CHAPTER ONE

INTRODUCTION TO THE STUDY

1.1 Introduction

Disability is defined as the physical or mental condition that brings about limitation to the functioning of the affected individual (Siebers, 2008). There are different kinds of disabilities, and these include physical, mental, intellectual, and learning impairments. (Albrecht, Seelman & Bury, 2001). According to Albrecht et al. (2001) physical disability is an impairment that affects the motor functioning of an individual. On the other hand mental disability tempers with the functioning of the brain, more especially, when it comes to memory. An intellectual disability involves a permanent limitation of the person's ability to learn, more especially when it's new information as the retrieval of old information can also be a struggle. Learning disability is not as different from intellectual disability. According to Albrecht, et al., (2001) just as in learning disabilities, within intellectual disabilities the central part of the brain is also affected and this contributes to the person's ability to perceive, see, hear and interpret information. In addition linking the information to the already existing one becomes a challenge (Albrecht et al., 2001).

1.2 Statement of the problem and rationale for the study

For time immemorial, children living with disabilities have been marginalised, stigmatized, and barely treated as functional human beings due to their inability to perform certain daily tasks that a person regarded as 'normal' can perform (Gargiulo, 2016). The term disability creates an impression of inability; however, the definition is not what has turned most people to see disability in that manner. There are number of programmes which have aimed at addressing the needs of the children who are living with disabilities. These include Inclusive Library Model (ILM) which was initiated by the librarians from the United States and Canada. This model seeks to eliminate the challenges faced by the children who are living with disabilities and their families by making sure that libraries are accessible, and the library is accessible to be used by a child who is living with any form of disability (Kaeding, Velasquez & Price, 2017).

In addition, the other programme which was initiated by the World Health Organisation [WHO] (2001) in response to inclusivity for the children who are living with disabilities is the Oral Hygiene (OH). This OH programme mostly focused on the children with intellectual disabilities, to curb the dental plague problem that was found to be a challenge amongst children with intellectual disabilities. This therefore shows that there are a number of studies (Kaeding, Velasquez & Price, 2017); Anders, 2010; WHO, 2001) that have been written in the past focusing on the well-being of the children living with disabilities. Moreover, several programmes which accommodate children with different types of intellectual disabilities have been initiated before. However, there seem to be a gap and/or lack of studies that focus on the experiences or challenges that are faced by primary caregivers living with children with cognitive disabilities.

Therefore, the rationale for this study was to explore the challenges faced by the primary care-givers living with children with cognitive disabilities. It was anticipated that the study would contribute to programmatic interventions that can be employed by social service professionals when working with care givers of children with cognitive disability. It was also envisaged that the research might contribute to the development of support guidelines that can be used by care givers working with children with cognitive disability. These guidelines might enhance their knowledge about the condition and they may also help them to develop better coping mechanisms.

1.3 Definition of terms

Primary care giver- According to Dellmann-Jenkin, Blankemeyer and Pinkard, (2000) a primary caregiver is an individual who takes primary responsibility for someone who cannot fully take care of themselves, the primary care-giver can be a family member, a trained professional or any other person who takes on the roles of being a primary care giver. A house mother is regarded as a primary care giver in this research.

House mother- This is an individual who takes care of the children placed in a home or Child and Youth Care Centre, she takes on the responsibilities of being a primary care giver to the children, elderly or youth who are delegated under her authority Aguiló, Lopez-Barbeito, García, & Aguiló, 2017).

1.4 The purpose of the study

The purpose of the study was to explore the challenges which are faced by primary caregivers of children living with disabilities in Colin House Child and Youth Care Centre, in Benoni.

1.5 Overview of the research approach and design

The proposed research was qualitative in nature, and a case study was used as a research design. The criteria for inclusion of research participants were women who were house mothers all working as primary caregivers at Colin House Child and Youth Care Centre in Benoni. A non-probability-purposive sampling procedure was used to select 7 participants who took part in the study. The age of participants ranged between 29 to 56 years. An interview was also conducted with a key informant. The research tool was an interview schedule, which was administered through one-on-one individual interviews. The data was analysed using thematic analysis.

1.6 Limitations of the study

The house mothers were interviewed in a workplace setting as they verbalised that they did not need an alternative venue, they were also told that the director and the Colin House social worker gave the go ahead that they can be interviewed as part of the study. That could have led them in giving social desirable responses, which could have been the first limitation to the study.

The participants also preferred giving responses in their home languages as they assumed that since when the researcher was from the same racial group then their language would be understood. They voiced out that sometimes they can fully explain their emotions through the usage of the home language. So when the researcher was transcribing verbatim, it was a challenge to translate to English.

1.7 Organisation of the study

Chapter one: It provided the introduction to the study, rationale for the study and the significance of the study.

Chapter two: The chapter focuses on the literature and also examines theory and research relating the challenges faced by the primary care-givers in caring for children with cognitive
Chapter three: This chapter describes the research design and of the study.

Chapter four: A presentation and discussion of the research findings is given in this chapter

Chapter five: This is the last section of the research report and it provides the main findings, conclusions and recommendations which emerged from the research findings.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

With the rise of children with disabilities that need intensive care, there is also a rise in the need of primary care-giver who specialize in the field. However, their needs also need to be taken care of so that they would be able to take care of the children with cognitive disabilities in an effective way. According to Resch et al. (2010) there are different challenges which affect the primary care givers of children with cognitive disabilities, they include the lack of financial resources, and lack of family support. These will be discussed further in this chapter.

2.2 Children and disability: an overview

Cognitive disability is an umbrella term for different kinds of cognitive or rather intellectual disabilities (WHO, 2001). There are different kinds of cognitive malfunctions in children such as the likes of autism which is a cognitive dysfunction which affects the left-hand hemisphere of the brain and later results in motor dysfunctions. There is dementia which is more related to memory, so a child with dementia finds difficulty in remembering things as the short-term memory is mostly affected which deals with information that just presented itself in the brain (WHO, 2001).The World Health Organisation further defined intellectual disability as a significant impairment on intelligence, there is also a huge reduction on the ability to adapt on socially acceptable behaviour and there is disturbances with regards to the development of the condition before they reach the age of 18 and it usually goes on throughout the years of their lives (WHO, 2001). The World Health Organisation further distinguishes between the different kinds of intellectual disabilities, they classify them under four categories which are; Mild Intellectual Disability which has less impact on the speech used in a daily basis and there is still high ability of self-care, that is the reason why it is difficult to spot this population as they might not be in contact with any service provider due to the invisibility of the disability.

The second category is the Moderate Intellectual Disability, this is whereby there needs to be supervision when it comes to self-care as there is a slight change on motor reflexes and one other thing is that they tend to be slower in comprehension. The third category is that of Severe Intellectual Disability which makes one to have a visible motor impairment, this is because the Central Nervous System gets damages. The last one is the Profound Intellectual Disability which incorporates all that has been explained on the first three categories. In Sweden there has been a research on cognitive disability done by Beck, Rush, Shaw and Emery (1979), the study defined cognitive disability as an invisible impairment that is either pre-birth, during or post birth. This kind of invisible disability is said to be a disabler in such a manner that the functioning of the child is at a lower rate than what one would have expected taking into consideration the developmental stage.

2.3 Cognitive disabilities in children

In Sweden there has been a research on cognitive disability done by Beck, Rush, Shaw and Emery (1979), the study defined cognitive disability as an invisible impairment that is either pre-birth, during or post birth. This kind of invisible disability is said to be a disabler in such a manner that the functioning of the child is at a lower rate than one would have expected taking into consideration the developmental stage.

