

**Hope in parents of a child with autism  
spectrum disorder**

**Angela Cogzell**

**March 2018**

**Hope in parents of a child with autism spectrum disorder**

by

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Submitted in partial fulfilment of the requirements for the degree

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## Ethical Statement

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The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, the applicable research approval. The author declares that she has observed the ethical requirements in terms of the University of Pretoria's Code of ethics for researchers and the Policy guidelines for responsible research.

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Angela Cogzell

March 2018

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# Ethical Clearance Certificate

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## Declaration of Originality

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I, Angela Cogzell (student number 27029078), hereby declare that all the resources consulted are included in the reference list and that this study titled: *Hope in parents of a child with autism spectrum disorder* is my original work. This dissertation has not been previously submitted by me for any degree at this or any another university.

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Angela Cogzell

March 2018

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## Declaration – Language Editor

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### TO WHOM IT MAY CONCERN (DECLARATION OF EDITING)

Angela Cogzell's dissertation, **Hope in parents of a child with autism spectrum disorder**, was language-edited by me between August 2017 and February 2018. It was, of course, the author's prerogative to accept or reject my suggested changes.



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1 March 2018

## Abstract

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### Hope in parents of a child with autism spectrum disorder

by

**Angela Cogzell**

Supervisor: Dr Suzanne Bester

Co-supervisor: Dr Alfred Haupt du Plessis

As the number of children diagnosed with autism spectrum disorder (ASD) in South Africa increases annually, so too does the number of parents raising these children. The issue addressed by this study is the gap in current literature on the hope experiences in parents of a child with ASD in South Africa. While numerous research studies have dealt with the experiences of parents raising a child with ASD, majority - specifically in Africa - focus on the negative experiences. Very few studies have been conducted on hope experiences and ASD, and these are almost exclusively within an international context.

The purpose of this exploratory qualitative case study was to explore and describe the hope experiences of parents raising a child with ASD. The conveniently selected participants (two females) each had a child who was attending The Autism School<sup>1</sup>, an intervention centre in Johannesburg. An interpretive phenomenological approach allowed the researcher to understand the unique, subjective meaning that parents assign to their own experiences. Data were collected using a semi-structured interview and a participant research journal for each participant.

Parents raising a child with ASD experience a variety of hope related experiences that either enhance or diminish hope. Health professionals either reduced hope by giving information at the time of the diagnosis that was not specific enough, or enhanced hope by interacting with the parents in a way that enhanced learning. Hope was also enhanced when parents felt connected with sources of support. Generating options to address the challenges experienced enhanced survival related hope whereas feelings of powerlessness over certain situations resulted in reduced hope. Being able to

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<sup>1</sup> The name of the intervention centre has been changed to ensure the anonymity of the participants.



regulate emotions was important in enhancing survival related hope. Spiritual related hope was enhanced when in conjunction with the practical interventions the parents pursued, they were able to rely on a higher power to bring about change in the child through hoping for a miracle. These findings may be useful for health professionals working with these parents as it may provide a new way of understanding and supporting them.

### **Key words**

- Attachment
- Autism spectrum disorder
- Hope
- Mastery
- Positive psychology
- Spirituality
- Survival

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# Chapter 1

## Overview and Rationale

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### 1.1 INTRODUCTION AND RATIONALE

From 2007 to 2012, the prevalence rate of autism spectrum disorder (ASD) increased to 2% of the general population making it one of the most common neurodevelopmental disorders (Blumberg et al., 2013; Mulligan, MacCulloch, Good, & Nicholas, 2012). The number of children affected by ASD is rising by 10% to 15% every year in the United States of America (Greef, & Van der Walt, 2010). It is estimated that approximately 270 000 children under the age of six are affected by ASD in South Africa (Greef, & Van der Walt, 2010), and Fewster and Gurayah (2015) state that this number is increasing by 5000 annually.

The often debilitating effects of the disorder and its increasing prevalence have caused researchers to acknowledge the importance of understanding how parents experience raising a child with ASD and the challenges they face (Faso, Neal-Beevers, & Carlson, 2013). Various studies have focused on these experiences (Hutton, & Caron, 2005; Benderix, Nordstrom, & Sivberg, 2007; Myers, Mackintosh, & Goin-Kochel, 2009; Meirsschaut, Roeyer, & Warreyn, 2010; Ogston, Mackintosh, & Myers, 2011; Faso et al., 2013; Mulligan et al., 2012; Topin et al., 2012; Neff, & Faso, 2015), which range from confusion, doubt, and ambiguity to joy and hope (Kearney, & Griffin, 2003).

Children with ASD present with a unique combination of symptoms making accurate diagnosis and treatment problematical (Grinker et al., 2012). This is further complicated in the South African context because of the limited resources and support services available to assist parents in caring for their children (Huws, Jones, & Ingledew, 2001). These stressors can have harmful effects on the family (Greef, & Van der Walt, 2010).

Numerous research studies have dealt with the negative experiences of parents raising a child with ASD (Greef, & Van der Walt, 2010), but more recently the research focus has shifted to the potentially positive experiences in this regard (Greef, & Van der Walt, 2010). Research has shown that most parents raising a child with ASD today can live meaningful, rewarding lives while remaining optimistic about their child's future (Hutton, & Caron, 2005; Faso et al., 2013).

The parents reported undergoing personal growth and learning a lot as a result of their experiences (Benderix et al., 2007; Myers et al., 2009). Things they learnt included compassion, tolerance, patience, and understanding (Benderix et al., 2007; Myers et al., 2009). They reported also an increase in their confidence and assertiveness (Myers et al., 2009).

The experience of raising a child with ASD gave the parents a new perspective on life and the opportunity to re-examine their beliefs, values, and priorities (Myers et al., 2009; Martins, Walker, & Fouché, 2013). They gained new insight into the world of disabilities and learnt how to appreciate the small things in life and to love their children as they were (Myers et al., 2009). They reported also experiencing a greater sense of coherence, control, and strength through this new way of seeing their lives (Myers et al., 2009).

Hope has a positive impact on personal well-being (Myers et al., 2009) and can relieve stress and depressive symptoms that may interfere with parental ability to engage in interventions aimed at helping their child (Meirsschaut et al., 2010).

In their study, Myers et al. (2009) reported an improvement in family dynamics, characterised by an increase in support for one another, as a result of having a child with ASD. The families in the study adjusted positively to the challenges and, contrary to prior belief, marriages were enriched and the experience also had a positive impact on the child's siblings (Myers et al., 2009).

In all the studies that have been conducted on parents' experiences of raising a child with ASD, only four have focused specifically on hope and ASD (Ogston et al., 2011; Faso et al., 2013).

Ogston et al. (2011) conducted a mixed-methods study on hope and worry in mothers with a child with ASD and found that hope often served as a protective factor against psychological distress, depression, anxiety, and worry. However, such mothers sometimes experienced hope and worry that might not have been related to their children and their diagnoses (Ogston et al., 2011). In addition to its protective properties, hope has also been linked to health benefits, positive psychosocial outcomes, and the use of more adaptive coping techniques in response to the challenges of raising a child with ASD (Ogston et al., 2011). The ability to frame negative experiences in a positive way can also be influenced by hope (Ogston et al., 2011).

Various studies have revealed that the challenges faced by parents raising a child with ASD undermined their experiences of hope, but self-compassion, a component of hope, was found to counter this process and strengthen the parents' resilience (Neff, & Faso, 2015). By extending goodwill to themselves, the parents experienced uplifting emotions that made them emotionally resilient and therefore better able to enjoy greater life satisfaction (Neff, & Faso, 2015). When disappointment was experienced, self-compassion enabled them to comfort and support themselves while recognising the shared nature of human suffering (Neff, & Faso, 2015). This encouraged them to try new approaches positively associated with goal re-engagement, greater motivation, and persistence (Neff, & Faso, 2015). Self-compassion enabled them to cope with challenging situations by making them aware of the destructive nature of negative thoughts and emotions and therefore less likely to view their child's behaviour as difficult and problematic (Neff, & Faso, 2015).

Another aspect of hope that was found to contribute to resilience and well-being in the mothers as well as the fathers of a child with ASD (Faso et al., 2013) was vicarious futurity, that is, "the hope and despair a parent feels for the future of their child" (Faso et al., 2013, p. 1). An increase in vicarious hope was associated with more life satisfaction, less parenting stress, and less depression (Faso et al., 2013).

The ability to move forward, after a diagnosis is made, and to consider the next step in the intervention is influenced by how the diagnosis is presented to the parents (Mulligan et al., 2012). How the diagnosis is conveyed has the potential to influence their perception of hope and, ultimately, their ability to cope with the disorder (Mulligan et al., 2012). A diagnosis that is given in a hopeful manner, a manner that focuses on strengths, can empower parents (Mulligan et al., 2012).

The above studies are studies that have been conducted on hope and ASD, yet these studies have been conducted only in an international context. The research that has been done on ASD in Africa has tended to focus on aetiology, diagnostic characteristics, and co-morbid disorders (Ametepee, & Chitiyo, 2009; Bakare, & Munir, 2011a; Grinker et al., 2012; Springer, van Toorn, Laughton, & Kidd, 2013). Other research has focused on the lack of knowledge and awareness of ASD, the consequences of this, and the lack of services to deal with the disorder (Bakare, & Munir, 2011a; Bakare, & Munir, 2011b; Grinker et al., 2012). The deficit-based approach to ASD research in Africa can be seen in the focus on what is wrong or not working well as opposed to what is positive and working well (Ametepee, & Chitiyo,

2009; Bakare, & Munir, 2011a, Bakare, & Munir, 2011b; Grinker et al., 2012; Springer et al., 2013).

Two studies conducted recently in South Africa focused on the experiences of raising a child with ASD (Greef, & Van der Walt, 2010; Martins et al., 2013). While Martins et al. (2013) explored both the positive and negative experiences of a father raising a child with ASD, Greef and Van der Walt (2010) focused on the characteristics and resources that promote resilience in families dealing with the challenges of raising such a child (Greef, & Van der Walt, 2010). Both studies identified hope as an important part of a parent's experience (Greef, & Van der Walt, 2010; Martins et al., 2013). Martins et al. (2013) found that the hope that a father experienced was related to the child receiving the help it needed. Greef and Van der Walt (2010) found that maintaining hope enabled the parents to adjust to the challenges associated with having a child with ASD.

The studies showed that how a situation is appraised influenced the level of stress experienced, the impact each situation had on their psychological well-being, and how they coped with the challenges (Martins et al., 2013). Two types of coping were identified: avoidant coping and problem-focused coping (Martins et al., 2013). Avoidant coping involved not thinking about the challenges or the future of the child (Martins et al., 2013) while problem-focused coping involved the restructuring of the problem in a positive way while still accepting the reality of the situation (Martins et al., 2013). A positive outlook helped the parents meet the challenges facing them (Greef, & Van der Walt, 2010).

In the study conducted by Greef and Van der Walt (2010), hope also played a role in helping the parents adapt to having a child with ASD. The parents reported feeling hopeful following the diagnosis because they could then receive the help needed to improve their chances of a better outcome and future (Greef, & Van der Walt, 2010).

The fathers believed that the experience gave them the opportunity to grow and develop through managing their challenges successfully (Martins et al., 2013). They could also help other parents by being able to identify developmental delays in their children (Martins et al., 2013).

While both studies indicated a shift towards a more positive focus in ASD research in South Africa, more research on the positive experiences of raising a child with ASD is needed. Greef and Van der Walt (2010) focused on resilience in general, which meant that individual concepts, such as hope, received limited attention in the broader focus

of the study. The same limitation was seen in the research conducted by Martins et al. (2013), which covered the general experiences of fathers raising a child with ASD. Thus, there is a need for an in-depth study on the hope experiences of a parents raising a child with ASD in the South African context.

The rationale for this study is based on my experiences as an instructor at The Autism School during the period 2011 to 2016. During that time, I collaborated with the parents of a child with ASD on the implementation of an intervention programme. While providing feedback to the parents on their child's progress or training them in aspects of their child's programme, I saw that some parents appeared to be more hopeful than other parents. This led me to wonder whether or not the experience of hope prompted parents to be more actively involved in their child's programme and how it affected their child's progress. I started to ask myself why some parents were more hopeful than other parents, what factors influenced their sense of hopefulness, and how this impacted their experience of raising a child with ASD.

## **1.2 PURPOSE OF THE STUDY**

The purpose of this exploratory case study was to explore and describe the hope in two parents who had a child with ASD at The Autism School. For the purposes of this research, hope was defined as "A future-directed, four channel emotion network, constructed from biological, psychological, and social resources. The four constituent channels or life domains are the mastery, attachment, survival, and spiritual systems (or sub-networks). The hope network is designed to regulate these systems via both feed-forward (expansion) and feedback processes (maintenance) that generate a greater perceived probability of power and presence as well as protection and liberation" (Scioli et al., 2011, p. 79).

## **1.3 RESEARCH QUESTIONS**

### **1.3.1 PRIMARY RESEARCH QUESTION**

What are the hope experiences of parents raising a child with ASD?

### **1.3.2 SECONDARY RESEARCH QUESTIONS**

- What events/instances enhance or diminish the experience of hope in parents who have a child with ASD?
- How does parents' hope relate to the life domains of mastery, attachment, survival, and spirituality?

## **1.4 WORKING ASSUMPTIONS**

For the purpose of this study, I made the following assumptions.

- Raising a child with ASD will influence the lives of the parents.
- Parents raising a child with ASD will experience challenges.
- Parents raising a child with ASD have strengths and resources.
- Parents raising a child with ASD will experience some degree of hope that falls on a continuum of hopelessness and hopefulness.
- Each parent raising a child with ASD will have a unique experience in raising that child.
- The parents of a child receiving some form of intervention will be more hopeful than the parents of a child who is not receiving any form of intervention.
- The knowledge that the researcher has, as a result of her prior exposure to children with ASD may bias her understanding of the data collected.

## **1.5 CONCEPT CLARIFICATION**

The key concepts of the study, namely autism spectrum disorder (ASD), and hope are clarified below.

### **1.5.1 AUTISM SPECTRUM DISORDER**

Autism spectrum disorder (ASD) is a term used to categorise the disorders previously known separately as autistic disorder, pervasive developmental disorder, and Asperger's disorder (American Psychiatric Association, 2013). These disorders present with two common key symptoms: deficits in social communication and restrictive repetitive behaviours or interests (Stankovic, Lakić, & Ilic, 2012), but each symptom presentation can be placed on a single continuum ranging from mild to severe (American Psychiatric Association, 2013; Martins et al., 2013). These disorders are therefore classified as spectrum disorders because there can be a variety of different presentations of the disorder (Martins et al., 2013).

Parents raising a child diagnosed with ASD, according to the criteria set out in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) took part in this study. The children of the parents interviewed presented with varying levels of severity and with differing presentations of the same disorder. The parents therefore each had a unique experience of their child and the hope they experienced as they raised their child with ASD.

### **1.5.2 HOPE**

Hope has been defined differently by different researchers (Benzein, & Berg, 2005; Feudtner et al., 2010; Kashdan et al., 2002). It has been conceptualised as a positive cognition (Seligman, & Csikszentmihalyi, 2000), goal-directed behaviour (Snyder, Randa, & Sigmon, 2002), a skill (Scioli, & Biller, 2010), and a life-sustaining force (Bally et al., 2014). Due its complex nature, researchers have not yet reached consensus on a universal definition of hope (Mack et al., 2007).

For the purposes of the present research, hope was defined as “a future-directed, four channel emotion network, constructed from biological, psychological, and social resources. The four constituent channels are the mastery, attachment, survival, and spiritual systems (or sub-networks). The hope network is designed to regulate these systems via both feed-forward (expansion) and feedback processes (maintenance) that generate a greater perceived probability of power and presence as well as protection and liberation” (Scioli, Ricci, Nyugen, & Scioli, 2011, p. 79).

This definition by Scioli et al. (2011) offers a multidimensional approach to understanding hope as it incorporates the life domains of mastery, attachment, survival, and spiritual systems.

### **1.6 DELIMITATIONS AND LIMITATIONS**

The study was confined to interviewing the parents (and analysing the participants' research journals) of a child who had been diagnosed with ASD and who at the time of the study was attending The Autism School in Johannesburg.

The use of convenience sampling in the study decreased the generalisability of the findings. In addition to the sampling technique used, the study focused on unique participants (in a unique setting) who had unique experiences of raising a child with ASD. These experiences differed between parents in different contexts, thus further limiting the generalisability of the data collected.

The presence of the researcher during the data collection might also have influenced the research findings as the participants might have provided the answers they thought the researcher expected.

## **1.7 SIGNIFICANCE OF THE STUDY**

This study may well contribute to the existing literature in the fields of hope and ASD. The findings may provide greater insight into the *positive* experiences of parents raising a child with ASD thus contributing to the knowledge of the general experiences of parents raising such a child. By identifying the factors that may influence the experience of hope, these factors can be targeted during intervention programmes to support parents and assist them in positively coping with the challenges associated with raising a child with ASD. The study may also help raise awareness of these hope experiences and thus inform the practice of health professionals in a way that facilitates the development of resilience in parents raising a child with ASD.

## **1.8 OUTLINE OF RESEARCH APPROACH, PARADIGM, AND PROCESSES**

Table 1.1 provides an overview of the research approach, paradigm, and processes used in this study. A detailed analysis of the methodological choices is given in Chapter 3.



**Table 1.1: Framework of research process** (Adapted from Loots, 2011, p. 14)

<b>Background to the study</b>		
<b>Theoretical framework</b>	<b>Experience</b>	<b>Literature review</b>
Integrative theory of hope (Scioli et al., 2016).	Working with parents who have a child with ASD.	<p>ASD challenges (Huws et al., 2001; Heiman, &amp; Berger, 2008; Ekas, Lickenbrock, &amp; Whitman, 2010; Grinker et al., 2012; Martins et al., 2013; Alli, Abdoolah, &amp; Mupwose, 2015).</p> <p>Positive experiences (Myers et al., 2009; Kausar et al., 2003; Meirsschaut et al., 2010; Heydari et al., 2015).</p> <p>Hope experiences (Lloyd, &amp; Hastings, 2009; Faso et al., 2013; Ogston et al., 2011; Mulligan et al., 2012).</p>
<b>Research questions</b>		
<b>Primary research question</b>	<b>Secondary research questions</b>	
<ul style="list-style-type: none"> <li>What are the hope experiences of parents raising a child with ASD?</li> </ul>	<ul style="list-style-type: none"> <li>What events/instances enhance or diminish the experience of hope in parents who have a child with ASD?</li> <li>How does parents' hope relate to the life domains of mastery, attachment, survival, and spirituality?</li> </ul>	

<b>Research approach</b>				
<b>Epistemological paradigm</b>	<b>Methodological paradigm</b>	<b>Research design and sampling</b>	<b>Data collection</b>	<b>Data analysis and interpretation</b>
Interpretive phenomenological approach (Kumar, 2012; Penner, & McClement, 2008; Mayoh, & Onwuegbuzie, 2015; Creswell, & Miller, 2000; Lopez, & Maggs-Rapport, 2000; Shaw, 2010b).	Qualitative research (Creswell, 2014; Hugh-Jones, 2010; Nieuwenhuis, 2007b; Merriam, 2004; Penner, & McClement; Lopez, & Willis, 2004; Gravetter, & Forzano, 2009).	Exploratory case study (Nieuwenhuis, 2007c; Zainal, 2007; Babbie, 2008; Gravetter, & Forzano, 2009; Yin, 2009; Baxter, & Jack, 2008; Willig, 2008).  Convenience sampling (Maree, & Pietersen, 2007; Gravetter, & Forzano, 2009).	Semi-structured interview (Babbie, 2008; Gill et al., 2008; Gravetter, & Forzano, 2009; Nieuwenhuis, 2007c; Rolwey, 2012).  Participants' research journals (Jacelon, & Imperio, 2005; Lopez & Willis, 2004; Willig, 2009; Lewis et al., 2005).	Interpretative phenomenological analysis (Creswell, 2000, Pringle et al., 2011, Willig, 2008)
<b>Strategies to ensure quality of research</b>				
Credibility: reflexivity, member checking, triangulation (Thomas, & Magilvy, 2011; Baxter, & Jack, 2008; Creswell, 2014).	Transferability and generalizability: thick descriptions (Thomas, & Magilvy, 2011; Baxter, & Jack, 2008; Willig, 2008).	Dependability: audit trail (Willig, 2008; Shaw, 2010a; Thomas, & Magilvy, 2011).	Confirmability: reflexivity (Thomas, & Magilvy, 2011).	
<b>Ethical considerations</b>				
<ul style="list-style-type: none"> <li>• Permission from the Ethics Committee</li> <li>• Informed consent (Allan, 2011; Gravetter, &amp; Forzano, 2009; King, 2010; Babbie, 2008).</li> <li>• Privacy, confidentiality and anonymity (Allan, 2011).</li> </ul>			<ul style="list-style-type: none"> <li>• Voluntary participation (Gravetter, &amp; Forzano, 2009; Allan, 2011; Babbie, 2008).</li> <li>• Protection from harm (Allan, 2011; Willig, 2008).</li> <li>• No deception (Gravetter, &amp; Forzano, 2009).</li> </ul>	

## 1.9 OVERVIEW OF STUDY

The following section provides an outline of each chapter in this mini-dissertation.

### ❖ CHAPTER 1: INTRODUCTION, RATIONALE, AND OVERVIEW

Chapter 1 covers the background, purpose, and rationale for the study. The primary and secondary research questions are stated, followed by the working assumptions. An overview is then given of the research process as well as the clarification of the concepts of the study. The delimitations and limitations were considered followed by the significance of the study.

### ❖ CHAPTER 2: LITERATURE REVIEW

Chapter 2 explores the literature on the experiences of parents raising a child with ASD. This includes the challenge and the positive experiences. The role of hope in parental well-being is then explored, followed by an exploration of the literature on the hope experiences of parents raising a child with ASD. The chapter ends with an outline of the theoretical framework of the study, namely an integrative theory of hope.

### ❖ CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

Chapter 3 covers the research methodology and design. Participant selection, data collection, documentation, data analysis, and interpretation are then discussed. Finally, quality criteria and ethical considerations are dealt with.

### ❖ CHAPTER 4: FINDINGS OF THE STUDY

The findings of the study are presented in Chapter 4. Each theme concludes with a recursive literature review.

### ❖ CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

In the final chapter, the questions presented in Chapter 1 are answered using the results of the study. This is followed by a discussion of the contributions of the study, problems and limitations, and recommendations for future research.

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## **Chapter 2**

### **Literature Review**

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#### **2.1 INTRODUCTION**

The number of children being diagnosed with ASD is increasing, and it is therefore becoming more important to understand the experiences of the parents who are raising them. The purpose of this chapter is to provide the reader with an in-depth understanding of literature on the experiences of parents raising a child with ASD.

Faso et al. (2013) argue that in order to gain a proper understanding of the experiences of parents raising a child with ASD, both positive and negative parenting experiences need to be considered. The chapter accordingly begins with a discussion of parents' negative experiences followed by their positive experiences.

Even though parents raising a child with ASD have to contend with numerous challenges, many such parents are still able to experience well-being (Neff, & Faso, 2015). The chapter then explores the concept of well-being and the role that hope plays in maintaining well-being despite the problems and challenges experienced. After this, the literature review of international and national research on the hope experiences of parents raising a child with ASD is discussed.

The final section of the chapter outlines the guiding theoretical framework of the present study, namely the integrative theory of hope of Scioli, Scioli-Salter, Sykes, Anderson and Fedele (2016).

#### **2.2 PARENTING A CHILD WITH AUTISM SPECTRUM DISORDER**

Parenting a child with ASD is seen as a unique experience consisting of both negative and positive features (Kausar et al., 2003). In the following section, the challenges experienced by parents in raising a child with ASD are explored in detail followed by a discussion of their positive experiences.

##### **2.2.1 CHALLENGES EXPERIENCED**

The challenges or problems parents experience when raising a child with ASD have been well documented in both the international and national literature (Huws et al., 2001; Heiman, & Berger, 2008; Ekas et al., 2010; Grinker et al., 2012; Alli, Abdoolah, & Mupwose, 2015). These challenges begin before obtaining a formal diagnosis as

parents become aware that their child's development is different from that of other children their age (Martins et al., 2013), which may be as a result of impairments in communication, social interaction (Mulligan et al., 2012; American Psychiatric Association, 2013), or other behavioural manifestations such as tantrums (Faso et al., 2013), aggression, or self-injurious behaviour (Neff, & Faso, 2015).

When parents consult health professionals regarding their child, they often experience them as initially unresponsive to their concerns about their child's development (Ogston et al., 2011). Health professionals are often hesitant about misdiagnosing young children because many of the behaviours associated with ASD are considered significant only after the age of two years. The health professionals may then make a formal diagnosis only after the child has turned two despite the earlier presence of developmental difficulties (Moh, & Magiati, 2012). It may thus take a number of years before a formal diagnosis is made, resulting in health professionals appearing unresponsive to parents' initial concerns (Ogston et al., 2011).

Health professionals consider ASD a complex diagnosis as the presentation and the severity of the impairments may vary widely (Martins et al., 2013). Because ASD is a spectrum disorder, its core features occur along a spectrum or a continuum ranging in severity from mild to severe (Martins et al., 2013). Thus, two children diagnosed with ASD may present significantly differently based on the unique combination of where on the continuum they are with regard to the core features of ASD (Stankovic et al., 2012). To further complicate the diagnostic process, children may also present with additional specifiers such as intellectual or language impairments or other neurodevelopmental, mental, or behavioural disorders (American Psychiatric Association, 2013).

Although there are international clinical guidelines to assist health professionals in the diagnostic process (Moh, & Magiati, 2012), no such guidelines exist in the African context (Abubakar, Ssewabtaba, & Newton, 2016). Cultural linguistic diversity and ethnicity, for example, are factors that often result in later diagnosis (Wang, & West, 2016). Owing to unique cultural influences, the African context differs significantly from other contexts thus highlighting the need for diagnostic processes that acknowledge culturally influenced factors such as play interactions and social routines (Abubakar et al., 2016).

Once a diagnosis has been made, parents may initially find it difficult to accept (Wang, & West, 2016). Wang and West (2016) argue that some parents have difficulty accepting an ASD diagnosis because ASD is a relatively new disorder, and, in addition,

there is limited awareness of ASD in developing countries. Ogston et al. (2011) found in their research that difficulty in accepting an ASD diagnosis is often due to ASD not presenting like other disorders, such as Down syndrome, which can be diagnosed based on physical features and confirmed by genetic testing.

