# Using a cell phone application to support caregivers of children with Autism Spectrum Disorder

by

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Submitted in partial fulfilment of the requirements for the degree

**Magister Educationis**
**(Educational Psychology)**

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**PRETORIA**
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# DECLARATION OF ORIGINALITY

I, Kerry-Beth Pelser, declare that the dissertation **“Using a cell phone application to support caregivers of children with Autism Spectrum Disorder”** which I hereby submit for the degree Masters Educationis in Educational Psychology at the University of Pretoria, is my own work and has not previously been submitted by me for a degree at this or any other tertiary institution.

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Ms. K.B. Pelser

October 2019

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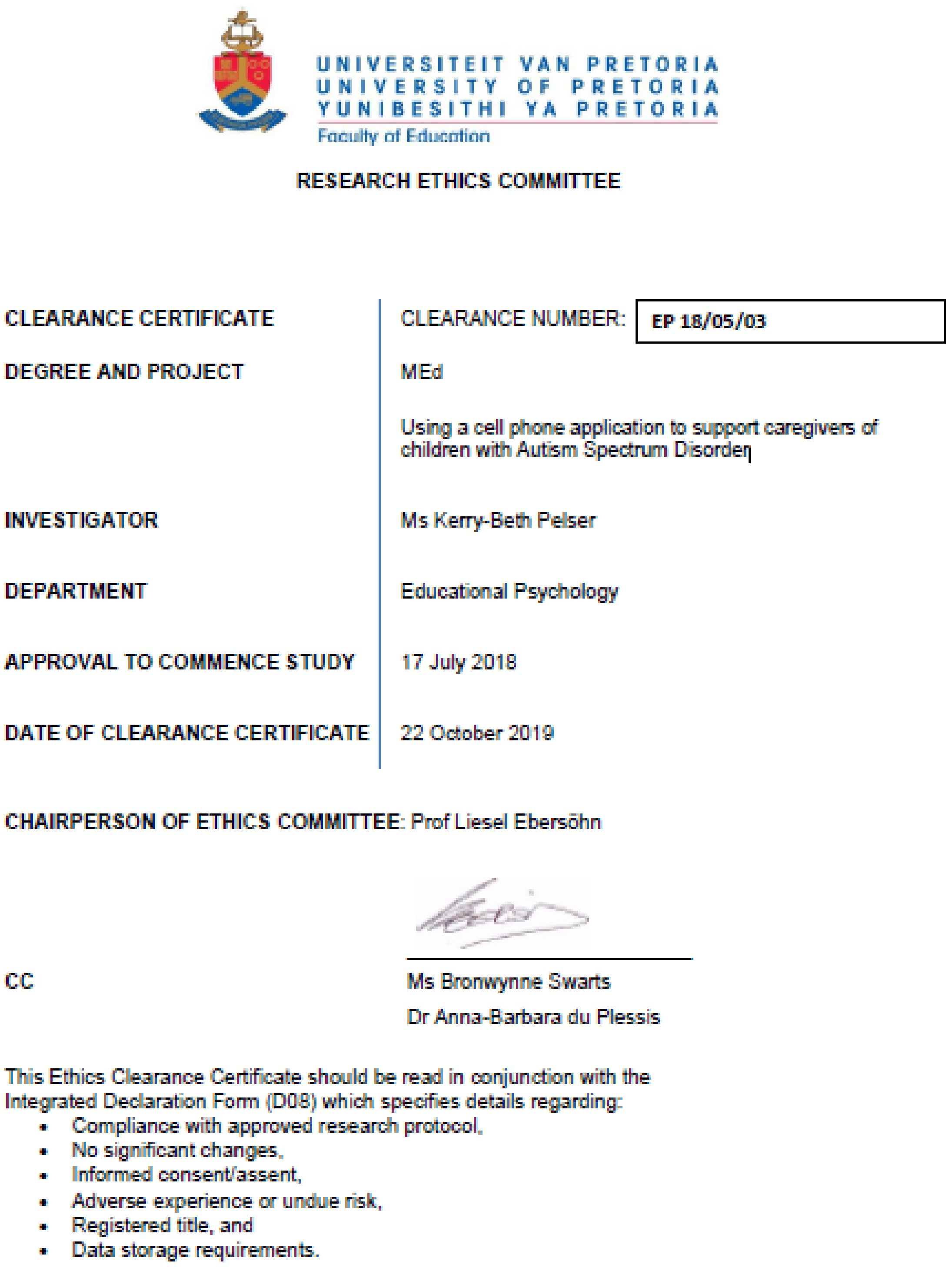

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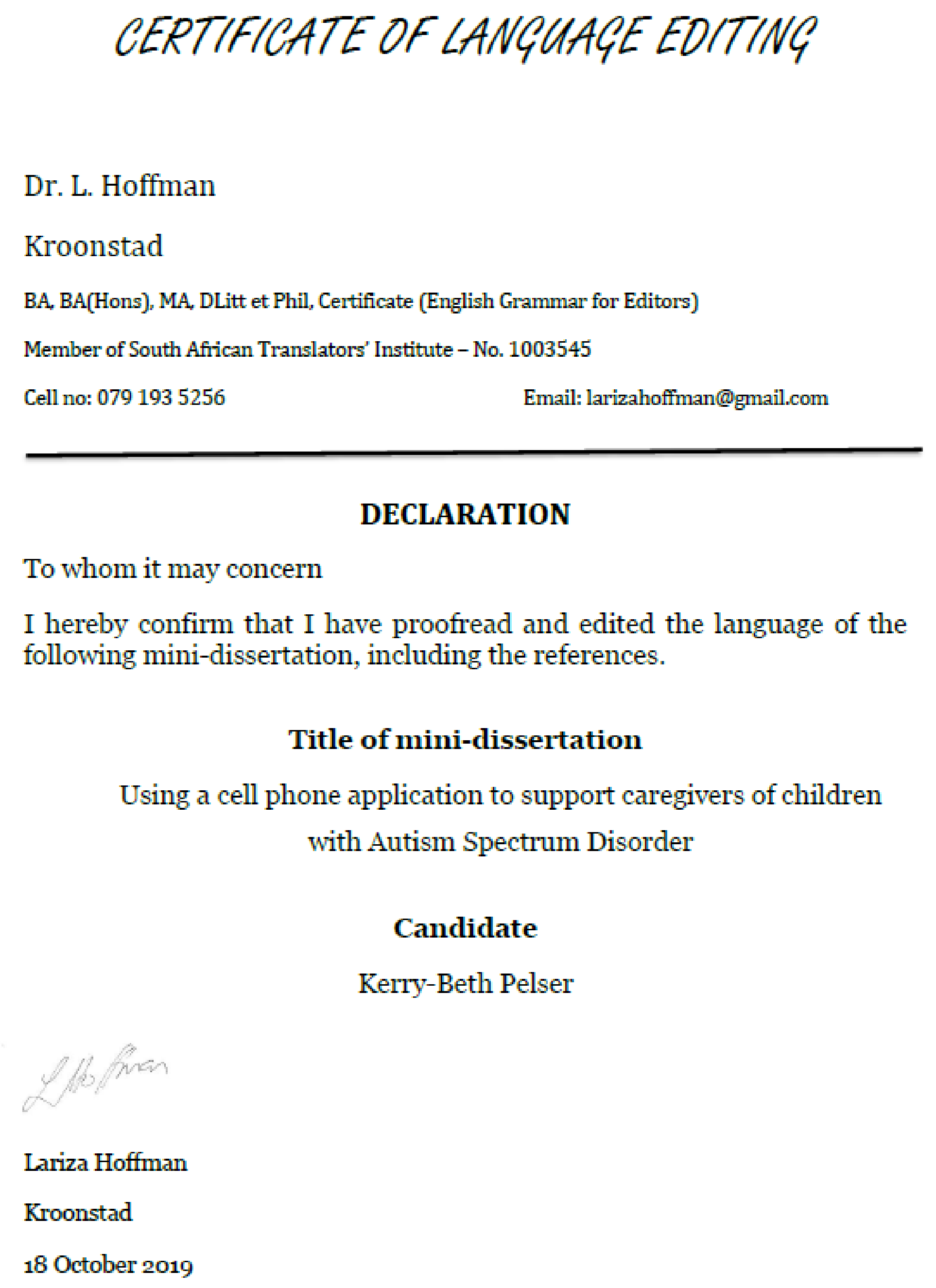

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**DECLARATION**

To whom it may concern

I hereby confirm that I have proofread and edited the language of the following mini-dissertation, including the references.

**Title of mini-dissertation**

Using a cell phone application to support caregivers of children with Autism Spectrum Disorder

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*In loving memory of my precious mom, Michele Berry, and granny, Bethia Berry, who didn’t get to see me complete my studies, but who I carry in my heart always.*

# ABSTRACT

This mini-dissertation aims to explore the daily realities faced by caregivers of children with autism spectrum disorder and the implications thereof on the use of a cell phone application that can assist in easing the tension between the need for support and the lack of resources to secure that support whenever necessary. Bronfenbrenner's bio-ecological systems theory, in addition to the assets-based approach, forms the basis on which the study is conceptualised. Using a qualitative approach, a case study research design was used to select the participant by means of purposive sampling. The research participant used the application that was selected for a period of ten days, after which a semi-structured interview was conducted as the primary mode of data collection. The data were then analysed, using inductive thematic analysis, after which themes and subthemes were derived. The findings of the study indicated that the research participant faces a meaningful lack of financial support and social support, and that the cell phone application was seen as a useful tool for supporting her child in spite of this. The study contributed to expanding the current research body on this topic. A major limitation was the sample size of the study being too small for the results to be generalised. Recommendations include that cell phone applications be designed with users' cultural and language preferences in mind and that more studies of this nature be done.

**Key words:** Autism spectrum disorder; cell phone application; support; resource-constrained context; South Africa; case study design

# LIST OF ABBREVIATIONS

| | |
|---|---|
| ABA | Applied Behaviour Analysis |
| app | application |
| ASD | autism spectrum disorder |
| IBT | Individualised Behaviour Treatment |
| PECS | Picture Exchange Communication System |
| TEACCH | Treatment and Education of Autistic and Related Communications Handicapped Children |

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# CHAPTER ONE - INTRODUCTION AND BACKGROUND TO THE STUDY

## 1.1 INTRODUCTION

Autism spectrum disorder (ASD) is generally regarded as a neurodevelopmental disorder distinguished by challenges in communication and social interactions, along with repetitious, predictable behaviour as well as possible cognitive and sensory integration challenges (Abubakar, Ssewanyana, & Newton, 2016; American Psychiatric Association, 2013; Mthombeni & Nwoye, 2018; Zeng et al., 2017). ASD, or autism, tends to present in varied ways, therefore making it challenging to diagnose and support (Koudstaal, 2016). In fact, a plethora of issues related to the diagnosis of and intervention with children with ASD in South Africa have been brought to light, such as the absence of screening and diagnostic measures which are suitable for use in the South African population, as well as limited access to suitable healthcare services (Chambers et al., 2017).

With the abovementioned characteristics of ASD in mind, as well as the challenges regarding quick and correct diagnosis and appropriate intervention, it follows that children with ASD, as well as their caregivers, tend to experience lowered quality of life due to the difficulties involved in medical, social and educational contexts (Abubakar et al., 2016). The primary caregivers of children with ASD tend to experience diminished psychological well-being, mostly due to stress, and generally experience poorer overall physical health (Catalano, Holloway, & Mpofu, 2018), a phenomenon that has been coined the ‘ASD disadvantage’ (Salomone et al., 2018). As pointed out by Franz, Chambers, Von Isenburg and De Vries (2017), the ‘ASD disadvantage’ could be contributed to the absence of social support, the caregivers overlooking their own physical, mental and emotional needs, as well as feelings of alienation (Sabrin, Kris, & Amy, 2011).

The poorer quality of life for children, especially those living in resource-constrained contexts, can also be explained by the lack of money for, or access to, public transport to get to centres where they can be diagnosed and supported (Blokland, 2014; Van

Biljon, Kritzinger, & Geertsema, 2015). In terms of the education system, there seems to be limited resources available to support children with special needs in education. A recent South African study reported that approximately 135 000 children with ASD do not have access to the specialised education that they need (Van Biljon et al., 2015). Even taking into account that urbanisation has been increasing steadily throughout the past few years, there could still be a large percentage of the population living in rural areas (Brand South Africa, 2013). Most rural areas lack intervention programmes, access to specialised education professionals, as well as the appropriate schools to support children with ASD effectively, due to a lack of access to resources in the country at large (Mthombeni & Nwoye, 2018).

The dilemma of diagnoses and appropriate intervention for many children with ASD and their parents or caregivers in resource-constrained contexts thus begs an answer.

## 1.2 RATIONALE OF THE STUDY

In an attempt to address the lack of access to appropriate diagnoses and intervention, while keeping in mind the limited resources available, solutions will have to be sought outside traditional intervention pathways, such as applying technology, which, ironically, is often only associated with well-resourced contexts. It is predicted that by 2020, the quantity of smartphones in the world will be the same number as if 70% of the world population each owned one (Nguyen & Silva, 2016). There seem to be exponential increases in the use of cell phones and technology worldwide, including in South Africa. In South Africa, specifically, there were the same number of cell phones as people living in South Africa in 2009, but this was probably due to one person owning a number of cell phones (Kreutzer, 2009). According to Chigada and Hirschfelder (2017), there is a high percentage of cell phone ownership in South Africa, as much as 89%, which holds potential for a number of cell phone-based opportunities in future.

Researching the possibilities of a cell phone application (app) to be used by caregivers of children with ASD specifically in resource-constrained contexts, may be one way to help overcome the limited available support by using modern technology that is increasingly becoming available to all members of the population. Such an application could be the beginning of a noteworthy shift in support and psycho-education of ASD in South Africa. Because little is currently known about how ASD is perceived and supported in resource-constrained contexts in South Africa, and the potential that cell phone applications (apps) hold in this regard, this study may bring to light some unexpected and necessary information that could assist various stakeholders (including educational psychologists) in further researching and developing the means to support those who care for a child with ASD in the face of constrained resources.

## 1.3 PURPOSE OF THE STUDY

Valid and reliable research needs to be conducted in order to contribute to alleviating the tension between the lack of available support services for ASD in resource-constrained contexts and the increasing demand for such services by using available technology. The purpose of the study is to investigate the pilot implementation of an existing cell phone application to support caregivers of children with ASD in resource-constrained contexts in South Africa who do not have easy access to professionals specialising in ASD intervention. Ultimately, after the pilot study, the application can be improved and made available to other caregivers of children with ASD. In addition, once the implementation has been done successfully, the application may even form the basis for diversification to support caregivers of children with various other challenges in South Africa.

## 1.4 RESEARCH QUESTIONS

In order to investigate the use of technology in the form of a cellular phone application to support caregivers of children with ASD in resource-constrained contexts in South Africa, the primary research question of the study is:

What are the experiences of caregivers of children with ASD of a cell phone application to support their children in resource-constrained contexts?

Secondary research questions are:

- What support is needed by children with ASD for optimal wellness?
- What are the needs of caregivers with children with ASD, generally and in resource-constrained contexts?
- What criteria should cell phone applications adhere to in order to be user-friendly, generally and in resource-constrained contexts?

The working assumptions for conducting a study to answer the stated research questions are discussed next.

## 1.5 WORKING ASSUMPTIONS

Throughout this mini-dissertation, it is assumed that:

- one is able to support caregivers over a distance, where one-on-one interaction between a specialist and a client is not necessarily needed at all times;
- based on the current cell phone trends, cell phones will be more available in the future (Beger, 2014);
- caregivers are integral collaborators in supporting children with ASD;
- caregivers can be empowered to support children with ASD;
- every child has strengths; and
- assets can be found in any situation.

## 1.6 CONCEPT CLARIFICATION

### 1.6.1 Autism Spectrum Disorder (ASD)

ASD is an enduring and prevalent neurodevelopmental disorder described by challenges in language, communication and social interaction patterns, as well as persistent motor mannerisms, which tend to begin in the early years of one’s life or when one faces particularly challenging social situations (Perry, Flanagan, Geier, & Freeman, 2009). Autistic disorder, pervasive developmental disorder and Asperger syndrome are encompassed by the term ‘autism spectrum disorder (ASD)’ (American Psychiatry Association (APA), 2013; Duchan & Patel, 2012).

### 1.6.2 Cell Phone Application

A cell phone application is software that can be downloaded onto a cell phone in order to fulfil a specific purpose or augment the capacity of a cell phone to perform a specific task (Purcell, 2011).

### 1.6.3 Support

Support can be understood as to give encouragement or help medically, emotionally and/or educationally, in order to promote successful adaptation or better well-being (Henderson, Johnson, & Moodie, 2014).

### 1.6.4 Resource-Constrained Perspectives

For the purpose of the study, the term ‘resource-constrained context’ refers to a community where there is limited access to infrastructure and amenities (Aliber, 2003), often due to a lack of financial and physical assets possessed by the members of that community. Rural areas are most often associated with being resource-constrained contexts. Hall, Kaufman and Ricketts (2006) describe rural areas as areas that lack urbanism, where a tendency towards agriculture is evident, fewer inhabitants live per area and less infrastructure is available and/or accessible. Urban areas are seen as areas that have a high density of people and infrastructure and a high demand for resources, which are often accessed from outside of these urban areas (Satterthwaite, 2011). Alexandratos (2005) points out that it is possible for an urban area to be seen as a resource-constrained context.

## 1.7 CONCEPTUAL FRAMEWORK

The bio-ecological systems theory of Urie Bronfenbrenner will be the core framework used in the study, as his theory places individual, social, economic and educational matters in context. This will be done by incorporating the perspective of an asset-based approach. More detail on the conceptual framework will be presented in Chapter Two.

### 1.7.1 Bio-Ecological Systems Theory

Bronfenbrenner’s bio-ecological systems theory holds that a child’s development is influenced by the multiple systems – the micro-, meso-, exo- and macro-systems – in which a child functions and the interactions between those systems (Aucamp, Steyn, & Van Rensburg, 2014). With this theory in mind, I aim to examine the proximal processes where there is interplay between the systems of a child with ASD, his or her family system, school and society at large, and where the neurodevelopmental system as part of the micro-system is an added influence to be considered.

### 1.7.2 The Asset-Based Approach

This approach involves using the strengths in people, their environments and their relationships in order to assist them in pursuing a better life and maintaining an action-orientated mind-set towards being the agents of change in their own lives (Kretzmann & McKnight, 1993; Mathie & Cunningham, 2003). This approach is applicable to the study as it aims to empower caregivers to support the children with ASD in providing them with contextualised ideas for the support that they would otherwise not have had access to.

## 1.8 PARADIGMATIC PERSPECTIVES

In the setting of a case study (see Section 1.9 for reasons for the selection of a case study) to investigate the experiences of caregivers of children with ASD, the most appropriate epistemology for the study would be interpretivist, with the methodology being a qualitative approach. It should be noted that the incongruity between planning and practice was highlighted during the selection of the participants for this study and therefore more detail on these paradigmatic perspectives will be provided in Chapter Three.

### 1.8.1 Epistemological Paradigm

According to Scotland (2012), interpretivism involves the concept of relativism, which posits that people's realities differ from one another. This means that these realities are in fact individually constructed and based on the interpretation of real-world occurrences. An assumption, therefore, would be that each person's sense of reality differs from the next.

Because the use of interpretivism entails the study of the construction of people's own realities and the beliefs that go with them (Wahyuni, 2012), an important limitation could include that legitimacy and trustworthiness would be difficult to account for with total confidence, especially considering that the interpretation of such information may be done differently by different researchers (Scotland, 2012). Any possible claims made to suggest generalisability of the results should be proposed cautiously.

According to Scotland (2012), the nature of data collection involved with interpretivism tends to lend itself to more easily disclosing information that should otherwise have been kept undisclosed, as open-ended and more persistent promptings often lead to more numerous discoveries of what could include confidential information. To prevent confidential information from becoming public information, I will follow all ethical guidelines meticulously.

### 1.8.2 Methodological Paradigm

The qualitative approach is described by Grossoehme (2014, p. 109) as “the systematic collection, organisation, and interpretation of textual material derived from talk or conversation. It is used in the exploration of meanings of social phenomena as experienced by individuals themselves, in their natural context”. Taylor, Bogdan and DeVault (2015) posit that the qualitative approach involves obtaining descriptive information about participants, while permitting dynamic, fluid aspects to research, contrary to those of a quantitative approach (Corbin & Strauss, 2012). This is because it allows for appreciation of the richness of the participants’ experiences in an in-depth manner (Yin, 2016). A vital objective is to delve into the detail of the participants’ experiences of the cell phone application in order to determine its utility within a resource-constrained South African context.

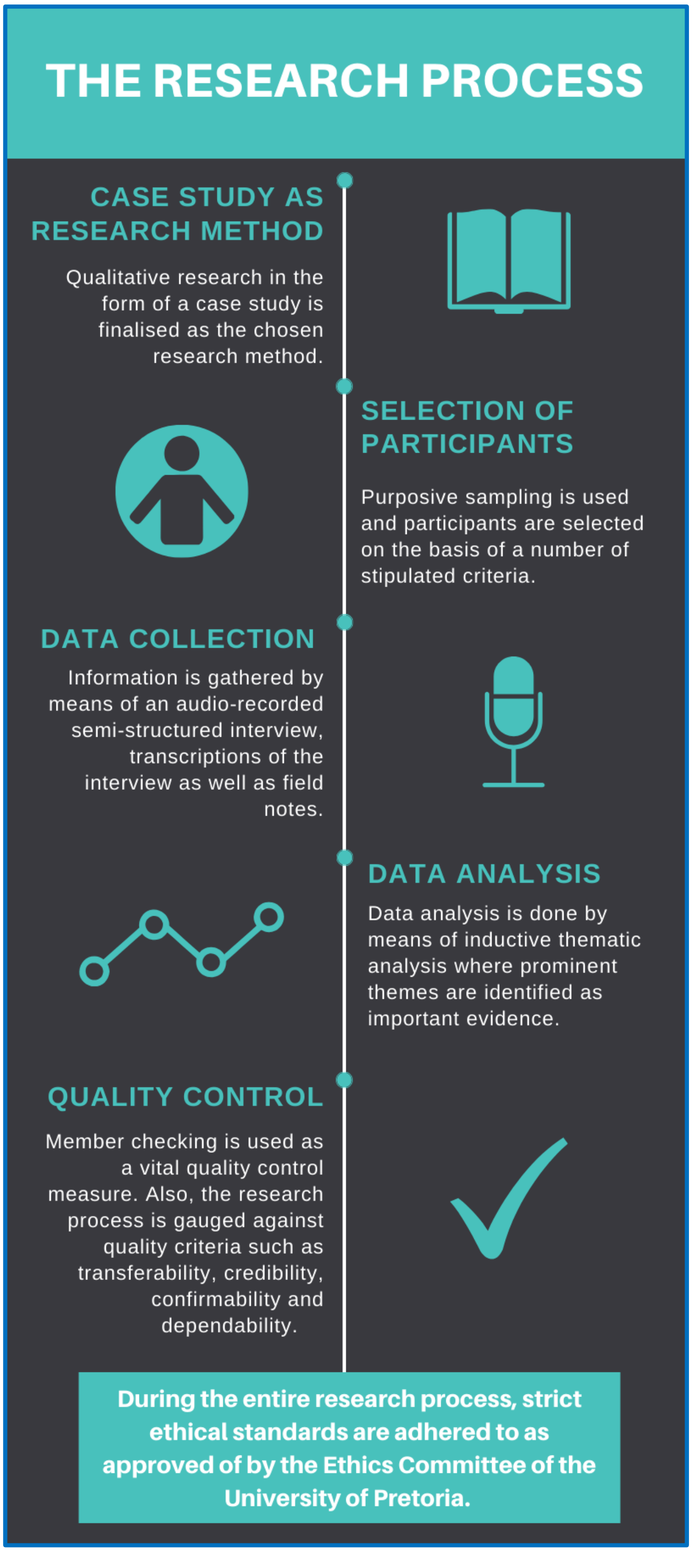
It is important to remember that the results obtained cannot be generalised with the same certainty as with quantitative methodologies (Atieno, 2009). This is mostly due to the small sample sizes and thorough in-depth investigations of individual experiences involved in qualitative approaches. Although a qualitative approach to data collection allows for the formation of new theories as well as inductive reasoning, ambiguities and communication gaps can pose as important challenges in terms of accuracy of these new theories (Atieno, 2009).