2.4 Challenges related to raising children with cognitive disabilities

According to Hassall, Rose and McDonald (2005) the hardest thing about raising the child who has cognitive disability mostly lies on the social support which they get from their families and the communities at large. What Hassall, Rose and McDonald (2005) found when they did a research with parents who are raising a child who has a disability is that most of them have emotional breakdowns as the stress gets more when the child is growing due to schooling and them realising that they are fully dependent on their parents. This was said to be quite strenuous. Social affiliation and integration of people with cognitive disabilities in South African societies is a greatest issue, according to Brittain (2004) as sport is one of the social ways of interaction and affiliation; people living with disabilities still find it hard to be part of it with no prejudice and stereotype. One other challenge that the primary care-givers encounter in raising a child with cognitive disabilities is the behaviour patterns that the child undergoes, going back to the definition of intellectual or learning disability which included the difficulty of grasping information as fast as a child that is considered to be “normal” can. A child with cognitive disabilities mostly gets resilient as they can possibly be facing difficulties in adapting to the environment and developmental issues.

On the research conducted by Resch et al. (2010) there seem to be four main challenges which are faced by the primary care-givers of the children who are living with any kind of disability, with the inclusion of intellectual disability. The first challenge which is faced by the primary care-givers is access to information with regards to how they can better cope with taking care of the child, there are also none or limited services which addresses such. The second challenge is that of financial resource, this is the most prominent challenge more especially because children who are living with disabilities are considered to be a special case which means that there is a high demand for them to be placed in special schools which do not come in cheap. The third challenge is that there is still a huge struggle in them being socially accepted, hence there is a stigma around them which makes it hard for them to cope with at school or even in communities which the affects the care-giver as they must go a thousand miles in enhancing their self-efficacy. The last challenge as outlined by Resch et al. (2010) is family support, we all come from different families of which some are supportive and others are not. The parent in other families are the only ones who responsible for taking care of the child, which then puts a strain to the primary-care giver. Those are the four main challenges which are faced by the primary care-givers who are living with children who are living with cognitive disabilities.

According to Plant and Sanders (2007) there is lot of stress which comes with raising a child with intellectual disabilities, such can be a resultant of many factors which have been mentioned above about the financial strain and lack of family support. Primary caregiving is regarded as a job that requires lot of time and patience, which then somehow forces the primary caregivers of children living with cognitive disabilities work long hours than a normal worker (Yantzi, Rosenberg and McKeever, 2007). In a research conducted by Yantzi, Rosenberg and McKeever (2007) it was found that long working hours becomes a huge challenge for the primary caregivers as they struggle to be productive in their jobs. Another concern which results from long working hours was that it affects the well-being of the primary caregiver.

2.5 Impact of the challenges which are faced by primary care-givers in taking care of children with disabilities

On the research that was conducted in Botswana by Kang’ethe (2014) it was been found that demotivation becomes one of the major implications resulting from taking care of a child with cognitive disabilities. What happens is that the primary care-givers somewhere along the way lose interest and strength to continue taking care of the children.

2.6 Support mechanisms for caregivers of children with cognitive disabilities

Social support plays a huge role as being a mechanism that the primary care-givers can get in order to make parenting or taking care of a child with disabilities a lot easier. Not much research has been done in this area, however on the study that was conducted by Armstrong and Birnie-Lefcovitch (2005) it was found that formal support (one that is offered by the family) and informal support (offered by friends and people close) plays a huge role in enabling the parents (as primary care-givers) to cope better. According to Cohen and Wills (1985) social support comes in very handy in the primary caregivers doing their job effectively, it has been found that satisfaction which results from support networks such as from friends and family has shown good attitude from the caregiver and increased personal well-being (Kang'ethe, 2014). So, it comes in very important that primary care-givers make time to socialise with other people and not be at work all the time so that they could distress. There has been limited research done on the ways in which the coping mechanisms of the primary care-givers can be sharpened with the aim of enhancing the growth of the child who is living with cognitive disabilities. Research done by Crnic et al. (2017) looked at the intervention programmes which have tried to focus on the coping strategies of the children who are living with cognitive disabilities, such include the early intervention processes which relook at the parenting skills, parenting processes and the behavioural problems in children with cognitive disabilities as it has greater influence on the child and the family outcomes.

Another research which has been done to address such is the one done by Cauda-Laufer (2017), the research had two goals. The first goal was to investigate the relationship between the parent's coping strategies looking at their emotional distress or mental health. The second goal was to see if the positive and adaptive coping would yield an impressive mental health considering that social support is already in place. However, the results of the study show that the parents coping mechanisms of the parents had no link whatsoever with their emotional distress. The results showed revealed that the parents actually reported their own personal experiences as the ones which yielded stable results which were related to them not coping due to social exclusion, financially strained due to the high demand of the child who is having intellectual disability.

Studies have shown that suppression is also used as a way of coping in the workplace, according to Mostert and Rothmann (2006) suppression is regarded by employees with an inclusion of primary care-givers when their needs in the workplace are not met. So, in other words when the challenges which have been noted above are not taken into consideration by those who are in authority; the primary care-givers find suppression as a solution to that as a way of keeping their jobs and not be seen as people who enjoy complaining more than working. The other reason why suppression is also regarded as a way of coping is that there is a thinking that every job comes with its challenges, and even when they do not like what they experience at work they just continue and avoid verbalising their feelings.

2.7 Conclusion

With the growth of primary care-giving in South Africa for children who are living with cognitive disabilities, which the literature has revealed the need for the challenges faced by the house mothers to be addressed with the aim of increasing the positive outcome for meeting the needs of the children. As indicated that most of the challenges that primary care-givers face revolves around access to information, the studies found that there are limited services available for the primary care-givers who are taking care of the children living with cognitive disabilities (Resch et al., 2010). Social support and social acceptance of the children with disabilities has also been a struggle for the primary care-givers to be able to socialise the children, which then does not limit the stigma attached to cognitive disabilities (Hassall, Rose and McDonald, 2005). The study done by Resch et al. (2010) also revealed family support as an essential factor contributing to care-giving, it showed that the more support provided to the primary care-givers then more positive results.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter will be focusing on methodological processes that were adhered to in addressing the aim and objectives of the study. The chapter discusses the approach that was employed as a guideline for the study, it looks at the selection of the research sample from the population, the research instruments and the procedures on how the data collected was analysed. Furthermore, the strengths and limitations of the research methodology are explored in detail, and lastly the chapter looks at the ethical considerations which were taken into account during the study.

Research question

What are the challenges faced by primary care-givers living with children having cognitive disabilities in Benoni, Johannesburg.

3.2 Research Aim and Objectives

Primary aim

- The primary aim of the study was to explore the challenges faced by primary care-givers living with children having cognitive disabilities.

Secondary objectives

- To explore the factors contributing to the decision of becoming a primary caregiver to children with cognitive disabilities.
- To explore challenges faced by primary care-givers looking after children living with cognitive disabilities.
- To explore the perceived impact of the challenges experienced by primary caregivers while working with children with cognitive disabilities.
- To understand the support and coping mechanisms employed by primary care-givers in looking after children with cognitive disabilities.

