedure and Data Collection**

The research project was conducted under the title approved by the Ethics Committee of the North-West University, Potchefstroom Campus, namely: Developing sustainable support to enhance quality of life and well-being for children, youth and families in South Africa: A transdisciplinary approach. The ethical number is NWU-00060-12-A1. The data collection took place at the participants' private residences, which ensured anonymity. Permission to conduct the study was obtained from the individual participants through informed and written assent and consent. Participation was voluntary, and all information was treated as confidential. The participants' names and potential identifying details were not made known in the final research dissertation. The participants were informed of the option to withdraw at any stage of the research without consequences. Data were then collected by means of conducting semistructured group interviews, unstructured individual interviews and individual reflective journals. The participants were instructed to make a drawing in the journal of the way asthma was experienced in their relationships, and to also make daily entries regarding their relationships. All of the interviews were audio-recorded and transcribed. Member checking (Nieuwenhuis, 2007) of the research findings was done by involving participants in analyzing the data. The trustworthiness of the study was also ensured through crystallisation (Ellingson, 2009) and literature confirmation of the findings.

## **Data Analysis**

The data gathered from the journals and interviews were analyzed by means of Thematic Analysis (Braun & Clarke, 2006). This entailed searching for themes within the data, and then reviewing, defining and naming the themes. The drawings in the journals were analyzed by means of a Shared Analysis (Theron et al., 2011) where participants described and clarified their drawings during the unstructured individual interviews, and themes and patterns were

then identified. The Constant Comparative method (Michie & Abraham, 2004) was used to find major themes in analyzing the field notes.

## Results and Discussion

Themes and subthemes which emerged during the Thematic Analysis are outlined in the table below and subsequently discussed in detail.

**Table 1: Themes and Subthemes Which Emerged from Data-Analysis**

Themes	Subthemes
Polarities in terms of emotions	Positive emotions
	Negative emotions
Polarities in terms of relationship	No change in relationships
	Positive impact on relationships
	Negative impact on relationships
Experience of roles in the relationship as a result of asthma	Parental roles
	Adolescent roles
Other factors experienced in the management of asthma	General factors
	Resources

The following abbreviations were used in quoting participants:

A – Adolescents with asthma

M – Mothers of adolescents

F – Fathers of adolescents

The quotations from participants were originally in Afrikaans, and freely translated in English for the purposes of the submission of the article according to the guidelines of the Qualitative Health Research Journal. The original Afrikaans quotations will only be included if the article is published by the journal.

### Theme 1: Polarities Experienced in Terms of Emotions

It was clear from the interviews and also from the journal descriptions that all the participants experienced mixed emotions regarding the diagnosis and presence of asthma in their family.

Two sub-themes were identified:

### *Subtheme 1: Positive Emotions*

With most participants there was a definite relief after the asthma diagnosis had been made. The reason for this was that a solution for the asthma symptoms had been found and that parents knew how to help the adolescent. This relief was voiced by fathers, mothers and one of the adolescents. One of the parents stated that "...it was a relief to know what she needed and what we had to do to help her" (M3). Another parent confirmed this relief by saying: "...she was only a year old when the doctor said she has asthma, and then we at least knew what it was..." (F4). This relief was also evident when an adolescent said: "It was a relief for me too, to get rid of the coughing" (A1). These feelings of relief were also noted in the field notes. It was specifically noted that: "the parents in particular described the experience of their child's diagnosis in detail and also the subsequent feelings of relief."

According to Bowden and Greenberg (2010), families receiving a diagnosis might experience relief because the problem can be managed and they receive a validation of their child's illness.

Some parents expected all along that the symptoms experienced by the adolescent could be asthma and therefore they were not shocked by the actual diagnosis. One parent stated, "I suspected what it was, because I did research on the internet and quickly realized this is exactly what happened. So it was not a shock for me to hear she has asthma" (F1).

In addition, feelings of joy and relief were experienced by some participants when the adolescent's asthma was under control. One adolescent said: "I was very happy when I did not cough after a race" (A1). Parents stated: "A feeling of relief when he did not cough like the night before" (F3), and "Happiness to see she is also happy and satisfied after she had a good race without any asthma problems" (F1). According to Zabar et al. (2013) some individuals experience happiness when their disease symptoms are under control.



### *Subtheme 2: Negative Emotions*

There were also negative feelings experienced by family members after they had been confronted with the diagnosis. The desire to be disease-free was expressed by all the adolescents, and one parent. This desire was evident with adolescents when they stated that "...there were a lot of times when I wished the coughing was not there" (A1), and "I wish I did not have asthma" (A4). Another adolescent said: "Sometimes I think children without asthma have a better life than I do, because they never have to worry when they go near animals or do sport that they will not be able to breathe" (A2). The parent stated: "...it's a concern for any parent; it's not something you want [asthma]" (F2). According to Freedman et al. (1998), asthmatic adolescents long to be disease-free because they hate bodily imperfections and wish to be normal. Phelps and Hassed (2013) confirm this by stating that adolescents want to see themselves to be as normal as possible.

Negative feelings also surfaced as a result of parents feeling helpless. Most of the parents experienced despondent and frustrated feelings because of the implications of living with asthma in the family. One parent said: "I feel despondent and tired today. I am so tired of the arguing in the house" (M3). Another parent confirmed these feelings by stating: "I feel helpless and powerless; I do not know what to say to her" (M4). A father also said: "I feel helpless" (F4). By the time the adolescent has been diagnosed with asthma, both the adolescent and parents might be exhausted and confused (Lewis, 2006), and this might result in the parents as caregivers feeling helpless, hopeless, and discouraged (Falvo, 2013).

In addition, feelings of disappointment were expressed by one family in particular because of the decreased athletic performance of the adolescent as a result of asthma. The adolescent stated that "I was sometimes disappointed [in myself]", and, "I sometimes wondered if my mom and dad are maybe disappointed in me" (A1). The mother said: "I tried hard not to show the disappointment, but it was very difficult" (M1). The father confirmed

these feelings of disappointment by stating: “I tried to never let her see the frustration and disappointment, because I do not want her to feel like a failure” (F1). Broomes and Broomes (2007) state that unmet expectations, (for example reduced performance as a result of asthma) can trigger feelings of disappointment.

It was also clear from the findings that the life-threatening nature of asthma had a profound effect on the parents and adolescents. Most participants expressed feelings of fear and anxiety in anticipation of an asthma attack and its implications. Parents stated, *inter alia*, that “I must say I had, and still have a fear that he can die as a result of an asthma attack” (F2), and, “Yesterday I had that anxiety again that I experience every time with an asthma attack, I couldn’t sleep last night and when I did, I had nightmares” (M3). Adolescents confirmed these feelings of fear and anxiety by saying: “I am so scared of getting an asthma attack one day and having to go to hospital” (A4), and, “When I think of asthma it makes me stress sometimes, because I know it can cause my death, especially when my chest closes up from animals, then I always worry I might get an attack at the wrong time” (A2).

I also noticed these feelings of fear and anxiety during interviews and in the journals, and I specifically noted that “they [parents] described their child’s asthma attack in meticulous detail, even if it had happened more than ten years ago. I could see the event upsets them a great deal and that the fear, anxiety and concern remain.”

Adolescents and their parents often experience increased levels of anxiety, as well as a fear of death as a result of a possible asthma attack (Brandt, 2001; Jarret & Costello, 1996; Naimi & Apter, 2010). Rhee et al. (2007) report that adolescents with asthma in particular live with a fear of death on a daily basis.

Doka (2013) confirms these polarities in emotions experienced by the adolescents and their parents as a result of asthma. He states that individuals with a life-threatening disease and their families might “experience a range of many-sometimes-contradictory-emotions

simultaneously”. The full range of emotions individuals generally experience in everyday life might also be present in life-threatening diseases such as guilt, anger, fear, anxiety, joy and happiness according to Doka (2013).

