The experiences of caregiving and the coping strategies of informal caregivers of people with major neurocognitive disorders

Londeka Manyathi

216039020

Submitted in partial fulfilment of the requirements for the degree of Master of Social

Sciences (Clinical Psychology) in the Discipline of Psychology

School of Applied Human Sciences - Faculty of Humanities and Social Sciences

University of KwaZulu-Natal,

Pietermaritzburg, South Africa

Supervisor: Mrs Xoli Mfene
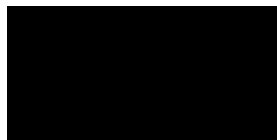
Ethical Approval Number HSSREC/00001775/2020

2023

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Mrs. Xoli Mfene

ACKNOWLEDGEMENTS

All glory and honour to God who has carried me until this far and gave me the grace to succeed in this journey.

To my supervisor, Xoli Mfene, I am truly thankful for your guidance and support. This has been a long journey, but you never gave up on me.

To my mentor, Zethu Makatini, the Founder of Bessie Makatini Foundation, I thank you for opening the doors of your organisation so that I could learn. Thank you to all the caregivers who shared their experiences with me.

To my family, you are too many to mention individually. I appreciate every one of you for your support and unconditional love.

To my friends and colleagues, thank you for walking this journey with me, and allowing me to run besides you as my comrades. I celebrate you.

ABSTRACT

Caregivers of people with major neurocognitive disorders (MNCD) experience considerable burden, which might lead to psychological difficulties. As a result of their caregiving experiences, it is important for caregivers to develop positive coping skills. This study aimed to explore the experiences and coping strategies of informal caregivers of people living with major neurocognitive disorders. Further, this study was conducted to establish if there are any support programmes available for informal caregivers of individuals with severe neurocognitive impairments. A mixed methods research approach was adopted. Nine informal caregivers were sampled through a non-probability purposive technique. Data were collected through semi-structured interviews and psychometric scales on caregiver depression, burden, and coping. Further, data were analysed using reflexive thematic analysis. Psychometric scales were scored and interpreted based on their interpretive manual. The findings suggest that informal caregivers of persons with major neurocognitive disorders endorsed more negative than positive experiences. However, they seemed to cope with the caregiving situation. More active coping strategies, such as acceptance and building resilience, mediate the negative experiences. Informal caregivers reported the availability of respite and psychosocial interventions such as those offered by the Bessie Makatini Foundation. In conclusion, it was recommended that while addressing caregiver needs and creating support interventions, support programs like those conducted by the Bessie Makatini Foundation should consider the various family dynamics.

LIST OF TABLES

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION

Major Neurocognitive Disorders (MNCDs) are a cluster of neurodegenerative diseases characterised by cognitive impairment and a decline in independence for daily activities (American Psychiatric Association [APA], 2013; World Health Organization [WHO], 2019). Berman et al. (2019) stated that most cases of progressive MNCDs extend across more than one stage. Cognitive impairment is impacted in the early stage. The middle stage has more memory loss and reliance on support with activities of daily living. There is severe cognitive weakening in the last stage, making persons with MNCDs unable to care for themselves without help with living activities. In the end stage, persons with MNCDs become visibly fragile and signs of end-life become evident. At this stage, persons with MNCD are fully dependent on their caregivers and the caregiving role becomes more prominent and challenging (Mahomed & Pretorius, 2022).

1.1 Problem statement

The World Health Organization (2021) and Bessat et al. (2023) estimated that approximately 1.9 million people with MNCDs live in Africa. Moreover, the prevalence of MNCDs was high and predicted to increase considerably by 2050 (Mahomed & Pretorius, 2022). As the disease increases it is predicted that the number of people living with disability and dependency caused by the disease will also increase because of the disease's effect on cognitive functioning and daily activities of living. This will mean that more people will become dependent on caregiving. According to Ames et al. (2020), people living with MNCD are mostly cared for at home. In addition, many families of those with MNCD also prefer to care for their loved ones at home (Mfene et al., 2023). This makes family members the informal caregivers for people with MNCDs.

Dolničar et al. (2022) broadly defined informal caregivers as individuals without training in healthcare who provide care for family members, other relatives, partners, friends, and neighbours with a disability, long-term psychiatric or medical illness, or problems related to ageing. Family caregivers care for their affected relatives by attending to their individual, medical, domestic, economic, and conveyance requirements (Mahomed & Pretorius, 2022). The caregiving role is usually faced with challenges and may be devastating for both the person with MNCD and their family because of the degenerative nature of the disease. In addition, as informal caregivers usually do not have formal caregiver or nursing training and are unpaid for their duties, the role has been reported to cause significant burden and distress (Lin et al., 2019). In addition, literature shows that it is more exhausting for informal caregivers to assist with basic activities of daily living such as bathing than providing support with instrumental activities such as shopping (Abdin et al., 2021).

The caregiving role can negatively impact informal caregivers' health and burden them considerably (Costa et al., 2020). Chiatti et al. (2020) stated that family caregivers caring for persons with MNCD have an increased risk of depression and reduced well-being, with greater increased mortality than informal caregivers caring for older persons without MNCDs (Costa et al., 2020). Family caregivers have varying needs regarding support, including practical assistance such as preparing food and emotional support when they feel overwhelmed. However, many caregivers did not access formal services until they reached crisis point and thus struggled to cope successfully in their caregiving roles (Mahomed & Pretorius, 2022).

Lastly, half of the global cost of dementia is attributed to informal care (WHO, 2022). This is because informal caregivers spend significant time caring for persons with MNCD, which then permits those with MNCD to continue living at home for longer periods before being institutionalised (Bleijlevens et al., 2017). In turn, some caregivers have to give up formal employment to care for their loved ones at home (Barakova et al., 2022). In addition, due to

the increased psychological and medical burden of caregiving, informal caregivers end up contributing to what would otherwise be a significant healthcare cost (Chignell & Zhang, 2020).

1.2 Purpose of the study

Much literature on caregivers of dementia sufferers is focused on the negative outcomes or experiences (Baumbach et al., 2021; Egilstrød et al., 2022; Colantonio et al., 2018), with most of the studies showing that the caregiving role adversely affects the physical health status of informal caregivers of persons with MNCD (Beerens et al., 2018). The caregivers experience psychological challenges associated with their caregiving role. They report high levels of anxiety and depressive symptoms (Ahmad et al., 2021). Also, adequate support is largely unavailable to them and often, support interventions are only made when problems accumulate (Gratton & Yamin, 2019). There is a scarcity of studies demonstrating that caring for those with MNCDs might benefit the caregivers (Chong et al., 2020; Leocadie et al., 2018). In particular, there is a dearth of African or South African literature focusing on the experiences of informal caregivers. Therefore, this study seeks to fill some of the gaps in the literature on the experiences of informal caregivers of people with MNCDs in South Africa and increase knowledge in this field. Hence, this study aims to explore the experiences and coping of informal caregivers of people with MNCD.

In addition, the literature will help to bring more awareness about the experiences of informal caregivers and help to create interventions and mobilise support and training for them. More knowledge and awareness concerning the experiences of informal caregivers might also help in providing on the ground information that can be used to develop policies that advocate for the incorporation of caregiver care into the healthcare of people with MNCD. A study by Mfene et al. (2023) reported on the importance of multidisciplinary (MDT) care for people

with dementia and their families and the importance of including caregivers in care planning. Lastly, this study explored not only the challenges but also the overall experiences of informal caregivers, hoping that positive experiences and positive coping strategies can be expanded on and incorporated into training programmes for informal caregivers.

1.3 Study objectives

The main aim of the study was to explore the experiences and coping strategies of informal caregivers of people with MNCD.

The objectives of this study were:

- To explore the experiences of informal caregivers of people living with MNCDs.

- To explore the coping strategies of informal caregivers of people living with MNCDs.

- To explore the availability of support services for informal caregivers of people living with MNCDs.

1.4 Research questions

- What are the experiences of informal caregivers of people living with MNCDs?

- What are the coping strategies adopted by informal caregivers of people living with MNCDs?

- What are the support services available for informal caregivers of people living with MNCDs?

1.5 Important concepts and operational definitions

Informal caregiver: Informal caregivers care for persons (with MNCD) without payments; their relationship with the care recipient is due to personal ties (Merrilees et al., 2016).

Formal caregiver: A formal caregiver is a professional, paraprofessional, or volunteer associated with a service system who provides care at home, in community agencies, or institutions or residential facilities (Merrilees et al., 2016).

Coping: Coping is a process involving cognitive and behavioural responses used by a person in reaction to stresses that are perceived to exceed their resources (Ali et al., 2022).

1.6 Structure of the dissertation

This dissertation consists of six chapters that address the above aspects as follows:

Chapter one introduces the study. It briefly provides the relevant background information to the study, outlines the research problem, states the purpose and objectives of the research, and summarises the significance of the study. Chapter two reviews relevant literature and the theoretical framework of the study. Chapter three describes the methodology; it provides the methodological outline and describes the research design and the procedures used to choose participants for the data collection and analysis. Chapter four presents the findings; it takes the reader through the findings from in-depth interviews. These responses from the informal caregivers are adequately nuanced to give the reader a clear picture of the context within which data was collected. Chapter five discusses the findings, describing the most important research findings related to the study's topic and comparing them to prior research findings and published work. Chapter six concludes the thesis with the study's conclusions, recommendations, and limitations.

1.7 Conclusion

This chapter introduced the current study by discussing the following topics: problem statement, the purpose of the study, objectives of the study, research questions, essential concepts and operational definitions, and the structure of the dissertation.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

The study objective was to explore the experiences of informal caregivers of persons with major neurocognitive disorders (MNCDs). The study further explored the caregivers' coping strategies and support services available. In this chapter, the researcher reports on the reviewed literature related to these aspects of the topic.

2.2 Definition and characteristics of informal caregivers

Caregiving is the provision of extraordinary care for individuals with either medical or psychological illnesses who are no longer self-sufficient (Addabbo et al., 2021). The care provided to people with illnesses is either informal or formal. Informal caregivers are friends and family members who provide primary care for people with illnesses such as MNCDs (Hoefman et al., 2017). On the one hand, informal caregivers are not paid for the care that they provide. On the other hand, professional caregivers are caregivers found in homecare and residential and nursing institutions and they receive payment for providing care to individuals with MNCDs (Fabius et al., 2022).

Globally, most informal caregivers are women and older adults (Schirra-Weirich et al., 2021). This trend has also been reported in South Africa, where there are more female caregivers than males (Harris & Thafeng, 2022). This is because females are the principal support figures in most families (Harris & Thafeng, 2022). The global average age of informal caregivers is over 50 years. Families are responsible for the needs and care of adults who are no longer self-sufficient. Most people with MNCDs receive care from their spouses. In cases where the spouses are deceased or unfit to provide care, adult children often take over the role of caregiving (Addabbo et al., 2021). It is more likely that the adult daughter and daughters-in-

law take on more caregiving duties than the sons and sons-in-law. While family members sometimes share caregiving tasks, one person is more likely to provide most of the care (Addabbo et al., 2021; Harris & Thafeng, 2022).

In the South African population, the largest prevalence of informal caregivers is amongst Black South Africans (Mahomed & Pretorius, 2022); it is found that the rate of Black informal caregivers is double that of other races in South Africa. Hence, the few studies that have been conducted with informal caregivers in the country have included mostly Black South Africans as participants (Mahomed & Pretorius, 2022; Harris & Thafeng). However, most of the research has focused on the caregivers' understanding and knowledge of the disease and not particularly on their experiences and how they cope with the caregiver role (Hanssen & Mkhonto, 2018; Mfene et al., 2023;).

2.3 The experiences of informal caregivers

Caregiver experiences are influenced by many factors, which include the state of the relationship between the caregiver and the person with MNCD, the extent of dependency, the severity of the disorder, social restrictions, role conflicts, perceived competence of the informal caregivers, and role capacity (Fadeyi, 2020). Some of the themes found by previous researchers who explored the involvements of informal carers of individuals with MNCDs include loyalty; anticipatory grief; lack of support; psychological distress; and sacrifices made (references). These will be discussed in the following sections.

2.3.1 Loyalty

Some adult child caregivers of persons with MNCDs consider their caregiving responsibility as a chance to fortify their relationship with their parents (Groennestad et al., 2022). For these caregivers, the diagnosis of MNCD produced positive outcomes between the caregiver and

care recipient, contributing to more solid bonding (Boyce et al., 2020). This strengthening of ties also applied to other diseases, such as cancer (Costa et al., 2020); this was linked to the family unity required to deal with the disorder and to the type of disease. MNCD has a poor prognosis and that puts pressure on persons with MNCD and their carers; however, closer family bonds reduce the burden (Heyn et al., 2019).

In Cross et al.'s (2018) study, caregivers of persons with MNCDs stated their loyalty as caregivers. They personally took responsibility for the safety, maintenance, and well-being of their relative with MNCD because they did not trust other people to fulfil the caregiver responsibilities. Maybe their concept of duty came from *Ubuntu*, an essential principle of African nations (Chisale, 2018). *Ubuntu* is the principle of caring for each other's well-being and fostering a spirit of mutual support (Chisale, 2018; Mohammed & Pretorius, 2022).

Furthermore, spousal caregivers expressed that spending more time together with their partner with MNCD facilitated the experience of closeness (Gangopadhyay et al., 2020). They highly treasured the opportunity to share values, experiences, and unity with their family member with MNCD during their last years. The feelings of gratitude and appreciation shown by the care recipients were also important for continuing caring. The caregivers experienced closeness in their relationships after the onset of MNCD. They described their relationships in compassionate and caring ways despite the challenges related to caregiving (Bielderman et al., 2022).

