A PROGRAMME TO EMPOWER CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NON-GOVERNMENTAL ORGANISATIONS

by

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DEDICATION

This thesis is dedicated to:

My amazing son Ayaan. *May your love and encouragement always inspire me to be the best that I can be for you.*

and

My mum, dad, brothers and sister for their continuous support, encouragement, patience and love.

DECLARATION

Student number: 57533032

A PROGRAMME TO EMPOWER CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NON-GOVERNMENTAL ORGANISATIONS is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

18 February 2021

Signature Date

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ABSTRACT

The purpose of this study was to develop a programme to empower caregivers who care for children who are differently abled at Non-Governmental Organisations (NGOs) with skills and knowledge to effectively address the challenges they face. An exploratory, descriptive and contextual research design with a qualitative methodology was conducted in three phases, which consisted of data collection from caregivers and NGO managers, after which a conceptual framework was developed that guided the development of the programme following Dickhoff's Practice Orientated Theory. The population in this study composed of two groups, caregivers who care for children who are differently abled at NGOs (n=9) and NGO managers (n=7). The purposive sampling technique was used to select participants for the study; however, the exact sample size was determined by the data saturation point. Data was collected by conducting individual semi-structured in-depth interviews with caregivers and NGO managers. Interviews were audio recorded using an audio tape recorder. Data was analysed according to the 6 phases of thematic analysis proposed by Braun and Clarke (2006). Data collected from the qualitative study and the developed conceptual framework provided a foundation for developing the operational programme to empower caregivers who render care to children who are differently abled at NGOs. The study highlighted challenges caregivers experience that makes it difficult to optimally carry out the duties their caregiving role entails. The study revealed that caregivers experience difficulties with bathing, feeding, nappy changing, medication management and stimulation for their care recipients, due to lack of training. The study also revealed that caregivers do not have the necessary coping skills to overcome the stressors they experience as a result of the caregiving role. Furthermore, the study found that caregivers feel their roles are not recognised by the community. The lack of community recognition causes a negative chain of events that leads to potentially high physical and emotional health risks for the caregiver. It is envisaged that the developed programme could be used to empower caregivers at NGOs for children who are differently abled with skills and knowledge to effectively address the challenges they face so that they can render optimal care to the children they care for who are differently abled.

KEY WORDS: Non-Governmental Organisations, Caregivers, Children who are differently abled, Empowerment programme, NGO managers, Experiences, Programme development, Caregiver support, Community Based Rehabilitation, Occupational Therapy and Primary Health Care.

LIST OF ABBREVIATIONS

CBR	Community Based Rehabilitation
HSREC	Health Studies Research Ethics Committee of UNISA
HPCSA	Health Professions Council of South Africa
HST	Health Systems Trust
IPRs	Interpersonal Relationship Skills
NGO	Non-governmental organisation
OT	Occupational therapy
OTASA	Occupational Therapy Association of South Africa
PHC	Primary Health Care
PWDs	People with disabilities
SA	South Africa
STATS SA	Statistics South Africa
UNICEF	United Nations International Children's Emergency Fund
UNISA	University of South Africa
URERC	Unisa Research Ethics Review Committee
WHO	World Health Organisation

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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Chapter one establishes the fundamental basis of this research study. The background information, the purpose, the significance of the research study and the theoretical foundations of the study are delineated and justified. The importance of the study and the envisaged contribution of the study are also discussed in this chapter, thus giving the reader a better understanding of the research topic. This chapter furthermore provides definitions of key terms, describes the research methodology and research design and concludes by describing the outline of the structure of the dissertation.

Childhood is a profoundly crucial stage in the life of an individual. What a child experiences during childhood has direct implications on the rest of their lives (Britto, Lye, Proulx, Yousafzai, Matthews, Vaivada, Rao, Fernald & Bhutta 2017:92). Childhood experiences have greater implications on the lives of children who are differently abled. It is therefore vital that children who are differently abled receive and have access to programmes that will help them function at their optimal level. Intervention programmes for children are often not inclusive for children who are differently abled due to several barriers. Children who are differently abled should be afforded the same rights as children who do not have disabilities (Department of Women, Children & People with Disabilities 2012:54). It is however shocking to report that children with disabilities are often marginalised.

Many non-governmental organisations (NGOs) caring for children who are differently abled in South Africa are not equipped with the skills, knowledge and resources to render effective care to children who are differently abled. Rendering ineffective care to children who are differently abled has far-reaching negative implications on the disabled child and all relevant stakeholders.

Community-based rehabilitation (CBR) is an effective approach that can be used to effectively attend to the needs of children who are differently abled. CBR is an empowerment approach that is intersectoral. Having programmes that empower caregivers to render effective care for children who are differently abled will be of benefit not only to children who are differently abled and their families, but to other stakeholders such as the NGO and the community in which the NGO is situated as well.

1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM

South Africa is among the 193 countries who have taken on the responsibility of fulfilling their obligations under the Convention on the Rights of Persons with Disabilities. Included in this responsibility is to ensure that all children, including children who are differently abled, enjoy the rights afforded to them without any discrimination (UNICEF 2013:75). According to the United Nations (UN), approximately 250 million of the 600 million individuals globally who have a disability are children and approximately 10% of children have a disability where long term caregiving and prolonged access to health care is needed (UNICEF 2013:86). The global prevalence of disabilities ranges between 0.2% and 0.3% with a distinct difference between developed and developing countries (Oskoui, Coutinho, Dykeman, Jette & Pringsheim 2013:511). Most disabilities are a lifelong disorder, which therefore has no cure (Bolster, Dallmeijer, de Wolf, Versteegt & van Schie 2017:211). There are however various interventions available which lessen the effect of disabilities and improve the quality of life of those affected by disabilities (Bolster Dallmeijer, de Wolf, Versteegt & van Schie 2017:212). Most low-income countries have limited services available to families and children who are differently abled that results in many children who are differently abled being neglected or underserved (Oskoui et al 2013:511).

Accurate data on the prevalence of children who are differently abled in South Africa is difficult to establish, however, data that was last gathered during the 2011 national census revealed that approximately 2.1 million children in South Africa have a disability thus making the prevalence of children with disabilities in South Africa to be 11.2% (UNICEF 2012:6). The highest prevalence of children who are differently abled in South Africa was found in the age group 0-4 years as 28% of children in this category were found to have a disability. The category of children aged 0-9 years had a prevalence of disability that was less than half of those in the 0-4 years category as 10% of children in this age category were classified as having a disability (UNICEF 2012:6).

Many children who are differently abled are cared for by caregivers in low and middle-income countries in areas that are underdeveloped and have restricted access to training and skills development to optimally care for them (Oskoui et al 2013:516). This results in a situation where children who are differently abled receive inadequate care that directly affects their functional performance.

The functional performance of children who are differently abled is subjected to the caregiver’s ability to render effective care which is reliant on the training caregivers receive; therefore, adequate caregiver training is fundamental to the health and wellbeing of children who are differently abled (Kruijsen-Terpstra, Ketelaar, Jongmans, Gorter & Verheijden 2014:792). NGOs give caregivers opportunities to render CBR services that empower people who are disabled to live their lives to the fullest regardless of their limitations or difficulties, contribute to the community and make use of the resources available. Many NGOs for children who are differently abled in underdeveloped areas have caregivers employed that are experiencing numerous challenges when it comes to caring for children who are differently abled at the NGOs. Caregivers require comprehensive programmes that will empower them to render effective care to children who are differently abled. It is of utmost importance that caregivers have knowledge, skills, training opportunities, recognition and support to render optimal care for children who are differently abled (Meintjes & van Belkum 2013:182).

If caregivers of children who are differently abled are empowered, the care to be provided to their recipients will improve and then children’s physical, emotional, social and functional well-being will be enhanced. Empowering caregivers will not only be of benefit to children who are differently abled, but to caregivers as well. When caregivers receive adequate support, their own risks of distress or declining health is reduced (Meintjes & van Belkum 2013:182).

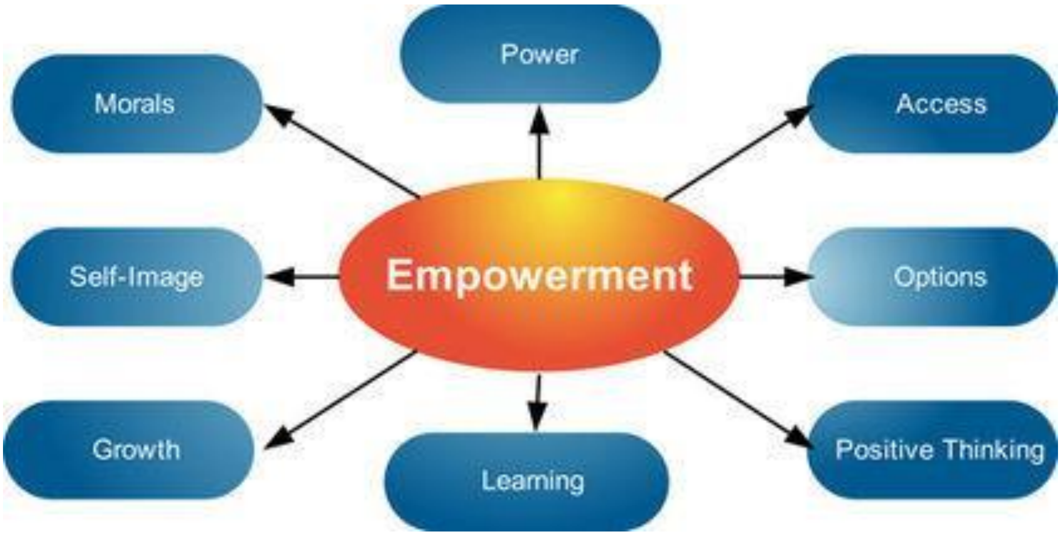


Figure 1.1: A picture depicting aspects of empowerment (Toh, n.d.)

Empowerment refers to the ability of individuals or groups to be in charge of the situation they are in and to also accomplish goals and objectives for that specific situation. Empowerment also refers to how powerful individuals feel inside, if they have the information and skills they need to achieve goals and what powerful action they are taking to achieve goals and objectives. Interactional empowerment is a crucial type of empowerment caregivers should possess (UNICEF 2015:79). This type of empowerment represents how caregivers use their knowledge when interacting with relevant stakeholders. According to Elphick (2017:4), support, communication, mediation, negotiation, compromise, persuasion, critical awareness and self-advocacy are all crucial aspects of interactional empowerment which caregivers at NGOs caring for children who are differently abled were observed to lack.

The provision of education, resources and self-awareness is seen as a motivation empowerment process, giving great power to its recipients (Adams 2008:21). The concept of empowerment is based on the impression that it is possible to help people to cope and feel better through discourse and reflection between the professional and the client in need as well as the caregiver. By implementing an empowerment strategy, the professional encourages the client and caregivers to expose their weaknesses and limitations so that they could effectively come up with a strategy to effectively care for themselves or receive effective care from caregivers (Hage & Lorensen 2015:236).

People reach the point of feeling empowered through programmes that empower them to change their behaviour in some positive way, helping clients to find resources within and outside the client and helping with the adjustment into the caring situation. The experiences and needs of caregivers at NGOs for children who are differently abled need to be empirically investigated in order to guide caregivers in rendering optimal care to children who are differently abled at NGOs as well as guide relevant CBR stakeholders in providing ideal support to caregivers at NGOs.

According to the Freid (2018:13), the empowerment of caregivers is possible when:

- Caregivers feel that they are equal partners in the process of caring for children who are differently abled,
- The public is aware of and understand their roles and responsibilities,
- Caregivers have easy access to support systems,
- NGO managers effectively assess, plan for and support caregivers in the caregiver process,
- Communication is effective in providing caregivers with information.

Even though CBR has been, and currently is advocated as one of the essential approaches to meet the needs of people (including children) with disabilities, there is sadly no comprehensive national strategy on CBR in South Africa (UNICEF 2015:9). Children who are differently abled therefore lack access to inclusive services at the community level, particularly primary health care (PHC) that should be made accessible and affordable to all in South Africa. Hendricks, Buch, Seekoe, Bossert, & Roberts (2018:1) mention that decentralizing the South African health care system ensures quality of health care services as well as access to health care services for the most vulnerable population such as women, children and people with disabilities (PWDs). Some provincial governments in South Africa have entered into partnerships with NGOs to plan and implement CBR services for children who are differently abled; however, there is no unified national strategic position on CBR that is evident in Gauteng not being included in these provincial governments.

South Africa (2005) states that the government is responsible for providing all-inclusive services to children, prioritising funding and access of services to the poor and children who are differently abled. NGOs render services to children as stipulated by the Act; however, the funding NGOs receive does not cover the entire cost of providing services to these vulnerable children (UNICEF 2015:76).

Even though lack of funding is a major obstacle for NGOs catering for children with disabilities there are other challenges NGOs experience such as the NGOs management and the staff they employ do not fully understand the nature of services that children who are differently abled require (UNICEF 2012:77).

1.3 RESEARCH PROBLEM

South Africa is among the many countries that implements Community Based Rehabilitation (CBR). The Framework and Strategy for Disability and Rehabilitation Services in South Africa (South Africa 2015:6) highlights the need for improved integrated disability and rehabilitation services ensuring access to PWDs. An occupational therapist thus has a vital role to play in implementing CBR services. Occupational therapists in communities have to provide services to NGOs that have been set up in communities to help care for children who are differently abled. Caregivers therefore play a fundamental role and are an integral part of the intervention process of children who are differently abled. Although caregivers play a vital role in caring for children who are differently abled, they still lack support, education, recognition and communication from stakeholders. The lack of support for caregivers is highlighted by Geiger (2012:2) who states that numerous NGOs in South Africa have untrained caregivers caring for children who are differently abled.

Occupational Therapists working with children assist them to function at their optimal level in activities of daily living utilizing methods that are either, curative, rehabilitative or preventative in nature regardless of the setting where children are cared for (O'Brien & Kuhaneck, 2020:15). Occupational therapists possess the necessary skills, knowledge and expertise to intervene at NGOs to ensure the optimal functioning of children at the NGOs. O'Brien and Kuhaneck (2020:16) further add that programmes where caregivers are trained to care for disabled children generate positive results for children’s physical, cognitive, perceptual and emotional wellbeing. The onus on the occupational therapist in the community setting is thus to empower caregivers by educating them and training them to carry out an effective caregiving service utilizing resources which are readily available to them. Zuurmond, Nyante and Baltussen (2018:45) strongly recommend the empowerment of caregivers of children who are differently abled to ensure optimum care for the children they render care to.

From a personal perspective, the researcher has worked for district health services rendering CBR services to NGOs providing care to children who are differently abled. The researcher has also been responsible for the fourth-year occupational therapy community block where responsibilities include giving CBR seminars to fourth year students as well as clinical supervision of undergraduate students placed at various NGOs in and around the Soshanguve and Ga-Rankuwa community. Some of these NGOs where students are placed include NGOs that provide care to children who are differently abled. The researcher has observed that many caregivers at NGOs are untrained which results in caregivers focusing on only fulfilling the basic needs of the children they care for at the NGO. This includes, feeding, dressing, bathing and diaper changing. NGO managers complain that they do not have programmes, protocols or guidelines for caregivers that will enable them to render effective care to children who are differently abled. Comprehensive care, which encompasses effective rehabilitation of children who are differently abled, is thus often not implemented by caregivers that has a negative impact on the NGO, the caregiver and most importantly the children who are differently abled.

A limited number of studies have been conducted to explore the challenges, experiences and needs of caregivers who render care to children who are differently abled. This information is crucial for developing programmes for caregivers. The scarcity of programmes that empower caregivers of children who are differently abled is unfortunate as it is only through empowered caregivers that children who are differently abled receive comprehensive optimal care. Hence, the need for conducting this study was realised in order to try to fill up the gap that is existing.

1.4 PURPOSE OF THE STUDY

1.4.1 Research purpose

According to Creswell and Plano Clark (2017:127), the purpose statement determines the key notion of the research study and the basis for the intent of the research study. The purpose statement also sets the objectives of the study.

Creswell and Plano Clark (2017:127-128) further add that an appropriate qualitative purpose statement includes information of the phenomenon to be explored, the research participants and the research context.

The purpose of this study was to develop a programme to empower caregivers who care for children who are differently abled at Non-Governmental Organisations.

1.4.2 RESEARCH QUESTIONS

In order to develop a programme to empower caregivers who care for children who are differently abled at NGOs, the following research questions were formulated:

- What are the experiences of caregivers providing care to children who are differently abled at NGOs?
- What are the challenges experienced by caregivers at NGOs caring for children who are differently abled?
- What support do the managers at NGOs caring for children who are differently abled provide to caregivers?
- What programme can be developed that will empower caregivers at NGOs to effectively care for children who are differently abled?

1.4.3 RESEARCH OBJECTIVES

The objectives of the study were to:

- Explore and describe the experiences of caregivers providing care to children who are differently abled at NGOs.

- Identify challenges experienced by caregivers at NGOs caring for children who are differently abled.
- Explore and describe the support that managers at NGOs caring for children who are differently abled provide to caregivers.
- Develop a conceptual framework that will facilitate the development of a programme which will empower caregivers at NGOs caring for children who are differently abled.
- Develop a programme that empowers caregivers at NGOs to effectively care for children who are differently abled.

1.5 SETTING

This study was conducted at various NGOs that provide care to children who are differently abled in semi-urban areas in Pretoria. Interviews were conducted at caregivers and NGO managers' natural settings. Burns, Grove & Gray (2015:9) describe a natural setting as a setting where the researcher does not manipulate the environment where the study is being conducted. An office on the physical premises of the selected Non-Governmental Organisations who render care to children who are differently abled was used for interviews.

1.6 SIGNIFICANCE OF THE STUDY

The ultimate significance of this study was entrenched in the value of the developed programme being implemented. Children who are differently abled, caregivers, NGOs, and the government could all benefit from the developed programme.

NGOs caring for children who are differently abled could benefit by their caregivers being empowered to provide better care to children who are differently abled. Improvement in the provision of services may increase credibility of the NGO, thus improving financial support from the government and potential donors.

When caregivers are empowered with skills to provide improved care to the clients of the community that they serve, the skills acquired by caregivers will not only improve the quality of care but also aim at protecting the clients that receive this care. The clients and their families will benefit, as the clients will receive quality care that will equip them to function and be less dependent. The caregivers will share their knowledge with the families of children who are differently abled, assisting the families to be more actively involved in caring for their children. The developed programme could be used by therapists in the community employed by district health services to provide efficient and effective support to caregivers at NGOs for children who are differently abled in numerous communities. The programme could also be used for developing a curriculum for training home-based carers who care for people with disabilities.

The developed programme could provide a means of continually improved quality of community and healthcare system performance in partnership with children who are differently abled, caregivers and relevant CBR stakeholders.

Implementing a programme that empowers caregivers who care for children who are differently abled at NGOs could be an effective strategy to provide support to NGOs that cater for children who are differently abled thus ensuring that caregivers are empowered to implement valuable support for children who are differently abled at NGOs. The developed programme could therefore assist in improving the recognition, resiliency and supportive resources for caregivers in collaboration with CBR stakeholders in the community.

The urgent and continued need for government level planning and provision of support for NGOs caring for children who are differently abled is crucial. NGOs are more likely to receive support from the government if they have competent trained staff who deliver effective services to the clients that they care for.

This research study could serve as a fundamental building block for further research in the area of caregivers of children who are differently abled. Formal research is needed to further present an evidence base for effective guidelines and programmes that will empower NGOs and caregivers to provide optimal caring services for children who are differently abled consequently allowing children who are differently abled to enjoy their basic human rights.

1.7 DEFINITION OF KEY TERMS

Brink, Van der Walt & Van Rensburg (2012:91) state that terms which are cited in the research questions should be defined in order for the researcher and the reader of the research report to be clear regarding the meaning of those terms. Creswell (2014:45) has a different stance regarding which terms should be defined and mentions that deciding which terms should be defined is a matter of judgement by the researcher, however those terms which readers are unlikely to know the meaning of should be defined. The following terms selected from the background of the research and the research questions applies to this study:

Caregiver

A caregiver can be any individual rendering acts of nurturing, providing or attending to someone who is in need of such services. A caregiver can provide informal unpaid services or formal remunerated services to the family members or friends who have physical, psychological, or developmental needs, Musich, Wang, Kraemer & Hawkins (2018:153). In this study, a caregiver is an individual employed at an NGO who renders direct care to children who are differently abled.

Care Recipient

Freid (2018:2) states that a person who receives care in the health care context is referred to as a “patient” and a person who receives care in the social context is referred to as a “client”. An individual adult with a chronic illness or disability who requires constant assistance with activities of daily living in order to function on a daily basis is referred to as the client or care recipient (Family Caregiver Alliance, 2006). In this study, the terms “care recipient” and “children who are differently abled” are used interchangeably to refer to the individual receiving care from the caregivers.

Community Based Rehabilitation

Community Based Rehabilitation (CBR) is a strategy based on community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities, their families and communities and the appropriate health, education, vocational and social services (WHO 2010:11). In this study, CBR refers to the rehabilitation and equalization of children who are differently abled and the equalization of opportunities of caregivers who care for children who are differently abled.

Differently abled

Differently abled, used interchangeably with the word 'disability' is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual with a health condition and that individual's contextual factors (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji 2006:119). In this study, differently abled refers to children with physical, emotional and cognitive disabilities. Differently abled and disabled abled are used interchangeably throughout the thesis.

Empowerment

Empowerment refers to the ability of individuals or groups to be in charge of the situation they are in and to also accomplish goals and objectives for that specific situation. Empowerment also refers to how powerful individuals feel inside, if they have the information and skills they need to achieve goals and what powerful action they are taking to achieve goals and objectives (Elphick 2017:4). In this study, empowerment refers to equipping caregivers with skills and knowledge to effectively address the challenges they face in their caregiving role in order for caregivers to render effective care to their care recipients.

Experiences

Merriam-Webster (2016, sv "experience") defines experiences as "something personally encountered, undergone or lived through". In this study, the term experiences refers to what caregivers of children who are differently abled at NGOs encounter on a daily basis.

Needs

The Oxford Dictionary of English (2010, sv “need’) defines needs as being “essential or very important rather than just desirable”. A need is therefore something that is seen as a necessity. In this study needs refers to the physical, psychological, spiritual and material needs of caregivers.

Non-Governmental Organisation

NGOs refer to organisations that are private that pursue activities that relieve suffering, support the poor, protect the environment, provide basic social services and or undertake community development (Lewis 2016:2). This study focuses on NGOs that render care to children who are differently abled.

Occupational Therapy

In this study occupational therapy refers to the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, routines, and rituals in home, school, workplace, community, and other settings (American Occupational Therapy Association 2014:44).

Programme

A programme is defined by Shao, Müller and Turner (2012:345) as a training plan that is either formal or informal with the aims of improving knowledge, skills and attitude in a chosen field. In this study, the programme refers to an empowerment programme for caregivers of children who are differently abled at NGOs.

1.8 THEORETICAL FOUNDATIONS OF THE STUDY

1.8.1 RESEARCH PARADIGM

The word “paradigm” has its originations in the Greek word “paradeigma” which refers to a pattern, an example or sample (Azizi 2014:1574). Thomas Kuhn who is one of the most prominent historians and philosophers of the 20th century first described the word paradigm as a philosophical way of thinking in 1962 (Kivunja 2017:26). The existing definition of a paradigm still has its foundations in the Greek word “paradeigma” as the definition still contains the concepts of pattern and example. Burns, Grove and Gray (2015:58) explain research paradigms as a grouping of logically connected, systematic concepts and propositions that navigates the researcher to adequately carry out the research process. Burns, Grove and Gray (2015:58) add that research paradigms denote how researchers perceive, understand, interpret, and think about the environment. It is like a lens that hones our focus on reality. Kumar (2014:31) concurs with Burns et al (2015:58) and adds that paradigms offer the researcher a framework that helps guide how the research process is undertaken. Paradigms ensure that the researcher’s choices in the research process are congruent with their values.

Additionally, one could describe a paradigm as a framework composed of the basic assumptions, ways of thinking, and methodology that are frequently acknowledged by members of a scientific community (Guba & Lincoln 1994:105-116).

Polit and Beck (2017:9) substitutes the term paradigms with the term worldview and identifies four different worldviews, namely; postpositivism, constructivism, advocacy/participatory and pragmatism. The worldview adopted in this study is the social constructivist worldview. Social constructivism is a worldview often used in qualitative research which assumes that individuals aspire to understand the world around them (Creswell 2014:4). Subjective meanings are empirical to understanding a phenomenon at hand. The goal of research using a social constructivist worldview is dependent on the research participants' views of the phenomenon being investigated (Creswell & Plano Clark 2017:24). Constructivist researchers thus focus on the context of the research participants putting great emphasis on the meaning’s others have about the world. A detailed understanding of caregivers’ experiences, challenges and training needs was explored in this study with the goal of developing a conceptual framework that facilitated the development of a programme to empower caregivers who care for children who are differently abled at NGOs.

Some scholars define a paradigm as a framework containing the assumptions about the phenomenon under study, research structures, and how the research is conducted. Numerous authors classify these assumptions into four parts namely; ontology, epistemology, methodology and methods (Scotland, 2012:9, Ritchie, Lewis, McNaughton Nicholls & Ormston 2014:4; Creswell & Plano Clark 2017:21 & Polit & Beck 2017:10). The four assumptions applied to this study are described as follow:

Ontological Assumptions

Ontology is the study concerned with the nature of the world, reality and what there is to know about the world and reality (Ritchie et al 2014:5). Polit & Beck (2017:10) consider ontological assumptions the starting point of all research, from where epistemological and methodical assumptions logically flow. Polit and Beck (2017:10) further add that ontological assumptions specify that reality is not fixed but made up of research participants' experiences and exists within a particular context, therefore many constructions of reality are possible. In this study, considering the espoused description of ontology from numerous authors, the nature of providing care to children who are differently abled at NGOs is effectively described by caregivers and managers at NGOs through describing their experiences and challenges related to providing care to children who are differently abled. The ontological assumptions applied in this study are in line with ontological assumptions proposed by Schell, Gillen, Scaffa and Cohn (2014:36-39) which are;

- “Human beings are viewed as ever changing, interconnected with ever changing environments, occupy time with ever changing occupations, and thereby transform and are transformed by their actions, environments and states of health”. This translates into the belief that each person is unique and experiences reality from their unique point of view. The individual’s unique experiences of reality need to be explored by qualitative researchers. Caregivers’ experiences and challenges related to providing care to children who are differently abled in the context of the NGO where they are employed was explored and described in this study.

Epistemological Assumptions

Epistemology is concerned with knowledge about the world and what forms the basis of reality (Ritchie et al 2014:6). Knowledge in this study is acquired through inductive processes following a bottom-up approach by making observations of the world which forms a foundation for developing new concepts, insights and theories (Ritchie et al 2044:6-7 & Yin 2016:100). The epistemological assumptions applied in this study are in line with epistemological assumptions proposed by Schell et al (2014:39-41) which are;

“Knowledge about a specific phenomenon is primary and serves as the key subject that integrates all other knowledge and clarifies the desired consequences of action. Towards the end, knowledge is pieced together in-for-and-with the present practice situation that is continuously changing; therefore, the essence of knowledge is both bound and fluid and contingent upon the arising practice moment”. In this study, knowledge was acquired through exploring and describing the experiences and challenges of caregivers providing care to children who are differently abled at NGOs. Knowledge was also acquired through exploring and describing the support that managers at NGOs caring for children who are differently abled provide to caregivers.

Axiological Assumptions

Axiology is concerned with values and ethics which includes what is good, beautiful and morally desirable (Schell et al 2014:41). Axiology involves working in partnership with clients within their context to accomplish meaningful and satisfying participation in their context thereby optimising their potential, well-being and health (Schell et al 2014:41). The impact of the researchers’ enduring values should be acknowledged and reported in qualitative approaches by the researcher positioning herself (Creswell, 2014:22). In this study, the researcher provides insight into the relationship between the researcher and what is being reported and the circumstances of data collection that includes the background to the study and how excess was gained to the participants.

Okafor (2011:33) defines ethics as a code of moral standards of conduct for what is “good” and “right” as opposed to what is bad or “wrong”. Kumar (2014:288) concurs with Okafor’s definition and adds that being ethical implies that one abides to the code of conduct for a specific profession and deviating from the code of conduct is considered unethical. Kumar (2014:282-289) mentions that researchers have to consider ethical issues regarding the various stakeholders involved in a research project, namely; research participants, the researcher and the funding body.

Methodological Assumptions

Creswell and Plano Clark (2017:18) mention that methodological assumptions are those assumptions made by the researcher regarding the methods used in qualitative research. Yin (2016:8) describes qualitative research methodology as a research approach that involves looking at characteristics, or qualities, that cannot easily be reduced to numerical values. Marshall and Rossman (2016:2) further add that qualitative research is pragmatic in nature, fundamentally interpretive and focuses on the subjective experiences of human beings. Qualitative research was thus used in this study as a complex; detailed understanding of caregiver's experiences, challenges and needs was required to analyse the concept of caregiving that ultimately facilitated the development of a programme to empower caregivers who care for children who are differently abled at NGOs. Challenges caregivers experience was established by interviewing caregivers in the context where services are rendered. The support that managers at NGOs caring for children who are differently abled provide to caregivers was also explored in this study. The qualitative research methodology allowed the caregivers and NGO managers to tell stories unencumbered by what was expected to be found or what was read in literature.

1.8.2 THEORETICAL FRAMEWORK

Theory is a structured way of thinking about a given phenomenon. It is formulated to explain, predict and understand phenomenon. Theories are also formulated to challenge and extend existing knowledge within the parameters of critical bounding assumptions (Birks & Mills 2015:2).

Dickson, Adu Agyem and Emad (2018:159-160) describe the theoretical and conceptual framework as the route of a research study and firmly embeds the study in theoretical constructs. The theoretical framework consists of concepts with their definitions and references from literature about an existing theory that is relevant to an envisaged study thus enabling research findings to be more meaningful and acceptable to the theoretical constructs in the specific research field. In this study, the Practice Oriented Theory of Dickoff, James and Wiedenbach (1968) and the Caregiver Support Framework (Alzheimer's Society of York 2018) was applied as a guiding model of practice for supporting, understanding and interacting with caregivers as well as to develop the programme that will empower caregivers.

1.8.2.1 CAREGIVER SUPPORT FRAMEWORK

In this study, an adapted version of the Caregiver Support Framework was used as a conceptual framework for developing the programme to empower caregivers as well as a guide to develop the data collection tool. This framework was also used as a guide to develop the programme that will empower caregivers. The original framework has been adapted as it views caregiving as being voluntary and unpaid. The original framework was also adapted as it applies mainly to caregivers of clients with Dementia. In the context of this research, caregivers are those who have been employed by NGOs to provide care to children with various disabilities and are remunerated financially.

The caregivers support framework was developed to empower caregivers through acknowledging and appreciating the contribution caregivers make, improving supportive resources and to improve their collaboration intersectorally (Alzheimer’s Society of York 2018:11). The major components of this model include; identify and recognise referral and navigation, caregiver assessment and care plan, caregiver education and support and lastly, monitor and re-evaluate caregiver care plans. The five major components of this model as stated by the Alzheimer’s Society of York (2018:11-12) are discussed below:

Identify and Recognize

This component concerns the public’s awareness, recognition and acknowledgment of the value and crucial contribution caregivers make to society.

Referral and Navigation

This component concerns NGOs managers and relevant stakeholders increasing the support that help caregivers link with the right resources to access the appropriate type of support timeously and in a supportive manner.

Caregivers Assessment and Care Planning

This component concerns health care and community Organisations enhancing their caregiver assessment and care planning skills and tools in order to create and update unique care plans for the caregiver whenever the need arises.

Caregiver Education and Supports

This component concerns expanding the delivery of caregiver education and training resources, workshops and programmes which provide support to caregivers to improve their knowledge, skills, confidence and resilience .

Monitor and Re-evaluate Caregiver Care Plans

This component concerns monitoring what influences the support provided to caregivers has made caregivers to provide effective care to the children who are differently abled that they care for.

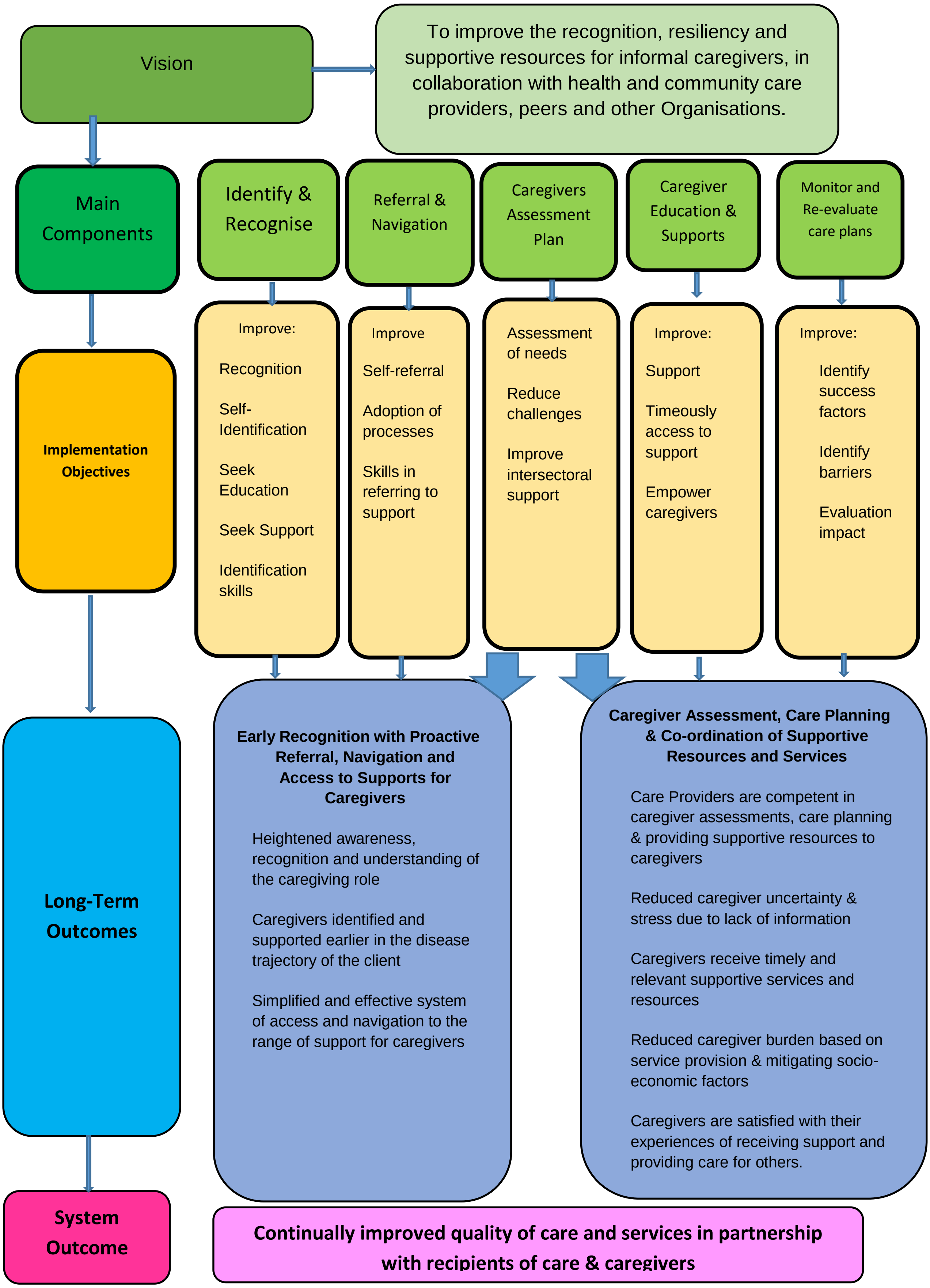


Figure 1.2 Caregivers Support Framework

1.8.2.2 The Practice Orientated Theory of Dickoff (1968)

The practice orientated theory of Dickoff et al (1968) was selected for this study, as the nature of caregiving is practical. Schulz and Eden (2016:90) argue that caregivers require knowledge and skills relevant to their particular needs; therefore, caregiver knowledge has a need for a practice theory. The most erudite interpretation of practice theory was by Dickoff et al (1968:418) who defined theory as “a Conceptual Framework to Some Purpose”. Four levels of theory organised as a hierarchy are identified by Dickoff et al (1968:419-422). Included in the first and second level is the development of taxonomies, third level theories include the development of models and fourth level theories include situation production theory which is a type practice theory (Dickoff et al 1968:419-422). As stipulated by Dickoff et al (1968:421) practice theories contain three essential ingredients:

1. Goal content that is specified as the aim for the activity.
2. Prescription for the activity to achieve the goal content.
3. A survey list to supplement prescription for the activity and prepare for future prescription for activity to achieve the end goal.

The practice orientated theory of Dickoff et al (1968) (in Jooste and Mothiba 2014:5-11) was used to develop the conceptual framework that facilitated the development of the programme to empower caregivers who render care to children who are differently abled at NGOs. The activities of the Dickoff et al’s Survey List (1968) were used to produce the reasoning map described in detail in chapter 4 of this thesis. The six components of the Survey List are as follows:

Agent

In the context of this study, the agent refers to the person who will use the programme. In this context, there are two agents, NGO managers and occupational therapists.

Recipients

Recipient refers to the person who will be receiving activities from the agent. In the context of this study, recipients will be caregivers of children who are differently abled at NGOs for whom the empowerment programme was developed.

Context

The context is composed of the environment where the activities take place. In this study, the context was the caregiver’s immediate working environment that is the NGOs where children who are differently abled children are cared for.

Dynamics

Dynamics refer to challenges in the context where caregivers render care to children who are differently abled. These challenges were explored and understood in the first phase of this research project.

Procedures

The procedure refers to the process to be used to empower caregivers. This is achieved through thorough orientation of caregivers on employment, needs analysis to identify their areas of learning and education to be addressed in order to help caregivers provide quality care to the children who are differently abled. Procedures also refers to continuous training to address new developments.

Terminus (outcomes)

This is referred to as the outcome of the process; it also refers to the desired outcome an agent aspires to achieve by applying a particular process. In this study, the terminus refers to the caregivers who will be empowered through a programme to equip them with skills and knowledge to address the challenges they face.

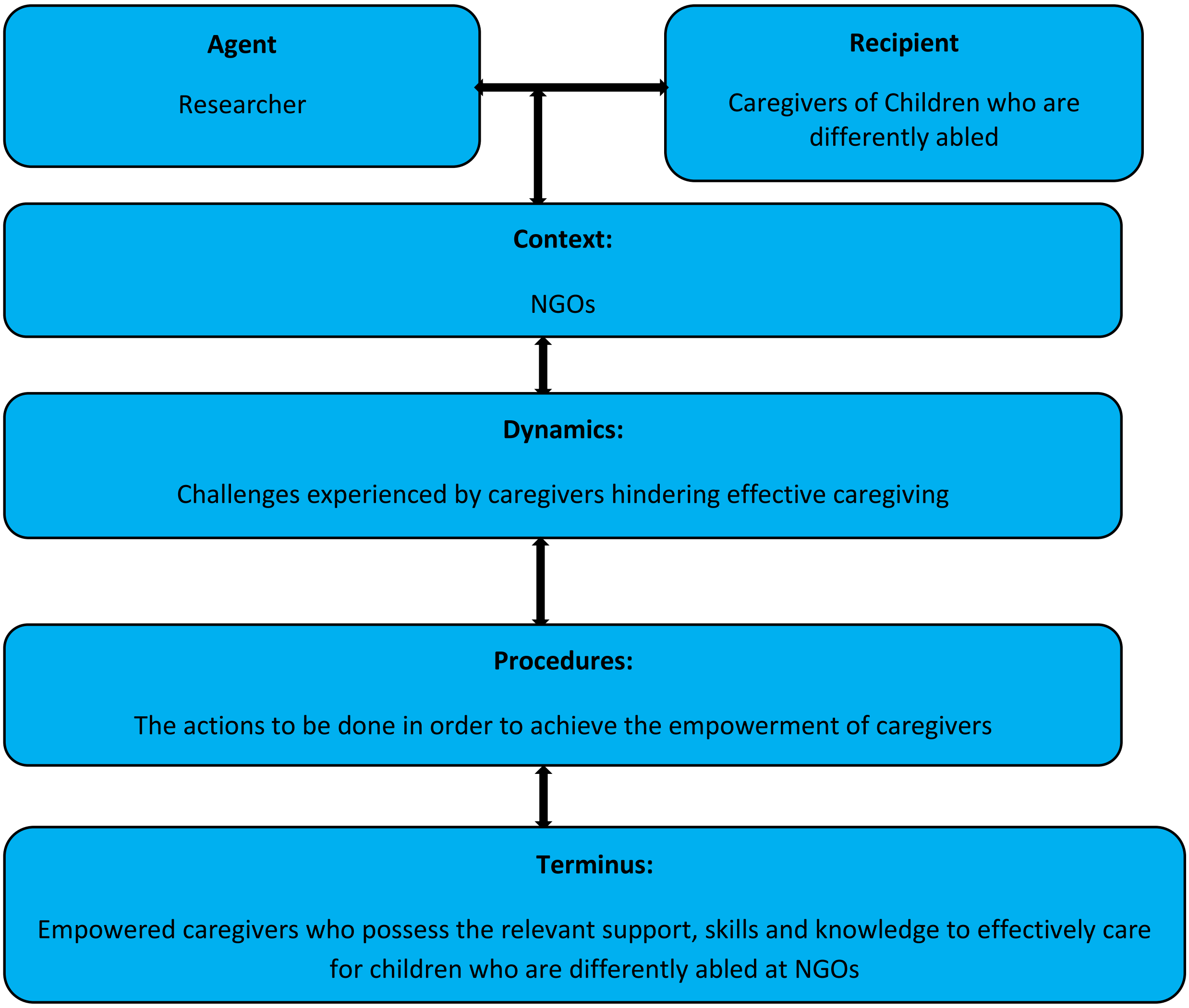


Figure 1.3: A conceptual diagram for the empowerment of caregivers of children who are differently abled at NGOs.

1.9 RESEARCH DESIGN

The research design is the overall logical plan used to collect and analyse data (Yin 2016:83). The researcher followed an exploratory, descriptive and contextual research design with a qualitative methodology. In this study, the research design included three phases to conduct the research that was as follows: Phase 1 – the qualitative study, Phase 2 – the Conceptual framework and Phase 3 – programme development and evaluation. Research design and methodology is discussed in detail in Chapter three of this study.

1.10 SCOPE OF THE STUDY

The focus of this study was on developing a programme to empower caregivers who care for children who are differently abled at NGOs.

Because this study followed an exploratory, descriptive and contextual research design with a qualitative methodology and had a small sample size, the results of this study cannot be generalized to all caregivers at NGOs in South Africa who render care to children who are differently abled.

1.11 STRUCTURE OF THE THESIS

Chapter 1

Chapter one orientates the reader to the study by providing a comprehensive background of the study. The purpose of the study, the significance of the research study and the theoretical foundations of the study are described. The importance of the study and the envisaged contribution of the study are also discussed in this chapter. This chapter furthermore provides definitions of key terms, describes the research methodology and research design and concludes by describing the outline of the structure of the dissertation.

Chapter 2

Chapter two provides the theoretical knowledge in relation to the study. Reviewing the literature provides a theoretical framework and comprehensive overview of prior research regarding empowerment of caregivers of children who are differently abled at NGOs. Included in the literature review is an overview of disability, disability models, caregivers and empowerment**.**

Chapter 3

Chapter three describes the research design and methodology followed by the researcher to undertake the research. The population, sampling, data collection, data analysis and ethical considerations have been explained in detail. Furthermore, measures to confirm trustworthiness of the study are also discussed.