3.3 Research approach and design

The study was qualitative in nature. A qualitative study approach can be used to understand the social aspects in a descriptive manner, which is why this study used it to understand the challenges which are faced by primary care-givers of children living with cognitive disabilities (Engel & Schutt, 2005). One of the elements of a qualitative research approach is that it uses participants' observation and case studies, which makes it easy for the researcher to get in-depth responses form the participants. According to Creswell (2012) qualitative research refers to a method used by researchers when they are aiming at understanding the lived experiences of the participants. Qualitative research is based on the constructivism assumption, this assumption holds on the view that the participants are the ones who can be narrators of their own subjective experience (Creswell, 2012). In Creswell (2012) it is also evident that the goal of the qualitative researcher within the constructivism perspective is to rely on the participants' views of what is being studied. According to Creswell (2012) one of the advantages of qualitative research is that it provides data about the structure, order and patterns found among human groups located in different social settings. The second advantage of a qualitative study approach is that there is an in depth covering of the subject, which means that it enables the researcher to pay attention in detail. The disadvantages of a qualitative study approach is that as it is highly dependent on the skills of the researcher, that makes the findings to be more prone to biasness of the researcher, therefore what the researcher could make out of the findings can be posted and not exactly what the participant was implying when data was being gathered (Creswell, 2012).

A case study was used as a research design. According to Galletta (2013) a case study is used by the researcher when he or she explores, in depth, an event or an activity. What is important to note is that case studies are bounded by time and activity, informative data collection tool needs to be used as a way of getting more from the participants, which serves as an advantage as time limit is given to the participant. The advantage of a case study is that it has the longitudinal effect on the investigation of an individual, group or an event (Galletta, 2013).

3.4 Population and sampling procedures

A population is defined by Ren et al., (2014) as a group of people who have the characteristics which are valuable to the study. The population for this study was comprised of primary care givers (house mothers) of the Colin House Child and Youth Care Centre in Benoni. To be more specific the study was focusing on primary care givers who are house mothers who have stayed with children with any kind of cognitive disability for a period of a year and more. For other primary-care givers such as the house mothers, it will not be the case that they have raised the child as they might have had the opportunity to stay with the child that has a cognitive disability not that long.

The study took into account the non-probability sampling technique whereby there is no element of randomising the sample. The purposive sampling technique also known as the judgemental, selective or subjective sampling was used as a sampling method, as the research was aiming to get information from specific individuals who are already staying and working with children who are living with disabilities. According to Masson (2010) the researcher does purposive sampling with an assurance that the participants would have interest in the study, and they are chosen on a simple basis of having the ability to adhere to the objective of the study and be able to answer the research question with no doubt. In de Vos et al. (2005), it is found that purposive sampling is when participants are chosen based entirely on the researcher's judgment in that a sample would be composed of elements that contain the characteristic, representative or typical attributes of the population.

A population is defined by Pilot and Hungler (1999) as "an aggregate or totality of all the objects, subjects or members that conform to a set of specification". In this study the population was house mothers who are regarded as primary care-givers in Benoni. A sample which was taken from the population was made up of 7 house mothers employed by the Greater Benoni Child Welfare in Benoni, which granted permission for the study (Appendix F). The eligibility criteria in the study were that participants should have been working as house mothers for children with any kind of cognitive disabilities for a year or more, they also need to have a certificate in child care training and first aid training. According to Pilot and Hungler (1999), eligibility criteria "specify the characteristics that the people in the population must possess in order to be included in the study sample." And lastly the Colin House social worker who was used as a key informant gave a verbal consent to be part of the study.

According to Cresswell (2009) non-probability sampling implies that not every element of the population has an opportunity for being included in the research sample, which continued in limiting the generalisability of the findings (Creswell, 2009). The research sample was made of 7 participants working as house mothers and consisted of 7 women; aged between 29 and 56. All the participants were black in racial category and South African citizens with one participant from Zimbabwe, then the key informant was an Indian woman; a South African citizen who is aged 31 years. She has 8 years working experience as a social worker and 2 years working experience as a Colin House social worker also a supervisor for the participant who are primary caregivers in Colin House. The small number of the sample did not lead to less accurate results of the study but, limited the study in generalising the findings, since not all the population was represented in the sample (Engel & Schutt, 2005).

3.5 Research Instrumentation

The researcher made use of semi-structured interview schedule, According to Brinkmann (2014) a semi-structured interview schedule can be used in a qualitative research as a way of getting information. The other quality of the semi-structured interview schedule is that both closed and open-ended questions can be used as a way of gathering data (Brinkmann, 2014). The researcher made use of two semi-structured interview schedules, one for the participants and one for the key informant (Appendix C and Appendix D). Both of the semi-structured interview schedules had open-ended questions and close-ended questions. The importance of the research instrument was that it enabled the researcher to have more opportunities in engaging with the participants and the key informant, that is because it made probing to be much more easier and flexible enough in making sure that the thoughts behind the responses were also captured. The flexibility of the research tool also allowed the objectives of the study to be met. According to Cohen and Crabtree (2006) the first advantage of a semi-structured interview schedule is that it allows the researcher to be competent, that is because it allowed the researcher to plan the interview questions beforehand so that the follow up question were easily anticipated. The tool also provided reliable, comparable qualitative data which paved a way of understanding the content better. When interviewing the participant, the researcher was able to observe the non-verbal communication which brought about understanding the emotions behind the responses of the participant (Cohen, 2006).

When the participants were interviewed they were very open, but that cannot be a concluded that they did not give social desirable answers, there was no participant who wished to be interviewed outside the work premises as it was planned that there would be a different venue for a primary care-giver who would not be comfortable being interviewed at the workplace. It was predicted that the respondents might give responses which are desirable, more especially because they were made aware that there is a possibility of the results being published (Brinkmann, 2014). It should be noted that the use of semi-structured interview schedules was time-intensive, this was because the research also made use of the open-ended questions which enabled the respondents to further elaborate on the information they shared (de Vos et al., 2011). However, time was managed as the questions had a structure. So the importance of using the semi-structured interview schedule in that case was not to get single responses as to avoid limiting data collected (Engel & Schult, 2005).

3.6 Pre-testing the research instrument

Before the participants were interviewed, a very important part of the research instruments process was used and that is called piloting or pre-testing. This is whereby the researcher uses questions constructed for the study to see if they will acquire information as expected, or they just raise a number of other questions which then leads the study astray. This tool also helped the researcher to see if there was something to be added or taken out before the actual study commences. Furthermore, it should be noted that the information which was obtained during the pretesting of the research instrument, was not reported at the end of the study, since their role was to build the research instrument and not merely answer the research question (Tracy, 2012).

Pre-tests were used as a tool to gather data from an individual who has the experience of being the house mother but will not be used as a participant for the study. The tool was used to gather general information relevant to the challenges which are faced by the house mothers in a general form. One of the greatest advantages of this tool is that it allows the researcher to have a better picture of what could be expected from the actual participants, and it is less intrusive in nature (Jamshed, 2014). The other advantage of pre-tests is that they allowed the researcher to have an opportunity for learning. However, the major disadvantage is that the pre-test made the researcher to be bias as there were already expectations of what the respondents would say when the actual data was gathered (Jamshed, 2014).