## **Theme 2: Polarities Experienced in Terms of Relationships**

The findings clearly showed that all participants experienced mixed beliefs and opinions about the impact asthma had on the relationships in the family. Three sub-themes were identified:

### *Subtheme 1: No Change in Relationships*

Some participants were of the opinion that asthma had no impact or an insignificant role to play in the parent-adolescent relationship. One reason for this was that all but one of the adolescents had been diagnosed with asthma in early childhood, and thus they always had to cope with the management of asthma in their relationships. Adolescents voiced this in the following ways: “Our relationship has always been the same to me, because I have had asthma since I can remember” (A2), and, “...because it [relationship with parents] has been the same since I can remember” (A4). Parents confirmed this belief by saying, “I would say it [relationship with adolescent] has always been the same, because she was so small when she was diagnosed...” (M4), and, “I do not think it [asthma] really plays a role, maybe because he has had it from childhood, it’s normal to us, it is how it has always been and always will be” (M2).

According to Kosciulek (2007), families might describe their lives and relationships as normal, even though they experience a significant illness like asthma. This can be attributed to chronic illness becoming a way of life in families (Bowlby et al., 2010).

### *Subtheme 2: Positive Impact on Relationships*

From the findings it was evident that most participants believed that asthma had a positive impact on the parent-adolescent relationship. The experience of adolescents’ asthma thus

resulted in closer and improved relationships between family members. One reason for this is the belief that parents know their children with asthma better than they would have if they did not have asthma. An adolescent described this in the following way: "...they know before I say anything; it's like a sixth sense. I think they know me better because I have asthma", and, "...I think it makes us closer..." (A3). Parents confirmed this by stating: "I would say we have a stronger bond, I know her better than I would have if she didn't have asthma. Or maybe just in another way, you know" (M3), and, "Yes I would also say we have a stronger bond as a result of her asthma, definitely, we can compare it with our other daughters. I have a premonition with her that I do not necessarily have with the others" (F4). According to Kaduson and Schaefer (2000), experiencing the stressors of chronic illness such as asthma can strengthen family relationships and result in family members becoming closer rather than more distant.

### *Subtheme 3: Negative Impact on Relationships*

Findings showed that adolescents' asthma in the family also had a negative effect on the parent-adolescent relationship. A contributing factor seemed to be adolescents' doubt about their own capabilities, and in addition, parents also doubting the adolescents' abilities as a result of asthma. An adolescent stated: "Before a race I doubted myself and wondered if I will be able to give my best and do well", and, "When I coughed after a race I wondered if I will recover enough for the next one" (A1). Parents confirmed these feelings of doubt by stating: "I wondered in silence whether she will be able to continue while she is coughing so much" (M1), and, "I was unsure before a race if she would be able to give her best" (F1). Even though adolescents face self-doubt as a normal part of their development (Crawford, 2007), a study done by Schulze et al. (1994) reported that adolescents with asthma in particular had considerable self-doubt. This can be attributed to the changes in physical

ability (decreased stamina and increased fatigue) that accompany many chronic illnesses (Sorocco & Lauderdale, 2011).

From the findings it was also evident that conflict in the family as a result of the adolescent's asthma had a detrimental effect on the parent-adolescent relationship. All but one participant expressed this belief. A reason for the conflict is adolescents' tendency to find parents reminding them to take their medication irritating and perceiving it as 'nagging'. This often caused friction and conflict between parents and adolescents. Adolescents voiced this in the following ways: "I sometimes get very irritated when my mom constantly asks me if I have used my pump and drank my pill..." (A2), and, "My dad is again nagging me today and it irritates me so much you do not understand" (A3), and, "It's a day after the game and my mom is still nagging me to use my pump even if I say I'm fine I do not need it. It makes me angry!" (A4). Parents seemed to be aware of this irritation and confirmed it in the following ways: "Today there was conflict again in the household between father and daughter. She can get so irritated when he just asks her a simple question about her asthma" (M3), and, "It usually ends up in an argument, 'leave me alone dad'" (F4). According to Hopson (2012), chronic illness tends to have a negative effect on the parent-child relationship. A contributing factor to conflict between adolescents and parents is the challenging developmental phase adolescents find themselves in which marks an increased need for autonomy and independence from their parents (Naimi & Apter, 2010). This might result in conflict between parents and adolescents as adolescents perceive their caregiver or parent's care and concern as being irritating and nagging (Penza-Clyve et al., 2004).

These polarities in the parent-adolescent relationship were described by me in my field notes as follows: "Even though the families appeared very close and I could see the strong bonds between them, I also sensed underlying tension and conflict. This often surfaced during the interviews when they answered questions together, and had

different opinions and beliefs. I sensed that the ‘difficult’ teenager stage contributed to the conflict.”

Half of the participants also expressed the opinion that the adolescent developmental phase complicates the management of asthma and subsequently relationships in the family. Mothers, fathers and adolescents voiced this belief. Adolescents experience their parents’ care and concern regarding asthma as increasingly irritating as they get older. They expressed this in the following ways: “They have always been like that, but I think it got worse for me as I got older” (A4), and, “I like it that they worry about me and look after me, but as I get older it also starts to irritate me” (A2). Parents were of the opinion that the adolescent stage has a negative impact on not only asthma management, but also the parent-adolescent relationship. One parent stated: “Look if she didn’t have asthma she would probably have gone through the same difficult phase, but the asthma makes it worse regarding our relationship because it results in us arguing” (M4). Another parent confirmed this by saying: “The difficult teenager phase she is going through does not make it [the relationship] any easier” (F4). The developmental stage adolescents face can be particularly challenging, not only for the affected adolescents with asthma but also their families. It poses unique additional challenges to the adolescent with a chronic illness such as asthma (Boltin, 2001; O’Donohue & Tolle, 2009).

The findings also showed that parents perceive the family’s full schedules and busy lives to negatively influence relationships. One parent said: “I must say it makes it [relationships] more difficult, or rather more complicated to interact with each other every day because our lives are so busy” (M3). This belief was also evident with regard to another parent: “...our program is just so full every single day, it makes it difficult, I think in today’s life it is so sad that you do not have alone time with each other anymore, and it makes it difficult to really describe what your relationship is with them [family members]” (M4).

According to Hassett (1996), family's busy schedules can result in them feeling out of touch with one another, thus negatively impacting on family members' relationships.

Literature confirms these findings of polarities in parent-child relationships as a result of chronic illness such as asthma. According to Seligman and Darling (2007) chronic illness in families can have negative, positive or no impact on family relationships. Hynson (2012) confirms this by stating that although the negative impact of chronic illness on family relationships are well known, families' relationships can also be strengthened by the experience of a chronic illness.

### **Theme 3: Experience of Roles in the Parent-Adolescent Relationship with Regard to Asthma**

It was clear from the findings that parents and adolescents have distinct and often contradictory roles in their relationship with regard to the adolescent's asthma. These roles were divided into two sub-themes.

#### *Subtheme 1: Parental Roles*

Most of the parents strongly perceived it as their duty to manage their child's asthma. Parents voiced this belief in the following ways: "She forgot the other day [to take her medication], then it is my duty to make sure she takes it, even if it irritates her" (F3), and, "It's my duty as a parent to make sure she is okay, so sometimes I have to push her with regard to her asthma. I have to check if she used her medication, I mean what if she gets an asthma attack and end up in hospital and it's because I did not check up on her" (M4).

Another parent stated: "She has not left home yet, she is still our responsibility whether she likes it or not. We cannot just leave her to manage it [asthma] on her own, because she has such a big risk for getting an attack. She is on the strongest medication, her asthma is severe, and it's a risk every day" (M3). According to Findley et al. (2013), the management of their

child's asthma can be seen as an extension of parents' basic roles of protecting and nurturing their children.

All of the participants reported parental overprotection as a result of the adolescents' asthma. Mothers, fathers and adolescents voiced this belief. Parents stated: "I know I am overprotective of him, I have always been and still is" (M2), and, "If I compare my older son with him, if I look at it objectively, we overprotect him because he has asthma" (F2). Other parents said: "...maybe too much [caring], one could even say we tend to be a bit overprotective with times" (F4), and, "My fears and concerns form part of the overprotection; it causes me to be even more overprotective" (F3). One adolescent described her parents' overprotection in her reflective journal with regard to her drawing: "Then I immediately see my dad and mom next to me, standing very close (sometimes TOO close). It has always been like that since I can remember" (A3). Another adolescent confirmed this by stating: "...they have always been like that" [overprotective] (A4). I also noted this phenomenon in my field notes: "I noticed during the interviews that the parents had a very protective, perhaps even overprotective attitude toward their child with asthma. They seemed intensely focused on their child, sometimes finishing their sentences." According to Friedman (2008) the parents of adolescents with asthma tend to have an overprotective style of parenting. Brandt (2001) described parental overprotection as a destructive behavior and risk factor to the adolescent coping effectively.