Chapter 4

Chapter four provides details on data analysis, data presentation and data description of the research findings and literature control. Thematic presentation of qualitative data from phase one of the studies is present with direct quotations from caregivers and NGO managers.

Chapter 5

In chapter 5, the thematic presentation of qualitative data from the caregivers and NGO managers is interpreted and discussed in view of relevant literature with the detailed elements of a particular theme being discussed.

Chapter 6

Chapter 6 describes the conceptual analysis of the study that is developed based on Walker and Avant's (2011:160) process of conceptual analysis.

Chapter 7

Chapter 7 discusses the development and the content of the programme to empower caregivers of children who are differently abled at NGOs.

Chapter 8

Chapter 8 includes a general summary of the research study. Contributions made by the study, recommendations derived from the findings and limitations of the study are also highlighted in this chapter.

1.12 SUMMARY

This chapter served as a platform for deliberating the fundamental basis of this study. The background information of the study was outlined, and the purpose, the significance of the research study and the theoretical foundations of the study were stated and discussed.

The significance of the study and the envisaged contribution of the study was also discussed in this chapter. This chapter furthermore provided definitions of key terms, briefly described the research methodology and research design and concluded by providing a description of the outline of the structure of the dissertation. In the next chapter, a complete overview of prior studies regarding empowerment of caregivers of children who are differently abled at NGOs is provided.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Caregivers of children who are differently abled are one of the most significant contributing factors in ensuring the health, wellbeing and overall survival of the children that they care for. They are responsible for creating conducive environments, which facilitate the process of optimally assisting these children who are differently abled that they render care to. Caregivers however face many challenging conditions, which results in them feeling disempowered and ultimately makes it difficult for them to optimally fulfil their caregiver role.

This chapter intends to provide a comprehensive overview of prior research regarding empowerment of caregivers of children who are differently abled at NGOs. This literature review will demonstrate to the reader both what is known about the research topic as well as what is yet to be known which ultimately points out the rationale for this specific research study.

The following literature review begins with a discussion of disability, including the prevalence of disability across the globe and various models of disability. Following this discussion, this literature review will specifically address caregivers of children who are differently abled at NGOs. Lastly, caregiver empowerment will be explored.

2.2 DISABILITY

2.2.1 Disability Overview

Defining disability is a contentious issue as there are opposing views regarding exactly which categories the umbrella term “disability” refers to. Despite the numerous definitions of disability, rights-based definitions of disability share common elements, even though their definitions may differ.

The WHO (2001:8) defines disability as “an umbrella term for impairments, activity limitations and participation restrictions”. It designates aspects that are negatively related to an individual who has a disability interacting with their environment and factors that are regarding to be personal. The WHO (2001:5) recognises the three dimension of disability as:

Body structure or function impairments and impairments in mental functioning e.g. the loss of memory and losing vision.

Limitation in activities required for effective function, such as speech difficulties, hearing impairments, impairments with gait and cognitive impairments such as decision making and problem solving.

Restrictions in participating in activities of daily living as basic activity of daily living, leisure, work, education and health management.

The Convention on the Rights of Persons with Disabilities (UN 2006:8) highlights the evolving concept of disability and elaborates on their description of disability, describing people who are disabled as having long-term physical, intellectual, mental or social impairments which hinders the individual’s ability to optimally and effectively participate on an equal basis with other individuals in society.

While the term disability is common, experts in the field of disability do not agree on its usage. Chhabra (2016:1) views the word disability as a derogatory term as this places the emphases on the disability and not the individual. Chhabra (2016:1) recommends that the word ‘disability’, be replaced with “differently abled”. Andrews, Forber-Pratt, Mona, Lund, Pilarski & Balter (2019:7) have an opposing view on the use of the term ‘disability’ as they argue that using the term disability is vital to supporting disability culture. They argue that getting rid of the term disability is ill advised and harmful as it induces distress and frustration among those who are disabled.

Common components of disability thus include the presence of an impairment; internal and external barriers, which impede on full and equal participation, abilities the disabled person possess, restricted access to opportunities because of environmental barriers and societies’ negative perception and attitude toward disability.

2.2.2 Models of Disability

How one defines and understands disability is dependent on the specific model of disability adopted (Retief & Letšosa 2018:1). Models of disability not only aid in defining disability but also play a crucial role in understanding the impact of disability on function, establishing needs to ensure the allocation of appropriate resources, determining costs and directing governmental and legislative effort addressing disabilities.

Numerous models of disability exist; however, all models take on one of two main approaches (Christian Blind Mission 2017:20). The first approach is the individual approach, which views the individual as having a problem; hence, the emphasis is on the individual. The second approach views society as having a problem and not accommodative of people who have disabilities. Four main models of disability are outlined in the Disability Inclusive Development Toolkit (Christian Blind Mission 2017:20) and include; the medical model, the social model, the charity model and the human rights model.

2.2.2.1 Medical Model of Disability

The medical model of disability views disability as a medical condition whereby an individual experiences a personal tragedy. In this model, a distinct contrast is made between the disabled person who has to deal with their disability and society who are regarded to be functioning ‘normally’ (Ross & Deverell 2010:16). Jackson (2018:2) mentions two central principles of this model; firstly, a person’s disability can be diagnosed, rehabilitated or cured. Secondly, all interventions offered to a person with a disability, is done so by professionals only. Carlson (2010:5) highlights the implications surrounding the stigma, which is associated with disabilities.

Authors often refer to the medical model as a “personal tragedy model”, because disability is viewed in a very negative manner such as a shameful, disgraceful condition, something bad, preventable and something which cannot be cured.

According to Creamer (2009:24), people who have a disability are those who digress from what is regarded to be normal and therefore derogatory terms such as ‘cripple’, ‘invalid’, ‘mentally retarded’, ‘handicapped’ are all derivatives from the medical model. This model of disability is responsible for persons without a disability superior to persons with a disability (Johnstone 2012:16).

Kasser and Lytle (2005:13) criticise the medical model for only regarding biological factors to be contributing to an individual’s disability and totally disregard all other possible factors such as social and environmental factors. Medical professionals who adhere to the medical model of disability regard people with disabilities in a very negative light as they believe that People with Disabilities (PWDs) have a very poor prognosis and poor functional outcomes, as most disabilities are permanent therefore PWDs would take on the sick role (Llewellyn, Agu & Mercer 2014:257).

This model of disability is very limiting to PWDs as it views disability through a narrow and clinical lens, therefore, many do not accept this model as it is not holistic and does not address factors other than biological factors that contribute to disability. It overlooks the abilities of many PWDs and does not believe that PWDs can be independent and functional optimally.

2.2.2.2 Social Model of Disability

The social model of disability emerged as a result of social and rights movements in the 1960’s to address disparities which existed among gender, sexuality, disability and race rights (Jackson 2018:4 & D’Alessio 2011:44) and was developed in the 1800s by a British disability activist who was also an academic. According to the social model of disability, disability is socially constructed and contrasts with the medical model of disability. This model of disability attributes disability to barriers imposed on PWDs such as physical, societal, family, community and the environment issues.

The social model of disability does not view PWDs as having a disability, rather, disability is viewed as something that PWDs experience which is dependent on how society views PWDs and their needs. Disability is thus viewed as a societal contrast and not as a medical impairment as with the medical model of disability.

There are several reasons as to why people are impaired, and this alone does not translate into disability. Bolt (2005:539) emphasises that it is society, which causes disability. Levitt (2017:591) argues this notion as society is not the only factor that causes disability. Levitt (2017:591) further mentions that other factors such as; environmental, social, physiological, cognitive and emotional factors have a role to play in disability.

According to the social model of disability, the reformation of society is what ultimately “cures” a disabled person from their disability (Jackson, 2018:6). In contrast to the medical model of disability which focuses on medical cures and impairment, this model is different to the biomedical model which is based on medical cures where the focus is on the impairment, the social model of disability focuses on the disadvantages posed on PWDs by society as people’s attitudes towards PWDs are also central to the social model of disability (Intellectual Disability Rights Service 2009).

Oliver (2013:1024) states that “the social model can be disseminated much more widely than only to disability professionals in developed countries”. This statement translates into not only disability professionals making use of this model but also non-professionals such as PWDs themselves and caregivers of PWDs.

It has been proven that the social model of disability has been successfully used across the globe for PWDs as it has successfully challenged discrimination and ostracism of PWDs and enabled PWDs disabled equal opportunities in society.

2.2.2.3 The Charity Model of Disability

Duyan (2007:71) views the charity model of disability as an invalid, outdated model of disability which views PWDs as individuals who are misfortunate victims of their circumstances who society should pity and be sympathetic towards. The charity model of disability views PWDs as individuals in need of care and assistance as they are incapable of taking care of themselves (Duyan 2007:71). This model is often used by charities as a means of fundraising and results in PWDs as being seen as charity cases. The Charity Model does not advocate for equal opportunities for PWDs. The model does not support people with disabilities to live their lives in a manner they wish; it is not concerned with civil rights, independent living, meaningful employment or equal access to education.

The charity model does not result in many real changes for PWDs. It is a model that warrants PWDs dependent on others. It is a model where others do good for those who are disabled and thus the main benefit is on those who give charity as it makes them feel good about themselves for helping others. This model of disability is seen by Mawson (2013:411) as a model which oppresses PWDs as negative terms such as “handicap”,” mentally retarded” and “crippled” has emerged from this model.

2.2.2.4 The Human Rights Model of Disability

The human rights model of disability is a model of disability that is very similar to the social model of disability. Degener (2017:43) articulates this model as one which greatly contributes to a disability theoretical framework policy as a strong emphasis is placed on the human dignity and worth of PWDs. The human rights model of disability acknowledges that there are PWDs who face numerous life challenging conditions (Brewer, Brueggemann, Hetrick & Yergeau 2012:5). According to Degener (2017:47) the human rights model of disability identifies the three following crucial aspect related to PWDs:

- Respect and support should be afforded to PWDs as disability is regarded as a normal part of human diversity.
- PWDs should be afforded the same rights as those who are not disabled as every human being is entitled to the same human rights.
- Disability and impairment should in no way restrict or affect an individual’s ability to basic human rights.

The human right model of disability recognised disability as a human rights concern and ensures that the human rights of all PWDs are protected and promoted thus empowering PWDs. PWDs are entitled to the very same human rights as their non-disabled counterparts. This model addresses respect and acceptance of PWDs, specific prejudices, attitudes and other barriers, which makes it difficult for PWDs to enjoy basic human rights.

Additionally, the human rights model of disability emphasises government and society’s responsibility to ensure inclusion and participation of PWDs as well as ensure that the legal, political, social and physical environment fully supports the human rights of all PWDs.

A number of authors have recognized the value of using both the human rights model and the social model of disability to inform strategies for disability inclusive development in African countries.

2.3 PREVALENCE OF DISABILITY

The WHO (WHO 2012:29) estimates the global prevalence to disability to be approximately 11%, with 80% of the world's disabled population residing in developing countries. Approximately 20% of the world's poorest population have some kind of disability (WHO, 2011:29).

According to the WHO (2012:29), 15.6% of individuals who are 15 years and older live with a disability. The Institute for Health Metrics and Evaluation (2012:12) estimates this figure to be higher at approximately 19.4%. Of these, 2.2% have very substantial difficulties in functioning and are categorized as having a disability which is severe such as quadriplegia, blindness, severe depression and amputations.

The United Nations (UN) states that approximately 250 million of the 600 million individuals globally who have a disability are children and approximately 10% of children have a disability where long term caregiving and prolonged access to health care is needed (UNICEF, 2013:86). The global prevalence of disabilities ranges between 0.2% and 0.3%, with a distinct difference between developed and developing countries (Oskoui et al 2013:511). In contrast, Thompson (2017:5) does not provide a numerical value for the prevalence of childhood disability; however does agree that childhood disability is more prevalent in developing countries than developed countries due to a number of socioeconomic factors. Most disabilities are a lifelong disorder that therefore has no cure (Bolster et al 2017:211). Bolster et al (2017:212) further explains that most disabilities do not have a good prognosis, however, various interventions available which lessen the effect of disabilities and improve the quality of life of those affected by disabilities. Most developing countries have limited services available to families and children who are differently abled which results in many children who are differently abled being neglected or underserved (Oskoui et al 2013:511).

The prevalence of disability for children who are of school going age children in high income countries is 2.8% and in Africa 6.4% (WHO 2011:30). Accurate data on the prevalence of children who are differently abled in South Africa is difficult to establish, however, data which was last gathered during the 2011 national consensus, revealed that approximately 2.1 million children in South Africa have a disability thus making the prevalence of childhood disability in South Africa to be 11.2% (DSD, DWCPD & UNICEF 2012:6). The highest prevalence of children who are differently abled in South Africa was found in the age group 0-4 years as 28% of children in this category were found to have a disability. The category of children aged 0-9 years had a prevalence of disability that was less than half of those in the 0-4 years' category as 10% of children in this age category were classified as having a disability (DSD, DWCPD and UNICEF 2012:6).

2.4 LEGISLATIVE FRAMEWORK

Government through improving disability legislation and policies protects the rights and wellbeing of children who are differently abled. The South African Constitution stipulates that everyone is equal before the law and has equal protection and benefit of the law. Discrimination of any type is strictly prohibited, including discrimination towards people with disabilities (South African Human Rights Commission 2018:1). South Africa is one of the many countries who have taken on the responsibility of fulfilling their obligations under the Convention on the Rights of Persons with Disabilities. This responsibility includes ensuring that all children who are differently abled enjoy the rights afforded to them without any discrimination (UNICEF 2013:75).

The Convention on the Rights of Persons with Disabilities is an international agreement that guarantees the human rights of all PWDs are supported and protected.

Broderick (2014:404) lists the following eight fundamental principles enclosed in the CRPD as:

- Freedom choices
- Non-discrimination
- Full and effective participation and inclusion
- Respect for, and acceptance of people with disabilities being regarded as a part of human diversity and humanity
- Equal opportunities being afforded to PWDs

- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children who are differently abled and respect for the right of children who are differently abled to preserve their identities.

The Framework and Strategy for Disability and Rehabilitation Services in South Africa is a framework for inclusive rehabilitation services for people with disabilities across all levels of health within the South African Health Care System. The Framework is based on the premise that the burden placed by disability on households, communities and the country could be reduced provided that people with disability are provided with rehabilitation services which are accessible, affordable and appropriate. Rehabilitation services are paramount to an individual transitioning from acute health facilities to the community (South Africa 2015:3). The Framework and Strategy for Disability and Rehabilitation Services in South Africa (South Africa 2015:6) highlights the need for improved integrated disability and rehabilitation services, ensuring access to people with disabilities. Rehabilitation professionals such as occupational therapist, speech therapist and physiotherapist have a vital role to play in implementing CBR services. Occupational therapists in communities have to support NGOs that have been set up in communities to help care for children who are differently abled. Caregivers therefore play a fundamental role and are an integral part of the intervention process for children who are differently abled. Even though caregivers play a vital role in caring for children who are differently abled, they still lack support, education and communication from stakeholders. Geiger (2012:2) criticizes the support afforded to NGOs as many NGOs in South Africa who care for children who are differently abled have caregivers who are not trained.

According to the Department of Social Development (DSD 2012:6), the White Paper on The Rights of Persons with Disability was developed to improve the lives of all PWDs. The foundation to the White Paper on The Rights of Persons with disability is a legislative framework which includes programmes and policies that the South African Government has developed and implements. The goal of the White Paper is to “build on the progressive policies and programmes that our government has and continue to implement over the past number of years to make more positive and meaningful change for persons with disabilities and their families” (DSD 2012:7). Numerous authors criticize the White Paper as it mentions what should be done to improve the lives of PWDs but fails to mention strategies on exactly how the goals can be achieved (De Vries Venter, Jacklin, & Oliver 2013:794; Officer & Shakespeare 2013:87; Roy & Roy 2012:86).

Community Based Rehabilitation is an approach grounded on principles of community development for the rehabilitation, equalisation of opportunities and social integration of all PWDs, the families of PWDs, communities and the appropriate governmental sectors. CBR empowers PWDs to take action to improve their own lives and contribute rather than drain or deplete whatever scarce resources are available, thereby benefiting all members (WHO 2010). Even though CBR has been, and currently is advocated as one of the essential approaches to address the requirements and needs of people (including children) with disabilities, there is sadly no comprehensive national strategy on CBR in South Africa (UNICEF 2013:9). Children who are differently abled therefore lack access to inclusive services at the community level, particularly PHC that should be made accessible and affordable to all in South Africa. The Health Systems Trust (2015:1) mentions that decentralizing the South African health care system ensures quality of health care services as well as access to health care services for the most vulnerable population such as women, children and people with disabilities. Some provincial governments in South Africa have entered into partnerships with NGOs to plan and implement CBR services for children who are differently abled; however, there is no unified national strategic position on CBR that is evident in some provinces not being included in these provincial governments.

The Children’s Act (South Africa 2006) states that the government is responsible for providing all-inclusive services to children, prioritising funding and access of services to the poor and children who are differently abled. NGOs render services to children as stipulated by the Act, however, the funding NGOs receive does not cover the entire cost of providing services to these vulnerable children (UNICEF 2012:76).

Even though lack of funding is a major obstacle for NGOs catering for children who are differently abled there are other challenges NGOs experience such as the NGOs management and the staff they employ who do not fully understand the nature of services that children who are differently abled require (UNICEF 2012:77).

2.5 NON-GOVERNMENTAL ORGANISATIONS (NGOS)

Yaziji and Doh (2009:668) state that the term ’NGO’ has been in existence since the 1950’s. Mostashari (2005:2) does not agree with Yaziji and Doh (2009:668) regarding the initial development and use of the term NGO. According to Mostashari (2005:2), the word ‘NGO’ has been in existence since 1945. The term 'NGO' was created by the UN when they desired to consult with NPOs and the private sector who were not dependent on the government. The United Nations defines an NGO as “any non-profit, voluntary citizens’ group which is organized on a local, national or international level. Task-oriented and driven by people with a common interest, NGOs perform a variety of services and humanitarian functions, bring citizens’ concerns to governments, monitor policies and encourage political participation at the community level” (Alger 2002:93). Mostashari (2005:3) categorizes NGOs into two groups. NGOs that have to acquire resources to sustain the programmes they run and NGOs that take on the main role of advocacy. NGOs are governed by a board which has the function of capacity building and development of management and governance tools.

According to Statistics South Africa (2015:3), South Africa had a registered number of 127000 registered NGOs and 50000 unregistered NGOs. NGOs in South Africa differ in size and in the services they offer. To function effectively, NGOs have to collaborate with the government and other stakeholders. The Centre for Child Law (2017:4) states that NGOs for children who are differently abled offer valuable services to children who are differently abled, however, these NGOs are not equipped with adequate resources to provide quality care.

2.6 CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NGOS

A caregiver can be any individual who renders care to a person who is unable to care for himself or herself. A caregiver can provide informal unpaid services or formal remunerated services to anyone who has psychological, physical and developmental needs (Musich et al 2018:153). Capri (2017:2) adds that a caregiver is one who supports care recipients in performing their basic activities of daily living. Li and Song (2019:25) categorise caregivers in two main categories namely; formal caregivers and informal caregivers. Formal caregivers receive remuneration for their services and are employed by individuals or institutions such as a NGO. Informal caregivers provide care, to care recipients without being remunerated. A prerequisite for formal caregivers is that they have to have received some training in their field of practice. Ku, Liu, & Wen (2013:2) view formal caregivers as health care professionals.

The caregiver role is one that carries with it a high level of responsibility. The Alzheimer's Society of York (2018:9) states that the caregiver role could be very overwhelming as it is active, intense and encompasses many duties. This is supported by Walga (2019:7) who found the caregiving role to be very demanding as all the tasks expected by caregivers to implement places a great deal of responsibility on the caregivers. Geiger (2012:2-3) divides the basic roles for caregivers who care for children who are differently abled into two categories namely, major roles and minor roles. Major roles entails caring for the children's basic essential needs such as feeding, bathing, and giving medication. Minor roles include stimulation and exercise to ensure optimum development (Geiger 2012:3). Science Care (2015:1) acknowledges that the caregiving role is demanding as it takes on countless roles and responsibilities. It includes providing basic care, to care recipients and the administering of medication.

A study conducted by Wilkins, Bruce and Sirey (2009:540) found emotional support to care recipients is the most frequently performed task by caregivers, this is closely followed by assistance to care recipients with basic activities of daily living and care recipient medication management.

2.6.1 Challenges experienced at NGOs

The act of caregiving could be a very rewarding experience for caregivers and could also be an experience that results in undesirable consequences for the caregiver (Jones, Hadjistavropoulos, Janzen & Hadjistavropoulos 2011:56). Caregiver burden is described as the emotional, physical, social and financial implications of providing care to people with disabilities and illness (Diameta, Adandom, Jumbo, Nwankwo, Obi & Kalu 2018:1).

Caring for children who are differently abled places persistent psychological and physical demands on the caregiver, which could result in the caregiver experiencing high levels of stress. Due to the nature of their work, caregivers who care for children who are differently abled experience many stressors, however, lack the ability to apprise and cope with stressors, which negatively affects the caregiver’s health and functioning. The psychological stressors caregivers experience often manifest itself in not only psychological problems but physical problems as well which all affect the quality of life of these caregivers. The caregiving role often causes physical and psychological stress for the caregiver. Theofilou (2012:3) explored the psychological effects of caregiving and found that caregivers experience symptoms such as; depression, anxiety, guilt, anger, insomnia, generalized muscle pain and headaches.

Phillips, Ragas, Hajjar, Tom, Dong, and Simon (2016:178) infers that caregivers who are in a poor physical and psychological state are at a higher risk of providing poor quality care to care recipients.

Recognition of caregivers by community members is regarded as an extrinsic reward to caregivers (Akintola 2010:6). Schneider (2020:185) found that caregivers being undermined by the community and not receiving the recognition they deserve caused caregiver’s discontent. Caregivers need inclusive programmes that empower them to render effective care to their care recipients. It is therefore crucial that caregivers receive recognition and support to render optimal care for children who are differently abled (Meintjes & Belkum 2013:182).

Gustafsson and Bootle (2013:73) identify an additional challenge caregivers experience when they start providing care, to care recipients for the very first time. This major challenge is the caregiver having to take on the responsibility of providing care, to care recipients without prior experience, resulting in caregivers being ill prepared. Caregiver preparedness has a very strong link to caregivers having a positive first impression (Alvariza, Häger-Tibell & Holmet 2020:15). Caregiver preparedness denotes the readiness of a caregiver for carrying out all the caregiving tasks related to their caregiving role. Caregiver preparedness has a strong link to caregivers feeling less anxious and burdened and could assist with overcoming the negative aspects of caregiving. Wang, Molassiotis, Chung, and Tan (2018:95) add that caregiver preparedness increases positive feelings such as hope and leads to better overall caregiver health. Norinder, Goliath and Alvariza (2017:310) suggest that caregivers who feel they are prepared, provide better care to their care recipients. A strategy that could be used to improve caregiver effectiveness is understanding and improving caregiver's level of readiness to start rendering care, to care recipients (Marx, Parker, Huang, Scerpella, Piersol, & Gitlin 2019:181). Lutz, Young, Creasy, Martz, Eisenbrandt, Brunny and Cook (2017:880) list numerous factors that influence caregiver's readiness to assume the caregiver role. These factors include the presentation of the care recipient, the characteristics of the caregiver, caregiver knowledge, skills and availability of resources to carry out their caregiving duties.

Caregivers have to be allocated the reagent resources if they are to render optimal caregiving services to children who are differently abled (Soni, Lynch, McLinden, Mbukwa-Ngwira, Mankhwazi, Jolley, Virendrakumar, Bedford & Gercama (2020:7). In addition to caregiver skills, Sonie et al (2020:7) found that a lack of resources posed a further challenge to the provision of optimum quality care to children who are differently abled. According to WHO (2010:26), governments are willing to accept and implement CBR programmes at National level. This is challenging as many countries lack resources to implement and sustain CBR programmes. Lack of resources therefore is a challenge not only on the macro level but on the micro level (NGOs) as well.

NGO managers often experience challenges communicating with caregivers. The Alzheimer's Society of York (2018:5) mentions good communication between the caregiver and manager as a requirement to assist the manager to provide support to the caregiver. NGO managers should follow up with their caregiver through the means of communication regarding any challenge's caregivers are experiencing personally and at work.

The Alzheimer's Society of York (2018:5) further mentions good communication between the caregiver and manager as a requirement to assist the manager to provide support to the caregiver. Managers should communicate with caregivers to enquire how they are doing, feeling and managing with their caregiving role.

2.6.2 Caregiver training

Bosch (2015:156) found that most caregivers in rural areas start rendering care, to care recipients without having undergone any training. A study by Burgdorf, Roth, Riffin, and Wolff (2019:835), published in the JAMA Internal Medicine Journal, found that 93% of caregivers providing care to adults have never received training to carry out their caregiving role.

Elkins and Rustin (2019:387) conducted a study on caregiver training needs at two different caregiver conferences and found that most caregivers required more training on health issues and use of resources. Training in areas such as diaper changing, potty training, bathing and transferring were also expressed as a need. Furthermore, the study by Elkins and Rustin (2019:387) revealed that caregivers also needed training on the conditions care recipients present with and how to interact with care recipients. Caregivers also expressed the need for training on how to improve physical interactions with their care recipients, how to exercise patience, compassion and kindness. Bosch (2015:164) highlights the importance of providing training to improve the skills and knowledge of caregivers. Caregiver training enhances the quality of life of caregivers and improves the quality of care that care recipients receive. Caregiver training also improves the problem-solving skills of caregivers and decreases the negative effects of caregiving.

2.6.3 Monitoring Caregivers

It is essential for caregivers to be monitored to determine the success of their caregiving services. Schulz and Eden (2016:165-166) suggest that caregivers should be assessed prior to resuming their caregiving duties. The very same assessment methods should be used to monitor outcomes after a period of time. Comparing these two results will indicate what works well and should be maintained and also what needs to be improved to render better caregiving services (Schulz & Eden 2016:7). Caap-Ahlgren and Dehlin (2002:375) suggest that the caregiver burden could be minimized by recognizing caregiver’s functional status and negative psychological symptoms they display. The physical and psychological impact of caregiving should be assessed qualitatively or quantitatively to ensure caregivers receive timeous assistance.

Family Caregiver Alliance (2006:17) proposes caregiver monitoring and assessment to be ongoing. Caregivers should be reassessed on a regular basis to determine if they are rendering effective services to their care recipients. Family Caregiver Alliance (2006:182) does not provide a specific time period for caregiver assessments; however, do propose that the frequency of caregiver assessments is dependent on the goal of the NGO programme and the population being cared for.

Addressing childhood disability is complex and therefore requires an intersectoral collaborative approach. Philpott and Muthukrishna (2019:729) emphasize, “Children who are differently abled stand to gain from an array of services and interventions to support their development”. Philpott and Muthukrishna (2019:729) add that intersectoral collaboration is essential to improve effective services for children who are differently abled. The Framework and Strategy for Disability and Rehabilitation Services in South Africa (South Africa 2015:13) claims that services for the disabled should be affordable, accessible and appropriate. Providing support to caregivers of children who are differently abled is considered an indirect service to children who are differently abled and should be implemented by various government departments. NGO managers should therefore seek outside support for the caregivers they employ. Support should not only focus on improving caregiver’s skills and knowledge but also psychological support for caregivers.

2.7 Empowerment

Despite numerous research studies confirming the crucial role NGOs for children who are differently abled and caregivers of children who are differently abled play in providing support to families, communities and society, the needs of caregivers are often overlooked, disregarded and misunderstood. In short, literature pertaining to the challenge’s caregivers experience strongly suggests that the majority of caregivers at NGOs for children who are differently abled do not feel empowered and therefore emphasizes the need for caregiver empowerment. Caregivers of children who are differently abled often feel disempowered as they lack the skills and knowledge to provide optimal care to their care recipients (Mathye & Eksteen 2016:295). Caregivers also often feel that they are not recognised, do not receive enough support from relevant stakeholders and feel overburdened by their socioeconomic risk factors. The high number of disempowered caregivers is affirmed in the Framework and strategy for Disability and Rehabilitation Services in South Africa (South Africa 2015:7) which highlights the high number of NGOs who have untrained caregivers looking after children with disabilities. The provision of education, resources and self-awareness is seen as an empowerment process, giving great power to its recipients (Elphick 2017:3). The concept of empowerment is based on the impression that it is possible to help people to cope and feel better through discourse and reflection between the professional and the client in need as well as the caregiver. Hage and Lorensen (2015:236) argue that by implementing an empowerment strategy, caregivers are given the opportunity to expose their weaknesses and limitations that ultimately helps them to effectively come up with a strategy to effectively care for themselves and others. Numerous authors agree that programmes which help caregivers to change their behaviour in some positive way, helping caregivers to find resources within and outside the client and helping caregivers with the adjustment into the caring situation are all ways of helping caregivers reach the point of feeling empowered (Hage & Lorensen 2015:238; Elphick 2017:5; Freid 2018:10). Caregivers who feel empowered therefore provide better care to children who are differently abled.

2.8 CONCLUSION

From the information provided in the literature review overview, it is evident that many children who are differently abled at NGOs are not receiving adequate optimum care due to disempowered caregivers experiencing numerous challenges in carrying out their caregiving duties. The researcher believes that one cannot be satisfied with existing literature regarding caregivers of children who are differently abled as it is very limited, especially in the context of developing countries. A limited number of studies have been conducted to explore the challenges, experiences and needs of caregivers who render care to children who are differently abled. Even less literature exists on the topic of caregiver empowerment. This information is crucial for developing programmes for caregivers. The scarcity of programmes that empower caregivers of children who are differently abled is unfortunate as it is only through empowered caregivers that children who are differently abled receive comprehensive optimal care. Formal research is needed to further present an evidence base for effective guidelines and programmes that will empower NGOs and caregivers to provide optimal caring services for children who are differently abled consequently allowing children who are differently abled to enjoy their basic human rights.

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

In chapter two, a comprehensive overview of prior research regarding empowerment of caregivers of children who are differently abled at NGOs was provided. Chapter three describes the research design, population, sampling, methods of data collection and data analysis. This chapter furthermore describes ethical considerations related to data collection and concludes by discussing measures employed to ensure trustworthiness.

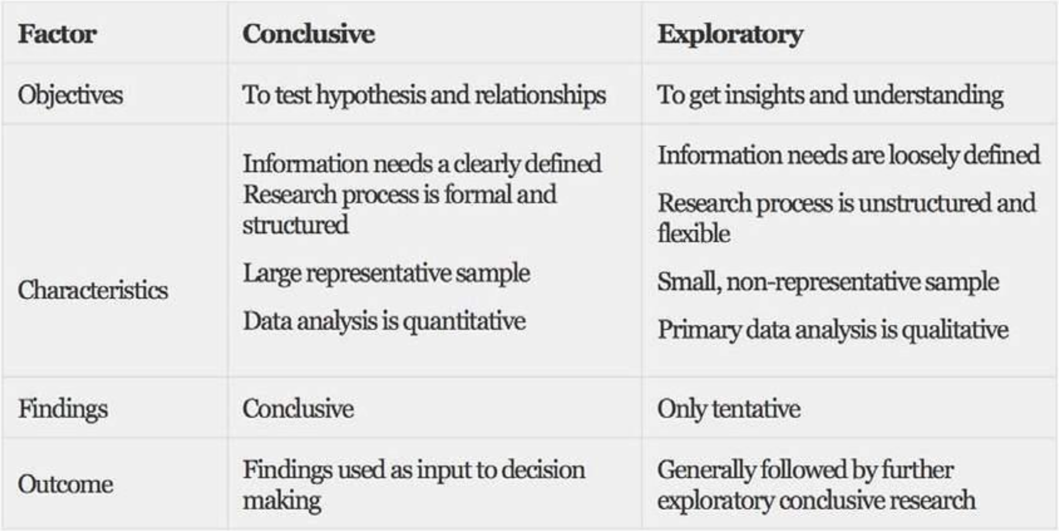
3.2 RESEARCH DESIGN AND METHODS

3.2.1 Research design

A research design provides a detailed plan on how to answer the research questions of a study. Kumar (2014:40) mentions that a research design is a practical plan that the researcher uses to accurately and objectively answer research questions. Kumar (2014:40) further indicates that the research design decides, describes, justifies and explains exactly how a researcher will find answers to their research questions. Yin (2016:83) concurs with Kumar's (2014:40) explanation of a research design and likewise, describes a research design as the overall logical plan used to collect and analyse data. McMillan and Schumacher (2010:55), add that a research design encompasses a plan for choosing research sites, subjects and processes for data collection to address the research questions as effectively and efficiently as possible.

Research designs provide a detailed plan and directions for procedures for qualitative, quantitative and mixed methods research approaches. The selected research design is dependent on the nature of the research problem, personal experiences of the researcher and who the audiences of the study are (Creswell, 2017:41). Kumar (2014:123) highlights two main functions of a research design. The first function involves identifying and developing procedures that are necessary to conduct a research project. The second function involves ensuring procedures undertaken during the research study are valid, objective and accurate .

Research designs can be classified into two major categories; exploratory and conclusive. Marshall and Rossman (2016:78) state that exploratory research is undertaken with the objective of investigating little-understood phenomena therefore providing insight and understanding into an area of which not much is known. Zaborek (2015:41) describes conclusive research as a research design that is employed to help reach conclusions and make decisions. With conclusive research designs, research findings of exploratory studies can be verified and quantified. The category of research design that was employed in this study is the exploratory research design.



Factor	Conclusive	Exploratory
Objectives	To test hypothesis and relationships	To get insights and understanding
Characteristics	Information needs a clearly defined Research process is formal and structured Large representative sample Data analysis is quantitative	Information needs are loosely defined Research process is unstructured and flexible Small, non-representative sample Primary data analysis is qualitative
Findings	Conclusive	Only tentative
Outcome	Findings used as input to decision making	Generally followed by further exploratory conclusive research

Figure 3.1 Table comparing conclusive and exploratory research designs

The researcher made use of a qualitative research design which is exploratory, descriptive and contextual in nature.

3.2.1.1 Qualitative Research

Qualitative research seeks to explore, describe and understand the meaning individual or groups attribute to a social or human phenomenon (Creswell & Plano Clark 2017:42-45; Yin 2016:8; Kumar 2014:133; Marshall & Rossman 2016:2). Qualitative research involves looking at characteristics, or qualities, that cannot easily be reduced to numerical values (Yin, 2016:8). Marshall and Rossman (2016:2) further add that qualitative research is pragmatic in nature, fundamentally interpretive and focuses on the subjective experiences of human beings. Leedy and Ormrod (2020:133) highlight two commonalities of qualitative research. The first being that qualitative research phenomenon occurs in the natural setting of the research participants. The second commonality is that the research phenomenon is studied in-depth. Marshall and Rossman (2016:2-3) list five characteristics of qualitative research and five characteristics of qualitative researchers which have all contributed to the researcher choosing to employ a qualitative research approach. The characteristics are as follows:

Characteristics of qualitative research

- Occurs within the natural world
- Makes use of multiple methods which respects the humanity of the participants and are interactive
- The focus is on the context of the research participants
- Is developing and evolving and not tightly figured
- Is essentially interpretive

Qualitative research was thus employed in this study since a complex; detailed understanding of caregivers' experiences, challenges and training needs was required to develop a conceptual framework that facilitated the development of a programme to empower caregivers who care for children who are differently abled at NGOs. Caregivers' experiences, challenges they experience and needs were established by interviewing caregivers in the context where services are rendered. This allowed the caregivers to tell stories unencumbered by what is expected to be found or what was reviewed in the literature. NGO managers were also interviewed to establish the support they offer caregivers. The researcher followed an exploratory, descriptive and contextual research design with a qualitative methodology.

3.2.1.2 Explorative design

The explorative design was used in all 3 phases of the research study. Ritchie et al (2014:32) describes explorative research as addressing the reason why the phenomena occurs and what aspects influence their occurrence. This description is supported by Kumar (2014:13) and Marshall and Rossman (2016:78) who mention that explorative research is undertaken to explore an area where there is not much known, to investigate the possibilities of undertaking a particular research study and to generate hypotheses for further research. With an explorative design, one thus examines a subject with the aim of gaining further insight relating to the specific subject. The goal of an exploratory research design is not to find a definitive answer, but rather to gain an in-depth understanding of the research phenomenon at hand (Labaree 2016:5). The exploratory research design was appropriate for this study as researchers intended on exploring and understanding the experiences, challenges and training needs of caregivers at NGOs for children who are differently abled from the caregivers' point of view. Exploring the caregiver's experiences and needs, as well as NGO manager's perspectives on support offered to caregivers formed a foundation for the conceptual framework and the development of the empowerment programme. The exploratory design was also suitable for this study as not much is known by the researcher regarding the experiences and challenges that caregivers who care for children who are differently abled at NGOs experiences as well as what support do NGO managers offer caregivers. It was crucial for the researcher to:

- Explore and describe the experiences of caregivers providing care to children who are differently abled at NGOs.
- Identify challenges that caregivers at NGOs caring for children who are differently abled experience
- To explore and describe the support that managers at NGOs caring for children who are differently abled provide to caregivers.

Gaining in-depth insights into the three aspects listed above made it possible for the researcher to develop a conceptual framework that facilitated the development of a programme to empower caregivers at NGOs caring for children who are differently abled.

3.2.1.3 Descriptive design

The descriptive design was applied in all three phases of the research study. Descriptive designs uncover facts and meanings that were not known before as this type of design observes, describes and documents the phenomenon of interest (Nassaji, 2015:130). This is done by: observing, describing and documenting information about a situation as it naturally occurs (Polit & Beck 2017:464; Marshall & Rossman 2016:78). In this study the researcher obtained subjective information from the caregivers as semi-structured individual in-depth interviews were conducted with caregivers and NGO managers regarding their experiences of providing care to children at NGOs with disabilities and to understand the support NGO managers provide to caregivers. After information was gathered, from caregivers and NGO managers a conceptual framework was developed which facilitated the development of the programme to empower caregivers providing care to children who are differently abled at NGOs.

3.2.1.4 Contextual design

The contextual research design was applied in all three phases of the research study. Contextual designs seek to understand research participants in their very own natural settings thus making it possible for the researcher to understand and develop in-depth insights into the lives of the participants. Holtzblatt and Beyer (2015:2-3) suggest that obtaining accurate and trustworthy information from research participants is fundamental in uncovering challenges which forms a basis to developing ways of addressing problems found. Yin (2016:9) terms contextual conditions such as social, institutional, cultural and environmental, which encompasses qualitative research.

This study focused on experiences of caregivers related to caring for children who are differently abled at NGOs where they are employed. Because this study was conducted in, and was about the caregiver’s immediate working environment, it adopted a contextual design. This is supported by Yin (2016:9) who states that focusing on events which take place in the immediate environment renders a research study to be contextual.

3.2.1.5 Theory Generation

Lederman and Lederman (2015:596) describe theory as the relationships between concepts or ideas related to the phenomenon of interest. Theory also explains how these relationships can predict behaviour or events. Furthermore, theory suggests ways that the phenomenon can be changed or controlled (Lederman & Lederman, 2015:596). Theory generation research consisted of generating an in-depth understanding of a phenomena by analysing qualitatively the collected data from different sources, sorting it into consistent categories (Beck, Weber & Gregory 2013:639). In this study, theory generation research consisted of three phases as outlined in the figure 3.2.

Phase 1 – the qualitative study, Phase 2 – the Conceptual framework and Phase 3 – programme development.

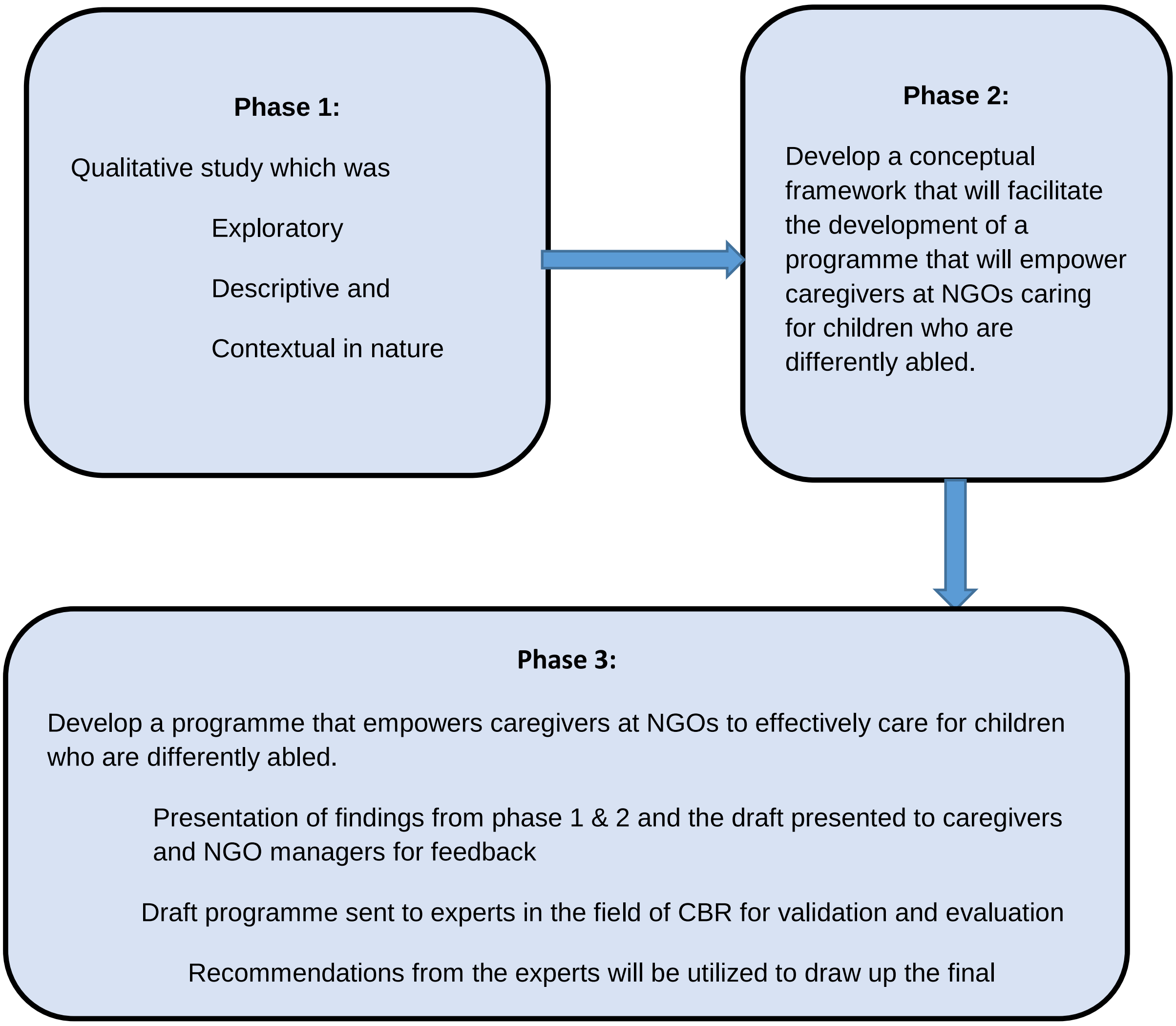


Figure 3.2: Research phases for this study

3.2.2 Research phases

3.2.2.1 Phase 1: Qualitative study

This qualitative study was undertaken to explore and describe the experiences of caregivers who render care to children who are differently abled at NGOs. This phase also identified the support that managers at NGOs caring for children who are differently abled provide to caregivers. The aim of this phase of the research was to explore and describe the experiences, challenges of caregivers and NGO manager's perspectives on support offered to caregivers, which assisted the researcher to develop a programme to empower caregivers who care for children who are differently abled. Detailed description for this section has been presented above.

