

# **Resilience characteristics of families with a child with type 1 diabetes**

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## **DECLARATION**

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## SUMMARY

A chronic illness such as type 1 diabetes does not only have an impact on the individual's physical and psychological well-being, but ultimately on the well-being of the family as a whole. The family typically fulfils the role of primary support structure for the diabetic child. Regardless of the physical and psychological challenges that form part of the illness, a large number of families are resilient. Families are able to adjust, adapt and cope adequately with a variety of life stressors. Consequently, this study aimed to identify and explore family resilience characteristics that are associated with family adaptation after the diagnosis of a chronic illness in a child. The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001) served as theoretical framework for this study. Fifty-one primary caregivers represented families with a child with type 1 diabetes who was a patient at a big state hospital in the Western Cape, South Africa. The study used a mixed methods approach and it was expected from the participants to answer an open-ended question and complete four self-complete questionnaires. The dependent variable in the study is family adaptation, measured with the Family Attachment and Changeability Index 8 (FACI8) (McCubbin & McCubbin, 2001). Based on the theory and previous studies, the following independent variables were used as measures: family hardiness (The Family Hardiness Index (FHI)), family patterns of communication (Family Problem Solving and Communication Scale (FPSC)) and family time spent together, as well as routines followed together (Family Time and Routine Index (FTRI)). The results show that family resilience characteristics that are significantly correlated with family adaptation are affirming communication in the family; the family's willingness to accept change as positive; and family time spent together and routines followed in the family. The most important resilience characteristic according to the qualitative data is the support and information received from the paediatric diabetes specialist at the hospital. The family's religious beliefs, and support received from their church, also play a significant role in their adaptation. This study contributes to the increasing need for and value of positive psychology. The study also creates an opportunity to educate families and medical personnel on the importance of implementing resilience characteristics in families to ensure better adaptation. Recommendations for future studies on resilience in families with a child with type 1 diabetes are made.

Key words: family resilience, type 1 diabetes, adjustment, adaptation

## OPSOMMING

'n Chroniese siekte soos tipe 1 diabetes het nie 'n enkelvoudige impak op die individu se fisiese en sielkundige welstand nie, maar uiteindelik ook op die gesin se welstand. Die gesin vervul tipies die rol van primêre ondersteuningsnetwerk vir die kind met diabetes. Ongeag die fisiese en sielkundige struikelblokke wat deel is van die siekte, bly 'n groot aantal gesinne steeds veerkragtig. Gesinne beskik oor die vermoë om verstellings te maak en aan te pas by 'n verskeidenheid van lewensstressors. Gevolglik het hierdie studie gepoog om gesinsveerkragtigheidskenmerke te identifiseer en te verken, nadat 'n kind met 'n chroniese siekte gediagnoseer is. Die *Resiliency Model of Family Stress, Adjustment and Adaptation* (McCubbin & McCubbin, 2001) het gedien as die teoretiese raamwerk vir hierdie studie. Een-en-vyftig primêre versorgers het hul gesinne in die studie verteenwoordig. In elk van die gesinne was daar 'n kind met tipe 1 diabetes wat 'n pasiënt was by 'n groot staatshospitaal in die Wes-Kaap, Suid-Afrika. Die studie het gebruik gemaak van 'n gemengde-metode benadering en het van die deelnemers verwag om 'n oopende-vraag te beantwoord, sowel as vier kwantitatiewe vraelyste te voltooi. Die afhanklike veranderlike in die studie was gesinsaanpassing, gemeet met die *Family Attachment and Changeability Index 8* (FACI8) (McCubbin & McCubbin, 2001). Gebasseer op die teorie en die bevindinge van vorige studies is die volgende meetinstrumente gebruik om die onafhanklike veranderlikes mee te meet: die *Family Hardiness Index*, *Family Problem Solving and Communication Scale*, en die *Family Time and Routine Index*. Die kwantitatiewe resultate toon die volgende gesinsveerkragtigheidskenmerke: positiewe kommunikasie wat in die gesin beoefen word; die gesin se bereidwilligheid om verandering te aanvaar en dit as positief te beskou; en gesinstyd saam en gesinsroetines wat beoefen word. Die belangrikste gesinsveerkragtigheidskenmerke volgens die kwalitatiewe data is die ondersteuning en inligting verkry vanaf die pediatriese diabetes-spesialis, die gesin se geloof en die ondersteuning wat hulle van hulle kerk verkry het. Hierdie studie dra by tot die toenemende behoefte aan en waarde van positiewe sielkunde. Die studie skep ook die geleentheid om gesinne en hospitaalpersoneel in te lig oor die noodsaaklikheid van die implementering en ontwikkeling van gesinsveerkragtigheidskenmerke vir die beter aanpassing van gesinne. Ten slotte word aanbevelings vir toekomstige veerkragtigheidsstudies in gesinne met 'n kind met tipe 1 diabetes gemaak.

Sleutelwoorde: gesinsveerkragtigheid, tipe 1 diabetes, verstelling, aanpassing

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## Chapter 1

### Introduction, motivation and aims of the study

#### 1.1 Introduction

For a holistic understanding of this study, it is important to define the concept of family. What is a family? How does resilience fit into the concept of family? Why is a study of the resilience characteristics in families with a child who has been diagnosed with type 1 diabetes important?

There are many definitions and descriptions of what a family is. The interpretation and understanding of family, however, is bound by time, context and culture (Falicov, 1988; McCubbin, Thompson, Thompson, McCubbin & Kaston, 1993). Within the South African context, known for its variety of cultures and languages, individuals are likely to differ about what exactly a family is. Despite the differing interpretations of family, the majority of families globally are nuclear families, and this has been the case since the 16<sup>th</sup> century (Esteinou, 2005). Nuclear families are regarded as families composed of two or more persons with relationship patterns between them that are indicative of functioning within and between family members (Bateson, 1972). It should be recognised, however, that the nuclear structure may differ from family to family, since family lifestyles differ from one another (Esteinou, 2005). The necessity of lifestyle changes bound to the diagnosis of a chronic medical condition such as type 1 diabetes mellitus is for the family, equivalent to the necessity of medical help, intervention and illness management for the diagnosed family member (Young & Unachukwu, 2012). In this study, families with a child with diabetes were recognised as nuclear-based families. Each child in this study belonged to a family, which means that they were looked after by a primary caregiver. The families in this study were understood to comprise an environment consisting of a primary caregiver and, if applicable, a life partner and her/his/their child(ren), living together in a home, sharing financial expenses, communicating on a daily basis and spending time together.

The family as a system is ever developing and is often confronted with a spectrum of crises (Laszloffy, 2002). The diagnosis of type 1 diabetes in a child is acknowledged as a crisis undergone by families (Pillay, Maunder & Naidoo, 2009). Parents have the general expectation that their child(ren) should be healthy and strong (Lowes, Lyne & Gregory, 2004). When a child is diagnosed with a chronic illness, parents tend to grieve over the situation and

experience feelings of disbelief (Lowe et al., 2004; Meleski, 2002). These feelings are exacerbated in families with a child with diabetes, because children with diabetes have an increased risk of developing psychological and physiological problems later in life (DeCoster, 2001). Despite the presence of a crisis, such as the sudden diagnosis and the omnipresence of a chronic illness, many families are able to adjust and adapt (McCubbin & McCubbin, 2001; Walsh, 2002). Over the past 20 years, many family researchers have shifted their deficit-based perception of the family to a strength-based perception, recognising the family as a resource for members experiencing a crisis (Nichols & Swartz, 2000).

Seeing that type 1 diabetes has a complex nature, with metabolic, heredity and hormonal factors (Martin, 1966), special assistance is required for managing the illness, not only for the diagnosed individual, but for the whole family (Meleski, 2002). Young and Unachukwu (2012) explain that diabetes management is difficult for patients, purely because the management of the illness tends to create a psychological burden in the life of the patient and family. Building and maintaining resilience in families with a child with type 1 diabetes can conceivably help families adapt to the child's illness. While a more positive outlook and acceptance of the diagnosis will not only create hardiness within the family, they are also likely to ensure better illness management by the child, thus lessening family stress (Young & Unachukwu, 2012).

## **1.2 What is family resilience?**

The concept of resilience is a largely debated one. Too many researchers debate that it is not clear whether resilience is a characteristic of something, an outcome-based theory, or a process (Ganong & Coleman, 2002). Ganong and Coleman (2002) also raise the question whether resilience needs to be accompanied by stressful situations filled with adversity. The answers to these questions are varied, but forerunner resilience researchers believe that resilience is a process (Hawley & De Haan, 1996; Patterson, 2002b; Walsh, 1996, 1998, 2002) in which there is an ability that a family can bounce back and withstand adversity in times of crisis. Luthar, Cicchetti and Becker (2000) report that a life situation filled with significant difficulty or stress, and adapting to the situation in a positive manner, are a process, of which the outcome is resilience. This study attempted to determine the characteristics of the family's process toward resilience in order to adapt to their stressful life situation.

In previous studies it was found that resilience characteristics that have come to play a dynamic role in a variety of families' lives are religious belief, a positive outlook on life, open

communication, spending time with family and friends, solving problems together as a family, social support, economic support and flexibility in the family (Walsh, 2002). All these characteristics form part of a process in which a family attempts to adapt to their stressful situation, moving forward and living resiliently. Resilience, however, is bound to constant change and growth, seeing that it is an outcome based on a process. The process can be ever changing and therefore the concept of resilience is not a fixed state, but rather a path characterised by certain traits, which may bring better adjustment and adaptation to the fore in crisis situations. In terms of this study, a family with a child with type 1 diabetes undergoes transitions from the day of diagnosis, and ultimately the children and parents go through transitions together (Meleski, 2002). The child and family as a whole need to adjust and adapt to the illness, while newly assigned roles and a variety of psychological, physiological and medical responsibilities need to be taken into account for a lifelong period (Meleski, 2002).

### **1.3 What is type 1 diabetes?**

Type 1 diabetes (fully defined in Chapter 3) is an autoimmune, chronic illness of a very complicated nature. It is an incurable condition with long-term self-management requirements (Meleski, 2002). Type 1 diabetes is primarily diagnosed in the childhood years (Mitchell et al., 2009), which creates immense stress for most parents (Monaghan, Hilliard, Cogen & Streisand, 2009). Type 1 diabetes necessitates insulin administration. Seeing that the body's pancreas does not produce insulin in type 1 diabetic patients, insulin administration via insulin pens or insulin pumps is necessary, and this can become complicated and problematic. Overall, a diagnosis of diabetes requires lifestyle changes, including changing eating patterns, regular exercise, administering insulin and informing all individuals who form part of the diabetic child's life how to manage the illness under various circumstances. In young children, a very low blood glucose reading, known as hypoglycaemia, cause immense stress in the lives of parents (Sullivan-Bolyai, Deatrck, Grappuso, Tamborlane & Grey, 2001). Psychological and physiological complications can form part of a diabetic's life, as well as the whole family's life. The diagnosis of diabetes in a family member does not only affect the diagnosed person, but ultimately the entire family. It therefore is important to have a closer look at how families adapt to a child's diagnosis of diabetes. Do families with a chronic stressor, such as childhood diabetes, even have the ability to adapt to their circumstances? This study takes a closer look at families with type 1 diabetic children and what the characteristics of these families are that have helped them to adapt to their situation and be resilient.

#### **1.4 Motivation for the study**

In general, research in the field of psychology has tended to focus on factors encompassing themes of pathology (Antonovsky, 1987). In the past two decades, a focus on the family and family functioning within a positive psychology framework has blossomed. (Seligman & Csikszentmihalyi, 2000). More studies contributing to the field of positive psychology will continue to highlight the benefits of maintaining a positive outlook on life, especially in times of crisis.

Research in the fields of chronic illness, specifically family psychology, has become increasingly important (Greeff & Wentworth, 2009). A chronic illness, such as type 1 diabetes, has become more prevalent in 21<sup>st</sup>-century families (Brown, Fouché & Coetzee, 2010). Incidence rates throughout the world are increasing rapidly (Van der Merwe, 2010). Although type 1 diabetes is primarily a genetically predisposed illness, the appearance of an increase in diagnoses of type 1 diabetes could be due to the poor management of type 2 diabetes (Young & Unachukwu, 2012). Seeing that diabetes diagnoses are increasing daily, it is important to determine how families can contribute to the management of stress and ensure adjustment, and ultimately adaptation, to a diagnosis of diabetes. According to Knafl and Gillis (2002), previous studies that have focused on families with a child with a chronic illness did not implement the results successfully to promote family adaptation. Conducting research within the field of diabetes and family resilience can contribute to a better understanding of the illness, as well as of how resilience may contribute in helping families to adapt effectively to the diagnosis and live healthy and happy lives.

Another important motivation for this study was the clear explanation of the precise differences between type 1 and type 2 diabetes. Together with the importance of the difference between the two diagnoses, it is also important to realise the difference between the psychological and physiological impact of the two illnesses. In the South African context, Van der Merwe (2010) has found that South Africans need to be better educated about the diagnosis of type 1 diabetes. It is important for families, friends, extended family members, as well as school and hospital personnel, to know how to take proper care of individuals with type 1 diabetes (Meleski, 2002). Research on the influences and resilience characteristics that can be implemented to manage diabetes more effectively will provide valuable information for the aforementioned people involved.

Known characteristics of family resilience in this regard will also be helpful for the establishment of intervention programmes for diabetic children and their families. Furthermore, a South African family resilience researcher, A. P. Greeff, stated in Greeff and Du Toit (2009) that limited research is available on family resilience in South Africa.

### **1.5 Aims of the study**

The primary aim of this study was to identify characteristics and resources that families possess in order to adapt to their child's diagnosis of type 1 diabetes. In response to answering the following research question, "What has helped your family to cope and adapt after your child has been diagnosed with type 1 diabetes", quantitative measures that operationalise McCubbin and McCubbin's (2001) Resiliency Model of Family Stress, Adjustment and Adaptation were used to identify family resilience characteristics associated with family adaptation. Furthermore, the answering of the following open-ended qualitative question, "What has helped your family to cope and adapt after your child has been diagnosed with type 1 diabetes?", also contributed towards reaching the objectives of this study.

This study also had secondary aims. The aim was to contribute towards the growing domain of positive psychology, moving a step away from research concentrating predominantly on deficits within society, especially within the family. It was also important to differentiate between diagnoses of type 1 and 2 diabetes to create a better understanding of the major stresses that may accompany the diagnosis of type 1 diabetes in the family. The minimal amount of research conducted on type 1 diabetes and family resilience in South Africa was also a concern and, lastly, the research aimed to provide parents of children with type 1 diabetes, as well as hospital personnel, with answers on how to adapt more successfully to the diagnosis.

### **1.6 Thesis outline**

After the introduction to the study provided in Chapter 1, Chapter 2 will elaborate on and explain the theoretical model, operationalization of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001) and provide the grounding of the theory in the topic chosen for this study. Chapter 3 will provide definitions, descriptions and previous research findings from studies within the fields of type 1 diabetes, positive psychology, and local and international research on family resilience. In Chapter 4, the methodological procedures of the study are clarified, with descriptions of the measurement instruments, participants, procedures and data analysis. The results of the study follow in

Chapter 5, which reports on the qualitative and quantitative findings of the study, together with figures, tables and scatterplot representations of the data. Finally, Chapter 6 interprets the results of the study in relation to previous research findings. Chapter 6 also provides the limitations and recommendations for similar studies in the future.

### **1.7 Conclusion**

It is evident that the diagnosis of type 1 diabetes in children affects not only the diagnosed child, but the whole family. In South Africa in particular, it is important to conduct more research in the field of diabetes, especially on how it is possible for the affected family to adapt to this diagnosis. It is imperative to identify the resilience characteristics of families caring for a child with diabetes, with the intent of strengthening families experiencing this crisis. This study may also contribute to the identification of key characteristics and resources that hospital personnel can utilise to support and educate families in their process toward adaptation to their child's diagnosis.

## Chapter 2

### Theoretical conceptualisation and grounding

#### 2.1 Introduction

The ability of the individual or family to be resilient encompasses the ability to bounce back from situations filled with adversity (Compton, 2005). In the past two decades, there has been an increase in interest in the field of family resilience (Ganong & Coleman, 2002; Haggerty, Sherrod, Garmezy & Rutter, 1996; Nichols & Schwartz, 2000; Walsh, 2002). According to McCubbin and McCubbin (1993b), the growing interest in family resilience is related to the fact that social scientists are interested in the likely role that resilience plays in the understanding of individual and family development, even under stressful conditions. Resilience can be seen as a multi-dimensional and ever-changing construct, and as an attribute that all individuals possess (Reivich & Shatté, 2002). In the past, however, research on resilience has to a great extent focused on the individual and on individual strengths (Walsh, 1996). The focus on individual resilience characteristics has shifted to the relatively new researched construct, family resilience (Hawley & DeHaan, 1996). The reason for the shift that has taken place in resilience research is that the family had primarily been interpreted as a unit of dysfunction (Walsh, 1996), rather than as a unit of functionality and support.

Interest has grown in family resilience research due to findings that indicate that individuals and families are able to live well and express love, despite adverse circumstances or experiences (McCubbin & McCubbin, 2001; Patterson, 2002a; Walsh 2002). In order to create a better understanding of family resilience and the applicability of family resilience research within psychological crisis situations, it is essential and useful to work from a model or theory. The Resiliency Model of Family Stress, Adjustment and Adaptation (further on called the Resiliency Model). (McCubbin & McCubbin, 2001) is the latest family resilience theory and model that serves as a foundation on which to build ideas and concepts around family resilience. This chapter will elaborate on the relationship and congruency between family resilience theory and positive psychology. The origins of individual resilience, growing into family resilience, will also be discussed. Together with the discussion around the growth into family resilience, the two positive constructs and crucial phases forming part of the Resiliency Model will also be discussed. Lastly, the suitability of the Resiliency Model for the identification of resilience factors in the family will be explained.

## 2.2 Positive psychology and resilience

Until now, a large number of theories in psychology have focused largely on lessening the symptoms of psychopathology (Bono & McCullough, 2006). In the past few years, greater emphasis has been placed on conducting research within the field of positive psychology (Watkins, Grimm & Kolts, 2004). Positive psychology generally refers to the study of positive emotions and character traits in humans (Seligman, 1998). Gable and Haidt (2005) further explain that positive psychology studies the contribution of certain processes that make people function optimally and flourish in life. Positive psychology does not, however, imply that the variety of research fields within psychology is negative. Positive psychology rather attempts to acknowledge that negative and positive aspects form part of life, while clinical psychology has largely focused on research on mental illness (Gable & Haidt, 2005).

Psychologists have called for an increase in focus on positive emotions (Gillham & Seligman, 1999), because the focus on negative emotions tends to underestimate the overall well-being that human beings are capable of possessing (Myers, 1999). A key factor in the elevated emphasis on the negative in psychology is because, after World War II, psychology became a science that focused largely on healing mental disorders (Seligman & Csikszentmihalyi, 2000). Gillham and Seligman (1999) state that psychology's aim has been to treat mental illness, create fulfilment in life and nurture talent. The purpose of positive psychology is to repair negative aspects of life, and alternate those negative aspects with positive aspects (Seligman & Csikszentmihalyi, 2000). The large number of psychology articles that are available focus mainly on the negative aspects and states of persons, with a remarkable ratio of 17 positively orientated articles to 276 negatively orientated articles (Diener, Suh, Lucas & Smith, 1999). This finding is supported by Myers (1999), who states that for every article focusing on positive emotions, such as joy and happiness, 21 articles are available on negative emotions, such as depression and anger. It is evident from this imbalance that it is of the upmost importance to conduct more research in the field of positive psychology.

Aaron Antonovsky (1996) was a forerunner in the field of positive psychology. Antonovsky (1979) was concerned with what he called salutogenesis, or the origin of health. The meaning lies in the term's two constituent parts, *saluto*, meaning health, and *genesis*, meaning origins – thus the origins of health (Antonovsky, 1979). Salutogenesis maintains a strength-based rather than a deficit-based focus, which tends to concentrate on the well-being of families and their

ability to bounce back from stressful situations (Antonovsky, 1987). Werner and Smith (1982) state that the concept of resilience inherently adopts a salutogenic-based manner of arguing.

According to Antonovsky (1996), a salutogenic orientation forms a vital part of research in the field of health promotion. A salutogenic orientation moves away from human pathology by rather concentrating on human health and well-being. The salutogenic view sees human beings at a particular point in their lives, somewhere along a continuum of health or disease (Antonovsky, 1996). Moreover, Antonovsky (1996, p. 13) states that the salutogenic orientation is “not a theory which focuses on keeping people well”. A salutogenic orientation derives from studying the preventive and curative ideas and practices of human beings. Salutogenesis aims to understand human beings from a health-oriented perspective.

From a resilience perspective, the focus of adaptation is on aspects such as bouncing back from stressful events, implementing hardiness and moving forward, which are inherently positive in nature (Cicchetti & Rogosch, 1997). Resilience can therefore be seen as a contributor to the field of positive psychology. Studies based on resilience theory therefore contribute to the small amount of research conducted within the field of positive psychology, especially when compared to research on human pathology. Two positive psychology constructs, individual and family resilience, will be discussed next.

### **2.3 Individual resilience**

Previously, research on resilience focused to a great extent on the individual's ability to overcome adversity (Walsh, 1996). Walsh (1996) points out that research on the individual's ability to recover after a sudden crisis has flourished in comparison to that on the family's ability to be resilient. In the past, family studies in general viewed the traditional family as deficit based (Walsh, 1996) and dysfunctional (Walsh, 2002). It was rather the individual who was viewed as possessing the ability to rise from adversity within the family. Interest in individual resilience flourished especially after the results of various studies indicated that children who grew up in unfavourable family circumstances did not necessarily grow up to be individuals who were negatively affected by their circumstances (Masten & Coatsworth, 1998).