Parents often express a need to ask questions and to be provided with useful information at the time of the diagnosis (Moh, & Magiati, 2012). Martins et al. (2013) found that parents are often frustrated by the lack of information thus making it more difficult for them to care for their child (Huws et al., 2001). Parents also want to know about the availability of different treatment options (Ogston et al., 2011). This may be a result of the limited number of support services available, specifically in South Africa (Grinker et al., 2012), the variable presentation of ASD thus precluding a standardised treatment plan, and the lack of a clearly defined prognosis for children with ASD (Ogston et al., 2011).

Accessing treatment is also experienced as a problem by some parents (Hutton, & Caron, 2005). In South Africa, the shortage of resources has resulted in limited treatment options to choose from (Heiman, & Berger, 2008; Grinker et al., 2012; Neff, & Faso, 2015). This contrasts with the experiences of parents in developed countries where various treatment options are available (Ogston et al., 2011). However, because of this variety of options, some parents report experiencing confusion and uncertainty about which treatment option to choose (Ogston et al., 2011; Wang, & West, 2016).

According to Hutton and Caron (2005), some parents involve up to seven different health professionals, ranging from therapeutic support staff to speech and occupational therapists, in the treatment of their child. These specialist interventions can place a considerable financial burden on parents (Ogston et al., 2011; Martins et al., 2013) compounded by expensive long-term medication, which is a common form of treatment for children with ASD (Martins et al., 2013; Lovell, & Wetherell, 2016).

Despite the variety of treatment options, there is no known cure for ASD, which is often difficult for parents to accept (Ogston et al., 2011). Treatment interventions focus largely on enhancing the child's functioning by ameliorating the symptoms of ASD (Louw, Bentley, Sorsdahl, & Adnams, 2013) and enhancing adaptive skills (Vasilopoulou, & Nisbet, 2016).

Children with ASD often experience difficulty in transferring the skills learnt in the therapeutic setting to the home environment despite the substantial resources invested by parents in therapeutic interventions (Alli et al., 2015).

This situation is often complicated by parents who complain that their involvement in intervention programmes is too limited (Hutton, & Caron, 2005; Benderix et al., 2007). Parental involvement is important as it has been related to parental empowerment (Myers et al., 2009) and improved intervention outcomes (Meirsschaut et al., 2010).

Added to the problem of accessing treatment is the problem of accessing an appropriate school environment (Topin et al., 2012). Mainstream secondary schools often lack the resources and trained staff required to meet the needs of a child with ASD (Topin et al., 2012). Training typically involves learning about curriculum modifications, instructional accommodations, and the designing of individual education plans (IEPs) (Moores-Abdool, 2010).

Topin et al. (2012) state that parents often report the transition from primary school to secondary school as a difficult experience. Selecting the right school is problematical not only because of limited schooling options but because it also frequently involves weighing up various factors – such as academic, social, and emotional support – and determining which is the most important for their child. Many parents believe that school staff members are often unwilling to acknowledge that different learners with ASD present in different ways and that they all have their own unique learning needs and strengths. Parents also report that insufficient time is allowed to prepare for the transition and that some schools have a negative attitude towards the inclusion of children with ASD.

The challenges parents experience can also be seen within the family system (Benderix et al., 2007; Meirsschaut et al., 2010; Mulligan et al., 2012). Raising a child with ASD can affect the parents' relationship. Increases in marital dissatisfaction and divorce rates are often a consequence of spousal neglect and the difficult decisions that have to be made regarding the needs of the child (Meirsschaut et al., 2010).

The relationship between parents and the siblings of the child with ASD can also be negatively affected as children with ASD require more care than typically developing children (Heydari, Shahidi, & Mohammadpour, 2015). Mothers of children with ASD often report feeling that they are not doing enough for their typically developing child in comparison to their child with ASD (Meirsschaut et al., 2010). Parents also often express concern about the emotional adjustment of their typically developing children as siblings frequently take on extra responsibilities to help alleviate the burden on their parents (Lovell, & Wetherell, 2016). Siblings are also at greater risk of developing emotional problems, internalising behaviours (Lovell, & Wetherell, 2016), and communication delays (Van der Linde et al., 2015).

The demands of caring for a child with ASD often result in parents adopting a routine-bound, rigid, and socially isolated life style (Lovell, & Wetherell, 2016; Martins et al., 2013; Woodgate, Ateah, & Secco, 2008). A general lack of understanding of ASD, including a lack of understanding of what is involved in caring for a child with ASD, often results in the isolation (Woodgate et al., 2008) and stigmatisation of the parents (Fewster, & Gurayah, 2015; Lovell, & Wetherell, 2016). Feelings of isolation are heightened in the context of an unsupportive system in which parents feel they have to maintain a defensive position and remain constantly vigilant in order to protect their child from the world (Benderix et al., 2007; Woodgate et al., 2008). Feelings of isolation are greater when family members fail to accept the diagnosis of ASD (Wang, & West, 2016). Family support is vital in helping parents of children with ASD cope with the challenges they experience on a daily basis (Wang, & West, 2016).

The effects of raising a child with ASD can also be seen in the challenges some parents experience in maintaining employment (Myers et al., 2009; Meirsschaut et al., 2010). Parents report often having to make career adjustments such as staying at home to provide full-time support to their child or turning down career advances in order to prevent disrupting the child with ASD's routine (Wang, & West, 2016). Parents thus adjust their life priorities by placing less emphasis on career success (Alli et al., 2015; Heydari et al., 2015).

As a consequence of these challenges, parents of children with ASD are reported to experience higher levels of exhaustion, stress, and psychological distress (Hutton, & Caron, 2005; Benderix et al., 2007; Myers et al., 2009; Meirsschaut et al., 2010, Mulligan et al., 2012, Neff, & Faso, 2015). This is often associated with an increase in mental health problems such as depression, anxiety, and other forms of psychopathology (Meirsschaut et al., 2010; Faso et al., 2013; Martins et al., 2013; Neff, & Faso, 2015). The degree of stress experienced is generally related to the severity of the symptoms and secondary challenges associated with ASD (Faso et al., 2013; Martins et al., 2013; Hsaio, 2016).

Numerous challenging (negative) experiences for parents have been identified in the research on ASD, yet researchers are now beginning to acknowledge also the many positive experiences for parents raising a child with ASD (Myers et al., 2009; Kausar et al., 2003). The following section explores the positive experiences of parents raising a child with ASD.



## 2.2.2 POSITIVE EXPERIENCES

Myers et al. (2009) explored how the lives of parents in America, Canada, Australia, New Zealand, England, and Ireland had been affected by raising a child with ASD. Positive psychosocial outcomes were reported as seen in improved family dynamics, increased support for one another, enriched marriages, and siblings who were positively impacted (Myers et al., 2009). Similar findings were reported by Kausar et al. (2003) where increased spousal support and the accepting attitudes and behaviours of extended family members resulted in greater cohesion within the family. This contrasts with the findings of Meirsschaut et al. (2010) and Heydari et al. (2015), outlined in the previous section, where divorce and emotional, internalising, and communication challenges were noted in the families.

In their research, Myers et al. (2009) found that the parents were able to find positive meaning in the challenges they experienced. This was seen in the parents who viewed their situation in a positive light and believed the challenges made them stronger. Positive meaning-making helped the families overcome the challenges and make sense of their lives, which gave them hope.

Kausar et al. (2003) and Myers et al. (2009) found in their research that through parenting a child with a disability, the parents underwent a positive transformation and saw the experience as an opportunity for personal growth and learning (Kausar et al., 2003). Parents learnt how to be more compassionate, patient, and understanding of others and developed a new understanding of the world of disabilities (Myers et al., 2009). They also learnt how to appreciate the small things in life and how to love their children as they were (Myers et al., 2009). The parents developed more self-confidence and assertiveness (Myers et al., 2009) and experienced an increase in personal resources, tolerance, and emotional stability (Kausar et al., 2003).

Part of this positive transformation was that the parents in the studies obtained a new perspective on life as they could re-examine their beliefs, values, and priorities, resulting in a new way of seeing their lives. The parents reported experiencing a greater sense of coherence and control as a result. By reprioritising what was most important in their lives, they could disregard 'unimportant' factors, such as people judging the behaviour of their child, which enhanced their perceived control over their situation (Myers et al., 2009).

The parents reported also a strengthened spirituality (Myers et al., 2009). The spiritual journey of the Iranian mothers, for example, often began with frustration and

questioning, but, after connecting with a higher power, a feeling of calm was reported (Heydari et al., 2015). The calmness was achieved by knowing that a higher power was in control, and the parents were thus able to gain support through relying on this higher power (Myers et al., 2009; Heydari et al., 2015).

The parents viewed a child with ASD as a blessing and saw the reason for the child's disability as being linked to a higher purpose (Myers et al., 2009; Heydari et al., 2015), which, in turn, was linked to the parents' own purpose in life (Kausar et al., 2003). This purpose included being able to define the child's disability in a positive way, providing comfort and care to the child, and learning to advocate for the child (Kausar et al., 2003).

These findings provide new insight into the consequences of the challenges experienced by parents raising a child with ASD. As outlined in the previous section, research on ASD has focused traditionally on the negative effects of raising a child with ASD, such as excessive stress and mental health problems (Hutton, & Caron, 2005; Benderix et al., 2007; Myers et al., 2009; Meirsschaut et al., 2010; Mulligan et al., 2012), but more recent research indicates that chronic exposure to such challenges does not necessarily result in negative health outcomes (Faso et al., 2013; Martins et al., 2013). Despite this, little research has been conducted on the specific factors that differentiate one parent from another resulting in one parent maintaining psychological well-being and not the other (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009). The concept, well-being, is discussed below followed by an exploration of the role hope plays in parental well-being.

### **2.3 ROLE OF HOPE IN PARENTAL WELL-BEING**

Sin and Lyubormirsky (2009) state that psychological well-being is not merely the absence of mental illness but rather the presence of positive psychological resources. These positive psychological resources include self-acceptance, positive relations, autonomy, and purpose in life. They act as protective factors that enable people to overcome adverse situations (Smith, 2006), experience improvements in quality of life, and prevent psychopathology (Seligman, & Csikszentmihalyi, 2000). Protective factors promote resilience in a person who is experiencing a challenging event and determine whether the challenge will result in psychological harm or in the person becoming stronger through confronting the challenge (Seligman, & Csikszentmihalyi, 2000; Smith, 2006).

Hope has been shown to have a positive impact on well-being and improved quality of life (Myers et al., 2009; Werner, 2012). The role hope plays can be related to the influence it has on increasing positive affect, improving self-esteem (Kashdan et al., 2002; Lloyd, & Hastings, 2009; Ogston et al., 2011; Bally et al., 2014; Shenaar-Golan, 2017), and decreasing psychological distress (Lloyd, & Hastings, 2009). Hope has been related to healthier behaviours and the use of more adaptive coping techniques (Ogston et al., 2011) such as exercise, eating well, and moderate alcohol use (Neff, & Faso, 2015).

Hope has also been linked to parents viewing their challenges (Myers et al., 2009) and their child's future prospects in a positive light (Shenaar-Golan, 2017). How parents view the child's disability and their current situation influences resilience (Kausar et al., 2003; Faso et al., 2013; Martins et al., 2013), coping techniques (Faso et al., 2013; Howell et al., 2015), and, ultimately, subjective well-being (Shenaar-Golan, 2017). Thus, how an experience is interpreted is more important than the actual experience itself (Benson, 2010; Shenaar-Golan, 2017). An indirect relationship therefore exists between hope and subjective well-being through positive meaning-making and perceptions (Shenaar-Golan, 2017).

Positive thinking is related not only to how parents view the challenges experienced, but also how they view themselves. Self-compassion, which is an important component of hope, has also been positively associated with well-being. Self-compassion involves extending goodwill to oneself, and, through this process, parents experience uplifting emotions that enable them to be more emotionally resilient and thus experience greater well-being (Neff, & Faso, 2015).

The role of cognitions in hope can be seen in the concepts contained in Snyder's theory of hope, hope agency, and hope pathways (Lloyd, & Hastings, 2009). High levels of hope pathways are considered an internal resource that enables parents to imagine several alternative ways of achieving a positive future (Lloyd, & Hastings, 2009; Shenaar-Golan, 2017). Hope agency is seen as the motivational aspect of hopefulness that can help parents persevere in the face of the stressors associated with raising a child with ASD (Faso et al., 2013). Hope agency is more important in how hope maintains well-being because motivation and perseverance assist in pursuing goals despite the challenges experienced (Lloyd, & Hastings, 2009).

Hope is therefore considered a key factor in parents' general well-being and consequently also a key factor in the experiences of parents raising a child with ASD.

## **2.4 HOPE EXPERIENCES OF PARENTS RAISING A CHILD WITH ASD**

This chapter has thus far shown the importance of understanding the challenging (negative) experiences as well as the positive experiences of parents raising a child with ASD. In addition to the general positive experiences brought about by hope, hope experiences help parents deal effectively with the challenges of raising a child with ASD (Ekas et al., 2010; Lloyd, & Hasting, 2009). The following section discusses the international and national literature on the hope experiences of parents raising such a child.

### **2.4.1 INTERNATIONAL STUDIES**

Lloyd and Hastings (2009) conducted a quantitative research study in the United Kingdom on the contribution of hope to resilience in parents of children with an intellectual disability. While the study focused primarily on such children, of the 139 children sampled, 56 were children with ASD. Hope was associated with an increase in positive well-being and a decrease in psychological distress and was therefore linked to the prevention of the development of depression in mothers and fathers raising a child with an intellectual disability. Hope helped develop resilience in the parents in the study by increasing their ability to identify and pursue alternative solutions to problems.

Faso et al. (2013) found in their study that hope could protect the parents of children with ASD from the negative effects of the stressors they encountered. The study investigated vicarious futurity and explored the positive as well as the negative aspects of parenting a child with ASD (Faso et al., 2013). Vicarious futurity is described as the hope and despair parents feel about the future of their child with ASD (Faso et al., 2013). The study highlighted the importance of considering positive as well as negative parenting experiences in order to gain a fuller understanding of the well-being of the parents. The relationship between parents and their child with ASD is complex, and by focusing exclusively on positive experiences, other factors and challenges that may be important to well-being may be overlooked (Faso et al., 2013).

Similar findings were reported in the mixed-methods study conducted in the USA by Ogston et al. (2011) who also explored positive as well as negative parenting experiences. They investigated the hope and worry of mothers raising children with ASD and with Down syndrome and found that the stressors of raising a child with ASD are often associated with depression, anxiety, and worry. However, hope was shown in their study not only to protect mothers from the harmful effects of these stressors

but was also related to health benefits, positive psychosocial outcomes, and the use of more adaptive coping techniques. This was linked to the parents' ability to plan and achieve desired goals for their children, resulting in less rumination on the challenges.

These three studies highlighted the importance of hope in maintaining parental mental health, yet they also had limitations. The research conducted by Lloyd and Hastings (2009) and Faso et al. (2013) were quantitative studies, which limited their ability to provide an in-depth understanding of the hope experiences that helped protect the parents' mental health. The research conducted by Lloyd and Hastings (2009) drew on Snyder's theory of hope as a theoretical framework, which resulted in hope being measured as goal-directed behaviour consisting of agency and pathways. This understanding of hope negates the influence of the broader system and concerns primarily the behaviour of the individual.

The research conducted by Faso et al. (2013) and Ogston et al. (2011) investigated hope in addition to negative experiences such as despair and worry. Hope experiences thus received less attention than if the studies had focused primarily on hope. Lastly, the samples used in the research of Lloyd and Hastings (2009) and Ogston et al. (2011) consisted of parents of children with ASD in addition to parents of children with other disabilities, which resulted in the parents of children with ASD receiving less research attention than if the study had focused primarily on these parents.

This limitation was identified also in the research conducted by Kausar et al. (2003), which covered the hope experiences of families of children with a wide range of developmental disabilities, including ASD. While the research produced valuable insights into the hope experiences of parenting children with developmental disabilities in general, limited attention was given to ASD itself.

Kausar et al. (2003) found that the parents in their research experienced raising a child with ASD as enriching. The experience helped them appreciate the value of life and feel compassion, love, and care in addition to creating hopeful and empathic attitudes. The parents reported the importance of focusing on the abilities of their child rather than on the child's disability. This positive focus was thought to contribute to hope and resilience. The final theme identified in the research was the influence that health professionals can have on parents' experience of hope. Some of the parents reported mixed experiences in their interactions with health professionals. While some health professionals were able to reduce the anxiety of the parents and give them support, other health professionals' negative evaluations of the child resulted in feelings of hopelessness in the parents.

The role of health professionals in maintaining hope was also covered in the research done by Mulligan et al. (2012) in Canada on how mothers experience the diagnosis of their child with ASD. They found that how a diagnosis is presented to a mother can influence her perception of hope and, ultimately, her ability to cope with the disorder. A diagnosis that is given in a hopeful manner and that focuses on strengths can empower mothers to move forward and consider the next step in an intervention.

The research conducted by Mulligan et al. (2012) had limitations as it focused only on a single experience in the life of parents raising a child with ASD, namely the diagnosis. This provides in-depth understanding of the hope in a single context but does not increase our understanding of hope during other experiences. The research covered also only maternal experiences – the common sample in most international research on ASD.

Topin et al. (2012) conducted a qualitative research study that focused also on a single life experience in the life of parents of children with ASD, namely the transition from a primary school to a high school in England. The study explored the hopes and concerns of the parents in the transition of their child with ASD from a mainstream primary school to a mainstream high school. Despite reporting feelings of stress and anxiety during the transition, the parents maintained their hope that their child would be able to attend a mainstream school, fit in, and keep up academically with her peers.

The parents' hope centred not only on the child attending a mainstream school (Topin et al., 2012) but also on her future in general (Hutton, & Caron, 2005; Neff, & Faso, 2015; Benderix et al., 2007). Hutton and Caron (2005) explored the impact of children with ASD on their families in rural New England. They found that despite the challenges experienced by the parents raising a child with ASD, many of them were able to thrive and live meaningful, rewarding lives while remaining hopeful about their child's future. The parents were thus seen to remain hopeful despite an uncertain future.

Similar findings were reported in a Texan study by Neff and Faso (2015), which focused on self-compassion, an important component of hope. The parents in the study were able to remain hopeful for the future through the practice of self-compassion, which involves being kind to oneself during challenging situations, recognising the shared nature of suffering, and being aware of negative thoughts and emotions. In challenging situations, the parents were less likely to view their child's behaviour as problematic, which facilitated positive coping and helped the parents comfort and support themselves. Self-compassion was positively associated with goal re-engagement and greater motivation and persistence, which enabled the parents to

attempt new solutions to challenges. Neff and Faso (2015) further reported that self-compassionate parents were also more likely to practise healthy behaviours, such as exercising, eating well, and using alcohol moderately, which are similar to the healthy behaviours identified by Ogston et al. (2011).

Increased hope for the future was also identified by Benderix et al. (2007) in their qualitative study in Sweden, in which they explored the experiences of ten parents of children with ASD who presented with behaviours so challenging they had to be placed in a group home. It was found that the parents experienced increased hope for the future as they saw their children's behaviour improving as a result of the out-of-home placement. The context of the group home also gave the parents the opportunity to share their experiences with the other parents. This highlights the importance of a support system in maintaining hope.

The focus of hope is also influenced by culture. Sarrett (2015) explored how ASD is experienced in different cultures around the world. Sarrett (2015) found that fewer therapeutic options, as seen in non-Western cultures, facilitated earlier acceptance. The parents from non-Western cultures in her study were more likely to relate statements of hope to statements reflecting reality and focused on a hope for basic needs. This contrasted with the parents in Western cultures who hoped for a change in the child's ASD-related behaviours.

The above studies have limitations in that the study conducted by Neff and Faso (2015) focused specifically on one component of hope, namely self-compassion, and the study conducted by Benderix et al. (2007) focused only on an isolated event in hope experiences, namely out-of-home placement. All four studies identify the focus of parents' hope but do not provide greater insight into parents' hope experiences.

The international research studies provide a good understanding of hope in the context of parents raising a child with ASD. The problem is that they were not conducted in South Africa. As Kausar et al. (2003) observe, every parent has a unique experience, and this is particularly the case for parents raising a child with ASD in South Africa due to the unique South African context. The following section discusses ASD research conducted in South Africa.

#### **2.4.2 SOUTH AFRICAN STUDIES**

At the time of the present research study, I as the researcher was unable to find any published research studies relating specifically to the hope experiences of parents

raising a child with ASD in South Africa. I could, however, find two studies on the general experiences of parents of a child with ASD in South Africa (Martins et al., 2013; Fewster, & Gurayah, 2015) and two dissertations on the same subject (Matenge, 2014; Van Rooyen, 2016). An additional study was found that focused on the characteristics and resources that enable parents to adapt to the challenges associated with raising a child with ASD (Greef, & Van der Walt, 2010). Although hope experiences were not the main focus of these studies, experiences of hope were identified in all five studies.

Martins et al. (2013) and Van Rooyen (2016) identified the need to better understand how South African fathers of a child with ASD make sense of their situation and to gain further insight into the coping methods they used. Van Rooyen (2016) found in her research that the process of obtaining a diagnosis was experienced as challenging while Martins et al. (2013) found that the fathers felt overwhelmed, guilty, anxious, confused, and disappointed when trying to come to terms with their child's diagnosis. Once an ASD diagnosis had been made, the fathers reported feelings of relief as they could then attribute the challenges of the child to the diagnosis. Martins et al. (2013), Matenge (2014), and Van Rooyen (2016) all reported that following the diagnosis, feelings of hope were experienced as a result of the parents being able to access the necessary support to help their child.

In their study, Martins et al. (2013) outlined the challenges experienced as well as the different coping methods that were used, which included problem-focused coping and avoidant coping. Problem-focused coping took the form of interventions, adapting existing discipline strategies in the home to accommodate the child's needs, and relocating in order to gain better access to services. The parents also reported gathering information and consulting with health professionals on a regular basis. Positive reframing – the restructuring of the problem in a positive way while still accepting the reality of the situation – was also used. This included viewing challenges as opportunities for positive self-development. Avoidant coping took the form of intentionally avoiding thinking realistically about the situation, focusing on the present moment, and religious coping. Religion was seen to offer hope and encouragement to the fathers of children with ASD. Martins et al. (2013) reported further that the fathers in their study also sought out alternative rewards by using their experiences with their child with ASD to have a positive impact on the lives of others. This was done by warning others about possible signs of developmental delays.

Matenge (2014) explored the experiences of the mothers of children with ASD. Feelings of hopelessness were identified as the doctors continually dismissed the



mothers' concerns about the development of their child (Matenge, 2014). Once a diagnosis had been made, feelings of hope were experienced because the diagnosis gave the mothers insight into the behaviours and challenges of their child. Hope centred on a miracle that would change the behaviour of their child with ASD. Matenge (2014) also identified positive experiences in raising a child with ASD such as positive learning experiences that would not otherwise have occurred.

Van Rooyen (2016), in contrast, focused on identifying resources for coping such as support from a spouse, participation in a hobby, knowledge, awareness, and the healthcare proficiency of the professionals involved. Being able to care for their child resulted in positive emotions on the part of the fathers who took pride in their child's achievements and skills. Feelings of hope increased when the fathers could see improvements in their child's ability and in their own ability to manage symptoms and interact with their child.

Greef and Van der Walt (2010) also identified the resources needed by parents, in particular, resources that promoted resilience in families. They found that maintaining a positive outlook and a hopeful stance were crucial in establishing resilience in parents raising a child with ASD. This enabled the parents to actively pursue solutions to the challenges they were facing, to look beyond the challenges, and to focus on available options. Faith in God gave meaning to these challenges.

Fewster and Gurayah (2015), too, identified the importance of parents remaining resilient. Their study explored the experiences and coping strategies of parents raising a child with ASD who attended a stimulation centre in South Africa that catered for children with physical disabilities and ASD. The parents reported that health professionals should encourage parents to become resilient and empowered in order to advocate effectively for their children. The parents added that health professionals should give parents at least some hope when communicating with them about their child.

A limitation of the research conducted by Martins et al. (2013), Fewster and Gurayah (2015), Van Rooyen (2016), and Matenge (2014) is that each study focused on the general experiences of parents raising a child with ASD. Most of the findings therefore covered the general challenges experienced by the parents with only an incidental focus on hope. As a result, not enough information is provided on hope experiences per se.

While some research attention has been given to the positive experiences of parents, this has focused mainly on coping (Martins et al., 2013; Fewster, & Gurayah, 2015; Van Rooyen, 2016) and resilience (Greef, & Van der Walt, 2010). Thus, the hope experiences of parents of children with ASD in South Africa remains largely unexplored.

As the number of children diagnosed with ASD increases across the globe (Faso et al., 2013; Martins et al., 2013) so does the number of parents who are raising these children (Fewster, & Gurayah, 2015). This increase calls for greater understanding of how parents adjust and cope with the accompanying challenges (Faso et al., 2013). The limited research on the hope experiences of parents raising a child with ASD in South Africa means that information is lost that could inform the practice of health professionals working with these parents. Understanding how hope relates to parental functioning is important for improving the lives of parents raising a child with ASD (Faso et al., 2013). South Africa is a unique, diverse country that needs a full description of the unique South African experience of ASD (Alli et al., 2015).

## **2.5 THEORETICAL FRAMEWORK**

In the present study, the integrative theory of hope of Scioli et al. (2016) served as the theoretical framework for exploring the hope experiences of parents raising a child with ASD. This framework provided a structured, comprehensive approach to understanding the complex nature of hope and how it develops.

Scioli et al. (2011, p. 79) define hope as a “future-directed, four channel emotion network, constructed from biological, psychological and social resources. The four constituent channels are the mastery, attachment, survival and spiritual systems (or subnetworks). The hope network is designed to regulate these systems via both feed-forward and feedback processes that generate a greater perceived probability of power and presence as well as protection and liberation”. This definition highlights the complex nature of hope as a system of interrelated parts.

The four interrelated parts, namely a control network, a social network, a safety network, and a spiritual network, constitute the hope network (Scioli, & Biller, 2010). These four subnetworks serve the four basic needs of mastery, attachment, survival, and spirituality (Scioli et al., 2016). These basic needs are discussed below.

According to Scioli et al. (2011), through hope, the need for mastery is met by addressing the need for control and establishing priorities. The need for attachment is

met through the provision of support and the sharing of experiences with others experiencing the same situation. Survival is maintained through trusting others and oneself. Finally, spirituality gives meaning and purpose to life. These needs are met as hope develops through the interaction of the five levels of influence, namely genetic and biological factors, early environmental influences, traits and character strengths, a faith system, and hope-generated beliefs, feelings, and actions (Scioli et al., 2016).