2.3.2 Anticipatory grief

The grief experienced by MNCD caregivers related to a specific feeling experienced as the illness progressed but prior to death (Cheung et al., 2018). In the process of MNCD, family caregivers saw gradual cognitive, social, and physical changes. They reported gradual losses in the course of MNCDs, which include the loss of personal independence, economic

opportunities, and health. Moreover, the model developed by Gastfriend (2018) highlighted the particular aspects of the grieving process experienced by dementia caregivers as they deal with the disease's compounded serial losses in memory, communication, and self-care. Other issues were dealing with the ambivalence caused by the disease's slow and unpredictable course and dealing with the person's personality change (Gastfriend, 2018).

Moreover, unresolved anticipatory grief caused harm to caregivers' mental health, physical health, and social relationships and increased their risk for the development of prolonged grief after the death of care recipients. Caregivers' health was further affected by the long period of caregiving, as persons with MNCD live for years with the disorder (Cheung et al., 2018).

Several other studies also investigated anticipatory grief in carers (Dehpour & Koffman, 2023; Liew et al., 2019; Köhler et al., 2019). According to Dehpour & Koffman (2023), anticipatory grief signified an abstruse state that was recognized as a quantifiable variable amongst caregivers. Assessment tools for the identification of anticipatory grief were found to be imperative for appropriate intervention to enhance well-being and positive bereavement experiences. Seven anticipatory grief assessment tools were identified. Cheung et al. (2018) compared the anticipatory grief, welfare, and burden of spousal and adult children caregivers. They explored the relationships between these variables. Spousal carers generally reported a higher anticipatory grief. They also made more sacrifices and became isolated from others. Moreover, in a study by Mahomed and Pretorius (2022), caregiver grief was a prominent finding among caregivers of persons with MNCDs. Most caregivers experienced a particular feeling of despondency. Caregivers described their experiences as worse than death because of the lack of closure (Cheung et al., 2018; Mohamed & Pretorius, 2022).

2.3.3 Lack of family support

Most caregivers reported feeling unaided in their caregiving role and received no tangible support from their family members with daily tasks of caregiving and emotional support. Caregiver support in literature is categorised into two kinds: instrumental caregiver support is referred to as assistance with daily tasks of caregiving, while emotional support improves caregiver well-being. In a study by Mahomed and Pretorius (2022), caregivers did not receive instrumental support, and most did not have much choice other than to become sole care providers; noticeably, some caregivers in their study did not feel sufficiently supported. The complexity of this dynamic increased the caregiver burden (Costa et al., 2020).

In addition, caregivers often lacked social contact and support and experienced feelings of social isolation (Chen et al., 2020). Cooper et al. (2020) investigated the effects of social support in reducing caregiver burden. They referred to two types of social support: psychological and non-psychological support. The results showed that caregiver burden was reduced by positive social interaction and emotional support, which reduced psychological stress when combined with less dysfunctional coping mechanisms and a more positive attitude towards MNCDs (Chen et al., 2020; Cooper et al., 2020;).

2.3.4 Psychological distress

Informal carers of persons with MNCDs reported considerable psychological suffering when caring for people with MNCDs, which was due to the workload, lack of information related to the more mature population, and expected death (Abreu et al., 2018). The loss of brain function in MNCD is associated with loss of emotional stability, social behaviour, and drive. In the advanced stage, the person with MNCD becomes more reliant on their caregiver, becoming utterly in need of assistance. The course of the disorder is not easy to predetermine, but it affects the family as well as the person with MNCD. High levels of anxiety and depression

were found in the family caregivers of people with MNCD. The burden caused by MNCDs was found to be a public health problem (Contreras et al., 2020).

Furthermore, taking care of people with MNCDs affected the mental health of informal caregivers, which sometimes resulted in persons with MNCDs being neglected or abused (Abreu et al., 2018). Caring for persons with MNCDs was experienced as difficult for caregivers because they had to decide on the appropriate help for the affected person. However, persons with MNCD commonly have unique needs (Contreras et al., 2020).

Extant literature reflected on the experiences of distress in family caregivers (Bakker et al., 2020; Abley et al., 2017; Aarsland et al., 2016). Informal caregivers described the pre-diagnostic phase of persons with MNCD as a time of ambiguity and frustration (Bakker et al., 2020). Despite the fact that many carers already provide care prior to diagnosis, diagnostic disclosure signals the beginning of the caregiving trajectory (Bakker et al., 2020). It was identified that the majority of informal caregivers have uncounted psychological challenges related to caregiving (Abley et al., 2017). According to the findings, a large percentage of carers for people with mild dementia reported feeling moderately or severely burdened, and they also had a higher chance of acquiring psychiatric problems.

Moreover, in a study by Mahomed and Pretorius (2022), all caregivers reported feelings of sadness and anxiety. The common reasons for these feelings were a breakdown in communication, behaviours that are challenging, and denial (Abreu et al., 2018; Mohamed & Pretorius, 2022).

2.3.5 Sacrifices made

Caregivers sacrificed because of caring for a person with MNCD, and their lives changed because of the various aspects of caregiving (Allen et al., 2022). Firstly, caregivers of persons with MNCDs became unemployed because of their care obligations. Employment relates to

human dignity and identity (Gallagher et al., 2019). Leaving work to focus solely on long-term care led to an increase in the caregivers' mental and physical burden because unemployment also meant the loss of financial independence. Therefore, family caregivers experienced various conflicts and challenges about leaving their jobs (Cabrera et al., 2022).

Secondly, caregivers often reduced their leisure activities to care for a family member with MNCD. However, family caregivers who engaged in home and leisure activities experienced lower caregiving burdens and depressive symptoms (Chen et al., 2020). A positive relationship existed between participation in social activities and life satisfaction (Baysari et al., 2020). Leisure activities increased caregivers' happiness. Consequently, a lack of leisure activities had enormous implications for family caregivers (Bieber et al., 2017). Giving up leisure activities was associated with the subjective burden on caregivers. Thus, it is essential to increase caregiver leisure activities, and this is best done by first understanding how caregivers spend their time. Lack of support and leisure activities determine the levels of anxiety. It is also important to create a culture that supports caregivers to leave caregiving and enjoy outside activities (Chiu et al., 2020).

2.4 Coping strategies

Coping refers to those reactions to life struggles that help prevent or regulate emotional suffering (Basnyat & Chang, 2017). Coping is an essential construct in the literature which explored the caregiving of persons with MNCDs. In this literature, coping referred to the hard work done by the caregivers to deal with challenges that seem beyond (DeLongis et al., 2020). The process of coping involves psychological appraisal and decision-making (Devi et al., 2022). Coping assists caregivers in handling traumatic events and reduced exposure to stressful situations. In Hockley et al. (2020), a number of coping methods were used by caregivers to negotiate and alleviate the stresses and burdens of caregiving. Thus, when seeking to

understand caregiver outcomes, giving attention to coping strategies used by caregivers is more important than only considering the condition of the person with MNCD. Various coping strategies have been adopted by informal caregivers of persons with MNCDs (Devi et al., 2022); these are described below.

2.4.1 Emotion-focused coping strategies

Emotion-focused coping strategies signified techniques used to control the emotional distress emerging from, in the context of this study, the person-environment relationship (Basnyat & Chang, 2017). Emotion-focused coping strategies incorporate avoidance, regression, and emotional emission. For Alessandrini et al. (2017), emotion-focused coping strategies are maladaptive if caregivers use them to facilitate feelings of self-blame, reduce airing of emotions, create excessive dependence, add to negative feelings and avoid taking action.

2.4.2 Problem-focused coping strategies

Problem-focused coping strategies concern direct actions taken to alter a threatening relationship between the individual and the environment. These strategies incorporate reasoning about the circumstances and carrying out the necessary steps to resolve the issue. Problem-focused coping strategies with an adaptation approach were adaptable, used interactive communication, ensured social support, acquired appropriate information, intensified feelings of personal control, maintained social functioning, and assisted in the facilitation of positive feelings (Alessandrini et al., 2017).

In terms of helping caregivers cope, in-house workers can be hired. Basnyat and Chang (2017) argued that this is a form of dual coping mechanism. Hiring help is a problem-focused coping strategy because caregivers are relieved from physical tasks, while the employed

support can represent an emotion-based coping strategy because it provides caregivers with an emotional buffer against the mental anguish and anxiety invoked by caregiving.

2.4.3 Other types of coping strategies

Other types of coping strategies include performing specific tasks. First, *appraisal-focused* coping strategies identify the source of the difficulty, attend to one element of the problem at a time, draw on relevant previous experiences, and practise responses to the situation. Secondly, *relationship-focused* coping strategies maintain and regulate social relationships. Thirdly, *cognitive-focused* coping strategies reframe the circumstances in more favourable language and facilitate acceptance of the situation (Alessandrini et al., 2017).

2.4.4 Coping strategies specific to caregivers of people MNCD

Some of the coping strategies that were identified as being specific to MNCD caregivers comprised redefining the condition, taking ordered steps, and correctly displaying of emotions (Del-Pino-Casado et al., 2019). Additionally, strategies included acceptance of the circumstances, relaxation, mystical support, distractions, looking for social backing, desiring the problem to disappear, and hiding genuine feelings from other people. Other coping strategies used by caregivers included caregivers' understanding of their right to get help and refusing to be personally responsible for patient behaviour (Alessandrini et al., 2017).

Further, *diversion* was another form of coping strategy applicable to caregivers. For example, hired support is a diversion coping strategy that permits caregivers to resume regular routines and have more time for self, family, and friends. Caregivers can resume hobbies and focus on their careers (Basnyat et al., 2017). Coping is an active process, and caregivers can choose to use specific coping strategies based on their needs and existing resources. Cultural

and societal pressures influence the choice of coping strategies. In some countries such as Singapore, the hiring of support for a demented parent was preferred over institutionalising them because the home was the perfect environment for elderly parents (Devi et al., 2022).

2.4.5 Acceptance and building resilience

Caregivers vary in their ability to cope with the behaviours and the psychological symptoms of people with MNCDs. Caregivers adapted their interactions with the person with MNCD to fit their current functioning (Cheon et al., 2022). According to Lai (2023), the strategies included reducing pace, simple communication, creating safe spaces, and avoiding arguments with the affected person. Such approaches reduced pressure for both parties.

As stated by Kumar (2017), some caregivers reported adapting their interactions with the person with MNCD as they became more aware of the dangers of confrontation (Kumar, 2017). Most caregivers described how they improved the home setup to cater for the affected person. These adjustments included daily routines and prompts in the homes. Such proactiveness demonstrated the caregiver's recognition of the behaviours of the person with MNCD as need-driven behaviour (Leung et al., 2021). They applied creativity and problem-solving that assisted the affected person to gain a sense of autonomy over themselves and their environment (Cheon et al., 2022).

Therefore, these approaches aided in the reduction of stress for persons with MNCDs and their caregivers. By contrast, several caregiver observation strategies were not always practical. Distraction techniques gave temporary relief to caregivers but without reducing the challenging behaviour (Leung et al., 2021).

Several caregivers compared their behaviour modification techniques as being similar to those applied to children (Kumar, 2017). Analogies of childcare helped build empathy in the caregivers (Cheon et al., 2022). However, some caregivers with nurturing orientations over-

supported the person with MNCD by assisting them in activities they were capable of completing independently (Kumar, 2017).

2.4.6 Humour

Several caregivers reported that humour was an essential tool in managing caregiving (Boyce et al., 2020). This was due to the seriousness of the challenges that caregivers experienced because of the behaviours of the person with MNCD. A sense of humour reduced caregiving stress and aided in maintaining a balanced perspective on the difficulties associated with MNCD. Using humour helped caretakers to maintain a healthy relationship with the care recipient (Cheon et al., 2022). Humour further assisted in dealing with challenging behaviours by reducing their seriousness; a sense of humour reduced stress. Additionally, humour caused caregivers to focus on the positive aspects of their relationship with the person with MNCD (Kumar, 2017).

2.4.7 Self-care

Informal carers also emphasised self-care in overcoming the obstacles of caregiving, as care responsibilities worsen mental and physical health (Cheon et al., 2022). Caregivers' emotional and physical ability to deal with the behavioural issues of the individual living with MNCD was restored by strategies like engaging in meaningful non-care activities, maintaining healthy habits, and taking a break from caregiving. Notably, research indicated that on days when persons with MNCD used adult day services, carers had fewer care-related pressures and fewer negative emotions (Annemans et al., 2016). The implication was that taking a break from caregiving had several advantages. Similarly, scheduling time for recreational events reduced the stress of caregiving (Dai & Moffatt, 2023).

2.5 Support interventions

Family caregivers were the most important resource available for people with MNCD, hence the importance of providing care strategies for them (Devi et al., 2022). Various support interventions have been suggested in past literature as being suitable for supporting caregivers of persons with MNCDs. These included in-house respite workers, support groups, psycho-educational support interventions, and social support interventions.

2.5.1 In-house respite workers

Informal caregivers use in-house respite workers as a resource to cope with their caregiving responsibilities (Devi et al., 2022). The hiring of in-house respite workers is dependent on the family's financial resources. Often, in-house respite workers give practical support such as feeding, dressing, and bathing (Devi et al., 2022). Although engaging the services of in-house respite workers has its costs, caregivers have more time to improve their economic situation through either being employed or self-employment (Basnyat & Chang, 2017).