3.8 Data Collection

The data was collected using one-on-one in depth interviews which lasted for an hour or an hour and few minutes for each participant. According to Johnson (2002) in-depth interviews are defined as an intensive interviewing technique which is used to get in-depth and quite sensitive information from the research respondents. Furthermore in-depth interviews allow a warm and safe space where self-disclosure is possible, with no worries of confidentiality being bridged at any given time or space. Before the participants were interviewed, they were firstly given the consent forms (Appendix B) to agree being respondents to the study. The participants were interviewed one on one and it was done in Colin House, not in the main office premises to avoid the work dynamics and them giving desirable responses (Johnson, 2002). According to Ayres (2008) one of the major advantages of using in-depth face to face interviews is that they allow the researcher to explore further the knowledge, understanding, views and interpretation of the social phenomenon which is cognitive disability at this point as it is the lived experience of the participants.

Additionally data was collected through voice-taping because as stated by Greeff (2011, p. 359) it “allows a much fuller record than notes taken during the interview”. A fuller record was used to make sure that no personal information could be disclosed. Informed consent was requested from all study participants prior to the recording (Appendix B). The consent forms was given to participants for ethical purposes and also to make sure that they participants were protected in being used or accused in anything related to the study (Tracy, 2012).The results were transcribed verbatim, that was for being able to take not of the themes as well.

There is a possibility that the participants may have provided social desirable answers, since the participants were told that the Director of the organisation has given a go ahead with the interviews. They were also aware that the Colin House Social Worker has allowed each house mother to take an hour off in case they might want to be interviewed during working hours. The data collected was then transcribed into verbatim and analysed using a thematic-content analysis, which required more time for the study, since the data was obtained directly from the stories shared by primary caregivers.

3.9 Data Analysis

Thematic content analysis was used as a method of analysing data of the research. According to Clarke and Braun (2014) there are steps or stages that a researcher needs to following when analysing data. The first step that the researcher used was to get familiar with the data which was obtained; this was done when the researcher went through the data transcripts after the data was gathered. The transcribed data was placed on a Microsoft Excel programme, whereby the researcher grouped it into different themes. According to Elo and Kyngas (2007) the researcher is expected to put aside personal attributes with regards to the findings aside, as they are considered to be completely irrelevant to the thematic-content analysis. The process of coding assisted the researcher to discover patterns among the collected data, which were then used to point to theoretical understanding of the work-related challenges experienced by primary care-givers of children living with cognitive disabilities (Babbie, 2004). The second step is producing initial codes; the trick in making codes was that the researcher had to make codes which did not get of the evidence of the original data obtained.

According to Guest, McQueen and Namey (2012) the third stage is searching for themes. After the codes were created the 4th stage becomes the reviewing of the data codes, there are two levels of reviews which needs to take place. The first level is reviewing the data obtained and placing it in a particular sequence, to ensure the first level notes were taken down and analyzed as to see if there were no themes which repeated themselves. Then the second level of ensuring that there is a relationship or no relationship between the themes was done by prioritizing between major and minor themes. Afterwards the themes were narrated, the two types of categories were compared and contrasted, to ensure that no categories are falsely categorized as a minor or major themes (Elo & Kyngas, 2007).

3.10 Trustworthiness

- *Credibility*

According to Merriam (1998) there are measures that the researcher undertakes to make sure reliability and validity of the data gathered from the participants. This paper focused on four of them; it look at credibility, dependability, conformability and transferability. Credibility refers to an extent in which the research findings are able to capture what is the truthfulness of what is occurring in the context and it also looks at whether the researcher understood what the research was all about and what it meant.

- *Dependability*

Dependability is the equivalent of reliability in a quantitative study and it refers to an extent in which the researcher makes sure that there is consistency in the research findings despite the ever-changing contexts of the study (Merriam, 1998). The consistency of the study is what Ezzy (2002) refers to the level in which the study can be conducted and be able to yield the same results. Below are the ways in which the researcher attempted to ensure the reliability of the study:

- The researcher used questions which were clear and understood by the participants

- Similar questions were used for every participant in order to stay on the lane with the research objectives.

- *Transferability*

According to Trochim (2006) transferability of the study refers to the degree in which of the research findings can be generalised to the other context or study. There was a small sample (n=7) out of the population of the primary care-givers around Benoni area, due to that challenges which are faced by primary care-givers can be understood using the information gathered from the study.

3.11 Ethical Considerations

The following ethic which should be applied when conducting research is given by the American Psychological Association (2002).

- *Informed consent*

According to Lavrakas (2008) it is important for the researcher to ask for voluntary written consent from the participants who will be part of the study. The consent to be part of the study was given by the participants through the provision of the Participant Information Sheet (Appendix A). Which outlined the aim of the study and gave important elements of the study such as the rights of the participants, they also had to sign consent forms (Appendix B) in order to agree being part of the study.

- *Respecting confidentiality*

As much as the research tool for the research is using the in-depth interview questions, where self-disclosure is expected to be quite high from both the interviewer and the interviewee; confidentiality is key and emphasised at the beginning of the interview so that the interviewee knew that information will not be disclosed. The participants were also made aware that the information provided was going to be used for a research report as a requirement for completing honours degree.

- *Non-maleficence*

The participants were assured that no harm was going to be caused unto them. This was done by virtue of them being told that should they feel uncomfortable whether with the setting of the interview, or the research questions then they had a choice to withdraw from the study or state what their preferences were.

- *Anonymity*

The participants were promised that they will stay anonymous throughout the whole study, they were assured that their personal information will not be revealed.

3.12 Conclusion

The chapter gave a clear outline of the research design and methodology. The research question, aim and objectives of the study were discussed. It specified the criterion of the participants and their characteristics, the pre-testing of the research instrument, the data collection method and the data analysis procedure that was followed. Furthermore, it explained how the ethical considerations of the study were adhered to. The methodology discussed in this chapter provides a backdrop to the findings presented and discussed n the following chapter.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF FINDINGS

4.1. INTRODUCTION

This chapter provides the presentation and discussion of the findings of the study in accordance with the research questions, aim and objectives of the study. The chapter begins with the presentation of the demographic information of the participants. Thereafter, it gives the findings with supporting evidence along with the literature that either proves or disproves the findings. More importantly the main aim of this chapter is to convey what was found after the data was collected and analysed (de Vos, et al., 2012).

4.2 Demographic information

Table 4.1 DEMOGRAPHIC PROFILE OF THE PARTICIPANTS (N=7)

Demographic factor	Sub-Category	No.
Gender of caregiver	female	7
Age of caregiver	21-30 years	1
	31-40 years	4
	41-50 years	1
	51-60 years	1
Work experience	1-5 years	3
	6-10 years	1
	11-15 years	2
	16-20 years	1
Child care training	House mothers	7

Table 4.1 represents the demographic profile of participants. The age of the participants ranged from 29 years to 56 years, they all have completed a qualification in child care and first aid training.

4.3 Themes arising from the data that was collected

Table 4.2 Table of themes that emanated from the study

Reasons for becoming a house mother	**Challenges with regards to taking care of a children with a cognitive disability**	**Impact of the challenges experienced**	**Coping strategies employed**
1. Passion	1. Long working hours 2. Less time for self 3. Lack of family time 4. Dysfunctional sleeping pattern 5 Lack of skills in enhancing the self-esteem of the child. 6 Emotionally demanding job	1. Demotivation	1. Family support 2. Supervision sessions with the Social worker 3. Support group 4. Suppression

4.3.1 Objective 1: Reasons for becoming a house mother for a child with cognitive disability

Passion

Findings from the study revealed that passion was one of the reasons why house mothers worked with children with cognitive disability. This passion was coupled with the fact that they believed that it was a calling for them to work with children who are living with disabilities. To support this finding, one participant commented:

If I did not have the love for it, trust me I would be somewhere else with my life (Emma).

