

**Exploring the experiences of informal primary
caregivers of women with advanced or
terminal gynaecological cancers**

by

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Master of Arts in the Faculty of Psychology at Stellenbosch University*

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DECLARATION

By submitting this thesis/dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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Abstract

Gynaecological cancers are a serious health problem affecting women across the world. According to the recent global cancer statistics, more than 1.3 million women were diagnosed with a gynaecological cancer and 671 920 women died as a result of this disease. There are five main types namely cervical, ovarian, uterine, vulva and vaginal cancer. These cancers originate in the reproductive organs of women and may affect their health, self-esteem, body image and romantic relationships. Informal cancer caregivers play a crucial role in a patient's illness trajectory because they provide the patient with physical, emotional, and financial support. Women with advanced or terminal gynaecological cancer particularly need support from their caregivers because they are at a delicate stage of their disease. Advanced or terminal cancer cannot be cured and thus, the challenges that caregivers experience may be unique because the possibility of death becomes greater. Yet, to my knowledge, there are no studies that have specifically explored the experiences of informal caregivers of women with advanced or terminal gynaecological cancer. For this reason, I have conducted this study.

I conducted semi-structured interviews with 16 participants. I recorded all the interviews, and transcribed the interviews verbatim. Thereafter, I analysed the data thematically by using the principles outlined by Braun and Clarke. I identified five themes namely, 1) navigating a complicated relationship with the patient: a caregiver's perspective, 2) the complexities associated with caregiving and the public healthcare system, 3) the effects of caregiving on the caregiver's health and well-being, 4) the support networks of informal cancer caregivers and 5) providing care in the context of a pandemic.

The findings highlight the challenges and positive changes that the informal caregivers experienced within their relationship with the patient. In addition, the findings indicate the importance of communication between healthcare providers and informal caregivers and the need for caregiver visibility. Furthermore, the findings highlight the impact of caregiving on the physical and emotional well-being of these caregivers. Moreover, the findings highlight the supportive resources available to the caregivers. Lastly, the findings in this study present novel experiences regarding providing care during the COVID-19 pandemic.

Keywords: informal caregivers, gynaecological cancer, advanced cancer, terminal cancer, experiences, cancer caregivers

Opsomming

Ginekologiese kankers is 'n ernstige gesondheidsprobleem wat vroue internasionaal affekteer. Na aanleiding van onlangse globale statistiek is meer as 1,3 miljoen vroue met 'n ginekologiese kanker gediagnoseer en 671 920 vroue het as gevolg van hierdie siekte gesterf. Daar is vyf hoofsoorte, naamlik servikale, eierstok-, baarmoeder-, vulva- en vaginale kanker. Dié kankers ontstaan in die reprodktiewe organe van vroue en mag hulle gesondheid, selfbeeld, liggaamsbeeld en romantiese verhoudings beïnvloed. Informele kankerversorgers speel 'n belangrike rol in 'n pasiënt se siekte-trajek want hulle verskaf aan die pasiënt fisiese, emosionele en finansiële ondersteuning. Vroue met gevorderde of terminale ginekologiese kanker het ondersteuning van veral hulle versorgers nodig want hulle is in 'n delikate fase van hulle siekte. Gevorderde of terminale kanker kan nie genees word nie en daarom mag die uitdagings wat die versorgers ervaar uniek wees aangesien die moontlikheid van afsterwe groter word. Nogtans, na my wete, is daar nie studies wat spesifiek die ervaring van informele versorgers van vroue met gevorderde of terminale ginekologiese kanker verken nie. Om hierdie rede het ek dié studie uitgevoer.

Ek het semigestruktureerde onderhoude met 16 deelnemers gevoer. Ek het al die onderhoude opgeneem en het dit verbatim getranskribeer. Ek het daarna die data tematies ontleed deur die beginsels van Braun en Clarke te gebruik. Ek het vyf temas geïdentifiseer, naamlik 1) die navigering van die gekompliseerde verhouding met die pasiënt: 'n Versorger se perspektief, 2) die kompleksiteit wat verband hou met versorging en die openbare gesondheidstelsel, 3) die uitwerking van versorging op die versorger se gesondheid en wel-wees, 4) die ondersteuningsnetwerke van informele kankerversorgers en 5) die verskaffing van sorg in die konteks van 'n pandemie.

Die bevindinge lig die uitdagings en positiewe verandering uit wat die informele versorgers in hulle verhouding met die pasiënt ervaar het. Die bevindinge het bykomend die behoefte aan versorger-sigbaarheid aangedui en die belangrikheid van kommunikasie met gesondheidsorgverskaffers. Verder het die deelnemersbeskrywings gesuggereer dat die verskaffing van sorg hulle fisiese en emosionele wel-wees negatief geraak het. Daarby is die belangrikheid van ondersteuning uitgelig. Laastens word nuwe ervaringe aangaande die verskaffing van sorg tydens die Covid-19-pandemie in die studie aangebied.

Sleutelwoorde: informele versorgers, ginekologiese kanker, gevorderde kanker, terminale kanker, kankerversorgers

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Chapter 1

1.1. Introduction

Gynaecological cancers are among the most common cancers diagnosed in women worldwide (Sung et al., 2021). According to the recent global cancer statistics, more than 1.39 million women have been diagnosed with a gynaecological cancer in 2020, while 671 920 women have died as a result of this disease (Sung et al., 2021). These statistics suggest that gynaecological cancers are a serious health problem affecting women globally.

The five main types of gynaecological cancers are cervical, ovarian, uterine, vulval and vaginal cancer (Mattsson et al., 2018). These cancers originate in the reproductive organs of women (Boa & Grénman, 2018). The symptoms experienced before a gynaecological cancer diagnosis depends on the location of the disease. One of the most common symptoms is vaginal bleeding (Knapp et al., 2021). This symptom is not always considered unusual by healthcare professionals (HCPs) as they may be present for other reasons (Evans et al., 2007; Henry et al., 2020; Lim et al., 2014). For example, women may experience vaginal bleeding because of uterine fibroids (Zimmerman et al., 2012), cervical or uterine polyps, endometriosis, an ectopic pregnancy, or infections such as cervicitis, vaginitis, and endometritis (Gray & Emans, 2007). Consequently, the need to eliminate other causes of these symptoms may result in a delay in the diagnosis of gynaecological cancer (Lim et al., 2014). This in turn, increases the risk of the progression of the disease which in turn, may impact the health and well-being of these patients.

The prognosis determines the type of treatment prescribed which either cures or delays the progression of the disease (Centers for Disease Control and Prevention [CDC], 2022). The treatment options that are recommended to women are surgery, chemotherapy, and radiation (Klastersky & Lossignol, 2011). Treatment is considered beneficial for the eradication of the disease or prolonging life. However, women who undergo treatment for gynaecological cancer have an increased risk of lymphedema, menopause, pelvic pain, vaginal dryness, painful sexual activity, fatigue, and diarrhoea (Campbell et al., 2019). These side effects can lead to additional threats to women's self-esteem, body image, romantic relationships as well as an increased risk for anxiety and depression (Klastersky & Lossignol, 2011).

Informal caregivers play an important role in a patient's illness trajectory because they provide the patient with physical, emotional, and financial support (Given et al., 2011). Informal caregivers are defined as individuals who provide patients with uncompensated

assistance on a regular basis (Datta & Kar, 2016). These caregivers are often well acquainted with the patient. Thus, informal caregivers are often the parent, spouse, sibling, and adult children (Datta & Kar, 2016). Research suggests that these caregivers fulfil multiple roles and need to adapt to the needs of the patient (Germeni & Sarris, 2015; Stenberg et al., 2012).

In South Africa, informal primary cancer caregivers are crucial because most of the population seek treatment at public hospitals (Maree et al., 2013). Public hospitals have limited resources such as a shortage of staff, admission beds and equipment (Manyisa, 2016). In addition to these shortages, patients are subjected to long waiting periods when seeking treatment at public hospitals (Manyisa, 2016). These limited resources contribute to shorter periods within hospitals for cancer patients who undergo treatment at these facilities (Stenberg et al., 2012). Consequently, primary caregivers are instrumental in assisting cancer patients with tasks that were previously completed by nurses (Given et al., 2008). This includes monitoring the patient's symptoms, providing the patient with pain medication, and keeping track of any side effects that the patient may experience (Given et al., 2011). With the high disease burden within the country (Narsai et al., 2021), HCPs need extra resources to provide patients with the support and care that they need. For this reason, informal cancer caregivers play an instrumental role within the healthcare system and the patient's life.

1.2. Advanced or terminal cancer

Patients with advanced or terminal cancer particularly need support and assistance from their informal caregivers. This is due to the sensitive stage of the disease. An advanced cancer diagnosis occurs when the cancer has spread from the original location to other parts of the body (National Cancer Institute [NCI], 2022). If a patient has advanced cancer, the possibility that treatment will cure the disease is unlikely (NCI, 2022). Similarly, patients diagnosed with terminal cancer cannot be cured through cancer treatment (NCI, 2022). Nevertheless, treatment is still considered useful to help reduce the size of the tumour, reduce the patient's symptoms or to slow down the progression of the disease (NCI, 2022).

When informal caregivers assist patients who have advanced or terminal cancer, the challenges that they experience are unique because the possibility of death becomes greater. This can have long lasting effects on the caregiver's health. Yet, to my knowledge, no studies have been conducted on the experiences of informal caregivers of gynaecological cancer patients diagnosed with advanced or terminal cancer. Considering the amount of time informal caregivers spend with the cancer patient and the bond that develops between them, it is important to understand the cancer experience from the caregiver's perspective.

1.3. Rationale

In South Africa specifically, cervical, and uterine cancer are two of the most common gynaecological cancers diagnosed among women (Cancer Association of South Africa [CANSAs], 2020). In 2020, the incidence of gynaecological cancer in South Africa amounted to 14 973 cases with the number of deaths amounting to 7680 cases (International Agency for Research on Cancer [IARC], 2021). These statistics suggest that gynaecological cancers are a health problem in South Africa.

There are several contextual factors that may impact the lives and well-being of informal caregivers of gynaecological cancer patients in South Africa. The pressure on the public healthcare system, poverty, and limited access to resources have to be taken into account when exploring the experiences of these caregivers in South Africa. Thus, the goals of this study is to provide insight the caregiving role and to identify the needs and challenges that informal caregivers highlight while fulfilling this role. This knowledge is crucial in raising awareness for caregivers in this context.

Most of the research that have been conducted on the experiences of informal caregivers of gynaecological cancer patients have occurred in first world countries such as United Kingdom (Lopez et al., 2012), Norway (Oldertrøen Solli et al., 2019) and Australia (Ussher et al., 2011). These studies have focused on the experiences of male partners of gynaecological cancer patients (Lopez et al., 2012; Oldertrøen Solli et al., 2019) and the relationship dynamics between informal caregivers and cancer patients (Ussher et al., 2011). While these qualitative studies provide insightful findings about the experiences of these caregivers, currently, there is a lack of research that focuses on the experiences of informal primary caregivers of advanced or terminal gynaecological cancer patients. Therefore, this study seeks to address this gap within the existing literature.

To my knowledge, there are no published studies that specifically and solely focuses on the experiences of caregivers of women diagnosed with any gynaecological cancer in South Africa. This limits the knowledge production among HCPs and members in society regarding the role and the needs of these caregivers in South Africa. For this reason, I decided to conduct a study on the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancer in South Africa. Informal cancer caregivers play an important role in the patient's life, within the healthcare system and in society. Thus, it is important to acknowledge and understand the role of these caregivers and the effects that it has on their mental health and well-being.

1.4. Significance of the study

This study is significant because it contributes to the limited literature on gynaecological cancer caregivers in South Africa. It provides gynaecological caregivers with a platform to voice their experiences which is an important process in facilitating change.

This study has the potential to highlight how the needs and challenges of advanced or terminal gynaecological cancer caregivers can be addressed in the future. In addition, this study can bring attention to the importance of caregivers mental health and the areas in which they need support.

Moreover, by caregivers sharing their experiences, they may highlight how they are being assisted by HCPs, their families, communities, and workplaces. This may provide important insight into the ways in which they are supported and assisted. In addition, the information provided by the caregivers in this study may provide insight into the way in which assistance with their needs can be improved.

Furthermore, the information may contribute to the development of effective and sustainable interventions for informal cancer caregivers of terminal or advanced gynaecological cancer patients.

Currently, there are no policies in place for informal cancer caregivers in South Africa. This study may contribute to highlighting the need for the implementation of formal policies. Moreover, this study may contribute to the creation and implementation of future policies to protect and assist informal cancer caregivers in this country.

1.5. Aim

The aim of this study was to explore the experiences of informal primary caregivers providing care and assistance to women with advanced or terminal gynaecological cancers in South Africa

1.6. Objectives

- To explore how gynaecological cancer caregivers perceive the caregiving role
- To explore the challenges that primary caregivers experience when caring for a gynaecological cancer patient
- To explore the sources of support available for gynaecological cancer caregivers
- To explore the experiences of gynaecological cancer caregivers regarding their interactions with healthcare providers
- To explore how caregivers perceive their relationship with the gynaecological cancer patient

- To explore how the coronavirus pandemic affected informal primary cancer caregivers

1.7. Conclusion and overview of chapters

In Chapter 1, I provided background information on gynaecological cancer and the effects that it has on women diagnosed with this disease. In addition, I provided a broad overview on the importance of informal cancer caregivers in the lives of cancer patients. Furthermore, I briefly defined advanced cancer and terminal cancer respectively. In addition to this, I highlighted the need for informal caregivers during the illness trajectory of patients with an advanced or terminal cancer prognosis. Lastly, I presented the rationale, the significance of the study, and the aim and objectives.

In Chapter 2, I will present the literature review and theoretical framework. In this literature review, I will provide further detail on the importance of informal cancer caregivers. I will present this discussion by highlighting the roles that they fulfil, challenges that they may encounter as well as the effects that caregiving has on the health and well-being of informal caregivers.

In Chapter 3, I will present my methods. I will describe the research design, participant recruitment, data collection, data analysis, and ethical considerations. I will also reflect on the research process.

In Chapter 4, I will present the findings of this study. In addition, I will discuss the findings in relation to prior studies and the theoretical framework.

In Chapter 5, I will present my concluding remarks. I will start by summarising the findings in relation to each objective. Thereafter, I will present the limitations of the study. Lastly, I will make recommendations for future research and for clinicians.

Chapter 2

Literature Review and Theoretical Framework

2.1. Introduction

In this chapter, I review and discuss studies that explored the experiences of informal cancer caregivers. My review of the literature is organised around 10 themes namely, 1) the increasing roles of informal cancer caregivers, 2) psychological distress experienced by informal cancer caregivers, 3) the physical effects associated with providing care, 4) managing the patient's pain, 5) the importance of supportive resources, 6) spirituality 7) communication between informal cancer caregivers and HCPs, 8) relationship dynamics between the informal caregiver and the cancer patient, 9) positive aspects of being a cancer caregiver and 10) the effects of the pandemic on informal cancer care. Thereafter, I discuss the theoretical framework and the way in which it contributes to this study.

2.2. The increasing roles of informal cancer caregivers

Informal cancer caregivers fulfil multiple roles to ensure that the patient's health and well-being is prioritized. One of the most important responsibilities that informal caregivers have is providing the patient with medical assistance, particularly in a home-based setting (Given et al., 2008). Informal caregivers develop a diverse range of skills such as overseeing the patient's needs (Given et al., 2008), cleaning, and treating the patient's wound (van Ryn et al., 2011), keeping track of new symptoms or side effects, and observing any improvements or changes within the patient after treatment (Given et al., 2008).

Informal caregivers may also need to accompany the patient to their medical consultations, communicate with HCPs about the needs of the patient and in some cases, make medical decisions on the patient's behalf (Ussher et al., 2011). In addition, practical tasks such as household chores, childrearing and being employed have also been reported as responsibilities fulfilled by informal cancer caregivers (Oldertrøen Solli et al., 2019). Studies have further shown that informal caregivers assist patients with their physical hygiene, bathroom activities, nutrition and eating habits (Adejoh et al., 2021; Cai et al., 2021; Ugur et al., 2014). Yet, the physical tasks are not informal caregivers only priority. Informal caregivers may also focus on the patient's mental health (Adejoh et al., 2021). In a study conducted in Uganda and South Africa, caregivers of patients with incurable conditions reported that they were the patient's confidant (Streid et al., 2014). They reported that the patient shared their fears, concerns and discussed their emotional well-being. Consequently, caregivers described having to support the patient in accepting their diagnosis. However,

some caregivers admitted that providing the patient with emotional support resulted in them feeling emotionally depleted (Streid et al., 2014).

Informal caregivers who provide cancer care while being employed may experience challenges. For example, a longitudinal study conducted with 191 patient-caregiver pairs in Canada found that 25% of caregivers reported changes in their employment status such as having to work less hours, take leave, quit, or were fired (Wadhwa et al., 2013). A recent systematic review has shown similar findings of informal caregivers who reported shifting from working full-time to part-time (Cai et al., 2021). Additionally, a study that utilized secondary qualitative transcripts from a broader study, found that advanced informal cancer caregivers from Uganda, Namibia and Zimbabwe rejected career opportunities to provide the patient with care and support (Adejoh et al., 2021). In this study, it was found that both male and female caregivers rejected career opportunities to provide care and assistance for their family members diagnosed with cancer (Adejoh et al., 2021).

While some caregivers may experience a change in employment status, others may experience a loss in productivity during the patient's illness trajectory (Angioli et al., 2015; Mazanec et al., 2011). For example, in a longitudinal study conducted with informal caregivers of advanced ovarian cancer patients in Italy, 146 employed caregivers reported that they experienced an average of 21% loss in work productivity (Angioli et al., 2015). This study, however, was limited by an important factor such as recall bias. Thus, the findings may not be an accurate reflection of the loss in work productivity. However, prior to Angioli et al.'s (2015) study, a cross-sectional, correlational study took place in the United States of America with 70 informal cancer caregivers of which 39 were employed (Mazanec et al., 2011). These employed caregivers reported that they experienced an average of 23% loss in productivity at their place of employment (Mazanec et al., 2011). This study's small sample size is, however, a limitation. Despite the limitations of the two studies described (Angioli et al., 2015; Mazanec et al., 2011), their findings suggest that informal cancer caregivers struggle with their productivity at their place of employment.

Balancing the various roles highlighted in this section may be challenging due to the amount of time that caregivers provide assistance and care. For example, in a study conducted with 104 primary caregivers in Italy, Pellegrino et al. (2010) found that 52% of caregivers spent more than eight hours providing care for the patient. These findings were similar to those of a recent study conducted by Rowland et al. (2017) with bereaved informal cancer caregivers. The caregivers in Rowland et al.'s (2017) study completed a survey which indicated that 90% of caregivers provided an average of 10 hours of care every day during the

last three months of the patients' lives. For many caregivers, their presence was crucial because they needed to be physically present to ensure that the patients' needs were met (Stenberg et al., 2012).

The lack of social interaction with others can have negative effects on the caregiver's independence and flexibility (Doumit et al., 2008). In a study conducted by Doumit et al. (2008), Lebanese caregivers reported that their sense of freedom changed when they became their family member's caregiver. They reported that they felt restricted and compelled to stay with the patient in case of a possible emergency. The literature also suggests that caregivers have trouble providing care for their children and the patient (Sercekus et al., 2014) and experience a decrease in the quality of their relationships (Arian et al., 2017). In addition, research suggests that caregivers experience isolation during the patient's illness trajectory (Streid et al., 2014).

Some studies also found that caregivers were financially responsible for the patient and their families (Cai et al., 2021; Streid et al., 2014; Wells et al., 2008). For example, in the study conducted by Streid et al. (2014), some informal caregivers reported that they were reliant on governmental grants to assist with their financial needs as well as those of the patient. However, these funds did not adequately meet the needs of the patient (Streid et al., 2014). In addition, due to the limited funding at their disposal, some caregivers reported that they could not provide their family with sufficient food. The caregivers in this study reported that that they were the only person responsible for their families finances and as a result, experienced anxiety because they could not adequately meet the patient nor their family's needs (Streid et al., 2014).

In a systematic review, it was found that costs such as medication, meals, tests added to the financial strain experienced by informal caregivers (Cai et al., 2021). Additionally, participants in Wells et al.'s (2008) study, reported that they experienced an increase in electricity, petrol, and water expenses when the patient moved into their home. They further reported that the increase in expenses affected their ability to provide for any other needs of their family (Wells et al., 2008). These findings suggest that informal cancer caregivers experience financial strain when providing the patient with care. While financial strain can affect informal caregivers during any stage of the patient's illness trajectory, Rowland et al. (2017) highlighted that the financial effects experienced by family members who provide care for terminal cancer patients are not recognised.

The responsibilities that informal cancer caregivers have toward the patient are important and instrumental during the patient's illness trajectory. Subsequently, as illustrated

in this section, these responsibilities can have personal consequences in caregivers' lives. Caregivers may experience changes in their employment status, social lives, and may have to provide the patient with emotional, physical, and financial support. These activities may need to be fulfilled while informal caregivers simultaneously support their families.

This section provides an important overview on the various responsibilities fulfilled by informal cancer caregivers. However, there are limited studies which explore the experiences of informal caregivers of patients with advanced or terminal cancer in South Africa. Thus, further studies may contribute to increasing knowledge on how these caregivers experience the increasing roles and responsibilities in South Africa.

2.3. The psychological distress experienced by informal cancer caregivers

Informal cancer caregivers experience a range of emotions when assisting the patient on a regular basis. Research suggests that these emotions include anxiety (Han et al., 2016), fear (Han et al., 2016; Sercekus et al., 2014; Stenberg et al., 2012), sadness (Leow & Chan, 2017; Sercekus et al., 2014), guilt (Han et al., 2016; Leow & Chan, 2017; Stenberg et al., 2012), frustration (Arian et al., 2017), and uncertainty (Stenberg et al., 2012).

Prior literature suggests that fear is one of the most common emotions reported by informal cancer caregivers (Maree et al., 2018; Han et al., 2016; Stenberg et al., 2012; Streid et al., 2014). Studies have found that informal caregivers report various reasons why they experience fear when providing care for the patient. These reasons include the fear of losing the patient (Maree et al., 2018; Streid et al., 2014), the fear of being diagnosed with cancer (Doumit et al., 2008), the fear of the unknown (Han et al., 2016) and the fear of the future (Stenberg et al., 2012).