Scioli et al. (2011) maintain that at the foundation of hope development is the biological makeup of the human body, which consists of structures and pathways that are designed to meet mastery, attachment, and survival needs. This is accomplished through specific structures such as the frontal lobes and oxytocin-related circuits. Genetic factors provide the basis for the development of hope-related traits that unfold as a result of early environmental influences, which include family, community, and culture. The emotional, social, and spiritual impact of these influences affects the development of higher level hope structures and provides opportunities for empowerment experiences and skills development (Scioli, & Biller, 2010).

Scioli and Biller (2010) believe that through the interplay of biological factors and early environmental influences, a locus of control develops, which in hopeful people is neither internal nor external but mediated through relationships. Hopeful people are trusting and open in their relationships and strive for deeper intimacy and stronger bonds. They also have survival traits that include beliefs about liberation, resilience, self-regulation, spiritual integrity, and immortality (Scioli, & Biller, 2010). This includes a personal faith system that calls for complete trust in another person, belief in a higher power, and, most importantly, faith in oneself. These influences give rise to positive thoughts, actions, and feelings, which are seen as visible manifestations of hope and reflect the hope-generated belief system (Scioli et al., 2016).

Hope experiences are complex experiences that are influenced by factors such as the interrelated subnetworks and the basic needs of mastery, attachment, survival, and spirituality (Scioli, & Biller, 2010). The integrative theory of hope was used in the present study because it provides a structured approach to understanding the hope experiences of parents raising a child with ASD by outlining the factors that are influenced by and, in turn, influence hope. The integrative theory of hope also provides insight into the factors involved in the development of hope, namely genetic and biological factors, early environmental influences, traits and character strengths, a faith system, and hope-generated beliefs, feelings, and actions (Scioli, & Biller, 2010).

The integrative theory of hope was used to inform the development of the interview schedule that was employed during the semi-structured interviews with the participants. Factors that can influence hope, as identified by each of the subnetworks, were explored through the questions asked. Factors in the control network, which has a locus of control that is mediated through relationships and the social network, were explored using questions related to interactions with friends, family members, and health professionals. Open-ended questions about hope and parenting a child with ASD provided insight into aspects of the safety network and spiritual network by yielding information on the meaning and purpose of life, resilience, spiritual integrity, and personal faith systems.

My knowledge of the integrative theory of hope informed my interviewing techniques by identifying which responses I would request clarification on. I used the theory to analyse the data collected during the interviews and during the review of the journal entries, which deepened my understanding of parental experiences of hope. The integrative theory of hope thus influenced all aspects of the present research study.

## **2.6 SUMMARY**

This chapter discussed what it is like to be a parent raising a child with ASD. In addition to the challenges these parents experience, positive experiences were also noted. The importance of hope and its role in the development of well-being was explored. The literature review covered international as well as national studies on the hope experiences of parents of a child with ASD and the benefits of these experiences.

Finally, the data collected were analysed on the basis of the integrative theory of hope of Scioli et al. (2016). This theoretical framework highlighted the complex nature of hope as a network and provided a structured approach to ensuring that all components of hope were included in all stages of the research process.

The following chapter covers the research approach, the methods of data collection, and the analysis and interpretation of the data. The quality criteria and ethical issues in the study are also outlined.

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## **Chapter 3**

### **Research Design and Methodology**

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#### **3.1 INTRODUCTION**

Chapter 1 outlined the research approach, paradigm, and processes used for the present study. This chapter discusses in detail the methodology beginning with the philosophical and methodological paradigms followed by an explanation of the research design and data collection techniques. Also explained are the documentation process, data analysis, interpretation methods as well as the steps taken to ensure the quality and ethical nature of the research.

#### **3.2 PARADIGMATIC PERSPECTIVE AND METHODOLOGICAL PARADIGM**

Situated within an interpretive phenomenological epistemological paradigm, this study made use of a qualitative methodological paradigm. The following section outlines the principles and assumptions of these paradigms and the justification for their use in the study.

##### **3.2.1 PARADIGMATIC PERSPECTIVE: INTERPRETIVE PHENOMENOLOGY**

An interpretive phenomenological paradigm was used in this study. Interpretive or hermeneutic phenomenology is a paradigmatic perspective that can be used to gain insight into previously unexplored phenomena (Kumar, 2012) relating to human experience and the meaning associated with such experience (Lopez, & Willis, 2004; Penner, & McClement, 2008). Interpretive phenomenology thus moves beyond mere descriptions of experiences and looks for meaning related to those experiences (Mayoh, & Onwuegbuzie, 2015).

Each individual's experience of a phenomenon is unique, and interpretive phenomenology seeks to understand the unique, subjective meaning that people assign to their own experiences (Shaw, 2010b; Kumar, 2012). Interpretive phenomenology helps researchers understand phenomena as experienced by individuals who have lived through them (Kumar, 2012) in order to gain insight into such individuals' actions and motivation (Lester, 1999).

Three assumptions underlie interpretive phenomenology (Lopez, & Willis, 2004), the first and most important of which is that the relation of the individual to his<sup>2</sup> lifeworld should be the focus of any research study (Lopez, & Willis, 2004). The term lifeworld refers to how the individual's reality is influenced by the world in which he lives (Creswell, & Miller, 2000; Maggs-Rapport, 2000; Lopez, & Willis, 2004; Wojnar, & Swanson, 2007; Mayoh, & Onwuegbuzie, 2015). It is the context of the individual that gives meaning to his lived experiences (Kumar, 2012). Understanding the individual can therefore not occur without taking into consideration his social, cultural, and political contexts (Lopez, & Willis, 2004; Kumar, 2012).

An extension of this is that an individual cannot remove herself from the context that influences her choices and provides meaning (Lopez, & Willis, 2004; Wojnar, & Swanson, 2007; Bradbury-Jones, Irvine, & Sambrook, 2010; Mayoh, & Onwuegbuzie, 2015). This leads to the second assumption which acknowledges the past experiences and knowledge of the researcher (Lopez, & Willis, 2004). In attempting to understand the experiences of research participants, the researcher draws on her own experiences (Bradbury-Jones et al., 2010), which are valuable and give meaning to the research process (Lopez, & Willis, 2004). As it is impossible to remove the knowledge that led the researcher to research the topic, she is required to make known any assumptions she made with regard to the research and explain how the assumptions will be used in the research (Lopez, & Willis, 2004).

The third assumption is that of situated freedom (Lopez, & Willis, 2004). Situated freedom means that individuals are free to make choices, but those choices are constrained by their contexts (Lopez, & Willis, 2004). Understanding the experiences of research participants and the meaning ascribed to those experiences is obtained through the narratives provided by the participants in relation to their contexts (Lavery, 2003; Lopez, & Willis, 2004).

The above discussion outlined the assumptions underlying interpretive phenomenology. The following section focuses on the limitations of this approach.

### **3.2.2 CRITICISM OF THE INTERPRETIVE PHENOMENOLOGICAL APPROACH**

A problem with interpretive phenomenological research is the central role of language in shaping situations and experiences (McManus Holroyd, 2007) and the limitations inherent in spoken language (Plunkett, Leipert, & Ray, 2013). Language is used to

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<sup>2</sup> Feminine and masculine pronouns (he, she, him, hers, his) should be regarded as interchangeable.

explain experiences and reality, yet language is not something that can be viewed objectively (McManus Holroyd, 2007) as there is no direct correspondence between language and experience (Hein, & Austin, 2001). Understanding language can be complicated when language is ambiguous or contradictory (Hein, & Austin, 2001). Language can also be interpreted explicitly or implicitly (Hein, & Austin, 2001).

An additional challenge that language poses is that participants may experience difficulty in accurately articulating their experiences (Hein, & Austin, 2001). The effect of this challenge can be reduced through the use of member checking, which enables the researcher to check the accuracy of the recounting of participants' experiences (Creswell, & Miller, 2000).

The researcher's experiences and prior knowledge influence his understanding of the world (Lopez, & Willis, 2004) and therefore also his understanding of participants' experiences (Maggs-Rapport, 2000; Davidsen, 2013; Mayoh, & Onwuegbuzie, 2015). The researcher needs accordingly to reflect carefully on his past experiences, preconceptions, personal values, assumptions, limitations, and biases in order to be aware of the influence they may have on the research process (Creswell, & Miller, 2000; Lavery, 2003; Whiting, 2008; Kumar, 2012; Creswell, 2014). The researcher will then be better able to engage with the experiences recounted by participants (Lopez, & Willis, 2004; Kumar, 2012). Groenewald (2004) and Whiting (2008) state that reflection should take place through all stages of the research process with the help of the researcher's journal. The prior knowledge and experiences of the researcher may be seen as a problem, yet the process of co-creation through the blending of the researcher's and participants' knowledge and experiences is what makes interpretive phenomenology so meaningful (Wojnar, & Swanson, 2007; Bradbury-Jones et al., 2010; Kumar, 2012).

Phenomenological research interviews have been criticised for possibly not always accurately reflecting what is most meaningful to those experiencing the particular phenomenon (Plunkett et al., 2013). The researcher's questions and presuppositions can influence the questions asked which, in turn, can influence the responses given (Plunkett et al., 2013). One way to overcome this problem is to give participants the opportunity to provide data that is most meaningful to them (Plunkett et al., 2013) through, for example, the participants' research journals, where they provide journal entries of hope experiences that are meaningful to them, thereby controlling the nature of the data (Plunkett et al., 2013). Data that complement the narrative interview data are thus provided (Plunkett et al., 2013).

The challenges arising from the central role of language in interpretive phenomenology were addressed in the present study through the use of member checking and data collection techniques that did not rely solely on spoken language, such as the participants' research journal. The participants' research journal enabled the participants to provide data on experiences that were meaningful to them as opposed to those identified by the researcher. To counter the problem of the researcher's prior knowledge and experiences, the researcher kept a researcher's journal so that she could reflect on her past experiences, preconceptions, personal values, assumptions, limitations, and biases in relation to the study.

### **3.2.3 JUSTIFICATION FOR THE INTERPRETIVE PHENOMENOLOGICAL APPROACH**

The purpose of the present study was to explore the hope experiences of parents raising a child with ASD. An interpretive phenomenological approach was appropriate as it helped the researcher better understand the participants' subjective experiences (Lopez, & Willis, 2004). Interpretive phenomenology promotes understanding of the meaning of these experiences as opposed to merely describing them (Lopez, & Willis, 2004).

Interpretive phenomenology also emphasises the importance of context in ascribing meaning to the subjective experiences of a person (Lopez, & Willis, 2004). By including a focus on contextual factors, the researcher is able to gain a deeper understanding of parental hope experiences that are culturally and contextually sensitive. The researcher can then better understand participants' unique world and how that world influences their experience of hope.

Interpretive phenomenology acknowledges the importance of the researcher's expert knowledge in guiding the research process (Lopez, & Willis, 2004; Mayoh, & Onwuegbuzie, 2015) through the blending of meaning from the world of the researcher and that of the participant (Lopez, & Willis, 2004). As the researcher in the present research had experience of working with children with ASD at the time of the research, and the parents had knowledge of raising a child with ASD, the unique combination of perspectives allowed for new meaning to be uncovered with regard to the hope experiences of parents.

Interpretive phenomenology requires the researcher to interpret research findings for practical application, education, research, and policy (Lopez, & Willis, 2004). Thus the research findings on the hope experiences of parents can have practical application in



research, healthcare, and education settings and may also inform the practice of health professionals working with parents of children with ASD.

### **3.2.4 METHODOLOGICAL PARADIGM: QUALITATIVE**

Qualitative research is described as “an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem” (Creswell, 2014, p. 4). Qualitative researchers acknowledge the diverse nature and meaning of human experiences (Hugh-Jones, 2010). The qualitative research approach enables the description of people’s experiences in order to gain a rich, idiographic, and holistic understanding of how people interpret and give meaning to their experiences and create their own reality (Nieuwenhuis, 2007b).

Creswell (2014) outlines six main characteristics of qualitative research. The first characteristic involves the researcher as a key instrument for collecting data (Creswell, 2014). The human instrument, the researcher, is immediately responsive and adaptive to the participant and is therefore the ideal means for collecting data (Merriam, 2004). Additional advantages include the researcher’s ability to immediately clarify and summarise the information provided and then to check for accuracy of understanding (Merriam, 2004).

The researcher is also personally involved with the topic of interest at every stage of the research process – another important component of the interpretive phenomenological paradigm (Penner, & McClement, 2008). When interview schedules are used, it is the researcher who creates them for the purpose of the research (Creswell, 2014), and, during interviews, the researcher and the participant co-create reality through the merging of their realities (Lopez, & Willis, 2004).

A qualitative research approach allows for an interactive relationship between the researcher, as a key instrument for collecting data, and the participant, which enables the uncovering of new insights (Nieuwenhuis, 2007b). Qualitative research is thus valuable for studying topics that are relatively unexplored (Kausar et al., 2003; Nieuwenhuis, 2007b). As the hope experiences of parents raising a child with ASD are relatively unexplored in South Africa, a qualitative research design was considered appropriate for the present research.

The second characteristic of qualitative research, which is also common in interpretive phenomenology, is the collection of data from multiple sources (Creswell, 2014). This enables the researcher to collect detailed descriptions of participants’ experiences

from different perspectives (Creswell, 2014) and to gain a fuller understanding of their life contexts (Lopez, & Wills, 2008).

The third characteristic is inductive data analysis (Creswell, 2014), which involves the use of a small set of observations as the basis for forming a general statement (Gravetter, & Forzano, 2009). The themes identified in the research thus arise from the data, and participants' experiences are reflected in the findings (Merriam, 2004; Nieuwenhuis, 2007a; Creswell, 2014).

Individual meaning from the perspective of participants is the fourth characteristic of qualitative research (Lopez, & Willis, 2004; Creswell, 2014). Qualitative researchers are interested in understanding the personal meaning that participants have constructed about their own reality and their own experiences (Merriam, 2002). Each participant's experience is valued for its uniqueness (Nieuwenhuis, 2007b).

The fifth characteristic is the importance of developing an in-depth understanding of the particular research problem (Nieuwenhuis, 2007b; Creswell, 2014). The researcher is required to identify all the factors involved in the topic under investigation (Creswell, 2014) in order to gain a holistic understanding of each unique participant's perspective (Nieuwenhuis, 2007b; Gravetter, & Forzano, 2009). Qualitative research thus focuses on the quality and depth of the information that is provided (Nieuwenhuis, 2007b).

The final characteristic of qualitative research is the role of the researcher in data collection (Creswell, 2014) with acknowledgement of the researcher's personal experiences and assumptions in understanding the experiences of participants (Penner, & McClement, 2008). The researcher is therefore required to reflect on her role in a study and how her background, culture, and experiences may influence the interpretation of the findings (Creswell, 2014).

The six characteristics of qualitative research highlight the advantages of a qualitative methodological paradigm. However, at the same time, the limitations of the paradigm should also be acknowledged. Such a limitation includes the difficulty in finding acceptable indicators of rigour (Wojnar, & Swanson, 2007). The quality criteria used to ensure the rigour of the present study are discussed in Section 3.7 below.

### **3.3 RESEARCH DESIGN: EXPLORATORY CASE STUDY**

An exploratory case study is defined as an in-depth inquiry into one or more instances of a phenomenon for the purpose of exploring that phenomenon in its own unique

context (Nieuwenhuis, 2007c; Zainal, 2007; Babbie, 2008; Gravetter, & Forzano, 2009). This is important when the boundaries between the phenomenon and its context are not clearly definable (Yin, 2009). Because an exploratory case study explores a particular phenomenon in its context, the holistic characteristics of real-life events can be revealed (Yin, 2009), enabling the researcher to better understand the dynamics of the situation and contextual factors that may influence the phenomenon (Nieuwenhuis, 2007c). Yin (2009) argues that attempting to understand real-life phenomena in the absence of important contextual information will result in incomplete understanding. As is also the case in interpretive phenomenological research, knowledge of how the environment influences a particular phenomenon is important as experiences cannot be separated from their context (Willig, 2008; Baxter, & Jack, 2008).

The main advantage of an exploratory case study is that in-depth information can be obtained that leads to a better understanding of a particular phenomenon and its meaning (Gravetter, & Forzano, 2009). The in-depth information provides a more personal and vivid explanation of the phenomenon (Gravetter, & Forzano, 2009), which permits the exploration of more complex phenomena that are often seen as beyond the scope of more controlled approaches (Gillham, 2000).

Another advantage of an exploratory case study is that it can be used to study relatively unknown phenomena (Gerring, 2004). It may also uncover factors typically excluded in other forms of research and may help identify new factors requiring further study (Gravetter, & Forzano, 2009). The researcher thus explores a phenomenon in order to identify themes as opposed to merely confirming existing theories (Hancock, & Algozzine, 2006; Yin, 2009).

Yin (2009, p. 84) maintains that case studies deal with “technically distinctive situations in which there will be more variables of interest than data points, and as one result, relies on multiple sources of evidence with data needing to converge in a triangulating fashion”. Multiple data sources are considered a major strength of case study research (Yin, 2009) as they provide a deeper, more comprehensive understanding of how participants make meaning (Nieuwenhuis, 2007c).

A single holistic case study was used in the present research to explore the topic of hope experiences in parents raising a child with ASD. Two participants were recruited for the study (Baxter, & Jack, 2008). Each participant served as a unit of analysis for the single case of hope experiences in the parents of a child with ASD in South Africa (Yin, 2009). Yin (2009) stresses the usefulness of a single holistic case study for

exploring previously unexplored phenomena, as in the case of the hope experiences of parents raising a child with ASD in South Africa.

Because the rigour of case study research findings is often questioned, Yin (2009) advocates the use of sound methodological research designs and practices to ensure adequate rigour in such research.

The inability to generalise findings has also been cited as a limitation in case study research (Nieuwenhuis, 2007c; Babbie, 2008; Gravetter, & Forzano, 2009; Yin, 2009). Generalisation is, however, not the aim of qualitative research where the emphasis is more on gaining insight into the phenomenon of interest (Nieuwenhuis, 2007c). The researcher endeavoured to report the findings with as much detail as possible and provide thick descriptions to allow readers to determine the applicability of the findings in other contexts (Baxter, & Jack, 2008; Woodside, 2010). Gravetter and Forzano (2009) believe that the extent and detail of the descriptions offsets this limitation. Case studies are valued for their focus on the unique characteristics of each participant, which are often overlooked in studies involving groups of individuals in the pursuit of generalisability (Gravetter, & Forzano, 2009).

Another limitation often attributed to the exploratory nature of case studies is that the information obtained cannot be used to determine an underlying mechanism to explain behaviour (Gravetter, & Forzano, 2009) or establish causal relationships (Yin, 2009). The present study, however, was not aimed at determining an 'underlying mechanism' but rather at gaining an in-depth understanding of the hope experiences and their meaning for parents raising a child with ASD. Yin (2009) and Gerring (2007) advocate the use of exploratory case studies to complement the data obtained from experimental research. They do not see the exploratory nature of a case study as a limitation but rather as a strength.

Some researchers believe that exploratory case studies should be used hierarchically as preliminary studies for further research (Hancock, & Algozine, 2006). Yin (2009) argues, however, that exploratory case studies can be used to provide valuable insights on their own.

### **3.4 BINDING THE CASE**

Baxter and Jack (2008) stress the importance of 'binding the case' to ensure that the research study is reasonable and that the research question can be answered within

the scope of the study. Binding the case involves outlining the boundaries of a case to indicate clearly what the case will and will not be (Baxter, & Jack, 2008).

The following sections provide details on how the case was bound in the present study.

#### **3.4.1 SELECTION OF THE RESEARCH SITE**

The Autism School was selected as the research site. The Autism School is an intervention centre that provides individualised education programmes to children with ASD. It has five branches in South Africa, and the participants for this study were selected from the branches in Johannesburg. The Autism School was considered a suitable research site as it provided access to a number of parents with experience in raising a child with ASD.

The site was conveniently chosen as it was easily accessible. Also, I was involved with The Autism School from March 2010 to December 2016 during which period I provided individual instruction to children with ASD and training to parents on managing challenging behaviour at the Pretoria branch. The participants for this study were selected from the branches in Johannesburg to ensure that the researcher had not previously worked with the participants.

#### **3.4.2 SELECTION OF THE PARTICIPANTS**

According to Gordon-Finlayson (2010), in qualitative research, the researcher selects participants on the basis of their individual characteristics and what they can contribute to the research. Penner and McClement (2008), too, state that in phenomenological research, it is important to select participants who have some experience of the topic under investigation.

Convenience sampling was therefore used to recruit the participants for the present study. Convenience sampling, a form of non-probability sampling, involves the selection of participants on the basis of their availability and willingness to take part in the research (Maree, & Pietersen, 2007; Gravetter, & Forzano, 2009). As the researcher had previously been involved at The Autism School in Pretoria, the participants were easily accessible.

The participants were required to meet the following criteria: (a) they had to be currently the parents of a child diagnosed with ASD, and (b) the child had to be currently attending one of the Johannesburg branches of The Autism School.

Two mothers of a child with ASD participated in the present research. Both mothers were between 40 and 50 years of age. Both mothers were married and had other children. One mother was raising a daughter, who was the youngest child in the family, while the other was raising a son who was the eldest child.

### **3.5 DATA COLLECTION**

A phenomenological approach to research makes use of multiple sources of data in order to provide an accurate understanding of the phenomenon under investigation (Penner, & McClement, 2008) as each data source contributes to the researcher's understanding of the phenomenon as a whole (Lewis, Sligo, & Massey, 2005; Baxter, & Jack, 2008). Multiple data sources also enhance the credibility and rigour of the research (Baxter, & Jack, 2008).

Both data collection methods were used to obtain the participants' narratives regarding the research topic (Lopez, & Willis, 2004). The content of an interpretive phenomenology inquiry is what the participants' narratives imply about their everyday experiences (Lopez, & Willis, 2004). Data were collected through semi-structured individual interviews and participants' research journals.

#### **3.5.1 SEMI-STRUCTURED INTERVIEWS**

The semi-structured interviews in the present study were conducted using predetermined questions that outlined the topic of interest (Nieuwenhuis, 2007c; Gill, Steward, Treasure, & Chadwick, 2008). Face-to-face interviews are effective ways to gain insights into the experiences of participants in phenomenological research (Penner, & McClement, 2008). Semi-structured interviews enable complex issues to be understood on a deeper level (Gill et al., 2008; Gravetter, & Forzano, 2009; Rowley, 2012) and allow participants the freedom to share their lived experiences (Nieuwenhuis, 2007c; Penner, & McClement, 2008; Hugh-Jones, 2010).

The questions outlined in the interview guide provided the general direction for the interview after which the participants in the present study were encouraged to do most of the talking (Babbie, 2008). The interviews lasted approximately 30 minutes.

The following interview guide, modified from the study conducted by Kausar et al. (2003), was used to guide the interview.

- What does it mean to be a parent of a child with autism?
- What does hope mean to you as a parent of a child with autism?

- Can you think of any events that have either enhanced or diminished your feelings of hope?
- What experiences made you feel more hopeful? And less hopeful?
- Can you think of any things that family members and friends did that made you feel more hopeful? And less hopeful? If so, what were they?
- Can you think of any things that professionals or service providers did that made you feel more or less hopeful?
- Is there anything you do on a regular basis that strengthens your feelings of hope?
- Is there anything else you would like to share with me?

### **3.5.2 PARTICIPANTS' RESEARCH JOURNALS**

Participants' research journals are journals written by participants for the purpose of a research study with the knowledge that the journals will be read by the researcher (Jacelon, & Imperio, 2005). Journals give the researcher access to participants' narratives about the topic of interest (Lopez & Willis, 2004) so that she can better understand their experiences from their perspective (Jacelon, & Imperio, 2005).

The journals were handed to the participants one week prior to the interviews to ensure that the questions asked during the interviews did not influence the information provided in the journals. Although the participants were not required to answer questions, the researcher provided a focus for the journal entries by providing the following guidelines, as outlined by Willig (2009): the participants were asked to keep a journal for one week and to make a journal entry once a day. The participants could make use of either audio-taping or written journal entries as the medium for keeping the journal. The participants were required to write about their hope experiences with their child with ASD.

The main advantage of a journal is the amount and type of data it provides (Lewis et al., 2005). This may include information that participants may not be comfortable sharing during a face-to-face interview (Willig, 2008). Journal entries over the course of a week provide a week's worth of information that would not have been obtained using other methods of data collection (Lewis et al., 2005). The data in the journal can also be accessed at a time that is convenient for the researcher (Creswell, 2014).

Because participants may have more time to reflect on their journal entries, they may provide narratives that are richer in detail and more considered (Lewis et al., 2005) thereby providing greater insight into their experiences from their own perspective

(Jacelon, & Imperio, 2005). Journals grant the researcher greater access to the language and words used by participants (Creswell, 2014).

Journals give participants the opportunity to reflect on their experiences on a daily basis (Jacelon, & Imperio, 2005). Information that is reported on a regular basis reduces the risk of participants forgetting important details (Willig, 2008) or recollecting inaccurately, which increases the reliability of the information (Lewis et al., 2005).

A disadvantage is that journals provide large amounts of data that can overwhelm the researcher (Lewis et al., 2005) requiring her to search for the information needed to answer the research question (Creswell, 2014). Participants may also record irrelevant information in their journals (Lewis et al., 2005), or the information provided may be incomplete (Creswell, 2014). The researcher in the present study attempted to reduce the effects of this disadvantage by providing guidelines for journal entries to the participants prior to handing them the journals.

### **3.5.3 AUDIO-RECORDING**

The information from the interviews in the present study was recorded with the help of an audio-recorder (Creswell, 2014) after permission had been obtained from the participants (Nieuwenhuis, 2007c). Audio-recordings are beneficial because the researcher is not required to take extensive notes and can rather concentrate fully on interacting with participants (Whiting, 2008). Interviews can also be replayed thereby enabling the making of transcriptions (Groenewald, 2004; Whiting, 2008; Rowley, 2012).

## **3.6 DOCUMENTATION**

Field notes, a researcher's journal, and audio-data transcriptions were used to document the research findings in the present study

### **3.6.1 FIELD NOTES**

In addition to audio-recordings, notes were taken during the interviews in a manner that was not disruptive to the research process (Nieuwenhuis, 2007c). This was done in order to note additional questions that might need to be asked at the end of the interviews (Nieuwenhuis, 2007c) and to note silences, pauses, and non-verbal behaviour (Whiting, 2008). Non-verbal behaviour can give additional insight into the words being spoken (Bailey, 2008).



### **3.6.2 RESEARCHER'S JOURNAL**

Because interpretive phenomenology makes use of the researcher's prior knowledge and assumptions, it is important for the researcher to note feelings and thoughts before, during, and after the interview with the help of a researcher's journal (Whiting, 2008).

### **3.6.3 TRANSCRIPTION**

Transcription is the translation of sound into text (Davidson, 2009). Forbat and Henderson (2005) maintain that transcription is the first step in the analysis process and provides the structure for the analysis and interpretation of data. For this reason, the transcription process is described below to ensure accountability for the choices made in how the interviews were transcribed.