### *Subtheme 2: Adolescent Roles*

The findings showed that in contrast to most parents perceiving it as their duty to manage their child's asthma, some parents also perceived the responsibility of asthma management to be that of the adolescents. This can be attributed to the transitioning period of responsibility adolescents and parents find themselves in regarding the adolescents' asthma management and medicine adherence. These parents believe the adolescents are 'old enough' to take



control over their disease. Parents stated: “I mean she is old enough, she knows when to take which medication with when she goes to athletics, so she can use it when she needs to” (M1), and, “In grade eleven you know how to manage your asthma if you’ve had it from such a young age, we taught her since childhood she has to manage her asthma otherwise she might get an attack, so I think it has become a part of her life now” (M3). Another parent stated: “Her asthma is her own responsibility, and she knows it” (F3). Zografos (2008) is of the opinion that parents often transfer the responsibility of asthma management to the adolescent.

All but one of the adolescents expressed a strong belief that they are capable of managing their own asthma. The findings showed that they clearly felt frustrated and irritated by their parents being involved in their asthma care, and feel they are ‘old enough’ to manage it on their own. One adolescent stated: “I feel they can completely leave me alone I can do it totally on my own, but my mom does not think so”; “I will be able to do it on my own; I do not find it difficult” (A2). The other adolescents said: “I can use the pump myself, I know when to” (A3), and, “I can really look after myself. I am grown up”; “When I do not feel well then I will say so, like I always do, when I’m cold I’ll put on a jacket, if I cannot breathe I’ll stop what I’m doing, it’s not like I overexert myself” (A4). Adolescents might want increased responsibility and control in managing their asthma, and might even resent the degree of dependence they still have on their parents (Mertig, 2007; Schneider et al., 2000).

The above parent-adolescent roles were noted in the field notes as follows:

“It was interesting that in some cases the parents wanted to pass the responsibility of managing the asthma to the adolescents, but they still did not seem to trust them enough to do it completely. They still ‘interfered’ quite often. I am not sure if this is out of habit, a need for control, genuine concern, or a lack of trust. Most of the adolescents seemed to be very irritated by this (except for one, who is significantly younger than the others). They feel they are old enough to manage their asthma

themselves. I suspect this portrays the parents' need for control and the adolescents' developmental need for autonomy.”

In contrast, findings also showed that adolescents tend to enjoy their parents' care and concern with regard to their asthma. These contrasting experiences of adolescents' belief in their capability and enjoyment of parental care often occurred simultaneously in situations. All of the adolescents voiced the feeling of enjoyment of parental care and concern regarding their asthma management. Adolescents stated: “It [the father's overprotection] shows me that he loves me very much, and he cares for me, he supports me a lot with the athletics, he is always there for me” (A1), and, “I like it when they worry about me and care for me...” (A2). This feeling was also evident with regard to the other adolescents: “...but it [parents' overprotection] also makes me feel safe” (A3), and, “...it's also nice to know they worry about me” (A4). Some parents seemed to be aware of this and confirmed it in the following ways: “I think even though it irritates him sometimes, he enjoys the attention he receives from having asthma” (F2), and, “I think she enjoys the attention she gets from us, even though she won't admit it” (F3). Even though adolescents experience an increased need for independence (Mertig, 2007), parents continue to be a primary source of nurturing and protection for adolescents, according to Joffe (2006).

Literature confirms these distinct roles and responsibilities in the parent-adolescent relationship. According to Mazze et al. (2012) the chronic illness of adolescents implies life-long responsibilities for both patients and their family members. Nansel (2006) add to this by stating that flexible roles and responsibilities between parents and their children in a partnership are required in order to successfully adhere to a chronic illness regimen.

#### **Theme 4: Other Factors Experienced in the Management of Asthma**

Participants also mentioned additional factors that influenced the way in which they manage adolescents' asthma in the family. Two sub-themes were identified.

### *Subtheme 1: General Factors*

It was clear from the findings that most participants believe they generally have good parent-adolescent relationships regardless of asthma, and handle stressful situations in the family well. This belief was voiced by mothers, fathers and adolescents. One parent stated that: “I think our family handles crises well, we work together as a team. For example I do the research, my wife handles the finances and works hard, and I take her [adolescent] to the doctor when necessary. We take turns when our jobs and time allow it” (F1), and, “I would say very well [handling of stress in relationships], our family is stable and happy and we handle stress well, even when I am away from home. We talk about everything and are close to one another” (F2). Another parent said: “We do not have problems, not besides the usual, I would say we have a stable family” (M3). Adolescents confirmed this belief by saying: “I think we have a very good relationship. They [my parents] are always there for me and my brother. I am especially close to my dad” (A1), and, “I would say I have a normal relationship with my parents, I do not think it is any different than my friends’ relationships with their parents. I think it’s [relationship with parents] actually good, especially with my mom” (A3). Johnson (2000) is of the opinion that families can maintain healthy parent-child relationships even though they are caring for a chronically ill child and facing the accompanying challenges.

In addition, the findings showed that significant adjustments in the families had to be made after the diagnosis of asthma regarding the family’s routines, lifestyle and precautions that needed to be taken. This was voiced by all the parents. A mother stated that “I think our way of life changed” (M1). Another parent said: “It was a big change in the family, but quickly became part of our lifestyle; I now know what she is allergic to, what will make her chest close up and so forth. I make sure I can handle it if it happens now”; “Everybody had to adjust, and look after her to a degree” (F3). A mother stated: “Our routine and lifestyle

changed significantly. The cough medicine and asthma pumps and physiotherapy that didn't have to be there before [the diagnosis]" (M3). Moreover, families need to make lifestyle changes and adaptations after the diagnosis to accommodate the illness, according to Dougherty (2005). This view is supported by Gopakumar and Gopakumar (2008), who maintain that families should take preventative measures to avoid situations in which adolescents might get an asthma attack or be exposed to harmful allergens.

### *Subtheme 2: Resources*

Some parents expressed a need for knowledge and a solution to the asthma symptoms adolescents experienced. One parent said: "Sometimes a feeling of desperation to find a solution for the problem and preferably a quick one", and, "You basically just need that solution" (F1). Another parent confirmed this need by stating: "It was my first child, and it [asthma] was a new experience, I did not have the knowledge I needed" (F4). According to Wooldridge (2005) adolescents and their families need to be involved in the process of problem solving and search for appropriate solutions for asthma.

It was evident from the findings that some parents also experienced financial strain as a result of adolescents' asthma management and treatment. Parents voiced this in the following ways: "...last week when I went to the pharmacy to buy her asthma pumps the pharmacist said our medical aid is depleted..."; "...it's very expensive; I mean who can afford it"; "...I stress about it..." (M1), and, "...because she [my wife] runs the household, she worries a lot about finances..." (F1). According to Peterson and Sterling (2005), families of children and adolescents with chronic illness such as asthma face unique and complex challenges which might include financial burdens.

### **Conclusion**

The research question has been answered through themes that discussed the participants' experience of their relationship with each other. One of the main dynamics that emerged from

the findings was the adolescents' and parents' mostly opposing and contradictory views about how the adolescents' asthma influenced their lives as a family and in particular the parent-child relationship. Contributing factors to the contrariety in emotions experienced by participants concerning asthma seemed to be the challenges and stressors associated with living with a chronic disease in the family, as well as individuals' subjective experiences thereof. The findings also showed a contrast in the participants' views on how asthma influenced the parent-adolescent relationship, ranging from not at all to a significant positive or negative impact.