2.5.2 Support groups

Support groups are formal programmes aimed at easing the demands on those persons engaged in the family caregiving enterprise (Brodaty et al.,2022). In support groups, peers provide emotional support and encouragement, as well as insight into successful strategies for dealing with the various aspects of caregiving roles. Learning from peers increases empathy and insight into challenges related to caregiving. Support groups encourage caregivers to share effective coping techniques (Chen et al., 2020).

2.5.3 Psycho-educational support interventions

Psycho-educational skills-building intervention significantly can impact the caregivers of persons with MNCDs' emotional well-being, quality of life, and attitudes towards caregiving (Bykovskyi et al., 2021). Interventions based on psycho-educational skills help maintain caregiver levels of well-being over time. Whilst those who did not receive interventions experienced deterioration, the benefit of psycho-educational interventions was substantial when caregivers attended a separate group from their relatives with MNCDs (Bykovskyi et al., 2021). In Ford et al. (2022) study, the support catered to the needs of a specific group of caregivers at a particular stage of caring, and the group was accessible, low-cost, and time-limited. In addition, early attention paid to caregivers' misunderstanding of the changes in their relative with MNCD reduced the risk of isolation and helped address caregiver needs (Bykovskyi et al., 2021). It is more helpful if the groups are a mixture of information, education, and social support (Ford et al., 2022).

2.5.4 Social support interventions

Social support also influences caregiver outcomes. Caregivers who engaged in social activities are less depressed than those who are socially isolated (Huang, 2022). The family is a fundamental support for caregivers. However, family conflicts also exacerbate caregiver distress (Konis et al., 2018). The family factors that increase caregiver distress include marital challenges, family conflict, boundary ambiguity, and problematic communication patterns (Morton et al., 2022). Caregiver well-being is positively correlated with the family's support to the caregiver as a leader of the caregiving system (Cleveland et al., 2018).

2.6 Theoretical framework

The theoretical framework clarifies the course of the research and firmly establishes the theoretical conceptions as the foundation of the research (Carl & Ravitch, 2020). The framework's overall goal is to increase the significance of research findings by ensuring generalisability, relevance, and reference to theory. Since the study explored the experiences and coping of informal caregivers of people with MNCDs, the resilience theory and stress and coping theory were used to frame this research.

2.6.1 Resilience theory

The resilience theory was developed by Garmezy (1991); it was used in this research to understand the experiences of caregivers and the impact of these experiences on them. Various definitions of resilience exist, but the common theme for resilience is the ability to overcome negative experiences or challenges and grow into a stronger, more flexible, and healthier person (Fisher et al., 2019). Importantly, resilience has dynamic traits that people develop at any point in time and under any circumstances (Aburn et al., 2016; Avery & Bekhet, 2018). Hence, the focus of the study is on whether or not the experiences of caregivers help them to develop resilience.

As stated by Anderson (2019), resilience theory focuses on the interaction between exacerbating and ameliorating factors of adverse events that have the potential to disrupt life. According to this theory, resilience is gained when homeostasis is restored following adversity (Droes et al., 2017). People who overcome challenges gain new insight and growth. However, Droes et al. (2017) reported that when people face adversity, they tend to cling to their comfort zones and turn down opportunities for growth to avoid disruption, therefore becoming less resilient.

Three factors have been reported as indicators for resilience in caregivers; these are resourcefulness, family dynamics, and one's economic status (Fealy et al., 2018; Kumar, 2017). Persons with resilience were able to maintain independence during times of adversity because of their personal resourcefulness. Seeking help when necessary was also a form of resourcefulness, termed social resourcefulness (Kumar, 2017). High levels of resourcefulness in people facing adversity means that those people perform better in their social roles when compared to people with low levels of resourcefulness (Avery & Bekhet, 2018; Baptista et al., 2016).

In addition, family dynamics are reported to influence resilience in both positive and negative ways (Fealy et al., 2018). Disagreements between family members are a potential source of conflict, as families may disagree on the best care plan for the person with MNCD. In addition, conflict can be perpetuated because of the unequal distribution of caregiving responsibilities among family members. In contrast, united families who cooperated with each other report greater resilience in dealing with the adversities associated with caring for a person with MNCD (Borson et al., 2021; Fealy et al., 2018).

Lastly, the economic status of informal caregivers of persons with MNCD is reported to influence resilience (Fealy et al., 2018), although it is unclear whether the association between resilience and the economic status is a direct one or whether the resilience of informal caregivers is more influenced by their perception of adequacy of income. Lower levels of income are associated with adverse negative outcomes and poorer physical health for informal caregivers. Those caregivers with higher income access better emotional support more advanced health care, and report fewer depressive symptoms (Fealy et al., 2018). Informal caregivers report a great need for financial assistance because of the substantial costs associated with caring for persons with MNCD (Droes et al., 2017; Fealy et al., 2018).

2.6.2 Stress and coping theory

This theory was developed by Lazarus and Folkman (1984), who described coping as the person's mental and behavioural efforts to deal with internal and external pressure (Lin et al., 2019). The theory posits that how challenges are appraised by individuals ultimately results in positive or negative adaptation. The theory further assumes that effective coping reduces risk factors for negative adaptation. Supporting the theory by Lin et al. (2019) state that people use both problem- and emotion-focused strategies to cope with stressful situations and the mode used predicts the outcomes. For example, problem-focused coping can moderate the potentially negative effects of emotion-focused coping in order to produce positive outcomes (Lin et al., 2019).

A study by Baptista et al. (2018) on informal caregivers of people with MNCD found that caregivers' coping was influenced by the stages of the disease, meaning caregivers used different coping styles at different times. For example, some caregivers experienced emotional distress immediately after the diagnosis of MNCD in their close relative (Duplantier & Williamson, 2023), whereas other caregivers showed poor coping and depressive symptoms as the disorder progressed to the severe stages and as the period of care increased. The caregivers who used more dysfunctional coping strategies were reported to experience increased caregiver burden (Baptista et al., 2018; Duplantier & Willaimson, 2023).

In addition, dysfunctional coping strategies have been found to be significantly related to anxiety and depression (Baptista et al., 2018). Informal caregivers who employed emotion-focused coping strategies report low levels of anxiety and depression (Baptista et al., 2018). Some of the emotion-focused coping strategies used include acceptance and positive reframing, in which adverse events are redefined so they can be more manageable for caregivers (Cassidy et al., 2022). The use of these positive coping styles is further associated with family caregivers caring for a person with MNCD in a study by Alnes et al. (2021).

2.7 Conclusion

In this chapter, the researcher reviewed extant literature on the experiences of informal caregivers of persons with MNCDs. The aim was to explore what has been studied and reported on informal caregivers' attitudes toward their caregiving experience, the coping strategies they use to deal with their challenges, and the support services available to them.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

The study's methodology specified the researcher's procedure in studying the topic (Bailey et al., 2020). It described the research design and methods for selecting participants, data collection, and analysis. In this chapter, the researcher describes the nature of this study and the data collection procedures used to elicit the experiences of informal caregivers of persons with major neurocognitive disorders (MNCDs).

3.2 The study design

A mixed methods approach was adopted in this study. The mixed methods research consisted of a qualitative and quantitative component (Vogt et al., 2021). A mixed methods approach was important for this research because the combination of quantitative and qualitative methods provided a broader and more complete vision of the experiences of informal caregivers and their coping strategies (Almeida, 2018). On the one hand, the qualitative approach was suitable for the researcher to understand the experiences of informal carers of persons with an MNCD. The goal was to understand the caregivers' coping strategies and access to support services. The term qualitative places importance on the qualities of information gathered, not experimentally measured in terms of quantity, amount and intensity. Ravitch and Riggan (2017). Thus, qualitative research emphasises depth rather than breadth (Carl & Ravitch, 2020). The aim was to produce descriptive data which sought to understand:

1) The experiences of informal caregivers of people living with major neurocognitive disorders.

2) The coping strategies of informal caregivers of people with major neurocognitive disorders.

3) The availability of support services for informal caregivers of people living with major neurocognitive disorders.

It is incontestable that rich descriptive data is best obtained through qualitative research (Bailey et al., 2020). The capacity to ask questions that elicit responses in participants' own words made the qualitative approach preferable to a quantitative one (Drinkwater et al., 2022). This particular aspect was essential in answering questions that seek to identify factors influencing the experiences and coping of informal caregivers of persons with MNCDs.

On the other hand, a quantitative approach was used to measure informal caregivers' coping, burden and depression. The quantitative psychometric scales helped to triangulate and objectify the data on the experiences and coping strategies of the caregivers. The purpose of using the triangulation was to obtain different but complementary data on the on topic. The use of mixed methods assisted in overcoming the limitations of quantitative and qualitative methodologies, permitting the researcher to obtain rich information that could not be obtained using each method alone (Almeida, 2018).

3.2.1 Research paradigm: An interpretivist approach

A common characteristic of social science research is that it is located within the confines of a particular paradigm (Baškarada & Koronios, 2018). A paradigm is a worldview that presents a definition of the social world linked to the related sources of information and appropriate methods to tap these sources (Carl & Ravitch, 2020). In this study, the researcher used interpretivism, which states that exploring and understanding the social world should be done from the researcher's and the participants' perspectives. Interpretivism is a school of thought emphasising the significance of interpretations and observation in knowing the social world. The underlying assumption of an interpretive paradigm is that the social world consists of

symbolic meaning observable in human acts, interactions, and language (Creswell & Poth, 2018). Reality is subjective and multiple and seen from different perspectives. Meanings derive from perceptions, experiences, and actions within a social context (Bailey et al., 2020).

Moreover, interpretivism asserts that a social researcher must explore and understand phenomena by interacting with the participants (Carl & Ravitch, 2020). In this case, the informal caregivers were the research participants. Through an interpretivist paradigm, methods such as interviews allowed the elicitation of informal caregivers' views regarding their experiences of informal caregiving. The purpose was to identify informal caregivers' experiences, coping strategies, and access to support services.

Furthermore, the interpretive paradigm strongly emphasised experiential data; this focus aimed to provide an enriched understanding, description, and explanation of human experience. The methodological implication of this theory of knowledge was to gather deeply nuanced data. The researcher interacted with people with direct experience of the phenomenon of interest (Bailey et al., 2020). Thus, the interpretivist paradigm presented the opportunity to get in-depth information about the experiences of informal caregivers.

3.2.2 The researcher as the key instrument

The researcher used what Shumba (2018) described as social intelligence to cultivate a relationship of trust with participants that led to the desired information. The researcher assumed the role of a primary instrument for executing the dual task of data collection and analysis. Before entering the field, efforts were made to develop essential skills necessary for a successful data collection exercise. These included listening, looking, posing questions, and interpreting issues. Careful and active listening motivated the interviewees to share their experiences (Creswell & Poth, 2018).

3.2.3 Study setting and context

Most of the participants were from Lamontville in Durban. The area is located in the eThekwini District of the KwaZulu-Natal province in South Africa. The population in the area is mostly Black South Africans but is growing more culturally and ethnically diverse. The Bessie Makatini Foundation is located in this area. The organisation provides support to informal caregivers of persons with MNCDs.

3.3 Sampling

This study's participants were informal caregivers of persons with MNCDs. As previously defined in the introduction chapter, informal caregivers do not receive payment for their care because of their personal ties to the affected person. The informal caregivers were purposively selected to participate in the study from the Bessie Makatini Foundation (see Appendix 1: Gatekeeper's letter). Purposive sampling was necessary because of the study topic. Purposive sampling is used to identify respondents who are most likely to produce suitable and useful information (Gentles & Vilches, 2017). The sampling criteria for recruitment included the following:

- The participants had to be informal caregivers or family caregivers of a person living with a major neurocognitive disorder.
- Both males and females were eligible for selection.
- The participants had to be above 18 years of age.

The reason for choosing participants from the Bessie Makatini Foundation was that the foundation had pre-screened the caregivers before they joined the organisation to ensure that they were caregivers of a person with MNCD. Before the sample was recruited, ethical clearance was obtained from the University of KwaZulu-Natal's Humanities and Social

Sciences Research Ethics Committee (see Appendix 2: Ethical clearance letter). After ethical clearance was granted, the gatekeeper requested consent from the caregivers for the researcher to access the database and contact them. The caregivers from the Bessie Makatini Foundation database received a call from the researcher to invite them to participate in the research. The research purpose and procedures were explained to the potential participants (see Appendix 3: Information sheet). The participants gave verbal consent, which was digitally recorded. Those individuals who consented to participate received a verbal explanation of the consent form (see Appendix 4: Consent form) because most participants did not have emails or smartphones, so emails could not be sent to them. The researcher and participants then agreed on set interview dates and times.

A pool of possible participants was established before the interviews commenced to increase the opportunity for selecting information-rich cases. Establishing a large pool of participants was necessary because, in qualitative research, details and depth take precedence over numerical accuracy (Barnett et al., 2018). Information-rich participants provided a great deal about the issues important to the purpose of the research. In the end, nine caregivers consented to participate in the study.

The sample size was determined by data saturation (Braun & Clarke, 2022). Data saturation is a point during data collection when no new information emerges. Saturation was assessed based on the extent of theme development and theme importance in the data collected (Bailey et al., 2022). After six interviews, the essential elements of the themes were already present (Alam, 2020). However, three more interviews were conducted after that, for accuracy.

3.4 Data collection

Data collection was conducted from December 2020 to March 2021.