## 1.9 RESEARCH METHODOLOGY

For the study, case studies will be used as a method of data generation, and participants will be selected on the basis of purposive sampling. The case study research design is an invaluable tool in capturing the complexity of the occurrences being researched, allowing for greater quality of the data obtained (Hamilton & Corbett-Whittier, 2013; Thomas & Myers, 2015).

Case studies are especially useful in situations where data can be obtained from participants being in their natural contexts, as this contributes to the richness of the data captured (Stavraki, 2014). These considerations are important in investigating participants’ experiences of the cell phone application to assist them in supporting the children with ASD. Also, the case study research design aligns with interpretivism (Stavraki, 2014).

Figure 1.1 below represents the research process in a nutshell. Further detail on each of the components can be found in Chapter Three, where the reasons for the particular choices, the advantages, limitations and ways to deal with the limitations are explained.



THE RESEARCH PROCESS

CASE STUDY AS RESEARCH METHOD

Qualitative research in the form of a case study is finalised as the chosen research method.

SELECTION OF PARTICIPANTS

Purposive sampling is used and participants are selected on the basis of a number of stipulated criteria.

DATA COLLECTION

Information is gathered by means of an audio-recorded semi-structured interview, transcriptions of the interview as well as field notes.

DATA ANALYSIS

Data analysis is done by means of inductive thematic analysis where prominent themes are identified as important evidence.

QUALITY CONTROL

Member checking is used as a vital quality control measure. Also, the research process is gauged against quality criteria such as transferability, credibility, confirmability and dependability.

During the entire research process, strict ethical standards are adhered to as approved of by the Ethics Committee of the University of Pretoria.

**Figure 1.1:** Diagram representing a brief summary of the research process

## 1.10 OUTLINE OF THE CHAPTERS

### Chapter One: Introduction and Background to the Study

In this chapter, a brief background and the rationale and purpose of the study are presented. The primary and secondary research questions, as well as the assumptions for the study, are stated. The paradigmatic perspectives are explored, followed by an overview of the research process. Here, reference was made to the steps taken in ensuring quality control and ethical research.

### Chapter Two: Literature Review

Chapter Two will locate the study within the current body of research available on ASD, the needs of caregivers and children with ASD in both international and local contexts, and the current trends in cell phone usage. Internet-based healthcare and current ways of supporting ASD are explored, followed by the criteria for a user-friendly cell phone application. Lastly, the conceptual framework of the study is presented.

### Chapter Three: Research Design and Methodology

In this chapter, the paradigmatic perspectives are discussed. The research methodology is described in detail, where the selection of participants and the selection of the most appropriate cell phone application to be used for the study are explored. The methods of data generation, documentation and analysis are then presented, followed by quality criteria and ethical considerations.

### Chapter Four: Research Results, Findings and Discussion

Chapter Four presents the results of the study, supported by themes and sub-themes that are generated from the data. Following this, the collective findings of the study as well as a discussion of these findings are presented.

### Chapter Five: Conclusions, Limitations and Recommendations

This final chapter addresses the research questions according to the results obtained, in addition to the literature presented in Chapter Two. The limitations of the study are explored, as well as possibilities for future research and development of apps for ASD in the South African context.

## 1.11 CONCLUSION

In a country where poverty, historical disadvantage and a lack of resources are added challenges to the already-challenging lives of families of children with ASD in resource-constrained contexts, the proposed study aims to assist in bridging the gap between a lack of resources and access to the necessary support. In Chapter One I discussed the rationale for undertaking the study, the purpose of the study, the research questions and the assumptions at the core of the study. I also presented a brief summary of the research process in the form of a diagram. In Chapter Two, I will present the literature review as well as a deeper look at the conceptual framework used in the study.

# CHAPTER TWO - LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

## 2.1 INTRODUCTION

The focus of the study is to investigate the usefulness of a cell phone application that can support caregivers of children with ASD, specifically in resource-constrained contexts. In order to contextualise the study, the nature of ASD will firstly be described, followed by the prevalence and causes of ASD. I will then investigate the current ways in which ASD is supported, including an exploration of the needs of caregivers and the needs of children with ASD, both internationally and locally. I will then explore the current state of internet-based healthcare and conclude with cell phone trends in South Africa and the requirements for a user-friendly cell phone application. Once ASD intervention and the possibilities for support are understood within the opportunities and limitations of cell phone technology, a conceptual framework for the research will be presented.

## 2.2 AUTISM SPECTRUM DISORDER

### 2.2.1 Understanding ASD

Autism spectrum disorder (ASD) is widely recognised as a disorder of the brain (Duchan & Patel, 2012) and difficulties with expressive language seem to be one of the most common features (Bakare & Munir, 2011). It is believed that all individuals with ASD exhibit challenges experienced in three main areas of life, often referred to as “the triad of impairments” (Bowen & Plimley, 2008, p. 3). These three areas include complications in social contact, communication and inflexibility of thought, which often occur alongside sensory issues (Bowen & Plimley, 2008). The term ‘autism spectrum disorder’ refers to a heterogeneous cluster of conditions, which encompasses “Autistic disorder, Asperger disorder or syndrome, and pervasive developmental disorder, not otherwise specified” (Duchan & Patel, 2012, p. 27).

In the Diagnostic and Statistical Manual of Mental Disorders – 5, which is used internationally as an authoritative source to diagnose ASD, ASD forms part of the

Neurodevelopmental Disorders cluster (APA, 2013). The diagnostic features of ASD are described as follows:

> The essential features of autism spectrum disorder are persistent impairment in reciprocal social communication and social interaction (Criterion A), and restricted, repetitive patterns of behavior, interests, or activities (Criterion B). These symptoms are present from early childhood and limit or impair everyday functioning (Criteria C and D). The stage at which functional impairment becomes obvious will vary according to characteristics of the individual and his or her environment. Core diagnostic features are evident in the developmental period, but intervention, compensation, and current supports may mask difficulties in at least some contexts. Manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level, and chronological age; hence, the term spectrum. (APA, 2013, p. 53)

ASD seems to be complex in that developmental impairments tend to vary greatly from one person to the next, and it tends to persist throughout the lifespan, affecting each person in different ways (Koudstaal & Erasmus, 2019). It is believed that the characteristics of ASD may be identified before the age of three years (Muideen, Kerim, & Mashudat, 2014); however, some of the symptoms may be masked until a later stage (Koudstaal, 2016).

There are a number of characteristics that can be seen as strengths in people with ASD, such as having the ability to be exceptionally attentive, determined and meticulous in particular situations, apart from other special aptitudes (Bathgate, 2017). Current African perspectives on autism are unclear, but will be addressed in as much as they relate to providing support to the caregivers of children with ASD.

The prognosis of children with ASD tends to vary greatly due to the severity as well comorbidities experienced, both of which will be discussed next.

(1) Severity of ASD

When ASD is diagnosed using the Diagnostic and Statistical Manual of Mental Disorders – 5, the level of severity is chosen according to the degree of difficulty in social communication as well as the nature of the repetitive patterns that accompany them, on a level between one and three (APA, 2013). The severity of the disorder dictates the extent to which support is needed (Koudstaal, 2016). Also, specifiers, such as “requiring support, requiring substantial support or requiring very substantial support” are used to interpret the diagnostic features on three different levels more easily (APA, 2013, p. 52).

(2) Comorbidities

ASD seems to have high rates of comorbidity with a number of somatic, sensory or psychological impairments, such as cognitive challenges, epilepsy, obsessive-compulsive disorder and attention-deficit hyperactivity disorder (Koudstaal & Erasmus, 2019). This makes the diagnosis of ASD challenging when the characteristics of ASD and the comorbid disorders are confounded (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). In a far-reaching national survey, Duchan and Patel (2012) found that 87,3% of the children between the ages of six and 17 years old who had been diagnosed with ASD also met diagnostic criteria for ADHD, behavioural or conduct disorders, developmental delays, or affective disorders, such as anxiety or depression, of which ADHD was the most common. According to Semrud-Clikeman and Ellison (2009), seizures and Tourette’s syndrome can be added to the abovementioned list.

Intellectual impairment seems to be common among African children with ASD (Bakare & Munir, 2011). Bakare and Munir (2011) found that more than 60% of all ASD cases in their study included intellectual disability, although one can question the results based on the validity of the instrument used to assess intellectual disability, and to the nature of ASD itself being a barrier to the valid assessment of intellectual ability. Bauman (2010) speculated that sleep disorders are highly prevalent in children with ASD, and metabolic disorders as well as gastrointestinal disorders seem to be commonly associated with ASD. A study investigating the co-morbidity burden of ASD on children and young adults in the United States of America found that there was a high prevalence of ASD found to be comorbid with Down’s syndrome, tuberous sclerosis (benign tumour growth) and muscular dystrophy had a high prevalence in children with ASD (Kohane et al., 2012). The diagnosis and intervention of comorbid conditions that are treatable is imperative in that it may result in an improved sense of wellbeing for children with ASD, leading to better quality of life and more effective intervention, as well as opening doors for identifying and more closely examining the specific systems that may play a role in the aetiology of ASD (Bauman, 2010).

Since an understanding of what ASD is has been established, the prevalence of ASD worldwide and in the South African context is discussed.

### 2.2.2 Prevalence of ASD

There seems to be uncertainty about the prevalence of ASD. According to Abubakar et al. (2016) and the World Health Organisation (WHO) (2017), one in 160 children has some form of ASD, globally, which stands in contrast to another source which cites that one in 88 children have some form of ASD (Zeng et al., 2017), and still other sources that cite that one in 68 children are on the autism spectrum (Bellomo, 2016; Koudstaal, 2016). According to Autism South Africa, every hour a child is born with autism in South Africa (2011, p. 1). The unfolding of what has been referred to as a global epidemic by a number of sources (Bateman, 2013; Leonard et al., 2010; Liu, King, & Bearman, 2010) is a call for concern in a country where awareness, support and resources are already seen as lacking, such as South Africa, and where poverty is rife (Mthombeni & Nwoye, 2018).

The incidence of ASD seems to be on the rise, causing a raised awareness of ASD worldwide (Chambers et al., 2017). A study done on ASD prevalence found that between 2001 and 2011, the prevalence of ASD among children between the ages of two to 17 years increased by approximately three and a half fold (Idring et al., 2015). It is argued, however, that this may simply be due to an improvement in the diagnostic tools used (Semrud-Clikeman & Ellison, 2009), an underestimation of the prevalence of ASD in the past (Duchan & Patel, 2012), or increased awareness and earlier diagnosis (Volkmar et al., 2004). According to Koudstaal (2016), there are no official statistics available that are specific to the South African context; however, according to Autism SA, the incidence of ASD within the last 40 years has increased by tenfold.

It was estimated in 2016 that about one in every 160 people had ASD globally, but limited research done in African countries may show this as an underestimation (Abubakar et al., 2016). ASD was previously seen as a ‘Western illness’, but due to the growth of research in the last two decades, there is no doubt that ASD occurs in children from Africa living abroad, as well as those living in Africa. There are even suspicions that there may be, in fact, a higher prevalence of ASD among African children than children of the Western world (Bakare & Munir, 2011).

The prevalence of ASD in populations found in sub-Saharan Africa is relatively unknown (Abubakar et al., 2016). The extent to which the general population has knowledge about ASD seems to be low in Africa, and especially low in sub-Saharan Africa (Bakare & Munir, 2011). It is believed that males are about four times more likely than females to be diagnosed with ASD (Duchan & Patel, 2012); however, this may be due to the under-diagnosis of ASD in girls because of differing characteristics (Mthombeni & Nwoye, 2018).

As the estimated prevalence of ASD has been established, the possible causes of ASD are explored.

### 2.2.3 Causes of ASD

A plethora of theories proposing different causes for ASD can be found in the literature, most of which have scanty scientific evidence to prove them, or use sample sizes that are not representative to prove statistical significance (Abubakar et al., 2016). The exact cause of ASD remains unknown, but most researchers believe that a combination of environmental and genetic risk factors is the most likely (Mthombeni & Nwoye, 2018).

The role of genetics in the development of ASD seems to be well documented, due to twin studies that prove that there is indeed a link between ASD and heritability (Duchan & Patel, 2012). Semrud-Clikeman and Ellison (2009) reported a study that claimed that the siblings of individuals with autism had an autism rate that was 50 times more than individuals of the general population. A study done in the United Kingdom showed a 60% concordance rate for ‘classic autism’ in monozygotic twins as compared to dizygotic twins who had no concordance at all (Duchan & Patel, 2012). Abubakar et al. (2016) reported on studies that found that an increased risk of developing ASD was linked with frequencies of 5-HTTLPR in particular alleles and genotypes. There is as yet no proof of a specific gene that supposedly causes autism, but the heritability of language difficulties seems to hold promise for future ASD research (Koudstaal & Erasmus, 2019).

A body of research claims that a number of medical conditions may predispose individuals to ASD or may develop as a result of ASD (Bauman, 2010). Fragile X syndrome, gene defects (Duchan & Patel, 2012), environmental toxins, viral infections (Koudstaal, 2016), advanced maternal age (Semrud-Clikeman & Ellison, 2009), prenatal exposure to chemicals, preterm births, low birth weights and maternal smoking are all believed to be possible risk factors for the later development of ASD (Duchan & Patel, 2012). However, Duchan and Patel (2012) are of the opinion that there is only a 10% chance of ASD being attributed to an underlying medical condition. Bakare and Munir (2011) found that the ASD aetiology proposed for African children included the spiritual beliefs and causes of neuropsychiatric disorders involved in the respective African cultures.

In light of the possible causes of ASD, the current ways of supporting children with ASD are explored.

## 2.3 CURRENT WAYS OF SUPPORTING ASD

Although ASD is a lifelong condition, early intervention can assist in lessening the severity or intensity over time, although the outcomes of this may vary (Koudstaal & Erasmus, 2019). Some of the latest evidence suggests that no single intervention method is appropriate and effective for everyone (Stevenson, Cornell, & Hinchcliffe, 2016); therefore, an eclectic approach should be used, according to the needs of each child (Koudstaal, 2016).

Conventional intervention involves teachers, speech and language therapists, physical therapists (Choueiri & Zimmerman, 2017), social workers, occupational therapists, psychiatrists and child psychologists to support children with ASD (Varrucciu, Manfedini, Di Santantonio, Roversi, & Di Sarro, 2017). In the absence of these professionals, general practitioners, clinic nurses and community workers are often the only role players in intervention. Ironically, the role of parents in intervention is omitted by many researchers.

Essentially, ASD seems to be supported through various interventions that target the child’s behaviour, diet, nervous system functioning (Davis, Finke, & Hickerson, 2016), social and communication skills (Stevenson et al., 2016), and development and education in order to facilitate inclusion in the community and optimal functioning (Volkmar et al., 2004). In terms of issues with sensory input, children with ASD often tend to need some kind of intervention by means of sensory approaches, often addressed by occupational therapists (Koudstaal & Erasmus, 2019).

There has been a 50% increase in the provision of psychopharmacological intervention for ASD within the past 15 years (Semrud-Clikeman & Ellison, 2009). The most frequently prescribed medication for ASD in children is antidepressant medication, followed by antihypertensive drugs as well as psycho-stimulants (Semrud-Clikeman & Ellison, 2009). Often, once specific behaviours are addressed through medication, speech and language therapy, occupational therapy, education, psychotherapy and further behaviour modification can be done with greater benefit.

There seem to be a large number of approaches and techniques that can be used in assisting children with ASD in these various areas, including Individualised Behaviour Treatment (IBT) (Volkmar et al., 2004), the Picture Exchange Communication System (PECS) (Mupawose, Alli, & Abdoola, 2015), narrative therapy (Stevenson et al., 2016), Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) and Applied Behaviour Analysis (ABA) (Volkmar et al., 2004), to name a few. Animal-assisted intervention seems to be a promising intervention for supporting children with ASD in improving in a variety of areas of functioning, although more research is necessary (O'Haire, 2013).

According to Volkmar et al. (2004), ABA has been the most commonly used and studied intervention for behaviour control [sic] in children with ASD (Mthombeni & Nwoye, 2018), up to recently. ABA is an intensive behavioural intervention (Choueiri & Zimmerman, 2017) that is based on a set of scientific principles that has been used to support children with ASD and is apparently backed by more than 100 years of research (Dillenburger & Keenan, 2009). According to Corsello (2005), ABA is one of the most well-known, most requested kinds of intervention for ASD, and is recognised as an effective intervention for ASD (Dillenburger & Keenan, 2009).

Cristea, Roxana and Felicia (2011) posit that whether ABA therapy is conducted by a parent alone or in collaboration with a psychologist, it has proven to be beneficial to children. Artoni et al. (2018), however, believe that the coherence of programs at home and at school is seen as vitally important in the success of ABA therapy, as monitoring behaviour is a pillar of ABA intervention.

In ABA therapy, the individual's behaviour is observed and targeted by means of a number of strategies, including the use of motivators (Artoni et al., 2018), in order to bring about an increase in both positive and significant behaviours (Koudstaal &

Erasmus, 2019). Discrete trial training is utilised, where each task is broken up into basic steps that steadily increase in difficulty (trials), which are then repeated until the individual is able to accomplish the task correctly and independently (Artoni et al., 2018).

According to Granpeesheh, Tarbox and Dixon (2009), ABA can be effective in bringing about improvement in a wide variety of spheres of functioning, including social functioning, school-work, independent living skills, job-related skills and challenging behaviours. According to Dillenburger, Keenan, Doherty, Byrne and Gallagher (2012), ABA can prove to be effective irrespective of the abilities or developmental stage of the person involved.

The use of ABA therapy is not without its criticism. Francis (2007) sees the approach to language acquisition used in ABA as outdated and points out the possibility of individuals developing complete dependency on prompting as a possible reality. Cascio (2015) expresses great concern about ABA therapy being far too rigid in its principles and not being conducive to the various role players tailoring approaches to the needs of individual children with ASD. Also, ABA is thought to cause children and their families unnecessary additional stress as well as being an expensive programme (Francis, 2007).

Next, the needs of caregivers of children with ASD are explored from an international perspective as well as a South African and resource-constrained context.

## 2.4 THE NEEDS OF CAREGIVERS OF CHILDREN WITH ASD

### 2.4.1 The Needs of Caregivers of Children with ASD from an International Perspective

In the lives of people with ASD, their primary caregivers tend to fill the most vital roles of all, hence much research has been done to study the family dynamics and effects of caring for a person with ASD on the caregivers (Nordahl-Hansen, Hart, & Øien, 2018). Their poorer psychological and physical health, the so-called ASD disadvantage, have been mentioned in Chapter One (Catalano et al., 2018; Salomone et al., 2018, p. 1189), which could result from the absence of social support, overlooking their own physical, mental and emotional needs, as well as feelings of alienation (Sabrin et al., 2011).

Salomone et al. (2018) found that being a single parent and having to parent more than one child with a disability at one time tends to intensify poor parental outcomes, while support from a partner was shown to be a protective factor. An increased rate of job losses and financial challenges also tend to plague caregivers of children with ASD in contrast to caregivers of children with other types of disabilities (Ruble, Murray, McGrew, Brevoort, & Wong, 2018). The financial challenges involved in caring for a child with ASD seem to be exacerbated for families that are ethnically and racially diverse (Ruble et al., 2018).

Ruble et al. (2018) posit that even though children with ASD tend to be consumers of a multitude of health services, their caregivers are commonly dissatisfied with the services provided to them. Searing, Graham and Grainger (2015) confirmed in their study that according to caregivers of children with ASD, the three key qualities in professionals that were helpful are being empathetic, having knowledge and understanding the obstacles faced by the family on a day-to-day basis.

Once the diagnosis of ASD is received by parents, their main concerns usually include the possibility that their child will not experience the future that they had once hoped for him or her, concerns of what would happen to the child if they could no longer care for him or her, and the biggest concern being to select the most suitable intervention for their child (Nordahl-Hansen et al., 2018). Behaviour management strategies, access to respite care and genetic counselling are also seen as important family needs (Davis et al., 2016).

The parents or primary caregivers of children with ASD typically become involved in the wellbeing of those, especially with comorbid intellectual disabilities, providing primary support, arranging legal guardianship and becoming medical decision-makers throughout the child’s adulthood (Ruble et al., 2018). It has also been pointed out that siblings without autism also then tend to face the possibility of having to take primary responsibility for their sibling in this way, should anything happen to their parents (Nordahl-Hansen et al., 2018).

In summary, according to Attfield and Morgan (2007), parents’ and caregivers’ needs in terms of dealing with their children’s ASD and supporting them may vary significantly. However, there seems to be common needs, including obtaining correct information from professionals in the field of ASD, knowing how to deal with the characteristics of ASD as uniquely manifested in their children, collaborating in finding the best way forward, accessing other services and being acknowledged and supported emotionally (Attfield & Morgan, 2007). Catalano et al. (2018) are of the opinion that support groups can be extremely beneficial to caregivers of children with ASD, in turn, improving outcomes for the children themselves.

It is believed that caregivers of children with ASD need information in order to feel empowered, to have their opinions acknowledged and to have an opportunity to tell their stories (Attfield & Morgan, 2007). One way in which an application may help, occurs when caregivers are erroneously still of the opinion that particular parental influences can cause ASD (Bateman, 2013). Their understanding of how to support the children will then also be wrong. Awareness of facts shown by research to be acceptable may be made known through the information rendered by the cell phone application. Through the study, I will attempt to hear the stories of three caregivers of children with ASD while ascertaining whether the cell phone application, designed to support them in caring for their child, indeed does so.

### 2.4.2 The Needs of Caregivers of Children with ASD from a South African and Resource-Constrained Perspective

Considerably less seems to be known about how caregivers of children with ASD experience their journeys if they are living in low as well as middle-income countries, due to a lack of resources and research into these areas (Dejene et al., 2016). According to Dejene et al. (2016), it is likely that most cases of ASD in resource-constrained countries go undiagnosed and there is a scarcity of provision and/or specialised schooling for children with ASD.

Some studies have shown that there is a significant burden on the quality of life perceived by African communities due to ASD (Abubakar et al., 2016). A component of this lowered quality of life can include families lacking the finances to cover basic living costs, let alone to seek support services (for either the child or the caregiver) and there seems to be stigma, social exclusion and discrimination experienced by children with ASD, as well as their caregivers (Dejene et al., 2016). Also, the planning of events and activities as well as family functioning as a whole tend to be different in a family where a child has ASD (Mupawose et al., 2015).

Franz et al. (2017) add that the lack of social support, limited knowledge about ASD, uncertainty of the prognosis, financial difficulties, marital strain, the shortage of facilities and lack of support services for children with ASD tend to compound the difficulties that caregivers of children with ASD face. Franz et al. (2017) add that where caregivers or parents do have access to professional help, they often feel that they are inadequately informed and that their ideas and opinions are overlooked by these professionals.

In sub-Saharan Africa, it seems to be particularly common for caregivers to believe that intervention will cure ASD and that the root cause is either entirely of a supernatural nature or a combination of supernatural and biomedical causes (Dejene et al., 2016). Supernatural factors include evil spirits, witchcraft, curses, punishment from a deity, or action of a supernatural being (Franz et al., 2017). Also, some members of the public are believed to think that ASD is contagious, compounding the stigma and emphasising the need for awareness surrounding ASD (Dejene et al., 2016).

Dejene et al. (2016) found that some unmet needs of South African caregivers of children with ASD could include education for the child, access to appropriate supportive professionals, access to information and advice about the condition. Within the education context, caregivers should be seen as teachers' partners in supporting their children with ASD, seeing that the caregivers are the key role players in their overall growth and development (Koudstaal & Erasmus, 2019).

In their scoping review of ASD in sub-Saharan Africa, based on the knowledge gaps found, Franz et al. (2017) recommend developing interventions that are within reach of and accessible to all South Africans that need it, putting more emphasis on interventions being caregiver-led, identifying coaches in the area that could support caregivers in various ways, conducting more informative programmes for the general public, as well as caregivers, and reminding people to refrain from generalising the story of one caregiver of a child with ASD to all caregivers of children with ASD.

A cell phone application could be very effective in making interventions become more within the reach of all South Africans, while allowing caregivers to be empowered in helping their children with ASD. In order to develop or select an appropriate cell phone application to fulfil this, the needs of children with ASD from an international as well as a South African perspective need to be explored.