Participants experienced specific and often contrasting roles and responsibilities of parents and adolescents regarding the management of asthma in the parent-child relationship. The conflict of adolescents' need for independence and parental regulation could be regarded as a contributing factor. Moreover, asthma had additional implications causing most families to make significant adjustments to their lifestyles and interactions within the family system. From the findings it was evident that the adolescence developmental phase had a profound effect on not only the opposing views of adolescents and their parents, but also on the experience of asthma as a chronic disease in family relationships. The experience of asthma in adolescence relating to the parent-child relationship was thus complex and multifaceted.

### **Recommendations**

The adolescents with asthma and their parents would benefit from a holistic family intervention program supporting them on various levels in coping with asthma as a life-threatening illness in their family relationships. The forming of support groups for families experiencing chronic illness could also aid them in coping with asthma successfully. Further research studies would need to be done to gain insight into how these interventions could be created and maintained in supporting families with chronic illness. In addition further

research on the experience of asthma in adolescence pertaining to the parent-child relationship is necessary. The research gap in this regard warrants an extensive survey.

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# **SECTION C**

## **EVALUATION RECOMMENDATIONS AND CONCLUSION**

### **1. INTRODUCTION**

The previous sections of the research described the orientation, methodology, literature review and findings of the research project. In this section the findings are evaluated and recommendations are made for adolescents with asthma and their parents. An evaluation of the research in terms of the findings meeting the problem and aim of the study was undertaken and is described below. Recommendations that would hopefully inspire some areas for future research endeavours are made, followed by a comprehensive conclusion.

### **2. EVALUATION OF RESEARCH**

#### **2.1 Research problem**

The exploration of the relationship between adolescents with asthma and their parents was addressed from a case study perspective to ascertain how they experienced the parent-adolescent relationship in the context of adolescents' asthma. The detrimental effect the implications of adolescents' asthma has on the parent-adolescent relationship was identified as the research problem.

#### **2.2 Research aim**

The aim of the research study was to explore and describe how adolescents with asthma and their parents experience their relationships with each other. The research aim was reached by following the research procedures and methodology set out in Section A part 1 of the dissertation.

### **2.3 Reflection of experience of researcher**

The researcher was diagnosed with asthma at the age of seven and thus experienced what the influence of chronic illness was in her own relationship with her parents. She expected to have biased or preconceived ideas during the data-gathering process, but managed to block her own preconceptions and expectations to a large extent, and gathered the data with an open mind. She was surprised at how willing the participants were to share information with her, and had pleasant interactions with them.

During the data gathering process the researcher sensed that most of the participants held back information during the group interviews, or were not completely honest in front of each other. It seemed as if they did not want to hurt each other's feelings, and they portrayed detail and events in a more positive light. During the individual interviews they were much more honest. The researcher did not expect this dynamic to occur in the group and individual interviews, even though it seemed obvious afterwards in dealing with sensitive topics. Some of the participants gave contradictory information in the individual interviews to that in the group interviews. The researcher gathered richer information during the individual interviews compared to that in the group interviews. The personal journals helped her to initiate conversation, but did not provide as much data as was expected. The researcher found that the participants perceived the personal journals to be a difficult task.

The researcher also sensed that the participants were never 'forced' to think about these topics before the study, often suppressing their feelings. Most of the participants told the researcher at the beginning of the data-gathering process that they had nothing to say about the subject, and afterwards how surprised they were at how many 'issues' surfaced when they answered the questions and made the journals. The researcher sensed that a greater awareness had been created. The researcher enjoyed the research process and gathered much more data than she expected to. She was surprised at how her own asthma experience with her parents differed from the findings of the research.

### **3. LIMITATIONS OF STUDY**

The study was limited by the small population size and the researcher could subsequently not generalise the research findings. A small contribution was made to fill the research gap by

exploring the experiences of the relationship between adolescents with asthma and their parents. Further research is however needed to explore the experience of chronic illness, and in particular asthma, in the context of the parent-adolescent relationship.

#### **4. RECOMMENDATIONS**

Findings showed that various aspects were involved in the management of asthma in family relationships. As a result the assistance given to these families needs to be of a holistic nature. Due to the relational context of chronic illness, the researcher recommends a family focused approach in helping to manage family relationships and reducing the potential for negative outcomes in family relationships. The intervention programme should address the relational, personal and educational needs of the family members. The holistic family intervention programme for coping with chronic illness could consist of the following components:

- *Psycho-education*

Psycho-education would provide families with information about the psychological and psychosocial aspects of a chronic disease such as asthma. It would also provide behavioural and cognitive techniques for developing the skills needed in coping with chronic illness in the family system (for example stress management, time management and problem solving).

- *Group Counselling/Family therapy*

Group counselling could be used as an intervention to improve communication and to deal with unresolved issues between family members. This might include resolving pre-existing or illness-related communication and other problems. Improved communication skills could aid in maintaining/restoring healthy family relationships.

- *Crisis intervention*

The content of the intervention would depend on the extent to which the family sees chronic illness as a state of emergency. Crisis intervention could be helpful in teaching the family specific strategies by means of which to deal with the crisis.

- *Support groups*

Support groups for chronic illness in families would address (among others) social support, coping, decision making and problem solving in family relationships.



This holistic family intervention programme is an example of how families dealing with chronic illness and in particular asthma, could be assisted in coping and maintaining/developing healthy family relationships.

## **5. CONCLUSION**

It was clear from the research findings that the experiences of the relationship between adolescents with asthma and their parents are complex. The participants' views were contradictory in various respects, and in particular those of adolescents and parents. As the adolescent developmental phase marks an increase in conflict, less time spent together and a generation gap between adolescents and their parents, it could be seen as a contributing factor to the contrasting beliefs and opinions found in the research.

In previous research studies on the impact of chronic disease on affected individuals, caregivers and families, this impact was described as predominantly negative. Although these studies confirm the negative emotions and impact on relationships which the participants experienced, findings also showed that some participants described their experiences as positive. They experienced relief when diagnosed, joy with absence of symptoms, and a closer parent-adolescent relationship as a result of asthma.

It was evident from the findings that parents and adolescents experienced distinct and often contrasting roles in the management of asthma in the parent-adolescent relationship. The experiences of adolescents in particular were contradictory. Most adolescents perceived themselves to be capable of managing their own asthma and often resented parental involvement, but also enjoyed their parents' concern, protection and care. This phenomenon can possibly be explained by the developmental transitioning phase in which adolescents are. Even though they strive towards independence and an identity separate from their parents, adolescents might still be dependent on their parents in numerous ways including for nurturing and emotional support. In addition, some of the parents also experienced ambivalent roles. Most of the parents perceived it as their parental duty to manage their child's asthma themselves while in contrast some transferred the responsibility of asthma management to the adolescent. This phenomenon could be attributed to parents gradually giving more responsibility to the adolescent regarding asthma management and medicine adherence. Parental perception of the roles and responsibility of asthma management might

also play a role, and can be influenced by the following aspects: Adolescents' level of maturity, autonomy, sense of responsibility, presence of risk behaviours detrimental to their health and the quality of the parent-adolescent relationship.

The findings showed that all the families faced challenges and adjustments unique to chronic illness, not only in practical ways, but also in their relationships. Most participants thus experienced adolescents' asthma to have a profound influence on the parent-adolescent relationship. The developmental phase of adolescents had a significant impact on the management of asthma in the parent-adolescent relationship, and families would benefit from assistance in successfully coping with asthma in this often challenging relationship.

# SECTION D

## ADDENDA

### Addendum 1

#### THEMATIC ANALYSIS

Data from the group and individual interviews, together with the individual reflective journals were read and re-read until patterns and categories emerged. The categories were then broadened and themes and subthemes formed.