3.2.2.2 Phase 2: Conceptual Framework

A conceptual framework explains, either graphically or in a narrative form the main things to be studied, the key factors, constructs or variables and the presumed relationships among them (Miles, Huberman & Saldana 2014). Kumar (2014:57) proposes that a conceptual framework forms the basis of the research problem. Kumar (2014:57) further explains that a conceptual framework forms the foundation of the research study that consists of theories which are entrenched in the research study. The conceptual framework designates aspects from the selected theoretical framework which comprises all theories the researcher has used to explain the research questions. The researcher used the method of conceptual analyses described by Walker and Avant (2011) for conceptualisation. The conceptual analysis is described in detail in chapter 6.

3.2.2.3 Phase 3: Programme Development

Data collected from the qualitative study (phase 1), and the developed conceptual framework (phase 2), provided a foundation for developing the programme to empower caregivers caring for children who are differently abled at NGOs. Additionally, the Caregivers Support Model, which is a logic model framework developed by the Alzheimer’s Society of York (2018) was used to develop the content programme.

The main concepts of the conceptual framework were identified from the qualitative phase which sought to understand the experiences, challenges and training needs of caregivers when rendering care to children who are differently abled.

The Practice Orientated Theory of Dickoff et al (1968) (in Jooste and Mothiba 2014:5-11) was used to develop the conceptual framework that facilitated the development of the programme to empower caregivers who render care to children who are differently abled at NGOs. The survey list of Dickoff et al (1968) which included the context, agent, recipient, dynamics, procedure, and terminus served as a basis for programme development. These six components of the Survey List are as follows:

Agent

In the context of this study, the agent refers to the person who will use the programme. In this context, there are two agents, NGO managers and occupational therapists.

Recipients

Recipient refers to the person who will be receiving activities from the agent. In the context of this study, recipients will be caregivers of children who are differently abled at NGOs for whom the empowerment programme was developed.

Context

The context is composed of the environment where the activities take place. In this study, the context was the caregiver’s immediate working environment that is the NGOs where children who are differently abled are cared for.

Dynamics

Dynamics refer to challenges in the context where caregivers render care to children who are differently abled. These challenges were explored and understood in the first phase of this research project.

Procedures

The procedure refers to the process to be used to empower caregivers. This is achieved through thorough orientation of caregivers on employment, needs analysis to identify their areas of learning and education to be addressed in order to help caregivers provide quality care to the children who are differently abled. Procedures also refers to continuous training to address new developments.

Terminus (outcomes)

This is referred to as the outcome of the process; it also refers to the desired outcome an agent aspires to achieve by applying a process. In this study the terminus refers to the caregivers who will be empowered through a programme to equip them with skills and knowledge to address the challenges they face. The conceptual framework is described in detail in chapter 5.

The programme was developed following the stages of development of the health education tool described by Arora, Sinha, Malhotra & Ranjan (2017:7-9) and the four activities of The Cyclic Curriculum Development Model of Nicholls and Nicholls (1978); which includes conducting a situational analysis, selecting objectives, selecting and organising content and selecting and organising teaching methods.

The process described by Arora et al (2017:7-9) has been adapted specifically for this study and is described in the three steps mentioned below. Developing an education programme such as a programme to empower caregivers is based on a three-step process that is illustrated in Figure 3.3 below.

Step 1: Define the purpose and goal of developing the education material (programme to empower caregivers)

This step involves the researcher to gather information that is relevant and distinctive to a specific community within a specific context to ensure that their needs are responded to in an effective and realistic manner. The step is collecting data through conducting individual interviews, focus group discussion and surveys. Interviews must be tape-recorded and should be transcribed verbatim. All data collected from the interviews is used to guide the researcher to generate topics that will be included in the programme.

Step one of the process was addressed in phase one of the study where caregivers and NGO managers were interviewed to explore and describe identify challenges, experiences and training needs of caregivers at NGOs caring for children who are differently abled and also to explore and describe the support that managers at NGOs caring for children who are differently abled provide to caregivers.

Step 2: Designing a rough draft of the programme

All data collected in step one is used to develop a preliminary draft. The preliminary draft is developed by designing headings and subheadings, writing detailed scientific content, developing interesting and relevant illustrations and finally printing out the first draft of the programme.

Exploring and describing the challenges, experiences and training needs of caregivers who render care to children who are differently abled at NGOs and identifying the support that managers at NGOs caring for children who are differently abled provide to caregivers assisted the researcher to develop the programme to empower caregivers who care for children who are differently abled.

Step 3: Validation and programme evaluation

Before a programme can be implemented on the target group, it is vital that it first receive proper validation by independent experts in the particular field of interest. Experts who are selected to undertake the validation of the programme should have previous experiences in the selected field that the programme is addressing. Experts comment on how appropriate and adequate the information the programme contains is and the presentation style of the programme from the perspective of the reader. Recommendations received from experts after the validation process has occurred should be accepted and integrated into the programme. A new updated version of the programme is then developed after corrections are addressed. Individuals who participated in the study should also be part of the validation process.

The programme to empower caregivers was validated by participants and experts in the field of CBR to ensure authenticity, accessibility and application of the programme for the relevant stakeholders, thereby giving caregivers and NGO management a sense of ownership of the programme. This was done by firstly having meetings with caregivers and managers from the NGOs who participated in the study. Findings from phase one and phase two of the study as well as the developed draft programme was presented at meetings that were conducted. Caregivers and NGO managers were given the opportunity to provide feedback and give their input regarding the draft programme, which was included in the final programme. The programme was then sent to experts in the field of CBR for validation and evaluation. Recommendations from the experts were utilized to draw up the final programme.

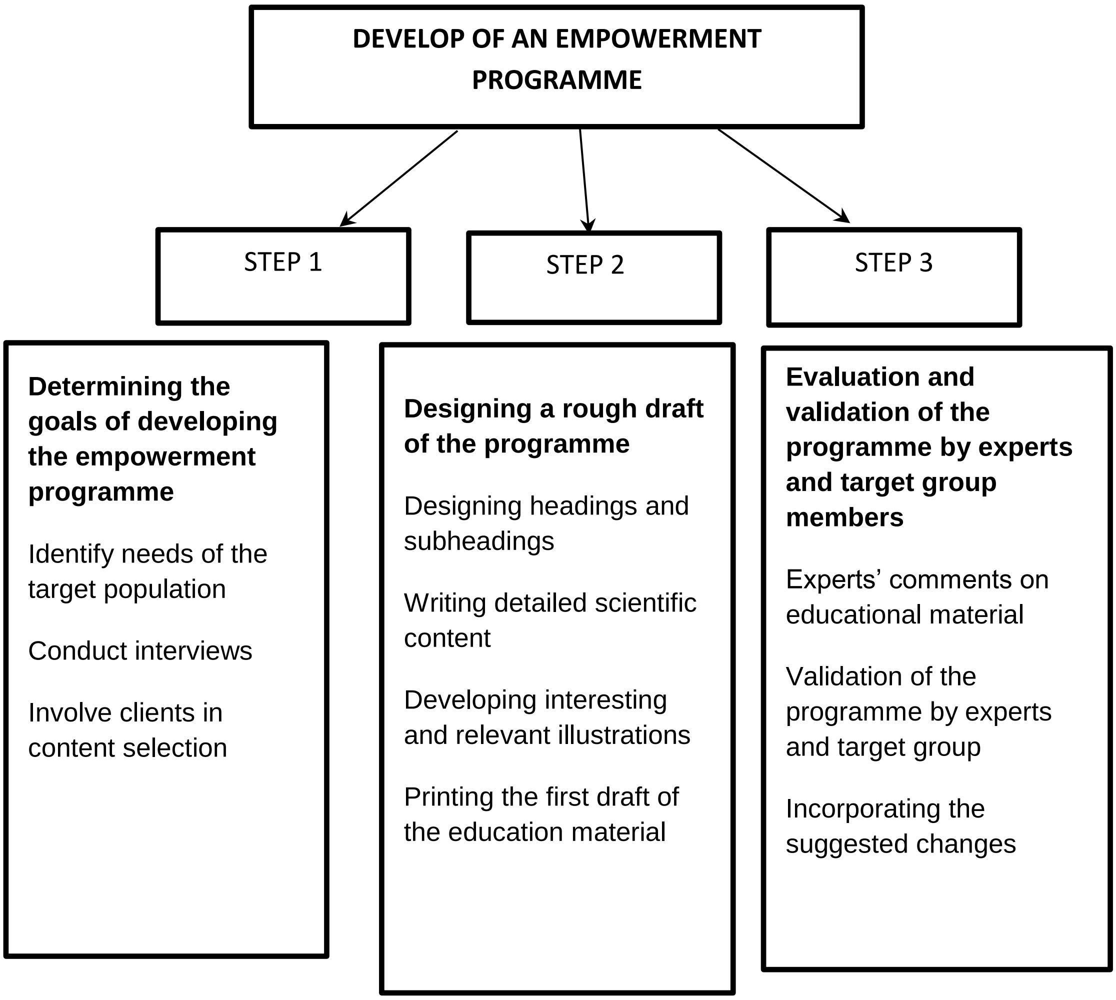


Figure 3.3: A model for a proposed empowerment programme for caregivers of children who are differently abled at NGOs (Adapted from Arora, Sinha, Malhotra & Rajan, 2017:6).

3.3 REASONING STRATEGIES

Burns et al (2015:400) refer to reasoning strategies as a process used to orderly organise ideas and thoughts which a researcher uses to reach conclusions which are meaningful. Reasoning strategies helps the researcher form foundations for arguments that the researcher uses to explore the research phenomenon at hand. Reasoning strategies the researcher used include; inductive reasoning, deductive reasoning, inferences, synthesis, analysis and bracketing.

3.3.1 Inductive reasoning

Qualitative research generally follows an inductive approach (Yin 2016:17). Creswell and Plano Clark (2014:53) refer to inductive reasoning as a bottom up approach where the researcher uses information gathered from participants to generate themes and then interconnect those themes to generate theory. Inductive reasoning starts from specific observations the researcher makes and then moves towards more general patterns (Shafaroodi, Kamali, Parvizy, Mehraban & O'Toole 2014:2).

The researcher used this reasoning strategy during the first phase of the study that was the situational analysis. This phase of the study was undertaken to explore and describe the experiences of caregivers who render care to children who are differently abled at NGOs. This phase of this research study was also conducted to identify the support that managers at NGOs caring for children who are differently abled provide to caregivers. Inductive reasoning was also used during data analysis where themes and sub-themes were developed.

The aim of this phase of the research was to explore and describe the experiences, challenges and training needs of caregivers and NGO manager's perspectives on support offered to caregivers, which assisted the researcher to develop a programme to empower caregivers who care for children who are differently abled.

3.3.2 Deductive reasoning

With deductive reasoning, the researcher develops arguments and assumptions that are based on research theory that already exists, and then uses these theories to test their arguments and assumptions (Zalaghi 2016:26). Deductive reasoning is based on a top-down approach to problem solving and therefore draws conclusions from existing theories.

The researcher used the deductive reasoning strategy while writing up the literature review as well as in chapter 5 where interpretation and discussion of findings were discussed in view of relevant literature.

3.3.3 Inferences

An inference is defined as the conclusion made by the researcher through the process of collecting previous evidence or information relating to the topic at hand, and then connecting this previous knowledge with new information (Polit & Beck 2017:160). Inferences thus involve drawing conclusions and making judgements based on facts and evidence.

Inferences was used in the first phase of the study which was the situational analysis where a qualitative research approach is used to gather evidence regarding the experiences of caregivers who render care to children who are differently abled at NGOs. This phase will also make use of inferences to identify the support that managers at NGOs caring for children who are differently abled provide to caregivers. The literature review also made use of inferences by collecting and processing precious evidence on the research topic.

Inferences were also made during phase two of the study where a conceptual frame was developed. The conceptual framework consisted of all theories the researcher has used to explain the research questions. The conceptual framework was developed based on the results from Phase 1 of the study. The survey list of Dickoff et al (1968) which includes the context, agent, recipient, dynamics, procedure, and terminus served as a basis of the formulation of the conceptual framework development.

Inferences were used to identify the main concepts of the conceptual framework from the qualitative phase which sought to understand the experiences, challenges and training needs of caregivers when rendering care to children who are differently abled.

3.3.4 Synthesis

Synthesis is a scientific process employed by the researcher to incorporate and integrate information gathered via qualitative and literature on a specific research topic. Synthesis of qualitative evidence is explorative and seeks to understand the experiences of individuals or groups. Schick-Makaroff, MacDonald, Plummer, Burgess & Neander (2016:188) mention that synthesis describes analysis and draws conclusions on the evidence research has produced. Synthesis also aids in deciding how effective health care interventions are (Schick-Makaroff et al 2016:178).

In this study, the researcher used synthesis in chapter two for the literature review and in chapter three where the researcher provided details on data analysis, data presentation description of the research findings in view of relevant literature. Synthesis made was possible to do thematic presentations of qualitative data from phase one of the study that was presented with direct quotations from caregivers and NGO managers. Synthesis was also used to achieve the aim of this research that was to develop a programme to empower caregivers who care for children who are differently abled at Non-Governmental Organisations.

3.3.5 Bracketing

Yin (2016:333) defines bracketing as a cognitive process whereby the researchers set aside their beliefs, values, predispositions, and prior assumptions in the process in designing, conducting and analysing a qualitative study. Yin (2016:288) argues that even though complete bracketing is impossible, the researcher should make every effort to cast aside her everyday assumptions about the external world and avoid imposing these assumptions on her study. The researcher used the bracketing technique in all three phases of the research study by setting aside any preconceived, subjective ideas and beliefs she had regarding the challenges and experiences experienced by caregivers who render care to children who are differently abled at NGO as well as preconceived notions regarding the support NGO managers offer caregivers they employ.

The researcher also used bracketing to develop the programme to empower caregivers which was based on the qualitative study as well as theoretical and a conceptual framework.

3.4 RESEARCH METHODS

According to Chinelo (2016:4) methodology is the core concept fundamental to all research as it refers to how one plans to go about investigating a phenomenon. Research methodology serves two key functions; firstly, it controls and dictates the acquisition of data. Secondly, it captures the data after acquisition and extracts meaningfulness from it (Chinelo 2016:4). Outlining the methodology of a study assists readers to acquire assurance in the techniques utilized by the researcher and ensures that the study can be replicated research methodology therefore answers questions related to data collection and data analysis.

3.5 POPULATION

Burns et al (2015:343) describe a population as particular individuals or elements who are the focus of the research and could form target and accessible populations of the study. Polit and Beck (2017:249) define a study population as a group of people, items, or objects from where samples can be taken with the goal of measurement. The population comprised of caregivers who care for children who are differently abled at NGOs and managers of NGOs who care for children who are differently abled.

3.6 SAMPLE

A sample is described as a carefully selected group of people from within a distinct population to estimate characteristics the entire population possess (Chinelo 2016:32). Qualitative researchers make use of a small number of participants that will provide in-depth information about the phenomenon at hand. Kumar (2014:28) highlights the ease in accessing respondents, the researcher’s judgement that the individual has broad knowledge about the research subject and the situation of interest as being factors that may influence the selection of the sample. It is not feasible to provide definite sample sizes; however, the number of participants in the study was determined by data saturation (Polit & Beck 2017:497).

Saturation refers to the process of gathering and analysing data up to the point where no new insights are being observed (Kumar 2014:248).

Saunders, Sim, Kingstone, Baker, Waterfield, Bartlam, Burroughs & Jinks (2018:1894-1897) highlight the uncertainty and inconsistency of how saturation should be used and acknowledge four models of saturation.

The first model is referred to as theoretical saturation that has a principle focus on sampling. This model of saturation relates to theoretical categories being developed.

The second model is referred to as inductive thematic saturation that has a principle focus on data analysis and relates to new codes and themes emerging during data collection.

The third model is referred to as a priori thematic saturation that has a principle focus of sampling. It relates to the extent to which identified codes and themes are denoted in the data collected.

The fourth model is referred to as data saturation that has a principle focus on the data collected. This model of saturation relates to the degree of repetition of new data that was already expressed in previous data.

Numerous authors infer that there is no predetermined sample size in qualitative research as the sample size in qualitative research is determined by the point of data saturation (Kumar 2014:229; Marshall & Rossman 2016:229)

3.6.1 Sample size

Hamed (2017:237) defines sample size as “a significant feature of any empirical study in which the goal is to make inferences about a population from a sample”. The sample size enables a researcher to generalize from a random sample and evade sampling errors and sampling biases. The sample size in this study was determined by the data saturation point. The data saturation point was reached after interviewing nine caregivers and seven NGO managers, when the researcher stopped gathering new information from participants during data analysis.

3.6.2 Sampling

Sampling is a statistical method of obtaining representative data or observations from a group or population (Kumar 2014:228). The number of participants in qualitative studies are generally small, therefore, non-probability, non-random sampling methods are used (Kumar 2014:247).

In this study, the purposive sampling technique also called judgement sampling was used which is defined as the deliberate choice of a participant due to the qualities the participant possesses (Kumar 2014:228). This sampling method was selected to ensure that only participants who have the required characteristics for the study are selected. The caregivers and NGO managers were selected from NGOs who render care to children who are differently abled, to purposefully inform an understanding of the research problems and central phenomenon in the study.

In order for a researcher to determine who to include and exclude from the study sample, the researcher should clearly define the inclusion and exclusion criteria, (Garg 2016:641). Patino and Ferreira (2018:84) stress the importance of having an inclusion and exclusion criteria for the study sample, which they mention is very important in the research process. Patino and Ferreira (2018:84) define inclusion criteria “as the key features of the target population that the investigators will use to answer their research question”. Factors such as demographic information, clinical and geographic characteristics are important to consider when outlining the inclusion criteria. Patino and Ferreira (2018:84) go on to define exclusion criteria as “features of the potential study participants who meet the inclusion criteria but present with additional characteristics that could interfere with the success of the study or increase their risk for an unfavourable outcome”. Participants who might not provide accurate and reliable information are aspects that should be considered when outlining the sample.

The specific inclusion and exclusion criteria used on the sample in this study are:

<u>Inclusion criteria:</u>

- Caregivers aged from 18 years upwards who have been employed at the NGOs who care for children who are differently abled for at least a month,
- Caregivers who have given consent to participate in the study,
- NGO managers who have been managing NGOs for at least six months,

- NGO managers who have given their consent to participate in the study.

Exclusion criteria:

- Caregivers who do not render direct care to children who are differently abled. This includes caregivers who render indirect are such as meal preparation and cleaning.

3.7 PILOT STUDY

“Pilot Study is a small-scale research project conducted before the final full-scale study” (Ismail 2018:1). Researchers agree that pilot studies test, support and refine certain aspects of a research study (Yin 2016:39; Marshall & Rossman 2016:105; Ismail 2018:2327). These aspects include the research strategy, the design, procedures used in fieldwork, the data collection instrument and the data analysis plan, estimation of resources and time required (Ismail 2018:2327; Yin 2016:39).

The pilot study was conducted by the researcher at an NGO caring for children who are differently abled. The NGO is set in Lotus Gardens, which is a semi-urban area managed by one manager who is also the owner and employs a total of five caregivers. The NGO provides care to a total number of 13 children with various disabilities such as cerebral palsy, severe intellectual disability, autism and spina bifida. The researcher conducted an individual in-depth interview with the NGO manager and one caregiver. The researcher conducted the pilot study with the aim of;

- Estimating the required time and cost for data collection
- Identify potential obstacles which could occur during the data collection process
- Refine the data collection tool
- Identify and minimise potential risks which could be encountered during data collection, analysis and interpretation.

From the pilot study conducted, the researcher identified that some questions were ambiguous and used medical jargon. The researcher went back to the interview schedule and simplified the questions. The findings from this pilot study were not included in the main findings of the study.

3.8 DATA COLLECTION APPROACH AND METHOD

Kabir (2017:202) describes data collection as the process used to gather information from research participants in a systematic manner that makes it possible for the researcher to answer the research questions and address the aim of the research study. Qualitative researchers depend on various data collection methods such as; participation in the research setting, direct observation, in depth interviewing and analysing documents and materials (Yin 2016:91; Marshall & Rossman 2016:141; Kumar 2014:171).

In an interview, the researcher asks the participants predetermined questions (Kumar, 2014:178). Leedy and Ormrod (2020:146) state that interviews conducted in qualitative studies are not as structured as interviews conducted in quantitative studies. Interviews in qualitative studies are usually open-ended and semi-structured.

Data collection in this study was facilitated through conducting semi-structured individual in-depth interviews with caregivers and NGO managers. Marshall and Rossman (2016:147) describe an in-depth interview as an interview that occurs during face-to-face interaction with two or more people who discuss a theme of mutual interest. Marshall and Rossman (2016:147) further add that in-depth interviews extract extensive detailed information from participants that helps to provide a deeper understanding of participants. Interviews were audio recorded using an audio tape recorder that was conducted by the researcher.

3.8.1 Data collection Process

A database of NGOs who care for children who are differently abled was obtained from disability organisations in Tshwane. Meetings were held with management from NGOs who care for children who are differently abled to firstly establish a relationship with NGOs and inform NGOs of the proposed study. Prior to the interviews being conducted, managers were contacted to arrange a suitable time, date and venue within the NGO for data collection.

Those participants who agreed to participate in the study and were eligible were then given information on what the study is about, benefits and risks of the study and arrangements made. They were informed that they could withdraw from the study at any time without victimisation. No personal information was included on the recording of the interview as well as on the transcribed interviews. The caregivers and NGO managers who agreed to participate in the study signed an informed consent form (Annexe C) and partook in the individual semi-structured interview.

3.9 DEVELOPMENT OF THE DATA COLLECTION INSTRUMENT

The researcher collected data through conducting semi-structured individual in-depth interviews with caregivers and NGO managers. The researcher used an interview guide which Yin (2016:147) describes as “a data collection tool containing a small subset of key words written on a compact piece of paper, tailored to the topics considered to be directly relevant to a given interview”. Yin (2016:147) further mentions that an interview guide is not a questionnaire however should contain key words that are followed by probes. Interviews were audio recorded using an audio tape recorder. It is crucial to note that two interview schedules were used, one for the caregivers and one for the NGO managers.

The interview schedule was developed using the caregivers support model framework developed by the Alzheimer’s Society of York (2018) as a basis and also ensuring that research questions were addressed. The caregivers support model framework guides the expectations which a programme to empower caregivers should focus on. The framework consists of six main components that includes; identify and recognize, referral and navigation, caregiver assessment and care plan, caregiver education and supports, and monitor and re-evaluate caregiver care plans.

3.9.1 Characteristics of the data collection instrument

The interview scheduled required pseudonyms, dates and respondent number for each participant. This information is right on top of the interview schedule and is followed by a section to complete respondent’s biographical information such as age, gender, level of education and duration of employment. Lastly, the interview schedule contained specific questions for caregivers and caregiver managers that related to the research objectives.

Probes are included on each interview schedule. The interview schedule for caregivers is found under Annexe G and for NGO managers under Annexe H.

3.9.2 Methods for successful conversation in qualitative interviews

Qualitative interviewing is not as easy as one perceives it to be, even when the researchers and research participants use the same vernacular (Yin 2016:144). Yin (2016:144-147) proposed the following "hints" to ensure a successful qualitative interview:

Speak in modest amounts

The researcher should try and speak less than the participant being interviewed and try and probe the participant in a manner which will provide extended monologues. Researchers need to also refrain from asking multiple questions which are entrenched in the same sentence. They should also refrain from asking multiple questions on top of each other without allowing the participant a chance to respond to the first question. To maintain a healthy conversation, the researcher should show a genuine interest in what the participants says.

In the current study, the researcher spoke in modest amounts by only asking the relevant questions as guided by the interview schedule and probing when necessary. The researcher also showed that she was generally interested in what the caregivers and managers were saying. This was evident in the researcher's non-verbal communication skills.

Be nondirective

In order for a researcher to allow participants to express their own meaning as part of their own way of understanding the world, the researcher should be as nondirective as possible. Participants should be afforded the opportunity to follow a sequence which differs from the one the researcher has planned and provided that boundaries for the interview has been set. In the current study, the researcher did not interrupt caregivers and managers during the interview.

Stay neutral

The researchers' body language, expressions and words should be portrayed with careful consideration in a neutral manner. Researchers' response to what participants say should not convey their own personal biases as this could have an effect on the participant's response. The researcher conducted the interview in a non-judgmental manner and used a neutral voice tone throughout the interviews conducted with caregivers and managers.

Maintain rapport

The researcher should maintain a good rapport with the research participant and by all means avoid conversations that might bring about unnecessary harm to research participants. The researcher maintained rapport by arriving on time at NGOs, greeting respondents with a warm smile, and was polite and respectful to all participants.

Consider using an interview guide

The interview guide should portray the broader researcher protocols that was developed but should however be modest in size. The researcher made use of an interview guide which is included in the appendices under annexe E and F. The interview guide has been described in detail under the description of the data collection tool.

Analyse when interviewing

Analysis occurs constantly during data analysis. The researcher makes decisions regarding probing, asking follow-up questions, sifting topics and also deciding when to adjust the original interview guide to be accommodative of new revelations. Analytic decisions made by the researchers should be made in such a manner that does not cause the research participant surprise. To clearly understand what respondents were saying, the researcher probed and asked follow-up questions.

3.9.3 Field notes

Field notes are a component of data collection and data analysis where recordings of unstructured observational data made by a researcher in the field during the process of data collection with the objective of enhancing data and providing a rich context for analysis (Marshall & Rossman; 2016:117-118; Yin 2016:168). Phillippi and Lauderdale (2018:281) state that the collection of field notes in qualitative data collection is mandatory as it encourages the researchers to diligently observe the environment and interactions, enhancement data collected from interviews, document observations made in the physical environment, improve on researcher impressions shortly after they occur, encourage the researcher to reflect on and identify and increase rigor and trustworthiness. In this study, descriptive field notes were taken and arranged according to the setting, participants, interview, and critical reflection (Phillippi & Lauderdale 2018:385).

3.10 Data analysis

McMillan and Schumacher (2010:56) describe qualitative data analysis as an inductive process of organising data into various categories organising followed by identifying patterns and relationships from those categories. Inductive methods of data analysis were used.

Data was analysed simultaneously with data collection. This simultaneous process of data collection and data analysis was done to enable the researcher to develop an understanding about the phenomenon in question and aided the researcher in determining when data saturation was reached.

Data was analysed according to the 6 phases of thematic analysis proposed by Braun and Clarke (2006) (in Jackson, McDowall, Mackenzie-Dave & Whiting 2018:193-203) which are as follows:

Phase 1: Familiarization

Audio recorded interviews were transcribed verbatim by the researcher. Interviews were transcribed the same day as they were conducted. This phase entailed the researcher carefully reading through the transcripts for the researcher to gain a deeper understanding into the meaning of the transcripts. The guide for transcribing audio records as described by (Moore & Llompart 2017:410-411) was during the transcription process. Moore and Llompart (2017:410-411) suggest the following two step process for transcribing:

- **Rough Transcription**
  During this step the researcher listened carefully to audio recording using noise cancelling headphones. As the researcher listened to audio recordings, verbal content of interactions were typed out without inserting any symbols.
- **Fine transcription**
  Subsequently to completing the rough transcription, the researcher went back to the saved document and added symbols that best represented the multimodal feature of the data that the researcher was analysing in-depth. Because the researcher did a multimodal transcription, it “was not necessary to transcribe absolutely every the participants did during the interview” Moore & Llompart 2018:412).

Phase 2: Coding

In this phase of data analysis, the researcher produced initial codes for the data collected. Patterns were identified in the data by grouping data sets that are alike.

Phase 3: Searching’ for themes

During this phase of data collection, the researcher generated themes by extracting, sorting and grouping relevant codes.

Phase 4: Reviewing themes

This phase involved a deeper review of the identified themes and involves 2 levels;

- Level 1: Themes were checked in relation to the coded extract.

- Level 2: A suitable thematic map of the data collected in generated.

Phase 5: Defining and naming themes

This step captured the core of what each theme consists of. By the end of this phase, the researcher was able to clearly identify what the themes are and what they are not.

Phase 6: Writing the report

The final phase of data analysis involved writing up the report by means of tables and figures in the form of word for word quotes that were used to support themes and sub-themes. The researcher considered her audience, the report was concise, coherent, logical, and non-repetitive and offered an interesting account of the story the data told.

3.11 ETHICAL ISSUES

3.11.1 Ethical issues related to sampling

Ethical behaviour represents a set of moral principles, rules, or standards governing a person or a profession to avoid evil. Beneficence (doing good) and non-maleficence (avoiding harm) are two of the most basic ethical principles. Yin (2016:47) mentions that a sample size could become a potential ethical issue if it is oversized or undersized. Research participants should not be exposed to unnecessary levels of harm and distress and should therefore be selected equitably (Yin 2016:49). The researcher in this study abided to the principle of saturation therefore ensuring an adequate sample size that was not too large or too small. The researcher also employed a sampling method that warranted only participants who have the required characteristics for the study are selected. The caregivers and NGO managers were selected from NGOs who render care to children who are differently abled, to purposefully inform an understanding of the research problems and central phenomenon in the study.

Access to participants in a research study is often dependent on a gatekeeper who possesses great power over the research participants (Yin 2016:123). Gatekeepers may pressure research participants into giving consent to participate in the research as well as influence the participants to answer in a way they deem favourable to the gatekeeper. Yin (2016:124) advises that the researcher be sensitive to the implications of how a research site has been accessed and how initial contacts might affect a study and its findings. To address ethical issues related to sampling, specifically with gatekeeping, the researcher informed NGO managers and caregivers of the potential study and issued them with information leaflets. Participants were also given and explained the content of the consent form.

3.11.2 Ethical issues related to data collection

Okafor (2011:33) defines ethics as a code of moral standards of conduct for what is “good” and “right” as opposed to what is bad or “wrong”. Kumar (2014:288) concurs with Okafor’s definition and adds that being ethical implies that one abides to the code of conduct for a specific profession and deviating from the code of conduct is considered unethical. Kumar (2014:282-289) mentions that researchers have to consider ethical issues regarding the various stakeholders involved in a research project, namely; research participants, the researcher and the funding body. Kumar (2014:284) and Ritchie et al (2014:77) mention that there are numerous ethical issues a researcher has to consider in relation to the participants involved in a research study such as; informed consent, beneficence, non-maleficence, privacy confidentiality and anonymity, justice and competency of the researcher. In this study, the researcher adhered to the ethical principles as follows:

Permission to conduct the research study

Ethical clearance

Prior to commencing with the research study, the researcher first obtained institutional approval by Unisa the Health Studies Higher Degree Ethics Review Committee. The ethical clearance certificate is included in the appendices under annexe A.

Permission from NGOs

After ethical clearance was obtained from HSREC and URERC, the researcher requested permission in writing from management at various NGOs who have been identified to potentially participate in the study. The letter seeking consent from NGOs is included in the appendices under annexe B.

Informed consent

Polit and Beck (2017:731) describe informed consent as an ethical principle where researchers are required to obtain participants' voluntary participation after the researcher informs them of all the possible benefits and risks of participating in the study. After NGO managers granted the researcher written permission to conduct the study, an appointment was made where caregivers and NGO managers were given information leaflets regarding the study. Caregivers and NGO managers who indicated willingness to participate in the study were informed on the date that interviews will be conducted. Before an interview was conducted, the participants who had indicated willingness to participate in the study were issued with a consent form after receiving accurate and appropriate information concerning the research project and participation in the research project. Participants were made aware that participation in the research project is voluntary and that no negative consequences will be suffered as a result of refusing to participate in the research projects. Participants were also made aware that they can withdraw from the study at any time they wish to. Participants were given the opportunity to ask the researcher anything concerning the research project before the consent form was signed.

Confidentiality and Anonymity

The ethical principles of confidentiality and anonymity entails protecting research participants so that their information is kept confidential and could never be linked back to the research participants (Polit & Beck 2017:719-723). To identify interviewees and ensure confidentiality, pseudonyms were given to each interviewee. This also ensured that the identity of interviewees was kept anonymous.

All personal information was removed from the data collection tool. Audio cassettes were identified by using codes and not names of participants. All transcripts and voice recordings are kept in a locked cabinet in the researcher’s office. Only the researcher has access to the transcripts and voice recordings. Only the researcher will have access to computer-based records. All computer files containing records are password protected.

The Unisa Policy on Research Ethics stipulates that data be retained for a minimum period of 5 years.

Data will therefore be retained for a period of 5 years. Thereafter documents will be shredded, and voice recordings will be deleted.

Beneficence and non-maleficence

These two ethical principles entails doing good and avoiding harm (Polit & Beck 2017:720). Caregivers, NGOs and children who are differently abled who are looked after by caregivers at NGOs will benefit from the programme to empower caregivers that was developed in this study. The level of risk in this study was medium. Caregivers were ascertained that they do not have to be anxious regarding their participation in the study. They were assured that anonymity would be guaranteed. There was a potential foreseeable risk of harm, which was minor and may have arisen when caregivers discussed the challenges they experience when caring for children who are differently abled at NGOs. It was planned that for participants who became distressed and required further psychological intervention to be referred to a clinic closest to them. Arrangements were made with staff at the NGO who were responsible for providing first aid to assist in that regard should any adverse event occur, however, the nature of the research did not pose a risk of injury to participants.

Privacy

All research that involves human beings should respect the participant's right to privacy where participants cannot be identified based on their responses. To ensure that the ethical principle of privacy was adhered to in this study, the researcher conducted a one to one basis with the door closed in a room allocated to the research at the NGO. Privacy was also ensured by giving each participant a unique pseudonym instead of using their names.

Competency of the researcher

The researcher has 13 years of experience working with NGOs and caregivers in the community and has successfully completed research projects at honours and masters levels. The researcher strictly adhered to all ethical principles, the approved proposal and her research competencies.

Respect

Each and every human being possesses intrinsic dignity and worth. All participants in the study were treated with respect, dignity and integrity regardless of their race, religions, socio economic status, educational level, culture and sexual orientation.

Debriefing of research participants

At the end of the research project, the researcher conducted a debriefing session with participants where there was a discussion with the participants regarding their participation in the research project. The researcher planned in advance that if there were any participants who experienced any adverse effects due to their participation in the research project, the researcher would ensure that the participant received intervention by referring them to the relevant health professional such as the psychologist at the local Community Health Care Center. Results of the study were disseminated to all participants during the debriefing session.

3.12 RIGOUR OF THE STUDY: TRUSTWORTHINESS

Creswell (2017:254) states that qualitative validity refers to the researcher using certain procedures to confirm the accuracy of the research findings and qualitative reliability refers to the consistency of the approach used by the researcher among different researchers and research projects undertaken. To ensure validity and reliability, the following strategies as recommended by Creswell (2017:260-266) were applied:

Credibility

Credibility contributes to a belief in the trustworthiness of data collected. Credibility was achieved through the following attributes: prolonged engagement; persistent observations; triangulation; referential adequacy and peer debriefing (Yin 2016:88). Triangulation refers to a procedure, piece of data or finding being verified in at least three different ways (Yin 2016:87). In this research study, the researcher gathered data using various methods such as individual semi-structured in-depth interviews, field notes and as observations. Data was gathered from caregivers as well as NGO managers. Referential adequacy refers to the materials, objects and tools that were used to collect and document data (Kumar 2014:380). An audio recorder and note pads were used to collect data in this study. The researcher located experts in the field of community-based rehabilitation and disability to conduct a peer review. They reviewed the insights and views and performed co-coding of the data.

Dependability

Dependability refers to consistency and reliability of research findings from data gathered even if observations are repeated on a similar sample in a similar context (Kumar 2014:219). In order to ensure dependability the research procedures and the process employed during the study has been documented in detail in order to enable future researchers to repeat the study.

Conformability

This involves ensuring that the findings reflect the results of the experiences and ideas of the participants, rather than the characteristics and preferences of the researcher (Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs 2014:5-6). In addition, all beliefs underpinning decisions made and methods adopted during the project were acknowledged within the final research report (Elo et al 2014:6). Conformability was ensured through triangulation to reduce the effect of investigator bias.

Transferability

Transferability which is related to the external validity of the research refers to the extent to which the research findings can be generalised to other people, contexts, times and outcomes (Yin 2016:106-107). Though the findings of this project are contextual, the researcher ensured external validity by conducting the research in a real–life setting as substantiated by Yin (2016:106). Detailed descriptions of the research setting and many perceptions about a research theme were provided as this will further ensure that the results were more realistic and richer (Creswell 2014:202). NGOs where participants were from were described in detail and caregivers and NGO managers who met the criteria gave their perspectives about certain themes pertaining to the research project.

3.13 SUMMARY

Chapter three outlined the research design and methodology followed by the researcher to undertake phase 1 (qualitative study/situational analysis) of the research study which was to determine the experiences and challenges of caregivers providing care to children who are differently abled at NGOs and also identify the support that managers at NGOs caring for children who are differently abled provide to caregivers. This chapter further provided a detailed description of the population, sampling, data collection, data analysis and ethical considerations. Furthermore, measures to confirm trustworthiness, validity and reliability of the study are also discussed in detail. The next chapter provides details on data analysis, data presentation, description of the research findings and literature control.

CHAPTER 4

ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

4.1 INTRODUCTION

In chapter three the research design and the methodology employed in the study were described in detail. Chapter 4 provides a presentation and analysis of data obtained through face-to-face semi-structured in-depth interviews. Thematic presentation of qualitative data from phase one of the study is presented with direct quotations from caregivers and NGO managers.

Creswell and Plano Clark (2014:247-248) reports that data analysis in qualitative research entails preparing and organising data contained in transcripts for analysis, then reducing the data into themes through a process of coding and condensing the codes, and lastly representing the data in tables or discussion. The data was analysed using thematic analysis, which is a widely used method of data analysis in qualitative research.

The researcher recorded information from the caregivers about their experiences of providing care to children who are differently abled at NGOs and from NGO managers regarding their experiences of managing caregivers at NGOs caring for children who are differently abled.

The researcher organised and prepared the data for analysis, which included transcribing interviews in verbatim through typing and writing the field notes. Transcription of interviews was done solely be the researcher. Assarroudi, Heshmati Nabavi, Armat, Ebadi, & Vaismoradi (2018:53), propose that data analysis is best conducted by coding each page of data by writing a code for the type of data, the source of data, and the pages of a transcript at the upper right-hand corner of each page of the transcript and then make copies of all the data which has been transcribed. The researcher made duplicate copies of all the original transcripts to enable; manual analysis of data, maintain an easy way of identifying various sources of data, and to analyse the transcripts manually. All transcripts were coded on the top centre of each page in the space provided in the following way: ‘T/A-3’ The letter “T” was used to abbreviate transcript, followed by the first letter of the participant’s pseudonym Amy (A) and the page number (3) of the transcript.

Data analysis consisted of two separate parts, firstly, one for the caregivers and lastly, one for the NGO managers. The data for the caregivers was analysed to explore and describe the experiences of caregivers providing care to children who are differently abled at NGOs. Data for NGO managers was analysed in reference to the support that managers at NGOs caring for children who are differently abled provide to caregivers.

The researcher analysed the significant statements, the generation of meaning units and the development of an essence description. The unitising data process was used to identify the units of meaning in the data. All interviewees were given a pseudonym and quotes from interview participants were labelled with the pseudonym to support identified sub-themes.

Data for the caregivers was analysed and presented first, then followed by the analysis and presentation of data from NGO managers.

TABLE 4.1: DEMOGRAPHIC INFORMATION OF CAREGIVERS

Pseudonym	Gender	Age	Role	Years employed	Level of Education
Ast Amy	F	48	Caregiver	1	Grade 11
Bridget	F	51	Caregiver	7	Grade 12
Charmian	F	37	Caregiver	4	Grade 11
Dora	F	40	Caregiver	6	Grade 11
Emma	F	40	Caregiver	3	Grade 11
Farah	F	48	Caregiver	3	Grade 11
Gemma	F	37	Caregiver	11	Grade 9
Hanna	F	47	Caregiver	3	Grade 8
Isabel	F	52	Caregiver	2	Grade 10

4.2 THEMES FOR CAREGIVERS

Rubin and Rubin (2012:194) describe themes as summary statements, causal explanations, or conclusions. Themes offer explanations as to the reason why things occur, what something means, or how the interviewee feels about the matter (Rubin & Rubin 2012:194). The researcher generated themes constructed from the objectives of the study as well as linking two or more concepts introduced by interviewees into one group, reasoning how they might go together as they are formulated through units of meaning. To facilitate the retrieval of what was said on each topic, data was coded, which was marked on a copy of the transcript from a word or phrase that represented what researchers thought the given participant's response meant. To generate themes with the supporting sub-themes, nine caregiver transcripts and seven NGO manager transcripts were analysed. This resulted in the formulation of five themes and seventeen sub-themes for caregivers as shown in table 4.2 below.

TABLE 4.2: THEMES AND SUB-THEMES FOR CAREGIVERS

Themes	Sub-themes
Caregivers roles to children who are differently abled at health care institutions including NGOs	● Basic care ● Medication and clinic visits
What motivates caregivers to render services to children in NGOs	● Passion ● Disabled self/relative ● Unemployment ● Pity
Caregivers perceptions regarding training offered by NGOs	● Never trained ● Content of training ● Frequency ● Need for training
Perceptions of caregivers on effectiveness of the services rendered	● Effectiveness of care
Challenges experienced by caregivers	● Initial impressions ● Rendering care ● Stress ● Lack of outside support ● Coping ● Poor community recognition

4.2.1 Theme 1: Caregivers roles to children who are differently abled at health care institutions including NGOs

Theme one highlighted different roles that are done by the caregivers in the NGOs. Theme 1 consists of two sub-themes existing underneath the umbrella of this theme. Sub-themes were generated from the themes that were mentioned above in table 4.2. The sub-headings below further illustrate the sub-themes substantiated by the transcript quotations of the caregivers.

4.2.1.1 Sub-theme: Basic care

Caregivers indicated that their main roles include provision of basic care to the children with disabilities as their recipients. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/H-1: "I teach them and stimulate them. Pampering, also teach them toiletry, teach them how to each…mmm"*
- *T/F-1: "Yoh, I take care of them, to know how they are, I feed them, I change their diapers, yes… something like that"*
- *T/C-1: "MR is the child who knows to do school but slow in the mind. The other one is hyper, but you must try to help him to write, to know how to eat, to know to bathe themselves. The other one is the CP, you must feed them, you must brush their teeth because they don't know how to do anything. You must help, like the MR, they need ummm, what do you call it…. Ummm… assistance. We bathe them, and we feed and we stimulate them, we make the stimulation, then exercise mm… and we train the other on (toilet training) coz the other one knows how to walk, but she doesn't feel nothing, maar we train them to be able to go to the toilet. She must know the toilet ".*
- *T/A-2: "Like in this job, you must bath… you must take them to bath If they are sick, take them to the clinic and ja… and you must as well as sometimes…. You must take care like your own child. Sometimes you must play with them, sing with them…mmm".*
- *T/B-1: "Yes when I pass the children, I first take off their diapers. Then I feel the temperature of the water. Then I wash the child and take a dry towel to dry the child".*
- *T/C1-2: "Like in this job, you must bath… you must take them to bath"*
- *T/C1-3: "Ja, some of them akere, they cannot sit by themselves, so you must protect them when you bathe them. The other hand is this side and on the other hand you must hold them, otherwise they will drown in the water."*

This sub-theme shows the main role caregivers partake in which includes basic care entails; bathing, feeding, dressing and stimulation.

4.2.1.2 Sub-theme: Medication

Participants showed that they are responsible for giving medication to the children who are on specific treatment for different ailments. Caregivers also alluded that they are responsible for accompanying these children to the clinic if they are sick or to get other medications. Quotations related to the sub-theme have been presented underneath.