Transcription in the present study began with the researcher listening to each of the audio-recordings and noting important issues raised in the interviews (Nieuwenhuis, 2007c; Rowley, 2012). Each recording was transcribed by the researcher in order to enhance her familiarity with the information and to obviate ethical issues (Dearnley, 2005; Creswell, 2014).

Verbatim transcriptions were made because of their appropriateness for interpretive phenomenological analysis (Shaw, 2010b). Denaturalised transcription, a form of transcription that removes individual elements of speech such as stutters and pauses, was used (Davidson, 2009). It was used also because the participants' complete transcriptions were returned to them for their approval and comment (Rowley, 2012; Willig, 2008). This served as a form of member checking. Inclusion of language features such as stutters and prolonged pauses can make a participant appear less articulate (Forbat, & Henderson, 2005). Denaturalised transcriptions were used to prevent harm/embarrassment to the participants during the process of member checking (Goldblatt, Karnieli-Miller, & Neumann, 2011).

## **3.7 DATA ANALYSIS AND INTERPRETATION**

Data analysis is the process whereby the meaning of gathered materials is uncovered in relation to the purpose of a study (Babbie, 2008). In the present study, the interview transcriptions and journal entries were analysed according to interpretive phenomenological analysis (IPA).

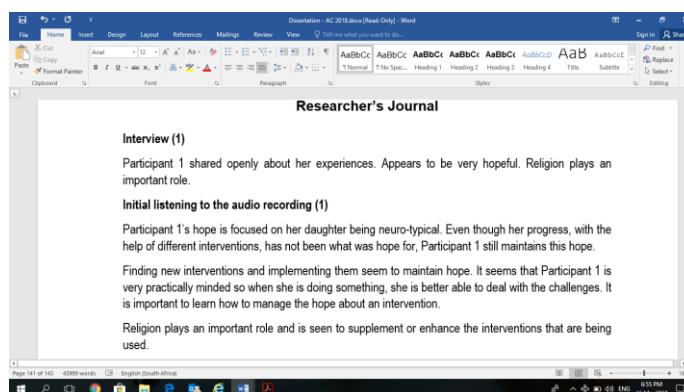
### 3.7.1 INTERPRETIVE PHENOMENOLOGICAL ANALYSIS

Interpretive phenomenological analysis (IPA) is influenced by the theoretical traditions of phenomenology and hermeneutics (Shaw, 2010b). From a phenomenological perspective, IPA focuses on understanding the meaning of human experiences whereas from a hermeneutics perspective, the focus is on the interpretation that is involved during the analysis of research data (Shaw, 2010b).

IPA is a process that involves active engagement with the data in order to identify themes and integrate those themes into meaningful thematic clusters (Willig, 2008). The main aim of IPA is to understand the meaning of personal and social experiences from the perspectives of the people experiencing them (Willig, 2008; Pringle, Drummond, McLafferty, & Hendry, 2010; Shaw, 2010b).

In the present study, the transcriptions and the journals were analysed using IPA. Each form of data was analysed inductively to reduce the data in order to identify the relevant data (Willig, 2008). The data was then analysed deductively according to the integrative theory of hope of Scioli et al. (2016).

The first step in IPA involved familiarisation with the data (Shaw, 2010b; Rowley, 2012), that is, listening to the audio-recordings and reading through each transcription (Groenewald, 2004; Willig, 2008; Shaw, 2010b). During this process, notes were made in the researcher's journal documenting any significant points of interest (Shaw, 2010b), initial thoughts, and observations (Willig, 2008; Creswell, 2014). This was done to obtain a general impression of the information and to reflect on its broader meaning (Groenewald, 2004; Creswell, 2014). Figure 3.1 provides an example of how this was done in the present study.



**Figure 3.1: Researcher's journal documenting first step in IPA**

The transcripts were then broken down into smaller sections (Shaw, 2010b). Each section was assigned a theme and labelled according to the essence of what was represented in the text (Willig, 2008). Each theme was taken from the raw data (Shaw, 2010b). Throughout the data analysis phase, the researcher continually referred back to the original text to ensure that the themes identified were consistent with the original data collected (Willig, 2008). Figure 3.2 provides an example of how this was done in the present study.

Line number	Theme
5	Challenges
6-7	Positive outlook Learning experience
16-19	Learning from the intervention centre
20-28	Challenges – maintaining consistency from school to home
35-40	Hope for the future
44	Positive behavioural change
45	Trust in others
46-49	Changes result in fewer negative thoughts
49-50	Less stress

**Figure 3.2: Assigning themes to subsections of the transcript**

In the third stage, the researcher listed all the themes identified during the second stage of analysis and determined how they related to one another (Willig, 2008). Each cluster of themes was given a label that captured their essence (Willig, 2008; Shaw, 2010b). Extracts from the transcripts that represented each theme were then identified (Shaw, 2010b). This, in addition to the researcher’s continually referring back to the original text, ensured that the themes identified were consistent with the original data (Willig, 2008). Figure 3.3 provides an example of how this was done in the present study.

Category	Themes
Personal growth	<ul style="list-style-type: none"> <li>New ways of thinking</li> <li>Creative problem solving</li> <li>Being present</li> </ul>
Hope for:	<ul style="list-style-type: none"> <li>Recovery / neuro typical child</li> <li>Independence</li> <li>Purpose in life</li> </ul>
Challenges:	<ul style="list-style-type: none"> <li>Child knowing purpose in life</li> <li>Focus on Activities of Daily Living</li> <li>Ensuring safety</li> <li>Aging parents</li> <li>Activities of Daily Living</li> <li>Past experiences</li> <li>Time, money and research</li> </ul>

**Figure 3.3: Relating themes to one another**

The final themes were derived from the clustered themes identified in the previous stage (Shaw, 2010b). The researcher then created a table of all the identified theme clusters, the subordinate themes, a quotation that illustrated each theme, and a reference to where the extract could be found in the transcription (Willig 2008). Only themes that contributed to a better understanding of the participants' experiences were included (Willig, 2008). This might have resulted in the exclusion of some themes that were not well represented (Willig, 2008). Figure 3.4 provides an example of how this was done in the present study.

Theme	Subtheme	Quotation
Attachment	Trust	He was a good diagnostician but I think he threw it out a bit fast. He could have been a little more gentler. He had to tell me the truth because I would never get moving. We also tried another school, but that didn't work because they were just using a speech therapist and occupational therapists, and they didn't know how to handle her. They told me to bring her for one session, but I was going to go for four sessions for a full eight hours. So I said like, forget it, you guys don't know what you are doing. They could have

**Figure 3.4: Final themes, subthemes and illustrating quotations**

IPA is idiographic in nature and therefore focuses on an individual level (Shaw, 2010b). As a result, data analysis takes place case by case (Shaw, 2010b). Having completed the analysis of the first case, the second case was then analysed in the same way (Shaw, 2010b).

The themes were used to guide the interpretation of the data by answering the question, "What has been learnt?" (Creswell, 2014). This information was then compared with the existing literature on hope experiences (Creswell, 2014).

A disadvantage of IPA is that it relies on the use of language in the analysis process (Willig, 2008). Thus participants' transcriptions will give an indication of how they talk about an experience as opposed to the experience itself (Willig, 2008). Member checking is a procedure that can be used to address this problem as it gives participants the opportunity to discuss and clarify interpretations, add new information (Baxter, & Jack, 2008), and ensure that experiences are accurately reflected (Creswell, & Miller, 2000).

IPA accepts that it is impossible to gain direct access to a participant's experience (Willig, 2008; Shaw, 2010b). This can be done only through the perspective of the

participant at a particular point in time (Shaw, 2010b). It is therefore important always to bear in mind the researcher's view of the world and his or her interaction with the participant as this will affect the analysis, which is only an interpretation of the participant's experience (Willig, 2008).

Another disadvantage is that while IPA is able to create rich, detailed descriptions of a person's experiences, it cannot explain why these experiences take place (Willig, 2008). The aim of the present research, however, was to explore the hope experiences of the participants and not to understand the causes underlying the experiences.

In order to mitigate the disadvantages of IPA, member checking was done in the present study and a researcher's journal kept. A researcher's journal provides an audit trail of the processes followed during the analysis phase (Shaw, 2010b). As the researcher's personal experiences and assumptions play an important role in understanding the experiences of participants, understanding how these experiences influence the data analysis process, as recorded in the researcher's journal, can enhance the transparency of qualitative research (Penner, & McClement, 2008; Shaw, 2010b).

### **3.8 QUALITY CRITERIA**

Shaw (2010b) maintains that psychological research should be judged according to scientific standards so that the findings can be considered a valid contribution to knowledge. Rigour in qualitative research is all about how the researcher can convince readers that the research findings are trustworthy (Thomas, & Magilvy, 2011). The following four components of trustworthiness are discussed below: credibility, transferability, dependability, and confirmability (Thomas, & Magilvy, 2011).

#### **3.8.1 CREDIBILITY**

Research is considered credible when it accurately describes human experience (Thomas, & Magilvy, 2011). Credibility can be enhanced through member checking, peer review (Thomas, & Magilvy, 2011; Willig, 2008), multiple sources of data collection (Baxter, & Jack, 2008; Creswell, 2014), and systematic presentation of the research findings (Willig, 2008).

Interview transcription review or member checking is a process whereby a copy of the transcribed data is made available to participants so that they can comment on the transcription (Willig, 2008; Bradbury-Jones et al., 2010). participants can also be

afforded the opportunity to read through the researcher's interpretation to allow them to discuss and clarify the interpretation or add new information (Baxter, & Jack, 2008; Bradbury-Jones et al., 2010; Goldblatt et al., 2011; Creswell, 2014). This ensures that participants' points of view are accurately reflected (Groenewald, 2004; Dearnley, 2005; Whiting, 2008; Bradbury-Jones et al., 2010).

Multiple sources of data should be used as each data source can be employed in the process of triangulation to enhance the credibility of the research (Lewis et al., 2005; Goldblatt et al., 2011; Creswell, 2014) and can contribute to the researcher's understanding of the research topic as a whole (Baxter, & Jack, 2008).

Willig (2008) argues that data should be presented in a systematic way that indicates how findings are based on the data (Willig, 2008). This can be done by providing examples of the data (Willig, 2008) and specific quotes from interviews and participants' research journals (Pringle et al., 2011). Readers can then assess the fit between the data and the researcher's interpretations (Willig, 2008).

In order to enhance the credibility of the present study, member checking and peer examination were carried out. The researcher also reflected with her research supervisor on the influence her prior experiences with children with ASD may have on understanding the data collected. The data, collected from multiple sources, were also presented systematically and included examples and quotes from the interviews and the participants' research journals.

### **3.8.2 TRANSFERABILITY**

Transferability refers to the degree that the findings in one context are applicable in other contexts (Thomas, & Magilvy, 2011). Baxter and Jack (2008) argue that details should be included in a report to enable readers to draw their own conclusions about the applicability of the findings. These details should include information on the participants and their life circumstances so that readers can be aware of contextual specificities thereby enabling them to evaluate the relevance and applicability of the findings (Willig, 2008).

In order to establish transferability in the present study, a thick description of the participants was provided.

### **3.8.3 DEPENDABILITY**

Dependability refers to the ability of other researchers to track the decision-making process used in a research project (Thomas, & Magilvy, 2011). This can be achieved by providing a detailed description of the steps taken during the research so that other researchers can assess the quality of the research (Willig, 2008; Shaw, 2010a; Thomas, & Magilvy, 2011).

In the present research, the researcher used a researcher's journal to provide an audit trail of the steps and decisions taken during the research process.

### **3.8.4 CONFIRMABILITY**

Thomas and Magilvy (2011) state that in order to achieve confirmability, a researcher has to maintain a reflexive stance. Throughout the research, he has to reflect on the process in his researcher's journal and follow the lead of the participants rather than directing them.

## **3.9 ETHICAL CONSIDERATIONS**

Research ethics refer to the morality, thinking, choices, and accountability of the researcher throughout the research process (King, 2010). The researcher in the present study adhered to high ethical standards throughout the research. Prior to commencing the research, ethical approval was obtained, and the director of The Autism School's permission was obtained to recruit two parents of children enrolled at The Autism School to participate in the proposed research study.

### **3.9.1 INFORMED CONSENT**

Informed consent was obtained from each of the two participants. Allan (2011) states that informed consent involves more than a participant signing a consent form. Informed consent needs to be an interactive process between the researcher and the participant that will enable the participant to make an informed decision with regard to her or his participation in the research (Allan, 2011). The decision is based on the participant's proper understanding of the purpose of the research, what will be done with the information collected, the participant's role in the research (Gravetter, & Forzano, 2009; King, 2010), and the possible risks involved (Babbie, 2008). The following criteria need to be met for consent to be considered valid: the participant must have adequate information about the proposed research, the participant must be able to understand the information, the participant must understand the consequences of

his decision to participate, the participant must have the ability to make a rational decision, and he must then be able communicate that decision (King, 2010; Allan, 2011). Gravetter and Forzano (2009) warn researchers that merely informing participants about a research study does not necessarily mean that they understand the information. They emphasise the importance of talking in terms that participants understand and allowing the participants to ask questions (Gravetter, & Forzano, 2009).

### **3.9.2 VOLUNTARY PARTICIPATION**

Once participants have all the necessary information regarding a research project, they must be allowed to decide whether or not they want to participate in the project (Gravetter, & Forzano, 2009; Allan, 2011). This decision must be made freely and voluntarily (Babbie, 2008; Allan, 2011). The participants in the present study were informed that they could refuse to answer any of the questions and that they could withdraw from the study at any time.

### **3.9.3 NO DECEPTION**

Deception in a research project occurs if the researcher purposely withholds information or misleads participants with regard to information about the study (Gravetter, & Forzano, 2009). No deception occurred in the present study. The participants had access to all the relevant information throughout the study.

### **3.9.4 PRIVACY, CONFIDENTIALITY, AND ANONYMITY**

Privacy has two dimensions: the right against intrusion and the right to confidentiality (Allan, 2011). The right against intrusion was observed in this study by asking the participants only questions that were necessary and relevant for the purposes of the research (Allan, 2011). The participants were not coerced into sharing information that they were not willing to share voluntarily.

The right to confidentiality entails not disclosing personal information shared by participants (Allan, 2011). King (2010) maintains that confidentiality in qualitative research is a challenging ethical issue for a researcher as the aim of qualitative research is to gain access to and to report on personal information provided by participants. This is done by exploring experiences in the personal contexts of participants (Willig, 2008; King, 2010).



The limits of confidentiality were therefore discussed with the research participants throughout the research process. This was done by explaining to the participants what would be done with the data collected and how their identities would be protected throughout the course of the research.

Pseudonyms were used to protect the identities of the participants. With pseudonyms, information shared by participants can be reported in a way that ensures their anonymity (Gravetter, & Forzano, 2009; Allan, 2011). The researcher took care not to report on views, experiences, and unique characteristics that could reveal the participants' identities. King (2010) emphasises the importance of protecting participants' identities in a way that does not compromise the value of a study.

### **3.9.5 PROTECTION FROM HARM**

Non-maleficence is defined by Allan (2011, p. 131) as “the duty that psychologists have not to harm people or to engage in behaviour where it is reasonably foreseeable that it can harm others, and to minimise harm when it is unavoidable”. Non-maleficence is considered a key principle in psychology (Allan, 2011).

Through their participation in research, participants can become aware of negative feelings, memories, or beliefs (Willig, 2008). The researcher in the present study monitored each participant for any potential harmful effects. She also informed the participants of support they could obtain to help them resolve any issues that might have arisen as a consequence of participating in the research.

### **3.9.6 DEBRIEFING**

In the present study, it was not necessary to inform the participants about the purpose and uses of the data at the conclusion of the research, as the researcher had been open with them about the aims of the research from the outset. King (2010) maintains that participants should rather be told how and where the research findings will be disseminated. The researcher should also ensure that participants have the researcher's contact details should they have any questions or concerns (King, 2010). In addition to providing information, the aim of debriefing is to counteract or minimise any harmful effects that may have occurred during the course of the research (Gravetter, & Forzano, 2009).

### **3.10 SUMMARY**

This chapter outlined the research methodology used to explore and describe the hope in parents raising a child with ASD. Interpretive phenomenology within a qualitative research methodological paradigm was discussed and included a consideration of the strengths and limitations of this approach. An exploratory case study research design, sampling strategy, and data collection and analysis strategies were outlined, and the measures taken to ensure quality and ethical research practices in the study discussed. The next chapter covers the results of the study.

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## Chapter 4 Findings of the Study

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### 4.1 INTRODUCTION

The findings of the study are presented in this chapter (Chapter 4). As indicated in Chapter 3, data were collected by exploring hope experiences by means of an interview and the research journal of two participants. The results of the findings are discussed below.

### 4.2 RESULTS OF THE STUDY

Four themes and nine sub-themes were identified on the basis of the analysis of the data collected, using the integrative theory of hope of Scioli et al. (2016). These themes and sub-themes are summarised in Table 4.1.

**Table 4.1: Overview of themes and sub-themes**

THEMES	SUBORDINATE THEMES
Theme 1: Attachment	Sub-theme 1.1: Support
	Sub-theme 1.2: Trust
Theme 2: Mastery	Sub-theme 2.1: Empowerment
	Sub-theme 2.2: Control
	Sub-theme 2.3: Positive future expectations
Theme 3: Survival	Sub-theme 3.1: Generating options
	Sub-theme 3.2: Emotion regulation
Theme 4: Spirituality	Sub-theme 4.1: Purpose in life
	Sub-theme 4.2: Higher power

A definition is provided for each theme and sub-theme followed by the inclusion and exclusion criteria. The findings are supported by extracts from the interviews and participants' research journals. The full transcript of the interviews and participants' research journals can be found in Appendix B. Each theme concludes with a recursive literature review.

#### 4.2.1 THEME 1: ATTACHMENT

Attachment is defined as an emotional bond between two people and is an important foundational component in the development of hope (Scioli & Scioli, 2004). The need for attachment with another person results in deeper levels of connection with that person (Scioli et al., 2011). These connections may continue throughout the lifespan of the people concerned and are enhanced by the knowledge that the presence of the other person is constant (Scioli et al., 2011).

Attachment is reliant on openness and trust in others and occurs in the context of a nurturing relationship (Scioli & Scioli, 2004; Scioli et al., 2011). Trust and openness are interrelated, because without openness, trust is undermined, and a lack of trust will prevent a person from experiencing openness (Scioli et al., 2011).

The need to be connected with another person is met through social and emotional support and being able to share experiences with someone facing a similar situation (Scioli et al., 2011).

As stated earlier, Theme 1 has two sub-themes: Sub-theme 1.1: Support, and Sub-theme 1.2: Trust. These two sub-themes will now be discussed on the basis of extracts from the data.

##### 4.2.1.1 Sub-theme 1.1: Support

Table 4.2 provides a working definition of support and also outlines the inclusion and exclusion criteria used for identifying the support experiences of the participants.

**Table 4.2: Working definition and inclusion and exclusion criteria for Sub-theme 1.1**

<b>WORKING DEFINITION: SUPPORT</b>	
The establishment of a close relationship characterised by kindness, love, affection, and companionship that enables one to experience an improved emotional state (Scioli et al., 2016).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data indicating a relationship characterised by kindness, love, affection, and companionship that results in emotional support.	Data not related to relationships and the experience of emotional support.

Two different experiences of support were identified in the data. Participant 1 described extensive support from her immediate family, that is, her older children and her husband:

*My kids are always praying and asking about my daughter with autism. (Interview P1, line 210)<sup>3</sup>*

She described the continuous support from her husband and acknowledged that she would not have been able to cope with the challenges associated with raising a child with ASD without his support:

*I have a lot of support. My husband has always been by my side, helping. He has been wonderful. There would be no way I would be able to cope with this but together we have made it. (Interview P1, lines 60-64).*

The support from her husband was experienced from the day the diagnosis was made:

*The paediatrician said to me that she is autistic. I was totally in shock. Thank goodness my husband was with me because I would not have made it back to the house. (Interview P1, line 257-261).*

The support from her children included knowing that as she grew older, there would always be someone to look after her child with ASD:

*I am not getting any younger. Caring for her is not something I could do forever. She does have many siblings who I know will not abandon her. (Interview P1, line 35-38).*

Participant 2's experience of support differed from that of Participant 1 due to the fact that her husband found it difficult to accept the things that their child with ASD did:

*Sometimes it is hard for him to accept things that our son does. Sometimes our son likes to shake his head, which he doesn't like, and makes noises, which he doesn't like. He's also not really educated about autism. (Interview P2, line 216)*

As a consequence of this, an extended family member was the main provider of support to Participant 2:

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<sup>3</sup> The responses of the participants are verbatim with only light editing to ensure fluent reading while maintaining the authenticity of the responses. The original unedited transcripts can be found in Appendix B.

*It's his aunt. She is very supportive of him. Even more supportive of him than me and his daddy. (Interview P2, line 207)*

Participant 2 reported that the support she received from someone who had gone through a similar experience gave her hope:

*She [fellow parent of child with ASD] was the main person that helped me throughout everything and gave me hope for my child. If it wasn't for her, I wouldn't have had hope. I wouldn't have had a school for my child, and I wouldn't have him the way he is today. (Interview P2, line 292)*

Neither of the participants reported receiving support from a formal support group. Participant 1 believed that she should rely more on a support group but experienced too many hassles getting such support:

*I am not good in creating a support system, and I know you are always told you should create a group, I just don't have the time and energy for it. In a way I am actually isolated because I'm busy with my own things. I don't have the time or energy. There are a lot of people I don't keep in touch with anymore. A relationship is something you need to cultivate. It's not a one-way street. (Interview P1, lines 211, 228).*

Another form of formal support mentioned by both participants was that provided by professional people. Participant 1 felt supported by her general practitioner (GP) who was willing to work with her. The GP listened to what she had to say as a parent with regard to the treatment of her child:

*Treating autism requires thinking out of the box with the supplements and the dietary interventions. So not every doctor will go for it. I am very thankful that I have a general practitioner who is willing. She is very open minded. But some doctors will see and they won't even consider it as an option for treatment. They see autism as a psychological disorder that has nothing to do with the physical. (Interview P1, lines 311-321)*

Participant 1 also felt supported by the case manager at her child's school as she was willing to collaborate with her in the use of a new intervention:

*Last night we had a skype consultation with a consultant regarding a new method that I have tried in the past with my daughter but haven't been very successful. But this time the case manager is also on board so I am very*

*hopeful that this time it will work and we will actually be able to get through to her. (Journal entry P1, line 38)*

Participant 2 also felt supported when the case manager expressed willingness to collaborate with her in solving any problems that occurred:

*If I have any problem or if I have any issue, I always consult the case manager and ask him what to do. Then we both sit down and we ask, will this be good or will that be good? How to resolve this issue? What to do? And how much will we do it? We work together. (Interview P2, lines 271-276)*

Participant 1 acknowledged the importance of social support and valued the role it played in enabling her to cope with the challenges of raising a child with ASD:

*I knew that even with all my faith and everything, it would be a challenge. I needed a support system. (Interview P1, line 61)*

In summary, the participants in the study both indicated that attachment was experienced through the social support provided that assisted them in coping with the challenges they faced in raising a child with ASD. They considered support from core family members as well as from extended family members as sources of hope. While neither of the participants reported receiving support from formal support groups, informal support from those with similar experiences helped in the development of hope. The participants felt supported by health professionals when they were able to work in a collaborative relationship with them and where their input as parents was valued.

#### **4.2.1.2 Sub-theme 1.2: Trust**

Table 4.3 provides a working definition of trust. The table shows also the inclusion and exclusion criteria used for identifying the trust experiences of the participants.

**Table 4.3: Working definition and inclusion and exclusion criteria for Sub-theme 1.2**

<b>WORKING DEFINITION: TRUST</b>	
An emotional state involving one's behaviour towards another person where a deeper level of connection is desired (Scioli et al., 2011). Through this connection there is greater assurance that support will be provided (Scioli, & Biller, 2003).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data indicating the presence or absence of a deeper level of connection with another person that results either in the assurance or doubt that support will be provided.	Data not indicating a deeper level of connection with another person that results in feelings that support will be provided.

Two different experiences of trust were described by the participants. Participant 2 reported experiencing trust in the management of the school, the school itself, and those who were involved in the implementation of her child's intervention programme at school:

*When I joined him at the school, that's where my hope went very far. I had full trust in the school, I had full trust in the therapists and full trust in the school's founder. The school's founder was the main person that helped me throughout everything and gave me hope for my child. (Interview P2, line 291)*

This trust was experienced because of the participant's belief in the ability of the child's therapy team to bring about change in her child's behaviour:

*I have full trust in the therapists that they try to do their best every day. Because of them my child changes every day. (Interview P2, line 45)*

The opposite was seen with Participant 1 who experienced a lack of trust in the health professionals who worked with her child. Her trust was undermined, for example, when the paediatrician did not notice important diagnostic characteristics in her child:

*She was a very bad diagnostician. My daughter was playing with the truck upside-down with the wheels. She was not playing properly. She should have seen that. Later I learnt that that is characteristic of autistic kids. (Interview P1, line 241)*

A lack of trust was thus experienced in the relationship between Participant 1 and the two paediatricians she consulted. The first paediatrician dismissed her concerns about her child and intimated there was actually something wrong with her:



*Even when the paediatrician saw her, he thought there was something wrong with me. He asked me if I was taking medication because my child seemed okay to him. (Interview P1, line 132)*

The second paediatrician intimated that she was the cause of her child's behaviour:

*Oh, the paediatrician really got me upset. She was telling me that something happened in my pregnancy or that the autism was because of medication I took. You don't know what the problem is, so don't throw it at me. (Interview P1, line 238)*

Participant 1's trust in her child's therapists was also undermined when the therapists were unable to manage her child's behaviour. Their recommendations regarding therapeutic intervention were also inadequate according her perception of her child's needs:

*We also tried another school, but that didn't work because they were just using a speech therapist and occupational therapists, and they didn't know how to handle her. They told me to bring her for one session, but I was going to go for four sessions for a full eight hours. So I said like, forget it, you guys don't know what you are doing. They could have told me to bring her less often or that they couldn't help her. (Interview P1, line 300)*

In summary, the participants in the study indicated that trust could either be increased if the parent experienced the professional as competent in effecting change in the child's behaviour, or it could be undermined if the parent experienced the professional as being incompetent in either accurately diagnosing or designing treatment plans for the child. Trust was seriously undermined when Participant 1 thought that she had been identified as the problem or as the cause of her child's behaviour.

#### **4.2.1.3 Findings on attachment**

The participants in the study reported using informal and formal support systems to help them cope with the challenges associated with raising a child with ASD. The use of informal and formal support systems is also noted in the literature (Boyd, 2002; Ekas et al., 2010).