At first I wanted to be a social worker and work with children that are living with disabilities, but I remember this one time I volunteered in Johannesburg child welfare and I just fell in love with what house mothers do. That is when I was convinced to be a house mother (Rhea).

My mother was a house mother taking care of the elderly back in our rural areas of Zimbabwe; she would come back with a smile on her face about how they have made her day. Her passion for the job inspired me, so I guess the passion for being a primary care-giver runs in the family. I do not see myself do anything else to be honest (Barbara).

4.3.2 Objective 2: Challenges faced by house mothers with regards to taking care of a child with cognitive disabilities

Long working hours

Findings from the study showed that the house mothers have long working hours, which is because they are required to be there for the children 24 hours a day and their shifts go as 4 days and 3 nights a week. During the day they have to perform the daily duties which include watching over the children, helping them with homework and other chores then during the night they have to take care of the small ones who need attention for almost throughout the night. This in turn results in them working more than 8 hours a day like a normal daily job.

Caregiving demands lot of time as the kinds demand attention at all time, so I believe that we as house mothers work long hours more than any other worker. It is literally a combination of a day shift and a night shift if you take a clear look at it (Anna).

Being a house mother was never easy, imagine working for the whole day and the whole night as times. I have been a house mother for years and still I cannot get used to the long *working hours, sometimes it gets better when there is no child that is less than 4 years old because then I get to have my sleep and wake up fresh for the daily chores* (Mercy).

Findings are commensurate with the fact that house mothers have longer working hours. Literature also states that primary care-givers of children who are living with disabilities find it very hard to leave the house and do something that will entertain themselves (Yantzi, Rosenberg and McKeever, 2007). That shows the long-term commitment to the job and less time to focusing on other thing. Now most of the time is spent working that taking a break from work, hence long hours are experienced as a challenge when one is a house mother.

Fatigue

From the findings the study proved that fatigue was also another challenge experienced by house mothers. It was revealed that attending to the academic needs of the child who is living with a cognitive disability was a challenge. One participant stated:

Being exhausted has turned into a usual thing even though I just never get used to it. Yes I do understand that one of my job requirements is to assist the child whom I am currently staying with when it comes to academics, but how do I do that effectively when the child comes back from school and already finds me tired from all the cooking and sleepless night I had?. (Mercy)

Back when there were no cameras to monitor our job, I used to take daily naps when the children were at school. But now I am even scared of passing out on the couch because I will be seen as someone who sleeps during working hours, so yes no matter how tired I am I drag myself to work even when I cannot anymore (Londiwe).

Being a social being has always been my trait and I am a person who is used to going out with friends on weekends, but ever since I started working as a house mother I never gets time nor energy to go out. This fatigue does not only affect me during working days, I just always feel tired to do anything (Barbara).

In response to fatigue experienced by house mothers, the key informant made the following comment:

Sometimes I would not be pleased when the house mothers do not do their job as expected, but I remember this one time I had supervision with one of the house mothers and she cried when she was explaining to me that the reason why she slept during working hours was *because she hardly slept at night as there is a little child in Colin house who cries at night. From there I understood that I sometimes it is not because they are lazy, it is not easy working effectively during the day whilst they hardly slept at night* (Naidoo)

These findings are in line with the current discussions in literature. Khanna et al., (2011), state that fatigue is one of the major issues for the primary-care givers of the children with different kinds of intellectual disabilities, as they constantly need supervision and attention.

Literature also supports that primary care-giving result in compassion fatigue for most of the primary care-givers, be it that they take care of the elderly or children (Keidel, 2002).

Less time for self

The finding have shown that the house mother hardly have time to themselves, that is because they have 20 children to look after so all the attention is given to them and it becomes a struggle for the house mothers to think of themselves. In their off days they are expected to at least have some time to themselves and do what will refresh their minds off, but it is hard doing so when all they can think about is just sleeping. This turns them into less social beings and they do not have time for social affiliation which plays a major role in 'me time' for the house mothers. This was expressed by participants who said:

I am a person who really enjoys being with other people, more especially my friends! But how do I make time for my friends when I barely have time to myself? It is just close to being impossible (Nthateng).

Sometimes I know that I need to have some time to myself, but I feel like all the time I do that I am being selfish. At work I am always paying attention to children, when I get home and think it is time for me to rest and just go to the spa my children need my attention as well. For real how does one even have time to sneeze though? (Emma).

On the study conducted by Yantzi and Rosenberg (2007) supports less time for self as a challenge for primary care-givers, it states that they are always space bound and face considerable challenges in leaving the house. It also proved that there is hardly time to be a social butterfly and get to spend time with friends, of which it also recommends that social affiliation is important.

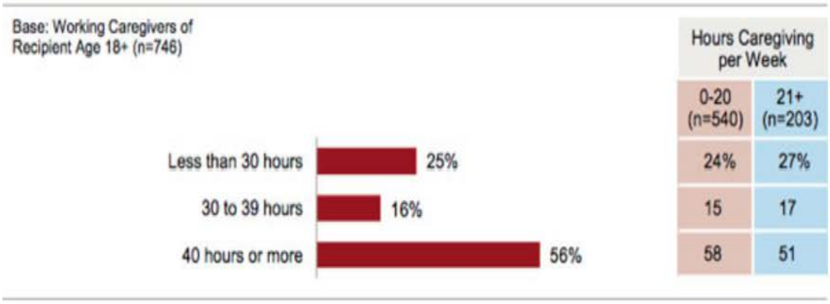
Less family time

As it has been sated above that the house mothers spend more time at the house where they have to take care of the children, it has been evident in the interviews that they have less family time and that results in them feeling bad as their families and mostly children feel neglected. So they always have a constant worry that they are not good parents.

There is a question that I got from my eldest son who was playing a soccer tournament and I could not attend it, he asked me why I became a mother because clearly I only spend most of my time with other kids and not him (Londiwe).

Figure 61: Number of Hours Worked per Week by Caregiver

N13. About how many hours a week, on average, do/did you work?



[National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]

The graph above supports the theme mentioned above which fatigue is, it shows the number of hours that a primary caregiver works on a weekly basis. Which supports that it is more hours than a normal job which requires just 8 hours a day and just 40 hours a week, the tables proves that there is 56% of primary caregivers who work more than 40 hours per week.

Dysfunctional sleeping patterns

Dysfunctional sleeping pattern was raised as a concern because it was considered as one of the reasons why there might be lower productivity at work for the house mothers, so what happens is that most of the house mothers verbalised that had they had enough sleep at night then they would be more productive at what they do. To support this finding, one participant verbalised that:

Some people doubt this but let me tell you something, sleep is important more especially when one is working with the kind of children I am working with. These individuals sleep early and wake up with so much energy, but how do I pick up their pace when I hardly slept at night? (Barbara).

Studies done on mothers being the primary caregivers of children with autism (which is regarded as a type of cognitive disability) Meltzer (2008) shows that they have poorer sleeping quality which leads to dysfunctional sleeping patterns.

Lack of skills in enhancing the self-esteem of the child

The house mothers strongly believe that there was supposed to be a training course with regards to enhancing the self-esteem of the children. To support this finding, one of the house mothers made the following remark:

Yes we do have supervision sessions whereby the behaviour of the child is discussed, but it becomes a problem when we just talk about it with the social worker and nothing much is done on how the house mother can deal with it so that the self-esteem of the child can be enhanced. I do not know if you understand me but if you can tell me what is the use of shouting the child who just explained that he or she feels useless in class or in front of peers for failing to understand most of the things to wake up tomorrow and go to class? I mean that child is still going back to the same situation and nothing was done, because even if I say all will be okay…what is it that is really going to be okay? (Londiwe).

