Exploring role strain in caregivers of children living with disabilities in Lobatse, Botswana

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Mini dissertation accepted in partial fulfilment of the requirements for the degree Master of Nursing Science-Psychiatric Community Nursing at the North-West University

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PREFACE

In accordance with North-West University General Academic Rules (A4.4.2 and A4.10.5), the article format was followed in reporting this research study. The research study was written in accordance with the North-West University Harvard referencing style. The mini dissertation was submitted in partial fulfilment of the requirements for the Master of Nursing Science degree in Psychiatric Community Nursing, and consists of three sections as follows:

Section 1: This section reports the overview of the study, introducing the research study on exploring role strain in caregivers of children living with disabilities in Lobatse-Botswana. The background, problem statement, as well as the research question, research purpose and the methodology are discussed in this section.

Section 2: This section contains the research article: A qualitative, explorative, descriptive and contextual study exploring role strain and experiences of caregivers of children living with disabilities in Lobatse, Botswana. The article has been submitted for possible publication in the Nursing Open Journal. This section, including the reference and the article, were arranged in accordance with the American Psychological Association (APA) editorial and referencing style, as stipulated by the above-mentioned journal author guidelines.

Section 3: This section focuses on a discussion with a reflection of the researcher on the research journey, conclusions, limitations as well as recommendations and proposed guidelines.

Ms. R. Machailo (supervisor) and Prof. M.P. Koen (co-supervisor) are the co-authors of the article “Exploring role strain and experiences of caregivers of children living with disabilities” in Section 2 of this mini dissertation. They have granted permission for the submission of this article for examination purposes in partial fulfilment of Master of Nursing Science degree in Psychiatric Community Nursing.

The mini dissertation page numbering, starting from the introduction to the end of the document is consecutive. While the arrangement of the manuscript was according to the author guidelines of the Nursing Open Journal, the remaining parts of the document were according to the North-West University guidelines.

PERMISSION LETTER FOR MANUSCRIPT PUBLICATION

I, Rorisang Machailo, the supervisor of the study ‘Exploring role strain in caregivers of children living with disabilities in Lobatse, Botswana’ hereby declare that this dissertation, written by Keletwaetse Sakwape reflects the research regarding the subject matter. I hereby grant permission that she may submit the article for examination purposes. I confirm that the dissertation submitted is in fulfilment of the requirements for the degree Masters Nursing Science in Psychiatric Community Nursing at the North-West University-Potchefstroom. The manuscript has been sent to Nursing Open Journal for publication.

DEDICATION

The researcher dedicates this study to her mother, and all informal caregivers caring for any dependent individuals, regardless of their condition. Moreover, the study can serve as a guide for institutions involved in the lives of caregivers, especially caregivers of people living with disabilities. The findings and recommendations of this study can aid in proposing guidelines to assist the caregivers of children living with disabilities.

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"In the multitude of my anxieties within me, your comforts delight my soul." Psalm 94:19.

My sincere gratitude goes to the Almighty Heavenly Father for his purpose in my life. He was my solace as I walked through the valley of darkness of the research process. During the tough times or darker days, He continually brought joy to my soul. He brought solutions to my troubles and availed gems who endured this overwhelming but interesting journey with me.

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To the study participants, you deserve a pat on your shoulders. Without you, this study would not have succeeded. Your insightful contributions and strength are admirable.

DECLARATION

I, **Keletwaetse Sakwape**, hereby declare the mini dissertation, "**Exploring role strain in caregivers of children living with disabilities in Lobatse-Botswana**" has never been submitted for examination by myself, or others, for a degree in any institution. The submission of the mini dissertation is in fulfilment of the degree of **Master of Nursing Science in Psychiatric Community Nursing** and I further declare that this is entirely my own work in design and implementation. All sources used in this study have full acknowledgement and referenced accordingly.

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LIST OF ANNEXURES

LIST OF ABBREVIATIONS

CCLD: Caregivers of Children Living with Disabilities

CLD: Children Living with Disabilities

CRS: Caregiver Role Strain

HREC: Health Research Ethics Committee

IHSL: Institute of Health Sciences-Lobatse

LTC: Lobatse Town Council

MoHW: Ministry of Health and Wellness

NWU: North-West University

S & CD: Social and Community Development

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ABSTRACT

Individuals living with disabilities demand the assistance of their loved ones, as they perform an indispensable role of informal caregiving to support them in performing their activities of daily living, something that can result in caregiver role strain. Caregiver role strain refers to the resultant emotional and physical stress experienced by individuals who help in the provision of care of their loved ones diagnosed with physical, emotional and behavioural problems

The aim of this study was to explore and describe the role strain experienced by caregivers of children living with disabilities in Lobatse, to contribute to guidelines that will promote their quality of life. The study was conducted to answer the research questions: What is the role strain experienced by caregivers of children living with disabilities in Lobatse; and what can be done to promote the quality of life of these caregivers in Lobatse.

The employing of a qualitative research design with an exploratory, descriptive, and contextual approach was to explore and describe caregiver role strain in caring for children living with disabilities. The researcher used a purposive sampling technique, and ultimately, obtained a sample consisting of 11 participants and reached data saturation. Semi-structured interviews took place telephonically, and were recorded using an audio recorder. The interviews were in Setswana, a language preferred by the participants and later transcribed verbatim, and subsequently translated into English. Data were analysed qualitatively using the content analysis method. Trustworthiness was through authenticity, credibility, dependability, transferability, and confirmability.

Four main themes emerged as follows: caring for a child with disability affects the overall health of the caregiver; caring for children living with disabilities puts financial strain on the caregivers; caring for children living with disabilities has an impact on other roles; strategies employed to cope with the strain of caring for a child living with disability. The themes were analysed along the study objectives and corroborated through the literature control.

Conclusions: The findings indicated that the role strain in caring for a child living with a disability has a negative bearing on the caregivers. Furthermore, the negative experiences they encounter as they execute the caregiving role overwhelms them. However, the caregivers described the various valuable strategies they employed in order to cope with the strain of the caregiving role, which included acceptance, social support, support groups and prayer. The basis for the guidelines proposed was on their comments and recommendations.

Key words

Caregivers; caring; children; disability; role strain

SECTION 1: OVERVIEW OF THE STUDY

This section reports the overview of the study, introducing the research study on exploring role strain in caregivers of children living with disabilities in Lobatse, Botswana, by delineating the background, the problem statement of the research study, as well as the research question and research purpose. The section further discusses the paradigmatic perspective, research methodology, measures to ensure rigour, and ethical considerations as explicated in the proposal.

1.1 Introduction

A significant proportion of individuals living with moderate to severe disabilities are unable to manage the demands of their daily life due to the cognitive and social skills impairments which are the significant cause of their struggles in life (Ghavari *et al.*, 2018:2). It is for this reason that individuals living with disabilities demand the assistance of their loved ones as they perform an indispensable role of informal caregiving to support them in performing their activities of daily living, something that can result in caregiver role strain (CRS). CRS refers to the resultant emotional and physical stress experienced by individuals who help in the provision of care of their loved ones diagnosed with physical, emotional, and behavioural problems (Brannan *et al*., 2018:30). CRS further refers to a mental state that succeeds an amalgamation of emotional, physical work and social burden associated with caring for chronically ill or disabled loved ones. Brannan *et al*. (2018:30) divides CRS into three categories namely: subjective internalised, subjective externalised and objective care strain. Subjective internalised CRS is individual's feelings as expressed by the caregiver (Accurso *et al.*, 2015:8). These feelings can include feelings of sadness, exhaustion, and guilt. Conversely, subjective externalised caregiver strain is the negative feelings directed towards other people such as hatred, resentment, embarrassment, and anger (Brannan *et al.,* 2018:30). Lastly, objective CRS is evident incidences that are trustily associated to incomparable caregiving such as financial issues, interrupted plans, and withdrawal from social interactions (Accurso *et al*., 2015:8). It is clear both internal and external CRS can have a profound negative bearing on the lives of caregivers of children living with disabilities (CCLD).

Notwithstanding the types of CRS, the strain of caring for children living with disabilities (CLD) emanates from causes such as lack of assistance in caring for CLD (Patel *et al.*, 2017:866). The lack of assistance is often due to the inability to solicit help for fear of

negative social consequences related to stigma attached to these children (Zhou *et al*., 2018:260). The researcher is of the view that due to the stigma the caregivers do not come out in the open to disclose about having CLD and the challenges they are facing in caring for these children, resulting in diminished or no support. Other factors associated with CRS include low socio-economic status, a working caregiver, illiteracy, or low level of schooling by caregivers, caregiver suffering from chronic illnesses such as hypertension, diabetes mellitus, dysfunctional families, and age of the caregiver (Barros *et al*., 2017:3632). These factors are consistent with those of a study conducted in other areas of Botswana that also reports factors such as lack of adequate support as a cause of caregiver role strain (Patel *et al*., 2017:866). CRS can have undesirable consequences on the wellbeing of the caregiver that necessitates enquiry for them to have assistance.

Caregivers of children who suffer from intellectual, physical, or psychological disabilities experience emotional and physical challenges associated with role strain (Lalvani, 2015:386). They sacrifice their energy, time, health and sometimes their jobs which can lead to negative consequences such as psychological, financial, and physical problems (Lalvani, 2015:386). Therefore, the researcher is of the view there is a need to explore the experiences of the caregivers in their caregiving role in Lobatse to inform the formulation of guidelines for CCLD.

1.2 Background

There is empirical evidence from studies conducted globally, including Southern African Community Development (SADC) countries, which suggests that CRS in caring for CLD is a worldwide concern and the subject has taken the central stage of discussion in many countries (Chiluba & Moyo, 2017:1; Rueda *et al*., 2016:282;). It is estimated that about 34 million caregivers in the world engage in the provision of care to individuals with enduring conditions and disabilities, but the issue of CRS is often disregarded (Centre for Disease Control, 2016; Minnes, Perry & Weiss, 2015:552). Disregarding CRS can have undesirable effects on the caregivers.

International trends show that caregivers of children living with disabilities, report more stress than parents of children without disabilities with resultant CRS (Minnes *et al*., 2015:551). Nevertheless, the impact of CRS differs across countries owing to the availability of resources to cushion its impact (Hussein, 2016:2). As support, a study conducted in the United States of America (USA) shows that CRS is lessened with the availability of social support services, such as respite care (Brown & Brown, 2014:2). CRS is however also a

challenge in other developed countries as demonstrated in a study conducted in Canada in which service delivery focused on the child and neglected the caregiver causing them distress (Minnes *et al*., 2015:552). Occasionally, in the previously mentioned study, caregivers labelled themselves as the forgotten members of the family as people would only be concerned about the wellbeing of the disabled client, disregarding the caregiver's welfare. It is in this regard that CRS in caring for CLD is a challenge worldwide.

Although Africa faces similar difficulties of CRS as the rest of the world, this problem is further compounded by cultural expectations (Chiluba & Moyo, 2017:2). Culturally, in the perspective of African countries, relatives are expected to bear the burden of caring for their CLD (Chiluba & Moyo, 2017:2). A study conducted in Kenya reveals CCLD undoubtedly face more challenges than caregivers of children without disabilities, which consequently puts more strain on their caregiving role (Ndirangu & Midigo, 2019:28). A study conducted in Malawi, which highlights that parents of CLD face with various challenges such as service inaccessibility and stigma which contributes to CRS, supports this (Masulani-Mwale *et al*., 2016:876). Clearly, caregivers play an essential role in supporting the CLD and these children are wholly dependent on them in performing activities of daily living.

Additionally, a study conducted in Zambia also reports that caregivers' welfare is often disregarded when assuming their caregiving role, with possible financial, physical and emotional consequences (Chiluba & Moyo, 2017:2). Similarly, a study conducted in Botswana also reported welfare challenges and inability to seek employment because of the time spent on caregiving (Kubanga *et al*., 2015:15). According to Kubanga *et al*. (2015:18), challenges posed by CRS have far-reaching negative consequences that range from stress to developing mental health problems. Notwithstanding the cultural influence on caring for CLD in Africa, the ramifications of CRS seem to be the same across nations.

Caregiver role strain can pose detrimental mental or psychological problems such as anxiety, burnout and depression, to caregivers which consequently would affect the caregiving role negatively (Chambers & Chambers, 2015:12). Moreover, the above-stated authors report that parents caring for CLD have poor quality of life. Their stress levels are higher with more inferior mental health status than the parents of children without disabilities (Zhou *et al*., 2018:260). The effects of caregiver role strain undoubtedly call for deliberate steps to develop programmes and policies for CCLD. The concept of caring for the caregivers has shed light on the importance of taking cognisance of the needs of caregivers to ameliorate CRS. It emphasises the importance of including family caregivers in the plan of care so that they too can receive physical and mental health care with the hope they

would extend that care to their CLD (Sullivan & Miller, 2015:11). However, there are no such policies yet developed in Botswana, although there have been significant strides made by the government to improve the livelihoods of people living with disabilities and their families. The government introduced the disability grant to assist the caregivers in the care of their family members living with disabilities, but the other needs for caregivers such as psychological care remain unattended (Ministry of Local Government, 2015). The need for this study cannot be overemphasised to inform the development of policies and guidelines for CCLD.

1.3 Problem statement

Although there have been studies on CRS conducted globally and in other African countries, there is limited research conducted on CRS in Botswana. The problem cannot be overemphasised in Botswana considering there is also an increase in the number of CLD in the country. According to the Botswana 2011 Population and Housing Census, the total number of CLD is 11296, making it 0.6% of the total population (Statistics Botswana, 2018:60). The above statistics translate as although there is limited research on role strain in caring for CLD in Botswana, it is evident there are many CLD being cared for. The parents of CLD face numerous challenges, such as physical and psychological problems emanating from the strain of caring for their loved ones with disabilities. CLD are wholly dependent on their caregivers to meet activities of daily living, thus they play a central role in caring for these children with resultant role strain. The researcher is of the view that their caregivers do not cope with caring for them due to several factors, such as low socio-economic status resulting in role strain hence the importance of exploring role strain in caring for CLD

1.4 Research questions

The researcher asks the following questions:

- What is the role strain experienced by caregivers of children living with disabilities in Lobatse?
- What can be done to promote the quality of life of caregivers of children living with disabilities in Lobatse?

1.5 Research aim

The aim of this study is to explore and describe the role strain experienced by caregivers of children living with disabilities in Lobatse, in order to contribute to guidelines that will promote their quality of life.

1.6 Research objectives

The objectives of this study are:

- To explore and describe caregiver role strain in caregivers of children living with disabilities in Lobatse.
- To propose guidelines that may promote the quality of life of caregivers of children living with disabilities in Lobatse.

1.7 Significance of the study

The government of Botswana and NGOs have made significant strides in addressing the disparity that existed in the delivery of services between people living with disabilities and the general population through provision of disability grant and free assistive devices. Nonetheless, the caregivers of people living with disability, including the CCLD, have nothing in place to abate strain associated with caregiving. Therefore, there is a need to close the gap that exists in the development of interventions geared at improving the health and wellbeing of CCLD in Botswana. By exploring role strain in caring for CLD in Lobatse, this study can provide insights into the experiences for this population so as to better understand their plight and contribute to guidelines to promote their functioning.

1.8 Paradigmatic perspective

Paradigmatic perspective refers to the basic expectations and beliefs of the world upon which the research's foundation is built (Polit & Beck, 2017:9). It is how the researcher perceives and interprets the research material. In this research study, the paradigmatic perspective included meta-theoretical, theoretical and methodological assumptions.

1.8.1 Meta-theoretical assumptions

Meta-theoretical assumptions are statements considered to be true but not meant to be tested (Hofstee, 2010:88). They describe the researcher's own belief of the three main nursing concepts, namely human being, environment and health.

1.8.1.1 The human being

Human being refers to the CLD and their caregivers. The researcher's view of a human being is based on the Christian opinion that a human being is a holistic unique creation, created as a reflection of God with three dimensions namely, spiritual, physiological and the psychosocial being. Human beings are unique special beings made by God to care and love

for others. Therefore, CCLD need to be cared for and loved as they do the same to their CLD.

In this study, the caregivers' and CLD's physical dimension denotes the physical needs, which need to be met for the human being to lead a quality life. For the CLD to live a quality life despite their condition, they need to be cared for and loved by their caregivers, while conversely, the caregivers need to be cared for and loved so they can extend quality care to their CLD. In addition to the physical being, the psychosocial dimension of the human being denotes the intrapersonal, interpersonal and their interaction with their environment, hence the need for effective interactive patterns that consequently lead to minimised caregiving role strain. Lastly the spiritual being denotes the CCLDs' belief and dedication to God, which helps to ease the burden they experience in the process of caring for their loved CLD.

1.8.1.2 The Environment

The researcher views the environment as made up of the external and internal aspects that are interrelated. The internal environment refers to the inner being of the person, that is the spirit and mind of the human being, which when unwell the person cannot function well. In this study, the internal environment is the caregivers' feelings that may cause their distress and dysfunction if not well cared for, consequently contributing to caregiver role strain. Furthermore, the role strain has a negative bearing on the internal environment of the caregiver, i.e., it can lead to a psychologically unstable caregiver with problems such as stress and depression. Caregivers are responsible for providing a therapeutic environment at home where they should ensure the provision of comprehensive care to the CLD, hence the need for a stable caregiver internal environment.

The external environment refers to the physical surrounding of the person. The homes in which the care is provided need to be conducive to promote the health of and prevent illnesses for both the caregivers and CLD.

1.8.1.3 Health

The researcher adopts the World Health Organization's (1978) definition of health, which describes health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (Halter, 2018:2)." The mental, physical and social health are interrelated. Therefore, if one of these aspects in the health of caregivers is negatively affected, the other two are affected.

In this study, CCLD's physical, social or mental health is affected by various factors during the process of caring for their CLD, hence the need to be accorded adequate and holistic support.

1.8.2 Theoretical assumptions

Theoretical assumptions for this study include the central theoretical statement and the theoretical definitions of key concepts.

1.8.2.1 Central theoretical statement

The research study focuses on the role strain experienced by CCLD and how it affects their quality of life with the view of reducing the effects of the role strain to improve the caregivers' quality of life. The researcher conducted an in-depth exploration of experiences of CCLD and described how the CRS influences the quality of life of the caregivers. The exploration and description of role strain in caring for CLD in Lobatse will lead to insight into their role strain. Thus, the study enabled the researcher to propose and recommend guidelines that will promote better quality life for CCLD.

1.8.2.2 Theoretical definition of key concepts

This study's theoretical key concepts are; caregivers, caregiver role strain, caring and children with disabilities which are discussed below and serves as a synthesis of evidence from literature.

1.8.2.2.1 Caregivers

Caregivers are individuals who aid in the provision of direct care to persons who are dependent on them (Roth *et al*., 2015:310). Care provided by caregivers can be formal or informal. The formal caregivers provide professional home care to their clients while the informal ones voluntarily carry out the caregiving activity at their homes without being paid (Verbakel *et al*., 2018:1100). Furthermore, these authors reports that informal care has the most overwhelming effects on caregivers because the health of the care-receivers prohibits them from doing certain things for themselves. Therefore, these caregivers deliver care to their loved ones voluntarily on a structural basis with no remuneration which strains them in the process as they care for people with physical, psychological and mental limitations. As caregivers for vulnerable populations, they help to create a compassionate and secure environment for their loved ones. They share their time and skills to help their loved ones be healthier and happier beings and to equip them to cope with the challenges brought by their

conditions. In addition to caring for the dependent individual's spiritual, practical, emotional and physical needs, caregivers manage their own needs, career and the whole family needs (Roth *et al*., 2015:310). In most cases, caregiving is performed by close family members such as a spouse, parents and children. Other extended family members such as grandparents, uncles, cousins, nieces, aunts and/ or even neighbours and friends can also take part in caring for the dependent family member.

For the purpose of this study, caregivers referred to any person who attends to the needs of the children with disabilities without any compensation (informally). In this study, caregivers consisted mainly of family members who were relatives or guardians of the child with disability, staying with the child and directly caring for them.

1.8.2.2.2 Caregiver role strain

Caregiver role strain refers to an overwhelming inability to perform one's role to the best of one's ability due to the burden experienced in the process of caring for their loved ones (Brannan *et al.,* 2018:30). As postulated by Kendal (2013:126): Anderson and Taylor (2011:112), role strain occurs when individuals experience stress and burden when discordant behaviour, obligations or expectations are linked to a single social role. The individual may experience competing demands and describe tension within a single role. The caregiver experiences intense feelings of anxiety and stress. Literature categorises caregiver role strain concepts into the positive and the negative. According to Hunt (2004:30) and Fekete *et a*l. (2017:2) the negative concepts of CRS include strain, stress and hustles while the positive concepts include caregiver satisfaction, caregiver esteem, gain from experience of caregiving and making a meaningful life through caregiving. Nonetheless, the concept of CRS is multidimensional, making it complex for a singular conceptualisation. For instance, some studies conclude that CRS is the stress encompassing the financial, social, physical, psychological, and emotional aspects of life (Bastawrous, 2012:7). Furthermore, literature also provides distinctive categories of CRS as subjective and objective, hence giving this concept a different definition. According to Bastawrous (2012:7), objective burden relates to instrumental or physical delivery of care or aid. Conversely, subjective burden refers to psychological or emotional consequences of objective burden such as stress. In this study CRS refers to the overwhelming strain and tensions experienced by CCLD due to the competing demands caused by the burden of caring for the CLD.

1.8.2.2.3 Caring

Caring refers to extending a helping hand to those in need or those who are dependent on other people for physical and psychosocial support (Drahosova & Jarosova, 2016:453). Caring is about a feel of interest and showing concern, and to receive care is a basic human need. It entails actively and selflessly taking care of another person that is humane and relates to the concept of altruism (Bolderston, 2010:199). The terms “caring” and “human care” are interchangeable in literature to denote provision of support that entails conveying of a deeper connection and involvement with the person in need of care (Watson, 2012:2). To this end, the aforementioned author states that humans can offer care without caring about or for the person in need of care. Caring is concerned with preserving another person’s dignity and conveying respect for the value of human lives and their right to self-determination (Rundqvist *et al*., 2010:36). Caregivers experience a sense of failure when, for any reasons, they are unable provide care when it is needed and preserve the dignity of those who cannot take care of themselves. The aim of the help should be to improve the quality of life for those in need. Caring can also be referred to as nursing as it involves the upkeep and loving services offered to the people in need to promote health, prevent and treat illnesses and rehabilitate the complicated conditions.