## 2.5 THE NEEDS OF CHILDREN WITH ASD

### 2.5.1 The Needs of Children with ASD from an International Perspective

Depending on where they are on the spectrum in terms of severity, children with ASD generally seem to struggle with a number of core skills, namely social interaction and understanding, social communication, rigid thinking, the use of their imagination and, often, accompanying challenging behaviours (Koudstaal, 2016). Because of these challenges, children with ASD tend to have a need for specialised education or support of some kind, especially in these areas (Franz et al., 2017). Support can be beneficial, because through support, the characteristics of developmental delays in children with ASD can be effectively improved so that cognitive growth can be stimulated (Manti, Scholte, & Van Berckelaer-Onnes, 2013).

Children with ASD can be supported in various ways and from a variety of disciplines, including speech and language therapy, occupational therapy, behaviour intervention, dietary adjustments, pharmaceutical intervention or through educational programmes (Davis et al., 2016). According to Bowen and Plimley (2008), it is of vital importance that the caregivers of children with ASD work closely with the multidisciplinary team of professionals supporting the child in order to be well-informed about the child's areas of growth and mobilise follow-up support wherever necessary. Without this support, intervention regimens may be less effective.

Specifically, children with ASD benefit from going for occupational therapy (specifically to work on possible sensory integration issues), speech therapy (to support with their communication challenges) (Adams et al., 2012) and play therapy (to work on important developmental differences encountered by children with ASD) (Phillips & Beavan, 2012). Attending a school specialising in supporting the needs of children with ASD can prove to be beneficial (Moreno, Aguilera, & Saldana, 2008).

Children with ASD may have a poorer health status overall (Duchan & Patel, 2012). It is believed that children with ASD should first have their physical complaints attended (Bateman, 2013). In addition to physical characteristics, Abubakar et al. (2016) believe that comorbidity of ASD with disorders such as ADHD and other intellectual or neurological disabilities is common. This is apparently especially prevalent in the African context, therefore giving the child appropriate medication to support the management of these disorders is not unusual (Abubakare et al., 2016; Oslund, 2013).

In a school setting, it could be seen as a need for teachers to have a thorough understanding of cognitive development in children with ASD in order for them to implement the most effective teaching strategies to accommodate them (Manti et al., 2013). As children with ASD learn in different ways than that of typically developing children, early intervention, appropriate education and parental involvement can prove to be effective in promoting social inclusion and actualising potential (Koudstaal, 2016). Also, understanding ASD, and the implications of it, can be crucial in allowing some children to accept, manage and explain their differences to their classmates (Stevenson et al., 2016).

In terms of education for children with ASD, it is believed that many children with ASD can benefit from going to school with typically developing peers, but it is important to acknowledge that special arrangements will most likely be necessary (Koudstaal & Erasmus, 2019). It is commonly recommended that the classroom environment be inclusive of the needs of children with ASD, which can be achieved by making use of structure, explicit instruction methods, extra support and by incorporating the child’s individual strengths where possible (Manti et al., 2013). Most often, however, it is necessary for any specialised education or support to be tailored to each child’s specific needs (Samadi, McConkey, & Kelly, 2012).

Incidences of bullying in the school, or even work environment, seem to be common in the lives of individuals with ASD, compounding the challenges that they face on a daily basis, and often leading to depression or anxiety (Nordahl-Hansen et al., 2018). This emphasises the need for a support system, that people with ASD often tend to find in their families or a church, where their feelings of self-worth can be bolstered and social skills can be developed within a safe environment (Stevenson et al., 2016).

### 2.5.2 The Needs of Children with ASD from a South African and Resource-Constrained Perspective

As the needs of children with ASD in South Africa and resource-constrained contexts are basically the same as those of children with ASD internationally, it should be obvious that in resource-constrained contexts, one of the main needs of children with

ASD and their families would be to have access to resources. Specifically, within the South African context, the lack of access to healthcare, rampant poverty, a lack of knowledge about ASD (Meiring, Seabi, Amod, Vorster, & Kern, 2016), a lack of access to early intervention for ASD (Meadan, Meyer, Snodgrass, & Halle, 2013) and inescapable stigmatisation all seem to add up to hinder the successful management of ASD in various ways (Chambers et al., 2017). In terms of schooling opportunities for children with ASD, Meiring et al. (2016) posit that only 30% of the South African schools that provide for learners with special education requirements cater for learners with ASD.

The tools for ASD screening and diagnosing that are valid for the African contexts seem to be few and far between, bringing a number of challenges into play when tools that are standardised to the populations of other countries are used (Abubakar et al., 2016). This is reason for concern, not only because assessment tools may be altogether unsuitable to the populations occupying the African continent, but also because there is increasing evidence that early intervention has the potential to change the developmental trajectory of numerous children with ASD (Chambers et al., 2017).

Early intervention that is of good quality involves using evidence-based information to facilitate support on the appropriate developmental level within the child’s home environment (Meadan et al., 2013). A well-designed app, based on thorough knowledge and research, may be able to bring support to those who need it the most in resource-constrained contexts. Support groups for ASD can be beneficial to both the children and their parents (Bowen & Plimley, 2008; Meadan et al., 2013), and this can be facilitated through a cell phone application, too. Internet-based healthcare attempts to help meet the needs of people who require interventions of various kinds.

## 2.6 INTERNET-BASED HEALTHCARE INTERNATIONALLY AND IN SOUTH AFRICA

Increased internet use and the growing interest in e-technology are fast creating the possibility for technology to be designed that allows for self-directed health management (Forker-Dunn, 2003). Advances in technology have also allowed for wide-spread access to the internet and accumulation of information about ASD, opening up numerous possibilities for networking, sharing information about ASD with the general public, medical professionals, the parents of children with ASD or people with ASD themselves. For teenagers and adults with ASD especially, taking away the necessity of face-to-face communication by means of technology allows for the by-passing of daily struggles of communication while still offering a sense of connection and community online (Stevenson et al., 2016).

Meadan et al. (2013) reported on a pilot program called 'i-PiCS' that allowed for parents to use internet-based interventions to support their children with ASD in America. They found that early interventions for children with ASD were particularly effective when they included family-orientated goals and emphasised children's strengths, making caregivers the most appropriate facilitators of these interventions, leading to benefits of enhanced communication skills and better family life. An important factor mentioned in their study included that the success of this program was heavily dependent on the speed and quality of internet available – an important factor to keep in mind when designing the cell phone application.

The implementation of this program involved an evaluation (done in person) by a speech and language pathologist, followed by a training session where the members of the i-PiCS team spoke to the caregivers either telephonically or by means of Skype video calling in order to train the caregivers in using the program (Meadan et al., 2013). The team members then trained the caregivers in using naturalistic teaching strategies, followed by coaching therein, also done through video calling on Skype, and then the speech and language pathologist conducted another evaluation in person (Meadan et al., 2013). Some important factors discussed by Meadan et al. (2013) in their study included the fact that low socio-economic status could hinder families in resource-constrained contexts from accessing internet connections at all.

A similar program called 'Map4speech' was developed in Singapore where caregivers were trained through interactive learning and regular feedback sessions to support children with ASD. The results showed that there were significant improvements observed in the parents' intervention behaviour and the communication abilities of their children after having used the application (Law, Neihart, & Dutt, 2018). Law et al. (2018) posit that mobile apps can lessen the effects of a lack of access to people specialising in interventions for ASD and decrease the time spent on waiting for access to appropriate interventions.

In another study, a computer-based rehabilitation programme called ‘CogMed’ was used in Sub-Saharan Africa to help participants living with HIV or schizophrenia improve their working memory and investigate possible barriers to the effectiveness of using a computer-based rehabilitation programme for this purpose (Ferreira-Correia, Barberis, & Msimanga, 2018). Computer-based rehabilitation programmes seem to hold great potential due to the fact that they can be made specifically applicable to the potential user, offering high levels of customisation and familiarity (Ferreira-Correia et al., 2018).

An internet-based training programme called ‘Autism Navigator®’ was designed for training primary healthcare professionals in South Africa in order to increase their knowledge of early signs of ASD in children so that more effective early diagnosis and intervention can take place (Chambers, De Vries, Delehanty, & Wetherby, 2018). This is an attempt to minimise what is referred to as the “research-to-practice gap” and accelerate the process of referral for children who are at risk for ASD (Chambers et al., 2018, p. 1511). It was seen as both feasible and cost-effective in providing wide-spread training for healthcare professionals who care for young children in South Africa (Chambers et al., 2018).

Some barriers to the effectiveness of this intervention that could be applicable to this study of cell phone application include challenges regarding computer or internet access, the expectation of negative outcomes and the experience of negative emotions, such as frustration when exercises are challenging. All of these barriers could lead to decreased use of the programme (Ferreira-Correia et al., 2018). These are important signs to look out for in assessing the relevance of the cell phone application investigated in this study.

In order to evaluate the applicability of this mode of intervention in resource-constrained contexts of South Africa, current cell phone trends must be explored.

## 2.7 CURRENT CELL PHONE TRENDS INTERNATIONALLY AND IN SOUTH AFRICA

Globally, the rates of smartphone ownership have increased due to improved availability and affordability, and it is estimated that the number of smartphone subscriptions will reach up to 70% of the global population by the year 2020 (Nguyen & Silva, 2016). This suggests that smartphones can prove to be an ideal mode through which even previously disadvantaged groups of people may access effective health care services (Jones, 2014). Although smartphone use worldwide is increasing rapidly (Nguyen & Silva, 2016), the increase in smartphone use in South Africa may not yet be big enough to be fully accessible by all of South Africa's rural population and people living in resource-constrained contexts where there are children with ASD. This is probably because the South African society remains one of the most inequitable in the world, causing disparities in access to information and communication technologies, let alone smartphones (Labadarios et al., 2013).

The affordability of mobile devices has improved steadily within the past few years, and in South Africa in 2016, there were believed to be 85.53 million cell phone connections (Ruxwana & Msibi, 2018). According to Chambers et al. (2018), in 2015 approximately 53,5% of South African households had at least one inhabitant that had access to the internet and 47,6% of those had access to the internet by means of a cell phone, giving cell phones the highest rates of internet penetration in Africa.

There seems to be numerous gaps in the current research applicable to South African rural and resource-constrained contexts, including the infrastructure found in such areas, as well as current internet and smartphone trends in these areas. This leaves much to be investigated in future, but the promise of the potential of this app remains as smartphone usage seems to continue to increase rapidly, in spite of disparities in urban and other areas (Labadarios et al., 2013).

In addition to current cell phone trends, the characteristics of a user-friendly cell phone application must be explored.

## 2.8 REQUIREMENTS FOR A USER-FRIENDLY CELL PHONE APPLICATION

There seems to be a multitude of cell phone applications available to smartphone users who have access to various app stores. The vast majority of health-related applications available on the internet are not regulated in any way with regard to being user-friendly, presenting any scientific evidence underlying the content of an app, or reporting on the actual effectiveness of the application (Boudreaux et al., 2014). However, there does seem to be a number of characteristics that sources deem as making an application more effective, as discussed below.

For parental intervention for ASD that is to be done by means of a cell phone application, training the parents prior to the commencement of intervention is seen as vital in order to allow for the intervention to be delivered in the natural context and to be embedded in daily routines, which has been proven to be highly successful (Law et al., 2018). Parental training can, therefore, be seen as a helpful method in ensuring user-friendliness for the caregivers.

Jones (2014) posits that the rehearsal or practice of skills is a vital element of current evidence-based programs that are widely accepted as effective. He also maintains that thorough consideration should be given to the theoretical, scientific and practical features of a particular technology-based intervention mode for it to reduce the current challenges to the provision of evidence-based services, and not to aggravate the user (Jones, 2014).

In their study on mobile health applications, Boudreaux et al. (2014) found that different application-users are very likely to find an application more helpful or less helpful depending on the detail in the application that addresses their specific conditions as well as particular personal factors. They, therefore, recommend that applications be reviewed and that feedback from application-users be taken into consideration while keeping up appropriate standards of privacy, safety, functionality and usability (Boudreaux et al., 2014). This research study will be one such study to address personal factors.

In their study on the user experience of cognitive behaviour therapy applications for depression, Stawarz, Preist, Tallon, Wiles and Coyle (2018) found that ensuring the privacy of users' details was one of the most prominent needs communicated by users who use applications to support mental health. They also point out that basing an application entirely on clinical theory alone is not enough if it is not combined with knowledge on how people interact with technology (Stawarz et al., 2018). The developers of the Maps4Speech app also added learning theory to the development of the application, so that the principles of learning were embedded in the application, to make it more effective when used.

While pointing out a number of key factors in developing an application, Rowles (2013) mentioned that internet connection, smooth user experience, cost-effectiveness, and access to updates and maintenance can be seen as important. Mummah, Robinson, King, Gardner and Sutton (2016) posit that human-centred thinking is the key to designing ground-breaking interventions that are helpful and applicable to the target market.

As drawn and adapted from the abovementioned characteristics, the following is a practical summary in the form of a checklist to be used to select the application for the study in a South African resource-constrained context:

- parental training;
- privacy of users;
- language that is easy to understand;
- reasonable data usage;
- cost-effectiveness;
- based on clinical research evidence, or current practice within the field;
- proof of effectiveness;
- opportunities for rehearsal or practice of skills;
- ease of navigation and access to information;
- embedded in principles of learning; and
- access to updates and maintenance.

These can also be regarded as criteria for application development.

Now that ASD intervention is understood within the opportunities and limitations of cell phone technology, a conceptual framework for the research will be presented.

## 2.9 CONCEPTUAL FRAMEWORK FOR THE STUDY

Forming the basis of the conceptual framework used for the study is Bronfenbrenner's bio-ecological systems theory, integrated with the asset-based approach.

### 2.9.1 Bronfenbrenner's Bio-Ecological Systems Theory

To conceptualise the development of a child with ASD, Urie Bronfenbrenner's bio-ecological systems theory is considered. It asserts that the interaction of a developing human and the environment in which the human exists causes behaviour to develop and that the process of development is therefore subject to influences from both immediate and larger surrounding systems (environments) (Bronfenbrenner, 1979).

This principle is capitalised on for this study in that it is an exploration of how children with ASD will ultimately benefit from the bi-directional influences between interconnecting systems in their lives (namely their caregivers and the use of technology and experts found in their environments, to name a few) to bring about the desired change (Aucamp et al., 2014). The influence of context is therefore dominant in this theory (Bronfenbrenner, 2005).

Because this model takes into consideration both the multidimensional aspects as well as the contextual considerations of human development, it suggests that there are multiple levels of complex interaction between a variety of systems in the life of each developing individual (Swart & Pettipher, 2016). Due to ASD being such a complex and multidimensional challenge, Bronfenbrenner's bio-ecological systems theory allows for appropriate consideration of the dynamic interplay among causes, characteristics, consequences and influencing factors, as well as modes of intervention and tools for the management of ASD (Megremi, 2014).

From a bio-ecological perspective, children with ASD as well as their caregivers are influenced continuously in various ways by the interacting systems surrounding them. A systemic orientation towards understanding their experiences is, therefore, necessary in order to comprehend more fully the deep underlying patterns of influence on the lives of caregivers and their children with ASD (Aucamp et al., 2014). Bronfenbrenner's bio-ecological systems theory (Bronfenbrenner, 1979) is presented in Figure 2.1 below and is adapted for applicability and the purposes of this study.

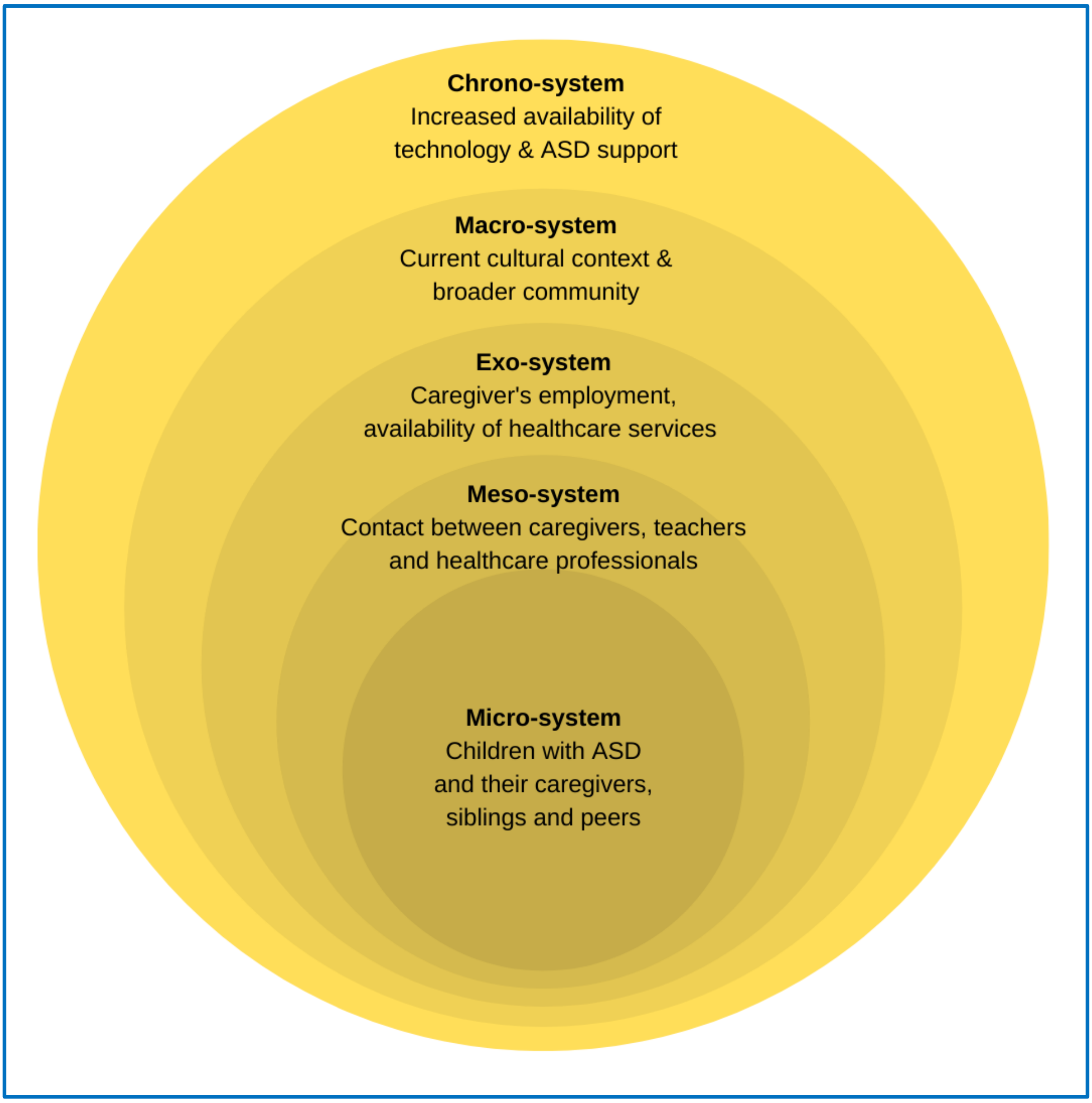


**Figure 2.1:** Conceptual framework of the study (adapted from Bronfenbrenner, 1979)

Bronfenbrenner (2005) divided a developing human’s ecological system into five interconnecting systems, namely the micro-system, meso-system, exo-system, macro-system and chrono-system. The micro-system consists of patterns of interaction between the individual and those around him or her in the immediate environment, such as those in the individual’s family, school or peer group, and therefore considers the roles and relationships involved therein (Keenan & Evans, 2009). Here we would find children with ASD and their caregivers, with their individual experiences of ASD, interacting with their caregivers, family members with whom they live and their school teachers, if they are attending school.

The meso-system involves the interactions occurring between two or more micro-systems in the individual’s life, for example, relations between the school, the home and the workplace (Bronfenbrenner, 2005; Swart & Pettipher, 2016). Also, relationships between parents and healthcare professionals fall into the meso-system, including the extent of parental involvement in intervention (Graves & Sheldon, 2018).

The exo-system consists of the broader social settings, establishments and cultures that the individual is not necessarily directly exposed to, however, which have a significant effect on their development (Keenan & Evans, 2009). An example of this would be the caregiver’s job security and the flexibility granted by the employer (if applicable) to allow the caregiver(s) to be excused from work in order to support their child with ASD in various ways (Graves & Sheldon, 2018). Various policies and legislation influencing the availability of healthcare services whenever necessary can be included in the exo-system as well (Robinson, 2018).

The macro-system consists of the dominant beliefs, resources and customs of the community in terms of the economic and social structures in place, overarching the preceding levels (i.e., micro-, meso- and exo-) in a specific instance (Aucamp et al., 2014; Bronfenbrenner, 2005). The values, beliefs and cultures that are prevalent in these contexts impact the consequent interactions on all other levels and are influenced by the broader community (Swart & Pettipher, 2016).

At this level, the belief systems held by the respective settings and establishments have a critical impact on the development of the individual (Bronfenbrenner, 2005). An example of this would be where the beliefs held by members of the community may be shaped by indigenous understandings of what causes ASD, and this can often determine whether early intervention is sought or not (Mthombeni & Nwoye, 2018).

Lastly, the chrono-system accounts for how the dimension of time impacts the development of an individual (Bronfenbrenner, 2005; Keenan & Evans, 2009). All factors that are time-related in terms of history, current events or even the ages of the people involved influence interactions within the various systems (Graves & Sheldon, 2018). In the case of this study, living in the 21st century, when the advances in technology make using a cell phone application for ASD support possible, it invariably impacts the interactions between all abovementioned systems, in addition to the development of children with ASD.

### 2.9.2 The Asset-Based Approach

The asset-based approach involves using the skills, capacities and resources within people or their environments (Mbetse & Ebersohn, 2003) in order to support people in pursuing a better life and maintaining an action-orientated mind-set towards being the agents of change in their own lives (Kretzmann & McKnight, 1993; Mathie & Cunningham, 2003). It aims to include people who may be seen as less powerful in society (including those who live in resource-constrained contexts or rural areas) in order to bring improvement and empowerment to the lives of all involved (Hipwell, 2009; Kretzmann & McKnight, 1993).

More than being relevant, flexible and practical, the asset-based approach can prove to be highly effective in that it allows for the people involved to develop a sense of responsibility and ownership towards the matter at hand (Mbetse & Ebersohn, 2003). This approach is very applicable for use with the caregivers of children with ASD in resource-constrained contexts, as the study aims to empower parents to use what they can access, such as smartphones, access to the application and data, so that they can support their children with ASD by providing them with support that they would otherwise not have had access to. The application can also mobilise the asset of good caregiver-child relations.

### 2.9.3 Integrating the Asset-Based Approach with Bronfenbrenner's Bio-Ecological Systems Theory

The asset-based approach links up well with Bronfenbrenner's bio-ecological systems theory in that the asset-based approach mobilises the assets on a systemic as well as an individual level (Eloff, Ebersöhn, & Viljoen, 2007). This means that if one ignores the interactions between the different systems in a particular situation, for example, community, school and family environments, it would not be possible to identify and consequently mobilise enough assets that could be valuable in advancing the cause (Venter, 2014). In the case of this study, some important assets include the increases in smartphone usage worldwide, causing cell phone and data costs to be more affordable in our country, resulting in access to the application that can support caregivers of children with ASD, especially, in resource-constrained contexts.

In addition to the practical application of this intended research, however, it is important to note that the theory of ASD which is currently used for clinical diagnoses and intervention in South Africa is dealt with from a Western perspective (Mthombeni & Nwoye, 2018). This therefore poses the need for current theories to be augmented, or replaced, in order to reflect a more applicable theory of intervention for South African population groups. Figure 2.2 shows the integration of Bronfenbrenner's bio-ecological systems theory and the asset-based approach that constitute the conceptual framework to be used in the study.