In response to the finding stated above, the key informants responded:

You know working with such children requires someone who understands them, it requires someone who can be able to figure out what to say when the child is feeling down. The house mothers might see it as just their job but the children regards them as their mothers who understand every emotion that they go through. So what I am saying is the house mothers need to be at the personal level of the child, sometimes they need to give advice to enhance motivation for the child to cope in the same situation the next day (Naidoo).

Emotional demanding job

It was alleged by the participants that it is difficult to separate emotions from their daily jobs because they work with very personal beings, this was also extracted from the above theme whereby the house mothers now have to work towards enhancing the emotional well-being of the child. One of the house mothers stated that:

It is true that I do get satisfaction from seeing a smile after so much frowning of a child, but it also drains me as it takes something away. My point is I do not want to end up feeling pity for the children, because that is when they will see that there is something different about them as compared to maybe their peers, some children at church and even at school as others are mixed with children that do not have a cognitive disability (Barbara).

The above statement made by the house mother was merged with what the key informant illustrated below:

What I have noticed is that no matter how much it can be preached that as a social worker or a house mother there should not be any emotions which are shown towards the clientele, and we are talking about children right now it is very impossible. Maybe there are others who are able to do so but I will tell you today that all the house mothers I have worked with fell in love with the kids, and it is all out of caring. So, when the child comes back crying from school and say he was called a "dumb" it can break the house mothers down and myself included. That is the reason why the house mothers and I became aware of the fact that it is just an emotional demanding job (Naidoo).

The findings are in line with literature written on effects of primary caregiving, as emotional strain is considered as one of the major effects (Ejem, Drentea & Clay, 2015).

4.3.3 Objective 3: Impact of the challenges experienced

Demotivation

Two of the participants were able to put it in the air that what they experience as a result of the challenges that they encounter in the workplace is demotivation. Others put it bluntly but technically put it in a sentence like the following remark which was made by one of the house mothers:

There were times I lost interest in doing my job because I felt like it is taking so much from me, I took a leave and came back a bit better so that is the reason why I continued working (Anna).

Do not get me wrong, I do love my job but sometimes I feel tired to even wake up and go to work. I would not say it is being lazy because physically I would be fine, just that I would not be emotionally ready to face all the challenges at work" (Rhea).

The above quotations highlight similar findings which were outlined in the research done by Kang'ethe (2014), as it was stated that due to the challenges that primary care-givers face; demotivation becomes the result.

4.3.4 Objective four: Support and coping strategies employed by primary caregivers with regards to taking care of children with cognitive disabilities

Family support

Most of the participants rose that without family support, it was really going to be hard for them to pull through. Most of them raised the concern that they all have children and always need a person who will take care of their children when they are at work, which becomes a great struggle so having a family that understands is like the greatest thing ever. Here are the comments which were made by most of the participants:

I have been working here for a period of 7 years and if my family did not understand that the thing that makes me to be away is work, it is what puts bread on the table then maybe I was going to quit a long time ago. I stated before that there was a time I did not have time to go and watch by eldest son play soccer, for him to feel that there was someone who at least cared I asked my brother who is self-employed and always home to go and watch him when he is playing. Yes even though it was not me, but I know that it made a whole lot difference in his life and that makes me glad (Londiwe).

My husband had a challenge with accepting that my job required me to sleep there, at some point he accepted that there are nights he needs to spend alone with the children. I do not know how it happened, but all I know is that if he was not there then it was going to be very hard for me to keep the job. At first the in-laws had a problem with their brother or son taking care of the children whilst he got married and still doing motherly duties (Rhea).

I only started working just a year ago, I stay in an apartment with my fiancé and it was very hard for him to understand that I need to go to work and leave him behind. But he has been very understanding for the past months, he even does laundry and cleaning unlike before when everything had to be done by me when I came back from my shift. So, yes he has been *very supportive as he realised that all I ever wanted was to work with children who are living with disabilities and it is my passion which nobody can separate me from* (Barbara).

According to Hassal, Rose and McDonald (2005) the increased social support in a form of marital happiness makes it easier for the primary care-givers to be satisfied in doing their job. This is what was raised by most of the participants that it was difficult for them to cope when their marital partners were not okay with them working such long shifts and mostly away from home.

Supervision sessions with the social worker

The finding proved that every house mother has a supervision session with regards to all the aspects that can interfere with their well-being. The house mothers did not reveal much information as what is discussed during the supervision session is mostly confidential matters. One of the participants shared the information illustrated below:

Sometimes I cannot wait to have supervision because that is where I get to offload; I get some tips on how to deal with other matters in an effective way that will be beneficial for the child I am working with. It becomes really easy when the social worker is in contact with the children so that what is discussed would not be seen as if I am making things up, what helps the most is to fill up the behaviour incident book so that I could keep track and know what to say during supervision. It is not easy dealing with a child that has cognitive disabilities and some element of support from the social worker in charge makes work a bit easier (Anna).

Research done on the coping strategies for primary caregivers regards networking in a form of group supervision as an important element in coping with the workload and some of the challenges which are encountered by house mothers (Marcum, Ashida & Koehly, 2018).

Support group

The house mothers formed a support group just 2 years ago when the new Colin House Social Worker took over, what happens is that there are usually two house mothers on duty on a daily basis. So the house mothers chose Saturday morning as the day they all meet and just talk about their challenges, and make sure there is fluidity in their work. One of the house mothers made the following remarks:

I have not been working with children who are living with a disability for a long time, so obviously I need the knowledge from the ones with experience. Truth is told that the support *group came through most of the time; it is way easier to understand the way from those who have travelled it* (Barbara).

Couple of times it has been suggested that we open a formal support group, where we will get to meet as house mothers on a weekly basis. The challenge is that we just never know which day to choose as people have commitments in different days, so we just need to sit down and discuss carefully (Rhea).

Despite the social support that the house mothers might get from one another, there is a greater advantage of the support group which enables them to share information that might be helpful in helping the children with their needs (Baum, 2004).

Suppression

When some of the participants were interviewed they had a challenge with the concerns that they raise with regards to having some difficulties in taking care of the children and still were not addressed. So they tend to supress their feelings as the last resort, they just carry on with their work and avoid being seen as people who complain and cannot do their job properly. The use of suppression as a coping mechanism is understood as the refusal to face problematic and challenging situations (Mostert & Rothmann, 2006), that is exactly what the house mothers tend to do all within the aim of being productive. The following remark was made by one of the participants:

In the years that I have been working with the children who are living with cognitive disabilities and was not coping with my workload, I have learnt to just push and sometimes there was a point I felt like quitting because I thought I was not making any difference in their lives but knowing that I still have to put bread on the table and being a primary care-giver is all I have known to do in my life (Mercy).

The above statement proves that there were cases when the house mother was emotionally drained by the kind of job she does, but she put that aside and thought of her family that needs the money and suppressed her feelings and carried on with her job.

4.3.5 Conclusion

This chapter focused on the main findings of the study, it explained each finding as per objective of the study which was outlined on the 3rd chapter. Afterwards it gave the evidence from the study, by providing the quotes from the verbatim which was kept from the interviews. Lastly it backed the findings with existing literature and whether it proved or disproved the finding. The summary of the findings which were found on this chapter will be provided on the next chapter.