Waller (2001) states that research on individual resilience is grounded firmly in longitudinal studies of children exposed to risk. One such individual resilience study found that individuals show resilience despite growing up in dysfunctional, abusive and alcoholic homes (Wolin &

Wolin, 1993). Resilience research therefore focused rather on individual resilience characteristics contributing to the individual's buoyancy (Luthar et al., 2000). Despite the focus on individual resilience and the dysfunctional outlook on the family context, interest has started to grow in family resilience since the 1980s (McCubbin et al., 1980; Walsh, 1996). Moreover, Cohler (1987) explains that research on individual resilience created an entryway for studies on resilience in the family and resilience in society or communities. Interest in resilience and a shift to family resilience has taken place mainly because the focus on the family as deficit-based, or pathological, has eventually moved toward a strength-based focus (Hawley & DeHaan, 1996).

#### **2.4 Family resilience**

McCubbin and McCubbin (2001) explain family resilience as the positive behavioural patterns and competency in individuals forming part of a family when withstanding stressful circumstances and adversity. As mentioned under the theme of positive psychology, a family resilience outlook is intertwined with salutogenesis, since family resilience integrates the family's exposure to possible strengths and restrictions (Greeff & Wentworth, 2009). A family resilience framework places the focus on growth (positive aspects) within families, rather than on their shortcomings (Greeff & Fillis, 2009). The positively directed orientation of resilience also provides the family with a sense of empowerment, because each member can be viewed as a survivor of a crisis (Hawley, 2000).

According to Walsh (1996), all families have the potential to be resilient, regardless of life circumstance or crisis. In the present study, the focus on resilience in families with a child with diabetes is aimed at the promotion of health within these families undergoing a crisis. By maintaining a positive outlook on life, families develop the ability to accept a chronic life stressor more easily, which also assists in promoting family health, rather than family pathology (Antonovsky, 1996). A positive outlook on life, despite unforeseen, stressful circumstances such as a disability or chronic illness in the family, has been found to contribute to better family functioning in some families (McCubbin & McCubbin, 1993a; Patterson, 1988; Tunali & Power, 1993).

McCubbin and McCubbin (2001) distinguish between four types of resilient families, namely regenerative families, versatile families, rhythmic families and traditional families. Regenerative families are usually understood as families who cope effectively with crises, and

show trust and respect to one another. Versatile families live according to their name, namely they can easily create change and are very flexible (McCubbin et al., 1980). Rhythmic families consider routines as being very important and therefore incidents in the family are more predictable (McCubbin et al., 1980). Lastly, the traditional family values traditions and celebrations such as religious occasions, birthdays, anniversaries and holidays (McCubbin & McCubbin, 2001). In order to understand and integrate this variety of existing family types, a family resilience model, such as the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001), is required.

## **2.5 The Resiliency Model of Family Stress, Adjustment and Adaptation**

The Resiliency Model of Family Stress, Adjustment and Adaptation (Resiliency Model) proposes an advanced and comprehensive framework of family resilience theory (McCubbin & McCubbin, 2001). McCubbin and McCubbin (2001) explain that a theory such as the Resiliency Model contributes to the understanding of inherent positive qualities that many families possess. McCubbin and McCubbin's (2001) interest was pricked when research findings concluded that, regardless of poor or healthy circumstances, some families fall apart, while others flourish. Studies conducted on abusive families (Kaufman & Ziegler, 1987), families with a member with a psychological disorder (Greeff, Vansteenwegen & Ide, 2006), poor single-parent families (Greeff & Fillis, 2009) and families with type 1 diabetic children (Brown et al., 2010) have all shown that families do have the ability to rise above their adversity, despite family stress and obstacles. The majority of families do not deteriorate to the point that they need therapy (McCubbin & McCubbin, 1993b). According to the last mentioned and other research findings on family resilience, it is sensible to make a further contribution towards this field of research on families in need.

The Resiliency Model is currently the most advanced model of family resilience and was preceded by four other models. The first model, developed in 1949, was Reuben Hill's ABCX model (McCubbin & McCubbin, 2001). Hill developed the ABCX model to investigate pre-crisis factors in families during World War II. The ABCX model consists of (A) the stressor, (B) the resources, and (C) the understanding of the lived stressor, which all add up to (X), the factor or lived crisis (McCubbin & McCubbin, 2001). Hill's ABCX model, however, did not include post-crisis factors as possible contributors to resilience, and therefore a second model was developed.

The second model of family resilience was the Double ABCX model (McCubbin & Patterson, 1983). Within the Double ABCX model, more liberty was given to the family's interpretation of various kinds of stressors and their personal view of valuable resources (Patterson & Garwick, 1994). The Double ABCX model included pre- and post-crisis factors contributing to resilience, and focused particularly on social support and coping strategies (McCubbin & McCubbin, 2001). McCubbin and Patterson (1983) decided to extend the Double ABCX model to the FAAR (Family Adjustment and Adaptation Response) model. This model emphasises family processes that involve the family's ability to juggle both demands and resources (McCubbin & McCubbin, 2001). The FAAR model, exact to the Double ABCX model, integrates pre- and post-crisis factors. McCubbin and McCubbin (2001) explain that the FAAR model specifically highlights the coping skills, coping mechanisms and problem-solving skills of the family during their process of adjustment.

The fourth model, created in 1989 by McCubbin and McCubbin (2001), was the Typology Model of Family Adjustment and Adaptation. This model also focuses on pre- and post-crisis factors, as well as on the family's fixed patterns of functioning and their judgment of their ability to buffer themselves against dysfunction (McCubbin & McCubbin, 2001).

The final and most advanced family resilience model is the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001). The Resiliency Model draws attention to the fact that individuals who grow up in hardship or have experienced trauma do have the ability to adjust and adapt positively to later life conditions (McCubbin & McCubbin, 2001). Four domains of family recovery are highlighted in the Resiliency Model. These are interpersonal relationships, well-being and spirituality, relations with the community, and structure and function (McCubbin & McCubbin, 2001). Furthermore, the model also stresses five levels of family appraisal in relation to the family's patterns of functioning, problem solving and coping. These levels comprise schema (CCCCC), coherence (CCCC), paradigms (CCC), situational appraisal (CC) and stressor appraisal (C). The five levels form part of the adaptation phase, which will be discussed in more detail in Section 2.5.1.

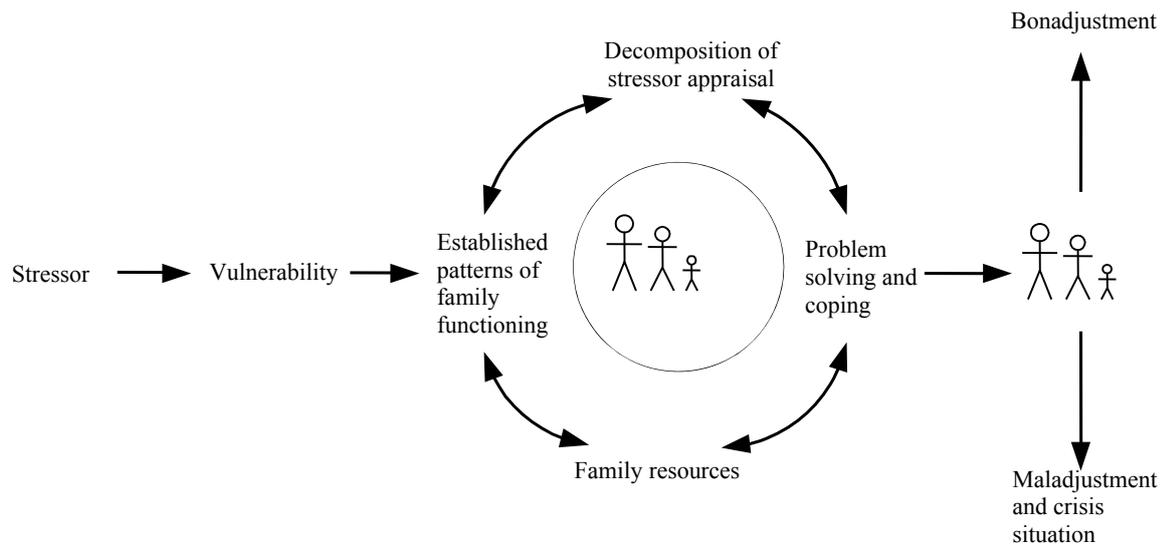
In line with McCubbin and McCubbin's (2001) motivation for resilience research and the development of the Resiliency Model, is Rutter's (1993) explanation of resilience as a positive outcome at the end of a high-risk continuum. According to Masten (1994), the word resilience, in reality, should only be used when referring to positive adjustment under tough life

circumstances. To underline the importance of positive outcomes under stressful circumstances, two different, but interrelated, phases are distinguished from one another, namely the adjustment phase and the adaptation phase. The adjustment phase is discussed first.

### **2.5.1 Phase of adjustment**

The level of adjustment of the family depends upon several elements and interacting components. Adjustment is related to protection, or protective factors. McCubbin, McCubbin, Thompson, Han and Allen (1997) describe protective factors as factors that guard the family against risk factors and increase the possibility that a family can adapt successfully after risk-filled circumstances. McCubbin et al. (1997) define risk factors as biological, social, economic or psychosocial hazards that may increase the possibility of a negative effect on the family, such as sudden unemployment or the diagnosis of a chronic illness in a family member. Furthermore, optimism, control over situations, family support and health are all protective factors for the family (Coetzee, 2007; McCubbin & Patterson, 1983). Of particular relevance to the present study, influence of poor health or the difficulty of managing an illness, such as type 1 diabetes, is of particular importance for the level of adjustment obtained by families in this study.

According to McCubbin and McCubbin (2001), family resilience research and the Resiliency Model have focused their attention, to a great extent, on five assumptions about family life. Firstly, that the hardships that families face are natural aspects in each family's life. Secondly, the family is capable of promoting growth within the family unit. Thirdly, protective mechanisms are implemented by the family to defend them from unforeseen stressors, and rather to focus on recovery after a major crisis. Fourthly, the family contributes to the broader community it is located in and uses resources within the community as buffering tools. Lastly, the family that is faced with definitive changes brought to the unit reinstates balance and order (McCubbin & McCubbin, 2001). Unfortunately, for many families, the outcomes are not as positive and smooth running as these five assumptions portray. The adjustment phase presented in Figure 2.1 sketches the progress or lack thereof made by a family faced with a stressor.



*Figure 2.1.* The adjustment phase of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001).

Within the adjustment phase it is assumed that the family is confronted with a stressor (A), such as the sudden diagnosis of a chronic illness in a child. The severity of the stressor, which is influenced by the family's level of stability before the crisis situation, interacts with the family's vulnerability (V). The intensity of the family's vulnerability to the crisis points in the direction of a complete high or low state of demands, which pile up. A pile-up of demands may include poor health conditions or financial problems for the family (McCubbin & McCubbin, 2001). The impact that a normal developmental characteristics may have on the family also forms part of their level of vulnerability. Vulnerabilities (V) are interrelated with the family's established patterns of functioning, or their typology (T) (McCubbin & McCubbin, 2001). The family's typology explains a variety of behavioural patterns that are followed and evidently come to mould the family. The three preceding components of the adjustment phase work together and interact with the family's resistance resources (B). McCubbin and McCubbin (2001) describe resistance resources as the abilities and capabilities of a family to handle a stressor(s) and attempt to maintain harmony and balance. A, V and T also interact with the family's stressor appraisal (C). A family's appraisal of the stressor can be described as their view of the severity of the stressor, and may range from unmanageable to manageable (Hill, 1949). Family resistance resources and family stressor appraisal interact with the family's ability or skill to manage stress, solve problems and attempt to cope (PSC) with stress (McCubbin & McCubbin, 2001).

Adjustment can be achieved on a continuum from bonadjustment (positive adjustment) to maladjustment (negative adjustment). Bonadjustment is an outcome where minor adjustments are made in order to overcome a stressful situation. Achieving and maintaining balance and harmony within the family is important in bonadjustment. Balance and harmony is especially important in the family's interpersonal relationships, spiritual beliefs and relationships with their community, seeing that it maintains and encourages structure and good functioning. On the other end of the adjustment continuum, maladjustment highlights disorganization, tension, stress and crisis. McCubbin and McCubbin (2001) explain that maladjustment is likely to result in a family crisis. A crisis interrupts the possibility of a family moving toward harmony and balance. If the family achieves bonadjustment, the family will be able to progress to the phase of adaptation. When a family is willing or able to take a step towards the direction of change, they move into the phase of adaptation (McCubbin & McCubbin, 2001), which is discussed in the following section.

### **2.5.2 Phase of adaptation**

When the family has successfully adjusted to their crisis, they move on to the phase of adaptation. The Resiliency Model emphasises a bundle of post-crisis or adaptation elements that describe the family's adaptation and their ultimate goal, namely to achieve balance and harmony, or bonadaptation. Within the adaptation phase, a crisis in the family is aggravated by the pile-up of additional external stressors (AA). Family functioning is not static and the family rarely deals with only one stressor at a time (McCubbin & McCubbin, 2001). Families can experience a pile-up of demands, especially families with a child with type 1 diabetes. It is not singularly the medical diagnosis and regimen that may create stress within the family milieu, but a variety of psychosocial factors. The pile-up of external stressors builds up to a family crisis situation (X). The interaction between piled-up stressors and the experience of a crisis leads to the family's vulnerability (V). When the family arrives at the point of vulnerability, their vulnerability reacts in terms of their established patterns of functioning (T), which may be influenced by their ethnic practices or spiritual beliefs. The AA, X, V and T factors interact with one another and make the family utilise their family resources (BB). Family resources within this context are things like family hardiness and support for one another (Coetzee, 2007). Family resources are interlinked with social support (BBB), such as within the church environment, community or neighbourhood, friends and extended family members.

Stressor appraisal (CC) can also be seen as a resource within the family, since the severity of a stressor(s) is assessed by the family. Stressor appraisal interacts with the family schema (CCC), in which expected family patterns, such as routines, trust and respect, are nurtured. Toward the end of the adaptation phase, family patterns of functioning and their appraisal are determined by the family's problem solving and coping (PSC) ability. PSC depends on the family's ability, as well as willingness, to solve problems by creating a change within their crisis-filled patterns and implementing new coping strategies. If the family solve problems properly and manage to cope optimally, they achieve family adaptation (XX). The family that creates adaptation within the family environment will move into bonadaptation. However, if the family does not achieve the full level of adaptation, maladaptation will be the outcome. The maladaptive family will naturally return to the beginning stage of piled up stressors (AA). This is due to the cyclical nature of the adaptation phase. Maladapted families will start over from AA, attempting to adapt adequately to their crisis situation. The complete process of adaptation is illustrated in Figure 2.2.

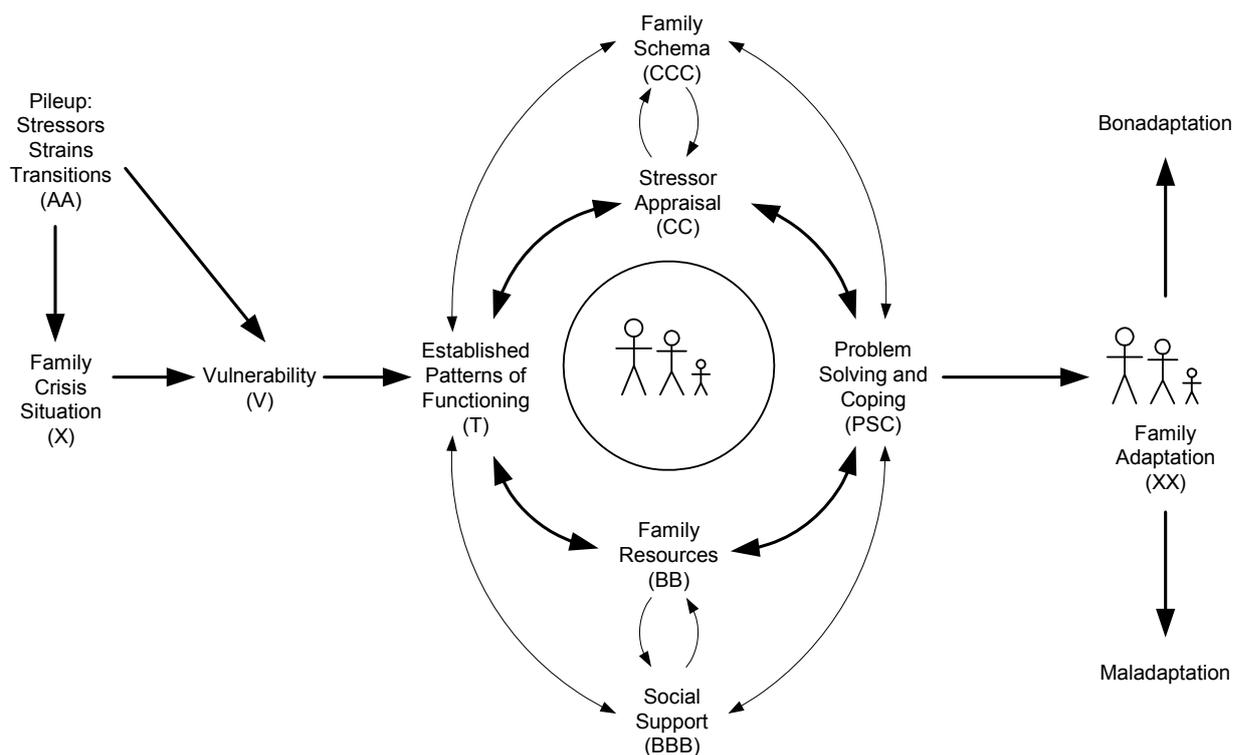


Figure 2.2. Adaptation phase of the Resiliency Model of Family Stress, Adjustment and Adaptation and the relational process of balance and harmony (McCubbin & McCubbin, 2001).

## **2.6 The applicability of the Resiliency Model for the present study**

Despite a large amount of psychology research that has focused predominantly on the pathological influences of the family environment (Patterson, 2002b; Seligman, 1998; Walsh, 2002), it has become evident that the family is the most prevalent source of support for family members (McCubbin & McCubbin, 2001). When the family is faced with a risk factor or stressor, such as the diagnosis of diabetes in a child or adolescent, it can be difficult for the family to cope, adjust and adapt to the diagnosis (McCubbin & McCubbin, 1993a). Walsh (2002) explains that a chronic illness does not only create one stressor for the family, but rather places a variety of demands on each family member. In addition, DeCoster (2001) found that not only does the diagnosed child have diabetes, but evidently, the entire family. This finding is related to the fact that diabetes in childhood and adolescence has a psychological impact on the entire family (Guthrie, Bartsocas, Jarosz-Chabot, & Konstantinova, 2003).

Children and adolescents with diabetes struggle with physical, mental and emotional complications (Guthrie et al., 2003) that tend to form part of the diagnosis. These complications need to be adjusted and adapted to by the whole family. The Resiliency Model is thus an appropriate model for exploring how families adjust and adapt to their child's diagnosis. McCubbin and McCubbin (2001) emphasize the importance of finding balance in the family through adjustment and adaptation to the diagnosis of a chronic illness within the family, since it may create a better health environment for the child. Moreover, the Resiliency Model not only describes the adjustment and adaptation processes of the family, but also recognises the important role that factors such as routines, social support and hardiness may play.

The handling and better acceptance of a regimented illness, such as diabetes (Zashikhina & Hagglof, 2009), can thrive in the space of open family communication, support and understanding (Brown et al., 2010). The implementation of the Resiliency Model not only offers adjustment and adaptation possibilities for families, but holistically incorporates the influence that routines, hardiness and communication may have on the family. In recognising the role that various factors can play in the adaptation of a child, adolescent and family, the Resiliency Model offers a relevant framework for exploration.

## **2.7 Conclusion**

The theoretical basis of this study was discussed in this chapter. Within the discussion, the distinctive relation between the diagnosis of type 1 diabetes and family resilience was explained. This chapter also aimed to introduce the growing interest in family resilience research. The relationship between family resilience studies and positive psychology was also highlighted with an elaboration of Antonovsky's view on salutogenesis within the paradigm of positive psychology. It was shown how the Resiliency Model was utilised in this study, with its focus on positive aspects found in families undergoing a crisis. Finally, the applicability of the Resiliency Model for the study was elucidated, with the intent of highlighting the importance of adjustment and adaptation for families with a child with a chronic illness, such as type 1 diabetes.

## Chapter 3

### Literature review

#### 3.1 Introduction

The occurrence of, and focus on, individual and family resilience within the paradigm of positive psychology was discussed in Chapter 2. An elaboration on the most current resilience model, namely the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001), was also provided. This chapter concentrates on the family living with a child with type 1 diabetes on a chronic basis. The family and diabetes are investigated by highlighting both the physical/medical and psychological impacts of type 1 diabetes on the diagnosed child and the entire family. This chapter also includes a discussion of the prevalence of, and research on, type 1 diabetes in South Africa, and how exactly family resilience contributes to better adaptation in families with a chronically present stressor.

The family is not a static unit, but rather a unit of constant change, shaped by biological and psychological influences (McCubbin & McCubbin, 2001). Within each sub-heading of this chapter, the importance of biopsychosocial influences that may have an impact on the families' adjustment and adaptation to the illness is highlighted. Furthermore, diabetes mellitus and both types of diabetes, type 1 and type 2, will be discussed. The prevalence of type 1 and 2 diabetes in the South African context will be highlighted, and physical and psychological setbacks, each with their particular difficulties, will be elaborated on. The general physical and psychological aspects that create difficulties for type 1 diabetic children and their families are bound to their developmental stage. The common aspects found in type 1 diabetic children and adolescents will also be discussed. In conclusion to the chapter, the contributing factors of family resilience that enhance and improve resilience in families where type 1 diabetes is present are discussed.