Informal support systems identified in the present study included support from a spouse or family member and support from other parents of a child with ASD. The importance of informal sources of support, particularly of spouses, was highlighted by Boyd (2002) and Ekas et al. (2010) who reported that spouses were often the first line

of support used by parents raising a child with ASD. Boyd (2002) found in his study that informal support was more effective than formal support and that a mother who received support from her spouse was better at relating emotionally to her autistic child than mothers who did not receive support from their spouse. Spousal support has also been associated with improved life satisfaction, hope, and psychological well-being (Benderix et al., 2007; Ekas et al., 2010).

In addition to spousal support, the participants in this study indicated that support had also been obtained from an extended family member. This is consistent with the literature, which reports that extended family members are also important sources of support (Boyd, 2002; Ekas et al., 2010). Mothers often pursue support outside of their marriage only when they do not receive the necessary support from their spouse (Ekas et al., 2010). This was most likely the case with Participant 2 who indicated that when she did not get support from her spouse, she was able to get support from an extended family member.

Participant 2 in this research indicated support provided by another parent going through a similar experience as an important source of informal support. The importance of parents being able to share their experiences with other parents going through a similar experience is widely reported in the literature (Boyd, 2002; Mackintosh, Myers, & Goin-Kockel, 2005; Benderix et al., 2007). Parents feel supported because the other parents are empathetic and understand what they are going through, which increases their hope for the future (Benderix et al., 2007). Ekas et al. (2010) found in their study that this kind of support was valuable because it could provide information as well as instrumental and emotional support.

Formal support indicated in the present study included support from health professionals such as general practitioners and case managers. Support from such health professionals has been identified in other research as a common form of formal support used by parents raising a child with ASD (Mackintosh et al., 2005). Some parents involve up to seven different health professionals in the treatment of their child (Hutton, & Caron, 2005). Kausar et al. (2003) state that health professionals should respond to parents with more sensitivity and empathy as they are in a position where they can influence the hope that parents experience.

The participants in this study felt supported in their interactions with health professionals when they were able to work in a collaborative relationship with them and where their input was valued. Good communication ability, listening skills, and professional competence are characteristics of effective health professionals with

whom parents are more likely to collaborate (Murray, Ackerman-Spain, Williams, & Ryley, 2011). Effective collaboration between parents and health professionals has been seen to result in empowerment, which can be used to enhance feelings of hopefulness in parents (Murray et al., 2011; Meirsschaut et al., 2010, Myers et al., 2009; Fewster, & Gurayah, 2015).

While formal support groups were not used by the participants in this study, their importance was acknowledged. Lack of time and energy had a negative influence on these parents' involvement in such groups despite their awareness of the benefits. These findings are consistent with the literature, which also notes that time, resources, and finances are obstacles to participating in formal support groups (Mandell, & Salzer, 2007; Mackintosh et al., 2005). Despite these obstacles, Mandell and Salzer (2007) found that many parents reported attending support groups believing that the benefits outweighed competing time and resource demands. Formal support groups give parents the opportunity to meet other parents of children with ASD, discuss their concerns, and extend their support network (Boyd, 2002).

The participants in the present study indicated that the trust relationship with a professional could be either enhanced or undermined. Skilfulness or competency enhanced the participants' trust in a professional's ability to work effectively with their child and bring about positive change. This was also noted in the study conducted by Tucker and Schwartz (2013) where parents who doubted the knowledge or skill of health professionals experienced a lack of trust in them. Angell, Stoners, & Sheldon (2009) also found that a lack of trust was detrimental to the parent-professional partnership.

In the present research, Participant 1 was identified as the problem when she consulted a professional about her daughter. She was also blamed by another professional for her child's ASD. This naturally undermined the trust relationship between her and the health professionals. Kausar et al. (2003), too, found that negative evaluations of health professionals reduced parents' feelings of hope.

#### **4.2.2 THEME 2: MASTERY**

Mastery is defined as the degree of control a person perceives he or she has in response to a challenging circumstance and is related to gaining control and power over the circumstance (Scioli et al., 2011). Scioli et al. (2016) report that focusing on goals and values, in addition to establishing priorities, is likely to increase feelings of

mastery. Goals are established in order to engage with a situation effectively and to gain mastery over it (Scioli et al., 2011; Scioli et al., 2016).

Mastery is associated with empowerment and involves action in the pursuit of change (Scioli et al., 2016). Empowerment can be achieved through inspiration by another person and through education (Scioli et al., 2016), which can be seen in the provision of information and through learning (Scioli, & Biller, 2010; Scioli et al., 2016).

Mastery can be divided into personalised mastery and attached mastery (Scioli et al., 2011). While attached mastery is dependent on another person guiding the empowerment process, personalised mastery involves empowerment that is driven by internal motivation (Scioli et al., 2011). Personalised mastery involves also openness and a positive expectation of the future (Scioli & Scioli, 2004).

As stated earlier, Theme 2 comprises three sub-themes: Sub-theme 2.1: Control, Sub-theme 2.2: Empowerment, and Sub-theme 2.3: Positive future expectations. Each sub-theme will now be discussed.

#### 4.2.2.1 Sub-theme 2.1: Control

Table 4.4 provides a working definition of control. The table also indicates the inclusion and exclusion criteria used for identifying the participants' experiences regarding this sub-theme.

**Table 4.4: Working definition and inclusion and exclusion criteria for Sub-theme 2.1**

<b>WORKING DEFINITION: CONTROL</b>	
The perceived influence, power, and responsibility that one has in relation to achieving a certain outcome (Scioli, & Biller, 2003). Control may be externally or internally mediated (Scioli et al., 2016).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data related to the degree of ability to plan and implement steps in order to achieve a certain outcome.	Data not related to the degree of ability to plan and implement steps in order to achieve a certain outcome.

Participant 1 believed that the general information she was given by a paediatrician regarding interventions and support services limited her ability to plan and implement steps in order to move forward following the diagnosis of her child. She had expected more specific guidelines on what to do:

*He just told me something general. I didn't know what to do from there. He just said, there is such a thing, but he didn't tell me go there, look at this website. He didn't tell me where to go, so I didn't know what to do. (Interview P1, line 277)*

Participant 1's ability to implement steps to influence her daughter's behaviour positively improved when she focused on the practical aspects of her plan:

*In the beginning I was actually lost. I didn't know what to do. So once I got more focused on the practical aspects of what to do, then things got a little bit better. I was not trying to focus on what I lost but Step A, Step B, what I am doing now. (Interview P1, line 69)*

Participant 1 thus felt lost until she was able to implement an intervention:

*I was at a loss for two weeks until we started to get things going. (Interview P1, line 287).*

For Participant 1, being able to implement an intervention made her feel more hopeful:

*Of course it is very encouraging when we try something new, a medical or diet intervention, or some educational intervention. Those things usually bring my hopes high. (Interview P1, line 118)*

Participant 2 also reported more hope when she was able to implement her intervention plan, which consisted of her enrolling her child at a school:

*When I enrolled him at school, that's where my hope went very far. (Interview P2, line 290)*

Being able to implement new interventions also enhanced Participant 1's experience of hope:

*As we were starting to do new things [interventions], I was hoping. (Interview P1, line 171)*

Participant 1 experienced powerlessness when she was unable to do anything to help her daughter when her daughter was unhappy:

*When you see her, especially when she is unhappy and something is really bothering her, and I don't know what to do to help her. And that is heart breaking. She is either in pain or some kind of bad feeling, but you don't know what to do. That's the worst. (Interview P1, line 183)*

The participants in the present study experienced mastery through the varying degrees of control they have over their circumstances. However, this control was negatively influenced when the information provided on ASD and on where to find out about different interventions was not specific enough to enable them to make sense of their child’s diagnosis and plan ahead. Developing a plan of action and actively implementing the plan in order to bring about change were important in helping the parents (participants) feel in control.

#### 4.2.2.2 Sub-theme 2.2: Empowerment

Table 4.5 provides a working definition of empowerment. The table also includes the inclusion and exclusion criteria used for identifying the empowerment experiences of the participants.

**Table 4.5: Working definition and inclusion and exclusion criteria for Sub-theme 2.2**

<b>WORKING DEFINITION: EMPOWERMENT</b>	
The perceived sense of being knowledgeable or strengthened through inspiration, through education by a role model, through new information, or through a group (Scioli et al., 2016).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data indicating being knowledgeable or strengthened through inspiration, through education by a role model, through new information, or through a group.	Data unrelated to being knowledgeable or strengthened through inspiration, through education by a role model, through new information, or through a group.

Both participants emphasised that raising a child with ASD had given them an opportunity to learn. Participant 2’s learning was related to her son and his education:

*You learn a lot and you experience new things every day. You learn new things every day as he goes to school. (Interview P2, line 7)*

Participant 1’s learning was related to enjoying the moment:

*One thing I have learnt in life is to enjoy the moment. I mean it in a positive way, I don’t mean be reckless. I mean enjoy the moment. (Interview P1, line 107)*

Learning took place through contact with the various health professionals working with her child or through personal research. Participant 1 had invested her resources in research in order to expand her knowledge of ASD:

*I have spent a lot of time, research and money. (Interview P1, line 153)*

Participant 2 relied on her interaction with the health professionals who worked with her son to gain knowledge about ASD:

*Sometimes when the case manager comes to see me, I always sit and ask him lots of questions. (Interview P2, line 87)*

Participant 2 believed that because of the knowledge she had gained, she was able to understand and communicate effectively with the case manager:

*I can sit there and communicate with the case manager and know what he is talking about. Other people wouldn't. If they sit with him, if you bring an unknown person with you, they won't know what he is talking about. (Interview P2, line 189)*

This understanding included the written notes provided by the case manager:

*When I read the case manager's notes, I know what he is saying. I understand. (Interview P2, line 194)*

Raising a child with ASD provided the parents in this study with an opportunity to learn which influenced their experience of mastery. The learning occurred through their interaction with health professionals and through personal research. By being empowered with knowledge about ASD, Participant 2 felt enabled to understand and communicate effectively with the people working with her son.

#### **4.2.2.3 Sub-theme 2.3: Positive future expectations**

Table 4.6 provides a working definition of positive future expectations. The table also includes the inclusion and exclusion criteria used for identifying the positive future expectations of the participants.

**Table 4.6: Working definition and inclusion and exclusion criteria for Sub-theme 2.3**

<b>WORKING DEFINITION: POSITIVE FUTURE EXPECTATIONS</b>	
The discovery and retention of favourable future outcomes (Scioli, 2007).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data indicating a positive expectation for the future.	Data indicating a negative expectation for the future.

The participants in the present research had various hopes regarding the future of their child. These future hopes included the recovery of their child:

*Hope means full recovery. That's my goal, that is my aim. I am putting a lot of time, effort and resources into a full recovery. Being a neuro-typical child.* (Interview P1, line 18)

Participant 1 described this hope further:

*Regarding my daughter, we are hoping that she will be normal. It may sound not normal, but that is what we are hoping for.* (Journal entry P1, line 12)

Participant 1 expressed hope for the future as a result of her daughter's improved sleeping patterns and positive mood. She hoped that these improvements would continue and have a positive influence on her daughter's learning ability:

*The past few days she has been sleeping pretty well and has been in a good mood. I am hoping that this will continue and that it will be conducive to her learning.* (Journal entry P1, line 20)

Participant 1 also expressed hope that the improvements already achieved would result in further improvements:

*We had a workshop at my daughter's school, and she was amazingly calm and did very well. This has given me a lot of hope for the future that she will do even better. Until now my feeling was that because of her lack of concentration and her hyperactivity she wasn't taking advantage of her school time, but she is doing much better, and she is also making a lot more sounds and that gives me hope.* (Journal entry P1, line 27)

Participant 1 expressed a hope for the future that her child would find her own unique ability:

*I am hoping that she will find her special ability to make a mark for herself in this world.* (Journal entry P1, line 6)

The future hopes of Participant 2 centred on her child having a family, finding employment, and developing skills:

*I want my son to have a family. I want him to get married. I want him to have a life. I want him to work. He must be able to use a computer. He must be able to know things.* (Interview P2, line 88)



Both participants hoped that their child would be independent in the future. Participant 2 expressed the hope that her son would be independent and able to support himself:

*I have a hope that he will be independent and that he will know what he is doing. I hope that he will be independent and support himself. (Interview P2, line 37)*

She also expressed the hope that her son would be successful:

*I hope that one day he becomes independent and successful. (Journal entry P2, line 18).*

Participant 1 described independence for her daughter in the following words:

*I want her standing on her own feet. Right now I can't leave her, it is 24/7. Even sleeping, I can't leave her alone for a second. (Interview P1, line 38)*

The parents in this study expressed personalised mastery through a hope for their child's future. The hopes they held included a hope for recovery, independence, skills development, and continued gains from current interventions.

#### **4.2.2.4 Findings on mastery**

Participant 1 highlighted the importance of receiving specific information regarding ASD support and where to find it. The provision of information is an important factor in empowering people to achieve mastery (Scioli, & Biller, 2010). Mack et al. (2007) found that information on the diagnosis and prognosis of a child with ASD could help in the management of parental distress following the diagnosis. Having access to more information that is relevant to their individual needs, and which enables parents to move forward, has been linked to a better quality of life and lower levels of stress (Willingham-Storr, 2014).

The parents in the present study experienced a sense of control when they were able to move forward, which entailed being able to establish a plan and carry it out. These parents reported that their hope was enhanced when they could see that the plan they had established was being implemented and they could see changes in their child's behaviour. Mastery manifests in planning (Scioli, 2007) and is related to an increase in the degree of control a person experiences in response to a challenging situation (Scioli et al., 2011). Greef and Van der Walt (2010) reported that hope prompted the parents in their study to actively pursue solutions to problems by focusing on the available options. This enabled them to plan and achieve desired goals, which has also

been linked to less preoccupation with problems (Ogston et al., 2011) and greater goal re-engagement (Neff, & Faso, 2015). Van Rooyen (2015) found that the fathers in her research experienced more hope when they could see improvements in their child's behaviour when comparing the behaviour before and after implementing an intervention.

Participant 1 in the present study felt powerless when there was nothing she could do to help her daughter. She was unsure about what was causing her daughter's distress and therefore did not know how to help her. Feelings of powerlessness have been related to hopelessness (Scioli, & Biller, 2009). Weiss, Wingsiong and Lunsy (2014) found that parents of children with ASD experienced feelings of hopelessness when they did not have a solution to a current problem – they felt uncertain about how to move forward or where to turn for support.

The parents in the present study reported undergoing a process of learning as a result of the experience of raising a child with ASD. This learning included learning about ASD, ASD interventions, and how to be present. Learning is an important part of the empowerment process that is related to mastery (Scioli et al., 2016). The findings of this study are similar to those of Kausar, Jevne and Sobsey (2003) and Myers et al. (2009) who found that the parents of children with developmental disabilities and ASD learnt how to be more compassionate, patient, and understanding of others and developed a new understanding of the world of disabilities. They also learnt how to appreciate the small things in life, how to love their children as they were, and how to advocate for their needs (Kausar et al., 2003, Myers et al., 2009). The mothers in the research conducted by Matenge (2014) reported that the learning that had taken place in themselves would not have happened had it not been for their children.

Learning in the present research took place through interactions with various health professionals and through conducting personal research. According to Scioli et al. (2011), mastery emerges in the interaction with a more knowledgeable person that results in learning or empowerment (Scioli et al., 2011). The findings of this study are similar to those of Hutton and Caron (2005) and Murray et al. (2011) who found that parents learnt through reading and through parent-professional interactions.

Empowering themselves with knowledge about ASD enabled the parents in the present study to understand their child and to communicate effectively with health professionals. Greef and Van der Walt (2010) found in their study that acquiring knowledge about ASD assisted the parents in knowing how to help their child and prevented the use of maladaptive coping strategies. Mulligan et al. (2010) found that

the parents in their research spent a lot of time learning about ASD through reading, conducting online searches, and consulting friends and family members. Sarrett (2015) found that the parents were able to learn strategies for language development and managing difficult behaviour from the therapists working with their child.

Both the parents in the present research were able to maintain hope for the future of their child. This hope centred on the child developing normal functioning, learning new skills, and enhancing his or her future employability. Positive future expectations have been linked to personalised mastery (Scioli, 2011), which involves empowerment driven by internal motivation (Scioli, 2011). Hope for the future, as identified in this study, is similar to that identified in other research, namely that parents are able to maintain hope for the future of their child with a disability (Hutton, & Caron, 2005; Benderix et al., 2007; Ogston et al., 2011, Sarrett, 2015). Hutton and Caron (2005) found that it was common for parents to hope that their child would achieve near-normal functioning and would be able to find meaningful work in the future (Benderix et al., 2007, Ogston et al., 2011).

The parents in this study expressed hope for increased independence and a future family for their child. Benderix et al. (2007) also reported parents hoping for an increase in their child's independence. Ogston et al. (2011) found that parents hoped that their child would be independent and get married in the future.

#### **4.2.3 THEME 3: SURVIVAL**

Survival is defined as coping, managing stress, and escaping from danger, with the focus on a person's ability to self-preserve (Scioli et al., 2011). Survival means dealing with the challenges experienced in life (Scioli et al., 2011). Survival entails coping with and regulating emotions in such a way that the person is not immobilised by fear or anxiety (Scioli et al., 2011). This also involves being able to see different options for solving problems (Scioli et al., 2016).

As stated earlier, Theme 3 comprises two sub-themes: Sub-theme 3.1: Generating options and Sub-theme 3.2: Emotion regulation. These sub-themes are discussed below.

### 4.2.3.1 Sub-theme 3.1: Generating options

Table 4.7 provides a working definition of generating options. The table also includes the inclusion and exclusion criteria used for identifying the participants' experience in this sub-theme.

**Table 4.7: Working definition and inclusion and exclusion criteria for Sub-theme 3.1**

<b>WORKING DEFINITION: GENERATING OPTIONS</b>	
The ability to create or discover alternative options through oneself and others (Scioli et al., 2016).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data indicating the generation and use of options in addressing a challenge.	Data that do not indicate the generation and use of options in addressing a challenge.

In an effort to generate options, Participant 1 reported trying to deal with the challenges associated with raising a child with ASD by attempting different types of treatments, including behavioural therapy, supplements, and dietary intervention:

*I don't think we have cracked exactly what it is, but we are trying from all angles ... supplement, diagnosis, diet, and behavioural therapy. (Interview P1, line 328)*

Participant 1 explained how generating options – a means of addressing survival needs – involved creative problem solving:

*Treating autism involves thinking out of the box. (Interview P1, line 311)*

Participant 2 gave an example of how she used creative problem solving to generate different options in order to meet a challenge she experienced when taking her son to the movies. She found that by taking him when there were fewer people in the cinema, instead of during times when there were more people who were likely to be bothered by the noises he made, she would be able to engage her son in an activity he enjoyed.

*My son likes going to the movies, but you have to schedule it in his own time because there are people around, and he likes making noises. People are not okay with that, so you have to schedule his own time to take him. (Interview P2, line 118)*

In this study, survival needs were met by the participants' ability to generate different options through creative problem solving.

#### 4.2.3.2 Sub-theme 3.2: Emotion regulation

Table 4.8 provides a working definition of emotion regulation. The table also includes the inclusion and exclusion criteria used for identifying the emotion regulation experiences of the participants.

**Table 4.8: Working definition and inclusion and exclusion criteria for Sub-theme 3.2**

<b>WORKING DEFINITION: EMOTION REGULATION</b>	
The ability to control emotional reactions and remain calm, resulting in less anxiety and fear (Scioli et al., 2016).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data indicating techniques used to control emotional reactions.	Data not related to techniques used to control emotional reactions.

Participant 2 indicated how the positive behavioural changes she observed in her son resulted in her having more hope. This then led her to have fewer negative thoughts – a means of regulating emotions and an important component in survival – and reduced the stress she experienced regarding her son:

*With him changing, you have more hope every day, and you have fewer negative thoughts. I don't have any stress for my son at the moment. (Interview P2, line 47)*

In addition to an increase in hope resulting in fewer negative thoughts, Participant 2 reported actively suppressing such thoughts:

*Sometimes you think a lot. You think maybe this can, maybe that could happen and then what. Sometimes I do have negative thoughts, but I try not to. (Interview P2, line 83)*

Although hope helps reduce negative thoughts and assists in regulating emotions, Participant 1 stressed the importance of regulating the amount of hope she experienced in relation to a specific intervention:

*New interventions usually bring my hopes high. At the beginning, I used to be so enthusiastic that this is going to be the solution. Now I have learnt to be a little more reserved, but it does give me hope that here is something that is going to move us forward. (Interview P1, line 121)*

Another strategy Participant 1 used to manage hope involved focusing on the present rather than focusing too far in the future:

*We take it one minute, one second at a time.* (Interview P1, line 171)

Participant 2 was able to regulate her emotions – resulting in less fear and worry regarding her son – by focusing on the knowledge that a plan of action was being implemented:

*When I sit at work and I know that my son is at school, I don't have any fears or worries about him.* (Interview P2, line 299)

Less stress was also experienced by Participant 2 as a result of knowing that her son was learning at school because her plan was being implemented:

*I don't have any stress about my son at the moment because I know that with regard to him going to school and learning, he is going to be a normal boy.*  
(Interview P2, line 49)

Participant 2 found that as her child's behaviour improved, her hope increased and she had fewer negative thoughts. Reducing negative thoughts – a technique used in regulating emotions, which is important for survival – was also achieved through actively trying not to think negatively about the child and what could happen. Her emotions were also regulated, resulting in fewer negative emotions being experienced, by focusing on the knowledge that a plan was being implemented to help her child and that he was learning at school. Participant 1 reported having to regulate the amount of hope she experienced in relation to an intervention. She also managed her hope by focusing on the present rather than the future.

#### **4.2.3 FINDINGS ON SURVIVAL**

Survival hope reflects people's perception of the options they have available in order to deal with a challenge they are experiencing (Scioli et al., 2016). Participant 1 in the present study reported generating different options to deal with the problems associated with ASD by pursuing different treatment options for her child. The parents in this study reported that the ability to solve problems creatively was important in generating options. Scioli et al. (2016) identified the ability to create alternative options as a survival resource. Such options could be discovered by the person experiencing the challenge or provided by others (Scioli et al., 2016).

There is currently no consensus or guidelines on which intervention will help which child with ASD (Mackintosh et al., 2012). Children with ASD present with a unique

combination of symptoms and behaviours resulting in uncertainty about the outcomes of interventions (Mackintosh et al., 2012). Ogston et al. (2011) and Mackintosh et al. (2012) believe that parents therefore need to know the different treatment options available as they have to identify for themselves which intervention strategy to pursue. This can be done through self-directed research, consulting with health professionals (Mackintosh et al., 2012), and networking with other parents (Boyd, 2002). Knowledge of the different treatment options available enables parents to actively pursue solutions to problems and to look beyond the problems (Greef, & Van der Walt, 2010). High levels of hope enable parents to imagine several alternative ways of achieving a positive future (Lloyd, & Hasting, 2009; Shenaar-Golan, 2017).

The parents in this study reported that improvements in the behaviour of their child resulted in more hope, which assisted in regulating their emotions. Self-regulation, particularly emotion self-regulation, is considered by Scioli et al. (2016) as an important component of survival. Emotion regulation includes finding ways to stay calm and feel less anxious (Scioli et al., 2016). The findings of this research reflect those of Bally et al. (2014) who found that hope had a calming effect. Ogston et al. (2011) found that hope was related to lower levels of anxiety and depression.

One strategy for emotion regulation, a component of survival (Scioli et al., 2016), that was identified in this study was managing negative thoughts and emotions, as highlighted by Participant 2. This was achieved by actively suppressing negative thoughts. Neff and Faso (2015), too, found that cognitions could influence emotions. Self-compassion is a component of hope that allows one to be aware of the influence of negative thoughts and emotions (Neff, & Faso, 2015). Such thoughts can be restructured so that the problem is seen in a positive light, which allows a parent to see a challenge as an opportunity (Martins et al., 2013). The parents in the research conducted by Bally et al. (2014) endeavoured to remain hopeful through purposeful positive thinking.

Fewer negative emotions were experienced by Participant 2 when she focused on the knowledge that an intervention plan was being implemented to help her child. Martins et al. (2013), Matenge (2014), and Van Rooyen (2015) reported that once they could access support services, parents were able to feel more hopeful.

As stated earlier, hope assists in regulating emotions; however, the importance was also noted in the present research of restructuring hope to ensure that it could be maintained. The parents in this research chose to focus on shorter time frames and to manage the extent of their hope regarding a certain intervention outcome. Reality

negotiation thus serves a protective function during survival situations (Scioli, & Biller, 2009). Restructuring hope, as outlined in the literature search conducted by Bally et al. (2014), involves taking one day at a time, which is less overwhelming for a person and therefore helps in sustaining hope. Bally et al. (2014) also reported on parents keeping hope possible by hoping for the best but preparing for the worst. This allowed them to keep hoping, while still remaining grounded in reality (Bally et al., 2014).

#### 4.2.4 THEME 4: SPIRITUALITY

Spirituality is defined as transcendence and eternal truths with reference to a higher power (Scioli et al., 2011). It is associated with a search for meaning or purpose in life (Scioli et al., 2016). Spirituality needs provide a sense of belonging through the expression of core values, which may relate to religion, spirituality, or God (Scioli et al., 2016).

As stated earlier, Theme 4 comprises two sub-themes: Sub-theme 4.1: Purpose in life and Sub-theme 4.2: Higher power. These sub-themes are discussed below.

##### 4.2.4.1 Sub-theme 4.1: Purpose in life

Table 4.9 provides a working definition of purpose in life. The table also includes the inclusion and exclusion criteria used for identifying experiences related to purpose in life.

**Table 4.9: Working definition and inclusion and exclusion criteria for Sub-theme 4.1**

<b>WORKING DEFINITION: PURPOSE IN LIFE</b>	
Interaction with the world that is purposeful and meaningful (Scioli et al., 2011, Scioli, 2016).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data indicating life purpose or meaning.	Data not related to life purpose or meaning.

While reflecting on what it meant to be a parent raising a child with ASD, Participant 1 described the meaning of life for her in general and how it influenced how she viewed the meaning of raising a child with ASD:

*Life for me means a challenge. (Interview P1, line 6)*



Participant 1 added that the challenge in her life was linked to her daughter and served as a means for personal growth for both herself and the people her daughter encountered:

*A person is brought to this world to grow. She is just one of those things in my life to enable me and all those she comes into contact with to grow. (Interview P1, line 7)*

Participant 1 had a clear idea of the meaning or purpose of her own life, and she wanted her daughter also to find her own purpose in life. The fact that she had not yet found it was painful for her.