3.4.1 Instruments

Data were collected using four instruments: an interview guide, the Beck Depression Inventory (BDI-II), the Zarit Caregiver Burden Interview short form (ZBI-12), and the Brief COPE Scale (BCS).

An interview guide was used (see Appendix 5: Interview guide). Using an interview guide ensured consistency in the interview procedure (Benny et al., 2021). The interview guide had several sections. The first section included demographic data. Questions about caregiving experiences, coping strategies, and available support followed this. This interview schedule was derived from the research questions mentioned above. However, these questions were broken down to cover content that would give much broader information for each research question. For example, for the first research question, which explored the experiences of the participants, the researcher formulated questions about the relationship with the person with MNCD, the hours spent on care, training, and understanding of MNCD. The second question was to find out more about how participants coped with caregiving. Therefore, participants were asked to share how they coped with caring for a person with MNCD, how they dealt with the negative feelings of those challenges, and what were some of the negative moments experienced. The last research question inquired about the support received by the participants. Hence, the participants were asked to explain what support they had received from family and non-family and how often they received support.

The Beck Depression Inventory (BDI-II) was used to assess the severity of depressive symptoms for all the study participants. As stated by Makhubela and Mashegoane (2016), the test is reliable and valid, and suitable to the South African population. The test is a self-report rating questionnaire that explores the individual's attitudes and depression indicators (Hassem & Laher, 2019). The BDI-II is evaluated according to the total score of each participant; different score brackets indicate various levels of depression. A score between 1 and 10 is

considered normal, whereas a score between 11 and 16 is indicative of mild mood disturbance. Borderline clinical depression is indicated by a score between 17 and 20. Scores between 21 and 30 indicate moderate depression and severe depression is indicated by scores between 31 and 40.

The BDI-II was used as an additional instrument to support the subjective responses provided by the participants in the semi-structured interview guide. The questions in the interview guide included factors such as gender, age, total hours spent on caregiving, relationship to the care recipient, and the level of support required. According to Chiatti et al. (2020), these factors are associated with self-reported symptoms of depression and anxiety among caregivers of persons with MNCD. For example, the participants in this study were asked how many hours per day they spent providing care? As reported in previous research, informal caregivers who spent more than six hours per day on care responsibilities reported symptoms of depression (Chiatti et al., 2020; Dietzel et al., 2021).

The Zarit Caregiver Burden Interview short form (ZBI-12) was used to evaluate subjective caregiver burden. The form was found reliable, valid, and suitable to the South African population (Ebrahimi et al., 2015). The ZBI-12 (short version) has 12 questions covering the personal strain and role strain domains. Each question was graded on a Likert scale of 0 to 4 points (*never* to *almost always*). The results are interpreted by analysing the total score. The scale score of 0 to 21 indicates no to mild burden, whereas the scale score of 21 to 40 shows mild to moderate burden. Any score between 41 and 60 means moderate to severe burden and scores above 61 indicates severe burden. High scores indicate more significant caregiver strain.

The ZBI-12 was interpreted in relation to the BDI and participant responses to the interview guide. Previous literature has indicated a high prevalence of depression among informal caregivers of persons with MNCD (Addabbo et al., 2021). The interview guide

included questions on the impact of caregiving on the social life of the participants. Informal caregivers who have less time for social life have reported higher caregiver burden. Different researchers have proposed numerous factors as predictors of caregiver burden (Branger et al., 2016; Liew & Yap, 2019; Lin et al., 2017). However, results are inconsistent because many studies have been undertaken in different cultural contexts and populations, and different scales were used to evaluate similar aspects of caregiver burden (Gratão et al., 2019).

The Brief COPE Scale (BCS) was used to assess the coping behaviours of caregivers (Cooper et al., 2008). The Brief COPE is a self-report questionnaire to assess people's coping behaviours and thoughts. A clinical study has found three composite subscales evaluating emotion-focused, problem-focused, and dysfunctional coping to be helpful and to have content validity (Cooper et al., 2008). The scale is made up of three subscales, measuring 14 facets of coping. The results are interpreted by looking at the answers to specific questions. For example, items 2, 7, 10, 12, 14, 17, 23, and 25 indicate that participants used problem-focused coping skills, which include active coping, use of informational support, planning, and positive reframing. Questions 5, 9, 13, 15, 18, 20, 21, 22, 24, 26, 27, and 28 indicate emotion-focused coping, characterised by venting, use of emotional support, humour, acceptance, self-blame, and religion. Questions 1, 3, 4, 6, 8, 11, 16, and 19 indicate avoidant coping characterised by self-distraction, denial, substance use, and behavioural disengagement. Internal reliability for the 14 subscales ranged from Cronbach alpha 0.57-0.90 (Cooper et al., 2008).

3.4.2 Data collection procedure

This study collected data using in-depth individual interviews and assessments, as described above. The qualitative research interview is closer to a dialogue than a question-and-answer session (Morton et al., 2019); this intensive, one-on-one interview entails a conversational partnership (Bailey et al., 2020). Barnett et al. (2018) referred to in-depth interviewing research

as responsive interviewing. The responsive interviewing model applied the interpretive constructivist philosophy, which aimed to create depth of understanding rather than breadth. Apart from having a flexible and adaptive design, responsive interviewing proved suitable because the study aimed to elicit informal caregiver interpretations of their own experiences and ways of coping with the challenges associated with caring for a person with MNCD. A flexible and adaptive design allowed necessary adjustments to both the interview schedule and the pool of participants. The qualitative interview unfolded as more of a disclosure between two parties, mutually developed during the interview session (Barnett et al., 2018).

The study was conducted during the COVID-19 pandemic. Since the country was in lockdown to prevent the spread of COVID-19, there was limited movement and gatherings. Therefore, interviews were conducted virtually via telephone calls. The telephone calls were also used so that the caregivers did not incur costs such as data expenses for the interview. According to Benny et al. (2021), telephonic interviews provide a balanced power distribution between the interview participant and the interviewer. It was also noted that telephonic interviewing positively encouraged the interviewees to speak more freely and gave greater control to the interviewees to direct the conversation toward areas perceived as necessary. All telephonic conversations with the participants were approximately one hour long and were recorded using a recording app on the interviewer's laptop. Two interviews were conducted in English and seven in isiZulu, as preferred by the participants.

After sharing a brief introduction, participants were allowed to ask questions, which allowed for an explanation that ensured that the participants understood the study (Barnett et al., 2018). In most cases, this helped ease the interview atmosphere and allowed for a natural conversation. Mistrust was also cleared by informing participants that they were not compelled to answer all questions if they felt uneasy responding to some and could stop the interview if

they wished. The open-ended interviews allowed participants to share their experiences regarding caring for a family member with MNCD.

In addition, the participants answered questions as specified by the BDI-II, ZBI-12, and BCS. The scales have pre-given responses and ratings. The researcher explained to the participants that they had to choose, from the pre-given responses, the answers that most reflected their experiences and feelings. The rating of the questions was also explained at the beginning of each scale and the questions were read to the participants in the order that they are provided on each form. To maintain consistency and save time, participants were requested to give numerical answers that matched their responses. For example, the ZBI rating is: 0 = Never; 1 = Rarely; 2 = Sometimes; 3 = Quite frequently; Nearly always = 4. Therefore, if the participant gave the answer 0 to the question: "Do you feel angry when you are around your relative?" it meant that the participant never felt angry when around their relative with MNCD.

3.4.3 Data analysis

The reflexive thematic analysis described by Drinkwater et al. (2022) was used to analyse the data. Drinkwater et al. (2022) defined thematic analysis as a qualitative analytic method where patterns or themes embedded in the data are identified, analysed, and reported. They posited that thematic analysis was inspiring because of emerging themes. The steps followed in the thematic analysis are described below.

Familiarisation with the data: Becoming familiar with the data in this phase, the researcher familiarised herself using information from the interview recording before transcribing that particular recording. No notes were taken after replaying each recording to give the researcher the opportunity to familiarise herself more with the data before transcription. The researcher transcribed by transcribing the interviews verbatim after listening to each recording. The interviews conducted in isiZulu were transcribed into isiZulu and

translated into English. When all interviews were transcribed, the researcher read the transcripts numerous times. At this point, the researcher made notes of common responses.

Generating initial codes: Codes were generated using the comments function in Microsoft Word (2016). It became possible to highlight the text associated with each code and note the codes in the side margin. Any piece of data found applicable to answering the study question(s) was coded. The researcher uncovered helpful codes, eliminated extraneous codes through numerous coding iterations, and increased familiarity with the data. In a spreadsheet, the researcher charted the development of the coding process, using the data items listed in the first column. This file contains all the codes created during the initial coding round, as well as information on each participant. This spreadsheet also contains the documentation of later rounds of the process (Drinkwater et al., 2022).

Generating themes: The researcher combined codes into initial themes, thus mapping the initial themes. The researcher studied the codes from each transcribed interview, which helped discover central themes representing shared ideas across the dataset. The researcher evaluated the significance of these themes and whether they related to the 36 interview questions at hand. The evaluation of themes also involved looking at the extent to which participants' discussions were patterned and revealing the underlying meaning these patterns hold, allowing the researcher to uncover the overall narrative as these themes were carefully explored (Drinkwater et al., 2022).

Reviewing potential themes: During this phase, a repeated review of the themes was carried out and meaningless candidate themes were excluded. Reviewing the connections between the data items and codes that underpinned each subject and sub-theme comprised level one. Candidate themes for the data collection were examined at level two. The resemblance of the themes to the study question was evaluated. Some of the sub-themes were reorganised (Drinkwater et al., 2022).

Defining and naming themes: The task here was to present a detailed list of themes and sub-themes. They were written in line with the dataset and research questions. The aim was to combine all themes to produce themes which related to the dataset's content and were informative about the research question(s). The researcher then identified relevant items when writing up the analysis. Multiple extracts were selected that related to specific themes. The researcher aimed to create an explanatory write-up (Drinkwater et al., 2022); the researcher then revised the theme order.

Producing the report: This sixth phase was the final review of the study and is presented in this thesis. The aim was to report the themes so that they connected logically and meaningfully while building a cogent data narrative. The report follows the structure for a Master's thesis (Drinkwater et al., 2022).

Feedback: Participants were informed that the results would be communicated to the relevant stakeholders in the Department of Health and published in scientific journals. Furthermore, a copy of the results will be shared with the Bessie Makatini Foundation. The participants may request a copy of the results should they need them. The contact details of the researcher have been included in the consent form (Drinkwater et al., 2022).

3.5 Ethical considerations

The research was ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (HSSREC/00001775/2020). The term 'ethical considerations in research' refers to the researcher's responsibility to protect research participants from any distress, harm, or vulnerability resulting from their participation in the study (Ketefian, 2015, p. 164). For the research to be deemed ethically acceptable, the researcher must forecast potential research outcomes and assess how they can favourably or unfavourably affect the research participants and society (Grenier & Merriam, 2019). To

ethically store data, the recordings were saved using pseudonyms and were password protected. A copy of each recording was sent to the research supervisor as per the University of KwaZulu-Natal rules for data storage. Lastly, the participants' rights, health, and safety were protected by the ethical precepts in the Belmont Report (1979), namely informed consent, confidentiality, autonomy, beneficence, and justice (Shore, 2006).

Informed consent is described as voluntary participation based on adequate information and understanding of the research and the implications of participating in the research (Baysari et al., 2020). Informed consent is often cited as the foundation of research ethics (Salmons, 2022). Obtaining informed consent was fundamental to satisfying ethical research principles of respect, beneficence, and justice. To ensure informed consent, the researcher provided the necessary information to the potential participants by reading the letter explaining the study's risks and benefits. The researcher used language that was understandable to the potential participants to ensure that they fully understood the purpose of the research. The potential participants were allowed to decide whether or not to participate in the study. The participants were all mature and did not have mental illnesses affecting their legal capacity to consent. Verbal consent was obtained from the participants, and the researcher indicated they had the right to withdraw their participation at any time without unfavourable outcomes.

Confidentiality: The researcher took precautions to safeguard the personal information of the participants by using pseudonyms instead of their names. Also, the researcher personally transcribed all transcripts. The saved recordings were password-protected.

Autonomy: According to Nortjé et al. (2019), the term 'autonomy' describes the freedom of an individual to choose which activities they will or will not engage in. Full autonomy necessitates that research participants comprehend the requirements, form an informed opinion regarding how participation will affect them, and freely choose whether or not to engage. The informed consent process, which involves fully disclosing the nature of the

study, its risks, benefits, and alternatives to potential research participants and giving them the time to ask questions before deciding whether or not to join, is the cornerstone of protecting autonomy.

In this study, the principle of autonomy was applied through the following process. An invitation letter was read out to each prospective participant. The letter provided the contact information of the researcher and her supervisor. It was explained to each person that the study involves research experiences of caregivers of persons with major neurocognitive disorders, their coping strategies, and the support available. Then the procedures involved were explained. These procedures included interviews and psychological measures to test caregivers' coping levels. Each participant's participation duration was estimated to be around an hour.

Moreover, it was explained to the prospective participants that participation in this research was voluntary, and participants could withdraw participation at any point. In the event of refusal/withdrawal of participation, the participants would not incur penalties, loss of treatment, or other benefits typically entitled to them.

Beneficence: The term 'beneficence' refers to the duty of the researcher or scientist to maximise advantages for the study participant and society while reducing the risk of damage to the participant. In this study, the ethical principle of beneficence applied as follows: There were no risks or discomforts identified for participants. However, the Bessie Makatini Foundation provided counselling support for participants who required the service. The participants were invited to direct any problems, concerns/questions to the researcher or the UKZN Humanities & Social Sciences Research Ethics Committee. The contact details for the committee were provided.

Justice requires proper participant selection, which means avoiding those who can be unjustly compelled into participating, such as offenders and institutionalised minors (Nortjé et

al., 2018). The criteria for participant selection in this study excluded people younger than 18 years of age and those unable to respond for themselves due to illness.

3.6 Trustworthiness of the study

According to Nowell et al. (2017), trustworthiness concerns how the researcher can be convinced and convince others that research findings are worthwhile. This study ensured trustworthiness through credible methods and sources of information, making the study dependable, confirmable, and transferable, as explained below.

Credibility in research refers to presenting convincing and believable findings (Nowell et al., 2017). In pursuit of this principle, the researcher ensured that the participants' views, including divergent ones, were respected and reflected in the presentation of findings and the analysis. In this study, credibility was achieved through triangulation with data from participants being collected both qualitatively and quantitively.

Dependability: According to Nowell et al. (2017), dependability refers to the degree to which the reader can be convinced that findings did indeed occur as the researcher declares they did. In this study, the researcher ensured dependability by providing thick descriptions of the various steps taken and giving justifications for decisions taken during the execution of the study in the field (Barrett et al., 2018). The research questions were carefully selected to fit the research design and study objectives.

Confirmability refers to the degree to which the study findings directly result from the study focus compared to the researcher's biases (Babbie, 2021). Although the researcher acknowledges their position in the research, the distinction between personal values and those of study participants is maintained, and this involves self-reflexivity (Nowell et al., 2017

Transferability: According to Nowell et al. (2017), transferability refers to the extent to which the outcomes can be applied to other contexts or with other respondents. The

researcher collected adequately detailed data and reported on it with the necessary accuracy. The aim was to allow the reader to judge transferability, also known as extensibility (Barrett et al., 2018). The researcher purposively selected participants from the database of the Bessie Makatini Foundation. The organisation supports persons with neurocognitive disorders and their caregivers, thereby increasing the likelihood of findings representing the experiences of informal caregivers. However, attention should be given to contextual factors if findings from this study are to be transferred to other contexts.

It is pertinent to end this chapter by declaring that all ethical considerations in the conduct of the study, as articulated in the research proposal and approved by the Research Ethics Committee of the University of KwaZulu-Natal, were observed.

<center>**CHAPTER FOUR: FINDINGS**</center>

<center>**4.1 Introduction**</center>

The research findings are presented in this chapter. The research objectives answered included understanding: (i) the experiences of informal caregivers; (ii) informal caregivers' coping mechanisms; and (iii) the availability of informal caregiver support services. The findings are structured to include both the thematic analysis and the findings of the psychometric tests. The reflexive thematic analysis method, described by Drinkwater et al. (2022), was used to analyse the data provided by the participants into the various themes.

<center>**4.2 Participant characteristics**</center>

Nine participants participated in the study; all participants were Black African and seven were females. Four were married and five were single. Five participants had completed high school, while four had obtained a tertiary qualification (see Table 4.1).

Table 4.1: Participants' demographic data

Participant	Gender	Marital status	Educational level	Employment status
1	Female	Married	Tertiary qualification	Employed
2.	Female	Single	High school	Unemployed
3.	Female	Single	High school	Employed
4.	Male	Single	Tertiary qualification	Self-employed
5.	Male	Married	Tertiary qualification	Retired
6.	Female	Married	High school	Self-employed
7.	Female	Single	High school	Unemployed
8.	Female	Single	High school	Employed
9.	Female	Married	Tertiary qualification	Unemployed

4.3 Thematic analysis

The thematic analysis produced the following seven themes: positive experiences, negative experiences, acceptance, spirituality and religion, positive reframing, informal support, and formal support (see Table 4.2). Direct quotations were used to substantiate the main themes emerging from the participants' responses to the research questions. Pseudonyms were used to protect the participants' identities.

Table 4.2: Themes that emerged from the data

Objectives	Themes

Experiences of informal caregivers	• Positive experiences
	    ○ Loyalty and duty
	    ○ Advocacy
	• Negative experiences
	    ○ Predeath grief
	    ○ Sacrifices made
	    ○ Behaviours that challenge
	    ○ Lack of support from family

Informal caregivers' coping mechanisms	• Acceptance • Spirituality and religious practices • Positive reframing

Availability of informal caregiver support services	• Informal support:
	    ○ In-house respite workers
	• Formal support
	    ○ Counselling
	    ○ Support groups

4.4. Theme 1: Positive caregiver experiences

Participants reported having various experiences with being caregivers. Some of the experiences expressed were positive, while others were negative. Two sub-themes emerged from caregivers' positive experiences. These were loyalty and duty and advocacy for major neurocognitive disorders (MNCDs).

4.4.1 Loyalty and duty

Most participants expressed devotion to their loved ones suffering from severe neurocognitive problems. They believed that no one else would comprehend and adequately care for their family member. Further, they indicated that it was their duty as children to look after their parent with severe neurocognitive impairments. They also thought that providing care to their affected parent could show them how much they loved, appreciated, and valued them. Therefore, the majority of the participants prioritised the safety, well-being, and care of their loved one suffering from MNCD. According to the reports:

> P7: *"... when she no longer brushes her teeth, sometimes she stays for a whole week without brushing her teeth ... but you will do* [it]. *It is your parent, yes; there is nothing to do"*.

> P5: *"Who must this go to? If not me, who? Because this is my mother. She is my world. She is the only parent I have. She is a blessing to me. Some wish they still have parents. I look back on my childhood. It was my turn."*

> P6: *"We do not want her to die before time ... we vaccinated so we can reduce her chances of contracting COVID-19 ... we protect her so that God can take her when it is her time."*

The caregivers' statements above centred on their dedication to caring for their elderly parent with severe neurocognitive impairments. Helping parents was a way to express gratitude for the prior kindness they had shown to the carer when they were children. More focus was on the loving and caring parent-child bond than on the sickness. The caregivers also provided concrete examples of how they continuously demonstrated their loyalty by helping with their parent's care. Maintaining normal levels of personal cleanliness and self-care for their loved ones who could no longer do so for themselves gave them tremendous happiness. The

caregivers had taken extra precautions to protect the lives of human beings under their care, specifically at some stage in the COVID-19 pandemic, which posed the threat of death. The caregivers' loyalty to their loved ones with neurocognitive ailments triggered them to value their lives, notwithstanding their condition.

4.4.2 Advocacy for major neurocognitive disorders

One-third of the individuals interviewed were fervent supporters of people with MNCDs. Sharing their expertise and caregiving experiences was a strategy to ensure that more people knew about the condition. They had the following things in common:

> P6: *"Granny's illness has interested* [me] *in talking to people about dementia. I wish I could get a chance to teach about dementia. Even when I preach, I do include it in my sermons. I feel that if I tell someone about dementia, I have revenged against dementia."*
>
> P8: *"No, I am free because I like elderly people. They deserve to be treated well in their last days. They are alive because of the grace of God. We do not know what the future holds."*

In the quotations above, the caregivers expressed their desire to educate the public about MNCDs so that more people can be aware of the disorder. The caregivers also expressed their views on the importance of respecting older persons.

4.5 Theme 2: Negative caregiving experiences

Participants also reported that their caregiving experiences were not always positive; instead, the participants also had some negative experiences. Their negative experiences were captured in the emergence of four sub-themes: (i) predeath grief; (ii) sacrifices made; (iii) challenging behaviours and symptoms; and (iv) lack of support.

4.5.1 Predeath grief

Most informal caregivers reported that they suffered from the grief caused by the knowledge and expectation that their family member with MNCD will ultimately die because of the disease. The caregivers expressed anger towards MNCDs and described the disorders as terrible diseases, worse than any other disease they had witnessed. They reported that feelings of sadness came from a sense of loss that most informal caregivers felt as they witnessed their family members deteriorate in front of them. The following was said:

> P6: *"Dementia is a terrible disease. It is more than all the diseases that I know. It is terrible to be alive when you are no longer there."*

> P1: *"I used to rely on her wisdom when making decisions. Like now, I need to do a traditional wedding. My father is late, and my mother is not 'there' to remind me of our family traditions".*

> P7: *"... I have learned that a person with this illness does not survive.*

The carers in the captions above felt they had lost their parents to the illness, and they experienced nostalgia for what was gone. Their parent's physical presence and incapacity to parent them was the leading cause of the misery they experienced. Many caretakers alternated between hope and sorrow. On the one hand, they believed that the person might get better, and on the other hand, they realised that the illness would eventually kill their relative.

4.5.2 Sacrifices made

Most informal participants explained how care work affected their lifestyles. They sacrificed their needs to care for a person with MNCD. Participants reported having limited financial resources to meet their personal needs because of being unemployed. Some caregivers explained that they had to rely on the pension playouts of the family members with MNCD. However, the available money was insufficient to cover the needs of the family members with

MNCDs and the informal caregivers, which led to informal caregivers having to prioritise the needs of ill family members over their own. The following were said:

P2: *"Not working is a problem. I can go to work in the morning and come back, that stresses me. I have personal needs that I cannot meet. Even if you do have some needs met, but that cannot be compared to someone who is working."*

P4: *"She lost everything she had because her partner stole everything she had. Immediately, I had to support her. She came back with only R500. Some people are so cruel."*

P9: *"Even when I tell them, 'Guys, I have to go somewhere', they all tell you, 'I have to do this', and no one is willing to help. It was so painful. Last year, my husband had an accident. There was only one day that my husband goes to check up; I must go with him. They were refusing and he ended up going alone.* [But] *I must support him."*

In the examples above, the caregivers discussed how providing care to relatives battling with MNCDS forced them to quit formal employment. Additionally, they spent their financial resources to support their ailing parents, who could not care for themselves. There were times when their caregiving responsibilities forced them to sacrifice supporting other family members.

Additionally, the caregivers sacrificed long periods of time taking care of family members. All the caregivers, except one, stated that they had spent at least three years caring for a family member with MNCD. According to the caregivers, there was never a time when care recipients could be left alone. Below are the assertions:

P3: *"Since June 2018 … the whole day, because the work is mine day and night."*

P4: *"It started about three years ago."*

P1: *"So, it is 24 hours when you look at it, because even that, to her, it is important that you listen to her. You cannot just leave her unattended."*

The caregivers' statements showed that caring for persons with MNCDs required a lot of time and full-time commitment. Often, caregivers had less time dedicated to attending to their personal needs.

4.5.3 Challenging behaviours and symptoms

Most informal caregivers explained that they were worried about the behaviours of their family member with MNCD. Troubling symptoms included wandering around, getting lost, and loss of memory. The following was said:

> P7: *"One day she was removed, and she went to a neighbour's house. She stayed, and they were understanding because they called the police … because other people could have killed her. So, they took her to the police station, and she said that she was not going out because she was waiting for her children from that house."*

The caregiver above explained her fear in the above quote when her mother walked to a neighbour's house without realising that it was not her home. The caregiver was concerned that her mother could have been killed.

> P9: *"The only thing I am worried about is that she is always walking around … But I am thinking of her, her own body, that she does not get tired. Since she wakes up early at 4 and sleeps at 2, you can think about that period, walking around. You only force her to sit down when she is eating, which is not more than 30 minutes. After eating, she will stand up."*

The caregiver's remarks above indicate her concern that her mother was not getting any rest because she constantly stayed on her feet, walked around the house, and only sat down during mealtimes.

The statement below explains how the caregiver realised that his mother was having a problem with her memory. She would forget such important details as where she intended to go. Later, her memory loss escalated, and she lost essential items and accused people of stealing from her. She would cook large meals and forget that she had prepared meals for more than a day, which culminated in being wasteful.

> P4: *"I noticed it a long time ago that she would forget things easily. She stayed in Ladysmith with her partner. So, she would leave the house to pick up a child from school. The next thing, she would drive to Durban. Then things escalated. She started accusing people of theft. You see, things got worse until I saw that she could not do some things that she used to do. For example, she was a person that loved to cook. So, when she cooked, she would cook much food and not put it in the fridge. I saw that something was not right."*

4.5.4 Lack of support from family members

Some participants received no support from close or distant relatives. They did not receive assistance with care activities. Hence, most of the informal participants carried out duties without assistance which exacerbated their struggles. The following were reported:

> P7: *"Nothing; when a person comes, they come as a stranger … no one thinks, even if I tell them to help me."*

> P9: *"It was then that I realised the kind of sisters I had … They told me that our mother had dementia. Everybody seemed to understand, but no one was helping out."*

> P4: *"I feel that the people she looked after should be doing better. I am not saying they should support her financially, but even to be just there for her is important. And my sister as well, I do not feel she is doing as much as she should. She should be doing more than me because she is female."*

In the above remarks, the caregivers elaborated on how family members distanced themselves from caring for relatives with MNCDs. Further, they did not respond, even when asked to assist. The caregivers also realised that even immediate family members did not give adequate support. Also, the participants shared similar views that caregiving was more a female role.

4.6 Caregiver coping

Participants reported that they adopted various coping mechanisms. This section first presents the specific coping mechanisms that were qualitatively expressed by informal caregivers. Secondly, the researcher presents the psychometric measurements of how informal caregivers coped with the pressures of caregiving.

4.6.1 Theme 3: Acceptance as a coping mechanism

Two-thirds of the participants stated that accepting the situation helped them with the strength to manage their roles as caregivers. The following were reported:

> P5: *"What helps is to accept the situation as it is."*

> P6: *"No, I feel like what I have done is enough. I even tell my husband that we should not worry that she has not bathed. Let us be satisfied that she is alive and happy."*

In the above quotations, the caregivers explained how accepting their family members' condition helped them to cope better. Further, the caregivers reported that accepting the person with MNCD without trying to change them became imperative.

4.6.2 Theme 4: Spirituality and religious practices to help with coping

More than half of the informal caregivers relied on faith and religious practices to cope with the adversities of caregiving. Hence, some of the caregivers alluded to praying about the challenges they encountered. Other caregivers explained how their faith assisted them in

reaching a point of acceptance of the caregiving situation. The informal caregivers believed that MNCDs were God's will. The following were said:

P7: *"She would sit flat on the floor until her legs were swollen, but she never became sick with any influenza disease, I asked God."*

P8: *"I have the faith. I know God does things His own way. My mother was also a woman of faith. This was the will of God. We do not know the future."*

The above statements show how the caregivers prayed about troubling situations and relied on faith for strength.

4.6.3 Theme 5: Positive reframing

The participants reported being able to reframe the challenges encountered more positively.

P6: *"She is with us, and she is valuable. Another thing I like is that her presence is felt."*

P4: *"I think something that keeps me is to say I am doing my best. I try to push it as hard as I can."*

In the above excerpts, the participants emphasised things they valued about their relatives with MNCDs rather than their illness or the challenges they encountered. They also acknowledged their caregiving contribution as sufficient, instead of focusing on what they could not do.

4.7 Caregiver depression, burden, and coping using psychometric scales

Participants' depression, burden, and coping were assessed using the BDI-II, ZBI-12, and BCS psychometric scales. The participants first answered the 21-item BDI-II; the results are shown in Table 4.3.

Table 4.3: Caregiver depression (BDI-II)

Participant (N=9)	Raw score	Score interpretation
1	2	Normal
2	4	Normal
3	0	Normal
4	10	Mild depression
5	0	Normal
6	1	Normal
7	9	Normal
8	8	Normal
9	8	Normal
Mean	**4.66**	
SD	**4.09**	

The analysis demonstrated that most participants showed no symptoms of depression, which suggested that they were coping with their caregiving situations. The results further illustrated that the participants seem to be using their coping skills and strategies effectively to cope with their situation. One participant showed mild depressive symptoms, which suggested that they were more prone to depression than the other participants.

The ZBI-12 screened for caregiver burden (Kuntawong et al., 2020). The results were as indicated on Table 4.4.

Table 4.4: Caregiver burden (ZBI-12)

Participant (N=9)	Raw score	Score interpretation
1	3	No to mild burden
2	15	No to mild burden
3	21	Mild to moderate burden
4	12	No to mild burden
5	0	No to mild burden
6	30	Mild to moderate burden
7	33	Mild to moderate burden
8	0	No to mild burden
9	30	Mild to moderate burden
Mean	**5.5**	
SD	**4.5**	

Half the participants experienced some degree of burden. The response suggests that the other half of the participants may be seen as coping well. These results were consistent with the previously stated results for the BDI-II which also showed that participants were using their coping skills and strategies effectively to cope with their situation.

Lastly, the Brief COPE Scale (Alessandrini et al., 2017) was administered, which assessed the coping styles of caregivers. The results were as indicated on Table 4.5.

Table 4.5: Caregiver coping (BCS)

Participant (N=9)	Problem-focused	Emotion-focused	Avoidant coping
1	32	21	8
2	40	24	8
3	32	18	8
4	36	28	8
5	32	24	8
6	40	18	8
7	36	28	8
8	40	16	8
9	32	24	8
Mean	**35.6**	**22.3**	**8**
Std. Deviation	**3.7**	**4.3**	**0**

According to the results, all the informal carers reported employing a more problem-focused coping style, which involved actively finding solutions to the obstacles they encountered. High scores indicated coping techniques addressed the factors causing stress. High scores also suggested psychological strength and a practical approach to problem-solving; they are predictive of positive outcomes. As previously stated, the participants reported receiving counselling and most reported being part of a support group for caregivers.

<center>**4.8 Caregiver support**</center>

The participants reported that they received various kinds of support. They firstly reported receiving informal support from in-home respite workers. Secondly, they reported having access to formal support in the form of counselling. Thirdly, they reported being supported by a support group that caters specifically for caregivers.

<center>**4.8.1 Theme 6: Informal support from in-home respite workers**</center>

As noted above, participants reported having both formal and informal support available to them. Most informal caregivers reported relying on hired in-home respite workers for instrumental support with practical caregiving tasks. The respite workers did some caregiving tasks, such as bathing the family member battling MNCD and preparing food. The caregivers indicated that the extra help from respite workers helped to ease the caregiving burden. Without such assistance, the informal caregivers felt that caregiving for their family member with MNCD was the same as full-time employment. Their caregivers felt relieved when there were respite workers to help them with their duties and it gave them time to rest.

> P5: *"There is a lady I hired to help me with care work. When she is bathing her, I will be preparing the food."*
>
> P9: *"I told myself that things would get easier* [by] *the time I found someone to look after her."*

In the above remarks, the informal caregivers explained how caregiving tasks were shared between themselves and hired workers, and the assistance relieved some pressure.

<center>**4.8.2 Theme 7: Formal support (counselling and support groups)**</center>

The caregivers mainly reported receiving counselling from the Bessie Makatini Foundation. The informal caregivers received practical advice on how to reduce caregiving stress.

P7: *"The management of Bessie Makatini Foundation helped me. They advised me to sleep with her in one room. Before that, I was sleeping in another room, and then I had to keep waking up."*

P9: *"The support team at Bessie Makatini Foundation was giving me support because, throughout all this time, when my dad was abusing and doing all kinds of things, she was the person who was supporting me."*

The above quotes show how the caregivers received advice on managing the challenges associated with persons with MNCDs, which included not sleeping at night and dealing with the conflict between the informal caregivers and other family members.

Almost all the informal caregivers used available support in the community, such as support groups for caregivers of persons with MNCD and expressed the benefit of attending support groups. The caregivers received information from the support group that helped them to understand MNCDs and to better manage and help persons with these disorders.

P5: *"Luckily, there is a support group at the Bessie Makatini Foundation. They help us to understand MNCDs. Sometimes there are seminars; that is where we get to understand the changes. We get to learn how to approach people with this illness."*

However, some informal caregivers were uncomfortable with the information about the challenges associated with the different stages of MNCDs.

P4: *"I could say that the support team at the Bessie Makatini Foundation made me understand dementia. Sometimes I attend seminars, but I do not enjoy attending these seminars via Zoom because you keep hearing things that are not positive. But I am hanging in there."*

In the above comment, P4 felt that learning more about impending difficulties just raised concern, perhaps as he was not ready to face the anticipated decline of his family member with MNCD. The Bessie Makatini Foundation organised workshops where caregivers could share their experiences and learn more about neurocognitive diseases, which the caregivers appreciated.

4.9 Conclusion

The research findings were presented in this chapter. The chapter focused on the themes that emerged after the data were thematically analysed. The themes were positive experiences, negative experiences, acceptance, spirituality and religion, positive reframing, and informal and formal support. The primary points raised by the participants in response to the research questions were supported with direct quotations. The next chapter presents a discussion of the findings.

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1 Introduction

This study (i) explored the experiences of informal caregivers of people living with major neurocognitive disorders (MNCDs) and (ii) explored the coping strategies of informal caregivers of people living with MNCD and the availability of support services for informal caregivers of people living with MNCD. This study's findings reflected on the informal caregivers' demographic information, their experiences, coping strategies used, and the support services available.

Nine informal caregivers participated in this study. The informal caregivers were unpaid care providers to persons with MNCD. They shared close relations with the people they cared for (Broese & de Boer, 2016). They were all Black South Africans, which forms the largest group of informal caregivers in South Africa (Harris & Thafeng, 2022). Women were over-represented among the caregivers, demonstrating that females were the principal support figures in families (Addabbo et al., 2021). The study provided evidence that relationship closeness remained even after the onset of MNCDs. Most participants were daughters taking care of their mothers with the illness. One participant cared for her mother-in-law but seemed to attribute the relationship the same value as the other caregivers did to their own mother.

All the participants in the current study cared for their mothers at home, and most of them had been providing care for over three years. Two participants reported that they had provided care for longer than ten years. According to Abdalla and Brookmeyer (2018), an MNCD is a condition that progresses for approximately ten years from diagnosis to death. Living together with a person with MNCD seemed to increase the stress and burden for the informal caregivers (Gangopadhyay et al., 2020).

5.2 Experiences of informal caregivers of people with major neurocognitive disorders

The participants reported more unfavourable than favourable experiences. The caregivers' duties in this study included tending to the personal, medical, domestic, financial, and transportation needs of those with MNCDs. Caregivers accompanied ill family members to medical appointments, explained symptoms to healthcare professionals, and ensured the proper administration of medication.

According to Chiti et al. (2018), MNCDs have two distinct features. These are cognitive decline in persons with the disorder and intrusion on their independence. However, the different types of MNCDs have unique patterns of behaviour, which posed different challenges to caregivers (Cowie, 2019).

Most participants reported loyalty to their family members with MNCD. The participants believed that caregiving of parents with MNCD was best performed by their children, as this was their responsibility. Overall, caring for a parent with MNCD was an indication of love, value, and appreciation. Children of persons with MNCD considered taking care of their parents as an honourable duty. They believed that they were obliged to care for them in their old age, regardless of their health status (Alavijeh et al., 2018). According to Johnston et al. (2020), cultural beliefs and knowledge about MNCD are directly influenced by acculturation as well as family-centred cultural values (such as filial piety and familism), especially in Asian and African communities, which is the reason why the participants preferred providing home-based care to parents with MNCD.

Most participants considered caregiving as an opportunity to reciprocate the care previously shown to them by their parents (Devi et al., 2022). The participants took responsibility for the personal hygiene of their parents with MNCD. There was an understanding that adult children become responsible for their elderly parents, as the presence of elderly parents was considered a blessing, even when they had MNCD. The caregivers tried

to preserve the lives of their family members, even if that meant taking extra precautions to prevent them from being infected with COVID-19. For example, one of the participants reported receiving the COVID-19 vaccine to prevent the coronavirus from spreading to older relatives with MNCD. According to Aso et al. (2020), MNCDs increase the risk of COVID-19. Therefore, preventing infection was vital for persons with MNCD and their caregivers.

A third of the participants used their experiences of providing care to promote the treatment of people with MNCDs through sharing their caring experiences on various platforms, including religious channels. There was consensus that people in the community lacked appropriate knowledge and occasionally held erroneous assumptions about people with MNCDs. As a result of the misinformed community, afflicted persons had a higher risk of dying because they could not receive help from other community members. According to Chaudhury and Seetharaman (2020), a conducive society for persons with MNCD is one in which both persons with the disease and their caregivers are empowered, supported to understand their rights, and included in the community.

The reported positive experiences indicated that the participants did not regard their caregiving tasks as a heavy burden. These results were consistent with the results for the ZBI-12, where five participants reported a zero to mild burden, and four reported a mild to moderate burden. This indicated that most participants felt some degree of burden by the task of caregiving, but none felt it was severe.

Also, most participants showed no symptoms of depression on the BDI-II, which indicated that they were coping with their caregiving situations by using coping skills and strategies effective for coping with their situation. As previously stated, the stress and coping theory by Lazarus and Folkman (1984) indicated that those who are able to give positive appraisal to their challenges adapt positively. In addition, most participants reported no depressive symptoms. This indicated that they used effective coping skills and strategies to

cope with their caregiving situation. Also indicated by these results was the emotional strength of the participants, as well as their healthy mental state. According to the resilience theory, one way to define a resilient person is someone who can not only endure challenges, but who becomes stronger and healthier because of their challenges (Avery & Bekhet, 2018).

Furthermore, most participants reported employing a more problem-focused coping style. They used coping techniques which they viewed as powerful enough to alleviate caregiver burden. Having high problem-focused coping skills also indicated the psychological strength of the participants (Alessandrini et al., 2017). This is supported by Furuta et al. (2019), who stated that active problem-focused coping skills effectively ameliorated the burden for caregivers.

Some caregiving experiences were reportedly negative. Most of the participants reported sadness and loss that came with the knowledge that MNCDs were incurable and fatal. They reported anger directed towards the condition. The study's participants believed that MNCDs were worse than other conditions because they 'took away' their relatives with MNCD before they died.

Other studies also reported anticipatory grief in caregivers of persons with MNCD. Cheung et al. (2018) found that spousal caregivers generally experienced higher levels of anticipatory grief and a more significant burden. They attributed the spousal grief that caregivers experienced to several losses, as caregivers witnessed a gradual cognitive, social, and physical decline in their loved ones. In addition, Mahomed and Pretorius (2022) found that other family members also experienced caregiver grief, as they witnessed the loss of identity in family members with neurocognitive disorders, as was the case in the current study.

In addition, participants described making sacrifices associated with their caregiving role and lifestyle changes. Most participants reported being unemployed and explained how limited access to financial resources resulted in their inability to meet personal needs.

Brimblecombe et al. (2020) stated that long-term unemployment of informal caregivers had an economic impact, while Banerjee et al. (2019) stated that informal caregivers who were not retired sought employment. There was a significant reliance on the pension fund of the family member with MNCD. However, these funds were insufficient to cover all the household expenses, including those of the affected person. The supplies needed were too expensive.

In some cases, the adult children had to become the financial providers for their parents with neurocognitive disorders. Similarly, to the current study, caregivers in a study by Mahomed and Pretorius (2022) described how they sacrificed financial opportunities and resigned from their place of work. Hence, Min et al. (2021) stated that losing out on work opportunities for long-term care can mean a loss of financial stability and position, increasing anxiety and distress. According to these authors, being employed can encourage improvement in caregivers' quality of life and self-esteem.

Furthermore, participants in this study reported sacrificing time to care for their parents with MNCD. The majority reported spending more than three years providing care to the affected family member. However, the concern was not only about the time spent over a long period but the time spent daily on caregiving duties and managing other caregiving-related responsibilities. The informal caregivers all felt that caregiving required 24 hours of their day. The care recipients reportedly always needed supervision. Cabrera et al. (2022) did not report on the time sacrificed by caregivers but on the sacrifice of leisure activities made by caregivers. Having fewer recreational activities had a negative impact on family caregivers' mental health by increasing caregiver burden.

Most informal caregivers described feeling worried about the behaviours of their family members with MNCD. The distress reportedly was based on the unpredictable nature of persons with MNCD. Many informal caregivers were concerned that their family members with MNCD would walk out into the streets and get lost (Young, 2018). The caregivers in the

current study were concerned about the safety of their care recipients because persons with MNCDs were often attacked in the community (Hanssen & Mkhonto, 2018). Another concern was that persons with MNCDs walked about all day without resting. Furthermore, almost all the participants reported that care recipients became forgetful at some stage.

Most participants reported receiving no support from close relatives, whereas they needed assistance with caregiving tasks. Informal caregivers expressed that being alone in caring for their family member with MNCD exacerbated their struggles. Mahomed and Pretorius (2022) found that only a few caregivers indicated they received the much-needed support. Most informal caregivers in this study reported that the stresses experienced during the development of MNCDs seemed to increase conflict in the family (Gangopadhyay et al., 2020).

These results are inconsistent with previous literature, where caregiving was shared among family members including teenagers (Ainamani et al., 2020; Bressan et al., 2020). According to Hall and Sikes (2018), most families share caregiving among family members, and siblings who had previously moved away from the family home increased the frequency of their visits home as they became involved in the caregiving process. However, in this study, the participants did not report sufficient support from their siblings and other relatives. The participants expressed their disappointment in their relatives who did not show support. There was a common belief among the participants that relatives were obliged to reciprocate the same support which had been offered to them. In contrast, Bullock et al. (2020) found that informal caregivers satisfied their emotional needs through caregiving rather than relying on other family members. Similarly, Haley et al. (2020) stated that not all family dynamics are positive and primary informal caregivers can become stressed by expectations from family members in addition to the person with MNCD.

5.3 Coping with caregiving

The second research question in this study considered the coping strategies used by the participants. Most participants in this study explained that accepting the situation gave them the strength to manage their role as caregivers. The caregivers accepted their family members with MNCD in their worsened condition, even to a point where constant supervision became necessary because of the cognitive decline. The caregivers expressed how they valued their relative with MNCD. Hence, they planned their lives to accommodate the affected family members. Han et al. (2022) examined the effects of acceptance on distressed family caregivers. Their findings showed benefits in accepting the unchangeable diagnostic situation and learning to acknowledge and accept negative feelings that can arise from caregiving situations.

Additionally, most participants relied on faith and religious practices to cope with the adversities of caregiving. Hence, some of the caregivers alluded to praying about the challenges they faced. Other caregivers explained how their faith assisted them in accepting the caregiving role. The informal caregivers believed that MNCDs were God's will. According to Avery & Bekhet (2018), faith is believing in something or someone more powerful than oneself.

Furthermore, the participants claimed that they could more positively and constructively frame their situation. The participants gave less weight to their relative's illness or troubles than to the traits and qualities they appreciated about them. In addition, they realised that their caregiving efforts were sufficient. Rather than concentrating on their limitations and weaknesses, they understood that the care they provided was adequate. By reframing their adverse circumstances, the participants used a cognitive-focused coping technique. As stated previously, cognitive-focused coping techniques help people accept their circumstances by reframing them in more positive terms (Alessandrini et al., 2017).

In addition, the participants stated that their experience of providing care for others sparked a desire to help others in a similar circumstance by disseminating more knowledge about MNCDs. The participants described how they became interested in discussing the illness with others. To combat stigma against the sufferers of MNCDs and their caregivers, the participants shared information about their experiences on all platforms open to them, including religious meetings. Individuals also became more interested in the welfare of senior citizens in general. They discussed the significance of treating senior citizens with dignity.

Although the participants were interested in helping other caregivers to cope, those caregivers could also benefit from receiving information on caring for persons with MNCDs. The literature review states that psycho-educational skills-building intervention positively affects caregivers' emotional health, quality of life, and attitudes toward providing care (Darwish et al., 2021). Caron et al. (2020) suggested disseminating information through podcasts. Caregivers could also be trained to communicate understandable information on MNCDs.

5.4 Support interventions

The third research question that informed this study was determining the formal and informal support available for caregivers of people with severe neurocognitive impairments.

Most of the participants reported that they had hired in-house respite workers to help them with the task of caregiving. Basnyat and Chang (2017) found that hired support workers managed tasks such as feeding, bathing, toileting, and walking. In-house respite workers reportedly eased the burden on informal caregivers. Informal caregivers' reliance on hired support provided diversion coping that enabled them to resume other enjoyable activities. Hired support also provided emotional support for informal caregivers. In some cases, hired assistants were the only companions to caregivers (Basnyat & Chang, 2017).

Further, the participants mainly reported receiving counselling from a non-profit organisation called the Bessie Makatini Foundation. As stated in the methodology section, recruited participants came from this organisation. Many informal caregivers reported receiving strategies that reduced caregiving stressors (Bullock et al., 2020). For example, some participants reported receiving advice on managing sleeping arrangements and coping with complex family dynamics, such as gender-based violence.

Moreover, the participants reported that support groups provided insight into successful strategies for dealing with various aspects of the caregiving role (Bullock et al., 2020). For example, some participants expressed gratitude for the support groups because of the increased understanding of how to approach MNCD. However, other participants reported difficulties during the support group meetings with listening to the negative experiences of other informal caregivers. In contrast, Bullock et al. (2020) stated that learning from peers provides emotional support and encouragement.

5.5 Conclusion

This study's findings reflected on the experiences of informal caregivers of people living with MNCDs, their level of coping and coping strategies, and the availability of support services for them. This study's findings focused on the common themes among participants' experiences. Focus was also given to the participants' demographics. The next chapter provides the conclusion of the study.

CHAPTER SIX: CONCLUSION

6.1 Introduction

This chapter provides the conclusions, limitations, and recommendations of this study. The study gave an opportunity to caregivers of persons with major neurocognitive disorders to speak about their experiences of caregiving and the coping strategies they use to address the challenges they encounter.

6.2 Conclusions

The participants reported more negative experiences than positive experiences. This indicated that the participants were realistic about their experiences and did not try to report only positive experiences. Also, the fact that participants had positive experiences to share in their caregiving experiences was an indication of their resilience. The participants seemed to have adapted positively to their caregiving experiences, not because of the absence of challenges, but because they were able to find some positives and used those to gain strength.

Moreover, the participants did not view their caregiving responsibilities as a major burden and as a result, they were psychologically healthy in that they showed no depressive symptoms. They were able to use their coping skills and strategies effectively to better handle the challenges associated with caring for a person with MNCD. They positively reframed the caregiving situation, developed good care plans, and ultimately accepted the caregiving situation. The participants reported that they relied on religious practices such as prayer to mitigate the challenges of caregiving.

Furthermore, the support provided by the Bessie Makatini Foundation to the participants was reported by all of them as valuable and effective. The organisation provided a good support network for the participants, as they were able to gain insight into MNCDs. They

were also able to be exposed to the experiences of other informal caregivers who shared not only effective coping skills and strategies, but also those that were ineffective. The organisation seemed to be very helpful and effective, assisting the participants by providing both individual and family counselling.

6.3 Limitations

This study has a few limitations. According to the DSM-5, MNCDs encompass a group of disorders in which the clinical deficit is cognitive function. The disorders included in this group are those in which impaired functioning has not been present since birth or early life and shows a decline from a previous level of functioning. The interview questions did not include levels of functioning in persons with MNCDs. During the interviews, the researcher briefly probed the participants to describe those with MNCDs. The purpose was to get an idea of the cognitive decline of the person with MNCD and the extent to which the participants supported them. However, only a little of that information was included in this report, as no prominent themes were deduced from that data.

Also, the use of telephone interviews was a limitation of the study. Face-to-face interviews would have been more suitable for building rapport between the research participants and the researcher. In addition, the use of telephonic interviews made gathering the test data cumbersome. Furthermore, the selection of participants from one organisation in one geographical area (Durban), was a limitation of the study because the sample was homogeneous and did not allow for the comparison with participants who had not received any formal support from the Bessie Makatini Foundation.

Moreover, during the interviews, the participants also responded to questions from the BDI-II, ZBI-12, and BCS. The scales have pre-set ratings and responses. The participants were informed by the researcher that they had to select the pre-given responses that best captured their experiences and feelings. Both questions and responses were read out to the participants. This process was cumbersome and difficult and may have affected the quality of the data.

6.4 Recommendations

The experiences of informal caregivers have been explored in literature. However, only some studies have explored persons living in South Africa. Therefore, it is recommended that further research should focus on this topic in the South African context. Further, in this research, participants were selected from the database of the Bessie Makatini Foundation. The organisation has support interventions for caregivers that mainly focus on psycho-education. It is also recommended that the government support the creation of more community entities like the Bessie Makatini Foundation to support caregivers. Future researchers could also consider comparing a sample of caregivers from the organisation with those who are not a part of it.

It is recommended that government programmes should consider the participants' experiences in this research when designing support interventions for caregivers of persons with MNCDs. It also recommended that support programmes such as those run by the Bessie Makatini Foundation should address the diverse family dynamics experienced by caregivers when addressing caregiver needs and developing support interventions. Such organisations should invest in developing more psycho-educational skills-building among caregivers by training them to communicate understandable information on MNCDs. Further investigation could also be done on popular social media platforms where information can be disseminated.

6.5 Conclusion

This chapter reviewed the main conclusions of the study. In addition, it discussed the study

limitations and made recommendations for future research and practice in the field of major

neurocognitive disorders care and caregiving.

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APPENDICES

Appendix 1: Gatekeeper's letter

BESSIE
5 Langa Place, Lamontville 4027
PO Box 42147, Lamontville, Durban
Tel 031 452 613   755,

FOUNDATION
Email:
Web:
Registration: 12

Mrs Xoli Mfene
School of Applied Human Sciences
College of Humanities
Pietermaritzburg Campus
University of KwaZulu-Natal

10th June 2020

RE: Research Project Collaboration

Dear Mrs Mfene

Further to our correspondence and video meeting of the 5th June 2020, and after consulting with the our management committee, I am now writing to confirm that Bessie Foundation, BMF, is willing to work with you and your team at the University of KwaZulu Natal on a research project focusing on carers of people living with dementia. BMF is prepared to be the 'gatekeeper' between the university team and our clients.

We look forward to receiving a draft of the Memorandum of Understanding outlining details of the collaboration

Best wishes

Stan Chidavaenzi (Operations Director)

Appendix 2: Ethical clearance letter

UNIVERSITY OF KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI
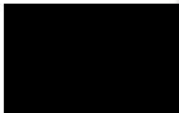
07 October 2020

Mrs Londeka Miranda Manyathi (216039020)
School Of Applied Human Sc
Pietermaritzburg Campus

Dear Mrs Manyathi,

Protocol reference number: HSSREC/00001775/2020
Project title: The experiences of caregiving and the coping strategies of informal caregivers of people with Major Neurocognitive Disorder (MNCD) in the greater Pinetown area
Degree : Masters

Provisional Approval – Full Committee Reviewed Protocol

This letter serves to notify you that your application received on 21 July 2020 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) on 26 August 2020. The protocol has been provisionally approved, subject to the following conditions set out below being addressed:

1. The data collected will be qualitative data although a tool which quantifies the coping ability will be used. This does not make the study a quantitative study. Please clarify this in the protocol.
2. Please adjust time frames.
3. Please indicate recruitment strategy of the participants.
4. What if you don't get answers from the six participants?
5. How will feedback be given to participants after the completion of the study?
6. Informed consent document: Please use HSSREC template.

Kindly upload your response on the RIG online system as soon as possible.

This approval is granted provisionally and the final clearance for this project will be given once the above-mentioned condition(s) has been met. Note that data collection may not proceed until final ethics approval letter has been issued after the remaining conditions have been met and approved by the research ethics committee.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours faithfully

....
Professor Urmilla Bob
(University Dean of Research)

/dd

Humanities & Social Sciences Research Ethics Committee
UKZN Research Ethics Office Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Tel: +27 31 260 8350 / 4557 / 3587
Website: http://research.ukzn.ac.za/Research-Ethics/

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

INSPIRING GREATNESS

Appendix 3: Information sheet

Dear prospective participant,

My name is Londeka Manyathi from the department of Psychology at the University of KwaZulu-Natal. My contact details are as follows: contact number 0833850408, email address miranda.manyathi@gmail.com.