In a study conducted with male partners of breast and gynaecological cancer patients in the United Kingdom, it was reported that informal caregivers found it challenging to cope with an uncertain future (Lopez et al., 2012). These caregivers further reported that they experienced distress because of the fear and uncertainty that they experienced when thinking of their future and the future of the patient.

In addition to fear, studies have found that caregivers also report experiencing guilt while providing the patient with care (Leow & Chan, 2017; Han et al., 2016; Stenberg et al., 2012; Wittenberg-Lyles et al., 2011). However, the reasons why caregivers experience guilt depends on their thoughts and emotions regarding the patient's diagnosis and their experience of being a cancer caregiver. For example, in a study conducted by Han et al. (2016), informal caregivers reported experiencing guilt because they believed that they caused the patient to be diagnosed with cancer. In this study, daughters who provided care for their mothers reported

that they believed that their behaviour towards their mothers prior to their diagnoses may have resulted in distress. Thus, they believed that the distress that their mothers experienced resulted in the onset of cancer. Similarly, partners who provided care for their wives also reported experiencing guilt. They, too, reported that distress caused by failed business ventures or financial constraints may have been the cause of their partners' diagnoses.

In a study conducted by Wittenberg-Lyles et al. (2011), informal caregivers also experienced guilt when they provided the patient with care. They reported that providing care was a challenge for them. As a result of this challenge, they admitted that they wanted the patient to pass away because they were unable to balance their lives with the responsibilities that accompanied the caregiving role. However, these participants reported that the thought of being relieved from their caregiving duties if the patient died caused them to experience guilt. Despite experiencing guilt, the participants reported that they were unsure of how to control or manage those thoughts. These findings particularly related to guilt suggests that the role of informal caregivers may have an impact on the caregiver's mental health.

Witnessing the patient in pain may also affect the emotional well-being of caregivers (Stenberg et al., 2012). In the study conducted by Stenberg et al. (2012), informal caregivers reported that they experienced distress and excessive guilt for not being able to provide the patient with adequate support when they experienced pain (Stenberg et al., 2012). The inability to reduce the pain that the patient experienced elicited feelings of disappointment from the caregivers. The reason why caregivers reported that they were disappointed with themselves was because they believed that they had disappointed the patient (Stenberg et al., 2012).

In addition to the emotions discussed, frustration, worry and anxiety are also emotions that informal caregivers experience (Arian et al., 2017). These emotions were highlighted in a study conducted by Arian et al. (2017) with informal caregivers of patients with terminal cancer. These participants reported that their frustration stemmed from seeing the patient lose hope when they continued to have hope for the patient and their recovery (Arian et al., 2017). In addition, these caregivers reported experiencing worry when they thought about the patient's cancer and the possibility of the cancer being genetic. They also reported worrying about how other family members would process the patient's death. In addition to all the emotions experienced by the caregivers in this study, they further reported that their anxiety and despair were related to the thoughts of the patient's pending death.

The frequency with which informal caregivers experience various emotions may be insightful. In a study conducted with informal caregivers, caregivers were asked to monitor

their moods for the week (Pellegrino et al., 2010). In this study, it was reported that the caregivers experienced at least two depressive, anxious, irritable, and fearful moods per week. This finding suggests that caregivers may be experiencing a range of different emotions on a consistent basis.

As illustrated in this section, informal caregivers experience various emotions during the patient's illness trajectory. Some of the emotions highlighted in prior studies were fear, guilt, frustration, and worry. These emotions together with thoughts of the future, can affect the mental health of these caregivers if not identified and sufficiently addressed.

This section highlighted some of the common emotions reported by informal caregivers in prior research studies. However, research on how the mental health of informal gynaecological cancer caregivers is affected when providing care for terminal cancer patients in South Africa is limited. Thus, it is important to explore the factors that impact the health and well-being of South African gynaecological cancer caregivers and the various emotions that they experience during the process.

2.4. The physical effects associated with providing care

Research suggests that informal caregivers experience physical effects while providing care for cancer patients (Wells et al., 2008). In a systematic review which consisted of six studies, the physical responses to care namely, insomnia, headaches, fatigue, bodily pain, high blood sugar and high or low blood pressure were reported by informal caregivers in four of those studies (Cai et al., 2021). Additionally, in two of the four studies which focused on the physical responses to care, it was found that participants who had chronic conditions prior to being a caregiver reported that their conditions worsened after becoming a caregiver (Cai et al., 2021).

In a study conducted by Sercekus et al. (2014), informal caregivers reported that they experienced headaches, a reduced appetite, weight loss, insomnia or fatigue. These caregivers attributed their physical effects to the grief and the stress that they experienced as caregivers. Some caregivers also reported that they did not have any pre-existing conditions prior to the caregiving role. However, while providing care, they developed conditions such as hypertension, eczema and psoriasis.

Informal caregivers in other studies also reported physical effects such as chest pain, stomach aches (Wells et al., 2008) and smoking (Streid et al., 2014). However, fatigue was one of the main physical effects experienced by informal cancer caregivers (Arian et al., 2017; Cai et al., 2021; Sercekus et al., 2014; Streid et al., 2014). The reasons why informal caregivers experienced fatigue varied from study to study. For example, in the study

conducted by Streid et al. (2014), some caregivers reported that they experienced fatigue because of their limited sleep schedule. The participants reported that they had to assist patients at night with their needs and thus, were unable to get enough sleep at night. In the study conducted by Arian et al. (2017), the caregivers reported that their vigilance when it came to the patients needs contributed to their fatigue (Arian et al., 2017). The changes in the caregivers sleep cycle not only contributed to their fatigue but also to their changes in body weight (Arian et al., 2017).

Research suggests that some informal caregivers may experience physical effects as a result of the emotions that they experience. For example, the participants in Wells et al.'s (2008) study, reported that worry was one of the reasons why they experienced negative physical responses in their bodies. Some of the factors that contributed to their concerns include the progression of the disease, the reoccurrence of cancer, the condition of the patient deteriorating or an inconsistent routine. The participants reported that experiencing physical effects made them aware of how their emotions affected their physical health. This encouraged the participants to be aware of their health and the need to prioritise their well-being. Their awareness regarding the importance of their health became evident when they reported that by prioritising their health, they could improve the way in which they cared for the patient.

The studies described in this section indicate that informal cancer caregivers experience many physical effects while providing care for the patient. As indicated, being vigilant and being available for caregivers during the evenings contributed to the fatigue of some caregivers. However, the emotional distress experienced by informal caregivers also affected and contributed to the physical effects that they experienced. Thus, it is important to explore the physical and emotional well-being of informal caregivers. In doing so, the connection between the mind and the body is highlighted and the effects thereof is known.

2.5. Managing the patient's pain

Informal caregivers play a crucial role in helping cancer patients treat and manage the physical pain that they experience (van Ryn et al., 2011). For this reason, caregivers need to learn how to execute various strategies to reduce the pain experienced by the patient (Mehta et al., 2014). However, implementing strategies to manage the pain of cancer patients can be challenging. In a study conducted by Mehta et al. (2014), informal caregivers described feeling unprepared to utilize pain relief strategies. In addition, the caregivers reported feelings of helplessness when the patient did not experience relief from their pain. An additional challenge reported by caregivers were pain relief strategies that were successful in the past

that became ineffective over time. Consequently, unsuccessful attempts at reducing the patient's pain resulted in caregivers experiencing distress. The caregivers reported that they were the only person responsible for managing the patient's pain and that this aspect of care was a distressing experience for them.

The decision-making process contributed to the challenges experienced by informal cancer caregivers when utilizing pain relief strategies (Oliver et al., 2013). For example, a study which focused on the experiences of hospice caregivers in the United States of America found that caregivers had trouble finding medication that provided the patient with adequate pain relief. In addition, these caregivers reported that determining the correct dosage of medication was a challenging aspect of managing the patient's pain (Oliver et al., 2013). Furthermore, the caregivers reported that they struggled to meet the time requirements to administer the patient's medication. They reported that the patient's noncompliance in accepting the medication added to the factors that contributed to their challenge of trying to manage their pain (Oliver et al., 2013). In addition to these challenges, witnessing the patient in pain was also found to be a distressing experience for informal cancer caregivers (Oliver et al., 2013).

While some informal caregivers may struggle to provide effective pain relief strategies, other informal caregivers may be hesitant to implement these strategies (Chi et al., 2018; Kusi et al., 2020; Wittenberg-Lyles et al., 2011). This can, in turn, affect the patient's comfortability during their illness trajectory (Chi et al., 2018; Kusi et al., 2020). For example, a study conducted with informal caregivers in the United States of America found that the participants feared administering pain relief medication to the patient because they believed that in doing so, they would be assisting the patient with death by suicide. The participants also reported that administering pain medication may hasten the timeline of the patient's death (Chi et al., 2018). Consequently, some of the caregivers in this study were unwilling to provide the patient with pain medication. Furthermore, some caregivers reported that they preferred the patient be alert instead of sedated which contributed to their unwillingness to provide the patient with pain medication (Chi et al., 2018).

Similar to the previous study discussed, the participants in Kusi et al.'s (2020) study reported that they were apprehensive about providing patients with prescribed medication. They reported that they only provided the patient with medication when the patient's pain became unbearable. This was due to the caregivers fears of addiction, hallucinations, and sedation. However, they also reported that when they provided the patient with medication

and it was unsuccessful in alleviating the patient's pain, then they increased the patient's dosage (Kusi et al., 2020).

As illustrated in these studies, informal cancer caregivers experienced challenges when trying to manage the pain experienced by cancer patients. As mentioned, caregivers were hesitant to provide patients with prescribed medication, with some struggling to determine the correct dose for the patient. Some caregivers however, increased the dose of medication depending on how effective they perceived the medication to be. These studies suggest that informal caregivers may be ill-equipped to manage the patient's pain and may need assistance, information, and training from HCPs.

2.6. The importance of supportive resources

Support may aid in the caregiver's experience of providing care. Studies have shown that family members and friends provide informal caregivers with emotional, financial, or practical support (Adejoh et al., 2021; Streid et al., 2014; Wells et al., 2008). Some of the ways in which caregivers experience support from family members include assistance with transport, childcare, and financial contributions (Wells et al., 2008).

Recent studies have also highlighted various ways in which families provide support for informal cancer caregivers (Adejoh et al., 2021; Streid et al., 2014). For example, the informal caregivers in Streid et al.'s (2014) study reported that their families provide food, medication, and necessities for the patient if they have the financial means to do so. In addition, the caregivers reported that some of their family members extended their support by gathering information about the patient's disease and sharing it with their caregivers (Streid et al., 2014).

Innovative methods of providing support were also highlighted by informal cancer caregivers in Adejoh et al.'s (2021) study. For example, the participants reported that their family or community members created fundraisers to generate funds for the patient's cancer treatment (Adejoh et al., 2021).

Although studies have pointed to informal caregivers receiving support, studies also show that informal caregivers provide their family members with support (Arian et al., 2017; Streid et al., 2014). This was evident in the study conducted by Arian et al. (2017) with informal caregivers who reported that they were concerned about other members of their family who were close to the patient. For this reason, some of the participants reported that they appeared strong and happy whenever they were in the presence of their family (Arian et al., 2017).

A lack of support from friends and family can, however, exacerbate the challenges experienced by informal caregivers. For example, in a study conducted by Lopez et al. (2012), male caregivers reported that they had insufficient knowledge about the needs of the patient yet, the support of their family and friends were non-existent. The lack of support from family and friends contributed to the participants experiences of loneliness and isolation.

The length of time spent with the cancer patient may also contribute to the feelings of loneliness and isolation experienced by informal caregivers. For example, in Stenberg et al.'s (2012) study, informal caregivers spent sufficient time in the patient's presence which often prevented them from seeing their family and friends. On the occasions that these participants were able to visit their support networks, they used the opportunity to speak about their challenges. However, the participants reported that they were shown little support from their family and friends.

Partners may, at times, find it difficult to discuss their emotions regarding providing care. This was described in Oldertrøen Solli et al.'s (2019) study with men who had wives with cancer. These caregivers reported that they found it challenging to share their experiences with their male friends who were not dealing with the similar circumstances. While some of these caregivers experienced support, others reported that they experienced abandonment during the patient's illness trajectory.

The studies discussed in this section focused on the supportive resources that informal caregivers received from their friends and family. As illustrated in some of the studies, some informal caregivers received emotional, financial, and material support from their loved ones. However, some studies also highlighted the lack of support experienced by informal caregivers. As indicated in this section, when informal caregivers could not depend on their support networks, it added to the burden that they experienced and subsequently, elicited feelings of loneliness and isolation.

2.7. Spirituality

Research suggests that spirituality forms an important part of the caregiver's life during the patient's illness trajectory (Arian et al., 2017; Doumit et al., 2008; Maree et al., 2018; Sercekus et al., 2014). For example, in a study conducted by Sercekus et al. (2014), most informal caregivers viewed God as their confidant. The caregivers reported that they communicated with God through prayer and confided in Him when they experienced sadness (Sercekus et al., 2014).

In addition to informal caregivers viewing God as their confidant, studies have also found that informal caregivers viewed God as their source of strength (Cai et al., 2021; Doumit et al., 2008; Maree et al., 2018). In the study conducted by Doumit et al. (2008), the participants reported that they relied on God during the patient's illness trajectory. In addition, the participants tried to make sense of the patient's diagnosis through spirituality. For example, the participants also reported that they believed that God gave the patient cancer and as a result, they accepted the patient's diagnosis (Doumit et al., 2008).

Similar to the beliefs described by the participants in Doumit et al.'s (2008) study, the participants in Wells et al.'s (2008) study reported that God was in control of the health and progress of the patient. The participants also stated that HCPs operated under the guidance of God. Furthermore, the participants reported that they believed God made the decisions in the patient's life (Wells et al., 2008).

In a recent literature review, it was found that some informal caregivers believed in the power of prayer (Cai et al., 2021). In two of the six studies included in the literature review, it was found that informal cancer caregivers prayed that the patient experienced an early recovery or that the cancer was in remission. In one of the studies, it was further found that the caregivers did not lose hope when the patients did not recover but instead continued praying by means of prayer camps or fasting (Cai et al., 2021).

As illustrated in this section, spirituality plays an important role in the lives of some informal cancer caregivers. As mentioned, some caregivers believed that God either caused the patient to have cancer or that God was in control of the patient's health outcomes. Most of the caregivers in these studies relied on prayer as their way of communicating with God. Some participants reported that they confided in God and others asked God to heal the patient. While spirituality was considered a coping strategy for informal cancer caregivers (Maree et al., 2018), these findings suggest that the caregiver's relationship with God was a source of comfort and support during the patient's illness trajectory.

2.8. Communication between informal cancer caregivers and HCPs

The communication between informal caregivers and HCPs are instrumental in caregivers fulfilling their roles as efficiently as possible (Barlund et al., 2021; Hashemi et al., 2018). For example, in a study conducted with bereaved family caregivers in Norway, it was reported that informal caregivers felt seen when HCPs acknowledged their presence (Barlund et al., 2021). However, the caregivers reported experiencing feelings of insecurity when HCPs provided them with insufficient information. Some caregivers also reported that they

experienced feelings of insecurity when HCPs did not present information in a timely manner (Barlund et al., 2021).

For informal caregivers of terminal cancer patients, the challenges in communication with HCPs can influence their caregiving abilities (Stilos et al., 2018). In a study conducted by Stilos et al. (2018), the effects of communication challenges were highlighted by informal cancer caregivers. The caregivers reported that they had questions that they wanted to ask the HCPs, yet they were unable to reach them. Consequently, the caregivers reported feeling abandoned by HCPs when they were inaccessible (Stilos et al., 2018). In addition, the caregivers expressed experiencing challenges when seeking information from HCPs about their preparations and expectations related to the patient's impending death (Stilos et al., 2018).

Similar needs were expressed in Hashemi et al.'s (2018) study with informal caregivers of terminal cancer patients in Iran. Caregivers asserted that HCPs had a responsibility to provide them with adequate information regarding the trajectory leading up to the patient's death (Hashemi et al., 2018). By providing adequate information, caregivers would be realistically prepared for what they had to face. In Hashemi et al.'s (2018) study, informal caregivers expressed the need to receive training to prepare them for a patient's end of life stage. They highlighted key areas that training courses could focus on such as pain management, feeding and washing the patient (Hashemi et al., 2018).

Research suggests that consistent information is important to informal caregivers (Nissim et al., 2017). In a study conducted with informal caregivers of advanced cancer patients in Canada, participants reported that if HCPs communicated with them consistently, they would receive the necessary guidance that they need at different points in the patient's illness trajectory (Nissim et al., 2017). This, the caregivers reported, would help them make informed decisions regarding the patient's care. This suggestion was made because caregivers reported that HCPs overloaded them with information at once yet very seldomly repeated the information during the different stages of the patient's illness trajectory (Nissim et al., 2017).

If informal caregivers are not provided adequate information and guidance, it may not be helpful for the patient. For example, in a study conducted in Greece by Germeni and Sarris (2015), some participants reported that they were inadequately prepared for their role by HCPs. Consequently, the participants opted to learn by means of trial and error. Caregivers who had access to family members who worked in the healthcare sector or other cancer caregivers sought information and help from them (Germeni & Sarris, 2015). The participants

reported that the lack of sufficient information received from HCPs elicited emotions such as helplessness and anxiety (Germeni & Sarris, 2015).

In addition to communication, the way in which HCPs and caregivers interact also plays a role in their relationship dynamic and the way in which caregivers perceive the caregiving role (Gilbert et al., 2010). For example, informal caregivers reported that HCPs who displayed kindness and accessibility elicited feelings of empowerment from the caregiver. The positive interactions with HCPs allowed them to feel in control of their caregiving responsibilities. However, caregivers who experienced inadequate information from HCPs regarding test results, caregiver tasks, supportive resources and the potential for disease progression reported feeling neglected by the healthcare system (Gilbert et al., 2010).

As described in these studies, informal caregivers expressed a need for HCPs to communicate with them about the patient's needs in a timely and consistent manner. Since many informal caregivers do not have the required training that HCPs and nurses have, some caregivers also suggested training or easier access to HCPs to answer their questions. These studies have highlighted that insufficient information and the quality of the interactions between HCPs and caregivers affected their perceptions regarding their ability to provide care.

2.9. Relationship dynamics between the informal caregiver and the cancer patient

The relationships dynamics change when a family member or partner takes on the role of providing care for a cancer patient. In previous studies, caregivers reported that the patient's personality changed or that they experienced mood swings (Maree et al., 2018; Sercekus et al., 2014; Ussher et al., 2011). Adjusting to these changes affected the relationship, and particularly, communication between the caregivers and the patients (Maree et al., 2018; Ussher et al., 2011). For example, in a study conducted with family cancer caregivers in South Africa, the participants reported that they had to deal with the negative emotions and behaviours that the patients displayed. These behaviours and emotions included anger, manipulation, and blame (Maree et al., 2018). These emotions were often directed towards the caregivers who, in turn, experienced thoughts of abandoning the patient (Maree et al., 2018).

In a study conducted with informal cancer caregivers in Australia, caregivers admitted to experiencing anger when the patient was experiencing mood swings (Ussher et al., 2011). However, the caregivers reported that they often silenced this emotion to avoid conflict with the patient. Furthermore, caregivers reported that they tolerated and accepted the patients negative moods because they believed that the patient changed because of their disease

(Ussher et al., 2011). Some caregivers did however, express their annoyance or anger towards the patient when confronted with the patient's mood swings. The caregivers reported that when doing so, the patient made them feel guilty for their emotional responses (Ussher et al., 2011).

In addition to changes in mood, communication can be challenging during the patient's illness trajectory. A study conducted by Goldsmith and Miller (2015) found that some couples communicated about medical facts and information rather than their emotions. One of the reasons reported by these participants were the notion that it helped them feel in control of the patient's diagnosis. Some couples also reported that discussing their emotions would not change the diagnosis and therefore, they perceived it as unnecessary.

An additional barrier that affected effective communication was the caregiver withholding their emotions from the patient. In the study conducted by Nissim et al. (2017), the caregivers reported that they experienced fear but withheld their emotions from the patient to ensure that the patient experienced positivity (Nissim et al., 2017).

Despite the challenges caregivers experienced when communicating with the patient, studies have also shown that caregivers experience empathy when witnessing the patient in pain (Doumit et al., 2008; Streid et al., 2014). Informal caregivers have reported that when they witnessed the patient in pain, they experienced their pain with them (Doumit et al., 2008; Streid et al., 2014). Some caregivers who reported experiencing pain when witnessing the patient in pain expressed their desire to take the pain of the patient upon themselves (Streid et al., 2014).

The studies described in this section indicate that the caregivers found it difficult to adjust to changes in the patient's mood and personality. However, some caregivers withheld their own anger or frustration because they attributed the changes of the patient to their disease. In addition, some caregivers avoided expressing their emotions with the patient because they either deemed it unnecessary or wanted to be positive around the patient. These studies suggest that changes in the relationship dynamic between caregivers and patients may affect the caregiver's well-being. Nevertheless, these studies have found that caregivers experience empathy while providing care for the patient.

2.10. Positive aspects of being a cancer caregiver

Cancer has the potential to change the mindset and outlook of caregivers and strengthen their relationships with others. A study has found that informal caregivers experienced fulfilment with the caregiving role, expressed appreciation for their own health and experienced happiness while being present with their loved ones (Leow & Chan, 2017).

In addition, informal caregivers reported that their bond with the patient was strengthened during the cancer experience (Stenberg et al., 2012). Furthermore, the participants reported that they also experienced more empathy and compassion for other (Stenberg et al., 2012).

The relationship between partners can also be positively affected because of the patient's illness trajectory. For example, male caregivers reported that the patient's illness trajectory caused them to become more vulnerable with the patient which enhanced their relationship (Oldertrøen Solli et al., 2019). In addition, the caregivers reported that they were able to learn more about the patient during their illness trajectory (Oldertrøen Solli et al., 2019). They further stated that, these positive changes in their relationship may not have happened had they not endured a life-changing event together (Oldertrøen Solli et al., 2019).

In these studies, caregivers indicated an appreciation for their health, a deeper connection with the patient and empathy and compassion for others. These studies suggest that the perspective of caregivers change when they provide care for a loved one and that personal growth may take place.