In this study, caring refers to assisting CLD to meet their physical and psychosocial needs. In addition, during the process of caring or carrying out the nursing duties, the CCLD are at risk of experiencing CRS should they not receive adequate support in fulfilling this challenging role.

1.8.2.2.4 Children living with disabilities

The researcher has adopted the definition of a child according to the Botswana Children’s Act (2009: A57), which defines a child as a minor otherwise referred to as a person below the legal age of majority, i.e., below 18 years. CLD are children who have restrictions in executing and accomplishing certain functions in a manner considered ordinary for their developmental stage (Miller & Rosenbaum, 2016:2). The authors mentioned above further state that the disabilities could affect the physical, mental, or cognitive functioning of the child. Moreover, CLD are more vulnerable to injuries and development of non-communicable chronic illnesses and developmental health problems which could be associated with various factors, such as health compromising behaviours, difficulties in accessing health services, etc. Thus, the growth and development of these children and their imminent life probabilities are dependent on the care they receive from their families, as well as from the

support and services their families receive, especially during the children's early ages of development. They depend on their caregivers to accomplish their particular needs and negotiate significant social and environmental hurdles to be able to take part in their daily life. According to Graham (2014:4), most developing countries unacceptably underrate the number of children living with disabilities. They acknowledge children living with moderate to severe disabilities, but in most cases ignore those with mild to moderate disabilities. The author further likens disability with dropping out of school and some not given a chance to enrol in school, making children living with disability to account for a higher proportion of school dropouts, without completing primary education. By staying at home without going to school, it increases the burden on their caregivers as they are expected to be with them all the time.

In this study, CLD refers to any vulnerable child or adolescent living with any type of disability and being dependent on their caregivers to meet their physical, psychological and social needs.

1.8.2 Methodological assumptions

The researcher adopted the Botes model (2009:8) as the guiding tool for the study. The model describes nursing at three levels being the nursing practice, nursing research and the nursing paradigmatic perspective. The researcher is of the same view as the Botes model's central theoretical proposition that nursing research is conducted to improve nursing clinical practice by bringing new knowledge and recommendations to promote good quality of life for these caregivers.

In the first level, which is the nursing practice, the belief is that nursing problems emanates from within the nursing practice and research is conducted to improve nursing practice.

In this study, the researcher identified CRS in caring for CLD as a problem within the nursing practice. This problem needed exploring to come up with recommendations to promote better quality of life for these caregivers. The researcher engaged in research, following the research process, which is the second level of the Botes model. The problem identified guided the researcher, which in this study was role strain in caring for CLD. According to Botes (2009:8), the third level is the meta-theoretical assumptions, which aims to influence the research decisions.

1.9 Research methodology

Research methodology is the overall type of research chosen to solve the research problem in a systematic way (Gray *et al*., 2017:683). The author further describes research methodology as a scientific way of studying various steps that the researcher adopts in solving the identified research problem. The research methodology refers to the research design and methods utilised in the study and discussed in detail below.

1.9.1 Study design

This study used an exploratory, descriptive, and contextual qualitative investigation as a design to gain insight and describe the role strain experienced by caregivers of CLD, as well as to inform guidelines that may promote the quality of life of CCLDs. The main concern of qualitative research is finding out the people's meaning about their world i.e., how they perceive and interpret their experiences (Holloway & Galvin, 2017:3), and its main emphasis is on how participants attach meaning to their subjective reality. The design is suitable for this study as it has the potential to allow the participants an opportunity to share their experiences on role strain in caring for CLD as well as explaining how they manage the role strain. An explorative study examines the precise information about how an occurrence or a phenomenon manifest, including other factors related to it (Polit &Beck, 2017:728). In this study, the exploratory research intends to discover the breadth of the phenomenon, which is caregiver role strain in caring for CLD and its manifestation. The researcher asked the central questions, and there was more clarification of the information on caregivers' experiences regarding role strain in caring for CLD. Through this, the researcher was able to gain a full insight of caregivers' experiences regarding role strain in caring for CLD in their natural setting.

The researcher used the descriptive design, which examined and described the experiences of participants as it happens in their real world at their natural settings (Burns & Groove, 2009:45). This design was suitable for this study because it enabled the CCLDs to offer a thorough description on their experiences regarding role strain in caring for CLDs as it happens in their natural settings and in their real-world context. Through qualitative data collection, the researcher explored, described, and contextualised the findings from the dominion of participants of which information sharing and communication occurred between the researcher and the participants who gained insight and echoed on the CCLDs regarding role strain in caring for CLDs.

1.9.2 Research methods

The research methods are the strategies used by the researcher to structure a study and to collect and analyse data (Polit & Beck, 2017:743). It is how the researcher generally strategises or puts an outline of their plan to logically and coherently integrate different components of the study (Hofstee, 2010:113). It helps the researcher to effectively address the research problem as it establishes the framework for the collection, quantity and analysis of data. The research methods for this study included the following:

- Study context, population recruitment, sampling and sample size
- Data collection, data analysis
- Trustworthiness, and ethical considerations.

1.9.2.1 Study context

Gray et al. (2017:353) explain the study context as a site where the study is carried out. The study was conducted in Lobatse, a town located in the Southern district, 70 km south of Gaborone, the capital city of Botswana. The town is about 70 km from the South African border in the south and has a frontier on the east where Botswana borders with South Africa. According to Statistics Botswana (2018:60), the percentage of people living with disabilities in Lobatse is 3.1% in a population of 28493 people, including the CLD. From the 1980s to date, Lobatse has been one of the towns in Botswana with support services for children with disabilities, such as Bothakga Primary School, which caters for this town and its environs, hence the selection of this setting for the study (Lebanna, 2016). The availability of such services for children living with disability provide support in the caring of these children, thus minimising the burden their caregivers would bear without such support. That still being the case, the support services for CLD are inadequate and this puts a strain on their caregivers. Moreover, the town has a scarcity of support services for families caring for children living with disabilities and this exacerbates the role strain the caregivers experience in caring for the CLD. Lobatse lacks support services for CCLD, such as respite care services, that would relieve the caregivers from having to care for these children every day for the rest of their lives, which can put a strain on them. This study was thus conducted in a natural setting in which the CCLD in Lobatse were allowed to partake in the telephone interview in a place and time they deemed suitable (Gray et al., 2017:353).

1.9.2.2 Population and sampling

This section describes the study population, sampling technique, sampling size inclusion and exclusion criteria.

1.9.2.2.1 Population

The study population included CCLD in Lobatse and registered with the Social and Community Development (S&CD) office. Social workers staff the S & CD office, offering social and welfare services to the community, which include registration of people living with disabilities for a disability grant. The social workers assess the CLD to establish the kind and extent of assistance they may need from their office. It is in this regard that the S & CD office is the relevant place when one seeks to contact CCLD. The target population was 23 caregivers, caring for CLD with moderate to severe disability, staying in Lobatse and registered with the S & CD.

1.9.2.2.2 Sampling technique

The researcher selected the sample from a population of all CCLDs staying in Lobatse, who were willing to take part in the research study to obtain information on a phenomenon (caregiver role strain), and represented the population of interest (Brink *et al*., 2008:124). The researcher used purposive sampling, which allowed the selection of participants who were information-rich on the phenomenon, from which the researcher could boundlessly learn about what the study was focusing on (Gray *et al.*, 2017:355). Since there was a need to solicit information from the participants who would be at their homes, the researcher used the S & CD office as the point of contact with the caregivers and requested their contact numbers from this office. CCLD registered with the S & CD office were included in the study. The prospective participants identified from the S &CD register and who met the eligibility criteria were contacted via the telephone and given a detailed explanation of the study to obtain informed consent to participate.

1.9.2.2.3 Sampling size

According to Gray *et al.* (2017:53), a sample size is the quantity of participants who essentially participate in the study. The authors further described it as a subsection of the available population that the researcher chooses to participate in a study. In this study, the sample size was determined by data saturation, i.e., when new data brought redundant information (Polit & Beck, 2017:744). There were interviews held with the CCLD, and their number was determined when no new information was yielded from the interviews. Gray *et al.* (2017:352) explains that in qualitative research, the focus and emphasis is on the quality of data obtained from the sampled participants versus the size of the sample. The sample size was 11 participants with whom the interview was conducted.

Inclusion criteria

The inclusion criteria were as follows:

- The participants included parents or guardians living or staying with and taking care of a child living with a disability.
- The CCLD should have been 18 years or above and should have cared for the child for more than six months.
- The CCLD should have been caring for a child aged below 18 years and having a moderate to severe disability (the classification already done by the S&CD office as they assess them for the disability grant)
- Only one member in a family participated in the study
- They should have been willing to communicate in either English or Setswana.

Exclusion criteria

The study excluded caregivers taking care of the CLD on temporary basis, e.g., those hired to care for the CLDs on part-time basis, either during the day or at night.

1.9.2.3 The role of the reseacher

The researcher submitted the proposed research study to the NuMIQ Scientific Committee for assessment and evaluation for scientific viability and reliability. The proposal was then submitted to the Health Research Ethics Committee (HREC) of the Faculty of Health Sciences, North-West University (Potchefstroom Campus) for ethical clearance. After obtaining ethical clearance from the HREC (see Annexure A), the researcher requested permission from the Ministry of Health and Wellness (MoHW) in Botswana and the Lobatse Town Council (LTC). Furthermore, the researcher identified an independent person who signed a confidentiality undertaking form (see Annexure B). After obtaining consent from the independent person, the researcher provided him with all the necessary information documents and consent forms that were delivered to the potential participants inviting them to participate in the study (see Annexure C and D). In addition, the researcher conducted the semi-structured interviews, transcribed, coded and analysed the data collected. During the interviews, the researcher used communication skills such active listening, reflection, clarifying, probing and summarising which shall be discussed in detail in Section 2.3.6.2.

1.9.2.4 Recruitment of participants

The participants were recruited through the S & CD office after permission was solicited from the MoHW and LTC. The researcher contacted the gatekeeper telephonically informing and explaining the details of the study. The gate keeper, who was the social worker in-charge at the S & CD office, provided a list and telephone contact numbers of candidates who met the eligibility criteria to a mediator who signed a confidentiality undertaking (see Annexure E). The mediator was a lecturer from the Institute of Health Sciences (IHS) and an independent i.e., a person with no conflict of interest in the study and without any relationship with the prospective participants. The researcher recruited the mediator through head of departments in the IHS and anyone who held a Master's degree and interested in the study could contact the researcher telephonically to be trained about the study. The mediator telephoned the identified caregivers and explained the purpose of the call to the eligible candidates. During call, the mediator advertised for and recruited participants (See Annexures F and G). The mediator then provided an independent person with the contact details of the prospective participants. The independent person was also a lecturer at the IHS. The independent person gave a detailed telephonic explanation of the study to obtain informed consent and then provided the researcher with the contacts of those who consented to participate in the study. The researcher then contacted the participants telephonically to make appointments for a recorded telephone interview for data collection.

1.9.2.5 Process of obtaining informed consent

The independent person gave a detailed explanation about the study through telephone calls and consenting participants had to provide verbal and written consent (See Annexure C). The independent person informed the participants about the purpose and process of the research. It was further explained that the interview was going to be conducted through the telephone and recorded. Ethical issues, such as privacy, confidentiality, beneficence, justice and autonomy, were addressed during the process of obtaining consent. The participants were informed that participation in the study was voluntary. In addition, participants were informed of their right to terminate the consent at any point they so wished and that there would be no recriminations should they wish to withdraw. After explaining the study, the independent person emailed the consent forms to the participants and they had four days to study the forms and decide before signing and returning to affirm their decision to consent, after which there was an appointment date made for the interview. After the four days of studying the consent forms elapsed, the participants were called and requested to get a

witness. A recorded telephone call was done, which involved the independent person, the participants and their witnesses. The independent person further explained the purpose and process of the study, whereby after which the participants and their witnesses were requested to sign the consent, scan it and email or fax it back to the researcher.

1.9.2.6 Data collection process

As described by Polit and Beck (2017:506), the researcher engaged in data collection knowing the prospective sources of data to gather the information to address the research problem. Nevertheless, the researcher did not rule out other possible sources of data that may come to light as data collection progressed. The researcher conducted semi-structured interviews through telephone calls and the interviews were recorded using an audio call recorder. The interviews lasted between 45 minutes and an hour. Open-ended questions explored the experiences of CCLDs on CRS, supported by the information noted during the calls, such as participants' silence or crying during the interview (See Annexure H). The discussion of these aspects follows, as well as data transcription.

1.9.2.6.1 Interview setting

The interviews were scheduled to take place at a location and time convenient for the participants (Dejonckheere & Vaughn, 2019:5). They were conducted telephonically on CCLD who met the inclusion criteria for the study. It was explained to the participants that they should do the interview call in a private and comfortable place with minimal interuptions i.e., where there would be no disturbing movement of people, no noise from people, radio or television, no extra calls etc. To ascertain the participants' comfort and privacy, the researcher confirmed with them first before proceeding with the interview. The participants were asked if they were free, comfortable and in a private place, or if they would like to reschedule due to comfort and privacy issues. In the same manner, the researcher conducted the interviews call from her office or study room at her house, where there were no disruptions. The researcher's other phones were switched off and a 'please do not disturb, interview in progress' printed note was put at the door to prevent any distractions during the telephone interview. Furthermore, the researcher availed a reliable tape recorder and conducted the interview in loud speaker mode to obtain a contingency recording in case the telephone audio recorder system failed. Conducting the interview with the phone switched to loudspeaker also enabled the researcher to freely take notes as the interview progressed. The researcher had two pens, a note pad to record field notes during the

telephone interview, diary to keep the contact information for the participants and appointment information.

1.9.2.6.2 Trial run

A trial run or pilot study is a smaller-scale sample version of the study conducted with the same research population, setting and plans for data collection and analysis (Gray et al., 2017:46). After obtaining NWU-HREC approval (Annexure A) and permissions from the MoHW (Annexure N) and LTC (Annexure O), and before fully undertaking the main study, the researcher conducted a trial run with the aim of refining the methodology, i.e., the population and sampling, data collection process and analysis. The researcher used the first interview as the trial run. It was conducted with a caregiver of a child living with a disability who met the eligibility criteria for the study. In this trial run, the data collection method used was the semi-structured interview and the field notes which assisted in reflections of the trial run experience and the valuation and conclusion thereof. The interview was conducted telephonically and lasted for about 50 minutes; an audio call recorder recorded the interview. The trial run enabled the researcher to acquire interviewing skills to determine the approximate time taken to complete the interview and determining if the CCLD easily understood the questions. According to Gray et al. (2017:260), interviewing is a prerequisite skill researchers should develop before conducting interviews in a research study, and it also has a direct effect on the quality of the data collected. Furthermore, the researcher was able to determine whether the proposed methods were effective in selecting participants and collecting appropriate data. The trial run interview was included as part of the data collected for the study.

1.9.2.6.3 Individual semi-structured interview procedure

The researcher used semi-structured interview as a data collection method which according to Bradshaw *et al.* (2017:4), is one of the prime sources of data collection in qualitative descriptive research. The conducting of individual semi-structured interviews is to acquire a comprehensive account of the participants' experiences on a particular topic (Botma *et al*., 2015:207). In this study the researcher collected data on CRS experienced by CCLD using an interview guide of semi-structured questions. The interview was in a language chosen by the participants, i.e., English or Setswana. There were open-ended questions asked, followed by probes and concomitant follow-ups. The questions were in English and translated to Setswana (See Annexures H and I).

The researcher initiated the individual semi-structured interview calls by greeting the participant and introducing herself. The introductions were followed by repeating the information on the purpose and nature of the study. The researcher confirmed that participation in the study was voluntarily and that participants were at liberty to pull out from the study at any time without fearing any adverse treatment. Also confirmed were the confidentiality and privacy of the participants' information. The researcher explained to the participants that the information collected from them will remain safe on password protected gadgets and under lock and key, and the only people who would have access to the information are the researcher, her supervisors and the co-coder. There was a reminder that there will be recording of the individual semi-structured interviews. The interviews commenced with three broad open-ended questions, followed by concomitant probes. The formulation of the open-ended questions was during the preparation of the interview schedule. The questions accorded the participants the liberty to respond spontaneously on their own enlightenment on the experiences they encounter in caring for CLD (See Annexure J).

The telephone interviews were guided by a semi-structured interview schedule. The researcher asked the participants the following questions:

1. What are your experiences on caring for the child living with a disability?
2. How do you cope with the strain in caring for this child?
3. What can be done to assist you in coping with the strain of caring for this child?

The researcher used interpersonal communication techniques such as reflection, exploring, clarifying and paraphrasing as described by Halter (2018:142), and discussed below.

a) Reflection

Reflection involves the interviewer's ability to pick up the participant's emotions as they narrate their story (Halter, 2018:142). It was a means of assisting the participants to understand their own thoughts and feelings. Reflections were in the form of a question or a simple statement that conveyed the researcher's observations of the participant when discussing sensitive issues. An example of a reflection question as asked by the researcher during the interview, "So, you mean the help from the school relived the stress?"

b) Exploring

Exploring involves asking supplementary questions to obtain specific information and examine important issues and experiences (Halter, 2018:142). Example of exploring, “Can you explain further on how your sexual relationship with your husband is affected by the stain of caring for your child?”

c) Clarifying

The researcher used probes which involved posing secondary questions during the interview to elicit a contextual detail, additional information and clarification on experiences the CCLDs shared on CRS (Gray *et al*., 2017:688). Seeking clarity helped the participant elucidate their own feelings and thoughts, as well as to maximize mutual understanding between the researcher and the participant (Halter, 2018:142). Example; “I am not sure if I am following you, what would you say is the main point of what you have just said?”

d) Paraphrasing

Paraphrasing means restating someone’s words using own words without altering the meaning (Halter, 2018:142). During the interviews, paraphrasing occurred when the researcher reiterated the basic content of the participant message in fewer words different from the participants’ but carrying the same meaning. The researcher used precise, simple and culturally appropriate terms, confirming an interpretation of the participants’ messages before the discussions could continue.

1.9.2.6.4 Field notes

Field notes are comprehensive notes and observations that the researcher makes during and immediately after the interview (Polit & Beck, 2017:521). In this case, the field notes were the things the researcher became aware of during the telephonic interview; the things the researcher heard, thought about, felt and experienced during the interview. Recording field notes was essential as it prevented the researcher from forgetting aspects not covered in the semi-structured interview that could affect the research findings. The researcher recorded field notes (See Annexure K), which were both descriptive and reflective and included demographic information (Polit & Beck, 2017:521). The researcher sought permission to record the field notes from the participants, and the recording occured immediately after the interview ended. The structure provided by Polit and Beck (2017:522) guided the researcher in writing the reflective notes, which included the theoretical and

personal notes. During the telephonic interview, the researcher set aside a log diary to record all events and discussions that took place during the interview. The researcher typed the field notes, labelled them accordingly and attached them to their respective transcriptions and included them in data analysis.

a) Reflective notes

Reflective notes included a record of researcher's thoughts, feelings, problems encountered during the interview, speculation of incidents, prejudices, impressions, and hunches (Polit & Beck, 2017:522). The researcher penned the reflective notes as follows:

Theoretical notes

According to Polit and Beck (2017:522), theoretical notes include researcher's reflections on their own thoughts and how they made sense of what ensued as the interview progressed. Thus, data analysis and data collection took place simultaneously as the researcher construed what arose during data collection.

Personal notes

The researcher took note of own feelings during the telephone interview. According to Polit and Beck (2017:522), the personal notes can encompass the researcher's reflections that correlate to the struggles and ethical dilemmas. The researcher recorded own feelings, reactions and emotions that arose as the interview progressed immediately after the interview concluded while still vresh in her memory.

1.9.2.6.5 Debriefing of the participants

As the participants went through a psychological and emotional process during data collection, relating the strain of caring for a child with a moderate or severe disability, after data collection they all underwent a telephonic debriefing process by a psychologist (See Annexure L).

1.9.2.6.6 Transcribing of data collected

The researcher transcribed data from the recorded telephone interviews verbatim (see Annexure J for an example of a transcript). All the interviews were conducted in Setswana, the language the participants preferred, transcribed verbatim and then translated to English. In addition to the audio recorded interviews, the researcher transcribed important additional data noted during the interview such as when the participants cried, sighed or were silent. According to Polit and Beck (2017:531), recorded interviews and field notes are the major

sources of data in qualitative studies. Furthermore, the authors emphasize that transcription of recorded data word-for-word is a critical step in preparing for data analysis.

1.9.2.7 Data analysis

The researcher conducted data analysis with the intent to organise and draw conclusions from the data collected from the participants (Polit & Beck, 2017:530). The researcher started the process of data analysis after completing the process of data collection and transcription. The researcher invited an independent co-coder to co-analyse the data. The co-coder was asked to sign a confidentiality agreement (see Annexure M). The researcher transcribed the recorded telephone interviews in preparation for the data analysis. According to Sandelowski (2000:338), data analysis in qualitative descriptive and explorative studies occurs concurrently with data collection. Thus, the researcher commenced the process of data analysis from the first interview going forward. The researcher used the content analysis process as a method of choice to analyse the collected data. According to Polit and Beck (2017:724), content analysis involves extraction, arranging and synthesising material from documents, which is often narrative data from a study that is qualitative according to key concepts and themes. The researcher used the four-step content analysis method, which mainly includes “decontextualisation, recontextualisation, categorisation and compilation” (Bengtsson, 2016:11). As a measure to ensure the credibility of the results, the researcher shared the protocol for the data analysis steps with the independent co-coder. The two reached a consensus on the themes and sub-themes of the data. The discussion of the content analysis steps follows:

1.9.2.7.1 Decontextualisation

This is the first step in data analysis whereby the researcher acquaints themselves with the content of the data (Bengtsson, 2016:11). This was achieved through reading and re-reading of the transcribed data while at the same time noting down the initial impression.