#### Participants:

<b>A1</b>	Female adolescent with asthma	Aged 14	Diagnosed age 12
<b>M1</b>	Mother of A1		
<b>F1</b>	Father of A1		
<b>A2</b>	Male adolescent with asthma	Aged 17	Diagnosed age 1
<b>M2</b>	Mother of A2		
<b>F2</b>	Father of A2		
<b>A3</b>	Female adolescent with asthma	Aged 17	Diagnosed age 4
<b>M3</b>	Mother of A3		
<b>F3</b>	Father of A3		
<b>A4</b>	Female adolescent with asthma	Aged 17	Diagnosed age 1
<b>M4</b>	Mother of A4		
<b>F4</b>	Father of A4		

**Examples of how categories, sub-themes and themes were formed:**

<b>Number of participants</b>	<b>Broadened Categories</b>	<b>Reflective journal's data (excerpts)</b>	<b>Group interviews' data (excerpts)</b>	<b>Individual interviews' data (excerpts)</b>
5	Desire to be normal/not have asthma	(A4) "Wens ek het nie asma gehad!" (A1) "Baie keer gewens dat die hoes nie daar was nie."	(F2) "Jy weet dis maar 'n bekommernis vir enige ouer, ek meen jy wil dit nie graag hê nie."	
3	Disappointment due to asthma	(A1) "Soms teleurgesteld", "Soms gewonder of my pa en ma dalk teleurgesteld is of was." (M1) "Probeer hard om nie die teleurstelling te wys nie – maar baie moeilik." (F1) "Ook die teleurstelling om haar te sien hoes na wedlope, want dit beteken dat sy met die volgende wedloop nie 100% kapasiteit gaan hê nie."		(P3) "Dat hy baie lief is vir haar, al dink sy dalk dat sy 'n mislukking is of hom teleurgestel het, deurdad sy nie presteer het nie" [met verwysing na die tekening in joernaal].
3	Joy/relief when asthma symptoms are absent	(A1) "Na 'n wedloop wanneer ek nie gehoes het na die tyd nie – was ek baie bly." (F1) "Blydskap om haar ook bly en tevrede te sien, nadat sy 'n goeie wedloop gehad het sonder asma probleme."		
7	Despondent, frustrated feelings as a result of asthma	(M3) "Ek voel moedeloos en moeg vandag." (F4) "Ek voel hulpeloos." (M1) "Magtelose gevoel dat ek 'niks' vir haar kan doen nie."	(F1) "En ek wil by sê by die magteloosheid, ek dink 'n frustrasie, omrede jy magteloos is, en jy, jy kan niks vir haar doen nie."	
10	Emotions	(A2) "As ek dink	(F2) "Ek moet sê	(M4) "...ek meen wat

	experienced in anticipation of an asthma attack	aan asma dan laat dit my partykeer stress, want ek weet dat dit my dood kan veroorsaak, veral as my bors toetrek van diere dan dink ek altyd dat ek dalk op die verkeerde tyd 'n aanval kan kry."	ek het gehad, en nogsteeds, en dit het ek weereens besef toe ek in die studie nou oor die goed begin nadink het, 'n vrees dat hy kan doodgaan as gevolg van 'n asma aanval."	as sy 'n asma aanval kry." (F4) "...wel dis verseker nie lekker om so konstant te worry nie, jy weet, is sy okay, gaan sy die netbal wedstryd oorleef."
6	Feeling of relief with diagnosis of asthma		(M1) "Ek dink ek was verlig in 'n mate, want ons het geweet, hoor hierso, nou gaan dit help." (F4) "...ek meen sy was 'n jaar oud toe ons haar by die dokter kry en hy se dis nou so, toe weet ons darm wat dit is." (A1) "...dit was vir my ook 'n verligting om die hoes klaar te kry."	
2	Suspected asthma diagnosis – did not come as a shock		(F1) "Ek het vermoed wat dit is, want uhm, wat ek gewoonlik doen met sulke goed is ek gaan doen bietjie navorsing en goed en so aan op die internet, en toe het ek gou agtergekom dit is nou presies wat gebeur het so ek het eintlik geweet wat dit is"; "so dit was nie vir my 'n skok om te hoor sy het asma nie."	
4	Doubt about own/child's capabilities due to asthma	(A1) "Ek het voor 'n wedloop getwyfel en gewonder of ek		

		<p>my beste kan gee en goed sal kan doen”;</p> <p>“...gewonder of ek regtig genoeg kompetierend was.”</p> <p>(M1) “...in stilte gewonder of sy nog sal kan aanhou terwyl sy so hoes.”</p> <p>(F1) “Onsekerheid voor wedlope of sy haar beste sal kan gee”; “...die afwagting en spanning tydens die wedlope om te kyk of sy end uit gaan kan volhou.”</p>		
11	<b>Conflict/negative effect on family as a result of asthma</b>	<p>(A2) “Ek raak partykeer baie geirriteerd as my ma my aanmekaar vra het jy jou pompie en jou pil gedrink.”</p> <p>(M3) “Konflik tussen haar en my man daaroor, [medikasie gebruik] atmosfeer in die huis.”</p>	<p>(M4) “Ek dink vir haar is dit meer van ‘n irritasie.”</p> <p>(F2) “Ja ek dink die konflik as gevolg van die irritasie wat hy het omdat sy ma hom so baie vra oor die asma, is ‘n uitdaging in ons verhouding want dan sal ek en sy ook baie keer daaroor stry, so dit betrek ons al drie.”</p>	<p>(A3) “Uhm ek sal sê, dit irriteer my obviously partykeer dat hulle so erg aangaan oor my asma, jy weet. Partykeer vra hul my dieselfde ding soos drie keer ‘n aand, en ek meen ek het dit mos die eerste keer al gehoor.”</p>
9	<b>Closer/improved relationships due to asthma</b>	<p>(M2) “Wat ons verhouding betref dink ek ek is nader aan hom omdat ek miskien voel hy het my meer nodig as sy ouer broer.”</p>	<p>(F4) “Ja sal ook sê dat ons ‘n sterker, uhm, band het met haar as gevolg van die asma, definitief ons kan dit vergelyk met die ander dogters. Ek het ‘n voorgevoel met haar, soos my vrou nou gesê het, wat ek nie so</p>	<p>(A3) “Uhm, ek dink my ouers ken my beter omdat ek asma het, en dit maak ons seker closer.”</p> <p>(M4) “Maar uhm, ek moet ook sê, soos ek laas keer genoem het, die asma het ons ook nader aan mekaar gebring, dit maak dat ek haar net</p>

			erg met die ander het nie.”	soveel beter ken, ek lees daai kind soos ‘n boek.”
8	No/insignificant change in relationships after asthma diagnosis		(F1) “...ek dink nie ons verhouding tussen ek en my dogter en ek en my vrou het verander nie, hetsy meer positief of meer negatief nie.” (M2) “Ek dink nie dit speel regtig ‘n rol nie, omdat hy dit van kleins af het, dis vir ons normaal, dit is maar soos dit nog altyd was en sal wees.”	(M4) “...ek sal sê dit [verhoudings] was maar nog altyd dieselfde, omdat sy so bitter klein was toe sy gediagnoseer is.” (A1) “Uhm dit was fine, dieselfde as altyd maar” [verhouding met ouers na diagnose].
6	Adolescent phase has negative impact on asthma			(M3) “Maar haar tiener fase maak seker dat dit ok nou weer erger is.” (A4) “Hulle was maar nog altyd so, uhm dink dit raak net vir my erger soos ek grootword.” (F4) “En haar uhm, moeilike tiener stadium waardeur sy gaan maak dit nie makliker nie.”
2	Parents perceive family’s busy schedules to negatively influence relationships		(M3) “Ek moet sê dit maak dit [verhoudings] moeiliker, of uhm eerder meer ingewikkeld omdat ons almal se lewens so besig is, om by mekaar uit te kom elke dag.” (M4) “...die program is net so groot, en ons is so oorvol elke liewe dag dat dit maak dit baie moeilik, so uhm ek dink vandag se lewe is dit so erg dat mens nie meer daardie	