#### 3.2 Diabetes mellitus

According to Adeghate, Schattner and Dunn (2006), diabetes mellitus is a chronic metabolic and endocrine disease. The reason why diabetes mellitus is considered a metabolic disease is because it affects the metabolism of carbohydrates, proteins, fats and electrolytes in the human body (Adeghate et al., 2006). Diabetes mellitus is also reckoned to be a product of the environment and of genetic predisposition (Adeghate et al., 2006). Viral infections, obesity and physical passivity, as well as environmental factors, are considered as external contributing

factors for the diagnosis of type 1 diabetes (Adeghate et al., 2006). Genetically predisposing factors can be explained as the individual's susceptibility for developing the disease on the basis of genetic inheritance (Adeghate et al., 2006). A susceptible gene may be triggered by an unhealthy lifestyle or viral infection, causing diabetes mellitus. Whether environmentally or genetically influenced, diabetes mellitus causes pancreatic  $\beta$  (beta) cells to break down in the pancreas of the body (American Diabetes Association, 2000). The destruction of the  $\beta$  cells causes the pancreas to generate an insufficient or zero amount of insulin to the body (American Diabetes Association, 2000). Daneman (2006) explains that type 1 and type 2 diabetes are only distinguished by the amount of  $\beta$ -cell failure in the pancreas. DeCoster (2001) furthermore explains that, when the pancreas is not able to supply enough insulin to the body, glucose builds up in the bloodstream. The build-up of glucose in the bloodstream damages blood vessels (DeCoster, 2001) and, over the longer term, various body organs. Zimmet (2003) estimates that diabetes mellitus will affect up to 300 million individuals by the year 2025. The two types of diabetes mellitus will now be discussed in depth for a better understanding of the different stressors that form part of family life for those families with a child with type 1 diabetes.

### **3.3 Type 1 diabetes mellitus**

Type 1 diabetes mellitus is also known as juvenile diabetes (Kaplan-Mayer, 2004). Type 1 diabetes is a chronic illness, most commonly diagnosed in children (Al-Fifi, 2010), hence the name juvenile diabetes. According to Felner et al. (2005), the peak ages of diagnosis are between four and six years and between 10 and 14 years of age. Type 1 diabetes mellitus typically starts in the childhood years (Zöllner & Delpont, 2011). Martin (1966) also highlights that a child diagnosed with type 1 diabetes during the childhood years usually has a genetic predisposition for developing diabetes due to poor insulin production by the pancreas. Bui and Daneman (2006) furthermore state that type 1 diabetes is the most commonly diagnosed metabolic disease in children and in adolescents. The body of a type 1 diabetic is marked by inefficient amounts of insulin produced for the body and, inevitably, for the complete metabolic system (Martin, 1966). Inefficient amounts of glucose enter the cells and insulin is consequently needed in order for glucose to travel into the cell membranes effectively (Martin, 1966).

Bodily symptoms of insulin deficiency are an insatiable thirst, extreme fatigue, irritability and sudden weight loss (Al-Fifi, 2010). These symptoms occur intensely over a short period of time, and the effects can be pervasive. The pervasive effects of extremely low or high blood

glucose levels may leave the individual in a semi-coma or full coma. People with type 1 diabetes are fully dependent on insulin taken externally, hence type 1 diabetes is also referred to as insulin-dependent diabetes (Kaplan-Mayer, 2004). Insulin is generally taken two to four times daily, dependent on age and blood glucose levels (Bui & Daneman, 2006), with the use of insulin pen injections on the thighs, upper arms or stomach, or through insulin pump injections (Kaplan-Mayer, 2004). Before the insulin can be injected, blood sugar levels need to be tested. The blood sugar level is tested before meals with a needle prick on a finger, swiftly placing the blood sample on a blood glucose stick, which is then placed in a blood glucose meter that provides a blood sugar reading. Consistent with the majority of readings, a diabetic physician will create an insulin injection plan for the child on the basis of a prescribed diet. The child will have to have an insulin injection before snacks and mealtimes every day.

### **3.4 Type 2 diabetes mellitus**

The majority of children diagnosed with diabetes mellitus, have been diagnosed with type 1 diabetes (Fagot-Campagna & Venkat Narayan, 2001). Increasing however, children, adolescents and adults globally, are diagnosed with type 2 diabetes mellitus (Tuomilehto et al., 2001). Brannon and Feist (2000) explain that type 2 diabetes is diagnosed when the pancreas does not provide sufficient amounts of insulin to the body. The primary reason for insufficient supplies of insulin in type 2 diabetes is because of a decrease in physical activity, unhealthy eating patterns and, in many cases, morbid obesity (Hamman, 1992; King & Dowd, 1990). Type 2 diabetes may also occur in cases of genetically impaired glucose tolerance levels (Neel, 1962). Type 2 diabetes is mostly associated with behavioural and environmental influences on the health of children and adults (American Diabetes Association, 2000; Hamman, 1992; Rewers, LaPorte, King & Tuomilehto, 1988).

Previously, type 2 diabetes mellitus was known as non-insulin-dependent diabetes (Meyer et al., 2000). In most diagnosed cases, type 2 diabetics do not require insulin injections, but rather rapid changes in diet and regular physical activity. Non-insulin-dependent diabetes can therefore be controlled with healthier food and drink intake, regular exercise and/or oral medication, such as Metformin. According to Zöllner and Delpport (2011), type 2 diabetes can wholly be prevented and treated by the aforementioned, much less complicated procedures, in contrast to type 1 diabetes. Type 2 diabetes is not as regimented as type 1, and does not require definitive insulin intake or following extremely strict dietary patterns. However, if an unhealthy lifestyle is perpetuated after the diagnosis of type 2 diabetes, insulin injections may be required.

### **3.5 Type 1 diabetes in the global context**

Globally, type 1 diabetes, alongside asthma, is the most commonly diagnosed chronic illness in children (Mullins et al., 2007). Daneman (2006) states that only 5 to 10% of diabetes diagnoses made globally are of type 1 diabetes. In 2005, 150 000 children between the ages of 0 and 17 years were diagnosed with type 1 diabetes in the United States of America (Centers for Disease Control and Prevention, 2005). The International Diabetes Federation (2007) found that diabetes in children and adolescents is increasing throughout the world at a rate of 2 to 5%. Bowes, Lowes, Warner and Gregory (2009) estimated that 440 000 children globally have type 1 diabetes. In the United Kingdom, approximately 25 000 people under the age of 25 years have been diagnosed with type 1 diabetes (The Information Centre, 2007). The highest rate of diagnosis of type 1 diabetes globally is in Finland, at 35 persons per 100 000 per year (Adeghate et al., 2006). Another region with a very high rate of type 1 diabetes is Sardinia in Italy (Ehehalt et al., 2009). In 1992, 49.3 per 100 000 persons were already globally diagnosed with type 1 diabetes (Daneman, 2006).

A study by Ehehalt et al. (2009) found that German children are more prone to become type 1 diabetics than children of Italian migrants in Germany. The incidence rate for German children was 14.8/100 000 per year, while that for the children of Italian migrants was 10.8/100 000 per year (Ehehalt et al., 2009). The lowest rate of diagnosis of type 1 diabetes is in Asian countries, as well as in Africa and Latin America (Rewers et al., 1988). Asia has an incidence rate of 0.5 to 1.3/100 000 per year (Adeghate et al., 2006). In 1993, China had the lowest incidence rate of type 1 diabetes diagnosis with 0.57/100 000 per year (Daneman, 2006). Australia also has a low incidence rate of 4.4/100 000 per year (Craig, Howard, Silink & Chan, 2000). A credible reason for the disparity in incidence rates of diabetes in the abovementioned countries and ethnicities may be due to differences in human cultural genetic composition, as well as environmental influences (LaPorte et al., 1985).

### **3.6 Type 1 diabetes in South Africa**

In comparison to American and European studies conducted on type 1 diabetes, very little research has been conducted on this topic in South Africa. There also is a lack of research on the psychological and physiological impact of the disease in South Africa compared to international diabetes research. Examples of aspects related to type 1 diabetes that are in urgent need of research in the South African context are incidence and prevalence rates of diabetes,

physical and psychological factors of the illness, the availability and cost of medical help, and the important component that this study investigated, namely the role of resilience in the family of a child with diabetes.

In a South African study conducted by Pillay et al. (2009), it is stated that roughly 20% of all South African children suffer from a chronic illness. The research was conducted on chronic diseases such as congenital heart disease, neurological disorders, asthma and HIV in South African children. However, little research is available on type 1 diabetes in children, especially from a focus on coping and adapting to the diagnosis. The prevalence rate of type 1 diabetes in South African children is not known (Pillay et al., 2009). The limited amount of information in the few South African studies on type 1 diabetes needs to be increased, seeing that the diagnosis of type 1 diabetes is increasing at a fast rate (Van der Merwe, 2010).

Gill, Huddle and Monkoe (2005) conducted a longitudinal study in Soweto, South Africa of type 1 diabetes and its impact on mortality rates. The study found that the mortality rate was more or less equal to rates in the USA under African-American type 1 diabetics (Gill et al., 2005). Gill et al. (2005), however, show that too little attention is paid to individuals with type 1 diabetes in Africa. Paying attention to the illness is very important, seeing that type 1 diabetes diagnoses are not only increasing year by year, but are mostly diagnosed during childhood (Mitchell et al., 2009). A diagnosis in childhood requires the necessary attention from, and knowledge of, medical personnel and parents in order to understand and help manage the child's illness to the best of their ability (Meleski, 2002).

A South African study on diabetes mellitus conducted by Mollentze and Levitt (2006) researched glucose intolerance levels of patients in various South African provinces. The first demographic and health survey in South Africa was conducted in 1998 and included 13 827 adults, with a response rate of 93% (Mollentze & Levitt, 2006). More than 60% of the participants were from urban areas. All the participants were 15 years of age and older. It was found that *Asian Indian* individuals had the highest rate of diabetes, followed by the *Coloured*, *White* and *African* groups (Mollentze & Levitt, 2006). Furthermore, the study found the highest prevalence of diabetes in KwaZulu-Natal, the Western Cape and Gauteng (Mollentze & Levitt, 2006). A lack within Mollentze and Levitt's study, as in other South African and African diabetes studies, is that no clear distinction is drawn between type 1 and type 2 diabetes

mellitus. This lack is relevant because of the psychological and physiological differences between the two types of diabetes.

Steyn, Fourie and Temple (2006) report that the prevalence rates for diabetes diagnosis in South Africa is 2.4% for men and 3.7% for women. In a study conducted in Cape Town, South Africa by Mash, Levitt, Van Vuuren and Martell (2008), mixed results for the prevalence rates of type 1 and 2 diabetes diagnosis were provided by the Metro District Health Services. In the Mash et al. (2008) study prevalence rates also refers to both type 1 and 2 diabetes diagnosis and does not create a distinction between the prevalence of the specific type of diabetes diagnosed in participants. Adeghate et al. (2006) and Karvonen et al. (2000) also state that research on and reports of the incidence and prevalence rates of type 1 diabetes in Africa have not been provided as extensively as in other countries of the world.

The only South African study that incorporated family resilience in families with a child with type 1 diabetes was conducted by Brown et al. (2010). The study included 16 South African families, each with a child with type 1 diabetes. The study focused on the physical and psychological influences that the illness had on the individual with type 1 diabetes, as well as the whole family. As in the present study, the construct of resilience within the family was also investigated in order to determine which resilience characteristics were present in families with a child with a chronic illness. Brown et al.'s (2010) study was the first to incorporate the importance of resilience within the family in order to optimise the possibility of adaptation in the family. The present study is thus the second study in South Africa to incorporate the importance and relevance of resilience characteristics within a type 1 diabetic family, with a larger sample in another geographical region.

### **3.7 Physical complications**

A myriad of physical complications can form part of a diagnosis of type 1 diabetes. The complexity of the illness, as well as the strict management regimen the illness requires, creates physical stress on the entire family (Lowe et al., 2004). Sandberg, Trief, Greenberg, Graff and Weinstock (2006) explain that the core instigators of physical complications for the diabetic patient are constant high or very low blood glucose readings. Chronic high or low blood glucose levels can create microvascular and/or macrovascular complications (Daneman, 2006). Microvascular complications include damage to the nerves and the eyes (which may lead to blindness), kidney failure and limb problems, especially in the feet and legs and often leading

to amputations (Trief et al., 2003). Macrovascular complications include cardiovascular diseases, such as coronary artery disease, hypertension and nephropathy (Daneman, 2006). According to Daneman (2006), type 1 diabetic patients have a tenfold greater chance of developing cardiovascular diseases than non-diabetic persons, particularly if they smoke and are obese. Another dangerous consequence of uncontrolled blood glucose is diabetic ketoacidosis (DKA). DKA is the result of inadequate amounts of insulin, leading to very high blood glucose levels that break down muscle and fat tissue (Charfen, Fernandez-Frackelton & Geffen, 2005). The breakdown of muscle and fat in the body causes an overproduction of ketones (Charfen et al., 2005). According to Charfen et al. (2005), DKA requires immediate hospitalisation in order to hydrate the patient, lower blood glucose levels and induce electrolytes to repair imbalances in the body. Bui and Daneman (2006) say that DKA is life threatening and may lead to morbidity and mortality in type 1 diabetic children and adolescents. DKA is often the result of a poor diet, little or no exercise and uncontrolled insulin injections, which cause blood sugar to rise (Daneman, 2001).

According to Guthrie et al. (2003), children under the age of five years tend to experience recurrent episodes of hyperglycaemia (very high blood glucose levels) and hypoglycaemia (very low blood glucose levels). The younger the age of diagnosis for type 1 diabetes, the greater the chance for cognitive deficits to develop (Ryan, Vega & Drash, 1985). Long-term effects of hypoglycaemia have come to show mild cognitive impairments in adolescents who were diagnosed with diabetes in childhood (Brands, Biessels, De Haan, Kapelle & Kessels, 2005; Ryan et al., 1985). The chances of developing cognitive deficits are greater when suffering from severe hypoglycaemia, since severe hypoglycaemia can lead to seizures or a loss of consciousness (Ryan, Gurtunca, & Becker, 2005).

### **3.8 Psychological impact**

The sudden diagnosis of type 1 diabetes in a child or adolescent can create profound psychological stress for a family. Stallwood (2005) points out that the numerous responsibilities that come with type 1 diabetes create different stresses for the members of the family. The fact that diabetes is such a complex illness and requires rapid lifestyle changes involves the whole family. Guthrie et al. (2003) state that diabetes not only affects the child with the diagnosis, but inevitably the whole family.

In some families, the siblings struggle to adapt to the diagnosis, since the diabetic child may receive plenty of attention (Guthrie et al., 2003). The siblings may feel left out and unimportant, and may develop feelings of jealousy toward the diagnosed sibling and their parents (Guthrie et al., 2003). The fact that the parents know that they spend more time with their diabetic child and on the illness itself can also create extra feelings of stress in the parents.

It is of the utmost importance that parents understand the complexity of the illness in order to enable their child to self-manage his/her illness (Sousa, Zauszniewski, Zeller & Neese, 2008). This may create plenty of stress for the parents, seeing that they need to be not only parents, but at the same time also educators. Parents are also not always sure whether they understand all the necessary aspects of the illness well enough to teach their child how to manage their diabetes. In a qualitative study by Bowes et al. (2009), parents declared that they still experienced stress and anxiety, even many years after the initial diagnosis. The parents feared that their knowledge and control of the illness were never good enough (Bowes et al., 2009). This supports Meleski's (2002) finding that parents experience constant uncertainty during the diagnosis and the later transitions that form part of the child's development and illness. Meleski (2002) explains that parents do not necessarily experience constant sorrow, but feelings of worry and sorrow resurface during specific incidents that form part of family life.

In addition, a child with diabetes can create significant stress within a marriage (Guthrie et al., 2003). Spouses need to share numerous responsibilities, such as food and medication purchases, food preparation, medication administration, exercise regimes and laying out the rules for the child (Coyne & Smith, 1994). Conflict may arise when spouses feel that one of them does not put as much effort into the management of the illness, or they may become critical of one another (Klausner et al., 1995). According to Bowes et al. (2009), mothers are more expressive about their emotions with regard to the illness, while fathers find it difficult to communicate their feelings. The differences in the sharing of emotional experiences and feelings with regard to a child with diabetes may also create stress within a marriage.

The lifestyle of a child with type 1 diabetes optimally needs to be regimented for better overall health care, which can lead to psychological stress for the whole family (Guthrie et al., 2003). Responsibilities may include specific ways of meal preparation, specific mealtimes, snacking, testing for blood glucose levels, injection of insulin and recommendations for exercise. A

household with a low income and high costs in health care creates further stress for families attached to a chronic illness (Guthrie et al., 2003).

Kovacs, Kass, Schnell, Goldston and Marsh (1989) found that parents take between nine and 12 months to adjust to the diagnosis of diabetes in a child. Lowes et al. (2004) also found that parents can take up to 12 months to overcome the shock of the loss of freedom and loss of child health. In contrast, Eakes, Burke and Hainsworth (1998) argue that parents never fully accept the illness, since certain events elicit memories and feelings of their deep loss. Eakes et al. (1998) explain that, at the time of diagnosis, parents describe their emotions as anxious, shocked, angry and full of guilt. As mentioned previously, genetic predisposition is necessary for the development of type 1 diabetes (Karvonen et al., 2000), and parents may feel guilty for knowing that they are responsible for carrying the susceptible gene over to their child. Furthermore, parents fear hypoglycaemia, which is associated with seizures or loss of consciousness in the child (Marrero, Guare, Vandagriff, & Fineberg, 1997) and can cause cognitive impairments (Ryan et al., 2005). Jessop and Stein (1985) highlight the ubiquitous feeling of uncertainty in parents with chronically ill children. Because of their uncertainty regarding the illness, parents of type 1 diabetic children struggle to adjust effectively and show tendencies to experience psychological distress (Stewart & Mishel, 2000).

### **3.8.1 Psychological impact during the childhood years**

In order to understand the possible impact that type 1 diabetes in a child may have on a family's ability to adapt effectively to the diagnosis, it is necessary to also consider the child's development stage. According to Erik Erikson's psychosocial development theory, an individual can be referred to as a child between the ages of two and 12 years (Erikson, 1963). Early childhood starts around the age of two years, while childhood stretches between six and twelve years of age, before the onset of puberty at approximately 13 years of age (Meyer et al., 2000). Adolescence, according to Erikson's theory, stretches between the ages of 13 and 18 years (McLeod, 2008). According to Landolt, Vollrath, Laimbacher, Hanspeter and Sennhauser (2005), both mothers and fathers of young children with type 1 diabetes experience major stress, even more so than parents with older diabetic children (Stallwood, 2005). A diagnosis of type 1 diabetes in a child creates greater shock and stress in parents, more severely if the child is an infant or toddler (Kushion, Salisbury & Seitz, 1991). Very young children require parents to take full responsibility for regimented tasks related to diabetes, such as blood glucose

monitoring, insulin injections, carbohydrate counting and the prevention of hyper- or hypoglycaemia (Kiess et al., 1998).

Numerous studies have highlighted parents' fear of hypoglycaemia in their young child (Cody, 2007; Guthrie et al., 2003; Mitchell et al., 2009; Monaghan et al., 2009; Sullivan-Bolyai et al., 2001). Hypoglycaemia adds a significant burden to parents with a child with diabetes, seeing that the symptoms of hypoglycaemia, such as dizziness, hunger or agitation (Streisand, Swift, Wickmark, Chen & Holmes, 2005), are not always easily or immediately recognisable (Boland & Grey, 2000). Moreover, severe and frequent hypoglycaemic episodes that go untreated can cause brain damage, comas or even death (Marrero et al., 1997). Fear of hypoglycaemia is worsened at night (Monaghan et al., 2009). Night-time management and monitoring of blood glucose can negatively affect parental functioning (Monaghan et al., 2009). According to Patton, Dolan, Henry and Powers (2007), parents often experience feelings of intense worry when their child goes to sleep.

Managing type 1 diabetes in a child can be extremely difficult when the child is fussy about food, drinks, the testing of blood glucose and the insulin injections (Cody, 2007; Sullivan-Bolyai et al., 2001). These are necessary tasks that need to be executed. Type 1 diabetes ultimately demands the parents of a young child to battle with their natural instinct of protection toward a child when injections need to be administered (Cody, 2007). Parents may feel as if they are the inducers of pain in their child, which is in contrast to their nature of nurturing a child. In addition, parents experience psychological stress, seeing that diabetic children are at a higher risk of poor academic achievement (Ryan, 2005) and adjustment problems (Grey, Cameron, Lipman & Thurber, 1995).

The diagnosis of type 1 diabetes can change the lifestyle of a family to such a profound extent that some parents need to quit or change their profession (Cody, 2007), which can also induce psychological stress in the family. A study by Wysocki, Huxtable, Linscheid and Wayne (1989) found that parents with diabetic children experience much greater stress than parents with non-diabetic children.

### **3.8.2 Psychological impact during the adolescent years**

As previously mentioned, Erik Erikson's psychosocial theory of development describes adolescence as the age category from 13 to 18 years (McLeod, 2008). This stage is

characterised by independence, a focus on academics, relationships and body image (McLeod, 2008). The parental psychological stress experienced with an adolescent with type 1 diabetes in the family comprises different challenges to those experienced with younger children. As Holmbeck, Friedman, Abad and Jandasek (2006) explain, the adolescent period is distinct with regard to its psychological, biological and social changes. Psychological changes during adolescence entail the formation of the adolescent's identity, his/her striving for independence and social acceptability, and sexual exploration (Hamilton & Daneman, 2002). Graber, Lewinsohn, Seeley and Brooks-Gunn (1997) further highlight multiple changes during the adolescent years, such as the onset of puberty, engagement in romantic relationships, differences in social patterns with parents and changing schools. For some parents and adolescents it is very difficult and stressful to adapt to the changes and demands of diabetes, together with the psychosocial changes associated with the onset of adolescence.

Bowes et al. (2009) explain that parents, especially mothers, find it difficult to give their adolescent children the responsibility of managing their illness independently. A possible explanation for this finding is that most parents help to manage tasks related to diabetes from childhood (Stoker Greene, Mandelco, Olsen Roper, Marshall & Dyches, 2010). However, some parents may give the adolescent full independence to look after his/her illness, although it has been found that many adolescents do not adhere to important health tasks during this stage. Kovacs, Goldston, Obrosky and Iyengar (1992) found major non-compliance in diabetes routines in a sample of adolescents with diabetes. Kovacs et al. (1992) also found that these adolescents were more prone to showing signs of psychopathology, especially depressive symptoms. Schilling, Knafl and Grey (2006) state that non-compliance during the adolescent years can also be due to psychological immaturity. Self-care regimes tend to decrease during the adolescent years (Schilling et al., 2006).