2.11. The effects of the pandemic on informal cancer care

The COVID-19 pandemic has impacted the world immensely. For those living with chronic diseases such as cancer, it increased the risk of compromising the health and well-being of cancer patients and their informal caregivers (Salha et al., 2022). In the context of hospitals and cancer centers, van de Haar et al. (2020) asserted that HCPs had a responsibility to prevent cancer patients from being exposed to COVID-19. As such, van de Haar et al. (2020) reported that seven cancer care centres in Europe restricted access to their facilities by conducting telephonic or web-based consultations and delaying surgeries or follow-up appointments that were not deemed as urgent. In addition, informal caregivers were also denied access to enter their centres (van de Haar et al., 2020). Many countries adopted these restrictions, including South Africa. However, the consequences of a lack of adequate access to healthcare increased the responsibilities experienced by informal caregivers (Su et al., 2021). Informal caregivers not only had to process the effects of the pandemic, but also had to manage the needs of the patients while focusing on their own physical and psychological needs. In addition, lockdowns, social distancing and isolation may have exacerbated the challenges that informal cancer caregivers experienced (Su et al., 2021).

It is important to acknowledge that cancer patients are a high risk population regarding infections, thus contracting COVID-19 can have adverse effects on their physical and psychological well-being (Salha et al., 2022). Consequently, informal caregivers had the

increased burden of ensuring that they did not contract the virus as that may have placed the patient's life in danger (Egan, 2020).

In a study conducted by Akkuş et al. (2022), with 250 informal caregivers, 76% expressed concern that they could contract the virus and 82% expressed concern regarding the patient potentially contracting the virus. In addition to this finding, the four main areas that caregivers found challenging were the lack of access to hospitals, insufficient contact with HCPs, the challenge of obtaining equipment such as masks and delays or challenges relating to the continuation of the patient's cancer treatment (Akkuş et al., 2022).

While studies exploring the health and well-being of informal cancer caregivers during the pandemic are limited (Cohen et al., 2021), a study conducted by Amaniera et al. (2021) with informal cancer caregivers in the United States of America, reported that they experienced isolation from their social networks which negatively affected their mental health. Additional factors such as financial strain and insufficient access to food also negatively affected the caregivers mental health and contributed to their feelings of isolation.

It is evident that the pandemic has added to the responsibilities and challenges experienced by informal cancer caregivers. Yet, more studies need to be conducted to understand the experiences of informal cancer caregivers during and after the pandemic. This is particularly important as the long-term impact of COVID-19, particularly on the health and well-being of informal cancer caregivers is yet to be known.

2.12. Theoretical Framework

2.12.1. Bronfenbrenner's ecological system's theory

In the ecological system's theory (EST), Bronfenbrenner (1979; 1986) proposes that there are five systems that an individual forms part of. Each system affects not only the individual's life but also their interactions with others.

The first system namely, the microsystem refers to the individual's closest social network as well as the responsibilities that form part of their daily lives (Bronfenbrenner, 1979). This includes romantic relationships, relationships with friends and family, the individual's relationships with work colleagues and their involvement in religious activities.

The mesosystem refers to the way in which different settings within an individual's microsystem are interrelated (Bronfenbrenner, 1979). In this system, the individual is exposed to multiple contexts within their microsystem which represent different ideologies, information, and expectations. For example, an individual's school rules may not be the same as their parent's rules. In the same way, an individual's friends may not have the same ideologies as the church.

The exosystem consists of rules and regulations within formal and informal structures that affect the individual directly but with whom the individual does not have direct contact (Bronfenbrenner, 1979). In other words, an individual does not have control over these policies despite it influencing their lives. These include work policies, and rules and regulations in hospitals.

The macrosystem refers to the economic, political, and cultural systems and ideologies that not only affect the individual but also serves as the blueprint for how each of the former social systems are navigated (Bronfenbrenner, 1979). These ideologies also affect every individual within a country. This includes, poverty, economic recessions, societal expectations of men and women and culture.

Lastly, the chronosystem refers to significant changes that occur during an individual's lifetime (Bronfenbrenner, 1986). These include historical events, environmental changes, and instrumental life transitions.

2.12.2. Applying the theoretical framework to this study

Bronfenbrenner's (1977; 1986) EST is an appropriate theoretical framework to use to understand the experiences of gynaecological cancer caregivers and how the role of caregiving can impede on various aspects of the caregiver's quality of life.

Since the microsystem focuses on the relationships and structures that form part of the individual's life on a regular basis, I explore how caregivers experience their relationship with the patient. In addition, I explore how providing care has affected their responsibilities, their jobs, their relationships with their families and friends and the supportive resources available to them.

In terms of the mesosystem, the caregiver is exposed to multiple contexts and fulfils multiple roles daily. Subsequently, the caregiver is exposed to different ideologies, information, and expectations. Thus, I explore how caregivers balance these expectations and ideologies.

In terms of the exosystem, the rules and regulations at hospitals and the caregiver's workplace may affect the caregiving role. Thus, I explore the caregivers experiences of the public healthcare system. I also explore employed caregivers perspectives regarding the possibility of being fired.

In terms of the macrosystem, the economy, poverty, societal ideologies, and cultural views of caregiving are factors that may also affect the caregiver's role. Thus, I aimed to explore how these factors influenced the caregiving role.

In terms of the chronosystem, the current COVID-19 pandemic is an applicable life event that has changed the lives of cancer patients and their respective caregivers. Consequently, I explore how this pandemic has affected the lives of informal gynaecological cancer caregivers.

2.13. Conclusion

In this chapter, I discussed various aspects that contribute to care and the way in which it can affect the lives and the health of informal cancer caregivers. These aspects included the increasing roles of informal cancer caregivers, managing the patient's pain, communication between HCPs and informal caregivers as well as the relationship dynamics between informal caregivers and cancer patients. In discussing these aspects, the findings highlighted that informal caregivers experience personal costs such as changes in employment status, changes in their social lives, the possibility and consequences of experiencing financial constraints and the physical and emotional impact of providing care.

Additionally, I highlighted the importance of support for informal cancer caregivers and described the role of spirituality as a source of comfort and support for these caregivers.

Lastly, I provided context on the effects that the pandemic may have had on informal cancer caregivers. The studies however, were limited and the long term effects of the pandemic, particularly related to the health and well-being of informal cancer caregivers is unknown.

Chapter 3

Research Methods

3.1. Introduction

In this chapter, I discuss the research methods utilized in this study. Firstly, I describe the research design, recruitment procedure, data collection procedure, data analysis and trustworthiness of this study. Thereafter, I provide a reflexive account of my experience conducting this research study. Lastly, I discuss the ethics that were adhered to while conducting this research project.

3.2. Research Design

I utilized an exploratory design for the research topic. Exploratory research aims to increase knowledge and provide an in-depth understanding of phenomena that have not been examined extensively (Stebbins, 2001). My reason for choosing an exploratory study stemmed from the lack of research that has been conducted on the experiences of informal caregivers of gynaecological cancer patients globally and in South Africa. Gynaecological cancer, particularly cervical cancer is the second most prevalent cancer diagnosed among women in South Africa (CANSAs, 2020). Thus, it is important to become aware of the needs of their caregivers as this will benefit both the caregiver and the patient.

The context of the pandemic also added to the uniqueness of caring for a cancer patient in South Africa. Currently, limited studies exist which focus on the experiences or the effects of providing care for advanced or terminal cancer patients during the pandemic. Thus, an exploratory design best suited this study.

In addition, I decided to conduct a qualitative study because it allows participants to share their subjective accounts of a particular phenomenon (Yilmaz, 2013). By choosing a qualitative research study, my goal was to provide participants with a platform to voice their experiences. This in turn, provided me with insight into various subjective realities regarding the caregiving experience.

3.3. Participants

There were several inclusion and exclusion criteria in this study. The caregivers who were eligible to participate in this study were unpaid individuals who provided most of the care for a gynaecological cancer patient in the advanced or terminal stage of their disease. In addition, it was important for patients to identify who they considered their primary caregiver. Thus, caregivers were only included in the study if the patients identified them as the individuals who provided them with the most assistance.

Thorough in-depth accounts were important in this study. For this reason, participants were required to provide care for a minimum of one month to be eligible to participate in the study. This requirement stemmed from the need to have enough caregiving experience with the patient to provide detailed accounts. The reason for the minimum requirement of one month was due to the nature of the disease. Because the patients were in the advanced or terminal stage of their disease, it was unlikely to determine when the patient would pass away. Thus, it was important not to place an unrealistic period on the caregiver's time with the patient.

In addition, participants who could speak and understand English or Afrikaans were eligible to participate in the study. The reason for the language criterion was due to the fact that I conducted the interviews myself and had to limit the interviews to the languages that I can communicate in.

The participants that were excluded from this study were caregivers who received compensation for providing care for the patient such as nurses and HCPs.

3.4. Recruitment procedure

Before I recruited participants, my co-supervisor, Professor Hannah Simonds, introduced me to the doctors, nurses, and receptionist in the gynaecological cancer clinic at an academic tertiary hospital. The reason why my co-supervisor introduced me to the other HCPs and nurses were to create awareness about my study and for them to be aware of potential participants.

Prof Simonds asked me to visit the clinic every Tuesday to meet patients who fit my inclusion criteria. Every Tuesday morning, after I entered the clinic, my co-supervisor would scan the files of each cancer patient to check if any patient had gynaecological cancer and whether the patient was in the advanced or terminal stage. If my co-supervisor was not in the clinic, the other HCPs would scan the files to identify patients whose caregivers may be potential participants. When patients who fit this criterion were identified, we discussed the best method to inform patients about the study. For example, patients who had early consultations met with HCPs first and finished their consultations. After the consultation, the HCPs told patients about my study and asked them if they wanted to be introduced to me and listen to my information on the study. If the patients agreed, I took them to a private office which provided me with a quiet space to introduce myself and discuss the study.

Patients who were waiting for long periods at the hospital, particularly with their caregivers were also told about my study by the nurse who specifically worked in the

gynaecology cancer clinic. It is important to note that caregivers were only allowed into the clinic for reasons such as an important conversation with a HCP or if the patient needed assistance with entering the hospital. The caregivers were then asked if they wanted to be introduced to me and discuss the details of my study. If the caregivers agreed, then the nurse introduced me to the caregiver. Thereafter, I took them to a private office which provided me with a quiet space to introduce myself and discuss the study.

If the caregivers were not present at the hospital and the patients were waiting for their consultations with HCPs, then the nurse identified patients with potential caregivers who suited my inclusion criteria. She was able to do this because of her relationship with the patients. When she identified patients with caregivers, she explained my study to them and asked if they wanted to be introduced to me and listen to the details of my study. If a patient agreed, she called me and introduced me. Thereafter, I took the patient to a private office which provided me with a quiet space to introduce myself and discuss the study.

An additional strategy included my supervisor or HCPs identifying patients by scanning their files and informing me of the potential patients that I could speak to. Thereafter, I called the patient's name and introduced myself. After introducing myself, I asked them if they wanted to speak with me in a private office about my research study. If they agreed, then they joined me in a private office to discuss the details of the study.

On the days that I was not at the hospital, my co-supervisor suggested that I leave my leaflets in the secretary's office so that HCPs were able to hand out the leaflets to patients with potential caregivers who suited my inclusion criteria. For this reason, I left my leaflets in the secretary's office for the entire period that I was granted permission to recruit participants at the hospital.

After the patient entered the office, I introduced myself, explained my study and handed them the leaflet (see Appendix A). Thereafter, I asked if there was someone who provided them with assistance and care. If they said yes, I proceeded to ask them to hand the leaflet to their caregiver. In addition, I asked them to ask their caregiver if they were interested in learning more about the study and possibly participating.

I also asked patients if they were comfortable to give me their number or the caregiver's number so that I could explain the study to the caregiver myself. This was done for two reasons. The first reason was based on the financial situation of the patient. Most patients told me that I needed to contact the caregiver myself because they did not have airtime or data to contact me by means of a phone call, WhatsApp, or SMS. The second reason was based on the rules and regulations of the hospital. While I was recruiting

participants, the caregivers were not allowed to be in the hospital because of the COVID-19 pandemic. This meant that many caregivers either waited outside for the patient or were waiting for the patient at home. If caregivers could not attend the patient's consultations, the hospital transport services would fetch the patient, or the patient would travel alone by means of a taxi or bus. Thus, the best way to communicate and explain the study to them was to contact them telephonically.

Patients agreed to give me their or the caregiver's number and told me that they would hand the leaflet to their caregiver and speak to them beforehand so that their caregivers could expect my call. When I called the potential participants telephonically, I introduced myself and asked the caregivers if they were willing to hear more information regarding my study. At this point, the caregivers either politely declined or agreed to listen to me. The caregivers that were interested allowed me to explain the goals of the study, the requirements of the study and what participation entailed. I then asked the caregivers if they wanted to take part in an interview with me. If a caregiver said yes, then we agreed on a day and time that best suited their availability.

In addition to recruiting at an academic tertiary hospital, I also tried to recruit participants through the Cancer Association of South Africa (CANSA). I contacted CANSA and asked permission to advertise my study on all their social media platforms. Once I received ethical approval for my study, they provided me with permission and proceeded to post my leaflet (See Appendix B) on their Facebook, LinkedIn, and Twitter accounts as well as their official website. The leaflet for this study remained on their website for a year. However, no potential participants contacted me during this period. For this reason, all the participants included in my study were recruited from one academic tertiary hospital.

3.5. Determining the sample size

The sampling methods used to recruit participants for this study were purposive and convenience sampling. Purposive sampling is utilized when a researcher aims to recruit participants that meet the requirements of the study (Etikan et al., 2016). I chose to use purposive sampling because it allowed me to focus on the informal caregivers who fit within the inclusion criteria of the study. This narrowed down the caregivers that I approached or contacted. Thus, I only approached and explained my study to patients who had advanced or terminal gynaecological cancer. This allowed the patients to understand that their caregivers were suitable for my study. In this way, purposive sampling made the process of searching for candidates successful and time efficient.

Convenience sampling is utilized when participants who are eligible for the study are easily accessible or are available at a particular time and place (Etikan et al., 2016). I chose convenience sampling because it allowed me to meet and approach caregivers at the hospital. If caregivers were not at the hospital, this sampling strategy allowed me to approach patients and explain my study to them. The communication with patients took place at a convenient place and time namely, the hospital on the days that they had consultations with HCPs.

Initially, I intended to recruit 20 participants for this study. However, many gynaecological cancer patients were not at the advanced or terminal stage during my data collection period at the hospital. Nevertheless, after 15 interviews, there were no new themes that emerged from the data. After the 15th interview, I conducted two more which increased the sample size to 17 participants. One of the interviews, however, was not included in my study because of problems with signal and the inability to hear the participant clearly. Therefore, the sample size of this study is 16 participants.

3.6. Data collection procedure

I collected data by conducting individual semi-structured interviews. I utilized semi-structured interviews because I was able to focus on various points of inquiry in a manner that was flexible (DeJonckheere & Vaughn, 2019).

I informed the caregivers that they could attend the interview with one of three mediums: a) telephonically, b) on a social media platform such as Zoom, Skype, Microsoft Teams or WhatsApp, or c) in person either at the hospital, their home, their workplace or in an office in the psychology department at Stellenbosch University. I informed the caregivers that I would reimburse their travelling expenses should they choose to attend in person interviews in one of the offices in the psychology department or in one of the offices at the academic tertiary hospital. I also informed the participants that reimbursement for travelling to the hospital would only take place if the interview was scheduled on a day and time that the patient was not scheduled for a consultation.

If South Africa had a level, 3, 4 or 5 lockdown restriction during the period of data collection, I informed the caregivers that face-to-face interviews were not a viable option. This was to protect the caregiver and patient from potentially contracting COVID-19 because of the interview.

Lastly, I informed the participants that I would reimburse their data expenses should they choose to attend the interviews on a social media platform. However, most of the caregivers preferred telephonic interviews. The reasons for telephonic interviews were a) not

being able to leave the patient to do a face-to-face interview, b) wanting to minimise the risk of contracting COVID-19 and c) not having a smartphone to do interviews on social media platforms. Thus, one interview took place in person at the hospital on a day and a time that the patient was scheduled for chemotherapy. The other 15 interviews were telephonic interviews.

As a result of most of the interviews being telephonic, I read the consent forms on the phone. Prior to the interview, I discussed the requirements and their rights as research participants. I also asked the participants if they were certain that they wanted to take part in the study. Thereafter, I asked them if they understood the consent form. If they agreed that they understood the consent form then I asked for their permission to record the interview. Once they said yes, I asked them if they agreed that I can ask them the same questions on the audio-recording device so that there could be a record that they agreed to participate in the study. All the participants said yes. When they said yes, I let them know that I started the recording and asked them: a) if they agreed that I explained the consent form to them, b) if they understood the consent form and c) if they gave me permission to record the interview. If they said yes to all these questions, I proceeded with the interview. The length of each interview ranged between 25 minutes to 120 minutes. In each interview, I used an interview guide which consisted of 14 questions (See Appendix G). Each participant was asked the same 14 questions. Informal prompts were also used as this provided more detail on some of the subjective accounts of the participants. In addition, informal prompts also allowed for a deeper understanding of their experiences.

3.7. Data analysis

Before I analysed the data, I transcribed each audio recorded interview verbatim. Once I completed the transcripts, I used the six phases of reflexive thematic analysis outlined by Braun and Clarke (2019).

The first phase entailed familiarisation (Braun & Clarke, 2019). In this phase, I became familiar with the data by transcribing all the interviews myself. I also read the transcriptions once I completed them which helped me to further immerse myself in the data.

The second phase entailed generating initial codes (Braun & Clarke, 2019). In this phase, I first uploaded my interview transcripts to Atlas ti, a computer software that aids in the coding process for qualitative research. Once my transcripts were uploaded, I coded each interview inductively. This was done by reading each transcript and creating labels to relevant sentences and paragraph that best described those sentences or paragraphs. I coded

the data by focusing on the experiences of the caregivers in each interview, rather than using pre-existing codes to guide the coding process. However, when coding the data, I already read articles on the experiences of cancer caregivers extensively. For this reason, I must acknowledge that I was not coding within a vacuum. Thus, I used both an inductive and deductive approach when I coded the data. However, to code as inductively as possible, I had weekly meetings with my supervisor who listened to the interviews and read the transcripts. My supervisor also oversaw the initial codes that were being generated. The interviews were coded semantically, and the total initial codes amounted to 325 codes.

The third phase entailed generating initial themes (Braun & Clarke, 2019). In this phase, I combined, merged, and linked all the codes that were similar and formulated various code groups. Each code group had their own name which focused on a particular and recurrent overarching code. Under each code group were subcodes with their own names and data linked to the main code. These code groups helped me organise the data, notice patterns within the data and groups similar patterns together. After organising the data, the initial codes of 325 were reduced to 177 codes. Thereafter, I drew a mind map to develop a full picture of the code groups and the patterns occurring within the data. This information allowed me to construct initial themes which I then discussed with my supervisor.

The fourth phase entailed reviewing the themes (Braun & Clarke, 2019). In this phase, I reviewed the names of my themes and consulted my supervisor to ensure that the themes and subthemes accurately described and reflected the data within their respective sections.

The fifth phase entailed defining each theme (Braun & Clarke, 2019). In this phase, I provided a descriptive name for each theme, all of which had been reviewed and approved by my supervisor.

The sixth phase entailed producing a report of the findings (Braun & Clarke, 2019). In this phase, I discussed the findings of my research by providing descriptive sections of information of the experiences of gynaecological caregivers in each theme. In addition, I discussed the findings in relation to prior studies on the experiences of informal cancer caregivers and in relation to the theoretical framework. To conclude the report, I discussed the limitations of my study and recommendations for further research on the topic of this study.

3.8. Trustworthiness

When qualitative research is undertaken, four principles should be applied to ensure the integrity of the research. These four principles are credibility, transferability, dependability, and transferability (Connelley, 2016).

Credibility refers to the methods that are utilized to ensure that the findings of the study is accurately represented by the researcher (Korstjens & Moser, 2018). In this study, credibility was maintained through the consistent observation and scheduled meetings with my supervisor (Connelley, 2016). In these meetings, we discussed the interview process, the findings of each interview and my own interpretations of the interviews. In addition to this, my supervisor monitored my data collection process and reviewed the codes of each interview (Shenton, 2004). Following the review of the generated codes, my supervisor and I had meetings discussing the codes. In addition to this, I consistently reviewed my interview transcripts to ensure that I interpreted the findings accurately (Korstjens & Moser, 2018).

Transferability refers to the extent to which the findings are applicable in different contexts (Korstjens & Moser, 2018). I applied the concept of transferability by describing the research process, the participants, and the context in which the study took place. These descriptions allow other researchers to understand and interpret the findings in the context in which the study took place and examine for themselves if this study is transferable in their context (Korstjens & Moser, 2018).

Dependability examines how stable and consistent the findings are over time (Korstjens & Moser, 2018). To ensure that the findings are dependable, I provided a detailed explanation of the methods utilized in this study (Shenton, 2004).

Confirmability is a principle based on ensuring that the findings are based on the data itself and not the subjective interpretation of the researcher (Korstjens & Moser, 2018). To ensure that this principle was met, I practised reflexivity to present and interpret the participants experiences as accurately as possible (Shenton, 2004).

3.9. Reflexivity

In this section, I reflect on my background and social position, my motivation for the study and the recruitment and data collection procedure.

I am a 24-year-old woman of colour born and raised in the Western Cape in South Africa. During my childhood, I became aware of the links between poverty, inequality and inequity and the effects that it has on the health and livelihood of people in South Africa. As I became older, my awareness regarding systemic issues and structural barriers and the impact that this has on an individual's health increased. This sparked my interest in health psychology.

I always knew that if I were to do a research project, it would focus on health and inequality. In my honour's year, I had to decide which supervisor I would choose based on the areas of research that they explored and that I was interested in. I chose my supervisor

because I was interested in exploring a study within the field of cancer research. While searching for a topic, I was drawn to gynaecological cancers because it was a group of cancers that were not spoken about within my community, friend groups or the schools I attended. For these reasons, I wanted to learn more about the effects of gynaecological cancer on the health and well-being of people. When I read articles about gynaecological cancer and the experiences of women living with these cancers, I learnt that women were often ostracised and stigmatised for this disease. However, I was unable to access sufficient resources regarding the support structures for these women. This made me curious as to whether women, particularly women in South Africa have people who provide them with care and support. When I tried searching for articles that provided the perspective and experience of caregivers of gynaecological cancer patients, limited studies appeared in my search engine. The articles I were able to find and read increased my curiosity regarding the experiences of gynaecological caregivers. For this reason, I decided to choose a topic that focused on cancer care and public health. I wanted insight into how systemic issues, poverty and cancer care affected the health and well-being of gynaecological cancer caregivers in South Africa. Additionally, I wanted to gain insight into the challenges that these caregivers experience and the type of supportive resources available to them.