			alleen tyd het met mekaar wat dit moeilik maak ook om regtig te sê wat is jou verhouding met hulle.”	
12	Parental overprotection as a result of adolescents' asthma	(F1) "...as ouer oorbeskermend teenoor haar op te tree en situasies te probeer vermy, waar sy asma kan kry!" (A3) "Dan sien ek ook onmiddelik my pa en ma langs my, wat baie naby aan my staan (partykeer TE naby) dit was nog altyd so, van ek kan onthou."	(M2) "So ek weet ek is oorbeskermend teenoor hom, was nog altyd en is steeds." (F2) "Ek wil amper vir jou sê, as ek my ouer seun met hom moet vergelyk, as jy eenkant staan en gaan kyk daarna, oorbeskerm ons hom omdat hy asma het."	(M3) "...omdat ons oorbeskermend is, is ons baie besorgd en attentive teenoor haar, veral toe sy klein was." (F3) "My vrese en bekommernisse is maar deel van die oorbeskerming, uhm omdat dit mos nou maak dat ek meer so is."
6	Parents perceive the responsibility of asthma management to be that of the adolescent	(M4) "Ek is seker ek is te hard...raak ek gewoon- nee sy is grootgenoeg sy kan na haarself kyk."	(F4) "Nee sy moet dit [medikasie] self gebruik sy weet mos wanneer sy moet en hoe dit is jy weet wanneer sy nie reg voel nie."	(F2) "So ek sal sê die verantwoordelikheid wat ons by hom gekweek het van kleins af, het definitief bygedra tot sy amazing sin van verantwoordelikheid. Ons het dit in hom ingedrill om self sy asma onder beheer te hou."
4	Adolescents believe they are capable of managing their asthma	(A4) "Vandag was 'n koelerige dag, ek was seker 9 keer vandag gevra is jy warm aangetrek? Jy gaan siek word! Soek jy 'n baadjie? Nee regtig waar ek is seker oud genoeg om te weet wanneer ek koud kry."	(A2) "Ek voel net hulle kan my heeltemal los ek kan dit totaal op my eie doen, maar my ma dink nie so nie"; "Maar ek sal dit op my eie kan doen, dis nie vir my moeilik nie."	(A3) "...en ek kan mos self my pompie gebruik, ek weet wanneer ook." (A4) "Ek verstaan dit nie. Ek meen hoe moeilik is dit nou om 'n baadjie aan te trek as ek koud is, ek weet mos wanneer, en 'n pompie te gebruik as my bors toe is. Dis mos nou nie flippen rocket science nie."



5	Parents perceive it as their duty to manage their child's asthma	(F3) "Sy het nou die dag vergeet, dan is dit my plig om haar te herrinner en seker te maak sy doen dit, al irriteer dit haar."	(M4) "Sy hou nie daarvan dat mens baie vrae vra nie maar ongelukkig as 'n ouer moet jy."	(F1) "Uhm ek sal sê, al daardie emosies maak dat ek dalk erger is oor haar, omdat sy half weerloos is as gevolg van die asma, uhm voel of ek haar moet beskerm, laat niks slegs gebeur jy weet."
7	Adolescents enjoy their parents' concern and care due to their asthma	(A3) "...maar dit laat my ook veilig voel."	(A2) "Maar dis vir my lekker as my ma nog partykeer vra gebruik jou pompie en goeters." (A3) "Maar dis ook lekker om te weet hulle gee so baie om jy weet."	(A1) "Uhm goed, veilig" [dat ouers altyd daar is]. (M2) "Hy het mos gesê hy hou daarvan dat ek hom herrinner en omgee, die aandag."
12	Adjustments in family after diagnosis (way of life, routines and precautions)	(M2) "As ek nou daaraan dink beseft ek dat ek heeltyd sy asma in my agterkop het. Ek sal altyd sorg dat daar in ons motors, sy skooltas, krieket tas, my handsak ens. 'n asma pompie is. Ons lewe rondom asma." (M2) "Daar is maar altyd allergie pille by my."	(M1) "Ek dink ons lewenswyse het verander" [na diagnose]. (F2) "...so aan die begin, daai eerste fase, was vir my persoonlik 'n redelike aanpassings fase gewees." (M1) "As sy hardloop byeenkomste toe gaan vat ek altyd die pompie, hy is altyd in die koelhouertjie, ons vat hom maar saam, vir ingeval hy is maar daar, mens weet nooit met die stof en so aan."	(M2) "...dis al deel van die leefstyl."
10	Family has good relationships and handle crises well	(A4) "My verhouding met my pa is goed"; "My verhouding met my ma is ook goed."	(F3) "Ek dink ek het 'n goeie verhouding met my vrou en kinders, uhm, ek is maar 'n familie	(F2) "Ek sal sê baie goed, ons gesin is baie stabiel en gelukkig hanteer ons druk baie goed selfs al is ek weg

			man so dit is vir my vrek belangrik om te weet dat hulle oraait is.”	van die huis af. Ons praat altyd alles uit as daar iets is, en uhm, ons is baie geheg aan mekaar.”
2	Parents' search for a solution and knowledge to adolescent's asthma symptoms	(F1) “Somtyds ‘n gevoel van desperaatheid om ‘n oplossing te kry vir die probleem [asma simptome] verkieslik ‘n vinnige oplossing.”	(F4) “Ja dis ‘n mens se eerste kind, ek bedoel dis mos nou weer ‘n nuutigheid en jy dra nie kennis van al die goed nie.” (F1) “Jy soek daardie oplossing net basies.”	
2	Financial strain due to asthma		(M1) “So laas week toe ek haar pompies gaan herhaal toe sê die man by die apteek luister die mediese fonds is uitgeput”; “...dis deksels duur, ek meen wie kan dit bekostig.”	(F1) “...maar omdat sy die huishouding uhm run, bekommer sy haar baie oor finansies.” (M1) “Jong ek wou dit nou nie voor haar sê nie, maar daardie pompies kos ‘n helse lot geld elke maand”; “Wie kan een duisend twee honderd rand ‘n maand daaraan spandeer? Mens stress daaroor.”

## Themes:

### 1. Polarities in terms of emotions

#### Sub-themes

- Positive emotions
  - Feeling of relief with diagnosis of asthma
  - Suspected asthma diagnosis-did not come as a shock for parents
  - Joy/relief when asthma symptoms are absent or under control
- Negative emotions
  - Desire to be disease free
  - Disappointment due to asthma

- Despondent, frustrated feelings as a result of asthma
- Emotions experienced in anticipation of an asthma attack

## **2. Polarities in terms of relationship**

### **Sub-themes**

- No change in relationships
  - No/insignificant change in relationships after asthma diagnosis
- Positive impact on relationships
  - Closer/improved relationships due to asthma
- Negative impact on relationships
  - Doubt in own/child's capabilities because of asthma
  - Conflict/negative effect on family as a result of asthma
  - Adolescent phase negatively impacts on management of asthma and relationships
  - Parents perceive family's busy schedule to negatively influence relationships

## **3. Experience of roles in the relationship as a result of asthma**

### **Sub-themes**

- Parental roles
  - Parents perceive it as their duty to manage their child's asthma
  - Parental overprotection as a result of adolescent's asthma
- Adolescent roles
  - Parents perceive the responsibility of asthma management to be that of the adolescent
  - Adolescents believe they are capable of managing their own asthma
  - Adolescents enjoy their parents' care and concern due to asthma

#### **4. Other factors experienced in management of asthma**

##### **Sub-themes**

- General factors
  - Family generally has good relationships and handle crises well
  - Adjustments in family after diagnosis
- Resources
  - Parents' need for a solution/knowledge
  - Financial strain on family due to asthma

## Addendum 2

### FIELD NOTES (Constant Comparative method- excerpts of major themes)

The diagnosis of asthma seemed to be a relief for most participants. The parents in particular described the experience of their child's diagnosis in detail and also the subsequent feelings of relief. I realised that some of them had a need for more knowledge about their child's disease, and also the financial strain often accompanying chronic illness. I also noticed during the interviews that the parents had a protective, perhaps even overprotective, attitude towards their child with asthma. They seemed intensely focused on their child, sometimes finishing their sentences. I found this very interesting. They also described their child's asthma attack(s) in meticulous detail, even if it had happened more than ten years ago. I could see that the event upsets them a great deal, and that the fear, anxiety and concern remain. They portrayed powerful emotions while describing the attack(s), and I realised for the first time how my parents must have felt with my asthma attack. In many cases this was also the first time that the adolescents heard their parent's version of events and their experience of their feelings been spoken out aloud, and I could see the surprise on their faces. I realised this could be because of the parents' attempts to 'stay strong' for their child's sake.