The fact that diabetic teenagers may strive for independence, but also not to take proper care of their diabetes, creates major stress for parents. In certain instances, adolescents become rebellious or angry about their illness. They do not want to adhere to the management requirements of the illness, or eat too little and do not administer insulin in order to lose weight. The difficulty lies in the parenting of such adolescents, because parents do realise that they need to provide their child with independence. It creates significant stress for the entire family if the adolescent does not adhere to important health routines. Non-adherence may lead to DKA

(Daneman, 2001). DKA can lead to hospitalisation, which will create feelings of worry and sadness in most parents (Bowes et al., 2009).

Furthermore, stress in adolescent diabetics may cause their metabolic control to deteriorate over time (Greening, Stoppelbein, Konishi, Jordan & Moll, 2007). Deterioration in metabolic control may be due to non-compliance with good diabetes management, but also due to pubertal growth and changes in hormones (Silverstein et al., 2005). Physical growth and an increase in hormonal activity decrease the body's sensitivity to insulin considerably (Silverstein et al., 2005). Insulin injections that need to be adjusted for physical activity, stress and hormonal changes can create immense stress for both the adolescent and the parents (Meneghini, 2007). The administration of too much insulin can cause a very low blood glucose reading, which may lead to hypoglycaemia. By default, hypoglycaemia causes weight gain in the adolescent because an overload of foods is eaten in order to increase blood glucose levels as quickly as possible. The possibility for diabetics to gain weight easily with insulin omissions causes teenage diabetic girls and young adult women in particular to develop eating disorders to control their body weight (Daneman, 2006). The independent control of diabetes tasks by adolescents sometimes cause eating problems in the form subjective control of incorrect or even no meals, very high or low doses of insulin, and no blood glucose testing, the consequences of which can create endless stress for the whole family. Another point of concern and a possible creator of stress in the family is the fact that adolescents who were diagnosed with diabetes at an early age could be more prone to episodes of hypoglycaemia (Cyrulnik, 2009; Strümpfer, 2005). This results in learning and information-processing problems (Holmes & Richman, 1985; Ryan, Vega, Longstreet & Drash, 1984).

According to Ryan (2005), children who have been shown to have poor blood glucose control tend to perform poorer academically than control groups. Additional support at school can be of help, but may create embarrassment for the adolescent with diabetes. Meneghini (2007) found that the social context may influence the control of diabetes to a great extent. Diabetics often feel self-conscious about their illness (Meneghini, 2007). Injecting insulin at school, before or after meals, especially in front of peers, may create distress (Meneghini, 2007).

Difficulty may arise when treatment tasks intervene with personal activities, such as sleepovers (Miller, 2009). Since the urge to strive for independence and freedom during adolescence is very strong, the daily tasks that diabetes demands may be interpreted as unnecessary, time

consuming, troublesome, and unfair (Bowes et al., 2009). Bowes et al. (2009) explain that when the child or adolescent with diabetes feels unwell, miserable, self-conscious or unfairly treated in life, the parents' experience of such feelings is even more distressing.

### **3.9 Factors contributing to family resilience**

Despite the numerous stressors that may form part of the life of a family with a child with type 1 diabetes in the home, or a chronic illness in general, these families are able to adapt to their circumstances (McCubbin et al., 1997). After extensive searches on the internet, databases available from the university, books and personal communication, it became evident that Brown et al.'s (2010) study on resilience characteristics in families with a type 1 diabetic child is the only study in South Africa similar to this study. Brown et al.'s study and this study focus on resilience characteristics of families with a type 1 diabetes diagnosis in the family. Other resilience studies in South Africa, as well as internationally, have rather focused on family resilience within a broader context (Hawley & De Haan, 1996; McCubbin & McCubbin, 2001; Walsh, 2002). Furthermore, resilience studies have also concentrated predominantly on family resilience and chronic conditions such as psychiatric disorders (Jonker, 2006), autism (Greeff & Van der Walt, 2010), heart-related trauma (Greeff & Wentworth, 2009) and childhood cancer (McCubbin, Balling, Possin, Friedrich & Bryne, 2002). McCubbin et al. (1997) identified open communication, family routines, extended family support, hope, parental strength and spirituality as overall key contributing factors of resilience in families. Furthermore, Duran-Ayndintug (1998) identified informal support, such as support from friends and extended family members, and formal support, such as schools, hospitals and churches, as contributing factors of family resilience.

Meleski (2002) highlighted the importance of informing the diabetic child's school teachers and friends of the illness and its requirements. When teachers and friends understand the illness and management of the illness better, parental stress can be lessened because the parents are aware that their child is surrounded during the day by individuals who will be able to look after the child properly. Students with type 1 diabetes who are at a school where the personnel understand the background of the illness show better glycaemic control and quality of life than control students (Wagner, Heapy, James & Abbott, 2006).

Walsh (1998) explains that open and clear communication reinforce a family and create a sense of support for one another. Direct communication also creates a sense of belonging, and the

members may feel that they fill a specific position in the family (Greeff & Fillis, 2009). Seeing that type 1 diabetes needs to be managed according to a strict regimen, the daily routines that are followed together by family members are considered as an important force of stability within the family (Patterson, 2002a). Routines and rituals in the family may also help to build family identity, and create a realisation of distinctiveness in the family, and of their unique situation. McCubbin et al. (1980) also highlight that each individual family member can be considered a resource for the family during stressful situations.

Families are able to rise above adversity with less difficulty when they are able to reframe their problem(s) as resolvable (Hawley & DeHaan, 1996). Showing acceptance of a chronic illness, such as type 1 diabetes, may help a family to adapt more easily to their new circumstance (Nakamura & Orth, 2005). Acceptance of a family stressor can also contribute to a diabetic's psychological well-being and better understanding of their illness (Nakamura & Orth, 2005). Hope is another characteristic that can help to instil feelings of protection in parents, lessening their experience of psychological distress and creating opportunities for resilience in the family (Mednick et al., 2007).

Family support plays an important role in the management of a child's diabetes (Geffken et al., 2008). It has been found that parental emotional support plays a significant role in the management of diabetic glycaemic control (Stevenson, Senskey, & Petty, 1991), which may contribute toward more family resilience. If the parents of diabetic youths are described as being supportive from the day of their child's diagnosis, as well as being supportive toward their child's diabetes-specific activities, the youths generally tend to show good glycaemic control (Hanson, Henggeler & Burghen, 1987; Steinhausen, 1982). Support within the family and for the family is intertwined with family adaptation, family hardiness, family communication and family time and routines followed together (McCubbin & McCubbin, 1993b, McCubbin et al., 1997).

Support, in whatever form, from social resources such as extended family members, friends and neighbours, can add greatly to resilience in families (Brooks, 1994). Social support from extended family members and family friends tends to help families adjust and adapt more effectively during times of crisis (Jonker, 2006; Walsh, 1998). Linker, Stolberg and Green (1999) furthermore state that extended family members play a significant role in a family's ability to cope and adapt to stressful life situations. Bronfenbrenner (1979) explains that

extended family members and friends, as well as larger social systems, create the opportunity for families to be socially competent, despite their circumstances.

Reed and Sherkat (1992), on the other hand, emphasise the important role of religion and spirituality in the resilience of families. These authors found religion to be a predictor of resilience and adaptation in the family's life cycle. A fundamental resilience characteristic is faith and/or spirituality (Angell, Dennis, & Dumain, 1998). Angell et al. (1998) explain that spirituality is a resource that enables families to understand, and in certain contexts overcome, their stressful circumstances. Distressed families can implement spirituality as a force that provides meaning and purpose to their circumstances.

Healthcare providers and school personnel also play an important role in families' ability to adapt effectively to their stressor. Healthcare professionals such as physicians, diabetes nurse educators, dieticians and social workers or psychologists play significant roles in the ability of the diabetic child and family to understand and cope with the illness (Bui & Daneman, 2006). A study by Bowes et al. (2009) found that almost all parents reported that they did not receive enough or appropriate emotional support from healthcare professionals at the time of diagnosis, nor on-going support. Via the implementation and development of certain family resilience characteristics, it is evident that, despite the chronic presence and duties that form part of diabetes, and its range of possible psychological or physiological complications, families are able to adapt to this crisis (Bowes et al., 2009).

### **3.10 Conclusion**

This study's primary focus was to determine what qualities or resources help families to adjust and adapt to their child's diagnosis of diabetes. In order to understand and gather information on this theme, this chapter provided a background of what exactly diabetes mellitus is. The importance of the differences between type 1 and 2 diabetes was also highlighted. Since the study's primary focus is on type 1 diabetes, the complexity and demands of the illness on the family were discussed in relation to the physical and psychological complications of the illness.

It is evident that the diagnosis of type 1 diabetes not only creates stress for the child or adolescent, but also for the whole family. Stress is easily created because type 1 diabetes is complex to manage and requires routinised behaviour. In order to be able to manage the illness effectively, the whole family needs to adapt to the illness. The possibility that a child with type

1 diabetes may develop additional physical complications is also a great point of concern for many families. However, despite a myriad of problems that may occur from the day of diagnosis, families have the ability to cope with the child's diagnosis. It is evident from the literature that extended family members, friends, healthcare personnel, family routines and religious beliefs are forces that tend to help families to cope with and adapt to their circumstances.

The research design and methodology of the present study are presented in Chapter 4.

## Chapter 4

### Research methodology

#### 4.1 Introduction

This chapter starts with a formulation of the research question and research design, followed by a description of the participants who took part in the study. This is followed by a discussion of the qualitative and quantitative measures that were used and, finally, the procedures and the analyses implemented in the study are presented.

#### 4.2 Research question

Diabetes in the family creates a diverse range of physical and psychological challenges for the parents of the diagnosed children (DeCoster, 2001; Walsh, 2002). A sudden diagnosis creates feelings of uncertainty (DeCoster, 2001), physiological problems such as hypoglycaemia (Litton et al., 2002) and psychological problems, exacerbated by stress and non-adherence to diabetes regimens (Marshall, Fleming, Gillibrand & Carter, 2002; McDougal 2002). These problems make it difficult for families to cope and adapt optimally. However, some families successfully adapt to the newfound needs of their diabetic child, while other families struggle to accept and adapt to the diagnosis. The families that struggle to adapt effectively need help and guidance to make adaptation easier for the child, as well as for the rest of the family.

As described in Chapter 1, previous studies that have focused on families with a child with a chronic illness did not use the knowledge gained to promote better family adaptation (Knafl & Gillis, 2002). Diagnoses of type 1 diabetes are increasing every year (Brown et al., 2010), especially in children and adolescents (Van der Merwe, 2010). It is especially during the childhood years that the successful management of type 1 diabetes can be a difficult and frustrating task for parents, because parents form part of the complex treatment regimen, that is demanded by type 1 diabetes (DeCoster, 2001).

South Africa is in need of better type 1 diabetes education, as well as information on how to take proper care of individuals with type 1 diabetes (Van der Merwe, 2010). The findings of the present study therefore can be implemented to educate and strengthen families with children with diabetes and consequently help them to adapt to their lifestyle changes. The results of the study can also be used to inform hospital personnel on how families can become more resilient

and adapt to their life situation. Hospital personnel can also be enlightened on the role which they play in the lives of the diabetic child and his or her family.

According to Greeff and Du Toit (2009) there is limited research available on family resilience in South Africa. Therefore, the present study can make a contribution to the growing body of research on family resilience. The present study aimed to identify resilience characteristics of families with a child with type 1 diabetes. Consequently, the research question for the present study was: What family resilience characteristics are present in families that have lived for at least six months with a child (between the ages of two and 17 years) with type 1 diabetes?

### **4.3 Research design**

This study employed an exploratory, cross-sectional research design with a mixed-methods approach. A cross-sectional design implies that information or data is gathered at one specific point in time (Olsen & St. George, 2004). Mixed-methods refer to the gathering and analysis of both qualitative and quantitative data (Creswell & Plano Blank, 2007). According to Creswell and Plano Blank (2007), combining qualitative and quantitative data types in social research creates opportunities to answer research questions more exhaustively.

Quantitative data on its own may not provide true representations of the context in which the research is conducted, while qualitative data on its own may be too personal and subjective in nature (Creswell & Plano Blank, 2007). This study thus used a mixed-methods approach in order to present data of a more representative nature for a sample of families with a child with type 1 diabetes in the home. Qualitative data was gathered using one open-ended question and quantitative data was gathered by the completion of a biographical and four self-report questionnaires. Both the qualitative question and the quantitative measures are based on the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001), so that characteristics within families that can be associated with family resiliency during adaptation to the demands put on the family by having a child with type 1 diabetes could be identified.

### **4.4 Participants**

As soon as ethical clearance was given by Tygerberg Hospital's chief director and the hospital's Health Research Ethics Committee, data collection proceeded. Contact was made with the head

of the paediatric diabetes unit and the paediatric diabetes nurse educator. The head of the diabetes unit, who is the co-supervisor of this study, provided the necessary staff names and numbers so that possible participants could be identified. As soon as contact was made with the diabetes nurse educator in charge of the paediatric diabetics, parent names and telephone numbers of all the registered diabetic patients between the ages of two and 17 years were provided. A non-probability sampling method was used for this study and all families that met the inclusion criteria were listed and contacted for participation in the study. Non-probability sampling denotes that the researcher does not know what the size of the targeted population will be (Neuman, 2003).

Inclusion criteria were set out and applied in deciding whom to include in the sample. The inclusion criteria included that the diabetic child had to be between the ages of two and 17 years and had to have been diabetic for a period of at least six months. All participants in the study had to be a primary caregiver of a child with type 1 diabetes. No children were included in the process of gathering data for this study. The child had to be a registered patient at Tygerberg Hospital's paediatric diabetes clinic. Only mother-tongue and second language speakers of Afrikaans and English could be drawn for the sample. Primary caregivers whose mother-tongue was isiXhosa were excluded from the study. This decision was based on the fact that 85% of people who visit the clinic were mother-tongue or second language speakers of Afrikaans and English, while only 15% spoke isiXhosa as their home language. The isiXhosa-speaking families were too few in number for meaningful between-group comparisons to be made.

For the recruitment of participants, a total of 126 names were made available from the Hospital's database. Out of the total of 126 patients on the list, eight were 18 years old and could not be included in the study. From the age of 18 years, diabetic patients are no longer treated in the paediatric unit at the hospital. As a result, 118 families were left that could possibly take part in the study. Ten out of the 118 possible families could not be reached because some of the contact numbers were incomplete, there was no contact number, or the child with type 1 diabetes lived in a children's home. Finally, 108 families could be contacted. A total of 44 families agreed to take part in the study immediately after a description of the study was provided. Another seven primary caregivers could be motivated to take part in the study during a visit to the doctor. In the end, a total of 51 primary caregivers agreed and took part in the study.

With regard to the gender of the children with type 1 diabetes, 20 (39%) were male and 31 (61%) were female. Given the age criterion set out for the study, their ages ranged from two to 17 years, with a mean age of 10.9 years ( $SD = 4.13$ ). Some of the children were as young as one year old when they were diagnosed with diabetes, while others were 16 years of age. The mean age of diagnosis for this sample of children with diabetes was 7.1 years ( $SD = 3.87$ ).

Of the 51 participants, six (12%) were male and 45 (88%) were female. Forty-two (82%) primary caregivers were the mother of the child, six (12%) primary caregivers were fathers and three (6%) were grandmothers. The age of the primary caregivers ranged from 25 to 61 years, with a mean age of 41.0 ( $SD = 7.55$ ). The study included only Afrikaans ( $n = 38$ , 75%) and English ( $n = 13$ , 25%) mother tongue speakers. As previously indicated, isiXhosa speakers were not included in the study.

Most of the primary caregivers were married ( $n = 34$ , 68%), eight (16%) were single, seven (14%) were divorced and two (4%) were cohabitating. The participants had to indicate the family structure of their family in the biographical questionnaire. Categories were created for single-parent, two-parent and extended families. Most of the children belonged to two-parent families ( $n = 35$ , 69%), followed by single-parents families ( $n = 14$ , 27%). Two children (4%) were living with extended family members. The number of people living with the child with diabetes ranged from two to twelve, with a mean of 4.6 ( $SD = 1.82$ ) people. Furthermore, all the participants resided in the Western Cape province, predominantly in rural areas.

With regard to the education level of the primary caregiver, only one parent had no formal school education. Seven (14%) caregivers had completed primary school education, 39 (76%) had completed high school education and four (8%) had obtained a university degree or college diploma. Household income was divided into three categories. More than half of the sample ( $n = 27$ , 53%) indicated that they earned less than R30 000 per year in 2011, 17 families (33%) earned between R30 000 and R120 000 per year, and seven (14%) families earned more than R120 000 a year. According to Statistics South Africa (2008), the average annual income for South African households in 2005 and 2006 was R74 589, and expenditure was R56 152. It is evident that the sample in this study consisted largely of families living in poverty, earning less than R30 000 per annum, which is well below the average South African income. According to the Poverty and Inequality Report (PIR), poverty in the South African context encapsulates the “inability of individuals, households, or entire communities, to command sufficient

resources to satisfy a socially acceptable minimum standard of living” (May, 1998, p. 3). A family defined as poor forms part of the poorest 40% of households in South Africa, while families classified as ultra-poor are the poorest 20% of South African households (May, 1998). Hirschowitz (2000) explains that the monthly expenditure of a poor family in 1996 was R600 to R1 000, while the very poor spent R600 or less. These statistics are in agreement with the average monthly income of the majority of this sample, obtaining at most, R2 500 per month.

#### **4.5 Measures**

Five measures were used to gather data for this study. The biographical questionnaire included questions for completion, together with a qualitative, open-ended question. The following open-ended question aimed to elicit personal responses with regard to what the caregivers think helped their families to adapt after the child had been diagnosed with type 1 diabetes: “What has helped your family to cope and adapt after your child has been diagnosed with type 1 diabetes?” In addition, four structured quantitative measures were employed to operationalise the Resiliency Model of Family stress, Adjustment and Adaptation. These measures were the Family Attachment and Changeability Index 8 (FACI8), the Family Hardiness Index (FHI), the Family Problem Solving and Communication (FPSC) scale, and the Family Time and Routine Index (FTRI).

The dependent variable in this study was family adaptation. As a family’s level of functioning is a direct indication of the family’s overall adaptation, the FACI8 was used as a yardstick for the measurement of overall family adaptation. The total score of the FACI8 provides an indication of the family’s ability to adapt to their crisis situation, which is the outcome of the resilience process. Subsequently, the other three measures were used to measure important independent variables that might reflect their association with family adaptation and, consequently, family resilience.

All the questionnaires were available in Afrikaans and English and were completed within 10 to 20 minutes. All measures were previously translated from English to Afrikaans, using the translation back-translation technique (Maneesriwongul & Dixon, 2004). What follows is a discussion of each of the measures used in this study.

#### **4.5.1 Biographical questionnaire**

The biographical questionnaire focused on information relating to the primary caregiver, such as gender, position in the family, age, marital status, home language, type of family, level of education and household income per year. The biographical questionnaire also asked the primary caregiver to supply biographical details of the diagnosed child, such as the gender of the child, the child's age, and the age when the diagnosis was made, given that no children took part in the study. Lastly, at the end of the questionnaire the participants were requested to respond to the open-ended question, which aimed to find out what had helped the families to cope and adapt after their child had been diagnosed with type 1 diabetes? The open-ended question was included to obtain personal views and experiences that would not be possible to obtain with the quantitative questionnaires alone. All supplementary and necessary information regarding the biographical details of the participants are presented in Appendix B.

#### **4.5.2 The Family Attachment and Changeability Index 8 (FACI8)**

As a measure of family functioning, the FACI8 was adapted by McCubbin and McCubbin (2001) from the Family Adaptability and Cohesion Evaluation Scale (FACES) (Olson, Portner & Bell, 1989). McCubbin and McCubbin (2001) aimed to develop a questionnaire that could be implemented in studies with African-American and Caucasian youths, as well as be ethnically sensitive. FACES is based on the Circumplex Model, a model of marital and family systems, grounded in systems theory (Olson, 2000). The Circumplex Model has three dimensions, namely family cohesion, flexibility and communication (Olson, 2000). The self-report scale measures the cohesion and flexibility aspects of the family (Olson, 2000). Measuring both dimensions linearly restricts the measurement of extreme behaviours in each dimension. As a result, FACI8 was developed to resolve this limitation. The FACI8 measures the level of family adaptation and is used as a yardstick of family functioning. Family adaptation and functioning are measured in terms of the extent to which the family has adapted since the time when great stress was introduced into the family. Two subscales, namely Attachment and Changeability, are used to measure overall family adaptation, expressing the overall functioning of the family. The instrument has a total of 16 items, which measure the family's level of Attachment and Changeability. The Attachment subscale has eight items and measures the strength of the family members' attachment to one another. The Changeability subscale also has eight items and measures how flexible family members are in their relationships. Items are completed on a five-point Likert-type scale, ranging from 1 = Never to

5 = Always. The scale measures how often a specific event comes to the fore at the present moment. Examples of items are *Family members discuss problems and feel good about the solutions* and *Each family member has input in major family decisions*. The internal reliability of the two subscales ranges between .73 and .80 (McCubbin & McCubbin, 2001). The validity of the FACI8 was confirmed by a significant correlation between the success of a treatment programme and FACI8 scores (McCubbin & McCubbin, 2001). In this study, the overall internal reliability (coefficient alpha) for the attachment subscale was found to be .71, and for the changeability subscale it was .83. For the total score, the internal reliability (coefficient alpha) was .47.