- *T/A-2: "Some of them I… If they are taking the medication, you must know like in the morning you give them their medication. If they must go to the clinic, I go with them and take their medication. Ja, that all".*
- *T/I-1: "I also do stimulation and give them medication."*
- *T/C-3: "To stimulate them, how we must feed them, how we must bathe them. With so many things. With the medication. With so many different things".*
- *T/E-1: "Yes, medication. And we are doing class activities. Teaching them how to write, Ja. Also change the diapers. Ja- everything".*

The sub-theme described above shows that medication management is an essential part of the caregiving role.

4.2.1.3 Sub-theme: Clinic visits

Caregivers have to often take their care recipients for their check-ups at the local clinic. Clinic was the last sub-theme identified and its quotation follows below.

- *T/A-2: "If they must go to the clinic, I go with them and take their medication. Ja, that's all"*
- *T/A-2: "If they are sick, take them to the clinic and ja… and you must as well as sometimes…."*

This sub-theme shows that even though clinic visits are a part of the caregiving role, only a few participants in this study perform this role.

4.2.2 Theme 2: What motivates caregivers to render services to children in NGOs

Theme 2 relates to the motive's caregivers describe as the main reason for them to fulfil their caregiving roles. These motives are the driving forces behind caregivers providing care to children who are differently abled. Theme 2 consists of four sub-themes existing underneath this theme. Four sub-themes were generated from this theme. The sub-headings below further illustrate the sub-themes substantiated by the transcript quotations of the caregivers.

4.2.2.1 Sub-theme: Passion

Caregivers highlighted that passion is one of the motives encouraging them to continue with the caregiving role. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/E-1: "I love children, but it's the first time I am working with disabilities.*
- *T/I-2: "I like this place. The money is not good. But I feel good and happy when I help these children. It is not more about money".*
- *T/I-1: "I'm happy; I love this work to look after the disability children".*
- *T/F-1: "Long time I start to be a caregiver, but I am a normal child. So I like children… so I decided to come and take care of them. I don't care if it is a disability or what, as long as it's children I love children".*
- *T/A-4: "It makes me feel so good, and connects me with the child. I love them".*
- *T/B-1: "I am all right, I enjoy my work. When I go home and come here, I feel like they are my children".*

The sub-theme discussed above show that most caregivers in this study fulfil their caregiving role due to the love they have for their care recipients.

4.2.2.2 Sub-theme: Disabled self/relative

Some caregivers indicated that they are motivated to fulfil the caregiving role due to them having a disabled relative, or because they themselves have a disability. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/C-2: "No one, she told me, just needed a job. No one was encouraging me. My child who had CP made me have strength for working with these children and I have the knowledge to work with these children because I have experience with mine. She need care, she need love".*
- *T/D-2: "Yoh, I am so happy. At first liked to be a nurse, but the problem of the home I don't have. I wanted to care for people. I wanted to do this of myself. Even my brother at home, he was doing standard… grade one right till grade 12. When we*

started doing… when he finished grade twelve he got his result, then he was starting to run mad".

- *T/D-2: "Yes, and even my mother She passed away last month. My mother was like a disabled".*
- *T/G-1: "I didn't work in my life. This is my first job. I… don't know what I can say. I am disabled. Like the same as these children. I started walking at the age of 7 years. That's why I wanted to care for them, because I have a disability".*

The sub-theme discussed above shows that having a relative who is disabled or having a disability is a motivating factor for caregiving.

4.2.2.3 Sub-theme: Unemployment

Unemployment emerged as one of the sub-themes under the umbrella theme motivation. Some caregivers are motivated to fulfil the caregiving role, as it is their only source of income. However, this was only mentioned by two participants. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/B-2: ". Aye, but God [shaking head]. My mother is sick. I don't have a father if I don't work here where must I get money. At least with the money I receive here I manage to take care of my mother?"*
- *T/H-1: "Ahhh, so no one. No one told me. I came here because I have no job. So I came here to render the services and it helps because I have a source of income, though very less but it's helpful".*

The sub-theme discussed above shows that 'money' is not the primary reason caregivers undertake the caregiving role.

4.2.2.4 Sub-theme: Pity

Some caregivers are primarily motivated to fulfil the caregiving role out of the pity they feel for children who are differently abled. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/H-1: "This thing, I love them. I was seeing them on the street. So when I see them I feel very sorry for them. I love them very much".*

- *T/D-2: "All of that made me want to look after children who are disabled. I feel shame. I felt sorry for them".*
- *T/C-2: "No one she told me, just me I needed a job. No one was encouraging me. My child who had CP made me have strength for working with these children and I have the knowledge to work with these children because I have experience with mine. She needs care, she needs love".*

The sub-theme discussed above shows that a few caregivers in the study undertake the caregiving role because they feel sorry for their care recipients.

4.2.3 Theme 3: Caregiver's perceptions regarding training offered by NGOs

Theme 3 outlines various aspects related to caregiver training. Theme 3 consists of four sub-themes existing underneath the umbrella of this theme. Sub-themes were generated from the themes that were mentioned above in table 4.2. The sub-headings below further illustrate the sub-themes substantiated by the transcript quotations of the caregivers.

4.2.3.1 Sub-theme: Never trained

There are caregivers who have never received any training prior to resumption of the caregiver role. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/E-1: "No, I received the training only when I already started to work with the kids".*
- *T/G-1: "No, I didn't train before. I only started to train once I was working here".*
- *T/H-1: "No, I got the training when I already started here".*
- *T/I-1: "Ja, I go to the workshop for two weeks, but only after I started to work here. First time I sat down and looked at the other caregivers when they were busy feeding them. After that I feed them".*

The sub-theme identified above shows that almost half of the caregivers in the study never received training before implementing their caregiving roles.

4.2.3.2 Sub-theme: Content of training

Caregivers who have undergone training described the content of their training and they alluded that it contained a caregiving role and more specifically dealing with children with disability. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/C-2: "They train us with disability children and sometimes children with autism and the cerebral palsy and umm… I forget the other one, what we call those children. To stimulate them, how we must feed them, how we must bath them. With so many things. With the medication. With so many different things".*
- *T/E-2: "The activities for the children. How to teach those children and how to make toys… yes with boxes or waste material".*

The sub-theme identified above highlights the content of training caregivers receive to be feeding, stimulation, bathing and teaching children with disabilities.

4.2.3.3. Sub-Theme: Frequency

Caregivers narrated that their training does not occur frequently and is inconsistent. Two participants who have received training revealed that it usually happens once a year. The quotations presented below support this sub-theme.

- *T/E-2: "Ja, once a year or twice a year".*
- *T/C-2: We were going only once to train. Sometimes the other place they call us to go to the training, the other one she comes here to train".*

The sub-theme identified above shows that caregiver training is insufficient.

4.2.3.4 Sub-theme: Need for training

Most caregivers expressed their need for training and indicated that the training will help them to acquire skills needed to teach those children to write and to help them to address those children's basic needs. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/D-2: “ehhh [laughing], aye, life is too painful. I can’t say it’s enough just because more kids are coming. I need more training for me. I want to train about teaching children. And for stimulation. I want to teach children to write, and to learn how people's lives must go. They must live like any people. They must, to take the children, maybe sometimes to go to the park to show how people, other people live because the other children don't go outside”.*

- *T/I-2: “I need help. Like for the training. Training I need for stretching them, and for feeding. These children, CP, they take a long time to swallow. I also need training for positioning them. I also need more training to know what is wrong with the children. That is the main thing that I need. I want it”.*

- *T/E-2: “Hey…. More education. Skills how to handle them, how to make them sit, how to feed them. I need to know what is wrong with them. I need to understand the condition of the children”.*

- *T/G-2: “More… more training because we have a different child with a disability . Today they have a child like this and we don’t know her or him, you understand. Tomorrow comes another child. We are supposed to need more training, because we don’t know them at the same, one place. I need more training, more training, and more training”.*

The sub-theme identified above shows the urgent need caregivers have for training. All caregivers in the study mentioned that they need further training.

4.2.4 Theme 4: Perceptions of caregivers on effectiveness of the services rendered

Theme 4 related to the perception caregivers have on the effectiveness of the services they render. Theme 4 consists of two sub-themes existing underneath the umbrella of this theme. Sub-themes were generated from the themes that were mentioned above in table 4.2. The sub-headings below further illustrate the sub-themes substantiated by the transcript quotations of the caregivers.

4.2.4.1 Sub-theme: Effectiveness of care

Some caregivers regard the services they offer as being effective because it makes a difference in the disabled children's lives from creeping to walking due to the training they provide to them as they provide care. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/F-2: "Yes, I am helping the children, but I want to give more service. So that I know how to help them more, yes. First time when I came here there was another girl, she didn't walk, she was just creeping and crawling. But as we trained her she walked . We are helping the children a lot".*

- *T/H-2: "Yes, it is helping them a lot. Because the other one when they came here, they didn't know all these things. They were crying all day, crying, crying. But now they are ok, they can talk to us. Someone they can go to the toilet. They can say we want food, we want water. Yes, we can see that there are changes… it is hard to explain. Because there are a lot of changes here. When I came here, it was not like this. But now you can see a light".*

However, there was one participant who felt that the care provided is partially effective because the participant felt that the service she provides is not good enough. See the quotation below:

- *T/F-3: "My stress is I feel maybe I didn't work well here with their children. Like I am not doing a good enough job".*

The sub-theme identified above shows that majority of caregivers in the study regard the services they provide to children with disabilities as effective.

4.2.5 Theme 5: Challenges experienced by caregivers

Theme 5 highlighted the challenges the caregivers experience in their caregiving role. The challenges experienced included shock from seeing these children who cannot do anything for themselves others can't even talk or move thus requiring to be assisted with activities related to basic care. This theme consists of six sub-themes existing as described underneath. Sub-themes were generated from the themes that were mentioned above in table 4.2. The sub-headings below further illustrate the sub-themes substantiated by the transcript quotations of the caregivers

4.2.5.1 Sub-theme: Initial impression

Caregivers report their initial reaction of the caregiving context to be shock, sadness and fear. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/A-1: "First time I was so shocked; I was like whoooooo. I am going to work here? But as the time goes, I see them just like any other child. Some they respond with their hands who can't talk, some they can talk, but they cannot talk properly".*

- *T/E-3: "I came here knowing nothing, but right now I am OK, but I want to know everything on how to care for the disabled children. At first I was very stressed.*

- *T/I-2: "I feel so bad. The first time, haai… it was so tough. Very tough. I was scared. But now I am happy".*

The sub-theme identified above shows that caregivers are not prepared for what to expect for when they first enter the caregiving context. Caregivers are initially shocked by the presentation of the children they are to provide care to.

4.2.5.2 Sub-theme: Rendering care

Caregivers express challenges relating to the main role, which is to render care to children who are differently abled. These challenges include challenges related to bathing, dressing, feeding, positioning and stimulation of their care recipients. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/A-1:" I see them like other children. If they are naughty, I beat them.*

- *T/B-2: "Aye… medication. The medication confused me, but I want to try my best... I don't do it and I want to do it, but it is difficulty".*

- *T/B-3: "There is another child here who was wearing diapers. I taught him how to go to the toilet. I told him "if you do not talk, I will beat you".*

- *T/A-3: "Ja, for the first time I had problems, but know I know. Even though I don't use the table I know in the morning, I must give what and what and what. In the night this and this and this… I know them all now".*
- *T/C-3: "Because of the other children it's a different child. The other one maybe the parents bring the children and we don't know how we must treat the children. We don't know how we must try to help them, especially those who are too hyper"*

The sub-theme identified above shows that most caregivers in the study experience challenges related to their caregiving roles.

4.2.5.3 Sub-theme: Stress

Stress is one of the sub-themes that emerged under the umbrella theme challenges. Caregivers experience stress as a result of their caregiving role. The quotations presented below are the ones found suitable in supporting this sub-theme:

- T*/A-3: "I was so scared and worried when I saw their hands because I didn't know when you eat the hands each and every day they become so white".*

- *T/F-3: "I just experienced some parents are not satisfied. They just came here talking bad. It's the experience I have. I sometimes feel stressed and tired. But that stress I didn't take at home. We talk here and finish here".*

- *T/H-3: "Is the parents, she came here, and I told her, her child is not going to the toilet. She told me I'm lying [crying]. It was painful, it was very painful".*

  - *T/I-3: "I sometimes stress, yoh… this children makes me stressed. Some of these children can beat you. When I'm stressed here my head pains".*

  - *T/F-1: "My stress is I feel maybe I didn't work well here with their children. Like I am not doing a good enough job".*

The sub-theme identified above shows that caregivers experience stress, as they are not equipped with the relevant skills and knowledge to render care to their care recipients. Two caregivers report the parents of the children they render care to as the source of their stress.

4.2.5.4 Sub-theme: Lack of outside support

Lack of outside support posed as another challenge caregiver's experience. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/F-1: "No, no one. No one else supports me".*

- *T/H-3: "Yes, I need someone to talk to because I can't deal with it myself.*
- *T/C4: "-No, nothing, we don't [laughing]. No support from outside.*

- *T/E/3: "No outside help, everything just happens here".*

- *T/F-3: "No, I don't get them. For now, they don't send me when I need support. I don't know, maybe next time when I need help… yes. If I have challenges, it is the managers who support me."*

- *T/H-2: "No support. And we want someone who can counsel us. Because sometimes we get a lot, so much stress ".*

The sub-theme identified above shows the need for caregiver support from outside, which is currently not provided to caregivers. Even though caregiver require outside support, it is not provided to them.

4.2.5.5 Sub-theme: Coping

Caregivers experience difficulty coping with all of the challenges they experience. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/A-4: "Ummmm, sometimes I use the painkillers, but I don't drink it regularly. I like to drink it before I sleep. I drink it and I sleep. In the morning, I wake up well".*

- *T/B-3: "I would go and sit in the toilet and drink warm water. When I go home, I would drink".*

- *T/H-2: "Aish I don't cope; I just buy pills, Disprine, and drink it. I get a lot of headaches. Lots of headache".*

- *T/I-3: "I tell the supervisor or the manager to help me. I take medication, Panado, when I have a lot of stress"*

The sub-theme identified above shows that some caregivers in the study make use of maladaptive coping strategies to an extent of taking pills in order to be able to sleep.

4.2.5.6 Sub-theme: Poor community recognition

The caregivers showed that there is a lack of community support offered to these children who are differently abled, which may be related to poor community recognition or lack of understanding by community members. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/C-3: "They don't know. Like how I saw my child. The community doesn't know how to help me with my child. They were feeling so scared of the disabled children. They don't know how I manage with the disabled children. I say how I manage, because it is my children. No one can say I don't want these children. I must make sure I can handle these children because God gave me these children. I must handle them".*

- *T/E-2: "No, they don't know, and they don't understand them. I would like them to know".*

- *T/F-2: "no, they didn't know. Some of them ask me what kind of a crèche is it where you work, and I tell them. Others talk about the money "ja, eengi, eengi, you get some more money because you work with disabilities". They didn't want it to know what kind of children I work with and what I do with them. They just talk about the money".*

The sub-theme identified above shows that caregivers in the study do not believe the communities in which they work recognize the valuable work they are doing at the NGOs. One caregiver stated that people in the community have stigma toward children who are differently abled. Caregivers also reported that people in the community do not know and do not understand what they do at the NGOs. Community members also do not understand why caregivers prefer to care for children who are differently abled

4.3 ANALYSIS, PRESENTATION AND DESCRIPTION OF THE FINDINGS FOR NGO MANAGERS

The population in this study consisted of caregivers and NGO managers. Data for caregivers has been presented and described above. This part of the data analysis focuses on data analysis for NGO managers. Seven NGO managers were involved in this study. The demographic data for NGO managers have been presented in table 4.3 below. Followed by the description of different themes and sub-themes.

TABLE 4.3: DEMOGRAPHIC INFORMATION OF NGO MANAGERS

Pseudonym	Gender	Age	Role	Years employed	Level of Education
Jane	F	52	Manager	11	Grade 12
Kelly	F	48	Manager	25	Grade 10
Lina	F	50	Manager	7	Grade 12
Maria	F	35	Manager	7	Bachelor’s
Nelly	F	51	Manager	7	Grade 12
Onica	F	53	Manager	7	Grade 10
Precious	F	21	Manager	1	Bachelor’s

4.4 THEMES AND SUB-THEMES FOR NGO MANAGERS

To generate themes with the supporting sub-themes, seven NGO manager transcripts were analysed. This resulted in the formulation of five themes and twelve sub-themes for caregivers as shown in the table below. This resulted in the formulation of five themes and twelve sub-themes for NGO managers as shown in the table 4.4 below.

TABLE 4.4: THEMES AND SUB-THEMES FOR NGO MANAGERS

Themes	**Sub-themes**
Processes followed in the appointment of a caregiver	● Requirements for appointment ● Age ● Readiness
Monitoring caregivers as outlined by NGO managers	● Method of monitoring ● Frequency
Challenges related to the management of caregivers	● Lack of training ● Lack of resources ● Poor communication skills
Managers expectations from caregivers	● Basic care ● Medication
Support offered to caregivers	● Internal support ● External support

4.4.1 Theme 1: Processes followed in the appointment of a caregiver

Theme 1 highlighted the processes followed by NGO managers to appoint caregivers. Three sub-themes emerged from this theme as presented in table 4.4 above. The sub-headings below further illustrate the sub-themes substantiated by the transcript quotations of the caregivers.

4.4.1.1 Sub-theme: Requirements for appointment

This sub-theme addressed the process NGO managers use when appointing a caregiver. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/J-5: "I told one of them here, I said "Hey girl, don't you know somebody who can come and join us here?" But some they bring their CV's here".*

- *T/K-1: "When they want a job, they submit the CV to head office and interview at head office".*

- *T/L-1: "Ok, when I hire a caregiver first of all I have to do an interview. After that, we give her some time. Then if we see that person she can work, then we call her so that she can start to work".*

- *T/M-1: "Yes, they do send CV's to those that can, otherwise, we just ask them to make an affidavit, who they are and their request and then I call them for an interview. From there on if it's a list I tell them "you are number three on the list" and then if you are called you will be working in this particular class. If they want to prepare themselves, they can prepare themselves. Unfortunately, the last caregiver that we employed had to start like the next day. But she was ready. She was ok with it".*

- *T/N-1: "Yes, we do assess them, because they send in their CV's. And then after that we ask them when they can come for an interview, we sit down with them, talk to them and learn how old they are, how experienced they are with children and how willing they are to learn working with these learners. Because they don't just come and know how to care for the little ones, and we do assess them".*

- *T/P-1: "Ok, so when we appoint a caregiver, the post is being advertised. Before they did not require matric, but these days we do require matric and at least with the certificate, you know others do have a communication care worker certificate, others did a bit of home based care training. So that is an advantage for you to be appointed or for you to get a job here. So they type the post and advertise it from the head office".*

The sub-theme identified above shows that there are inconsistencies with the procedure NGO managers use to hire new caregivers. None of the managers mentioned assessing skills and knowledge as part of the appointment process.

4.4.1.2 Sub-theme: Age

The age of potential caregivers is one of the most important aspects NGO managers consider when appointing caregivers. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/M-1: "The main thing that I look at unfortunately… I try not to employ very young caregivers. Mainly because some of them don't have kids and they get traumatised. So I will go for 30 above or 35 above. And that age group since we started, I find to be more stable and more reliable. Because if they are younger they still have other things to do like they are looking for a job and then in the middle of the month they just tell you "no, I got a job" and then they leave. So I will have to start training again. Thirty-five and above they are more stable, they are more matured in a way".*

- *T/N-1: "What I look at most of the time, I look at the age of the person. I believe that working with older people is better with these little ones because they need special care. The older people are more patient and more caring. So most of them already have kids of their own, so they know how to take care of children. So it needs all of your attention when dealing with these little ones. So if we look at younger people or younger generations, we find that most of the time they are on their phones. Even when the child there is having some seizures or something, they won't even recognize the child is suffering from something. Because they are always on their phones. And most of them don't respect their elders and they don't have that special care for little ones. Even for their own children they don't care for them that much. You find only a few do care. So with our learners we need a person with perseverance, is caring and loving".*

The sub-theme identified above shows that age is another important criterion NGO managers consider when hiring caregivers. NGO managers believe older caregivers are more mature, caring, stable, reliable and loving. They also believe older caregivers provide better care to children who are differently abled.

4.4.1.3 Sub-theme: Readiness

This theme relates to NGO managers' perception on when caregivers are ready to resume their caregiver role for the first time. The quotations presented below are the ones found suitable in supporting this sub-theme.

- *T/K-1: "I feel best when they know about disability children. Yeah, sometimes they go to training but not always before, they start".*

- *T/L-1: "Yes, yes, because firstly, we must show her all the work and if she is interested, she must come back tomorrow and work. If there's nothing or she's not interested, she* won't *come back again. She ran away. So if she comes back then she's ready to work with the children".*
- *T/N-1: "Before we can take someone to come and work with us, we put them on probation for a month or maybe two months and every three months we also do the assessment and see how they are".*

- *T/M-1: "Yes, after, maybe we assist them until we see that maybe no, this one can work alone... about two months to three months. That is where we can see now that the caregiver is coming right now".*

The sub-theme identified above shows when NGO managers feel caregivers are ready to fulfil the caregiving role. Most managers do not require caregivers to poses the required skills and knowledge necessary to care for children who are differently abled.

4.4.2 Theme 2: Monitoring caregivers as outlined by NGO managers

Theme 2 demonstrates the process NGO managers use to monitor caregivers. Theme 2 consists of two sub-themes existing underneath the umbrella of this theme. Sub-themes were generated from the themes that were mentioned above in table 4.5. The sub-headings below further illustrate the sub-themes substantiated by the transcript quotations of the caregivers.

4.4.2.1 Sub-theme: Methods of monitoring

This sub-theme relays the specific methods NGO managers use to monitor their caregivers. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/J-10: "Eehh… I come here every day, I monitor them. When they bath the kids I must make sure I am here. When they dish up, I must make sure to see what kind of a food they give the kids because I have a menu here. And then they must cook what they see there. I then also have these soft diet kids. I don't want them to give the soft diet ones you see… I must make sure that they cook the soft diet for the soft diet kids and the normal diet for the others. So I monitor them all night, in the evening when I go home I must make sure all the kids are bathed, they wear their pyjamas. Some are in the bed; some are watching TV…. And the supper is ready".*

- *T/M-3: "We look at the job description. And then we look at their classroom allocation and activities. So we will have a list of what they expected to and then go through that list. And whatever they are not able to achieve, we will check the reasons behind that and try and help them achieve".*

- *T/K-3: "When the children come at the centre, when we start, I go to all the classes…class to class to class. I go and see everything that they do".*

- *T/L-2: "I do have someone doing admin. My admin each and every day after she knocks in, she goes to the wards and checks the details for the caregivers in the book. When I came, I asked her what went wrong, and she will give me a report. Then I go back to the wards and I check for everything".*

The sub-theme identified above shows the monitoring of caregiver to be inconsistent and unreliable. Most managers monitor caregivers by observing them while they are involved in their caregiving duties.

4.4.2.2 Sub-theme: Frequency

This sub-theme relates to how often caregivers are monitored. The NGO managers indicated that monitoring is done during specified periods for example twice a year. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/P-2: "They are assessed twice a year".*
- *T/M-3: "This year we did not do it at all, but we do it quarterly.*
- *T/N-1: "At least after 3 months. Every month I call them and sit down with them "how do you feel working around these learners?" Most of them, they tell you "yoh, the first day, the first week, I almost took my bag and went home". But they grow to love these young ones. And obviously they end up getting a bond with the kids. It takes almost 3 months".*
- *T/L-2: "Almost every day. I assess them. I just look at what they do".*
- *T/P=2: "They are assessed twice a year".*
- *T/M-3: This year we did not do it at all, but we do it quarterly".*

The sub-theme identified above show that caregivers are not monitored frequently and that there is no set time frame for monitoring caregivers.

4.4.3 Theme 3: Challenges related to the management of caregivers

Participants highlighted that there are specific challenges encountered when managing caregivers. These challenges are related to training, resources and communication. This theme consists of three sub-themes seen table 4.4 above. The sub-headings below further illustrate the sub-themes substantiated by the transcript quotations of the caregivers.

4.4.3.1 Sub-theme: Lack of training

This sub-theme relates to caregivers not being adequately trained and the scarcity of training opportunities available to caregivers. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/O-1: "Yes, we do see the support that they need like training, sometimes they need training on how to deal with the conditions, because there are different conditions. Support, how to support the child, how to feed the child. So we do need support like that.*

- *T/P-2: "just feel like they are still in need of some more training because like now we are facing COVID-19 and some of the caregivers haven't gone for COVID-19 training which I feel is important they need to go to. And then also training on computer skills, because we do have some other caregivers here who have to record the relevant information they need to for the children, because they are still behind when it comes to that".*

- *T/P-3: "I am sure the skills, I think that is the main problem. Once they have the skills they will do their job better, and they will feel better, even me. Even me, I need more skills and knowledge. They need support on how to manage and deal with stress. There are a lot of caregivers who experience stress. Especially the first time when they deal with the children. Especially when you see this child, the disabled child, you tell yourself 'no, I can't do it', but when time goes then you tell yourself you will be fine".*

- *T/M-4" "At the moment my frustration is that I have an increasing number of children with autism and I don't have a caregiver that is strong enough to deal with children with autism. It's a bit of a challenge".*
- *T/N-2: "We really need first aid training, unfortunately the Department of Health promised to help us with that but it seems like they are also struggling to get the training done for us. But hopefully maybe next year things will be better. They also need to know more about these learners because the children are not the same. Our learners are always deeper learners, so we need to learn more and how to help them in our programme that we have with our learners. They also need personal knowledge or personal information. They also need to learn more about*

them, not only general knowledge but you know when you do something at your corner there is a way of doing things".

- *T/K-4: "Eehhh, it's the training! [Laughing]. It's the training, serious. The training is the biggest problem. We need more training, serious".*

The sub-theme identified above shows that all NGO managers experience the lack of training of caregivers as a challenge. All managers in the study revealed their major challenge is lack of caregiver training which makes is difficult for caregivers to render care to children who are differently abled at the NGO.

4.4.3.2 Sub-theme: Lack of resources

NGO managers experience the lack of resources as a challenge, which makes it difficult for them to effectively manage caregivers. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/P-2: "There is always a shortage of resources. We have a shortage of wheelchairs; we do not have enough tables for the kids, and also enough chairs, so ja, resources are a big problem, you can imagine".*

- *T/M-3: "At the moment we don't have communication boards and we have a good number now of children with autism. We don't have communication boards, we don't have um… our toilets are not very friendly, very spacious. We struggle to get I don't know what they call those handles that they can use from the sides. So we struggled a bit to get those. And then sensory therapy equipment, we don't have that".*

- *T/L-2: "Ok, sometimes they experience things like we don't have enough stuff, like soap, diapers, and some of the things they are using, they get frustrated".*

The sub-theme identified above shows lack of resource as another common problem managers experience. Some NGOs lack basic necessities such as soap, diapers and therapy equipment.

4.4.3.3 Sub-theme: Poor communication skills

Communication was the last sub-theme found under challenges that NGO managers experience managing caregivers. These participants alluded that most of the caregivers lack communication skills see quotations presented below:

- *T/P-2: "As I said, um, communication is a challenge because a lot of things I have to do for them because most of them don't have skills like computer training so even when it comes to all the information that needs to be processed when it comes to kids, I am the one who needs to do it for them. Whereas they can be the one who does all that for the kids. Education also comes once in a while. They bring activities here, they bring assessments. Some of them as they don't have matric and are old, they are not really good at reading and they are also not really good when it comes to writing, so sometimes it is a challenge, I have to explain to them what this means or how they should write it.*

- *T/N-2: "Sometimes they do feel scared to come to me as the manager, but I try to be as open as possible and to tell them that I am also human. They don't have to be scared to come to me if they have something to say. Sometimes I also tell them that we are a team, I am not the boss. I am also a staff member. And when we do something in the centre, I also tell them I am not scared, I also take a mop and mop. Every morning I do take a mop and feather dusters. Mop the floors, dust the cupboards. I do things with them and encourage them not to be scared to do things, like cleaning or whatever they are doing".*

- *T/J-8: "You know, maybe they are scared of me because they don't come to me. They gossip on their own. Maybe you can hear someone, maybe sometimes you call someone and do something, maybe in passing you hear… "Yoh, this one – she got a problem blah... blah... blah… I always tell them, if you have a problem, please come to me, don't be scared".*

The sub-theme identified above shows communication an additional challenge NGO managers experience when it comes to managing caregivers.

4.4.4 Theme: Managers expectations of caregivers

Theme 4 brings to light the expectations NGO managers have of caregivers when fulfilling their caregiver role. This theme consists of two sub-themes which were generated from it see table 4.4 above and their description has been included underneath with relevant quotations per sub-themes.

4.4.4.1 Sub-theme: Basic care

The sub-theme describes the basic care NGO managers expect caregivers to provide to their care recipients. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/P-1: "OK, so they as you know some of our kids cannot feed themselves. So they feed them, they bath them; they change their diapers and most importantly stimulation. Stimulation is important; once in a while, we do take them for stimulation programmes so that they know how to stimulate them. And then they also teach them, like we do have songs in the morning we teach them. They colour, they draw, those who can draw. So ja, all those kinds of things".*

- *T/N-2: "They have to welcome the learners from their transports. Make sure that they are clean at all times. Make sure that their environment, their classes are also clean. Before the learners arrive, the classes must be clean, no papers, it must be spotless. And then when the learners arrive they must be already ready to receive the learners. And make sure that the learners are ready. When the learner maybe from transport if the learner is already messed up the learner must go straight to the bathroom before they go to the class. And even the learners' appearance, their face must be always clean, even those who are drooling, their faces must be always wiped. Our learners look very good and very clean".*

- *T/M-2: "Ok, the first thing when the kids come, they do assessment. Full body assessment to check if there are no scratches or injuries so that we can report to* *parents, because sometimes they get injured in the transport and the parents will think the injury happened at school. So they do the first body assessment. And the 7 o'clock kids that take medication, normally they will eat at home and then they drink medication here. So they know how to do all the measurements for the medication. And then classes start. Those who are on the list for potty training, they have a roster for them. Then they will start with potty training. Now we provide them with breakfast, lunch, and snacks. They will follow the programme. We've got a programme, breakfast, exercise, activities then its lunch then its snacks. So they will go according to the programme".*

- *T/L-1: "They just feed the kids, change them, and then look after them, and take them to the hospital and the clinic because the children go there sometimes. They do work day and night. Some of them they take 7 days off and 7 days in, but during this pandemic they don't go home for 7 days, and then on Monday the go home for 7 days and the other shift they come in".*

The sub-theme identified above shows that managers expect caregivers to perform basic task when rendering care to their care recipient. Most managers state that the caregiving role entails basic care of the children such as; feeding, bathing, changing nappies, dressing stimulation, exercise, taking children to the clinic and administrating medication to children who require it.

4.4.4.2 Sub-theme: Medication

NGO managers expect caregivers to manage the medication of the children available at the NGO as their customers. This includes administering medication. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/O-1: Everything that needs to be done, especially for the children. They do exercises, they take care of the children like feeding, diapers, everything. Some of them give medication".*

- *T/N-2: “. They feed them on time and the medication is between 8 o’clock in the morning and 2 o'clock in the afternoon. So they also make sure the learner gets the medication on time, fed on time, even those who swallow slowly, they know how to handle them”.*

- *T/J-2: “No they don’t know what epilepsy means. They just saw the child fall down and it’s just like that. They don’t know what is happening to the child at that time. They don’t understand the condition. That is why I sometimes tell the caregivers “listen guys, when you give the child medication like most of the children here… like most of the children here, they are epileptics and they are chronic. So I told the caregivers “when you give the medication, don’t miss the time… the time is very important… neh… because the system must catch up the medication on the right time. You can’t give the children a medication at 10, 11…1... You know… That is where we are going to experience more of an epileptic child. So when we give them in time - let me say maybe you gave them at nine o clock, let it be nine o clock… don’t change the time! So that you are not going to experience more of the children falling for epileptic – and indeed we don’t. They come here, the children came here, and we can hear the parents say they are continuous… this child he or she is continuously fitting you know. Then when you take the child, I, I, I … when the parents tell me that, I already know that there is something wrong with the medicine. So that’s where I start now targeting the time, trying to give the child a medicine at the right time. Aahhh… within a week that child will never fall down”.*

- *T/L-1: “Yes, they do give them medication, but not all of them”.*

The sub-theme identified above shows consistency regarding medication management of caregiver roles between caregivers and NGO managers.

4.4.5 Theme 5: Support offered to caregivers

Participants indicated that caregivers need support both internally and externally. Theme 5 relates to the support the NGO offers to caregivers; it consists of two sub-themes as outlined in table 4.4 above. The sub-headings provided below further illustrate the sub-themes followed by quotations from participants.

4.4.5.1 Sub-theme: Internal support

This theme shows the internal support that is offered by the NGO to caregivers. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/J-8: "Like… eeeh... sometimes I told them "you guys, you are doing so well. The way I saw these children it shows me you are giving them medication, because if you have not done this I will see it very quickly". And then they even remind me when the kids are ready to go to the clinic. They even divide themselves. They take someone who is on night duty or even off and say "come and help us to take the child to the clinic".*

- *T/J-9: "By saying "you know guys, what you are doing is good and then one day, one day you are going to see a difference. There more I go up and down running around, you will definitely find someone who is going to pay you. Keep on the good job you are doing".*
- *T/N-5: "What I normally do. We have briefings every week, where we sit around and talk with them. Tell them what we are expecting to do that week, and those who are expecting to go to the clinic for their chronic treatment, they also inform us, and we have a form they fill for when they are taking the kids to the clinic or for check-ups and so on. And if they have a need at home, they are also welcome to come to the office to tell us their challenge. And if we can, we help them".*

The sub-theme identified above shows that NGO manager provide support to caregivers in the form of verbal praise, weekly meetings and general encouragement.

4.4.5.2 Sub-theme: External support

The final sub-theme identified under the theme relates to the external support caregivers receive. The quotations presented below are the ones found suitable in supporting this sub-theme:

- *T/J/11: "I always talk with social development to tell them to come and monitor the place. And then you know social development is social development… They come, they monitor the books and they tell me what to do. And then I actually do what they said I must do. I make the narrative for the department. The other stakeholders, they don't know me. I have a website here, if you can go to www.xxxxx.org, you will find us there. So some of the stakeholders get me there. Sometimes I just get a call from somebody that I don't know, and they said we see your Organisation on the website, we want to bring some food for the kids, or toys, or what do you want for the kids. The website has been a good tool for collaboration. I also go out to institutions like the university when I see these kids need OT's or Dental for these kids because I know Sefako Makgatho has speech, Dental OT, Physio… they have everything. Like even now, we don't have wheelchairs, the buggy ones. The only place I can get the wheelchair is Sefako Makgatho. When you go to SMU, you ask for the student to come and see the children, you make a good friendship with them. They know that there is M….Centre and CP children who need the buggy. It's easy for kids to get the Madiba Buggy".*

- *T/P-2: "Um, we are trying together with education to implement new training for the staff. As I am speaking right now, they have just finished one training session yesterday. Training was held online as you know we can't meet or do anything in person. They are now using WhatsApp for training. They are now using Zoom for training. So every now and then new training programmes are being implemented".*

- *T/M-3:" For example, now, last month, the Department of Education invited them for training on feeding. So now it's these online things. They struggle, with technology they struggle. But, they will give us positioning and the Department of Health organised on how to make toys, you know. Cost effective toys and the manager got training on the basic computer skills. The OT students when they come here, they show them how to make wedges, rollers. I write a letter to avail our services for the students, I normally write a letter to the OT. Their physios sent us a request. And then with the councillors in the community there may be too much dust, we will ask the councillor to get rid of the dust. We also normally visit* *pick n pay and ask for whatever donation we need. Normally Pick n Pay and Checkers".*

- *T/K-3: "Yes, because the people of education, they support too much about the toys. We also get the wheelchairs and the buggies. But the training I need, I need it – serious".*

- *T/L-3: "I tell them if the other stakeholders are here, like the university, they join them and show them how they must work with the kids. Even the Department of Education. Like if they are here, they call the caregivers and join them and show them how they must teach the kids".*

The sub-theme identified above shows that very little outside support is afforded to caregivers to help them cope with the numerous challenges they face.

4.5 SUMMARY

Chapter 4 provided details on data analysis, data presentation and description of the research findings has been done in chapter 5 of this study. Thematic presentation of qualitative data from phase one of the study was present with direct quotations from caregivers and NGO managers. The researcher generated themes from the available transcripts and sub-themes derived from caregivers and NGO manager's common responses, with their responses further being used to support the sub-theme. A clear outline of the themes and consequent sub-themes referencing the participant's responses was provided in the outcome statement.

A summary of findings from chapter four reveal the caregivers role to entail providing basic care to children who are differently abled, administering their medication and taking them to the clinic for their check-ups. Furthermore, results indicate that caregivers have different motives for why they perform the caregiving role. Motives range from passion right through to pity. Findings from this study highlight the crucial need for caregiver training as all caregivers in the study reported an urgent need for training. Most caregivers, except one, perceived the services they offer to be effective. Caregiver's experience numerous challenges related to their caregiving role. These specific challenges were found to be challenges with; rendering care to their recipients, stress, coping strategies, lack of outside support and poor community recognition of the caregiving role.

There are inconsistencies with the procedure NGO managers use to hire new caregivers. There is a trend among NGO managers to hire caregivers who are above 35 years of age. Managers first allow newly appointed caregivers to work with other caregivers before they feel they are ready to work independently. The monitoring of caregivers is unreliable, inconsistent and occurs infrequently. One of the major challenges caregiver managers experience is the challenge related to caregivers not having the skill and knowledge to care for children who are differently abled due to their lack of training. NGO managers also experience communication challenges with caregivers. An additional challenge NGO managers experience is lack of resources at the NGO for caregivers to optimally carry out their caregiving role. The expectation of managers of their caregivers is consistent to what caregivers in the study revealed their roles to entail, which includes basic care and administering medication. All caregivers receive internal support from NGO managers. Outside support is offered to NGOs but not from many sectors. There is no outside support available to caregivers who experience physical and psychological challenges.

CHAPTER 5

DISCUSSION OF RESULTS

5.1 INTRODUCTION

Chapter four provided a presentation and analysis of data obtained through face-to-face semi-structured interviews. Thematic presentation of qualitative data from phase one of the study was presented with direct quotations from caregivers and NGO managers. In chapter five, the thematic presentation of qualitative data from the caregivers and NGO managers is interpreted and discussed in view of relevant literature with the detailed elements of a particular theme being discussed. The discussion is divided into two parts. The first part is discussion of results obtained from caregivers and the second part is discussion of results obtained from NGO managers.

5.2 DISCUSSION OF RESULTS OBTAINED FROM CAREGIVERS

5.2.1 Theme 1: Caregivers roles to children who are differently abled at health care institutions including NGOs

All caregivers reported that their caregiving role entails providing basic care to children who are differently abled at the NGO where they are employed. The basic care caregivers provide to the children includes bathing, feeding, nappy changing, stimulation and potty training. Most caregivers mentioned that part of their caregiving role entails giving the children their medication. Regarding medication, one caregiver expressed her intense fear of giving children their medication, however, does have a desire to learn more about medication so that giving children their medication can also be added to her caregiving role.

Taking children for clinic visits is a role stated by two participants in the study, as parents are unable to take children to the clinic during the clinic operating hours. One caregiver reported to be performing general caregiving roles for the children as well as basic roles that are usually performed by support staff and cleaners. These general roles included cooking for the children and cleaning of the NGO premises. Performing general and specific roles makes it very difficult to manage her time.

Caregivers caring for children with intellectual disabilities report an additional role, which is the role of a teacher, where children are taught basic concepts. Caregivers are responsible for the emotional and physical support for those individuals who are unable to take care of themselves due to physical, emotional and cognitive impairments (Geiger 2012:10). Schulz and Eden (2016:41) report that the caregiver role varies and changes over time based on the changing needs of the care recipient. The caregiving role revealed in this study is discussed under the three sub-themes below.

5.2.1.1 Sub-theme: Basic care

A caregiver can be any individual rendering acts of nurturing or attending to someone who is in need of such services. The act of caregiving echoes the uniqueness of the caregiving role that entails providing emotional support, support with health and medical care, support with basic activities of daily living and referrals to relevant medical team members when the need arises (Schulz & Edin 2016:41). Caregivers could be formal or informal. What distinguishes the two categories of caregivers are the skills and knowledge of the caregiver and remuneration for caregiving services they receive. Formal caregivers are considered to be equipped with the required skills and knowledge to render care, to care recipients (Musich et al 2018:153). Majority of caregivers in the study reported their essential caregiving role to be that of providing basic care to children who are differently abled.

Basic caregiver roles revealed in the study concurs with (Schulz & Edin 2016:61), who regard the caregiving role as being diverse. Caregivers take on miscellaneous tasks, which makes their role to encompass numerous activities. Similar to findings from the current study, Coetzee (2016:160) mentions caregiving tasks to include; bathing, dressing, feeding, diaper changing, medication management and stimulation of care recipients.

Providing care to children with severe disabilities is a complex task due to the nature of disabilities these children present with. Due to lack of resources and availability of rehabilitation specialists, many children who are differently abled do not receive the appropriate care they need. To counteract this, a model referred to as ‘the medical home model' was established by the American Academy of Paediatrics in 2002 (Medical Home Initiatives for Children With Special Needs Project Advisory Committee 2002:185). This model proposes that children who are differently abled should receive continuous medical care in conjunction with health professionals that are community centred and culturally appropriate.

From what was revealed in this study, it is evident that the caregiver role is one that carries with it a high level of responsibility. Zarit (2014:1812) argues that those who are in need of caregiving services and do not receive it, have lower life expectancies. Numerous authors concur that without the services of caregivers, the burden on the health care system would be higher as more individuals would require to be hospitalized or placed in rehabilitation and care facilities (Northouse, Katapodi, Schafenacker, Weiss, 2012:243, Kutner & Kilbourn, 2009:844 and Porter, Keefe, Garst, McBride & Baucom, 2008:312).

5.2.1.2 Sub-theme: Medication and clinic visits

A frequently performed role of caregivers is that of managing a care recipient's medication. Caregivers are often not equipped with the skills and knowledge and are not prepared to manage intricate medications schedules of those they render care to (Look & Stone, 2018:423). More than half of the caregivers in the study have the role of medication management. Look and Stone (2018:425) contend, "Medication management is complex and involves many physical and cognitive activities for caregivers".

Despite the numerous challenges caregivers experience with medication management, they still do express the desire to learn so that they could optimally fulfil this role, as depicted in the excerpt above. According to Ogle, Cooke and Brandt (2015:17), caregivers may also benefit from being involved in programmes aimed at educating them about the medication regime of the children they render care to. Tools such as notes, calendars, reminders and checklists could be used to enhance the effectiveness of caregiver medication management as it will assist them to keep track of the various medications and the time when medication needs to be administered (Ogle et al 2015:17).

Children arrive at the NGO early in the morning and leave late afternoon. Caregivers therefore have an added responsibility of having to take their care recipients to the local clinic for their medical care.

A study conducted in South Africa by Mafune, Lebese and Nemathaga (2017:4), reports an additional role of the caregiver; where the caregiver has to often take their care recipients to the clinic for their general check-up and medication. Their study also found that nurses at the clinic were furious with caregivers who were not compliant to the care recipient’s medication regime. These are in line with the findings of this study.