*Be a kid who could find her purpose in life because I don't think that right now she is aware of her purpose in life which is actually the most painful thing for me. (Interview P1, line 23).*

In summary, spirituality needs were expressed by Participant 1 who viewed the meaning or purpose of her own life as a challenge, and she saw the challenges she experienced with her daughter as an opportunity for personal growth for both herself and other people who came into contact with her daughter. Because she was aware of her own purpose in life, she wanted her daughter also to determine what her own life purpose was.

#### **4.2.4.2 Sub-theme 4.2: Higher power**

Table 4.10 provides a working definition of a higher power. The table also includes the inclusion and exclusion criteria used for identifying the participants' experiences of a higher power.

**Table 4.10: Working definition and inclusion and exclusion criteria for Sub-theme 4.2**

<b>WORKING DEFINITION: HIGHER POWER</b>	
A connection or relationship with a force that is greater than oneself (Scioli, & Biller, 2003).	
<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Data referring to a higher power, faith-based actions, or the influence of a higher power.	Data not referring to a higher power, faith-based actions, or the influence of a higher power.

Both participants stressed the influence of a higher power in their lives. Participant 2 focused on the ability of a higher power to bring about change in her child in the form of a miracle:

*We pray to God that one day a miracle will be performed for my son to talk.*  
(Journal entry P2, line 20)

Participant 1 also believed in a higher power manifesting in a miracle, but she also believed that she would have to do something or improve herself in order for the miracle to happen:

*God is able to do anything in a second. I do believe in miracles. In order for that miracle to happen, what do you decide you are doing differently or better to be worthy of the supplements and everything making the difference.*  
(Interview P1, line 336)

This extract highlights Participant 1's belief in the role of a higher power in association with action taken by a parent. This belief is further explained:

*We are working in two levels that are parallel. One level is the level of the practical, supplements, diagnosis, diet, and behavioural therapy. What could make that work is the spiritual part. What God wants for me, what change does he want for me?* (Interview P1, line 339)

The action outlined by Participant 1 included different practical steps taken during the process of treating her child with ASD:

*One level is the level of the practical that is, supplement, diagnosis, diet, and behavioural therapy.* (Interview P1, line 340)

In addition to these practical steps, Participant 1 considered prayer a part of additional action:

*But I can't do it and expect for a miracle because maybe I am not worthy, maybe He is expecting that extra prayer.* (Interview P1, line 350)

In summary, both participants highlighted spirituality needs through the ability of a higher power to bring about change in the form of a miracle. In order for the miracle to happen, however, additional action had to be taken by the parents. This action could take the form of different interventions or additional prayer.

#### **4.2.4.3 Findings on spirituality**

Participant 1 in the present study stressed the importance of knowing the meaning or purpose of life not only for herself but also her child. She viewed the challenges she experienced while raising her child with ASD as an opportunity for personal growth. Spirituality is associated with a search for meaning or purpose in life (Scioli et al., 2016). Parental purpose is considered the ability to redefine the ASD diagnosis in a positive way, the ability to provide comfort and care to their child, and the ability to advocate for the needs of their child (Kausar et al., 2003). Having a purpose in life is a positive psychological resource that can protect people and enable them to overcome challenges in their lives (Sin, & Lyubormirsky, 2009; Smith, 2006).

In the present study, the role of a higher power was important for both participants. This role involved the hope for a miracle to bring about a change in their child's behaviour. Matenge (2014) also found that the hope of mothers of a child with ASD often centred on a miracle that would change the behaviour of their child.

Participant 1 viewed the action she was taking, which included implementing interventions and praying, as complementary to the role of a higher power. Scioli et al. (2016) define spirituality as religion or spiritual expression that is related to receiving strength through a connection to a higher power. Myers et al. (2009) found that the parents in their study believed that a higher power assisted them in meeting the needs of their child. Heydari et al. (2015) found that the parents believed that a higher power gave them strength to deal with the challenges they were facing. After connecting with a higher power, the parents reported feeling calmer in the knowledge that a higher power was in control. The parents were thus able to gain support through relying on this higher power (Heydari et al., 2015).

### **4.3 CONCLUSION**

This chapter outlined the hope experiences of two parents raising a child with ASD as identified through the analysis of data collected by means of participants' research journals and semi-structured interviews. The experiences were discussed in terms of four themes and nine subordinate themes according to Scioli et al.'s (2016) integrative theory of hope.

The final chapter (Chapter 5) covers the answers to the research questions presented in Chapter 1. The contributions and limitations of the study as well as possible areas for further research are also discussed.

## **Chapter 5**

### **Conclusions and Recommendations**

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#### **5.1 INTRODUCTION**

The purpose of this case study was to explore the hope in two parents both with a child with ASD at The Autism School at the time of the study. As indicated in Chapter 2, ASD research tends to focus on the challenges/problems and negative experiences of parents raising a child with ASD (Hutton, & Caron, 2005; Benderix et al., 2007; Meirsschaut et al., 2010; Mulligan et al., 2012). However, there are also positive experiences inherent in raising such a child (Myers et al., 2009; Kausar et al., 2003). It is therefore important to consider the positive as well as the negative experiences of parents with a child with ASD (Faso et al., 2013).

Little research has been conducted exclusively on the hope experiences of parents raising a child with ASD, especially in South Africa where approximately 270 000 children under the age of six are affected by ASD and where the number is increasing by roughly 5000 children annually (Greef, & Van der Walt, 2010; Fewster, & Gurayah, 2015). Thus, more and more parents are raising a child with ASD in South Africa with little understanding of their unique needs (Alli et al., 2015).

In this study, I used semi-structured interviews and participants' research journals to explore the hope experiences of parents with a child with ASD in South Africa. The insights gained from the study are of value because they can increase understanding of the unique experiences of such parents and shed light on how parents raising a child with ASD in South Africa experience hope.

This final chapter covers the answers to the primary and secondary research questions presented in Chapter 1. The challenges and limitations of the study are also discussed followed by recommendations for future research.

#### **5.2 REFLECTING ON THE RESEARCH QUESTIONS**

In answering the primary research question on the hope experiences of parents raising a child with ASD, I first considered the secondary questions that outline the external factors that may influence hope and its relation to the life domains as outlined by the guiding theoretical framework.

The interviews provided the richest data and produced most of the information needed to answer the research questions. The participants' research journals provided supplementary information to the data collected during the interviews.

## **5.2.1 SECONDARY RESEARCH QUESTIONS**

### **5.2.1.1 What events/instances enhance or diminish the experience of hope in parents who have a child with autism spectrum disorder?**

Hope in the parents in the study who had a child with ASD was enhanced when they felt supported by their family members and other people undergoing a similar experience. Support was also provided by the professionals working with their child – this support promoted the development of hope. It was experienced when the professionals were willing to collaborate with the parents and valued their input on intervention strategies. Hope was further enhanced when the parents were able to trust the professionals working with their child to bring about positive change in their child's behaviour.

The parents felt more hopeful when they were able to implement an intervention and could see improvements in the behaviour of their child. Hope was boosted also when the parents felt empowered with knowledge that enabled them to understand ASD and what the professionals working with their child were doing.

The parents in this study experienced more hope when they were able to find different options for solving the problems they encountered. Hope was strengthened when, in conjunction with the practical interventions pursued, the parents were able to rely on a higher power to bring about change in their child. The role of a higher power involved the hope for a miracle to effect change in their child's behaviour.

The events or instances that diminished the experience of hope for the parents in the study included lack of confidence in the professionals' competence. Hope was further reduced when the parents' concerns about their child were dismissed or when they felt blamed for the difficulties experienced by their child.

The parents experienced less hope also when they believed they were not given sufficient information on ASD and the available interventions. This made them feel at a loss about what to do following the diagnosis. Feelings of hopelessness were noted when the parents felt powerless in situations they had no control over. This was seen,

for example, when one of the parents felt there was nothing she could do to help her child who was distressed.

#### **5.2.1.2 How does parents' hope relate to the life domains of mastery, attachment, survival, and spirituality?**

The first life domain, mastery, relates to the degree of control experienced over a challenging situation. The parents in the study experienced less hope when they believed they were not given sufficient information on ASD and the available interventions when the ASD diagnosis was first made. This influenced their perceptions of their ability to establish and implement an effective intervention plan. They were, however, able to experience mastery and an increase in hope as a result of the learning they achieved through raising their child with ASD. This learning occurred in their interactions with the health professionals and through personal research.

Hope was enhanced in terms of the second life domain, attachment, when the parents were able to experience feelings of connection with informal as well as formal sources of support. This connection made them feel supported. Supportive health professionals were characterised as those willing to work with them as parents and those who valued their input in relation to intervention strategies. Trust in the parent-professional relationship boosted the parents' hope experiences. The parents were more hopeful when they felt they could trust the professionals' competence in treating their child. Hope was reduced when a lack of trust was evident in the parent-professional relationship as could be seen when one of the parent's concerns about her child were dismissed, when she was blamed for the problems experienced by her child, or when the professionals were considered incompetent.

The parents felt more hopeful when they experienced mastery through establishing control over the problems encountered with their child with ASD. This was seen when the parents were able to plan and implement steps to influence their child's behaviour positively. Hope, specifically hope for the future of their child, was enhanced when they could see improvements in their child's behaviour as a result of an intervention strategy. The opposite was also noted in the parents' sense of hopelessness when they felt they had no control over a situation, such as not being able to help their child when the child was upset.

The third life domain, survival, related to the parents' perceptions of their ability to generate options to deal with the challenges they experienced and their ability to regulate their own emotions. Hope increased when they were able to generate different

options to solve problems. Emotion regulation occurred when positive behaviour changes in their child were noted by the parents resulting in fewer negative thoughts and less stress, ultimately strengthening their experiences of hope. By actively suppressing negative thoughts and focusing on the intervention plan in place, the parents could reduce negative emotions and enhance their hope. Restructuring hope by focusing on shorter time frames and managing the extent of the hope experienced helped to ensure that hope could be maintained.

The fourth life domain, spirituality, related to the experience of more hope when, in conjunction with the implementation of practical interventions, the parents were able to rely on a higher power to bring about change in their child. The role of a higher power included the hope for a miracle to effect change in their child's behaviour.

## **5.2.2 PRIMARY RESEARCH QUESTION**

In this section, I provide the answer to the primary research question stated in Chapter 1: "What are the hope experiences of parents raising a child with ASD?"

The findings indicate that the parents in the study had a number of experiences related to their hope for their child with ASD. The parents experienced different factors that contributed to them feeling hopeful as well as factors that reduced their feelings of hope. These experiences were related to the life domains of mastery, attachment, survival, and spirituality.

Experiences with the health professionals resulted either in diminished or enhanced hope through mastery-related experiences. Hope-diminishing experiences occurred when the information given at the time of the diagnosis was not specific enough, resulting in the parents not knowing how to move forward following the diagnosis. Conversely, hope-enhancing experiences occurred when their interactions with the health professionals resulted in learning, which also occurred through personal research. The ability to plan and implement steps to influence their child's behaviour, and seeing improvements in the behaviour, were also experiences that resulted in mastery-related hope. When the parents felt they were powerless in certain situations, their hope diminished.

Hope-related attachment experiences included experiences that resulted in feelings of connection with informal as well as formal sources of support. These included feeling supported by family members and other parents undergoing a similar experience. Formal support included supportive relationships with health professionals consisting

of working together collaboratively. This collaborative relationship was based on the parents being able to trust the professionals to bring about positive change in their child, and the professionals being willing to work with the parents and valuing their input.

Generating options to deal with the various challenges experienced by them enhanced the parents' survival-related hope. The options enabled them to identify and implement different solutions to these problems. Survival-related hope experiences also included the ability to regulate emotions, which was achieved by focusing on the positive changes noted in their child and not thinking negatively about the future of the child.

Hope-related spirituality experiences were noted when, in conjunction with the practical interventions the parents pursued, they were able to rely on a higher power to bring about change in their child by hoping for a miracle.

### **5.3 CONTRIBUTIONS OF THE STUDY**

This study provided insight into the hope experiences of two parents raising a child with ASD. The study showed that the parents could and did have positive experiences related to their child with ASD. This finding can contribute to the existing knowledge on ASD and hope.

Valuable insight was gained into the experiences of two parents raising a child with ASD in South Africa, a part of the world where ASD research is limited and is predominantly deficits based.

The description of the hope experiences of the two parents of a child with ASD can help health professionals better understand and support those experiencing the challenges of raising such a child. Health professionals may now also be better able to provide information following a diagnosis in a way that helps parents move forward. They may now also be better able to assess, identify, and intervene with regard to parents who find it difficult to maintain hope.

The integrated theory of hope used in the study highlights the complex nature of hope and how the different life domains have an influence on parental hope experiences. This allows for an alternative understanding of hope that acknowledges the influence of the broader system on hope experiences in contrast with more commonly used theories of hope that focus primarily on the individual.



This study can inform future studies on the hope experiences of parents raising a child with ASD. Further intervention studies could be designed to include aspects of each of the life domains – based on the integrative theory of hope – to enhance the experiences of hope in parents of a child with ASD.

#### **5.4 PROBLEMS AND LIMITATIONS OF THE STUDY**

A number of problems occurred in the implementation of the present research, the first being the recruitment of the participants. After the initial meeting during which the research study was explained and the participants' research journal was handed out, two participants withdrew from the study. Those who chose to remain in the study might have been more or might have been less hopeful than those who chose not to remain. No attempt was made to control for the degree of hope in each parent or the severity of their child's ASD.

The second problem concerned the use of the participants' research journal. Both participants experienced difficulty in regularly recording their hope experiences. I therefore had to remind them on a daily basis to make a journal entry. Thus obtaining an in-depth engagement with the participants over a longer period of time was not realised.

An additional problem with the participants' research journal was that some of the entries were single-line entries that lacked detail thus making it difficult to understand the context of the entries. The journal also did not make provision for questioning to obtain contextual clarification. These brief entries complicated understanding of the parents' experiences and often resulted in data not being used.

#### **5.5 RECOMMENDATIONS FOR RESEARCH**

Based on the findings of this study, additional research is required to gain a better understanding of the hope experiences of parents with a child with ASD in South Africa. Further research should include the following:

- Exploratory studies with parents from different socio-economic status groups, specifically those in rural areas.
- Exploratory studies with parents from different intervention centres, with parents whose children are not attending an intervention centre, and with parents not receiving professional support.
- A study that makes use of an extended period of engagement with the participants.

- A mixed-methods study in which issues such as the severity of the ASD and the degree of hopefulness of the parent could be controlled to understand how those issues influence hope experiences.
- Additional methods of gathering data that align with a phenomenological and exploratory case study.
- An intervention study evaluating the effectiveness of a hope-enhancing programme for parents raising a child with ASD based on the life domains identified by Scioli et al. (2016).

## **5.6 CLOSING REMARKS**

The purpose of this case study was to explore the hope experiences of two parents with a child with ASD. Through my interactions with the parents, and after analysing the results of the study, I became aware of the importance of hope for parents in challenging situations such as raising a child with ASD. Hope should not be seen as parental denial of the problems experienced but rather as engaging with the reality of their situation. The following words of Hooven (2016), a mother raising a child with ASD, illustrate what hope means for her:

*“Hope is necessary. Hope is needed. Hope is real. Hold onto it.”*

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## **Appendices**

**Appendix A:**

Semi-structured interview schedule

**Appendix B:**

Transcripts of interviews and participants' research journals

**Appendix C:**

Coding of data

**Appendix D:**

Researcher's Journal

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### Semi-structured interview schedule

1. What does it mean to be a parent of a child with autism?
2. What does hope means to you, as a parent of a child with autism?
3. Can you think of any events that have either enhanced or diminished your feelings of hope?
4. What experiences made you feel more hopeful? And less hopeful?
5. Can you think of any things that family and friends did that made you feel more hopeful? And less hopeful? If so, what were they?
6. Can you think of any things that professionals or service providers did that made you feel more or less hopeful?
7. Is there anything you do on a regular basis that strengthens your feelings of hope?
8. Is there anything else you would like to share with me?

## **Appendix B**

### **Transcripts of interviews and participant research journals**



## 1 INTERVIEW (1)

2

3 A: What does it mean to you to be a parent of a child with autism?

4 R: Meaning? There is a lot of practical changes but as far as

5 meaning. Well part of it has to do with how I look at life in general.

6 Life for me means a challenge. A person is brought to this world to

7 grow. So she is just one of those things in my life to enable me and

8 all those she comes into contact with to grow. She is just a tool for

9 growth. That is just my perspective. Practical terms, a million things

10 have changed. My whole life has been turned upside down since

11 we realised something was wrong. My life has been completely

12 turned upside down. That's the philosophy behind it. It's all for

13 growth.

14 A: So your mind set is that, the things you come into contact with in

15 life are there to make you grow and become a better person.

16 R: Exactly.

17 A: And in terms of that, what does hope mean to you?

18 R: Well in her case, hope means full recovery. That's my goal, that

19 my aim. That I am putting a lot of time, effort, resources into actually

20 full recovery.

21 A: and what does a full recovery mean to you?

22 R: Being a neurotypical child. Be a kid who could a) be

23 independent, b) find her purpose in life because I don't think that

24 right now she is aware of her purpose in life which is actually the

25 most painful thing for me. I don't know towards where to bring her

26 because we are so wrapped up in the basics of functioning and

27 making sure that she is safe, that I don't feel yet that she knows

28 where she is going and that is actually the most painful thing. You

29 are just going to eat and drink and sleep and get up in the morning

30 and that's it.

31 A: So you know your purpose in life is to grow and become a better  
32 person and that's what you would like to find for her. So not just  
33 living the daily routine.

34 And even her daily routine happens to be extremely difficult. It's not  
35 something I could keep on doing. I am not getting any younger, I  
36 am close to 50, I'll be 50 in a month. It's not something I could carry  
37 on forever. She does have, thank goodness, many many siblings,  
38 who I know will not abandon her, but still I want her standing on her  
39 own feet, even without the purposeful part, the practical part.  
40 Because right now I can't leave her, it is 24/7. Even sleeping, I can't  
41 leave her alone for a second.

42 A: so there are all these things going on all the time and you are  
43 constantly there with her. To make sure that in her daily functioning  
44 she is ok. In relation to all these things that are happening, the  
45 practical changes, are there things that have decreased your hope  
46 or feelings of hope that you have?

47 R: It has been a bumpy road. There have been ups and downs.  
48 First of all, when she was diagnosed I was actually in mourning. I  
49 thought that this was it. I don't have a kid anymore.

50 A: you lost her.

51 R: Yeah, I lost her. The strongest feeling was the feeling of loss.  
52 Thank goodness it only took me three weeks to get out of it. But for  
53 three weeks I was in actual mourning as though I had lost a kid.  
54 When she was diagnosed. I had these vision, because I used to  
55 live in Israel, in a place where they had a programme for adult  
56 autistic men and it was horrifying seeing that. They were all like  
57 clicking and moving their head and shaking around. And I just  
58 thought that this was what my daughter was going to look like in ten  
59 years from now, 15 years from now. So I was totally broken. But  
60 thank goodness I have a lot of support. My husband has always  
61 been by my side, helping and I knew that even with all my faith and  
62 everything, it would be an up I needed a support system here. My

63 husband has been wonderful. So there would be no way I would be  
64 able to cope with this. So together we have made it. Also I  
65 happened, and I don't believe in happened, I happened to meet  
66 someone my husband was studying with and he told me he knows  
67 someone who made a full recovery and lives in Israel now. He  
68 actually got me in touch with school here. Because in the beginning  
69 I was actually lost. You don't know what to do. It's worse than  
70 mentally retard. You don't know what to do. So once I got more  
71 focused on the practical aspects of what to do now, then things got  
72 a little bit better. So I was not trying to focus on what I lost but step  
73 A, step B, what am I doing now. Saying that, I am not saying that I  
74 never break down and cry. I have a wedding coming up. My 21-  
75 year old daughter is getting married and we are going to Israel in  
76 August and I am just thinking about the practical things. Last time I  
77 had a wedding, I have 13 kids so we had a wedding last year too  
78 and we ended up staying there for two and a half months. I was  
79 going bonkers. Because I had no help there, she had no school and  
80 I just couldn't wait. I couldn't enjoy my grandchildren, I have eleven  
81 grandchildren and I couldn't enjoy them. I felt like torn apart. I just  
82 wanted to come back. I had help here, she has structure, I just  
83 couldn't take it anymore even though most of my family are there.  
84 So now I am thinking again, thank goodness we are only going for  
85 two and a half weeks three weeks nothing more. Because I am  
86 thinking I wasn't actually completely present there. I was so worried  
87 and so wrapped up in what to do with her, even though I had some  
88 volunteers taking her for walks too but it was us with her. And she  
89 did some things there (laughing) I am not even going to go into  
90 details. I lost my train of thought, where was I, so I am thinking  
91 again. I am talking to my daughter about what we are going to do,  
92 where we are going to meet. Saturday everybody is going to come  
93 and I am in tears. So what happened, nothing happened, I am just  
94 kind of overwhelmed by this. Am I going to enjoy this, I don't know  
95 A: so this is something that would normally be such a joyous  
96 occasion and you are so wrapped up in the planning...

97 R: How am I going to do it? I actually want to be present, it is so  
98 cute. You'll see on a lot of the photos I will tell you this grandchild  
99 he said this and he did this and all the antics. And I'm asking, am  
100 actually going to be able to sit down and enjoy this with them? And  
101 they say we'll send you to each home and we will take care of you  
102 for a few hours.

103 A: just to give you a few breaks.

104 R: And enjoyment. To be present. That's the problem. None of my  
105 kids understood that, my other kids. That they were so happy to  
106 have us there, but I didn't exactly enjoy it because I wasn't present.  
107 I didn't enjoy. That is one thing I have learnt in life is to enjoy the  
108 moment. I mean it in a positive way, I don't mean be reckless, I  
109 mean to enjoy the moment. The kid smiles, he says something cute,  
110 we laughing, playing together, enjoy it because it goes by so fast.  
111 You have no idea.

112 A: So to be fully in that moment despite what is going on in the  
113 background, this is what is happening now.

114 R: Exactly. So that is something that I am afraid of that I won't be.  
115 So with tears on the phone, my daughter didn't even realise it while  
116 I was talking to her.

117 A: So you say ups and downs.

118 R: yes, there are definitely ups and downs. Of course it is very  
119 encouraging when we try something new, medically or diet  
120 intervention or some educational intervention. Those things usually  
121 bring my hopes high. But I have learnt, at the beginning I used to  
122 be so enthusiastic, this is going to be the solution. Now I have learnt  
123 to be a little more subtle but it does give me hope that here is  
124 something that is going to move us forward.

125 A: so you have learnt how to manage those hopes. Like in the  
126 beginning it was this great new thing and it's going to be like that's

127 the cure but now you have learnt to be more cautious, try it out and  
128 see. Are there somethings that have helped?

129 R: Along the line, I think mostly, everything has helped a little bit.  
130 There were no wows. There was only one wow, that was in the  
131 beginning. That's why my hopes were really high was when we first  
132 diagnosed her, even when the paediatrician saw her, he thought  
133 there was something wrong with me. He asked me if I was taking  
134 medication because the kid seemed ok to her. But I knew  
135 something was amiss because she wasn't talking. She was about  
136 a year a year and a half maybe a little bit more. She wasn't talking  
137 and my kids all spoke at a year and I can say that, I have a lot of  
138 kids, she is my thirteenth child. She was already near two years  
139 and there were other things wrong too but I only realised later. I was  
140 sitting in the paediatrician's room and his phone goes off and she  
141 has a ringing tone of a rooster and it is startling. We both jumped,  
142 she didn't bat an eye lash, my daughter. So we are thinking that it  
143 is a hearing problem. We checked it of course and it wasn't a  
144 hearing problem. But what did help, and I noticed that she wasn't  
145 responding a lot is that we took her off dairy products and within  
146 three four days she was responding. Now that was a wow. So I was  
147 looking at that and thinking ah these other kids are not getting help  
148 like that out there. But everything was a little bit, a little bit. Every  
149 accomplishment is a lot of sweat. So that wow got us confused  
150 because I thought this is so easy. I just take her off dairy, and it  
151 wasn't so easy to take her off dairy because she was addicted to it.  
152 But it is easy in comparison to the results. So that was the only wow  
153 I have had along the journey. And I have spent a lot of time,  
154 research and money.

155 A: so it's a step wise thing, little bits and pieces that you have had,  
156 dairy was a big step but the rest are pieces coming together. Are  
157 there any experiences that you have had they have contributed to  
158 making you feel more hopeful in your journey?

159 R: yeah, you hear of these new interventions and if you didn't try  
160 something and you know you have got them in your bucket list to  
161 try and you want to try do them. We are doing a whole bunch of  
162 things and they are all helping. I have one week, and I happen to  
163 have it in one of my journals there, where she was really so calm, I  
164 could not believe it. There are times where she is bouncing off the  
165 walls, unless she is tired, she is totally ADHD, she doesn't sit down  
166 for a minute. They manage to sit her down, I don't. But normally she  
167 is like running all over. She is not hyper active, she is hyper, super-  
168 duper turbo hyperactive. And that one week she was like happy,  
169 she was engaged with us, she was calm. That was one week.

170 A: so you take it one week at a time.

171 R: one minute, one second at a time. As we were starting to do new  
172 things, I was hoping, but it wasn't. Or maybe it will be again, I don't  
173 know.

174 A: and then the flip side, somethings and experiences that you have  
175 done that have made you feel less, or things that have happened?

176 R: I don't want to disgust you but one of the things that really put  
177 me down is she played with her stool and she smeared it all over. I  
178 said God, this is my limit. I can't take this.

179 A: so you can handle so much but there is a line.

180 R: Go scrub all the little corners. Its horrifying. That's one of the  
181 things that really. And when you see her, especially when she is  
182 unhappy and something is really bothering her and I don't know  
183 what to do to help her. And that is heart breaking. I don't know what  
184 to do. She is either in pain or some kind of bad feeling but you don't  
185 know what to do. That's the worst. For her to be able to express her  
186 feelings but that's the worst part because of the communication  
187 because she is nonverbal. So that part puts you down too. Like I  
188 have some sleepless nights so if it is a sleepless night where she

189 is happy I'll go with it. But if it's one of those nights that she is  
190 banging her body, hitting her head, she doesn't normally hit her  
191 head but it does happen on a soft spot. She is smart enough not to  
192 do it on a wall or anything. But she is throwing her body all over,  
193 when she did that, she banged me in the eye and I got this spider  
194 thing in my eye, its fine now because its finally evaporating. It's just  
195 a floater, but it scared me because she hurt me, she hurt someone  
196 else. So when she gets into a sleepless night like that, she is  
197 frustrated, or in pain or I don't know what then that's something that  
198 puts you down. Or when you see that she is trying to talk. And she  
199 is trying and you can see all that effort and she is not managing.  
200 When someone says what's wrong and I say it ok, she is a beautiful  
201 kid, she is not distorted in any way. And everything seems to be  
202 perfect, the picture is perfect but the connection, something is  
203 wrong. Something in the connection is just not working. You see  
204 that also she is trying so hard so just doing it.

205 A: like if you could give her that little extra push.

206 R: yeah, oh man.

207 A: you spoke about your husband and the support that you have,  
208 can you think of some examples of what either family or friends  
209 have done, that have helped you to stay hopeful?

210 R: my kids, I would say they are always praying and always asking  
211 about her. I am not good in creating a support system, and I know  
212 you are always told you should create a group, I just don't have the  
213 time and energy for it. In a way I am actually isolated because I'm  
214 busy with my own stuff. I don't have the time or energy to. A lot of  
215 people I don't keep in touch with anymore, not purposely in a way  
216 but sort of, even like my parents, they end up calling me which is  
217 not nice, I should be calling them, they are my parents. And they  
218 are a little bit angry with me because I am here. They came from  
219 America to Israel. And I left and they didn't come to terms with that.

220 But I am going back anyway. And they are unhappy about that. So  
221 you are talking about support of friends and family, I am not so  
222 much in touch, no.

223 A: it sounds as though your immediate family structure is big  
224 enough with your kids and your husband.

225 R: That's what I am busy with.

226 A: it sounds as though you are too busy to be expanding it. It would  
227 be more hard work.

228 R: exactly. It is something you need to cultivate. It's not a one-way  
229 street. Any kind of relationship. I actually do have the time. I have  
230 a lot of help. I just don't have the energy. I think I have to call this  
231 friend that I haven't been in touch for a while and I keep on  
232 procrastinating.

233 A: and on the flip side, experiences with friends and family where  
234 they made you feel less hopeful?

235 R: not really, I haven't come across that, no.

236 A: and then professionals or service providers. You spoke about  
237 the paediatrician who thought...

238 R: oh the paediatrician really got me upset. She was telling me  
239 something that happened in my pregnancy or I have never been on  
240 medication. You don't know what the problem is so don't throw it at  
241 me. And actually, she was a very bad diagnostician. My daughter  
242 was sitting at the time, she was calm and she was playing with a  
243 truck. But she was playing with the truck upside down with the  
244 wheels. She was not properly. She should have seen that. Later I  
245 learnt that that is a characteristic of autistic kids. But then we did a  
246 battery of tests with her hearing, her hearing was fine and again I  
247 didn't know what to do. We had somebody over for Shabbat meal,  
248 Saturday meal, and he told me his uncle is a very good  
249 paediatrician. I was focusing on the fact that she wasn't talking that



250 I didn't actually notice that she regressed in many ways that that  
251 paediatrician pointed out later. I didn't notice.

252 A: so there were other things.

253 R: there were but I wasn't aware of it. You see what happened is  
254 she did develop ok but then she regressed. When we came here  
255 she was a year and four months old and my oldest daughter had  
256 just married a few months before and we moved here and  
257 everything was just too much for me. The paediatrician, when we  
258 went to him, he said to me she is autistic. I was totally in shock.  
259 Thank goodness my husband was with me because I was just like  
260 no don't waste your time, but he insisted on going with me, because  
261 I would not have made it back to the house. Autistic, I sat there  
262 thinking about the programme that they had in Israel for autistic  
263 adults. What on earth is he talking about? He started, she is not  
264 playing properly, not making proper eye contact. She does this, I  
265 started thinking, she used to do it but she is not doing it anymore  
266 and I didn't notice. I was just focusing on the speech all the time, I  
267 didn't notice. So he was a good diagnostician but I think he threw it  
268 out a bit fast.

269 A: it sounds like he just dropped it

270 R: but then he was trying to encourage me. There is diet  
271 intervention and he had a friend in medical school who was autistic.  
272 But did he manage to communicate and did he have friends? No.  
273 And there are many programmes and stuff. So he did give me, but  
274 I wasn't even listening. I had already shut down totally. It was like  
275 an earthquake, I don't know how to describe it, an atomic bomb. It's  
276 the least thing I expected. He could have been a little more gentler.  
277 He had to tell me the truth because I would never get moving. But  
278 also he just told me something general. I didn't know what to do  
279 from there. Until my husband spoke to his learning partner, he  
280 referred me to this person who had a kid who was fully recovered,

281 I didn't know what to do. He just said, there is such a thing, but he  
282 didn't tell me go there, go there, go look at this website, go...

283 A: the specifics

284 R: I reconstructed it later when I started doing my thing. But he  
285 didn't tell me where to go so I didn't know what to do.

286 A: and you sound like a very practical person. Once you get going...

287 R: exactly, so then I was at a loss for two weeks until we started to  
288 get things going. Also I was telling you that since she was two, two  
289 and a half we started the ABA programme, the chances of a full  
290 recovery are very good etc. it didn't happen. Her progress on the  
291 programme itself was very slow, very slow.

292 A: so that wasn't something you had anticipated.

293 R: no, I anticipated more. Even without a miracle, a large  
294 percentage of these kids do function at fully recovered or a very  
295 high level when you start early intervention. They were talking  
296 about early intervention and I started early intervention. She was  
297 really young. But it did not happen the way I had hoped.

298 A: where there any other service providers or professionals that you  
299 encountered that either added or have taken away from your hope?

300 R: we also tried another school, but that didn't work, with the  
301 medical aid because they were just using a speech therapist and  
302 OTs but they don't know how to handle her. They told me to bring  
303 her for one session and was going to go for four sessions for a full  
304 eight hours. So I was like forget it, you guys don't know what you  
305 are doing.

306 A: so people don't know what they are doing

307 R: they could have told me to bring her less or that they can't help  
308 her.

309 A: so it's more the behaviours

310 R: Exactly, you guys don't know how to handle her. And medically,  
311 not everyone does, it's a little bit thinking out of the box, the  
312 supplements and the dietary interventions. So not every doctor will  
313 go for it. So I am very thankful that I have a general practitioner who  
314 is willing because the doctors I usually consult with are from the  
315 states. So when I need some prescription stuff, she is very open  
316 minded, thank goodness, I don't have a problem getting a  
317 prescription because I would have to wait to have it delivered from  
318 the states. I do manage because sometimes I don't have a choice.  
319 But it makes things a lot more tedious and difficult. But some they'll  
320 see and they don't even look into it. Autism is considered a  
321 psychological disorder and it has nothing to do with the physical  
322 which the milk fiasco told me it is not. The change was so  
323 unbelievable that it just shed light on the whole thing. I was sceptical  
324 in the beginning but when I saw the change with the milk, I saw the  
325 correlation was there.

326 A: so it's not just a psychological disorder, there is something bigger  
327 going on.

328 R: diet has an effect on cognition, for sure. I don't think we have  
329 cracked exactly what it is but we are trying from all angles.

330 A: but it sounds like it is something that keeps you going, putting all  
331 the pieces together, trying this intervention, trying this supplement,  
332 trying this diet and seeing what happens.

333 R: exactly

334 A: you mentioned your faith and God. In terms of religion how does  
335 that play a part in staying hopeful?

336 R: because God is able to do anything in a second. I do believe in  
337 miracles. In order for that miracle to happen, as much as he wants  
338 it for me... actually what we are doing is, my husband keeps  
339 reminding me, we are working in two levels that are parallel. One

340 level is the level of the practical. So supplement, diagnosis, diet,  
341 behavioural therapy. What could make that work is the spiritual  
342 part. Like what God wants for me, what change does he want for  
343 me? So my husband reminds me, what did you decide you are  
344 doing differently or better to be worthy of the supplements and  
345 everything making the difference. So that's how we are actually  
346 working. For something to work or not to work, it is his decision.  
347 That is the right path to go because we live in a natural world. We  
348 can change it by our behaviour, deeds etc

349 A: so it is a combination approach. It is not just one sided.

350 R: exactly. One side will not work without the other. I can't not do  
351 anything and expect for a miracle, it doesn't work that way either.  
352 But I can't do it and expect for a miracle because maybe I am not  
353 worthy, maybe he is expecting that extra prayer.

354 like you were talking about, that growth and becoming a better  
355 person.

356 R: Exactly.

357 A: and is there something that you do on a regular basis that help  
358 strengthen these feelings of hope?

359 R: I pray all the time.

360 A: so prayer is a big component. Is there anything else you would  
361 like to share with me?

362 R: I think we have covered all the bases.

## 1 Diary entries (1)

### 2 **6 June 2017**

3 So I am supposed to speak about hope but that is a bit of a problem  
4 though I am living with a lot of hope. I am hoping, and I just spoke  
5 to my husband, that one day my daughter will be normal. Not only  
6 will she be normal but she will find her special ability to make a mark  
7 for herself in this world. I am looking into different therapies right  
8 now, besides what she is doing now in the ABA at school at  
9 (school), mainly RPM. I might have some cooperation from her  
10 case manager, even though it's a totally different method, I am  
11 putting a lot of hope in that. We have been very overwhelmed with  
12 a lot of things, very busy. Regarding (my daughter) we are hoping  
13 that she will be normal. It may sound not normal but that is what we  
14 are hoping for.

### 15 **7 June 2017**

16 Today she had a very good mood which was very encouraging and  
17 hoping that this will carry on. No whining, no crying, relatively  
18 happy. Thank goodness for that.

### 19 **25 June 2017**

20 My message of hope today is the fact that the past few days she  
21 has been sleeping pretty well and had a good mood. I am hoping  
22 that this will continue and will be conducive to her learning which  
23 her pace of learning hasn't been great so I hope that this will help.  
24 I am very hopeful with that respect.

### 25 **26 June 2017**

26 I meant to record this on the 26<sup>th</sup> of June because on the 26<sup>th</sup> of  
27 June we had a workshop at (daughter's) school and she was  
28 amazingly calm and did very well. This has given me a lot of hope  
29 for the future that she will do even better because until now my  
30 feeling was that because of her lack of concentration and her super-  
31 duper hyperactivity, she wasn't taking advantage of her school time

32 but she is doing much better and she is also making a lot more  
33 sounds and that gives me hope.

34 **28 June 2017**

35 Last night we had a skype consultation with (consultant) regarding  
36 a new method that I have tried in the past with (daughter) but hasn't  
37 been very successful. It is called RPM. It is a way of education and  
38 through education you get communication. But this time (case  
39 manager) is on board too so I am very hopeful that this time it will  
40 work and we will actually be able to get through to (daughter)  
41 because her biggest obstacle in her daily living is communication.  
42 So if we get to communicate and she gets to communicate what  
43 she thinks and we can teach her things and enrich her world greatly  
44 and we don't just get stuck on the basics of functional things. Her  
45 life will be a lot more interesting and purposeful and that gives me  
46 a lot of hope because that part is extremely depressing. To think  
47 that we are just always getting her or teaching her really basic skills  
48 and never getting to education or understanding life or the world  
49 around her.

## 1 INTERVIEW (2)

2

3 A: What does it mean to you to be a parent of a child with autism?

4 What does that mean for you?

5 N: It's a different experience. It's a challenging one. But being with  
6 him is awesome and for me I don't have a problem with my baby  
7 being autistic. You learn a lot. And you experience new things every  
8 day. The most important thing is that you must be able to handle  
9 your child every day and you must be very supportive of him every  
10 day and you must be able to understand where he is coming from.

11 A: It sounds like there are a lot of positives and lots of negatives in  
12 that answer as well. You mentioned that there is a lot of learning  
13 that takes place. For you, in the journey that you have had so far,  
14 what have been some of those areas that you have had to learn?  
15 What have you learnt from your son?

16 N: firstly, you learn new things every day as he goes to school every  
17 day. He has new things every day from the therapists where you  
18 teach him new things. They teach him how to be. Most importantly  
19 they teach him the discipline of how to be. But sometimes at home  
20 it is different. As a mother it is different where you don't feel like  
21 disciplining him. You feel like whatever he asks for you just want to  
22 give it to him. For example, he knows he likes phones and some  
23 times he needs to be disciplined with the phones and told "no, you  
24 can't have". He loves watching movies and stuff. He loves to watch  
25 youtube and stuff and most of the time on the weekend I do allow  
26 him. But on the other hand at school they are very well disciplined  
27 where they don't allow him unless he does something good and as  
28 a reward he gets it.

29 A: Its so much easier as an instructor who has to work with him for  
30 a session for three hours, compared to a mom for the other hours

31 in the day. I hear what you are saying, it is a challenge to discipline  
32 him all the time.

33 A: so what does hope mean to you as a parent who has a child with  
34 autism?

35 N: I have a lot of hope for my baby and I hope one day that he will  
36 be what I want him to be. I have a hope that one day he'd be a  
37 grown up boy and he'd be all independent and he will know what  
38 he is doing. At least, you have that hope where he would be  
39 independent and support himself. You know, he could do things  
40 and have that hope one day that he will have his own family.

41 A: so independence is very important for you. Can you think of any  
42 events that have enhanced your feelings of hope? Any specific  
43 things that have happened that make you feel more hopeful?

44 N: Every time (child)'s behaviour changes. His behaviour changes  
45 and I have full trust on the therapist that they try to do their best  
46 every day. Because of them (child) changes every day. With him  
47 changing, you have more hope every day and you have less  
48 negative thoughts every day. Sometimes he does things that you  
49 can't imagine that a normal child would do and I don't have any  
50 stress for (child) at the moment because I know that with regard to  
51 him going to school and learning, he is going to be a normal boy.  
52 Where he can think and do things.

53 A: so seeing those positive behaviour changes, gives you so much  
54 hope for the future.

55 N: To be honest with you, I have seen some kids out there. If you  
56 go to think about it, (child) is different. He knows everything. He  
57 knows when he wants something and you are not giving it to him.  
58 He knows that when my mom comes home from work I need to ask  
59 her for the phone. You know those types of things. He knows when  
60 he



61 does something, he gets disciplined in a loving way. He knows now  
62 that he is not going to get anything. He knows that he should not  
63 do it. Things like that, he knows most things.

64 A: So the fact that he knows and is aware of his surrounds and  
65 discipline...

66 N: and he knows when he is with his brother, that if his brother  
67 irritates him then he beats him up. (child) beats him up. If anybody  
68 irritates him then he comes to me and starts beating me up because  
69 he doesn't know what to do. In a way he wants me to help him to  
70 move the... his brother out of the way.

71 A: he has his own way of making meaning.

72 N: he knows his foods very well. He knows what he doesn't like he  
73 doesn't eat. So by the way he is a sensible child.

74 A: so there are no grey areas, you know what to expect with (child),  
75 Its not one way or the other. You know that today he is going to like  
76 these foods and that is the way it is.

77 N: We know what he likes and he chooses his.

78 A: so food he is quite picky.

79 N: he likes fries rather than home food. He likes takeaways. He  
80 likes everything.

81 A: so you said that these, so you see how his behaviour changes  
82 and it gives you more hope and you link that having more hope to  
83 having fewer negative thoughts. How does that work for you?

84 N: sometimes you think a lot. You think maybe this can, maybe that  
85 could happen and then what.

86 A: so all the negative thoughts of what could go wrong?

87 N: sometimes I do but I try not to. Sometimes I when (case  
88 manager) comes to see me, I always sit and ask him lots of

89 questions. I tell him I want my  
90 son to have a family, I want  
91 him to get married. I want him  
92 to have a life. I want him to work. Even if one day he can't read or  
93 write. Maybe one day he can read, maybe not write he must be able  
94 to use a computer, he must be able to use a laptop. He must be  
95 able to know things.

96 A: it sounds like you want him to be practical. Computer skills are  
97 practical.

98 N: have lots of computer skills. And if you have to think about it,  
99 there is no doubt that these kids are intelligent. Their way of  
100 thinking, their way of doing things is very different compared to  
101 normal kids.

102 A: He has his own way of doing things but there is no doubt that he  
103 is an intelligent young boy and he can do things but in his own way,  
104 not the way that we put expectations on him.

105 A: you say that when you meet up with (case manager) you  
106 bombard him with lots and lots of questions. So it is a nice  
107 opportunity for you to learn more.

108 N: Learn more, ja.

109 A: Learn more from (case manager)?

110 N: I would say to you, to be honest they are with him most of the  
111 time. They know him better than me. They know how to handle him.  
112 Sometimes as a mom, in some instances, I can't handle (child). In  
113 a way there, sometimes you would take him to the mall, he doesn't  
114 want to sit in the trolley, he wants to walk. And when he walks he  
115 just wants to touch everything. And he wants to go in every shop,  
116 so there are ways in which you can't handle him. He needs a quiet  
117 environment where he can be able to sit and watch TV or maybe  
118 do something else. For him to be in a mall is a very exciting thing.

119 You have to cautious of where he is walking and what he is doing.

120 You can't leave him to follow you, which he won't, he is not going

121 to follow you. So it becomes difficult for me there. Also (child) likes

122 going to watch moves, going

123 to movies. But sometimes

124 you know you

125 have to schedule in his own time. Because there are people around

126 and he likes making noises and stuff. So people are not too OK with

127 that. So you have to schedule his own time to take him in his own

128 time.

129 A: so making ways for things to work out that benefits for all those

130 involved.

131 A: have there been any events that have reduced the hope that you

132 experienced? Or reduce the hope you have?

133 N: I don't know what to say but I am not having negative thoughts

134 on my hope. I don't want to

135 A: you don't want to. You don't want to go there. You want to make

136 sure that your hopes stay positive.

137 N: I want to because (child) is a normal child and like I was saying

138 he knows everything. Like what this child would know, (child) would

139 know. It's just the part where he can't speak and communicate with

140 me that's the problem. You know (child) would know that if you pick

141 up your car keys, (child) would know that you are going out.

142 A: so he picks up on those cues

143 N: and if you drive along the road and say if you are taking the same

144 routes as school but you are not going to school and he is thinking

145 in his mind, oh I am going to school now and he will cry.

146 A: because he is expecting school

147 N: and he is thinking, oh I don't want to go now. Even when I am  
148 driving with him, he will always tell me, I don't want to go home I  
149 want to go somewhere and he will make me put my indicator on not  
150 to come home.

151 A: so he will manipulate the situation to get you to go where he  
152 wants to go.

153 N: maybe if he is bored at home, or doesn't want to be at home. He  
154 wants to go out. Those types of things.

155 A: are there any things that friends and family do that help you to  
156 feel hopeful?

157 N: No. If you go to think about it, not many people are learned about  
158 this. And not many people know about autism because I have been  
159 his mom and I have understood this thing. Not many people  
160 understand. Not many people have educational thoughts about it.  
161 They wouldn't think. An example, me and you, if we are sitting with  
162 (child) and we know if he is shaking his head or making a noise, we  
163 would know maybe he wants something, maybe we can offer him  
164 something. We can take the tablet to him and ask him what is it that  
165 you want? Maybe he wants to eat something, maybe he wants to  
166 change the channel. Me and you would think like that but family  
167 outside that are not learned about this would not think that way.  
168 People would think (child) shaking his head is mad, he is not OK

169 A: so they don't understand

170 N: they don't understand the way of autistic kids, they don't  
171 understand the way they are. People don't. To be honest with you,  
172 people out there are not learned about this. They don't understand,  
173 they don't have knowledge about it. So if it brings them to a stage  
174 where they can think anything about the child. For example, if I have  
175 to see an abnormal child, I understand where the child is coming  
176 from, that he is abnormal and that it is not his fault. Some kids look  
177 alike, most of them, but if you go to look at them they are the cutest

178 kids, they all look the same. They are the cutest kids. And if you  
179 don't have a literate mind, you're not going to know. It is going to  
180 be hard for you to accept them for what they are.

181 A: do you find that family and friends aren't willing to learn. So if you  
182 try to explain to them that he is doing this...

183 N: maybe one out of ten.

184 A: so very few of them.

185 N: very few of them.

186 A: So you have encountered very little acceptance in family, friend  
187 circles, in general?

188 N: basically old traditions don't know anything.

189 A: so it is the older

190 N: so it's the older school. So they wouldn't know about what's  
191 autism and what's autistic kids and what's to be. You know those  
192 things. They don't know.

193 A: they don't know and they are not willing to change or learn?

194 N: I don't think so. They have no knowledge about anything. Like I  
195 can sit there and communicate with (case manager) and know what  
196 he is talking about. People wouldn't. If they sit with him, if you bring  
197 an unknown person they won't know what (case manager) is talking  
198 about.

199 A: it's like he speaks a different language completely

200 N: especially when I read his notes, I know what he is saying. I  
201 understand.

202 A: because you have educated yourself in such a way, to  
203 understand your son and what he needs. And that's why you can  
204 speak (case manager)'s language. But you have taken the initiative  
205 to go and learn.

206 N: yes

207 A: in terms of your support system, it sounds like (case manager)  
208 as (child)'s supervisor, his team and then are there any people who  
209 you can rely on?

210 N: rely on as in

211 A: for emotional support or for

212 someone to be with you on

213 this journey

214 N: No. It's his aunt. She is very supportive of him. Supportive of him  
215 in a way even more than me and his daddy. Where ever she goes,  
216 if anybody has to say anything about him or look at him in a funny  
217 way, she gets defensive and offended by it. She doesn't like it. She  
218 would explain to him, the baby is autistic, and that's why he is doing  
219 what he is doing. She defensive about it, she doesn't like it.

220 A: you say she is very supportive and very protective over him. You  
221 mentioned (child)'s dad...

222 N: (child)'s dad to be honest with you, I'm not going to lie to you but  
223 sometimes it is hard for him to accept things that (child) does.  
224 Sometimes (child) likes to shake his head which he doesn't like and  
225 (child) makes a noise which he doesn't like. He's also not much  
226 educated about autism. He doesn't know about it. So sometimes I  
227 fail to explain to him, in my own way but sitting here with you, you  
228 would understand where I am coming from. It is easy for me to  
229 communicate with you because you know all about it. It is easy for  
230 me to sit and communicate with (case manager) because we know  
231 about it. We know what the challenges, we know what is what. But  
232 if you put (case manager) and him, I don't think he would  
233 understand what (case manager) is saying.

234 A: and does that make it challenging for you?

235 N: it does. I just I learn to ignore. You know. I don't give much of a  
236 statement.

237 A: so when he gets annoyed with something (child) is doing, it is  
238 easier to ignore than to engage.

239 (child): than to explain all the time the same thing. I am not going to  
240 do that.

241 A: you get to the point where you have tried to explain, you have  
242 tried to educate, you have tried to inform and

243 N: and if you don't understand than suit yourself, I can't

244 A: it sounds like you have all the patience in the world for (child) but  
245 for other people there is a little bit less.

246 N: at the end of the day, I can't deal with a person who doesn't have  
247 a mind. It is hard for me. Especially when you explain to them and  
248 they don't understand. It becomes hard for me. Like the aunt, we  
249 can communicate together, we know. We can speak about what's  
250 what. (child) is a very independent child. We don't baby him. I  
251 especially don't baby him. If (child) thinks he wants to play with me  
252 then he comes to play with me. If I feel that I want to go play with  
253 him, I go there. And if I feel that if I am lying in the bedroom and he  
254 wants to come inside, that's his choice. And then he gets out of the  
255 bed then he goes to his other room. Then he decides he no he  
256 doesn't want to sleep and then goes to watch TV. Sometimes he  
257 wakes up three o'clock in the morning and wants to watch TV. And  
258 maybe five o'clock he goes to bed. That's his own independence  
259 which I don't stop him from. I can't baby him and make him sleep  
260 and all those things. He goes to sleep when he feels like.

261 A: that links with the hope you mentioned in the beginning of having  
262 an independent son who is able to do what he wants to do. His own  
263 purpose.

264 N: I don't sit him on my lap and make him sleep. He knows his  
265 times.

266 A: when he is ready he will. Can you think of anything that  
267 professionals or service providers, different people you have  
268 encountered in your journey, things they have done to enhance  
269 your hope for (child)?

270 N: professionals outside?

271 A: well you mentioned (case manager). We know that because you  
272 have seen the positive behaviour change, but anyone else that you  
273 have encountered. Maybe before he was diagnosed, maybe during  
274 the

275 diagnostic procedure. Anything they have done to either enhance  
276 or diminish that hope experience that you have?

277 N: no, not really besides school no one else.

278 A: and by school you mean the autism school.

279 N: if I have any problem or if I have any issue I always consult (case  
280 manager) and ask him what to do. And then we both sit down and  
281 we both suggest, will this be good or will that be good. How to  
282 resolve this issue and what to do and how much we do it.

283 A: Sound like you two work together as a good team.

284 N: we work together

285 A: it's not just like (case manager) the professional and mom

286 N: and if he has a problem he always mails me or messages me.  
287 Do this or I need this or whatever it is. Like at the moment, (child)  
288 is walking on his toes and we are always prompting him to walk  
289 nicely and you know (child) sometimes he gets to comfortable  
290 walking on his toes. So I suggested to (case manager) we need to  
291 get him inner shoes. The ones made of plastic so that those things  
292 can keep his feet down. So we work together.



293 A: so you make recommendations together and the team  
294 implements it. So your journey with (child), from the beginning,  
295 when he was first diagnosed, how did you experience that?

296 N: it was a shock for me. It was a worry for me. It wasn't a good  
297 feeling at first. Its not what I expected him to be him. But on the  
298 other hand, when I joined him at the autism school, that's where my  
299 hope went very far. I had full trust on the school and I had full trust  
300 on the therapists and full trust on (manager at school). She was the  
301 main person that helped me throughout everything and gave me  
302 hope for my baby. If it wasn't for her I wouldn't have had no hope  
303 and I wouldn't have had a school for my baby and I wouldn't have  
304 had (child) the way he is today.

305 A: the autism school gives you, it sounds like a plan, you know  
306 what you are doing with (child).

307 N: when I sit at work and I know that (child) is at school, I don't have  
308 no fears or worries about him.

309 A: you know that he is safe but he is also learning and developing  
310 and growing.

311 N: yes

312 A: is there something you do on a regular basis that strengthens  
313 your feelings of hope.

314 N: yes. I know on a daily basis that he is ok and is doing fine and is  
315 learning new things every day.

316 A: so those thoughts keep you going.

317 N: yes. And knowing him that they teach him to be a normal child  
318 and a normal person to do things.

319 A: is there anything else that you would like to share that you think  
320 that I should know in order to better understand your experiences.