1.9.2.7.2 Recontextualisation

This step involves dividing the content into units after the meaning units are acknowledged (Erlingsson & Brysiewicz, 2017:96). This process occured while keeping the study objectives and questions in mind for the researcher to keep a clear focus on the aim of the research. The researcher re-read the original text alongside the finalised meaning units. This was achieved by using different colours to extricate each meaning component in the original text.

a) Descriptive information

Descriptive information included descriptions of the participants and the researcher's factual account of particular activities and events that occured during the interview (Polit & Beck, 2017:521). In this study, the researcher noted and recorded the time, date and an account of particular incidences that transpired during the interview.

1.9.2.7.3 Categorisation

In this step, the codes for the condensed units are developed (Bengtsson, 2016:12). It is at this stage that themes and sub-themes were developed. In this step, the researcher divided the coded materials into fields based on various attentions of the study.

1.9.2.7.4 Compilation

After establishing the themes and sub-themes, they are sorted according to how they answer the questions describing the phenomenon (Erlingsson & Brysiewicz, 2017:96). This step was realised as the researcher conducted analysis concurrently with the writing up. The researcher focused on exploring how the participants made sense of their experiences on CRS in caring for CLD and transformed the experiences into their awareness.

1.9.2.8 Intergration of literature

Literature review is an extensive review and summary of research on a topic in which the researcher has interest, often organized to contextualize a research problem, offering a synopsis of existing knowledge of the research problem (Polit & Beck, 2017:733). In this study, the researcher undertook literature review to compare and authenticate the research findings obtained in this study with related literature and current findings on CRS experienced by CCLD. The literature review also provided a scientific basis for the research and to identify new information acquired from this study.

1.9.2.9 Trustworthiness

In this study, the researcher ensured trustworthiness of the results through paying attention to the accuracy and confirming the participants' meaning ascribed to the information shared. According to Polit and Beck (2017:161), rigour means the quality of the research, ensuring that the results of the study are truthful and valid. In this study, the researcher ensured trustworthiness and rigour through the use of triangulation. Triangulation according to Polit and Beck (2017:563) refers to converging information gathered from the use of various

methods for data collection and interpretation about a phenomenon to come up with a truthful depiction of reality. The researcher used different methods of recorded telephone interview and recorded notes of anything noted during the interview and, as she listened to the telephone audio records of the interviews. Additionally, to further ensure the quality of the results and to test the integrity of the questions, the researcher treated the first interview as a “pilot study”. The recorded telephone interview was listened to by both the researcher and the supervisors before proceeding with the subsequent interviews. After data collection, the researcher and the co-coder analysed the data and reached a consensus on the themes and sub-themes from the findings. To further meet the requirements of ensuring rigour and trustworthiness, the researcher applied the epistemological standards of credibility, authenticity, conformability, dependability and transferability as discussed below.

1.9.2.9.1 Credibility

Credibility, also referred to as the truth-value of the research in qualitative research refers to the assurance that the data collected and its interpretations are true according to the perspective of the participant (Polit & Beck, 2017:559). This study obtained credibility by exploring the lived experiences of CCLD on the strain they experience due to the responsibility of caring for these children and comparing it with other previous research. Credibility was established by implementation of strategies such as prolonged engagement with the CCLD. This was for the purpose of building trust and rapport in order to obtain a comprehensive account of their experiences. Before the interview calls, the researcher called the consenting CCLD to make appointments for the interview. Moreover, confirmation calls verified the appointment for the interview call before the actual interview. The researcher made these calls for the purpose of strengthening the relationship with the CCLD. The researcher used semi-structured interview questions to explore the CCLD accounts concerning CRS. The participants had adequate time and permitted to relate their experiences without any interruptions. The researcher asked probing questions to get a comprehensive and thoughtful understanding of the experiences of the CCLD regarding CRS. Credibility of the findings was also heightened through peer examination whereby a co-coder experienced in co-coding and qualitative data analysis was engaged in the data analysis process (Thomas & Magilvy, 2011:153), and a consensus was reached with the researcher. Furthermore, reflexivity enhaced credibility as the researcher wrote the field notes, which were also subjected to data analysis, immediately after the interview calls. The researcher focused on self-analysis and reflection in order to be aware of own sensitivity and self-knowledge; appreciated their role in the conception of knowledge; cautiously

monitored self on the bearing of their biasness, personal experiences and beliefs on data collection, analysis and interpretation (Dodgson, 2019:220: Gray et al., 2017:65).

1.9.2.9.2 Confirmability

Confirmability refers to the neutrality or independence of the data and interpretations made from the study (Polit & Beck, 2017:723), and to the degree to which the findings can be validated by others. In this study, ensuring conformability was by involving a co-coder experienced in qualitative research. The co-coder received the raw data on the audio-recordings which she analysed independently and then reached a consensus with the researcher. Moreover, the enhancing of confirmability throughout the study was because the supervisors repeatedly checked the study, and through reflexivity as the researcher recorded the field notes, which were also subjected to data analysis.

1.9.2.9.3 Dependability

Dependability refers to the degree to which the study can consistently produce same results overtime if it repeated on the same participants under the same conditions or within a similar setting (Polit & Beck, 2017:559). Farrelly (2013:150) explains that customarily, the view of consistency of the findings is grounded on the assumption of replicability, i.e., whether matching results can be obtained if the same thing can be re-investigated. Thus, dependability accentuates the essentiality of the research to justify the continually changing milieu within which the study takes place. According to Anne (2015:278), dependability can be warranted using an audit trail, step-wise replication triangulation, a code-recode strategy and peer examination. To this end the researcher enhanced dependability through an audit trail, i.e., the researcher examined the investigatory process and the findings to authenticate the data. To account for all the decisions and activities to illustrate how data collection and analysis occured, and to corroborate the investigatory process, the researcher kept safe the following documents: interview audio recordings, verbatim transcriptions, field notes and data analysis raw data. The other strategy the researcher used to ensure dependability was step-wise replication whereby the researcher and an experienced co-coder separately analysed the same data and a consensus discussion with the co-coder conducted to compare their findings. In addition, the researcher enhanced dependability through a code-recode strategy, whereby the same data were coded twice at separate times. The findings from the two codings were compared to find out if they produced the same results. Furthermore, the researcher ensured dependability through peer examination, in which the researcher discussed the study process and findings with colleagues experienced in

qualitative research. The last strategy used to ensure dependability was expert supervision, as the researcher's supervisors were experts in psychiatric mental health nursing sciences and qualitative research.

1.9.2.9.4 Transferability

Transferability refers to the extent to which the findings of the study are applicable to other groups or settings (Polit & Beck, 2017:560). Even though there is an assumption that every individual is unique, the researcher is of the view that the findings of the study can be applicable to other caregivers caring for children living with disabilities in similar settings. The researcher enhanced transferability through thick description of the methodology. There was a detailed description of the inquiry process was provided as the researcher gave a detailed elucidation of the research process, i.e., from the description of the methods through to data analysis, and at the end produced a final report on the study. According to Anne (2015:278), dense description can assist other researchers to reproduce the study with comparable conditions in other contexts. Ensuring transferability was through purposive sampling and voluntary participation. The participants ware purposively identified through the S& CD office and they received an explanation on the purpose, objectives and research questions, to give them an opportunity to make an informed decision and voluntarily participate in the study.

1.9.2.9.5 Authenticity

Authenticity refers to the extent to which the researcher faithfully and impartially demonstrates different realities in the collection, analysis, and interpretation of data (Polit & Beck, 2017:720). Authenticity enhancement was through an audit trail which made use of the interview audio recordings, verbatim transcriptions, field notes and data analysis raw data for audition of the data collection and analysis. The researcher conveyed the voices of the CCLD genuinely and fairly during data collection, verbatim transcription, analysis and reporting.

1.10 Ethical considerations

According to Polit and Beck (2017:137), it is imperative to exercise care when using human beings as study participants in order to protect their rights. To this end, the researcher applied for permission to conduct this study from the North-West University Scientific Committee of (NuMIQ) as well as the Faculty of Health Research Ethics Committee (HREC). Following approval by the HREC, the researcher also requested permission from the MoHW

and LTC, which were granted before data collection could commence (See Annexures P and Q). Furthermore, the researcher observed ethical principles such as respect for human dignity, justice, beneficence, confidentiality, privacy and anonymity of the participants throughout the study. According to Gray *et al.* (2017:157), the nursing profession is determinedly grounded on the ethical principles of respect for persons, justice and beneficence and these ethical principles that guide nursing practice are the standards for nursing research conduct.

1.10.1 Respect for humanity

According to Polit and Beck (2017:140), the ethical principle of respect for human dignity includes the right to self-determination and the right to full disclosure which are the two main elements in which informed consent is founded on.

1.10.1.1 The right to self determination

This principle holds the view that prospective participants are autonomous beings and can make their own decisions (Halter, 2018:92). In this study, the participants received full details about the study so that they could make an informed decision on whether to participate or not. Moreover, the participants were informed that participating in the study was voluntary and that they had the right to choose whether to participate or not, and that there would be no recriminations should they wish not to participate or decide to withdraw from the study during the process.

1.10.1.2 The right to full disclosure

This principle holds the view that for people to make informed voluntary decisions, they deserve the right to be given full details about the intended study (Polit & Beck, 2017:140). The researcher fully described the study to the participants, which included the full description of the study, the purpose of the study, the participant's right to voluntarily decide whether to participate in the study or not, an explanation that the participants had the right to withdraw from the study if they so wished and that there would not be any penalties if they decided to withdraw. Moreover, they received information about the risks and benefits of the study and that there was no renumeration for participation in the study. However, they would be reimbursed in case of any inconveniences.

1.10.2 Justice

According to Polit and Beck (2017:142), the ethical principle of justice holds the view that participants have the right to fair treatment. The researcher treated all the participants fairly and gave whatever was due to them. For example, if a participant used their own money to make a telephone call for the purpose of the study, they were duly reimbursed. The research requirements or recruitment criteria were the basis for selection of participants. No participant was included or excluded from participating in the study based on their vulnerability. Furthermore, participants received full details about the study. The independent person as well as the researcher explained the participants' rights to other ethical principles, such as confidentiality, privacy, autonomy among others, so that they could make an informed decision.

1.10.3 Beneficence

This principle is concerned with the wellbeing of participants. The emphasis is on the right to no harm to participants, i.e., the study should yield more benefits than risks to the participants (Polit & Beck, 2017:139). The participants were protected from any form of harm or discomfort, and there was a plan of intervention in case they experienced some form of discomfort. Participants who experienced emotional discomfort were referred to a psychologist. That still being the case, the psychologist conducted a debriefing for all participants after the interview.

1.10.4 Privacy

Participants in a study are entitled to the right to privacy and should not experience unnecessary intrusion into their lives (Polit & Beck, 2017:141). The researcher ensured privacy by conducting the interviews telephonically and not sharing the recorded interview with unauthorised persons. According to Polit and Beck (2017:147), there are various ways through which participants' right to privacy can be maintained and guarded, which includes anonymity and confidentiality.

1.10.4.1 Confidentiality

The researcher has an obligation to safeguard all the information shared by participants from unauthorised access, modification, loss, theft, or use (Polit & Beck, 2017:723). Confidentiality in this study was through safekeeping the information collected from participants in a lockable room, in a lockable cupboard and in an encrypted password protected computer.

1.10.4.2 Anonymity

Anonymity is the right to privacy, safeguarded by not linking the collected information directly to the participants (Polit & Beck, 2017:147). In this study, the use of codes instead of participants' names ensured anonymity.

1.11 Data management

There was sharing of the data captured from the participants with the co-coder for analysis. The data, which were in audio format, were transferred to and saved in the researcher's password protected computer and subsequently deleted from the phone on which they were recorded during the interview. Also saved in the password protected computer were other electronic documents, such as soft copies. According to the university policy, the electronic data have to remain in the university for 5 years before it can be destroyed. Hard copies are to remain in lockable cupboards in a locked room, and will be shredded after the awarding of the degree. During the study, only the student, supervisors and co-coder had access to the data. Participants' data were kept anonymous by labelling the data with codes throughout the study.

1.12 Dissemination of results

Dissemination of research results was through article publication in research journals upon completion of the study, and the findings through the "kgotla" meetings (customary gatherings), i.e., the results were communicated to the village health committee who shall further circulate the results to the community. This committee usually has slots at customary gatherings for discussion of any health-related information. The stakeholders who granted permission for the study study received a copy of the research results. The researcher also presented the study at research conferences. For direct dissemination of results to the participants, the researcher informed them through email and Google meetings, and through telephone calls for those who did not have access to internet.

1.13 Conflict of interest

Conflict of interest happens when the researcher or any individual taking part in the study has interest in the outcomes of the study that may lead to a personal benefit that might thus, compromise the authenticity of the research (Polit & Beck, 2017:139). The conflict of interest may be real, probable or apparent and may involve financial or non-financial gain. It may affect or may seem to affect the researchers' neutrality and judgement which can wear away

the confidence in the study. In this study, the researcher and supervisors pronounced that they had no conflict of interest in the study.

1.14 Summary

Section 1 discussed the introduction, background of the research study, the problem statement, research question, the purpose of the research perspective, and gave a detailed description of the research methodology, which comprises of the research design and methods. Moreover, trustworthiness and ethical considerations used in the study were discussed. The next section (section 2) shall be the manuscript for the article: Exploring caregiver role strain in caring for children with disabilities in Lobatse

1.15 Study outline

Section 1: Overview of the research study

Section 2: Article: Exploring role strain and experiences of caregivers of children living with disabilities in Lobatse submitted to Nursing Open Journal

Section 3: Conclusions, limitations, and recommendations.

SECTION 2 ARTICLE: EXPLORING ROLE STRAIN AND EXPERIENCES OF CAREGIVERS OF CHILDREN LIVING WITH DISABILITIES IN LOBATSE

Journal: Nursing Open

Title: Exploring role strain and experiences of caregivers of children living with disabilities.

Date of submission: 14th October 2021

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Abstract

Aim: To explore and describe caregiver role strain in caregivers of children living with disabilities.

Design: This study used qualitative explorative, descriptive and contextual design.

Methods: 11 participants were purposively chosen from caregivers of children receiving help from the social and community development office. Data collection used semi structured interviews and data saturation occurred with the 11 participants. The data were analysed using content analysis process. The Consolidated criteria for Reporting Qualitative research guidelines were used for reporting.

Results: Four main themes were identified: caring for a child with disability affects the overall health of the caregiver; caring for children living with disabilities puts financial strain on the caregivers; caring for children living with disabilities has an impact on other roles; and strategies employed to cope with the strain of caring for a child living with disability.

Key words

Caregivers; caring; children; disabilities; role strain

1. Introduction

Giving birth to a child with a disability brings profound consequences for the family, as it necessitates that at least one member of the family, especially the parents, assumes the role of caregiver. Studies on caregiving of children living with disabilities (CLD) have emphasised the strain exerted on caregivers due to the several difficulties and stresses of caregiving (Beighton & Wills, 2017: 330)). To this end, the researcher is of the opinion that caregivers do not openly disclose having a child with a disability and the difficulties they encounter as they execute their caregiving role, leading to minimal or no support. A study conducted in Botswana by Patel *et al*. (2017), reported lack of adequate support as a factor that causes caregiver role strain (CRS). To this end, CRS can have objectionable consequences on the welfare of the caregiver which enforces the need for investigation in order to assist them.

2. Background

CRS is a world-wide concern as suggested by empirical evidence form studies conducted globally including the Southern African Community Development (SADC) countries (Chiluba & Moyo, 2017; Rueda *et al*, 2016). About 34 million caregivers engage in the provision of care to individuals with enduring conditions and disabilities but the issue of CRS is often disregarded (Centre for Disease Control, 2016; Minnes, Perry & Weiss, 2015). Unheeding CRS can have objectionable effects on the caregivers. The international trends indicate that caregivers of children living with disabilities (CCLD) report more stress due to CRS than parents whose children have no disabilities (Minnes *et al*., 2015). Nevertheless, the bearing of CRS varies across countries owing to the resources at their disposal (Hussein, 2016). A study conducted in the United States of America (USA) supports this and indicates that the availability of social support services, such as respite care, cushions the effects of CRS (Brown & Brown, 2014). However, Minnes *et al*. (2015) argue that CRS is also a challenge in developed countries where social support services are rampant as demonstrated in a study conducted in Canada in which there was distress on caregivers because of service delivery concentrating more on the child and neglecting the caregiver. Attention focuses more on the welfare of the incapacitated and in the process neglects the caregivers' wellbeing, thus becoming the "forgotten" members of the family. It is in this repute that CRS in caring for CLD is a worldwide phenomenon.

African countries face similar problems of care giving role strain as the rest of the world, mainly due to cultural expectations on caring for these children (Chiluba & Moyo, 2017). According to these authors, the African cultural viewpoint and expectation is that the burden

of caring for the CLD be borne by their families. Regardless of the influence culture has on caring for CLD in Africa, the implications of CRS are the same across all countries. Ndirangu and Midigo (2019) in a study conducted in Kenya revealed that CCLD unquestionably face more huddles than caregivers of children who are not incapacitated, which subsequently puts more strain on their caregiving role. Masulani-Mwale *et al*. (2016) supported this assertion in a study conducted in Malawi, in which the CRS experienced by parents of CLD are a result of several hitches, such as stigma and inaccessibility to support services. That still being the case, CLD wholly depend on their caregivers in carrying out their activities of daily living, and the caregivers play a critical role in supporting these children with resultant negative ramifications on their lives.

A study conducted in Zambia reports negative implications on the livelihoods of the caregivers due to caregiving role, with the possibility of ensuing physical, emotional and financial difficulties (Chiluba & Moyo, 2017). Likewise, a study conducted in Botswana reported that due to the time the caregivers spend in their caregiving role, they are unable to seek for employment (Kubanga *et al*., 2015). According to Kubanga *et al*. (2015), the challenges brought by the CRS have all-encompassing negative consequences that range from stress to developing mental and physical health problems. Though there is no evidence in literature about role strain in Botswana, there is an increase in prevalence of CLD. It can thus be concluded with empirical evidence that CRS brings unflattering mental or psychological difficulties such as anxiety, burnout and depression to the caregivers and subsequently affect the caregiving role negatively (Chambers & Chambers, 2015). This study can give understanding of the experiences of the CCLD in order to improve insight on their difficulties. Thus, the gap that exists in the knowledge of the role strain that they experience need to be closed. Therefore, this study was conducted to explore and describe the role strain experienced by caregivers of children living with disabilities that would aid in proposing guidelines to assist this population.

Research question

- What is the role strain experienced by caregivers of children living with disabilities?

Research aim

- To explore and describe the role strain experienced by caregivers of children living with disabilities.

3. Research methodology

According to Gray *et al.* (2017:192), research methodology is described as the major type of research used for the study. It comprises of the research design and methods that were utilised in the study.

3.1. Research design

The research aimed to explore and describe CRS experienced by CCLD. To accomplish this goal, the researcher conducted an explorative, contextual and descriptive qualitative research study. Through this qualitative method, the researcher was able to explore the role strain experienced by caregivers of children living with disabilities in the bid to have an in-depth understanding of how they make sense of their worlds. This design was appropriate for this study because it enabled the CCLD to offer an in-depth description of their experiences concerning role strain in caring for CLD as it ensues in their natural settings and in their real-life background.

3.2. Research methods

The research methods for this study included the study context, population, data collection, data analysis, trustworthiness and ethical considerations.

3.2.1 Population

The sample consisted of 11 participants, who comprised of ten women and one man, aged between 30- 65 years. Three caregivers had declined to participate in the study, citing discomfort with sharing sensitive information over the phone, since the interviews were conducted telephonically because of covid-19 protocols. A purposive sampling method recruited the participants through the Social and Community Development (S&CD) office after obtaining approvals from the ethics committee and other relevant institutions. The researcher determined the sample size through data saturation (Polit & Beck, 2017).

Eligible participants were: a parent or guardian living or staying with and taking care of a child living with a disability; 18 years or above and had cared for the child for more than six months; caring for a child aged below 18 years and whom had a moderate to severe disability.

3.2.2 Data collection

During data collection and as suggested by Polit and Beck (2017), the researcher engrossed herself in the collection of data, with knowledge of the prospective sources of information to

amass the data to address the research problem. The first author, who was a master's degree researcher and working as a professional psychiatric mental health nurse educator carried out all the interviews which were exclusively between the researcher and the participants. Data collection was completed in 3 months i.e., it was started on the 19th April 2021 and completed on the 10th July 2021. The author conducted the interviews in Setswana, a language which was preferred by all the participants. The duration of the interviews ranged from 45 minutes to an hour. The researchers predetermined semi-structured open-ended questions to guide the interviews; which took place telephonically and the researcher used an audio recorder to record the interviews. Immediately after each interview, the researcher wrote the field notes which were also subjected to data analysis. The first interview was a trial run, with the intention to refine the interview questions and the methodology where necessary. The information obtained from the trial run became part of thec data for the study.

3.2.3 Data analysis

The process of data analysis was preceded by verbatim transcription of the recorded data collected through telephone interviews. The first author who collected the data in Setswana proceeded to translate the transcripts to English. Upon completion of data transcription, data analysis took place, aimed at organising and drawing conclusions from the data provided by the participants (Polit & Beck, 2017). The researcher chose content analysis process to conduct data analysis. The researcher utilised the four-step content analysis method which primarily includes "decontextualisation, recontextualisation, categorisation and compilation" (Bengtsson, 2016). According to Polit and Beck (2017), content analysis comprises of extraction, arranging and synthesising narrative data from a study that is qualitative according to vital impressions and themes. An independent co-coder was involved in co-analysing the data, and the researcher shared the protocol for the data analysis steps with her as a measure to ensure credible results. The two coders reached a consensus on the themes and sub-themes of the data. Following compilation of the results, the findings were returned to the participants for authentication and direct dissemination of results to the participants was conducted through telephone calls. The reporting of this study followed the guidance of the Consolidated criteria for reporting qualitative studies (COREQ;) checklist (Tong *et al*, 2007).

3.2.4 Trustworthiness

The researcher applied the epistemological values of authenticity, credibility, transferability, dependability and conformability to safeguard rigour and trustworthiness (Creswell, 2014). In this study, the guarantee of authenticity was through the availability of an audit trail. The enactment of strategies such as engaging with the CCLD for a prolonged period in order to build trust and rapport enhanced credibility. Furthermore, reflexivity heightened the credibility as the writing of field notes occurred immediately after the interviews and the researcher subjected them to analysis. The researcher continuously monitored self through reflection and self-analysis to deter possible biasness from personal experiences and beliefs during data collection, analysis and interpretation (Dodgson, 2019: Gray *et al*., 2017). The researcher ensured transferability of results through thick description of the data. Dependability was reflected through an audit trail, i.e., external reviewers examined the research process and the findings to verify the data. In this study, conformability was ensured by involving a co-coder experienced in qualitative research, who independently analysed the raw data after which they reached a consensus on the themes with the researcher.