5.2.2 Theme 2: Motivation for caregiving

The theme regarding motivation for caregiving consisted of four sub-themes; passion, disabled self/relative, unemployment and pity. Caregivers conveyed a range of motives for why they are involved in providing care to children who are differently abled. The majority of the caregivers reported their motive for caregiving to be passion. They report to love caring for children who are differently abled as this makes them feel very happy and connected to the children they render care to.

Four caregivers revealed personal reasons for why they render care to children who are differently abled. Three caregivers report their motive for caregiving to be their own relative who is disabled. One caregiver had a daughter who was born with cerebral palsy and sadly passed on at the age of twelve. One caregiver is driven to do her job because her mother and brother both have a chronic disability. There is only one caregiver who decided to become a caregiver because she herself was born with cerebral palsy.

Two caregivers stated their motive for caregiving was that they were unemployed. This shows that most caregivers are not doing their job for remuneration only.

Only a minority of caregivers report their motive for caregiving to be pity. They feel very sorry for the children who are disabled and feel that disabled children need their love and care. Feeney and Collins (2016:950) state that not much is known about the specific motives that drive caregivers to take on the caregiving role. Caregiver motives are important to establish as it determines the quality of care caregivers offer to their care recipients (Feeney & Collins, 2016:951). This study brought to light three motives for caregiving, which are consistent with findings from literature.

5.2.2.1 Sub theme: Passion

Majority of the caregivers in the study describe ‘passion’ as their foremost motive for caregiving. Caregivers report to love caring for children who are differently abled as this makes them feel very happy and connected to the children they render care to. Caregivers working with children who are differently abled found more satisfaction and had positive attitudes towards caring for children who are differently abled as compared to caring for children who do not have a disability. This is supported by a study conducted by Adams (2008:3) which shows that caregivers who had experience working with children who are differently abled were more willing to accept disabled children under their care in comparison to children who did not have a disability.

5.2.2.2 Sub-theme: Disabled self/relative

Some caregivers revealed personal reasons for why they render care to children who are differently abled. Three caregivers report their motive for caregiving to be their own relative who is disabled. Bridget had a daughter who was born with cerebral palsy and sadly passed on at the age of twelve.

A study conducted by Bingham (2017:109) found that some caregivers take on the caregiving role because they had a child who has regrettably passed on due to their disability. One caregiver in the study mentioned that she is driven to do her job because her mother and brother both have a chronic disability. Gemma is the only caregiver in the study who decided to become a caregiver because she herself was born with cerebral palsy.

5.2.2.3: Sub-theme: Unemployment

A study by Zahed, Emami, Bazargan-Hejazi, Eslami, Barekatain and Zamani-Alavijeh (2019:5) revealed that few caregivers stated monetary reasons as a primary reason for undertaking the caregiving role. This coincides with findings from the current study, as only two caregivers are motivated to perform their caregiver role because they are unemployed and need the money to survive.

Caregivers in the study are not primarily motivated by the remuneration they receive for their caregiving role. Autonomous motivation refers to the connection, self-sufficiency and competency that caregivers experience in their caregiving role (Kindt, Vansteenkiste, Loeys, Cano, Lauwerier, & Verhofstadt 2015:1740). Numerous studies established that caregivers who were autonomously motivated to undertake the caregiving role experienced a lesser amount of exhaustion and stress than caregivers who were driven to undertake the caregiving role due to obligations such as financial obligations (Badr, Smith, Goldstein, Gomez 2015:156; Kindt et al 2015:1741; Kindt, Vansteenkiste, Loeys, & Goubert 2017:679).

5.2.2.4 Sub-theme: Pity

Hanna and Farah were propelled into the caregiving role out of pity for children who have disabilities. Lynch and Lobo (2012:2132) explain compassion fatigue to occur due to the caregiving relationship originating from caregivers feeling pity and a deep sense of sorrow for their care recipients. This is consistent with findings from the current study. Caregivers who do experience compassion fatigue might display symptoms such as anxiety, depression, sleeping difficulties and cynicism (Slatten, Carson, & Carson 2011:330).

5.2.3 Theme 3: Caregiver training

Four caregivers reported to have never received training prior to already resuming their caregiving roles. Caregivers were sent on training only a while after starting their jobs. One caregiver reported to have received on the spot training, as she had to see what other caregivers were doing for two weeks before she could render care to the children who are differently abled. After resuming duties, some caregivers were sent for training. The duration of the training they receive is very short. One caregiver reported that her training lasted only five days. Some caregivers have received training on how to stimulate children who are differently abled. Their training also entailed feeding and bathing. One caregiver attended training where she was taught how to make toys from recycled material. All caregivers who received training expressed that the training was effective, however not enough. Caregiver training does not occur frequently. Caregivers stated that they receive training only once or twice a year. Each and every caregiver in the study expressed the need for more training. They mentioned that they still required more training on; knowing about the children's diagnosis, correct positioning, exercising, feeding, stimulation and handling. Caregivers in this study are caregivers who were employed having no experience caring for children who are differently abled. Caregivers of children who are differently abled have to take on very challenging responsibilities; responsibilities they have to fulfil without having undergone any training. The implications of poor caregiver training is seen in both the care recipient and the caregiver (Stajduhar, Funk & Outcalt 2013:658). The sub-themes below discuss issues around caregiver training revealed in this study.

5.2.3.1 Sub-theme: Never trained prior to caring for children who are differently abled

Most caregivers reported to have never received any training prior to resuming their caregiving roles. Caregivers were sent on training only after starting their jobs. One caregiver reported to have received on the spot training, as she had to see what other caregivers were doing for two weeks before she could render care to the children who are differently abled.

Similarly to the current study, Mapira, Kelly and Geffen (2019:6) found that most community workers had to resume duties without having undergone necessary training. The results of the current study are also consistent with a study by Burgdorf et al (2019:835), which revealed that more than three quarter of caregivers are actively performing their caregiving roles without having undergone any training.

5.2.3.2 Sub-theme: Training content

Guyard, Michelsen, Arnaud, Lyons, Cans, and Fauconnier (2015:1600) account that caregivers of children who are disabled are tasked with conducting the daily care requirements of the child and the decisions that are made with regards to the care offered. In this respect, some of the caregivers reported that the content of their training included conducting the daily requirements of the children.

Care work is not regarded as a structured formal profession. The training care workers receive is thus often inconsistent, inadequate and not accredited (Mapira et al 2019:2)

5.2.3.3 Sub-theme: Frequency

Improving caregiver skills is more effective in improving the health and functional outcomes of their care recipients, as opposed to only providing psychosocial support to caregivers (Litzelman, Kent, Mollica and Rowland 2015:360). Caregiver training should not be a once off, as caregivers have to continuously develop their skills and knowledge to render effective care to their care recipients. The current study revealed the frequency of caregiver training to be infrequent.

5.2.3.4 Sub-theme: Need for training

Despite some caregivers reporting to have undergone some type of training, all caregivers in this study voiced their imperative need for more training. They mentioned that they still required more training on; knowing about the children’s diagnosis, correct positioning, exercising, feeding, stimulation and handling.

Children’s ability to learn, thrive optimally and construct relationships that are healthy is directly dependent on the quality of care they receive. Caregivers of children who are differently abled are often overwhelmed with all their caregiving tasks, as they do not possess the skills and knowledge necessary to care for these children. It is imperative that caregivers of children who are differently abled are empowered with the necessary knowledge and skills to provide optimal care to their care recipients (UNICEF 2013:4).

5.2.4 Theme 4: Perception on the effectiveness of services rendered

Most caregivers perceive the services they render to the children to be effective, even though they feel they could render better services should they undergo more training. Caregivers believe they are making a lot of positive changes to the lives of the children that they care for as well as the NGOs. Caregivers mentioned that due to their hard work, some children show vast improvement and now have skills that they did not initially have. There was only one caregiver who feels unsure about the effectiveness of the services she renders as she stated that she feels like she is not doing a good job. She also mentioned that this feeling of failure causes her stress. Caregiving itself is a very beneficial act which could lead to caregivers feeling good about themselves and learning new skills. For caregivers to reap the benefits of their caregiving role, they should have a positive perception on the effectiveness of the services they render, (Schulz & Sherwood, 2008:27).

5.2.4.1 Sub-theme: Effectiveness of care

Providing care to a care recipient is beneficial for both the caregiver and the care receipt as it improves the quality of life for both. The benefits for the care recipient are more obvious than the benefits for the caregiver. For the caregiver, caregiving could be a very rewarding, fulfilling experience. If caregivers feel that the services they render are effective, they experience better physical and emotional health outcomes (Dean 2020:1). There was an agreement between almost all the caregivers that the services they render are effective.

Moral-Fernández, Frías-Osuna, Moreno-Cámara, Palomino-Moral & Del-Pino-Casado (2018:10) add that performing the caregiving role makes it possible for caregivers to realize their worth and have an optimistic view on life. Correlational research has suggested that the training of caregivers is a cornerstone for quality in early care. Caregivers who are equipped with the skills and knowledge to care for their care recipients provide better quality of care than caregivers who lack skills and knowledge (Burchinal, Cryer, Clifford & Howes 2002:10).

In contrast to caregivers feeling the services they render are effective caregivers in numerous South African studies undertaken felt they did not have sufficient skills to care for children who are differently abled, which made them believe the services they render to children who are differently abled to be ineffective (Mathye & Eksteen 2015:295; Mhaule & Ntswane-Lebang 2009:132; Sandy, Kgole, & Mavundla 2013:346). Caregivers are often provided with limited training opportunities and insufficient resources (Geiger 2012:13; Bingham et al 2017:109). This closely narrates the previously discussed sub-theme that the caregivers subjectively felt that the training they received was insufficient. Minority of caregivers in this felt and perceived the services they offer as ineffective.

Parkinson, Forsyth, and Kielhofner (2006:5) describe The Model of Human Occupation (MOHO) as a commonly used model in occupational therapy that explains how a person's occupation is motivated, patterned and performed. The model explains that, for a person to be motivated to perform any occupation, they have to believe that they are effective. If they deem themselves ineffective, then they would probably not be motivated to perform an occupation or exert maximal effort when performing an occupation. If caregivers feel they are ineffective they would probably not optimally perform the caregiving role, which will have a direct impact on the care children who are differently abled receive.

5.2.5 Theme 5: Challenges caregivers experience

Three participants described their initial impression when they were first employed as caregivers as a challenge which they had to overcome. Caregivers were initially shocked, as they did not know what to expect in terms of how children with severe disabilities present. One caregiver mentioned that when she first started at the NGO she was very scared when she saw the disabled children, as she has never interacted with a disabled child before. Most caregivers mentioned numerous challenges related to their specific caregiving role. Caregivers find it difficult to handle some children, especially those who display difficult behaviours. Two caregivers stated that they beat children who do not behave accordingly.

Giving children medication is another challenge some caregivers reported to experience, as the dosage of medication and the time given have to be precise. Caregivers render care to children with various disabilities, which makes it difficult for caregivers to know how to help children with these different disabilities.

Stress is a common challenge experienced by most participants in the study. The condition of the children causes caregivers to experience stress and anxiety as most caregivers stated that they do not really understand the condition of the children they care for. Two caregivers mentioned that parents of the disabled children they care for contribute to the stress they experience, as the parents of the children do not address them in a respectable manner. One caregiver reported to be experiencing stress that is caused by children physically beating them. One caregiver said that her stress is mainly due to her feeling as though she is a failure and not rendering good enough services to the children.

Four caregivers reported maladaptive coping stress to deal with stress that occurs due to their caregiving role. Three participants self-medicate using over the counter painkillers. One caregiver mentioned that when she gets home from work she drinks alcohol to help her cope with the stress of her caregiving job.

Caregivers expressed lack of outside support as being another challenge. They narrated that they receive support from other caregivers at the NGO and caregiver managers, however, they do not get any support from outside the NGO, which they reported to need. One caregiver highlighted the outside support she requires is counselling, as her job is stressful.

Caregivers in the study do not believe the communities in which they work recognize the valuable work they are doing at the NGOs. One caregiver stated that people in the community have stigma toward children who are differently abled. Caregivers also reported that people in the community do not know and do not understand what they do at the NGOs. Community members also do not understand why caregivers prefer to care for children who are differently abled. Twenty years ago, not much was known about the challenges caregivers experience (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan 2001:740). Since the 1990's, numerous studies regarding caregiver challenges have been conducted that has revealed common challenges to be; caregivers lack of skills and knowledge, caregivers' own physical burdens, sleep deprivation, depression, stress anxiety, feeling of despondency and helplessness (Pallangyo & Mayers 2009:482

& Mendez-Luck; Kennedy & Wallace 2009:228). This study revealed six main challenges caregivers experience, discussed under the sub-themes below.

5.2.5.1 Sub-themes: Initial impression

Caregivers in the current study described their first impression and initial reaction as shock or feeling intensely overwhelmed, as they were not expecting to see children who are severely disabled.

A positive first impression is one of the factors that determines caregiver preparedness (Alvariza et al 2020:15). Caregiver preparedness is described as the perceived readiness of caregivers to undertake the caregiving role that includes the provision of physical and emotional support to those in need (Schumacher, Stewart, Archbold, Caparro, Mutale, Agrawal 2008:54).

Ferrell and Mazanec (2009:150) suggest that a strong relationship between caregiver's preparedness and caregiver burden exists. A study by Scherbring (2002:74) revealed caregivers who were not prepared for the caregiving role were more at risk of caregiver burden. Unprepared caregivers in the study also reported a lower quality of life. A recent study by Alvariza et al (2020:15) found that caregiver preparedness is linked to a positive first impression.

5.2.5.2 Sub-theme: Rendering care

Caregivers are liable for creating favourable environments that facilitate the process of assisting these children who are differently abled that they render care to. Caregivers however face many challenging conditions, which makes it difficult for them to optimally fulfil their caregiver role. Most caregivers mention numerous challenges related to their specific caregiving role. Caregivers find it difficult to handle some children, especially those who display problematic behaviours. Two caregivers stated that they beat children who do not behave accordingly.

Giving children medication is another challenge some caregivers reported to experience, as the dosage of medication and the time given have to be precise. Caregivers render care to children with various disabilities who all have their specific needs, which makes it difficult for caregivers to know how to help children with these different disabilities. There are varieties of factors, which pose challenges to caregivers of children living with disabilities. Among these factors are; the physical condition of the caregiver, level of knowledge of the caregiver, nature of the child's disability, age of the caregiver and financial cost of caregiving (Ndadzungira 2016:99). As previously discussed under the theme 'training' all caregivers in the study expressed the challenges they faced due to lack of knowledge about the different conditions of the children under their care.

5.2.5.3 Sub-theme: Stress

The caregiver role is physically and emotionally demanding for caregivers, which often results in them experiencing high levels of stress. Caregivers take on great responsibilities when they care for children who are differently abled. Children who are differently abled are not easy to care for, as they require intricate care to perform activities of daily living, even the most basic activities such as bathing and dressing. Caregivers thus experience many stressors but are not able to cope with the negative effects of the caregiving role. Due to the nature of their work, caregivers who care for children who are differently abled experience many stressors resulting in the deterioration of caregivers physical and psychological welling.

Findings from the study are consistent with literature that identifies anxiety, depression and insomnia as psychological demands of stress (Cora, Partinico, Munafo, & Palomba 2012:45). Stress could also have physical manifestations such as body aches and pains. Research shows that caregivers who are unable to cope with the stress they experience have a lower life expectancy than caregivers who can manage their stress in a healthy manner (Braun, Mikulincer, Rydall, Walsh & Rodin 2007:4835).

Programmes and interventions aimed at helping caregivers should focus on teaching caregiver skills to deal with the problems the care recipients present with. Equipping caregivers with skills and knowledge to optimally perform their caregiving role could help in drastically reducing stress caregivers experiences (Bosch 2015:178).

The Transactional Model of Stress and Coping (Lazarus & Folkman 1984) is constructed on the assumption that stress, which arises from challenges, is a person-situation interaction that is dependent on the subjective cognitive judgement that arises from the interaction between the person and environment. Lazarus & Folkman (1984) propose that for an individual to effectively cope with their challenges and stress, there has to be a match between the changeability of the stressor that currently confronts the individual and the appropriate form of coping applied to the stressor. This model explains caregiver's challenges and coping mechanisms. This model defines stressors as problematic and challenging conditions and states that people react to stressors in adaptive ways by making use of coping strategies, which may shape health and functioning outcomes. Knight (2000:146) mentions that the Transactional Model of Stress is widely used in the field of caregiving as it comprises of the following;

- Contextual variables (gender, race, age, relation of caregiver to the care recipient),
- Demands on the caregiver result from caring for the care recipient,
- Caregivers appraisal of the experience as stressful or satisfying,
- Mediators of stress such as the caregivers coping styles,
- Support from others,
- Negative and positive outcomes of caregiving (distress or mastery).

The stress and coping model is the most widely used framework for caregiver interventions that equip caregivers to effectively address the challenges they experience in their caregiving role thus leading to caregiver empowerment (Chadiha, Adams, Biegel, Auslander & Gutierrez 2004:104).

5.2.5.4 Sub-theme: Coping strategies

Findings of this study revealed that some participants self-medicate using over the counter painkillers while others drink alcohol to help them cope with the stress of their caregiving job. The findings of this study concur with previous research. Some caregivers reported maladaptive coping strategies to deal with stress that occurs due to their caregiving role. Prior studies have identified stress as a negative impact of caregiving (Theofilou 2012:3).

Findings reveal that there is a crucial need for all stakeholders involved with NGOs for children who are differently abled to address the adverse effects caregivers' experience.

5.2.5.5 Sub-theme: Lack of outside support

The study revealed that caregivers are receiving inadequate support from outside. Caregivers narrated that they receive support from other caregivers at the NGO and NGO managers, however, they do not get any support from outside the NGO, which they reported to need. Hanna highlighted the outside support she requires is counselling, as her job is stressful.

Those who come into contact with the caregiver are in a position to provide support. Other caregivers, governmental services and professional services could offer support. Support caregivers could receive is reliant on individual caregiver's personal experiences and circumstances (Posner 2015:93). When caregivers receive adequate support, their own risks of distress or deteriorating health is reduced (Meintjes & van Belkum 2013:182).

5.2.5.6 Sub-theme: Poor community recognition

"Regardless of the type of barrier to role recognition, when the caregiver role is not identified- it can be challenging for the caregiver to become informed and empowered to meet his/her own needs or become a partner in the care process" (The Alzheimer's Society of York 2018:9). The Alzheimer's Society of York (2018:9) further iterates that not recognising the caregivers role could set off a negative chain of events which leads to potentially high physical and emotional health risks for the caregiver.

The vital role caregiver's play is one that should not go unrecognized. Caregivers are crucial members of the team involved with children who are differently abled as they contribute greatly to the South African Health care system, particularly the Primary Level of Health Care.

Plöthner, Schmidt, de Jong, Zeidler and Damm (2019:16) conducted a study to determine the needs of informal caregivers who care for the elderly. Their study found four main needs the caregivers had namely: respect, support, encouragement and recognition. The need for community recognition is also highlighted by Li and Otani (2018:16) who mentions caregivers' need for acknowledgement and recognition as being one of the most important needs of caregivers. Caregivers who are not recognised by their community are often demoralized and experience higher levels of stress than caregivers who receive community support and recognition (Schneider 2020:186).

5.3 DISCUSSION OF RESULTS OBTAINED FROM NGO MANAGERS

5.3.1 Theme 1: Appointing a caregiver

There are inconsistencies with the procedure NGO managers use to hire new caregivers. One manager reported that when a caregiver is required the post would formally be advertised stating grade 12 as a compulsory requirement. Most NGO managers require a CV; however, it is not always essential to submit a CV. Some managers conduct a formal interview, while others conduct a semi-formal interview. None of the managers mentioned assessing skills and knowledge as part of the appointment process. One NGO manager mentioned that she would ask other caregivers at the NGO if they knew of anyone who needed a job and would appoint a caregiver based on whoever is willing and available to work at the NGO. The manager chose this method of appointment because the turnover of caregivers at her NGO is high and because most people do not want to care for children who are differently abled.

Age is another important criterion NGO managers consider when hiring caregivers. One manager stated that she avoids hiring young caregivers as most caregivers who are young do not have children or do not have as much experience with children as older caregivers do. According to the manager, the lack of experience with children makes caregivers more susceptible to being traumatized when they have to care for children who are disabled. NGO managers believe older caregivers are more mature, caring, stable, reliable and loving. They also believe older caregivers provide better care to children who are differently abled.

One manager reported that caregivers are ready to care for children at the NGO once they have attained knowledge about disabilities, however caregivers do not always have to be trained before they start rendering care to children. Two managers stated that a new caregiver first works with other caregivers until they can work independently. The very same two managers also stated that new caregivers are put on a probation period for two to three months. Home Care Pulse (n.d.) mentions the recruitment and hiring of caregivers to be one of the biggest challenges home care agencies experience, as there is not a set criterion for hiring caregivers. The sub-themes below provide more insight into the process NGO managers use to appoint a caregiver and the crucial aspects they consider.

5.3.1.1 Sub-theme: Process

The process of recruiting and selecting employees in any type of Organisation is considered beneficial as it contributes to finding the most appropriate candidate for the required job. According to Kapur (2018:1), recruitment and selection is a process that should be undertaken by the human resources department within an organisation. The recruitment and selection process involves general screening, sourcing candidates, shortlisting, and lastly selecting the most suitable candidate for the job (Tutorials Point, 2016:15). Results of the study show that the recruitment and selection process among NGOs are not consistent and do not always follow the correct process. There are discrepancies with the procedure NGO managers use to hire new caregivers. Most NGO managers require a curriculum vitae (CV); however, it is not always essential to submit a CV. None of the managers mentioned assessing skills and knowledge as part of the appointment process.

Caregivers of children who are differently abled are tasked with providing basic essential care to their care recipients. Due to the nature of the caregiver’s tasks, the caregiving role is one that has high levels of responsibilities attached to it. Competency-based analysis provides an inclusive description of the job-relevant knowledge, skills, abilities and attitudes that are associated with competent job performance. To ensure that caregivers are competent and will render the best caregiving services to the vulnerable population they serve, caregiver’s competency should be assessed during the selection process. Assessing caregiver’s competency involves assessing their knowledge, skills and abilities related to the caregiving role. Numerous authors agree that assessing competency is an effective way of scrutinizing the abilities of candidates to optimally perform the given tasks of a specific job and to determine if candidates have the characteristics the job requires (Saif, Saqub, Rehman, Rehman, Rehmans, Nawa & Naqeeb 2013:110).

5.3.1.2 Sub-theme: Age

NGO managers single out age as one of the most important factors they consider when appointing a caregiver. NGO managers believe caregivers who are older are more responsible, stable, compassionate and provide better overall care to children as they have experience taking care of children.

The researcher could not find any literature to support NGO managers beliefs regarding age of caregivers and their level of competency. Contrary to findings from this research, Van Borm, Burn and Baert (2019:20) found that there is a lot of stigma related to age, particularly being older in the workplace. They also found that recruiters in general perceive older individuals to have decreased skills, knowledge, flexibility and trainability levels.

5.3.1.3 Sub-theme: Readiness

Understanding the level of readiness caregivers have to start rendering care, to care recipients may help to improve the effectiveness of caregivers undertaking their caregiver duties (Marx, Parker, Huang, Scerpella, Piersol & Gitlin 2019:181). Factors such as care recipient diagnosis, personal characteristics of the caregiver and resource availability all contribute to caregiver readiness. Lutz et al (2016:182) listed numerous factors that influence caregiver’s readiness to assume the caregiver role. Findings from the study illustrate that NGO managers do not assess caregiver readiness.

5.3.2 Theme 2: Monitoring caregivers

Two sub-themes emerged from the theme of monitoring caregivers namely method and frequency. Managers revealed unreliable inconsistent methods of monitoring caregivers. Most managers monitor caregivers by observing them while they are involved in their caregiving duties. One manager mentioned a more formal approach that is recorded on a daily basis. Caregivers are observed and their performance is recorded in a monitor book. The book is then passed on to the manager. Even though this method is a bit more formal, it is important to note that the person who does the NGOs administration is the one responsible for monitoring caregivers. The manager has no knowledge or experience regarding children who are differently abled, yet she is entrusted with the task of monitoring caregivers.

One manager revealed that she monitors caregivers on a daily basis. She described that she monitors caregivers by just observing what they do.

Two managers mentioned that they monitor caregivers once every quarter. One manager stated that she does monitor caregivers, however has not had a chance to monitor caregivers in 2020. Gosling and Edwards (2006:12) define monitoring as a “systematic and continuous collecting and analysing of information about the progress of a piece of work over time”. As discussed in the sub-themes below, NGO managers do not use a standardized consistent method of monitoring and assessing caregivers.

5.3.2.1 Sub-theme: Method

Caregivers have to be monitored to determine the success of their caregiving services. It is imperative that caregivers are assessed prior to them independently caring for care recipients as well as on an ongoing basis using the same initial assessment to determine progress and identify gaps. Results of assessments conducted over time should be compared, as this is a more structured and reliable method of monitoring which ultimately leads to having caregivers that are more competent (Marx et al 2019:7). The monitoring of caregivers NGO managers mention in the study alludes to micro management of caregivers. NGO managers do not have a formalized, consistent method of monitoring the caregivers they manage.

None of the NGO managers in the current study mentioned monitoring caregiver’s physical and psychological wellbeing. The negative impact of caregiving can be reduced if physical and psychological impairments are identified and addressed in a healthy manner (Caap-Ahlgren & Dehlin 2002:375). The physical and psychological impact of caregiving should be assessed qualitatively or quantitatively to ensure caregivers receive timeous assistance.

5.3.2.2 Sub-theme: Frequency

The current study found that caregiver assessment is informal and does not occur frequently at NGOs. Assessment includes mainly observation and a discussion with caregivers. Caregivers' skills and knowledge are not assessed or monitored.

Monitoring of caregivers should occur frequently and should therefore occur on a regular basis (Family Caregiver Alliance 2006:17). A specified time period for caregiver assessment has not been identified in the literature the researcher consulted. The Family Caregiver Alliance (2006:182) does however suggest that caregiver assessment and monitoring is dependent on the NGO as well as their care recipients.

5.3.3 Theme 3: Challenges managing caregivers

All managers in the study revealed their major challenge is lack of caregiver training which makes it difficult for caregivers to render care to children who are differently abled at the NGO. Managers also highlighted that caregiver stress is a challenge at the NGO; therefore, caregivers require training on how to deal with stress. Most managers mentioned that caregivers lack skills and knowledge to care for children who are differently abled. This possesses a challenge to the managers and results in some managers becoming frustrated. One manager notes the lack of first aid skills caregivers have as being one of her major challenges. Lack of resources is another common problem managers expressed. Some NGOs lack necessities such as soap and diapers which the majority of the children require. NGOs also lack therapy equipment such as tables, chairs and communication boards. Mobility devices are also not available to all children at NGOs.

Some managers identified communication as another challenge when it comes to managing caregivers. Two managers said that caregivers feel scared to approach them and would rather gossip among other caregivers if they have issues. NGO managers have to fulfil the basic functions of management that includes planning, organising, staffing, directing, and controlling (Okafor 2014:94). Collings and Swartz (2011:1310) state that those who manage caregivers should direct them to suitable resources for support. NGO managers should also provide psychoeducational support, skills-training, and therapeutic counselling interventions for caregivers. NGO managers in the study revealed various challenges they experience when managing caregivers.

5.3.3.1 Sub-theme: Lack of training

NGO managers share the same sentiment as caregivers regarding caregiver training. All NGO managers mention lack of caregiver training as their primary challenge.

“Funds for NGOs” (n.d.) suggest a process for arranging caregiver training. Firstly, NGO managers have to identify training needs of caregivers through administering questionnaires and conducting focus group interviews. NGO managers then set the objectives of the training programme in conjunction with professionals who offer the training; lastly, the content of the training programme is finalized.

5.3.3.2 Sub-theme: Lack of resources

A recent article by Soni et al (2020:7) revealed that children who are differently abled fail to reach their maximum potential due to caregivers not having the necessary skills. Soni et al (2020:7) found that a lack of resources coupled with the lack of caregiver skills and knowledge add to the challenges caregivers experience. NGO managers who participated in the study mentioned lack of resources as another potential challenge.

Findings from the study concur with global findings regarding the lack of resources to implement Community Based Rehabilitation. CBR is an approach of delivering services to the general population, and not a service in itself, therefore the vehicle on how services are delivered is crucial. Caregiver empowerment is a crucial principle of CBR. Numerous countries adopt the CBR strategy, however, experience great difficulty implementing the strategy due to the lack of resources. Lack of resources therefore is a challenge across all levels of the health care system.

5.3.3.3 Sub-theme: Communication

Some NGO managers expressed communication between themselves and caregivers as an added challenge. Managers feel that caregivers are scared to approach them if they have any challenges and would rather discuss their issues with other caregivers at the NGO.

Managers have to sustain good communication between them and the caregivers. Home Care Pulse (n.d.) states that effective communication between NGO managers and caregivers is paramount to the relationship NGO managers have with their caregivers. Effective communication provides managers with an opportunity to inform and build healthy relationships with caregivers. Home Care Pulse (n.d.) suggests that "Caregivers who are comfortable with supervisors are more capable of meeting goals and requirements that build business".

5.3.4 Theme 4: Managers expectations of caregivers

The expectation of managers of their caregivers is consistent to what caregivers in the study revealed their roles to entail. Managers state that the caregiving role entails basic care of the children such as; feeding, bathing, changing diapers, dressing stimulation, exercise, taking children to the clinic and administering medication to children who require it. One manager stated that caregivers have to do a full body assessment of each child when they arrive first thing in the morning. They observe the body for any marks and injuries and report it to the parents as some children are injured in their transport on the way to the NGO. This study brought to light the various expectations NGO managers have of their caregivers. The expectations NGO managers have of caregivers correlate with what caregivers mentioned their roles to be.

5.3.4.1 Sub-themes: Basic care and medication

Manager's expectations of their caregivers is consistent with what caregivers in the study revealed their roles to entail. Managers state that the caregiving role entails basic care of the children such as; feeding, bathing, changing diapers, dressing stimulation, exercise, taking children to the clinic and administering medication to children who require it. Precious described what she expects from caregivers at the NGO she managers in the excerpt below:

The caregiver role is extremely demanding as it includes providing basic care, to care recipients and the administering of medication. Managers expectation of caregivers in the current study is consistent with Geiger (2012:2-3) who mentions that caregivers of disabled children have the roles of feeding, bathing and administering medication to their care recipients.

5.3.5 Theme 5: Support offered to caregivers

Managers provide internal support to caregivers by acknowledging the hard work they do. They do this verbally. Managers also support caregivers by always encouraging them. One manager in particular encourages her caregivers promising them that if they work they might one day find someone who pays them better. One manager has weekly meetings with her staff members where staff can express any challenges they have. Staff are also encouraged to approach the manager for support related to any difficulties they are experiencing at home.

One manager only receives support from Social Development. Most managers reported to have received support from the Department of Education and from universities who send their students to treat the children who are differently abled.

There is unfortunately very little outside support when it comes to the caregivers having to deal with their unique challenges. This sentiment was shared by caregivers who stated that internal support is available; however, they do not get outside support and do not know where to go for support other than the NGO itself. Caregivers support has numerous positive outcomes for the caregiver as well as the care recipient. Caregivers who are supported tend to understand their care recipients better and also experience less depression, stress and anxiety than caregivers who do not receive support (The Alzheimer's Society of York 2018:4-5). The two sub-themes discussed below provide more insight into the support caregivers in this study are offered.

5.3.5.1 Sub-theme: Internal support

Effective communication is paramount to managers providing satisfactory support to caregivers they manage. The Alzheimer’s Society of York (2018:5) mentions good communication between the caregiver and manager as a requirement to assist the manager to provide support to the caregiver. Managers should communicate with caregivers to enquire how they are doing, feeling and managing with their caregiving role. The current study found that NGO managers provide internal support to caregivers through verbal communication by acknowledging and praising the hard work they perform.

The Alzheimer’s Society of York (2018:9) mentions that caregiver support should occur timeously in the caregivers’ care trajectory and outlines caregivers support to include; physical, emotional, financial, educational and spiritual support. Managers can further support caregivers by assessing caregivers’ needs and goals; developing personalized plans for support.

5.3.5.2 Sub-theme: External support

Most managers mentioned that they receive external support from the Department of Education and universities Allied Health Departments. Universities send students to NGOs to assist with therapy.

Due to the complexity of the caregiving tasks, an intersectoral collaborative approach is needed to ensure children who are differently abled receive the best care (Philpott & Muthukrishna 2019:729). Services for PWDs should be offered following the principles of PHC. Services should therefore be accessible, affordable and should address the needs of PWDs (South Africa 2015:13).

5.4 SUMMARY

In chapter five, the thematic presentation of qualitative data from the caregivers and NGO managers was interpreted and discussed in view of relevant literature obtained from the participants' responses, with the detailed elements of a particular theme being discussed.

The exploration and description of the experiences of caregivers providing care to children who are differently abled at NGOs was discussed under four themes and seventeen sub-themes in conjunction with literature control.

The exploration and description of the experiences of NGO managers at NGOs caring for children who are differently abled regarding their management of caregivers was discussed under five themes and twelve sub-themes in conjunction with literature control.

CHAPTER 6

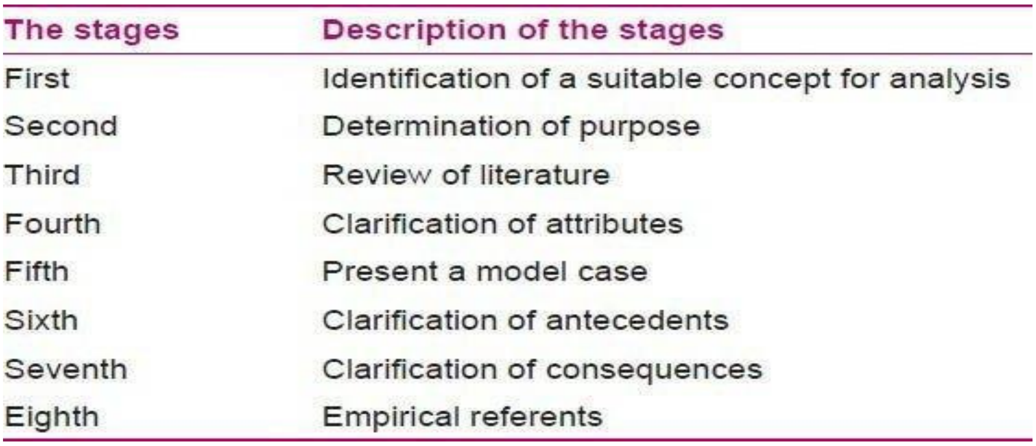
CONCEPTUAL ANALYSIS

6.1 INTRODUCTION

In Chapter 5, results obtained from phase one of the study were discussed based on the experiences of caregivers rendering care to children who are differently abled at NGOs and the experiences of NGO managers at NGOs caring for children who are differently abled regarding their management of caregivers. Results of the study were discussed in conjunction with literature control.

Chapter six describes the conceptual analysis of the study that is developed based on Walker and Avant's process of conceptual analysis (2011:160).

A strong concept has to be concrete and robust, it must name what it is referring to, it must be well defined and its use in theory should be distinct (Walker & Avant 2011:157). Walker and Avant (2011:158) defines concept analysis as "a process of examining the basic elements of a concept, it helps us to distinguish concepts from ones that are similar to, but not the same as, the concept". While many methods were available for concept analysis, Walker and Avant developed an eight-step model that was easiest to understand and was specific to nursing. The eight steps of concept analysis proposed by Walker and Avant (2011:158) are depicted in figure 6.1.



The stages	Description of the stages
First	Identification of a suitable concept for analysis
Second	Determination of purpose
Third	Review of literature
Fourth	Clarification of attributes
Fifth	Present a model case
Sixth	Clarification of antecedents
Seventh	Clarification of consequences
Eighth	Empirical referents

Figure 6.1: Walker and Avants' eight stages method for concept (Aarabi, Rafii, Cheraghi, & Ghyasvandian 2014).

6.2 IDENTIFICATION OF A SUITABLE CONCEPT FOR ANALYSIS

The concept empowerment was identified as the key concept in the development of the programme. Walker and Avant (2011:157) note that concepts are the building blocks of theory and that they change over time, periodically requiring up to date and in-depth analyses in order to discover not only their historic uses, but also their current contextual meanings. This allows researchers the opportunity to develop accurate operational definitions of the variables specifically related to their studies. Concepts that are well-delineated can then be investigated in a number of different studies and potentially used to explore group differences and responses to interventions that otherwise might not be compared. The purpose of this investigation is to analyse not only the concept of empowerment but also to check its relationship with caregivers and NGO managers working with children who are differently abled at NGOs. Empowerment is an significant concept in care for children who are differently abled as numerous authors agree that caregivers of children who are differently abled experience stress and anxiety which ultimately results in a feeling of powerlessness (Egerod, Bergbom, Lindah, Henricson, Granberg-Axell & Storli 2015:160; Cora, Partinico, Munafo & Palomba 2012:45). Wallerstein (1992:1997) adds that powerlessness is one of the risk factors that contributes to disease. To overcome powerlessness would thus mean empowerment.

6.3 DETERMINATION OF THE PURPOSE

The purpose of this concept analysis was to define the concept of empowerment in relation to assisting caregivers with skills and knowledge in rendering care to children who are differently abled.

6.4 REVIEW OF LITERATURE

According to Walker and Avant (2011:1-2), “If the aim is to construct an operational definition, the next step would be to find a research instrument that accurately reflects the defining attributes of the concept”.

A preliminary expanded literature search without limiters revealed that a formal concept analysis of empowerment of caregivers of children who are differently abled has not been published within the CBR domain, thus providing additional support for the need for a formal concept analysis of caregiver empowerment. To better define the concept of empowerment within the field of CBR, a more limited search was performed. Of the 38510 articles that contained the word “empowerment,” only one scholarly paper written on the concept of empowerment related to caregivers of children who are differently abled was found (Bunning, Gona & Newton 2020:1-21). To distinguish the use of empowerment related to caregivers in the community setting, a new search, was conducted in accord with recommended mesh terms, which means that the words ‘empower’ and ‘caregiver’ ‘non-governmental Organisation’ or ‘disability’ were used in PubMed.

The origins of the concept of empowerment is inherently linked to health, where self-care and self-responsibility is evident in literature relating to health care. Caregiver self-care and self-responsibility is often compromised due to all the demand of the caregiving role. The search was then limited to articles related to empowerment of caregivers of children who are differently abled, which found 567 articles that mentioned “empowerment”. The 558 articles were excluded because the researcher did not include a definition for empowerment. After the review, nine articles were found to correspond with the purpose and were included in the final analysis.

6.5 DEFINITIONS

To explore empowerment, the individuals performing the concept analysis must first establish what the word has meant from various sources and within disciplines. As a case in point, empowerment was defined in the *Merriam-Webster Online Dictionary* (2016, sv “empower’) as “the act or action of empowering someone or something: the granting of the power, right, or authority to perform various acts or” (para. 1). Added to the definition of empowerment was “the state of being empowered to do something: the power, right, or authority to do something” (para. 2) (Merriam-Webster Online Dictionary, 2016, sv “empowerment’). Another definition from the Cambridge Advanced Learner’s Dictionary (2020, sv “empower”) was “the process of gaining freedom and power to do what you want or to control what happens to you” (para. 1). Finally, the Oxford Dictionaries (2010, sv “empowerment”) defines empowerment as “the act of giving somebody the power or authority to do something” (para. 2).

The word ‘empowerment’ is used in numerous contexts where it is used as an expression that conveys strength and self-direction. The words ‘authority’ and ‘power’ are two words derived from the word ‘empowerment’. The word ‘empowerment’ was promulgated in the 1950’s during the time social organisations were protesting against issues of power and imbalances (Kendal 1998:1). The numerous definitions used in various contexts for the word ‘empowerment’ creates confusion regarding its definition. Kendall (1998:2) argues that very few definitions of empowerment are grounded on inductive research, which has resulted in empowerment within the health field not being validated by those who would be empowered. Some authors use the WHO definition of health promotion, which is “the process of enabling people to increase control over and to improve their health (1986:1), as their starting point when defining empowerment.

Rappaport (1987:121) defines empowerment as “the mechanisms by which people, Organisations and communities gain mastery over their lives’. This definition confirms that empowerment occurs within individuals and within communities. Gibson’s (1991:359) definition is very similar to that of Rappaport (1987:21) as she indicated that “empowerment is a social process of recognizing, promoting and enhancing peoples’ abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their own lives”. Perkins and Zimmerman, (1995:577) provide a more comprehensive description of empowerment that illustrates a more supportive approach where concepts of helping partnerships and decision making that is more prominent than consciousness-raising and radical actions. Perkins and Zimmerman describe empowerment as a concept that applies to individuals, organisations and communities, meaning that is applicable across all levels of health care. People can therefore be empowered in various ways including, community organisation participation, involvement in community and organisational decision-making and sharing leadership. Control, resources mobilisation skills, and accessible community resources are all outcomes of empowerment (Perking & Zimmerman 1995:578).

Rappaport (1987:121) and Kieffer (1984) both describe empowerment as a development concept encompassing enhanced growth and potential on the individual, family and community level. Kieffer (1984:9-10) outlines four stages of the development of concepts. The four stages correspond to Erikson's (1980) developmental stages:

Stage 1: Individuals at this stage participate; however, they are unsure, not confident and confused whereas, the authority and powers structures are clear. This stage is equivalent to the infancy developmental stage.

Stage 2: Individuals at this stage are mentored and supported which results in collaborative and supportive problem solving. In this stage individuals' external helps individuals to get a better understanding of their situation that helps them to accept responsibilities allocated to them. This stage is equivalent to the late childhood stage.

Stage 3: Individuals are provided with activities that confront and encounter the challenges they experience within their situations. In this stage skills such as survival and leadership skills are established. The stage is equivalent to the adolescence stage.

Stage 4: Individuals at this stage integrate the knowledge from what they have learned into their setting and everyday tasks. This stage is equivalent to the adulthood stage.

In the field of management, empowerment is described as the view that individuals have the power to effectively perform their job. Empowerment is thus seen as the vehicle for interaction, progressive change and attaining team success through individual achievement (Applegarth 2006:4). According to Jones, Latham and Betta (2013:1632), employee empowerment ostentatious due to the hierarchy levels that exist within organisations. Jones et al (2013:1644) describes empowerment within organisations as agreement with decision making, participation and working within a team. Empowerment exists on three levels namely the personal level where the individual gains control in everyday life as well as participation within the community, the small group level where individuals share their experiences with groups and influence them and lastly the community level where empowerment encompasses resource utilisation and way to improve community control.

The field of medicine demonstrates empowerment as support provided to individuals where individuals are enabled and motivated to take the required steps to improve their health in a way that is self-directed (Bann, Sirois & Walsh 2010:745). Bann et al (2010:745) adds that patient empowerment is patient centred which relies on an empathetic, caring, therapeutic health professional relationship. The therapeutic relationship is paramount to patient empowerment as it helps relieve symptoms the patient is experiencing. From the perspective of occupational therapy, the goal of occupational therapy is to empower patients by improving their quality of lives, enabling patients to be autonomous beings who are in control of their own lives. Occupational Therapy empowers patients by promoting independence (Schell et al 2014:1).

From the perspective of nursing, empowerment is described as a process where an individual is instilled with hope, encouragement, confidence through promoting their health and wellbeing. In nursing, empowerment refers to improving the quality of life and physiological conditions of patients (Akpotor & Elohor 2018:746). Nurses must therefore have a clear balance of control, clarity of goals and power in the process of empowering their patient.

As depicted in the literature provided above, there are numerous opposing views of empowerment. The definition of empowerment the researcher therefore adopts is “the capacity of people to be in control of the condition they find themselves in and to also achieve goals and objectives for that specific situation. Empowerment also refers to how powerful individuals feel inside, if they have the information and skills they need to achieve goals and what powerful action they are taking to achieve goals and objectives”.

6.6 DEFINING ATTRIBUTES

Determining the defining attributes takes place after the researcher has examined all of the possible uses of the concept. Walker and Avant (2011:163) mention defining attributes as “the heart of concept analysis”. Defining attributes are those characteristics that are repeated multiple times and the ideas most frequently associated with that concept (Walker & Avant 2011:162-163). After extensive review of the definitions and the use of the term empowerment in the literature, this researcher proposes the five defining attributes of empowerment namely:

- A mutual and supportive relationship
- Knowledge
- Skills
- Power within oneself
- Self determination

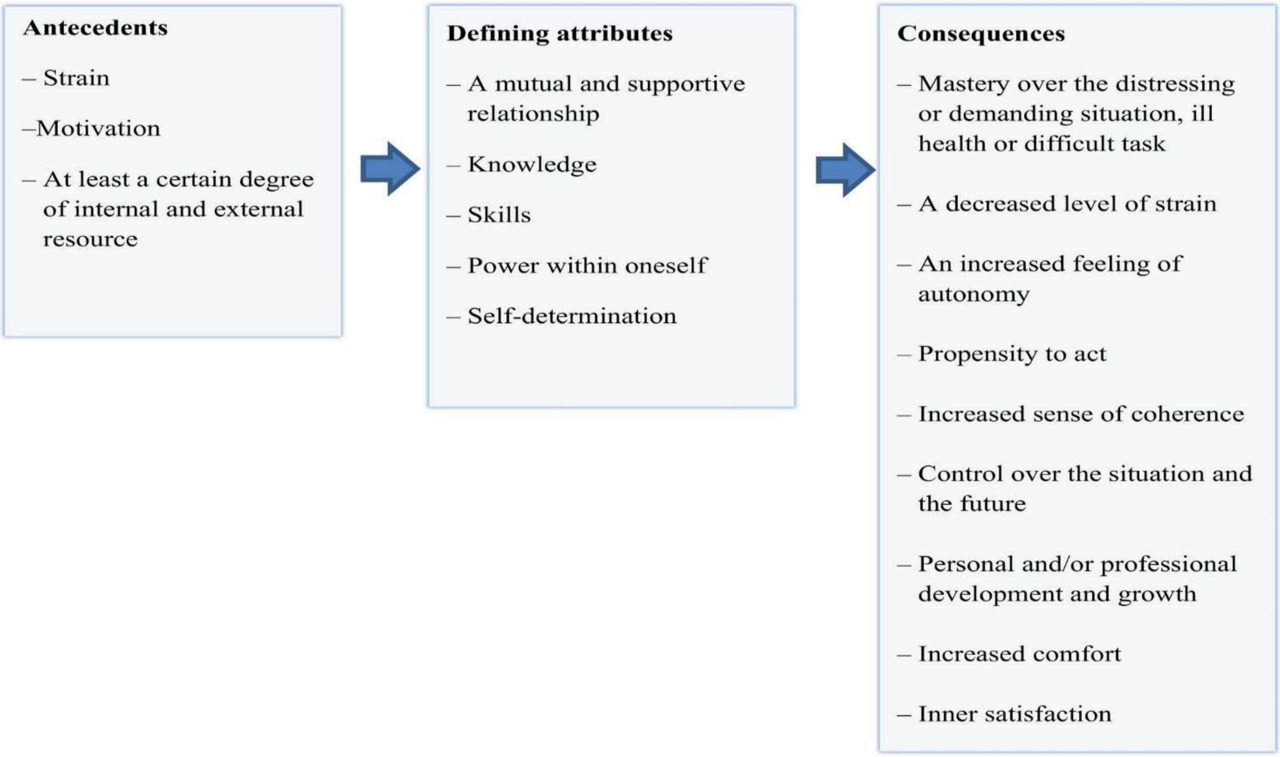


Figure 6.2: Overview of the empowerment concept in the field of health (Wahlin 2017:170).

In the context of health care, defining attributes of the concept empowerment included the transfer of skills in order to improve patient care. A study conducted by Alexander and Welzel (2010:450) indicated that empowerment of voluntary health workers (VHWs) is a concrete and logical process involving the creation of a safe and supportive environment conducive to participatory and experiential learning with involvement of professionals as facilitators. Emphasis must be placed on learning, which is a decentralised and continuous process. This type of empowerment enables the environment that fosters self-development and creative expression and can be a powerful strategy for community-based organisations to nurture a sustainable empowerment process.

6.7 MODEL CASE

According to Walker and Avant (2011:163), a concept analysis must provide several examples of the use of the concept. The first should be a model case demonstrating all defining attributes of the concept. Model cases could be real life examples, examples found in literature and examples constructed by the researcher (Walker & Avant, 2011:163). The model case of the concept of empowerment, therefore, incorporated all the following components of empowerment: (a) the human being in addition to homeostasis: (b) mutual and supportive relationship, (c) knowledge, (e) skills, (e) power within oneself and (f) self-determination. The model case has been constructed by the researcher.

Mary, a 54 years old caregiver was employed 7 months ago at an NGO for children who are differently abled. Prior to being employed at the NGO, Mary worked as a cleaner. Her elderly mother fell ill which resulted in Mary having to take care of her mother. Mary often missed work and as a result of poor attendance, she was fired. From a neighbour, Mary heard the NGO who looks after children who are differently abled was looking for a caregiver to work the nightshift. Mary was interested in the job as she had no income and relied solely on her mother’s pension. The job also seemed perfect to Mary as she could look after her mother during the day and her sister could look after her mother during the night while she is at work. Mary, having successfully raised three children, assumed that taking care of disabled children would be an easy task.

The moment Mary set foot in the NGO she felt very uneasy, as it was not the environment she was expecting. She was welcomed to the institution by screeching sounds, children lying all over the floor, children not well kept, grown children who she regarded as babies as they were unable to do anything, not even sit. The environment seemed unstructured, which overwhelmed Mary.

Mary did not know what to expect regarding her interview. To her surprise, all the interview entailed was her giving consent to work at the NGO and signing a form that

Mary was unable to understand. Mary was congratulated by the NGO manager on being successful on attaining the job and was told to start the following day. Mary returned the following day, a bit apprehensive, but ready to do whatever was required of her, as she needed the income.

Mary was orientated to the facility, introduced to other staff and within an hour of starting her new job was allocated five children with cerebral palsy to take care of. All five children Mary had to care for, were totally dependent. Mary immediately regretted her decision of taking on the role of caregiver but could not turn back as she already agreed and needed the income. Mary felt stressed, overwhelmed, and sad that the children were in the state they were in. Mary had no idea how to care for these kids. She felt terrible as she felt she doesn't know how to make a positive contribution to the lives of these kids. Basic tasks such as bathing kids, feeding kids, dressing kids etc. were very difficult for Mary to perform. Mary also felt scared that she might cause more harm than good for the kids.

As time passed on, Mary lost the drive to go to work, she however forced herself. Work stress started taking a toll on her, as she did not have the required knowledge and skills to look at children who are differently abled. Mary started experiencing physical and psychological symptoms she never experienced before, she was depressed, anxious, struggled to sleep, had constant headaches and body pain. Mary resorted to drinking alcohol every day as a method to cope.

One of the caregivers at the NGO, whom Mary had confided in, alerted the manager about Mary’s troubles. The manager set up a meeting with Mary to discuss all the challenges she was experiencing. The manager learned of the impact the caregiving role had on Mary. The manager also highlighted that Mary’s problems were mainly due to not being trained. Mary lacked the skill and knowledge to care for the children she was allocated. Mary’s manager was very empathetic towards her. She arranged for Mary to receive mental health services at the local clinic. Mary agreed to go to the clinic for help and realized that she had a choice to accept or refuse help. The manager also realized the urgent need for caregiver support and training. The manager contacted Gauteng Department of Health Region C and requested the services of a rehabilitation team. Within the first month, the team would provide services to the NGO once a week where they would equip caregivers with knowledge and skills to effectively do their job. Thereafter the rehabilitation team would provide support to the NGO once every two weeks. Even though some of the training sessions occurred during Mary’s off time, she made it a point that she attended all training. The rehabilitation team also started a support group that is managed by the caregivers themselves. Caregivers attend the support group once every two weeks.

Mary now feels confident in what she does. She loves her job and feels that she is making a positive contribution to the lives of the children she cares for. Mary also knows that whenever she experiences challenges, her manager's door is always open. Mary now experiences less symptoms of stress and when she does experience stress she knows how to handle it in a healthy manner using all the tools she was taught at the clinic where she attended their mental health services.

The model case narrated above shows all five defining attributes of empowerment.

6.8 BORDERLINE CASE

Walker and Avant (2011:164) described borderline cases “as those examples or instances that contain most of defining attributes of the concept being examined but not all of them. The following borderline scenario utilized all attributes of the concept of empowerment except skills and self-determination.

The Gauteng Region C Rehabilitation team embarked on a project for community participation and collaboration to improve the quality of life of people with disabilities in the community. A meeting was planned with NGOs, community members and PWDs to bring all their challenges to light. The community reported their problems as lack of resources, stigma, lack of opportunities and lack of support. The rehabilitation team then asked community members to form a committee. The rehabilitation team then told the community members to form a committee that can go to the local council and get their support for PWDs within the community.

The above borderline case does not show all defining attributes of empowerment. The rehabilitation team tried to establish relationships with the community and tried to address the needs of the community and tried to include the community to some extent in decision-making, the rehabilitation team failed to transfer control to the community. The rehabilitation team also failed to empower the community with skills and knowledge on how to go about fostering support from the council and how to address the challenges they face.

6.9 CONTRARY CASE

Walker and Avant (2011:166) considered a contrary case as a clear example of “not the concept”. In the following contrary case, no attributes were clear; therefore, no empowerment was achieved. The contrary case is thus the exact opposite of the model case.

A caregiver from the NGO takes a child with spastic cerebral palsy to the occupational therapist at the local clinic. Because the child is immobile, the occupational therapist prescribes a Madiba Buggy for the child that will help with correct position and as a mode of mobilization for the child who has to be carried around everywhere. The therapist then takes the child and places the child in the Madiba Buggy and gives the caregiver a date for the follow up appointment.

In the contrary case, no defining attributes of empowerment are present. The OT used the medical model to address the problem. The OT failed to gather more information about the child’s environment, which has very limited space and cannot accommodate a Madiba Buggy. The OT also failed to educate the caregiver on the Madiba Buggy, how it is used and all precautions to take.

6.10 ANTECEDENTS AND CONSEQUENCES OF EMPOWERMENT

Antecedents are events and incidents that have to transpire prior to the concept occurring (Walker & Advent 2011:167). In the context of this study, strain, motivation and at least a certain degree of internal and external resources are identified as antecedents. The following three antecedents appeared with the concept of empowerment. Strain relates to the challenges caregivers experience, which makes it difficult for them to cope. Motivation must exist for the empowerment process to occur. Motivation is described as the motives that bring about a certain behaviour in an individual, it is considered as the willingness to do something for the purpose of interest, pleasure and enjoyment. Motivation depends on values, interests, beliefs, perception and personal causation and behaviour (Guay, Chanal, Ratelle, Marsh, Larose & Boivin 2010:712). Availability of internal and external resources are also necessary for the empowerment process.

Walker and Avant (2011:167) describe consequences as events that happen as a result of the concept. Empowerment leads to improvement in the self-esteem of individuals, ability to set realistic goals, solving problems effectively, decreased strain and increased satisfaction and control.

6.11 EMPIRICAL REFERENTS

The final step of Walker and Avant’s (2011:168) concept analysis model required identifying empirical referents ways so the defining attributes of the concept in question could be measured. There are unfortunately few tools available that measure empowerment, however many tools exist that measure concepts which are related to empowerment. Fabriana (2011:181) mentions the Power as Knowing Participation in Change Tool Version II (Barret 1986), which is a tool that measures a woman's perception of participating in change. The Nurse-Patient Interaction Tool (Krouse & Roberts 1998) measures the perceived support of a woman's perception of the nurse-client relationship regarding control, power and issues related to treatment. Faulkner (2001:676-686) developed the Empowerment Scale which is a scale consisting of 12 items, using a 7-point Likert scale.

6.12 SUMMARY

This chapter provided the conceptual analysis for ‘empowerment’ and revealed an operational definition of caregiver empowerment in the context of NGOs for children who are differently abled, through the use of generated attributes, antecedents and consequences of caregiver empowerment.

The following chapter describes the development of the programme to empower caregivers of children who are differently abled at NGOs.

CHAPTER 7

THEORETICAL FRAMEWORK AN EMPOWERMENT PROGRAMME

7.1 INTRODUCTION

In chapter six, the conceptual analysis of the study that was developed based on the process of concept analysis by Walker and Avant (2011:160) was described. In chapter 7, the Survey List by Dickoff et al (1968:415) is described based on the results from Phase 1 of the study. Phase 1 of the study and the Survey List by Dickoff et al (1968) provided a foundation for developing the programme to empower caregivers caring for children who are differently abled at NGOs.

In the current chapter, the development of the programme to empower caregivers of children who are differently abled at NGOs is described in detail. Programme development refers to following a continuous systematic process to plan, implement and evaluate activities a programme consists of (Kwata 2015:13). The programme in this study is an empowerment programme to equip caregivers of children who are differently abled at NGOs with skills and knowledge to address the challenges they face.

7.2 DEVELOPMENT OF THE CONCEPTUAL FRAMEWORK AND REASONING MAP

“A conceptual framework explains, either graphically or in narrative form the main things to be studied, the key factors, constructs or variables and the presumed relationships among them” (Miles et al 2014:257). The conceptual framework for the current study is developed based on the findings from Phase 1. Concepts in the developed conceptual framework is in accord with the Practice Orientated Theory of Dickoff et al (1968) and description of concepts in this conceptual framework is in accordance with survey list as outlined by Dickoff et al (1968:417). Dickoff et al (1968:417) describe the three fundamental components of a conceptual framework as:

- The goal describing the aim of the activities in a study,
- Describing activities which are used to reach the goal,

- A survey list supporting the presentation of the activities that is used to attain the goal.

A conceptual framework facilitates the connection between literature and results of a research study. It allows for the conceptualization of research findings in practice (Kamenye, Scholastika & Van Dyk 2016:119).

The Practice Orientated Theory of Dickoff et al (1968:434) which consists of six components (agent, recipients, context, dynamics, procedures and terminus) is used to develop the conceptual framework.

The activities of the Dickoff et al's Survey List (1968) was used to produce the reasoning map. The reasoning map visually depicts the interactions between the agent and recipient, within a specified context or environment. The challenges with the context are also depicted in the reasoning map because the challenges in conjunction with the context will decide the specific procedure to follow to attain the terminus. The reasoning map is depicted in figure 7.1 below.

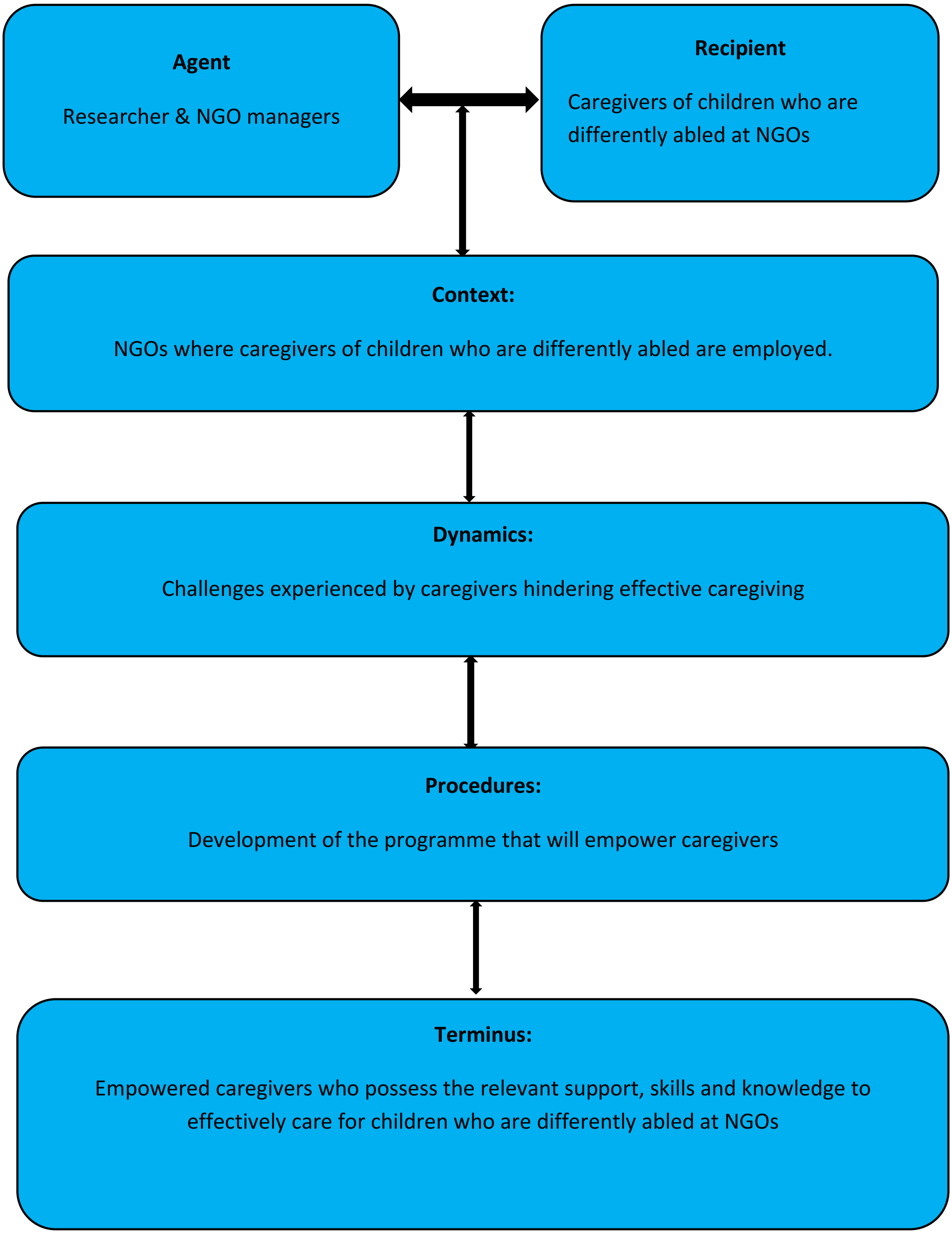


Figure 7.1: A reasoning map for the development of a programme to empower caregivers of children who are differently abled

7.2.1 The agent: Researcher and NGO managers

The agent refers to an individual who performs the activity required to reach the outcome. Stanhope and Lanster (2015) regard an agent as an individual who possesses the specialized values, attitudes, and behaviours required to facilitate the process of change. An agent therefore is equipped with knowledge to make a positive change in the lives of the recipients. In the context of this study, the agent refers to the researcher who is a qualified occupational therapist and an occupational therapy lecturer who will develop the programme to empower caregivers who render care to children who are differently abled with skills and knowledge to effectively address the challenges they experience with regards to their caregiving role. The agent also refers to NGO managers who will be responsible for ensuring caregivers are trained.

“Occupational Therapist uses the client’s active engagement in meaningful, purposeful and socio-culturally approved activities to remediate occupational dysfunction caused by illness, injury, developmental delay, lack of environmental resources and opportunity” (Occupational Therapy Association of South Africa, n.d.). The Canadian Association of Occupational Therapist (2018:1) describes an occupational therapist as a qualified health care professional who helps clients with functional impairment achieve their maximal level of functioning in all activities of daily living. In South Africa, Occupational therapists undergo four years of training to obtain a bachelor’s degree. The occupational therapist using the art and science of occupational therapy, works intersectorally, using the principles of the primary health care approach to negotiate and provide appropriate services of an acceptable standard to individuals, groups and communities. Services provided are accessible, appropriate and at a cost, the community can afford considering the communities expressed needs.

Occupational therapy aims to empower occupationally dysfunctional clients and their caregivers to carry out their everyday personal management, work / productive and recreational activities at their optimum level of independence. Occupational therapists demonstrate dignity and self-respect towards their clients in order to facilitate a better quality of life, improved health, illness management, skill development, recovery and a healthy lifestyle.

Knowledge, skills and values that were required by the agent to develop the empowerment programme for caregivers is illustrated in Figure 7.2 below.

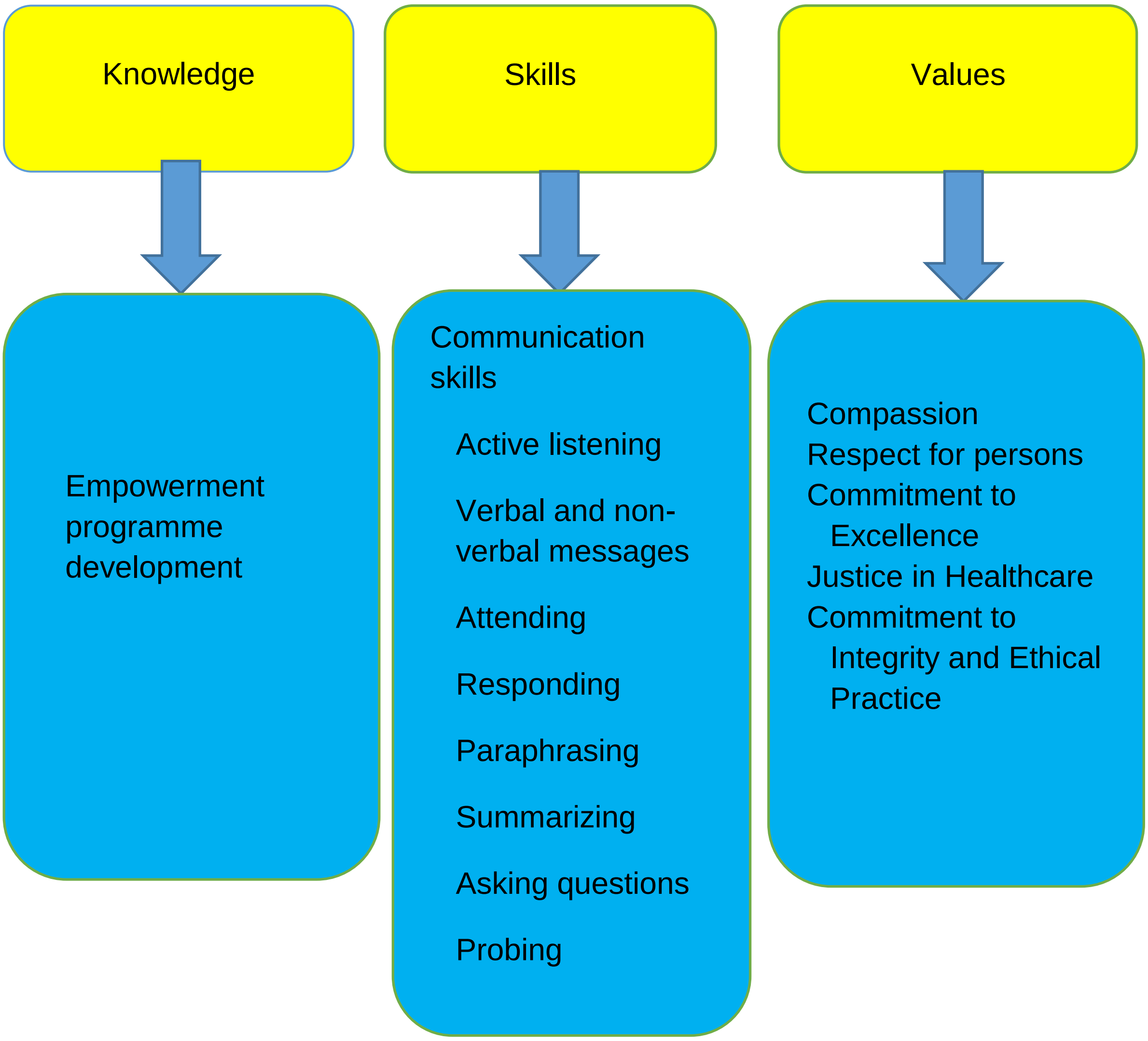


Figure 7.2: Characteristics of the agent (researcher).

7.2.1.1 Knowledge

The Merriam-Webster online dictionary (2011, sv "knowledge"), denotes knowledge as "the fact or condition of knowing something with familiarity gained through experience or "the fact or condition of being aware of something" or "the range of one's information or understanding” or “the sum of what is known: the body of truth, information, and principles acquired by humankind”.

The researcher being the agent in this study has possessed specialized knowledge on various subject matter to successfully develop the programme to empower caregivers who care for children who are differently abled at Non-Governmental Organisations with skills and knowledge to effectively address the challenges they face in their caregiving role. The researcher had to have scientific knowledge, knowledge in the field of childhood disabilities, knowledge regarding programme development, knowledge regarding the South African Health Care System, knowledge regarding caregivers and knowledge regarding adult learning theories. The agent in this study is a qualified occupational therapist and lecturer in occupational therapy with 14 years working experience in the private and public sector. The researcher has a special interest in Primary Health Care and lecturers in the field of Community Based Rehabilitation. The researcher also has experience offering support to caregivers of children who are differently abled. Phase one of the study allowed the agent to attain a comprehensive understanding of:

- The experiences of caregivers providing care to children who are differently abled at NGOs,

- The experiences of NGO managers at NGOs caring for children who are differently abled regarding their management of caregivers.

The agent used the research findings from phase one of the study to develop the content of the empowerment programme.

7.2.1.2 Skills

Interpersonal Relationship Skills (IPRs) was paramount to the researcher successfully undertaking phase one of the study. IPR skills were required to build a rapport and interact with NGO managers as well as during interviews with NGO managers and caregivers. Describing or defining IPRs is complex as it covers numerous aspects such as interpersonal relationships, interactive behaviour and competence socially. Communication is perceived to be one of the most important IPRs that enable constructive interactive behaviour and interpersonal relationships (Guirdham 2002:161). To understand interpersonal behaviour and relationships, one has to have an understanding of perceptions, attitudes, values, personality traits, emotions, goals, empathy, awareness of own emotions and beliefs. Khan, Khan, Zia-Ul-Islam and Khan (2017:4) describes communication as the ability to pass on information in a meaningful way through speech, writing or gestures. Kabir (2017:95) recognizes eight types of basic communication skills; active listening, verbal and non-verbal messages, attending, responding, paraphrasing, summarizing, asking questions and probing.

Active Listening

Agents need to be competent active listeners. Active listening encourages participants to express themselves freely because they feel as though they are being listened to and understood by the agent. The agent actively listened to respondents during the interview, did not say much, however, expressed acceptance and empathy towards the respondents. Active listening skills used by the researcher during the semi-structured in-depth interviews included; use of minimal encouragers, use of open body language, repeating back some of the words the speaker said, paraphrasing, summarizing and reflecting.

Verbal and non-verbal messages

The most common method that people use to convey messages to each other is through the means of verbal communication. Agents should always communicate to recipients in a respectful manner. Through verbal communication, the recipients can hear, interpret and correctly understand the agent. Non-verbal communication is also important when communicating with recipients. Gestures, body language, facial expression and posture, have to be considered when communicating non-verbally. Verbal and non-verbal skills used by the researcher during the semi-structured in-depth interviews facilitated good participation and easy expression from recipients.

Attending

An agent paying close attention to everything said and done by their recipients is referred to as attending. The agent closely observes the recipient's non-verbal communication making it easy for the recipients to open up and honestly share their experiences. Attending makes it possible for agents to listen actively. Attending is a skill agents should make use of throughout the interview process. The procedures (development of the programme that will empower caregivers) and terminus (empowered caregivers who possessive the relevant support, skills and knowledge to effectively care for children who are differently abled at NGOs) is dependent on the recipients' (caregivers of children who are differently abled at NGOs) context and dynamics (challenges experienced by caregivers hindering effective caregiving).

Responding

In order to respond, the agents need to pay close focused attention to the recipient's verbal and non-verbal communication as well as their emotions. To respond effectively, the agent needs to sustain active concentration and interest in their recipients and what they are communicating. If an agent does not display adequate responding skills, the recipients will not provide sufficient information regarding their experiences as caregivers. The attitude the agent shows towards the recipients is a method of the agent reflecting. By reflecting, the agent validates respect, acceptance and value of the recipients.

Paraphrasing

Paraphrasing refers to rewording what someone has said to try to understand them. During the semi-structured in-depth interview the agents says what the recipients has said, in the agent's own words without changing the meaning of what the recipient has said (Meyer 2004:40). In order to paraphrase the agents needs to listen actively. An agent paraphrases to show the recipients they are being understood, clarify what was the recipient has said, facilitate elaboration from the recipient, and to see if the agent's perception regarding what the recipients says is correct (Kabir 2017:16).

Summarizing

Summarizing occurs when the agent succinctly repeats the major points of what was discussed in the interview (Kabir 2017:17). Summarizing enables the agents in conjunction with the recipients to identify a theme in what is being said by the recipients.

According to Kabir (2017:18) summarizing serve the following purposes:

- Clarifies emotions for the agent and recipient,
- Connects various aspects of the message the recipient is portraying,
- Analyses what has been done,
- Starts and closes the interview,
- Helps to change topics,
- To serve as a transition when changing topics.

Ask questions

Questioning is the most important aspect of the semi-structured in-depth interview. It helps the agent understand the respondent’s experiences. Agents should have knowledge about techniques used when questioning and how to apply these techniques (Kabir 2017:19).

The agent developed an interview scheduled by reviewing literature pertaining to the objectives of this study. The interview schedule consisted of two separate interview schedules, one for caregivers at NGOs and one for NGO managers. The interview schedule consisted of main questions that had possible probing questions underneath.

Probing

Using probes, the agent follows up with recipients during an interview to elaborate on what they are saying (Creswell & Plano Clark 2014:244). The agent undertakes that they do not know or comprehend all the agent is saying and therefore ask further questions to gain clarity from the recipient.

7.2.1.3 Values

Hahn and Kreger (2015:2) describe values as what influences one’s view of what is worth doing or aiming at, and what is the correct way to act. Values belong to a common sense and cultural view of life and are usually associated with strong emotions. Values are felt as duties and one cannot behave contrary to values without feeling guilty or inadequate (Hahn & Kreger 2015:2). The values the agent should possess are in accordance with The International Charter for Human Values in Healthcare (Rider, Kurtz, Slade, Longmaid, Ho, Pun, Eggins & Branch 2014:273-280).

Compassion

Compassion is vital to relationships among human beings. Compassion entails putting oneself in the shoes of others to have a deeper understanding of their situation. Health professions deal with human lives, human beings who are in vulnerable conditions. To help those in need of care, health professionals have to show compassion. The agent has to put herself in the shoes of the caregivers to understand their experiences, especially their challenges when it comes to caring for children who are differently abled. According to the International Charter for Human Values in Healthcare (2014:3), health professionals have to possess capacities for; caring, empathy and self-awareness.

Respect for persons

The HPCSA (2017:2) mentions respect for persons as one of the core ethical values and standards for good practice. Health professionals must respect every patient and regard them as possessing intrinsic dignity and worth. The agent had to respect caregivers and caregiver managers, regardless of what they narrated their experiences to be. Caregivers and NGO managers' autonomy, privacy and confidentiality has to be respected throughout the research process.

Commitment to Excellence

The agent must commit to implementing excellence through all phases of the study. In order to commit to excellence the agent should commit to the following:

- Provision of the best possible service to recipients,
- Effective communication with recipients,
- Self-awareness,
- Continuous professional development in the field of expertise,
- Beneficence and non-maleficence.

The procedure and terminus will ensure that the recipient's best interest is being met.

Justice in Healthcare

"Health care practitioners should treat all individuals and groups in an impartial, fair and just manner" (HPCSA 2017:2). The agent should advocate for the right to equality where the recipients have access to information and quality through the empowerment programme.

Commitment to Integrity and Ethical Practice

The agent should commit herself to the highest standards of personal integrity by always adhering to ethical rules; maintain professional independence while practising within high standards of competence when interacting with recipients and developing the empowerment programme.

7.2.2 Recipients

Recipient refers to the person who will be receiving activities from the agent. According to Meyer (2004:12), the one who benefits from the procedure is referred to as the recipient. Recipients are individuals who hear and see the messages that are transmitted from the agent (Basavanthappa 2009:32). In the context of this study, recipients are caregivers of children who are differently abled at NGOs for whom the empowerment programme is for. The characteristics depicted in the diagram below are characteristic the recipients are required to have to enable them to benefit from the empowerment programme.

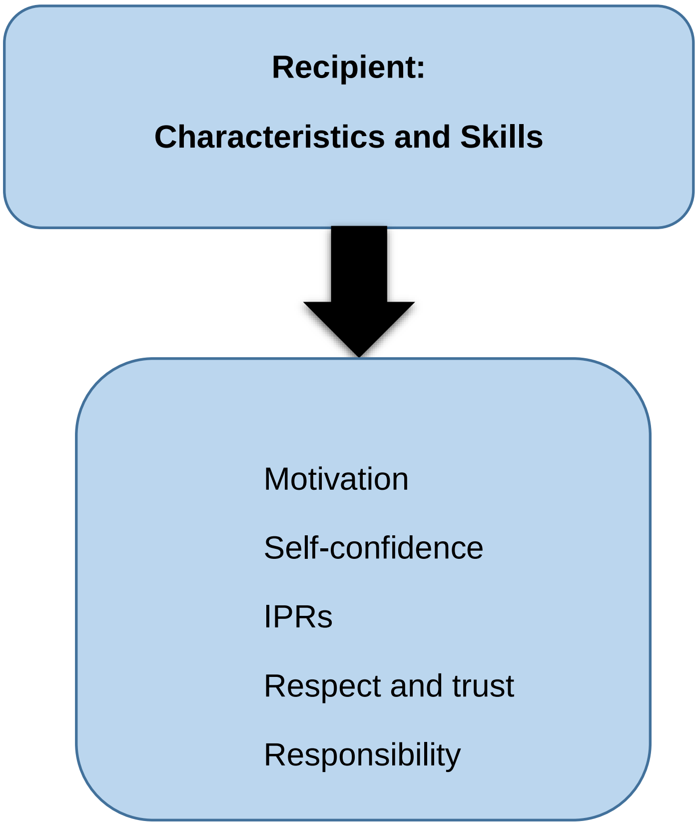


Figure 7.3: Characteristics of the recipient (caregiver)

Motivation

Motivation is described as the motives that bring about a certain behaviour in an individual. It is considered as the willingness to do something for the purpose of interest, pleasure and enjoyment. Motivation depends on values, interests, beliefs, perception and personal causation and behaviour (Guay et al 2010:712). Recipients should be motivated to participate in the developed programme. They should also be motivated to want to learn and provide the best possible care to the children they care for.

Self-confidence

Recipients should believe in the effectiveness in what they do. The self-confidence of recipients is influenced by; knowledge of what one's abilities are, a consciousness of one’s present and potential abilities, attitude, a sense of efficiency which includes the perception of how one controls one’s own performance and achieves the outcome.

Interpersonal Relationship Skills (IPRs)

The recipient requires adequate IPRs to communicate effectively with the agent in order to achieve the terminus. The recipients have to also effectively communicate with other stakeholders such as NGO managers and the interdisciplinary team.

Respect and trust

Recipients are in contact with various stakeholders, including the agent. In order to benefit from the programme, recipients have to trust that the agent has their best interests at hearts and is therefore assisting them. Recipients should also trust that the agent is equipped with the knowledge, skills and experience to empower them.

Responsibility

Recipients have the responsibility of providing physical and emotional support to the children they care for. They take care of all the basic needs of the disabled children who require their services. Recipients have to therefore do good (beneficence) and avoid doing harm (non-maleficence) when rendering care. It is also the responsibility of each recipient to improve their knowledge and skills in order to provide the best possible care to the children they render care to.

Compassion

Recipients work with disabled children who are viewed as being vulnerable and marginalized in society. Recipients should be sensitive to the needs of the children they care for. They should be sensitive, empathetic and provide the best possible care and support to children who are differently abled

7.2.3 Context

The contexts where an activity occurs is referred to as the Framework (Dickoff et al 1968:435). The context is composed of the environment where the activities take place. In this study, the context is the recipient’s immediate working environment that is the NGOs where children who are differently abled children are cared for. The research study was contextual as the contextual research design was applied in all three phases of the research study. The researcher collected data from caregivers and NGO managers at the premises of the selected Non-Governmental Organisations who render care to children who are differently abled. The programme that was developed from the study will be used to empower caregivers at NGOs for children who are differently abled with skills and knowledge to effectively address the challenges they face, so that they can render optimal care to the children cared for.

7.2.4 Dynamics

Dynamics denote the energy source and impetus of an activity thus being the challenges in the context where caregivers render care to children who are differently abled (Dickoff et al 1968:435). The dynamics were derived from phase one of the study where that emerged from this study where the challenges caregivers experiences were explored and understood. The dynamics of this study are in line with the themes and sub-themes that emerged from phase one and are depicted in the figure 7.4.

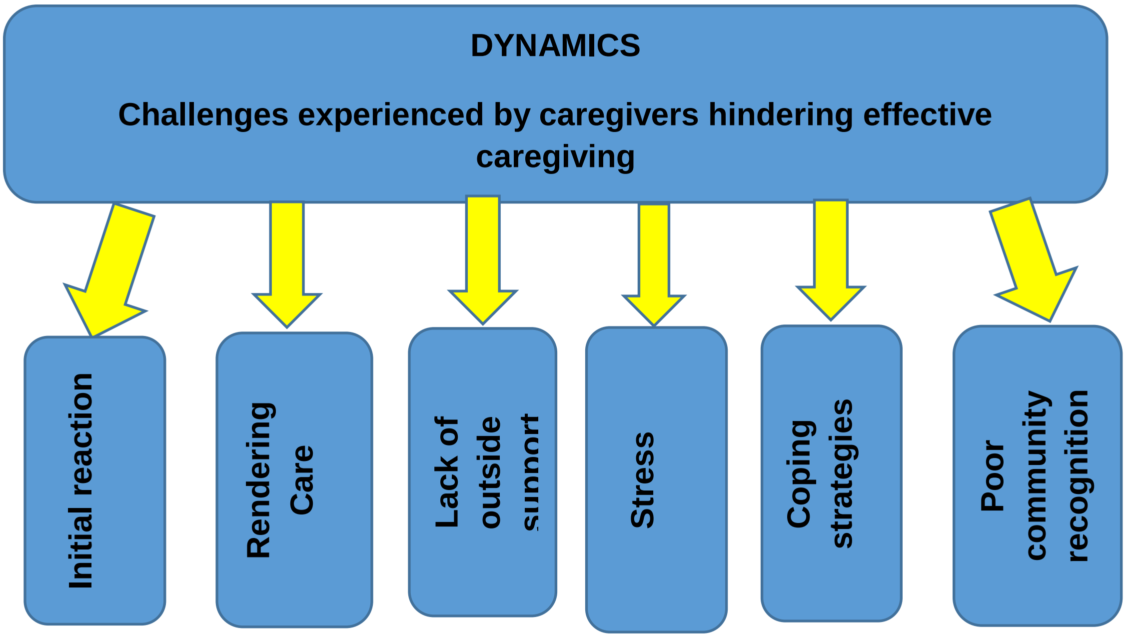


Figure 7.4: Dynamics

Initial reaction

Caregiver preparedness is linked to a positive first impression. The initial reaction caregivers described was that of shock or feeling intensely overwhelmed, as they were not expecting to see children who are severely disabled. Caregivers did not know what to expect, as they were not exposed to children who are differently abled before. Caregivers were ill prepared and scared to undertake the caregiving role that includes the provision of physical and emotional support to those in need. Caregivers who are not prepared for the caregiving role are at a higher risk of experiencing caregiver burden.

Rendering care

All caregivers stated they experience challenges when it comes to implementing activities to fulfil their caregiving role. Due to the lack of training, caregivers find it challenging to perform basic tasks for the children such as bathing, feeding, handling, stimulation and medication management. Caregivers not only lack the basic skills required to care for children who are differently abled, they also lack the knowledge regarding the different conditions and diagnosis children present with.

Stress

The demands of caring for children who are differently abled results in caregivers experiencing stress which manifests physically and psychologically. Caregivers complained of headaches, backache, insomnia and sadness. Not having undergone adequate training adds to the caregivers stress. Programmes and interventions aimed at helping caregivers should focus on teaching caregiver skills to deal with the problems the care recipients present with. Providing caregivers with skills and knowledge to optimally perform their caregiving role could help in significantly reducing stress caregivers experience.

Lack of outside support

All caregivers in the study mentioned lack of outside support as a challenge. Caregivers acknowledge that they do receive support from NGO managers and other caregivers, but do not receive support from outside. Caregivers expressed they require more support in terms of training and also professional medical support to deal with the physical and psychological effects of their job. Caregivers who receive inadequate support experience more stress than those who receive support. Caregivers who are supported provide better care to their care recipient.

Poor community recognition

Caregivers in the study do not consider their communities to know, understand and recognize the valuable work they are doing at the NGOs. Caregivers also reported that community members do not understand why they take on such a difficult role of caring for children who are differently abled, as stigma towards disabled people still exists in many communities. Caregivers who are not recognized by their communities often become demoralized and experience higher levels of stress than caregivers who receive community support and recognition (Schneider 2020:186). Caregivers who are recognised become informed and empowered to meet their own needs, or become partners in the care process (Freid 2018:9).

7.2.5 Procedure

The procedure refers to the protocol that will be used to guide the activities which makes it possible for the agent to reach the determined goal and objectives. It consists of orderly steps that are implemented in the form of activities. The procedure in this study refers to the process of 'how' caregivers will be empowered. This was done by the development of the programme that will empower caregivers who render care to children who are differently abled at NGOs. Information adopted from the qualitative study and the developed conceptual framework was used to supplement the content of the programme.

Data collected from the qualitative study (phase 1) and the developed conceptual framework (phase 2) provided a foundation for developing the programme to empower caregivers who render care to children who are differently abled at NGOs with skills and knowledge to address the challenges they experience.

The following four activities of The Cyclic Curriculum Development Model of Nicholls and Nicholls (1978); was adopted as the process to follow for the development of the programme:

CONDUCTING A SITUATIONAL ANALYSIS

This entails the researcher gathering information that is relevant and distinctive to a specific community within a specific context to ensure that their needs are responded to in an effective and realistic manner. This step involves collecting data through conducting individual interviews, focus group discussion and surveys. Interviews were tape-recorded and were transcribed verbatim. All data collected from the interviews were used to guide the researcher to generate topics that will be included in the programme.

Step one of the process was addressed in phase one of the study where caregivers and NGO managers were interviewed to explore and describe their experiences. The experiences of caregivers in relation to their caregiving role was explored and the experiences of NGO managers at NGOs caring for children who are differently abled regarding their management of caregivers was explored.

SELECTING OBJECTIVES

The objectives of the empowerment programme was selected based on the findings of the situational analysis and concepts derived from the conceptual framework that was conducted following The Practice Orientated Theory of Dickoff et al (1968).

SELECTING AND ORGANISING CONTENT

The content for the empowerment programme was organised according to the findings from the situational analysis, conceptual framework and from the selected objectives.

SELECTING AND ORGANISING TEACHING METHODS

The methods or strategies to be used during the implementation of the programme will be selected based on the content and objectives to be covered.

7.2.6 Terminus

The terminus is referred to as the outcome of the process; it also refers to the desired outcome an agent aspires to achieve by applying a particular process. Findings from the current study show that caregivers' experiences lack the skills and knowledge to optimally carry out their caregiving task. In this study, the terminus refers to the caregivers who will be empowered through a programme to equip them with skills and knowledge to address the challenges they face. Through empowered caregivers children who are differently abled receive comprehensive optimal care and caregivers can have a good quality of life.