321 N: I have mentioned everything about him. But if there is anything  
322 you need to ask me you are most welcome.

1 **Diary entries (2)**

2 **Day 1**

3 Makes sounds with hands and mouth.

4 **Day 2**

5 Went to toilet just to get youtube

6 **Day 3**

7 Playing with soap and washing dishes

8 **Day 4**

9 Wants youtube if not then he prefers bubble bath

10 **Day 5**

11 He loves food. He loves to warm his food in the microwave.

12 **Day 6**

13 Today he unpacked my draw and unfolding clothes.

14 **Day 7**

15 Played with sand and water.

16 **My hopes and my experiences**

17 I have high hopes for my baby. I hope that one day he becomes

18 independent and successful. We pray to God that one day a miracle

19 is performed for him to talk. My experiences are wonderful. I have

20 experiences every day. My baby is awesome. He is something else

21 that a parent would love to have. He is amazing. Every day is a new

22 challenge and experience.

23

## Coding of data

## Break down transcript into smaller sections – assign a theme (1)

Line numbers	Theme
6-13	Purpose in life Personal growth
18-23	Hope for: <ul style="list-style-type: none"> <li>• Recovery / neuro typical child</li> <li>• Independence</li> <li>• Purpose in life</li> </ul>
24-30	Challenges: <ul style="list-style-type: none"> <li>• Child knowing purpose in life</li> <li>• Focus on Activities of Daily Living</li> <li>• Ensuring safety</li> </ul>
34-36	Challenges: <ul style="list-style-type: none"> <li>• Aging parents</li> <li>• Activities of Daily Living</li> </ul>
37-38	Support: <ul style="list-style-type: none"> <li>• Siblings</li> </ul>
47	Positive and negative experiences
48-53	Diagnosis a period of mourning
54-59	Previous experiences
60-64	Support: <ul style="list-style-type: none"> <li>• Spouse</li> </ul>
65	Destiny
66-67	Positive stories from others
68	Creating connections
69-73	Focus on practical
74-77	Practical planning can be overwhelming
78-79	Support: <ul style="list-style-type: none"> <li>• Assistance</li> <li>• Schooling</li> </ul>
80-81	Being present
82	Help: <ul style="list-style-type: none"> <li>• Structure</li> </ul>
83	Challenges despite support
86-87	Being present
88	Challenges despite support

89-90	Previous experiences
90-94	Practical planning can be overwhelming
97-100	Being present
101-102	Challenges despite support
104	Being present
105	Not being understood
106-111	Being present
119-121	Hope: <ul style="list-style-type: none"> <li>• Interventions</li> </ul>
122-124	Learning to manage hope
129	Small gains
133-143	Challenges: <ul style="list-style-type: none"> <li>• Professionals not acknowledging parent concerns</li> </ul>
144-146	Hope: <ul style="list-style-type: none"> <li>• Intervention working</li> <li>• Immediate change</li> </ul>
148-149	Small gains
152	Effort compared to gains
153-154	Challenges: <ul style="list-style-type: none"> <li>• Time, money and research</li> </ul>
159-162	Hope: <ul style="list-style-type: none"> <li>• New interventions</li> <li>• Intervention working</li> </ul>
169	One day at a time
172-173	Hope: <ul style="list-style-type: none"> <li>• Failed intervention might work at a later point</li> </ul>
176-181	Challenge: <ul style="list-style-type: none"> <li>• Past experiences</li> </ul>
182-199	Hope diminishing experiences: <ul style="list-style-type: none"> <li>• Child unhappy, bothered, in pain</li> <li>• Not knowing what to do</li> <li>• Not being able to communicate feelings</li> <li>• Self-injurious behaviour</li> <li>• Hurting others</li> <li>• Child trying but not succeeding</li> </ul>
200-204	Child's normal appearance
210-217	Support positive: <ul style="list-style-type: none"> <li>• Children</li> </ul> Support negative: <ul style="list-style-type: none"> <li>• Time and energy required for a support group/ network</li> </ul>

228-232	Support negative: <ul style="list-style-type: none"> <li>• Energy required for a support group/ network</li> </ul>
238-240	Blamed for child's disorder
241-247	Professionals missing important diagnostic characteristics
250-257	Parent missing important diagnostic characteristics
258-261	Support: <ul style="list-style-type: none"> <li>• spouse</li> </ul>
262-263	Past experiences
264-267	Parent missing important diagnostic characteristics
267-268	Presenting the diagnosis gently
270-273	Hope: <ul style="list-style-type: none"> <li>• information on intervention</li> <li>• real life stories</li> </ul>
274-276	Presenting the diagnosis
277	Need to know in order to take action
278-279	Need specific information
281-285	Need specific information
286-288	Taking action
288-297	Hope diminishing: <ul style="list-style-type: none"> <li>• slow progress</li> <li>• Not getting the expected results</li> </ul>
298-310	Professionals not knowing what they are doing
311-320	Professionals: <ul style="list-style-type: none"> <li>• Thinking creatively</li> <li>• Being open minded</li> <li>• Being willing to listen to the recommendations of the parent</li> </ul>
321-328	New ways of thinking
328-329	Creative problem solving
334-339	Faith system
340-341	Practical action
341-348	Faith system <ul style="list-style-type: none"> <li>• Becoming a better person</li> </ul>
349-353	Combining spiritual and practical
354-356	Personal growth
357-359	Faith system

## List all themes and relate to one another (1)

Personal growth	<ul style="list-style-type: none"> <li>• New ways of thinking</li> <li>• Creative problem solving</li> <li>• Being present</li> </ul>		
Hope for:	<ul style="list-style-type: none"> <li>• Recovery / neuro typical child</li> <li>• Independence</li> <li>• Purpose in life</li> </ul>		
Challenges:	<ul style="list-style-type: none"> <li>• Child knowing purpose in life</li> <li>• Focus on Activities of Daily Living</li> <li>• Ensuring safety</li> <li>• Aging parents</li> <li>• Activities of Daily Living</li> <li>• Past experiences</li> <li>• Time, money and research</li> <li>• Child's normal appearance</li> </ul>		
Support:	<table border="0"> <tr> <td> <ul style="list-style-type: none"> <li>• Siblings</li> <li>• Spouse</li> <li>• Positive stories from other children</li> </ul> </td> <td> <ul style="list-style-type: none"> <li>• Assistance</li> <li>• Schooling</li> <li>• Structure</li> <li>• Creating connections</li> </ul> </td> </tr> </table>	<ul style="list-style-type: none"> <li>• Siblings</li> <li>• Spouse</li> <li>• Positive stories from other children</li> </ul>	<ul style="list-style-type: none"> <li>• Assistance</li> <li>• Schooling</li> <li>• Structure</li> <li>• Creating connections</li> </ul>
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Support negative	<ul style="list-style-type: none"> <li>• Challenges despite support</li> <li>• Not being understood</li> <li>• Time and energy required for a support group/ network</li> </ul>		
Experiences	<ul style="list-style-type: none"> <li>• Positive and negative</li> <li>• Previous</li> </ul>		
Diagnosis	<ul style="list-style-type: none"> <li>• Professionals not acknowledging parent concerns</li> <li>• Period of mourning</li> <li>• Presenting the diagnosis gently</li> <li>• Parent missing important diagnostic characteristics</li> </ul>		
Hope:	<ul style="list-style-type: none"> <li>• Interventions</li> <li>• Intervention working</li> <li>• Immediate change</li> <li>• New interventions</li> <li>• Intervention working</li> <li>• Failed intervention might work at a later point</li> <li>• information on interventions (specific information)</li> <li>• real life stories</li> <li>• Effort compared to gains</li> <li>• Learning to manage hope</li> </ul>		
Positive outlook	<ul style="list-style-type: none"> <li>• Acknowledging small gains</li> <li>• One day at a time</li> </ul>		
Hope diminishing experiences:	<ul style="list-style-type: none"> <li>• Child unhappy, bothered, in pain</li> <li>• Not knowing what to do</li> <li>• Not being able to communicate feelings</li> <li>• Self-injurious behaviour</li> <li>• Hurting others</li> </ul>		

	<ul style="list-style-type: none"> <li>• Child trying but not succeeding</li> <li>• slow progress</li> <li>• Not getting the expected results</li> </ul>
Taking action	<ul style="list-style-type: none"> <li>• Need to know in order to take action</li> <li>• Practical action</li> <li>• Practical planning can be overwhelming</li> </ul>
Professionals negative	<ul style="list-style-type: none"> <li>• Not knowing what they are doing</li> <li>• Blamed for child's disorder</li> <li>• Professionals missing important diagnostic characteristics</li> </ul>
Professionals positive:	<ul style="list-style-type: none"> <li>• Thinking creatively</li> <li>• Being open minded</li> <li>• Being willing to listen to the recommendations of the parent</li> </ul>
Faith system	<ul style="list-style-type: none"> <li>• Becoming a better person</li> <li>• Purpose in life</li> <li>• Combining spiritual and practical</li> <li>• Destiny</li> </ul>

### Break down transcript into smaller sections – assign a theme (2)

Line number	Theme
5	Challenges
6-7	Positive outlook Learning experience
16-19	Learning from the intervention centre
20-28	Challenges – maintaining consistency from school to home
35-40	Hope for the future
44	Positive behavioural change
45	Trust in others
46-49	Changes result in fewer negative thoughts
49-50	Less stress
51-52	Hope for the future – positive schooling and learning
55-79	Seeing the positive in the child - assets Hope for the future
80-84	Negative thoughts
85-86	Suppressing negative thoughts
86-87	Learning
88-89	Sharing hopes with professionals
89-90	Adjusting expectations
91-95	Hope for the future – practical skills learning
95-101	Viewing positive – assets
102-108	Learning from professionals

109-113	Challenges
114-115	Understanding the child's needs
115-119	Challenges
120-123	Flexible problem solving
128-131	Suppressing negative thoughts
132-149	Viewing positive- assets
150-156	Negative social support <ul style="list-style-type: none"> <li>- Knowledge</li> <li>- Understanding</li> <li>- Awareness</li> </ul>
164-169	Negative social support
169-170	Understanding
171-173	Positive assets
173-175	Lack of knowledge
178-180	Unwilling to learn
183-189	Lack of awareness Unwilling to learn
190	Collective understanding
207-212	Positive social support – defending
215-220	Negative social support <ul style="list-style-type: none"> <li>- Knowledge</li> <li>- Awareness</li> <li>- Understanding</li> </ul>
221-224	Collective understanding
225-226	Uninformed
227-236	Challenging – unwilling to learn and understand
239-241	Unable to understand
241-243	Collective understanding
243-258	Independence
271-272	Positive social support – addressing problems
272-284	Working as a team
288-289	Initial negative feelings
289-291	Positive – finding a school
291-292	Trust
293-296	Positive social support – people going through the same experience / professional
299-300	Decrease in negative emotions
301-305	Learning and developing
306-308	Positive thoughts
309-310	Learning and developing



**List all themes and relate to one another (2)**

Challenges	<ul style="list-style-type: none"> <li>• Consistency from school to home</li> </ul>
Positive future expectancy	<ul style="list-style-type: none"> <li>• Hope for future</li> <li>• Share future hopes with professionals</li> <li>• Practical skills learning</li> <li>• Independence</li> </ul>
Learning experience	<ul style="list-style-type: none"> <li>• Intervention centre</li> <li>• Professionals</li> </ul>
Hope enhancing	<ul style="list-style-type: none"> <li>• Positive behavioural change</li> <li>• Change – fewer negative thoughts</li> <li>• Positive schooling and learning</li> <li>• Finding a school</li> </ul>
Attachment	<ul style="list-style-type: none"> <li>• Trusting others</li> <li>• Collective understanding</li> <li>• Defending</li> <li>• Addressing problems together</li> <li>• Working as a team</li> <li>• Shared experience</li> </ul>
Emotions	<ul style="list-style-type: none"> <li>• Less stress</li> <li>• Focus on positives/ positive thoughts</li> <li>• Negative thoughts</li> <li>• Adjusting expectations</li> <li>• Understanding the child</li> <li>• Decrease negative emotions</li> </ul>
Options	<ul style="list-style-type: none"> <li>• Flexible problem solving</li> </ul>
Hope diminishing	<ul style="list-style-type: none"> <li>• Negative social support <ul style="list-style-type: none"> <li>○ Lack of knowledge</li> <li>○ Unwilling to learn</li> <li>○ Awareness and understanding</li> </ul> </li> </ul>

## Final themes, subordinate themes and illustrating quotations

Theme	Subtheme	Quotation
Attachment	Trust	<p>He was a good diagnostician but I think he threw it out a bit fast. He could have been a little more gentler. He had to tell me the truth because I would never get moving.</p> <p>We also tried another school, but that didn't work because they were just using a speech therapist and occupational therapists, and they didn't know how to handle her. They told me to bring her for one session, but I was going to go for four sessions for a full eight hours. So I said like, forget it, you guys don't know what you are doing. They could have told me to bring her less often or that they couldn't help her.</p> <p>She was a very bad diagnostician. My daughter was playing with the truck upside-down with the wheels. She was not playing properly. She should have seen that. Later I learnt that that is characteristic of autistic kids.</p> <p>Even when the paediatrician saw her, he thought there was something wrong with me. He asked me if I was taking medication because my child seemed okay to him.</p> <p>Oh, the paediatrician really got me upset. She was telling me that something happened in my pregnancy or that the autism was because of medication I took. You don't know what the problem is, so don't throw it at me.</p> <p>When I joined him at the school, that's where my hope went very far. I had full trust in the school, I had full trust in the therapists and full trust in the school's founder. The school's founder was the main person that helped me throughout everything and gave me hope for my child.</p> <p>I have full trust in the therapists that they try to do their best every day. Because of them my child changes every day.</p>

	Support	<p>Treating autism requires thinking out of the box with the supplements and the dietary interventions. So not every doctor will go for it. I am very thankful that I have a general practitioner who is willing. She is very open minded. But some doctors will see and they won't even consider it as an option for treatment. They see autism as a psychological disorder that has nothing to do with the physical.</p> <p>So I am very thankful that I have a general practitioner who is willing she is very open minded.</p> <p>I might have some cooperation from her case manager, even though it's a totally different method, I am putting a lot of hope in that.</p> <p>Last night we had a skype consultation with a consultant regarding a new method that I have tried in the past with my daughter but haven't been very successful. But this time the case manager is also on board so I am very hopeful that this time it will work and we will actually be able to get through to her.</p> <p>If I have any problem or if I have any issue I always consult Phillip and ask him what to do. And then we both sit down and we both suggest, will this be good or will that be good. How to resolve this issue and what to do and how much we do it.</p> <p>If he has a problem he always mails me or messages me. Do this or I need this or whatever it is.</p> <p>She does have, thank goodness, many many siblings, who I know will not abandon her.</p> <p>I have a lot of support. My husband has always been by my side, helping and I knew that even with all my faith and everything, it would be an up I needed a support system here. My husband has been wonderful. So together we have made it.</p> <p>I had help here.</p> <p>My kids, I would say they are always praying and always asking about her.</p> <p>I have a lot of help.</p> <p>Thank goodness my husband was with me because I was just like no don't waste your time, but he insisted on going with me, because I would not have made it back to the house.</p>
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		<p>It's his aunt. She is very supportive of him. Supportive of him in a way even more than me and his daddy.</p> <p>Like the aunt, we can communicate together, we know. We can speak about what's what.</p> <p>I just I learn to ignore. You know. I don't give much of a statement. than to explain all the time the same thing. I am not going to do that.</p> <p>Sometimes it is hard for him to accept things that (son) does.</p> <p>He's also not much educated about autism. He doesn't know about it.</p> <p>They have no knowledge about anything basically old traditions don't know anything.</p> <p>And if you don't have a literate mind, you're not going to know.</p> <p>they don't understand the way of autistic kids, they don't understand the way they are. People don't. To be honest with you, people out there are not learned about this. They don't understand, they don't have knowledge about it.</p> <p>Not many people understand. Not many people have educational thoughts about it. They wouldn't think</p> <p>not many people are learned about this. And not many people know about autism</p> <p>It is something you need to cultivate. It's not a one-way street. Any kind of relationship.</p> <p>I am not good in creating a support system, and I know you are always told you should create a group, I just don't have the time and energy for it.</p> <p>None of my kids understood that</p> <p>I just couldn't take it anymore even though most of my family are there I happened to meet someone my husband was studying with and he told me he knows someone who made a full recovery.</p> <p>She was the main person that helped me throughout everything and gave me hope for my baby. If it wasn't for her I wouldn't have had no hope and I wouldn't have had a school for my baby and I wouldn't have had (son) the way he is today.</p>
Mastery	Empowerment	It is easy for me to sit and communicate with (case manager) because we know about it.

		<p>That is one thing I have learnt in life is to enjoy the moment.</p> <p>You learn a lot. And you experience new things every day. You learn new things every day as he goes to school every day.</p> <p>I always sit and ask him lots of questions.</p> <p>because I have been his mom and I have understood this thing.</p> <p>I know what he is saying. I understand.</p> <p>I have spent a lot of time, research and money.</p> <p>When I read the case manager's notes, I know what he is saying. I understand.</p> <p>Like I can sit there and communicate with (case manager) and know what he is talking about.</p>
	Positive future expectation	<p>I tell him I want my son to have a family, I want him to get married. I want him to have a life. I want him to work. He must be able to know things.</p> <p>hope means full recovery. That's my goal, that my aim.</p> <p>Being a neuro-typical child.</p> <p>Regarding my daughter, we are hoping that she will be normal. It may sound not normal, but that is what we are hoping for. she will find her special ability to make a mark for herself in this world</p> <p>she had a very good mood which was very encouraging and hoping that this will carry on.</p> <p>She has been sleeping pretty well and had a good mood. I am hoping that this will continue and will be conducive to her learning.</p> <p>she was amazingly calm and did very well. This has given me a lot of hope for the future that she will do even better.</p> <p>I have a lot of hope for my baby and I hope one day that he will be what I want him to be.</p> <p>I have a hope that one day he'd be a grown up boy.</p> <p>he could do things and I have that hope one day that he will have his own family.</p> <p>he must be able to use a computer, he must be able to use a laptop.</p> <p>Be a kid who could be independent.</p> <p>I want her standing on her own feet.</p>

		<p>I have a hope that one day he'd be all independent and he will know what he is doing.</p> <p>you have that hope where he would be independent and support himself.</p>
	Control	<p>Because in the beginning I was actually lost. You don't know what to do. So once I got more focused on the practical aspects of what to do now, then things got a little bit better.</p> <p>I was at a loss for two weeks until we started to get things going.</p> <p>So I was not trying to focus on what I lost but step A, step B, what am I doing now.</p> <p>Of course it is very encouraging when we try something new, a medical or diet intervention, or some educational intervention. Those things usually bring my hopes high.</p> <p>she wasn't responding a lot is that we took her off dairy products and within three four days she was responding</p> <p>We can change it by our behaviour, deeds etc</p> <p>One side will not work without the other. I can't not do anything and expect for a miracle.</p> <p>When you see her, especially when she is unhappy and something is really bothering her, and I don't know what to do to help her. And that is heart breaking. She is either in pain or some kind of bad feeling, but you don't know what to do. That's the worst.</p> <p>As we were starting to do new things, I was hoping.</p> <p>when I joined him at the autism school, that's where my hope went very far.</p> <p>But also he just told me something general. I didn't know what to do from there.</p> <p>And there are many programmes and stuff. So he did give me, but I wasn't even listening.</p>
Spirituality	Purpose in life	<p>A person is brought to this world to grow.</p> <p>So she is just one of those things in my life to enable me and all those she comes into contact with to grow.</p> <p>It's all for growth.</p>

		<p>find her purpose in life because I don't think that right now she is aware of her purpose in life which is actually the most painful thing for me.</p> <p>Life for me means a challenge.</p>
	Higher power	<p>because God is able to do anything in a second.</p> <p>I do believe in miracles.</p> <p>what we are doing is, we are working in two levels that are parallel. One level is the level of the practical. What could make that work is the spiritual part.</p> <p>what change does He want for me.</p> <p>But I can't do it and expect for a miracle because maybe I am not worthy, maybe he is expecting that extra prayer.</p> <p>I pray all the time.</p> <p>What did you decide you are doing differently or better to be worthy of the supplements and everything making the difference.</p>
Survival	Generation of options	<p>Like at the moment, (son) is walking on his toes and we are always prompting him to walk nicely and you know (son) sometimes he gets to comfortable walking on his toes. So I suggested to (case manager) we need to get him inner shoes. The ones made of plastic so that those things can keep his feet down. So we work together.</p> <p>it's a little bit thinking out of the box.</p> <p>I don't think we have cracked exactly what it is but we are trying from all angles.</p> <p>Also (son) likes going to watch moves, going to movies. But sometimes you know you have to schedule in his own time. Because there are people around and he likes making noises and stuff. So people are not too OK with that. So you have to schedule his own time to take him in his own time.</p>
	Emotional regulation	<p>you have more hope every day and you have less negative thoughts every day</p> <p>I don't have any stress for (son) at the moment because I know that with regard to him going to school and learning, he is going to be a normal boy.</p> <p>sometimes you think a lot. You think maybe this can, maybe that could happen and then what. sometimes I do but I try not to.</p>

		<p>I am not having negative thoughts on my hope. I don't want to. when I sit at work and I know that Z is at school, I don't have no fears or worries about him.</p> <p>I know on a daily basis that he is ok and is doing fine and is learning new things every day.</p> <p>And knowing him that they teach him to be a normal child and a normal person to do things.</p> <p>Of course it is very encouraging when we try something new, medically or diet intervention or some educational intervention. Those things usually bring my hopes high. But I have learnt, at the beginning I used to be so enthusiastic, this is going to be the solution. Now I have learnt to be a little more subtle.</p>
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### Researcher's Journal

#### Interview (1)

Participant 1 shared openly about her experiences. Appears to be very hopeful. Religion plays an important role.

#### Initial listening to the audio recording (1)

Participant 1's hope is focused on her daughter being neuro-typical. Even though her progress, with the help of different interventions, has not been what was hope for, Participant 1 still maintains this hope.

Finding new interventions and implementing them seem to maintain hope. It seems that Participant 1 is very practically minded so when she is doing something, she is better able to deal with the challenges. It is important to learn how to manage the hope about an intervention.

Religion plays an important role and is seen to supplement or enhance the interventions that are being used.

Experiences influence hope. When the child is upset and you don't know why or what to do about it, when the child engages in behaviours that harm self or others, or behaviours that disgust or when she tries something she can't do and just can't. Previous expose to ASD influenced how the ASD diagnosis was understood.

How the challenges are experienced is related to purpose in life of parent and child. Difficult to know purpose in life when the practicalities of daily living are still challenging. The practicalities often remove from normal enjoyment and being in the moment.

Even with help, raising a child with ASD is still challenging. Closer support systems are more important than extended support systems. All relationships require work and ultimately energy which a parent may not necessarily have.

Professionals influence hope by accusing the parent of being the cause of the disorder, not picking up on important signs, providing the diagnosis using a gentler approach, after the fact giving hope doesn't help because of the shut down as a result of the being given the diagnosis, general information given not specifics on what to do, professionals not knowing what to do, professionals being more creative in their interventions, previous perception that ASD is only a psychological disorder and not a physical (milk removal disproved it).

#### Read through the transcript (1)

Exposure to challenges is for personal growth.

Hope for independence.

Both positive and negative experiences are noted. Process after diagnosis is like mourning the loss of the child. Not knowing what to do initially is negative but once a plan is established the experiences are more positive. No longer focussing on the child that was lost. Feelings of being overwhelmed.

Torn between the other family members and the child with ASD. Not being able to be completely present. As supportive as family members are, they don't truly understand the experience.

Initially intervention provided hope for a solution but now the hope is just for each intervention to move the family forward. When an intervention brings about dramatic change the hope is greater.

Spousal support. Other family members asking about the child. Harder to expand and maintain a larger support network.

Faith. Others praying for the child.

Taking things one step at a time.

It doesn't look like there is anything wrong with the child.

Focusing on one thing the child isn't doing and missing the other warning signs. Especially when the skills developed and then regressed.

### **Significant points of interest, thoughts and observations (1)**

- Being able to do something to help the child (practical focus)
- Positive outlook as a result of purpose in life
- Influence of past experiences
- Role of the support system – close family support important but less so the extended support system
- Preordained plan
- Managing hope.
- Role of professionals
- Appreciating small gains
- Reducing hope – not being able to do anything, harm and disgusting behaviours

Interesting that the extended support system is seen as more of a burden than support.

Presenting facts to offer hope after a diagnosis, not effective.

Importance of specific strategies to follow as opposed to general steps.

Thinking out of the box with interventions OR a professional being willing to accept information provided by the parent on strategies or interventions.

Viewing ASD as not only a psychological disorder but a physical disorder. Not being able to see something physically wrong makes it difficult to know something is wrong.

Interventions working on a practical and spiritual level.

### **General impression of info and reflect on broader meaning (1)**

Good understanding of both hope enhancing and hope diminishing experiences.

Important influencers – spiritual system, support system, positive outlook, reframing challenges, past experiences, professionals, re-evaluating hope and small steps.

## **Interview (2)**

Participant 2 appeared very tired in comparison to the initial meeting. She shared openly about her experiences. At times I wondered if she was giving me the answers she thought I would like to hear especially when it involved the school.

### **Initial listening to the audio recording (2)**

Participant 2 is aware of the challenges of raising a child with ASD but chooses rather to focus the positive experiences. Learning opportunities from the child with ASD, from those who know about ASD and about the child

Lots of hope. Focusing on independence, practical and living a normal life. Readjusting future expectations. Solving problems in flexible ways. Positive behavioural changes, seeing behaviours like other children (neurotypical). Knowing in a different way, intelligent in a different way. Trust. Fewer negative thoughts, no stress – hope for future, school, purposefully stopping negative thoughts. Social support challenging with people who are educated in ASD and aren't willing to try learn or understand. Others protective over him.

### **Read through the transcript (2)**

Things that the parent needs to become in order to be there for the child. Emphasis on focusing on the positive assets of the child and less of a focus on what the child can't do. Being able to share hope experiences with the professionals working with the child. Working as a team.

Line 292 should have asked for clarification on what hope Participant 2 gets from hope. Is it in the context of a fellow parent with a shared experience or in a professional context.

### **Significant points of interest, thoughts and observations (2)**

Participant 2 found the intervention centre also immediately following her son's diagnosis and therefore does not seem to have any negative experiences with other professionals (outside of the context of the child's intervention centre). As the family is unwilling to learn and understand about the challenges surrounding ASD, Participant 2 has lost patience in being able to educate them. Important to be able to share hopes with someone who understands where you are coming from and is working with you in order to pursue those hopes.

### **General impression of info and reflect on broader meaning (2)**

Despite the challenges experienced and the fact that Participant 2 does not appear to have the most supportive family, she is hopeful for the future of her son. It appears that a parent only needs one or two truly supportive people in order to remain hopeful.

She appears to be aware of his limitations but is able to focus on the positives and look at what he can do to keep her hopes for his future alive. Not only is there an important of a positive outlook but also actively suppressing negative thoughts.

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