#### **4.5.3 The Family Hardiness Index (FHI)**

The FHI was developed by McCubbin, McCubbin and Thompson in 1986 (McCubbin & McCubbin, 2001). The overall measurement of family hardiness gives an indication of the family's ability to resist stress and be durable in times of hardship (McCubbin & McCubbin, 2001). Family hardiness also facilitates family adjustment and adaptation when exposed to a crisis situation. Hardiness also refers to families that regard change as beneficial for the family. The scale has three subscales that measure commitment, challenge and control. The commitment subscale evaluates how the family is able to work together, to what extent they depend on one another and the internal strength there is between family members (McCubbin & McCubbin, 2001). McCubbin and McCubbin (1997) explain that the challenge subscale concentrates on the assessment of the family's attempt(s) to be innovative, explore new experiences and be willing to learn from those experiences. Lastly, the control subscale attempts to assess the family's view or sense of being in control of family life, rather than influenced by outside events or circumstances. Family hardiness is assessed on a five-point Likert-type scale with 20 items, with answering options ranging from false, mostly false, mostly true, true, to not applicable. The option chosen as most appropriate within the specific family context provides a description of the family's current situation. Example of items in the FHI are *We have a sense of being strong even when we face big problems*, and *We strive together and help each other no matter what*. The FHI has a good internal reliability of .82. Validity coefficients range from .20 to .23 with regard to criteria such as family satisfaction, time and routines and flexibility (McCubbin & McCubbin, 2001). This study obtained a reliability coefficient of .59 for the total scale. The subscale reliability coefficients obtained in this study were .62, .49 and .76 for challenge, control and commitment respectively. In South

African studies by Brown et al. (2010), Greeff and Fillis (2009), and Jonker (2006) of black, white and coloured participants, internal reliability coefficients of .54, .36 and .60 respectively were found.

#### **4.5.4 The Family Problem Solving and Communication Scale (FPSC)**

This measure was developed specifically for research on family stress and resiliency, measuring the problem solving and communication component of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001). The FPSC is a 10-item instrument with a four-point Likert-type scale, ranging from False = 0, Mostly False = 1, Mostly True = 2, to True = 3. The measure was developed by McCubbin, McCubbin and Thompson in 1988 (McCubbin & McCubbin, 2001). The FPSC assesses patterns of communication in the family on a continuum with opposite poles of communication, ranging from positive to negative communication (McCubbin & McCubbin, 2001). Communication plays a vital role in the family's ability to cope, to solve problems and to be resilient in problem-filled life situations. McCubbin and McCubbin (2001) clarify that the type of communication used by the family provides a worthy indication of the extent to which families manage stress, strains and hardship, but also are able to function optimally, adjust and adapt. The two subscales of the FPSC measure affirming and incendiary patterns of communication. Affirming communication is a positive form of communication. This type of communication articulates support and care and creates a calm environment for communication. An example of an item to assess affirming communication is *We talk things through till we reach a resolution*. On the other hand, incendiary communication patterns are negative in nature. Incendiary communication inflames stressful situations and intensifies conflict, and may include instances of yelling, screaming and fighting (McCubbin & McCubbin, 2001). Such communication was assessed with items such as *We yell and scream at each other* and *We make matters more difficult by fighting and bring up old matters*. The internal reliability (Cronbach's alpha) for the total scale is .89, and .86 and .78 for the affirming and incendiary communication subscales respectively. The test-retest reliability coefficient for the FPSC is .86 (McCubbin & McCubbin, 2001). In this study, an alpha reliability of .76 was found for the total FPSC scale, .85 for the affirming communication and .53 for the incendiary communication subscales.

#### 4.5.5 The Family Time and Routine Index (FTRI)

In 1986 McCubbin, McCubbin and Thompson designed the FTRI (McCubbin & McCubbin, 2001). This measure was created to evaluate the various activities and routines that families use in their daily life. The evaluation of time spent together as a family and the routines they follow are reasonably dependable indications of family stability and integration (McCubbin & McCubbin, 2001). Evaluating time spent together and routines followed in the family creates opportunity to better manage stress and increase family resilience. The FTRI consists of 32 items divided into eight subscales, each item assessed on a four-point Likert-type scale (ranging from False = 0 to True = 3). Each statement is answered according to the degree to which the item fits the family situation the best. The eight subscales used to measure important areas of family time and routines are Parent-child togetherness (predictable communication between the parents and children), Couple togetherness (predictable routines that encourage communication between spouses), Child routines (predictable routines that accentuate the child's sense of independence), Meals together (predictable routines that encourage family togetherness during mealtimes), Family time together (predictable togetherness through special events, quiet time and family time), Family chores routines (predictable routines that encourage children's homework responsibilities), Relatives connection routines (predictable routines that encourage communication with relatives), and Family management routines (predictable routines that promote family management styles). The FTRI does not have a total score, such as the FACI8, FHI or FPSC. In this measurement, each subscale measures the extent to which family time is spent together and routines are implemented and followed together as a family. Examples of items of the FPSC are *Family has a quiet time each evening when everyone talks or plays quietly*, *Parents have time with each other quite often* and *Whole family eats one meal together daily*. The overall internal reliability of the FPSC is .88 (McCubbin & McCubbin, 2001). Validity coefficients for the scale range from .24 to .34, with specific reference to family bonding, family satisfaction, marital satisfaction, family celebrations and family coherence (McCubbin & McCubbin, 2001). Reliability coefficients found in this study were .90 for the total scale, .55 for parent-child togetherness, .80 for couple togetherness, .38 for child routines, .76 for meals together, .77 for family time together, .83 for family chores, .76 for contact with relatives, and .67 for family management.

## **4.6 Procedure**

An office in the paediatric diabetes unit of Tygerberg Hospital was made available for interviews with the caregivers before or after the child had been seen for his/her trimester appointment. Before an interview was conducted with a participant, the participant was asked to complete an informed consent form, and read and signed the study's information leaflet. After permission was granted, he/she was given the biographical questionnaire with the open-ended question and four quantitative measures to complete in the presence of the researcher. After the biographical details were completed, the participant was asked to respond to the open-ended question in writing. If a participant was unable to write a response to the open-ended question, the researcher wrote exactly what the participant stated his/her answer to be. After the open-ended question had been answered, the four quantitative measures were completed by selecting the answer most applicable to the family's situation or environment. The total time spent per interview varied between 10 and 30 minutes.

After the questionnaires had been completed, the researcher made sure that everything was filled in as required. Each participant then received a R30 voucher for their participation and was thanked for their time and willingness to take part in the study. All datasets could be used for analyses, since each one was completed in full. After all the identified and available participants had been seen, the data was prepared for the analyses.

## **4.7 Data analysis**

This study used a mixed methods approach in which both qualitative and quantitative methods of data gathering and analysis were carried out. Qualitative and quantitative methods of analysis will now be discussed.

### **4.7.1 Qualitative data analysis**

According to Braun and Clarke (2006), thematic analysis used in the analysis of qualitative data does not require a detailed pre-existing theoretical framework, or technologically advanced computer-based analyses in order to analyse data correctly. Rice and Ezzy (1999) describe the thematic analysis process as one of identifying themes through accurate, in-depth reading and re-reading of the data. Thematic analysis can be used within various theoretical frameworks, such as the Resiliency Model of Family Stress, Adjustment and Adaptation, and would be able to determine themes by making use predominantly of researcher judgment

(Braun & Clarke, 2006). In thematic analysis, developed themes can be categorised according to certain codes allocated to them (Fereday & Muir-Cochrane, 2006). There are two types of coding, namely open coding and axial coding. The inductive approach, open coding, allows the researcher/analyst to generate themed categories for the data, because the process allows congruent concepts to be identified with their properties traced in the data (Strauss & Corbin, 1998). Axial coding relates existing categories to created subcategories (Strauss & Corbin, 1998). Strauss and Corbin (1998) explain axial coding as coding (subcategories) created around the “axis” of a category.

Before thematic analysis was applied and codes were created for the analysis in this study, the researcher read through the data a number of times. Re-reading the data leads to familiarisation with the data (Lacey & Luff, 2001). As soon as this familiarisation was completed, the researcher was able to gather themes from the data and continue the process of creating open codes for the data. Eventually, 11 codes were created, namely religion, extended family, friends, life partner, diabetes nurse educator, diabetes specialist, eating habits, reading, family, and nutritionist. Using thematic analysis, the reality of participants’ experiences could be reported authentically. Thematic analysis is a flexible research tool in that themes can be determined by the researcher in various ways and simultaneously provide rich and detailed results (Braun & Clarke, 2006).

#### **4.7.2 Quantitative data analysis**

Concerning the quantitative data, each individual response to the biographical questionnaire and four quantitative questionnaires was captured manually in Microsoft Excel and sent to a senior statistician at the Centre for Statistical Consultation of Stellenbosch University. The senior statistician imported the responses into the statistical program Statistica (Statsoft Incorporated, 2011). With regard to the biographical questionnaire, ANOVAs (analysis of variance) were done to test for mean differences between groups. Variables that were analysed and compared were the gender of the primary caregiver, the position of the primary caregiver in the family, the age of the caregiver, marital status, home language, type of family (single parent, two-parent, extended), the number of people living together, the level of education, income per year, the gender of the child, child age, the age at which the child was diagnosed, and the number of other siblings in the home.

Reliability analyses (Cronbach's alpha coefficients) for each scale together with its subscales were also done. Scatterplot outputs were calculated to provide the Spearman correlation coefficients ( $r$ ). Howell (1999) explains that a scatterplot is a figure in which data points are plotted against one another. A regression line, the line drawn across all the data points, is the line showing the greatest fit of the relationship between the independent and dependent variables (Howell, 1999). A regression line in an upward direction or from the left to the right of the scatterplot denotes a positive correlation, whereas a line with a downward slope denotes a negative correlation. In the case of a regression line with no slope, there is no relationship between the variables. The Spearman correlation coefficient was used because of the fact that various categories of variables needed to be compared in order to identify the relationship between the dependent variable (family adaptation) and the independent variables. Lastly, best-subset regression analyses were done to identify how well the best combination of independent variables predicted the variance of the dependent variable. The best-subset regression analysis allowed the researcher to gain more knowledge about the combination of resilience characteristics that may contribute to the prediction of the family's adaptation.

#### **4.8 Ethical considerations**

Within the field of human research, ethical consent is of paramount importance. Brody, Gluck and Aragon (1997) explain that obtaining informed consent for human research in the field of behavioural sciences is a standard and familiar process that needs to be followed. Before any actions could be taken for participant recruitment and data gathering, the strict ethical guidelines of Stellenbosch University's Tygerberg Campus, Health Research Ethics Committee had to be followed. Afrikaans and English copies of the Human Research Ethics Committee's (HREC) application form, informed consent form, information leaflet, drug trial form and checklist form had to be completed. Together with these documents, the study protocol, a protocol synopsis and the investigator's declaration forms had to be handed to the committee. After the HREC of Tygerberg Hospital had sent an ethical clearance number and notice number. This study was thereby cleared and ethically approved.

Ethical considerations by the HREC include the acknowledgement of every participant's informed consent to take part in the study, participants need to understand what the aim of the study is and how the research will be conducted. Furthermore, it was obligatory to indicate that participation was completely voluntary and that the confidentiality and anonymity of the participants would be ensured at all times. Informed consent was regulated by handing out an

information leaflet and informed consent form. The leaflet and consent form were read and signed by the participants in the presence of the researcher. Confidentiality, privacy and anonymity of the participants were ensured by not requesting the indication of a name or surname in any of the ethical research documents or questionnaires. In all the ethics-related forms provided by the HREC, it was clearly stated that participation was completely voluntary, even in instances where a participant had indicated that he/she would take part in the research but did not want to take part anymore. Caregivers' rights, beliefs, language preferences, culture and race were respected at all times during the period of data gathering.

#### **4.9 Conclusion**

This chapter provided a description of what this research study entailed. All the participants resided within the Western Cape, and were from rural environments. In order to produce saturated qualitative and quantitative results, as well as identify resilience factors that facilitate adaptation in families from different socio-economic backgrounds with a child with type 1 diabetes, a mixed methods approach was used. This chapter provided descriptions of how the research study was conducted, why it was conducted, how it was designed, what the set ethical procedures were that were followed, and how the data was analysed. After all these steps were followed, the results could be delivered, and these will be reported on in the next chapter.

## Chapter 5

### Results

#### 5.1 Introduction

The results of both the qualitative and quantitative data are presented in this chapter. Firstly, the qualitative results are presented in a table according to the frequency of themes gathered from the answers obtained from the open-ended question. Secondly, all the Spearman correlations are presented. Thirdly, three scatterplots indicating the significant correlations between family adaptation (FACI8 total score) and the total scores of the independent variables (obtained with the FHI, FPSC and FTRI) are shown. Fourthly, an analysis of variance (ANOVA) is presented to show the possible mean differences that may exist between subgroups within the sample. Finally, the results of the best-subset multiple regression analysis are reported.

#### 5.2 Qualitative results

The qualitative component of the study created the opportunity to gather information about the family's personal context and their understanding of the resources that contribute to better family adaptation. The qualitative data contained rich details of the participants' experiences, of what they believed had helped their family cope and adapt after their child was diagnosed with type 1 diabetes. Having used thematic analysis, the codes developed could be assigned to two main themes, namely family resources and social resources. Family resources in this study were interpreted as resources residing within individuals in the family, or resources received from the family as a whole. The families' religious beliefs and practices, food prepared for and eaten by the diabetic child and family, and gaining knowledge by reading the available literature on the illness, resided within the family. Social resources encompassed all information and support obtained from a social supportive network. A social supportive network was found to be any help and/or support received from the diabetes specialist, the diabetes nurse educator, members of the extended family, friends, a life partner of the primary caregiver and the hospital nutritionist. The qualitative themes and their prominent codes are presented in Table 1.

Table 1

*Family and Social Support Resources Identified by the Primary Caregivers (N = 51)*

	Frequency	(%)
Family resources (Internal resources within family)		
Family (husband, wife, partner and children emotional support)	27	52.9
Religious beliefs (belief in God, support from pastor and church groups)	19	37.3
Eating habits of child (healthy eating and exercise vs. unhealthy meals)	10	19.6
Reading (diabetes literature – articles, books, magazines, pamphlets)	5	9.8
Social resources (External resources to family)		
Diabetes specialist (information, knowledge, patience, acknowledgement)	28	54.9
Diabetes nurse educator (organisation, information, recommendations)	15	29.4
Extended family (grandmother and grandfather support, aunts and uncles)	13	25.5
Friends (conscious of child's specific diet, making phone calls to the family, assisting family during period of hospitalisation)	8	15.7
Life partner (support and help received from husband or boyfriend)	5	9.8
Nutritionist (information, eating plans, understanding circumstances)	2	3.9

The most prevalent family resource that emerged from the data was the support of family members residing together in the home of the child with diabetes. Family members in this instance included the primary caregiver of the child, the primary caregiver's life partner, and possibly siblings of the diabetic child. The primary caregivers conveyed that "our family supports one another" and "we understand everything together and help each other". Religious beliefs and prayer were the family resource mentioned second most frequently by the participants. Family members believed that "the pastor prayed for our child and God helps us". Some primary caregivers also explained that "the church group prays for us and helps to raise

money for us". The food that is prepared for the family and what the diabetic child eats on a daily basis, whether healthy or unhealthy, also played an important role in the manner in which the primary caregiver experienced strength within him-/herself (n = 10; 19.6%), as well as for the family. Caregivers felt that "when I cook meat and vegetables with little salt and sugar, I feel good", "It makes it easier for our family when everyone eats the same food" and "when he eats chips and sweets I feel bad, but sometimes he must". A small number of participants (n = 5; 9.8%) conveyed that reading literature on type 1 diabetes had helped the family as a whole to understand the illness better and to have more regard for what the child's experiences and what the needs of the child were. Diabetes literature helped families in that "we wanted to know more about diabetes so that we can help our child" and "we must know what to do when her sugar goes down".

Social support for the family (n = 28; 54.9%) came primarily from the support, information and supervision provided by the paediatric diabetes specialist. Participants described the specialist as "the doctor always helps us", "he is patient and makes us understand what to do". The diabetes nurse educator (n = 15; 29.4%), extended family members (n = 13; 25.5%), friends (n = 8; 15.7%), a life partner (n = 5; 9.8%) and hospital nutritionist (n = 2; 3.9%) provided the families with the ability to adjust, as well as to adapt to the child's diagnosis.

### **5.3 Quantitative results**

Spearman correlations were calculated to determine the relationships between potential resilience variables, measured by the three quantitative questionnaires (family hardiness (FHI), family patterns of communication (FPSC), and family time spent together and routines followed (FTRI)), and the dependent variable family adaptation (measured with FACI8). A summary of all the Spearman correlations is shown in Table 2. Graphical representations of the correlations between family adaptation and the total scores obtained with the three independent measures are presented in the scatterplots in Figures 5.1 to 5.3. Finally, the ANOVAs calculated to test for differences between groups are presented.

#### **5.3.1 Spearman correlations**

Spearman correlations were calculated to determine the correlations between family adaptation (measured with FACI8) and the other variables (measured with the FHI, FPSC and FTRI). The results are shown in Table 2.

Table 2

*Spearman Correlations Between the Independent Variables and Family Adaptation (N = 51)*

Variable	r	p
Family Hardiness Index (FHI)		
Commitment (family work together)	0.40	< 0.01**
Challenge (innovative, exploration, willingness to learn)	0.58	0.00**
Control (family sense of being in control)	0.33	0.02*
FHI total score (family stress resistance and durability during hardship)	0.54	0.00**
Family Problem Solving and Communication Scale (FPSC)		
Affirming communication (positive, articulates support)	0.50	0.00**
Incendiary communication (negative, intensifies conflict)	-0.59	0.00**
FPSC total score (hybrid patterns of communication used in family)	0.62	0.00**
Family Time and Routine Index (FTRI)		
Child routines (predictable routines highlighting child independence)	0.44	0.00**
Couple togetherness (routine encouraging communication between spouses)	0.31	0.03*
Mealtimes together (encourage family togetherness during mealtimes)	0.31	0.03*
Parent and child togetherness (communication between parent and child)	0.50	0.00**
Family togetherness (family togetherness during special event/quiet time)	0.49	0.00**
Contact with family (encourage communication with relatives)	0.22	0.13
Family chores (encourage child homework responsibilities)	0.48	0.00**
Family management (routines promoting family management styles)	0.45	0.00**

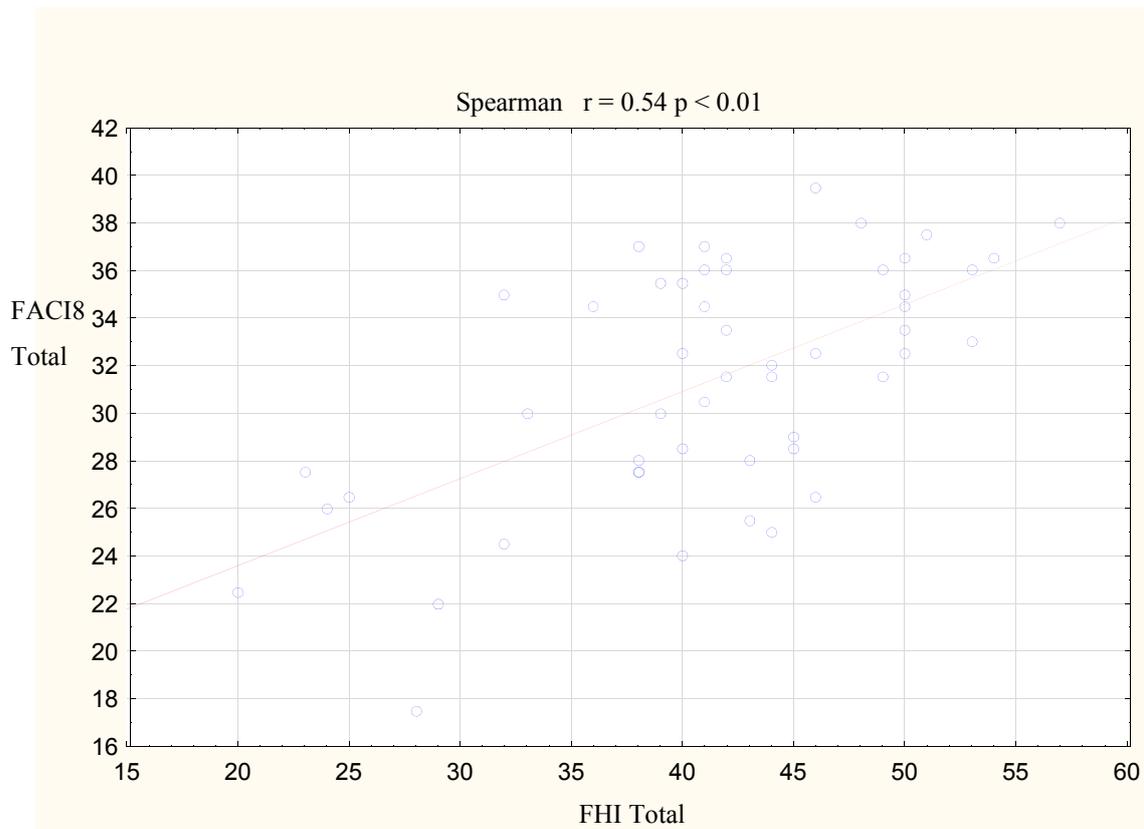
Note. \* $p \leq 0.05$  \*\* $p \leq 0.01$

From Table 2 it can be seen that positive patterns of communication used in the family have the strongest correlation with family adaptation. Furthermore, viewing crises as a challenge and family time spent together were also strongly correlated with family adaptation.