7.3 DEVELOPMENT OF THE EMPOWERMENT PROGRAMME FOR CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NGOS

Phase one of the study explored and described the experiences of caregivers who render care to children who are differently abled at NGOs. This phase also explored and described the experiences of NGO managers at NGOs caring for children who are differently abled regarding their management of caregivers. Findings from phase one revealed that caregivers are disempowered due to the numerous challenges they experience. These specific challenges were found to be challenges with; rendering care to their recipients, stress, coping strategies, lack of outside support and poor community recognition of the caregiving role and poor communication skills.

Data collected from the qualitative study (phase 1), and the developed conceptual framework (phase 2), provided a foundation for developing the programme to empower caregivers caring for children who are differently abled at NGOs. Additionally, the Caregivers Support Model, which is a logic model framework developed by the Alzheimer’s Society of York (2018) was used to develop the content programme.

The programme was developed following the stages of development of the health education tool described by Arora et al (2017:7-9), which includes; defining the purpose and goal of developing the education material, designing a rough draft of the programme, validation of the programme by experts and target group members. The 4 activities of The Cyclic Curriculum Development Model of Nicholls and Nicholls (1978) was also used and includes conducting a situational analysis, selecting objectives, selecting and organising content and selecting and organising teaching methods.

7.3.1 Title of the programme

An empowerment programme for caregivers of children who are differently abled at Non-Governmental Organisations.

7.3.2 Purpose of the empowerment programme

The purpose of the empowerment programme is to equip caregivers of children who are differently abled at NGOs with skills and knowledge to address the challenges they face which phase one of the study identified as:

- Negative first impressions of the NGO context resulting in poor caregiver preparedness,
- Challenges performing basic tasks for the children such as bathing, feeding, handling, lifting and carrying and medication management. Caregivers not only lack the basic skills required to care for children who are differently abled, they also lack the knowledge regarding the different conditions and diagnosis the children they care for present with,
- Stress due to the demands of caring for children who are differently abled that manifests physically and psychologically,
- Lack of outside support. Caregivers require more support in terms of training and professional medical support to deal with the physical and psychological effects of their job. Caregivers who receive inadequate support experience more stress than those who receive support. Caregivers who are supported provide better care to their care recipient,
- Poor community recognition causes caregivers to become demoralized and experience higher levels of stress,
- Poor communications skills.

7.3.3 Objectives of the programme

- **To empower caregivers at NGOs with skills and knowledge regarding children who are differently abled in order for them to feel more prepared to carry out their caregiving role effectively**
  This objective will address the challenges caregivers experience with performing their basic tasks for the children such as bathing, feeding, handling, lifting and carrying and medication management. This objective will also address the lack of

knowledge caregivers have regarding the different conditions and diagnosis of children.

- **To empower caregivers with tools and coping strategies to effectively manage stress**
  This objective will address the maladaptive coping strategies caregivers use to cope with the stress they experience as a result of their caregiving role that will help reduce the physical and psychological manifestations of stress they experience.
- **To improve community awareness and recognition of the contribution caregivers make**
  This objective will address caregiver morale and motivation, as caregivers who are motivated will experience less stress. Caregivers who are recognized become informed and empowered to meet their own needs or become partners in the care process.
- **Empower caregivers with effective communication skills**
  This objective will address the challenge caregivers experience when it comes to communicating with their managers. Caregivers who are able to communicate effectively will be able to communicate their needs and any challenges they experience to their managers who are in a position to provide support, including arranging for outside support. Caregivers who are supported will experience lower levels of stress and will be in a better position to cope with their stress in a healthy manner.

7.3.4 Programme structure

The programme is a five-day programme scheduled to be implemented at the NGO where caregivers work. The programme is structured according to the programme; process, approach and content.

7.3.5 Programme Processes

The education programme is made up of the following three phases depicted in figure 7.5 below:

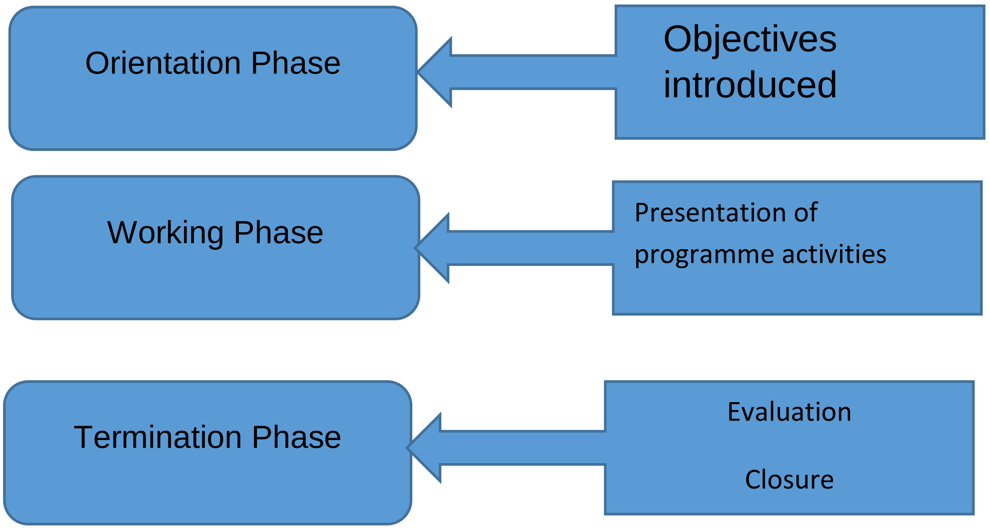


Figure 7.5: Programme processes

7.3.6 Educational Approaches

Kolb's Experiential Learning Theory and Knowles' Theory of Andragogy provided the structure on which the programme is developed. Experiential learning refers to learning from experience or by doing. Lewis and Williams (1994:14) explain that with experiential learning, adults first immerse themselves in an experience and are then encouraged to reflect on their experience in order to develop new skills, new attitudes and new methods of thinking. Knowles (1980:43) defines andragogy as "the art and science of helping adults learn, in contrast to pedagogy as the art and science of teaching children. Pedagogy assumes that adults are ready and eager to learn and should therefore have their learning organized into a curriculum that is standardized that progresses in a systematic manner" (Knowles 1980:44).

Kolb's Experiential Learning Theory

Kolb's experiential learning theory is one of the most prominently used educational theories in the field of higher education (Healey & Jenkins 2000:186). The following educational principles stream from the philosophy of experiential learning:

- Respect for learners and their experiences,
- Begin learning with the learners experience of the subject matter,
- Creating and holding a hospitable space for learning,
- Making space for conversational learning,
- Making space for feeling and thinking,
- Making space for inside-out learning,
- Making space for learners to take charge of their own learning.

Developing the effectiveness of learners, students become empowered to take on the responsibility for their learning through understanding the methods that help them learn and the skills required to learn what they find uncomfortable (Keeton, Sheckley & Griggs 2002:47). The empowerment programme is developed based on experiential learning cycle as shown in the figure 7.6 below.

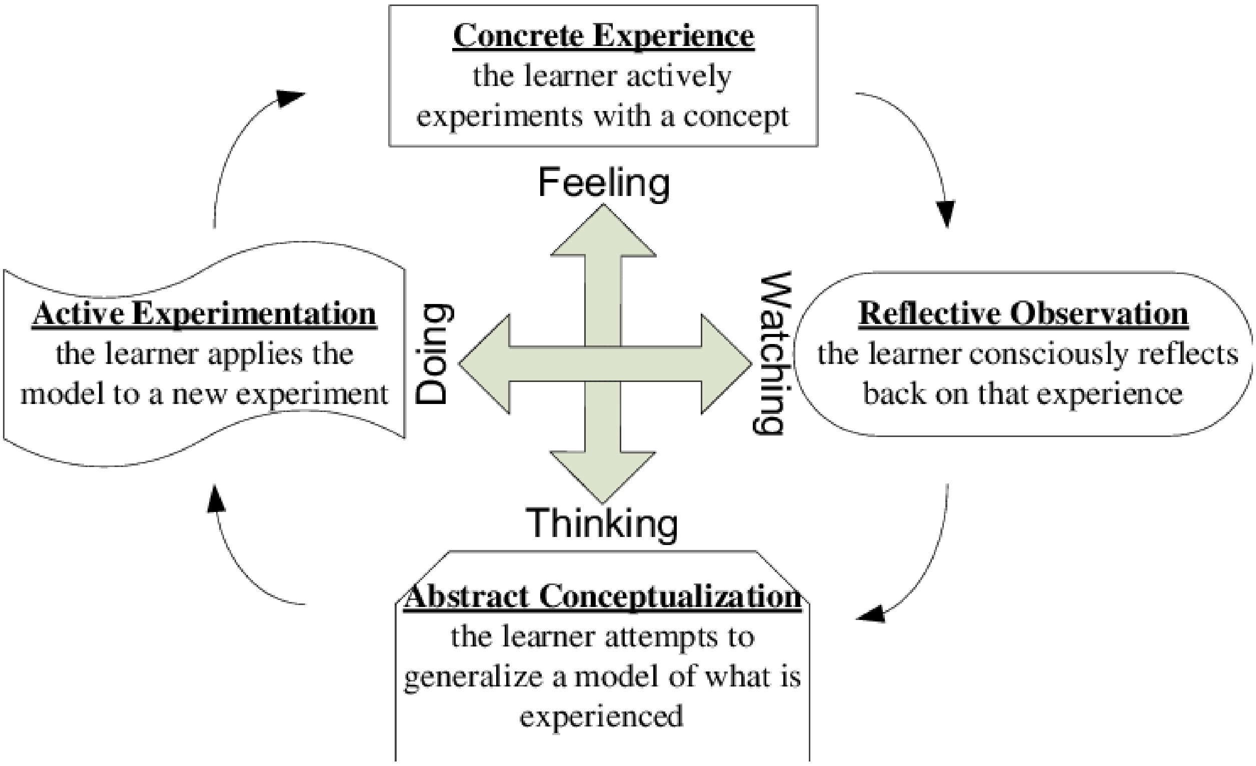


Figure 7.6: Four stages of the Kolb's Experiential Learning Cycle (Konak, Clark & Nasereddin 2014).

Concrete experience

This stage provides the foundation for the process of learning. This stage will assist caregivers to develop their own ideas and arrange their thinking in line with the challenges they experience providing care to children who are differently abled at NGOs. Caregivers make use of their immediate context and experiences within that context to reflect on the situations they experience at the NGO. With concrete experience, caregivers gain solid experience through performing new tasks.

Reflective observation

In this stage, caregivers use discussion and reflective questions to reflect on new experiences and observations.

Abstract conceptualization

This stage helps caregivers solve problems and come up with solutions to actual challenges they experience in their working environment at the NGO.

Active experimentation

In this stage, caregivers apply all they have learned to their caregiving context. Caregivers test what they have learned through the creation of new experiences.

Knowles' Theory of Andragogy

Knowles (1980:59) states that when andragogy principles are translated into a process for planning and operating educational programmes, the process turns out to be different from the curriculum planning and teaching processes used in youth education. According to Knowles (1980:59), andragogy involves the following phases:

- Establishment of a climate which is conducive to adult learning,

- Creation of organisation structure for participatory planning,
- Determining learning needs,
- Formulation of objectives,
- Implementation of the objectives,
- Evaluation.

Adult learners must be included in the planning and evaluation of teaching activities. Adults learn through personal experience, including the mistakes they make. According to Knowles, adult learners are mature and need to be involved in planning and evaluation of their learning activities.

7.3.7 Content of the empowerment programme

Data collected from the qualitative study (phase 1), and the developed conceptual framework (phase 2) was used to compile the empowerment programme. The content of the programme included activities to empower caregivers with skills and knowledge they require to address the challenges they experience. The contents included activities that provide skills and knowledge required by caregivers to carry out their caregiving role effectively. The content also included activities to empower caregivers with tools and coping strategies to effectively manage stress. Furthermore, activities to improve community awareness were also included in the programme. Lastly, the content addressed activities to improve community awareness and recognition of the contribution. Lastly, the contents address effective communication skills. The development of the empowerment programme is depicted in table 7.1 below.

TABLE 7.1: A PROGRAMME TO EMPOWER CAREGIVERS WHO RENDER CARE TO CHILDREN WHO ARE DIFFERENTLY ABLED AT NGOS WITH SKILLS AND KNOWLEDGE TO ADDRESS THE CHALLENGES THEY EXPERIENCE

Aspects of the programme	Description of aspects
Title of the programme	An empowerment programme for caregivers of children who are differently abled at Non-Governmental Organisations.
Aim of the programme	To equip caregivers of children who are differently abled at NGOs with skills and knowledge to address the challenges they face implementing their caregiver role

Objectives of the programme	- To empower caregivers at NGOs with skills and knowledge regarding children who are differently abled in order for them to feel more prepared to carry out their caregiving role effectively - To empower caregivers with tools and coping strategies to effectively manage stress - To improve community awareness and recognition of the contribution caregivers make - Empower caregivers with effective communication skills
Structure of the programme	The programme is structured to be implemented over a five-day workshop
Approaches used in the programme	- Kolb's Experiential Learning Theory - Knowles' Theory of Andragogy
Teaching methods	- Lectures - Group discussions - Role- play
Target audience	Caregivers who care for children who are differently abled at NGOs
Phases of the programme	- Phase 1 (Orientation phase) - Phase 2 (Working phase) - Phase 3 (Termination phase)

TABLE 7.2: PHASES OF THE PROGRAMME

Phase of the programme	**Description of phase**
Phase 1 (orientation phase- day one)	- General introduction - Welcome all caregivers - Ice breaker - Introduction of the empowerment programme - Overview of the aims, objectives and purpose of the programme - Setting ground rules together with caregivers
Phase 2 (Working phase)	- Activities to empower caregivers at NGOs with skills and knowledge regarding children who are differently abled in order for them to feel more prepared to carry out their caregiving role effectively. - Activities to empower caregivers with tools and coping strategies to effectively manage stress. - Activities to improve community awareness and recognition. - Empower caregivers with effective communication skills
Phase 3 (termination phase)	- Evaluation of the programme - Feedback from caregivers - Closure of the workshop

7.3.8 Description of the empowerment programme

The empowerment programme is described in relation to the objectives of the programme.

Objective 1: To empower caregivers at NGOs with skills and knowledge regarding children who are differently abled in order for them to feel more prepared to carry out their caregiving role effectively.

To address the challenges caregivers experience with optimally fulfilling their caregiving role, the following needs to be addressed:

- Caregivers need to be educated on the common disabilities children at the NGOs present with (cerebral palsy, autism and severe intellectual disabilities),
- Caregivers need to be educated on how to bath their care recipients,
- Caregivers need to be educated on how to feed their care recipients,
- Caregivers need to be educated on how to handle care recipients,
- Caregivers need to be educated on how to lift and carry care recipients,
- Caregivers need to be educated on medication management.

Objective 2: To empower caregivers with tools and coping strategies to effectively manage stress.

- Caregivers need to be provided with information on stress and its causes,
- Caregivers need to be provided with information and tools on how to cope with stress.

Objective 3: To empower caregiver with tools on how to improve community awareness and recognition

- Caregivers need to be provided with information on how to foster community participation,
- Caregivers need to be provided with information on how to improve their awareness and recognition in the community.

Objective 4: To empower caregivers with effective communication skills

Caregivers need to learn how to communicate effectively with their managers in order to elicit the support they require.

7.4 IMPLEMENTATION

7.4.1 Orientation Phase

During this phase, participants are welcomed and introduced to the empowerment programme. Participants are then given registration forms to complete that contain a part on consent for participation in the programme. The facilitators provide participants with information on general logistics, the purpose of the programme and the objectives of the programme. Expectations of the programme are discussed with the group members and ground rules are also set and agreed upon by all group members and the facilitator. An icebreaker activity is then done where group members get to know each other better and become more comfortable in the context of the programme being implemented.

7.4.2 Working Phase

7.4.2.1 Part 1: To empower caregivers at NGOs with skills and knowledge regarding children who are differently abled in order for them to feel more prepared to carry out their caregiving role effectively

The aim of part one is to help caregivers gain knowledge on how to provide basic care to the children who are differently abled they care for. Caregivers have to first be educated on disabilities before they can be taught any other skills. The following process presented in the table below is followed to address Part 1 of the programme:

TABLE 7.3: SPECIFIC CONTENTS OF THE EMPOWERMENT PROGRAMME

Task	Content	Strategies
Educate caregivers on the common disabilities children at the NGOs present with (cerebral palsy, autism and severe intellectual disabilities).	● Definition of disability ● Common features of diagnoses children at the NGO present with (cerebral palsy, autism, severe intellectual disabilities and epilepsy) ● Causes of disability ● Effects of disability	● Lecture in the form of a PowerPoint presentation. A video and pamphlets of disabilities will be used in the lecture ● Group discussion referring to specific challenges they experience with children with the different diagnosis
Educate caregivers on how to bath their care recipients	● Overview on difficulties with bathing ● Strategies to overcome challenges bathing ● Equipment for bathing ● Prevention of caregiver back pain	● Lecture (video and demonstrations) ● Group discussion ● Demonstration with a return demonstrations on a mannequin

		● Critical incidents
Educate caregivers on how to feed their care recipients	● Overview on difficulties with feeding ● Positioning ● Food consistency ● Jaw support ● Utensils ● Nutrition ● Saliva control	● Lecture (pictures and demonstrations) ● Group discussion ● Demonstration with a return demonstration ● Critical incidents
Educate caregivers on how to lift and carry care recipients	● Overview on difficulties with carrying and lifting children ● Caregiver back care and injury prevention ● Carrying children with different presentations ● Transfers to and from wheelchairs, buggies, mats and plinths ● Equipment for carrying ● Lifting children from various position	● Lecture (video and demonstrations) ● Group discussion ● Demonstration with a return demonstration ● Critical incidents
Educate caregivers on how to handle care recipients	● Overview on difficulties physically handling care recipients ● Good handling techniques ● Bad handling techniques ● Handling during ADLs	● Lecture (video and demonstrations) ● Group discussion ● Demonstration with a return demonstration ● Critical incidents
Educate caregivers on medication management (to be done by a professional nurse)	● Recognize common medication used by care recipients ● Importance of record keeping ● Identify prescribed medication ● Understand common errors that can occur ● Storing medication ● Disposing of medication ● Contra indications, allergies and overdoses ● Tools for medication management	● Lecture ● Critical incidents ● Group discussion

7.4.2.2 Part 2: To empower caregivers with tools and coping strategies to effectively manage stress

The aim of part two is to help caregivers gain knowledge and skills on how to cope with the stress they experience as a result of their caregiving role in a healthy manner in order to reduce the physical and psychological manifestations of stress they experience.

Objective	Content	Strategies
Educate caregivers on stress	● Define stress ● Causes of stress ● Symptoms of stress ● Effects of stress	● Lecture ● Group discussion ● Critical incidents
Educate caregivers on skills to cope with stress	● Steps to manage stress ● Coping strategies - Calming Coping Strategies - Emotion-Focused Coping Strategies	● Critical incidents ● Role play

	- Solution-Focused Coping Strategies	

7.4.2.3 Part 3: To empower caregivers with skills on how to improve community awareness and recognition

Objectives	Content	Strategies
Caregivers need to learn skills on how to foster community participation Caregivers need to learn skills on how to raise community awareness and recognition	● Definition of community ● Description of community development ● Principles of community development ● Stakeholders in the community ● How to foster community participation ● Strategies to improve community awareness	● Lecture (PowerPoint and video) ● Group discussion on how to implement what was learned and strategies that can be developed

7.4.2.4 Part 4: To empower caregivers with effective communication skills

Objectives	Content	Strategies
To empower caregivers with effective communication skills	● Description of the communication process ● Role of effective communication in the caregiving context ● Barriers to effective communication ● Methods for effective communication	● Lecture ● Critical incidents ● Group discussion ● Role play

7.4.3 Termination phase

In the termination phase, participants are required to evaluate the programme to determine if there were any problems encountered during the training programme and what could be done to remedy those problems. Participants will be requested to complete the evaluation of the entire programme on the very last day. The termination phase ends with the closure of the programme. The programme evaluation form for participants is labelled annexe J.

7.5 FACILITATION TECHNIQUES

Otim (2013:8) defines facilitation as “the art of bringing adults together the learning, by helping adults learn through self-discovery”. Facilitation is used to empower groups as it consists of relinquishing control over the outcome of a specific process through handing over the responsibility to group members. Facilitation techniques are used to recognize challenges to address issues identified by a group and adapts fresh ideas to what the needs of the group are. The following facilitation techniques are used in the programme:

Icebreakers

According to Bonk and Khoo (2014:122) icebreakers are activities which include discussions and questions that help group participants relax, integrate with others and the learning process. The functions of icebreakers in this study are:

- To learn more about group members and the facilitator,
- Help group members relax,
- Motivate, encourage and energize,
- Overcome social barriers,
- Facilitate creativity among group members,
- Facilitate interaction among group members,
- Create a conducive atmosphere for learning.

By starting the programme with icebreakers, group members realize what commonalities they share among each other. Icebreakers create a conducive learning environment that is sincere, friendly and welcoming. According to the Pennsylvania Child Welfare Resource Center (2012:1), the activities chosen for the icebreaker are dependent on the goals of the programme, the audience, the duration of the programme and the amount of group participants. The icebreaker should be related to their caregiving role. An example of an icebreaker that could be used is described below:

Caregivers could be asked to travel to put themselves in the shoes of any of the differently abled children they care for and answer the following questions

- How do you experience life as a child who is differently abled?
- What support do you need from your caregiver?

Lecture

According to Farooq (2014:1), a lecture is a teaching method where information about a certain topic is delivered to an audience using visual tools such as; PowerPoint presentations, videos and pictures. Matiru, Gasser and Schlette (1995:300) listed the following skills that are important when delivering lectures:

- Clarity: Use clear simple language that is not ambiguous. Concepts that are new to the audience should be defined, clarified and paraphrased,
- Organisation: The lecture should be well structured in a logical manner,
- Emphasis: Main ideas should be emphasized through the use of voice and body language,
- Orientation: Provide an outline of the lecture contents right in the beginning of the lecture so that the audience is prepared for what to expect,
- Examples: Examples are very important and makes it easier for the audience to understand what is being portrayed in the lecture,
- Feedback: Informs the lecturer if the participants understand what is being thought. This is done through the lecturer asking the audience questions and using probes.

Role-play

Group members are given a scenario and deliberately place themselves in the scenario situation in order to gain an understanding of the life experiences of others and to gain a fresh perspective on their own experiences.

Group discussions

Participants are divided into small groups (3-5) and have a reasonably unstructured exchange of ideas regarding a specific topic, problem or issue. Through group discussion, knowledge richness is heightened through the facilitator guiding the discussion. All group discussions should end with a reflection on what was learned.

Demonstration with a return demonstration

The facilitator demonstrates a specific task where the group is shown exactly how a task is performed. Group members are then asked to perform what was demonstrated. Through the technique simulation, potential is enhanced.

Critical incidents

Group members’ are requested to describe personal incidents related to a specific topic being presented and then asked to use that incident as a base for analysis. Knowledge synthesis is heightened when group members are instructed to reflect on their own experience. Knowledge richness is improved by the use of listening groups to examine a critical incident and report back on the group members’ reflections and findings. The facilitator should persist that group members continue to produce practical solutions even after solutions from the group have been discussed. New ideas from the group could be very beneficial.

7.6 RESOURCES THE PROGRAMME REQUIRES

- Physical environment,
- Refreshments,
- Laptop,
- Projector,
- Stationary,
- Doll / mannequin,
- Feeding utensils,
- Plastic bath,
- Plinth,
- Gym mats,
- Chair,
- Wedge,
- Gym ball,
- Roller,
- Videos.

7.7 SUMMARY

Chapter 7 described the conceptual framework of the study which was developed based on the results from Phase 1 of the study and The Survey List by Dickoff et al. (1968) which consisted of the agent (researcher), recipient (caregivers), context, procedure, dynamics and terminus. The characteristic required of the agent and the recipient in development and success of the programme was also discussed.

Furthermore, Chapter 7 also described the development of the empowerment programme for caregivers of children who are differently abled at NGOs. The programme was developed based on the results from the qualitative study and the Survey List by Dickoff et al. (1968). The conceptual framework (phase 2) provided a foundation for developing the programme to empower caregivers caring for children who are differently abled at NGOs. The structure of the programme that included the programme process, programme approach and content was discussed. Additionally, educational approaches which served as a foundation for the programme developed was discussed in relation to its application to the programme. Facilitation techniques and required resources to ensure the success of the programme implementation was provided. The following chapter provides a general summary of the research study. Contributions made by the study, recommendations derived from the findings and limitations of the study are also highlighted in the following chapter.

CHAPTER 8

CONCLUSIONS, RECOMMENDATIONS, CONTRIBUTION AND LIMITATIONS OF THE STUDY

8.1 INTRODUCTION

Chapter 7 described the development of the programme to empower caregivers of children who are differently abled at Non-Governmental Organisations. In chapter 8, the conclusions, contributions of the study, limitations of the study and recommendations in relation to the empowerment programme for caregivers of children who are differently abled at NGOs are discussed.

8.2 AIM OF THE STUDY

The aim of the study was to develop a programme to empower caregivers who care for children who are differently abled at NGOs with skills and knowledge to effectively address the challenges they face in their caregiving role so that they are able to render effective care to the differently abled children they care for. The aim of the study was achieved through formulation of the following four objectives:

- Explore and describe the experiences of caregivers providing care to children who are differently abled at NGOs.
- Identify challenges experienced by caregivers at NGOs caring for children who are differently abled.
- Explore and describe the experiences of NGO managers at NGOs caring for children who are differently abled regarding their management of caregivers.
- Develop a conceptual framework that will facilitate the development of a programme which will empower caregivers at NGOs caring for children who are differently abled.
- Develop a programme that empowers caregivers at NGOs to effectively address the challenges they experience.

8.3 CONCLUSION OF THE STUDY

According to Ebrahim (2018:2), the conclusion of the study helps readers comprehend the importance of the research study after they have completed reading the research document. The conclusion synthesises key points from the study. The conclusions of the study are formulated on the experiences of caregivers providing care to children who are differently abled at NGOs and the experiences of NGOs managers at NGOs caring for children who are differently abled regarding their management of caregivers.

8.3.1 Objective 1: Explore and describe the experiences of caregivers providing care to children who are differently abled at NGOs

This objective was achieved through conducting nine semi-structured in-depth interviews with caregivers of children who are differently abled at NGOs. The findings revealed the following:

- The caregiving role entails providing basic care to children who are differently abled at the NGO where caregivers are employed which includes: bathing, feeding, nappy changing, medication management stimulation and potty training.
- Caregivers are motivated by passion, having a disabled relative, unemployment and pity to perform the caregiving role.
- Caregivers perceive the services they render to the children to be effective, even though they feel they could render better services should they undergo more training.

8.3.2 Objective 2: Explore and describe the challenges of caregivers providing care to children who are differently abled at NGOs

This objective was also achieved in phase one of the study where semi-structured in-depth interviews were conducted on caregivers of children who are differently abled at NGOs. The findings revealed the following challenges:

- Caregivers lack adequate training,
- Negative first impression of the caregiving context,
- Rendering care to their care recipients,

- Stress,
- Maladaptive coping strategies,
- Lack of outside support,
- Poor community recognition.

8.3.3 Objective 3: Explore and describe the experiences of NGO managers at NGOs caring for children who are differently abled regarding their management of caregivers.

This objective was achieved through conducting seven semi-structured in-depth interviews with managers of NGOs who care for children who are differently abled. The findings revealed the following:

- NGO managers do not have a standardized process for appointing a caregiver. There are inconsistencies with the procedure NGO managers use to hire new caregivers.
- Monitoring of caregivers by managers is unreliable, inconsistent and does not occur frequently.
- The major challenges NGO managers experience is; lack of trained caregivers, lack of resources, poor caregiver communication and lack of outside support for caregivers.

8.3.4 Objective 4: Develop a conceptual framework that will facilitate the development of a programme which will empower caregivers at NGOs caring for children who are differently abled

The practice orientated theory of Dickoff et al (1968) was used to develop the conceptual framework that was used to facilitate the development of the programme to empower caregivers who render care to children who are differently abled at NGOs based on the results from Phase 1 of the study. The six components included the agent, recipient, context, dynamics, and procedures and terminus. The agent was the researcher, recipients were caregivers, contexts were the NGOs where caregivers are employed, dynamics were all the challenges caregivers experience, procedures was the programme to empower caregivers who render care to children who are differently abled at NGOs and the outcome was empowered caregivers who have the knowledge and skills to address the challenges they face regarding their caregiving role.

8.3.5 Objective 5: Develop a programme that empowers caregivers at NGOs to effectively address the challenges they experience

Data collected from the qualitative study (phase 1) and the developed conceptual framework (phase 2) provided a foundation for developing the operational programme to empower caregivers who render care to children who are differently abled at NGOs. The programme consisted of four parts:

- Part 1: To empower caregivers at NGOs with skills and knowledge regarding children who are differently abled in order for them to feel more prepared to carry out their caregiving role effectively.
- Part 2: To empower caregivers with tools and coping strategies to effectively manage stress.
- Part 3: To empower caregivers with skills on how to improve community awareness and recognition.
- Part 4: To empower caregivers with effective communication skills.

8.4 LIMITATIONS OF THE STUDY

The current study produced significant results; however, it was not without limitations. The following is a discussion of limitations that might have affected the results found in the current study:

- Results of this study cannot be generalised to caregivers at NGOs for children who are differently abled across South Africa as the study was conducted at NGOs in what is considered to be semi-urban areas. Given the relatively homogeneous demographic characteristics of the caregivers that participated in the study, the study could be replicated among populations that are more diverse.
- The researcher is an occupational therapist and lecturer who has had prior contact with NGO managers and caregivers. This could have resulted in participants exaggerating or understating their experiences.
- The focus of the current study were caregivers of children who are differently abled at NGOs and not NGO managers. Phase one of the study revealed that NGO managers are experiencing challenges and require support to overcome the challenges they experience.

8.5 CONTRIBUTIONS OF THE STUDY TO THE BODY OF KNOWLEDGE IN PUBLIC HEALTH

- Evidence was generated that revealed the challenges caregivers at NGOs for children who are differently abled experience.
- Developing a programme to empower caregivers of children who are differently abled at NGOs could be an effective strategy to provide caregivers with knowledge and skills to think critically about the challenges they experience and to develop strategies to act on and effectively address the challenges they face. Empowering caregivers of children who are differently abled to develop and increase their skills and knowledge ultimately results in caregivers efficiently fulfilling their caregiver role to children who are differently abled.
- The developed programme could assist in improving the recognition, resiliency and supportive resources for caregivers in collaboration with CBR stakeholders in the community.
- The urgent and continued need for government level planning and provision of support for NGOs caring for children who are differently abled is crucial. NGOs are more likely to receive support from the government if they have competent, trained staff who deliver effective services to the clients that they care for.
- The researcher developed a conceptual framework that provided a foundation for developing the programme to empower caregivers who render care to children who are differently abled at NGOs.
- This research study serves as a fundamental building block for further research in the area of caregiver’s empowerment for people with disabilities.
- The researcher developed a programme to empower caregivers of children who are differently abled at NGOs with knowledge and skills to think critically about the challenges they experience and to develop strategies to act on and effectively address the challenges they face. Empowering caregivers of children who are differently abled to develop and increase their skills and knowledge ultimately results in caregivers efficiently fulfilling their caregiver role to children who are differently abled.

8.6 RECOMMENDATIONS

- Newly appointed caregivers should be provided with training prior to resuming their caregiving duties.
- NGOs should expose their caregivers to various training programmes on a regular basis.
- Future research should be conducted to explore the challenges NGO managers experience.
- The developed programme should be implemented in conjunction with rehabilitation staff at NGOs who care for children who are differently abled in the Gauteng Department of Health Region C.
- The urgent and continued need for government level planning and provision of support for NGOs caring for children who are differently abled is crucial. NGOs are more likely to receive support from the government if they have competent, trained staff who deliver effective services to the clients that they care for.

8.7 CONCLUDING REMARKS

The current study undertaken contributes to the ongoing contribution of knowledge regarding the empowerment of caregivers who care for children who are differently abled. This study has revealed the challenges caregivers face. This study also brought to light the experiences of NGO managers regarding their management of caregivers. The aim and objectives of the study were met as indicated in all three phases of the study.

The conclusions, contributions of the study, limitations of the study and recommendations in relation to the empowerment programme for caregivers of children who are differently abled at NGOs was also provided in this chapter.

The researcher is of the opinion that this study will empower caregivers of children who are differently abled.

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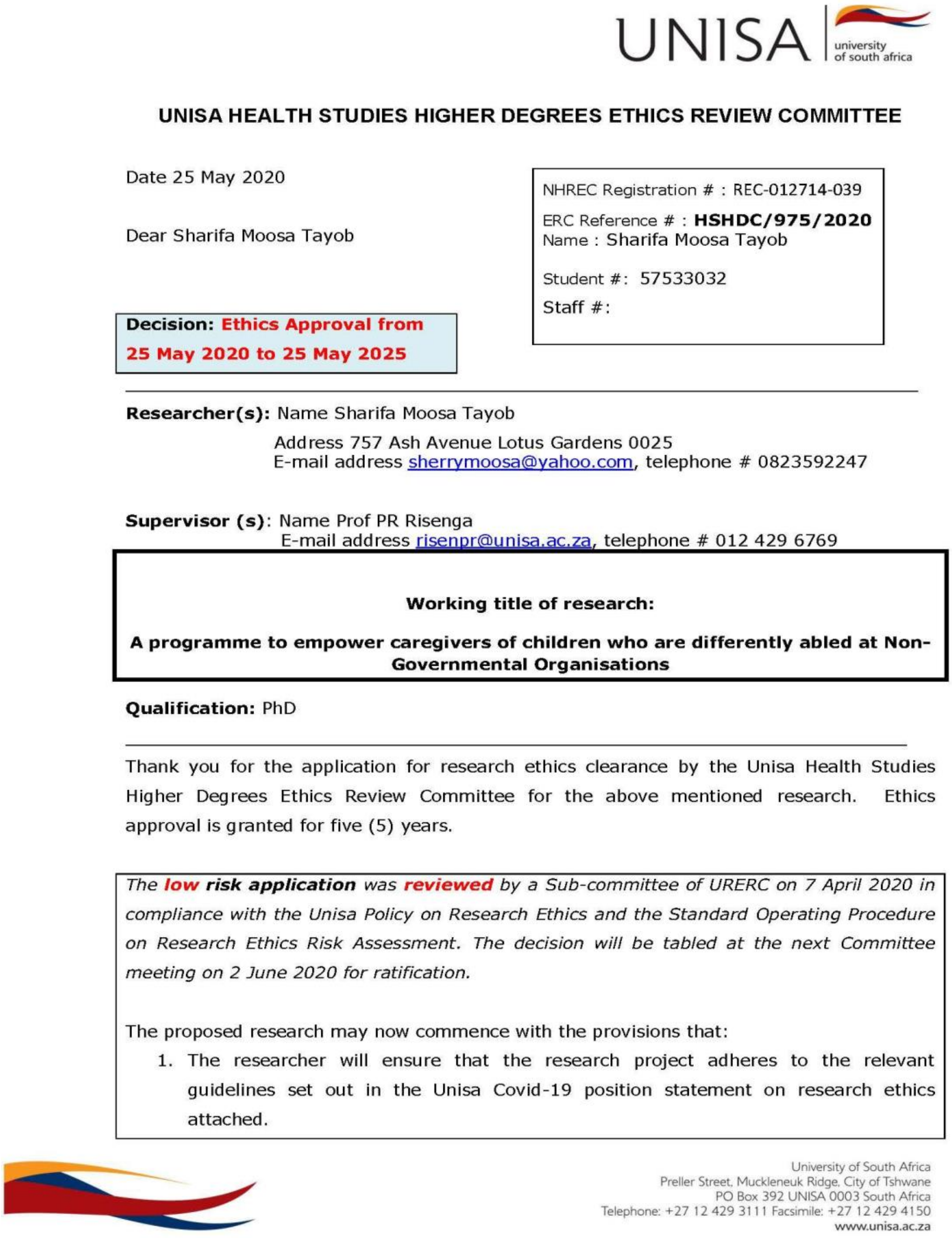
ANNEXE A

APPROVAL FROM



UNISA
university
of south africa

UNISA HEALTH STUDIES HIGHER DEGREES ETHICS REVIEW COMMITTEE

Date 25 May 2020

Dear Sharifa Moosa Tayob

NHREC Registration # : REC-012714-039
ERC Reference # : **HSHDC/975/2020**
Name : Sharifa Moosa Tayob
Student #: 57533032
Staff #:

Decision: Ethics Approval from 25 May 2020 to 25 May 2025

Researcher(s): Name Sharifa Moosa Tayob
Address 757 Ash Avenue Lotus Gardens 0025
E-mail address sherrymoosa@yahoo.com, telephone # 0823592247

Supervisor (s): Name Prof PR Risenga
E-mail address risenpr@unisa.ac.za, telephone # 012 429 6769

Working title of research:

A programme to empower caregivers of children who are differently abled at Non-Governmental Organisations

Qualification: PhD

Thank you for the application for research ethics clearance by the Unisa Health Studies Higher Degrees Ethics Review Committee for the above mentioned research. Ethics approval is granted for five (5) years.

*The **low risk application** was **reviewed** by a Sub-committee of URERC on 7 April 2020 in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment. The decision will be tabled at the next Committee meeting on 2 June 2020 for ratification.*

The proposed research may now commence with the provisions that:

1. The researcher will ensure that the research project adheres to the relevant guidelines set out in the Unisa Covid-19 position statement on research ethics attached.

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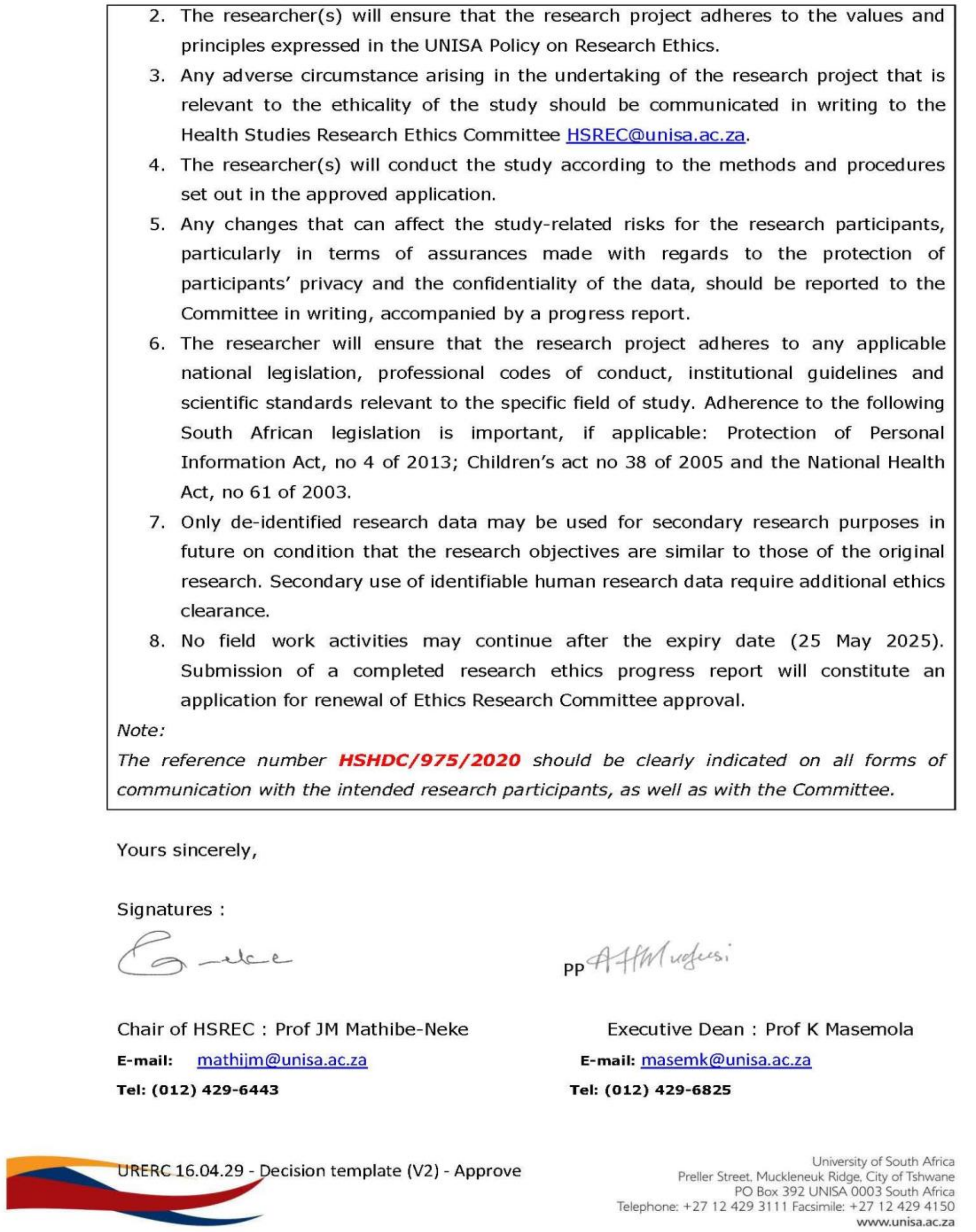


2. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
3. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the Health Studies Research Ethics Committee HSREC@unisa.ac.za.
4. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
5. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.
6. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
7. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
8. No field work activities may continue after the expiry date (25 May 2025). Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

The reference number ***HSHDC/975/2020*** *should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signatures :

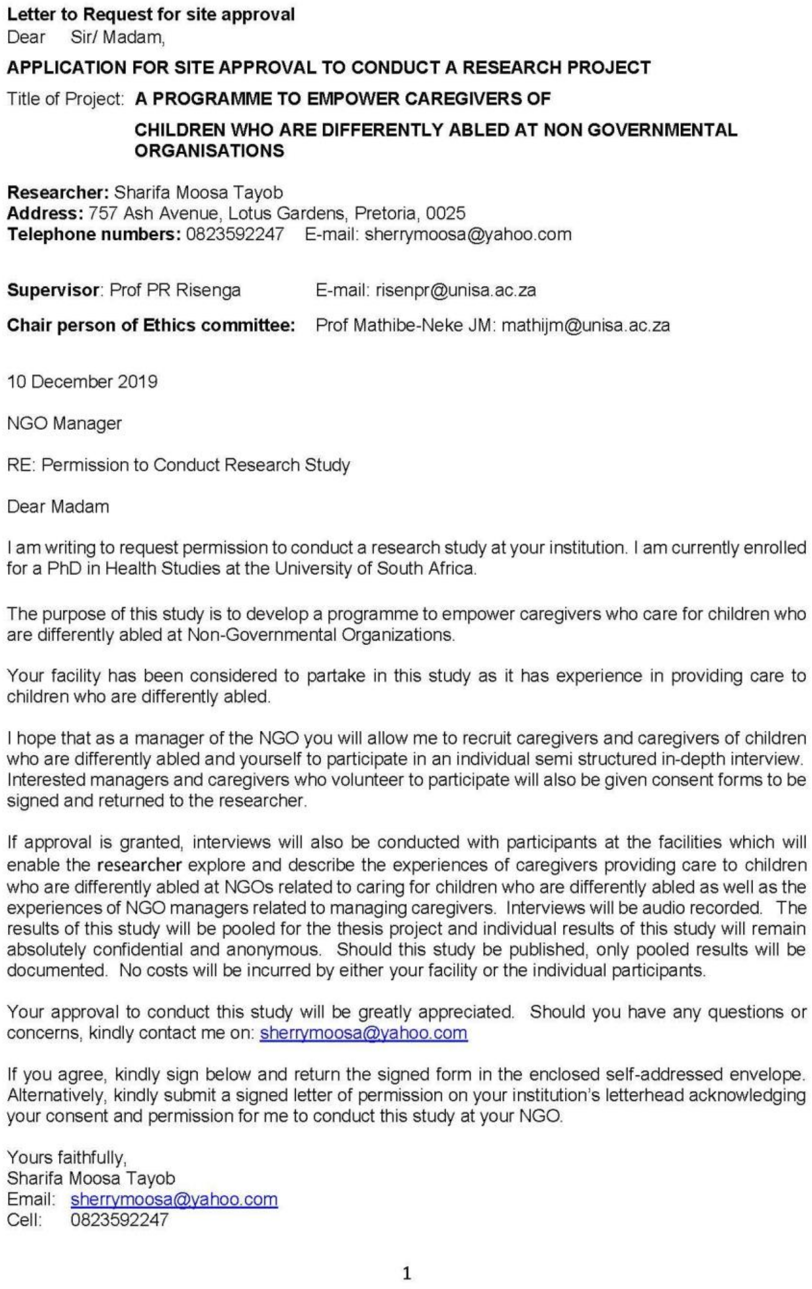
PP

Chair of HSREC : Prof JM Mathibe-Neke
E-mail: mathijm@unisa.ac.za
Tel: (012) 429-6443

Executive Dean : Prof K Masemola
E-mail: masemk@unisa.ac.za
Tel: (012) 429-6825

ANNEXE B

LETTER SEEKING CONSENT FROM NON-GOVERNMENTAL ORGANISATIONS



Letter to Request for site approval
Dear Sir/ Madam,

APPLICATION FOR SITE APPROVAL TO CONDUCT A RESEARCH PROJECT

Title of Project: **A PROGRAMME TO EMPOWER CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NON GOVERNMENTAL ORGANISATIONS**

Researcher: Sharifa Moosa Tayob
Address: 757 Ash Avenue, Lotus Gardens, Pretoria, 0025
Telephone numbers: 0823592247 E-mail: sherrymoosa@yahoo.com

Supervisor: Prof PR Risenga E-mail: risenpr@unisa.ac.za

Chair person of Ethics committee: Prof Mathibe-Neke JM: mathijm@unisa.ac.za

10 December 2019

NGO Manager

RE: Permission to Conduct Research Study

Dear Madam

I am writing to request permission to conduct a research study at your institution. I am currently enrolled for a PhD in Health Studies at the University of South Africa.