Prior to collecting data, I thought that all the participants that were recruited at the academic tertiary hospital experienced challenges or poverty. I found that patients who do have medical aid or who are middle class also receive treatment at a public hospital because of how expensive treatment at private hospitals can be. However, majority of the participants that were in this study lived in low-resourced communities and experienced financial difficulties. Most of the participants and patients did not have smart phones, airtime to contact or message me and at times, struggled to accompany the patient to the hospital because of financial constraints. Many participants also reflected on two main concerns: a) ensuring that they had money to provide the patient with enough treatment supplies to treat their wounds and b) ensuring that there was enough food for the month. Many of these participants received very limited financial support while providing care for the patient. At times, particularly after an interview when the caregiver shared their financial concerns with me, I experienced various emotions. For one, I experienced sympathy for these caregivers because caring for someone who has cancer at such a delicate stage, having to maintain their own emotions around the patient and experiencing financial difficulties all at once is a very challenging task. However, I also admired these caregivers. I was in awe of the strength, resilience, positive attitude, and hope that they expressed. In addition, the unconditional love

that they expressed for the patient and their willingness to take on the caregiving role was truly inspiring. While sympathy and admiration were two of my core emotions after each interview, I could not help but feel disheartened by the systemic barriers that these caregivers faced. Nevertheless, I feel immense gratitude that the caregivers trusted me with their life experiences and that their perspective and their voices can be highlighted in this study.

While recruiting participants, I met many gynaecological cancer patients. There were many instances when I spoke to a patient who had advanced or terminal cancer who told me that they did not receive any support and that they took care of themselves. In other words, these were patients who did not have caregivers and were not eligible for my study. Upon speaking to my co-supervisor at the tertiary hospital, she told me that many women with gynaecological cancer do not receive support. Meeting and speaking to these patients every week was challenging and inspiring. It was difficult for me to see them struggle to walk or sit silently. It made me sad that they did not have support during their illness trajectories. Yet, they inspired and lifted my spirits every week during the recruitment process. I witnessed their strength and resilience. Many smiled and laughed with me and with each other. Witnessing how they supported each other and exchanged advice was truly encouraging.

The patients whose caregivers were eligible for my study inspired me as well. The eagerness with which they were willing to explain the study to their caregivers and have their caregivers stories told was remarkable. Having to recruit participants during a pandemic and having to ask the patients to hand their caregivers my leaflets because I could not meet the caregivers myself was one of the most difficult aspects of the recruitment process for me. However, I am grateful to these patients for being willing to pass on the leaflets, provide me with their or their caregiver's contact details and for sharing their enthusiasm regarding my study.

Like the recruitment process, the data collection process was difficult. Majority of the interviews were telephonic which proved to be challenging, particularly because of signal issues. While I wish I could have done the interviews in person, the context of the pandemic posed too big of a threat to conduct in person interviews. Many caregivers were worried about the well-being of the patient, and it gave me and the caregivers peace of mind to eliminate any potential possibility that the patient could contract COVID-19. Thus, I am grateful to the participants that they shared their stories with me, particularly under very challenging circumstances such as telephonic phone calls.

The stories of these caregivers have taught me many lessons in terms of selflessness, love and viewing care as a privilege rather than a burden. Again, I cannot express my

gratitude enough to these participants. They have truly contributed to the way in which I view the world, shaped my research experience, and fuelled my passion for social justice. Their stories have inspired me, and I hope their stories will inspire those who read it as well.

3.10. Ethical considerations

This study was approved by the Health Research Ethics Committee at Stellenbosch University (S21/04/075) (See Appendix D). Permission to conduct this study at Tygerberg Hospital was obtained by the Western Cape Department of Health (See Appendix E).

Prior to each interview, I explained the nature of the study, the requirements, the aim and objectives and the responsibilities of the research participants to each participant. In addition, I communicated on the leaflet and in person or telephonically that this study was confidential, voluntary, and independent of the academic tertiary hospital. Moreover, each participant was informed that their names would be replaced with a pseudonym to protect their identities.

In addition, and prior to the interview, I communicated to the participants that they were free to withdraw from the study at any point. The participants were also informed that they could refrain from answering questions that could cause them emotional discomfort. I also communicated verbally and on the consent form that neither the participants nor the patients would experience any negative repercussions should the participant decide to withdraw from the study.

In terms of safety precautions, the one participant who attended a face-to-face interview was required to wear a mask and sanitize their hands before entering the office in which the interview was conducted. The office itself was clean and sanitized. In addition, the chairs of the participant and myself were 3 meters apart before, during and after the interview. The participant also received snacks after their face-to-face interview. All the snacks were packaged and opened directly by the participant before they consumed them.

As a result of most of the participants attending their interviews telephonically, all the participants provided verbal consent on the recording device. Before they provided verbal consent, I explained the consent form to these participants. Once they provided consent and with the permission of the participant, I started the recording and asked the participant to confirm that I have read the consent form to them, that they understood the information on the consent form and whether they agreed to have the interview recorded. Once the participants provided confirmation regarding the above-mentioned statements, we started the interview.

While the questions prepared for the interviews were not intended to cause the participants emotional distress, the contact details of the Welgevallen Community Clinic in Stellenbosch were provided to the participants (see Appendix H). I communicated to the participants that the counselling services of the Welgevallen Community Clinic was free of charge and that they had the option of online and in person counselling. In addition, each participant received the contact details of the South African Depression and Anxiety Group (SADAG) and Lifeline South Africa.

Initially, I indicated that each participant would receive a R100 Checkers voucher as a token of appreciation (see Appendix C). However, I made an amendment (see Appendix F) and received permission from the HREC to send the participants R100 CashSend because they lived too far to receive the Checkers voucher in person (see Appendix C).

I also requested an amendment to remove the requirement which stated that participants must live with the patient. This amendment request was approved by the HREC.

To protect and safeguard the data that was collected, the consent form of the only participant who attended a face-to-face interview with me, was locked in a cupboard in my supervisor's office. In addition, the data was stored in a folder on my laptop which is password protected. The data was also backed up on Dropbox to which only my supervisors and myself had access to. Since this study is completed, the data will be securely stored for five years. Thereafter, the data will be destroyed.

There were emotional and physical risks associated with this study. There was an emotional risk associated with sharing personal experiences as well as the physical risk of contracting COVID-19 through face-to-face interviews. While I have outlined strategies that I utilized to mitigate these risks, these factors made this is a medium-risk study.

3.11. Conclusion

In this chapter, I discussed the research design, recruitment procedure, data analysis and ethical considerations which formed the foundation of fulfilling the aims and objectives for this study. In addition to this, I reflected on my experience while conducting this research.

Chapter 4

Findings, Discussion and Theoretical Framework

4.1. Introduction

In this chapter, I present and discuss the findings of this study. Firstly, I provide an overview of the demographic information of the participants. Thereafter, I discuss five themes namely 1) navigating a complicated relationship with the patient: a caregiver's perspective, 2) the complexities associated between informal caregiving and the public healthcare system, 3) the effects of caregiving on the caregivers' health and well-being, 4) The support networks of informal cancer caregivers and 5) providing care in the context of a pandemic. Each theme has subthemes except for theme 5. After the findings of each theme are presented, I discuss the findings in relation to prior studies and apply the theoretical framework.

4.2. Demographic information of participants

The sample size of this study was 16 participants. The participants' ages ranged from 22 to 77 (see Table 1). Most of the participants in this study were adult children (n=7) providing care for their mothers diagnosed with a gynaecological cancer. Most of the participants indicated that they were unemployed (n=7) or retired (n=6). In terms of household income per month, most participants either reported that their household income was less than R2000 (n=4), less than R5000 (n=3), or less than R8000 (n=3). In addition, most of the patients were diagnosed with cervical cancer (n=8). Lastly, most of the patients had a terminal prognosis (n=13).

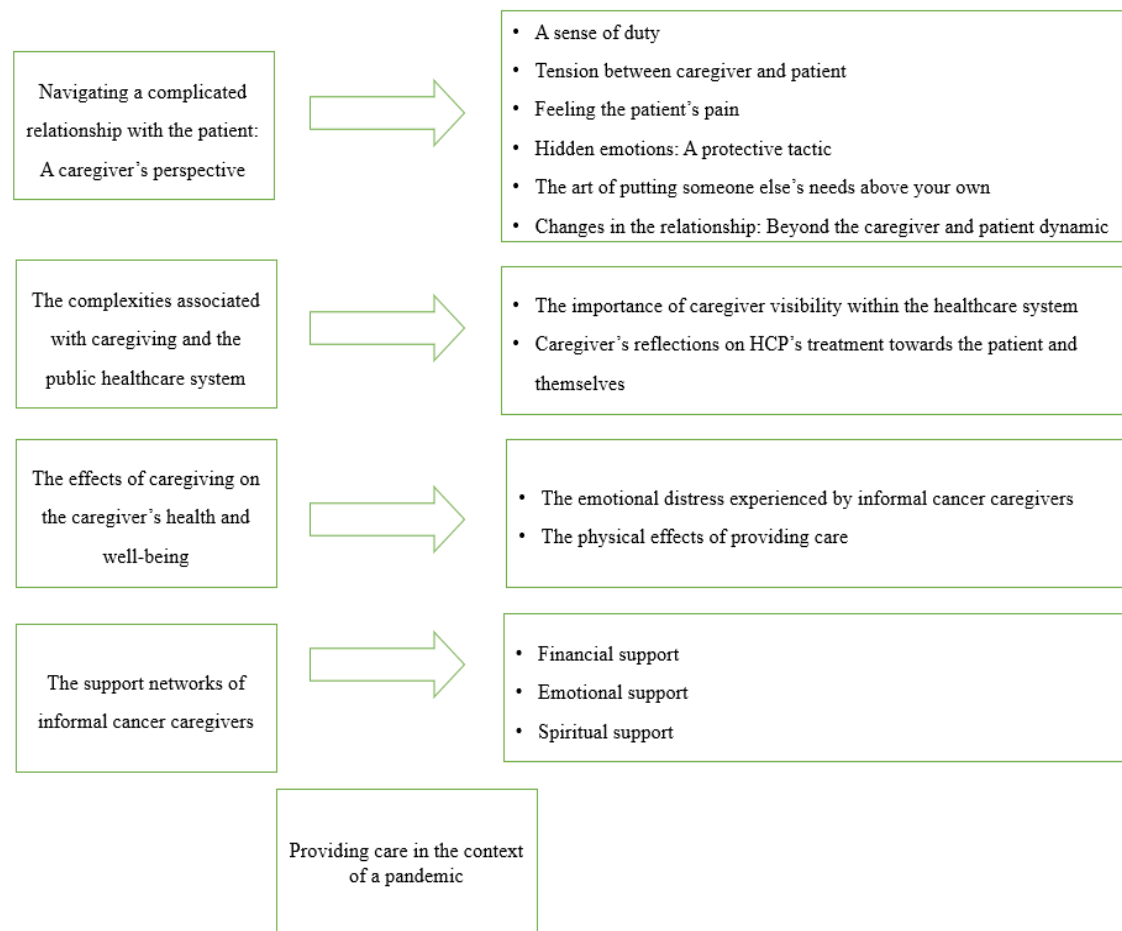
Table 1

Demographic information of participants

Description	Total
Age	
Not specified	1
20-30	2
31-40	3
41-50	3
51-60	2
61-70	3
71-80	2

Relation to patient	
Partner	4
Sibling	1
Parent/Parent-in-law	3
Adult child	7
Adult niece	1
Employment status	
Employed	3
Unemployed	7
Pensioner/Retired	6
Household income	
Not specified	1
Less than R2000	4
Less than R5000	3
R5000	1
Less than R8000	3
Less than R10 000	2
R10 000	0
Above R10 000	1
Above 15 000	1
Highest level of education	
Not specified	1
Completed primary school	1
Attended high school but did not complete matric	7
Completed matric	2
Attended university/technikon/college but did not graduate	1
Graduated from university/technikon/college	4
Number of children	
Not specified	1
0	3
1	1
2	6
3	2

4	0
5	3
<hr/>	
Type of cancer	
Cervical	8
Ovarian	4
Uterine (endometrial)	2
Vulva	2
Vaginal	0
<hr/>	
Prognosis	
Advanced	3
Terminal	13
<hr/>	
Treatment	
Not specified	1
Surgery	3
Chemotherapy	14
Radiation	6
<hr/>	

Figure 1*Themes and subthemes from the data*

4.3. Navigating a complicated relationship with the patient: A caregiver's perspective

Most of the participants reported that they experienced a complex relationship dynamic with the patients during their illness trajectories. This included changes in the nature of their romantic relationships and within relationships between parents and adult children. One of the main objectives reported by caregivers was placing the needs of the patient, the person whom they loved, above their own needs. For many of these participants, the patient was one of the most important people in their lives. Thus, they viewed caregiving as an important responsibility and for some, caregiving was considered an honour or a blessing. Many participants reported that their willingness to take on the caregiving role affected other aspects of their identity, well-being, and livelihood. They also reported on several difficulties that they experienced such as communicating with the patient, adjusting to their moods, and witnessing the patient in pain. Yet, most participants reported a deep connection with the

patient and expressed immense gratitude to have been present and at the patient's side throughout their experience with cancer.

In the section below, the various complexities that occur within the relationship between the caregivers and the patients are discussed from the caregivers' perspective. In this section, I describe the a) sense of duty experienced by informal caregivers, b) the tension between the patient and caregiver, c) the caregivers' experience of feeling the patient's pain, d) the caregivers' experience of hiding their emotions, e) the caregivers' experience of placing the needs of the patient above their own and f) the changes in the relationship between the patient and the caregiver.

4.3.1. A sense of duty

In this study, most of the participants reported that it was their duty to provide the patient with care. All the participants were related to the patient that they provided care and assistance for. These relationships ranged from mother, daughter, sister, aunt, and mother-in-law to romantic partners. The sense of duty that these participants experienced were based on a) the nature of their relationship with the patient, b) the patient's choice to be assisted by the respective caregiver, c) the caregiver's desire to be the patient's primary caregiver, and d) familial or personal beliefs about the concept of care and caregiving. Despite the sense of duty that was expressed, all the participants reported that it was their choice to be the primary caregiver of the patient. The nuances between experiencing a sense of duty and the choice to be the primary caregiver is expressed in the statement below:

"She [the patient] and my dad took me in [when she was in foster care], that time I was about 15, 16 years old [...]. There's no way I can repay my gratitude towards them. Of taking me in, opening their hearts and doors me for me, understand, that is also the reason why I did it." - Jazmin

In addition to this statement, in the interview Jazmin reported that her mother cried and told her that it was too much strain for her to be taking on the caregiving role. However, Jazmin disagreed. She explained that *"she needed my help and I needed to be there for her"*. This statement further illustrates that she wanted to provide her mother with support and that becoming her mother's caregiver was her choice.

Some participants reported that they became the patient's caregiver because there was no one else who could take on the caregiving role. This is indicated by Sarah, a 27-year-old daughter, who described how she became her mother's caregiver in the statement below:

"Uhm, basically I was working and then, uhm, with the chemo she got really sick and there was literally nobody. I'm the only daughter and my brothers are not like, I can't say not

that interested but they obviously can't take care of a female like a female would because uhm, at the time she would need my help to, bathing, someone to bath her, to give her, her medication, to feed her and obviously she can't take care of things around the house like cooking and cleaning so basically that just fell on me and that is how it started. Uhm... I had to leave my job, ja because of her, because there was nobody else that could do that for her." - Sarah

In this extract Sarah reflects on her experience of being the only person in her mother's life to assist her with her needs. Her statement suggests that she experienced a sense of duty to provide her mother with care. In addition, the extract highlights a gendered view of providing care. Her statement suggests that in her household women are tasked with providing care for each other regardless of their other responsibilities. Sarah's statement also appears to suggest that she may not have had much choice in becoming her mother's primary caregiver given her mother's circumstances. Yet, in the interview, she stated that despite the factors that contributed to her becoming her mother's caregiver, it was still a choice that she had to make.

Some participants reported that they wanted to provide the patient with care instead of hiring paid caregivers. This is expressed below in a statement made by James, a 64-year-old husband of a patient with endometrial cancer:

"It was my decision. I told her from the beginning she's not gonna tell me to get someone or whatever. I'm responsible. I'm married to her. So it's my duty to perform any, any duties around the house. Cleaning the house, washing, anything, I must do it. I'm her husband." - James

The statement made by James indicates his view on his role as his wife's caregiver as well as his role as his wife's husband. His extract suggests that responsibility, care, support, and attentiveness towards his wife is important to him. It is clear from the extract provided that James believed that it was not only important for him to adopt the caregiving role, but that he expected himself to do so. By stating that he "must do it" and by declaring that he is her husband, his statement suggests that he is aware of the unity and support which comes with marriage and his extract highlights his desire and willingness to provide support and care for his wife. Furthermore, the extract by James suggest that he does not have a gendered view of providing care nor does he view domesticated household chores as his wife's job. This further suggests that he may view unity and support as important aspects within his marriage.

Like James, Rhule, a 22-year-old male reported that he did not want his mother to hire people to take care of her. In addition, in the interview, he reported that his mother asked him to provide her with care. Consequently, Rhule reported that he moved from Kwazulu-Natal to Cape Town to become his mother's primary caregiver. Rhule's reason for becoming a primary caregiver is described in the quotation below:

"I had to help my mom and I didn't want her to hire people to help her you know because people talk around here so I just, I just felt like I had to do it." - Rhule

In this extract, it appears that Rhule felt obligated to provide his mother with care. By stating that *"people talk around here"*, he references the notion that people in his community talk about the lives and behaviours of others. By including the notion that *"people talk"* he may have suggested that he did not want to be discussed, judged, or looked down upon if he did not accept the caregiving role. Hence why he *"felt like [he] had to do it"*.

As mentioned, some participants reported that the patient was their relative which, in turn, prompted them to be the patient's caregiver. This is expressed by Mary, a 67-year-old mother in the example below:

"She didn't ask me, but I mean I know I need to look after her because I'm her mother." - Mary

By stating that she *"need[s] to"* look after her daughter, and that she is her mother, Mary suggests that she believes that it is her duty to become her daughter's primary caregiver because of her title as "mother". However, it should be noted that in the interview, Mary mentioned that her daughter and grandson lived with her. In addition, she reported that her daughter did not have anyone else to provide her with care. These factors may have also played a role in Mary feeling responsible to do so.

Research suggests that informal cancer caregivers may experience a sense of duty when adopting the caregiver role (Blinka et al., 2022; Githaiga, 2017). Studies have shown that family or cultural expectations play a significant role in caregivers decision to adopt this role (Blinka et al., 2022; Githaiga, 2017). For example, in African cultures, family is an important aspect within their lives, cultures and society (Githaiga, 2017). In some cases, family is considered more important than the individual (Githaiga, 2017). Thus, for informal caregivers who adopt this view, becoming a caregiver may be viewed as an important and necessary role.

In addition, for some caregivers, the caregiver role may be viewed as a personal responsibility or moral obligation (Blinka et al., 2022). For others, the caregiver role may be a means to express their gratitude for their family member or to repay them for everything

that they have done in their lives (Blinka et al., 2022). Furthermore, for individuals who provide care for their partners, the caregiving role may be viewed as a way to indicate their love or commitment to their partners (Blinka et al., 2022). Thus, there are various reasons and factors that contribute to a caregiver's decision to become a cancer patient's informal primary caregiver.

The various factors which contributed to the caregivers' decision to become an informal caregiver were highlighted in this section. These factors indicate the significant ways in which the microsystem affects an individual, their decisions, and their responsibilities. From an ecological system's theory perspective (EST), the microsystem is the innermost layer of the ecological model and consists of an individual's relationships, career, and neighbourhood (Bronfenbrenner, 1979). As interpersonal relationships such as family form an integral part of an individual's life and experiences, it is possible to suggest that the relationship between the patient and the caregiver prior to the onset of cancer may have played a role in the caregivers' decision to take on the caregiving role.

4.3.2. Tension between the patient and caregiver

The dynamics between family members change when they are placed into new roles such as the caregiver and the patient. As this study was conducted among caregivers of women with gynaecological cancer, the patients were women who typically cared for their caregivers prior to their illness. Their cancer resulted in a shift in roles within their families. For example, caregivers in this study fulfilled household chores, prioritised the patient's physical and emotional well-being, and provided care for immediate family members within their household.

Adult children who fulfilled the role of being a caregiver reported that this was a difficult phase in their lives as they were not accustomed to their mothers being dependent on them. Some of these caregivers reported that it was difficult for their mothers to rely on them which, in turn, resulted in them expressing frustration towards the caregiver. This is expressed in the example below:

"I got her some muesli and yoghurt for breakfast because we leave the house at 6am so it's too early for her to eat at that point, so I take that with so that she can eat there [at the hospital] and I put in little snacks but when we got there, the, the to the hospital, the muesli and yoghurt had fallen out. So now she's giving me a big fit so then I go, oh, you're such a crappy person, why didn't you put it in a bigger container, or you know, you, you kind of very hard on yourself sometimes." - Shannon, 47-years-old, daughter of patient with endometrial cancer

As expressed in the example above, Shannon engaged in negative self-talk when she witnessed her mother's reaction towards her because of the incident with the yoghurt. By reflecting on her words to herself such as *"you're such a crappy person"* and *"why didn't you"*, Shannon is conveying how she viewed herself and the way in which she provided care when a difficult situation arose. Her reflection on being *"hard on yourself"* suggests that being a caregiver may have impacted her on an individual level.

Jazmin, who provided care for her mother detailed the way her mother spoke to her when she was frustrated. This is indicated below with an example that took place when Jazmin was watching television with her mother in close proximity:

"I said mommy, did you see this, and she said ja, I'm not listening to you, I'm concentrating here, the children is working on my nerves. [...] And sometimes I will crack a joke with her and then she won't laugh, and she say it's not funny or things like that or she will just ignore me. But it's the pain also so I understand. [...] Sometimes it hurts ja, but ja." - Jazmin

Jazmin expressed understanding when she bore the brunt of her mother's frustration. However, by stating that *"it hurts"*, Jazmin is conveying how her feelings are affected when she is spoken to with frustration by her mother. In addition, the statement by Jazmin highlights how challenging interactions with the patient can be and the impact that it can have on the caregiver's emotions during this process.

Many caregivers in this study reported that the patient experienced mood swings due to frustration. As previously mentioned, the caregivers reported that they believed the frustration that the patient experienced stemmed from being in pain and being reliant on the caregiver to assist with their needs. The caregivers reported that they experienced their own frustration when confronted with the patients mood swings. Yet, most caregivers stated that they remained silent when the patient was *"lashing out"*. While some caregivers stated that they spoke to the patient when the patient was calmer to express their feelings regarding the way they were spoken to, others stated that they did not express how they felt. Many participants reported that it was important to be understanding when dealing with the patient's emotions and struggles during their cancer experience. For this reason they preferred to be empathetic when the patient experienced mood swings instead of being reactive. This was indicated by Katie in the description below:

"Their moods change yes, but we cannot show them that we feel irritated by them or how their behaviours are affecting us. All that I can do is to cut it off and go ahead with what I am doing because if I am going to be irritated around her then she is going to think that I am not interested in helping her." (Translated)- Katie, 37-years-old

Similarly to Katie, Talia did not want to express her emotions when her mother experienced mood swings. She explained that:

“I get sad sometimes, mmm she makes me so sad. Like I don’t, I don’t want her to be in pain. I don’t...I don’t... so most of the time, I don’t want to burden her with anything, so I just say I’m sorry if I upset you”- Talia, 38-years-old

This statement by Talia suggests that she wanted to keep the peace when her mother experienced anger or frustration because of her pain. By stating that *“I don’t want to burden her with anything”*, Talia suggests that she preferred to keep her thoughts and emotions to herself in an attempt to not aggravate any situation that could cause her mother any additional pain or distress. Her statement above thus indicates deep empathy for her mother.

During the caregiving experience, it is not unusual for caregivers to report that they experienced tension with the patient. In this study, some caregivers experienced tension when the patient did not listen to them or adhere to the rules of HCPs. The caregivers in this study reported that they were responsible for the eating habits of the patients and that they experienced frustration and concern when the patient was unable to consume food. Some caregivers reported that they felt that the patient was not trying hard enough to eat or that they were giving up. This was expressed by Nelson, a husband providing care for his wife, in the description below:

“It’s, it’s, it’s, difficult man, because look, it’s almost as if I am going to lose her, you know? It’s almost as if she doesn’t listen,[...], it’s almost as if she doesn’t understand or listen with regards to how important it is to eat even if it’s just a teaspoon of this, a teaspoon of that, with the medication. A person cannot drink five pills and eat one spoon of food so that is what, I assume that is what messes up the sugar and everything in her body. Then the fight starts, you must eat, you must eat [...]. It’s sometimes difficult to explain to her. It is what it is”. (Translated)- Nelson, 77-years-old

It is evident from Nelson’s statement that he was deeply concerned about his wife’s well-being and that her lack of eating caused him distress. In his interview, he explained that he was unable to give his wife all her medication at the allocated time because she did not consume enough food to drink all the tablets that she needed to. He stated that he would often have to allow her to take breaks while eating by only giving one or two tablets at a time with every meal or snack. During his wife’s meal times, Nelson stated that he took a walk around or in their home instead of standing by her when she was eating because he did not want her to feel pressurised by him. In his interview, Nelson further reported that the process of watching his wife struggle to consume food was the most difficult aspect of care for him.

Tension between informal caregivers and cancer patients have been documented within the literature prior to this study (Maree et al., 2018; Sercekus et al., 2014; Ussher et al., 2011). Research suggests that informal caregivers find adapting to and accepting the mood swings of the cancer patient to be a challenging aspect of providing care (Maree et al., 2018; Sercekus et al., 2014; Ussher et al., 2011). However, the literature provides evidence that informal caregivers prefer to withhold expressing their own emotions when confronted with the patient's mood swings (Ussher et al., 2011).

In addition, informal caregivers have expressed the challenge of managing their own emotions when they are deeply affected by the way in which they are spoken to and treated when the patient is experiencing changes in their moods (Maree et al., 2018; Sercekus et al., 2014; Ussher et al., 2011). Therefore, the findings presented in this section is consistent with the findings of prior literature which highlights how the changes within the patients mood or personality affect the emotional well-being and behaviour of their informal caregivers (Maree et al., 2018; Sercekus et al., 2014; Ussher et al., 2011).

From an EST perspective (Bronfenbrenner, 1979), the relationship dynamic between the patient and the caregiver can be observed within the microsystem. The primary caregiver spends majority of their time with the patient. Thus, they are the ones who are experiencing the mood swings of the patient. For this reason, their own emotions are being affected by the emotional and behavioural responses of the patient. Yet, despite the possibility of the patient's mood swings negatively affecting the emotional well-being of the caregiver, the caregivers exercise patience, tolerance, and acceptance within their relationship with the patient. In addition, the caregivers empathise with the patient's emotional well-being and therefore, remain silent when experiencing the patients mood swings to prevent the patient from experiencing additional emotional distress. This complex dynamic highlights how this important relationship within the caregiver's microsystem can affect the caregiver.

4.3.3. Feeling the patient's pain

One of the most distressing aspects of providing care was witnessing the patient in pain. Most of the participants reported that there was nothing that they could do to reduce or eradicate the pain that the patient experienced which made them feel helpless. Many stated that all they could do was be present in those moments and assure the patient that they would be okay. In addition, some of the participants reported that they felt the pain that the patients' experienced. Kurt, a 56-year-old husband providing care for his wife with ovarian cancer, reported that it was difficult for him to witness her in pain. This is indicated in the quotation below:

“And if she’s got pain then I’ve got pain. I just wish I could take, I could take, when she was so heavy in pain, that I could take some of it away, but you can’t, you can’t err, carry it over, you know what I mean?” -Kurt

In the statement above, Kurt expresses a desire to reduce the pain that the patient is feeling. His statement reflects the challenge of wanting to help the patient yet being unable to do so. His statement also highlights how helpless caregivers can feel when the patient is going through one of the difficult aspects of the cancer experience, namely experiencing pain. Furthermore, his statement suggests that witnessing the patient in pain yet being unable to help can cause caregivers to experience emotional turmoil.

Like Kurt, Jazmin also experienced her mother’s pain during her mother’s illness trajectory. This is expressed in the quotation below:

“I felt that pain. I felt that pain with her. That is the worst thing. I could feel that pain without my mommy even knowing. I just used to cry in silence because I could feel that pain that she has and it was, it was, oh, it was pain that I don’t want to experience again.” -Jazmin

The statements provided by Kurt and Jazmin highlight the impact of caregiving on the emotional well-being of informal cancer caregivers. Their statements also suggest that witnessing the patient in pain is one of the challenging aspects of providing the patient with care. Limited studies have displayed findings that focus on caregivers who report experiencing the pain that the patient experienced. However, this finding is consistent with two studies which indicated that their participants reported experiencing the pain of the patient (Doumit et al., 2008; Streid et al., 2014). In addition, the caregivers in Streid et al.’s (2014) study also described the desire to reduce the pain of the patient by taking it upon themselves.

From an EST perspective, human connection forms part of the microsystem (Bronfenbrenner, 1979). Thus, the emotions that the caregiver experiences when witnessing the patient in pain indicates how their connection with the patient impacts their well-being during the cancer experience.

4.3.4. Hidden emotions: A protective tactic

Many participants reported that they believed that it was important to hide their own emotions from the patient. This included crying silently, in a corner or in their bedroom when they were certain the patient would not hear them. In addition, some caregivers reported that they avoided any conversations about how they felt with the patient. They reported that they wanted the patient to have hope and to be positive, particularly when the patient was

struggling to cope with their own emotions. Thus, crying was seen as a negative act that would further emotionally distress and drain the patient. For this reason, many participants did not express nor discuss their emotions with the patient. Mary, a mother of one of the patients explained why she hid her emotions from her daughter in the statement below:

“I don’t want to show her that I’m emotional you know. So I don’t want to put her in a state that she think oh, I’m a nuisance or so.”- Mary

Some participants utilized different strategies to hide their tears from the patients. One of the participants, namely Sarah, stated that when her mother cried, she tried her best not to cry with or in front of her. She explained that:

“Most of the time I try not to [cry] because uhm, I know in times like that, things that they need is, that she needs, the last thing that she needs is for me is to be more emotional than she is, so I try to keep me really strong and not [cry]. So I would, most of the time, I would cry when I’m alone or everything is done. I would do, I would cry and be sad and whatever but sometimes it’s just really hard to stop, so the tears would just go and then I would hug her or so, so that she doesn’t need to see my face while she’s crying”- Sarah

Sarah utilised the strategy of comforting her mother with a hug as a way of preventing her mother from seeing her tears. Anna, however, left the room when her daughter-in-law experienced pain and cried. This is expressed in the quotation below:

“Many times when she had pain and she would cry then I don’t want to show her that I’m crying then I will tell her, I’m coming now, I’m quickly going to the toilet, [and] then I enter the bathroom and I wipe my face with a wet cloth. [After doing so] I come in [to the room] so that she doesn’t see that I cried.” (Translated)- Anna

Some participants reported that by showing emotion, they made the patient weak, sad, or hopeless. Thus, in many cases, the participants believed that they had no choice but to be brave in front of the patient. Shannon who provided care for her mom explained why she hid her emotions in the statement below:

“I, I know what the doctors said. I know the treatment is for buying time, but I don’t want her to feel like she’s just getting another day. I want her to feel like she’s fighting for something. And if I’m going to be crying in front of her, she’s going to think that’s it”- Shannon

The findings in this section highlight that the caregivers were concerned about the emotional well-being of the patients. These findings also highlight how important it was for the caregivers to protect the patients from as much emotional distress as possible. Thus, most of the caregivers preferred to remain silent or hide their own emotions from the patients.

Again, this highlights how important the patient and the relationship with the patient is within the caregivers' microsystem (Bronfenbrenner, 1979).

The findings in this section is consistent with prior studies which focused on the experiences of informal cancer caregivers (Arian et al., 2017; Sercekus et al., 2014). Prior studies have found that informal cancer caregivers do not express their emotions to or in front of the patient (Arian et al., 2017; Sercekus et al., 2014). Prior literature have also highlighted that informal caregivers believed that it would not be conducive to the patient's well-being to be confronted with their thoughts and emotions (Arian et al., 2017; Sercekus et al., 2014).

4.3.5. The art of putting someone else's needs above your own

Most participants perceived the patients' needs as more important than their own. Some participants sacrificed financial stability, their hobbies, quality time with their children and partners and risked the possibility of being fired. The caregivers were aware that the patients needed their presence and their help at any given point in time and thus, had to make difficult decisions such as resigning from their jobs, taking family or unpaid leave when necessary and assisting the patient with what they needed. However, most of the participants reported that the decisions that they made during their time as the patients' caregiver was to ensure that the patients' needs were met to the best of their ability, regardless of how it affected their well-being and their livelihood.

One participant, namely James, decided to significantly reduce the amount of time he spent making music to provide care for his wife. For James, music was more than just an income. It was a passion which brought him a lot of joy in his life. However, when his wife was diagnosed with cancer, he decided to make his wife his main priority. He reflects on his decision in the quotation below:

"You see most of the times, I was a busy man. I'm making music and that requires a lot of time. So I decided to just cut, cut it off man. It is important but this is more important. It's only like, it, it brings in money, it brings in money but err, that was part of my, my lifetime. I liked to play music, but I told the guys that listen here, music is part of my life, but I've got this problem on hand and the house, my wife, and the house, that is my first priority so you guys will become my second priority. Even if it's important, it doesn't like, I won't go out of my way with that kind of things. I'd rather stick at home to see what's, what's wrong, what's happening here because there's nobody else that I can rely on." - James

For some participants, putting the patient's needs above their own meant spending less time with other important members of their lives and families. Some participants admitted that it was challenging however, they were happy to do so if it meant that they could

take on this role for the patient. In addition, some participants reported that their partners and children understood the importance of them taking on the caregiver role and accepted the changes in their lives. However, other participants admitted that by putting the patient first, their other relationships or jobs suffered which negatively impacted them. Sarah, a mother to a young son, explained that by providing care for her mother, she had to spend less time with her young son. This affected her emotionally as she reported that she felt that she was not as present in his life as she was prior to her mother's diagnosis. This is described in the quotation below:

"I have to send him away so that I can just do for my mother what I need to do and that, this is really on a personal level but that really messes up my relationship with my son because, not mess up the relationship between us because I will always be his mother and whatever, but it's just I have to spend less time with him so his more on the daddy side, and sometimes that's really like emotional for me because now he mentions them all the time and everything he says and does is them and it's supposed to be me." – Sarah

Another participant namely Jazmin reported that she decided between an income or being fully present for her mother. Jazmin had a creche which was operated by both her mother and herself. However, when her mother was diagnosed with cancer, she decided that it was best to close the creche to most of the children. She explained that:

"When she was diagnosed with the cancer neh, I then told the parents listen here, I'm sorry but my mom is, my mom has cancer. I can't look after my mom and the children. Money wasn't the option now because my mom's health was more important than the money at the moment. I know we needed the money but taking care of the kids and my mother wasn't gonna work out for me" - Jazmin

Some participants reported that they were consistently taking leave or leaving work early to tend to the patient's needs. One of the participants namely, Carmelo reported that in his first month of being his partner's caregiver, he already used all his family responsibility leave days. However, he still asked his employer if he could take days off or work part-time. He reported that his employer knew about his partner's diagnosis but that *"an employer is an employer and that they are focused on making money"* (translated). Nevertheless, Carmelo reported that even though he needed his job to provide for his partner and their children, he chose to make her his priority. This is expressed in the quotation below:

"I choose to look after my partner instead of having regrets in the future. If something might happen to my partner in the future then I at least know that I was there [for her]" - (Translated) Carmelo

In addition to the statement above, Carmelo reported that he knew there was a risk of getting fired for being absent at work, arriving late to work, and leaving his place of employment early. However, he stated that when his partner messaged him to let him know that she was not feeling well, he left his place of employment to either make sure that she was well or to provide her with any assistance that she required.

One of the participants namely Shannon, explained how she placed the health of her mother (the patient) above her own. She explained that her daughter, together with her mom had health-related needs that needed to be met. Thus, when Shannon could not afford to buy everything her mother and daughter needed for their health conditions, she reported that she was then unable to meet the needs of her own health condition. This is described in the quotation below:

“ I have asthma, I’m also not on medical aid by the way. I buy my, my meds cash so if I don’t have enough cash to buy my mom’s stuff or my daughter’s stuff for their health then ten to one, what I won’t buy is my inhalants” – Shannon

In this section, the participants reflected on various ways in which they placed the patients’ needs above their own. In doing the activities described in this section, the participants highlight how selfless the act of care is. Nevertheless, the caregivers reported that despite the sacrifices that they had to make, they chose to make the patient their main priority. Prior research suggests that prioritising the needs of the patient is a common theme in literature among informal cancer caregivers (Maree et al., 2018; Tranberg et al. 2021).

From an EST’s perspective (Bronfenbrenner, 1979), the macrosystem may be influencing the dynamic between caregiver and patient. Culture and societal views form part of the macrosystem and can influence every system within the individual’s life (Bronfenbrenner, 1979). For example, ubuntu can be considered a motto in Africa which place emphasis on the importance of community (Gathogo, 2008), compassion and valuing and respecting each other (Matolino & Kwindigwi, 2013). In addition, in Africa, there is an emphasis placed on the importance of family (BeLue, 2017). Thus, it may be possible that caregivers in South Africa, particularly family cancer caregivers believed that it was important to place the needs of the patient above their own. This includes prioritising the patient’s health and well-being.

In addition to the macrosystem, the exosystem entails policies, rules, and regulations which may impact the lives of informal caregivers (Bronfenbrenner, 1979). However, the caregiver does not have control over these rules and policies (Bronfenbrenner, 1979). This was highlighted by Carmelo who risked the possibility of being fired due to the number of

days that he worked part-time to assist his partner. By deciding to place his partner's needs above his own, the consequences included the possibility of losing employment and experiencing financial constraints.

In terms of the mesosystem, the way in which the caregiver's different microsystems are interrelated may affect their lives (Bronfenbrenner, 1979). For example, some caregivers reported having trouble fulfilling their work roles while providing the patient with care. In addition, some caregivers reported that the relationship with the patient affected some of their relationships with their partners or children. Thus, while caregivers viewed providing care as their duty and a choice, there were personal costs that occurred which may have impacted their health and well-being.

4.3.6. Changes in the relationship: Beyond the caregiver and patient dynamic

Some of the participants reported a shift within their relationship with the patient. They reported that they either experienced an improved relationship or a deeper connection with the patient. For example, when James and Carmelo were asked about their relationship with their respective partners, they explained that:

“Uhm, I feel loved. I think, I think I'm more in love now than before. Much, much more in love now than before. That's now the honest truth.” - James

“I'm learning so much from her[the patient]. I'm actually learning how much I really love her. How much she means to me.”(Translated)- Carmelo

In addition, James further explained how the relationship dynamic between him and his wife changed since she's been diagnosed with cancer. This is described in the statement below:

“I never used to like err, my wife telling me to do this and that. That was not on for me but now I've changed a lot. I've changed. I'm a changed man. I need to, to listen, to be respective at all times. Respect. If she wants anything or tells me anything, must listen, listen. Irrespective a man or whatever. Err, yes, I need to, the habits have changed now. The habits have changed. It's all turned around now. Guys will tell you, hey you sissy, you just want to be in [the] house, in doors, you sissy. I'm not a sissy. I'm assisting my family. You assist your family.”- James

Relationships between children and parents either changed or stayed the same. Some of the adult children who were caregivers for their mothers reported that their relationship dynamic with their mothers improved. They experienced a closer connection with their mothers and were grateful that their experience as their mothers' caregivers made such a positive impact in their relationship. Talia, one of the participants who reported that she

always had a close relationship with her mother, stated that their relationship changed in a way that brought them even closer than before. This is expressed in the quotation below:

“We’ve become companions. We used to be mother and daughter but now we’ve become companions. Uhm, like I see her in a, in a, I’m grateful that I’m there for her, you see, and I am, I feel honoured that I’m there for her.” - Talia

She further explained that one of the important things that she did with her mother was to tell her that she loved her, and she expressed her need to hear those words as well. This is expressed in the statement below:

“I tell her I love her, and I wait until she says I love you too. If she doesn’t, I say well, well I’m still standing here” - Talia

Two daughters who provided care for their mothers, namely Sally and Sarah, expressed an improved relationship with their mothers. Sally, who lived in a different province from her mother for 25 years prior to her mother’s diagnosis expressed her delight in being able to bond with her. This is described in the quotation below:

“That I could lie next to her on the bed, and we could bond with each other. You know, that, that is what I’ve longed for, for so many years” – Sally, 49 years old

For Sarah, the process of providing care also improved her relationship with her mother. Prior to her mother’s diagnosis, Sarah explained that she and her mother never had the type of relationship where they would *“talk in each other’s faces”*. What she meant by this was that they did not share their thoughts and emotions with each other about different aspects of their lives. She may have also been conveying that they lacked the ability to be vulnerable with each other. However, after Sarah became her mother’s primary caregiver, their relationship entailed being open and vulnerable with each other. She explained the change in their relationship dynamic in the quotation below:

“It did bring us a little closer, so we have a better understanding now when it comes to feelings and how I feel and seeing her, so I also get to share a lot of things, like when it comes to my goals, with her now and I didn’t, we never had such conversations in the past. So now, I’m able to tell her this and this and that so ja, once things get all sorted and get better and then at least I will know that I have her support also, in whatever that I, whatever I’m taking on.” - Sarah

The relationship between an informal caregiver and patient can result in a deeper connection built beyond the caregiver and patient dynamic. This is highlighted by James and Carmelo who experienced being more in love with their partners and by Sarah and Sally who experienced an improved relationship and deeper connection while providing care for their

mothers. Prior studies suggest that informal caregivers can experience a deeper connection with cancer patients during their illness trajectories (Wells et al., 2008; Ussher et al., 2011). These findings suggest that the shared experience may contribute to the connection that is developed between the caregiver and the cancer patient.

Looking at these findings from an EST perspective, the caregiver's relationship with the patient is one of the most important relationships in their microsystem (Bronfenbrenner, 1979). Thus, changes within their relationship dynamic is to be expected. This is because the disease affects both the patient and the caregiver (Kayser et al., 2007). Therefore, the deep connection between caregiver and patient is a prime example of how the relationship within the microsystem impacts the caregiver's life and their own experiences (Bronfenbrenner, 1979).

4.4. The complexities associated with caregiving and the public healthcare system

In this study, the caregivers reflected on their experiences providing care for the patient within the public healthcare system. The participants discussed their relationship with the patient's HCP and their perspective on the way in which HCPs treated the patients and themselves. While caregivers reflected on their thoughts and experiences with HCPs, it became clear that the dynamic between caregivers and HCPs was complex.

In this section, the importance of caregiver visibility within the public healthcare system will be discussed. Thereafter, the caregivers reflections of HCPs treatment towards the patients and themselves will be presented and discussed.