3.2.5 Ethical considerations

The researcher obtained ethical approval to conduct this study from the North-West University Health Research Ethics Committee (HREC). Subsequent to the approval by the HREC, the researcher further applied for authorisation to conduct the study from the Ministry of Health and Wellness (MoHW), the town council and the S & CD office, which were granted to the researcher prior to commencing with data collection. The researcher upheld confidentiality and anonymity by concealing the names of the participants on the transcripts or during discussion of the findings.

4. Results

4.1 Participants demographic description

A total of eleven (N=11) CCLD took part in the study and one (n=1) of them was a male whilst the rest were females constituting the highest number of the sample (n=10). The participants were of a black race with ages ranging from 29 to 69 years. From the total of 11 participants, five (n=5) had tertiary education and the rest attained secondary education level. 81.8% (n=9) of the participants were the mothers to the CLD, while one was the father and the other was the grandmother. The minimum period of caregiving was four years while the maximum was 14 years. Of the 11 participants, six had formal employment which added to their strain of caregiving while the remaining five were not employed and focused on the care of the CLD (Table 4.1). No participant dropped out during the data collection process.

Table 4.1 Demographic profile of participants

Participant	Age	Gender	Level of education	Employment status	Duration of caregiving	Relationship to the child
A	50	Female	Secondary	Not working	5 years	Mother
B	45	Female	Secondary	Not working	10 years	Mother
C	69	Female	Secondary	Old age pensioner	6 years	Grandmother
D	58	Male	Secondary	Working	5 years	Father
E	40	Female	Tertiary	Working	4 years	Mother
F	54	Female	Tertiary	Working	14 years	Mother
G	47	Female	Secondary	Not working	7 years	Mother
H	35	Female	Tertiary	Not working	8 years	Mother
I	29	Female	Secondary	Not working	4 years	Mother
J	40	Female	Tertiary	Working	12 years	Mother
K	49	Female	Tertiary	Working	7 years	Mother

Four main themes and their sub-themes have been identified and will be discussed as follows:

4.2 Theme 1: Caring for a child living with a disability affects the overall health of the caregiver

4.2.1. Sub-theme 1: Physical health

Various physical health issues such as fatigue, backaches, waist ache etc. were described as emanating from the strain of caring for the incapacitated children. The strain of caring for their CLD resulted in various physical ailments because of constantly carrying wholly dependent children around. The CCLD reported that due to the endless fatigue and stress, they now experience disturbed sleep, confirmed through these quotes:

> "Then in the morning I sometimes experience body pains……Hence, I sometimes experience body pains.... When my child is not well, I do not sleep well." (Participant D)

> "I have issues with my back. I have severe pains on the shoulders…I am now becoming physically weak…., I only get to rest when she goes to sleep." (Participant G)

4.2.2. Sub-theme 2: Mental health

The participants described the impact that caring for their CLD has on their mental health. They voiced the various mental health repercussions brought about by the strain of caring for their CLD. The CCLD reported feeling mentally drained because of the continuous care they give to their children; they do not have time for their own wellbeing. The strain of the caregiving role and other factors has left them with psychological ramifications such as low self-esteem and unending worry etc.

> "I'm so drained because there is no 'me' time…., I pretend to be happy and cheerful..." (Participant E)

> "I have low self-esteem, sometimes I fail to do things because I cannot speak for myself well." (Participant H)

4.2.3 Sub-theme 3: Emotions experienced by caregivers

It is emotionally draining to care for a CLD. Participants expressed various emotions emanating from the strain of caring for their CLD as evidenced below:

> "I felt sad when I wondered why people are ill-treating my child..., it hurts me emotionally when I realise that I got angry at him…" (Participant F)

> "I have feelings of guilty, regretting some of the things I did in the past." (Participant I)

4.3 Theme 2: Caring for a child living with a disability puts great finacial strain on the caregivers

Financial strain is a definite barrier for most of the CCLD especially those who are not working. They experience financial burden in caring for the CLD. The CCLD spend substantial amount of money on various things that support the children such as supplies, transportation to school, health facilities and assistive devices. They stated that even though the CLD receive a grant, the money is not enough to meet the children's special demands. The quotes below support the experienced financial struggle:

> "With the little salary we have at home, my child's needs are also included, we cater for her needs too." (Participant A)

> "I do not have any source of money. Any little money I get, as he can't do anything for himself, I spend it on helping him." (Participant C)

4.4 Theme 3: Caring for a child living with a disability has an impact on other roles

4.4.1 Sub-theme 1: Caregiver not able to work

Several participants stated that the demands of caring for their children make it difficult for them to work. They cannot work or quit their jobs to focus on caring for their CLD.

> "…if I can find a job, I cannot work freely because I would be worried about my child." (Participant B)

> "I am not working. My job is this child. I used to work, but when my child started school, I quit my job to focus on her care." (Participant G)

4.4.2 Sub-theme 2: Caring for a child with a disability disturbs work productivity

Though most CCLD expressed they are unable to work due to caring for their children, a few who are working reported that caring for CLD has a negative bearing on productivity at work. They linked the low productivity to fatigue and loss of time due to taking CLD for medical check-ups. The children need frequent medical attention; hence they spend most time away from work, thus leading to failure to achieve work objectives.

"It affects my productivity at work. And then taking her for the check-ups it would mean I request for some time off at work," (Participant J)

"Then we get to the challenge of working while caring for your child… It disturbs my work schedules…." (Participant K)

4.4.3 Sub-theme 3: Reduction in social engagement and interaction in community activities.

Some CCLD indicated that since they started the caregiving role, they are unable to go out or attend social events as they used to. They spend most time at home caring for their CLD.

"…I cannot attend to social events because I have to be with my child all the time." (Participant G)

"I cannot go out; I cannot go anywhere. I am only able to go out once in a month." (Participant H)

4.4.4 Sub-theme 4: Being a wife and mothering other siblings

In addition to the caregiving role, caregivers reported that they are wives and mothers to their other children, which adds to the strain they are experiencing. They expressed feelings of guilt as it seems as though they neglected the other children to focus on the one with a disability.

"I am a married woman and there are some societal expectations on me.…my child has siblings who also need my attention." (Participant A)

"Sometimes I feel that I am not into his younger brother. Because he plays independently, and does this and that. My focus is on this one with a disability." (Participant I)

4.5 Theme 4: Strategies employed to cope with the strain of caring for a child living with disability.

4.5.1 Sub-theme 1: Acceptance of the situation

The acceptance of the children's diagnoses appeared to be the key component of dealing with the children's disabilities. Accepting the children and the developmental delays provided the caregivers with a truthful viewpoint of the disability and aided them to adjust and cope.

"I cope with the role strain because I have accepted the situation." (Participant B)

"I manage through positive mind set. I have accepted the situation I am in." (Participant D)

4.5.2 Sub-theme 2: Religion gives carers hope for the future

They emphasized the role played by their spiritual beliefs in coping with the strain of caring for the CLD. Their spiritual beliefs influenced their interpretation of the reasons God let them have their child in those conditions, hence they engaged in prayer to surrender all their challenges to God.

"I help myself through prayer and attending church most often." (Participant B)

"I would pray and present my issues to God." (Participant G)

4.5.3 Sub-theme 3: Support groups

Being members of support groups of CCLD is one of the strategies used by some caregivers to cope with the strain of caring for their CLD. The CCLD considered the support groups to be a crucial basis for emotional support as illustrated below:

"There is a support group which was created by the occupational therapist. That is where the caregivers of children with this disability vent out." (Participant E)

"In the support group we speak the same language. We help each other in many ways." (Participant J)

4.5.4 Sub-theme 4: Social Support

Most CCLD expressed that the support they receive from other people, be it family members, church brethren or work colleagues gives them some sense of relief and helps them to cope with the strain of caring for their CLD.

"I get good support from my sisters." (Participant F)

"Since the birth of my child, my family and relatives have been there for me" (Participant I)

"At least the good thing is that the support I get from my husband and my parents is awesome" (Participant J)

5. Discussion

According to Ghazawy *et al.* (2020), as the strain of caring for a child living with a disability increases, caregivers can face exposure to mental and physical health difficulties, which may affect their quality of life if they cannot receive support. In this study, the participants described the overall health of the caregiver as one of the challenges they experience in the care of the CLD.

The CCLD expressed experiencing various physical health issues such as fatigue, backaches and waist ache which they associated with the strain of caring for their incapacitated children. This is consistent with the findings of a study conducted by Patel *et al.* (2017), which revealed that various caregivers voiced the physical challenges of caring for a child with a disability. Similar to the findings of this study, the afore-mentioned study revealed back ache as one of the common health problems among the participants. Furthermore, the findings of this study are consistent with the study conducted by Muller-Kluits and Slabbert (2018), whereby caregivers described lack of sleep, chronic fatigue, lower backache, and pains on the shoulders as other physical problems they encountered due to the strain of caring for their loved ones with physical disabilities.

As in our study, literature shows it is emotionally draining to care for a CLD. In our study, the participants expressed various negative emotions emanating from the strain of caring for their CLD such as sadness, feelings of guilt etc. Other studies support these findings as shown by a study conducted by Asa *et al.* (2020), which indicate that participants caring for CLD encountered various psychological difficulties, such as feelings of frustration, anger and sadness due to various reasons, such as rejection of their children by the community and negative labelling the CCLD receive, as a result of having a child with a disability. However, consistent with a study conducted by Patel *et al.* (2017), some participants also expressed that notwithstanding the psychological challenges they encounter, caring for the CLD gives them some positive rewarding psychological effects. One of the participants expressed that seeing her child showing some minor developmental improvements gives her a satisfying feeling that at least her efforts are not in vain.

The findings of our study reveal that caring for CLD puts a lot of financial burden on the care givers. The CCLD expressed that they experience financial strain due to the demands of caring for their CLD which is consistent with the findings of the study conducted by Muller-Kluits and Slabbert (2018). In the afore-mentioned study, participants revealed numerous financial problems they encountered which included medical and equipment expenses. This study further revealed other expenses such as for specialised schools and transport

expenses which demand exorbitant fees resulting in financial difficulties especially if the caregiver was the main benefactor. Additionally, being unemployed as the caregiver can put more financial burden on the family of a child with a disability, because in addition to the general family expenses, they also incur special expenses on caring for the child (Patel, 2017). As indicated, the various demands of caring for a CLD is costly and the CCLD have to spend money on things such as assistive devices, special diet and general supplies etc. This financial strain worsens due to the caregivers' inability to work because of the demands of caregiving.

Caring for a child with a disability has impact on other roles. According to Patel *et al.* (2017), the demands of caring for CLD make it difficult for their caregivers to work. Similarly, some of the CCLD in this study reported that they are unable to work, due to focusing on caring for the CLD. These results correspond with those of a study conducted by Muller-Kluits and Slabbert (2018), where almost half of the caregivers were not working at all and cared for their disabled children. In this study, some participants reported they never worked at all because of the responsibility of caring for the CLD while some quit their jobs to focus on the caregiving role. Due to lack of support with enduring and long-lasting care, recreational facilities or jobs that are disability friendly, the CCLD could not have alternative provisions to take care of their responsibilities. Michael *et al.* (2019) further asserts that the CCLD cannot keep regular employment because of the overdependence by the CLD which limits their movements.

Caring for a CLD in conjunction with having a full-time employment reduces productivity at work. As expressed by the CCLD in this study, caring for a child with a disability disturbs work productivity. They stated that caregiving increases the total load on their time budget. Due to juggling caregiving responsibilities and work, the caregivers reported they could not meet their objectives due to fatigue and spending most time away, especially due to frequent medical check-ups needed by the children. The findings are supported by Fast (2015) in a study that revealed working caregivers have decreased productivity at their jobs especially public sector employees. They miss most days at work due to the caregiving responsibilities, which consequently affects their productivity negatively.

The CCLD voiced the inability to participate in community or social events. This is consistent with a study conducted by Asa (2020), which reported that the role of caring for a CLD imposes some limitations on the caregivers in participating in community engagements and social activities. Some even experienced a change in social behaviour, such as resorting to silence as a defence mechanism, to avoid discussing their issues with other people whom

they deemed lacked understanding. Notwithstanding the need to be with their children fulltime, the CCLD also understood the necessity to socialise or take part in social events as it helped alleviate their emotional strain. Consistent with literature, they reported that spending most time with the children alone can put them at risk of feeling isolated, especially if they do not have alternative forms of support (Baumgardner, 2019).

Some CCLD expressed that the strain of caregiving was made worse by their multiple roles of also being wives and mothers to other children. This brought feelings of guilt to some as they felt they did not give the other children and spouse the attention they deserved, because of focusing more on the child living with a disability. According to Ziapour and Khosravi (2020), the CLD need more care owing to their distinct and special needs. Thus, they receive added care compared to their healthy siblings. This situation may contribute to the experience of feelings of guilt by the CCLD and sometimes anger towards the other children and spouses, when they demand their deserved attention. However, literature also suggests that some CCLD especially mothers, view this as a rewarding motherly sacrifice, which satisfies and motivates them to move forward positively with the caregiving role (Ziapour & Khosravi., 2020).

CCLD employ various strategies to cope with the strain of caring for a child living with disability. In this study, the key component of dealing with children with disabilities was acceptance. In promoting acceptance of their situations, the motivation for the CCLD was to view the CLD in a positive way. The participants' acceptance of the children's developmental challenges assisted them to adjust, cope and move on. Acceptance seems to be unwaveringly associated to coping with a diagnosis. Some of the CCLD, especially the mothers, reported that upon learning about the diagnosis of their children's specific severe disability, they felt a sense of relief in their confusion and uncertainty surrounding their children's delays, as they now felt they had something substantial and made sense to deal with. The CCLD linked the diagnosis of the disabilities with the start of a distressful journey which they were now able to prepare for positively. Concordant with literature, acceptance of their children and their conditions appeared to be a vital aspect of the caregivers' experiences and contributed effectively in letting them cope with the strain of caregiving (Heer *et al*., 2015). Thus, from the findings of our study and available literature, it can be concluded that there is a positive association between coping and caregivers' acceptance. To this end, accepting their situations aided the CCLD to move forward effectively and embrace interventions intended to assist them manage the caregiving role.

One way used by CCLD to cope with stress effectively is to engage in one's spirituality, such as use of prayer (Oti-Boadi, 2017). According to the CCLD understudy, prayer is one of the critical components in coping with the strain of caring for the CLD. Their spiritual beliefs influenced how they interpreted the children's disability and thus motivated their acceptance and coping. The study conducted by Oti-Boadi (2017), in which mothers caring for children with disability reported they were strong believers of God and believed that God gave them those children for a purpose, supported the findings of our study. Thus, they found it fit to surrender all their caregiving challenges to God to help them overcome their struggles.

To cope with stress of caring for CLD, the CCLD held a view that being members of a support group accorded them a reliable source of support, and helped them to overcome the emotional strain of the caregiving role. According to Heer *et al*. (2015), there is a positive link between being involved in support groups and coping. In the afore-mentioned study, there was a recurring theme of positive experience of being engaged in caregivers' support groups. There was a strong belief by the caregivers that support group presented the caregivers with a noteworthy form of support, assisting them to cope with emotional strain related to their caregiving role.

Support in all its forms is important in dealing with strain from caregiving. Formal and informal support as suggested by the CCLD is important in relieving the caregivers' stress. Most CCLD stated they receive social support from their families and the church. They reported to receive social support in the form of emotional support and practical support, which involves directly assisting in the care of the child such as bathing and feeding, as well as provision of financial help. According to Michael *et al.* (2019), as the caregivers especially mothers receive social support, the strain and stress of caregiving lessens. Isa *et al.* (2016) further assert that interacting positively with family members has a significant impact on the mental health outcomes of the caregiver. Thus, family members' positive support decreases the detrimental effects on the caregivers' mental wellbeing. Social support is a considerable source of coping as it decreases stress and enhances individual adaptation by promoting positive emotions while reducing negative emotions. Hence, providing social support goes a long way in ameliorating the psychological and physiological hardships experienced by CCLD in caring for their CLD.

6 Limitations

The study explored CRS on caregivers of children living with different disabilities which may limit the obtaining of accurate insight on the CRS as it relates to specific disabilities. CRS can be diverse across the caregivers for children with different conditions and at varying stages. Furthermore, even though there were rich data obtained from the interviews, the sample size for the study was small and the findings cannot be generalised to a broader population.

7 Conclusion

Caring for a CLD goes beyond ‘ordinary’ caregiving as the caregivers have to deal with challenges associated with the CLD’s special needs. Through use of an explorative-descriptive qualitative approach, this study set to investigate the experiences and coping strategies for CCLD. A semi-structured interview took place with 11 CCLD in a bid to explore their CRS in caring for CLD. The CCLD appeared to experience various extents of CRS. During the interviews, the CCLD evidently indicated that they struggle with financial, emotional, physical and social strains due to caregiving. Due to lack of long-term care for their children, respite care services and support for the caregivers, the CCLD endure a great deal of CRS which affects their quality of life.

SECTION 3: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

3.1 Introduction

This section offers the conclusion, deliberates on the study's limitations, and make recommendations for education and research based on the results as well as proposed guidelines for practice that may enhance the quality of life of CCLD. The researcher will also give her own critical reflection on the research study.

3.2 Summary

This study was aimed at exploring and describing the CRS in caring for CLD. The investigation and description of CCLD enhanced understanding on their experiences in caring for their CLD. The results obtained from this study made clear that CCLD encounter diverse experiences in caring for their CLD. However, those with similar experiences revealed them at varying degrees. The findings indicate that caring for CLD has a negative impact on the health of the CCLD, i.e., it negatively affects the physical and mental wellbeing. Furthermore, due to the special needs of their CLD, the CCLD experience financial strain in providing for their children. The social lives of the CCLD are also affected negatively as their movement out of their homes is limited. They could not attend social events as before they had their CLD. Most CCLD were not working while some quit their jobs due to their caregiving demands. Meanwhile, those who were working were not effective at work due to fatigue and missing most days attending to their children's needs. Due to the negative effects encountered by the CCLD, they subsequently experienced emotional strain in the form of negative feelings such as sadness, guilt and anger. Notwithstanding the CRS they experience, the CCLD expressed having coping strategies to deal with their role strain, which includes acceptance, prayer, support groups and social support.

3.3 Limitations

Data were collected through telephone interview due Covid 19 pandemic restrictions. The researcher was of the view that this hindered collection of rich in-depth information as compared to a face-to-face interview. The researcher did not have access to the participants' body language and non-verbal cues from the participants' environment, which could have enhanced the researcher's insight into the participants' experiences. Furthermore, the researcher could not build good rapport with the participants, which also affected the quality of data gathered. Moreover, the telephone interview approach led to some eligible

participants declining to participate in the research, citing they could not share their experiences over the phone with stranger, whom they cannot meet at any point.

There were 11 participants, which makes the sample size small for generalisation of the findings. Most Botswana communities share similar backgrounds but it cannot be definitely confirmed that all the CCLD in Botswana have similar experiences. The communities may vary in certain aspects, such as demography, which may have a bearing on how a particular community views disability in children and consequently affects the experiences of the caregivers in that community.

Lastly, the study explored the CCLD's experiences in caring for diverse disabilities which may have limited obtaining precise understating of CRS as it associates with specific disabilities. CRS can manifest differently in caring for children with varied disability diagnoses at different phases. Moreover, the researcher explored the CRS as experienced by one member of the family, leaving the views of others. This could have led to a partial impression of the effects of the CRS as experienced by the family as they take part in caring for the child.

3.4 Recommendations

The discussion in this section provides recommendations for nursing education, research and proposes guidelines based on existent literature, and a conclusion drawn from the findings of this study.

3.4.1 Recommendations for nursing education

In order to improve care for CCLD, there is a need for evaluation of the nursing curriculum, both at diploma and degree level, offered at nursing colleges and the University of Botswana respectively to include teaching on psychosocial issues related to disability, CRS and their effects on physical and mental wellbeing of CCLD. The nursing managers and nursing educators should work in partnership to accomplish this endeavour.

There is a need for nursing colleges educators and university lecturers to collaborate with nurse managers and disability coordinators in the district in designing education programmes for student nurses which would provide insight on CRS and caring for caregivers. As literature links CRS and development of mental health problems, such as stress and depression, there is also the need for improvement of the curriculum to incorporate the care for caregivers to ameliorate the effects of CRS.

Furthermore, the nursing educators and clinical instructors should collaborate with the nurse mangers to deliberate on challenges encountered by the nurses when assisting CCLD in order to incorporate the challenges in the nursing curriculum and professional nurses' in-service trainings. There is need to update the nursing educators on the latest developments in the nursing practice regarding caring for CCLD. This could in return enable the educators to apply the knowledge in the syllabus. The student nurses and nursing educators should be involved in in-service trainings conducted in the healthcare facilities with the aim to improve the care for CCLD and to strengthen the working partnership between the nurse managers and the nurse educators.

3.4.2 Recommendations for nursing research

The researcher recommends the conducting of further research on the topic relating to CRS and care for CCLD. The research should take place in other different settings, be it in the district or any other place in Botswana. Future research studies might provide more knowledge and insight into CRS experienced by CCLD, as well as revealing new information that could assist the CCLD to overcome their challenges in caregiving. In addition, this knowledge can assist nurses to improve their service delivery to the CCLD.

There is also a need to conduct a quantitative study, which would allow for a bigger sample, with more demographic variation, and for generalisation of the findings. The conducting of a quantitative study could further find correlation between CRS and specific disabilities since the current study focused on general disabilities without specifying them.