The purpose of this study is to develop a programme to empower caregivers who care for children who are differently abled at Non-Governmental Organizations.

Your facility has been considered to partake in this study as it has experience in providing care to children who are differently abled.

I hope that as a manager of the NGO you will allow me to recruit caregivers and caregivers of children who are differently abled and yourself to participate in an individual semi structured in-depth interview. Interested managers and caregivers who volunteer to participate will also be given consent forms to be signed and returned to the researcher.

If approval is granted, interviews will also be conducted with participants at the facilities which will enable the researcher explore and describe the experiences of caregivers providing care to children who are differently abled at NGOs related to caring for children who are differently abled as well as the experiences of NGO managers related to managing caregivers. Interviews will be audio recorded. The results of this study will be pooled for the thesis project and individual results of this study will remain absolutely confidential and anonymous. Should this study be published, only pooled results will be documented. No costs will be incurred by either your facility or the individual participants.

Your approval to conduct this study will be greatly appreciated. Should you have any questions or concerns, kindly contact me on: sherrymoosa@yahoo.com

If you agree, kindly sign below and return the signed form in the enclosed self-addressed envelope. Alternatively, kindly submit a signed letter of permission on your institution's letterhead acknowledging your consent and permission for me to conduct this study at your NGO.

Yours faithfully,
Sharifa Moosa Tayob
Email: sherrymoosa@yahoo.com
Cell: 0823592247

ANNEXE C

CONSENT FORM

Department of Health Studies

Research Topic:	**A PROGRAMME TO EMPOWER CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NON GOVERNMENTAL ORGANISATIONS**
Supervisor:	Prof PR Risenga
Researcher:	Sharifa Moosa Tayob (sherrymoosa@yahoo.com); (0823592247)

I, ___________________ (respondent name), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to participate in the study. I also agree to be audiotape during the interview and feedback sessions.

I understand that I can refuse being audiotaped even in the course of the conversation and feedback sessions; the consequence of which will be an exclusion from participation.

I understand that my participation is voluntary and that I am free to withdraw at any time without penalty (if applicable).

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I have received a signed copy of the informed consent agreement.

Respondent Name & Surname…………………………………………………… (please print)

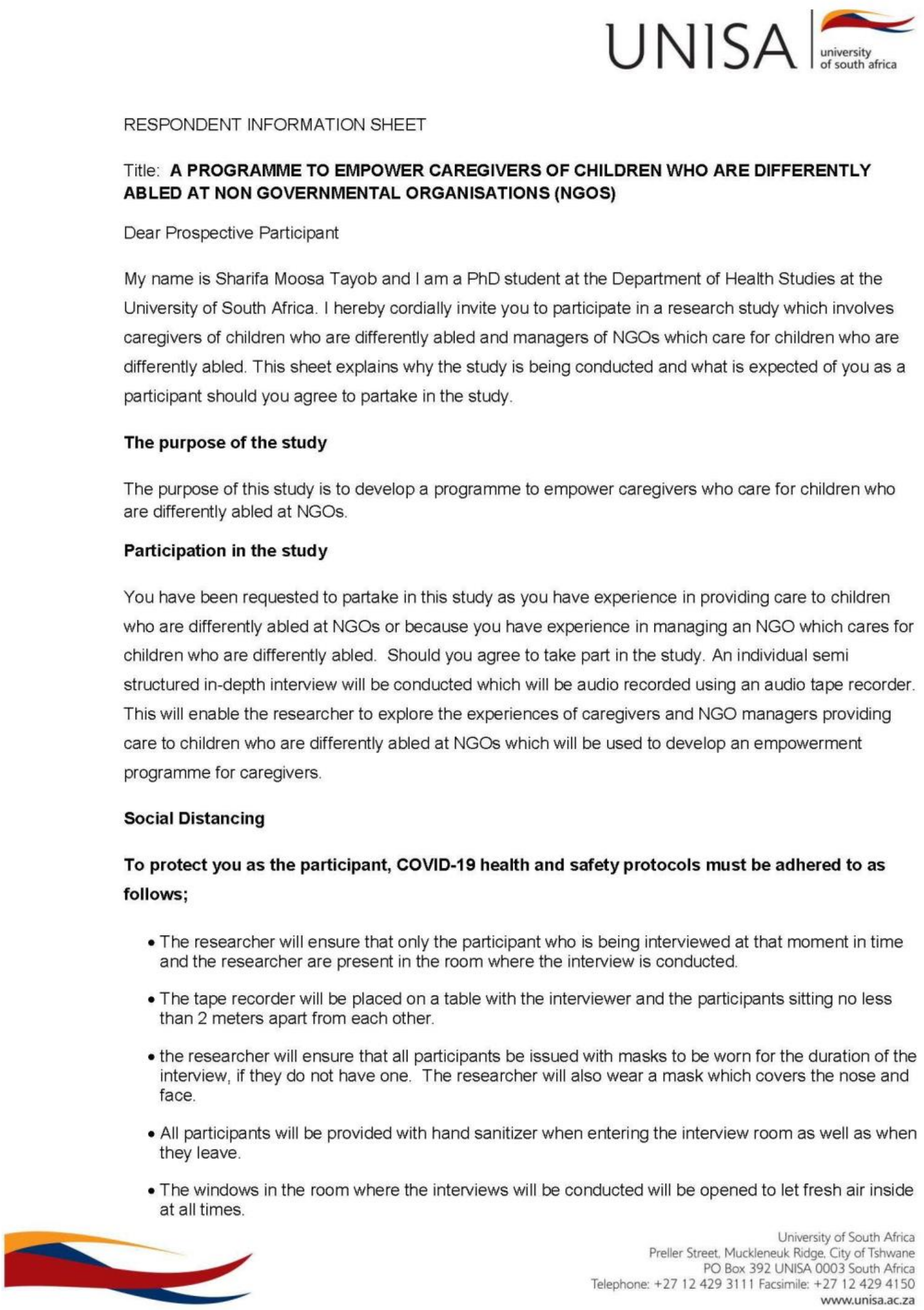
Respondent Signature……………………………………………..Date…………………

Researcher's Name & Surname SHARIFA MOOSA TAOB (please print)

Researcher's signature……………………………………………..Date…………………

ANNEXE D

RESPONDENT INFORMATION LEAFLET



RESPONDENT INFORMATION SHEET

Title: **A PROGRAMME TO EMPOWER CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NON GOVERNMENTAL ORGANISATIONS (NGOS)**

Dear Prospective Participant

My name is Sharifa Moosa Tayob and I am a PhD student at the Department of Health Studies at the University of South Africa. I hereby cordially invite you to participate in a research study which involves caregivers of children who are differently abled and managers of NGOs which care for children who are differently abled. This sheet explains why the study is being conducted and what is expected of you as a participant should you agree to partake in the study.

The purpose of the study

The purpose of this study is to develop a programme to empower caregivers who care for children who are differently abled at NGOs.

Participation in the study

You have been requested to partake in this study as you have experience in providing care to children who are differently abled at NGOs or because you have experience in managing an NGO which cares for children who are differently abled. Should you agree to take part in the study. An individual semi structured in-depth interview will be conducted which will be audio recorded using an audio tape recorder. This will enable the researcher to explore the experiences of caregivers and NGO managers providing care to children who are differently abled at NGOs which will be used to develop an empowerment programme for caregivers.

Social Distancing

To protect you as the participant, COVID-19 health and safety protocols must be adhered to as follows;

- The researcher will ensure that only the participant who is being interviewed at that moment in time and the researcher are present in the room where the interview is conducted.
- The tape recorder will be placed on a table with the interviewer and the participants sitting no less than 2 meters apart from each other.
- the researcher will ensure that all participants be issued with masks to be worn for the duration of the interview, if they do not have one. The researcher will also wear a mask which covers the nose and face.
- All participants will be provided with hand sanitizer when entering the interview room as well as when they leave.
- The windows in the room where the interviews will be conducted will be opened to let fresh air inside at all times.

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

Withdrawal from the study

You can decide to withdraw from the study at any time. You are requested to voluntarily participate in the study and therefore you are under no obligation to consent to participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. There is no penalty or loss of benefit for non-participation, and non-participation will in no way affect your employment at the NGO. If you decide to withdraw from the study after your interview has already been conducted, all recordings and transcripts will be destroyed and your data will not be used. If you do change your mind after giving consent to participate in the study, please contact the researcher using the telephone number or email address at the end of this leaflet.

Potential benefits of taking part in this study

Developing a programme to empower caregivers of children who are differently abled at NGOs could be an effective strategy to provide caregivers with knowledge and skills to think critically about the challenges they experience and to develop strategies to act on and effectively address the challenges they face. Empowering caregivers of children who are differently abled to develop and increase their skills and knowledge ultimately results in caregivers efficiently fulfilling their caregiver role to children who are differently abled.

Consequences for participating in the research project

Participants may feel that by taking part in the study they may influence their relationship with management of the NGOs, however, participating in the research will not influence your relationship with management in anyway. There are no anticipated risks associated with taking part in this study and if you experience any difficulties you can discuss this with the researcher.

Information and identity confidentiality

In order to enable you to answer as candidly as possible confidentially is ensured during the interviews.

Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the study group.

The information that is collected will be kept private and stored securely and safely on the researchers' computer. The computers are protected with a password. Your name will not appear on any information.

Your will be assigned a fictitious name when the information is being written in a report by the researcher.

The collected data will be safeguarded and kept confidential. All data collected will be stored securely and confidentially for five years and then destroyed.

Payment or any incentives for participating in this study

Participants will not be remunerated in any way for their participation in the study. Participants will also not incur any costs by participating in the study.

Ethics approval

This study has been reviewed and approved by the Research Ethics Review Committee at Unisa. If you have any further questions or concerns about this study or request to see the approval certificate, please contact the researcher.

The findings/results of the research

The findings of this research will be disseminated to you at a presentation which will be conducted at the NGO where you are employed.

Should you have any queries kindly contact:

Ms Sharifa Moosa Tayob on sherrymoosa@yahoo.com or 0823592247.

You are also welcome to contact the Chairperson of the University of South Africa's Health's Studies Research Ethics Committee (HSREC) Prof Mathibe-Neke JM via email: mathijm@unisa.ac.za

Thank you for taking time to read this information sheet and for participating in this study.

Sincerely,

Sharifa Moosa Tayob

ANNEXE E

INTERVIEW SCHEDULE FOR CAREGIVERS

PSEUDONYM: ________________

DATE________________

Respondent Number: ________

Research Topic: A PROGRAMME TO EMPOWER CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NON-GOVERNMENTAL ORGANISATIONS

Interview Guide for caregivers of children with disabilities

Biographical details

Age: ___________

Gender: ____________

Level of education ____________

Duration of employment at NGO: _______________

Interview questions:

- **Tell me about your experiences of caring for children who are differently abled here at this NGO?**
  Probing questions
- What are some of the demands that this job places on you?
- Have you had any stressful experiences as a result of your caregiving role at this NGO? If yes, could you share some of those stressful experiences you have had in this job.
- How do these challenges affect you physically and psychologically?
- Could you share with me some of the satisfying experiences you have had in this job.
- How do you manage to cope with the stressful experiences and challenges of this job?
- Tell me how prepared you felt to start caring for children who are differently abled when you first started this job.

- **How do you feel about the services you render to children who are differently abled here at the NGO?**

  Probing questions
  - How do you think the services you render to the children who are differently abled benefit them?

- What positive changes do the services you render to children who are differently abled bring to this NGO?
- What do you find most rewarding about caring for children with children who are differently abled?
- Do you feel others are aware of the contribution you make here at the NGO?

- **Tell me about the support you receive in your role as a caregiver to children who are differently abled**

Probing questions

- Tell me about the support you receive from management of this NGO.
- Tell me about the support you receive from any other organisation outside of this NGO.
- What type of support would you like to receive?

- **What are your specific needs when it comes to fulfilling your role as a caregiver at this NGO?**

  - What are your specific needs when it comes to skills to care for the children at the NGO?
  - What are your specific needs when it comes to knowledge regarding the children who are differently abled at the NGO?
  - Do you have needs related to anything else regarding your role as a caregiver at this NGO? If yes, could you kindly share those needs with me.
  - Do you require support to overcome the challenges you experience in your role as a caregiver? If so, what type of support do you require?

ANNEXE F

INTERVIEW SCHEDULE FOR NGO MANAGERS

PSEUDONYM: _____________________ DATE:_______________

Respondent Number: ________

Research Topic: A PROGRAMME TO EMPOWER CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NON-GOVERNMENTAL ORGANISATIONS

Interview Guide for NGO managers

Biographical details

1. Age: ___________
2. Gender: ____________
3. Level of education ____________
4. Duration of employment as a manager at the NGO: _______________

Interview questions

- **Tell me about your experiences when it comes to managing caregivers.**

  Probing questions

✓ What are some of the challenges you feel caregivers experience?
✓ What do you find challenging when it comes to managing caregivers?
✓ What do you expect from caregivers in carrying out their caregiving role?
✓ What knowledge and skills do you feel caregivers at this NGO require?

- **Tell me about the support that is provided to caregivers?**
  Probing questions

✓ Tell me what do you do to improve caregiver skills and knowledge?
✓ How do you keep caregivers motivated?
✓ What resources are caregivers provided with to effectively address the challenges they experience?

- **Tell me about the process you use to monitor caregivers.**

- **How do you collaborate with other stakeholders such as the government and the private sector to support caregivers?**

- **What do you feel can be improved on to empower caregivers?**

ANNEXE G
TRANSCRIPT OF A CAREGIVER INTERVIEW

TRANSCRIPT OF AN INDIVIDUAL SEMI-STRUCTURED IN-DEPTH INTERVIEW TO EXPLORE AND DESCRIBE THE EXPERIENCES OF NGO MANAGERS AT NGOS CARING FOR CHILDREN WHO ARE DIFFERENTLY ABLED REGARDING THEIR MANAGEMENT OF CAREGIVERS.

PSEUDONYM: ________________ DATE: 04/06/2020 TIME: 12:30

Respondent Number: C2

Interview Guide for caregivers

Biographical details

1. Age: 51
2. Gender: Female
3. Level of education: Grade 12
4. Duration of employment as a manager at the NGO: 7 years

Interview Process

Researcher: Good day mam

Participant: Good day

Researcher: Thank you for agreeing to participate in this study.

Can you tell me about your experiences looking after the children here at this center.

Participant: When I come early in the morning, I wash my hands and then make porridge. First, before you give the children the food they must wash their hands. And when they finish washing their hand, you take the food and put it in the room where they eat. Some children can take the food and eat. I have to take the food and feed them. When I am finished I take wet wipes to clean their mouths. The other children can't move their fingers then I take the ball to help him use their fingers. I also exercise with the children. For the child who is not good, every day before I go home I call the child and “I say come here”. I take the water and put it in the bath. Then the child takes her underwear and washes it. She knows I always train her how to wash her underwear very well. The other child didn't sit right when he crossed his feet. So I take a ball and I put it in the middle of his feet.

Researcher: What are some of the demands that this job places on you?

Participant: It is the first time I work like this my sister. I want to dedicate my mind to the children like this.

Researcher: What does it require of your mind to do?

Participant: I am all right. I enjoy my work. When I go home and come here, I feel like they are my children. 11:30 they must eat snacks if we don't have the snacks at least we must make juice.

Researcher: You make juice for the kids?

Participant: Yes for all the 25 kids here.

Researcher: What else do you do for the kids?

Participant: I wash the clothes for all the kids.

Researcher: What else?

Participant: I've washed the clothes for the kids and I also cook in the kitchen for the kids. There is something else I want to know but I am confused.

Researcher: What is that?

Participant: Aye… medication. The medication confused me, but I want to try my best...

Researcher: So at the moment you don't do it?

Participant: I don't do it and I want to do it, but it is difficult.

Researcher: Do you also bath the children?

Participant: Yes when I pass the children I first take off their diapers. Then I feel the temperature of the water. Then I bathe the child and take a dry towel to dry the child.

Researcher: Is there a special way to hold the children?

Participant: Yes exactly, but I don't know. I also feed the children who can't eat. I have to hold a child in the proper position so that they can eat.

Researcher: Can you tell me what was difficult for you to do when you first started working here anyone please

Participant: When I started working here, it was on a Sunday. I was drinking so much. I am so sorry to tell you I was drinking.

Researcher: No, it is fine you can be honest. I appreciate your honesty. Why were you drinking so much?

Participant: Because of stress. When I first started, I felt so guilty to see the disabled kids like that. But I pray.

Researcher: So in the beginning it was hard.

Participant: In the beginning, I was even crying to see the kids like this. Aish, aish… why God created these kids to be that way

Researcher: Did it make you feel stressed?

Participant: Yes, when I was sleeping I used to picture that other one who is 25 years. She is 25 but she looks like a child… haai

Researcher: When you started, did you know what to do?

Participant: No but sis “N” taught me.

Researcher: How did you cope with the challenges you experienced?

Participant: There is another child here who was wearing diapers. I taught him how to go to the toilet. I told him “if you do not talk, I will beat you”. It’s been months now he doesn’t wear diapers, he wears underwear.

Researcher: How did the challenges affect you psychologically?

Participant: In the beginning, it did affect me psychologically but now it doesn’t.

Researcher: When you were having these stressful problems, how did you cope?

Participant: I would go and sit in the toilet and drink warm water. When I go home, I would drink. But now I don’t have any problem. Praying also helped me.

Researcher: When you first started here did you feel you were prepared?

Participant: No, I didn't know I would get children like this I thought it was for the old age not for children like this. Aye, but God [shaking head]. My mother is sick. I don't have a father. If I don’t work here, where must I get money?

Researcher: How do you feel about the services that you render for these children here?

Participant: I don’t have any problem. From my side I make them happy.

Researcher: Do you think everything you do for the children is helping them?

Participant: Yes, it is helping them a lot. I do things the children can’t do for themselves.

Participant: What positive changes did you see with your help with these children?

Participant: Three are now potty trained and can bathe themselves. The children are happier.

Researcher: What do you find most rewarding about your job?

Participant: I need the money to eat. I am so happy to work with these children. I feel blessed.

Researcher: Do you feel the people in the community know about what you are doing here?

Participant: No, they don’t know. Other people say they cannot work here. They can’t change the children’s diapers. Maybe they want me to change my mind about working here. That’s why I don’t want friends.

Researcher: Does it make you feel stressed when they say all these bad things about your job?

Participant: Yes. I even told my next-door neighbour to come and work here. She said, “aye… those children are so and so and so. Then I told her “no, don’t talk like this”. I told her “You are going to still be pregnant and you don’t know what God will give you:

Researcher: Tell me a little bit more about the support you receive as a caregiver?

Participant: If I need help I go to the manager and tell her I need help with something.

Researcher: What type of stuff do you ask for help?

Participant: With some of the things I must do. The manager trained me to cook. And how to dress the bed of those kids.

Researcher: Did you get any support to help you to feed, bath and position the child?

Participant: No, but I look at how the other caregivers were doing these things. But hey! I 'm just looking because it is so tough. However, I do want to know about the medication

Researcher: Are you getting any help to learn of the medication?

Participant: No, I only know how to use the medication scale. The scale I learned at Kgabalatsane. I take the scale and I weigh myself. Then I take the child and stand on the scale and minus my weight to see the child’s weight.

Researcher: Apart from the manager, do you get support from outside Organisations?

Participant: No, you are the first outside person that is coming to help here.

Researcher: Would you like more support?

Participant: I want to learn more so that I know how to help the other children here. The one child here, when she is sitting she keeps falling to the side. I want to know how to help her to sit properly. And I want to learn about exercising with kids.

Researcher: What is it that you think you need when it comes to doing your job here?

Participant: I need to learn the medication and how to teach the children to drink from a cup and feed. And to help them to sit right.

Researcher: Do you have any needs when it comes to knowing what problems these children have?

Participant: I want to know more about the children’s sickness.

Researcher: What other needs do you have?

Participant: I would like to go out there and learn more to care for the kids.

Researcher: Do you require more support?

Participant: Yes, I need more support.

Researcher: Support like what?

Participant: I want it more…. Support for the kids. I want to help the kids and I want to know how.

Researcher: Thank you so much mmm, we are now done with the interview

ANNEXE H
TRANSCRIPT OF A MANAGER INTERVIEW

TRANSCRIPT OF AN INDIVIDUAL SEMI-STRUCTURED IN-DEPTH INTERVIEW TO EXPLORE AND DESCRIBE THE EXPERIENCES OF NGO MANAGERS AT NGOS CARING FOR CHILDREN WHO ARE DIFFERENTLY ABLED REGARDING THEIR MANAGEMENT OF CAREGIVERS.

Interview Guide for NGO managers

Biographical details

1. Age: 52
2. Gender: Female
3. Level of education: Grade 12 & Ancillary Nursing
4. Duration of employment as a manager at the NGO: 11 Years

Interview Process

Researcher: Good day mam

Participant: Good day

Researcher: As we have discussed last week after giving you the information leaflet. My name is Sharifa Moosa Tayob and I am a PhD student at the Department of Health Studies at the University of South Africa. My study involves caregivers of children who are differently abled and managers of NGOs that care for children who are differently abled. The purpose of this study is to develop a programme to empower caregivers who care for children who are differently abled at NGOs. In order to enable you to answer as candidly as possible, confidentiality is ensured during the interviews. Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the study group. Thank you for signing the consent form and agreeing to participate in this interview. I am going to be asking you a few questions now.

Participant: It’s a pleasure

Researcher: Can you tell me about your experiences when it comes to managing the caregivers

Participant: Eeeeh… The experience… to become a manager to the caregivers is too difficult because… they come and go. They come and go, you know somebody comes and looks for a job and when they come here they find this eh eh different disability kids and they run away. That is why I can't keep the caregivers so long.

Researcher: So the turnover is quite high?

Participant: Very!!!

Researcher: On average how long would a caregiver stay?

Participant; ahhhhh…. About 3-7 months. I've never been with a caregiver for 3 years or even for a year.

Researcher: Never?

Participant: Never…. That will be a… aye… I've never

Researcher: What do you think are some of the challenges the caregivers are experiencing?

Participant: The challenge of care… caregivers are experiencing mostly money. The payments, because the government does not give us funding. Eeeh….eeeh, they don't get anything, they are the volunteers who have a challenge .

Researcher: And challenges when it comes to them looking after the kids?

Participant: Aaaah… the challenges for them to look after the kids, they don't know how to handle these kids, because remember these kids are not normal as the children at home. They have a disability. So they don't have any experience to handle them. More, more of ehhh.. to .. to… positioning them, to feed them, to bath and how to dress them.

Researcher: So that is more with the skill?

Participant: Yes!

Researcher: And with the knowledge, knowing about the illnesses the children have?

Participant: Ehhh… ehhh…ehhh… about the knowledge, when the parents bring the child neh, they bring the child with the medication, with the referral and that is where we can know the problem or the sickness of the child. That's where we can grab something from the child. When the parents give us the referral, we take the child to the clinic and that is where the clinic will tell us the children…. this child is epileptic or………..

Researcher: So if they say the diagnosis for example, epilepsy, does the caregivers understand?

Participant Yes…

Researcher: Do they understand what epilepsy means?

Participant: No, they don't know what epilepsy means. They just saw the child fall down and it's just like that. They don't know what is happening to the child at that time. They don't understand the condition. That is why I sometimes tell the caregivers "listen guys, when you give the child medication like most of the children here… like most of the children here, they are epileptics and they are chronic. So I told the caregivers ``when you give the medication, don't miss the time… the time is very important… neh… because the system must catch up with the medication on the right time. You can't give the children mediation at 10, 11…1.. You know… That is where we are going to experience more of an epileptic child. So when we give them in time - let me say maybe you gave them at 9 o'clock, let it be 9 o clock… don't change the time! So that you are not going to experience more of the children falling for epileptic – and indeed we don't. They come here, the children came here, and we can hear the parents say they are continuous… this child is continuously fitting you know. Then when you take the child, I, I, I … when the parents tell me that, I already know that there is something wrong with the medicine. So that's where I start now targeting the time, trying to give the child a medicine at the right time. Aahhh… within a week that child will never fall down.

Researcher: So it's under control?

Participant: It's under control. Let me tell you Sharifa, I've never seen the child falling down with the fitting. I've never been in this - because we control the medicine with the time.

Researcher: So that is the challenges the caregivers experience, now, what do you find it challenging when it comes to you as a manager having to manage the caregivers

Participant: Some of them…. Yoooooo … they are so difficult for these people. Some they don't listen. Some they don't listen, you can say "don't feed the child while the child is sleepy, you must hold the child so they can swallow very easily" they don't understand. Just because of the child is, they cannot sit down. But you must try to force them to sit. You cannot be with a 9-year-old who is always sleeping. You must try to exercise them, at least… even if you don't exercise them, rub her… rub them. Take the Vaseline, rub them and then exercise them so that they can sit.

Researcher: So that's a challenge when it comes to them following your instructions?

Participant: Yes! And then I said, "when you bathe, don't just grab the child and bathe , talk to them, call the name of the child, and then tell the child "now you are going to bath". The child must know that now is bathing time, you know. You can't just grab the child and bath and dress... no! no! no… prepare the child. Somewhere somehow, the heart. And the child must hear now it's time to bath. That is why these disabled children, most of them, are too stiff. But when you talk to him, when you say "Lerato now I am dressing you", It becomes easy for you. You'll see Lerato now, try to pull up the hands, because Lerato knows that now is time for… this lady is going to dress me now. But when you grab the child and bathe… no the child becomes so scared.

Researcher: So you find it challenging that you tell them what to do but they don't do what they are supposed to do.

Participant: Yes! And I sometimes think maybe they can find somebody, some different people to come and tell them. Because me it's me {laughing}.

Researcher: Do you think they are motivated?

Participant: I don’t think so… I don’t think so. You know Sharifa, eeem… I’m the one who's got a vision for this, they don’t have it. What is in me, they don’t have it. I’m the one who always thinks about the kids. Now it is winter, I must tell the caregivers “How many blankets are you using for the kids”, they don’t care. They can call me while I am somewhere maybe trying to find something for the kids… “the toiletries up, there’s nothing we can do” and I said to them “there’s milk in the fridge, there is Kellogg’s, why can’t you take the milk and Kellogg’s and mix and give the kids… use your brain” you see… they don’t do that. You must always think for them. I don’t know if they are scared… I … I… I... don’t understand.

Researcher: So as a manager, managing caregivers, what is it all that you do to manage them?

Participant: I must make sure they have everything starting from cleaning materials, toiletries, food… all the resources. I must make sure so that it can be easy for them to use it for the children.

Researcher: With the challenges when it comes to managing the caregivers, you mentioned that they don’t do what you tell them to do

Participant: Ja…. Even now I think maybe some of the things I told them they do it when I am here. When I am out they say… urg… they just… and I am not here 24/7.

Researcher: What other challenges do you find managing the caregivers?

Participant: Aish!!! They don’t do what I want for these kids. That is why I even put the cameras to look after them even when I am at home. I must see them when they bathe the kids, when they feed them, when they clean them. Remember, sometimes they just forget to tell me “there is no cleaning material” while the cleaning material is here, here, here in the office. Or the Colgate, and when you say guys I was with you yesterday, why didn’t you tell me that the Colgate is finished? And then they will tell me “We forgot”, just like that”. And then how about the teeth of the kids today? “We didn’t brush their teeth '' and we must now take the Colgate outside at 12 o'clock and start brushing teeth.

Researcher: So do you have to constantly have to tell the caregivers what to do?

Participant: Yes, and you must also check every day they've got everything. They've got soap for the kids, soap for washing, Colgate, Vaseline, diapers… everything, even the warm clothes now that it is winter.

Researcher: Do you have challenges when it comes to absenteeism of the caregivers?

Participant: No, they come and they come on time. The problem… when you see the caregivers they don't come…. You must know that now she decided that she won't come anymore.

Researcher: So when they stop coming do they communicate with you?

Participant: No… no they just stop.

Researcher: So that is also a challenge?

Participant: That's the major problem… they just stop. You will see for yourself.

Researcher: Does it take you a long time to find a replacement?

Participant: Yes! You know you must take someone who has experience. Like yesterday I hired one lady… that lady she never went to school. She doesn't know how to write or read, but she's got experience with these kids. She worked for another Organisation for three years. But because she can't write or read, maybe they were taking advantage of her.

Researcher: Is reading and writing a requirement for caregivers?

Participant: Yes… after you give the child medication you must report.

Researcher: Do they write in a file?

Participant: Yes, so that I can see that…. I must be sure that the child is on medication. You write and you sign… you even write the time.

Researcher: What is the criteria that you use when you want to hire a new caregiver?

Participant: I told one of them here, I said "Hey girl, don't you know somebody who can come and join us here?" But some bring their CV's here.

Researcher: So when they come, what is it that you look for in the person?

Participant: Eeh… I look at the age… the experience, and the love that she has for the kids.

Researcher: So passion is a big thing?

Participant: Yes, very big.

Researcher: What do you expect from the caregivers when it comes to them carrying out their caregiving roles?

Participant: You know Sharifa the caregivers must be [long pause] must have love, must have passion for the kids…. ne. They must know what they are doing They must not come here just to please somebody outside there that they are doing something, while when they are in here they don't do nothing. You know there are people maybe… There is somebody who is pleasing maybe their neighbours that "me I am not; I'm not staying at home every day. There is somewhere that I go… But while you are there you are doing nothing. You just sit here, at the end of the day you go home, tomorrow you are here. While you are here you do nothing. You must come here with the passion; you must know that you work with the different persons

Researcher: So except for passion and love for what they do, what else do you expect from the caregivers.

Participant: Cleanliness and good food. You can't just cook, because that child cannot say the food is not nice. You must cook something that you can eat. When you say you are a caregiver, you must care for everything. The child must be clean, eat nice food and then be on a clean surface. You must make sure… you must take care of that child- because you must know that child is helpless. They can't even scratch for themselves. So, you must know that you must cut their nails, you must clean their ears, you must cut their hair so the child must be nice, they must be presentable. There is one thing I hate in the centres, most of the centres have this smell. You know the disabled people, they have this little bit of smell. That thing, I don't want it. I want a… you can't be in a smelly place. You must think of that person who must stay here for 24 hours. What about the smell? So I told them "you know guys, eeeh… everything that you are doing for yourself, do it for the kids. Everything… when you are thirsty, know that one also, she is thirsty… when you want to eat orange, that one also, she wants to eat orange... so try to give them.

Reacher: So it’s putting yourself in their shoes?

Participant: Yes! When you feel cold, they also feel cold. When you feel hot, they also feel hot. There is no difference between you and them. The only thing is, they can’t say nothing, they can’t walk. They can’t do some of the things that you can do like talk and walk you know… or cooking for themselves But the feelings and everything, they are the same.

Researcher: What knowledge and skills do you feel the caregivers here require?

Participant: Caring of the kids. The most important thing… caring of these kids. I don’t mind cooking, cleaning… no! Caring of the kids [clapped hands].

Researcher: And when you say caring of the kids, what exactly does that mean?

Participant: I’m talking about positioning them, to feed them… how to feed them, how to place them you know… You know these kids, some of them are like dolls. When you put them in the wheelchair, like now, I admitted one child here , he is from Benoni, and the parents when they bring that child. They didn’t tell me that the boy has bedsores… you see. And wena you see the boy there he is wearing a trouser and a jersey. You look at the boy there, only to find that there is a bedsore there. After the parents leave in the evening when you bathe the boy then… ja… [Long pause]

Researcher: You notice it then?

Participant: Yasus!!! And then they said to you. This boy cannot swallow; you must give him a soft diet… but you can see man… this boy… haai man- he doesn't get full, from the soft diet. And when they come to visit, they always bring the Danone – the yogurt. And I say no man… a 10-year-old boy… Danone! Soft diet! Now let us try this boy's normal diet. Ah!!! When you give him the normal diet, the boy starts eating, starts jumping, and starts singing you know. And while the other leg of the boy is like this [demonstrating the position of the child’s leg], and there is a bed sore. It seems like the boy has been sleeping in one direction for 10 years.

Researcher: So the caregivers should also know how to identify a bedsore, they should know about the feeding?

Participant: yes… that’s why I call the parents and I take the boy to the clinic. They gave me the medication, and then now with the little experience that I have, I don’t have experience, but the little that I have, I told them” no guys when you sit this boy on his wheelchair, try to pull his legs and put some ball here [demonstrating in between the legs]. But when you put the ball in the middle of the legs, he started crying you see. And then with this bedsore, let’s start treating it and maybe it will be better. But when I saw the bedsore, that bedsore its long been there. Because it doesn't… it's now better… but haai... it’s not healing.

Researcher: Earlier, you mentioned medication, the importance of caregivers knowing how much and when to give? So that is a skill and knowledge they should have?

Participant: Yes, I made the sketch. But not all of them give the medication. I identify one or two And we draft something and then they know. Helen takes 1 tablet of Respiral and EpilimCR300 and then in the evening one tablet of CR300… you know like that… When you know nothing, you just go there to the notice board and go and see. And then I bought this medicine divider at Dischem. I wrote the name of the children who takes the medicine every day. And then every day we put the medicine on each of the blocks of that box. And then, when you go to the notice board, you open it and take the medication and give the child. After they give the child they record it.

Researcher: So those that record must know how to read and write?

Participant: Ja, now. At the end I came, I saw the recordings. I check there … I signed it.

Researcher: Can you tell me about the support that is provided to caregivers?

Participant: Aish! {shaking head]…uuuh… they don’t get support from outside. They always get support from me. And then the support I give them is when somebody brings many things here. I divide it to them and give them.

Researcher: Is that like groceries?

Participant: yes… yes.. yes..

Researcher: And support in terms of training?

Participant: No… There is nobody who gives them support. I am the only one.

Researcher: What other support do you give them?

Participant: Like… eeeh.. sometimes I told them “you guys, you are doing so well. The way I saw these children it shows me you are giving them medication, because if you have not done this I will see it very quickly”. And then they even remind me when the kids are ready to go to the clinic. They even divide themselves. They take someone who is on night duty or even off and ask them to “come and help us to take the child to the clinic”.

Researcher: If the caregivers come to you and tell you that they are having problems and so stressed at work- how do you support them in that instance?

Participant: You know, maybe they are scared of me because they don’t come to me. They gossip on their own. Maybe you can hear someone, maybe sometimes you call someone and do something, maybe in passing you hear… “Yoh, this one – she got a problem blah... blah... blah… I always tell them, if you have a problem, please come to me and don't be scared.

Researcher: So that is also a form of support?

Participant: I said this office is not only mine, it’s for you also. You must come to me, whatever problem that you have.

Researcher: What do you do to improve their skills and knowledge?

Participant: Aish! Not so much. I motivate them. I also invite LSPID from the department of education.

Researcher: What does LSPID do?

Participant: Eehhh... LSPID… it’s in the Department of Education ne. They try to teach the children from 3 years to 18 years. And we work with them, and they take the caregiver. They take the caregivers to a workshop for 3 days., while they sleep in the hotel you see. And when they come here they must know how to teach the kids. That thing is so important for us. They mostly work with profound children. With the… the… Cerebral palsy children they call awareness, the Autism they call them transitional. So they class them, they place them in a classroom, one of the caregivers must teach the kids. On that, our kids now know how to sing, how to read; 1, 2, 3, 4… up to 10, how to pray. They know even some, we have two boys now who can tell us when they want to go to the toilet, we are no longer using diapers for them. They even took me to the training.

Researcher: So that is one of the things you have done to improve their skills and knowledge. What else do you do as a manager to improve the skills and knowledge of the caregivers?

Participant: Uummm… haai! Nothing more, because you know I always see them in the meeting, and then I say to them "guys, each and every one must tell me their problems so that we can come up with the solution you know… we can see if we can try to solve their problems. If you have a problem just tell me, from home or maybe here and then so that we can see if we can solve it. They talk sometimes, but that you can find some people don't want some people to know their problems… some are reserved.

Researcher: How do you keep caregivers motivated?

Participant: By saying "you know guys, what you are doing is good and then one day, one day you are going to see a difference. There more I go up and down running around, you will definitely find someone who is going to pay you. Keep on doing the good job.

Researcher: What resources are caregivers provided with to effectively address the challenges they have?

Participant: Remember they work with the groups. You can find this group saying the other group doesn't work.

Researcher: Groups, you mean the caregivers?

Participant: Yes, they said "that group haai they give us a lot of work. When they go home you did one, two three, and are not found then we must work on what they were doing… This one is a bad influencer and she influences us with one, two three. Like now before you came I bought vegetables… and when the vegetables came, we cut the vegetables and we put it in the fridge so that when we prepare food for the kids we must just take them from the fridge. The team who were here yesterday, were supposed to cut the cabbage so they left that cabbage in the storeroom. So the team who are here now, are complaining about the one who was … and they said one lady is a bad influencer, she told the others “you must not do it”. You know, there is always a bad influence on them. You can find some are fine, but one is a devil there.

Researcher: And how do you manage that?

Participant: Yoh! [Holding both sides of her head], Sharifa, it's giving me a headache, I can’t manage that one. I’m not lying, because when somebody is influencing… one person can influence five persons, I rather tell that person to go because she is going to influence, the rest of them, and nothing will go smoothly inside there.

Researcher: Earlier you mentioned with the giving of medication you have a chart to remind them of the medications to give and the chart, so that’s also a resource that you use to manage them?

Participant: Yes, yes. And I also provide them with everything they need to take care of these kids. With that I won’t go wrong. I don’t want to hear them say “ja it's dirty here because we don’t have pine gel, we don’t have handy Andy, no we didn’t cook because there is no food, we didn’t bathe them because there is no soap to bathe them”. I try by all means to buy everything for them so that they can be easy for them to take care of the kids

Researcher: Tell me about the process you use to monitor them.

Participant: Eehh… I come here every day, I monitor them. When they bath the kids I must make sure I am here. When they dish up, I must make sure to see what kind of a food they give the kids because I have a menu here. And then they must cook what they see there. I then also have these soft diet kids. I don’t want them to give the soft diet ones you see… I must make sure that they cook the soft diet for the soft diet kids and the normal diet for the others. So I monitor them all night, in the evening when I go home I must make sure all the kids are bathed.. They wear their pyjamas. Some are in bed; some are watching tv…. And supper is ready.

Researcher: You also mentioned earlier the files, they have to write in the files.

Participant: Yes, they have to write in the files, and I check the files. When the files are fine I sign. But when it’s not fine, I am not signing. They must explain to me why this thing is not the way it is.

Researcher: How do you collaborate with other stakeholders to support caregivers?

Participant: I always talk with social development to tell them to come and monitor the place. And then you know social development is social development… They come, they monitor the books and they tell me what to do. And then I actually do what they said I must do. I make the narrative for the department. The other stakeholders, they don't know me. I have a website here, if you can go to www.xxxxx.org, you will find us there. So some of the stakeholders get me there. Sometimes I just get a call from somebody that I don't know, and they said we see your Organisation on the website, we want to bring some food for the kids, or toys, or what do you want for the kids. The website has been a good tool for collaboration. I also go out to institutions like the university when I see these kids need OT's or Dental for these kids because I know Sefako Makgatho has speech, Dental OT, Physio… they have everything. Like even now, we don't have wheelchairs, the buggy ones. The only place I can get the wheelchair is Sefako Makgatho. When you go to SMU, you ask for the student to come and see the children, you make a good friendship with them. They know that there is Machipa and CP children who need the buggy. It's easy for kids to get the Madiba Buggy.

Researcher: How has that been challenging to try to get them to assist?

Participant: Its challenging, because like now ever since I wrote the letter to OT in 2018, I already gave up because they don't help.

Researcher: From your point of view, what do you feel can be improved to empower caregivers?

Participant: They must get training… first things first. You know when they get training, and somebody must at least give them something at the end of the month.

Researcher: When you say something, what do you mean:

Participant: Stipend, that will motivate them… That's the only thing that will motivate them. But the training is very important, the workshop is very important.

Researcher: Thank you so much for your time, I really appreciate it.

ANNEXE I

LETTER FROM LANGUAGE EDITOR

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24 FEBRUARY 2021

To whom it may concern

RE: LANGUAGE AND TECHNICAL EDITING

This letter serves as confirmation that the thesis by **SHARIFA MOOSA TAYOB**, a doctor of literature and philosophy candidate titled "**A PROGRAMME TO EMPOWER CAREGIVERS OF CHILDREN WHO ARE DIFFERENTLY ABLED AT NON-GOVERNMENTAL ORGANISATIONS**" was edited by Rosemary's Proofreading & Editing Services.

Kind Regards

R MALULEKE (LANGUAGE EDITOR)

ANNEXE J

PROGRAMME EVALUATION FORM

Caregiver empowerment programme evaluation form

Dates of training _____________ to _____________

Location where training was conducted: ____________________________

Dear Participant

Kindly complete the evaluation form for this training programme by ticking your level of agreement with each question below.

		Strongly Agree	Agree	Disagree	Strongly Disagree
1	The training is important				
2	The training has improved my knowledge and skills				
3	The objectives of the training was clearly explained				
4	I understood the content of the training				
5	The content of the training is relevant to my line of work				
6	Enough time was given for each section of the training				
7	Methods used in the training helped to improve my learning				
8	I am going to implement what I have learned in this training programme to my work situation				
9	What about the training did you find useful?				
10	What was about the training did you not find useful?				
11	What changes do you think needs to be made to improve the training programme?				