### 5.3.2 Scatterplots

Scatterplots of the correlations of the total scores for the three independent measures with the total score of FOCI8 are presented in this section. The scatterplot presentations are included to show possible nonlinear relationships that are not necessarily fully presented in the simple

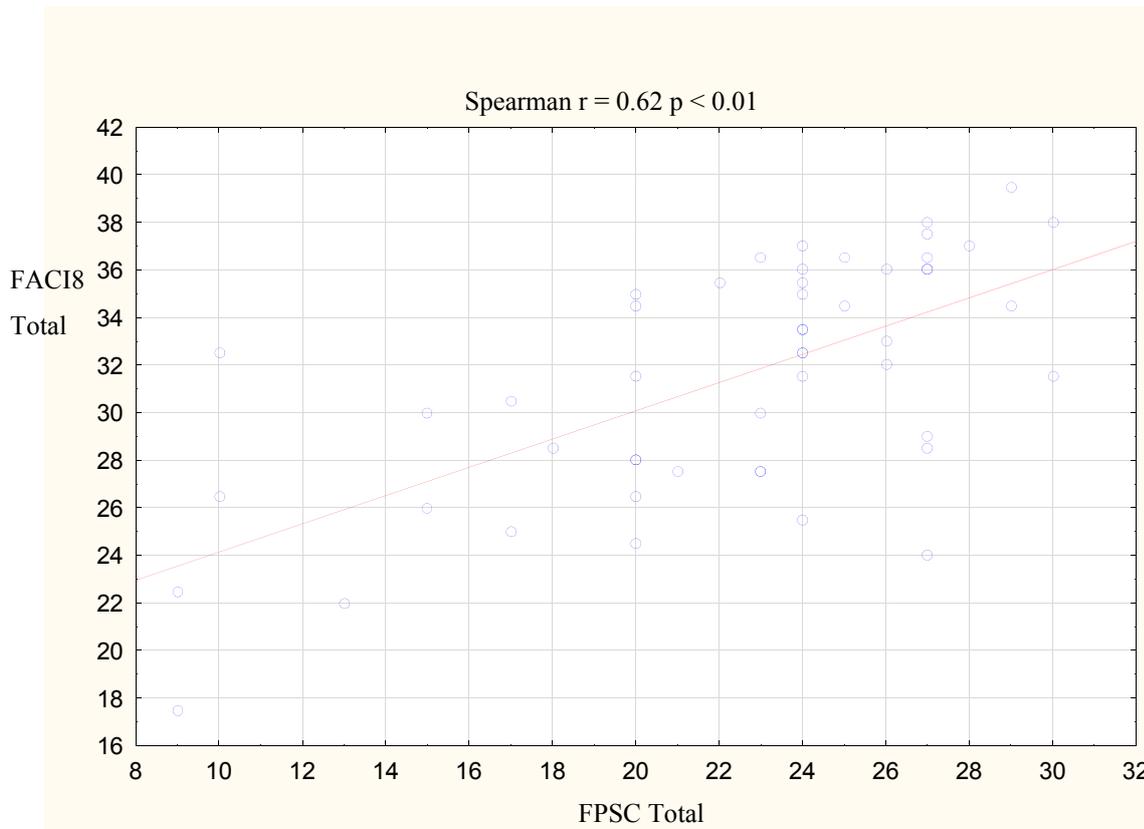
correlation (Graziano & Raulin, 2010). Figure 5.1 shows a graphical representation of the correlation between the family's level of adaptation (FACI8) and the family's ability to be durable in times of hardship (total score on the Family Hardiness Index).



*Figure 5.1.* The correlation between Family Adaptation (FACI8 scores) and Family Hardiness (FHI total score).

It is evident from Figure 5.1 that there is a significant positive correlation between family adaptation and the family's ability to resist stress and to be durable during times of hardship (FHI total score) ( $r = 0.54$ ,  $p < 0.01$ ). This correlation illustrates that the family's hardiness – their ability to be durable in times of hardship (McCubbin & McCubbin, 2001) and to interpret change as beneficial for the family – solidifies them to adapt more successfully to crisis situations. The significant correlation of family hardiness with family adaptation in this sample of families living with a child with type 1 diabetes in the home emphasises the important role that family hardiness plays in buffering against life stressors, and adapting more easily to crisis situations.

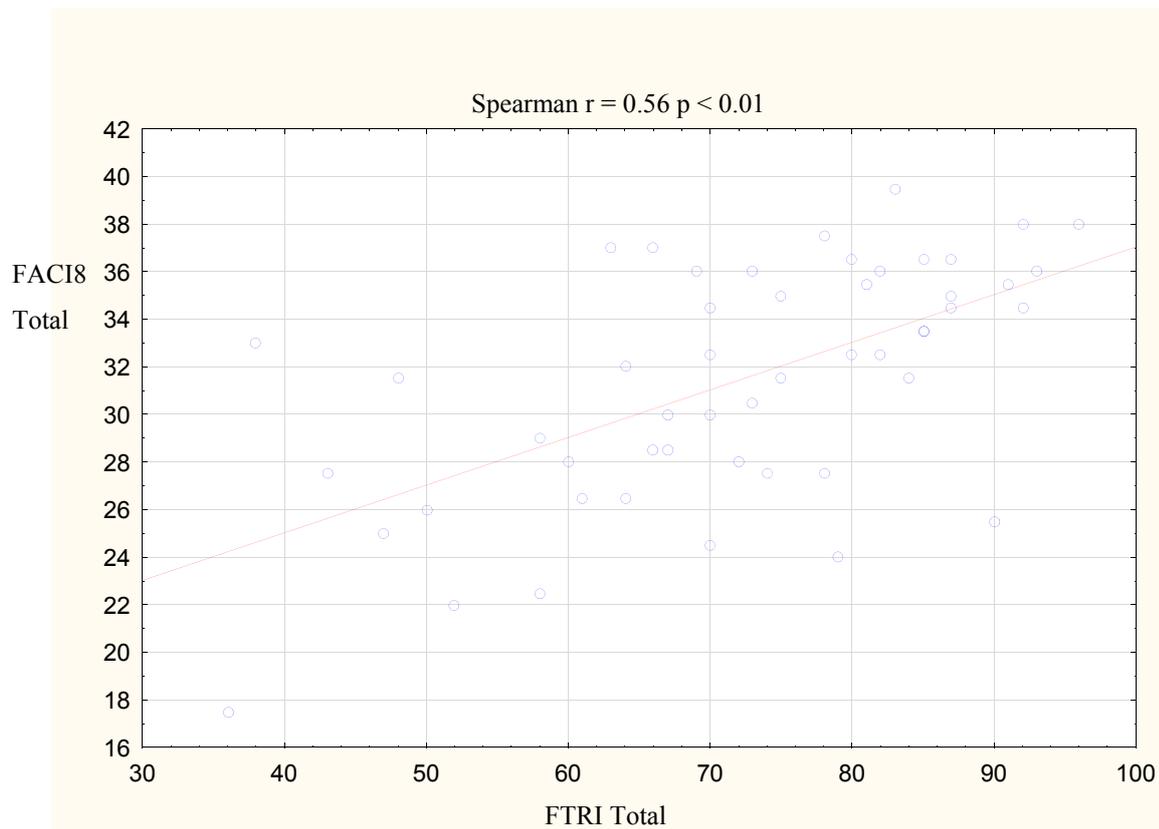
In Figure 5.2. a significant positive correlation is shown between family adaptation and the overall, hybrid patterns of communication implemented by the families.



*Figure 5.2.* The correlation between Family Adaptation (FACI8 scores) and Family Problem-Solving and Communication (FPSC total score).

The importance of the quality of communication for the purpose of adaptation after the diagnosis of type 1 diabetes is revealed in the strength of the correlation ( $r = .62$ ,  $p < 0.01$ ) between these two variables. The quality of the communication shared appears to play a primary role in the family's overall ability to adapt. The results obtained with the two subscales of communication (correlations with family adaptation, see Table 5.2) indicate that affirming communication, namely communication of a positive, supportive and calm nature, is significantly associated with family adaptation in times of crisis ( $r = .50$ ,  $p < 0.01$ ). In contrast, incendiary communication patterns of a negative nature, which may contain conflict and yelling, show a significant negative correlation with family adaptation ( $r = -.59$ ,  $p < 0.01$ ).

Figure 5.3 shows a scatterplot of the correlation between family adaptation and family time and routines followed (Family Time and Routine Index).

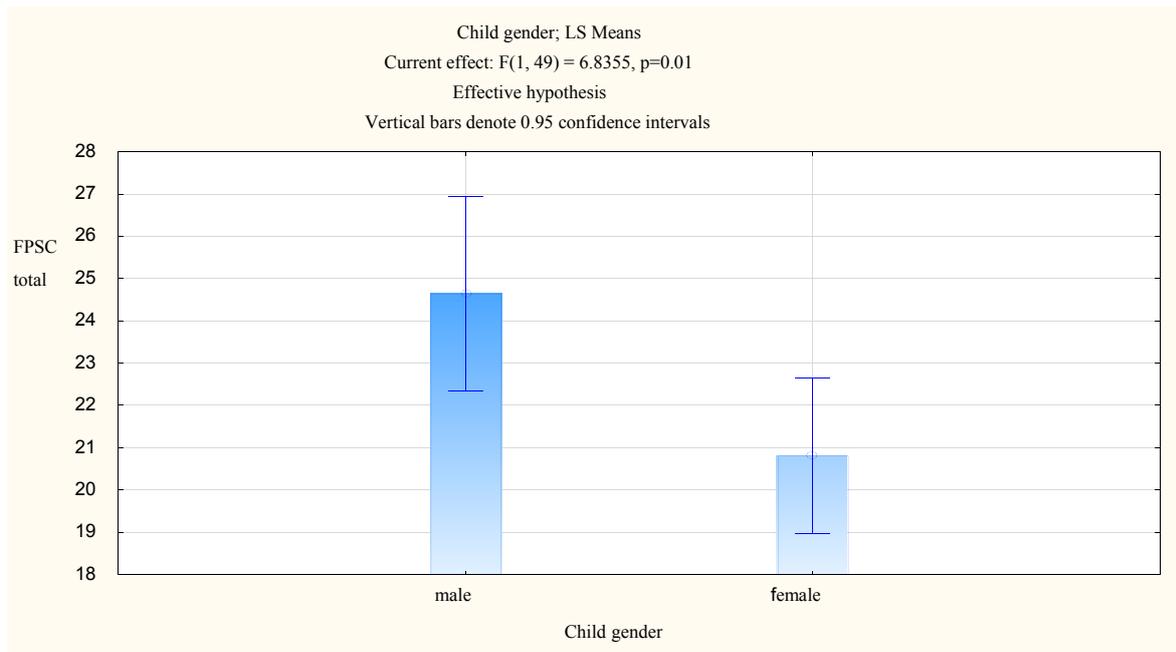


*Figure 5.3.* The correlation between Family Adaptation (FACS scores) and Family Time and Routines (FTRI total scores).

Family time spent together and routine(s) followed appear to have a significant association with the successful adaptation of families to their crisis ( $r = 0.56$ ,  $p < 0.01$ ).

### **5.3.3 Analysis of variance (ANOVA)**

ANOVAs were done to test for possible mean differences that may exist between subgroups, based on child age, family income, child gender, home language, family race, and age of the primary caregiver. It was found from the analyses of the total scores for each of the independent variables that child age, family income, home language, family race, and age of the primary caregiver showed no significant difference between the groups. A trend that could be found from the ANOVAs was a difference in communication patterns in families with a son with diabetes versus families with a daughter with diabetes. Figure 5.4. provides an illustration of the differences in communication patterns in families with diabetic sons and daughters.



*Figure 5.4.* A box and whisker plot diagram demonstrating differences in communication patterns in families with either a son or a daughter with diabetes.

The box and whisker plot in Figure 5.4 shows a significant difference in the patterns of communication used by families with sons with diabetes versus families with daughters with diabetes.

Table 3 summarises the F-statistics obtained for testing for mean differences between groups for two independent variables and the dependent variable. To detect any differences between groups with regard to family adaptation, the groups were distinguished based on family income, and the child's gender was divided into two groups in order to identify whether there were any differences between families with a diabetic son or daughter based on the three variables in Table 3. Race was another important variable. Racial groups, namely *White*, *Coloured* and *Black*, were created to look for differences between racial groups based on family adaptation, family hardiness and family problem solving and communication patterns. The last ANOVA that was completed was the search for differences based on the age of the primary caregiver. Primary caregivers were split into two age categories, from 20 to 40 years and from 45 to 65 years.

Table 3

*Summary of the Relationships between Four Demographic Variables and Family Adaptation, Family Hardiness and Family Problem Solving and Communication*

Variable	ANOVA F-statistic	p
Family Income (< R30 000 p/a, R30 000 to R120 000, > R120 000+)		
Family Adaptation (FACI8 Total)	.29	.75
Family Hardiness (FHI Total)	.56	.58
Family Problem Solving and Communication (FPSC Total)	1.21	.31
Child Gender (son/daughter)		
Family Adaptation (FACI8 Total)	.24	.63
Family Hardiness (FHI Total)	.93	.34
Family Problem Solving and Communication (FPSC Total)	6.84	.01
Family Race (White, Coloured, Black)		
Family Adaptation (FACI8 Total)	2.50	.12
Family Hardiness (FHI Total)	1.65	.20
Family Problem Solving and Communication Scale (FPSC Total)	.40	.85
Primary Caregiver Age (20 to 40 yrs vs. 45 to 65 yrs)		
Family Adaptation (FACI8 Total)	.24	.09
Family Hardiness (FHI Total)	.15	.29
Family Problem Solving and Communication (FPSC Total)	.23	.10

From Table 3 it can be seen that no significant differences could be found between any of the groups based on the total scores on FACI8, FHI and FPSC. A significant difference between two groups could only be found on the total scores for the FPSC. This significant difference was the difference in communication patterns in families with sons with type 1 diabetes and families with daughters with type 1 diabetes. Families with diabetic sons used more affirming, positive communication in the home, in comparison to families with daughters, who used more negative, incendiary communication in the home.

### 5.3.4 Regression analysis

A best-subset regression analysis was done to determine how well the independent/predictor variables, namely family hardiness, family problem solving and communication, and family time and routines, would explain variance in the dependent variable, family adaptation. The results are shown in Table 4.

Table 4

*A Summary of the Multiple Regression Analysis for the Dependent Variable (FACI8 Total score)*

N = 51	B (beta)	t (47)	p
Intercept		3.58	0
Family Hardiness Index Total (FHI Total) (family stress resistance and durability during hardship)	0.26	2.09	0.04
Family Problem Solving and Communication (FPSC Total) (hybrid patterns of communication used in family)	0.34	2.69	< 0.01
Family Time and Routine Index (FTRI Total) (the experience and feeling of togetherness as a family unit)	0.33	3.08	< 0.01

The p-values smaller than 0.01 (see Table 4) provide an indication that the three predictor variables contribute significantly to the prediction of family adaptation. The best predictors of family adaptation were the nature of the communication used by the family and the family time spent together and routines they followed, at 34% and 33%, respectively. Close to the influence of communication on family adaptation is the time spent together and routines followed by the whole family. Family hardiness is also a predictor of family adaptation, but the role of shared commitment and acceptance of change as a factor of growth makes a lower contribution to overall family adaptation and resilience.

A summary of the calculated statistics relevant to the regression analysis is shown in Table 5.

Table 5

*A Summary of the Prediction of Variation in Family Adaptation (FACI8 Total score) Found From the Measured Predictor Variables*

Statistic	Value
Multiple R	0.76
Multiple R <sup>2</sup>	0.58
Adjusted R <sup>2</sup>	0.55
F(3,47)	21.38
p	0.00
Standard error of estimate	3.33

The R-value<sup>1</sup> in Table 5 indicates a strong positive correlation between the true and estimated FACI8 values of the three predictor variables (see Table 4), namely family hardiness, family problem solving and communication and family time and routines. The R<sup>2</sup>-value<sup>2</sup> indicates that 58% of the variation in family adaptation (FACI8 total score) is predicted by the three independent variables. Multicollinearity<sup>3</sup> between the three independent variables is low and acceptable, with tolerance levels above .20.

## 5.4 Conclusion

This chapter provided a description of the qualitative and quantitative results that were found in this study. Qualitative results were obtained by the identification of themes and codes assigned to the data with the use of thematic analysis. Certain codes supplemented the quantitative results. These codes shared the personal experiences and a view of the whole family's experience of the stressor. A fair number of codes were in agreement with the results obtained from the quantitative questionnaires. The results of the Spearman correlations, scatterplots, ANOVAs and regression analysis were also presented and discussed in this

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<sup>1</sup> The R value measures the accuracy of the probability of future outcomes for a predicted model (Steel & Torrie, 1960).

<sup>2</sup> The multiple R<sup>2</sup> statistic provides information regarding the goodness of fit of the regression equation according to multiple independent variables predicting the dependent variable.

<sup>3</sup> Multicollinearity is an indication of the accuracy and level of the correlations between two or more predictor variables. Tolerance levels less than .20 indicates multicollinearity.

section. On combining the two sets of results (qualitative and quantitative) it became evident that the qualitative themes and quantitative results supported one another. Comparing the qualitative results with the quantitative results furthermore indicated additional factors that were associated with better family adaptation, such as religious beliefs. The results can be explained by the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001), indicating that the theory ultimately provided a framework to operationalise family resilience qualities in families with a child with diabetes. The results will be discussed in the next chapter, along with the conclusions based on the results, the limitations of this study and recommendations for future studies.

## Chapter 6

### Discussion, limitations and conclusion

#### 6.1 Introduction

Chapter 6 comprises a blend of previous research and the results obtained in this study. In the discussion, the aims of the study are shared according to the quantitative and qualitative results respectively. Both types of results confirmed previous findings from family resilience and chronic illness research. Variables that were not measured quantitatively in this study, but found in previous research to be meaningful in the prediction of family resilience, were identified qualitatively in this study. All the findings discussed are interwoven with the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001). The limitations of this study and recommendations for future studies on family resilience and diabetes research follow accordingly. Finally, a concise conclusion of the chapter is given.

#### 6.2 Discussion

The aim of this study was to gather and analyse information from primary caregivers, as the representatives of their families, on what has helped their families to cope with and adapt to a child's diagnosis of type 1 diabetes. In congruence with the aim of this study, the discussion entails descriptions of the variables and themes that were found to be associated with family adaptation and, ultimately, with resilience in the family.

According to the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001), as well as research by Walsh (1996, 1998, 2002), all families have the ability to rise above stressful life circumstances. Families have the ability to adjust and adapt to situations that may be interpreted as a crisis by the family. Stinnett and DeFrain (1985) report that some families facing a crisis together enrich their relationships and create a sense of love and caring that would otherwise not have taken place. The results of this study confirm that most families do find ways to adjust and finally adapt to the crisis of a child diagnosed with type 1 diabetes.

All families employ different resources in the process towards adaptation. Previous resilience research and the Resiliency Model suggest particular characteristics to be of primary

importance in a family's overall resilience. This study found type 1 diabetes diagnosis not to be an illness which causes complete dysfunction and distress in the family, but rather found that families have the ability to adjust and adapt to the diagnosis of a chronic illness in a child.

### **6.2.1 Quantitative discussion**

Regarding the results obtained using the four quantitative measuring instruments, the most prevalent resilience characteristics of the families in this sample were affirming communication, family hardiness and family time and routines. These resilience characteristics are discussed below.

#### **6.2.1.1 Communication**

Most families indicated affirming communication to be their primary source of growth in their process toward adaptation (see Table 2). Communication of a positive nature, inducing calmness, creating a sense of care and supporting one another during conversations, helped this sample of families to adapt to their life situation dominated by a chronic stressor. Families that implement communication are regarded as healthy families (Stinnett & DeFrain, 1985). Walsh (1998, 2002) also confirms that open, clear, consistent, empathic and humorous communication is a key factor in family resilience. A South African study (Brown et al., 2010) very similar to this one also found affirming communication to be the primary source in facilitating adaptation in families with a type 1 diabetic child in the home. Other South African studies focusing on family resilience characteristics found open communication among family members to also promote resilience within the family (Greeff & Van der Merwe, 2004; Jonker & Greeff, 2009; Robinson, 2007; Roodt, 2011).

Incendiary communication patterns, which are negative and intensify conflict and may include screaming and yelling, have a direct negative impact on family adaptation. This was confirmed in this study, which showed that incendiary communication has a significant negative relationship with family adaptation (see Table 2).

#### **6.2.1.2 Family hardiness**

Within the measurement of overall family hardiness, the component of challenge (accepting the circumstances that life may hold and handling them innovatively) showed the most significant positive correlation with family adaptation, in comparison to commitment and

control in the family. Commitment has also been found to show a positive correlation with family adaptation, although not as strong a relationship as between family adaptation and challenge. Walsh (2002) found family hardiness, specifically family traits underlining the challenge component, as key contributors to family adaptation. Key processes that can be identified as challenge-filled scenarios are making decisions together as a family, learning from previous mistakes, averting crises, being flexible in actions and decision-making, and accepting life's challenges with positive end goals in mind (Walsh, 2002). The results showed that, by using innovation and accepting challenges and life stressors (see Table 2), the families were able to adapt more easily to their child's diagnosis. By accepting the stressors that form part of a chronic illness such as type 1 diabetes, the adaptation process can be simplified. Thinking positive thoughts and being flexible as a family have been found to be two of the most prominent family resources facilitating resilience (Hawley, 2000; McCubbin & McCubbin, 1993b). Commitment and control were also found to be significantly correlated with family adaptation in this study, although the correlations with family adaptation were lower than the correlation found for the challenge component (see Table 2).

### **6.2.1.3 Family time and routines**

Meleski (2002) found that families with a child with type 1 diabetes use a variety of adaptation resources, such as support from outside of the family (friends, colleagues, health professionals and extended family members), allocating a sense of meaning to the illness, and attempting to manage the illness to the best of their abilities (physiologically and psychologically). In this study, the only measured aspect of family time and routines that did not show a significant relationship with family adaptation was contact with the extended family, such as a grandmother or grandfather of the child. Contact with family illustrates that children do not visit their grandparents often, little effort is made to make plans for visitation in general by the whole family, and telephone or direct conversations with the grandparents take place less than once a week.

The other seven measures of family time and routines all showed significant positive correlations with the family's adaptation to their child's diagnosis. The most significant correlations with family adaptation found among the seven subscale measures of the family time and routine index were parent and child togetherness, family togetherness, family chores, family management and child routines respectively. Family routine refers to practices that are repetitively used in the family by two or more family members (Spagnola & Fiese, 2007). The

Family Time and Routine Index (McCubbin et al., 1997) focuses predominantly on the type of activities and routines families follow together, as well as the level of importance that is placed on these activities and routines (McCubbin & McCubbin, 2001). Fiese et al. (2002) explain that family routines are entwined with communication, continuity and commitment to one another. Spagnola and Fiese (2007) report that family routines that are followed regularly provide families with a sense of predictability, leading to the creation of an environment with specific behaviour and emotional support. This predictability may lead to the improvement of the family's overall development and adaptation (McCubbin et al., 1997).

The time spent together as a parent or primary caregiver with a child with diabetes, the time spent together as a family in the home, doing chores together, managing the household, introducing routines within the family, and spending quality time together as a couple, played important roles in the lives of the participating families (see Table 2). Gordon Rouse, Longo and Trickett (2000) support this finding by reporting that sharing in household tasks, setting clear rules and boundaries and pursuing hobbies together contribute toward resilience in the family.