These fears and concerns are often subconscious and not spoken about in the family. Even though the families appeared very close, and I could see the strong bonds between them, I also sensed underlying tension and conflict. This often surfaced during the interviews when they answered questions together, and had different opinions and beliefs. I sensed that the 'difficult' teenager stage could contribute to the conflict. It was interesting that in some cases the parents wanted to pass the responsibilities of managing the asthma to the adolescent, but they did not seem to trust them enough to do it completely, as they still 'interfered' quite often. I am not sure if this is out of habit, a need for control, genuine concern, or a lack of trust. Most of the adolescents seemed to be very irritated by this (except for one, who is significantly younger than the others). They feel they are old enough to manage their asthma themselves. I suspect this portrays the struggle between the parent's need for control and the adolescent's need for autonomy.

### **Addendum 3**

#### **CONSENT FORM FOR RESEARCH**

##### **INFORMED CONSENT FORM for parents of child participant.**

The information in this document will provide the participant with the necessary details in order to make an informed decision about voluntary participation in this study.

Title of study:

Experiences of the relationship between adolescents with asthma and their parents.

Institution:

North-West University (Potchefstroom Campus).

Name and contact details of researcher:

Marike Rossouw

082 399 7857

The requirements of participants and reason for choosing the participant:

- Participants include both adolescents and parents.
- Adolescents must be between the ages of 14 and 18.
- Adolescents must still be living with both biological parents.
- Adolescents must have been diagnosed with asthma by a medical practitioner longer than a year previously.
- Adolescent must currently receive medication/treatment prescribed by the relevant practitioner.

The participants were chosen on the grounds that they meet the criteria as set out above.

What is the purpose of this study?

The purpose of this research will be to use a case study design to qualitatively consider and describe how adolescents with asthma and their parents experience their relationships with each other.

What will be expected of the participant and what exactly will it involve?

The participants (adolescents and parents) will be expected to keep a reflective journal individually from the date of signing this document until the date of the interview.

Participants will also be expected to attend one group interview session of approximately an hour and a half (adolescent and parents together) and an individual interview session. The researcher will discuss a convenient date, time and venue with the participants.

Each participant will be asked to make a drawing in the journals in their own time. The focus will be on the content of the drawing and not the quality.

What are the potential discomforts and/or potential dangers and/or permanent consequences (however negligible) that participation in this study involves?

The researcher can foresee no discomfort, dangers or permanent consequences to participants as a result of participating in this study. If emotional needs should arise, referrals will be made to appropriate professionals.

What precautions have been taken to protect the participant?

The researcher will adhere to a strict ethical code that will ensure the well-being of participants at all times, and is continuously under supervision.

Is any payment or benefits offered to the participant when participating in this study?

No payment will be offered. Snacks and beverages will be available at the interview session for the enjoyment and comfort of the participants. The knowledge that may be gained by means of this study may benefit other persons or communities.

What potential general benefits which may arise from the study are there for the broader community?

The exploration of the relationships between adolescents with asthma and their parents are of vital importance in order to understand how the well being of individuals and families with chronic disease, in particular asthma, can be improved in the future.

How will the findings of this study (general, as well as individual results) be made available or conveyed to the participant?

The research findings will be part of a published magisterial thesis.

**As the researcher, I confirm to the participant that the above information is complete and correct.**

**Signature of researcher:**

**Date:**

**Place of signature:**

**You are invited to take part in the research study as described above. It is important that you also read and understand the following general principles, which are applicable to all participants in the research study:**

1. Participation in this study is completely voluntary and no pressure, however subtle, may be placed on you to take part.
2. It is possible that you might not derive any benefit personally from your participation in the study, although the knowledge that might be gained by means of the study might benefit other persons or communities.
3. You are free to withdraw from the study at any time, without stating reasons, and you will in no way be harmed by so doing. You may also request that your data no longer be used in the study.
4. By agreeing to take part in the study, you are also giving consent for the data that will be generated to be used by the researcher for scientific purposes as she sees fit, with the caveat that it will be confidential and that your name will not be linked to any of the data without your consent.
5. You will be given access to your data upon request, unless the Ethics Committee of North-West University has approved temporary non-disclosure.
6. A summary of the nature of the study, the potential risks, factors that might cause you possible inconvenience or discomfort, the benefits that can be expected and the known and/or probable permanent consequences that your participation in the study might have for you as participant, are set out for you in the explanation above.
7. You are encouraged to ask the researcher any questions you might have regarding the study and the related procedures at any stage. The researcher will gladly answer your queries and will also discuss the study with you in detail, if that is your need.
8. The study aims are always secondary to your well-being and actions will always place your interests above those of the study.



**I, the undersigned** *(full names and surname)* have read the preceding premises in connection with the study, as discussed in this informed consent form, and have also heard the oral version thereof and I declare that I understand it. I have also initialled every page. I was given the opportunity to discuss relevant aspects of the project with the researcher and I hereby declare that I and my child may voluntarily take part in the study.

**Signature of the guardian of the participant:**

**Date:**

**Signed at:**

**Witnesses:**

**Signature of witness 1:**

**Date:**

**Signed at:**

**Signature of witness 2:**

**Date:**

**Signed at:**

## **Addendum 4**

### **AGREEMENT BETWEEN MEDICAL PRACTITIONER AND RESEARCHER**

The medical practitioner hereby agrees to the following:

- To contact existing patients who fit the criteria of the research study on behalf of the researcher in order to determine whether they will be willing to participate in the study.
- To make the details of the patients who are willing to participate and who have given oral consent known to the researcher.
- The practitioner will have no further responsibilities after the details of patients willing to participate have been given to the researcher.

The researcher will at all times adhere to a strict code of conduct and will keep the details of the medical practitioner and patients confidential.

**The researcher will discuss the protocol and all aspects of the study with the relevant practitioner before the patients are contacted.**

**Signature of researcher:**

**Date:**

**Place of signature:**

**Signature of medical practitioner:**

**Date:**

**Place of signature:**

## **Addendum 5**

### **SEMISTRUCTURED GROUP INTERVIEW SCHEDULE**

The questions were asked to the adolescent and parents together.

The participants' biological information was also established (age, marriage status etc.).

1. Tell me about your experience of the diagnosis in your relationships.
2. How did you experience your relationships after the diagnosis?
3. What specific changes occurred regarding your relationships after the diagnosis?
4. Tell me about the specific challenges in your relationships after the diagnosis.
5. What would the positive aspects be that came from the diagnosis regarding your relationships?
6. How would you view yourself and your relationships with your parents/child at this moment?

## **Addendum 6**

### **JOURNAL SUBMISSION GUIDELINES**

(Note: This is a shortened version of guidelines applicable to the research article; for the complete guidelines consult the following website: <http://qhr.sagepub.com/>)

#### **Journal submission guidelines**

##### **Qualitative Health Research Journal (QHR)**

Qualitative Health Research, widely referred to as *QHR*, is an international, interdisciplinary, refereed journal for the enhancement of health care. Published monthly, it is designed to further the development and understanding of qualitative research methods in health care settings. The journal is an invaluable resource for researchers, practitioners, academics, administrators, and others in the health and social service professions, and graduate students who seek examples of qualitative methods.

##### **Comprehensive, Timely Coverage from a Variety of Perspectives**

Issues of *QHR* provide readers with a wealth of information, including articles covering research, theory, and methods in the following areas:

- Description and analysis of the illness experience
- Health and health-seeking behaviours
- The experiences of caregivers
- The sociocultural organization of health care
- Health care policy
- Related topics

Articles in *QHR* examine an array of timely topics such as chronic illness; risky behaviour; patient-health professional interactions; pregnancy and parenting; children's perspectives on health and illness, and much more. In addition the journal addresses a variety of perspectives, including cross-cultural health, family medicine, health psychology, health social work, medical anthropology, sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

## **Publisher**

*QHR* is published by Sage Publications, Inc., 2455 Teller Road, Thousand Oaks, CA 91320, USA; [www.sagepub.com](http://www.sagepub.com); telephone 800-818-7243

## **JOURNAL STYLE**

### **General Information**

This section of the Guidelines covers matters of *QHR* journal style, which are not subject to author preference; adherence is required.

### **Important Considerations**

- *Qualitative Health Research* is a peer-reviewed journal. Only complete, finished manuscripts should be submitted for consideration.
- We do not publish stand-alone abstracts, *quantitative studies*, manuscript outlines, pilot studies, manuscripts-in-progress, letters for inquiry, or literature reviews. Research articles must be *pertinent to health*.
- Write both the abstract and the text of your manuscript in *first-person*, active voice.
- For best results, review this entire document prior to preparing your and submitting your manuscript.

### **General style**

We ask authors considering submission to *QHR* to review these guidelines, survey several issues of the journal, and make their own decision regarding the “fit” of their article for *QHR*’s mission.

In general, *QHR* adheres to the requirements of Sage Publications, Inc., and the guidelines contained in the *Publication Manual of the American Psychological Association* [“APA”], **6<sup>th</sup> edition** (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10-4338-0562, spiral bound), with regard to manuscript preparation and formatting. Elsewhere in these Guidelines this book is referred to as the *APA Publication Manual*, or just APA.

- When APA rules and *QHR* guidelines conflict, follow *QHR*.

## Confidentiality and Protection of Identity

*QHR* is committed to protecting the identity and confidentiality of research study participants. With the exception of participatory action research (PAR), *no information* that could potentially allow identification of a participant – or even a *specific study site* – should be included in a submitted manuscript, or, subsequently, included in a published article.

## Word Choices

It is always best to use the most precise language possible to convey important data, concepts, and findings. Because *QHR* is an international journal published in U.S. English, there is the added need to avoid commonly used English terms (colloquialisms, slang) that might be misinterpreted by or confusing to readers whose first language is something other than English.

(Only some of the examples are included here)

Word or phrase	Consideration
as	Do not use this word when your meaning is <i>because</i> .
amongst	Use <i>among</i> instead.
can't, don't and so forth	Use <i>cannot</i> , <i>do not</i> , and so forth. Do not use contractions unless they are part of a quotation.
due to	Use <i>because of</i> instead.
etc.	Use <i>and so forth</i> instead.
may	Do not use this word in place of <i>might</i> . Use <i>may</i> for permission, <i>might</i> for possibility, and <i>can</i> for ability.

## BASIC DOCUMENT PREPARATION

**Note:** Do not use any coding or formatting that is not described within these Guidelines!

### Document Setup and Formatting

Document file type:	Submit only documents created in Microsoft Word, and only with the regular extension of .doc or .docx (do not submit manuscripts with .docm, .rtf, .pdf or other extensions).
Paper size:	Letter, 8.5 x 11 inches, with portrait orientation

Margins:	1 inch (1”); approximately 2.5 cm.) on all sides
Line numbers:	None
Line spacing:	Exactly “double”, with 0” before and 0” after

### Order of Manuscript Elements

Compile the elements of your manuscript in the following order:

Document 1:	Title page (required)
Document 2:	Abstract and keywords (required) Main manuscript text (required) Notes (if any) References (required) Appendices (if any) Tables (if any)
Document 3:	Figure 1 (if any)
Document 4:	Figure 2 (if any; and so forth, with each subsequent figure in a separate document)

### Formatting of Manuscript Elements

**Note:** For ease in locating needed information, the various elements are listed below in alphabetical order, and not in the order of anticipated use.

(Only some of the applicable elements are included as examples here)

Font size: text	Use 12-point font for everything except in tables, figures and (if applicable) conversation analysis.
Font size: tables and figures	Use only 8-point font in tables and figures
Font style: headings, title page, abstract, keywords, tables and figures	Use Gill Sans font style for all of these. This includes figure/table numbers, titles, text within figures/tables, and citations or explanatory notes below the figures/tables. Note: If you do not have font on your

	computer, please use Arial instead.
Font style: main manuscript	Use Times New Roman font for the main body text. Also, use Times New Roman font for the text (not the headings) of author's notes, acknowledgements, declarations of conflicting interests, funding statements, footnotes and bios.
<i>Italics</i> should be used only:	As appropriate in the reference list (see APA) as appropriate in level-2,3 and -4 headings, to introduce non-English words, or <i>unusual</i> concepts (2 to 3 words) and then only when the new word or concept is first introduced in the manuscript; subsequent use of the same word(s) should be in regular Roman font.
Headings	All headings, without exception, are to be set in Gill Sans/Arial, 12-point font.
<i>QHR</i> uses 4 distinct levels of headings (H = Heading) including:	H1 – <b>Flush Left, Bold Text, in Title Case</b> H2 – Flush Left, <i>Italicized Text</i> , in Title Case H3 – Flush left, <i>italicized text</i> , sentence case, ending with a period. Try to avoid this heading if possible and use only H1, H2 and H4. H4 - Indented (.5" or 1.3cm.), <i>italicized text</i> , in sentence case, and ending with a period.
Use at least two heading levels:	For manuscripts with 2 heading levels, use H1 and H2 For manuscripts with 3 heading levels, use H1, H2 and H4 (not H3) For manuscripts with 4 heading levels, use H1, H2, H3 and H4
Justification of margins:	All text should be left justified
Length of manuscript:	There is no predetermined word or page



	limit. Provided they are ‘tight’ and concise, without unnecessary repetition and/or irrelevant data, manuscripts should be as long as they need to be.
Line spacing:	Everything, in all elements of the manuscript, from the title page through the references and tables (if any), must be exactly double spaced. The only exception: Text within a figure should be single spaced.
Paragraphs:	Paragraphs are to flow, one after the other, without additional line breaks and with no extra space between paragraphs. Leave a blank (double-spaced) line between the abstracts and the keywords.
Indentation in paragraphs:	Indent the first line of every new paragraph by approximately 1.3 cm. except: The first line of the abstract and keywords The first (opening) paragraph of the manuscript text Paragraphs immediately after level-1 and level-2 headings.
Keywords:	Keywords should follow on the same page as the abstract. Leave a blank, double-spaced line between the abstract and the keywords. Include keywords selected only from the QHR Keyword List, and list them exactly as they are shown in the keyword list, in lowercase letters, horizontally across the page, in the order in which they appear on the keyword list. Try so select at least 5 keywords. Individual keywords should be separated by semicolons. Do not capitalize the first keyword unless it is a proper name.

	Do not add a period (full stop) at the end of the keywords.
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## Preparation of Manuscript Elements

Title Page:	<p>Should include the following, in order:</p> <ul style="list-style-type: none"> <li>- Article title</li> <li>- Author names</li> <li>- Author affiliations</li> <li>- Corresponding author information</li> <li>- Author's note – optional</li> <li>- Acknowledgements – optional</li> <li>- Declaration of conflicting interests</li> <li>- Funding</li> <li>- Bios</li> </ul>
Abstract and Keywords:	<p>Abstract should be placed at the top of page 1 of the main manuscript document.</p> <p>It should be a single paragraph, no more than 150 words in length, and briefly describe your article. It should not contain headings or citations, and should not be divided into sections. Place your keywords below the abstract, on the same page.</p>
Main Manuscript:	<p>The main text of the manuscript begins at the top of page 2 of the document, immediately after the abstract page. Write your article in the first-person, active voice. The main text of the manuscript should be broken into appropriate sections by the use of section headings. Sections should flow in a logical sequence, and include, at a minimum, Methods, Results and Discussion (these are level-1 headings). Other level-1 headings and</p>

	<p>subheadings may be used at the author's discretion. The author may choose to use different names for the three main sections, but the basic content should be that which would appropriately fall under the headings of Methods, Results and Discussion. For in-text citations use APA 6<sup>th</sup> ed. Use only U.S.-English spelling.</p>
<p>References:</p>	<p>The reference list should include complete references for the sources used in the preparation of your manuscript. Every reference must be cited in the text. The reference list should begin on a separate page. Use only the 6<sup>th</sup> ed. of APA as your source of instruction for references.</p>
<p>Appendices:</p>	<p>Appendices are not encouraged, and are published only at the editor's discretion. If included, appendices should be placed in the main manuscript document following the reference list, and before any tables.</p> <p>Appendices must be referred to in text. Place tables, one per page, at the end of the main manuscript document, after the references.</p>