CHAPTER FIVE

MAIN FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1. Introduction

This chapter provides the summary of the main-findings with regards to the challenges which are faced by primary care-givers taking care of children living with cognitive disabilities at Colin House Child and Youth Care Centre in Benoni. It also gives the recommendations with regards to the findings for the study, and also the recommendations for future research.

5.2 Summary of the main findings of the study

The research study explored the challenges faced by primary care-givers of children living with cognitive disabilities living at Colin House Child and Youth Care Centre in Benoni.

Reasons for being a primary care-giver for children with cognitive disabilities

The findings revealed that passion was the main reason motivating primary care-givers to work with children who are living with cognitive disabilities. The participants verbalised that if they did not have the love for the profession, then possibility is that they were not going to be house mothers as it wants someone who has the love for the children and the perseverance to go through each day despite the challenges that they face.

Challenges faced by primary care-givers living with children with cognitive disabilities

Participants revealed that long working hours were one of the challenges. They indicated that they worked shifts that had long hours, and that their job required them to also work during the night as they still needed to check upon the younger children who needed supervision most of the time. Due to being at work most of the time, the house mothers hardly ever had time to be with their families which was regarded as a challenge to most of them. In addition, the other concern which was raised by the house mothers was that they experienced dysfunctional sleeping patterns because of fatigue.

Participants also indicated that enhancing children’s self-esteem and helping them to accept their disabilities were a challenge, and these resulted in house mothers regarding their job as emotionally draining. However, this was expressed by house mothers who considered themselves as not having the necessary skills that could help them to motivate children so that they would believe in themselves.

Support and coping mechanisms employed by primary care-givers in dealing with their children's cognitive disability.

Participants verbalised that there were a couple of coping mechanisms which they employed in coping with being a primary care-giver of children with cognitive disabilities. They mentioned family support as one of the important aspects in enabling them to cope at work, and that if their families did not come through in helping them cope with the pressure at work then it was going to be difficult for them to be effective in what they do. There was a participant who indicated that she was not coping with taking care of her children, and had her husband not came through she was going to find it very hard to be there for her children on a full time basis as they also demanded her attention just as much as her job.

The participants also pointed out that the weekly supervision session that they have with the Colin House social worker are also effective in them coping. That is because they get to vent out on what bothers them and also seek for professional advises on how to deal with the children and some of the challenges that they encounter with regards to their jobs. Participants also pointed out that there is a social media support group that they have opened, it assist them in discussing and sharing information mostly on what they are not coping with. They showed that it is important as there are others who have been working as primary care-givers for longer and have lot of information. The support group is also utilised by the house mothers to provide support for each other, more especially due to the challenge mentioned earlier on of being emotionally drained. The other most important reason for opening the group was for them working together in trying to think of ways in which they can enhance the children's lives through their ways of grooming them and being able to get rid of the stigma that some of the children are exposed to at school and enhance their self-esteem.

In addition, the use of the support group mostly helped the house mothers to share information which helped them with ideas that they could employ in dealing with their children's cognitive disability, especially, when they are in the mainstream schools. The last coping mechanism that they resort to is suppression, this is whereby they just accept that emotional is a strain that comes with the job and they just have to deal with it.

The main finding that was evident from the study revealed that there were many challenges which are faced by the house mothers who are primary care givers for children living with cognitive disabilities. The study showed that the lack of training in taking care of the child with special needs is what leads to emotional drainage, which then results in the house mothers feeling very demotivated as they feel like they are not meeting the job standards and are not able to help the children as they would have loved to. That showed that there is a greater need of training which will help eradicate the challenges that they far

5.3 Recommendations

The following recommendations were established resulting from the findings of the study.

5.3.1 Recommendations for Social Work interventions

It is recommended that services of an occupational social worker be sort in order to address the concerns that are raised by the house mothers in their practice in taking care of the children who are having different kinds of cognitive disabilities. Occupational social workers are needed to look after the well-being of the employees (Du Plessis, 1990).

It is recommended that group supervision be done, as it might help to avoid miscommunication between the house mothers. The online support group can continue and other issues can be discussed in a group setting to avoid the house mothers in feeling like their feelings are being neglected hence others ended up reverting to suppression as a coping strategy.

Finally, intensive child care training for the house mothers is also recommended. Training should involve disability training so that house mothers may not find themselves in a tight spot and not knowing how to take care of the children with cognitive disability.

5.3.2 Recommendations for future research

Research might need to be done on the challenges that are encountered by house mothers or primary care-givers in different organisations.

Research can also be done on the coping strategies which can be utilised by the primary care-givers taking care of the children who are living with cognitive disabilities within the South African context.

5.3 Concluding comment

Disability falls within a category of the most recognised vulnerable group in our society, which means that there is a need for primary care-givers to take care of the needs that children living with disabilities face on a daily basis. So, as much as there is a need for primary care-givers there is also a greater need for the well-being of the primary care-givers to be taken care of so that they can give optimal care which is needed. With that said, it should be a priority for the challenges of the primary care-givers to be addressed in organisations in which they are placed. There is also a perceived need for further training of the primary care-givers so that they can be good in their area of expertise, and to provide care that is efficient to the children they take care of.

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APPENDIX A

EXPLORING THE CHALLENGES FACED BY PRIMARY CARE-GIVERS LIVING WITH CHILDREN WITH COGNITIVE DISABILITIES IN BENONI, JOHANNESBURG

PARTICIPANT INFORMATION SHEET

Good day,

My name is Neo Mohapi and I am currently in my final year of studying Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research regarding challenges that are faced by primary care-givers living with children with cognitive disabilities. It is hoped that the information gathered could assist social workers to gain insight into the views of the primary care-givers who face challenges on a daily basis, and could make the other social service providers to gain insight on how they can intervene in making the primary care-givers cope better.

As a member of the community and residing in Benoni, you are ideally positioned to contribute to my research. I therefore wish to invite you to participate in my study. If you accept my invitation, your participation would be entirely voluntary and you are free to withdraw from the study at any time without penalty. There are no risks or personal benefits for participating in this study. If you agree to take part, I will arrange to interview you at a time and place that is suitable for you. The interview will last approximately one hour. If you choose to participate, you may refuse to answer any questions that you feel uncomfortable with answering. If you decide to participate, I will ask your permission to tape-record the interview. No-one other than the researcher and the supervisor will have access to the tapes. The tapes will be kept in a locked cabinet for two years following any publications or for five years if no publications emanate from the study. A copy of your interview transcript without any identifying information will be stored permanently in a locked cabinet and may be used for future research. Please be assured that your name and personal details will be kept confidential and no identifying information will be included in the final research report. The results of the research may also be used for academic purposes only (including books, journals and conference proceedings) and a summary of findings will be made available to participants on request.

Please contact me on 084 718 0340 or 876116@students.wits.ac.za, or my supervisor, Mr Nkosiyazi Dube at ndube@cartafrica.org if you have any questions regarding my study. We shall answer them to the best of our ability. If you have any concerns and complaints about the study, please contact the **Human Research Ethics Committee (Non-medical) Contact Details:** Chairperson: Jasper.Knight@wits.ac.za or the administrator: Mr Shaun Schoeman Tel 011 717 1408 or Scoeman@wits.ac.za.

Thank you for taking the time to consider participating in the study.

Yours sincerely,

Neo Mohapi

APPENDIX B

CONSENT FOR PARTICIPATION IN THE STUDY

I hereby consent to participate in the research study. The purpose and procedures of the study have been explained to me.