A specific family routine that is important in the home of a child with diabetes is mealtime routines. Mealtimes together with the family can ensure better eating habits, communication and that blood glucose testing and insulin administration are done (Blum-Kulka & Snow, 2002). This family characteristic can create a sense of togetherness for the family. Furthermore, consistent and regular communication between spouses or partners creates support in their relationship, which lessens strain for the whole family (Meleski, 2002). The results also suggest that the sharing of work and responsibilities in the home helped to minimise extra home stresses for the whole family and lessened the constant concentration on the child's illness.

Gordon Rouse et al. (2000), McCubbin and McCubbin (2001) and McCubbin et al. (2002) state that contact with other family members and friends may contribute to a family's resilience. In this study, however, the quantitative and qualitative results were not in agreement with the aforementioned statement and assumption of the Resiliency Model. Probable reasons for this contradictory finding in this study will be elaborated on in the discussion of the qualitative results in the next section.

In summary, positive communication, family hardiness in the form of accepting the challenge, family time spent together and routines followed together help the family in their process of adapting to the child's diagnosis. It was also important, however, to take into consideration whether the age of the child may have had an impact on the family's overall resilience. As an example, the time spent together and routines implemented in a family may be affected by the child's age, seeing that early childhood is characterised by actively participating in daily life actions and rhythms (Spagnola & Fiese, 2007). Furthermore, children and adolescents with diabetes require different diabetes management regimens and approaches. During childhood, parents need to take complete responsibility for their child's diagnosis, while adolescents become more independent (Hamilton & Daneman, 2002; Stallwood, 2005). In a comparison of the possible differences that could exist in families with a diabetic child or adolescent, based on the level of adaptation in the families, no significant differences could be found between families with a child or adolescent with diabetes.

### **6.2.2 Qualitative discussion**

The qualitative findings from the open-ended question in the study were in agreement with the quantitative results that were found to be most significant in this study. However, findings that contradict those of previous research on resilience in families were also found. When comparing the qualitative findings with the quantitative findings, it was clear that a number of unmeasured variables in the quantitative part of this study have come to play important roles in many of the families' lives. These unmeasured characteristics in the quantitative part of the study that emerged in the qualitative results are: the support and care from the diabetes specialist, religious belief, support and education provided by the diabetes nurse educator, eating habits of the child, reading material on diabetes, and diet plans provided by the nutritionist (see Table 5.1).

Most of the families indicated that the information, support and guidance received from and patience of the diabetes specialist helped their families to cope and adapt to their child's diagnosis. The National Network for Family Resiliency, Children, Youth and Families (1995) suggest that networks providing support and resources and family-friendly professionals can help buffer against stress and promote confidence in families. Service providers for children and families may lend a hand in strengthening the family's resilience through preventative programmes that are flexible (National Network for Family Resiliency, Children, Youth and Families, 1995). The role of family-friendly professionals was furthermore highlighted in this

study, given that many families believed the support and education provided by the diabetes nurse educator facilitated their family in the process of adaptation. According to Meleski (2002) it is important that nurses, such as the diabetes nurse educator, understand specific stressors related to diabetes, as well as emotions involved in the child and family, and that the family's attitude towards a child's diagnosis may lead to stress or create a burden for the family. Nursing interventions should focus on educating parents and providing them with the necessary skills and diabetes information in order to understand, accept and adapt to their situation (Meleski, 2002).

Included under the umbrella of family friendly hospital professionals is the diabetes nutritionist. Certain families felt that the nutritionist helped their family to adapt more successfully to the child's diagnosis. The nutritionist equipped some families with the necessary information regarding the correct diet and eating habits for the child. If this information is not obtained by some families, or is misunderstood, it may create immense stress for the child and the family, and may have an impact on treatment adherence.

The theme of religious beliefs was found to be the third most prevalent answer to the open-ended question, as well as a theme that often formed part of casual conversations with the researcher. Primary caregivers, and ultimately the families, interpreted their religion, religious beliefs and participation in church activities, as well as socialising with church friends and pastors, as an extremely important resource for adaptation. Brown et al. (2010) also found that families find meaning in their child's diagnosis via their religious beliefs. Religion provides the family with a sense of control over stressful circumstances and the opportunity to add interpretative meaning to the child's diagnosis (Brown et al., 2010). Patterson (2002a) is of the opinion that families' views of the world are embedded in their religious beliefs. Canda (1999) defines religion as an institutionalised pattern of belief that includes moral values and rituals that help to add meaning in the individual or family's search for meaning in life. Canda (2001) found that religious belief specifically makes a contribution to resilience in individuals who have an illness. Sevensky (1981) reported that religion may serve three important functions for people who are ill. Religion may provide meaning to the illness, serve as a practical resource and add hope to the life situation (Sevensky, 1981). It is clear that families found their religious beliefs to be an important source of help, hope and provision of meaning to the child's diagnosis of diabetes.

Two further social resources that were identified and that are in agreement with previous family resilience research (Brown et al., 2010; Greeff & Van Der Merwe, 2004; McCubbin et al., 2002; Meleski, 2002) are the support from the family and from the primary caregivers' life partner. In this study, the family members living with the child with diabetes were found to be the second most important resource for the families to cope and adapt to the child's diagnosis. Many family members felt that they could share their worries and concerns with other members of the family. Furthermore, the participants reported that they believed the family members in the home understood the demands and routines that were part of the illness. Family members were aware of, and understood, that there was an ever-present concentration on the type of foods prepared, the time of serving meals, the activities that the family could be involved in and how to help one another during specific circumstances, such as a hypoglycaemic episode. This cultivated a sense of consideration between family members and the child with diabetes. Ultimately, understanding the family situation and the chronic illness can lead to an increase in respect among the family members. In being thoughtful of their situation, the family develops a sense of sympathy for their circumstances, which is important because the whole family needs to adjust to new roles and responsibilities as a result of the child's diagnosis (Meleski, 2002).

This sample of primary caregivers was predominantly mothers/women, some of whom revealed that their life partners (boyfriends or husbands) contributed most toward the family's process of adaptation. Ray and Ritchie (1993) state that the majority of everyday burdens that form part of the life of a child with a chronic illness rest primarily on the mother. Although both the mothers and fathers of diabetic children experience a great amount of stress, fathers tend to stress mildly in comparison with the mothers of diabetic children (Mitchell et al., 2009). In this study, a few of the mothers indicated their husbands or boyfriends as the primary source of resilience within the family. It should be borne in mind, however, that the mothers and fathers of older children with type 1 diabetes, such as adolescents, show less stress than the parents of younger diabetics (Stallwood, 2005). Nonetheless, this study did not find any differences in the resilience characteristics of families with a child or an adolescent with diabetes.

In contrast to family resilience studies with other crises and findings, but in accordance with Brown et al.'s (2010) study, support from the extended family and friends was not found to be a family resilience resource in this study. Although support from extended family and friends

was established theme in the qualitative data, they were not nearly as important as the themes of hospital personnel support, religious beliefs and family support (see Table 5.1). In a South Korean study of nuclear families with a child with type 1 diabetes, the support from, and interaction with extended family members were regarded as extremely important (Lee et al., 2004). Universally, family resilience studies have found support from extended family and friends to be a primary contributor to better family adaptation and overall family resilience (Brooks, 1994; Delamater, 2009; Greeff & Fillis, 2009; Linker et al., 1999; Walsh, 1996; Werner, 1993). The findings of the present study, as far as support from extended family and friends is concerned can conclude that extended family and friends tend to show little support of the families. Many primary caregivers responded qualitatively that the members of the extended family and the friends of the family did not truly bother to understand the illness and its possible physical and psychological implications better. The friends and members of the extended family also seemed to show little willingness to help the family out during times of severe physical or psychological strain on the child and family, as well as during hospitalisation. In the qualitative question answered, the participants also indicated that, during times of celebration, many of them felt that friends and family did not see the need to cater for special cool drinks or food, and showed little understanding of the mealtime routines that form part of the family. Brown et al. (2010) also found that social support in the form of support from extended family and friends was a less important factor of family resilience. They found that the families in their study reported that it was difficult to entrust their child to the hands of friends or family members, seeing that these people did not have much knowledge of the chronic illness.

Another resilience resource for some families was reading articles and pamphlets on type 1 diabetes. Gaining more information about and knowledge of the chronic illness and insulin administration helped certain families to understand the life situation of their child and the family better. Accumulating knowledge of diabetes contributed to a better understanding of and adaptation to the illness. The eating habits of the child, as well as the types of food that were prepared for various mealtimes, also tended to influence some families in their process of adapting to the diagnosis. Unhealthy and uncontrolled eating habits of the child can be life threatening. Some participants indicated that their overall family adaptation improved when they prepared healthy food. Healthy food included vegetables and salads, non-fatty meats, a little bread and occasionally sweets and chips for the child, as well as for the rest of the family. Adaptation with regard to the eating habits of the child was also bettered when the child ate

healthily and administered his or her insulin according to the orders of the diabetes specialist. In order to meet these everyday requirements, such as monitoring the diet of the child, and his/her blood glucose levels, insulin injections and urine ketones (Plotnick & Henderson, 1998), the whole family needs to lend a hand and support one another. If these activities are not managed effectively, short- and long-term complications may arise, and the families may experience great stress and chronic feelings of worry (Stallwood, 2005).

A variety of demographic variables identified in previous diabetes research that were found to be important variables of coping and resilience in families experiencing a crisis such as the diagnosis of a child with diabetes were taken into consideration and measured in this study. Variables such as family income (Amato & Wang, 2000; Greeff & Fillis, 2009), the gender of the child (Naar-King et al., 2006), the age of the child (Bui & Daneman, 2006; Delamater, 2009; Hatton, Canam, Thorne & Hughes, 1995), the race of the family (McCubbin & McCubbin, 1993b), and the age and gender of the primary caregiver (Guthrie et al., 2003), may give rise to significant differences in how families progress towards adaptation. It was important to determine whether specific variables show differences between the groups in this study. The analyses showed that there were no significant differences between groups with regard to child age, family income, home language, race, the age of the primary caregiver and the family's ability to adapt (see Table 5.3). The only significant difference that could be found was based on the gender of the child with diabetes. It was found that families with a son with diabetes tended to communicate differently than families with a daughter with diabetes. Families with diabetic sons used more affirming communication than families with daughters with diabetes.

### **6.3 Limitations of this study and recommendations for future studies**

This study had limitations. The sample was rather small ( $N = 51$ ) and each family was represented by only one member, whose perceptions of the family may be limited or biased and open to subjectivity. It is also recommended that future studies in this field of diabetes research make use of larger samples, to make them more representative of a region or country. The participants resided predominantly in Cape Town, in the Western Cape region of South Africa. A more complete understanding of family resilience qualities in similar study populations would require future studies in other geographical regions in South Africa. More than one family member should also be considered to obtain a more comprehensive view of family functioning. The analysis of the reliability of the scales also showed rather low alpha

coefficients for the total scores for FACI8, FHI and FTRI. The low reliability coefficients may be due to participants who did not understand the quantitative questions posed in the questionnaires. Participants also might have chosen answers inconsistently or did not understand the questions correctly, and therefore purely chose an answer to provide an answer to the question. This problem may be solved if participants with higher educational qualifications are included in similar future studies.

A cross-sectional research design was implemented over a period of two months. Future studies on diabetes and family resilience should make use of a longitudinal design. A longitudinal study is important to provide a more complete understanding of lived resilience (DeHaan, Hawley & Deal, 2002).

Future research on families with children with type 1 diabetes can also concentrate to a larger extent on the family type or structure, such as single-parent households or extended family households. It will also be beneficial to investigate what differences exist between families from a very low socio-economic background, who are listed at a state medical hospital, and families from a higher socio-economic background receiving private hospital care.

An important theme that was mentioned by nearly every participant was the psychological impact of the diagnosis on the parents of the child, and ultimately on the family. Meleski (2002) points out that the day of diagnosis may be filled with sadness, grief and uncertainty, while the parents may experience a state of psychological imbalance. A purely qualitative study in the form of interviews or focus groups may lead to context-specific findings on coping and adaptation in families with a child with diabetes. New and relevant findings may provide an opportunity to develop and implement new family intervention programmes for families with a child with type 1 diabetes.

It is suggested that future quantitative and qualitative studies on families with a child with diabetes should focus on the influence and role that paediatric diabetes hospital staff fulfil in the life of the child, and of the family. Furthermore, it is evident from the qualitative results of this study that future family resilience research in the field of diabetes should incorporate the importance of the distinct role that religious beliefs and/or spirituality may play in these families' lives.

The participants in this study were predominantly Afrikaans-speaking coloured people. Future South African studies on family resilience and the diagnosis of diabetes could incorporate more English-, Xhosa- and Zulu-speaking families. In order to elicit more interest and participation in future studies, incentives with a rand value higher than R30 might motivate more families to take part.

#### **6.4 Conclusion**

This study aimed to identify qualities associated with family adaptation in families living with a child with type 1 diabetes mellitus. With the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001) as theoretical framework, resilience qualities in the families were explored and measured. The identified family resilience qualities can be used to determine how families with a type 1 diabetic child function. From the results it is evident that family communication, family hardiness and time spent together as a family, and the routines followed, are important resilience characteristics of families with a child with type 1 diabetes. Furthermore, it was evident that not focusing on important aspects such as the care provided by hospital staff, religious beliefs, and the day of diagnosis, limit the findings of this study to a certain extent.

Although a variety of limitations of this study and recommendations for future studies were discussed, this study did contribute to our understanding and knowledge of qualities that help families to adapt when a child is diagnosed with type 1 diabetes. Ultimately, this study serves the purpose of lending a hand to families and hospital staff dealing with diabetes. Families can be encouraged to develop and implement certain family characteristics in order to adapt to their child's diagnosis. Similarly, hospital staff dealing with diabetes can be informed to focus on those aspects that assist families to adapt to the chronic stress and worry in the family environment when living with a child with a chronic illness.

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**APPENDIX A****Biographical information**

All information in this questionnaire is strictly confidential and your information will be anonymously processed.

Please cross the box most appropriate to you, or complete the statement in the space provided:

**Primary caregiver information:**

**Sex:** Male  Female

**Who is the primary caregiver?** Mother  Father

Sister  Brother

Grandmother  Grandfather

Aunt  Uncle

Niece  Nephew

Family friend

**Age:** .....

**Race:** *White*  *African*

*Coloured*  *Indian*

Other.....

**Marital status:** Married  Divorced

Remarried  Widowed

**Home Language:** Afrikaans  English

Xhosa  Other.....

**Type of family:** Single-parent  Two-parent

Extended  Other.....

**Number of people living in the home:** .....

**Living in:** ..... (town or city)

**Highest level of education:** Primary school  High School

Degree/Diploma  None

**Income group:** Low-income (less than R30 000/year)

Middle-income (between R30 000 and R120 000/year)

High-income (above R120 000/year)

**Child (Type 1 diabetic) information:**

**Sex:** Male  Female

**Age:** .....

**Age of child when diagnosed with Type 1 Diabetes:** .....

**For how long (weeks/months/years) has the child had Type 1 Diabetes?**

.....

**Does the child have any other siblings?**

Brother  Sister  Brother and Sister  None



## APPENDIX C

## HREC application form

	<b>1. STELLENBOSCH UNIVERSITY FACULTY OF HEALTH SCIENCES</b>	
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**HEALTH RESEARCH ETHICS COMMITTEE 1 AND 2 APPLICATION FORM**

<b>SECTION 1: DETAILS OF APPLICANT/PRINCIPAL INVESTIGATOR</b>		
Name and Title: Miss Guz�lle Joanita Koegelenberg		Professional Status: Student
University Division and Department:		Stellenbosch University, Department of Psychology
Complete Postal Address:		
Telephone No:	Fax No:	Cell No:
E-mail address:		
<b>SECTION 2: TITLE OF STUDY</b>		
Title of Research Project: Resilience characteristics of families with a child with type 1 diabetes.		
Sponsor's Protocol No (if applicable) -		
<b>SECTION 3: STUDY FOR DEGREE PURPOSES</b> <span style="float: right;">Not applicable <input type="checkbox"/></span>		
Name of Degree: MA in Psychology		Supervisor: Prof. A. P. Greeff
Division/Department: Department of Psychology		E-mail: apg@sun.ac.za
Contact No: (021) 808 3464		

OFFICE USE ONLY

Approved by HREC 1		Approved by HREC 2		Project ID
Conditional				
Provisional				
Direct				
Final				
<b>SECTION 4: DETAILS OF SUB-INVESTIGATORS</b>				
Name and Title		Position		Division/Department
1. Prof. A. P. Greeff		Supervisor		Department of Psychology
2.				
3.				
4.				
5.				
<b>SECTION 5: DETAILS OF COLLABORATING INVESTIGATORS</b>				
Name and Title		Position		Division/Department
1. Dr. E. W. A. Zöllner		Co-supervisor		Department of Paediatrics
2.				
3.				
4.				
5.				
<b>SECTION 6: WHERE WILL THE STUDY BE CONDUCTED?</b>				
1. Tygerberg Hospital				<input checked="" type="checkbox"/>
2. Stikland Hospital				<input type="checkbox"/>
3. Karl Bremer Hospital				<input type="checkbox"/>
4. Faculty of Health Sciences				<input type="checkbox"/>
5. Other: please list				<input type="checkbox"/>
<b>SECTION 7: HUMAN SUBJECTS RESEARCH PROTECTION</b>				

1. Does the Research involve Human Subjects who are Alive <input type="checkbox"/> Dead (includes identifiable tissues specimens) <input type="checkbox"/> Medical Records only <input type="checkbox"/>		
2. Will any medicine be tested during the investigation?	Yes	No
2.1 If Yes to question 2, is the medicine approved by the Medicines Control Council?		
2.2 If yes to question 2.1, is the medicine registered for the dose which will be used in this specific project?		
2.3 If Yes to question 2.1, is the medicine registered for the indication(s) which will be used in this specific project?		
2.4 If No to question 2.1, is the medicine approved by the Medicines Control Council for your use in this specific project?		
2.5 If No to question 2.2 and/or 2.3, is the medicine approved by the Medicines Control Council for your use in this specific project?		
3. Will any radioactive material be administered to the patient during the investigation?		
4. Is any biohazardous material (*) involved in the project?		
5. Have you acquainted yourself with the code of conduct regarding the Ethics of research and this Institution and do you undertake to fully comply with it at all times?		
(*) <i>“Biohazardous material” refers to recombinant DNA molecules, viruses, fungi, parasites, bacteria and all other potentially biohazardous material or products that are dangerous to both the experimental patient and the researcher, and which is patient to ct stricontainment specifications and safety measures.</i>		
<b>SECTION 8: STUDY TYPE</b>		
Industry Sponsored Clinical Trial <input type="checkbox"/>	Self Initiated Clinical Trial <input type="checkbox"/>	
Retrospective Record Review <input type="checkbox"/>	Laboratory-Based Research <input type="checkbox"/>	
Qualitative Research <input type="checkbox"/>	Prospective Descriptive Study <input type="checkbox"/>	
Other <input type="checkbox"/>	Please state type if 'Other':	
<b>SECTION 9: HOW IS THIS RESEARCH FUNDED? STATE APROXIMATE TOTAL BUDGET</b>		
1. Industry R	2. NIH R	
3. Internal/Self	4. Other/ US Fed Agency R	
5. External SA Grant R	6. Internat. Grant R	
<b>SECTION 10: SIGNING OF APPLICATION</b>		

**Applicant:** .....

**Supervisor:** .....

**\*Departmental Head:** .....

**\*The Departmental Head may delegate this authority to a Divisional Head if he/she deems this appropriate.**

**The following obligatory documentation must be attached to this application form:**

#### **PROTOCOL SUMMARY (Obligatory)**

Please provide a protocol synopsis or summary of the proposed research, **in addition to the full Protocol**, that is between **800 and 1500 words** long / no longer than 2 pages. The Protocol Synopsis or summary should contain the following:

- Title
- A short introduction, motivation and literature overview (1 paragraph only)
- Research question or hypothesis
- Aims and Objectives
- A concise summary of the methodology
- Description of subject population including characteristics, age range and number of subjects
- If the Research will require blood draws, bone marrow biopsy samples, other biopsies or the collection of tissues, etc., performed solely because of participation in the Research, please indicate the exact amounts and frequency with which the samples will be taken
- Anticipated risks as well as the precautions taken to minimize risk
- Anticipated benefits
- Ethical Considerations

**Checklist (Obligatory):**

**General**

**OR**

**Clinical Trial**

**Investigator Declaration for principal, co and sub investigators (Obligatory)**

**Investigator CV s**

**Protocol**

## APPENDIX D

### Afrikaans HRjohannEC information leaflet

**TITEL VAN DIE NAVORSINGSPROJEK: Resilience characteristics of families with a child with type 1 diabetes**

**VERWYSINGSNOMMER: N11/06/184**

**HOOF-ONDERSOEKER: Guz lle Koegelenberg**

**ADRES:** Departement Sielkunde, Universiteit Stellenbosch, 7600, Suid-Afrika

**KONTAKNOMMER: -**

Geagte Deelnemer

My naam is Guz lle Koegelenberg en ek is 'n Meestersgraad (Sielkunde) student aan die Universiteit van Stellenbosch. Ek wil u graag uitnooi om deel te neem aan 'n navorsingsprojek wat ondersoek gaan instel na watter veerkragtigheidskenmerke u gesin oor beskik, sowel as hoe hierdie kenmerke moontlik kon bydra tot u gesin se aanpassing by u kind se diagnose met Tipe 1 Diabetes.

Neem asseblief u tyd om die inligting wat hier verstrekk word goed deur te lees. Dit verduidelik die nodige detail van die projek. Kontak my asseblief, indien u ekstra verduideliking of helderheid oor enige aspek van die studie benodig. Hou ook in gedagte, dat u deelname **heeltemal vrywillig** is, en u vry is om u deelname te stop. Indien u nee s , sal dit u geensins negatief affekteer nie. U is ook vry om op enige stadium van die studie te onttrek, al het u ingestem om deel te neem.