4.4.1. The importance of caregiver visibility within the public healthcare system

Most of the caregivers reported that they never communicated with the HCPs. Thus, they only knew what the patient told them. There were a variety of reasons for the lack of communication between caregivers and HCPs. These reasons included a) lockdown regulations during COVID-19, or b) the patient as the primary receiver of their medical information. Some caregivers were satisfied with the information that the patient provided them. However, others were wary about whether they were receiving accurate or all the information that HCPs provided the patient. For example, Katie reported that she received information about her aunt when she was present at the hospital. However, when she did not accompany her aunt to the hospital, she reported that HCPs would not inform her about her aunt's well-being. When I asked her how she felt about not receiving information from HCPs, she stated that:

“I don't feel good about it because she [her aunt] does not provide all the information” (Translated) – Katie

Jazmin, one of the caregivers who did not have any communication with HCPs reflected on the importance of HCPs communicating with caregivers in the quotation below:

“I mean in general, what if, if, if, they, there’s other people at hospital [HCPs] that only have contact with that person [the patient] and the other person [the patient] is not telling the whole truth to the others [caregivers], but the doctor knows what’s going on, but the other people [caregivers] is just taking this person’s [patient’s] word and here the person [patient] die or something worse is happening” - Jazmin

Some participants received some information from HCPs. One of the participants, namely Peter communicated with HCPs when he accompanied his daughter to the hospital. However, Peter mentioned that there was an important piece of information that has not been shared with him. He stated that he wanted to be informed about his daughter’s prognosis so that he could “live with it”. He further elaborates on the need to know his daughter’s prognosis in the description below:

“All that I want to know now is....doctor must now be honest with me. Now I am going, going to ask, doctor, be honest with me and tell me if my daughter’s cancer has spread. Is it a stage too far? Is there still hope for her? Or whatever it is. Other than what I know so far, I only know that she has cancer and that she is getting chemo and further than that, I don’t know anything. He can say the cancer has spread and then I know that”.
(Translated)- Peter

There were participants who reported that they had not communicated with HCPs nor were they unhappy about the lack of communication. Kurt was one of the participants who had no issue with his lack of communication with his wife’s HCPs. He expressed the lack of communication with the HCPs in the description below:

“No, there was no communication. I didn’t see her doctors... err... we couldn’t be around when the doctors were around. No doctor came to speak to me” -Kurt

When I asked Kurt how he felt about the lack of communication he received from HCPs, he described his thoughts which is reflected in the description below:

“I just thought maybe they [HCPs] feel it’s private. They want to speak to the patient. I’m not the patient and you know, with Covid, less people in the hospital, it was better that way.” - Kurt

As demonstrated in the findings of this section, the lack of information provided to caregivers affected the well-being of some caregivers who wanted to be mentally and emotionally prepared for any outcome during the patient’s illness trajectory. Thus, the lack of recognition and visibility that informal caregivers experienced within the healthcare system

affected their ability to receive important information about the patient's health. In addition, a lack of communication and transparency between caregivers and HCPs elicited wariness and concern in some caregivers. These findings suggest that the lack of visibility and communication between HCPs and informal caregivers can affect the well-being of caregivers who want to be informed and prepared for the potential health outcomes of the patient.

The findings in this study indicate that some informal caregivers want consistent communication with HCPs. This finding is consistent with the findings highlighted by the informal cancer caregivers in Nissim et al.'s (2017) study who expressed the importance of consistent information and guidance from HCPs at different points of the patients' illness trajectories.

In contrast to the findings in this study, a prior study conducted by Barlund et al. (2021) found that informal cancer caregivers reported experiencing feelings of insecurity when they received inadequate information or when information was not provided in a timely manner. However, most of the participants in this study did not communicate with HCPs. For this reason, the finding in Barlund et al.'s (2021) study was not present in this study.

When applying the EST perspective (Bronfenbrenner, 1979), it is important to note the rules and regulations of public hospitals which form part of the exosystem. These rules and regulations directly affect caregivers. However, the caregivers do not have control over the rules and regulations within the healthcare system (Bronfenbrenner, 1979). For example, some participants reported that they wanted HCPs to inform them about the well-being of the patient and update them on the patient's prognosis. However, there are regulations in place to protect the patient's right to privacy and HCPs are bound to doctor-patient confidentiality. Thus, HCPs can only provide caregivers with information about the patient if the patient has given the HCP permission to do so.

In terms of the microsystem (Bronfenbrenner, 1979), some participants reported that they did not believe that the patient provided them with all the medical information after consultations with HCPs. In contrast, other participants reported that they were happy with the information that the patient provided them with. This may highlight the relationship dynamic between the patient and caregiver within the caregiver's microsystem.

4.4.2. Caregiver reflections on HCPs treatment towards the cancer patients and themselves

Most of the participants who reported on HCPs treatment towards the patient and themselves were those who had permission to enter the public hospital during the pandemic and communicated with HCPs fairly regularly. One of the reasons why some caregivers were

allowed into the hospital during the pandemic was because the patient needed the physical assistance of their caregiver. Most of the time, when caregivers were allowed in the hospital, it was due to the patient having a disability such as being in a wheelchair, deaf or being too frail to walk on their own thus, depending on their caregiver's physical support.

Some participants reported that they were satisfied with the way in which HCPs treated the patients and themselves. This is described in two examples below:

“Very supportive people, especially the team of [academic tertiary hospital]. Very supportive. They have been so good uhm, and so professional from day one. Uhm, they know my face, even when they used to say: no you can't come in, you must sit there and there, you know, they know me by now, I'm like a shadow, always there. So they've been very supportive, very accommodating uhm, really very professional. Honestly. They do go the extra mile, I feel, for their patients”- Talia

“I've never, I won't say I had a, any bad experience at the hospital. Not at all, in fact, you know what, I actually, they were wonderful. They treated my mother so, so well. She used to always, they used to always smile and laugh at her because she used to always make jokes with them and they knew me as well, we had a very good relationship. Honestly speaking.”- Sally

Carmelo, one of the caregivers whose partner was diagnosed with stage four cervical cancer reported on how worried he and his partner was when she received her diagnosis. He reported that after his partner had spoken to an oncologist, it was as if he witnessed a new person. With that statement he meant that his partner was calm when she relayed the information that she received from the oncologist. While reflecting on his experience with HCPs he reported that:

“They actually gave us peace.” (Translated)- Carmelo

The HCPs mostly communicated with his partner however, the way in which they communicated with her and the way in which she relayed information provided him with a positive view of HCPs. Thus, it was not his relationship with HCPs that gave him peace but the effective manner they provided information to his partner which gave her peace which in turn, resulted in him experiencing peace. This indicates the importance of empathy, compassion, and kindness from medical staff when communicating sensitive information such as a cancer diagnosis.

The statements above indicate that the caregivers appreciated the effort of HCPs when communicating with the patient and themselves. These examples also indicate that positive

interactions are necessary as it puts the caregiver at ease if the patient is well-taken care of by HCPs.

Some participants did not have a good experience with HCPs. This is indicated in the quotation below:

“They, they, they sometimes inconsiderate, inconsiderate. You don’t have to be nice, hey, you don’t need to be nice but at least, you need to treat patients as human. Humanity, humanity is very important and always try to make the person feel at ease, you know, always. I’m not the doctor but I can see some doctors, they don’t care. There’s no like encouragement. Their encouragement lacks”- James

James’s statement indicates that he was unhappy with the way his wife was treated by HCPs. Based on his statement, it seems as if the HCP was cold and lacked empathy when communicating with his wife. This statement from James indicates the importance of empathy when communicating with patients and caregivers.

Sarah, who had not communicated with her mother’s HCP expressed how she felt when she saw her mother’s wound and how it affected her perception of HCPs. This is described in the quotation below:

“Okay I’m not gonna say they were negligent or anything, but I just felt like they could have made more sure of what they were doing and where it came to the radiation and the burning of her insides, so there, they could’ve been a little bit better”- Sarah

She continued her explanation by stating that:

“To see it and to clean around it, it’s really not a nice sight, really, it’s not. She was constantly in pain because she couldn’t move because the whole time, she was cut like from the middle right up. So that, ugh, I don’t know, it gave me a other point of view about doctors ja”-Sarah

Sarah’s statement indicates that she was unhappy with the way in which her mother’s body was treated by HCPs when she underwent radiation. It is clear that she believed that they could have handled her mother’s body with more care. Consequently, her perception of HCPs have shifted in a negative manner.

As illustrated in this section, the way in which HCPs treat patients and their caregivers plays a crucial role in the caregiver’s experience of the patient’s illness trajectory and the healthcare system. The statements presented in this section highlight that respect, kindness and empathy is crucial within the dynamic between informal caregivers and HCPs.

Research suggests that informal cancer caregivers experience different interactions with HCPs (Stilos et al., 2018; Wells et al., 2008) . Therefore, their experiences vary

depending on their relationship with HCPs. For example, some informal caregivers have negative experiences with HCPs which may affect their well-being and impact their role as a caregiver (Stilos et al., 2018). For others, the relationship with the patient's HCPs may be positive (Wells et al., 2008).

In a study conducted by Stilos et al. (2018), the participants reported that they felt abandoned when HCPs were unavailable. In addition, these participants reported that they could not receive answers to their questions nor were they able to adequately prepare for the patient's impending death (Stilos et al., 2018). However, this is in contrast with the findings of this study as some of the participants were able to communicate with HCPs. In addition, some of the participants in this study reported that the HCPs treated the patient and themselves well. Furthermore, some participants reported that they were able to receive information and have their questions answered. Moreover, most of the participants in this study did not discuss nor did they mention preparing for the impending death of the patient. For these reasons, the findings of this study contrasts with those of Stilos et al.'s (2018) study.

In terms of the positive experiences with HCPs, informal cancer caregivers in Wells et al.'s (2008) study reported that HCPs provided them with information and emotional support. The finding from Wells et al.'s (2008) study was similar to the positive statements reported by some of the caregivers in this study. For example, some participants in this study reported that the HCPs were supportive to them. In addition, one participant reported that HCPs provided him and his partner with peace.

In terms of the EST perspective, the chronosystem contributed to the caregivers inability to communicate with HCPs. The chronosystem refers to any life changing event that occurs in an individual's life (Bronfenbrenner, 1986). As discussed by some of the participants in this study, the COVID-19 pandemic affected the rules and regulations at public hospitals. Caregivers were not allowed to accompany the patients into the hospital during the lockdown period in South Africa. Thus, they were unable to provide the patient with physical support during their medical consultations nor could they visit patients who remained in hospital. In addition, the pandemic affected the macrosystem because the regulations in hospital were adhered to throughout South Africa (Bronfenbrenner, 1979).

4.5. The effects of caregiving on the caregiver's health and well-being

Providing care for a cancer patient may impact informal cancer caregivers physically and emotionally. In this section, the emotional distress experienced by informal cancer

caregivers will be discussed. Thereafter, the physical effects of providing care will be discussed.

4.5.1. The emotional distress experienced by informal cancer caregivers

Most of the participants in this study reported that they experienced emotional distress. More specifically, most of the participants reported experiencing stress, helplessness, sadness, and fear. Some of the participants reported that the emotions that they experienced were a result of witnessing the patient in pain, the wound that they treated, the financial constraints that they experienced and their need to be present for the patient, particularly for practical tasks. In this section, helplessness, stress, sadness, and fear will be discussed.

4.5.1.1. Helplessness. Most of the participants reported feeling helpless when the patient experienced pain. Participants stated that all they could do was provide the patients with medication, be present to comfort them and offer words of encouragement. Yet, participants reported that they were unable to reduce the pain experienced by the patient and that, the inability to do so, negatively affected them. This is expressed in the examples below:

“It made me feel sad you know, because I couldn’t help her, I knew I couldn’t help her, and she was sick and crying and I just wanted to help her any way I could, but I couldn’t”. -Rhule

“Most of the time I felt helpless, especially when mom has pain and I can’t, you know there wasn’t words, that you can, you can talk to her but for me it was like, no matter what you say, that words don’t really take the pain away that she has. So, most of the time, I felt so helpless, seeing her in so much pain”- Jazmin

These extracts highlight the caregivers’ need to provide support and assistance yet being unable to. These extracts further indicate how helpless informal caregivers can feel when they are unable to help the patient.

4.5.1.2. Stress. Some participants experienced stress during the patient’s illness trajectory. Some of the reasons that caregivers attributed to their stress included the possibility of losing the patient, balancing their multiple roles, trying to prevent hurting the patient’s wound and experiencing financial constraints. In terms of financial constraints, many caregivers reported that they needed to ensure that there was food for the patient to eat. This was a concern that contributed to the stress of most caregivers of this study. This is expressed by Sarah in the quotation below:

“So when it comes to the food, everybody has to eat. You can’t go sleep hungry; I can’t have her be hungry so it’s really tough, stressful at times because there has to be something. You know... I can’t... she can’t have medication if she doesn’t eat”.- Sarah

When Sarah was asked how these financial constraints have affected her, she explained that:

“Financially, I don’t know what the correct word is, but I would really say it broke me. Literally. We never even have something to spend for something nice on myself or like, I’m used to doing things like that, like I mentioned, I would go out, I would go out with my son or so. I’m unable to do those things so financially, really, this cancer experience is as horrible as seeing my mom lay there.”- Sarah

The statements made by Sarah indicated that the financial struggles that she experienced resulted in her feeling stressed. In her second statement, she indicates that the financial constraints that she experienced while providing care was equally as difficult as seeing her mother sick and frail.

For one participant, namely James, being careful when it came to the wound of his wife was a stressful experience. This is expressed in the quotation below:

“Taking her to hospital and she can’t like sit properly in the car and any wrong movement in the car, if it like...there going over a bump or so, there’s like holes in the road, it affects the wound and then there’s like pain. Pain I could see on her face immediately and that did stress me out a lot”.- James

James reported that he experienced stress when he took take his wife to the hospital. He tried to prevent hurting her when he was driving however, when she experienced pain as a result of the potholes in the road, it affected him. In his interview, he reported that he found it difficult to see his wife in pain, thus, by having to fulfil an activity that he knew could potentially hurt her was stressful.

The possibility that the patient may die can be a stressor for caregivers as well. When Rhule was asked if he experienced any stress, he said yes. When he was asked what the cause of his stress was, he stated that it was the thought of losing his mother. This is expressed in his quotation below:

“Not having my mom around because I love her. I really do.”- Rhule

The participants experienced different stressors during the patient’s illness trajectory. However, one of the main reasons why they experienced stress was because they wanted to make sure that the patient’s needs were met. This is illustrated by James who wanted to make sure his wife was not in pain while he was driving, by Sarah who ensured that there was enough food for the patient and themselves and by Rhule who expressed concern regarding the possibility of his mother passing away. Needs are not only physical but also encompasses the individual’s mental health. Thus, the stress that caregivers reported indicate how much

they cared for the patient as well as the need to ensure that the patient's physical and emotional well-being was well taken care of.

4.5.1.3. Sadness. Most participants experienced sadness during the patient's illness trajectory. The factors that contributed to their sadness included witnessing the patient's body deteriorating, witnessing the patient in pain, discussing the patient's cancer diagnosis with others, and witnessing the distress that the patient experienced. In terms of witnessing the patient's change in appearance, Lola stated that:

"It's actually sad to see how, how she looks now and...but we take it day by day."
(Translated) – Lola

In addition to witnessing the patient's bodily changes, witnessing the patient in pain caused some participants to experience sadness. James described how he felt when seeing his wife in pain in the quotation below:

"The, the only time I'm experience sadness is when she got this pain. The heavy pain where she's crying. The pain and, and I, I'm asking myself that there's nothing that I can do. I can only watch, stand next to her but that's [when] I'm feeling sad and what makes me sad in this life is, you will always ask the question, why must this happen to me? Why must it happen to me? Why must it happen to her?" - James

Some caregivers reported that financial constraints were stressful, and that the consequences thereof elicited emotions such as sadness. This was expressed by Mary, who wanted to be present for her daughter, particularly at the hospital however, financial constraints made it difficult for her to do so. Mary explained that it was difficult for her to attend the doctor's consultations and chemotherapy sessions with her daughter as there was no financial means for her to travel with her. She elaborated on the effect that this had on her daughter's and her own emotional well-being in the description below:

"It does hurt me. She, she... one time she cried, and she said nobody is going with her to hospital, but I can't help it" - Mary

Some caregivers could not provide physical support for the patient in the hospital due to the COVID-19 pandemic. This resulted in some caregivers experiencing sadness. For example, Rhule explained that when his mother had to go to the hospital with an ambulance during the lockdown regulations, he was unable to join her in the ambulance or at the hospital. He described the thoughts that were going through his mind when she was at the hospital in the description below:

"I thought she was going to die or something... and that made me very sad. It made me very very sad, and I couldn't be with her" - Rhule

In addition, some participants experienced sadness when they witnessed the patient sad. For example, Nelson reported that he experienced sadness when he saw his wife struggling with her own emotional well-being. He explained that when it seemed as if she wanted to give up, he moved and sat in a corner where no one could see him. This was done to prevent crying in front of his wife as he reported that expressing tears in front of her would not help her in that moment. He also reported that when others asked about his wife and her well-being, he experienced sadness. This is described in the quotation below:

“Sometimes, when I talk about it, when people ask me questions then I get lost [in my thoughts], almost as if she is going to die now but then I try to just take a deep breath, then wipe my cheek then I am okay.” (Translated)- Nelson

Furthermore, some participants reported having trouble witnessing the patient’s wound. These participants reported that it affected them emotionally because it was challenging to see the person that they loved in that manner. Sally explained that:

“The fact that I had to now carry my mother, she is... she’s not... she has her legs, she has her arms, she has every part of her body, but because that part is so raw, she cannot, you know do things for herself. So, seeing your parent in this position is, it’s heart-breaking. It eats you up inside. Literally eats you up inside.”- Sally

Sadness was one of the main emotions that the participants experienced. As illustrated in the above-mentioned statements, there were a variety of reasons why caregivers experienced sadness. However, the main reason why caregivers experienced sadness was because of how the cancer experience was affecting the patient physically and emotionally.

4.5.1.4. Fear. Some participants reported experiencing fear during the patient’s illness trajectory. In addition, some participants reported that the fear that they experienced stemmed from the possibility of losing the patient through death and the consequences that that would have for them. For example, Peter expressed his fear about the possibility that his daughter may die in the description below:

“I’m thinking of the road, the way forward. That’s what I think about. If something happens to her, what will become of me?” (Translated)- Peter

Similarly to Peter, James also experienced fear pertaining to what the future would hold for him if his wife passed away. This is described in the quotation below:

“Fear, worry, what’s gonna happen, what’s gonna happen if, if that person is not gonna be here anymore. How would life treat you or how’s things gonna change.”- James

Additionally, Talia described her fear of losing her mother in her statement below:

“I feel like if she doesn’t, if we don’t beat this thing, I’m going to lose my mom and I feel like, I feel like I’m not ready because it’s always been me and her, you see. She’s the only person I have, and I always feel like I’m not ready yet and maybe it’s me holding on so tightly that makes her fight even a bit more. I don’t know but I just keep telling her all the time, Mommy, I’m not ready to lose you like, you have to fight you know. And I don’t think I’m gonna be ready, but I just feel like for now, I just don’t even want her to think of giving up.” - Talia

Some participants reported on the fear of waking up one day and realising that the patient had passed away. This was described by Shannon in the quotation below:

“The biggest thought is that I will come into the room one day and she’s just not there. That is the biggest one. I don’t know if I would be able to handle that.” - Shannon

The fears of the caregivers centred around the possibility of losing the patient. It was clear that these fears affected the participants negatively, especially because there was a possibility that their fears could become reality.

The findings in this subtheme suggest that providing informal cancer care can affect the emotional well-being of caregivers. Research has highlighted that informal cancer caregivers experience a wide range of emotions effects during the patient’s illness trajectory (Arian et al. 2017; Sercekus et al., 2014; Wells et al., 2008). For example, in Sercekus et al.’s (2014) study, informal cancer caregivers reported experiencing emotions such as sadness, shock, irritation, fear of losing the patient, guilt, and hopelessness. This finding is consistent with the findings reported by caregivers in this study as fear, and sadness were two of the emotions that the participants experienced. However, none of the participants in this study reported experiencing any guilt or hopelessness during the patient’s illness trajectory.

In addition, informal cancer caregivers in Arian et al.’s (2017) study reported that they experienced frustration and concern when providing the patient with care. These findings were consistent with findings in this study. However, the factors that prompted these responses were different. For example, in Arian et al.’s (2017) study, informal cancer caregivers reported experiencing frustration when the patient had lost hope when they, as the caregivers, had not. However, in this study, participants did not report experiencing frustration when they believed the patient was losing hope.

The emotions described in this subtheme are not uncommon during the patient’s cancer experience. However, what the findings in this study highlights is the notion that these emotions may have an impact the health and well-being of informal caregivers.

When applying the EST, it is evident that the macrosystem contributed to the risk factors experienced by the caregivers. Most of the participants in this study reported experiencing financial constraints. As mentioned, one of the main concerns for caregivers was having sufficient food for the patient, for themselves and their households during this process. Based on the EST (Bronfenbrenner, 1979), poverty is an issue within the macrosystem because it affects the economy, and society. As Bronfenbrenner (1979) suggests, an issue that is embedded in the macrosystem affects every level of the ecological system. This means that poverty affects the economy (macrosystem), the rules, regulations, and policies in society (exosystem) as well as the individual's health, their relationships, their communities, and their supportive resources (microsystem). In addition to the macrosystem, the exosystem is also important in understanding the rules and regulations for informal cancer caregivers. For example, in South Africa, there are no policies that provide informal cancer caregivers with financial assistance or recognition in the same capacity as paid caregivers.

4.5.2. The physical effects of providing informal cancer care

Some of the participants reported experiencing different physical effects to their body. For this reason, this section is divided into three subthemes namely insomnia, fatigue, and additional physiological responses to care. Each subtheme will be discussed in this section.

4.5.2.1. Insomnia. Some participants reported experiencing insomnia at night. For these participants, the cause of their insomnia was primarily due to their concern for the patient. The participants concerns included a) wondering if they had fulfilled their roles as caregivers adequately for the day, b) thinking of the patient in pain and c) thinking of what they could do to reduce the pain that the patient experienced. Some participants also reported that thoughts of the future, and the possibility of the patient dying contributed to the insomnia that they experienced. One of the participants namely, Sally described her thoughts in the description below:

“When you go to bed, you’re gonna wonder, you gonna wonder is she sleeping fine? Is she okay? Is she not in pain? You know what, does she need me now? Did I give her medication? Things like that will run through your mind. That is what goes through a person’s mind when you take care of a cancer patient and that’s my, my version of it, you know.” - Sally

Being aware of the suffering of the patient made it difficult for some participants to sleep. This was expressed by Shannon in the description below:

“If I see her in pain right before I go to bed, I’m laying there going how can I treat the pain and I just lay there” - Shannon

These extracts highlight how consumed caregivers can be with thoughts of the patient. The extracts also indicate that informal caregivers think about if they have fulfilled their roles adequately and how they can improve on assisting the patient. These findings thus, suggest that the caregiving role may be impacting the physical health of caregivers as they are unable to sleep peacefully at night.

4.5.2.2. Fatigue. Many participants reported experiencing fatigue during the patient's illness trajectory. They reported that they were tired and attributed their fatigue to lack of sleep and negative thoughts which kept them awake at night. Additional factors that contributed to their fatigue was having to wake up at night to help the patient reach the bathroom or having to provide the patient with company when they struggled to sleep. One of the participants, namely Anna explained that:

“At night then I feel a little tired but then she tells me to go to sleep. Then I go to sleep, but I don't sleep well because I can hear her at night when she wants to go to the toilet. And if she wants to go to the toilet at night then I lie awake or I go help her reach the bathroom and then she does her thing and then when she is done then she will call me. She will say she is now finished, and I have to take off her wet clothes. Then I will take off her wet clothes, then I will put dry clothes on for her” (translated)- Anna

Some participants were concerned about how the patient would cope having to manage going to the bathroom on their own. They knew the patient either experienced pain, had a catheter, or had a wound that was healing. In some instances, some patients wore nappies or pads because of how delicate their wounds were. Thus, because this was an important aspect of care, caregivers could not rest because they needed to provide the patient with support and care during these vulnerable moments.

As mentioned, some participants kept the patient company at night. They reported that they did not want the patient to be alone while they slept, nor did they want the patient to engage with their thoughts by themselves. This is expressed by Carmelo in the description below:

“At night then she is awake then she can't sleep then you must also stand up and give her whatever she wants, or you just stand up because you don't want her to be awake by herself. So then I sit, I sit up and talk to her. [...] but it makes you tired, it exhausts you. It exhausts you.” (Translated)-Carmelo

These extracts highlight the various factors that contributed to the fatigue that the caregivers experienced. However, the extracts further emphasise that despite the fatigue

experienced by the caregivers, they remained considerate and aware of the needs of the patients and placed those needs above their own.

4.5.2.3. Additional physiological responses to care. Some of the participants experienced a wide range of physiological responses in addition to insomnia and fatigue. This includes back pain, muscle soreness, headaches, and weight loss or weight gain.

For one of the participants, namely, Sally, the physical pain she experienced in her back was a challenging part of the caregiving process. However, she often remained silent about her back pain as she did not want to alarm her mother about the physical effects that the caregiving role was having on her body. This was expressed by Sally in the description below:

“I used to literally carry her, and I promise you my back used to literally break but I would just take that pain. I would never show her that I’m in pain. I will never ever show my mother I’m in pain. I would just, you know, hide it from her. I would just like, If I had to just like have a pain, I would just go behind the sofa and I would just stand up and away where she can’t see me and you know, deal with this pain.”-Sally

Some participants reported having their own physical conditions independent of the caregiving role and thus, attributed any physical problems to their predetermined health conditions. In addition, some of these participants described how their physical conditions affected their ability to provide adequate care and assistance for the patient at times. James who was living with diabetes explained that:

“There are many times that I’m like, I got no energy. I feel like there’s no energy. I’m weak. I don’t know, [if] it’s because of this err, diabetes. It makes you feel weak at times but err, I’m helping myself, supporting myself and I’m getting through it. It’s possible. Just stay focused that’s all.”- James

It is clear from this subtheme that the physical well-being of caregivers were negatively affected during the illness trajectory. Prior studies have also reported on the physical effects of providing informal cancer care. For example, fatigue, pain (Arian et al., 2017), a change in appetite, weight loss and insomnia (Sercekus et al., 2014) were all physical effects reported by informal caregivers in prior research. The findings in this study thus, further highlight the detrimental effects that providing care can have on the body of the caregiver.

Based on the EST (Bronfenbrenner, 1979), the physical and emotional effects discussed in this theme provide some insight into the effects that a relationship can have on the individual. As mentioned, providing care for the patient has a direct influence on the

caregiver's life (Bronfenbrenner, 1979). Therefore, sadness, stress, fear and helplessness were emotional responses to care and insomnia, fatigue, and back pain were physiological responses that the caregiver experienced as a result of caring for an important person within their microsystem.

Most of the caregivers reported completing physical tasks by themselves without the help from support structures such as family and friends. This indicates the lack of physical support available within the microsystem of the caregivers in this study (Bronfenbrenner, 1979). The lack of physical support also affected the health and well-being of these caregivers (Bronfenbrenner, 1979).

4.6. The support networks of informal cancer caregivers

Most of the participants reported experiencing some form of support during the patient's illness trajectory. The support they received often stemmed from very few people in their lives, however most participants reported that they were happy with the amount of support they received from their friends and family. Their reflections regarding the support that they experienced were divided into three categories namely, financial support, emotional support, and spiritual support.

4.6.1. Financial support

Most participants reported that they experienced financial constraints while providing care for the patient. Participants reported that they were pensioners, unemployed or struggled to balance their financial responsibilities while providing care and working full-time. Some participants reported that their family or church members provided financial support in the form of food or money. This is illustrated in the quotation below:

“The stuff we had to get my mom was very expensive but luckily my mom's friends also, they bought her gauze stuff because the hospital only gave her two or four and we needed that stuff, so they blessed my mom with that stuff and the church uhm, also gave us food parcels”- Jazmin

In addition, Sally who was the primary caregiver for her mother reported that her siblings provided her and their mother with financial support. She explained that:

“I won't say it affected me in any way to be honest because my sisters provided everything. As I said to you, I'm not working. They provide everything. If my mom needs anything, I just have to phone them and they will, it will just be there in the next half an hour or something.”- Sally

In Sally's case, finances did not negatively affected her life or her well-being. Her sisters provided her with financial support thus, her primary focus was to take care of her

mother. Like Sally, Rhule did not have to worry about finances. His mother provided him with financial support. This is expressed in the quotation below:

“Nah, it didn’t affect me financially because while she was sick, she was still working, you see.”- Rhule

When sharing his thoughts on his mother working while living with cancer, he stated that:

“I just felt like I had to get a job so she can stop working and start looking after herself because she’s sick”- Rhule

As indicated in the extract, it bothered Rhule that his mother had to work during her cancer experience. Thus, he was worried about the effect that providing financial support for herself, and her children was having on her health.

Financial constraints can exacerbate the challenges that caregivers and patients experiencing during the illness trajectory. Thus, many participants recognised the financial contributions that were made by their family and church members, and they were grateful for the support that they received.

4.6.2. Emotional support

Most participants experienced some form of emotional support during the illness trajectory of the patient. Some participants received support from their partners, their family members, and their friends. When reflecting on the support that they received, they mentioned the people who they could and felt comfortable with to discuss the patient’s diagnosis and well-being. However, this was not always the case. Most of the time, the participants discussed how the patient was doing and not necessarily how they were feeling. For example, Kurt described the support he received in the quotation below:

“No, they were always supportive. All of them. Family, friends always, always asked how she’s doing. They would phone at night, in the morning, during the day.”- Kurt

He further elaborated by stating that:

“All of my biker buddies was always there asking how she’s doing, how am I doing. Sometimes I used to think they were more worried about me than about [the patient].” – Kurt

Kurt was one of the participants who reported that his wife was his main priority. He reported that the cancer experience was not about him. It was about his wife. He also reported that he struggled to talk about his emotions. Thus, it is understandable that his friends would ask about his well-being and that it felt strange to him.

Sally however, stated that her experience as her mother's primary caregiver strengthened her marriage because, despite not living in the same province as her husband, he was still supportive of her. She explained that:

"That's the person I speak to because we've been through this with his mom. I was with him through that you know, so he can relate to me, and I can relate to him, you know, so when I'm in that, that, that depression mode then he will just take me out of it. He just knows how to take me out of it. He would video call me and you know, he will just tell me things that will make me laugh and he will just take my mind completely out of it." - Sally

As mentioned, discussing the patient has also been a positive way in which the caregivers experienced receiving emotional support. This is described by Lola in the quotation below:

"Then we (the family) talk about her and then I will say she feels this way, or she feels like this, and they actually ask me, actually, the family really cares because every day they will ask how she is today, how does she feel, and then I will say, no, she's okay. I will also ask her, and she will say no, tell them I'm okay and they visit her often as well."

(Translated)- Lola

Some of the participants reported that speaking to others about the patient's illness trajectory helped their own emotional well-being. Lola who, as shown in the previous quotation, communicated consistently with her family about her sister's illness trajectory, explained that discussing the patient's diagnosis was important and cathartic. This is expressed in her statement below:

"I think it's good if a person talks about it. To get it off your chest." *(Translated)- Lola*

In addition to having family members as supportive resources, some participants reported that their friends provided them with support as well. In the description below, Katie described how she felt after speaking to her friends, particularly, those who had experience with a family member living with cancer:

"It feels good because it is someone who understand what you are going through and who is really uhm, supportive. It's always good to communicate about how you feel especially if it is with someone who also knows what you are going through with a family member." *(Translated)- Katie*

Some participants have however, reported that they received little support from their family members. Talia explained that the only support she received was from those in her

household which included her mother (the patient), her children and her brother. This is described in the quotation below:

“The only support we have here is each other in this household. That’s the only support we have and uhm, her few friends but not the family. [...] They are less than one hand that is supporting us.”- Talia

Talia reported that she was happy with the support that she received however, she was also angry that her extended family had not been supportive of her mother during her illness trajectory. This is illustrated by the description below:

“It makes me angry. It makes me feel like oh so, when you need us, ja you know, we good enough but now that we need you like you’re missing. Like you’re supposed to be family. [...] Family is family but they’re missing, some of them are missing. I don’t know. I don’t know. I feel like some of them expected her to be dead already. Like some of them expected her to die already and she’s still here and they just gone. So I feel like, I feel like since they gone, I feel like they should stay missing.”- Talia

The statement above indicates how hurt Talia felt by the lack of support of her extended family. Her description highlights why supportive resources are a crucial part of a caregiver’s life and the patient’s illness trajectory.

In this study, most of the participants were able to communicate to at least one individual about the patient’s illness trajectory. These participants reported that they felt good after speaking to someone about the patient. This allowed the participants to report on the patient’s progress, present updates and discuss the patient’s well-being. However, most participants reported that they did not share their thoughts and emotions with others. Many participants relied on their spiritual relationship with God and reported that they would speak to Him. This will be discussed in the next subtheme.

4.6.3. Spiritual support

Many participants reported that their spiritual beliefs played an important role their experience as informal caregivers. Most participants had a relationship with God and reported that they prayed and trusted Him during the patient’s cancer experience. Some participants reported that they spoke to God or a priest when they needed someone to confide in regarding their thoughts and emotions. For example, Peter reflected on how he felt after speaking to his priest in the description below:

“I feel much better. Much better, yes. The pressure is a bit less. I feel very good.”
(Translated)-Peter

Some participants reported that they believed that God played a contributing role in the patient's cancer diagnosis. Kurt, a husband of one of the patients presented this perspective in the description below:

"I can't stress, we can't stress and say err, we got cancer now...No! It's God. If God put, if it's a challenge from God then you must face it."-Kurt

Kurt reported that he was not concerned about his wife's cancer diagnosis because God had provided them with this challenge. Based on Kurt's statement, he viewed his faith in God as a means to understand and accept his wife's diagnosis.

Some participants believed in the power of prayer and reported that they prayed about the patient's diagnosis to God. This is illustrated by Talia in the quotation below:

"There's a lot of praying going on. Even my, even my oldest daughter, she's now 15, uhm, we are very uhm, into the word of God, and so there's a lot of praying because you know, the doctors are healers, but we feel like God is the healer amongst healers. He's the greatest healer you know. If he says yes then whatever we say doesn't matter so we are just uhm, basically living in faith that everything will be better. That God will heal her. We are on that level now."- Talia

The findings in this subtheme suggest that the participants sought comfort and understanding from their relationship with God.

By viewing the theme of support, the findings in this section suggest that support is an important protective factor that can be utilized to reduce some of the negative effects that caregiving has on the health and well-being of informal caregivers. Studies have shown that the cancer experience can facilitate stronger family bonds, and that in some cases, caregivers are able to lean on their family and friends for support (Sercekus et al., 2014; Wells et al., 2008). These findings are consistent with those in this study as caregivers reported that they experienced various forms of support and expressed gratitude towards their family, friends, and religious leaders such as priests. However, studies have also shown that some caregivers do not receive support from their friends and family during the patient's illness trajectory (Sercekus et al., 2014; Stenberg et al., 2012). This was evident in this study as well as one of the participants reported that her extended family was not present and supportive towards her as the caregiver nor towards her mother, the patient.

In addition to supportive family and friends, studies have also shown that informal cancer caregivers rely heavily on their spirituality and their relationship with God to help them through the patient's illness trajectory (Doumit et al., 2008; Maree et al., 2018; Sercekus et al., 2014; Wells et al., 2008). Some studies have found that caregivers reported

praying to God about the patient and confiding in Him about their thoughts and emotions (Doumit et al., 2008; Maree et al., 2018; Sercekus et al., 2014; Wells et al., 2008). These findings were consistent with those in this study as caregivers mostly relied on their relationship with God and viewed Him as their confidant.

In terms of the EST, the findings in this section highlight the importance of supportive relationships within the caregiver's microsystem (Bronfenbrenner, 1979). In addition, the findings suggest that caregivers who are surrounded by supportive individuals may have positive experiences while providing care. In addition, the findings suggest that some of the challenges that caregivers experience may be reduced when provided with various forms of support. This, in turn, may have a positive impact on the health and well-being of informal cancer caregivers.

4.7. Providing care in the context of a pandemic

The participants in this study reported different experiences when reflecting on providing care during the COVID-19 pandemic. All the participants experienced the lockdown regulations that South Africa was placed under while the patients were undergoing treatment or attending medical consultations. When reflecting on their experiences, most of the participants reported that they were vigilant during the COVID-19 pandemic. In addition, they reported that they sanitised their hands, and followed the COVID-19 protocols everywhere they went. For example, in the description below, Talia described the vigilance that she exercised during the lockdown regulation period:

“The fear of going to hospital you know, corona is out there, and catching it, you know you super vigilant about your surroundings, and you super vigilant about where you eat and what you touch and what you don't touch and how you do things now. Everything needs to be sanitized. Your hands must be washed. Even when we come back from the shop, we wipe down everything like, we are super uhm vigilant about that still.”- Talia

The statement by Talia provide some insight into how challenging it was to provide informal cancer care during the pandemic. Some of the participants echoed the sentiments of Talia and reported that they had hand sanitiser in their homes, or their cars. In addition, participants reported that they wore a mask when they were outside of their homes or around other people. Furthermore, most of the participants either limited the number of people who could visit them or told their families and friends not to visit their homes at all. This was expressed by Lola in the quotation below:

“We always made sure that there wasn't a lot of people that visited us and especially to be careful for her sake” (Translated)- Lola

Limiting visitors and being careful was the participants way of protecting the patient from contracting COVID-19. However, one of the most challenging aspects of providing care for the patients during the lockdown period was being unable to accompany them into the hospital. Talia described her thoughts on this challenge in the description below:

“She [mother] started her journey alone because we weren’t allowed to go in with her...and when she was in hospital for uhm, procedures, I, you know, you couldn’t go and visit her. [...] Waiting for her to switch her phone on and getting information from her, that makes you anxious. You anxious because you want to know what’s going on. That has been the downside of the whole pandemic. [...] That’s been the most frustrating experience for me.” - Talia

Some of the participants, like Talia, wanted to provide the patient with physical support, and wanted to see for themselves how the patient was doing. Yet, they were unable to do so. These participants could only communicate with the patients through phone calls or messages. Some of the participants reported that they experienced frustration during that period because they were not receiving communication from HCPs either. Jazmin described her experience of having her mother in hospital during the pandemic in the statement below:

“We couldn’t go [to the hospital], cause we couldn’t see her, and we would video call her, but it was difficult because we couldn’t give her a hug or give her a kiss.” -Jazmin

The statement by Jazmin indicate how difficult it was for informal caregivers to provide support and comfort for patients who were in hospital. Some participants reported that not being able to see the patient in person negatively affected them.

Entering the hospital during the pandemic increased the possibility of the patient contracting COVID-19. One of the participants, namely Shannon, reported that her mother contracted COVID-19 while being admitted to hospital in the gynaecological ward. She reported that her mother was transferred to the COVID-19 ward however, a few days later, she received the call to fetch her mother from the hospital. Shannon reported that she was unhappy with the HCPs decision to discharge her mother from hospital. Her thoughts and emotions about this event is described in the description below:

“I uhm, kind of a little bit upset about the, I mean I went, and I said to my mom, now understand I have a household of five children as well, so I had to go fetch her at the covid ward and I was rather irritated because when I got there uhm, they sent, they told me also I must go find a wheelchair for her because she can’t walk out now. It was my duty to even find a wheelchair and, and, and it just irritated me more. I felt like I was putting my life and my family’s life at risk going into the hospital uhm, especially into the covid ward” - Shannon

When Shannon and her mother was in her vehicle, Shannon's mother apologised for putting her daughter and grandchildren's lives at risk. Shannon reported that she assured her mother that it was not her fault. This is illustrated in the description below:

"I told her not to worry about it because I could get it outside. I just felt at the, that the hospital themselves should have not let her go home but I do understand that they needed the bed for someone who was more ill than her"- Shannon

In the case of Shannon, we can see that the pandemic contributed to the challenges that some caregivers experienced. One of the consequences of Shannon's mother contracting COVID-19 at the hospital was the fact that it delayed the treatment that she needed to receive.

While the caregivers adhered to the COVID-19 protocols to protect the patient, some reported that they did not fear that the patient would be affected by COVID-19. These caregivers either stated that the patient was vaccinated or that they did not believe that COVID-19 was real. When we discussed if the participant experienced fear regarding the possibility of the patient contracting the virus, Peter stated that:

"No, because she has her, she has her, she took her jabs. [She] took both Pfizer's".
(Translated)- Peter

Similarly to Peter, Nelson also stated that he had no fear regarding the patient contracting the virus. He stated that:

"I'm not scared of covid. Covid is no one's playmate [...] but we follow the rules, and we are always careful." (Translated)- Nelson

In addition to this statement, Nelson also explained that he and his wife, was going to take the booster as well. His description is in the quotation below:

"We are vaccinated, and I already asked the doctor if she can go, if we can go for the booster so she said yes, she can go before the chemo so, so we are planning to go for the booster and that will also help."(Translated)- Nelson

However, some participants were not keen on taking the vaccine nor were they sure if the patient should take the vaccine. In the descriptions below, Kurt described how the pandemic affected him and shared his thoughts on the vaccine:

"As a caregiver, covid, covid affected me ja but not my wife's illness because I lost my father, my sister, friends, family, lots of friends, lots of family and you know, I was thinking...my sister had cancer, she survived cancer, then she gets this... freaking jab and then there she's gone. That is why I don't want to go for it."- Kurt

In addition to this statement, Kurt also reported that the information he received regarding whether cancer patients could take the vaccine was confusing. This is expressed in his description below:

“The other thing is, when we asked the doctors if she must go for the jab, some of them said yes, some of them said no. That was very confusing.” -Kurt

As indicated in the above extract, the contradicting information that Kurt received as well as his experience of his sister’s passing contributed to his hesitancy regarding whether his wife should take the vaccine or not.

A novel finding that was described by one of the participants namely James, was the fact that he contracted COVID-19 before his wife was diagnosed with ovarian cancer. He stated that she provided him with care during that process however, he was concerned about whether the COVID-19 virus was still lingering in their home and whether his wife would contract it during her cancer trajectory. His description is in the quotation below:

“I was like sceptic, scared because maybe the err, the virus, the covid virus was like heavy still around in, in the house, outside and inside but I did cover myself, protect myself and her whenever I was doing any medication or assisting her. I covered myself and, and just hope that I won’t affect her with this virus whatever anything coming through because she was like vulnerable and weak, and anything was like possible then. But thank you, thank you to this day, up to this day nothing happened.” - James

The caregivers in this study have however, also highlighted positive outcomes that occurred because of the pandemic. For example, Carmelo reported that his partner contracted COVID-19 which prompted them to go to hospital. In the description below he described how the pandemic helped his partner:

“So she sat there with corona and after corona she continued being sick, so we found out that she has this sick [cervical cancer] you understand. So corona actually helped us in a way.” (Translated)- Carmelo

In addition to Carmelo’s positive perspective of the pandemic, some participants reported that the pandemic facilitated bonding between the caregiver and the patient and within their families. Sarah described how the pandemic positively affected her family in the description below:

“It wasn’t that bad because at least we, at least as a family, we got to spend more time together than we do when covid wasn’t there so ja. [...] She err, said that one doctor told her that she could have like a max of 9 months to live uhm, if she doesn’t take the chemo

so she feels that uhm, that was good for her. Having all her children [sit] around her every day, that if she had to die, at least she had her last days with, with us”-Sarah

This is one of the first studies to explore the experiences of informal cancer caregivers during the pandemic in South Africa and globally. Thus, the findings in this section are novel. Despite the limited literature available on this topic, there are information from two studies that can be highlighted in this section. For example, a recent study which focused on informal caregivers who provided care during the pandemic, found that 76% of caregivers of a sample of 250 were concerned that they could contract COVID-19 and 82% from the same sample were concerned that the patient would contract COVID-19 (Akkuş et al., 2022). These findings were similar in some ways to the findings of this study. For example, some participants were worried about the possibility of them or the patient contracting COVID-19, hence their vigilance. However, other participants reported that they were not concerned about COVID-19, and that the patient was fully vaccinated.

In another recent study conducted by Amaniera et al. (2021), informal cancer caregivers reported that they experienced isolation from their social networks during the pandemic. This, in turn, affected their mental health. This finding contrasts with the findings in this study as most of the participants experienced improved relationships with their family members and with the patient during the pandemic.

From an EST perspective (Bronfenbrenner, 1986), the chronosystem played a role in the experiences of informal cancer caregivers in this study as the pandemic forms part of the changes and life events that occur within the chronosystem. The pandemic contributed to the lack of communication with HCPs and the strict regulations within the public healthcare system. This made it a challenging experience for caregivers who wanted to be present during the patient’s medical consultations or treatment. However, the pandemic also contributed to the relationships within the caregiver’s microsystem (Bronfenbrenner, 1979; 1986). Most of the participants reported that they experienced a closer relationship with those in their households or families which would not have occurred had the pandemic not prompted them to spend more time with each other during the national lockdown regulations.