You are invited to consider participating in a study that involves research on caregiving experiences. The study also involves the coping strategies of informal caregivers of people with major neurocognitive disorder (dementia) in the greater Pinetown area. This research aims to explore and study the caregivers' experiences and their coping methods and support services available to assist them with the stresses associated with caring for people with neurocognitive disorder. The study will include an interview and psychological measures for testing caregivers' coping levels. If you choose to enrol and remain in the study, your participation is expected to be one hour.

There are no risks or discomforts that have been identified for participants. However, tele-counselling support will be provided by the Bessie Makatini Foundation for participants who may require the service. We hope the study will create the following benefits: Improving the disorder's knowledge and the appropriate care. Reduce the burden on caregivers and improve the quality of life by directing them to service providers who provide evidence-based services, such as the Bessie Makatini Foundation.

Participation in this research is voluntary and participants may withdraw participation at any point. In the event of refusal/withdrawal of participation, the participants will not incur penalties, loss of treatment, or other benefits they are typically entitled to.

To protect the participant's personal/clinical information confidentiality, the researcher's supervisor will hold the information in a password-protected file accessible only to the researcher and her supervisor. After five years, in line with the university's rules, the supervisor will dispose of the information by shredding or burning.

The results may also be communicated to the relevant stakeholders in the department of health and published in scientific journals. You can request a copy of the products should you need them.

This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (HSSREC/00001775/2020).

In the event of any problems or concerns/questions, you may contact the researcher at 0833850408 or the UKZN Humanities & Social Sciences Research Ethics Committee; contact details are as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

PrivateBagX54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557- Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

CONSENT

I (Name)…………………………………. have been informed about the study entitled the experiences of caregiving and the coping strategies of informal caregivers of people with major neurocognitive disorder (dementia) in the greater Pinetown area by Londeka Manyathi.
I understand the purpose and procedures of the study.

I have been allowed to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about any available compensation or medical treatment if an injury occurs to me due to study-related procedures.

Suppose I have any further questions/concerns or queries related to the study. In that case, I understand that I may contact the researcher at 0833850408 or miranda.manyathi@gmail.com.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers, then I may contact:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

PrivateBagX54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557 - Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

Additional consent

I hereby provide consent to:

Audio-record my interview YES / NO

Video-record my interview YES / NO

_____   _____

Signature of Participant   **Date**

_____   _____

Signature of Witness   **Date**

(Where applicable)

_____   _____

Signature of Translator   **Date**

(Where applicable)

Appendix 5: Interview guide

Semi-Structured Interview Guide: English version

Demographic data
Name
Sex
Age
Race
Nationality
Language
Religion
Highest education level
Occupation
Marital status

Experiences of caregiver

What is your relationship to the person that you are providing care for?

2.1.1 What specific care are you providing for people with major neurocognitive disorder daily?

E.g., specific tasks that they manage or are responsible for.

How long have you been providing this care?

Are you a paid caregiver: Yes/No; Full-time: Yes/No; Part-time: Yes/No?

How many hours do you provide care?

Did you receive any training as a caregiver? Yes/No

Explain

What is you understanding of this person's condition?

2.1.2 What are some of the difficulties that you have faced when dealing with people with major

cognitive disorder?

2.1.3 What do you enjoy about helping people with major cognitive disorder?

Do you feel that you are sufficiently equipped to care for the person? Yes/No

Explain

Coping

2.2.1 How do you cope with caring for a person with major neurocognitive disorder?

2.2.2 How do you deal with the negative feelings that are a result of those challenges?

2.2.3 What are some of the negative moments you have experienced while caring for the person with MNCD?

What are some of the positive moments you have experienced as a caregiver for a person with MNCD?

List the three most important needs which can contribute to your job satisfaction as the caregiver of a person with MNCD.

What has been the impact of caregiving on your family?

…Own physical health

…Mental health

…Social life

…Financial implications

Support services

2.3.1 What support have you received as a caregiver from your family and outside of your family?

2.3.2 How often do you receive this support?

2.3.3 Is this formal or informal support

2.3.4 Who offers this support?

What has been your experience of this support?

Do you feel that this support is enough? Please explain.

What other support would be beneficial to you?

2.3.5 Are there any services in your community that care for people with this condition?

Beck Depression Inventory-II

This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire.

1.

0 I do not feel sad.

1 I feel sad

2 I am sad all the time and I can't snap out of it.

3 I am so sad and unhappy that I can't stand it.

2.

0 I am not particularly discouraged about the future.

1 I feel discouraged about the future.

2 I feel I have nothing to look forward to.

3 I feel the future is hopeless and that things cannot improve.

3.

0 I do not feel like a failure.

1 I feel I have failed more than the average person.

2 As I look back on my life, all I can see is a lot of failures.

3 I feel I am a complete failure as a person.

4.

0 I get as much satisfaction out of things as I used to.

1 I don't enjoy things the way I used to.

2 I don't get real satisfaction out of anything anymore.

3 I am dissatisfied or bored with everything.

5.

0 I don't feel particularly guilty

1 I feel guilty a good part of the time.

2 I feel quite guilty most of the time.

3 I feel guilty all of the time.

6.

0 I don't feel I am being punished.

1 I feel I may be punished.

2 I expect to be punished.

3 I feel I am being punished.

7.

0 I don't feel disappointed in myself.

1 I am disappointed in myself.

2 I am disgusted with myself.

3 I hate myself.

8.

0 I don't feel I am any worse than anybody else.

1 I am critical of myself for my weaknesses or mistakes.

2 I blame myself all the time for my faults.

3 I blame myself for everything bad that happens.

9.

0 I don't have any thoughts of killing myself.

1 I have thoughts of killing myself, but I would not carry them out.

2 I would like to kill myself.

3 I would kill myself if I had the chance.

10.

0 I don't cry any more than usual.

1 I cry more now than I used to.

2 I cry all the time now.

3 I used to be able to cry, but now I can't cry even though I want to.

11.

0 I am no more irritated by things than I ever was.

1 I am slightly more irritated now than usual.

2 I am quite annoyed or irritated a good deal of the time.

3 I feel irritated all the time.

12.

0 I have not lost interest in other people.

1 I am less interested in other people than I used to be.

2 I have lost most of my interest in other people.

3 I have lost all of my interest in other people.

13.

0 I make decisions about as well as I ever could.

1 I put off making decisions more than I used to.

2 I have greater difficulty in making decisions more than I used to.

3 I can't make decisions at all anymore.

14.

0 I don't feel that I look any worse than I used to.

1 I am worried that I am looking old or unattractive.

2 I feel there are permanent changes in my appearance that make me look

unattractive

3 I believe that I look ugly.

15.

0 I can work about as well as before.

1 It takes an extra effort to get started at doing something.

2 I have to push myself very hard to do anything.

3 I can't do any work at all.

16.

0 I can sleep as well as usual.

1 I don't sleep as well as I used to.

2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.

3 I wake up several hours earlier than I used to and cannot get back to sleep.

17.

0 I don't get more tired than usual.

1 I get tired more easily than I used to.

2 I get tired from doing almost anything.

3 I am too tired to do anything.

18.

0 My appetite is no worse than usual.

1 My appetite is not as good as it used to be.

2 My appetite is much worse now.

3 I have no appetite at all anymore.

19.

0 I haven't lost much weight, if any, lately.

1 I have lost more than five pounds.

2 I have lost more than ten pounds.

3 I have lost more than fifteen pounds.

20.

0 I am no more worried about my health than usual.

1 I am worried about physical problems like aches, pains, upset stomach, or

constipation.

2 I am very worried about physical problems and it's hard to think of much else.

3 I am so worried about my physical problems that I cannot think of anything else.

21.

0 I have not noticed any recent change in my interest in sex.

1 I am less interested in sex than I used to be.

2 I have almost no interest in sex.

3 I have lost interest in sex completely.

Interpreting the Beck Depression Inventory

The Beck Depression Inventory is evaluated according to the table below.

Total Score_____Level of Depression

1-10_____These ups and downs are considered normal

11-16_____Mild mood disturbance

17-20_____Borderline clinical depression

21-30_____Moderate depression

31-40_____Severe depression

over 40_____Extreme depression

Zarit Burden Interview assessing caregiver burden

0 = Never; 1 = Rarely; 2 = Sometimes; 3 = Quite frequently; Nearly always = 4

Question	Score
1. Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4. Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5. Do you feel angry when you are around your relative?	0 1 2 3 4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0 1 2 3 4
7. Are you afraid what the future holds for your relative?	0 1 2 3 4
8. Do you feel your relative is dependent on you?	0 1 2 3 4
9. Do you feel strained when you are around your relative?	0 1 2 3 4
10. Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12. Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4
13. Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	0 1 2 3 4
15. Do you feel that you don't have enough money to take care of relative in addition to the rest of your expenses?	0 1 2 3 4
16. Do you feel that you will be unable to take care of your relative much your longer?	0 1 2 3 4
17. Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4

Question	Score
18. Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19. Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20. Do you feel you should be doing more for your relative?	0 1 2 3 4
21. Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22. Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Interpretation of the Zarit Burden Interview (22-items)

The Zarit Burden Interview is evaluated according to the table below.

Total score range: 0 to 88

0-21: no to mild burden

21-40: mild to moderate burden

41-60: moderate to severe burden

≥ 61: severe burden

Brief COPE questionnaire

The following questions ask how you have sought to cope with a hardship in your life. Read the statements and indicate how much you have been using each coping style (Carver, 1997).

1 = I have not been doing this at all; 2 = I have been doing this a little bit; 3 = I have been doing this a medium amount; 4 = I've been doing this a lot.

	I have not been doing this at all	A little bit	A medium amount	I have been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real".	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5 I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape	1	2	3	4
10. I've been getting help and advice from other people.	1	2	3	4
11. I've been using alcohol or other drugs to help me get	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive	1	2	3	4

	I have not been doing this at all	A little bit	A medium amount	I have been doing this a lot
13. I've been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

Interpretation of the Brief COPE Scale

A normative percentile is presented based on data from a non-clinical sample of athletes (Bayer et al., 2020). Interpretation by way of normative percentile helps contextualise results in comparison to typical responses of regular individuals.

In addition, a clinical percentile is presented which compares responses to clients receiving outpatient mental health services (Hegarty & Buchanan, 2021). A percentile of 50, for example, represents an average score for a client in psychological therapy, whereas a percentile of 90 indicates that the respondents scored higher than 90 percent of other individuals in treatment.

During interpretation it is most helpful to look at the pattern of responding across the three subscales. Consistently low scores on all subscales may indicate either:

- The respondent does not feel they have many stressors to cope with. For example, that life is stress free.
- A lack of reflective capacity or resistance to disclose personal information.
- The respondent does not have many coping skills.

Problem-Focused Coping (Items 2, 7, 10, 12, 14, 17, 23, 25)

Characterised by the facets of active coping, use of informational support, planning, and positive reframing. A high score indicates coping strategies that are aimed at changing the stressful situation. High scores are indicative of psychological strength, grit, a practical approach to problem solving and is predictive of positive outcomes.

Emotion-Focused Coping (Items 5, 9, 13, 15, 18, 20, 21, 22, 24, 26, 27, 28)

Characterised by the facets of venting, use of emotional support, humour, acceptance, self-blame, and religion. A high score indicates coping strategies that are aiming to regulate emotions associated with the stressful situation. High or low scores are not uniformly associated with psychological health or ill-health, but can be used to inform a wider formulation of the respondent's coping styles.

Avoidant Coping (Items 1, 3, 4, 6, 8, 11, 16, 19)

Characterised by the facets of self-distraction, denial, substance use, and behavioural disengagement. A high score indicates physical or cognitive efforts to disengage from the stressor. Low scores are typically indicative of adaptive coping

Viv O'Neill   **17 Kinnoull Road**
M.A. (Couns. Psych.) (Natal)   **Pelham**
                                                                       Pietermaritzburg
Counselling Psychologist   **3201**
(Regd. Health Professions Council of South Africa)
PR. No. 8634041   **Cell: 083 464-7666**

9th August 2023

To Whom It May Concern

This confirms that I have language edited the following Master's thesis by Londeka Manyathi:

The experiences of caregiving and the coping strategies of informal caregivers of people with major neurocognitive disorders.

The thesis was edited for grammar, spelling, punctuation, and layout. The Reference List format was checked, and in-text citations were cross-checked against it.

Please note that I am not responsible for any changes undertaken since completing the editing process.

V.C. O'Neill

Appendix 7: Turnitin report

LM masters thesis

PRIMARY SOURCES

1 Tomoko Omiya, Masami Kutsumi, Sakiko Fukui. "Work, Leisure Time Activities, and Mental Health among Family Caregivers of the Elder People in Japan", Healthcare, 2021
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2 Kevin L. Baker, Noelle Robertson. "Coping with caring for someone with dementia: Reviewing the literature about men", Aging & Mental Health, 2008
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3 Ray, R. A., and A. F. Street. "The dynamics of socio-connective trust within support networks accessed by informal caregivers", Health An Interdisciplinary Journal for the Social Study of Health Illness and Medicine, 2011.
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4 Nikolaos Athanasios Anagnostopoulos, Yufan Fan, Muhammad Umair Saleem, Nico Mexis et al. "Testing Physical Unclonable Functions Implemented on Commercial Off-the-Shelf
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5   Áine Teahan, Attracta Lafferty, Eilish McAuliffe, Amanda Phelan, Liam O'Sullivan, Diarmuid O'Shea, Gerard Fealy. "Resilience in family caregiving for people with dementia: A systematic review", International Journal of Geriatric Psychiatry, 2018   <1%
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8   Chantal Viscogliosi, Nathalie Dame, Jordan Mino Roy, Romane Duquette-Laplante et al.   <1%