Hierdie studie is aanvaar en goedgekeur deur die **Gesondheid Navorsing Etiek Komitee (GNEK)** by die Universiteit van Stellenbosch en sal uitgevoer word volgens die aanvaarde en toepaslike Nasionale en Internasionale etiese riglyne en re ls, insluitend di  van die Internasionale Deklarasie van Helsinki, Oktober 2008.

Die navorsingsvraag vir hierdie studie is: Watter gesinsveerkragtigheidskenmerke is teenwoordig in gesinne wat reeds vir ten minste ses maande saam met 'n kind (tussen die ouderdomme van 2- en 12-jaar) met Tipe 1 Diabetes, geleef het. Deelname aan die studie sal behels, die teken van die ingeligte-toestemmingsvorm, voltooiing van biografiese-inligting, sowel as die beantwoording van een kort oop-einde-vraag en vier vraelyste. Ten alle tye gedurende data-insameling, sal streng vertroulikheid en privaatheid gehandhaaf word. U naam of van sal nie gebruik word, of beskikbaar gestel word, op enige tydstip gedurende die studie nie. U regte, geloof, taalvoorkeur, kultuur en ras sal ten alle tye gerespekteer word. Selfs in die geval waar u aangedui het u is bereid om deel te neem aan die studie, sal u nie geforseer word om steeds aan die studie deel te neem nie. Indien u besluit om die studie te verlaat of om te onttrek op enige stadium gedurende die navorsingsproses, is u welkom om dit te doen. Al die biografiese- en vraelys-inligting sal nie beskikbaar gestel word aan enige ander individu, anders as die navorser, studieleier en statistikus nie. Al die data wat met die

vraelyste ingesamel is, sowel as die kwalitatiewe vraag beantwoord, sal gestoor word op die navorser se persoonlike en veilige rekenaar-databasis.

**Indien u bereid is om deel te neem aan hierdie studie, teken asseblief die aangehegde Verklaring- en Toestemmingsvorm** (*handig dit in by die ondersoeker*)

Vriendelike groete,

Guzéle Koegelenberg  
Hoof-ondersoeker

## **Verklaring deur deelnemer**

Deur onderaan te teken stem, ek ..... in om deel te neem aan die navorsingstudie getiteld, *Resilience characteristics of families with a child with type 1 diabetes*.

Ek verklaar dat:

- Ek die aangehegde inligtingsblad gelees het en dat dit is geskryf in 'n taal waarin ek vlot en gemaklik is.
- Ek het die kans gekry om vrae te vra, en al my vrae is volledig beantwoord.
- Ek verstaan dat deelname aan die studie vrywillig is en ek is nie gedruk om deel te neem aan die studie nie.
- Ek mag kies om die studie op enige tydstip te verlaat en sal nie te nagekom word, of bevooroordeeld behandel word op enige manier nie.
- Ek kan gevra word om die studie te verlaat voordat dit voltooi is, indien die navorser voel dit is in my belang, of as ek nie die studie-plan volg, soos ooreengekom nie.

Geteken by (*plek*) ..... Op (*datum*) ..... 2011.

.....

**Handtekening van deelnemer**

## APPENDIX E

### Afrikaans HREC informed consent form

**TITEL VAN DIE NAVORSINGSPROJEK:** Resilience characteristics of families with a child with type 1 diabetes

**VERWYSINGSNOMMER:** N11/06/184

**HOOF ONDERSOEKER:** Prof. A. P. Greeff

**ADRES:** Departement Sielkunde, Universiteit van Stellenbosch, 7600, Suid-Afrika

**KONTAKNOMMER:** Tel. +27 021 8083464, Faks. +27 021 8083584

U word uitgenooi om deel te neem aan 'n navorsingsprojek. Neem asseblief u tyd om die inligting wat hier verstrekk word deur te lees. Dit verduidelik die detail van hierdie projek. Vra asseblief vrae vir die navorsingstudent of enige van die dokters betrokke by die studie, indien u enige vrae het oor 'n deel van hierdie projek wat u nie goed verstaan nie. Dit is baie belangrik dat u volledig tevrede is met u verstaan van wat hierdie navorsing behels, asook hoe u betrokke kan wees by die studie. U deelname is **heeltemal vrywillig** en daarom kan u besluit om u deelname aan die projek op enige stadium te stop. Indien u nee sê, sal dit u geensins op enige manier, negatief affekteer nie. Dit staan u vry om ter enige tyd van die studie te onttrek op enige punt, al het u aangedui u wil deelneem.

Hierdie studie is goedgekeur deur die **Navorsing Gesondheid Etiek Komitee (NGEK) by die Universiteit van Stellenbosch**. Dit sal uitgevoer word volgens die etiese riglyne en reëls van die Internasionale Deklarasie van Helsinki, Suid Afrikaanse Riglyne vir Goeie Kliniese Praktyk en die Mediese Navorsingsraad (MNR) se Etiese Riglyne vir Navorsing.

➤ **Waaroor handel hierdie navorsingstudie?**

- *Deelnemers sal gewerf word om deel te neem aan die studie, wat uitgevoer sal word in die Neurologie Kamer, Pediatriese Diabetes Eenheid, Tygerberg Hospitaal.*
- *Die doel van die studie is om die verkrygte resultate wat gevind word te gebruik om die betrokke families en mediese personeel in te lig, hoe om disfunksionele dinamiek binne gesinsverhoudings te verminder en hoe om optimale gesinsaanpassing en -funksionering te vermeerder. Die navorsing sal ook 'n bydra lewer tot die beperkte inligting wat beskikbaar is oor gesinne wat saamleef met 'n persoon met 'n chroniese toestand soos Tipe 1 Diabetes.*
- *Nadat toestemming verkry is van die superintendent van Tygerberg Hospitaal en die eenheid-hoof, Dr. Ekkehard Zöllner, sowel as versorger-kontakbesonderhede van die Diabetes Suster Opvoeder, Fiona Liebenberg, sal primêre versorgers van kinders met Tipe 1 Diabetes Mellitus, geregistreer by Tygerberg Hospitaal se Pediatrie Diabetes Eenheid, telefonies gekontak word om hulle in te lig oor die studie, die doel van die studie, wie die navorser is en wat 'n persoon se deelname aan die studie behels, sowel as of hulle bereid is*

*om deel te neem aan die studie. Die versorger sal gevra word wanneer hul kind se volgende afspraak by die Diabetes Kliniek is. Die datum van die volgende afspraak sal gebruik word om die versorger persoonlik te ontmoet en die onderhoud te voer. Die persoonlike ontmoeting sal gebruik word om toestemming van die versorger te kry, of hy/sy bereid is om deel te neem aan die studie, deur die ingeligte toestemmingsvorm te teken, en voort te gaan met die onderhoud en die voltooiing van vraelyste. Deelname aan die studie behels die voltooiing van 'n Universiteit Stellenbosch Ingeligte Toestemmingsvorm, 'n biografiese vraelys, 'n kort geskrewe/gesproke oop-einde vraag en vier selfvoltooiings-vraelyste. Die voltooiing van al die vraelyste sal hoogstens 30 minute duur. Gesproke antwoorde sal deur die navorser op die vraelyste ingevul word. Ten spyte van die primêre versorger se bereidwilligheid om aan die studie deel te neem, word hy/sy nie gedwing om voort te gaan met deelname nie. Indien 'n deelnemer besluit om nie meer deel te neem aan die navorsing op enige stadium in die navorsingsproses, staan dit hom/haar vry om te onttrek van die projek, sonder enige nagevolge. Al die primêre versorgers sal ontmoet word op 'n Maandagoggend, voor hul kind se Diabetes Kliniek-afspraak, tussen 08:00 en 14:00. Na die kind se afspraak by die kliniek, sal die primêre versorger en die kind by die navorser aansluit en vergesel word na die Neurologie kamer op die Pediatrie Diabetes Eenheid vloer, verskaf deur Diabetes Eenheid personeel by Tygerberg Hospitaal, om die oop-einde vraag en vraelyste te voltooi. Die navorser sal dus teenwoordig wees tydens die voltooiing van die vraelyste. Indien enige vrae mag ontstaan gedurende die antwoord-proses sal die navorser beskikbaar wees om hulp/bystand aan die deelnemer te bied. Na die voltooiing van al die vrae, sal die deelnemer voorsien word van 'n Checkers-koepon ter waarde van R30. Die jaar waarin die studie voltooi is, sal terugvoer oor die navorsingsbevindinge meegedeel word by die Tygerberg Akademiese week.*

➤ **Hoekom is u genooi om deel te neem?**

- *U is genader om aan die studie deel te neem omdat u die primêre versorger van 'n Tipe 1 Diabeet kind is, asook 'n geregistreerde pasiënt by Tygerberg Hospitaal se Diabetes Eenheid is. U sal daartoe in staat wees om die basiese inligting te verskaf wat benodig word om uit te vind hoe verskillende gesinne aanpas by die kind se diagnose met Tipe 1 Diabetes.*

➤ **Wat sal u verantwoordelikhede wees?**

- *U verantwoordelikhede tydens deelname aan die studie behels die voltooiing van 'n ingeligte toestemmingsvorm, 'n biografiese vraelys, die beantwoording van een kort vraag, met betrekking tot u gesin se vermoë om aan te pas en te "cope" met u kind se diagnose van Tipe 1 Diabetes en laastens, die voltooiing van vier vraelyste.*

➤ **Sal u baat vind deur deel te neem aan die navorsing?**

- *Ja, 'n voordeel van die studie is dat u, as deelnemer, moontlik aanpassings- en veerkrachtigheidstegnieke, asook kenmerke van aanpassing en veerkrachtigheid in u gesin kan implementeer.*

- **Is daar enige risiko's betrokke wanneer u deelneem aan die navorsing?**
  - *Ja, daar is 'n risiko dat sommige van die vrae stresvol kan wees om te beantwoord. Indien u enige stres beleef gedurende of na die onderhoud, staan dit u vry om Prof. Awie Greeff (021 808-3464) te kontak vir gratis hulp/bystand.*
- **Indien u nie instem om deel te neem nie, watter alternatiewe is daar?**
  - *U is nie verplig om deel te neem aan die studie nie. Indien u besluit om nie deel te neem aan die studie nie, sal u steeds normale behandeling ontvang van die navorser en ander betrokkenes by die studie. U kan vry voel om Prof. Awie Greeff (021 808-3464) te kontak vir meer inligting rondom sielkundige hulp/bystand vir persone met Tipe 1 Diabetes, of gesinne met 'n lid/lede met Tipe 1 Diabetes.*
- **Wie sal toegang hê tot u mediese rekords?**
  - *Alle inligting wat van u as die deelnemer ingesamel word, sal as hoogs vertroulik hanteer word en sal bewaar word deur die navorser. Indien die tesis gebruik word vir 'n publikasie, sal u identiteit ten alle tye anoniem bly. Die enigste persoon wat toegang sal hê tot al die data, is die navorser. Alle informasie sal veilig gestoor word op die navorser se persoonlike rekenaar. 'n Statistikus sal slegs kyk na die numeriese data wat ingesamel is, en sal hanteer word as hoogs vertroulik. Dit sal ook so bewaar word.*

**Sal u betaal word om deel te neem aan die studie en is daar enige kostes betrokke?**

U sal voorsien word van 'n Checkers-koepon ter waarde van R30 vir u deelname aan die studie. Vervoer- en maaltydkostes sal nie gedek word deur die navorser nie. Daar sal geen kostes vir u betrokke wees wanneer u aan die studie deelneem nie, aangesien die onderhoude gevoer sal word op Maandae, wanneer u kind nodig het om sy/haar dokter te spreek tydens hul afspraak.

**Is daar enigiets anders wat u moet weet?**

- U kan Dr. Ekkehard Zöllner kontak by, tel. (021) 938-9663, indien u enige verdere navrae het, of probleme ondervind.
- U kan die **Gesondheid Navorsing Etiese Komitee** kontak by (021) 938-9207 indien u enige bekommernisse of klagtes het, wat nie volledige deur die studieleier gedek is nie.
- U sal 'n kopie van hierdie inligting- en ingeligte toestemmingsvorm ontvang vir u eie rekordhouding.

**Verklaring deur deelnemer**

Deur onderaan te teken stem, ek ..... in om deel te neem aan 'n navorsingstudie getiteld, *Resilience characteristics of families with a child with Type 1 Diabetes*.

Ek verklaar dat:

- Ek het self, of ek het hierdie inligting- en ingeligte toestemmingvorm vir my laat lees en dit is geskryf in 'n taal waarin ek vlot en gemaklik is.
- Ek het die kans gehad om vrae te vra en al my vrae is volledig beantwoord.
- Ek verstaan dat deelname aan die studie vrywillig is en dat ek nie gedruk was om deel te neem nie.
- Ek mag besluit om die studie ter enige tyd te verlaat en sal nie te nagekom word, of bevooroordeeld behandel word op enige manier nie.
- Ek mag gevra word om die studie te verlaat voordat dit nog voltooi is, indien die studie-leier/navorsers voel dit is in my beste belang om nie deel te neem nie, of wanneer ek nie die studieplan volg, soos ooreengekom nie.

Geteken by (*plek*) ..... op (*datum*)  
..... 2011.

.....  
**Handtekening van deelnemer**

.....  
**Handtekening van ooggetuie**

## Verklaring deur ondersoeker

Ek *Guzéle Koegelenberg* verklaar dat:

- Ek het die informasie in hierdie dokument verduidelik aan .....
- Ek het hom/haar aangemoedig om vrae te vra en het genoeg tyd geneem om die vrae te beantwoord.
- Ek is tevrede dat hy/sy al die aspekte van die navorsing, soos hierbo beskryf, duidelik verstaan.
- Ek het nie 'n interpreteerder gebruik nie. (*Indien 'n interpreteerder gebruik word, moet hy/sy die verklaring onderaan teken.*)

Geteken by (*plek*) ..... op (*datum*) ..... 2011.

.....  
**Handtekening van ondersoeker**

.....  
**Handtekening van ooggetuie**

## Verklaring deur interpreteerder

Ek, *Dr. Ekkehard Zöllner* verklaar dat:

- Ek as die mede-ondersoeker het *Guzéle Koegelenberg* bygestaan om die inligting in hierdie dokument te verduidelik aan (*naam van deelnemer*) ..... in die taalmedium Afrikaans/Engels.
- Ons het haar aangemoedig om vrae te vra en genoeg tyd te neem om vrae te beantwoord.
- Ek het 'n feitelike weergawe van wat aan my gegee is, oorgedra.
- Ek is tevrede dat die deelnemer die inhoud van hierdie ingeligte toestemmingsvorm volledig verstaan en dat al sy/haar vrae volledig beantwoord is.

Geteken op (*plek*) ..... op (*datum*) ..... 2011

.....  
**Handtekening van interpreteerder**

.....  
**Handtekening van ooggetuie**

## APPENDIX F

### English HREC information leaflet

**TITLE OF THE RESEARCH PROJECT: Resilience characteristics of families with a child with type 1 diabetes**

**REFERENCE NUMBER: N11/06/184**

**PRINCIPAL INVESTIGATOR: Guz lle Koegelenberg**

**ADDRESS:** Department of Psychology, Stellenbosch University, 7600, South Africa

**CONTACT NUMBER: -**

Dear Participant

My name is Guz lle Koegelenberg and I am a Masters Research Psychology student from Stellenbosch University. I would like to invite you to participate in a research project that aims to investigate what resilience characteristics your family possess, as well as how these characteristics may have contributed to your family's process of adapting to your child's diagnosis with Type 1 Diabetes.

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

The research question for this study is: What family resilience characteristics are present in families who have lived for at least six months with a child (between the ages of two and twelve years) with Type 1 Diabetes? Participating in the study will entail the signing of the informed consent form, completion of biographical details, as well as the answering of one short open-ended question and four questionnaires. At all times during data gathering, strict confidentiality and privacy will be maintained. Your name or surname will not be used or made available at any point during the study. Your rights, beliefs, language preference, culture and race will be respected at all times. Even in the case where you have indicated participation willingness, you will not be forced to take part in the study. If you decide to leave or withdraw at any point during the research gathering process, you are welcome to do so. All the biographical and questionnaire information will not be made available to any other individual, other than the researcher, supervisor and statistician. All the data obtained from the questionnaires, as well as the qualitative question answered, will be stored on the researcher's personal and secure computer database.

**If you are willing to participate in this study please sign the attached Declaration of Consent and (*hand it to the investigator*)**

Yours sincerely,

Guzéle Koegelenberg  
Principal Investigator

### **Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled **Resilience characteristics of families with a child with type 1 diabetes.**

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... On (*date*) .....  
2011.

.....

**Signature of participant**

## APPENDIX G

### English HREC informed consent form

**TITLE OF THE RESEARCH PROJECT:** Resilience characteristics of families with a child with type 1 diabetes

**REFERENCE NUMBER:** N11/06/184

**PRINCIPAL INVESTIGATOR:** Prof. A. P. Greeff

**ADDRESS:** Department of Psychology, Stellenbosch University, 7600, South Africa

**CONTACT NUMBER:** Tel. +27 021 8083464, Fax. +27 021 8083584, Cell. 0722733905

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

➤ **What is this research study all about?**

- *Participants will be recruited to take part in the study which will be conducted in the Neurology Room, Paediatric Diabetes Unit, Tygerberg Hospital.*
- *The aim of this study is to use the found results to inform families involved and medical staff how to reduce dysfunctional dynamics within family relationships and how to increase optimal family adaptation and functioning. The research will also make a contribution to the limited amount of information gathered around families who live with a person with a chronic condition, such as Type 1 Diabetes.*
- *After obtaining permission from the superintendent of Tygerberg Hospital and the unit head, Dr. Ekkehard Zöllner, as well as caregiver contact information from the Diabetes Nurse Educator, Fiona Liebenberg, primary caregivers of children with Type 1 Diabetes Mellitus, registered at Tygerberg Hospital's Pediatric Diabetes Unit, will be contacted telephonically to inform them about the research, the objectives of the study, who the researcher is and what participating in the study will entail, as well as whether they are willing to take part in the research. The caregiver will be asked when their child's next*

*appointment at the Diabetes Clinic is. The date of the next appointment will be used to meet the caregiver personally and conduct the interviews. The personal meeting will be used to get confirmation from the caregiver, whether he/she is willing to take part in the research by signing the informed consent form and continue with the interview and completion of questionnaires. Participation in the study will encompass the completion of a Stellenbosch University Informed Consent Form, a biographical questionnaire, a short written/oral open-ended question and four closed-ended questionnaires. The completion of the open-ended question and four closed-ended questionnaires, will take a maximum of 30 minutes to complete. Orally provided answers will be filled out on the questionnaires by the researcher. Despite the primary caregiver's willingness to participate in the study, he/she is not forced to continue with participation. If a participant decides not to take part in the research at any point in the research process, he/she may withdraw from the project, without any consequences. All the primary caregivers will be approached on a Monday morning before their child's Diabetes Clinic appointment, between 08:00am and 14:00pm. After the child's appointment at the clinic, the primary caregiver and child will accompany the researcher to the Neurology room on the Paediatric Diabetes Unit floor, provided by Diabetes Unit staff at Tygerberg Hospital, to complete the open-ended question and questionnaires. The researcher will thus be sitting in during the fill out/oral answering of the questionnaires. If any questions may arise during the answering process the researcher will be available to provide help/assistance to the participant. After the completion/answering of all the questions the participant will be provided with a Checkers voucher worth R30. The year in which the study is completed, the results of the study will be presented at the Tygerberg Academic week.*

➤ **Why have you been invited to participate?**

- *You have been approached to take part in this study because you are the primary caregiver of a Type 1 diabetic child who is a registered patient at Tygerberg Hospital's Diabetes Unit. You will be able to provide the basic information needed to find out how different families with a child with Type 1 Diabetes, adapt to the child's diagnosis.*

➤ **What will your responsibilities be?**

- *Your responsibilities will entail the completion of an informed consent form, the completion of a biographical information document, answering one short question regarding your families' ability to adapt and cope with your child's diagnosis of Type 1 Diabetes and lastly, the completion of four questionnaires.*

➤ **Will you benefit from taking part in this research?**

- *Yes, a benefit of the study is that you, as the participant, can implement possible adaptation and resilience characteristics and techniques in your family.*

- **Are there any risks involved in your taking part in this research?**
  - *Yes, there is a risk that some of the questions may be distressing for you to answer. If you experience any stress during or after the interview you may feel free to contact Prof. Awie Greeff (021 808-3464) for free assistance.*
  
- **If you do not agree to take part, what alternatives do you have?**
  - *You are not obliged to take part in the study. If you choose not to participate in the study you will still receive normal treatment. You can feel free to contact Prof. Awie Greeff (021 808-3464) for more information on psychological help/assistance for people with Type 1 Diabetes or family members with a member with Type 1 Diabetes.*
  
- **Who will have access to your medical records?**
  - *All the information gathered from you as a participant will be treated as highly confidential and will be protected by the researcher. If the thesis will be used in a publication, your identity will remain anonymous. The only person who will have access to all the data is the researcher. All information will be securely stored on the researcher's personal computer. A statistician will only look at the numerical data collected, and will be treated as highly confidential and will be protected. If it is used in a publication or thesis, the identity of the participant will remain anonymous.*

**Will you be paid to take part in this study and are there any costs involved?**

You will be provided with a Checkers voucher worth R30 for your participation. Transport and meal costs will not be covered by the researcher. There will be no costs involved for you, if you take part in the study, seeing that the interviews will be held on Mondays, when your child needs to attend their doctor's appointment.

**Is there anything else that you should know or do?**

- You can contact Dr. Ekkehard Zöllner at tel. (021) 938-9663 if you have any further queries or encounter any problems.
- You can contact the **Health Research Ethics Committee** at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled *Resilience characteristics of families with a child with type 1 diabetes*.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) .....  
2011.

.....  
**Signature of participant**

.....  
**Signature of witness**

### Declaration by investigator

I *Guzéle Koegelenberg* declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. *(If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ..... on (*date*) .....  
2011.

.....  
**Signature of investigator**

.....  
**Signature of witness**

### ➤ Declaration by interpreter

I *Dr. Ekkehard Zöllner* declare that:

- I assisted the investigator *Guzéle Koegelenberg* to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/English.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....  
.....

.....  
**Signature of interpreter**

.....  
**Signature of witness**