I understand that:

- My participation in this study is voluntary and I may withdraw from the study without being disadvantaged in any way.
- I may choose not to answer any specific questions asked if I do not wish to do so.
- There are no foreseeable benefits or particular risks associated with participations in this study.
- My identity will be kept strictly confidential, and any information that may identify me, will be removed from the interview transcript.
- A copy of my interview transcript without any identification will be stored permanently in a locked cupboard and may be used for future research.
- I understand that my responses will be used in the write up of an honours project and may also be presented in conferences, book chapters, journals or books.

With regards to the audio-taping

- I understand that the audio tape will be kept in a safe and secure location, where nobody unassigned will have access to it.

- The audio will be transcribed, and any information which may identify me will be removed from it.

- When the data analysis and write-up of the research study is complete, the audio-recording of the interview will be kept for two years following any publications or for six years if no publications emanate from the study.

- The transcript with all identifying details directly linked to me will be removed, or be stored permanently and may be used for future research.

- Direct quotes from my interview, without any information that could identify me and be cited in the research report or other write-ups of the research.

Name of Participant: ____

Date: ____

Signature ____

APPENDIX C

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR EXPLORING THE CHALLENGES FACED BY PRIMARY CARE-GIVERS LIVING WITH CHILDREN WITH COGNITIVE DISABILITIES IN BENONI, JOHANNESBURG

Demographic Information

Gender: Male ☐ Female ☐

Age group in years: 18-30 ☐

31-40 ☐

41-50 ☐

51-60 ☐

61 years and older ☐

<u>Questions for the primary care-givers</u>

1. Explain to me what you think the term disability mean to you?

2. What do you think cognitive disability mean in children?

3. Are you aware of the kind of cognitive disabilities which can affect a child?

4. Are there any skills that one needs to have in order to care for a child with the kind of cognitive disability he or she has?

5. What are some of the reasons which persuades one to be a primary care-giver?

6. What are some of the challenges that you face on a daily basis with regards to taking care of the child with that kind of cognitive disability?

7. What could be some of the implications with regards to the challenges that primary care-givers face?

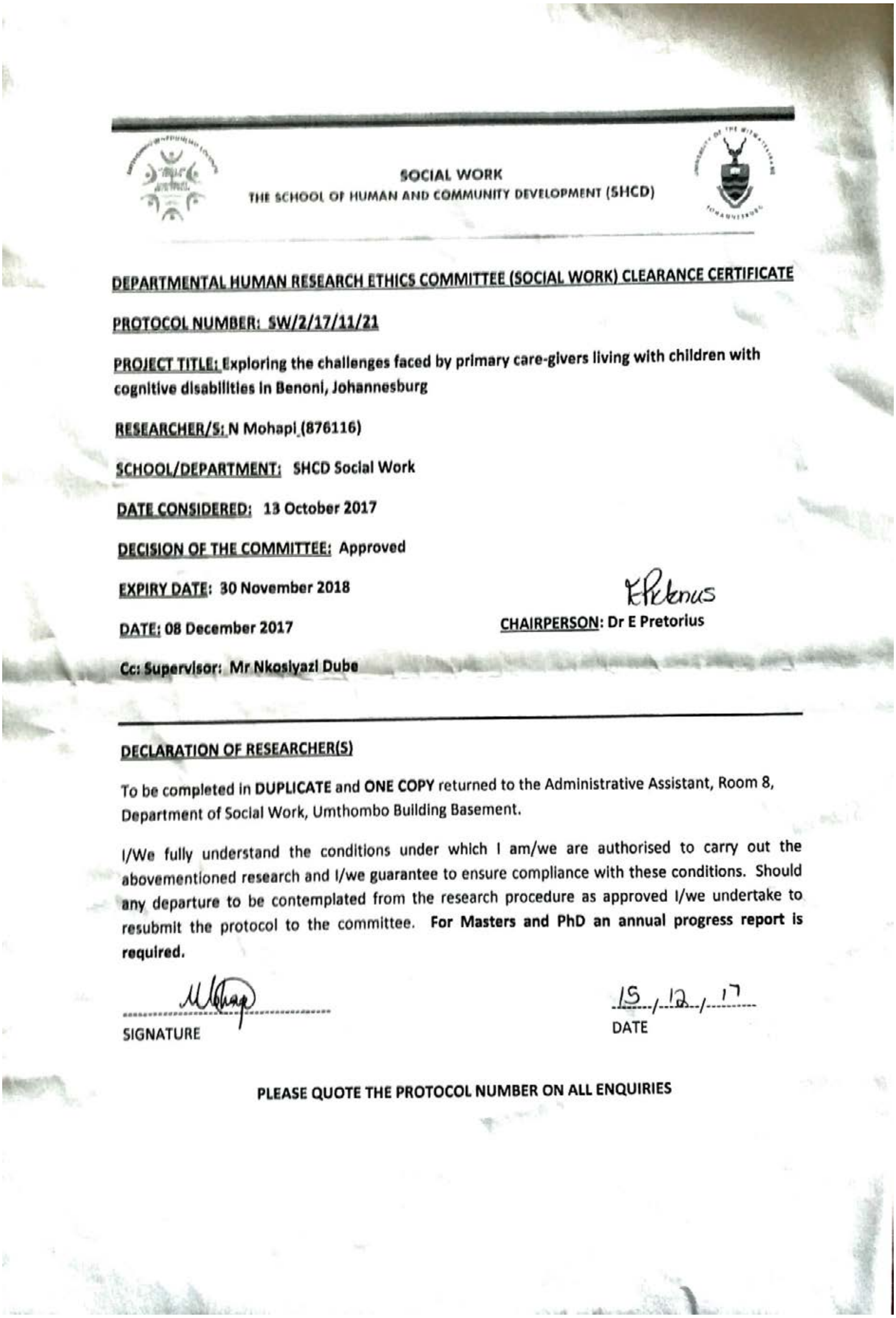
8. How do you cope with these challenges?

APPENDIX D

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR THE KEY INFORMANT OF THE STUDY

1. What are some of the challenges which primary care-givers face?
2. Are the primary care-givers open enough to state some of the challenges that they face?
3. Are their challenges addressed by the organisation?
4. Which programmes are put into place in addressing the challenges faced by the primary-givers?

APPENDIX E



SOCIAL WORK

THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

DEPARTMENTAL HUMAN RESEARCH ETHICS COMMITTEE (SOCIAL WORK) CLEARANCE CERTIFICATE

PROTOCOL NUMBER: SW/2/17/11/21

PROJECT TITLE: Exploring the challenges faced by primary care-givers living with children with cognitive disabilities in Benoni, Johannesburg

RESEARCHER/S: N Mohapi (876116)

SCHOOL/DEPARTMENT: SHCD Social Work

DATE CONSIDERED: 13 October 2017

DECISION OF THE COMMITTEE: Approved

EXPIRY DATE: 30 November 2018

DATE: 08 December 2017

EPretorius

CHAIRPERSON: Dr E Pretorius

Cc: Supervisor: Mr Nkosiyazi Dube

DECLARATION OF RESEARCHER(S)

To be completed in **DUPLICATE** and **ONE COPY** returned to the Administrative Assistant, Room 8, Department of Social Work, Umthombo Building Basement.

I/We fully understand the conditions under which I am/we are authorised to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the committee. **For Masters and PhD an annual progress report is required.**

SIGNATURE

15/12/17
DATE

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES