A Phenomenological Study of Home-Based Caregivers Providing Palliative Care to Terminally Ill Patients at Mahlathi Village, Mopani District, Limpopo Province

by

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DECLARATION

I declare that the (mini-dissertation/dissertation/thesis) hereby submitted to the University of Limpopo, for the degree of (Master of Arts in Clinical Psychology) has not previously been submitted by me for a degree at this or any other university; that it is my own work in design and in execution, and that all material contained herein has been duly acknowledged.

Mafuma

08 April 2024

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Date

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Dedication

I dedicate this dissertation to my Lord and saviour Jesus Christ and Father God who have made all of this to be possible. My late son, Nhlelo Kylie Chauke, late father, Charles Mudunwazi Mafuma, and late mother-in-law, Maria Nkhensani Ndlamini-Chauke. You may no longer be with us, but I know you are with me each and every day. To my partner, Lawrence Chauke, thank you for your love, support and standing with me through it all. My mother, Molly Vulani Mafuma-Makhubele, father, Abel Hasani Makhubele and younger sister, Nsuku Holy Mafuma, thank you for your endless support and encouragement.

List of Acronyms and Abbreviations

Acronyms	Abbreviations
Department of Health	DOH
Faith-Based Organisation	FBO
Human Immunodeficiency Virus/ Acquired Immunodeficiency Virus	HIV/AIDS
Non-Governmental Organisation	NGO
Outreach Team Leader	OTL
World Health Organization	WHO

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Abstract

Home-based caregivers are a very important part of multidisciplinary teams in the health profession. They work together with health professionals to ease the burden of care on hospitals by providing care to patients in the comfort of their home. However, as they give care, they encounter many challenges that affect the quality of their work. Many studies have been conducted on home-based caregivers. Nonetheless, there are not many that address the motivation and coping strategies that home-based caregivers use to cope with challenges.

The current study aimed to explore the lived experiences of home-based caregivers providing palliative care to terminally ill patients in Mahlathi Village, Mopani District, Limpopo Province. A qualitative research approach using a phenomenological design was used. Twelve home-based caregivers (eleven females and one male) aged between 41 and 59 years old were sampled to form part of the study. The participants were selected using a purposive sampling method. Data collection was conducted through semi-structured interviews with the home-based caregivers. The interviews were conducted in Xitsonga and translated into English.

The study used interpretive phenomenological analysis (IPA) to analyse the findings. The study revealed that home-based caregivers remain highly motivated to do caregiving work despite the challenges that come with it. Helping community members, personal experiences and a lack of employment were pointed out as the themes. The study further showed challenges and positivity about home-based caregiving. The experiences of the home-based caregivers when working with patients, families of patients, families of the home-based caregivers, community members and institutions where they work were discussed.
Psychological experiences of the home-based caregivers and coping mechanisms were also identified. The study concluded that home-based caregivers experience many challenges when caring for terminally ill patients. However, the support from their own families, colleagues, supervisors, and community makes their work easier. It is recommended that the Department of Health set aside time for home-based care programmes to ensure their effectiveness. Increasing home-based caregivers' salaries to improve on their livelihood should receive attention of the department.

Keywords: Home-based caregivers, motivational perceptions, palliative care, psychosocial challenges, coping

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Chapter 1: General Orientation of the Study

1.1. Background of the Study

Globally, communities face a rise in chronic and non-communicable diseases. These include human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), cancer, Tuberculosis (TB) and cardiovascular diseases (Morris, 2013). The burden of non-communicable diseases in low- and middle-income countries places pressure on their health care systems (Witter et al., 2020). To reduce these constraints home-based care programmes were developed (World Health Organization [WHO], 2014). Similarly, South Africa has an increasing number of people living with non-communicable diseases other than HIV/AIDS (Pillay-Van Wyk et al., 2016). As a result, it became difficult for hospitals to cope with the rising numbers (Department of Health [DOH], 2013). Hospitals have experienced a high admission of patients, followed by a shortage of beds, lack of resources and inadequate staff (Kagee et al., 2011). To relieve the burden from hospitals, home-based care was introduced (Campbell et al., 2008). However, this was not meant as a substitute for hospital care but to complement remedial and restorative care (National Guidelines for Community and Home Care [NGCHBC], 2015).

Non-governmental organisations (NGOs), community-based organisations (CBOs), faith-based organisations (FBOs) and the government are key role players that train home-based caregivers (Ankitola, 2008). Home-based caregivers deliver home-based care services to South African communities in their homes (Van Pletzen et al., 2013). Home-based caregivers are drawn from local communities (Moshabela et al., 2015), mostly unemployed and insufficiently literate to get better employment opportunities (Qalinge, 2011). For many years home-based caregivers have been on the frontline of rendering home-based care services to patients and support to their families (Motswasele-Sikwane et al., 2020). They offer physical, psychosocial, palliative, and spiritual care to patients and their families to assist them in maintaining their independence and helping to increase their quality of life (Mamba & Ntuli, 2014). Home-based caregivers carry the burden of providing care to terminally ill patients (Smith, 2023). Common struggles of home-based caregivers include fatigue, burnout, attending to a great number of patients, facing the death of their patients, inadequate or no remuneration, lack of training and lack of motivation (Oliver et al., 2015). This often leads to emotional fatigue reflected through distress, exhaustion, and emotional strain. Being overwhelmed, result in damage to the morale of home-based caregivers (Makina-Zimalirana et al., 2023). Home-based caregivers report being overloaded by work (Tripathy et al., 2016), therefore, causing them to feel burnt out and emotionally exhausted (White et al., 2017). Another challenge that impedes on their performance is incentives (Colvin et al., 2021). Lack of support from the government their workplace, and family members of patients can be demotivating to home-based caregivers (Hangulu & Ankitola, 2017; Maripa et al., 2019). Beside the challenges home-based caregivers encounter, there are some rewards that come out of this kind of work. The work done by home-based caregivers enhances the health of patients andcommunities (Mobula et al., 2015). WHO (2002) maintains that home-based caregivers ensure that ill people have available health and social welfare. They also empower and give hope to terminally ill patients. White et al. (2017) indicatedthat home-based caregivers experience satisfaction in their work because they get to improve people’s lives. Akintola (2010) further postulated that interacting with patients and changing their health behaviours is fulfilling for home-based caregivers. A study conducted in the Eastern Cape found that visits by home- based caregivers improved maternal and child health (Le Roux et al., 2015). Further, home-based caregivers in the Western Cape were satisfied when their work was recognised and appreciated by community members (Smith et al., 2020). Therefore, despite the challenges and growth experienced by home basedcare givers, it appears that little is known on their experiences as they provide palliative care.

1.2. Research Problem

Demands of caring for patients may compromise the quality life of the caregivers (Kontrimiene et al., 2021). Generally, home-based caregivers conduct everyday house visits to their patients’ homes and these visits usually take 45 minutes to an hour (Oliver et al., 2015). Activities that they perform include bathing, feeding, shopping, cooking, counselling and massaging bed sores

(Thabethe, 2011). Additionally, they assist with screening, educating about diseases, health promotion, working with pregnant women, tracing defaulters, collecting medication on behalf of patients, and ensuring that patients adhere to medication regimes (Ama & Seloilwe, 2010; Nyalunga et al., 2019; Thomas & Pillay, 2021). Sometimes home-based caregivers are expected to perform tasks that are external to home-based care (Mpembeni et al., 2015). This results in them feeling overworked, burnt out and physically exhausted (Mashau et al., 2016; Nyalunga et al., 2019). This may be more challenging and draining for those who deal with patients who need palliative care. Added to the challenges is lack of support and appreciation from the community, families of patients, managers and their place of work affect home-based caregivers' productivity (Kangethe, 2009a). In many cases, home-based caregivers are not consistently and appropriately recognised (National AIDS Committee of South Africa [NACOSA], 2013). At times others experience lack of support from other governmental institutions (Naidoo et al., 2018). In extreme situations some experienced stigma and discrimination during visits to their patients' homes (Ama & Seloilwe, 2010). Stigma and discrimination were reported in Northwest province (Engelbrecht et al., 2017) and some African countries such as Malawi (Pindani et al., 2013).

Previous research has indicated that, at times, home-based caregivers felt like they were not meeting the needs of their patients as a result of unrealistic expectations placed on them (Austin-Evelyn et al., 2017). Patients and their families expected that home-based caregivers bring them something when they visit (Ankitola, 2008). A study in KwaZulu-Natal (in Kwa Dabeka and Clermont), asserted that community members had expectations that were not in line with home-based caregiving work. These involved home-based caregivers buying food and electricity for them, being called when someone is in labour, and being requested to provide body massages (White et al., 2017). The same was echoed in a study done in Gauteng where patients expected home-based caregivers to provide food parcels as well as for them to fix their water and electricity problems (Munshi et al., 2019).

Caring for terminally ill patients can place even more negative emotional demands on home-based caregivers, and as a result it can have harmful consequences on their psychological make-up (Musoke et al., 2022). For example, in a study by Ama and Seloilwe (2011) in Botswana it was identified that home-based caregivers experienced feelings of hopelessness and helplessness following the sudden death of their patients. Similarly, Ramuhaheli and Erasmus (2012) reported that home-based caregivers were emotionally disturbed by the death of their patients. The burden of home-based caregiving leads to stress and anxiety, and most home-based caregivers struggle to cope with work demands and other responsibilities (Scheffler & Mash, 2020). In view of the challenges faced by home-based caregivers is important to understand the rationale behind them continuation of caregiving work in spite many daily challenges. There is also dearth of knowledge on experiences and coping strategies of home-based caregivers in South Africa (Ankitola, 2008), especially those taking care of patients who need palliative care. Thus, there is a need to investigate home-based caregiver's psychological and social experiences. Together with how they cope in caring for patient in need of palliative care.

1.3. Operational Definitions of Concepts

1.3.1. Psychosocial

This concept involves both psychological and social aspects (Webster, 2023). In this study, psychosocial denotes psychological and social factors affecting the home-based caregivers when providing palliative care to terminally ill patients.

1.3.2. Home-based Caregiver

This is someone who provides assistance to sick persons in the comfort of their home. Home-based caregivers are either trained or untrained (WHO, 2019). Home-based caregiver in this context means a trained health care worker who provides palliative care to terminally ill patients.

1.3.3. Palliative Care

Palliative care is an approach that improves the quality of life of patients (both adults and children), and their families, associated with life-threatening illnesses. It lessens suffering through early identification, correct assessment and treatment of pain (WHO, 2018). Palliative care in this study is the care offered by the home-based caregivers to terminally ill patients.

1.3.4. Terminally Ill Patient

This term portrays a person who has a disease that cannot be cured (Kagan, 2022). A terminally ill patient in the study refers to a person who has a disease that requires palliative care from a home-based caregiver.

1.4. The Purpose of the Study

1.4.1. Aim of the Study

This study aimed to explore the experiences of home-based caregivers providing palliative care to terminally ill patients in Mahlathi Village, Mopani District, Limpopo Province.

1.4.2. Objectives of the Study

The objectives of the study were:

- to understand home-based caregivers’ perceptions of their work.
- to determine home-based caregivers’ notions of work experience.
- to identify psychosocial experiences of home-based caregivers.
- to appraise coping strategies of home-based caregivers.

1.5. Significance of the Study

From the literature consulted above, it is clear that home-based caregivers are faced with many obstacles daily. This study was undertaken in order to close the gaps in the body of knowledge with regards to home-based caregivers’ motivation and coping measures they employ to cope. This study can help the Department of Health with information that they can use to address the challenges that home-based caregivers face. Furthermore, the results demonstrate the relevant coping strategies at play that assist home-based caregivers.

1.6. Conclusion

In summary, home-based caregivers work under dire circumstances that make it difficult for them to provide quality and appropriate care. However, in the midst of these challenges, they continue to provide care even when they work in unfavourable conditions and are not rewarded for their work. It is important to understand their motivations for caregiving, the challenges they experience at work on a daily basis, how the challenges affect them psychologically, and how they cope with these challenges.

1.7. Outline of the Dissertation

Chapter 1: General Orientation of the Study. Focus of the chapter was on introducing the topic to the reader. Besides giving the rationale for undertaking the research, the chapter covers the background of the study, the research problem, the operational definition of concepts, the purpose of the study, the aim of the study and the research objectives, the significance of the study and provides an outline of the dissertation. *Chapter 2: Literature Review* reviews literature on the subject matter under study. This chapter reviewed recent existing literature about home-based caregivers in order to identify the gaps in knowledge. It also provided a link to selected theoretical frameworks to the phenomenon being studied. The subtopics covered include global perspectives on home-based care, African perspectives on home-based care, psychosocial challenges of home-based care, and two theoretical frameworks (ecological system theory and the transactional model of stress and coping). *Chapter 3: Research Methodology* includes an introduction, as well as a discussion of the research design and approach, sampling, data collection, data analysis and quality criteria. The researcher also indicated justification for applying research method. *Chapter 4: Presentation and Discussion of Research Results* involves the presentation and discussion of the findings as conveyed by the research participants. The researcher’s lessons gained and reflections on the study are also discussed. *Chapter 5: Discussion of findings,* are done based on recent relevant literature to the topic. This was done in support of the findings with reference to empirical evidence. The final chapter, *Chapter 6: Limitations, Conclusion and Recommendations*, includes the study’s limitations, conclusions and recommendations. This will assist policy makers in ensuring that home-based care programmes are effective in rendering their services.

Chapter 2: Literature Review

2.1. Introduction

When conducting a literature review, one consults and reads the work of other researchers (Fink, 2014). By reviewing literature, a researcher is able to identify gaps in knowledge and contribute towards the existing body of knowledge. A review aids the researcher to locate exactly where their proposed study fits in the field of study (Bless et al., 2013). This chapter will focus on the following topics: global perspectives of home-based care; African perspectives of home-based care; and the psychosocial challenges of home-based caregivers. The theoretical frameworks, namely ecological systems theory and the transactional model of stress and coping theory, will also be discussed.

2.2. Global Perspectives of Home-Based Care

Chronic illnesses put a burden on the health care system (Centre for Disease Control and Prevention [CDCP], 2022). This is attributed to the realisation that home-based caregivers are acknowledged to alleviate the shortage of health care professionals in health settings (WH0, 2021), resulting in the development of national guidelines and local manuals on providing home-based care (WHO, 2002). Home-based care programmes are available in low-, middle- and high-income countries (Perry et al., 2014). In developing countries, home-based care programmes have evolved over the past two decades in response to the HIV pandemic and the accessibility of antiretroviral therapy (Wringe et al., 2010). Throughout Africa there has been an increase in the reliance of home-based care (Root & Whiteside, 2013). Kang'ethe and Mangwiro (2015) noted the efficacy of home-based caregivers in African countries and communities. Middle-income and developed countries over many years have also shifted care from hospitals to home care models (Perry et al., 2014; Vincent& Amalberti, 2016).

Most family members in developed countries are usually not prepared for the caring role (Connolly & Milligan, 2014). They opt for their family members be cared for at institutional homes (Gomes et al., 2013). For example, in the United States, home-based caregivers have been of assistance to many seniors living with terminal illnesses (Rogers, 2018). The chronically ill, disabled and aging individuals indicate that they value the work done by home-based caregivers in Australia (Hussain et al., 2018). Korean and European countries such as Spain, Italy, Denmark and Sweden have home-based caregivers help with ill patients (Soong-Nang Jang et al., 2012).

2.3. African Perspectives of Home-Based Care

Home is commonly a place that is favoured by patients who are terminally ill and the support of their families is important (Woodman et al., 2016). Many patients who are terminally ill depend on family members to care for them (O'Neil et al., 2018). In many African cultures, one person's problem is everybody's problem. The same applies to when one family member is sick: responsibility for care lies on close and extended family members (Hlabyago & Ogunbanjo, 2009). Van Deventer and Wright (2017) reported that families felt that caring for their loved ones was their responsibility and obligation. This notion is based on the practice of *ubuntu*, which posits that the family is responsible for caring for their sick loved one (Makhele & Mulaudzi, 2012). However, the people that bear the brunt of caring for the sick are mostly women because of African cultural beliefs that caregiving duties should be performed by women (Gilbert & Selikow, 2011).

Families caring for an ill family member are always welcoming of support and visits by home-based caregivers. This is because they regard it as beneficial as it assists in reducing the burden of care (Mamatsharaga et al., 2022). A research study based in Malawi found that immediate family members or spouses cared for chronically ill patients and home-based caregivers also visited these homes to provide care. The same study also mentioned that families of sick family members viewed home-based caregivers' work as complementary to activities done by the family (Pindani et al., 2013). These findings were supported by Moshabela et al. (2015) in Bushbuckridge where clients and their families preferred working together with home-based caregivers. A study done in the Western Cape found that family caregivers provided hands-on caring for their sick loved one. However, they also valued home-based caregivers' visits to support them (Scheffler & Mash, 2020). Raninga and Motloung (2013), in their study in KwaZulu-Natal, noted that families were thankful of home-based caregivers' visitations to assist them with bathing, household chores, and monitoring their intake of medication. On the other hand, some African families viewed home-based care as something that is foreign to them as a result of the influence of culture, religion, personal beliefs and a lack of knowledge (Makhele & Mulaudzi, 2012; Mashau et al., 2014). A study conducted in Ghana (Adklu District) reported that families did not understand the importance of home-based caregivers' visits (Konlan et al., 2021). A study by Grant et al. (2021) in KwaZulu-Natal shows that families felt that home-based caregivers lacked confidentiality and could not be trusted, while other families leaned on traditional medicine for health care and were consequently against western medical interventions (Mabetha et al., 2021). Furthermore, some families were reluctant of home-based caregivers' visits because they held onto religious beliefs that were against them using medical treatment (Mashau et al., 2014).

2.4. Psychosocial Challenges of Home-Based Care: Psychological Challenges

2.4.1. Burnout

Home-based caregiving is physically demanding and often takes a toll emotionally on home-based caregivers leading to burnout and depression (Hlabyago & Ogunbanjo, 2009). The majority of home-based caregivers reported feeling stressed (Lindt et al., 2020) and burned out as a result of caregiving work (Mashau et al., 2015). A study by Kupa and Geyer (2020) in Tshwane revealed that home-based caregivers felt stressed as a result of increased workload. This was consistent with home-based caregivers in KwaZulu-Natal who were burned out due to having lots of work to do (Ankitola et al., 2013). Walking long distances also contributed to the burnout home-based caregivers experienced (Mashau & Davhana-Maselesele, 2009). Home-based caregivers in Zambia noted that walking long distances was tiring because by the time they get to their patients' residences they are already tired but still have to care for the patients (Mbale & Chileshe-Chibangula, 2017). This was also the case for home-based caregivers in Khayelisha who reported that walking long distances in the sun caused them fatigue when they reached patients' homes (Ramuhaheli & Erasmus, 2012).

Large numbers of patients requiring care also led to burnout of home-based caregivers (Moshabela et al., 2015). Home-based caregivers in Kanye in Botswana reported feeling stressed and fatigued because of caring for multiple clients (Kang'ethe, 2010). Similarly, home-based caregivers in Gauteng mentioned that caring for many patients was stressful (Uren & Graham, 2013). These findings were supported by Valjee and Van Dyk (2014) where it was reported that home-based caregivers experienced burnout due to caring for many patients. From the variety of literature discussed, it is clear that home-based caregivers carry out tasks that are emotionally and physically draining. These make them susceptible to burnout and distress daily thus affecting their quality of work because they are mostly fatigued when they get to their patients' homes. Being overloaded with too many patients to care for further increases their tiredness and predisposes them to stress.

2.4.2. Compassion Fatigue

Home-based caregivers find their work emotionally and psychologically taxing at times (Kupa & Geyer, 2020). Their daily experience is characterised by frustration and fatigue (Makina-Zimalirana, 2023). Mashau and Davhana-Maselesele (2009) mentioned that home-based caregivers in Venda expressed feelings of helplessness when they found their patients living in poverty with no food and water to drink. This concurred with Mbale and Chileshe-Chibangula's (2017) study in Zambia which found that home-based caregivers experienced stress from seeing patients living in poor conditions. Home-based caregivers in Bushbuckridge also conveyed feelings of helplessness when they visited terminally ill patients without food and there was nothing they could do to help (Sips et al., 2014).

The challenges that accompanied home-based caregiving work are damaging to home-based caregivers' mental and emotional health (Ankitola, 2008). In Khayelitsha, home-based caregivers felt emotionally disturbed when some of their patients died in their hands (Ramuhaheli & Erasmus, 2012). Home-based caregivers in Kenya experienced insomnia, frequent headaches, felt frustrated and their appetite was affected when they thought of their unwell patients (Khaturi-Ogola et al., 2014). Most home-based caregivers in Venda

(Mutale) were affected emotionally when the condition of their patients was not improving despite their dedication to care (Mashau et al., 2016). Home-based caregivers in KwaZulu-Natal mentioned that witnessing the daily deterioration of health in their patients affected them mentally (Valjee & Van Dyk, 2014). In the Western Cape, home-based caregivers felt anxious and stressed because they struggled balancing caregiving work and their personal lives (Scheffler & Mash, 2020). Home-based caregiving precipitates psychological experiences such as frustration, depression and stress. This continues to make the work of the home-based caregivers more challenging. The challenges that stand out include witnessing the death of their patients, together with poverty they were subject to.

2.4.3. Home-Based Caregivers and Coping Strategies

The most common coping strategies employed by home-based caregivers are emotion-focused coping and problem-focused coping strategies (Uren & Graham, 2013). Emotion-focused strategies reduce distress by using strategies such as avoidance and denial, while problem-focused strategies are focused on finding solutions to the problem (Lazarus & Folkman, 1984). The efficacy of coping strategies is dependent on how well they help the home-based caregivers to cope with the challenges (Valjee & Van Dyk, 2014).

Home-based caregivers use various coping strategies to confront psychosocial challenges affecting them (Owokuhaisa et al., 2023). In Venda, home-based caregivers reported developing a thick skin to cope with the burdens that accompanied their work (Mashau et al., 2014). Home-based caregivers in Gauteng coped with challenges of caregiving through support from their families, their spiritual practices, alcohol, music and relaxation (Uren & Graham, 2013). Home-based caregivers in Kenya resorted to emotion-focused coping strategies by having a positive outlook regarding caregiving work and praying for divine help to do their work (Khathuri-Ogola et al., 2014). In a study based in Tshwane, home-based caregivers survived work challenges through support fromcolleagues and supervisors (Kupa & Geyer, 2020). The work home-based caregivers do daily result in them having to develop coping strategies to assist them. Most commonly, these include emotion-focused and problem-focused coping strategies. Research has shown both forms of coping to be efficacious.

2.5. Psychosocial Challenges of Home-Based Care: Social Challenges

2.5.1. Financial Challenges

Home-based caregivers indicated that inadequate salaries are a major challenge they encounter in caregiving work (Ramuhaheli & Erasmus, 2012). This is because some of them have no other sources of income other than home-based caregiving (Njau et al., 2015). For example, home-based caregivers in Gauteng, North West and Limpopo mentioned that their salaries are very low andinsufficient for their basic needs (Lekganyane & Alpaslan, 2019). Home-based caregivers in Venda shared the same sentiments that their stipends were not enough to sustain them (Mashau et al., 2015). In North West (Madibeng District), home-based caregivers reported that their financial incentives were inconsistent, which discouraged them from continuing with caregiving work (Seutloali et al., 2018). Mamba and Ntuli (2014) were in support of this finding, reporting that home-based caregivers’ stipends in Soweto were very little and at times they would go for months without remuneration. Some home-based caregivers generated other means to sustain themselves financially because they came from poverty-stricken families (Qalinge, 2011). Home-based caregivers in Kenyadid farm work, casual labour and household work (Kathuri-Ogola et al., 2014); while some home-based caregivers in a Gauteng study resorted to stealing fromthe patients that they were caring for (Uren & Graham, 2012). Home-based caregivers in KwaZulu-Natal requested financial assistance from their families and friends to help during difficult periods (Ankitola, 2008).

The burden of caregiving also placed a strain on home-based caregivers’ finances (Ama & Seloilwe, 2010). This is because they worked in poverty-stricken communities (Wringe et al., 2010). On some occasions, home-based caregivers used their own money to assist patients and their families. In Bushbuckridge, for example, home-based caregivers had to use their own money to ensure that patients went to the clinic to collect their medication (Sips et al., 2014). Home-based caregivers sometimes had to use the little stipend they received to buy food and pay for transportation to hospital for their patients to ensure adherence to medication (Cataldo et al., 2015). Based on these findings, it is apparent that finance is a challenge to the home-based caregivers’ livelihoods as their minimal income is not enough to carry them through the whole month. This results in home-based caregivers feeling disheartened. However, it does not only impact them, but their families as well. For some, this resulted in them being motivated to seek out other sources of income.

2.5.2. Support from Health and Community Members

Most home-based caregivers report not receiving support when doing their work. They are disheartened with the lack of recognition, support and respect from health workers, patients, families of patients and the community (Motswasele-Sikwane et al., 2020). Home-based caregivers in North West province have expressed feelings of frustrations from the absence of supervision and support from health care professionals (Qalinge, 2011). Home-based caregivers in Botswana (Kanye) shared similar sentiments of dissatisfaction due to the non-existent support of health personnel (Kangethe, 2009b). In KwaZulu-Natal, home-based caregivers also indicated a lack of support from their managers and their organisation (Valjee & Van Dyk, 2014). Patients did not show appreciation for the work that home-based caregivers were doing. Instead patients made unfair demands on the home-based caregivers (Ankitola, 2008). In Gauteng, specifically in Northern Madibeng, patients were not acknowledging the work that the home-based caregivers were doing (Motswasele-Sikwane et al., 2020). Home-based caregivers in Venda observed a lack of involvement from the families of ill patients (Mashau & Davhana-Maselesele, 2009). In one study in Durban, KwaZulu-Natal, families of patients did not help home-based caregivers with caring for ailing patients (Hangulu & Ankitola, 2017).

Further, it has been found that home-based caregivers indicated the absence of support or cooperation from the community (Nyaphisi & Obioha, 2015). Home-based caregiver in Kanye in Botswana also indicated an absence of support from community members (Kang’ethe, 2010). Home-based caregivers in Botswana also did get the support they expected from the government (Ama & Seloilwe, 2011). A lack of support is another challenge that demoralises home-based caregivers. The absence of acknowledgement from the government and health workers is the most daunting, in addition to no support from their patients and the community they serve. Taken together, all these factors make them feel insignificant and unrewarded.

2.5.3. Stigma and Discrimination

Home-based caregiving work often results in stigma and discrimination by community members, patients and families of patients. A study by Mashau et al. (2014) revealed that community members in Venda (Mutale) linked home-based caregivers to diseases such as HIV/AIDS and TB. In Bushbuckridge, home-based caregivers were associated with people living with HIV/AIDS by community members (Mlotshwa et al., 2015). As a result of the stigma and discrimination, some families of terminally ill patients did not want home-based caregivers to visit their homes (Mamba & Ntuli, 2014). Home-based caregivers in Kanye (Botswana) indicated that some families did not even want to disclose that they had a sick person in the home (Kangethe, 2009b). In the same vein, Soweto families will even go to the extent of denying that they have a sick person in the house (Mamba & Ntuli, 2014). In KwaZulu-Natal similar results were reported where families denied that they had a sick family member (Ankitola, 2008). This is attributed fear of stigma from neighbours when they are seen with a home-based caregiver (Mashau & Davhana-Maselesele, 2009).

Thus, stigmatisation is a hindrance to home-based caregiving work as it contributes to the lack of trust by community members (Mashau et al., 2014; Mlotshwa et al., 2015). Community members in Lesotho maintained that home-based caregivers lacked confidentiality (Seutloali et al., 2017). Altogether, these factors may cause patients defaulting on treatment, meaning more visits for home-based caregivers. The patients and their families as well as community members' perceptions of home-based caregivers' work results in stigma and discrimination. This causes resistance from the patients, families and community members, which ultimately affects the work of home-based caregivers.

2.5.4. Risk of Infections and Lack of Health Supplies

The duties that are performed by home-based caregivers put them at risk of contracting infections. Most of them expressed having a fear of infections when providing care (Njau et al., 2015). These include changing diapers, feeding, bed baths, oral hygiene, care of sores and wounds, cleaning vomit amongst others

(Mamba & Ntuli, 2014). Lack of supplies and care kits, gloves and other first-aid supplies, make provision of caregiving difficult (Mbale & Chileshe-Chibangula, 2017). In North West province, for example, one study showed that home-based caregivers indicated that they did not have gloves, aprons and masks and were consequently vulnerable to infections (Motswasele-Sikwane et al., 2020). Lack of health supplies and fear of infections led home-based caregivers to improvise care because they could not attend to their patients' needs (Mamba & Ntuli, 2014). Home-based caregivers in Bushbuckridge who were fearful of contracting infections used bread plastic wrappers due to shortage of gloves (Mlotshwa et al., 2015). Home-based caregivers in an Umlazi Township (KwaZulu-Natal) used hand sanitisers to prevent against infection (Zikhathile & Atagana, 2018). Home-based caregiving work is at times a risky job that exposes the caregivers to infections. The lack of precautionary measures such as gloves, masks and disinfectants make the provision of caregiving work difficult.

2.6. Theoretical Frameworks

The theoretical frameworks adopted for the study are ecological systems theory and the transactional model of stress and coping. The ecological theory is chosen because it explains the interaction of the home-based caregivers and ecological influences from the home-based caregivers' own families, patients, communities, the government and the organisations they are affiliated to. On the other hand, the transactional model of stress and coping is significant in explaining how home-based caregivers cope with the effects of home-based caregiving work and the associated ecological influences that impact them.

2.6.1. Ecological Systems Theory

In 1979, American Psychologist Urie Bronfenbrenner developed the ecological systems theory. Bronfenbrenner explains how a child grows and develops in interaction with the environment and the impact the child has on the environment. The environment has an influence on the child as a set of nested structures, each inside the next like a set of Russian dolls (Bronfenbrenner, 1979). He termed the nested structures ecological systems that a person interacts with, with each nest further from the previous one (Velez-Agosto et al., 2017). These ecological systems are the microsystem, mesosystem, exosystem and macrosystem (Ettekal & Mahoney, 2017). The theory was chosen because the study aimed not only to investigate the psychosocial challenges of the home-based caregivers, but also to gain an understanding of how they relate with their own families, patients, the community, their workplaces and the government.

2.6.1.1. Microsystem. The microsystem is defined as any context that the person in focus has immediate experience of and personal interaction with in a direct way (Bronfenbrenner, 1979). The microsystem is the smallest of all systems andit is the immediate environment in which the child lives (Psychology Notes Headquarters, 2019). An example of this system is the relationship between an individual and his or her parents, siblings, or school environment (Velez-Agosto et al., 2017). At this level, the researcher wanted to understand how the families of the home-based caregivers perceive their work as caregivers and how the psychosocial challenges the job brings about affected their relationships with their close family members. Literature from the context of Lesotho has indicated that home-based caregivers' relationships with their families were strained because they would use their last remaining funds to travel to work knowing well they were not being remunerated (Nyaphisi & Obioha, 2015).

2.6.1.2. Mesosystem. The mesosystem comprises the interactions of the variety of microsystems that the children find themselves in (Psychology Notes Headquarters, 2019). An example of the mesosystem is the relationship between the individual's family and their school teachers or administrators (Velez-Agosto et al., 2017). In this system, the study examined home-based caregivers' interactions with their patients in terms of how the patients understand their work and how the caregivers' experience working with various patients on a daily basis. Mlotshwa et al. (2015) asserted that patients would expect home-based caregivers to bring them food during their visits. Home-based caregivers also had to deal with patients' mood swing and rudeness when they visited them (Ankitola, 2008).

2.6.1.3. Exosystem. This system contains the linkages and processes taking place between two or more settings, where at least one does not comprise the developing person, but where events occur that indirectly influence processes within the immediate settings the developing person lives in (Bronfenbrenner, 1994). An example of an exosystem is a father who is not promoted due to an indifferent boss at work, with the consequence that he takes out this frustration on his children by mistreating them (Psychology Notes Headquarters, 2019). At this level, the research determined the community members' views of home-based caregivers work when caring for terminally ill patients in the community. Seutloali et al. (2018) study on Lesotho home-based caregivers reported that communities left all responsibilities of care to terminally ill patients.

2.6.1.4. Macrosystem. The macrosystem is defined as the system of ideology and the organisation of social institutions common to particular social classes, ethnic groups or cultures to which a person belongs (Bronfenbrenner, 1979). This system entails children's cultural patterns and values, especially their beliefs and ideas, as well as political and economic systems (Psychology Notes Headquarters, 2019). At this level, the study will examine the reactions of government as well as the organisations that home-based caregivers are affiliated to.

2.6.2. The Transactional Model of Stress and Coping

Lazarus and Folkman (1984) developed the transactional model of stress and coping, which postulates that stress is an appraisal (evaluation) of situations people find themselves in. The transactional model posits that people experience two stages of appraisal before they are eventually stressed and can respond to stress. These stages are termed primary and secondary appraisal. In primary appraisal the situation is evaluated in order to find out if it is relevant to the individual, specifically, whether it will bring about gain or harm. If it brings gain, the individual does not worry about it; when it is harmful, the individual decides if it is dangerous or not. If it is dangerous, the person then moves on to secondary appraisal. In secondary appraisal, a person makes a decision whether they are capable of coping with the situation by looking at the demands of the situation and the resources available. If one feels that the demands outweigh the resources, negative stress is experienced which results in the engagement of coping strategies.

The theory argues that we adopt either problem-focused or emotion-focused coping strategies. Emotion-focused coping is directed at lessening emotional distress by using mechanisms such as avoidance and denial. Emotion-focused coping is used to maintain hope and optimism, to deny both fact and implication, to refuse to acknowledge the worst, and to act as if what happened did not matter (Lazarus & Folkman, 1984). On the other hand, problem-focused coping strategies are similar to those used for problem solving. Problem-focused efforts are often directed at defining the problem, generating alternative solutions, generalising alternatives in terms of their costs and benefits, choosing among them and acting (Lazarus & Folkman, 1984). The theory was selected because the study aimed to probe how home-based caregivers cope with the psychosocial challenges they experience daily when providing palliative care to terminally ill patients. From the literature review, one can realise that home-based caregivers experience a burden of care that causes them tremendous stress that at times interferes with the provision of home-based care services. The transactional model of stress and coping helped the researcher comprehend how the home-based caregivers view the stress of caring, coping strategies they employ, how they deal with the psychosocial challenges they experience and whether they receive support.

2.7. Summary

From the above discussion it is clear that home-based caregivers experience many psychosocial challenges that have a negative effect on their lives at work and outside work. Lack of remuneration or inconsistency in this respect makes home-based caregiving work difficult as they need money to survive. The lack of support in this regard makes it more unbearable for the home-based caregivers to continue feeling motivated to go on providing care. The review also indicated that there are a variety of studies on home-based caregiving challenges. However, but there are limited studies based on how they cope with these challenges, notwithstanding continue to render voluntary services.

Chapter 3: Research Methodology

3.1. Introduction

Research methodology encompasses the plans that are used to collect and analyse data for research in order to discover new information and create a better understanding of a particular topic (Hesse-Biber & Leavy, 2011). The topics covered in this chapter are the research approach and design, research setting, study population, inclusion and exclusion criteria, study sample and sampling, data collection, data analysis, quality criteria, and finally ethical considerations.

3.2. Research Approach and Design

Research design refers to a strategy that a researcher selects to integrate a research study (Fouche et al, 2021). This study adopted a qualitative research approach using a phenomenological design. Qualitative research involves understanding people's experiences in a humanistic and interpretive approach (Jackson et al., 2007; Maree, 2019). The qualitative approach allowed the researcher to obtain an in-depth understanding of the home-based caregivers' experiences from their perspective when providing care to terminally ill patients. The chosen approach helped justify the home-based caregivers' motivation to continue with their caregiving work regardless of the challenges. The approach was also helpful in exploring the home-based caregiver's coping strategies with daily problems.

A phenomenological design is an approach in qualitative research that captures the experiences of people with similar identities or phenomena (Creswell, 2013). The phenomenology design was used for the study to focus on individuals who have direct experience of home-based care, which in this case are the home-based caregivers. The phenomenology design also assisted in concentrating on the home-based caregiver's experiences when providing palliative care to terminally ill patients at Mahlathi Village.

3.3. Research Setting

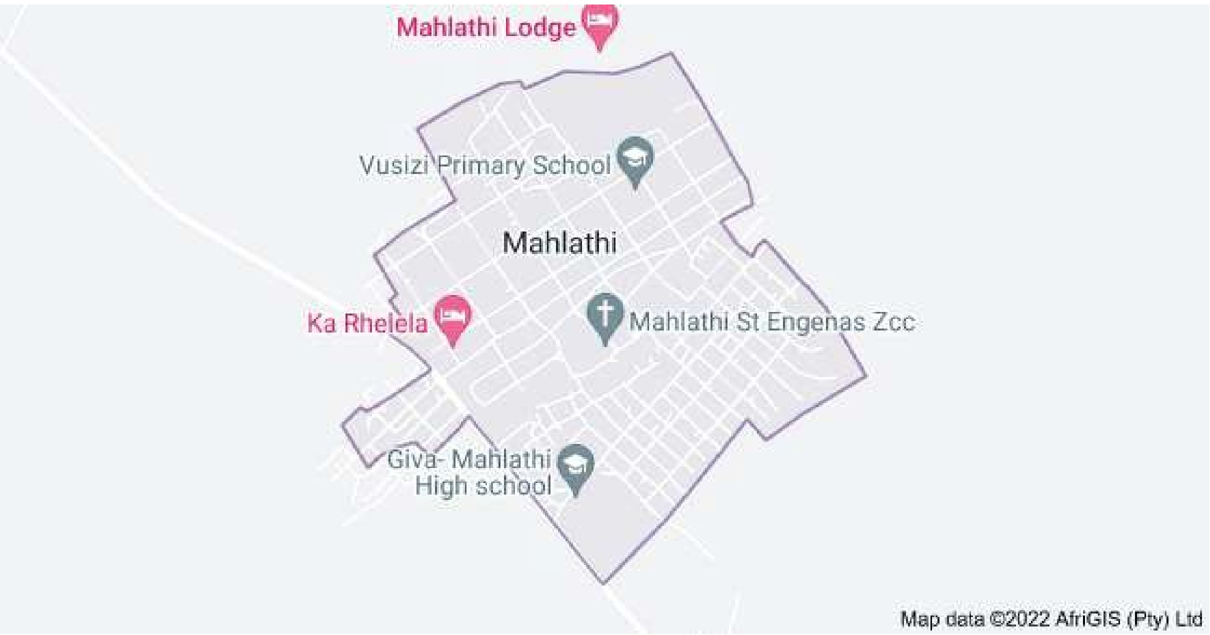
The study was conducted in Mahlathi Village, Mopani District, South Africa. Mahlathi is a village located in Greater Giyani Municipality in the Limpopo Province. The village is 33 kilometres outside of Giyani Town. There are 12 home-based caregivers serving in Mahlathi Village.

Residential areas in Mahlathi Village are largely mud-constructed and roofed with wattle trees and thatch. Other houses are those referred to as Reconstruction Development Programme (RDP) which are donations from the government. There are fewer reconstructed houses built with cement bricks. There is a 17 kilometre gravel road from Giyani township. The municipality regularly do some repair work. Two pipes supply water to the whole village. Donkey carts and water bottles are used to collect water. Some villagers have boreholes.

There is no clinic at Mahlathi Village. Health care services are accessed at the Khakhala-Hlomela clinic. The clinic is situated at Khakhala Village, which is 13 kilometres from Mahlathi Village. There are seven churches at Mahlathi Village: two Zion Christian Church (ZCC), two Apostolic Churches and three Faith-based churches. The village has two schools, a high and primary school. There are no networks or associations that assist home-based caregivers. Other essential services, such as grocery shops and government services are accessed in Giyani Town.

Figure 1

Map of Mahlathi Village



(Google Map, 2022)

3.4. Study Sample and Sampling

3.4.1. Sampling

Sampling is a process of choosing people from a population to study them. These people usually represent the population as a whole (Maree, 2019).

3.4.2. Purposive Sampling

The study has employed purposive sampling in choosing the representative sample. Purposive sampling is also known as judgemental, selective or subjective sampling (Welman et al., 2005), and it is a type of non-probability sampling where the researcher uses their judgement to select participants to be part of a study (Palinkas et al., 2015). Purposive sampling was selected because the targeted individuals were home-based caregivers specifically providing care to terminally ill patients. The sample consisted of twelve home-based caregivers - eleven were females and one male. They were all black, Xitsonga speaking, and their ages ranged between 41 and 59 years.

3.4.3. Selection Criteria

The selection criteria that were used to identify the participants were inclusion and exclusion. They are defined as the traits of individuals that either allow them to be included or excluded in a study sample (Garg, 2016). Inclusion criteria are described as features in a population that a researcher uses to answer research questions. Examples of inclusion criteria are among others, demographic, clinical, and geographic characteristics (Patino & Ferreira, 2018). In this study, being a home-based caregiver working in Mahlathi Village was considered an inclusion criterion. Exclusion criteria include factors that disqualify an individual from partaking in a given study (Garg, 2016). These individuals may have elements that can interfere with the success of the study. Thus, causes risk for an unfavourable outcome. Home-based caregivers who were not residing in Mahlathi Village were not incorporated in the study.

3.4.4. Study participants

The study participants were 12 home-based caregivers from Mahlathi Village. They were informed by the qualitative, phenomenological design that aimed to gain insight into caregiving work from the point of view of the home-based caregivers themselves.

3.5. Data Collection

After obtaining ethical clearance from the University of Limpopo ethics committee as well as permission from the home-based caregivers' manager and supervisor at Khakhala-Hlomela clinic (see Appendix 1: Clinic in Charge Permission Letter), the researcher proceeded to make appointments with the home-based caregivers to collect data. The home-based caregivers availed themselves at the agreed time with the researcher. Interviews were conducted at Khakhala-Hlomela clinic as the setting was convenient for the home-based caregivers. All interviews were done in Xitsonga, a language preferred by the home-based caregivers. The interviews lasted for 45 to 60 minutes. The demographic information of the home-based caregivers was collected as well (see Appendix 4: Demographic Information of Participants).

Data was collected through semi-structured interviews (see Appendix 5: Interview Guide) in order to determine individuals' perceptions, opinions, facts, their reactions to their surroundings, and potential solutions to their challenges (De Vos et al., 2011). The guide was translated in Xitsonga to accommodate the participants. Interviewing is collecting data by asking participants' semi structured face to face questions (Harvey, 2012). Semi-structured interviews were preferred because the current study aimed to afford the home-based caregivers an opportunity to express their lived experiences as they provide palliative care to terminally ill patients. Field notes and tape recordings were used to accurately capture the data. Welman et al. (2005) describe field notes as detailed notes and observations made by the interviewer or researcher. For this purpose, a tape recorder is particularly useful. When using field notes, the researcher should take note of any non-verbal behaviour of the respondents (Fouche et al., 2021). Tape recordings were used to record the responses of the home-based caregivers in order to aid the researcher to concentrate on the interview and lead each interview without worrying about recalling all the information. Field notes were useful in noting non-verbal cues elicited by home-based caregivers in the interviews.

3.6. Data Analysis

The data was analysed by means of interpretative phenomenological analysis (IPA). The main goal of the IPA is to delve into how individuals make sense of their experiences (Smith, 2011). It rests on the assumption that people are 'self-interpreting beings' (Sydor, 2019), which means they are involved in interpreting the events, objects and people in their lives. IPA also draws on essential principles of phenomenology, hermeneutics and ideography (Pietkiewicz & Smith, 2014). The focal point in phenomenology is how individuals perceive their experiences as opposed to describing the phenomena in accordance with predetermined categorical system, conceptual and scientific criteria (Pietkiewicz & Smith, 2012). In hermeneutics lens, the researcher needs to understand people's outlook and their languages which resonates with their experience of the world (Sydor, 2019). The third principle that IPA rests upon is Idiography. Idiography focuses on analysing extensively single cases and looking into the individual’s perspectives of participants in their unique contexts (Pietkiewicz & Smith, 2014). The process of data analysis unfolded in thefollowing four phases.

3.6.1. Phase 1: Multiple Readings and Making Notes

In this phase, the researcher closely and repeatedly reads the transcribed transcripts; if there are audio tapes they listen to them a number of times (Smith, 2011). Reading and listening frequently aids the researcher to immerse themselves in the data, and helps them remember the atmosphere of theinterview and context in which it was conducted (Pietkiewicz & Smith, 2014). Re-reading the transcripts and listening to audio tapes provides the researcher newinsight (Smith & Osborn, 2007). In this study, the researcher re-read the transcripts and listened to recordings several times in order to gain new perspectives and immerse themselves in the data collected. The researcher alsomade note of behaviour, mannerisms and non-verbal cues as observed.

3.6.2. Phase 2: Transforming Notes into Themes

This phase focuses on transcribed notes, and then on the transcripts (Pietkiewicz & Smith, 2012). The rationale is to transform the notes into emerging themes and to formulate a phrase that can capture a theme, which is concise and at a slightly high level of abstraction (Pietkiewicz & Smith, 2014). The current study drew more attention to notes than transcripts to ensure the transformation of notes to themes.

3.6.3. Phase 3: Seeking Relationships and Clustering Themes

In this stage, connections between themes are examined and grouped in accordance with their similarity. This is followed by providing clustering to a given label and its description (Pietkiewicz & Smith, 2012). Therefore, the identified themes were grouped in accordance with how they were similar (Pietkiewicz & Smith, 2014). In the study, the researcher looked at connections between the themes that emerged from the collected data, grouped them according to their similarities, and described them.

3.6.4. Phase 4: Writing Up a Study

Finally, the researcher writes a narrative account of the study. This entails taking the identified themes and writing about each of them. Each theme is described and exemplified, with responses from the interviews with the participants (Pietkiewicz & Smith, 2014). The researcher at this stage wrote the dissertation to present the findings of the interviews with home-based caregivers. The findings were also discussed in conjunction with literature.

3.7. Quality Criteria

Fouche et al. (2021) highlighted four criteria that are used to ensure quality in qualitative research. These are credibility, transferability, dependability and confirmability. Lincoln and Guba (1985) also included reflexivity as part of assuring quality criteria. These criteria are detailed below.

3.7.1. Credibility

Credibility has to do with inquiries such as how congruent the findings are with reality. In other words, how does the researcher ensure that the reader will believe their findings? (Maree, 2019). Ways to ensure credibility include prolonged engagement, persistent observation, referential adequacy, and member checks (Babbie & Mouton, 2001). The researcher ensured that the report encompassed the researcher’s integration and that of the participants.

To ensure credibility in the study the following credibility strategies were used as adapted from Babbie and Mouton (2001):

- **Prolonged engagement:** In the study, the researcher probed the research questions numerous times until sufficient data was acquired.
- **Persistent observation:** The researcher identified relevant issues related to the study topic and focused on them.
- **Referential adequacy:** This involves the material utilised to record findings. These materials can be audio or video tapings. The researcher utilised a tape recorder, notes and a mini-dissertation report to capture the responses of participants.
- **Member checks:** This criterion involves examining sources of information and checking interpretations of the data with the aim of evaluating

respondents' intentions, correcting errors and obtaining supplementary data. The researcher consulted with the home-based caregivers constantly for clarity to avoid errors in data and misinterpretation.

3.7.2. Transferability

Transferability is the extent to which research results can be transferred to another context or setting with other participants (Babbie & Mouton, 2001). This is also known as transferability judgement (Korstjens & Moser, 2018). The researcher in this study engaged with numerous academic texts as well as with the research participants to ensure that the findings can be transferred to other populations of home-based caregivers.

3.7.3. Dependability

Dependability involves considerations of stability of findings over time. It is described as participants' evaluations of the findings, interpretations and recommendations of the study in the sense that all the data received are from the respondents (Korstjens & Moser, 2018). The study strived for dependability by making sure that if it were to be repeated with the same participants, the same or similar findings would be present.

3.7.4. Confirmability

Confirmability is the degree to which the research findings could be confirmed by other researchers (Korstjens & Moser, 2018). Steps must be taken by the investigator to ensure that the findings are the result of the experiences and ideas of the participants. The researcher in the study kept the audio taped interviews and field notes of the findings of the research to ensure that the findings are auditable by the research supervisors.

3.7.5. Reflexivity

Reflexivity is defined as the researcher's self-conscious critique, appraisal and evaluation of how their own subjectivity and context influenced the research process (Olmos-Vega et al., 2022). Personal reflexivity in the study was achieved by the researcher approaching the study from a place of having no preconceived ideas about home-based caregivers. The researcher conducted introspection by putting aside elements of her own views that might have had an influence on the research. This assisted in establishing a clearer picture of the reported results reflecting the participants’ experiences.

Researcher bias was kept in check by constantly reminding herself of the aims and objectives of the study. This aided the researcher to stay focused on the purpose of the study and eliminated bias by discussing the interpretations with the research supervisors.

3.8. Ethical Considerations

3.8.1. Permission to Conduct Study

The research proposal was reviewed at the University of Limpopo, Department of Psychology, presented at the Faculty of Humanities, School of Sciences and the researcher requested permission from the Turfloop Research Ethics Committee (TREC/94/2021: PG), where permission to conduct the study was granted. After permission was granted, then the researcher asked permission from Limpopo Department of Health, Khakhala-Hlomela Clinic’s manager and the supervisor of home-based caregivers (see Appendix 1: Clinic in Charge Permission Letter).

3.8.2. Informed Consent

Informed consent implies that the participants are made aware of the type of information being sought by the researcher and its purpose (Kumar, 2014b). Research participants need to understand what will be required of them during their participation, how their identities will be protected and how results will be disseminated (De Plooy-Cilliers et al., 2014). Home-based caregivers gave written informed consent (see Appendix 3: Participant’s Informed Consent) as proof of their participation in the study. The researcher utilised an information sheet (see Appendix 2: Participant’s Informed Consent Information) to explain to the home-based caregivers the nature of the study and what was expected from them as participants.

3.8.3. Confidentiality and Anonymity

Confidentiality means that the research participants’ identities will be protected (Bless et al., 2013). Anonymity is assured by not matching the participants' identities to the data (Du Plooy-Cilliers et al., 2014). The researcher ensured confidentiality by not making known the information of participants to anyone, unless caregivers wanted to be identified. The researcher did not use identifying information of the home-based caregivers when reporting and discussing the results.

3.8.4. Avoiding Harm

In order to avoid harm, the researcher observes the slightest dangers that are possible and guards against them in order to protect the well-being of the participants (Babbie & Mouton, 2001). Therefore, the researcher made sure to make prior arrangements with the counselling centre to ensure that those who were emotionally affected could be referred to the nearest Psychology centre at Nkhensani Hospital in Giyani Town. During the interviews there was no home-based caregiver that required psychological intervention.

3.9. Conclusion

In summary, the chosen research methods assisted the researcher to get answers to the questions in the interview guide in order to obtain responses that were rich, detailed and provided the home-based caregivers' perceptions of their work. In addition, IPA was adopted in order to generate a broader understanding of home-based caregiving work and how this work influences the lives of home-based caregivers.

Chapter 4: Presentation of Findings

4.1. Introduction

This chapter presents the findings of the study subsequent to data collection. These findings initially include the demographics of the participants. The main themes, themes and sub-themes follow this as they represent the lived experiences of the participants when providing palliative care to terminally ill patients in Mahlathi Village. The chapter closes with a summary of the findings.

4.2. Research Process

The following procedure is the research process from the notes initiated in the researcher's journal. The use of the journal was necessary to record experiences during the research course, my reflections, challenges, and significant aspects during the data collection process. The researcher encountered several challenges, such as, scheduling of appointments and thoroughly engaging with interpretative phenomenological analysis. She was doubtful and seemed more confused with the process because it was new to her. This shortcoming was overcome by reading and continuous engagement with the data. On the other hand, some processes such as sampling, and the interview process went through according to plan. Meanwhile, the researcher observed the critical aspect in the process to be journaling, supervision and personal debriefing which empowered the researcher during the process. The experience allowed the researcher to minimise bias and co-create while interacting with the participants.

4.3. Demographics of the Participants

Table 1 illustrates the demographics of the participants. Twelve home-based caregivers participated in the study where most were female and only one was male. Their ages ranged between 41 and 59 years old. Five of the participants were married, with another five unmarried and two widows. The majority of the participants' highest level of education was secondary education (Grade 12). All of them were working as home-based caregivers and have more than 10 years' experience in the field.

Table 1

Demographics of the Participants

Participant	Gender and Age	Years of Experience	Education	Marital Status
1.	Female, 54 years old	20 years	Grade 12	Widow
2.	Female, 49 years old	20 years	Grade 12	Married
3.	Female, 57 years old	21 years	Grade 12	Unmarried
4.	Female, 48 years old	18 years	Grade 12	Unmarried
5.	Female, 52 years old	15 years	Grade 12	Married
6.	Female. 55 years old	20 years	Grade 12	Married
7.	Female, 41 years old	19 years	Grade 12	Unmarried
8.	Female, 48 years old	20 years	Grade 12	Widow
9.	Female, 53 years old	20 years	Grade 12	Unmarried
10.	Female, 58 years old	20 years	Grade 12	Married
11.	Female,59 years old	19 years	Grade 12	Unmarried
12.	Male, 47 years old	14 years	Grade 11	Married

4.4. Presentation of the Findings and Themes

4.4.1. Main Themes, Themes and Sub-Themes

Table 2 provides a clear description of the themes identified during data analysis. These themes were guided by the main aim, objectives and research questions of the study.

Table 2

Presentation of the Results and Themes

Superordinate Themes	Themes	Sub-theme
Perceptions of their work	Motivation	Helping community members Personal experiences Lack of employment
	Duties of home-based caregivers	Roles of home-based caregivers
	Positivity of home-based caregivers	Advocating for healthy lifestyle Nursing patients to health Empowering patients to adhere to treatment
	Social challenges of home-based caregivers	Insufficient and irregular salaries Work overload Lack of government support
Notions of work experiences	Experiences with patients	Patients' negative attitudes Patients taking advantage of home-based caregivers Patients' unrealistic expectations

		Poverty of patients
	Experiences with families of patients	Denial of patients
	Experiences with home-based caregivers' families	Supportive familial environment
	Experiences with community members	Accepting communal society
	Experiences with institution	Affirmative workplace setting
Psychological experiences	Emotional distress	
Coping mechanisms	Institutional support	Support from supervisors Support from colleagues Training in the workplace
	Personal coping mechanism	Extra work for income Ignoring work challenges Caring for their own families and house chores

4.5. Understanding Home-Based Caregivers' Perceptions of Their Work

4.5.1. Motivation

The participants in this study reported many reasons why they were in the home-based care profession. They commonly indicated that their motives were guided by the love that they had for their community and their desire to help people. The rise in the numbers of individuals living with terminal, chronic and life-threatening illness was another cause. However, some attributed their participation in home-based care to their own life experiences and a lack of employment opportunities.

4.5.1.1. Helping Community Members. The participants gave accounts of many community members experiencing ill health, physical ailments, inadequate knowledge of health matters, frequent loss of life, and reluctance to seek medical care. Therefore, they observed a need to volunteer as home-based caregivers in order to educate people about diseases, health, treatment, adherence to treatment and prevention of illness. Participants expressed their views as follows:

> *I am a home-base carer because I love my community and I want to see them live.* [Participant 6, female, 55 years old]
>
> *I saw that many people were dying because of lack of knowledge about diseases. Many community members were dying ofHIV/AIDS and TB because they did not have knowledge. That is what made me to choose the job in order to help them.* [Participant1, female, 54 years old]

Participant 3 voiced her reasons in this manner:

> *I became interested in home-based caregiving because our community members are not able to understand matters of going to the hospital. You find that a person is very sick, but they don't like going to the hospital.* [Participant 3, female, 57 years old]

4.5.1.2. Personal Health Experience. Other participants were inspired by their own personal health experiences to become home-based caregivers. They mentioned that they were once admitted to hospital and received good care in the hands of nurses. For this reason, they decided to be home-based caregivers in order to extend the same affection to others. These are their stories:

> *I saw it important in 1999 I was very sick. I saw grace, I did not even believe I was going to come back. That is when I realised that these people [nurses] are important. When there was a call for home-based caregivers to volunteer. I saw it fit that I become a home-based caregiver because I was helped too by the nurses.* [Participant 11, female, 59 years old]
>
> *There was a time I was very sick. The hospital nurses took good care of me. That is the reason I became a home-based caregiver so can help others too.* [Participant 9, female, 53 years old]

4.5.1.3. Lack of Employment. The remainder of the participants were driven to do home-based caregiving work due to a shortage of employment opportunities. Thus, when the opportunity presented itself, they saw it as a way to keep themselves busy:

> *I was invited to volunteer because it was work that was started by women. I went ahead as I was not working at the time and wanted be busy.* [Participant 12, male, 47 years old]
>
> *I volunteered because I was unemployed back then and there was nothing I was doing.* [Participant 8, female, 53 years old]

The above participants are clear about their motivating forces with regards to their involvement in home-based giving work. The majority described the love they have for their community and helping its members as they saw many people living with illnesses requiring palliative care. Nonetheless, the remaining participants were influenced by their own health, personal experiences, and the scarcity of employment.

4.6. Duties of Home-Based Caregivers

Participants in this study specified that they sign in daily at 07:00 in the morning at the local clinic. Thereafter at 08:00 they report to their respective demarcations where they do house-to-house visits until 16:00.

4.6.1. Roles of Home-Based Caregivers

They detailed their daily duties as consisting of the following tasks: following up on their regular patients where they monitor their adherence to medication; tracing patients who defaulted medication; dressing patients' wounds; screening patients; referring patients further; and instructing families how to care for bedridden patients. They also collect medication on behalf of patients at the clinic; educate patients on various diseases and personal hygiene; refer patients to the clinic for further management; and educate pregnant women and new mothers about immunisation of babies. They describe their duties as follows:

> *When we get to the patients' homes there are different things that we do. It can be that we are going to trace on that day or to follow up on the patient's medication drinking, especially those who are on TB and HIV/AIDS treatment.* [Participant 5, female, 52 years old]

Another participant described her day as follows:

> *When I find a pregnant woman I must teach them about breastfeeding so that they know that it is important more than milk that is bought. I am responsible to teach her about antenatal classes, booking and caring for herself during the pregnancy time.* [Participant 6, female, 55 years old]

On the basis of the above extracts, it appears that the participants have an understanding of what their day-to-day work entails. They have outlined that their work involved many duties that are dependent on their patients' needs. Nevertheless, the main tasks that are performed everyday include collecting medication for patients, monitoring treatment adherence, dressing wounds, educating families on caring for a bedridden patient, and educating about diseases, personal hygiene, pregnant women and babies.

4.7. Positivity of Home-Based Caregiving

During the interviews, the participants outlined elements about their work that they enjoy and felt a sense of fulfilment from. The aspects identified are as follows: advocating for healthy lifestyle in patients and community members; nursing patients to health; and empowering treatment adherence by patients. They explained that seeing patients taking their health seriously, caring for patients to help them return to health, and compliance to treatment plans gave them the courage to carry on working.

4.7.1. Advocating for Healthy Lifestyle in Patients and Community Members

The participants articulated that they observed members of the community becoming conscious of their health, taking initiatives to be healthy and knowledgeable about diseases. This made them love their work even more and made them feel content. They found pleasure when patients and members of the community prioritised their health after exchanging knowledge with them. The participants had the following to say:

> *Community members now know about diseases because of us.* [Participant 5, female, 52 years old]
>
> *Most now know that when they are sick they have to go to the clinic as they are going to get help there.* [Participant 10, female, 58 years old]

The above excerpts show that the participants are delighted that their work is ensuring that members of the community are aware of their health and are reaping the benefits thereof. They are happy that the knowledge they share with the patients is utilised and helps to change their outlook on health matters, even sometimes to the point where most of the patient's initiate seeking medical care on their own.

4.7.2. Nursing Patients to Health

The participants voiced yet another point that makes their work rewarding, which is the nursing of ailing patients back to a full recovery. They communicated that restoring patients to health was one of the meaningful experiences of home-based caregiving that led to work satisfaction. This is because they disliked patients' mortality due to sickness. They shared their sentiments as follows:

> *When my patients get better and not die. I become very happy because I have made them live.* [Participant 4, female, 48 years old]
>
> *I like it when I have followed up many times on a sick patient and they end up living.* [Participant 9, female, 53 years old]

It is clear that the participants are pleased with the amelioration of patients' health under their care. For them, seeing the effectiveness of their dedication to care was satisfying. This also enhanced their confidence in home-based caregiving work.

4.7.3. Empowering Patients to Adhere to Treatment

The participants in the study shared more gratifying moments of home-based caregiving work. Particularly, they expressed contentment when patients are empowered to adhere to their treatment without constant follow ups from the participants. This is especially after they have educated them about the treatment's benefits. Some participants would even go to an extent of using themselves as examples to promote adherence. They had this to say:

> *After teaching some patients about how important it is to take medication. They begin to understand why they should drink. They take it and become better.* [Participant 6, female, 55 years old]
>
> *Some will say, 'Wow even you are taking treatment?' They end up seeing that they are not alone and decide to take their medication.* [Participant 8, female, 48 years old]

From the above findings it is obvious that the participants find pleasure in the contributions they are bringing towards patients' lives, specifically with regards to changing their perception towards treatment. Using themselves as points of reference seems to be working in the patients' favour as well.

4.8. Social Challenges of Home-Based Caregiving

The participants also disclosed negative sentiments centred around home-based caregiving work. These negativities are inconsistent and irregular salaries, work overload, and lack of support by the government. They described these challenges as a hindrance to the efficient provision of home-based care and as a major setback in their work.

4.8.1. Insufficient and Irregular Salaries

Participants told of how their salaries were inconsistent and not enough to cover their needs. They noted that the earnings were limited to meet their basic needs and care for themselves and their families. Further, their remuneration did not match with the nature of work that they did. These concerns were raised with the government, but unfortunately to no avail:

> *We don't get enough money here. I am going to pension now with nothing!* [Participant 10, female, 58 years old]

> *Our salary is too small you know and there are many things that it has to cover everything that I and my family need.* [Participant 3, female, 57 years old]

Another participant added:

> *It becomes difficult to continue coming to work when you are getting money that is small and it is not coming monthly*. [Participant 1, female, 54years old]

From the participants' point of view, it is evident that finance is a threat and a major challenge to home-based caregiving work. It also is affecting the livelihoods of the participants and their abilities to keep up with the demands of day-to-day life.

4.8.2. Work Overload

The participants delineated that they experienced pressure to do additional work that was continuously presented to them by their clinic managers and supervisors. The added work was sweeping and cleaning the clinic, togetherwith counting people in the village. They stated that the work add-ons affected their home-based caregiving work and compromised their quality of care providedto patients:

> *The work is too much, lately we are even told to count patients and submit statistics like census people. It is too much when you add it with the one for seeing our patients.* [Participant 12, male, 47 years old]
>
> *I hate extra work that we are given by in charge and OTL because it gets in the way of my work with patients.* [Participant 2, female, 49 years old]

The additional work was regarded as time-consuming, exhausting, unnecessary and unrelated to home-based care by the participants. Hence, these additional tasks had an adverse impact on their day-to-day work schedule, which interfered with their home-based caregiving work.

4.8.3. Lack of Support from the Government

The participants denoted frustration and emotional distress with the absence of support from the government, which was primarily expressed as a lack of permanent positions from the Department of Health (DOH). They stipulated that they have been classified as working on a temporary basis. Every year they renew their contracts with the DOH but are not signing for permanent posts. This was infuriating and discouraging to them.

> *DOH and government don't care about us. They don't give us stationery like pens, uniforms and copies for work things. Not to mention money, I mean there is no increase nothing.* [Participant 8, female, 48 years old]

> *Every year am renewing a contract with no rise in money, no word from the government and DOH.* [Participants 11, female, 59 years old]

Inadequate support from the government was demotivating to the home-based caregivers. For this reason, they were left with many questions and uncertainties about their future. The lack of permanent employment also made them have no sense of direction and career prospects in home-based care.

4.9. Home-Based Caregivers' Notions of Work Experiences

4.9.1. Experiences with Patients

During the interviews the participants stipulated that they experience many challenges with patients when providing care. These problems include the following: patients' negative attitude towards them; patients taking advantage of them; patients' unrealistic expectations; and poverty of patients. The conduct of patients caused the participants to feel underappreciated and exploited at times.

4.9.1.1. Patients' Negative Attitudes. The participants echoed feelings of dissatisfaction with their patients' negative attitudes towards them. The participants explained that some showed no appreciation of their efforts to help them and thus felt discouraged by their behaviour towards them. The participants voiced the following:

> *There was this other patient that stopped going to the clinic. When I went to trace, he said to me when I started going to the clinic I did not tell anyone*

> *so even when I go back I won't tell anyone! I was so sad when he said this, I was just trying to help not tell them what to do (with a low voice)*. [Participant 9, female, 53 years old]

Others will say, 'I know I am sick but I don't need you to be coming here to see me like am a baby!' This becomes disturbing in my mind you know because I am helping nothing else. [Participant 2, female, 49 years old]

The patients' manner of communication with the participants is a barrier to the successful delivery of home-based care. It also is discouraging for the participants because they are caring for the patients with good intentions that, in return, are not valued and appreciated by the patients.

4.9.1.2. Patients Taking Advantage of Home-Based Caregivers. The participants felt disheartened by being taken advantage of by patients. They expressed that their acts of kindness were abused at times by some patients. Participants would assist the patients with money to collect treatment only to find out that it was used for something else.

> *I once gave money for a patient of mine to go to the clinic to take pills. I found out later that he went to drink alcohol with my money.* [Participant 8, female, 48 years old]

> *Some patients even expect that we bring them some food while they get grant. You find that about two people in the family get grant. Where do they think I get the money to buy food for me and them? (Irritated).* [Participant 5, female, 52 years old]

Another participant added that:

> *These patients use us! They think we are stupid. I gave this one money to go the clinic to take pills only to see him sending children to buy bread and not go to the clinic (angry).* [Participant 10, female, 58 years old]

From the above comments it is apparent that the exploitation by patients was perceived as unacceptable by the participants. It made the participants feel used and like their work was not valued.

4.9.1.3. Patient's Unrealistic Expectations of Home-Based Caregivers. The frequent visit of the participants to patients' homes resulted in expectations from the patients. Some things expected included daily visits, prolonged stays, stealing of clinic medications and donations received in the past. The following excerpts illustrate their views:

> *Sometimes you find that I visit a patient, as am about to leave they say, 'Please steal some syrup for me I have flu.'* [Participant 9, female, 53 years old]

> *In the past we use to have porridge donations from Kruger National Park. We use to give one to patients in our demarcations, lately we no longer receive those donations. Some patients will say if you don't have don't porridges don't come here.* [Participant 8, female, 48 years old]

Another added:

> *There patients who want you to visit them every day, they even ask and become angry about it.* [Participant 4, female, 48 years old]

> *Other patients when you entered their house they don't want you leave. They want us to sit with them the whole day*. [Participant 5, female, 52 years old]

The above viewpoints make plain that the demands of patients were discouraging the participants' visits. This is because they did have the capacity to meet their unrealistic expectations. As a result, this contributed to some of the predicaments affecting the quality of home-based caregivers and their relationship with patients.

4.9.1.4. Poverty of Patients. The participants in the study asserted that the destitution of their patients was quite stressful to them. For this reason, they had to share their limited resources with them in order for them not to default treatment.

> *You can see as a carer sometimes that the family is too poor*. [Participant 12, female, 47 years old]

> *Sometimes you find that there is mealimeal but no relish. You are force to make a plan quickly so they can drink pills.* [Participant 4, female, 48 years old]

The impoverished status of the patients was taxing on participants' restricted supplies that they had to give portions to the patients. This caused them emotional distress as they had to prioritise the well-being of the patients, in addition to their own well-being and that of their own families.

4.10. Experiences with Families of Patients

4.10.1. Denial of Patients

The participants reported that the only issue they had with families of patients was them denying that they had a bedridden patient at home. Some families would keep the patient inside the house to prevent them from being seen. At times there would be hearsay from neighbours and community members that there was a severely sick person in a certain home. The families would only admit and request help from the participants when they could no longer control the patient's health state. Their thoughts were vocalised in this way:

> *At times we will hear rumours in the village that family so and so are hiding a sick person. We go there and they will deny it all.* [Participant 4, female, 48 years old]

> *The neighbours will tell us that there is a sick person in that home but they will say, 'NO, there is not sick person here!'* [Participant 10, female, 58 years old]

The families of patients also made the participants work harder. This is because their fear of acknowledging the presence of a bedridden patient resulted in them being too sick for an intervention, which would delay the work of home-based caregiving.

4.11. Experiences of Home-Based Caregivers' Families

4.11.1. Supportive Familial Environment

In the interviews all of the participants reported tremendous support from their families. They cited that their families recognise the work that they are doing for the community and they encourage them to keep going even despite accompanying challenges. Some of the participants' family members also assisted them with resources such as money to go to work.

> *Our families got used to it that we are supposed to leave and come back in the evening. They support us so much; the support is there.* [Participant 7, female, 41 years old]

> *My family does not have a problem; they support us very much. They even say I am the family nurse (laughs).* [Participant 3, female, 57 years old]

The support of their families made home-based caregiving work more bearable. It seems as though having their families by their side was a beacon of hope for them and that it was one of the driving forces that keep them going even when the going gets tough.

4.12. Experiences of Community Members

4.12.1. Accepting Communal Society

The home-based caregivers mentioned experiencing support from the community, which makes their work smooth and enjoyable. However, they indicated that there are some members of the community that are resistant. Despite this, most of the community members are welcoming and realise the value of their work. They expressed their views as follows:

> *The community, I will say 85% they give us support as we go around. They call us nurses as they see the work that we do even though we are not nurses***.** [Participant 12, male, 47 years old]

One participant added by saying:

> *As we do door to door the community members support and welcome us. It is not like in the past.* [Participant 2, female, 49 years old]

The understanding that the community members hold of the value of the home-based caregivers' work motivated them to do their work despite challenges. This made them feel respected, indicating their resilience to continueworking.

4.13. Experiences with Institutions

4.13.1. Affirmative Workplace Setting

The participants also spoke about the huge amount of support that they receive from the clinic in charge and the supervisor. They explained that they obtain all health supplies and material that they need to work with, and that at times the clinic in charge and supervisor accompanied them when they did house-to-house visitations. This is how they articulated themselves:

> *The clinic shows big support, like me I had a bedridden patient. They gave me gloves. Linen savers and disinfectants.* [Participant 8, female, 48 years old]
>
> *They do support us; they even give is health kits to work with.* [Participant 4, female, 48 years old]

The cooperative working relationship that they had with the clinic in charge and supervisor made the participants' work manageable. This resulted in the participants realising that they are not alone because there are people who are actually undertaking the journey with them and backing them up.

4.14. Psychological Experiences of Home-Based Caregivers

The participants reflected on how some of the challenges associated with home-based caregiving work affected them psychologically. They referred to matters of finances, lack of support from the government and lack of permanent positions as key factors that were detrimental to their psychological well-being.

4.14.1. Emotional Distress Due to Home-Based Caregiving Work

Most of the participants experienced feelings of emotional suffering about the long-standing problems of salaries, permanent employment and absence of support from the government. They expressed themselves as follows:

> *I am old now approaching pension. It is obvious that I am not going to get a pension, I have to wait for grant that put stress on me. All my hard work for nothing*. [Participant 11, female, 59 years old]
>
> *You get stressed, I mean when are things going to be okay? We have just been working so long.* [Participant 9, female, 53 years old]

From the above-mentioned quotes, there is a clear indication that the strains that go along with being a home-based caregiver are harmful to their mental health. It kept them distraught and unsure about their futures.

4.15. Coping Strategies of Home-Based Caregivers

The participants come across many hardships that were averse to their emotional health because these problems remain unresolved. The participants discussed how they tackle the difficulties. They dealt with them through support that they receive from their supervisors and managers, support from colleagues, training in the workplace, and their own individual coping strategies.

4.15.1. Support from Supervisor and Manager

The participants alluded that their supervisor and clinic in charge are the greatest sources of their support. They explained that they are the ones who assist them to cope with the obstacles that confronted them at work. They described the following:

> *Every Friday we have a meeting with co-workers, OTL [Outreach Team Leader supervisor] and in-charge. In these meeting we tell them the problems we face in the field, these problems are written down and they give us solutions on how to solve them*. [Participant 12, male, 47 years old]
>
> *Every week we have meetings they ask what problems we are having and they write down and follow up on them.* [Participant 8, female, 48 years old]

The advocacy of the participants from the clinic in charge and supervisors seem effective when it comes to handling work crises. It also aided in solving everyday struggles at work.

4.15.2. Support from Colleagues

The participants signified that they work as a team and in pairs, specifically at demarcations that are closer to each other. They mentioned in the interviews that they help one another with the problems that they face at work. They also have a WhatsApp group where they talk through some of their predicaments. They had the following to say:

> *We help each other on everything and it always well, because we work together not as one by one*. [Participant 11, female, 59 years old]

> *We talk and help one another as colleagues we don't hide anything.* [Participant 3, female, 57 years old]

The social support gained from other participants proves to be successful in surviving the circumstances that comes with the profession. It also suggests that the burden of caring is easier for them with the emotional support of their colleagues.

4.15.3. Training in the Workplace

The participants also conveyed that the work development training presented was useful in addressing some of the situations encountered at work. They detailed that the training improved the way they communicated with patients and helped them build stronger relationships with their patients. Furthermore, the training opportunities assisted in making referrals for patients' management.

> *Some of these patients are very rude, but the training on communication it helps us to be patient and talk nicely to them.* [Participant 5, female, 52 years old]

> *The trainings do help us to think fast and to apply some tricks as well to make sure that they drink pills. We can say things like, 'I am also sick' so that they can believe and drink their pills*. [Participant 3, female, 57 years old]

The skills the participants attained in training seem to function in a way that assists them in managing impolite patients and helps improve their communication skills with their patients. It also helps them to identify patients in need and make referrals.

4.16. Personal Coping Mechanisms

Besides the support from the supervisor and training in the workplace, the participants indicated that there are personal activities that they do to cope with the challenges that they experience in the workplace. Some specified doing other jobs to forget. These jobs are household chores, caring for their own families, and ignoring the challenges.

4.16.1. Extra Work for Income

Two of the participants had additional work that they do after hours to supplement them with extra income. The extra work helped the participants to avoid overthinking about work problems and gave them an opportunity to make personal earnings.

> *When am not at work I am sewing, especially on weekends. This help me to feel good and even forget that there are problems at work.* [Participant 12, male, 47 years old]
>
> *In my own time I run my business. I sell airtime and cool drinks.* [Participant 7, female, 41 years old]

It is apparent that the side jobs are helpful to the participants as they help relieve some of the financial obligations that they have. Moreover, it minimises the strain that home-based care work brings about.

4.16.2. Ignoring the Work Challenges

Other participants conveyed that they do not focus on the challenges that they encounter at work once they knock off. They mentioned that they cope by eluding them and doing their own things.

> *When I knock off I no longer think about work stuff. I choose to block it in my mind so that it does not come.* [Participant 1, female, 54 years old]
>
> *When am at home I don't think about work or other people. I do my own things*. [Participant 3, female, 57 years old]

These avoidance methods employed by the participants seem to be efficient, particularly in lessening the tension that comes with the home-based caregiving work. Additionally, this approach helps aid relaxation.

4.16.3. Caring for Their Own Families and House Chores

The majority of the participants outlined that they survived work burdens by taking care of their own families. They also watch television, garden and perform household chores. All of these activities were done when they knocked off at work and on weekends.

> *To distract myself from work stuff. I spend time with my family and clean my house*. [Participant 2, female, 49 years old]
>
> *When am at home I watch TV; I love Nigerian movies. I do a lot of gardening too; I love planting trees*. [Participant 6, female, 55 years old]

The personal coping strategies also prove to be efficacious, giving the participants time to get in touch with themselves and the world around them. It also helped them engage in different things that are not work related to relieve stress and sooth their minds.

4.17. Summary of Results

The study sample consisted of twelve participants who were selected through a purposive sampling method. The participants were between the ages of 41 and 59 years old, stationed in Mahlathi Village working at Khakhala-Hlomela Clinic. The participants were all Xitsonga speaking and the interviews were conducted in Xitsonga. The study results showed that home-based caregivers in this study face many challenges daily. The findings revealed that the home-based caregivers are motivated by helping community members. They also have clear roles of what their work entails. Both the favourable and unfavourable elements of home-based caregiving were highlighted as well. The unpleasant aspects included work overload, lack of support from the government, and insufficient and irregular salaries. The pleasant factors included empowering patients to adhere to medication, nursing patients to health, and advocating for a healthy lifestyle.

The study also examined the home-based caregivers’ experiences with patients, families of patients, their own families, community members and institutions. Based on their experiences with patients, home-based caregivers were negatively affected by poverty of patients, negative attitude of patients, unrealistic expectations, and being taken advantage of. Additionally, home-based caregivers were affected by the denial of sick family members of patients who were on palliative care. These challenges were expressed as detrimental to their mental health. Nonetheless, the support that they receive from the clinic, through training at work and via personal coping mechanisms appeared to be effective. They reported their own family members, their community and their clinic to be extremely supportive.

Chapter 5: Discussion of Findings

5.1. Introduction

This chapter will be focused on discussing the themes of the study, together with the implication of theory. These themes will be discussed in conjunction with literature as well as the implication of theory based on the findings of the study. These themes include understanding home-based caregivers' perceptions of their work, home-based caregivers' notions of work experiences, psychological experiences of home-based caregivers, and coping strategies of home-based caregivers. The theories that will be reviewed are ecological systems theory and the transactional model of stress and coping. A summary of the discussion will conclude the chapter.

5.2. Understanding Home-Based Caregivers' Perceptions of Their Work

5.2.1. Motivation

It is important that it is understood why home-based caregivers keep on providing care despite the difficulties they face. According to Ama and Seloilwe (2011), the choice of becoming a home-based caregiver is motivated by many factors. Mlotshwa et al. (2015) argued that home-based caregivers are mostly motivated by altruism and are dedicated to serving their communities. Similarly, Uren and Graham (2012) supported that home-based caregivers' motivation included the willingness to help the community and was altruistic in nature.

5.2.2. Helping Community Members

Lekganyane (2020) states that home-based caregivers are guided to home-based care by inward passion of helping other people in need. Findings from this study indicated that some of the home-based caregivers got involved in home-based care because they wanted to bring about change in the community. This was after seeing many people suffer as a result of TB, HIV/AIDS and other physical illnesses requiring care. Ankitola (2011) identified the same reasons that home-based caregivers were motivated, namely wanting to help their community and alleviate community members' sufferings from diseases. Similarly, Kupa and Geyer (2020) noted that home-based caregivers' motives were to help community members in need. Valjee and Van Dyk (2014) stated that home-based caregivers were motivated by helping their community. In a study by Tripathy et al. (2016) in India (Haryana), home-based caregivers were motivated by help they wanted to give to the community. A study by Mlotshwa et al. (2015) also found that home-based caregivers wanted to help their communities and patients.

5.2.3. Personal Health Experience

While some home-based caregivers in the study were compelled by helping the community, others mentioned being led to home-based care by their personal lived experiences of being cared for. A study by Lekganyane (2020) investigating home-based caregivers in Limpopo, Gauteng and North West showed that caregivers were once cared for in the past, which resulted in their passion for home-based care. In Ankitola’s (2011) study, the home-based caregivers differed by saying that they have been pushed to going into home-based care by caring for ailing family members. Home-based caregivers in Mlotshwa et al.’s (2015) study were moved by their own experience of being sick and cared for by home-based caregivers.

5.2.4. Lack of Employment

The study also showed that the remainder of the home-based caregivers in Mahlathi Village were propelled by their status of unemployment to join the industry while some were called by friends to join home-based care. In the same studies mentioned above, the home-based caregivers indicated similar reasons (Ankitola, 2011; Lekganyane, 2020). Home-based caregivers from Tanzania in the Morogoro region were also moved to join home-based caregiving by the hope of employment opportunities (Mpembeni et al., 2015).

In a study by Kigozi et al. (2020) in Mangaung Metropolitan District in the Free State province, home-based caregivers were in home-based care because of unemployment. Some home-based caregivers in a study by Mlotshwa et al. (2015) also attributed their involvement in home-based care due to lack of employment. Thabethe (2011) added that home-based caregivers were pushed by their state of unemployment to go into home-based caregiving.

5.3. Duties of Home-Based Caregivers

Home-based caregivers do many day-to-day tasks as guided by their patients' needs (Mamba & Ntuli, 2014). They trace, screen, and educate patients and the community about diseases, and refer patients for further medical interventions (Thomas et al., 2021). Other responsibilities consist of follow-up visits, supporting patients with health issues, and ensuring adherence to treatment (Nyalunga et al., 2019).

5.3.1. Roles of Home-Based Caregivers

The results in the study suggested that home-based caregivers performed many activities during their visits with patients. Among these obligations were following up on their regular patients, monitoring treatment adherence, referring, screening, and tracing defaulters, dressing wounds, bathing bedridden patients, educating patients about health and caring, collecting treatments on behalf of patients, working with pregnant women, and the immunisation of children. These findings were consistent with those of home-based caregivers in the Northern Cape (De Aar) (Ramukumba, 2020). Similarly, home-based caregivers in Soweto also did tracing, follow ups, health education, cleaning wounds, nursing patients, screening and referring (Mamba & Ntuli, 2014). A study in Tshwane District also revealed that home-based caregivers did follow-up visits, educated about health matters, monitored adherence to treatment, and did house-to-house visits every day (Nyalunga et al., 2019).

5.4. Positivity of Home-Based Caregiving

Ankitola (2010) reported that home-based caregivers were fulfilled by the improving health of their patients as a result of their work. Ndambo et al. (2022) emphasised that home-based caregivers felt positive with the increase in health awareness of community members and patients. Ramukumba (2020) is in support of these findings and revealed that home-based caregivers were pleased by the useful contribution they made to patients' and community members' health.

5.4.1. Advocating For Healthy Lifestyle in Patients and Community Members

Within this study, home-based caregivers experienced positive experiences when they noticed patients and community members becoming health conscious following their teachings. This is consistent with findings by Hemphil et al. (2019) that home-based caregivers in the United States of America in Washington DC were gratified when their patients and community members upheld healthy living. In Ankitola's (2010) study, home-based caregivers were thrilled when patients and community members adopted positive healthy lifestyles as a result of their services. A study in India in Haryana, home-based caregivers felt inspired following patients and community members improved health and behaviour because of their work (Tripathy et al., 2016).

5.4.2. Nursing Patients to Health

According to Valjee and Van Dyk (2014), home-based caregivers are satisfied when patients' health status improves. The home-based caregivers in this study indicated that nursing their patients to healing was one aspect that made home-based caregiving worthwhile for them. These views were consistent with research by Jobson et al. (2020) that indicated that patients regaining their health was a positive aspect for the home-based caregivers. Mpembeni et al. (2015) further postulated that changing the failing health of their patients was experienced as something positive by the home-based caregivers. A study in Khayelitsha noted that home-based caregivers found pleasure in improving their patients' health (Tsolokile et al., 2014). In support of this, Seutloali et al. (2018) reported that home-based caregivers were joyful due to patients' recovery. In Malawi, home-based caregivers also felt good when there was a reduction in the number of patients requiring care (Ndambo et al., 2022). Nursing patients back to health provided satisfaction for home-based caregivers in Limpopo (Tshitangano & Olaniyi, 2018).

5.4.3. Empowering Patients to Adhere to Treatment

The home-based caregivers in this study indicated that observing patients comply with medication was one of the gratifying experiences in their work. This was similar to findings by Mamba and Ntuli (2014) who reported that home-based caregivers found pleasure in seeing patients taking their medication diligently. The same theme was echoed by Hemphil et al. (2019) that home-based caregivers were pleased when patients adhered to treatment. Mantell et al. (2022) identified that work by home-based caregivers increased treatment adherence of patients. A study in the Limpopo province by Tshitangano and Olaniyi (2018) also showed that patients were taking their medication without home-based caregivers monitoring them.

5.5. Social Challenges of Home-Based Caregiving

Home-based caregivers report many challenges when providing care (Engelbrecht et al., 2017). The greatest of them all related to finances (Khathuri-Ogola et al., 2014; Ramukumba, 2020). Seutloali et al. (2018) study also highlighted incentives as a great challenge. Lack of support by the government (Qalinge, 2011).

5.5.1. Insufficient and Irregular Salaries

Finance was reported to be one of the major problems by the home-based caregivers in this study. They noted that their monthly earnings were very little to provide for themselves, their families and basic resources. They also specified that they were not paid timeously. These findings are the same as those of Mashau et al. (2015) where home-based caregivers were getting paid monthly; however, the money was not coming in every month and was very low. Ramukumba (2020) also found that home-based caregivers were remunerated, yet the money was inadequate to meet their needs. Motswasele-Sikwane et al. (2020) emphasised that the home-based caregivers raised concerns of their low stipends.

5.5.2. Work Overload

The results of this study showed that home-based caregivers in Mahlathi Village were dissatisfied with the extra duties that were expected of them in addition to home-based caregiving work. These extra duties were not related to home-based care and affected their daily schedule. In support of this, Seutloali et al. (2018) reported that home-based caregivers raised complaints of increasesin their workload. Valjee and Van Dyk (2014) pointed out that home-based caregivers had a challenge with high workloads. In a study by Zikhathile and Atagana (2018), home-based caregivers were against high workloads. In a study by Musonda et al. (2021) in Zambia, home-based caregivers disagreed with the workload in their workplace. Mamukeyani (2021) supported these findings, arguing that home-based caregivers in Ndzhelele, Makhado Municipality, were unhappy with the workload dealt with on a daily basis. In another study, home-based caregivers also raised concerns with regards to work overload (Uren & Graham, 2013). A study in Cape Town indicated that home-based caregivers experienced work overload (Maripa et al., 2019). A Zimbabwean (Chegutu District) study also indicated that home-based caregivers' work was affected by too much work that they had to do (Kabonga & Zvokuomba, 2021). Work overload was echoed by home-based caregivers in the Western Cape (Johnson et al., 2022).

5.5.3. Lack of Support from the Government

The present study also revealed that the home-based caregivers did not get any support from the government. This was in relation to permanent employment and salary raises. A study by Valjee and Van Dyk (2014) similarly found that home-based caregivers complained of not getting support from the government with regards to positions and their concerns. Home-based caregivers did not receive support from the government regarding issues of permanent positions, government employee benefit, and money (Ramuhaheli & Erasmus, 2012). In a study by Qalinge (2011), home-based caregivers also did not get any support from government.

5.6. Home-Based Caregivers' Notions of Work Experiences

Home-based caregivers have different experiences in the workplace (White et al., 2017). Participants in this study reported their experiences inside and outside of work. These encompassed their interaction with patients, families of patients, their own families, the community, and their place of work. They reported difficulties and frustration when working with patients, resistance from families of patients, and tremendous support from their families, community, and place of work.

5.6.1. Experiences with Patients

5.6.1.1. Patients' Negative Attitudes. Being a home-based caregiver consists of dealing with patients' negative attitudes (Ankitola, 2008). In this study, home-based caregivers perceived the behaviour of their patients towards them as unacceptable. Some of the patients were impolite when home-based caregivers visited them. These results were supported by Johnson et al. (2022), which also indicated that home-based caregivers were welcomed with rudeness by their patients. The same study by Johnson et al. (2022) also indicated disrespect towards home-based caregivers. Engelbrecht et al. (2017) noted that home-based caregivers dealt with negative attitudes from patients. Research by Valjee and Van Dyk (2014) reported that patients would scream and be angry towards home-based caregivers. Ankitola (2009) highlighted that home-based caregivers encountered moody and hostile behaviour from their patients. The negative attitudes of patients were reported as discouraging by home-based caregivers (Mbale & Chileshe-Chibangula, 2017).

5.6.1.2. Patients Taking Advantage of Home-Based Caregivers. The home-based caregivers in this study felt that their efforts were taken for granted by their patients. They indicated that they would assist some of their patients with money to go collect medication; however, the money would be used for something else instead. Johnson et al. (2022) found that home-based caregivers felt taken advantage of when patients did not do as they told them each day they visited. The same study also showed that patients were guided to exercise and brought medication, but they would not do as they were told by the home-based caregivers. In one study, home-based caregivers stated that when they monitored patients to drink medication, they acted as if they had swallowed (Cataldo et al., 2015). Therefore, home-based caregivers felt used by these acts.

5.6.1.3. Patients' Unrealistic Expectations of Home-Based Caregivers. A visit of a home-based caregiver to a patient is accompanied with impractical expectations from patients (Ankitola, 2008). Home-based caregivers in this study also felt exploited by the requests that their patients had on each visit. Some patients expected frequent follow-up visits, stolen medication from the clinic, and donations of soft porridges. This is consistent with views by Kang'ethe (2011) who indicated that home-based caregivers could not keep up with patients' daily demands. Patients in a study by White et al. (2017) expected home-based caregivers to bring them food, buy electricity and send them messages frequently. Smith et al. (2020) noted that home-based caregivers could not keep up with patients who constantly made demands. Cataldo et al. (2015) also revealed that home-based caregivers felt exploited by their patients' on-going demands of financial assistance, food, and support with materials.

5.6.1.4. Poverty of Patients. According to Ankitola (2008), witnessing the impoverished state of patients' livelihood made home-based caregiving work difficult. This is because most home-based caregivers experienced the poverty of patients first hand (Wringe et al., 2010). The current study revealed that the destitution of patients was a hindrance to home-based caregiving work and treatment adherence. As a result, home-based caregivers had to share their own food with them to ensure that they do not default on their medication regimes. The poverty of patients was established to be a setback for home-based caregivers (Engelbrecht et al., 2017), which is supported by a study conducted by Johnson et al. (2022) where home-based caregivers observed poverty of patients as a challenge to caregiving work.

5.7. Experiences with Families of Patients

5.7.1. Denial of Patients

Families often denied to home-based caregivers that they had sick patients in their homes (Ankitola, 2008). In a study by Johnson et al. (2022), home-based caregivers saw families denying the presence of an ailing patient. Mashau et al. (2014) highlighted that families refused home-based caregivers' entry even when they knew that they had a sick patient. Similarly, Moetlo et al. (2011) identified that families of patients did not agree that they have a bedridden patient. Mamba and Ntuli (2014) noted that families denied terminally ill patients accessing home-based caregivers during home visits. Home-based caregivers in this study also reported families of their patients refused them access to see their sick patients.

5.8. Experience of Home-Based Caregivers’ Families

5.8.1. Supportive Familial Environment

In this study, home-based caregivers disclosed that they had great support from their own families. They gave them courage to continue caring despite challenges. Smith et al. (2020) shared similar sentiments that families of home-based caregivers were very supportive of their work. Similarly, the findings in a study of home-based caregivers reported that they felt supported by their family members (Ama & Seloilwe, 2011). Moshabela et al. (2015) also found that the families of the home-based caregivers were of great support. Mohangi and Pretorious (2017) showed that home-based caregivers received support from their family members. Home-based caregivers in an investigation by Uren and Graham (2013) also drew support from their family members.

5.9. Experience of Community Members

5.9.1. Accepting Communal Society

Community members in this study were receptive to home-based caregivers and their work. A study by Kabonga and Zvokuomba (2022) in Zimbabwe showed that home-based caregivers experienced great support from the community members. In a Kenyan study by Gundo (2013), home-based caregivers stated that they felt respected by the community they served. Ankitola (2010) found that community members were accepting of home-based caregivers. In a study by Tripathy et al. (2016), support from the community was much appreciated by home-based caregivers. A study by Pindani et al. (2013) in Malawi confirmed that the community appreciated the work done by home-based caregivers. Similar findings were reported by Le Roux et al. (2015). A study in four sub-Saharan countries (Ethiopia, Kenya, Malawi and Mozambique) found that support of the community was evident in home-based caregivers (Kok et al., 2016). Mpembeni et al. (2015) also highlighted that home-based caregivers were respected by the communities they served.

5.10. Experience with the Institution

5.10.1. Affirmative Workplace Setting

The results of this study showed that the clinic management and the supervisor of the home-based caregivers were actively involved in their work and supported them throughout. In their study, Kupa and Geyer (2020) found that home-based caregivers were affirmed by the managers at work. Daniel et al. (2010) identified that home-based caregivers were part of a supportive workplace environment. Home-based caregivers in another study mentioned that they had a good work relationship with their team leaders (Ramukumba, 2020). A study in the Eastern Cape by Le Roux et al. (2015) mentioned that home-based caregivers succeeded because of their supportive workplace. In a study by Kok et al. (2016), home-based caregivers described being part of a supportive workplace. Similarly, home-based caregivers in Tsolokile et al. (2017) study noted a supportive workspace. In their study in Durban, Ankitola and Chikoko (2016) noted that home-based caregivers were mentored and supported by the professionals they worked with.

5.11. Psychological Experiences of Home-Based Caregivers

Home-based caregiving is experienced as emotionally demanding by home-based caregivers (Lekganyane & Alpaslan, 2019). Therefore, the home-based caregivers end up being in distress (Ankitola, 2011).

5.11.1. Emotional Distress due to Home-Based Caregiving Work

This study showed that the home-based caregivers experienced emotional distress as a result of the challenges of home-based caregiving. This finding is similar to that of Ankitola et al. (2013) who reported that home-based caregivers experienced high levels of stress due to their work. Valjee and Van Dyk (2014) mentioned an increase in emotional strain due to home-based caregiving work. Home-based caregivers in Mashau et al.’s (2016) study reported emotional distress due to caregiving. A study by Thabethe (2011) found that home-based caregivers suffered emotionally due to caregiving. In their study, Kupa and Geyer (2020) found that caregiving work was experienced as emotionally draining by home-based caregivers. Similarly, Van Deventer and Wright (2017) noted feelings of emotional distress experienced by home-based caregivers. Pindani et al. (2013) also provided evidence from their study that home-based caregivers experienced emotional turmoil due caregiving work.

5.12. Coping Strategies of Home-Based Caregivers

Working as a home-based caregiver can be strenuous and tiring (Uren & Graham, 2013). To cope with their work, home-based caregivers utilise a variety of coping strategies (Kathuri-Ogola et al., 2014). Most home-based caregivers use emotion-focused and problem-focused coping strategies (Mguwata, 2020). These coping strategies are important in regulating the physical and psychological burden of caring (Kazemi et al., 2021).

5.12.1. Support from Supervisor and Managers

According to Mantell et al. (2022), adequate support enables home-based caregiving work to be adaptable. Home-based caregivers are said to survive home-based care challenges if they are given enough support (Lekganyane, 2016). The findings of this study showed that home-based caregivers received support from the clinic in charge and their supervisor. This support was valued and appreciated as it made home-based caregiving work bearable despite its challenges. This is consistent with a study by Sips et al. (2014) where home-based caregivers received adequate support from their clinic and supervisors. Similarly, Daniel et al. (2012) agreed that home-based caregivers enjoyed support from their supervisors. Home-based caregivers in another study also valued support from their supervisors and clinic (Kupa & Geyer, 2020). Tsolekile et al. (2018) postulated that home-based caregivers had support from their supervisors. In support of the above points, Nyalunga et al. (2019) confirmed that home-based caregivers in Tshwane District felt supported by their team leaders.

5.12.2. Support from Colleagues

The results of the study showed that to be able to manage the challenges they experienced, the home-based caregivers derived help from their fellow colleagues. They worked as a team and in pairs. They shared their daily experiences at work and assisted each other with solutions. Similarly, the findings of the study conducted by Kupa and Geyer (2020) established that home-based caregivers worked as a team and supported one another. Another study by Lekganyane (2016) revealed that home-based caregivers leaned on collegial support when faced with problems at work. In their study, Valjee and Van Dyk (2014) indicated that home-based caregivers persevered through assistance from their colleagues. Smith et al. (2020) highlighted that home-based caregivers valued the backup they received from their colleagues and Mantell et al. (2022) further postulated that home-based caregivers worked as a team to ensure that they solved daily challenges they came across. These same findings were also echoed by Mashau et al. (2015) where home-based caregivers benefited from working closely with their colleagues.

5.12.3. Training in the Workplace

Tsolekile et al. (2018) suggests that training in home-based care is valuable to home-based caregivers when dealing with challenges. These constant training sessions are regarded to be of help to the home-based caregivers (Tripathy et al., 2016). In the findings, home-based caregivers reflected on the usefulness of workplace training in tackling challenges that came with home-based care. Ankitola (2010) highlighted that training the home-based caregivers received placed them in a better position to deal with problems at work. Another study by Hangulu and Ankitola (2017) found that the training opportunities became very helpful when dealing with challenges that came with home-based caregiving. Similarly, Kupa and Geyer (2020) note that the training offered to home-based caregivers helped them in tackling daily predicaments at work. Nyalunga et al. (2019) also added that home-based caregivers referred to their training when they encountered challenges.

5.13. Personal Coping Mechanisms

5.13.1. Extra Work for Income

This study revealed that some home-based caregivers had to do additional work to subsist themselves with financial challenges. They resorted to sewing and selling cool drinks, for example. In support, a study in Uganda reported that home-based caregivers coped with financial challenges by resorting to doing extra jobs for added income (Ndu et al., 2022). Ankitola (2008) further indicated that home-based caregivers cope with financial issues by doing work outside caring such as trading and hairdressing. Engelbrecht et al. (2017) expressed that some of the home-based caregivers were self-employed to close the gap on their finances. Oliver et al. (2015) also emphasised secondary sources of generating money by home-based caregivers.

5.13.2. Ignoring the Work Challenges

The study further indicated that home-based caregivers utilise other means of coping, such as disregarding the challenges at work. This was consistent with findings by Mohangi and Pretorious (2017), which reported that home-based caregivers would knowingly select to not solve the challenges they faced. Uren and Graham (2013) established that the home-based caregivers coped with challenges at work by deciding not to take notice. Maripa et al. (2019) found that home-based caregivers were coping by overlooking problems at work. Likewise, Kazemi et al. (2021) in Iran showed that home-based caregivers coped by consciously choosing not to focus on present problems.

5.13.3. Caring for Their Own Families and House Chores

The study also showed that the home-based caregivers coped by taking care of their own families and doing house chores. The view expressed by Oliver et al. (2015) was that home-based caregivers were coping with work challenges by spending time with their families. This is further strengthened by Kupa and Geyer (2020) who reported that home-based caregivers resorted to doing household chores and caring for their own families as a way of coping. A study conducted in Cape Town found that home-based caregivers also cope by focusing on household tasks (Johnson & Frantz, 2021). Another study in the Western Cape by Smith et al. (2020) pointed out that home-based caregivers cared for their families as a coping mechanism. In Uren and Graham's (2013) study on home-based caregivers, it was reported that they cared for their families to reduce the burden of care experienced in their jobs.

5.14. Implications of Theory

The theories that guided the study are ecological systems theory and the transactional model of stress and coping. The ecological systems theory was selected to give insight into the home-based caregivers' interactional experiences with their families, patients, communities, government and workplace. The transactional model of stress and coping was incorporated to understand what coping strategies are most likely used by the home-based caregivers and whether they are effective or not.

5.14.1. Ecological Systems Theory

The environmental backgrounds are called ecological systems and consisted of the microsystem, mesosystem, exosystem and macrosystem (Bronfenbrenner, 1979). The microsystem was to give awareness of the feelings of home-based caregivers' families towards their work. The findings showed that the families of home-based caregivers are very supportive of their work. They expressed that they give them courage to continue despite the challenges they encounter. Additionally, their families help support them financially.

From the mesosystem, the home-based caregivers experienced negative experiences when working with patients. They had to find ways of dealing with negative attitudes, being taken advantage of, unrealistic expectations, and poverty of patients.

In relation to the current research, the exosystem was of aid in comprehending the community members' reactions towards home-based caregiving work. The home-based caregivers received support from the community members. They mentioned that their work is valued and appreciated by the community members and this served as a protective factor for them

In relation to this macrosystem, the findings showed that the families of home-based caregivers are very supportive of their work. They expressed that they give them courage to continue despite the challenges they encounter. Additionally, their families help support them financially. The findings showed that they received support from the clinic in charge and supervisor in the workplace. However, no support from the government was mentioned in terms of salary increases, permanent employment contracts, uniforms and stationery. Thus, the systems perspective, home-based caregivers seemed to receive support from the microsystem and exosystem, while on the other hand, they tended to be experiencing challenges, resistance and less support from the mesosystem and marcosystem.

5.14.2 The Transactional Model of Stress and Coping

The study found that the home-based caregivers in Mahlathi Village handled the predicaments they faced at work hands on. They mostly exercised both problem-focused and emotion-focused coping strategies. The problem-focused strategies were consulting their supervisor, managers and colleagues for advice and support, while also applying the knowledge that they obtained from their training. The emotion-focused coping strategies that the home-based caregivers in the study used were disregarding the problems and choosing to focus on caring for their families and doing household chores in their own homes. The home-based caregivers reported all the strategies they employed as being useful in dealing with the challenges.

5.15. Summary

This chapter concentrated on discussing the results of the study, which were the themes that were identified during the data analysis. These themes are to understand home-based caregivers’ perceptions of their work, home-based caregivers’ notions of work experiences, psychological experiences of home-based caregivers, and coping strategies of home-based caregivers. These themes were analysed together with the implications of the theoretical frameworks, which included ecological systems theory and the transactional model of stress and coping. The themes were discussed in association with existing literature and the two theoretical frameworks.

Chapter 6: Summary and Conclusion

6.1. Introduction

This final chapter focuses on discussing the findings based on the experiences of home-based caregivers who are providing palliative care to terminally ill patients in Mahlathi Village, Mopani District, Limpopo Province. The findings were guided by supporting literature. This chapter discusses the limitations of the study, conclusions, recommendations and finally provides an overall summary of the research.

6.2. Limitations of the Study

The study concentrated on experiences of home-based caregivers providing palliative care to terminally ill patients in Mahlathi Village. Therefore, the findings are only applicable to home-based caregivers in Mahlathi Village. Additionally, the authenticity of the results are reliant on the truthfulness of the participants.

6.3. Conclusion

The study sought to research home-based caregivers' lived experiences when providing palliative care to terminally ill patients in Mahlathi Village. The objectives of the study were to understand home-based caregivers' perceptions of their work, to determine home-based caregivers' notions of their work experiences, to identify psychological experiences of home-based caregivers, and to appraise coping strategies of home-based caregivers. A purposive sampling method comprising twelve home-based caregivers was used. The home-based caregivers' ages ranged between 41 years old to 59 years old.

The study concludes that the home-based caregivers in Mahlathi Village had numerous challenges in their workplaces, including challenges with the conduct of their patients. The greatest challenge at work was inadequate and inconsistent salaries, which made their activities of daily living difficult. They reported that the money they earned was minimal and that it was not enough to last until the next payment in order to care for their own families and cover their basic needs. Additional work unrelated to home-based caregiving was a hindrance to the offering of quality care and was strenuous on the home-based caregivers. This is because more time had to be spent on those extra duties instead of caregiving, thereby disturbing their daily routine. The absence of support from the government also made caregiving work more of a burden as the home-based caregivers' concerns remained unaddressed. The study further revealed that the behavioural conduct of patients towards the home-based caregivers was demotivating as the home-based caregivers were very much dedicated to their work and gave so much of themselves, and so to be rejected, unvalued and their efforts unrecognised by some of their patients was disheartening.

The study also showed that the problems experienced by the home-based caregivers resulted in psychological distress as it became too much for them to bear. Nevertheless, the study also highlighted that the home-based caregivers had high levels of motivation to carry on with their work regardless of these challenges. Their motives included assisting the community members, advocating for positive health behaviours for members of the community and their patients, nursing patients to health, and encouraging adherence of treatment. The support that they received from their managers, colleagues, their families, the community, positive aspects of their work and their individual coping mechanisms helped ease the burden that came with providing care under dire circumstances.

6.4. Contributions and Recommendations

The study contributes to the existing body of knowledge and contributes towards filling a gap in the shortage of literature on motivation and coping modes of home-based caregivers. Moreover, it will assist the Department of Health, government and relevant organisations responsible in training home-based caregivers to enhance home-based care programmes.

6.5. Recommendations

6.5.1. Recommendations for the Department of Health

- The department should make efforts to make time for home-based care programmes to ensure that they are more effective as they play a big role in relieving the burden on hospitals by promoting health and treatment adherence.

- The issue of salaries can also be addressed in order to improve the livelihood of the home-based caregivers, which can help encourage more people to enter the profession.

6.5.2. Recommendations for Home-Based Caregivers

- It is recommended that the home-based caregivers psychoeducate their patients on home-based care and home-based caregivers' duties. This will assist in ensuring that patients are more informed so that the boundaries set up by the caregivers are acknowledged and respected.
- The home-based caregivers may assert themselves to their managers and supervisors to reduce the workload that they have.

6.6. Summary

This qualitative research study, based on phenomenological design, explored the experiences of home-based caregivers providing palliative care to terminally ill patients. The conclusions were that the home-based caregivers experience many challenges daily in their interactions with patients, the communities they work in and at work. However, the coping strategies that they employ daily makes their work bearable and sometimes even fulfilling. Additionally, recommendations for the Department of Health and home-based caregivers were made.

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Appendices

Appendix 1: Clinic In Charge Permission Letter

The manager

____

Dear: Sir/ Madam

REQUEST TO CONDUCT RESEARCH AT THE ORGANISATION

My name is Ntwanano Melta Mafuma, am currently completing a master’s degree in Clinical Psychology at the University of Limpopo. One of the preconditions of the degree is writing a research paper (Mini-Dissertation). The tittle of myresearch paper is: **A phenomenological study of home-based caregivers providing palliative care to terminally ill patients at Mahlathi Village, MopaniDistrict, Limpopo Province**

The aim of the study is to explore the psychological experiences of home-based caregivers providing palliative care to terminally ill patients at Mahlathi village. I hereby request approval to undertake my research at your organization.

The participants will be required to sign a consent form, prior to taking part in the research. This is to show that they agree to participate voluntarily in the research. Data will be collected making use of a tape recorder and field notes. Recorded interviews and field notes will be kept confidential and identification of information such as names of participants will be not mentioned to ensure anonymity and to protect participants from harm. The research findings will be presented in the research paper and archived at the University of Limpopo. For further information concerning the research, be liberty to contact me or my supervisor.

Yours Sincerely

Mafuma

Ntwanano Melta Mafuma

Clinical Psychology Masters student

0836177198/0792520468

Prof JP Mokwena

Supervisor

015 268 2322

Appendix 2: Participant's Informed Consent Information

2. (a): English version

Dear: Home-Based Caregiver

My name is Ntwanano Melta Mafuma, am currently completing a master's degree in Clinical Psychology at the University of Limpopo. One of the preconditions of the degree is writing a research paper. The tittle of my research paper is: **A phenomenological study of home-based caregivers providing palliative care to terminally ill patients at Mahlathi Village, Mopani District, Limpopo Province.** The aim of the study is to explore the psychological experiences of home-based caregivers providing palliative care to terminally ill patients at Mahlathi village, Mopani District, Limpopo Province.

Participation is voluntary. Your participation will involve an individual interview lasting 45 to 60 minutes. The interview will be recorded using a tape recorder and written down in a form of notes. Recorded data and the notes will be used strictly for research purpose. Your identification information will not be included in the research and shall be kept confidential. Before participating you will be required to sign a consent form that will serve as proof that you have agreed to take part in the research as a participant and your responses will be recorded.

Yours Sincerely

____

Ntwanano Melta Mafuma

0836177198/ 0792520468

2. (b): Xitsonga version

Eka: Home-based caregiver

Vito ra mina i Ntwanano Melta wa ka Mafuma; ndzi xichudeni e Univhesithi ya Limpopo. Laha ndzi endlaka kona master's degree ya Clinical Psychology, thlelo no endla ndzavisiso. Nhlokomhaka ya phepha ra mina ra ndzavisiso hi leyi landzelaka: **Ndzavisiso wa mithlothlo leyi ti home-based caregivers va hlanganaka na yona loko va karhi va hlayisa vanhu lava vabyaka swinene e tikweni ra ka Mahlathi, Mopani District, exifundzheni xa Limpopo**. Xikongomelo nkulu xa ndzavisiso hi leswaku: Ku lavisisa mithlothlo leyi ti home-based caregivers va hlanganaka na yona loko va hlayisa vanhu lava vabyaka swinene etikweni ra ka Mahlathi, Mopani District, exifundzheni xa Limpopo.

Ku nghenelela ka nwina eka ndzavisiso lowu ahi ku sindzisiwa kambe i ku navela ni ku tsakela ka nwina. Ku nghenelela ka nwina ku ta katsa mbulavurisano lowu nga tekaka ti minite ta makume mune ku fika ka makume ntsevu. Mbulavurisano lowu wu ta va lowu kandiyisiwaka ni ku thlela wu tsariwa ehansi. Mikandiyiso leyi yi ta tirhisiwa ntsena hi xikongomelo xa ndzavisiso ni ku hlayisiwa ya Univhesithi ya Limpopo. Mavito ya nwina ma ta sirheleliwa, ku hlayisa xindzuti xa nwina. Mi nga se nghenelela eka ndzavisiso lowu. Mi ta kombeliwa ku sayina fomo leyi nga ta va vumbhoni bya leswaku mi pfumerile ku nghenelela eka ndzavisiso hi nwexe ku nga ri hi ku sindzisiwa. Inkomu.

Wa Nwina

____

Ntwanano Melta Mafuma

0836177198/ 0792520468

Appendix 3: Participant’s Informed Consent

3. (a) English Version

I verify that the researcher explained to me the nature the purpose and aim of the study. I have also read and understood the participant informed consent information. I participate in the study willingly and below are my identification information.

Participants name ___________________________

Contact no _________________________________

Participant’s signature:	Date:
________________________	____________________
Researcher’s Signature:	Date:
_____________________	_____________________
Interview Date:	Time:
________________________	____________________

3. (b) Xitsonga Version

Ndzi tiyisisa leswaku mulavisisi, undzi hlamuserile xikongomelo xa ndzavisiso. Ndza hlayile, ndzi thlela ndzi twisisa vuxokoxoko bya papilla ro kombela ku nghenelela ka mina eka ndzhavisiso. Ndza pfumela ku nghenelela eka ndzavisiso, Laha hansi i vuxokoxoko bya mina ni sayino.

Vito ni xivongo xa munghenelerisi________________________________

Nomboro ya riqingho ____

Sayino wa munghenelerisi: Siku: _______________

Sayino wa mulavisisi Siku _______________

Appendix 4: Demographic Information Form

4. (a) English

Thank you for showing interest in the study, which focuses on the exploring experiences of home-based caregivers providing palliative care to terminally ill patients at Mahlathi Village, Mopani District, Limpopo Province.

Below is demographical information required for participants of the study.

Please fill in the required information in the blank spaces provided.

Age of participant: ________________________________

Gender: ________________________________

Marital status: ________________________________

Highest qualification: ________________________________

Year(s) of experience: ________________________________

Any training as a home bases caregiver: Yes:_______No:_____ If yes, please explain ____________________

____

____

____

____

Signature: ___________________

Date: ___________________

4. (b) Xitsonga Version

Ku tsakela ka nwina ku nghenelela eka ndzavisiso swa nkhenseka swinene. Ndzavisiso lowu wu langutana na mithlothlo leyi ti home-based caregivers va hlanganaka na yona loko va hlayisa vanhu lava vabyaka swinene etikweni ra ka Mahlathi, Mopani District, exifundzheni xa Limpopo.

Mi komberiwa ku tsala vuxokoxoko bya nwina eka mavangwa lawa ya landzelaka laha hansi

Malembe ya mungheneleri: ________________________________

Rimbewu: ________________________________

Xiyimo xa swa vukati: ________________________________

Dyondzo leyi pasiweke ya le henhla: ________________________________

Lembe/Malembe ya ntokoto: ________________________________

U thwaserile ku va home-based caregiver: Ina:_______Ee: _____

Loko hlamulo ku ri Ina, hlamusela: ______________________________

____

____

____

____

Sayino: __________________

Siku**:** __________________

Appendix 5: Interview Guide

5. (a) English Version

Objectives	Interview questions
1. To understand home-based caregivers' perceptions of their work	**Probe on:** • Why did you become a home-based caregiver? • How is your day like as a home-based caregiver? • What do you like about being a home-based caregiver? Explain • What they don't like about home-based caregiving work? Explain
2. To determine home-based caregivers' experiences of their work	**Probe on experiences:** • as they provide/interact with patients • relatives reactions of the patients • caregivers's famiy reactions • community reactions • their institution reaction and support
3. To identify psychological experiences of home-based caregivers	**Probe on:** • the difficulties you experience when working with patients • the most painful thing about your work • the most rewarding thing about your work
4. To appraise coping strategies of home-based caregivers	**Probe on:** • how do you deal with daily challenges experienced at work? • what do you do to relax when you are not at work? • who is your sources of support and explain why?

5. (b) Xitsonga Version

Swikongomelo nkulu	**Swivutiso swa mburisano**
1. Ku twisisa leswaku tani hi ti home-based caregiver ma twisisa xiyimo xa ntirho wa nwina ke?	**Vutisisa hi:** • Hinkwakolaho ka yini mi hlawurile ntirho wa ku va home-based caregiver? • Siku tani hi home-based caregiver ri va ri languteke njhani? • Xana I yini mi xi tsakelaka hi ntirho wa nwina? Hlamuselani hi vuenti • I yini mi nga swi tsakeliki hi ntirho wa nwina? Hlamuselani hi vuenti
2. Ku langutisa ntokoto lowu ti home-based caregivers ti nga langutana na wona entirhweni	**Vutisisa hi ntokoto:** • Loko mi karhi mi hlayisa vavabyi • Leswi maxaka ya vavabyi va mi vonisaka swona • Midyangu ya nwina yi mi vona njhani ntirho wa home-based care • Vaaka tiko va vona njhani ntirho wa home-based care • Entirhweni kona va vona njhani ntirho was home-based care na swona, nseketelo wo huma entirhweni ma wu kuma ke?
3. Ku lavisisa ntokoto wa miehleketo eka ti home-based caregivers	**Vutisisa hi:** • Ku tikeriwa loko mi ku hlanganaka na kona loko mi ri karhi mi hlayisa vavabyi • Leswi swi vavisaka swinene hi ntirho wa nwina • Leswi vuyerisaka hi ntirho wa nwina
4. Ku twisisa tindlela leti ti home-based caregivers va langutanaka na mithlothlo ya ntirho wa vona	**Vutisisa hi:** • Xana mi langutana njhani ni mithlothlo ya siku na siku entirhweni? • Loko mi nga ri ku tirheni mi endla yini ku hungasa? • I mani a mi seketelaka eka ntirho wa nwina, hlamuselani leswaku hikokwalaho ka yini?

Appendix 6: Ethics Clearance Certificate

University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 3935, Fax: (015) 268 2306, Email:anastasia.ngobe@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE

ETHICS CLEARANCE CERTIFICATE

MEETING: **08 June 2021**

PROJECT NUMBER: **TREC/94/2021: PG**

PROJECT:

Title:	A phenomenological study of home-based caregivers providing palliative care to terminally ill patients a Mahlathi Village, Mopani District, Limpopo Province
Researcher:	NM Mafuma
Supervisor:	Dr JP Mokwena
Co-Supervisor/s:	Ms NJ Masola
School:	Social Sciences
Degree:	Master of Arts in Clinical Psychology

PROF P MASOKO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE
The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

Note:

i) **This Ethics Clearance Certificate will be valid for one (1) year, as from the abovementioned date. Application for annual renewal (or annual review) need to be received by TREC one month before lapse of this period.**

ii) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee, together with the Application for Amendment form.**

iii) **PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.**

Appendix 7: Ethics Permission from Department of Health

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health

Ref : LP_2021-07-012
Enquires : Ms PF Mahlokwane
Tel : 015-293 6028
Email : Phoebe.Mahlokwane@dhsd.limpopo.gov.za

Ntwanano Melta Mafuma

PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below**;**

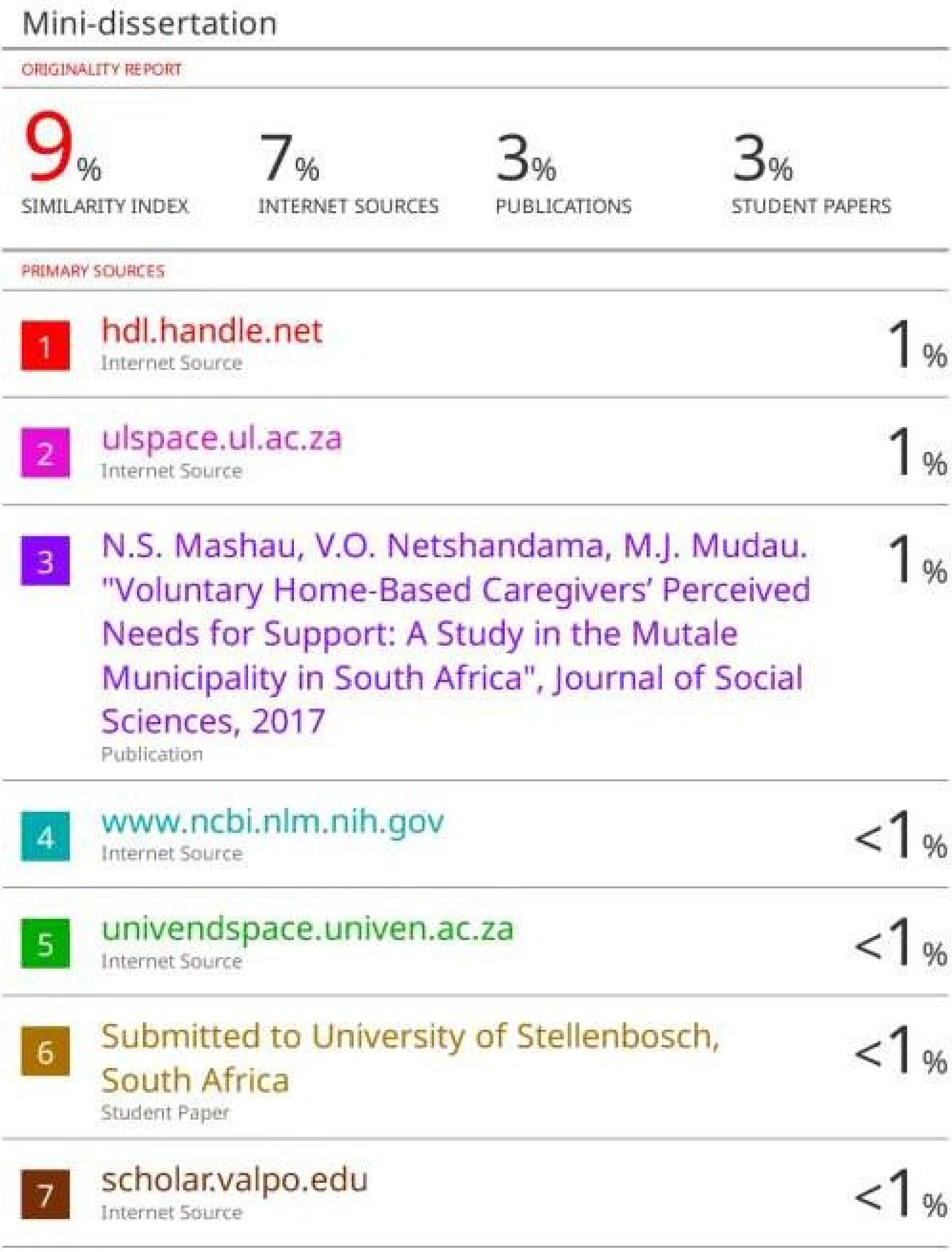
A phenomenological study of home-based caregivers providing palliative care to terminally ill patients at Mahlathi Village, Mopani District, Limpopo Province.

1. Permission to conduct research study as per your research proposal is hereby Granted.
2. Kindly note the following:
    a. Present this letter of permission to the institution supervisor/s a week before the study is conducted.
    b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
    c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    e. The approval is only valid for a 1-year period.
    f. If the proposal has been amended, a new approval should be sought from the Department of Health
    g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

Head of Department **Date** 12/08/2021
pp

Appendix 8: Turnit in report



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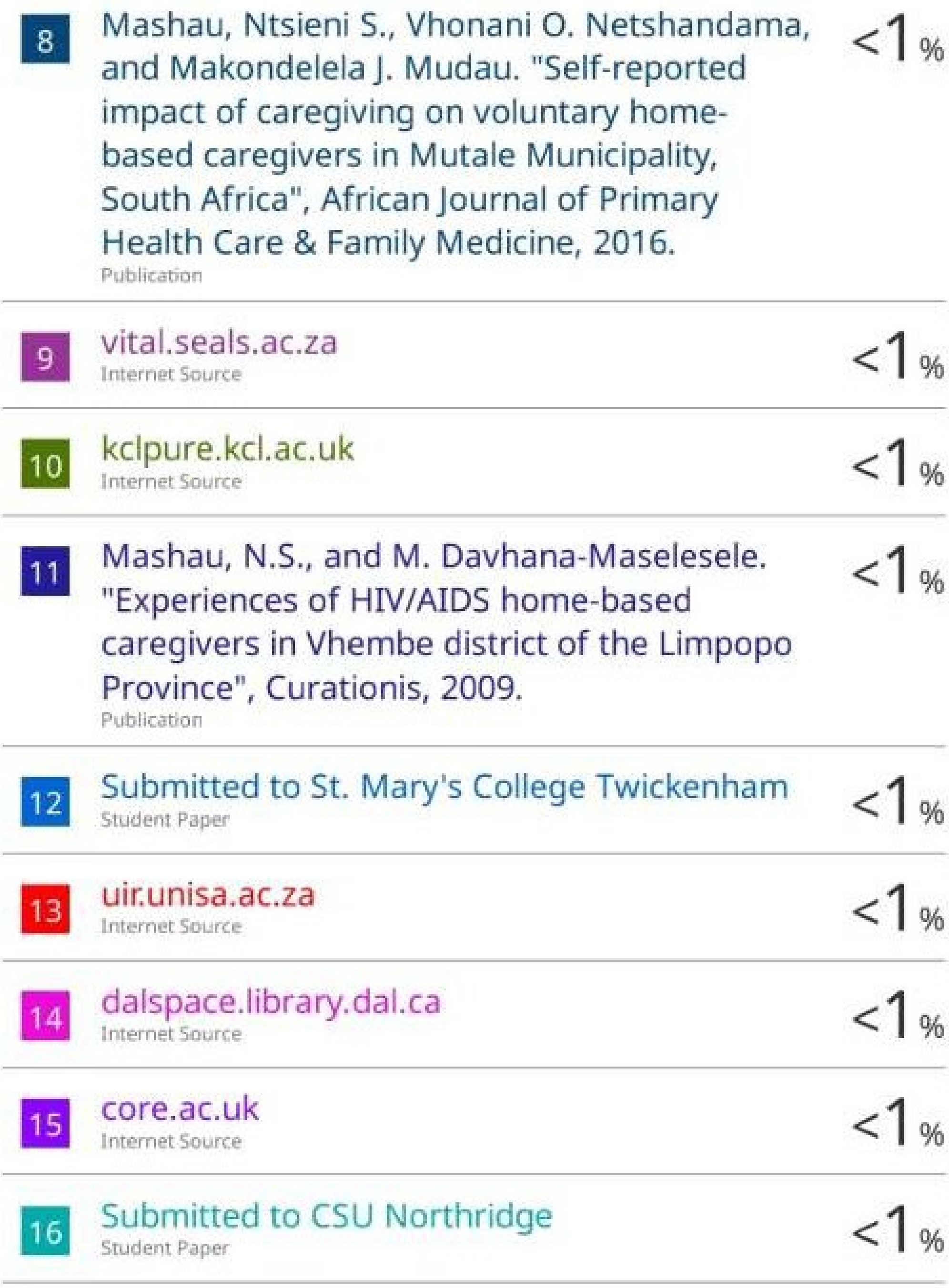

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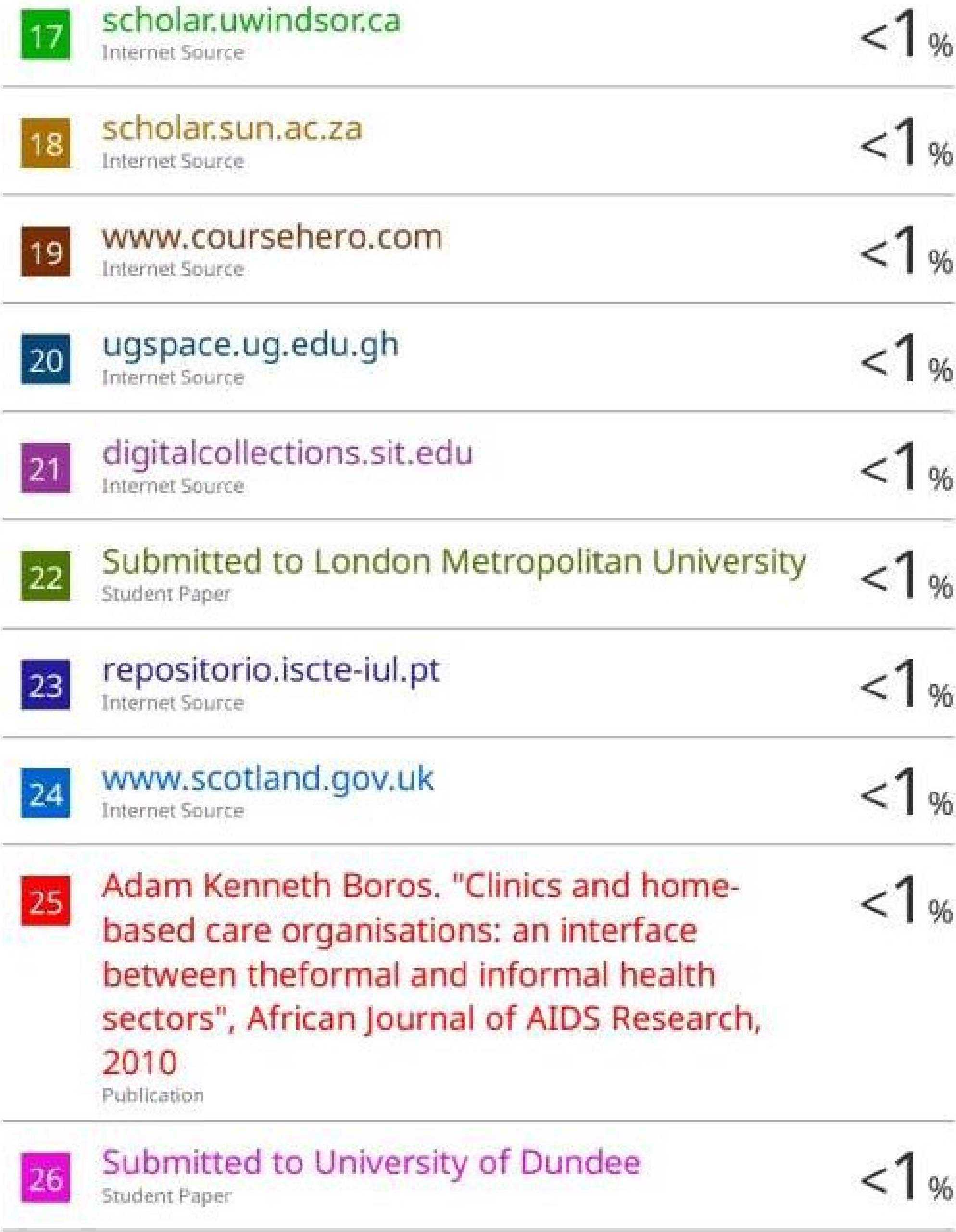

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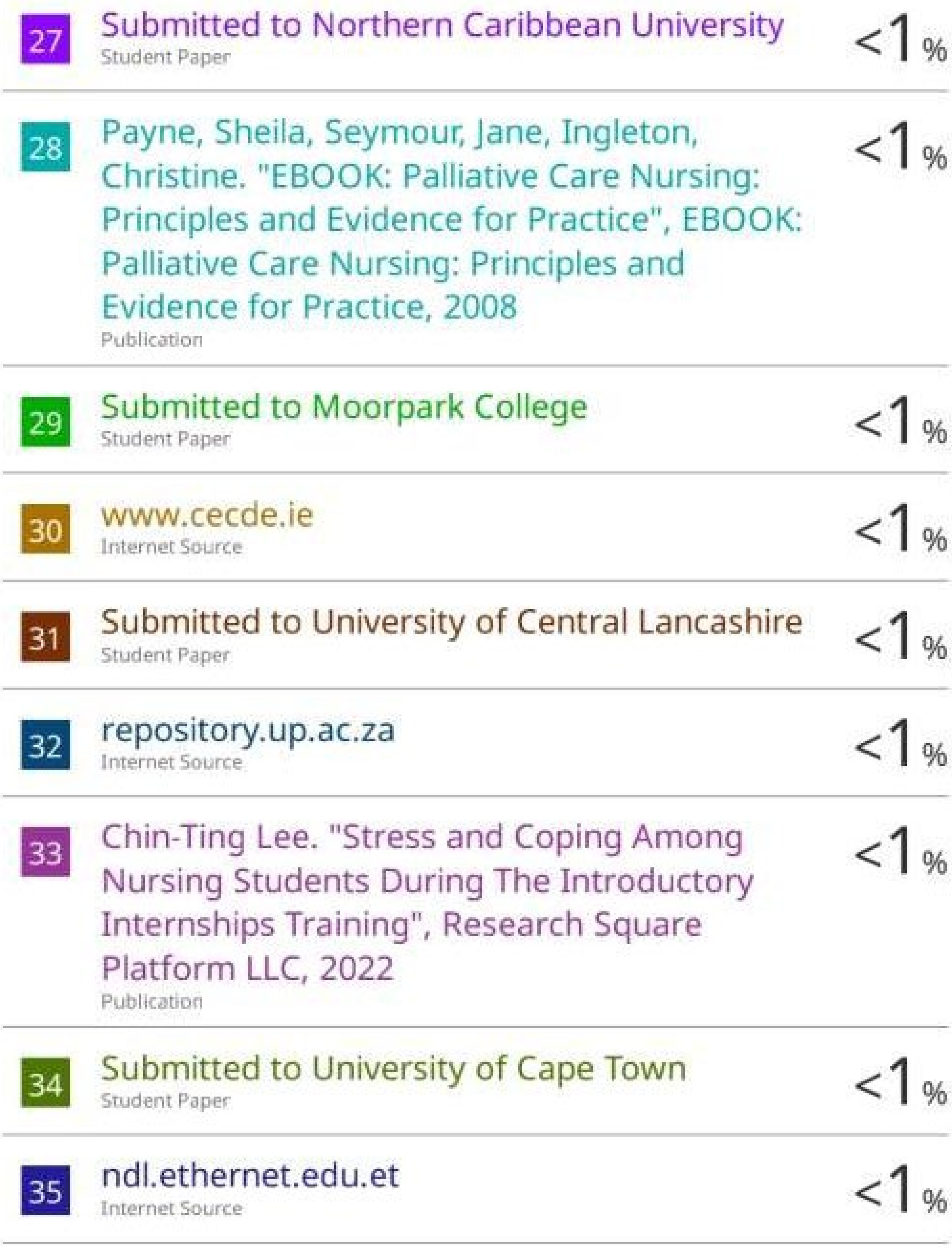

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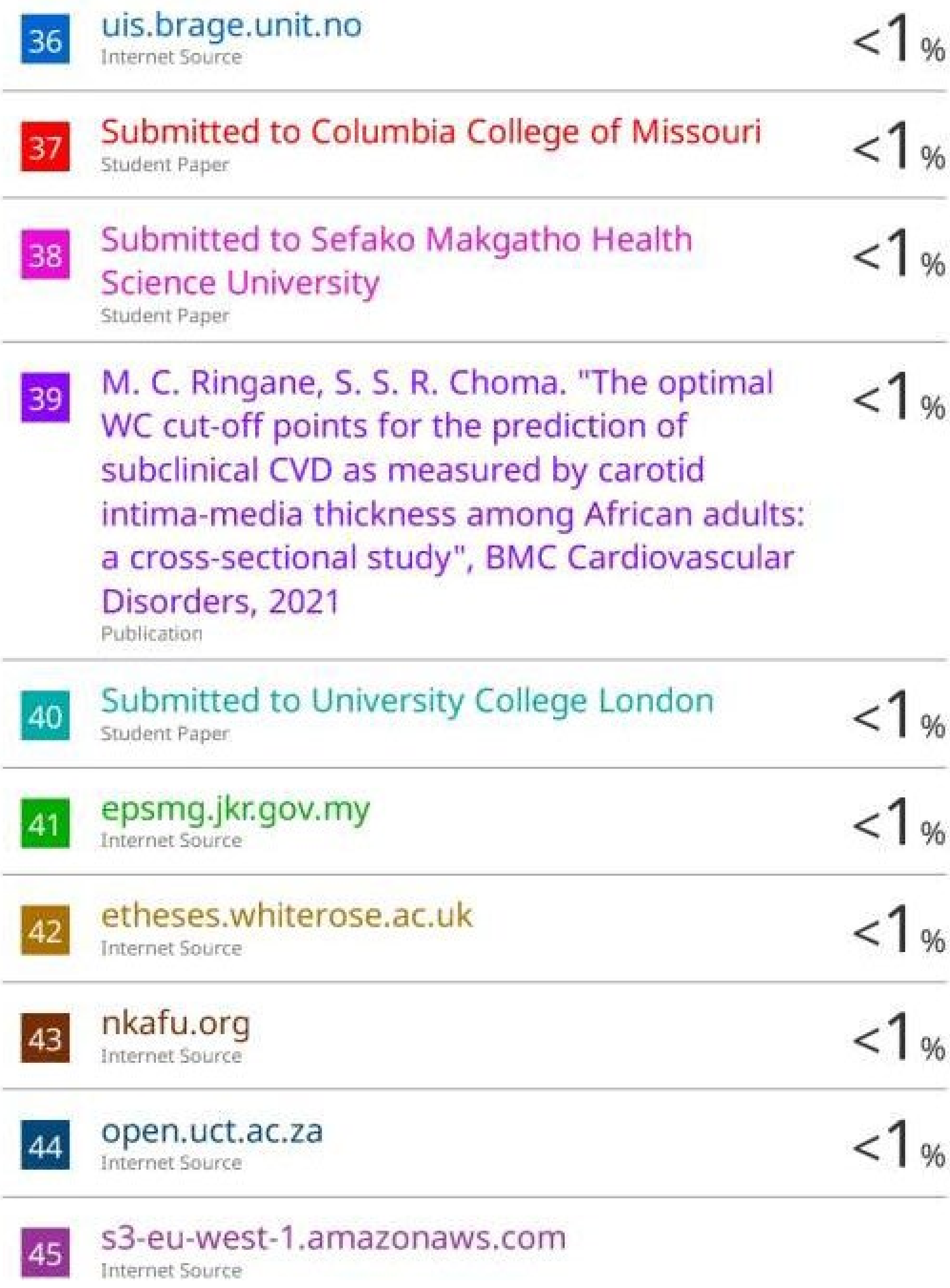

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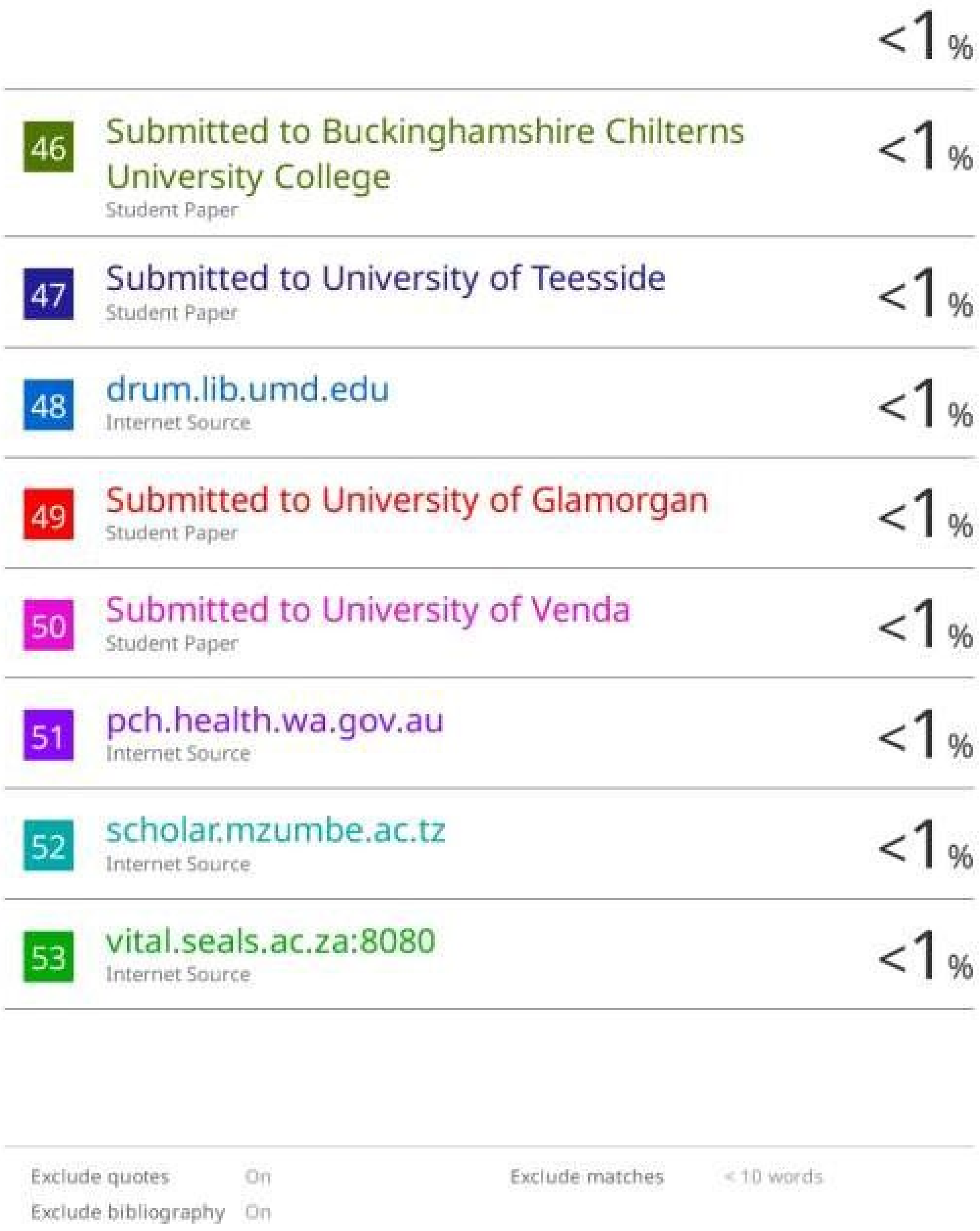

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