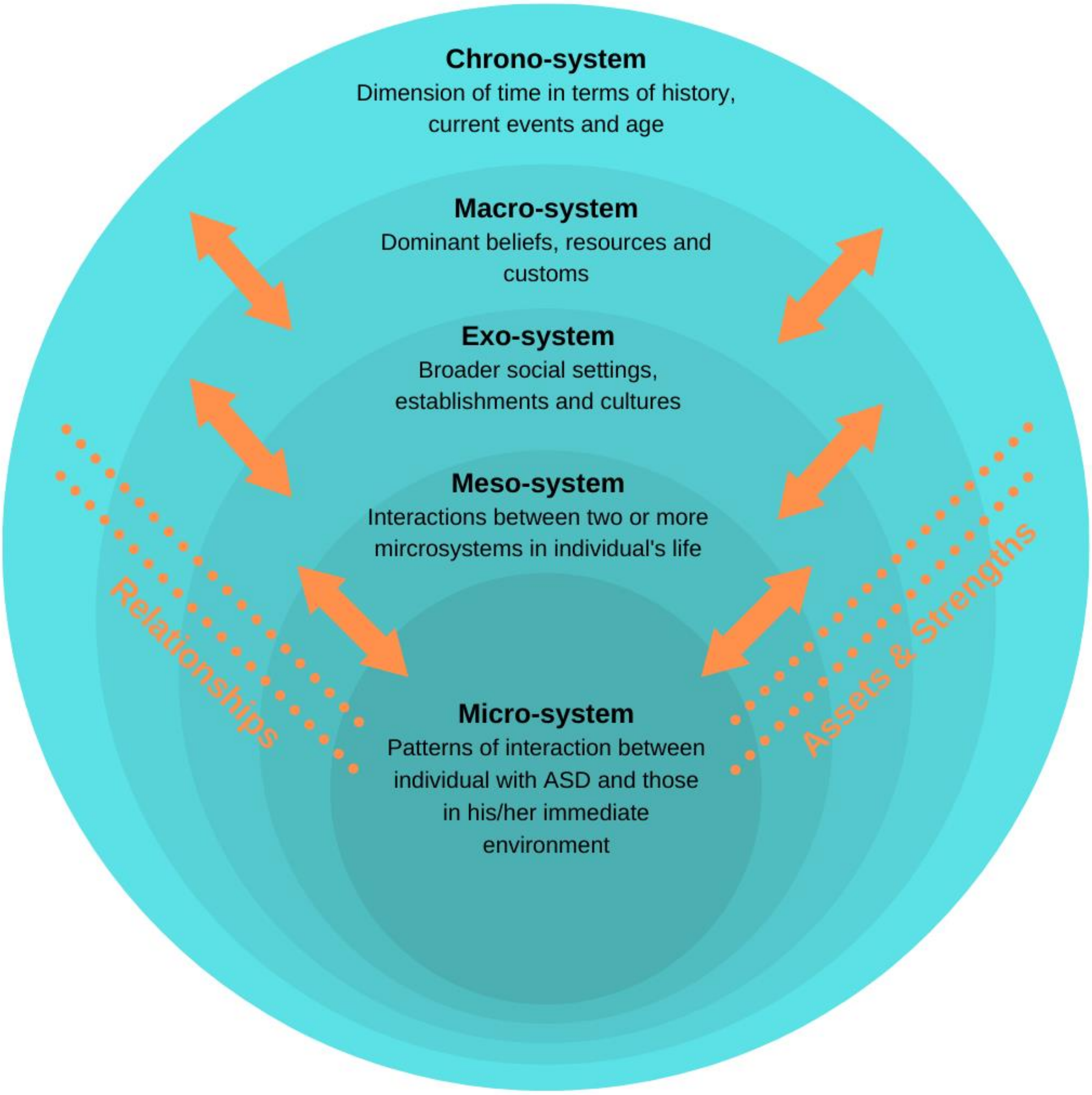


**Figure 2.2:** A visual representation of the integrated conceptual framework to be used in the study

## 2.10 CONCLUSION

Internet technologies that are more widely accessible than some medical and support professionals, especially in resource-constrained contexts, hold extensive potential for parents to be able to learn how to apply evidence-based techniques in order to support their children with ASD and to have access to support that is of a high quality (Meadan et al., 2013). Researching the applicability of a cell phone application to be used by caregivers of children with ASD specifically in resource-constrained contexts may be one way to overcome the limited available support by using modern technology that is increasingly becoming available to all members of the population. Such an application may be the beginning of a noteworthy shift in support and psycho-education of ASD in South Africa.

Chapter Three will address the research paradigm, methodology, data generation and documentation as well as data analysis and interpretation in order to research the usefulness of a cell phone application for caregivers of children with ASD in resource-constrained contexts. Also, central to the entire research process, the quality criteria and ethical considerations will be discussed in this chapter.

# CHAPTER THREE - RESEARCH DESIGN AND METHODOLOGY

## 3.1 INTRODUCTION

Chapter Two gave background to the research question as posed in Chapter One. Based on the nature of the research question, Chapter Three will discuss the epistemological and methodological paradigmatic perspectives, followed by the selected research design to answer the primary research question, namely '*What are the experiences of caregivers of children with autism spectrum disorder of a cell phone application to support their children in resource-constrained contexts?'* The sampling, data collection methods, data documentation and data analysis will also be discussed. Lastly, quality criteria and ethical considerations are examined.

## 3.2 RESEARCH PARADIGMS

Research paradigms are differing sets of fundamental assumptions that researchers both use and adhere to in order to conceptualise how reality is viewed in their research (Wahyuni, 2012), and the best way(s) in which to research the aspect of reality under scrutiny. In the case of a study that investigates the experiences of caregivers of children with ASD, the interpretivist paradigm seems most appropriate. Qualitative research is therefore the key approach chosen for research methodology. Below the core characteristics of interpretivism and qualitative research are explored, as well as the benefits and challenges involved in making use of interpretivism and qualitative research.

### 3.2.1 Epistemology

According to Scotland (2012), interpretivism involves the concept of relativism, where people's realities differ from one another and are co-constructed by means of constant social interaction. This means that people's realities are in fact individually constructed and based on the interpretation of real-world occurrences according to their own differing backgrounds, values and experiences (Wahyuni, 2012). An assumption, therefore, would be that each person's sense of reality differs from the next.

Because interpretivism as a research paradigm entails the study of the construction of people's own realities and the beliefs that go with them, research is usually done through direct personal interaction such as taking part in dialogue with participants (Wahyuni, 2012). In this study, it will be done by means of semi-structured interviews with the caregivers of children with ASD, as the main aim of the study is to allow these caregivers to tell their stories and communicate their experiences of using the cell phone application.

According to Stavraki (2014), single interpretive cases can offer rich, in-depth accounts of participants' experiences and reflections in their specific contexts. Also, delving into how and why complex occurrences take place is possible when making use of the interpretivism paradigm (Williams, 2000), which is particularly applicable for this study.

An important challenge, however, could include that legitimacy and trustworthiness may be difficult to account for with total confidence, especially considering that the interpretation of such information may be done differently by different researchers (Scotland, 2012). This emphasises the importance of incorporating reflexivity into the entire research process and being cautious in generalising results (Williams, 2000).

Reflexivity is seen as a process in which the researcher continuously engages in self-reflection in order to remain aware of possible biases and emotions that could potentially hamper the accuracy of the data collection and interpretation process (Stanley, 2014). Reflexivity is, therefore, used to ensure the transparency of the researcher's subjective role. I intended to make use of process notes and debriefing with my supervisor to ensure reflexivity in my research. Member-checking (to be discussed in 3.6.2) will also contribute to the accuracy of fit between the research participant's views and the way in which data were interpreted (cf. Nowell, Norris, White, & Moules, 2017).

According to Scotland (2012), the nature of data collection involved with the interpretivist paradigm tends to lend itself to more easily disclosing information that should otherwise have been kept undisclosed, as open-ended and more persistent promptings often lead to more numerous discoveries of what could include confidential information. To prevent confidential information from being disclosed outside this study, I will follow all ethical guidelines meticulously during the entire research process. Ethical considerations are to be discussed in Section 3.7.

### 3.2.2 Methodological Paradigm

Qualitative research is able to answer questions that are vastly divergent from questions that quantitative research can answer (Barbour, 2008) and is ethnographic and interpretive in nature (Atieno, 2009). The qualitative approach is described by Grossoehme (2014, p. 109) as “the systematic collection, organisation, and interpretation of textual material derived from talk or conversation. It is used in the exploration of meanings of social phenomena as experienced by individuals themselves, in their natural context”. Taylor et al. (2015) posit that the qualitative approach involves obtaining descriptive information about participants, while capturing the complexity of the data, contrary to a quantitative approach (Corbin & Strauss, 2012). Unlike quantitative research, qualitative research can answer vital questions such as ‘How?’ and ‘Why?’ in much fuller detail (Barbour, 2008).

According to Atieno (2009), there are a number of assumptions to keep in mind when using qualitative designs, such as that qualitative researchers are more concerned with the process than the outcomes, as well as the meanings attached to it; the researcher is the principal apparatus through which data collection and analysis take place; fieldwork is a vital part of the research process; the research is descriptive in nature; and the process of research is inductive.

Qualitative research allows for appreciation of the richness of the participants’ experiences in an in-depth manner (Yin, 2016), and exploring phenomena through a variety of lenses (Baxter & Jack, 2008). With qualitative data, one is able to deliver accounts of social constructs that are unmatched in richness and context (Wahyuni, 2012), and one can make sense of apparent discrepancies through qualitative research (Barbour, 2008). A vital objective in this study is to delve into the detail of the participants’ experiences of the cell phone app in order to determine its utility within South African resource-constrained contexts. As mentioned in Section 3.2.1, I will ensure the transparency of the research process as far as possible.

Qualitative researchers are often criticised for not incorporating enough scientific rigour (Barbour, 2008). Also, ambiguities and communication gaps can become challenges in terms of accuracy of any new theories that are contemplated (Atieno, 2009). Qualitative research mostly make use of small sample sizes to allow thorough, in-depth investigations of individual experiences; therefore, it is important to remember that the results obtained cannot be generalised with the same certainty as with quantitative methodologies. However, generalisability is not the goal of qualitative research (Barbour, 2008), and so a qualitative approach remains ideal for this study in particular.

Qualitative research is also criticised for focusing too much on personal experience and not enough on the interaction between personal experience and social, economic, institutional and cultural conditions (Barbour, 2008); however, the use of Bronfenbrenner's bio-ecological theory allows for these interactions. Other challenges faced by qualitative researchers often include the data collection process being time and resource consuming and that data analysis can prove to be challenging for the researchers (Atieno, 2009). As the researcher in the study, I deem these demands as worthy of my time and resources in order to uncover evidence that I believe can potentially assist in bringing improvement to many people's lives, especially those living in resource-constrained contexts.

## 3.3 RESEARCH DESIGN

### 3.3.1 Case Study Design

According to Baxter and Jack (2008), there are a number of types of case studies that can be conducted, such as explanatory, exploratory, descriptive, multi-case, intrinsic, instrumental and collective case studies. For the purpose of this study, the exploratory type is most applicable, as the aim is to explore the experiences of caregivers of children with ASD. Case studies will be used as the design for data generation. The case study research design is an invaluable tool in capturing the complexity of the occurrences being researched, allowing for greater quality of the data obtained (Hamilton & Corbett-Whittier, 2013; Thomas & Myers, 2015).

It is especially useful in situations where data can be obtained from participants being in their natural contexts, as this contributes to the richness of the data captured (Stavraki, 2014). These considerations are important in investigating participants' experiences of the cell phone application to assist them in supporting the children with ASD. Also, the case study research design aligns with the interpretivist paradigm within qualitative research because of its nature of exploration (Diefenbach, 2009; Stavraki, 2014).

According to Zainal (2007), researchers select either a multiple-case design or a single-case design. In this study, a multiple[1]-case design will be used to conduct an exploratory study (cf. Zainal, 2007) due to the need for exploration of caregivers' experiences of the cell phone application.

Using case studies is advantageous in that it will allow a real-life, holistic view of the realities and interconnecting factors (Hamilton & Corbett-Whittier, 2013), in this case, of caregivers of children with ASD. The fact that the data are collected in the same context as that in which the phenomena occur, adds to the richness of the data obtained (Zainal, 2007). Also, Zainal (2007) points out that case studies are better able to explore the complexities of real-life situations that are not otherwise captured by surveys or experimental research.

It is argued that case studies lack rigour, and that the data obtained are often influenced by researcher bias and influence (Zainal, 2007). Also, due to the small sample sizes, most findings cannot be generalised. Case studies can generate much data and too much data that are not kept and managed appropriately could prove to be challenging to the accuracy of data analysis over time (Baxter & Jack, 2008; Zainal, 2007).

In an attempt to avoid this challenge, any possible apps will be kept to the specific context of participants, and the data obtained will be stored in an organised manner. Accurate data collection and analysis will enable me to obtain thick descriptions, capture complexities and develop context-embedded accounts (cf. Stavraki, 2014) of these caregivers of children with ASD.

According to Baxter and Jack (2008), a few key fundamentals that one can use to enhance the overall trustworthiness of a case study include writing the research question clearly; ensuring the case study design is appropriate for the chosen research question; choosing sampling strategies that are appropriate to the study; collecting and managing the data collected systematically; and analysing the data correctly. With

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[1] Only one participant who fulfilled the selection criteria participated, resulting in the study becoming a single-case design (refer to selection of participants in Section 3.3.3).

the help of my supervisor, I intended to fulfil each of these criteria in order to ensure the trustworthiness of the study.

### 3.3.2 Selection of the Site

The selection of the Itsoseng Clinic (in Mamelodi, Pretoria) as the research site was based on its location in a resource-constrained context (Blokland, 2014) which is within driving distance for the researcher. Itsoseng Clinic was, therefore, selected on the basis of convenience sampling so that all participants are accessible to me as researcher at this site, which was a major advantage. In addition, the clinic is managed by the Department of Psychology in the Faculty of Humanities of the University of Pretoria, with which the Department of Educational Psychology in the Faculty of Education of the University of Pretoria has liaised before. See Appendix A and Appendix B for the request and consent for using Itsoseng Clinic.

### 3.3.3 Selection of Participants

Convenience or purposive sampling is a type of non-probability sampling that involves the selection of participants based on them being part of a target population and meeting a set of particular criteria (Etikan, Musa, & Alkassim, 2016). Purposive sampling is greatly effective in that only participants with information-rich and relevant contexts are chosen to take part in the study (Hamilton & Corbett-Whittier, 2013), which will prove to save time and resources during the research process (Etikan et al., 2016).

Important challenges of using convenience sampling are that data should not be taken as representative of the population, and that sampling may be subject to selection bias, therefore causing generalisation to be limited (Acharya, Prakash, Saxena, & Nigam, 2013). To avoid this, I will ensure that all results are appropriately contextualised, and I will keep to the same routines and methods of data collection for all participants as far as possible. Three participants who are caregivers of children with ASD at Itsoseng Clinic will be selected.[2]

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[2] Although three possible participants were found, one participant could not be contacted, probably due to a change in contact details. Another participant did not have a confirmed diagnosis of ASD for his/her child, and it was suspected that the child had global developmental disorder. Only one participant remained, and even though she was waiting for an official diagnosis of ASD, representatives of the Itsoseng Clinic were sure about the diagnosis of ASD.

Purposive sampling is used to narrow down specific aspects of cases so that the researcher may work solely with particular participants who will be best suited to assist with the specific research being done, and therefore possibly discover insight about participants within these more unique contexts (Duan, Bhaumik, Palinkas, & Hoagwood, 2015). This is especially appropriate for the proposed study as the caregivers of children with ASD who are willing to use the cell phone application are sought out in order for findings to be made about the utility of the cell phone application if used in that specific context.

The selection criteria for participants include the following:

- The participant cares for a child between the age of three and six years old. Children with ASD are often diagnosed between these ages. It will also imply that participants will have similar needs for support, namely preschool children, as opposed to the differing needs of children of various ages. Selecting parents with children within a specific age range is important as most apps are developed with a specific age group in mind. Caregivers of children who are chronologically older, but behaviourally within the age span, will also be considered.
- The child has a confirmed diagnosis of ASD with few co-morbid conditions.
- The participant possesses basic interpersonal communicative skills (BICS) (Cummins, 2016, p. 940).
- The participant lives in a resource-constrained context.
- The participant possesses a smartphone and has access to data.

These criteria give way to the use of homogenous sampling, which is one of the purposive sampling methods that concentrates on using participants who have specific traits in common (Etikan et al., 2016). In this case, the participants selected would have similar life experiences for me to draw on in collecting data about being the caregiver of a child with ASD and the usefulness of the cell phone app in providing support.

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As this is a mini-dissertation of limited scope, it was decided, after consultation, to proceed with the research, even though only one participant was involved. It is possible that the participant chosen could have a disorder that is comorbid with ASD. However, it should be noted that no signs of repetitive patterns or inflexible social contact were observed.

See Appendix C[3] for an example of the letter of consent that participants[4] had to complete prior to interviewing.

### 3.3.4 Selection of the Cell Phone Application

For the purposes of this study, only apps that support both social and cognitive development in children with ASD are considered and compared for use. Because challenges in social and cognitive development commonly form part of the core features of ASD (Losh, Childress, Lam, & Piven, 2008), a cell phone application that supports these aspects of development could prove to be helpful. Table 3.1 compares some of the applications considered for the study using the criteria set in Chapter Two (Section 2.8)

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[3] The original consent form for the participant contained a reference to eight weeks. However, that was shortened to ten days to accommodate the availability of the application selected, which was available without cost for ten days only.

[4] Only one participant was selected for the study. The child of the research participant is nine years old, which does not fulfil the initial selection criteria. However, because only one participant is involved, the age of the child is not relevant to selection. For the purposes of application selection, the age of the child is relevant, but due to the child experiencing possible developmental delays as well, the application for children of a pre-school age is still seen as appropriate.

**Table 3.1:** Comparing a number of cell phone applications

| Name of app | Reasonable data usage (Size) | Cost of app | Skills addressed | Popularity due to easy navigation (number of downloads) | Recommended age group | Easy to navigate and access information (ratings) | Intended use by | Based on clinical research evidence | Privacy | Opportunities for rehearsal |
|---|---|---|---|---|---|---|---|---|---|---|
| Teach Autistic Children | 2.4 MB | Free | Teaching tips for children and adults with autism | 10+ | 3+ years | Unknown | Teachers | Unknown | Unknown | Unknown |
| Language and Cognitive Therapy for Children (MITA) | 214 MB (thereafter, no Wi-Fi needed) | R969.99 | Improves overall development, specifically language, attention and visual skills; used by the children | 100 000+ | Age 5 years and below | 4.7 ★ | Parents & children | Yes (based on ABA principles) | Unknown | Yes |
| Jade Autism | 15.02 MB | Free | Stimulating reasoning, cognitive and logical develop-ment | 10 000+ | 3+ years | 4.4 ★ | Children | Unknown | Unknown | Yes |
| Autism Help | 26.32 MB | Free | Cognitive skills involving meeting and achieving | 5 000+ | 3+ years | 4.0 ★ | Parents and children | Yes (use of scientifically proven diagrams) | Unknown | Yes |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | day-to-day needs | | | | | | | |
| Autism – How to Help your Child | 35 MB | Free | Parental and educational support information | 10 000+ | 3+ years | 4.0 ★ | Parents | Unknown | Unknown | Unknown |
| Autism Guide | 10.15 MB | Free | Offers information and explores intervention and educational options | 500+ | 3+ years | Unknown | Parents or teachers | Unknown | Unknown | Yes |
| ABA Dr Omnibus for Parents | 427 MB | 1 month subscription : $6.99 (Free ten-day trial) | Social skills, language skills, attention and comprehension | 1000+ | 3+ years | 4.3 ★ | Parents and children | Yes (ABA therapy principles) | Unknown | Yes |

The ABA DrOmnibus for Parents application was chosen as the most appropriate application to use in this study, as it addresses the development of language and social skills in children with ASD, it was developed for use by non-therapists, that is, parents or caregivers, and is based on ABA therapy which has been recognised as a highly effective strategy for supporting children with ASD for decades (Dillenburger et al., 2012). An added bonus is that the application can be used free for a trial period of ten days.

The application will be loaded onto the smartphone of the participant. One support session to facilitate training, based on the literature review (Law et al., 2018; Meadan et al., 2013), will be provided during which the participant will be shown how to navigate the application, as well as the first four topics. After approximately five days, another support session will be scheduled in which challenges will be addressed, and the next four topics will be navigated and supported.

## 3.4 DATA GENERATION

The term 'data generation' is seen as most appropriate in this study, as it communicates the active role played by the researcher as the collector and analyst of the data (Barbour, 2008). Primary data will be collected by means of a semi-structured interview with a caregiver of a child with ASD as the experts of his/her own life (Wahyuni, 2012). Semi-structured interviews are neither completely fixed nor completely free, giving it a degree of flexibility where the researcher can start the interview with a number of pre-determined questions at hand but allow the interview to take place in a more conversational way (Seabi, 2011). Specific answers can also be probed. The semi-structured interview will be conducted individually, in person and at one time only after the participant has used the application for a period of ten days. See Appendix D for the semi-structured interview schedule.

When it comes to structuring an interview, Rubin and Rubin (2012) posit that main questions, follow-up questions and probes can help one keep the conversation organised and assist in getting the data that one needs. It is anticipated that asking for examples and explanations will assist researchers in gaining deep insight into the views of the interviewees, and probes can assist in maintaining the flow of the conversation while clarifying information (Wahyuni, 2012).

Semi-structured interviews can be useful in obtaining both rich and applicable information from the participants in the form of a dialogue, as the researcher has the advantage of being able to concentrate on specific topics, while not being limited to them (Gill, Stewart, Treasure, & Chadwick, 2008; Rabionet, 2011).

According to Seabi (2011), there are a number of factors to keep in mind when conducting a semi-structured interview for data collection including building rapport with the interviewee before going straight into the key topic questions; taking one's own as well as the interviewee's non-verbal cues into account to provide thick descriptions; avoiding the use of questions that are too open-ended or questions that only require a one-word answer; listening more than one speaks during the interview in order to allow the interviewees to speak at length about their knowledge and experiences; and making use of probes (Harrell & Bradley, 2009). Barbour (2008) emphasises the importance of using active listening in order to make the most of the insights gained during the interview.

Rubin and Rubin (2012) believe that the interviewer and interviewee should be viewed as conversational partners and that qualitative interviews are similar to normal conversations; however, interviews are supposed to be more detailed, focused, and in-depth than normal conversations, where one person answers more questions while the other asks more questions. According to Barbour (2008), a semi-structured interview schedule could contain a number of well-thought-out questions that are open-ended as well as a number of accompanying prompts that could be helpful to the interviewer in cases where there is risk for specific information being overlooked while maintaining a conversational style.

This type of interview will allow me to gather data from the caregiver who meets the set criteria, in order to explore his/her experiences of using the cell phone app to support his/her child with ASD. The interview is also meant to supply the caregiver, who I suspect may feel like he/she is 'unheard', with a voice and allow him/her an opportunity to tell his/her story freely.

## 3.5 DATA DOCUMENTATION

For documentation of the data obtained, I will make use of audio recordings of the semi-structured interview, note taking of the environment and non-verbal behaviours, and transcriptions of the audio recordings.

### 3.5.1 Audio Recordings

I intended to use two voice-recording methods to ensure full data capture in case of technological malfunction, especially as the interviews would only take place on one occasion for each participant. Audio recording can be very useful in freeing up the interviewer to concentrate more on listening actively to the interviewee and formulating follow-up questions instead of having to write down every concept that is brought up during the conversation as well as still listening actively and formulating follow-up questions (Rubin & Rubin, 2012).

### 3.5.2 Field Notes

When taking notes during an interview, it is important not to let the taking down of these notes interfere with the interviewer's listening, as this is also an opportunity for the researcher to take note of non-verbal cues (Doody & Noonan, 2013). This can be especially helpful to the researcher for jotting down possible follow up questions before they are forgotten, making notes of communication that is not picked up on in audio-recordings and helping to pace the interviewee in the speed of answering (Rubin & Rubin, 2012).

Throughout the process of data collection, I will make use of field notes, which will basically be honest, written explanations of my experiences and observations during the interviews (cf. Seabi, 2011). These field notes can be useful in supporting and justifying the evidence obtained from the audio-recordings and transcriptions, and can be important tools in keeping track of possible personal bias which could influence the data obtained (Hamilton & Corbett-Whittier, 2013; Seabi, 2011). See Appendix F for the field notes that were collected during this study.

### 3.5.3 Transcriptions

It is almost always necessary for audio recordings to be transcribed in order for the information to be analysed and examined in detail so that patterns can be discovered and meaning can be made from the data (Bailey, 2008). After the interviews have taken place, I will transcribe the recordings in order for data analysis and interpretation to be done effectively.