3.4.3 Proposed guidelines for practice

The discussion that follows covers proposed guidelines that may promote the quality of life of caregivers of children living with disabilities in Lobatse, Botswana. The discussion addresses the second objective of the study. The proposed guidelines are geared towards suggesting approaches that the nurses can use to advocate for resources for CCLD. The guidelines can be implemented by the government, nurses coordinating disability programmes in the district, the nurses caring for people living with disabilities in the non-governmental organisations and nurses who come into contact with CCLD during service delivery. The use of the guidelines will be in conjunction with national policy on care for people living with disabilities. Below are the proposed guidelines based on the findings of the study:

3.4.3.1 Proposed guidelines for the government

The government should supply the CLD with the necessary equipment or devices such as special wheelchairs, braces and walking frames, which can alleviate the physical strain the caregivers experience due to carrying them around. Due to their incapacitation, the CLD are wholly dependent on their caregivers, hence they carry them around most of the time. The child needs registering for supply with assisting devices immediately he/she receives the disability diagnosis. The diagnosing doctor should prescribe the equipment and liaise with or refer the caregiver to social workers and disability coordinators for registration of the child for the necessary equipment.

Most CCLD appreciated that the government provide their children with a disability grant, but it seems it is inadequate to cover all the necessities needed by the CLD. To supplement the inadequate grant money, the government should supply the CLD with the necessities, such as food and toiletries. Supplying the CLD with the basic commodities can reduce the CCLD expenditures and assist in reducing the financial strain and stress experienced by the CCLD.

The government should also put more focus in building special schools for the CLD. The initial enrolment of the CLD in these special schools should be as early as kindergarten. The presence of these schools and enrolment of the CLD could alleviate the strain their caregivers are experiencing, as their children will spend most time at school under the care of specialised teachers. This would ameliorate their various aspects of strain, such as the health related and financial strain. Admitting the CLD in special schools could relieve the caregivers of the physical and mental strain, as they would spend less time caring for their children. It could also relieve them of their financial strain as they may be able to work, without having to spend all day at home caring for their children. Moreover, the mental stress could reduce, as there are high possibilities of improved rehabilitation for the CLD at school, unlike when they are home with their caregivers who have limited knowledge on the care of their children.

The government should collaborate with non-governmental organisations in establishing respite care services; these would assist the CCLD to regain stability in their lives. CCLD would be allowed time to recuperate from the strain of caregiving. Moreover, it would accord them the agility to attend to other vital aspects of their lives such as the freedom to attend social events and find jobs for those who cannot work because of caring for the CLD.

3.4.3.2 Proposed guidelines for management

This study recommends that the district health managers should have guidelines on public education and awareness programmes aimed at sensitising the community on disability and the associated caregiver role strain. The public education campaigns should be timely and conducted on regular basis. One of the factors reported to contribute to the caregivers CRS was the knowledge deficit in caring for their children. Sometimes, their mental health strain worsens because of the limited knowledge they have about their children's conditions and the care they require. To this effect, there should be intense and comprehensive educational programmes to make the public aware of the disabilities, challenges brought by having CLD, how to care for these children and the need to support the CCLD.

Even though the CCLD experience mental and emotional strain, it appears there in nothing in place to help them overcome their psychological strain. Therefore, the district health managers should come up with guidelines of a programme to provide the CCLD with regular counselling sessions in a bid to assist them cope with the strain of caregiving. The design of the programme should engage CCLD in focused and active problem-solving strategies relating to caregiving in order to reduce the strain of caregiving and consequently improve the caregiver's quality of life. It should systematically address the fundamental processes that informal caregiving systems must address, regardless of the child's diagnosis or phase of care.

3.4.3.3 Proposed guidelines for nurses in practice

Home-based care visits programmes by professional nurses need to be strengthened. The programmes design should provide structured home visits by professional nurses to CCLD. The home visits would be timely in order to check on how the CCLD are faring in their caregiving role at home, and to accord them the necessary support they might need.

There should be more CCLD support groups led and coordinated by the professional nurses and disability nurse coordinators in order to intensify the caregivers' coping strategies. Support groups could act as admirable resources for CCLD. They should offer resources, information and strategies specific to caring for a CLD. In addition, they should act as source for emotional support and reduce social isolation by the CCLD.

3.5 Critical reflection

This research reflected the researcher's personal experience. She grew up in a family with a child living with a disability. During the period of her upbringing, she could see the struggle her parents were going through caring for her sibling living with a disability. In choosing this topic, and despite the fact the family member is now an adult, she wanted to relate what her family went through with what other caregivers are going through in the caregiving role. The process conducting the interviews presented to the researcher a zoomed view of the experiences of CCLD. She got a closer look of how the CCLD reflected on their journey of caring for CLD that resonated well with what her family also experienced. The questions asked made them think deeply and share some thought-provoking reminiscences with her.

From reading the integrated literature discussions, the researcher is of the view that the research question was adequately and satisfactorily answered. The data gathered provided rich and valuable information, which made it possible to achieve the aim. The findings provided an opportunity for the development of new questions with the capacity to add more valuable information and provide a basis for future research studies relating to this topic.

Albeit the success realised in conducting the study, there were challenges in recruiting the participants. This was largely due to the fact that data collection took place telephonically because of the Covid-19 pandemic restrictions, and most participants were uncomfortable sharing information with a stranger over the phone. Most participants declined to participate in the study as they preferred a face-to-face interview. They used a Setswana idiom, "mafoko a matlhong," which means that body language tells the truth, i.e., non-verbal cues are a critical aspect for both the interviewer and participant during an interview. The process of recruiting participants and data collection needed perseverance and it took a while to complete. Additionally, the researcher had a challenge keeping track with the set interview questions.

Data analysis commenced upon completion of the data collection process. The process of conducting data analysis began with renewed enthusiasm and energy; it felt as if the researcher was starting afresh. Nevertheless, at times she experienced fatigue and frustration when working on this study because the amount of time and energy spent on this research were overwhelming.

Above all, the researcher feels privileged to have engaged with participants of this calibre in this study. The participants comprised caregivers from different scopes of life, young and old, working and non-working, literate and illiterate, etc. Their composition contributed to the rich data, which provided diverse experiences of the caregiving role. Furthermore, the

researcher had an eye-opening and rewarding understanding of the field of research, which cannot be traded for anything, through working with her supervisors. The researcher's work on this research study has undoubtedly taught the researcher the worth of perseverance and hard work in achieving ones' objectives. One of the crucial lessons she learnt from embarking on this research journey was to distinguish between ones' own time and the time for study. The researcher had a challenge balancing the two. She spent most time on her research work and realised she neglested herself many a times. This contributed to the fatigue she experienced in conducting this study.

Reflecting on this study, one cannot dispute the high prevalence of CLD in Lobatse, and the overwhelming experiences encountered by their caregivers. One wonders how the caregivers overcome the overwhelming experiences and continue contentedly with their lives. This research study assisted the researcher in realising that there is endurance based on hope in the caregiving endeavour and that the CCLD have an innate determination to lead a meaningful life amid their experiences. She had a challenge in conceptualising and describing meanings on the problem statement because of the limited studies conducted on the topic in Botswana. Nonetheless, the lives of the CCLD and the contribution that might be made by this study in adding to the scope of knowledge on the topic gave the researcher motivation to endure. Even though it was challenging, the support from her family, friends and supervisors kept her going; without their support it would not have been possible. Generally, this study yielded a meaningful and positive experience, evidenced by the knowledge she acquired and the growth in confidence in her research skills. She is hopeful that this study will encourage CCLD to find meaning in the caregiving endeavour, help them to discover their innate strength and be aided in realising that they can thrive even in challenging times. Moreover, she is indebted to the courageous participants for participating in this study. If they were unable to speak up and share their experiences, there would not be any basis for gaining insight on this phenomenon that affects many families.

3.6 Final conclusion

The study's objectives were to explore and describe caregiver role strain in caregivers of children living with disabilities, as well as to propose guidelines that may promote the quality of life of caregivers of children living with disabilities in Lobatse. Individual semi-structured interviews enabled the researcher to collect rich data, which assisted in the accomplishment of the objectives. There was substantiation of the study findings through direct quotes and literature integration, added to the guidelines proposed. The information obtained from the study augments the existing body of knowledge on the topic, and policies can be reviewed using the findings of this research study.

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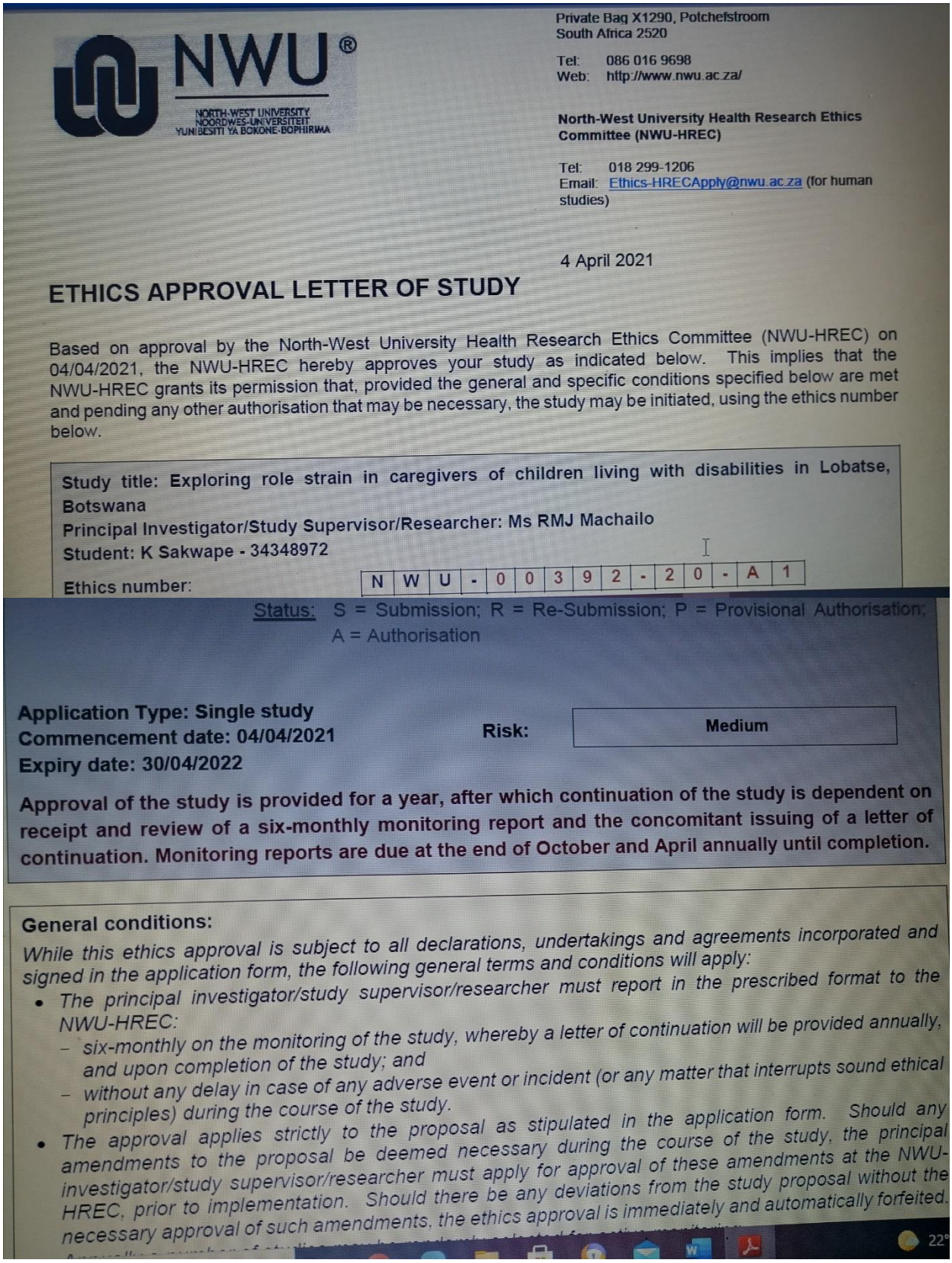
ANNEXURES

ANNEXURE A: HREC APPROVAL



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4 April 2021

ETHICS APPROVAL LETTER OF STUDY

Based on approval by the North-West University Health Research Ethics Committee (NWU-HREC) on 04/04/2021, the NWU-HREC hereby approves your study as indicated below. This implies that the NWU-HREC grants its permission that, provided the general and specific conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study title: Exploring role strain in caregivers of children living with disabilities in Lobatse, Botswana
Principal Investigator/Study Supervisor/Researcher: Ms RMJ Machailo
Student: K Sakwape - 34348972

Ethics number: N W U - 0 0 3 9 2 - 2 0 - A 1

Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation

Application Type: Single study
Commencement date: 04/04/2021
Expiry date: 30/04/2022

Risk: **Medium**

Approval of the study is provided for a year, after which continuation of the study is dependent on receipt and review of a six-monthly monitoring report and the concomitant issuing of a letter of continuation. Monitoring reports are due at the end of October and April annually until completion.

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, the following general terms and conditions will apply:

- *The principal investigator/study supervisor/researcher must report in the prescribed format to the NWU-HREC:*
  - *six-monthly on the monitoring of the study, whereby a letter of continuation will be provided annually, and upon completion of the study; and*
  - *without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study.*
- *The approval applies strictly to the proposal as stipulated in the application form. Should any amendments to the proposal be deemed necessary during the course of the study, the principal investigator/study supervisor/researcher must apply for approval of these amendments at the NWU-HREC, prior to implementation. Should there be any deviations from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.*

necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.

- *Annually a number of studies may be randomly selected for active monitoring.*
- *The date of approval indicates the first date that the study may be started.*
- *In the interest of ethical responsibility, the NWU-HREC reserves the right to:*
  - *request access to any information or data at any time during the course or after completion of the study;*

9.1.5.4.2 Ethics Approval Letter of Study 1

- *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process;*
- *withdraw or postpone approval if:*
  - *any unethical principles or practices of the study are revealed or suspected;*
  - *it becomes apparent that any relevant information was withheld from the NWU-HREC or that information has been false or misrepresented;*
  - *submission of the six-monthly monitoring report, the required amendments, or reporting of adverse events or incidents was not done in a timely manner and accurately; and/or*
  - *new institutional rules, national legislation or international conventions deem it necessary.*
- *NWU-HREC can be contacted for further information via Ethics-HRECApply@nwu.ac.za or 018 299 1206*

signature has problems.

Special conditions of the research approval due to the COVID-19 pandemic:

Please note: Due to the current status of the study i.e. (individual face-to-face semi-structured interviews with caregivers of children with disabilities in Lobatse, Botswana), this study will be able to proceed during the current alert level, following submission of an amendment request to include a COVID-19 risk mitigation strategy to protect researchers and the public from possible COVID-19 infection (as setup according to the document entitled "COVID-19 research risk assessment and management approach" (Prof Minrie Greeff, 29 June 2020)"). When wanting to amend an approved research study impacted by the COVID-19 pandemic, the existing SOP (2.2.4_SOP_Ethics_1.4) for this process still remains in place. The process to be followed is clearly discussed under Section 8.4 of this SOP entitled, "Application for an amendment to an approved study". The process as described in this SOP is handled via the expedited process. This SOP is freely available on our website at the following URL i.e. http://healthsciences.nwu.ac.za/healthethics/sops. The process that should be followed, is as indicated below:

a. Ensure all your amendments are indicated in yellow highlight in the amended documents.

b. Submit your request to Ethics-HRECApply@nwu.ac.za, with a cover letter with a specific subject title indicating, "Amendment request (COVID-19): NWU-XXXXX-XX-XX". The letter should include the title of the approved study, the names of the researchers involved, the nature of the amendment/s being made (indicating what changes have been made as well as where they have been made), which documents have been attached and any further explanation to clarify the amendment request being submitted.

c. Name the emails, to which you attach the documents that you send, with a specific subject line indicating that it is an amendment request e.g. "Amendment request (COVID-19): NWU-XXXXX-XX-XX". This e-mail should indicate the nature of the amendment.

The review of this request will be handled via the *expedited process*. If successful, the researcher will receive a letter indicating that amendments were approved and the study can proceed. Please note that if it is determined that the researcher has proceeded with the research, without first amending a study and obtaining the appropriate permission, they will be seen to have either have violated good research practice or been

non-compliant and the necessary steps will be taken.

Special in process conditions of the research for approval (if applicable):

a. Please provide the NWU-HREC with a copy of a goodwill permission letter from the Social and Community Development Office of Lobatse, granting access to the facilities at this entity.

b. Please provide the NWU-HREC with copies of the signed confidentiality agreements with the co-coder, transcriber and independent person, when they become available.

As the study progresses the aforementioned conditions should be submitted to Ethics-HRECProcess@nwu.ac.za with a cover letter with a specific subject title indicating "Outstanding documents for approval: NWU-XXXXX-XX-XX." The letter should include the title of the approved study, the names of the researchers involved, that the documents are being submitted as part of the conditions of the approval set by the NWU-HREC, the nature of the document i.e. which condition is being fulfilled and any further explanation to clarify the submission.

The *e-mail*, to which you attach the documents that you send, should have a *specific subject line* indicating the nature of the submission e.g. "Outstanding documents for approval: NWU-XXXXX-XX-XX". The e-mail should indicate the nature of the document being sent. This submission will be handled via the expedited process.

The NWU-HREC would like to remain at your service and wishes you well with your study. Please do not hesitate to contact the NWU-HREC for any further enquiries or requests for assistance.

Yours sincerely,

Digitally signed by
Prof Petra Bester
Date: 2021.04.06
14:15:29 +02'00'

Chairperson NWU-HREC

ANNEXURE B: STANDARD NWU CONFIDENTIALITY AGREEMENT INDEPENDENT PERSON

CONFIDENTIALITY UNDERTAKING

entered into between:

Independent person

I, the undersigned

Prof / Dr / Mr / Ms _____

Identity Number:_____

Address:_____

hereby undertake in favor of the **NORTH-WEST UNIVERSITY**, a public higher education institution established in terms of the Higher Education Act No. 101 of 1997

Address: Office of the Institutional Registrar, Building C1, 53 Borcherd Street, Potchefstroom, 2520

(hereinafter the “NWU”)

1 Interpretation and definitions

1.1 In this undertaking, unless inconsistent with, or otherwise indicated by the context:

1.1.1 “Confidential Information” shall include all information that is confidential in its nature or marked as confidential and shall include any existing and new information obtained by

me after the Commencement Date, including but not be limited in its interpretation to, research data, information concerning research participants, all secret knowledge, technical information and specifications, manufacturing techniques, designs, diagrams, instruction manuals, blueprints, electronic artwork, samples, devices, demonstrations, formulae, know-how, intellectual property, information concerning materials, marketing and business information generally, financial information that may include remuneration detail, pay slips, information relating to human capital and employment contract, employment conditions, ledgers, income and expenditures and other materials of whatever description in which the NWU has an interest in being kept confidential; and

1.1.2 "Commencement Date" means the date of signature of this undertaking by myself.

1.2 The headings of clauses are intended for convenience only and shall not affect the interpretation of this undertaking.

2 Preamble

2.1 In performing certain duties requested by the NWU, I will have access to certain Confidential Information provided by the NWU in order to perform the said duties and I agree that it must be kept confidential.

2.2 The NWU has agreed to disclose certain of this Confidential Information and other information to me subject to me agreeing to the terms of confidentiality set out herein.

3 Title to the Confidential Information

I hereby acknowledge that all right, title and interest in and to the Confidential Information vests in the NWU and that I will have no claim of any nature in and to the Confidential Information.

4 Period of confidentiality

The provisions of this undertaking shall begin on the Commencement Date and remain in force indefinitely.

5 Non-disclosure and undertakings

I undertake:

5.1 to maintain the confidentiality of any Confidential Information to which I shall be allowed access by the NWU, whether before or after the Commencement Date of this undertaking. I will not divulge or permit to be divulged to any person any aspect of such Confidential Information otherwise than may be allowed in terms of this undertaking;

5.2 to take all such steps as may be necessary to prevent the Confidential Information falling into the hands of an unauthorised third party;

5.3 not to make use of any of the Confidential Information in the development, manufacture, marketing and/or sale of any goods;

5.4 not to use any research data for publication purposes;

5.5 not to use or disclose or attempt to use or disclose the Confidential Information for any purpose other than performing research purposes only and includes questionnaires, interviews with participants, data gathering, data analysis and personal information of participants/research subjects;

5.6 not to use or attempt to use the Confidential Information in any manner which will cause or be likely to cause injury or loss to a research participant or the NWU; and

5.7 that all documentation furnished to me by the NWU pursuant to this undertaking will remain the property of the NWU and upon the request of the NWU will be returned to the NWU. I shall not make copies of any such documentation without the prior written consent of the NWU.

6 Exception

The above undertakings by myself shall not apply to Confidential Information which I am compelled to disclose in terms of a court order.

7 Jurisdiction

This undertaking shall be governed by South African law be subject to the jurisdiction of South African courts in respect of any dispute flowing from this undertaking.

8 Whole agreement

8.1 This document constitutes the whole of this undertaking to the exclusion of all else.

8.2 No amendment, alteration, addition, variation or consensual cancellation of this undertaking will be valid unless in writing and signed by me and the NWU.

Dated at Potchefstroom this _____ 20____

Witnesses:

1 .....

2 ....

(*Signatures of witnesses*) (*Signature*)

ANNEXURE C: INFORMED CONSENT-ENGLISH

HREC Stamp

INFORMED CONSENT DOCUMENTATION FOR CAREGIVERS OF CHILDREN LIVING WITH DISABILITIES

TITLE OF THE RESEARCH STUDY: Exploring role strain in caregivers of children living with disabilities in Lobatse- Botswana

ETHICS REFERENCE NUMBERS:

PRINCIPAL INVESTIGATOR: Ms Rorisang Machailo

POST GRADUATE STUDENT: Keletwaetse Sakwape

ADDRESS: North-West University. Potchefstroom campus

CONTACT NUMBER: 00267 71823639

You are being invited to take part in a **research study** that forms part of a master's degree. The study is on exploring caregiver role strain in caring for children living with disabilities.

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

This study has been approved by the **Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (NWU-00392-20-S1)** and will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles, Processes and Structures (DoH, 2015) and other international ethical guidelines applicable to this study. It might be necessary for the research ethics committee members or other relevant people to inspect the research records.

What is this research study all about?

- We plan to conduct a study on exploring caregiver role strain (strain experienced by caregivers) in caring for children living with disabilities. This study will be conducted in Lobatse in the year 2020. The participants to be involved in the study are caregivers of children living with disabilities. The study will explore the strain that caregivers encounter when caring for children living with disability. Caregivers of children who suffer from an enduring condition such as physical disability etc. experience emotional and physical challenges as they sacrifice their time and health with resultant negative consequences. Through your participation in this study, your input and recommendations will aid in contributing to guidelines and enhance the quality of life for CCLD, hence and your participation is valuable.
- This study will be conducted in Lobatse through a telephone call. The study will be conducted by a student at North-West University under the supervision of an experienced health researcher trained in advanced psychiatry. The supervisor is a psychiatric nurse with more 15 years clinical experience and also has experience in qualitative research.
- We hope to reach data saturation after interview of about 12 participants.

Why have you been invited to participate?

- You have been invited to be part of this research because you are taking care of a child who is living with a disability.
- You also fit the research because there is possibility of you experiencing role strain due to caring for a child living with a disability.
- You will not be able to take part in this research if you care for a child who is above 18 years old, and/ or taking care a child living with a disability on a temporary basis.

What will be expected of you?

- You will be expected to participate in a semi-structured interview which will take roughly an hour. There will be three questions you will be expected to answer, which will be followed by probes and concomitant follow-ups. The interview will take place once with a possibility of a follow-up interview.
- You will be expected to share your experiences on role strain in caring for a child living with a disability
- You will be expected to comment and come up with recommendations which will help in contributing to guidelines for caregivers of children living with disability.

Will you gain anything from taking part in this research?

- The gains for you if you take part in this study will be to experience direct psychological benefits as you go through the process of expressing your feelings, which at the same time produces a sense of relief and inner healing.
- The other gain of the study is for it to assist in contributing to guidelines which are going to be used to help caregivers of children living with disabilities

Are there risks involved in you taking part in this research and what will be done to prevent them?

- The risk to you in this study is the possibility of experiencing feelings of discomfort which will be provoked by self-disclosure and expression of feelings on your experiences in caring for a child living with a disability, but will be managed by engaging a counsellor if you can breakdown during the interviews. The counsellor will be on guard in case there are any eventualities.
- There are more gains for you in joining this study than there are risks.

How will we protect your confidentiality and who will see your findings?

- Anonymity of your findings will be protected by addressing you with a code or number instead of your name.
- Your privacy will be respected as the interview will be conducted telephonically and your results will be kept confidential by not sharing it with anyone without your consent. Only the researchers and the co-coder will be able to look at your findings. Findings will be kept safe by locking hard copies in locked cupboards in the researcher's office and for electronic data it will be password protected. (As soon as data has been transcribed it will be deleted from the recorders.) Data will be stored for 5 years.

What will happen with the findings or samples?

- *The findings of this study will only be used for this study*

How will you know about the results of this research?

- We will give you the results of this research upon completion of the study through publication and presentation in research conference and at customary gatherings.

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

- There is no funding for the study.
- You will not be paid to take part in the study.
- Telephone expenses will be paid for those participants who will use their own airtime to contact the researcher.
- There will thus be no costs involved for you, if you do take part in this study.

Is there anything else that you should know or do?

- You can contact Keletwaetse Sakwape at 00267 71823639 or kmsakwape@gmail.com or Rorisang Machailo at 0027 723905302 or Rorisang.Machailo@nwu.ac.za if you have any further questions or have any problems.

- You can also contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206 or carolien.vanzyl@nwu.ac.za if you have any concerns that were not answered about the research or if you have complaints about the research.

- You will receive a copy of this information and consent form for your own purposes.

Declaration by participant

By signing below, I …….…… agree to take part in the research study titled: Exploring role strain in caregivers of children living with disabilities in Lobatse- Botswana

I declare that:

- I have read this information/it was explained to me by a trusted person in a language with which I am fluent and comfortable.

- The research was clearly explained to me.

- I have had a chance to ask questions to both the person getting the consent from me, as well as the researcher and all my questions have been answered.

- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.

- I may choose to leave the study at any time and will not be handled in a negative way if I do so.

- I may be asked to leave the study before it has finished, if the researcher feels it is in the best interest, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..……. on (*date*) ……...…….. 20....

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

Declaration by person obtaining consent

I *(name)* ……..…… declare that:

- I clearly and in detail explained the information in this document to

  …….
- I did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I gave him/her time to discuss it with others if he/she wished to do so.

Signed at (*place*) .....…..……. on (*date*) ……...…….. 20....

....
Signature of person obtaining consent **Signature of witness**

ANNEXURE D: INFORMED CONSENT-SETSWANA

HREC Stamp

MOKWALO WA TETLA YA GO TSAYA KAROLO MO PATLISISONG KE BATLHOKOMEDI BA BANA BA BA NANG LE BOGOLE

SETLHOGO SA PATLISISO: Go sekaseka manokonoko a go imelwa ga batlhokomedi ke go tlhokomela bana ba ba nang le bogole mo Lobatse- Botswana.

ETHICS REFERENCE NUMBERS:

MOTLHOTLHOMISE MOGOLO: Ms Rorisang Machailo

MOITHUTI: Keletwaetse Sakwape

ATERESE: North-West University. Potchefstroom campus

NOMORE YA MOGALA: 00267 71823639

O lalediwa go tsaya karolo mo **patlisisong** e e boletsweng fa godimo, ele bontlha bongwe jwa dithutotsa me. Patlisiso e itebagantse le go **sekaseka** manokonoko a go imelwa ga batlhokomedi ke go tlhokomela bana ba ba nang le bogole.

Tsweetswe, tsaya nako go bala mokwalo o otlhe, oo tlhalosang ka patlisiso e ka botlalo. Tsweetswe botsa mmatlisise kgotsa motho ope fela yoo tla beng ago tlhalosetsa ka patlisiso e dipotso ka karolo epe fela eo ka tswang o sa e tlhaloganye.

ka patlisiso e. go botlhokwa go gore o kgotsofalele gore o tlhaloganya ka botlaloka patlisiso e, le gore eka go ama jang. Go tsaya karologa ga patelediwe, ebile o gololesegile go ka itlhophela go sa tsaya karolo. Fa oitlhophela go sa tsaya karolo, ga go kake ga go ama ka tsela epe fela ee sa siamang. Gape le fa o ka itlhophela go tsaya karolo, o gololesegile go ka tlogela ka nako epe fela eo e eletsang.

Patlisiso e e letleletswe ke **komiti ee laolang dipatlisiso ya sekolo se segolo sa Bokone-Bophirima (NWU-00392-20-S1)** ebile e tla diragadiwa go ya ka melawana le ditsamaiso tsa Dipatlisiso tsa Botsogo: Ditsetlana, Ditsamaiso (DoH, 2015) le melawana e mengweya mafatshefatshe ee tsamaelanang le patlisiso e. Go matshwanedi gore komiti ya dipatlisiso kgotsa bangwe b aba maleba ban ne ba lekola dipampiri tsa patlisiso.

Patlisisi e itebagantse le eng?

- Re ikaelela go dira patlisiso go sekaseka manokonoko a go imelwa ga batlhokomedi ke go tlhokomela bana ba ba nang le bogole. Patlisiso e e tla dirwa mo Lobatse mongwageng ono wa 2020. Batho ba bat la akarediwang mo patlisisong e ke batlhokomedi ba ban aba ba nang le bogole. Patlisiso e tla a go sekaseka manokonoko a go imelwa ga batlhokomedi ke go tlhokomela bana ba ba tshelang ka bogole. Batlhokomedi ba bana ba ba nang le makoa a a tshwanang le go tshela le bogole le a mangwe, ba itemogela dikgwetlho mo maikutlong le mo mmeleng jaaka ga ba dirisa nakole botsogo jwa bone go tlhokomela, mo go felelang go baka ditlamorago tse di sa itumediseng. Go tsaya karolo mo patlisisong e, le megopolo eo tla e ntshang,ditla a thusa go tokafatsa melwana le go rotloetsa botshelo jo bo itekanetseng mo batlhokomeding jwa bana aba ban ang le bogole. Ke ka moo go tsaya karolo ga gago go leng botlhokwa.

- Patlisiso e tla dielwa mo phaposing ee faphegileng ko dikagong tsa bodiredi jwa tlhokomelo ya batho mo malwapeng kgotsa ko lwapeng lwa gago fa ele gore le siametse go ka direla puisano go sena sekgoreletsi sepe. Patlisiso e tla dirwa ke moithuti ko sekoleng se segolo sa Bokone-Bophirima (ko South Africa) ko tlase ga tlhokomelo ya moeteledipele yoo nang le maitemogelo a dingaga tse di fetang lesome le botlhano mo booking jwa botsogo jwa tlhaloganyo ebile ana le maitemogelo gape mo patlisisong ee dirwang ka puisano.
- Re solofela go wetsa patlisiso morago ga go dira puisano ya patlisiso le batho ba ka nna lesome le bobedi.

Ka goreng olalediwa go tsaya karolo?

- O lalediwa go tsaya karolo mo patlisisong e ka gore o tlhokomela ngwana yoo nang le bogole.

- Gape go na le kgonagagalo ya gore o be o babalelwa ke manokonoko a go tlhokomela ngwana yoo nang le bogole.
- Ga o kake wa letlelelwa go tsaya karolo mo patlisisong fa ele gore ngwana yoo nang le bogole yoo mo tlhokomelang o na le dingwaga tse di fetang lesome le borobabobedi.

Go solofetswe eng mo go wena?

- O solofetswe go tsaya karolo mo patlisiso-puisano ee tla a tsayang sebaka sa oura. Go tla a nna le dipotso dile tharo tse o solofetsweng go di araba, tse di tla a latelwang ke dipotso-tlhotlhomiso go latedisa se o se buileng. patlisiso-puisano e tla dirwa gangwe fela mme go na le kgonagalo ya go boelela fa sengwe se sa tlhatswega.
- O solofelwa go tlhalosetsa mmatlisisi kwa maitemogelo a gago ka manokonoko a go tlhokomela ngwana yoo nang le bogole.
- O solofelwa go akgela le go tswa ka megopolo ee tla thusang go tokafatsa melawana ya batlhokomedi ba bana ba ba nang le bogole.

Ao tla boelwa ke sengwe fa o ka tsaya karolomo patlisisong e?

- Dipoelo tse oka diitemogelang ke tse di amang maikutlo jaaka o tla be o bolelela mmatlisisi maikutlo le dikakanyo tsa gago, se se tla beng se tlisa pholo le thokgamo mo moweng'
- Poelo e nngwe ke go tswa ka megopolo ee tla thusang mo go tokafatseng melawana eelaolang batlhokomedi ba ban aba ban ang le bogole,

A go tsaya karolo go ka go baya mo diphatseng le gore go ka dirwa eng go di thibela?

- Diphatsa tseo ka di itemogelang ke maikutlo a a sa iketlang aa tla beng a kgoberwa ke go bua ka dilo tse di go tshwenyang mo maikutlong tse di bakiwang ke manokonoko a go tlhokomela ngwana yoo nang le bogole, mme fa go ka direga gore maikutlo a gago a kgoberege thata le go tlisa go sa iketla mo mowing o tla isiwa ko go b aba sidilang maikutko go go thusa.
- Go nale dipoelo mo go tseyeng karolo mo patlisisong go feta diphatsa tsateng

Re tla sireletsa jang sephira sa gago le gore ke mang yoo tla bonang maduo a gago?

- Sephiri sa maduo a gago se tla a sirelediwakago go go bitsa ka nomore kgotsa tlhaka mo boemong jwa leina la gago.
- Sephiri sa gago se tla tlotlwa ka go gore puisano e tla dirwa ka mogala go sena motho ope gape yoo reeditseng puisano. Maduo a gago a tla sirelediwaka go sa a arogana le ope ko ntle ga tetla ya gago. Babatlisisi le yoo thusang go kanoka maduo ke bone fela batla kgonang go bona maduo a gago. Maduo a tla bewa mo tshireletsegong ka go lotlelela mo dikobotong kgotsa mo sebalamakgolong se se sireleditsweng ka dinomore tsa sephiri. (Mme fa maduo a sena go kwalololwa sentle, a tla sutlhiwa mo sekapa mantsweng). Maduo a tla bewa mo tshireletsong dingaga dile tlhano.

Go tla diragala eng ka maduo a patlisiso e?

- *Maduo a patlisiso e a tla dirisediwa mopatlisisong e fela.*

Otla itse jang ka maduo a patlisiso e?

- Re tla goitsise ka maduo a patlisiso e ka go maranyane, mme fa o sena maranyane re tla go leletsa ka mogala.

A o tla duelwa go tsaya karolo mo patlisisong le gore a e tla a go babalela mo tirisong ya madi?

- Ga gona madi aa ntsheditsweng godirisiwa mo patlisisong e.
- Ga o kake wa duelwa go tsaya karolo mopatlisisong e.

- Madi a go letsa a tla a neelwa ba ba tla tshwanelwang ke go letsa ba ikgolaganya le mmatlisisi.
- Ka jalo ga ona go dirisa madi a gago ka gope go tsaya karolo mo patlisisong e.

A go na le sengwe gape se o tshwanetseng go se itse kgotsa go se dira?

- O ka leletsa b aba latelang: Keletwaetse Sakwape mo 00267 71823639 kgotsa kmsakwape@gmail.com kgotsa Rorisang Machailo mo 0027 723905302 kgotsa Rorisang.Machailo@nwu.ac.za fa ona le dipotso kgotsa matshwenyego ape hela mabapile patlisiso e.

- Oka ikgolaganya gape le ba Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206 kgotsa carolien.vanzyl@nwu.ac.za fa o nale matshenyego a a sa arabiwang ka patlisiso e kgotsa fa o ngongoregela sengwe mabapi le patlisiso e.

- O tla neelwa moriti wa pampiri e gore oe ipeele.

.

Thurifatso ka motsaya karolo mo patlisisong

Ka go baya monwana fa tlase fa, nna …….ke dumalana go tsaya karolo mo patlisisong ya setlhogo se se latelang: **Go sekaseka manokonoko a go imelwa ga batlhokomedi ke go tlhokomela bana ba ba nang le bogole mo Lobatse-Botswana.**

Ke rurifatsa gore:

- Ke badile ka patlisiso mo kwalong o kgotsa ke tlhaloseditswe ka yone eke motho yoo tshephegang ka puo e ke e itseng ebile kee tlhaloganya.

- Ke tlhaloseditswe ka botlalo ka patlisiso e.

- Ke ntse ke tshono ya botsa yoo neng a ntlhalosetsa ka patlisiso e le mmatlisisi ebile dipotso tsa me di arabilwe.

- Ke tlhaloganya gore gotsaya karolo mopatlisisong e ga go patelediwe, ebile gak e a patelediwa go tsya karolo.

- Ke ka itlhophela go tlogela patlisiso nako nngwe le nngwe fa ke batla go tlogela, mme ebile ga nkake ka tsewa ka la molemaka tsela epe fela.

- Ke ka kopiwa go tlogela go tsaya karolo mopatlisisong nako nngwe le nngwe fa mmatlisis a bona go tshwanetse kgotsa fa ke sa sale tumalano ya patlisiso morago.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 20....

....
Monwana wa motsayakarolo **monwana wa mosupi**

Thurifatso ka yoo tlhalosang ka go tetla ya go tsaya karolo

Nna*(leina)* ……..…… ke rurifatsa gore:

- Ke tlhaloseditse…… ka botlalo se se mo mokwalong o

- Ga ke adirisa moranodi.
- Ke mo rotloeditse go botsa dipotso gape ke tsere nako ee maleba go di araba.

- Ke kgotsofalela gore o tlhaloganya dikarolo tsotlhe ka patlisiso e jaaka re buisantse ko godimo.

- Ke mo letleletse go buisana le ba bangwe ka patlisisoe fa a eletsa go dira jalo

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 20....

..... ……
Monwana wa yoo tlhalosang ka tetla ya go tsaya karolo **Monwana wa mosupi**

Thurifatso ka mmatlisisi

Nna*(leina)* ……..…… ke rurifatsa gore:

- Ke neetse ……..go tlhalosa ka botlalo ka mokwalo jaaka ke mo rutintshitse o dira jalo.
- Gake a dirisa moranodi
- Ke ne ke le teng go araba fa motsya karolo a ka eletsa go botsa dipotso tse dingwe.
- Tetla ya go tsya karolo e tserwe ke motho yoo ikemetseng ka nosi a sa amane ka gope le patlisiso e.
- Ke kgotsofalela gore o tlhaloganya ka botlalo dikarolo tsotlhe tse di amanang le patlisiso e jaaka go tlhalositswe fa godimo.
- Ke kgotsofalela go o ntse le nako ya go buisana le ba bangwe ka patlisiso e faa eleditse go dira jalo.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 20....

....

Monwana wa mmatlisisi **Monwana wa mosupi**

ANNEXURE E: STANDARD NWU CONFIDENTIALITY AGREEMENT MEDIATOR

CONFIDENTIALITY UNDERTAKING

entered into between:

Mediator

I, the undersigned

Prof / Dr / Mr / Ms _____

Identity Number:_____

Address:_____
___

hereby undertake in favor of the **NORTH-WEST UNIVERSITY**, a public higher education institution established in terms of the Higher Education Act No. 101 of 1997

Address: Office of the Institutional Registrar, Building C1, 53 Borcherd Street, Potchefstroom, 2520

(hereinafter the “NWU”)

1 Interpretation and definitions

1.1 In this undertaking, unless inconsistent with, or otherwise indicated by the context:

1.1.1 “Confidential Information” shall include all information that is confidential in its nature or marked as confidential and shall include any existing and new information obtained by me after the Commencement Date, including but not be limited in its interpretation to, research data, information concerning research participants, all secret knowledge, technical information and specifications, manufacturing techniques, designs, diagrams, instruction manuals, blueprints, electronic artwork, samples, devices, demonstrations, formulae, know-

how, intellectual property, information concerning materials, marketing and business information generally, financial information that may include remuneration detail, pay slips, information relating to human capital and employment contract, employment conditions, ledgers, income and expenditures and other materials of whatever description in which the NWU has an interest in being kept confidential; and

1.1.2 "Commencement Date" means the date of signature of this undertaking by myself.

1.2 The headings of clauses are intended for convenience only and shall not affect the interpretation of this undertaking.

2 Preamble

2.1 In performing certain duties requested by the NWU, I will have access to certain Confidential Information provided by the NWU in order to perform the said duties and I agree that it must be kept confidential.

2.2 The NWU has agreed to disclose certain of this Confidential Information and other information to me subject to me agreeing to the terms of confidentiality set out herein.

3 Title to the Confidential Information

I hereby acknowledge that all right, title and interest in and to the Confidential Information vests in the NWU and that I will have no claim of any nature in and to the Confidential Information.

4 Period of confidentiality

The provisions of this undertaking shall begin on the Commencement Date and remain in force indefinitely.

5 Non-disclosure and undertakings

I undertake:

5.1 to maintain the confidentiality of any Confidential Information to which I shall be allowed access by the NWU, whether before or after the Commencement Date of this undertaking. I will not divulge or permit to be divulged to any person any aspect of such Confidential Information otherwise than may be allowed in terms of this undertaking;

5.2 to take all such steps as may be necessary to prevent the Confidential Information falling into the hands of an unauthorised third party;

5.3 not to make use of any of the Confidential Information in the development, manufacture, marketing and/or sale of any goods;

5.4 not to use any research data for publication purposes;

5.5 not to use or disclose or attempt to use or disclose the Confidential Information for any purpose other than performing research purposes only and includes questionnaires, interviews with participants, data gathering, data analysis and personal information of participants/research subjects;

5.6 not to use or attempt to use the Confidential Information in any manner which will cause or be likely to cause injury or loss to a research participant or the NWU; and

5.7 that all documentation furnished to me by the NWU pursuant to this undertaking will remain the property of the NWU and upon the request of the NWU will be returned to the NWU. I shall not make copies of any such documentation without the prior written consent of the NWU.

6 Exception

The above undertakings by myself shall not apply to Confidential Information which I am compelled to disclose in terms of a court order.

7 Jurisdiction

This undertaking shall be governed by South African law be subject to the jurisdiction of South African courts in respect of any dispute flowing from this undertaking.

8 Whole agreement

8.1 This document constitutes the whole of this undertaking to the exclusion of all else.

8.2 No amendment, alteration, addition, variation or consensual cancellation of this undertaking will be valid unless in writing and signed by me and the NWU.

Dated at Potchefstroom this _____ 20____

Witnesses:

1 .....

2 ....

(*Signatures of witnesses*) (*Signature*)

ANNEXURE F: RECRUITMENT MATERIAL- ENGLISH

TITLE OF THE RESEARCH STUDY: Exploring role strain in caregivers of children living with disabilities in Lobatse- Botswana

ETHICS REFERENCE NUMBERS: PSB002/110/01/2019

PRINCIPAL INVESTIGATOR: Ms Rorisang Machailo

POST GRADUATE STUDENT: Keletwaetse Sakwape

ADDRESS: North-West University. Potchefstroom campus

CONTACT NUMBER: 00267 71823639

1. You are hereby cordially invited to take part in the above-mentioned research study that forms part of my master's degree.

<table>
<tr>
<td>2. Would this study be a good fit for me?

• Interested persons should be parents or guardians living or staying with a child living with a disability.
• Should be aged 18 years or above and should have cared for the child for more than six months.
• Should be caring for a child aged below 18 years and having a moderate to severe disability
• Only one member in a family will participate in the study
• Should be willing to communicate in either English or Setswana.</td>
<td>3. Benefits of the study

4. The gains will be psychological benefit. The interview will provide you with an opportunity to reflect on issues relating to caring for a child with a moderate to severe disability and gain insight on how the strain of caring for the child by association has affected you and find solutions on how to avert negative effects.</td>
</tr>
<tr>
<td>RISK OF PARTICIPATING

The study is of a medium risk. You experience sadness, anger and anxiety during the interview. Nevertheless, a psychologist will be on standby to assist in the event you experience overwhelming negative experiences.</td>
<td>5. Decline to participate/privacy

6. You are free to decline to participate anytime without penalty or judgement. Your personal details will not be made available to anyone who is not part of the research team</td>
</tr>
<tr>
<td>7. Date:
8. 2019-2021</td>
<td>9. Cost:
10. Phone costs will be covered by the researcher</td>
</tr>
</table>

ANNEXURE G: RECRUITMENT MATERIAL- SETSWANA

SETLHOGO SA PATLISISO: Go sekaseka manokonoko a go imelwa ke tlhokomelo ya bana ba ba tshelang ka bogole mo batlhokomeding ba bone mo Lobatse-Botswana.

ETHICS REFERENCE NUMBERS:

MOTLHOTLHOMISE MOGOLO: Ms Rorisang Machailo

MOITHUTI: Keletwaetse Sakwape

ATERESE: North-West University. Potchefstroom campus

NOMORE YA MOGALA: 00267 71823639

O LALEDIWA GO TSAYA KAROLO MO DIPATLISISONG TSE DI BOLETSWENG FA GODIMO, ELE BONTLHA BONGWE JWA DITHUTOTSA ME.

GO TLHOKEGA ENG GORE MOTHO A TSEYE KAROLO

- Batho b aba nang le kgatlhego mo patlisisong e e thswanetse go nna batsadi kgotsa batlhokomedi ba ban aba ba tshelang le bogole.
- O tshwanetse wa bo ole dingwaga tse di fetang lesome le boroba bobedi, ebile o ntse le ngwana yo mo Nakong ee fetang dikgwedi tse thataro.
- Ngwana o tshwanetse a bo ale dingwaga tse di ko tlase ga lesome le boroba bobedi, gape ana le bogole jo bo mog a gagre go ya ko go jo bo tseneletseng.
- Motho ale mongwe fela mo lwapeng ke ene a tla tsayang karolo mo patlisisong.
- O tshwanetse gore o be o kgona go bua Sekgowa kana Setswana.

DIPHATSA TSA GO TSYA KAROLO

- Patlisiso e e ka nna ya ama maikutlo a mo tsya karolo faa bua ka maitemogelo a go tlhokomela ngwana yoo tshelang ka bogole.

MOLEMO WA GO TSAYA KAROLO

- Go tsya karolo go tla nna mosola mo maikutlong a motsya karolo.
- Motsya karolo o tla neelwa sebaka sa bo bua maitemogelo a gagwe ka go tlhokomela ngwana yoo tshelang ka bogole.
- Go bua ka maitemogleo a go tlhokomela ngwa yoo tshelang ka bogole go tla fokotsa kwelo tlase ya maikutlo ke tlhobaelo e motsaya karolo a ka tswang a na le yone.

SEPHIRI SA MOTSAYA KAROLO

- Go tsaya karolo mo patlisisong ga go patelediwe, ebile o kgona go tlogela nako nngwe le ngwee o e batlang go tlogela go sena ditlamorago dipe.
- Go tsya karolo gag ago e tla nna sephira sag ago le babatlisise.

• Batsaya karolo ba ka nna ba itemogela kwelo tlase le tlhobaelo ya maikutlo. • Mme le fa go ntse jalo, bo molemo jwa go tsaya karolo bo feta diphatsa tsa teng. • Go tla nna le motho yoo sedilang maikutlo yoo tla thusang ba maikutlo a bone a ka kgoberegang fa ba bua ka maitemogelo a bone mabai le go tlhokomela ngwana yoo thselang ka bogole. experiences.	
Kgwedi: 2019-2021	**TLHWATLHWA YA GO TSAYA KAROLO** Ba batlisise ba tla tsaya boikarabelo jwa dithwatlhwa tsa go letsa

ANNEXURE H: INTERVIEW GUIDE-ENGLISH

INTERVIEW GUIDE

Questions

1. What are your experiences on caring for the child?
2. How do you cope with the strain in caring for this child?
3. What can be done to assist you in coping with the strain of caring for this child?

ANNEXURE I: INTERVIEW GUIDE-SETSWANA

DIPOTSOTSO TSA PATLISISO

Dipotso

1. O itemogela eng ka tlhokomelo ya ngwana yoo tshelang ka bogole?
2. O kgona jang go emelana le manokonoko a go tlhokomela ngwana yo?
3. Go ka dirwa eng go go thusa go emelana le manokonoko a go tlhokomela ngwana yo?

ANNEXURE J: SAMPLE OF TRANSCRIPTION

Participant/ researcher	Transcription
Participant	Yes madam.
Researcher	Good day madam.
Participant	Yes madam.
Researcher	Okay madam. I am Mma Sakwape again.
Participant	Yes maa.
Researcher	I am checking if we can go ahead with the interview as appointed.
Participant	Yes madam. You can go ahead.
Researcher	Okay madam. The interview will be between the two of us, no one else can participate in the interview.
Participant	Okay madam.
Researcher	No one will have access to this interview except myself and my research supervisors.
Participant	Yes mam.
Researcher	Again, I will not use your name or anything that can identify you or connect you to this interview. Anonymity will be kept by using codes such referring you as participant 'A' or 'B'.
Participant	Uh huh.
Researcher	Yes. You are free to withdraw from the interview anytime you feel like. You won't be punished nor prejudiced if you withdraw.
Participant	Uh.
Researcher	Again, you are free to abstain from answering any question you do not feel like answering. You still won't be prejudiced nor punished for doing that. It is your right.
Participant	Uh huh.
Researcher	The significance of this study is to add to the existing literature on caregiver role strain experienced by caregivers of children living with disabilities.
Participant	Uh.
Researcher	Furthermore, the findings of this study can be used in the formulation of guidelines send policies for the caregivers of people living with disabilities.
Participant	Okay madam.
Researcher	Okay madam. Let me start by asking you what your experiences are in caring for a child living with a disability.
Participant	Thank you so much madam. Firstly, let me start by affirming that indeed I have a child living with a disability. She is a girl aged twelve years. She is a child who is unable to do anything for herself. When I say she is unable to do anything for her, I mean she cannot go to the toilet by herself, she cannot feed herself, she can't walk, she ant talk. She is wholly dependent on us to carry out her activities of daily living. Let me sure that it is a long story about my experiences in caring for such a child. I realised that my child has a disability when she was, I think she was around three years of age. She had delayed developmental milestones. She was constantly seen by doctors who assured me that the child will be fine, it is just an issue of low body weight. I remember that one day I went to see a paediatrician in Gaborone, who informed me that my child has a condition called cerebral palsy. I asked him what he meant by cerebral palsy. He replied by saying let me write it for you, go and research about it and we will talk about it afterwards. When I got home, I researched about the condition and got to

	understand what was awaiting me ahead. That is what made me in a situation that I realised that my child's condition needs someone with a calm attitude, who has counselled herself and accepted her situation. Let me assure that caring for a child of my child's condition is not an easy thing. For example, currently my child is a fat person, and she is heavy when carrying her around. It is a challenge to carry her around as one end up complaining of backache. I end up complaining of general body pains because I carry her around the house, when I bath her and when doing everything for her. But let me assure you that at least the good thing is that the support I get from my husband and my parents is awesome. And that caring for such a child is not an easy job. The fist challenge is the cost of house helpers, they demand a lot of money to assist us care for our children. When you pay a maid P1000, mine would need P2000. You can see that it is expensive to maintain this child. Then at the same time you should also consider that the resources we need for the care of children living with disabilities in Botswana, in terms of schools, in terms of equipment; it is still a challenge.
Researcher	Uh huh.
Participant	So, that on its own is an overwhelming challenge, that at time I would sit alone and cry asking myself what is really happening in my life. Asking God questions; why me God, why this. Hey! It is a challenging thing tota madam to be a parent of a child living with a disability.
Researcher	Uh huh. You explained that your child is wholly dependent on you. What resources do you need to assist you in the strain of caring for your child?
Participant	Resources?
Researcher	Yes madam.
Participant	Ehee. Let me assure you that my child uses disposable nappies. And I have to appreciate that the government is helping us here and there. But it is not 100%. When I say the government is helping, I mean we get a supply of nappies. Sometimes we get the supply, sometimes we don't. and these nappies madam, they do not come cheap. If you get to Clicks, you find 20 nappies costing P300. And this 20 does not last for a month. You find that in a day she uses more than 3 nappies. So, the first thing if the financial challenges, one needs to have a lot of money. Government provides a disability cash of P450. That money is not enough, but we appreciate it. It is important to appreciate the help that the government is trying where possible. But the issue of financial challenges is overwhelming. Another challenge is supporting devices. Currently my child needs a specialised wheelchair, which I am running around to see if the health personnel cannot assist me to get it. So that I can go with her to the shops, so that I can go with her anywhere I would wish to. And then, issue of house helpers is a challenge. You find a helper today, the next day she tells you that she cannot manage anymore be cause the child is heavy. Some would go silently without saying that they cannot manage. But as a mother of a child with special needs, you will understand. So, these are the things we need help in.
Researcher	Uh huh.
Participant	Okay madam. I do not know if I answered the question adequately because I said many things.
Researcher	Yes madam. When explaining about the challenges you are facing, you mentioned that your child needs a special wheelchair. Can you explain how

	this wheelchair will relief you of the strain you experience in the care of your child?
Participant	It can reduce the strain to some extent. Because it would be an issue of, I will be able to go with her anywhere I want, okay?
Researcher	Uh.
Participant	When I say it can reduce to some extent, when we want to chill outside the house, we would be able to take her with us, using that wheelchair. If I want to go the shops with my child, she would be in that wheelchair. She is a child who crawls, and her clothes get destroyed easily. As someone who moves around by crawling, even with cleanliness it can assist.
Researcher	Uh huh. As you explained on the challenges, you reported that caring for your child affects you financially because of the cost of things she needs. Can you explain on the financial strain that you experience in the care of your child?
Participant	Okay madam. As already mentioned, the house helpers we hire to assist us with the care of our children do not come cheap. And it is not everyone who can agree to take care of children in this condition. You would ask the person that because my child has a challenging situation, I would pay you P1700 monthly. This maid would be taking care of this child at the same time with her siblings. I have three children, whom on the other hand need money for school fees and other things. Their care on the other hand adds to the challenges. The other thing is the cost of nappies madam. The best way is for me to create a rump for him at home. If the wheelchair could be availed, some of the other things one would give up and accept that indeed you cannot base the care of your child on someone else. But in terms of food, my child does not need special diet. The main issue is the helpers. The issue is nappies. The issue is that my child goes for check-ups frequently. Today I go to Ramotswa for speech therapy, the next day I take her to the physiotherapist. So, that on its own I need petrol, I need to buy her food on the way. All this care is upon me.
Researcher	Uh huh. So, caring for your child is costly for you because you need many things for her care?
Participant	Yes madam.
Researcher	Uh huh. Again, when we started, you reported that you appreciate the help that you receive from the government. Can you briefly talk about the assistance you have already received from the government to assist you in the care of your child?
Participant	From the government?
Researcher	It can be from the government or from anywhere else, to assist you in the strain of caring for your child.
Participant	Okay madam. Let me show that from the government the assistance I get is the monthly disability grant of P400 and disposable nappies. As I explained at the beginning, sometimes we get them but sometimes we are told that they are out of stock, which would mean that it is now up to the parent to see to it that her child has nappies. That is the only thing I can assure you about. Abd all the specialists who attend to my child are from the government. In that line the government is really trying.
Researcher	Uh huh. Okay. What other responsibilities do you have, in addition to caring for your child?
Participant	My responsibilities?

Researcher	Yes. You take care of your child. But you also have other responsibilities in your life. Which are those responsibilities which add to the burden of caring for your child?
Participant	Okay madam. I am a mother, I am a sister, I am a daughter and at the same time I am an employee. Monday to Friday, 0730 hours to 1630 hours, I would be at work. During the weekend, the care of all my children is upon me. At the same time as you know our rural life situations, the next day you are told there is there is some event at home. I have to be there to support my mother, be it my mother-in-law or my biological mother. So, these social events I have to be there to support friend and relatives.
Researcher	Then, how does caring for your child affect your relationship with your friends and relatives as you just reported that you are supposed to support them?
Participant	Eish! It is a difficult one madam, because it is not always that I manage to attend to the social events. There are times whereby there won't be anyone to care for my child while I am away. And therefore, I would then be not able to attend to that even, be it a funeral or a wedding. In that case I end up not attending the social event. At the same time, during family gatherings, I am not able to actively participate in the event when I am with my daughter because she likes harassing and beating other kids. So, I will be forced to closely monitor her in order to make sure that she does not harass other kids. In all honesty, a child living with a disability is a challenge.
Researcher	Uh huh. So, you mean caring for a child living with a disability is a challenge, is it overwhelming and makes it difficult to relate well with other people.
Participant	Yes madam. It is like that.
Researcher	Uh huh. You mentioned that you are working. How does caring for your child affect your productivity at work?
Participant	Heish! It affects my productivity at work. As I have already explained that my child has to go for check-ups most frequently. And then taking her for the check-ups it would mean I request for some time off at work, otherwise I would have to request for a leave. And I should mention that having an understanding supervisor, whom you have told your situation helps. For now, I would say that the are not giving me a tough time. It's just that two years back is when I had a challenge because I was transferred to a far station. And therefore, it was difficult emotionally, financially and otherwise. It was not easy to be with my child because she had remained this side. So, I was not able to check on her most frequently. It was a painful situation. When it happened that I come, I had to take some few days for leave so that the people remaining with her this side can have an opportunity to rest. And to run around and take her for her check-ups. But one thing I appreciate is that my supervisors, because I had explained my situation to them, they were supportive and understanding. It's just that requesting for leave days from work frequently is not okay. But to be honest, they were supportive.
Researcher	Uh huh. Kindly explain how your transfer to a further station affected your care for your child.
Participant	It is that the place is far. And travelling home is expensive. Be it done on the road or by air. It was so expensive that I ended up missing some of her medical check-ups. It was also an issue that I did not even have money to travel most often.

Researcher	Uh huh. Now, explain how the strain of caring for your child affects your health.
Participant	I am sick madam. I am sick. I am now also attending to physiotherapy. Even mentally, it has affected me emotionally because I ask myself questions every day. I am worried about what is going to happen in future. And currently, the most thought traumatising me is 'what if I die, what is going to happen to my child'. Again, my daughter is 12 years old. She will soon start her menses. I am wondering what will happen, since she I somebody who is unable to do anything for herself. These are the things that when I think of, my feelings get messed up. The physical health is much better because I do physiotherapy, because of the effects of carrying her around, and she is too heavy.
Researcher	Uh huh. I hear that for physical problems yo attend to physiotherapy. Can you explain on the symptoms you experience which are caused by the strain of caring for your child?
Participant	It is severe fatigue, backache and waist ache as I have indicated that I bend a lot when bathing her. I also have to carry her around, making sure that she is comfortable. I frequently carry her, changing her nappies. So, I end up having backache. The fatigue madam. I am always tired. When people rest over the weekend, for me is getting into another challenge. At night, my daughter like waking up, one would wonder why. I sleep with one eye open.
Researcher	Uh huh.
Participant	So, when she wakes up at night, it would mean waking up too and attending to her. You comfort her to sleep again. She would sleep, the after 30 minutes, she wakes up again. It is a challenge. I do not have time for rest.
Researcher	Uh huh. So, you experience various symptoms including lack of sleep.
Participant	Yes madam.
Researcher	And you also reported that you are emotionally affected. Kindly explain how you are emotionally affected and the feelings brought by this strain of caring for you child.
Participant	Hey! How do I explain this one? Eish! You ask yourself questions madam. You ask yourself questions alone, which have no answers. When you look at her age mates, who are 12 years of age, you see them looking smart in their uniforms, going to school, and you think about your daughter that you just bath her and spends the rest of her day on a couch doing nothing. She can't read, she can't talk. She is just a child of God right there. These are the things which makes one to start thinking too much. Like I was explaining that you end up asking God questions, you ask yourself many questions which you do not have answers to.
Researcher	Uh huh.
Participant	So, one ends up with messed up feelings most of the time. And when people talk about their kids, iyoo! By the way she is the only daughter. When people talk about their daughters, when you get unto the shops you see nice girls 'clothes, you know that even if you can buy for your daughter, she would just wear them and be in the house. When you try to plait her hair, she destroys it. You cannot put ear rings on her ears, she removes them. These are the things when you think about, you can't buy her shoes, she removes them. It is a challenge my sister. You live with recurrent headache, asking yourself, why this?' that I why I was telling you that what pains me most is the thought of what the future holds for my child.

Researcher	Uh huh.
Participant	That is what hurts me most.
Researcher	Uh huh. You are always thinking about your child's future. And you live with feelings of anxiety and sadness.
Participant	Yes madam. Again, a child in this condition, when you are at work, having left her with somebody else, you can never trust if that person will care for your child 100%. You get what I am saying? When you take her to your mother, for example, my siblings a re boys. I ask myself if they would not take advantage of my child while my is still busy with some other things, and abuse her sexually. I always have those kinds of thoughts. When you leave her with the house helper, you get worried that even if she can beat her, she cannot tell you. Even if she can spend the whole day with hunger, she cannot tell me that she spent she did not eat anything. So, having a child who cannot speak for herself is a challenge. It is not easy at all. I do not know how I can explain it. But it is hard, it is difficult madam.
Researcher	Uh huh. So, this situation according to your understanding, it needs you and you as the parent only?
Participant	Yes madam. Full-time care.
Researcher	Uh huh. Now, how do you cope with the strain of caring for your child?
Participant	It is only through prayer madam. Only prayer. And then we also have a support group of mothers who have children living with disabilities. When it is difficult, one would post in the group of the challenge they are facing and ask the other members how they managed such a situation. So, I cope through prayer and the support system as I was telling you that I have the support of my family. Sometimes my mother remains with her, helping me with her care, so that I can go to the shops and do grocery shopping. Sometimes I ask my sister-in-law to remain with her as I do this and that. Hey! The support I get from my family; my husband, my siblings and his siblings. This is the support that helps me to cope with the strain of caring for her. But above all, you give everything to God. You tell God that, God, you know why you put me into this situation.
Researcher	Uh huh. You talked about a support group. How does this support group help you to cope with the strain of caring for your child?
Participant	Madam, in the support group we speak the same language. That is the bottom line. We speak the same language. And we share on the type of doctors that help us, and others copy. We help each other in many ways. Be it about schools, be it about doctors, and so forth. Even about our children's situations and challenges, and how we each cope with the challenges we encounter. We really help each other. There are times whereby we meet and do commemorations on cerebral palsy day. We once met the ministry oh health personnel and shared with them about our experiences. And all those things indicate that we speak the same language. In all honesty, it helps us.
Researcher	So, in the support group you speak the same language.
Participant	Thank you very much.
Researcher	Uh huh. You talk about prayer and God. What is the church's contribution in helping you to cope with the strain of caring for your child?
Participant	Heish! Mma, the church is the institution in which during pleasant and tough times is there for its members. Even my church brethren, they sometimes take their time to come and pray with us. That on its own helps to calm my emotions. It brings hope that in one of the good days, my child will be like

	other children. It brings a sense of hope. With the condition of my child, you have hope that through your prayers, one day your child will stand up and walk. You stay with that hope. You don't lose hope at all.
Researcher	Uh huh.
Participant	Yes madam.
Researcher	You also reported the contribution of your family, even your husband, in supporting you to cope with the strain. Can you explain more on the extent of their contribution in helping you cope with the strain of caring for your child? What feelings does it bring to you?
Participant	There is nothing pleasurable like staying around people who give a child like mine so much love. They give her happiness. They give her support. She has brothers. You would one day see one of her brothers wiping her drooling saliva away with a tissue. Later on, you see her father chilling and playing with her on the other side. That on its own brings so much comfort in you as a mother. Even though it is sad that mothers always take the bait for their children, but in this one I am not alone.
Researcher	Uh huh.
Participant	Uh.
Researcher	So, your family support brings the sense of hope in that you realise that you are not alone in the challenge.
Participant	Yes madam. Uh.
Researcher	Apart from what you have already explained, how else do you cope with the strain of caring for you child?
Participant	Can you come again?
Researcher	You have already talked about coping through prayer, church, family and support group. Now I was asking how else you cope with the strain of caring for your child apart from the ones you mentioned?
Participant	Those are the only ways helping me to cope, that I have already mentioned.
Researcher	Uh huh. When you talked about the support group, you mentioned that you even talk about schools for these children. Can you explain how is the situation with your child concerning school?
Participant	Ehee. What I can say is that my child used to school at Cheshire. I do not know if you know it, the one in Mogoditshane
Researcher	Okay madam.
Participant	And to find a place for your child to school at Cheshire is a mountain climb challenge because you would apply and it would take ages to get a response. They would put the child on the waiting list for their series of assessments. But they are clear that if they admit a child, it is only for one year. But fortunately for me, mine was admitted for two years because they were saying that they could see some bit of improvement. Then after two years my child returned to stay at home.
Researcher	Uh huh.
Participant	The good thing about Cheshire is that they admit the child into their boarding to stay in the school. The parent goes there only to check on her. They break for school holidays in July and December. As the parent my duty was to check on her as and when, and bringing whatever she would need such as clothes. They assisted my child with everything; feeding, bathing and all.
Researcher	Uh huh.