## 3.6 DATA ANALYSIS AND INTERPRETATION

Data analysis is the process in which raw interview data are transformed into evidence-based interpretations that can be used for drawing inferences from one's findings (Rubin & Rubin, 2012; Wahyuni, 2012). The data are generally first prepared by means of storing, transcribing the audio recordings and then cleaning the data, and then qualitative data analysis takes place where codes are given to specific themes found in the data (Wahyuni, 2012). I intended to use inductive thematic analysis, a type of qualitative content analysis that is widely used for the purposes of qualitative data analysis and interpretation (cf. Braun & Clarke, 2006).

Inductive thematic analysis is a method for recognising, analysing, arranging, defining and reporting on the themes that are found in qualitative data (Nowell et al., 2017). It is seen as an effective way of analysing prominent themes in the information that has been collected, while still being flexible and maintaining the detail and richness of the data (Braun & Clarke, 2006). This data analysis method ensures that no detail is left out from the data obtained (Guest, MacQueen, & Namey, 2011) through the semi-structured interviews with the selected caregivers of children with ASD.

It is important that the opportunity for those confronted with ASD on a daily basis to speak up about their experiences and not be down-played by the data analysis method and the findings that are ultimately drawn from that information. The significance of thematic analysis falls in what the common threads found throughout the entire data set reveal about the phenomenon under investigation (Vaismoradi, Turunen, & Bondas, 2013). The flexibility and spontaneity of thematic analysis caters to the need of obtaining rich and detailed data; however, it can pose as a threat to the consistency and coherence of the findings throughout the study due to this flexibility and due to limited extensive literature to inform researchers who are new to the field (Nowell et al., 2017).

Thematic analysis proves to be a very transparent, systematic technique for data analysis in that it has a number of simple procedures that can be easily followed (Joffe, 2012; Nowell et al., 2017). Braun and Clarke (2006) provide six phases of analysis to ensure the smooth running of the inductive thematic analysis process, to which I intended to adhere, as follows: (1) familiarising oneself with the data; (2) generating the initial codes; (3) identifying themes; (4) reviewing these themes; (5) defining and naming these themes; and (6) reporting on one's findings. All through the process of data collection, analysis and reporting, it is of vital importance that rigour is the overarching intention throughout (Vaismoradi et al., 2013). In order to ensure authenticity in this study, I intended to make use of the quality criteria stipulated below.

ATLAS.ti 8 (2018) Scientific Software Development GmbH, Berlin was used to do the initial coding of the data. The rest of the process of data analysis was done manually thereafter.

## 3.7 QUALITY CRITERIA

Whether qualitative research is seen as rigorous or not has long been debated in the literature (Wahyuni, 2012). If a study is trustworthy or has rigour, it means that research findings are worthy of the attention of other researchers because it is based on objectively analysed evidence (Nowell et al., 2017). Qualitative research seeks to yield knowledge that is credible and interpretations that are accurate in understanding and emphasising the uniqueness and contexts of phenomena (Wahyuni, 2012).

The most common measures of scientific rigour in qualitative studies are transferability, credibility, confirmability and dependability (Vaismoradi et al., 2013), which parallel internal validity, external validity, reliability and objectivity in quantitative research (Wahyuni, 2012).

### 3.7.1 Transferability

Transferability entails the extent to which the findings can be applied in other contexts or settings, or the generalisability of it (Wahyuni, 2012). The lack of generalisability of qualitative research as compared to that of quantitative research is well documented in the literature; however, researchers can provide thick descriptions in order for other researchers to be able to judge the transferability to another site for themselves, as transferability may still be possible once careful adjustments have been made (Nowell et al., 2017; Wahyuni, 2012).

### 3.7.2 Credibility

Credibility refers to the accuracy with which studies investigate what they aim to investigate and the extent to which the data are actually reflected in social phenomena

(Wahyuni, 2012). Credibility can be ensured in a study by employing the method of member checking, where findings and interpretations are checked with the participants (Nowell et al., 2017), and by making sure that the method used, means of evaluation and the data obtained from the study are all triangulated where possible (Wahyuni, 2012).

### 3.7.3 Confirmability

Confirmability is the extent to which other researchers can confirm the findings of one's study due to the findings reflecting the participants' experiences and not the researcher's own experiences (Wahyuni, 2012). To ensure confirmability, it is recommended that researchers include the reasons for their choices throughout the study so that other researchers can easily understand how and why the decisions were made (Nowell et al., 2017). According to Nowell et al. (2017), including an audit trail (consisting of all the raw data, transcriptions, notes generated during the study) can allow for other people to follow how decisions were made throughout the study, creating a sense of transparency.

### 3.7.4 Dependability

Dependability involves doing and explaining one's research process in such a way that, in future, other researchers could use a similar research framework (Wahyuni, 2012). Dependability can be ensured by making sure that the entire research process is well-documented, traceable and logical (Nowell et al., 2017), including, for example, the interview questions (Wahyuni, 2012).

For the study, I intended to adhere to all of the above as far as possible in order to ensure that the research is of good quality.

## 3.8 ETHICAL CONSIDERATIONS

Ethics is the set of norms of conduct that distinguishes between behaviour that is suitable and behaviour that is unsuitable (Hamilton & Corbett-Whittier, 2013). Psychological research is obligated to create knowledge that is founded on principles of respect and the protection of human rights and so adherence to ethical standards is expected from all professionals involved in conducting research (Allan, 2016). As a student psychologist registered with the HPCSA, I will strive to conduct all stages of the research in an ethical manner, as the use of ethical practices is seen as essential all through the research process (cf. Hamilton & Corbett-Whittier, 2013). Specifically, I will respect the principles of permission, consent, confidentiality, trust, non-maleficence and professional ethical conduct.

Qualitative research is seen as having a number of unique ethical challenges due to the nature of interactions with participants being more personal, deep, lengthy and occurring within their own environments (Ponterotto, 2013). In order to increase the sense of accountability within psychological research as a whole, it is most commonly necessary for researchers to obtain permission from an official research governance structure before commencing with any form of data collection (Barbour, 2008).

Permission was obtained from the Ethics Committee of the Faculty of Education at the University of Pretoria in order to commence the study, and the probability of working with vulnerable participants (living in resource-constrained contexts) was acknowledged (see the ethical clearance certificate included in Appendix E as well as proof of the permission granted by the director of Itsoseng Clinic, Dr Blokland, in Appendix B).

Explicit consent from participants is vital in ethical research practices, as participants' right to dignity and autonomy should always be respected (Allan, 2016). Respecting someone's autonomy holds that they participate voluntarily and that they may withdraw at any time, without any detrimental consequences whatsoever (Doody & Noonan, 2013). Participants should be made aware of what is expected of them, what the possible risks involved in taking part in the study are, as well as the limits of confidentiality, in easy to understand language (Allan, 2016) (Refer to Appendix C for the letter of informed consent).

Ponterotto (2013) points out that when doing research in multi-cultural contexts, it is important to consider the impact that cultural attitudes as well as language nuances may have on communication between the researcher and the participant; therefore, the level of language used in both informed consent and questioning must be appropriate. Written consent forms, containing all details of the research in easy to read English, will be signed by both the participants and the researcher before the semi-structured interview commences. Participants will be offered the services of a translator to ensure clear communication.[4]

Issues of confidentiality are contained in the informed consent form, where participants agree to have their identities and data kept private (see Appendix C). Barbour (2008) posits that there is much more to confidentiality than just making use of pseudonyms and keeping personal details undisclosed. Because recordings are seen as identifiable data, it is of the utmost importance that all recordings and transcriptions be kept private (Harrell & Bradley, 2009), and that even details such as the participant's gender or age be changed to maintain privacy (Barbour, 2008).

The audio recordings obtained from the semi-structured interviews, field notes, the signed consent forms, as well as the transcriptions that are formulated from them are seen as highly confidential and classified as property of the University of Pretoria and will be kept private by use of password protection on my personal laptop (cf. Wahyuni, 2012). It will then be handed over to be put away in the allocated safe-keeping spaces where there is limited access at the University of Pretoria, according to the ethical requirement.

Respect for the participants involved in a study is vital (Hamilton & Corbett-Whittier, 2013), and so the deception of participants involved in research is rarely accepted by ethical committees (Allan, 2016). There was no need for deception of the participants involved in the study, and so participants were fully informed about the reason for the research as well as all possible risks involved in taking part in it. It is also important that the participants are introduced to the recording equipment before beginning the interview (Gill et al., 2008). As the researcher, I will be sure to brief the participants before beginning each interview on the presence of the recorder, along with any other issues of concern.

The principle of non-maleficence holds that researchers only work within their areas of competence and that they prioritise the prevention of foreseeable harm to participants (Allan, 2016). Although discussing the topics handled during the semi-structured interviews may be cathartic to participants who may be disregarded or unheard in everyday life (Barbour, 2008), it is difficult to anticipate the reactions of

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[4] The offer of a translator was declined.

participants before, during and after the interview (Ponterotto, 2013). For this reason, there will be a psychologist accessible to the participants who will be on stand-by at all times during the data collection process.

I am fully aware that my role as an ethical researcher is of integral importance throughout the research process. Often, in spite of having taken all the necessary precautions, it is not possible to completely avoid ethical dilemmas that may arise during the research process and so it is important for the researcher to be flexible in order to recognise and address these issues as they arise (Hamilton & Corbett-Whittier, 2013). Ponterotto (2013) posits that to be a vigilant ethical researcher, one's own self-awareness, familiarity with one's competence boundaries and respect for the participants' personhood are essential. I intended to conduct myself with the utmost professionalism and respect for both the qualitative research process and the participants involved.

## 3.9 SUMMARY

In this chapter, the use of qualitative research located within the interpretivism paradigm was explored. The case study research design with the purposive selection of participants was examined for use in the study. In addition to this, the methods of the generation, documentation, analysis and interpretation of data throughout the study were discussed. Ways to ensure quality control and ethical research practices then concluded the chapter. Chapter Four will present the results of the research, followed by a discussion of the findings.

# CHAPTER FOUR - RESEARCH RESULTS, FINDINGS AND DISCUSSION

## 4.1 INTRODUCTION

In Chapter Four, an overview of the research process is given, followed by the research results in terms of four respective themes and the corresponding subthemes. I then discuss the findings before concluding the chapter.

## 4.2 OVERVIEW OF THE RESEARCH PROCESS

In order to put the results and findings in context, a brief overview of the research process is presented in Table 4.1.

**Table 4.1: Steps in the research process applied to the study**

| Step | Application to the study. |
|---|---|
| Ethical clearance | Application approved by the Faculty of Education Ethics Committee of the University of Pretoria (refer to certificate, Appendix E). |
| Site selection | Itsoseng Clinic was selected through convenience sampling.<br>Permission was obtained (refer to Appendices A and B).<br>Itsoseng clinic was the venue for all meetings.[5] |
| Participant selection | One participant was selected through purposive sampling, according to selection criteria. Consent was obtained (refer to Appendix C). |
| App selection | Based on the literature review, and commercially available apps, a selection was made according to criteria which included affordability, accessibility and scientific rigour in developing the app. |
| Introductory meeting | The research participant and researcher met, the study was explained and consent was obtained (refer to Appendix C for consent; refer to Appendix F for fieldnotes). |
| First support session | The application was installed on the smartphone, the participant was shown how to use the app, and the first four learning categories to be |

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[5] Unfortunately, the semi-structured interview was conducted in a room in the Law Building adjacent to Itsoseng Clinic. The participant was unable to make an appointment during office hours, due to work demands; therefore, the semi-structured interview took place on a Saturday. The participant was monitored for emotional stress, and would have been referred to the clinic should I have picked up signs of distress.

| | |
|---|---|
| | covered with the child were introduced to the participant (refer to Appendix F for fieldnotes). |
| Second support session | Various concerns were addressed, such as there not being electricity to charge the cell phone for a number of days, therefore the research participant was given a power bank that could be used to charge the phone and so eliminate the need for electricity for the duration of the ten-day trial. The participant was introduced to the next four learning categories that were then to be done with the child thereafter (refer to Appendix F for fieldnotes). |
| Data generation | The participant's experience of the application was investigated by means of a semi-structured interview, of which the interview schedule can be found in Appendix D. |
| Data analysis | The interview was transcribed (refer to Appendix G). During the process of inductive thematic analysis, the transcription was read and codes were assigned to various phrases that either had parallel meanings or occurred a number of times. Some of these codes were then combined to form subthemes and, ultimately, themes. The initial stage of inductive thematic inductive analysis was done by using ATLAS.ti 8, after which it was done manually. |
| Member checking | Member checking of the transcription and the derived themes was done in order to confirm that the transcription was correct and that the meanings derived from the data in the form of themes and subthemes were indeed what was meant by the participant. |
| Disseminating the results and findings | Completion of Chapter Four and Chapter Five. |

## 4.3 RESULTS OF THE STUDY

### 4.3.1 Introduction

In this section, four themes are discussed in addition to the applicable sub-themes. Different colours are used to indicate the excerpts from the semi-structured interview as well as parts of my field notes that converge to support these themes and subthemes accordingly, in other words, every theme (and sub-themes) and corresponding excerpts are the same colour.

Figure 4.1 serves to provide a brief overview of various themes and subthemes that emerged during the data analysis process, showing the colours used throughout this chapter. Although the study primarily researches the usefulness of the app, the other themes contribute to understanding the participant's needs in a resource-constrained context, in other words, what is required from such an application to be supportive, and, therefore, the other themes serve to strengthen the results of the usefulness of the app.

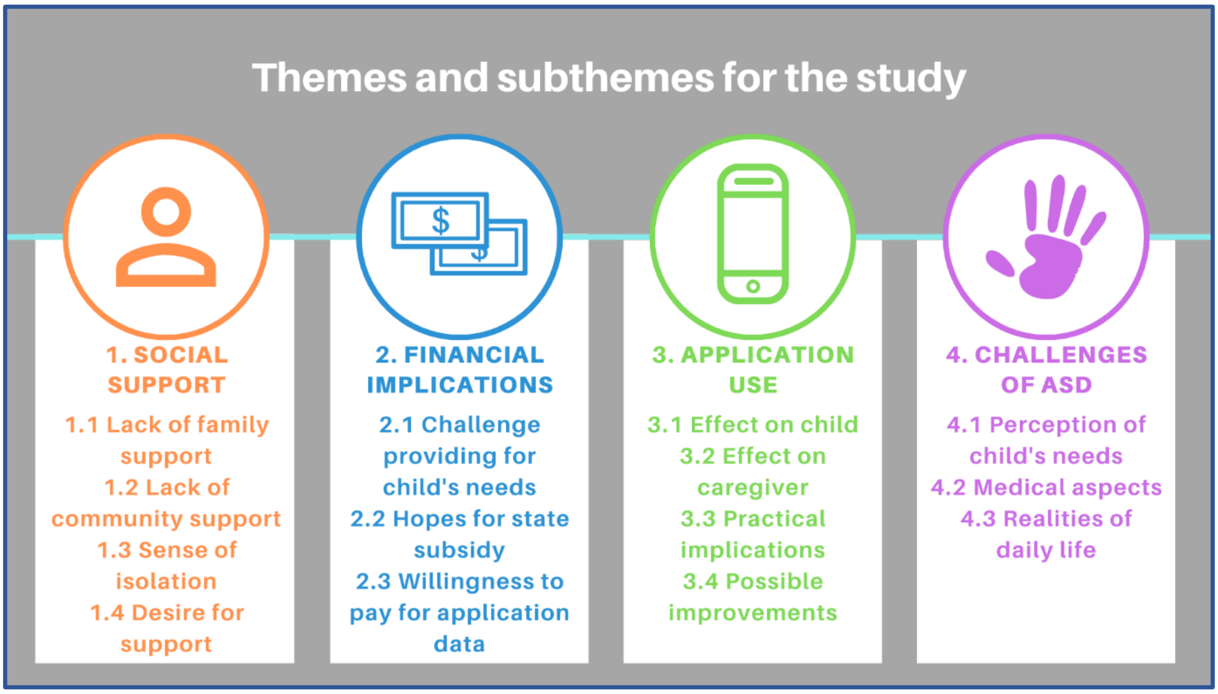

**Figure 4.1:** Overview of the themes and subthemes used in the study

### 4.3.2 Relevant Background of the Research Participant

The participant is a 27-year-old woman and a mother of three who lives in Mamelodi with her husband and children. She works full-time as a domestic worker in Villeria. During the week, when the younger two children are at school, the participant pays an elderly lady in the neighbourhood to look after her eldest daughter (nine years old) who shows characteristics of ASD and seems to be developmentally delayed. Although she is waiting for a formal diagnosis of ASD, representatives of the Itsoseng Clinic are of the opinion that she will indeed be diagnosed with ASD. Thus, for the purposes of the study, her child will be referred to as “with ASD”.

During the research process, the participant managed to be excused from work in order to see me on a number of occasions; however, for the last session which was to be the semi-structured interview, we had to reschedule our meeting to a Saturday. The participant had to make use of two taxis in order to meet me at the University of Pretoria, Mamelodi Campus, and then two taxis to get home again, each time.[6]

It is estimated that the participant earns a minimum wage salary, and struggles to supply the needs of her family in addition to the needs of her child with ASD. She currently awaits the formal diagnosis of her child so that she can apply for a grant to help her provide for her family, including her child with ASD.

### 4.3.3 Theme 1: Social Support

During the data collection and analysis, it became clear that the research participant lacks support from her family members (Subtheme 1.1), does not have any form of social support from members of the community (Subtheme 1.2), experiences feelings of isolation (Subtheme 1.3) and desires support (Subtheme 1.4). The criteria that were used to either include or exclude data in the subthemes mentioned can be found in Table 1 in Appendix H.

#### Subtheme 1.1: Lack of family support

When asked whether she has support from other people, the participant made no reference to any family members supporting her in any way and that her husband "is not that … very supportive" (Appendix G, p. 12). The participant expressed that in order to be a good mother to her child with ASD, she needs "someone who's going to support me" (Appendix G, p. 56) because "my husband is not that supportive, you know?" (Appendix G, p. 56).

#### Subtheme 1.2: Lack of community support

It was evident from the data collected that the members of the community do not support the participant or her child with ASD in any way. To support this, the participant referred to a situation in the past, before she managed to put a fence around her yard, where her child with ASD wandered off to various parts of the community. She described the members of the community as telling her child to go away by saying "we don't want you here! We don't want you here!" (Appendix G, p. 43). The participant reflected that this incident as "so pain [sic] for me" (Appendix G, p. 43) that she

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[6] Monetary compensation was given to the participant to reimburse her for her transport fees, as this was an unforeseen expense for the participant, who already has limited resources.

resolved to borrow money from her employer and build a secure fence around her property so that she could take care of her child with ASD (Appendix G, p. 43).

After the participant put up the fence so that she could lock the gates and prevent her child with ASD from wandering out of the yard to neighbours, she recalled people saying "oh, you are punishing her!" (Appendix G, p. 43). She expressed frustration and recounted that "they were complaining, but all of a sudden they starting to say I'm making her life difficult" (Appendix G, p. 43).

When asked about whether she is supported by anyone, the participant reflected that "I always struggle alone" (Appendix G, p. 12) and that she just has to make things work on her own.

She also mentioned unwanted advice. Even people that she has just met, tell her that they "know someone who's going to make her good or make her right" (Appendix G, p. 45). The participant, however, said, "no man, it's not" (Appendix G, p. 44).

### Subtheme 1.3: Sense of social isolation

When asked whether she knows of other people who have children like her child, or someone else who has a child that is seen as different that she could talk to, the participant expressed that she knows of no one else (Appendix G, p. 12). Also, the participant is of the opinion that other people perceive both her and her child differently (Appendix G, p. 43). She expressed that "if you have this kind of child, people, they will see you like you are different to them" (Appendix G, p. 46) even though she believes that "I'm not different" (Appendix G, p. 46).

Also, the participant recalled a number of occasions where, after seeing her child with ASD, people in the community said, "it's a witch!" (Appendix G, p. 44) or "it's a witch, people bewitched her" (Appendix G, p. 44). After being asked whether this happens often or seldom, the participant replied that "they always say that" (Appendix G, p. 44). When referring to how people see her child, she wished that people would "see her like she's not a crazy person" (Appendix G, p. 44) and expressed that "she's not crazy and she's not a naughty one" (Appendix G, p. 44).

### Subtheme 1.4: Desire for social support

It was evident that the participant desires more support. She expressed that "sometimes it's hard because I wish I could meet someone who get the same problem with me so" (Appendix G, p. 12) that they could "sit down and talk" (Appendix G, p. 12). She seems to long for contact with other caregivers of children with ASD so that they "can share the problems that we are facing as mothers with these children" (Appendix G, p. 45) because "we face a lot of problems, I think" (Appendix G, p. 45) and expressed that "I think they are going through what I am going" (Appendix G, p. 45). When asked whether being in contact with other caregivers of children with ASD would change something for her, she replied "yes, a lot I think" (Appendix G, p. 45). In terms of what the participant thinks would change, is something that I could have probed.

When discussing the incidents where people in the community have accused her or rejected her and her child in various ways, the participant expressed with longing "I wish people, they can know that it's … she got Autism – she's not crazy" (Appendix G, p. 45) and that "she's not a naughty girl" (Appendix G, p. 45).

### 4.3.4 Theme 2: Financial Implications

A prominent theme throughout the interview was the lack of financial resources and a desire to obtain financial support by means of a grant. The subthemes of Theme 2 include the challenges involved in providing for the child's needs (Subtheme 2.1), hopes for a state subsidy to be granted (Subtheme 2.2) and willingness to pay for app data (Subtheme 2.3). The criteria that were used to either include or exclude data in the subthemes mentioned can be found in Table 2 in Appendix H.

### Subtheme 2.1: Challenges in providing for the child's needs

The participant seems to struggle to provide for her child with ASD in addition to the rest of her family, because she says "you see she's different with the other kids" (Appendix G, p. 7). After mentioning that she earns little money, she said, "that's the problem – that one, from my salary I used to take that money to look after her and to buy her stuff, to buy food for herself" (Appendix G, p. 13).

This is because her child needs to "eat different food with [sic] us because … the doctor gave me the instruction for her food" (Appendix G, p. 7). She mentioned that "she must only have the 100% stuff" (Appendix G, p. 8) which means that "sometimes I struggle with the food because the doctor said I must not give the white food" (Appendix G, p. 8). She, therefore, has to incur the cost of buying her child other types of food "because she eat [sic] the different food with us" (Appendix G, p. 13).

The participant's child currently does not attend school "because … I don't have money to take her to the schools that she can learn" (Appendix G, p. 52). While the participant is at work during weekdays, she pays "an old lady I know" (Appendix G, p. 11) to watch her. Even though the participant is not paying school fees for the child to attend a special school, "she pays a lady to look after her child" (Appendix F, p. 3), which is necessary for her safety and wellbeing.

She mentioned that her child often loses her shoes, for example, and then "you can't ask her where's the shoe gone, she's not going to show you" (Appendix G, p. 7). She also mentioned that her child tends to wet her bed "when she's sleeping at night" (Appendix G, p. 7), which makes it necessary to buy diapers for her to wear at night. She also expressed that if she had money, she would be able to "go to the doctors and see what's wrong" (Appendix G, p. 58) instead of waiting for about three years for a diagnosis (Appendix G, p. 57).

### Subtheme 2.2: Hopes for a state subsidy

The participant expressed that she does not "get a lot of money" (Appendix G, p. 12) and her husband does not "get a lot of salary also" (Appendix G, p. 13). She expressed that if she got "that grant of mine" (Appendix G, p. 7), she would "be able to buy her [the child] stuff" (Appendix G, p. 7). Her child would be able to "have her own … like own the things for herself" (Appendix G, p. 7). After bringing up the fact that she hoped to secure a grant to help her provide her child with what she needed, she affirmed that the grant would enable her, the mother, to "just look after her nicely" (Appendix G, p. 7).

The research participant voiced the opinion that if she gets the grant money, she is "going to be a good mom" (Appendix G, p. 55), because she is going to give her daughter "what she want [sic]" (Appendix G, p. 55). According to the mother, because the grant is "a lot of money" (Appendix G, p. 52), the application process seems to be long and complicated, and so the participant is currently "waiting here for the doctor to give us that letter. That letter so that she can get the grant" (Appendix G, p. 19).

### Subtheme 2.3: Willingness to pay for app data

In spite of not earning enough money to fully provide for all the needs of her child with ASD, the participant found the cell phone application useful in teaching her child. When asked whether she would be able to afford buying data for the app, she said, "I think that I am going to be able to afford it" (Appendix G, p. 64) and that she would be "willing to pay" (Appendix G, p. 49). She said, "but I wish I could have that app. I will pay" (Appendix G, p. 51).

## 4.3.5 Theme 3: Application Use

This theme reflects the use of the application itself. The subthemes that fall under Theme 3 include effect on child (Subtheme 3.1), effect on caregiver (Subtheme 3.2), practical implications (Subtheme 3.3) and possible improvements (Subtheme 3.4). The criteria that were used to either include or exclude data in the subthemes mentioned can be found in Table 3 in Appendix H.

### Subtheme 3.1: Effect on the child

When asked whether she thought the application had changed something in her child with ASD, the participant said, "yes – much, much, much, much" (Appendix G, p. 29). The participant mentioned that her child never used to sit on her lap previously, but since they started using the app, she has wanted to sit on her lap so that they could use the application together. This is supported by her saying "but you see today she want [sic] to sit on me because when we are at home I always put her here" (Appendix G, p. 21). When asked whether the child still wanted to sit on her lap since the application had expired, the participant replied "no, no, no" (Appendix G, p. 22).

When asked whether she thought that her child had learnt anything important from the app, the participant expressed that she thought her child had learnt how to draw shapes. This is supported by her saying "she can make herself like a circle or a what what … ya[7]" (Appendix G, p. 15), which did not happen before the application – "no, no, no, she was not able" (Appendix G, p. 15).

The participant said that she thought that her child had learnt the colours on the application well enough to be able to relate it to real life. When asked to describe this,

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[7] 'Ya' reflects the Afrikaans word for 'yes', which is 'ja'.

she said, “she know [sic] how to pick the colours” (Appendix G, p. 20). She also mentioned that “the stuff to wear – like it’s black and the orange. If she want [sic] to wear that stuff” (Appendix G, p. 20), she would “take my hand and show me that I want this one” (Appendix G, p. 20), which she was not doing before having used the app.

It was evident that the child had enjoyed using the application and wanted to continue using it, as the participant said, “she take [sic] the phone and I must put it on. I said it’s expired and it’s off now, we can’t play” (Appendix G, p. 23). She continued, “but you can see she still want [sic] to play” (Appendix G, p. 23) even though “it’s not there anymore” (Appendix G, p. 23). Even during the course of app use, the participant said that her child had been enjoying using the application (Appendix F, p. 2).

### Subtheme 3.2: Effect on the caregiver

The participant seemed to experience an increased bond with her child due to the application and said, “we are more bonding now” (Appendix G, p. 21), and expressed that she was “happy for that” (Appendix G, p. 22). She said that “we have deeper connection” (Appendix G, p. 22) and that “she never sit [sic] on my … (gestures at lap) before” (Appendix G, p. 21). She also felt that the application made it easier to keep her child near her, and that “the moment I take the phone” (Appendix G, p. 13) her child would be “staying inside with me and then she want [sic] to play” (Appendix G, p. 13). She reported that this was “much better and much easier” (Appendix G, p. 13) for her.

When asked about the effect of the application on her, the participant expressed that the application “taught me a lot” (Appendix G, p. 73) and that it showed her how to teach her child. She said, “I must find the colours and teacher [sic] her” (Appendix G, p. 72) and, “I must draw the numbers also. I think I must do that for her” (Appendix G, p. 72). She said, “I must teach her everything, because I don’t have the app now” (Appendix G, p. 72). When asked whether the application inspired this, she replied, “Yes. Yes I think I’m going to try [to] do that” (Appendix G, p. 72).

The participant expressed that she loves the app, that it “brought something good” (Appendix G, p. 16) and that she desires to have it by saying “with the app that is that I love it, Kerry, and it’s nice to have an app, but the problem is just that it’s only for 10 days, we can’t have it forever” (Appendix G, p. 72).

### Subtheme 3.3: Practical implications

The application was used for the duration of the ten-day trial. During this time, the application was used almost every day, barring three days in which the participant explained that "we spent the whole weekend without electricity so then we spent the whole weekend without playing it" (Appendix G, p. 50). For this reason, the ten-day trial was extended in order to ensure that she could still use the application for ten days in total, as this was what was agreed upon at the beginning of the study.

According to the participant, the application was used every day and they "played maybe for 30 [minutes] or for 1 hour" (Appendix G, p. 26) and that they were "doing that before she goes to bed, yes" (Appendix G, p. 26). When asked what effect the application use had on the child's sleep, the participant replied that the application made her child tired and therefore "she was sleeping fast" (Appendix G, p. 26).

According to the participant, her child found some categories on the application easier to master and others more difficult, such as "the numbers she struggled with it" (Appendix G, p. 13); however, when it came to shapes, "she did that well" (Appendix G, p. 13). When the child dealt with the category on emotions, the mother reported that it seems like "she was not much much happy with it" (Appendix G, p. 14).

In terms of battery use, she felt that the application "don't [sic] use a lot of battery" (Appendix G, p. 47) and in terms of the network coverage, "every time I want to play it was good" (Appendix G, p. 65). Also, she felt that "it use [sic] a little bit of data" (Appendix G, p. 48).

The participant seemed to enjoy using the app, and felt that "it was easy to work on" (Appendix G, p. 16) and that she never felt like she did not know what to do next (Appendix G, p. 36). She felt that there was nothing about what the application looked like that she would change (Appendix G, p. 32). She also liked that the use of the entire screen made it "so you can see properly" (Appendix G, p. 32). She also mentioned that "the English is very nice – you can understand it." (Appendix G, p. 36). It was evident that the participant's understanding of English was better than her expressive language, such as when she expressed herself during the semi-structured interview.

### Subtheme 3.4: Possible improvements

Some challenges encountered by the participant included the fact that the application was in English, which is not her home language; therefore, she had to translate everything for her child into her language – isiZulu. She found that, overall, "it was good, but some stuff was [a] little bit … a little bit difficult" (Appendix G, p. 24). Exactly what was difficult and why it was difficult could be probed in future.

For the animals category, she "decided to write down for … all the animals in Zulu" (Appendix G, p. 25) because it seemed that she found it a challenge to remember the names quickly enough in isiZulu (Appendix F, p. 2). An important improvement to the application would be for it to be "in your own language" (Appendix G, p. 25) so that "it will be much easier … yes" (Appendix G, p. 26).

It seemed to be a challenge to have to enter the password every time the application was used, as the participant mentioned that "you must not put the wrong password and the wrong pin" (Appendix G, p. 16), because then "it's not going to allow you to go there" (Appendix G, p. 16). She also reported that it took some time before the application opened up – "it took so long to be on" (Appendix G, p. 47).

Another challenge encountered by the participant and her child while using the application was that it would sometimes move on to the next question too quickly for her child to give an answer. She suggested that "you must add it also, that one to the app to be slowly" (Appendix G, p. 65). Also, another improvement that was suggested by the participant was for the application the make a sound when an answer has been chosen, so that one can know that an option has been pressed (Appendix G, p. 33).

In terms of possible additions to the categories on the app, the participant felt that something to teach the user the difference between right and wrong is "needed also" (Appendix G, p. 54) and that if "she doing the right things we say 'yes'" (Appendix G, p. 54). She suggested that something addressing "the behaviour also" (Appendix G, p. 54) would be good. When suggested, the participant agreed that something to teach users how to dress and wash could be useful (Appendix G, p. 55).

### 4.3.6 Theme 4: Challenges of ASD

In this theme, the manifestations of ASD in the life of the participant and her child with ASD are explored. The subthemes falling under Theme 4 include medical aspects

(Subtheme 4.1), the caregiver's perception of the child's needs (Subtheme 4.2) and the realities faced by the participant and her child on a daily basis (Subtheme 4.3). The criteria that were used to either include or exclude data in the subthemes mentioned can be found in Table 4 in Appendix H.

### Subtheme 4.1: Medical aspects

The participant's child is yet to be formally diagnosed, as she said, "until now, she's not get diagnosed yet" (Appendix G, p. 56) and "I'm waiting for a diagnosis" (Appendix G, p. 8). She feels that the process of getting a diagnosis "took so long since 2016" (Appendix G, p. 56) and that they "are on the waiting list" (Appendix G, p. 57) because she said, "they are waiting for someone" (Appendix G, p. 57) who seems to be a clinical psychologist. As a mother, the participant expressed concern about not knowing what is wrong with her child and the fact that "they have not even check [sic] her brain" (Appendix G, p. 58). She said that this made her feel "not very good at all" (Appendix G, p. 59).

So far, the participant's child seems to have epilepsy and is on medication for it (Appendix G, p. 41). It seems that the medication is helpful and "they [the pills] make a difference, yes" (Appendix G, p. 41), as it seems as though she does not get epileptic seizures as often anymore (Appendix G, p. 68). Even without a diagnosis, the doctor suspected that the child has ASD, prescribed other medication and gave the participant instructions for the type of food the child should eat (Appendix G, p. 7).

The participant sent me photographs of the medication boxes on WhatsApp after the interview took place, as promised (Appendix G, p. 41). The names of the medication are Epilim and Rispacor. The participant believes that the Epilim is for epilepsy and said that the Rispacor, "I think it's for the brain" (Appendix G, p. 41).

The participant reported that the community health clinic gives her the pills to give to her child, saying "one in the morning, one in the afternoon, one … They don't tell us what time must we give her" medication (Appendix G, p. 40). She seems to desire more information "because at the clinic they don't give the full information" (Appendix G, p. 67) and suggested that more information be given. It appeared that verbal information or information on the label of the container would have helped her (Appendix G, p. 67).

### Subtheme 4.2: Perception of child's needs

When asked what her child needs were, the participant said, "support and love, that's what I can say" (Appendix G, p. 59). When asked from whom the child needs support, she said, "support from both … Mmh … both parents and family and everyone" (Appendix G, p. 59). Throughout the interview, the participant reiterated the importance of being patient with her child and said, "they need you to be patient – you must not rush them. No" (Appendix G, p. 60).

The topic of the child's safety and protection emerged a number of times. The participant expressed that "because of the love you can scare [get scared] that she's going to go away [get lost]" (Appendix G, p. 41). She explained that is why "I borrow money from my boss so I put a fence for my … for Leah[8] and take care of here" (Appendix G, p. 12). Also, when speaking about the lady that looks after her child while she is at work, she added that "she got a good security there by her so Leah is safe eh" (Appendix G, p. 12). The issue of safety was particularly relevant as the mother was aware of a child who was non-verbal, like her child, who did get lost.

The participant sees it as important for her child to go to school (Appendix G, p. 5) and said that "if she go [sic] to school, I think it's going to be better me and for the other schools … for the other kids" (Appendix G, p. 6). Because she does not currently go to school, the participant sees it as important to teach her child and mentioned some things that she teaches her, such as "yes, I teach her how to colour" (Appendix G, p. 10). The participant has also taught her child how to go to the toilet herself (Appendix G, p. 10), how to move out of the way of danger (Appendix G, p. 71) and how to wash herself in the shower (Appendix G, p. 55).

### Subtheme 4.3: Realities of daily life

Even though the research participant feels that she is in control and she is able to do what she needs to do in order to help her child (Appendix G, p. 70), she does feel that she faces many challenges (Appendix G, p. 45). She allows herself to cry when she wants to cry so that "when I finish cry, I feel alright again" (Appendix G, p. 47). She also expressed that she has so many responsibilities that she does not "have time to sit and talk" (Appendix G, p. 46).

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[8] Pseudonym (refer to Appendix G, p. 1).

Even though her child is nine years old, the participant's child has a severely limited expressive vocabulary. This seems to concern her, as supported by her mentioning that the "problem is that she can't speak – I wish if [sic] she can talk" (Appendix G, p. 30). However, she is able to communicate with gestures and basic language, supported by the participant saying "she call [sic] me 'Mama'" (Appendix G, p. 69). Although she did say "Mama" once, my observation of the child during the duration of the semi-structured interview was that she is, really, mostly non-verbal.

It seems that being able to recognise and use numbers is important to the participant, as she said, "and I know she must learn about the numbers, you see?" (Appendix G, p. 32), and "that's what I cry for. You know, if she can know how" (Appendix G, p. 31). Also, she seems to attach importance to her being able to write her name. When she was speaking about skills she desires to teach her child, she said, "her name also, I think I must … draw her name" (Appendix G, p. 72).

As has already been referred to, the child wears diapers at night because she tends to wet the bed (Appendix G, p. 7). She also tends to "sleep different" (Appendix G, p. 8). Her mother mentioned that "she can't sleep at the same time with other kids" (Appendix G, p. 10). The child does not like loud noises, as the participant said, "remember that I told you that she's not in love with noise" (Appendix G, p. 34).

The participant mentioned that her child "was [a] little bit disturbing" (Appendix G, p. 5) on some occasions "when we are home", which the application helped to alleviate in a way (Appendix G, p. 5). Other daily realities include the child wandering off if not kept securely inside the yard (refer to Subtheme 1.2: Lack of community support), losing her belongings and eating different food to the rest of her family (refer to Subtheme 2.1: Challenge providing for child's needs).

## 4.4 COLLECTIVE FINDINGS AND DISCUSSION

The following section consists of a collection of the findings from the study in reference to the literature and the researcher's critical reflections. The content of the themes that were identified in the study is linked with relevant literature in order to identify similarities, differences or gaps in knowledge. The theme of social support is discussed first, followed by financial implications, app use and challenges of ASD.

### 4.4.1 Social Support

The results indicate that the participant experiences a lack of support from her family and her community, and that she desires more support. This finding correlates with literature suggesting that parents of children with ASD in South Africa tend to feel unheard and experience an absence of social support as well as practical assistance (Franz et al., 2017). The lack of support she experiences from her husband may be attributed to a patriarchal viewpoint of the husband, who generally does not become involved in childrearing matters, or various other reasons such as poverty or various social or economic motives (Franklin, Makiwane, & Makusha, 2014). It is also possible that a lack of understanding on his part could be the root of his avoidance or lack of interest.

The participant also expresses the desire to be in contact with caregivers of other children with ASD so that they can share the challenges that they face. This is supported by the findings of Lu et al. (2018) that found that the absence of a social support system is common in the life of a caregiver of children with ASD in developing countries. Research also concurs on the importance of social support for caregivers of children with ASD (Attfield & Morgan, 2007).

The fact that members of the community frequently refer to the participant's child with ASD as a witch, or as having been bewitched, confirms research done by Dejene et al. (2016) which holds that in sub-Saharan Africa, ASD if often attributed to traditional or supernatural forces such as curses, bewitchment or magic that can be cured or taken away, as advised by some of the community members. The participant also shares that it would be better if the people around her understood ASD. The lack of knowledge surrounding ASD is no surprise considering that awareness of ASD remains low on a global level (Wallace et al., 2012), let alone in resource-constrained contexts where awareness promotion is scarce.

The participant feels that the people around her treat her differently because of her child who is not seen as 'normal' but 'crazy' and she feels that she has to get by on her own. This is in line with literature that posits that in sub-Saharan Africa (and Southeast Europe), the family members of children with ASD very commonly experience stigma and that caregivers of children with ASD often experience discrimination as well as social exclusion (Daniels et al., 2017; Dejene et al., 2016).

Feeling different may have particular importance in a culture where collectivism is usually regarded as the norm. Whereas an individualist culture generally celebrates being different, and being different is sought out, the participant, who most probably has a perspective of collectivism, may find being regarded as different particularly challenging (Mesquita, 2001).

### 4.4.2 Financial Implications

The participant expresses that she does not have the money to send her child to school,[9] nor to provide adequately for all of her needs (such as food, clothes, nappies and day care); therefore, she hopes a disability grant will be allocated so that the subsidy from the grant can alleviate the financial burden and the additional costs involved with caring for her child. Daniels et al. (2017) found that having to support a child with ASD most commonly resulted in a significant financial burden. Kim, Kim, Voight and Ji (2018) found that caregivers of children with ASD often experience financial challenges due to having to employ specialised education and other therapeutic support services, which, in the case of this study, is not an option for the participant at this stage. The participant in the study clearly equated provision with being a good parent. This desire to provide for her child (and therefore be a good parent) may be linked to years of struggling to have her own basic needs met within a resource-constrained context.

The process of applying for the subsidy also seems to present a number of challenges, including waiting for a long period before the supporting documents that confirm the diagnosis, and therefore bring the application for the grant to fruition, can be obtained. This prolongs the experience of financial stress endured by the participant and her husband. It also prolongs the time before the child can benefit from support. Lu et al. (2018) showed in their study that parents of children with ASD in China tend to take on significantly more financial stress in order to provide for their children than those who have typically developing children. It is evident that the financial burden imposed on the caregivers of children with ASD to satisfy their needs and provide the appropriate support is compounded by limited access to resources of all kinds. As posited by Triegaardt (2005), even though millions of people in South Africa depend

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[9] This is not correct, as caregivers can send their children to school even if they cannot afford school fees. It is possible to apply for full exemption from paying school fees (Department of Basic Education, n.d.).

on the social grant system for survival, it has a history of ineffective administration, essentially leaving individuals to prove their own destitution to gain access to these grants. This was confirmed by the experiences of the research participant.

The participant expressed that she would be willing to pay for the data herself, should she own the app, because of the small amount of data used during the ten-day trial of the app, as well as the positive impact of it on her child and herself. However, this may likely cause repercussions in terms of other expenses that she would not be able to afford, further decreasing her quality of life. Decreased quality of life due to caring for a child with ASD is commonly experienced by caregivers of children with ASD (Catalano et al., 2018).

Unknowingly the participant echoed the advantages of a well-resourced context where diagnosis and intervention can be accessed more swiftly, when she reported that she will seek medical support to finalise the diagnosis if she has more money.

### 4.4.3 Application Use

The participant said that she thought that her child with ASD had learnt from the application and that she was able to relate some of the skills that she learnt from the application to real life. She also mentioned how she herself has learnt from the app, specifically on how to teach her child. Research exists that has proven that technology-based education has been successful in teaching people with ASD valuable skills, such as emotion recognition (Fletcher-Watson, Pain, Hammond, Humphry, & McConachie, 2016), even though the section on emotions was challenging for this particular child with ASD, according to her mother. The participant also said that she wanted the application and loved it. These remarks are in line with research that was done by Fletcher-Watson et al. (2016) who found that parents generally reported positive attitudes towards their technology-based intervention and saw it as suitable to their children’s needs.

The participant commented on how using that app contributed to her and her child with ASD to have an increased bond or deeper connection. In their research, Fletcher-Watson et al. (2016) found that children with ASD who used touchscreen technologies were observed to be more engaged and verbal while using them. If this was the case with the participant’s child with ASD, it could have increased engagement in the shared activity of using the app, therefore creating an even stronger sense of connection.

The training of parents on how to use the application before beginning an intervention with the child with ASD, which was seen as vital in the study done by Law et al. (2018), seems to have been confirmed in the success of the intervention in this study, where the participant was supported and trained in using the application effectively both before and during the use of the application. Also, the rehearsal of skills was seen as a way of improving the effectiveness of the application (cf. Jones, 2014), which was reinforced by the participant reporting that the questions in each category were done over and over again until the child mastered it.

As part of what is seen as smooth user experience, the use of easily understandable language is important (Rowles, 2013). Because the participant's receptive language seemed to be better than her expressive language, this, too would have contributed to what would be seen as the usability of the application (Boudreaux et al., 2014). The participant feels that even though it would have been much better if the application was in isiZulu, the level of English used was simple and easy to understand. If this had not been the case, it may have let to the experience of negative emotions, such as frustration, causing decreased use of the application (Ferreira-Correia et al., 2018).

Rowles (2013) suggested that cost-effectiveness was a key factor in developing an application. Data usage could be translated to cost-effectiveness, because high consumption of data would not be cost-effective and would therefore be demanding on the financial resources. This would be of even greater concern to someone living in a resource-constrained context, as supported by the concerns for financial implications expressed by the participant frequently during the study. In addition to this, the economical use of battery power would be seen as important due to the need for access to electricity, which is also sometimes a challenge faced by those living in resource-constrained contexts, such as the participant in the study.

Ensuring that the content of an application is based on clinical research is seen as important by Boudreaux et al. (2014). Also, the incorporation of appropriate principles of learning could make an application more effective (Stawarz et al., 2018). These are addressed in the application that was used for the study, in that it is based on the ABA therapy approach, which has been proven to be effective (Dillenburger & Keenan, 2009).

As could be gathered from the study, some changes that could be made in order to improve the functionality and effectiveness of the application include: allowing more time in which to supply an answer, have the application in the user's own language, adding a sound that indicates a choice has been made, adding a section on morals (right and wrong) as well as appropriate behaviour.

### 4.4.4 Challenges of ASD

The participant mentioned that her child had not yet been formally diagnosed, and she had been waiting since 2016 to know what the diagnosis is. This confirms existing literature by Dejene et al. (2016) who claimed that most children with developmental disorders, who live in resource-constrained countries or contexts, most likely stay undiagnosed and go without specialised education. In their study, Franz et al. (2017) found that parents of children with ASD in the South African context reported substantial delays in the diagnosis of ASD, which was most likely due to a lack of access to facilities and service providers who are able to diagnose and support children with ASD.

The participant expressed a need for more information about various issues, such as how to give her the prescribed medication in the correct way. In a study, it was found that most caregivers of children with ASD are uncertain regarding their children's prognoses and inadequate information is given to them by service providers (Franz et al., 2017). Attfield and Morgan (2007) posit that caregivers need good communication and helpful information from healthcare providers so that they can feel empowered and not overwhelmed.

Because she works during the week in order to provide for her family and still has to perform many other tasks in caring for her family, as well as her child with ASD, the participant expressed that even if she did have access to contact with other caregivers of children with ASD, she would not have the time to attend meetings or discuss issues. This is in line with the findings from a study done by Sabrin, Pizur-Barnekow and Darragh (2011) who found that caregivers of children with disabilities do not spend as much time socialising or taking part in leisure or recreational activities due to more hours spent giving care to their children.

The participant explained that she teaches her child with ASD and aspires to teach her more. This confirms the findings of Kim et al. (2018) that showed that caregivers tend to take responsibility for additional activities such as educating their children.

## 4.5 MERGING RESULTS, FINDINGS AND THE CONCEPTUAL FRAMEWORK

The conceptual framework used for the study was based on an integration of Bronfenbrenner’s bio-ecological systems theory with the asset-based approach. The results and findings of the study can be related to the chosen conceptual framework in various ways.

In the micro-system, interactions, called proximal processes, between children with ASD and their caregivers, siblings and peers are included. The findings of the study show that the cell phone application contributed to a stronger bond between the caregiver and her child and it inspired the participant to teach her child more when she is at home, in future. The results also show that the participant feels that she struggles to provide for her child’s physical needs.

The application seemed to keep the child in the vicinity, which helps to keep her safe – something that the participant seems particularly concerned about. The study shows that the participant is not supported by her family, feels socially isolated and would like more social support. Because she seems to lack access to a support structure of any kind, it leaves limited assets that can be utilised in this particular system.

In the meso-system, interactions between the caregiver, school personnel and healthcare workers are addressed. Because the child does not go to school, there is no contact with teachers or school personnel, leaving no assets that can be mobilised in that aspect. The findings of the study show that relations with healthcare professionals seem to be lacking in terms of involvement in the intervention process and the provision of information to the caregiver.

Included in the exo-system, the participant’s minimum-wage job does not earn enough money for her to fulfil the needs of her family; however, at times, it allows the caregiver flexibility in order to attend to her child with ASD in various ways. The study also shows that a lack of access to healthcare services has resulted in the child not having been formally diagnosed since 2016, and therefore the participant has not been able to apply for a grant to obtain extra money to provide for her child with ASD and provide appropriate intervention services. This slow process of diagnosis, intervention and application for a grant perhaps shows the disharmonious functioning between the systems. In the interim, the cell phone application was able to provide some means of intervention for the child with ASD and her caregiver.

The macro-system consists of the beliefs and customs of the broader community as well as the social structures in place. The study shows that the beliefs held by members of the community surrounding the causes and even the existence of ASD differ greatly to that of the caregiver. In addition to this, unwanted advice from various members of the community shows the lack of support faced by the participant and her child with ASD. Also, the participant is dependent on the provision of financial support in the form of a grant

The chrono-system, considers the influence of time on interactions between the systems and therefore development. Thanks to advances in technology, access to a smartphone and data allow the participant to use a cell phone application as a means of support for her and her child with ASD. These can be seen assets in this system, which are mobilised to bring about development in the life of a child with ASD, especially in the absence of availability of other services in other systems.

In spite of evident discordance between various systems in the case of the participant, the findings of the study indicate that the complex interactions between these systems do indeed lead to proximal processes, where the child with ASD developed by means of mobilising the assets contained in these systems. The utilising of assets that the participant has access to, such as a smartphone and data, has led to the improvement of her and her child’s life.

## 4.6 CONCLUSION

In this chapter, the results and collective findings of the study were discussed in detail in relation to existing literature on the topic, as well as the conceptual framework. Chapter Four served to highlight the vital components identified as themes in the data, namely social support, financial implications, application use and challenges of ASD and locate them in relation to current research.

In the following chapter, the conclusions that can be drawn from the study are discussed and answers are given to the research questions that were formulated in the first chapter. Accordingly, the contributions made by the study, the limitations that were involved and recommendations for future application, development and research are explored.

# CHAPTER FIVE - CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

## 5.1 INTRODUCTION

In Chapter Four, an overview of the research process as well as the results of the study were presented. Quotes from the raw data were provided in order to support the proposed subthemes and themes given. This was followed by a discussion of the findings from the perspective of the literature study and the conceptual framework. In Chapter Five, a summary of the chapters is given. The research questions that were posed in Chapter One are answered, the limitations of the study are explored, and further recommendations for the development of cell phone applications of this nature and future research are given.

## 5.2 OVERVIEW OF PRECEDING CHAPTERS

Chapter One provided a brief overview of the study. The background, rationale and purpose were introduced, followed by the research questions that the study set out to answer. The working assumptions implicit in the study were stipulated, followed by the clarification of various pivotal concepts contained in the dissertation. The conceptual framework, epistemology and methodology which overarched the entire research process were discussed in short, with the specific research design and method devised to answer the research questions.

In Chapter Two, the existing literature relevant to the research questions was discussed. Understanding ASD, the needs of caregivers of children with ASD, the needs of children with ASD, current ways of supporting ASD, internet-based healthcare, current cell phone trends in South Africa and requirements for a user-friendly cell phone application were discussed. Bronfenbrenner’s bio-ecological systems theory and the assets-based approach were then integrated as conceptual framework and their applicability to the study were explored.

In Chapter Three, interpretivism and qualitative research were discussed as underlying epistemological and methodological paradigms respectively. The case study design by means of purposive sampling as a non-probability sampling method was then discussed, followed by data generation through semi-structured interviews. Inductive thematic analysis was proposed as the mode for data analysis and interpretation. Quality criteria in terms of transferability, credibility, confirmability and dependability were explored and, lastly, the appropriate ethical considerations necessary for the execution of a fair and respectful research process were examined.

Chapter Four started with a brief overview of the practicalities involved in the research process. Following this, the results of the study were presented in terms of themes and subthemes that were identified during data analysis. The four main themes identified were social support, financial implications, application use and challenges of ASD. The findings of the study were then integrated with current literature and the conceptual framework.

## 5.3 ADDRESSING THE RESEARCH QUESTIONS

Based on the findings drawn from the study, the primary research question is addressed first, followed by the secondary research questions as specified in Chapter One. The culmination of these answers will show the contributions made by the present study.

### 5.3.1 Primary Research Question

> *According to the caregivers of children with autism spectrum disorder in resource-constrained contexts, what is the utility of a cell phone application to support them with children with autism spectrum disorder?*

The findings of the study, linked to Bronfenbrenner’s bio-ecological systems theory and the asset-based approach, as applied to a South African resource-constrained context, show that there is indeed potential for a cell phone application to be useful to the caregivers of children with ASD. After exploring the realities faced by the participant and her child with ASD and situating these realities within the conceptual framework, the possibilities for support, information and awareness carried by a cell phone application in almost every system are clearly seen. Figure 5.1 summarises how the findings of the study can be situated in the conceptual framework.

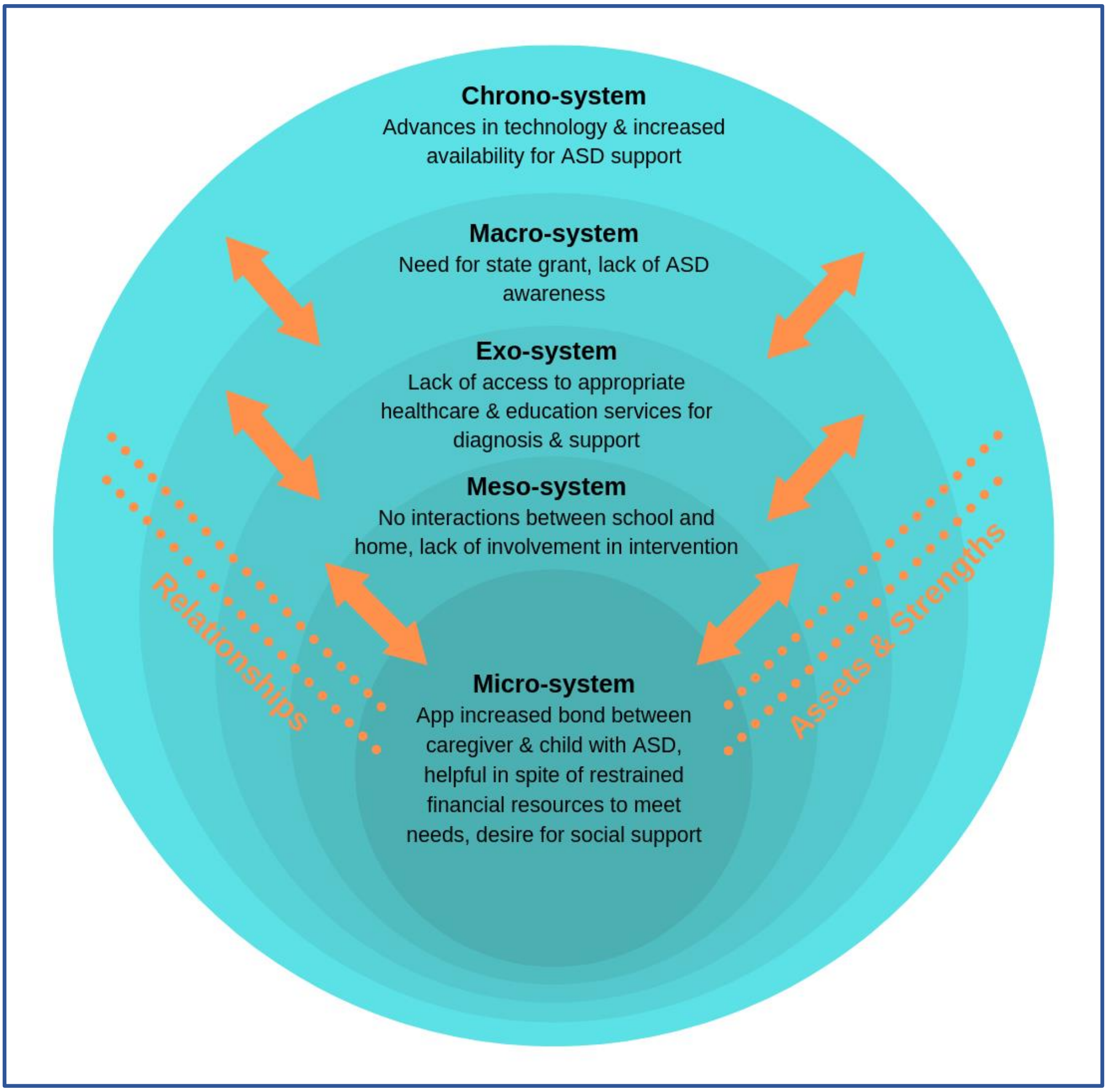

**Figure 5.1:** Findings of the study situated in the chosen conceptual framework

In all, the participant reported positive feedback concerning the helpfulness of the app. According to the participant, her child enjoyed using the application and showed both excitement and insistence in using the application when she arrived home from work in the evenings. She believed that her child managed to learn a number of skills from the application that she was able to reproduce in real life, such as recognising colours and drawing shapes. The participant found that using the application increased the bond between her and her child and it caused her child to stay in her vicinity rather than wandering off, which was always a concern for her in terms of safety. The emotional and cognitive advantages in the ten-day trial period the application was used, suggests possibility and improvement if the application can be used longer, and perhaps address more than cognitive skills (as the mother had suggested).

The participant found the application to be especially helpful in supporting her and her child with ASD in the interim, while waiting for a diagnosis and not having been given any support in the meantime. I believe that if the application could be this beneficial for a caregiver and her child with ASD living in a resource-constrained context, the impact of an application that is adjusted to suit the culture and language of the prospective users could be immense.

In the theory of acceptance for technology, Davis, Bagozzi and Warshaw (1989) attempt to explain and predict the behaviour of people who use computers or technology. They posit that people's intentions, the impression they have of the usefulness of the technology and the supposed ease of use are the main determinants of consistent use, where the most important first step of determining these is exploring the beliefs of the target population (Davis et al., 1989). I believe that this study forms an important first step in determining the needs and beliefs of the caregiver of a child with ASD who lives in a resource-constrained context so that effective cell phone applications that aim to support such caregivers can be developed.

### 5.3.2 Secondary Research Question One

> *What support is needed by children with autism spectrum disorder for optimal wellness?*

Table 5.1 contains a summary of the needs for optimal wellness of children with ASD generally and in a resource-constrained context, based on the conceptual framework, as evident from the case study in the research. The table also contains a summary of the needs of caregivers of children with ASD.

**Table 5.1:** A summary of the needs for optimal wellness of children with ASD generally and in a resource-constrained context

| Generally<br>(as obtained from the literature study) | Resource-constrained context<br>(as obtained from the case study) |
|---|---|
| Individual system | |
| Physical needs | |
| ➢ Clothing<br>➢ Sanitary items<br>➢ Food | ➢ Clothing, also to replace lost clothing<br>➢ Sanitary items, such as nappies<br>➢ Recommended food |
| Emotional needs | |
| ➢ General good emotional care | ➢ Patience<br>➢ Love<br>➢ Support from both parents |
| Social needs | |
| ➢ Opportunities to socialise | ➢ The child with ASD is kept separate from the rest of the community due to their beliefs of witchery. The child may be walking around in search of company. |
| Cognitive needs | |
| ➢ Stimulation through toys, interaction and other therapies | ➢ Initially, the mother was not aware of cognitive needs. The mother realised after using the application that the child with ASD could be taught particular facts and skills. |
| School system | |
| ➢ Special schools for children with ASD<br>➢ Inclusive schools for children with ASD | ➢ The child did not attend school. Based on what she learnt through using the app, the child may need more stimulation. |
| Health system (medical intervention and therapeutic intervention) | |
| ➢ Access to professionals to diagnose and provide intervention<br>➢ Access to professionals to prescribe medication | ➢ Access to professionals to diagnose. (Epilepsy was diagnosed, but not ASD. The child has been waiting since 2016 for formal diagnosis.) |

| | |
|---|---|
| ➢ Access to speech therapy, occupational therapy, play therapy and other types of intervention | ➢ Access to professionals to prescribe medication (medication was prescribed for the epilepsy). |
| Social system | |
| ➢ Parental support groups | ➢ The mother required support. No social support from family, friends or the community was available.<br>➢ Grants are available; however, it seems to be an ineffective process to apply for a disability grant (since 2016). |
| Economic system | |
| ➢ Generally, more finances are available to provide intervention for children with ASD | ➢ A lack of finances contributes to challenges regarding basic care, diagnosing, schooling and therapeutic intervention.<br>➢ A lack of coherence between the social system, health system and economic system to provide grants. |

As evident from the study, in a resource-constrained environment, it is possible that the needs of children with ASD centre on basic physical care, appropriate medical attention and specialised education. This may be due to a lack of infrastructure in the area as well as limited financial resources. In terms of providing for the child’s physical needs, being able to buy the clothing, sanitary items and suitable food needed for the child, in addition to providing for the needs of the rest of the family members posed as a challenge.

Emotionally, the participant believed that her child with ASD needed patience, love and support from both parents, which are necessary for optimal wellness.

In addition to having physical needs met, access to suitable medical support was seen as important. The participant’s child had epilepsy and took medication to manage the epilepsy. Because the participant’s child was yet to be diagnosed with ASD and had been waiting for a diagnosis since 2016, more access to appropriate medical professionals can be seen as an important need, as this in turn influenced access to a disability grant which could ease the financial burden. In all, access to medication and suitable medical attention can be seen as necessary for optimal wellness.

Due to limited financial resources and a lack of financial support, the participant was of the opinion that she could not afford to send her child to a suitable school. Because the participant works fulltime to provide for her family and the child needs constant supervision, an elderly lady in her community is paid to watch her child while she is at work during the week. In the case of this participant and her child with ASD, the cell phone application was seen by the caregiver as a means of support to bridge the gap where the child cannot go to school for special education, but can still learn skills at home. Also, using the application made the child want to stay in her mother's vicinity more readily, instead of wandering off, and so it assisted her caregiver in practically keeping the child safe.

It is important to note that the caregiver of the child with ASD was not aware of the different kinds of intervention that research has proven to be effective in ASD intervention. She focused on basic physical care, emotional support and medical support, although she experienced the latter to be inadequate for her and her child's needs. A comprehensive application to provide support may be impactful in providing support to caregivers of children with ASD in resource-constrained contexts.

Meadan et al. (2013) reported on a pilot program called 'i-PiCS', that allowed for parents to use internet-based interventions to assist their children with ASD in America. They found that early interventions for children with ASD were particularly effective when they included family-orientated goals and emphasised children's strengths, making caregivers the most appropriate facilitators of these interventions, leading to benefits of enhanced communication skills and better family life.

### 5.3.3 Secondary Research Question Two

> *What are the needs of caregivers with children with autism spectrum disorder, generally and in resource-constrained contexts?*

As already highlighted in the research question discussed above, financial support can be seen as a need for caregivers of children with ASD in resource-constrained contexts in order to provide for their families and their children with ASD. The participant expressed hope in being granted a state subsidy so that she would be able to provide for the needs of her child with ASD more effectively, as she currently experiences limited financial resources as a challenge in doing this. She would like to use the extra finances to provide in basic needs such as clothes and nappies, in stimulation needs such as toys and the app, in medical needs as in consulting a private practitioner to clarify the diagnosis, and in schooling needs.

The participant seemed to feel that she has little to no support from family and community members, even though she desires support and sees support as being necessary to be a good mother to her child with ASD. She expressed the desire to be in contact with other caregivers of children with ASD in the broader community so that they could share their struggles and be supported by one another.

The participant felt that some medical professionals did not give her enough information, specifically about the correct use of medication; however, it seemed to me that an overall lack of knowledge about the child's characteristics and specific needs were present. There also seems to be an absence of inclusion of the primary caregiver in intervention strategies, which ignores one of the greatest resources in the effective intervention of ASD.

Because the cell phone application allowed hands-on parental involvement, it empowered the participant in taking responsibility for her child's educational, and perhaps even emotional needs. If extra information specific to the intervention, medication and behaviour of children with ASD had been included in the app, this could have had an even more supportive effect on empowering the caregiver.

### 5.3.4 Secondary Research Question Three

> *What criteria should cell phone applications adhere to in order to be user-friendly, generally and in resource-constrained contexts?*

The list of criteria that apps should have is contained in Section 2.8 in Chapter Two. From the results, the following can be concluded as criteria for apps to be user-friendly in a resource-constrained context. Even though the participant felt that the level of English on the application was easy to understand, having the application in her home language would have been helpful, because she mentioned that translating everything to isiZulu was challenging.

Two minor adjustments that could have been beneficial to make the application even more effective, according to the participant were, firstly, to allow for a longer amount of time for answering questions before moving on to the next question and, secondly, to make a little sound to acknowledge that an answer has been chosen. In terms of the sounds made by the app, there was one activity where the participant's child did not enjoy the loud noises produced – a challenge regarding sensory sensitivity that is common to many children with ASD. To counter this, when the activity came up, they simply let the time elapse without making any noises before commencing.

Even though not brought up by the participant, I was of the opinion that particular parts of the categories contained in the application could be adjusted to be more culturally appropriate, for example, the faces of people in the emotions category were all those of Caucasian men. Because the child with ASD is part of an African family, she may not interact much with Caucasian men. This in itself may be confusing or even distracting, and in addition to this, the way in which emotions are expressed, perceived or named may differ culturally (Altarriba, Basnight, & Canary, 2003).

The participant found the application to be easy to navigate and visually and auditory attractive and pleasing. Also, the application was economical in its use of battery power and data, with which the participant was satisfied enough to willingly carry it as a cost to herself, if she had the application on her phone.

## 5.4 POSSIBLE CONTRIBUTIONS OF THE STUDY

The study attempts to add to the limited body of knowledge on ASD in the resource-constrained contexts of South Africa. By exploring and reporting on the realities faced by the caregivers of children with ASD who find themselves in contexts such as these, the study hopes to shed light on the utility of this type of easily accessible, cost-effective support.

Healthcare professionals, including Educational Psychologists, as well as application developers in South Africa, or even worldwide, can use the realities and experiences of this caregiver in a resource-constrained context of South Africa as a guide to develop apps that are more suited to our context and can be more helpful to the majority of South Africans who need access to well designed, appropriate cell phone applications. Apps to support caregivers with children with ASD may contribute to reducing the gap between available resources and the need for resources. Similarly, by building on lessons learnt from the application for caregivers with children with ASD, apps to support parents with children with other challenges can also be developed.

It is acknowledged that the generalisability of these findings is limited; however, any study of what caregivers of children with ASD who live in resource-constrained contexts experience on a daily basis can prove to be of value in further research on the topic, seeing that there is currently limited research on it in South Africa.

The application showed that one of the assets often overlooked in resource-constrained contexts, is optimising the relationships between people. As such, the application optimised proximal processes between the caregiver and her child, which led to deeper bonding as well as cognitive stimulation. The role of an Educational Psychologist in this respect could be seen as vital in terms of training and preparing the caregiver, monitoring the relationship between the caregiver and his/her child with ASD and using his/her expertise on childhood development to ensure that both the caregiver and his/her child with ASD have access to and utilise this tool in order to reach their potential.

## 5.5 CHALLENGES AND POSSIBLE LIMITATIONS OF THE STUDY

When it came to selecting research participants, only one potential candidate could be identified on the basis of her child presenting with characteristics of ASD, instead of having a formal diagnosis. The under-diagnosis of ASD in resource-constrained contexts, however, is supported by literature (Dejene et al., 2016). Due to the lack of diagnoses and therefore the identification of possible candidates out of all the clients at Itsoseng Clinic over the past two years, the criterion for participants with children without any co-morbid conditions had to be disregarded. In addition to this, the participant’s child seems to have developmental delays, which, although frequently co-occurring with autism, might possibly be indicative of other disabilities at play (Crnic, Neece, McIntyre, Blacher, & Baker, 2017).

The application was only used by the participant for the duration of the ten-day trial. Even though this does not seem like a particularly long time, the positive impact that the application had was still evident within days of using it. A barrier to the use of the application during the trial period was when the phone could not be charged due to a power cut for the duration of the weekend. The participant had the most time available to use the application with her child on weekends, which was a challenge; however, the trial period was then extended so that the application could be used for ten days in total.

Because the participant works during the week, she agreed to meet for the semi-structured interview on a Saturday. Her child with ASD had to accompany her to the interview, as there was no one else to look after her over a weekend. This led to a number of interruptions taking place during the interview, which were obviously not optimal conditions for a semi-structured interview to take place; however, it was a valuable indication of the reality that this participant faced on a daily basis, in a variety of settings.

Also, during the interview, it became evident that the participant's English proficiency was not on the level that I had originally estimated (understanding the introductory meeting and the support sessions could be indicative of fair English receptive skills; however, in an interview, expressive skills are required.) This led to me asking fewer open-ended questions and adjusting the questions in a way that I thought might be easier for the participant to understand. Unfortunately, access to a translator at Itsoseng Clinic was not possible during the weekend. This led to us to proceed with the interview without being able to arrange the assistance of a translator.

The use of inductive thematic analysis is not without its critics who believe that the researcher's own positioning and beliefs will, most certainly, in some way or another, influence the way in which the data is interpreted (Braun & Clarke, 2006). In an attempt to counter this, member checking was done, and no changes were made. An important and somewhat obvious limitation to the study is that it explored only one participant's experiences, and so the results cannot be assumed to be the same for other caregivers of children with ASD (or characteristics of ASD) in resource-constrained contexts.

## 5.6 RECOMMENDATIONS

In the following sub-headings, I address recommendations for developing an application to support caregivers and their children with ASD as well as recommendations for future research.

### 5.6.1 Recommendations for Developing an Application

Based on the information obtained from the study, in both the literature review as well as the results of the study, the following recommendations can be made for application designers who aspire to develop an application to support caregivers and their children with ASD in resource-constrained contexts in South Africa.

General features:

- Ensure that the content of the application is culturally appropriate.
- Make use of suitable languages for the application, that is, adding African languages.
- Allow enough time to answer questions before the following question is asked.
- Add a sound to indicate that an answer has been selected.
- Ensure that the application is easy to navigate and pleasing to the eye of a child.
- Be mindful that one of the characteristics of children with ASD is sensitivity to noise.
- Ensure that the application does not consume data or battery power too quickly.
- Make logging into the application simple.
- Ensure speed and quality of available internet.

Content:

- Provide accessible information for caregivers regarding ASD, intervention and resources.
- Make the content of the application comprehensive.
- Include family-orientated goals in the application.
- Use children’s strengths in the application.
- Base the content of the application on scientific evidence.
- Ensure that the content and activities in the application is based on learning theory.
- Provide parental training, or opportunities for the parents to practice.
- When possible, include video snippets demonstrating particular activities.

Ethics:

- Ensure the privacy of users.

Software specifications:

- Access to regular updates and maintenance.
- A regular reminder to have formal assessment done.
- A clause which does not hold the application developers responsible for misuse of the app.
- Give opportunities for users to give feedback and incorporate the feedback in the development of the final versions.
- Include research on how people interact with technology in the application development.

### 5.6.2 Recommendations for Future Research

Based on the findings of the present study, the following recommendations are made for future research:

- Further exploration of the experiences of caregivers of children with a formal diagnosis of ASD without comorbid disorders, in order to explore the effectiveness of the application being focused on children with ASD.
- Replication of the study with a larger group of participants from differing cultural and language groups who live in resource-constrained contexts, in order to improve generalisability.
- Incorporation of both qualitative and quantitative measures, the effectiveness of an application with a baseline of functioning compared to a post-app functioning over time may contribute much to the validity of the usefulness of such an app.
- The provision of portable chargers to participants at the beginning of the trial period in order to avoid barriers to application use due to shortages of electricity.
- Research on the integration of learning theories and technology for users without prior exposure to technology.
- Research on the use of apps to support caregivers with children with other disabilities or challenges.

- Research on the readiness of people in resource-constrained contexts to make use of technology.
- Research could be done whether an application should specialise in support for a specific challenge such as ASD, or whether an application should contain general guidelines in terms of language development, social interaction, cognitive stimulation and so forth.

## 5.7 CONCLUDING REFLECTIONS

I would like to conclude the final chapter with a few personal reflections on the research process. The challenge to find participants who fulfilled the selection criteria was discouraging, and I was initially convinced my research was compromised. However, having personally experienced the limited available access to healthcare for people in resource-constrained contexts, I was aware that alternatives for support had to be found.

Even though the study did not necessarily yield the answers I expected, it did yield answers, which are contained in the dissertation. I feel that my interactions with the participant led me to catch but a glimpse of the stark reality faced by caregivers of children with ASD living in resource-constrained contexts on a daily basis. In light of the increased accessibility to cell phones and the internet, the prospect of a cell phone application that can support parents and their children with ASD is both exciting and promising. The Fourth Industrial Revolution, with its emphasis on automation, may ironically bridge the gap between limited resources and intervention in resource-constrained contexts.

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# APPENDIX A - INFORMED CONSENT LETTER FOR ITSOSENG

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto

## INFORMED CONSENT

## DIRECTOR OF ITSOSENG CLINIC, MAMELODI

Dear Sir/Madam

I am currently busy with an MEd study in Educational Psychology at the University of Pretoria on the following topic: "**What are the experiences of caregivers of children with Autism Spectrum Disorder of a cell phone application to support with children in resource restricted areas?**" The research questions are as follows:

The primary research question: What are the experiences of caregivers of children with Autism Spectrum Disorder of a cell phone application to support their children in resource restricted areas?

Secondary research questions are:

1. What support is needed by children with Autism Spectrum Disorder for optimal wellness?
2. What are the needs of caregivers with children with Autism Spectrum Disorder, generally and in resource restricted areas?
3. What criteria should cell phone apps adhere to in order to be user friendly to caregivers of children with ASD, generally and in resource restricted areas?

I kindly request your support during data collection. Itsoseng Clinic has been identified as a clinic with many clients in resource restricted areas. If you could identify possible participants (according to several criteria), and explain the potential benefits of the study to them, I will greatly appreciate your time and effort. I realise that your client information is also confidential, and that a few calls made be you, in addition to your work load, will be required to secure the participants' involvement.

The study will consist of a single one-on-one semi-structured interview with three (3) interviewees. Their duration will be one hour, to be held at Itsoseng Clinic, Mamelodi, 8 weeks after the caregivers have used the app. This semi-structured interview will be audio-recorded and then transcribed, and I as the researcher will be taking down field notes.

All information, including the audio-recordings and transcriptions will be kept confidential at all times. Participants may withdraw partaking at any time. During this study, participants will not be hurt emotionally or physically. If serious challenges arise, I will refer participants to the services of an appropriate professional.

It is important that participants are aware that the cell phone application will require them to have a smart phone and it will most likely take 50mb of data, which on average should cost R0.50 per half an hour session of using the app. Also, any taxi fares to get to Itsoseng Clinic for the interview will not be paid by the University of Pretoria. Before commencing the semi-structured interview, I will explain the process of the interview to the participants and try to answer any questions they may have about it.

If you are willing to allow opportunity for this study to take place at Itsoseng Clinic, please sign in the space provided below. Thank you for your consideration of this request.

Yours faithfully,

Kerry-Beth Berry

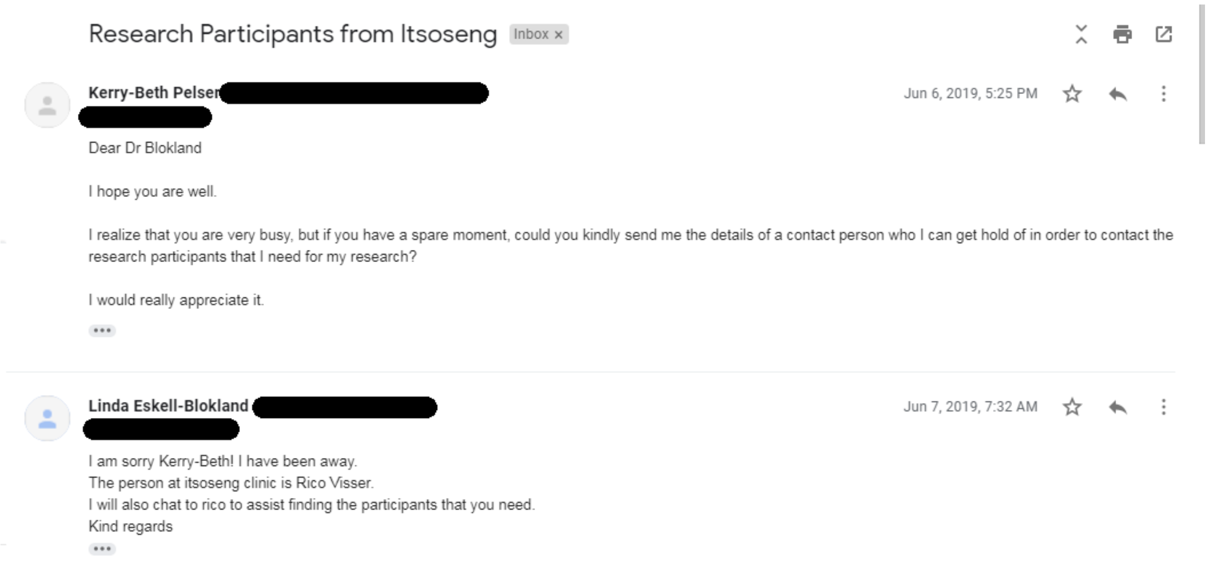
Student number: 16290918

Signed at ____________________ on __________________________________ 2018.

____________________________ ____________________________

Director Researcher

# APPENDIX B - EMAIL FROM DR BLOKLAND



Research Participants from Itsoseng

**Kerry-Beth Pelser** [redacted]
[redacted]

Jun 6, 2019, 5:25 PM

Dear Dr Blokland

I hope you are well.

I realize that you are very busy, but if you have a spare moment, could you kindly send me the details of a contact person who I can get hold of in order to contact the research participants that I need for my research?

I would really appreciate it.

**Linda Eskell-Blokland** [redacted]
[redacted]

Jun 7, 2019, 7:32 AM

I am sorry Kerry-Beth! I have been away.
The person at itsoseng clinic is Rico Visser.
I will also chat to rico to assist finding the participants that you need.
Kind regards

# APPENDIX C - INFORMED CONSENT LETTER

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto

## REQUEST FOR PARTICIPATION AND INFORMED CONSENT
## PARENTS

Dear Sir/Madam

I am currently busy with an MEd study in Educational Psychology at the University of Pretoria on the following topic: “**What are the experiences of caregivers of children with Autism Spectrum Disorder of a cell phone application to support children in resource restricted areas?**”

The study will consist of a single one-on-one semi-structured interview for the duration of one hour, to be held at Itsoseng Clinic, Mamelodi, eight (8) weeks after you have used the app. You will be contacted once a week to remind you to make use of the app. The semi-structured interview will be audio-recorded and then transcribed, and I as the researcher will be taking down field notes.

Please note that all of your information, including the audio-recordings and transcriptions, will be kept confidential at all times. You may withdraw your participation at any time. During this study, you will not be hurt emotionally or physically. If serious challenges arise, I will refer you to the services of an appropriate professional.

It is important that you are aware that the cell phone application will require you to have a smart phone and it will most likely take 50mb of data, which on average should cost R0.50 per half an hour session of using the app. Also, please note that any taxi fares to get the interviews will not be paid by the University of Pretoria. Before commencing the semi-structured interview, I will explain the process of the interview to you and try to answer any questions you may have about it.

If you are willing to participate in this study, please sign this letter as a declaration of your consent, i.e. that you participate in this project willingly and you understand that you may withdraw from the research project at any time. Under no circumstances will the identity of interview participants be made known to any parties/organisations that may be involved in the research process, except for the supervisor.

Thank you for your consideration of this request.

________________________________

(Participant)

| | |
|---|---|
| ________________________________ | ________________________________ |
| Ms Kerry-Beth Berry (Researcher) | Dr Anna-Barbara du Plessis (Supervisor) |
| Telephone number: 0721455383 | Email: anna-barbara.duplessis@up.ac.za |
| Email: kerrybethberry@gmail.com | |

# APPENDIX D - SEMI-STRUCTURED INTERVIEW SCHEDULE

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## Interview schedule

## Semi-structured interviews with participants, individually

## Duration: +/- 60 minutes

The purpose of this semi-structured interview is for me to get insight into the experiences you had with the cell phone application in assisting you with supporting your child with Autism Spectrum Disorder – I want to see if it worked.

I will be asking you a number of questions which I would like you to answer honestly, please. You may at any moment withdraw your participation if for some reason you feel uncomfortable. I will be audio-recording our session together, and I will be taking notes as we go along to make sure that I don't leave anything out. Will this be alright with you?

1. Where do you stay?

   __________________________________________________________

2. How old are you?

   __________________________________________________________

3. What is your highest educational level?

   __________________________________________________________

4. Are you married?

   __________________________________________________________

5. How many children do you have? How old are they?

   __________________________________________________________

6. Where do they go to school?

   __________________________________________________________

7. How did you feel when you first heard about the cell phone app? Tell me more

   __________________________________________________________

   __________________________________________________________

8. How did you find the cell phone app? Tell me more.

   __________________________________________________________

   __________________________________________________________

   __________________________________________________________

   __________________________________________________________

9. Did you notice a difference in your child’s behaviour after using the app? Tell me more.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
__________________________________

10. Is there anything else that you think your child struggles with (other than Autism Spectrum Disorder and its manifestations)? Tell me more.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
__________________________________

11. Has using this app brought any changes to how you and your child interact? Tell me more.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
__________________________________

12. Has using this app changed the way your child and his/her siblings interact with each other? Tell me more.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
__________________________________

13. When / how did you use the app?

________________________________________________________________________
________________________________________________________________________
_________________

14. Did using the app cause there to be any changes in your family? Tell me more.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
__________________________________

15. Do you feel that using the app has changed anything in you, your child or your family? Tell me more.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
__________________________________

16. How do you feel about the format of the app? Was it easy to navigate around it? Tell me more.

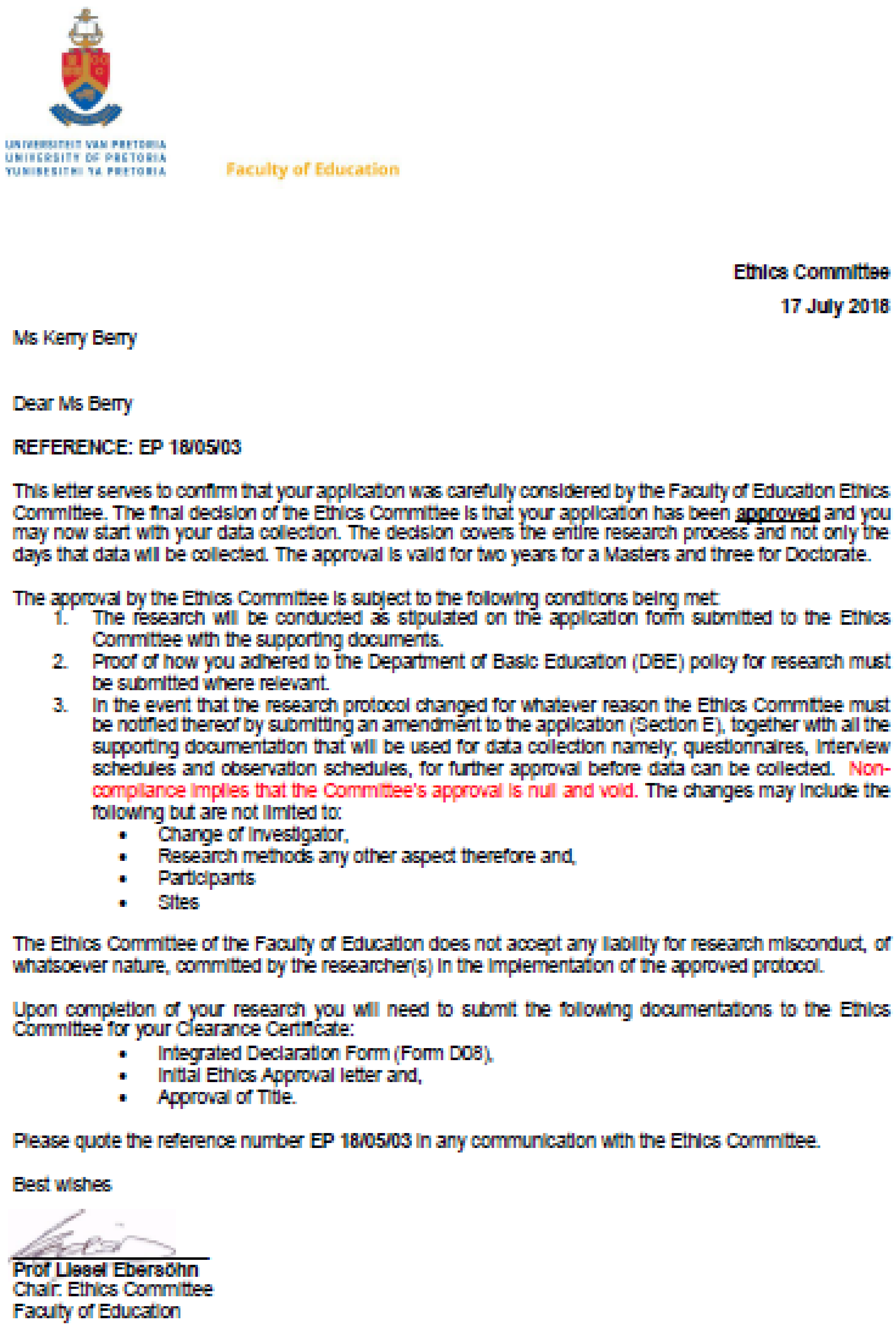
17. How do you feel about the words and the language used in the app? Tell me more.

18. How do you feel about the amount of data the app uses?

19. Was there anything in the app that made you feel frustrated?

20. Was there anything you would have changed about the app? Did it provide you with enough information?

# APPENDIX E - ETHICS APPROVAL LETTER



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Education

**Ethics Committee**
**17 July 2018**

Ms Kerry Berry

Dear Ms Berry

**REFERENCE: EP 18/05/03**

This letter serves to confirm that your application was carefully considered by the Faculty of Education Ethics Committee. The final decision of the Ethics Committee is that your application has been **approved** and you may now start with your data collection. The decision covers the entire research process and not only the days that data will be collected. The approval is valid for two years for a Masters and three for Doctorate.

The approval by the Ethics Committee is subject to the following conditions being met:

1. The research will be conducted as stipulated on the application form submitted to the Ethics Committee with the supporting documents.
2. Proof of how you adhered to the Department of Basic Education (DBE) policy for research must be submitted where relevant.
3. In the event that the research protocol changed for whatever reason the Ethics Committee must be notified thereof by submitting an amendment to the application (Section E), together with all the supporting documentation that will be used for data collection namely; questionnaires, interview schedules and observation schedules, for further approval before data can be collected. Non-compliance implies that the Committee's approval is null and void. The changes may include the following but are not limited to:
    - Change of investigator,
    - Research methods any other aspect therefore and,
    - Participants
    - Sites

The Ethics Committee of the Faculty of Education does not accept any liability for research misconduct, of whatsoever nature, committed by the researcher(s) in the implementation of the approved protocol.

Upon completion of your research you will need to submit the following documentations to the Ethics Committee for your Clearance Certificate:

- Integrated Declaration Form (Form D08),
- Initial Ethics Approval letter and,
- Approval of Title.

Please quote the reference number **EP 18/05/03** in any communication with the Ethics Committee.

Best wishes

**Prof Liesel Ebersöhn**
Chair: Ethics Committee
Faculty of Education

# APPENDIX F - RESEARCHER'S FIELD NOTES

| Field Notes: Introduction to Research Participant | |
|---|---|
| Date | 10 July 2019 |
| Facilitator | Kerry-Beth Pelser |
| Length of Session | 10:30-11:30 |
| Place | Consultation Room, Itsoseng Clinic, UP Campus, Mamelodi |

During this session, I briefly tried to build rapport with the research participant by getting to know her a bit and then introduced the basis of the study to the participant, explained what her role would be in the study and asked whether she would be interested in participating. She signed the consent form and seemed both relieved and excited about using the app to support her child, because the child doesn't currently go to school and so she has been wanting to teach her child in some way.

I also confirmed the details of her child, who is 9 years old. Although her child does not have a formal diagnosis of ASD, the research participant mentioned that the child has very delayed developmental milestones and a doctor suspects that it is ASD. She also takes medication for epilepsy, and is only able to say basic words like 'Mama'.

The participant seems to be quite proficient in English, so it will not be necessary to have a translator assist us for our sessions together. She has a smartphone of her own, but I still plan on taking a spare smart phone with me when we meet again in case it's a struggle to install the app on her phone due to there not being enough space or it being too old, or something like that. After this session, I left with great excitement at the prospect of not only obtaining information that holds incredible potential for ASD support in South Africa, but also making a difference and bringing improvement to someone's life in the process.

| Field Notes: Installation of as well as introduction to the app | |
|---|---|
| Date | 18 July 2019 |
| Facilitator | Kerry-Beth Pelser |
| Length of Session | 09:00-10:30 |
| Place | Consultation Room, Itsoseng Clinic, UP Campus, Mamelodi |

During this session, I found that the research participant's phone had too little space for me to install the app on, so I installed the app on my spare phone and gave it to her to use for the 10 day trial app. I explained how to use the app and gave the research participant a number line to make the mathematical questions easier for her for if she struggled. I introduced her to the first 4 categories of activities on the app and then told her that the next time I see her, I'll show her how to use the next 4 categories.

I also wrote down the passwords and number to call to check the amount of data left so that she could have them at all times. Unfortunately one has to log in to the app with the email address and password every time, and it's easy to make a mistake because the letters and numbers aren't shown as you type them in. This could lead to possible problems with logging in in future if the participant gets easily discouraged. If it comes up, I will try to handle it.

| Field Notes: Support session | |
|---|---|
| Date | 25 July 2019 |
| Facilitator | Kerry-Beth Pelser |
| Length of Session | 09:00-10:30 |
| Place | Consultation Room, Itsoseng Clinic, UP Campus, Mamelodi |

Four days after installing the app, the research participant sent me a message saying that the phone has been off because they don't have electricity to charge it. I told her it's not a problem, and that the next time I saw her, I would bring a charger that doesn't need electricity. I made sure to buy a power bank that could charge a phone 3 times before it needs charging, so that it would last the remainder of the 10 days.

During our session, I gave her the power bank, showed her how to use it, and introduced the next 4 categories on the app. She seemed a little hesitant about being able to remember certain words in isiZulu, especially the animal names, and therefore got the idea that she should write down the names of the animals in isiZulu so that she can recall them quicker while using the app.

Overall, the participant seemed positive about the app and it seemed like the child was enjoying using it. The research participant also didn't seem to encounter any difficulties with logging in or navigating the app. She almost seemed to know her way around the app better than me!

| Field Notes: Semi-structured Interview | |
|---|---|
| Date | 3 August 2019 |
| Facilitator | Kerry-Beth Pelser |
| Length of Session | 10:00-11:30 |
| Place | Computer Room, The Law Clinic, UP Campus, Mamelodi |

It quickly became evident that the research participant's use of English was not as developed as I had originally thought. Even though I had originally set the questions on the interview schedule thinking it was in basic English, during the interview, I didn't feel like I was able to ask as many open-ended questions as I had initially anticipated. In order to minimize confusion, I landed up using more closed-ended questions and tried to clarify often. Because of this, I had to deviate from the exact questions on the interview schedule so as to support the participant in understanding and responding to me. Also, because we met on a Saturday, it was not possible to get the help of a translator from Itsoseng Clinic.

Due to a lack of resources and support, the research participant's child had to come with her to the interview, because there is no one else to look after her on weekends. During the week she pays a lady to look after her child, but she was not available to watch her while the interview took place because it was on a Saturday. I brought a number of toys and things for the child to do while we spoke, however, the child tended to leave the room, wander off or engage in distracting behaviour throughout the interview, which obviously caused a number of interruptions and was therefore a limitation. I understand, however, that this is a true reflection of the reality that this caregiver faces on a daily basis in supporting her family, having a full time job and then supporting her child with ASD in a resource-constrained environment.

Even though this interview didn't run half as smoothly as I had hoped, I came away with a deep sense of admiration and respect for the research participant who seems to have so little support and very limited resources, but is still cheerful, consistently does her best to help her child and shows signs of resilience in spite of this.

# APPENDIX G - TRANSCRIPTION – COLOUR CODED

*Please note that this is just a sample of the analysed transcript of the individual interviews. The complete transcript is included on the compact disc (CD) attached to the last page of the mini-dissertation.*

Transcription for Semi-structured Interview

3 August 2019

Held at the Law Clinic, University of Pretoria Mamelodi Campus

Duration: 1 hour 15 minutes 7 seconds

**Key**

Kerry-Beth Pelser (researcher): K

Zintle* (research participant): Z

Leah* (research participant's child who has symptoms of ASD)

*True identity of participant is hidden due to ethical obligations to keep personal information confidential

(Before audio-recording commenced, consent was obtained to begin recording)

K: … I can't um… I can't write fast (laughs)

Z: Ok…

K: Ok… So the reason why we are doing the interview is because I want to hear if the app worked for you…

Z: Yes…

K: … And if something… you think it should have changed or, you know, anything that should have been different…

Z: Mmh…

K: … So we're just going to chat just like it's a conversation…

Z: Yes…

# APPENDIX H - INCLUSION AND EXCLUSION CRITERIA USED FOR THEMES

| **Theme 1** | **Criteria for inclusion** | **Criteria for exclusion** |
|---|---|---|
| *Subtheme 1.1*<br>Lack of family support | Reference that is made to family members who support the participant in any way with her child with ASD characteristics. | Reference that is made to non-family members who support the research participant in any way with her child with ASD characteristics. |
| *Subtheme 1.2*<br>Lack of community support | Experiences where the members of the community rejected the participant or her child, made her feel judged, and/or offered unwelcome advice. | Experiences where the members of the community did not reject the participant or her child, make her feel judged, or offer her unwelcome advice. |
| *Subtheme 1.3*<br>Sense of social isolation | Situations where the participant feels excluded, alone or that she is treated differently by others, due to their differing beliefs. | Situations where the participant does not feel excluded, alone or that she is treated differently by others due to their differing beliefs. |
| *Subtheme 1.4*<br>Desire for social support | Statements that express a desire for increased public awareness of ASD, the desire to share one's experiences, and the view that contact with other caregivers of children with ASD would bring change. | Statements that do not express a desire for increased public awareness of ASD, the desire to share one's experiences, and the view that contact with other caregivers of children with ASD would bring change. |

**Table 1:** Inclusion and exclusion criteria used for Theme 1: Social Support

| Theme 2 | Criteria for inclusion | Criteria for exclusion |
|---|---|---|
| *Subtheme 2.1*<br>Challenges in providing for the child's needs | Extra expenses that her child needs to survive (in terms of basic needs such as food, clothes, diapers, medical attention and education). | Extra expenses that are not specific to the needs of the child with ASD. |
| *Subtheme 2.2*<br>Hopes for a state subsidy | All referrals to grant money, the need for it and what would be done with it (in a broad sense). | All referrals to subjects other than grant money, the need for it and what would be done with it (in a broad sense). |
| *Subtheme 2.3*<br>Willingness to pay for app data | Opinions of being able to afford the data for the app, willingness to pay for the app and the desire to have the app. | Referral to other positive effects of the app. |

**Table 2:** Inclusion and exclusion criteria used for Theme 2: Financial Implications

| Theme 3 | Criteria for inclusion | Criteria for exclusion |
|---|---|---|
| *Subtheme 3.1*<br>Effect on the child | Changes that took place in the child's behaviour, as observed and reported by the caregiver. | Changes that seemed to occur in the mother rather than in her child. |
| *Subtheme 3.2*<br>Effect on the caregiver | Changes that took place in the caregiver due to the app. | Changes that took place in the caregiver that were not due to the app. |
| *Subtheme 3.3*<br>Practical implications | Daily logistical aspects and experiences of using the app. | Daily logistical aspects and experiences not related to using the app. |
| *Subtheme 3.4*<br>Possible improvements | Challenges and suggested improvements or additions to the app. | Challenges that were not applicable or to do with the app. |

**Table 3:** Inclusion and exclusion criteria used for Theme 3: App Use

| Theme 4 | Criteria for inclusion | Criteria for exclusion |
|---|---|---|
| *Subtheme 4.1* Medical aspects | Aspects pertaining to the medical side of ASD, healthcare, medication and awareness. | Aspects outside of the medical side of ASD, healthcare, medication and awareness. |
| *Subtheme 4.2* Perception of child's needs | The child's needs that are directly mentioned and those which are common themes in the mother's concerns. | Common themes in the mother's concerns that do not relate to the child's needs. |
| *Subtheme 4.3* Realities of daily life | Differences in daily activities that may be taken for granted in a home with children that are neuro-typical. | Daily activities that may be taken for granted in a home with children that are neuro-typical. |

**Table 4:** Inclusion and exclusion criteria used for Theme 4: Challenges of ASD