Participant	Uh. When she is at school, you do not need to worry about the house helpers. You are also able to live a free life, going to the shops, saying let me go to Game City, knowing that there are people caring for your child.
Researcher	Uh huh. Okay. What do you think can be done to assist you cope with the strain of caring for your child?
Participant	By the government?
Researcher	Uh.
Participant	Heish mma! As I have already explained, the P400 disability grant we get from the government we appreciate. I want you to understand that. But it is just too little to be honest. The money is way too little. At the same time, funds permitting, the government should increase the disability grant. And there should be special schools built for these kids. Furthermore, there should be adequate supply of all the resources and equipment for use by these children.
Researcher	Uh huh. So, the disability grant should be increased?
Participant	Yes madam.
Researcher	You also talked about special schools. Can you explain how these schools will assist you with coping with the strain you experience due to caring your child?
Participant	Hei mma! When the child is at school, she will be able to interact with the other kids, with special education teachers, physiotherapists and these other therapies all in one place. That on its own will help the child get her mind engaged, which I have faith that it can help our children get better.
Researcher	Uh.
Participant	The different personnel would help our kids in different portfolios under one room. One would do potty training; another one does speech therapy and so on. That would really help.
Researcher	Uh huh. You just how it can the children, can you now explain how it would help you as the caregivers?
Participant	Nothing excites like seeing your child taken to a place where there is hope and faith that you know that your child is getting better care. Not that at home she is not getting better care. As I explained, at home I would be away from home from half past seven in the morning until half pas four in the evening, not sure of how the one remaining with her treats her. So, when at school, with those specialists assisting her throughout the day, it can assist me emotionally. At the same time, it can assist even with cost of hiring house helpers, which is expensive.
Researcher	So, these special school can ease your emotional strain and reduce your financial burden?
Participant	Yes madam.
Researcher	Uh huh. Is there anything else that can assist you with strain of caring for your child, apart from those you have already mentioned?
Participant	I have told them all. The main thing is to avail special schools, for the government to relook in the disability grant and the resources they supply the children living with disabilities with.
Researcher	Uh huh. Okay. From my side I have covered all the question I wanted addressed, unless you have something to add concerning the strain you experience due to caring for your child living with a disability.
Participant	Maybe what I can say is that I do not know if would say our healthcare workers are not able to pick the children's situations in time. I am saying this because my child was diagnosed when she was about three years of

	age. Al along, we had been taking her for monthly child welfare clinic, but the doctors could not pick if she has a challenge. So, I sometimes believe that the doctors might somehow, because you would ask yourself as the mother of a child with this condition if the mistake happened at the hospital, and they kept it away from you or what could have happened, I do not know if this one falls under your scope. I am just saying it, but I really do not know.
Researcher	Ehee. So, you mean delaying to diagnose your child might have had an effect on the strain that you are experiencing?
Participant	Yes mam.
Researcher	Uh huh.
Participant	Uh.
Researcher	Okay madam. And we have come to the end of the interview. Thank you for your time and participation in the interview.
Participant	Okay madam.
Researcher	Oaky madam.

ANNEXURE K: FIELD NOTES GUIDE

- Field notes
- Log diary: kept to record conversations and events in the field.
- Descriptive information: factual data that include date, time, place, objective description of conversations and events, dialogue.
- Reflective notes:
  - Methodologic notes: reflections on the strategies used by the researcher to observe.
  - Theoretical notes: reflection on the researcher's thought on how they make sense of what is transpiring.
  - Personal notes: researcher's comments of own feelings in the field.

ANNEXURE L: LETTER TO THE PSYCHOLOGIST

P. O. Box 309
Lobatse

Botswana

10 August 2020

The Psychologist
Private Bag 30
Lobatse
Botswana

Dear Sir/ Madam

RE: REQUEST FOR PSYCHOLOGIST SERVICES DURING IN A RESEARCH STUDY

Topic: **Exploring role strain in caregivers of children living with disabilities in Lobatse- Botswana**

I hereby request your services in my research study to debrief and/or counsel participants after the process of data collection. I am conducting this study in partial fulfilment of my studies in Master of Community Psychiatric Nursing with North West University. The aim of the study is to explore and describe the role strain experienced by caregivers of children living with disabilities in Lobatse and to contribute to guidelines that will promote their quality of life.

This study is going to use a qualitative explorative and descriptive approach to explore and describe caregiver role strain in caring for children living with disabilities. The design is suitable for this study as it has the potential to allow the participants an opportunity to share their experiences on role strain in caring for children living with disabilities as well as explaining how they manage the role strain. Participants will be recruited from consenting caregivers of children living with disabilities who are going to be identified through the Social and Community Development office. The researcher will observe ethical principles such as respect for human dignity, justice, beneficence, confidentiality, privacy and anonymity of the participants throughout the study.

By exploring role strain in caring for children living with disabilities, this study can provide insights into the experiences for this population so as to better understand their plight and contribute to guidelines to promote their functioning.

This study has the potential to cause psychological discomfort to participants. The participants are anticipated to experience feelings of sadness, anger, anxiety and uneasiness due to reliving their experiences in caring for the children living with disabilities. In addition, the participants may experience emotional burden due to feelings of self-disclosure as they would be discussing their problems to a "stranger" being the researcher. It is in this regard that I request your services after the data collection process to assist in debriefing and/or counselling of the participants.

If you have any questions or for more information or clarity about this research, please contact the following:

- Investigator: Ms. Keletwaetse Sakwape (+267 71823639 or kmsakwape@gmail.com)
- The Supervisor (Principal investigator): Ms. R. Machailo (0027 723905302 or Rorisang.Machailo@nwu.ac.za)
- Co-supervisor: Prof. MP. Koen (Daleen.Koen@nwu.ac.za)

Thanks for your consideration.

Yours faithfully

Keletwaetse Sakwape

ANNEXURE M: STANDARD NWU CONFIDENTIALITY AGREEMENT CO-CODER

CONFIDENTIALITY UNDERTAKING

entered into between:

Co – Coder

I, the undersigned

Prof / Dr / Mr / Ms _____

Identity Number:_____

Address:_____
___

hereby undertake in favor of the **NORTH-WEST UNIVERSITY**, a public higher education institution established in terms of the Higher Education Act No. 101 of 1997

Address: Office of the Institutional Registrar, Building C1, 53 Borcherd Street, Potchefstroom, 2520

(hereinafter the “NWU”)

1 Interpretation and definitions

1.1 In this undertaking, unless inconsistent with, or otherwise indicated by the context:

1.1.1 “Confidential Information” shall include all information that is confidential in its nature or marked as confidential and shall include any existing and new information obtained by me after the Commencement Date, including but not be limited in its interpretation to, research data, information concerning research participants, all secret knowledge, technical information and specifications, manufacturing techniques, designs, diagrams, instruction manuals, blueprints, electronic artwork, samples, devices, demonstrations, formulae, know-

how, intellectual property, information concerning materials, marketing and business information generally, financial information that may include remuneration detail, pay slips, information relating to human capital and employment contract, employment conditions, ledgers, income and expenditures and other materials of whatever description in which the NWU has an interest in being kept confidential; and

1.1.2 "Commencement Date" means the date of signature of this undertaking by myself.

1.2 The headings of clauses are intended for convenience only and shall not affect the interpretation of this undertaking.

2 Preamble

2.1 In performing certain duties requested by the NWU, I will have access to certain Confidential Information provided by the NWU in order to perform the said duties and I agree that it must be kept confidential.

2.2 The NWU has agreed to disclose certain of this Confidential Information and other information to me subject to me agreeing to the terms of confidentiality set out herein.

3 Title to the Confidential Information

I hereby acknowledge that all right, title and interest in and to the Confidential Information vests in the NWU and that I will have no claim of any nature in and to the Confidential Information.

4 Period of confidentiality

The provisions of this undertaking shall begin on the Commencement Date and remain in force indefinitely.

5 Non-disclosure and undertakings

I undertake:

5.1 to maintain the confidentiality of any Confidential Information to which I shall be allowed access by the NWU, whether before or after the Commencement Date of this undertaking. I will not divulge or permit to be divulged to any person any aspect of such Confidential Information otherwise than may be allowed in terms of this undertaking;

5.2 to take all such steps as may be necessary to prevent the Confidential Information falling into the hands of an unauthorised third party;

5.3 not to make use of any of the Confidential Information in the development, manufacture, marketing and/or sale of any goods;

5.4 not to use any research data for publication purposes;

5.5 not to use or disclose or attempt to use or disclose the Confidential Information for any purpose other than performing research purposes only and includes questionnaires, interviews with participants, data gathering, data analysis and personal information of participants/research subjects;

5.6 not to use or attempt to use the Confidential Information in any manner which will cause or be likely to cause injury or loss to a research participant or the NWU; and

5.7 that all documentation furnished to me by the NWU pursuant to this undertaking will remain the property of the NWU and upon the request of the NWU will be returned to the NWU. I shall not make copies of any such documentation without the prior written consent of the NWU.

6 Exception

The above undertakings by myself shall not apply to Confidential Information which I am compelled to disclose in terms of a court order.

7 Jurisdiction

This undertaking shall be governed by South African law be subject to the jurisdiction of South African courts in respect of any dispute flowing from this undertaking.

8 Whole agreement

8.1 This document constitutes the whole of this undertaking to the exclusion of all else.

8.2 No amendment, alteration, addition, variation or consensual cancellation of this undertaking will be valid unless in writing and signed by me and the NWU.

Dated at Potchefstroom this _____ 20____

Witnesses:

1 .....

2 ....

(*Signatures of witnesses*) (*Signature*)

ANNEXURE N: PERMISSION LETTER FROM MOHW

PRIVATE BAG 0038
GABORONE
BOTSWANA
REFERENCE:

REPUBLIC OF BOTSWANA
MINISTRY OF HEALTH AND WELLNESS

TEL: (+267) 363 2500
FAX: (+267) 391 0647
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD

REFERENCE NO: HPDME 13/18/1 **21 January 2021**

Health Research and Development Division

Notification of IRB Review: **New application**

Keletwaetse Sakwape
P O Box 309
Lobatse

Dear Keletwaetse Sakwape

Protocol Title: **EXPLORING ROLE STRAIN IN CAREGIVERS OF CHILDREN LIVING WITH DISABILITIES IN LOBATSE- BOTSWANA**

HRU Approval Date:	21 January 2021
HRU Expiration Date:	20 January 2022
HRU Review Type:	Expedited Review
HRU Review Determination:	Approved
Risk Determination:	Minimal risk

Thank you for submitting new application for the above referenced protocol. The permission is granted to conduct the study.

This permit does not however give you authority to collect data from the selected sites without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health and Wellness within 3 months of completion of the study. Approval is for academic fulfillment only. Copies should also be submitted to all other relevant authorities.

Continuing Review
In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health

Research Division Office (HRDD), Office No. 7A.7 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: kgmmotlhanka@gov.bw As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 7A 7 or Ministry of Health website: www.moh.gov.bw or can be requested via e- mail from Mr. Kgomotso Motlhanka, e-mail address: kgmmotlhanka@gov.bw . In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

Reporting

Other events which must be reported promptly in writing to the HRDC include:

- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

If you have any questions please do not hesitate to contact Mr. K. Motlhanka at kgmmotlhanka@gov.bw, Tel +267-3632751. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely

Ms D. Mgadla
for /PERMANENT SECRETARY

MINISTRY OF HEALTH AND WELLNESS
RESEARCH DIVISION
21 JAN 2021
P/BAG 0038
GABORONE
REPUBLIC OF BOTSWANA

ANNEXURE O: PERMISSION LETTER FROM LTC

LOBATSE TOWN COUNCIL
Private Bag 0028, Lobatse, Botswana
Telephone: 5305800
Fax: 5332458
Email: lcouncil@gov.bw

15th February 2021

Ms. Keletwaetse Sakwape
P.O. Box 309
LOBATSE

Dear Sir/Madam

REQUEST FOR PERMISSION TO CONDUCT A RESEARCH- YOURSELF

The above subject matter refers.

We are in receipt of your letter dated 25th January 2021, in which you were requesting for permission to conduct a research project in Caregivers for Children Living with Disability.

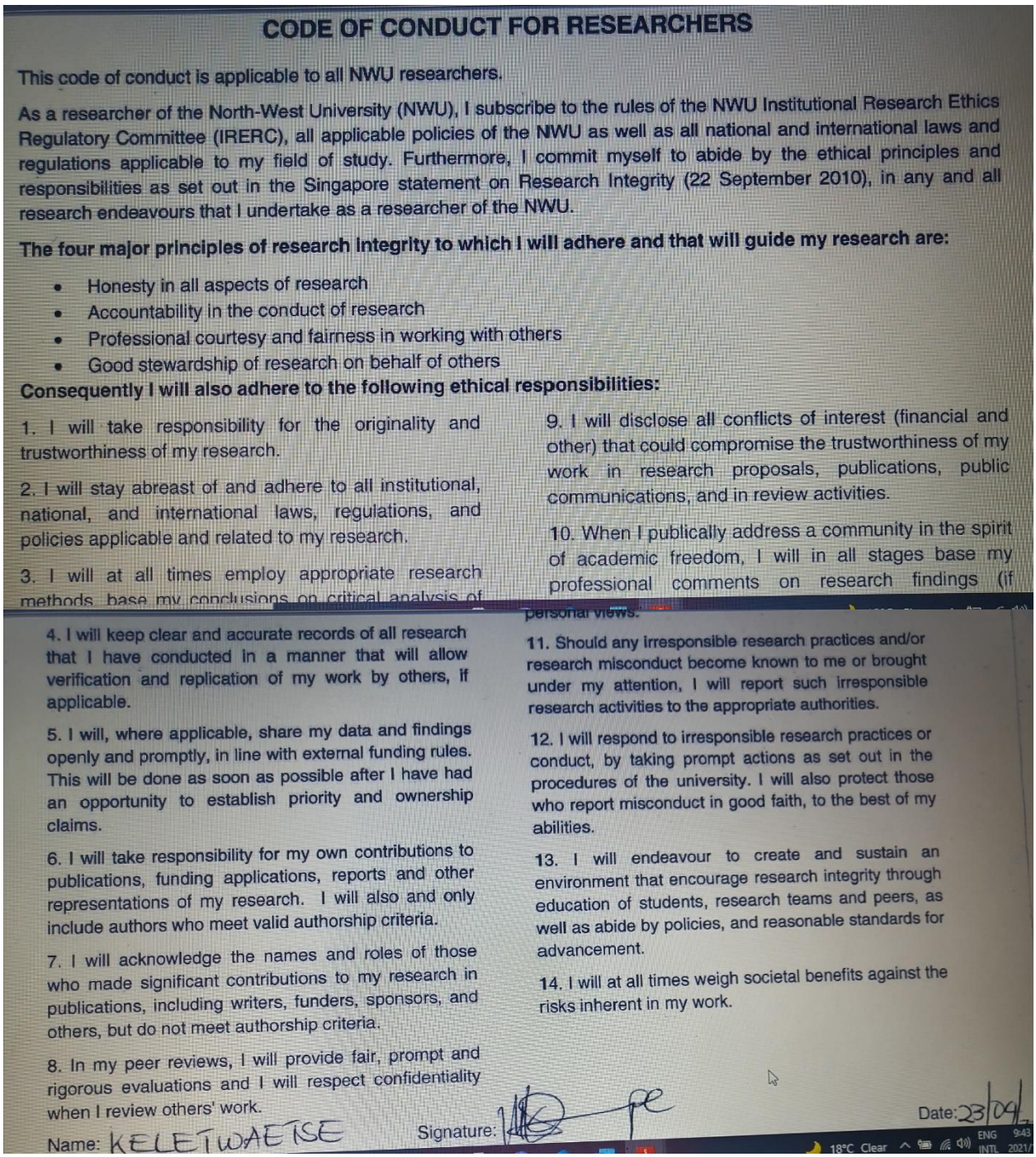
Your permission to conduct research from 1st March 2021 to 31st August 2021 is hereby granted. The permission is specifically for your studies.

Thank you.

Yours faithfully

M.M. Taukobong
For/Town Clerk

ANNEXURE P: RESEARCHER CODE OF CONDUCT



CODE OF CONDUCT FOR RESEARCHERS

This code of conduct is applicable to all NWU researchers.

As a researcher of the North-West University (NWU), I subscribe to the rules of the NWU Institutional Research Ethics Regulatory Committee (IRERC), all applicable policies of the NWU as well as all national and international laws and regulations applicable to my field of study. Furthermore, I commit myself to abide by the ethical principles and responsibilities as set out in the Singapore statement on Research Integrity (22 September 2010), in any and all research endeavours that I undertake as a researcher of the NWU.

The four major principles of research integrity to which I will adhere and that will guide my research are:

- Honesty in all aspects of research
- Accountability in the conduct of research
- Professional courtesy and fairness in working with others
- Good stewardship of research on behalf of others

Consequently I will also adhere to the following ethical responsibilities:

1. I will take responsibility for the originality and trustworthiness of my research.

2. I will stay abreast of and adhere to all institutional, national, and international laws, regulations, and policies applicable and related to my research.

3. I will at all times employ appropriate research methods, base my conclusions on critical analysis of

9. I will disclose all conflicts of interest (financial and other) that could compromise the trustworthiness of my work in research proposals, publications, public communications, and in review activities.

10. When I publically address a community in the spirit of academic freedom, I will in all stages base my professional comments on research findings (if personal views.

4. I will keep clear and accurate records of all research that I have conducted in a manner that will allow verification and replication of my work by others, if applicable.

5. I will, where applicable, share my data and findings openly and promptly, in line with external funding rules. This will be done as soon as possible after I have had an opportunity to establish priority and ownership claims.

6. I will take responsibility for my own contributions to publications, funding applications, reports and other representations of my research. I will also and only include authors who meet valid authorship criteria.

7. I will acknowledge the names and roles of those who made significant contributions to my research in publications, including writers, funders, sponsors, and others, but do not meet authorship criteria.

8. In my peer reviews, I will provide fair, prompt and rigorous evaluations and I will respect confidentiality when I review others' work.

11. Should any irresponsible research practices and/or research misconduct become known to me or brought under my attention, I will report such irresponsible research activities to the appropriate authorities.

12. I will respond to irresponsible research practices or conduct, by taking prompt actions as set out in the procedures of the university. I will also protect those who report misconduct in good faith, to the best of my abilities.

13. I will endeavour to create and sustain an environment that encourage research integrity through education of students, research teams and peers, as well as abide by policies, and reasonable standards for advancement.

14. I will at all times weigh societal benefits against the risks inherent in my work.

Name: KELETWAETSE

Signature:

Date: 23/04/

ANNEXURE Q: NUMIQ SCIENTIFIC COMMITTEE PROPOSAL REVIEW REPORT

Students name: K Sakwape

Title of study: Exploring role strain in caregivers of children living with disabilities in Lobatse- Botswana

Supervisor: R Machailo, MP Koen

Reviewers

CS Minnie	**A**
SM Lethale	**A**
Van Graan	**A**
B Serapelwane	**B**
N Scheepers	**A**

Key:

A. Approved with no / minor changes: can be corrected under the guidance of the supervisor
B. Not approved – major changes: To be resubmitted to same SC members with a rebuttal.
C. Deferred - The proposal considered non-viable or having other serious problems

Final option: A - resubmit to B Serapelwane only

Chairperson: CS Minnie

ANNEXURE R: LETTER TO THE CO-CODER

P. O .Box 309
Lobatse, Botswana

20 April 2020

Amori Marais
45 Shamé Mews
482 Farm Road
Pretoria
0841

Dear Madam

RE: REQUEST FOR YOU TO PARTICIPATE IN MY STUDY AS A CO-CODER

Topic: **Exploring role strain in caregivers of children living with disabilities in Lobatse- Botswana**

I hereby request you to take part in my study as a co-coder. I am conducting this study in partial fulfilment of my studies in Master of Community Psychiatric Nursing with North West University. You will be required to make a sign a confidentiality undertaking form to partake as a co-coder. The aim of the study is to explore and describe the role strain experienced by caregivers of children living with disabilities in Lobatse and to contribute to guidelines that will promote their quality of life.

This study is going to use a qualitative explorative and descriptive approach to explore and describe caregiver role strain in caring for children living with disabilities. The design is suitable for this study as it has the potential to allow the participants an opportunity to share their experiences on role strain in caring for children living with disabilities as well as explaining how they manage the role strain. Participants will be recruited from consenting caregivers of children living with disabilities who are going to be identified through the Social and Community Development office. The researcher will observe ethical principles such as respect for human dignity, justice, beneficence, confidentiality, privacy and anonymity of the participants throughout the study.

By exploring role strain in caring for children living with disabilities, this study can provide insights into the experiences for this population so as to better understand their plight and contribute to guidelines to promote their functioning.

If you have any questions or for more information or clarity about this research, please contact the following:

- Investigator: Ms. Keletwaetse Sakwape (+267 71823639 or kmsakwape@gmail.com)
- The Supervisor (Principal investigator): Ms. R. Machailo (0027 723905302 or Rorisang.Machailo@nwu.ac.za)
- Co-supervisor: Prof. MP. Koen (Daleen.Koen@nwu.ac.za)

Thanks for your consideration.

Yours faithfully

Keletwaetse Sakwape

ANNEXURE S: PROOF OF ETHICS TRAINING

NWU®
NORTH-WEST UNIVERSITY
NOORDWES-UNIVERSITEIT
YUNIBESITI YA BOKONE-BOPHIRIMA

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: +2718 299-1111/2222
Web: http://www.nwu.ac.za

Faculty of Health Sciences Ethics Office for Research, Training and Support

Tel: 018 299 2092
Email: minrie.greeff@nwu.ac.za

3 September 2019

Mrs Keletwaetse Sakwape

Dear Mrs Sakwape

PROOF OF ATTENDANCE AND ASSESSMENT

This letter certifies that you have attended the 2-day ethics training entitled:

The Basics of Health Research Ethics

(Accreditation number: PSB002/110/01/2019 from University of Free-State CPD accreditation department accredited by the HPCSA)

Presenter: Prof GW Towers (Chairperson: NWU-HREC) on the **18-19 July 2019**

This letter of attendance, serves as proof of ethics training and assessment and is valid for three (3) years and expires on 30 September 2022. (Where applicable, Ethics CEUs awarded: 14 CEUs)

Yours sincerely

Digitally signed by Prof Minrie Greeff
DN: cn=Prof Minrie Greeff, o, ou, email=minrie.greeff@nwu.ac.za, c=ZA
Date: 2019.10.02 11:12:29 +02'00'

Prof Minrie Greeff
Head of Health Sciences Ethics
Office for Research, Training and Support

Prof J du Plessis
Deputy Dean: Research and Innovation

Current details: (20536690) G:\My Drive\9. Research and Postgraduate Education\9.1.5.7 Training\ 9.1.5.7.6_Letter of Attendance_BOHRE_34348972.docm
3 September 2019

File reference: 9.1.5.7.6

ANNEXURE T: LANGUAGE EDITING WORK CERTIFICATE

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, KwaZulu Natal

Cell: 071 352 5410 E-mail: moramist@vodamail.co.za

Work Certificate

To	Ms. K. Sakwape
Address	Faculty of Health Sciences, North West University, Potchefstroom
Date	07/11/2021
Subject	Mini Dissertation: Exploring role strain in caregivers of children living with disabilities in Lobatse, Botswana
Ref	GS/KS/02

I, Gill Smithies, certify that I have proofed the following for language, grammar and style,

Mini Dissertation: Exploring role strain in caregivers of children living with disabilities in Lobatse, Botswana, by K. Sakwape,

to the standard as required by NWU, Potchefstroom Campus.

Gill Smithies

ANNEXURE U: PROOF OF MANUSCRIPT SUBMISSION