4.8. Conclusion

In this chapter, I presented the findings and discussed them in relation to prior literature and Bronfenbrenner’s ecological system’s theory. The findings were presented under five main themes which focused on the caregivers’ sense of duty, their relationship with the patient, their relationship with HCPs, their emotional and physical well-being and

the effects of providing care during the COVID-19 pandemic. The findings highlighted various ways in which the health and well-being of informal caregivers were affected while providing cancer care.

Chapter 5

Conclusion, Limitations and Recommendations

The aim of this study was to explore the experiences of informal primary caregivers providing care and assistance for women with advanced or terminal gynaecological cancers in South Africa. In this chapter, I will discuss the findings in relation to the research objectives. Thereafter, I will discuss the significance of this study, and the limitations of this study. Lastly, I will discuss recommendations for future research and for clinicians.

5.1. Summarising the findings and research objectives

In this section, I highlight each research objective and discuss how the findings presented in chapter four met each objective.

5.1.1. *Exploring how gynaecological cancer caregivers perceived the caregiving role*

The first objective was to explore how the informal caregivers of gynaecological cancer patients in this study perceived the caregiving role. In other words, how do the participants view and interpret their role as an informal cancer caregiver. In this study, the participants reported that the patient's well-being was one of their most important priorities. They perceived the caregiving role as their duty and as a result, many participants reported that they had to choose how they would navigate their other responsibilities. This included spending less time at work, taking family responsibility leave, or quitting their jobs. Some participants also reported that they spent less time with their partners or children. Despite the sacrifices that they made, they believed that it was important to be the patient's primary caregiver. For most participants, placing the needs of the patient above their own was an important aspect of providing care. These findings suggest that the participants understood the importance of the caregiving role and were willing to adjust their personal and professional lives to assist the patients during their life-changing cancer experience. These findings also highlight the selfless nature that is prevalent during the complex nature of care provision.

While most of the participants experienced a sense of responsibility for the patient's well-being, all the participants stated that it was their choice to be the patients' caregivers. They reported that they were happy to be the patient's caregiver with some reporting that it was an honour or a blessing to take care of the patient. These findings suggest that with the responsibility and duty that the caregivers experienced, they also experienced a sense of agency when adopting this role. The fact that each participant emphasised their ability to choose to be the patient's caregiver suggests that they experienced some form of freedom and autonomy in their decision-making process. The notion of freedom of choice suggests that the

caregivers were not forced into the caregiving role. However, it should also be noted that contextual factors and personal values also played a role in the participants decision to become a primary caregiver.

For some, the importance of honouring their partners, their marriage or their parents were motivating factors in taking on the caregiver role. For others, expressing gratitude towards their parental figure or repaying them for the opportunities that they were granted served as motivating factors. Additional motivating factors included the belief that it was the role of the parent to provide care for their daughter, the patient. Lastly, some participants reported that the participant did not have anyone else to take care of them. All these motivating factors contributed to their sense of duty. Yet, it does not negate the fact that all these caregivers had a choice regardless of the patient's circumstances.

All the caregivers strived to ensure that the patients' needs were met to the best of their ability. They knew that the role of providing care entailed assisting the patient with their needs and they welcomed this role. For many, being a caregiver also meant protecting the patient's emotional well-being. They reported that they were present when the patient was despondent, upset or crying during vulnerable moments of their illness trajectory. They also reported that they hid their own emotions from the patients to protect them from becoming more sad, hopeless, or despondent. These findings highlight the vulnerability that patients' experience during their illness trajectory and the significant role that caregivers play when it comes to the mental health of the patient. To my knowledge, there are no studies that explore how caregivers experience this important component of their role as a caregiver and how it subsequently impacts their own lives. In addition, it is important to note that the mental health of terminal and advanced cancer patients can affect their day to day lives as well as that of their caregivers. This is an important focus area that needs to be explored. In this study specifically, the participants did not have an in-depth discussion on how the mental health of the patients impacted them.

5.1.2. Exploring the challenges that primary caregivers experience when caring for a gynaecological cancer patient

The caregivers in this study experienced various challenges during the patient's illness trajectory. One of challenges was dealing with the mood swings of the patient. Some of the caregivers reported that dealing with the patients mood swings was difficult and required understanding and empathy on their part. They reported that they understood that the pain as well as being reliant on others may have been a frustrating experience for the patient. Some caregivers also reported that when the patient experienced mood swings, they had to

control and manage their own emotions to prevent upsetting the patient or having them believe that they were a burden. These findings further highlight my point on the importance of the mental health of the patient and caregiver. The findings in this section, particularly relating to mood swings suggest that caregivers suppressed their own emotions during the caregiving process. Most participants reported having to exercise understanding and empathy when they experienced frustration, particularly to how the patient was treating them. In relation to this point, some participants reported that their thoughts or emotions were not important because the well-being of the patient had to come first. They expressed that they did not want to contribute to the frustration or pain that the patient was feeling so they preferred to remain silent about their own frustrations or concerns. These behaviours may be to a detriment to the caregivers. This is an important area of concern that could be explored more in-depth in future literature. These findings would contribute to understanding how informal caregivers manage and cope with the mental, emotional, and behavioural challenges that they experience with a patient and how these challenges impact their own mental health. In specifically reviewing the findings of the study, I found that none of the participants reported extensively on how suppressing their emotions affected their health and well-being.

In addition to this, all the participants reported on how challenging it was to see the patient in pain. The participants reported feeling helpless and sad when witnessing the patient in pain. Some participants also reported feeling the pain with the patient and described wanting to take their pain upon themselves. These findings suggest that the act of care does not only facilitate a physical process but an emotional one as well.

Furthermore, most participants reported experiencing financial difficulties. As such, many caregivers reported that ensuring that they had enough money for food for the patient and themselves. This was an important finding in the study. This finding highlighted some of the contextual challenges that the caregivers experienced. In addition, some of the caregivers reported that financial difficulties contributed to the challenge of providing care because they experienced worry, concern, and stress when they felt like they could not meet the patient's needs. These financial difficulties persisted throughout their caregiving journeys thus, they experienced constant concerns about meeting the needs of the patient. Due to the context of South Africa, particularly pertaining to the inequality, limited resources, and financial constraints of a large majority of South Africans, this finding was important in the context of providing care. It highlighted the complex nature of providing informal cancer care with limited resources and how it affected the emotional well-being of these caregivers. Consequently, there is a need for further studies on how the social context and financial

difficulties impact the caregiving role. Future studies may provide more insight into how the caregiver is affected on an individual level when confronted with external stressors as well.

All the caregivers provided majority of the care for the patient. Thus, most of the caregivers fulfilled physical tasks by themselves. For some caregivers, this proved to be challenging as they reported that they experienced back pain by carrying or lifting the patient themselves. Many caregivers also reported experiencing fatigue because they needed to be awake at night to tend to the patient's needs. While some of the participants reported that they received support from a family member, friend or within their church community, it is important to note that most of the care was provided by one individual, namely the caregiver. It is also important to acknowledge and emphasize the magnitude of this role and the effect that it had on their physical and psychological well-being.

Most of the participants did not report any assistance from HCPs and thus, they had to navigate the process of completing arduous physical tasks while witnessing and supporting the patient when they were experiencing pain. It is also important to note how lonely the process can be for informal primary cancer caregivers. The participants highlighted how helpless they felt when witnessing the patient in pain yet no participant in my study reported on receiving guidance and assistance in managing their own emotions during that process. These findings suggest that there is a lack of adequate support for informal caregivers which in turn, may be detrimental to their own health.

5.1.3. Exploring the sources of support available for gynaecological cancer caregivers

All the caregivers experienced some form of support during the patients' illness trajectories. While most of the caregivers reported that they only had a few people in their lives that provided them with support, they expressed their gratitude to these people. The support that the caregivers described receiving were emotional, financial, and spiritual support. In terms of emotional support, some caregivers reported that their family and friends communicated regularly with them, asked how they were doing and asked about the well-being of the patient. The caregivers who received emotional support reported that speaking to others about the patient's illness trajectory made them feel better or "*lighter*".

Caregivers who received financial support reported that their family or church members provided food parcels, groceries or money which helped aid in the caregiver's care for the patient. In addition, the spiritual support that caregivers reported included speaking to a priest in their church or speaking to God. Many caregivers relied on their spirituality to cope with the patient's illness trajectory and often viewed God as their confidant during this process. In addition, caregivers tried to make sense of the patient's diagnosis by believing

that God had placed that challenge on their path and therefore, it was a challenge that they had to accept and embrace. Nevertheless, God was the participants main source of comfort and support during the patient's cancer experience.

When the caregivers spoke about the support that they received from others, they conveyed a sense of appreciation. They also experienced some form of comfort and acknowledgement that they were not alone in their role as a caregiver. These findings highlight the importance of emotional, financial, and spiritual support. In some cases, some of the participants did not receive each form of support but rather one or the other. These findings thus, suggests that emotional and financial support are important factors that can aid in relieving the concern that caregivers experience.

None of the participants in this study reported experiencing support from a counsellor, psychologist, social worker nor did any of the participants discuss their thoughts and fears with the patient's HCPs. These findings suggest that there is a need for professional assistance and support from HCPs during the caregiving process. It is, however, important to note that these caregivers were providing care during the acute phase of the COVID-19 pandemic thus, it may have been difficult to receive support from HCPs given the multiple responsibilities of HCPs at that time. However, in saying that, the fact that these caregivers adopted their role during two life-changing events, namely the cancer diagnosis and the pandemic, suggests that they needed more sources of support during this time.

5.1.4. Exploring the experiences of gynaecological cancer caregivers regarding their interactions with healthcare providers

The relationship dynamic between HCPs and informal caregivers were complex. In this study, most of the caregivers either had no communication or limited communication with HCPs. One of the main reasons for this lack of interaction were the lockdown regulations during the COVID-19 pandemic. Other reasons for the limited interactions between HCPs and caregivers were limited funds for transport to the hospital or household or work obligations. However, some participants reported that they were unhappy about not being informed about the patient's prognosis and medical consultations from HCPs.

In addition, some caregivers reported that they were concerned about whether the patient was telling them the truth or withholding information from them. Some of the caregivers reported that they wanted information from HCPs because they wanted to emotionally prepare themselves during the patient's illness trajectory. These findings suggest that informal caregivers experienced a sense of invisibility within the healthcare sector. These findings also convey a sense of frustration and concern from informal caregivers. Thus, these

findings highlight how a lack of information or a limited relationship with HCPs can result in feelings of exclusion and subsequently contribute to the concern and worry reported by informal cancer caregivers. It should, however, be noted that contextual factors such as financial difficulties, other responsibilities and the pandemic each contributed to the invisibility experienced by the caregivers. Thus, it is important for future research to explore how barriers within the caregivers' context contribute to their experience of their perceived relationship with HCPs. It may also be important to explore how the pandemic contributed to the perceived lack of relationship with HCPs and the implication thereof in terms the caregiver's mental health and their ability to provide adequate care for the patient.

Caregivers who were able to communicate with HCPs had positive or negative experiences. The caregivers who reported on their positive encounters stated that the HCPs were friendly to the patient and themselves, that they provided them with information when they asked questions and that they were happy with the treatment that they were providing the patient. However, the participants who reported that they had negative experiences stated that they were unhappy with the way the patient was treated. One participant in particular stated that HCPs were inconsiderate and did not encourage the patient. In addition, some participants were unhappy with the way the HCPs performed radiation on the patient. These participants reported that the incisions made on the patient's body made them unhappy and contributed to their negative views of HCPs.

The participants who reported positive experiences with HCPs highlighted the importance of communication, receiving clarity on their concerns or questions and reported a sense of warmth and attentiveness from HCPs. These positive experiences highlight how important the relationship between HCPs and informal caregivers are. They also highlight the need for caregiver visibility and support within the healthcare system. In addition, these positive experiences convey the notion that HCPs helped shape and prepared the caregivers for their role. The findings also suggest that the friendliness that HCPs conveyed formed part of acknowledging the caregivers within the hospital and within the patients' lives.

The caregivers who reported being unhappy with the incisions and subsequent wounds of the patient highlight how challenging it must have been for the caregivers to provide care in such a delicate phase of the patient's illness trajectory. The participants reported viewing HCPs negatively after seeing the scars or the locations of the incisions. These views may negatively influence the relationship between caregivers and HCPs if not addressed.

5.1.5. Exploring how caregivers perceive their relationship with the gynaecological cancer patient

The relationship between the caregiver and the patient was complex. Firstly, all the participants reported that they experienced a sense of duty towards the patient. This finding was also discussed in the first objective. Additionally and as mentioned, the participants reported that the patient's mood swings was a challenge that they had to accept and manage. Furthermore, participants reported that they put the patient's needs first and that they tried to assist the patient's physical needs and protect their emotional well-being.

As indicated in chapter four, witnessing the patient in pain, assisting with bathroom activities, and struggling to get the patient to eat negatively affected the caregivers' emotional well-being. Caregivers reported experiencing stress, fear, sadness, and insomnia during the patient's illness trajectory. The insomnia that caregivers experienced were attributed to their thoughts at night. Some caregivers reported that knowing that the patient was in pain or that the patient may need their assistance with bathroom activities made it difficult to sleep peacefully. In addition, thinking of the possibility of losing the patient and having the fear of waking up and seeing that the patient had passed on were also reported as factors that kept the caregivers' awake at night.

The stress that caregivers experienced were mainly due to financial constraints and having to manage their responsibilities at work and at home. Some of the caregivers reported that when the patient was not doing physically or emotionally well, that it negatively affected them. However, most of the caregivers reported an improved or deeper connection with the patient. Partners reported that they were more in love with the patient and adult children reported that they bonded with their mothers in a way in which they had longed for in previous years.

These findings suggest that the dynamic between the caregiver and the patient during the cancer experience may influence the caregiver's mental health. As indicated by the findings, caregivers fulfil many roles, yet the gravity of the caregiving role can be detrimental to the health of the caregivers. As shown in this study, the context of the caregiver together with their personal lives contributed to the struggles that these caregivers endured. Yet, none of the participants were provided with professional support or assistance with their emotions and their thoughts when confronted with the care and the potential death of the patient.

5.1.6. Exploring how the coronavirus pandemic affected informal primary cancer caregivers

All the caregivers in this study reported that they were vigilant during the pandemic and complied with the lockdown regulation rules of wearing masks, using hand sanitizer, and not socialising with others in their homes. Some caregivers reported that they did not fear the patient contracting COVID-19 because the patient and themselves were fully vaccinated. Others however, reported that they complied with the safety measures even though they did not believe in the reality of COVID-19 or the safety of the vaccine.

Some caregivers reported that not being present with the patient at the hospital was difficult and contributed to their frustration and concern because they could only receive information from the patient through phone calls or messages.

Lastly, most caregivers reported that the pandemic facilitated bonding between them and the patient or other family members. These caregivers reported that they developed a closer connection to their family members which would not have occurred without the presence of a pandemic. In addition to this, the caregivers reported that they spent more time with the patient because others could not visit the patient during the lockdown period of the pandemic.

The findings in this section was novel because the presence of the pandemic contributed to the way in which care was perceived and provided. These findings added important insight into the challenges that informal caregivers experienced. However, the findings also provide insight into the positive aspects that were elicited during the cancer experience. It is interesting to note how the pandemic positively contributed to the family unit and the quality time that caregivers were able to experience. It is important for further research to be explored on how the pandemic has affected cancer caregivers to provide a further in-depth discussion in this domain.

5.2. Significance of this study

This study is significant because it provided in-depth accounts of informal caregivers of gynaecological cancer patients in South Africa. According to my knowledge, this is the first study conducted on the experiences of caregivers with gynaecological cancer in South Africa. The reason for exploring the experiences of these caregivers were due to the incidence and mortality of women diagnosed with gynaecological cancers in South Africa. Thus, there is a need to understand the cancer experience from the perspective of caregivers in this domain.

Additionally, I specifically focused on the terminal or advanced stage of the cancer. Thus, the caregivers' experiences were unique in terms of when the provision of care was explored. This provided more insight into how caregivers experienced the period of care during a delicate stage of the patient's trajectory and how this impacted the caregivers.

Based on the literature that I engaged with and in searching for articles, I was unable to find many articles that explored gynaecological cancer caregivers during the terminal stage of the disease. This added to the exploratory nature of the study as there was a need to explore and provide the caregivers with a platform to voice their experiences.

In this study, contextual stressors such as financial constraints contributed to the study's significance. In addition, it provided insight into the impact that it had on the emotional well-being of the participants. One of the significant findings was the participants concerns about food. This was a prominent concern which heightened their sense of responsibility. When exploring the literature, there were limited studies which focused on the financial difficulties of caregivers, particularly in relation to food. Thus, this finding contributes to the literature in this regard.

Conducting this study during the acute phase of the COVID-19 pandemic also contributed to the significance of the study. Currently, there are limited studies on the experiences of informal caregivers who provided cancer care during the pandemic. Thus, there is limited knowledge on how this affected caregivers during the patient's illness trajectory. This knowledge is important because it provides insight into how the pandemic affected the health and well-being of caregivers during the pandemic. This study's findings were novel in that participants provided positive and negative experiences of providing care during the pandemic. These participants also highlighted how the pandemic affected their role within the healthcare system and with HCPs.

Furthermore, this study increased awareness regarding the needs of informal cancer caregivers in South Africa that are yet to be met and thus, there is a need for interventions that can facilitate that process. Lastly, this study highlighted the importance of implementing policies that can financially assist informal caregivers within their role.

5.3. Limitations of the study

The first limitation was language. I conducted the interviews in English and Afrikaans as those were the only languages that I am proficient in. This limitation served as a barrier to caregivers of gynaecological cancer patients who were not proficient in these languages.

The second limitation was that the study was conducted in one academic tertiary hospital in the Western Cape. This limitation thus, prevented me from exploring the

experiences of informal caregivers with HCPs from other public and private hospitals within the Western Cape and within other provinces in South Africa.

The third limitation was mostly using telephone calls as the method for the interviews. As mentioned in the method section, only one participant agreed to do a face to face interview. This interview took place in a private office in the hospital while the patient waited in the waiting room for her medical consultation. Most of the participants preferred telephonic interviews for various reasons such as a) not being allowed in the hospital, b) having to manage and fulfil other responsibilities and c) wanting to minimise the risk of contracting COVID-19 by staying indoors. However, telephonic interviews proved to be challenging due to connectivity and signal issues. In addition to this, most of the participants conducted the interview in their homes with the patient in a different section of their homes. This may have influenced how the participants answered questions and what they were willing to share in their interviews. Furthermore, the lack of face to face interviews may have made it difficult for the participants to feel comfortable to share information about their caregiving experience because they had not seen me in person.

5.4. Recommendations for future research

This study specifically focused on the experiences of informal cancer caregivers of gynaecological cancer patients. For this reason, only the caregivers' perspectives were documented. However, since the relationship with the patient was one of the main findings of this study, it is important to explore the patients' experience of their relationship with their caregivers while navigating their lives with an advanced or terminal cancer diagnosis.

An additional interesting study would be to explore the experiences of advanced or terminal gynaecological cancer patients and their informal caregivers in South Africa. This will allow the researcher to include the perspectives of both the patients and the caregivers in one study. This possible research topic could also aim to include individuals with diverse languages as well as those seeking treatment at public and private hospitals in South Africa.

As mentioned, caregivers in this study were providing care during the advanced or terminal stage of the patient's diagnosis. Thus, a study on the experiences of bereaved informal cancer caregivers of patients with gynaecological cancer in South Africa would contribute to the knowledge and experience of caregivers in this domain.

To my knowledge, this was the first study to explore the experiences of informal cancer caregivers during the COVID-19 pandemic in South Africa. Future research on how the pandemic affected informal cancer caregivers need to be explored. Additionally, in this study, the caregivers were providing care in the acute phase of the pandemic. Thus, the long

term psychological, physical, social, and financial effects are yet to be known. This is also an important avenue that needs to be explored.

Lastly, as illustrated in this study, the participants' experiences were not only challenged by financial difficulties, but they also experienced various emotions which negatively affected their emotional well-being. Thus, developing a psycho-social intervention to meet the psychological needs of these caregivers may be beneficial to their mental health in the long term.

5.5. Recommendations for clinicians

Short term training programs can be introduced to help informal caregivers feel equipped in their role as caregivers. In addition, information workshops may help increase the knowledge of informal caregivers regarding the patient's type of cancer and the tasks that they need to fulfil when providing home-based care.

In addition, there is a need for psychological services for informal cancer caregivers in South Africa. Thus, improved access to psychological services should be implemented in communities, particularly for those who do not have the financial means to seek or attend therapy. This can be done by training lay counsellors within communities to provide some support for these caregivers. In addition, advocacy groups and interventions in communities may also aid in the support that caregivers experience.

5.6. Conclusion

In this chapter, I discussed the study's findings in relation to the research objectives. Thereafter, I discussed the significance of the study, and its limitations. Lastly, I provided recommendations for future research and for clinicians.

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Appendix A

Physical Leaflet

Are you an informal primary caregiver of a woman with advanced or terminal gynaecological cancer?

You are invited to participate in a research study. The study aims to explore the experiences of informal, primary caregivers of patients with incurable gynaecological cancers.

To be able to participate:

- You need to be the primary caregiver of a women receiving treatment for womb cancer (cancer of the cervix, ovaries, uterus, vagina, and vulva)
- Treatment must be at Tygerberg Hospital for a minimum of one month.
- You must be taking care of the patient for at least one month or longer.
- You must be also 18 years or older,
- Speak English or Afrikaans,
- You must not get paid for being the patient's caregiver.

You will be asked to take part in an interview. In the interview, you will be asked about your experience of being the patient's caregiver. This interview will be 60-90 minutes long. The interview will be audio-recorded with your permission.

Participants will receive a token of appreciation from the researcher for attending the interview.

If you are interested in learning more about this study, please feel free to contact me.

This study is conducted under the guidance of the Department of Psychology at Stellenbosch

Principal Investigator

Chantè Odendaal

20758960@sun.ac.za

0848267036

Supervisor

Dr Rizwana Roomaney

rizwanaroomaney@sun.ac.za

Co-supervisor

Prof. Hannah Simonds

hsimonds@sun.ac.za

Appendix B

Online leaflet

Are you an informal primary caregiver of a woman with advanced or terminal gynaecological cancer?

You are invited to take part in a research study. The study aims to explore the experiences of people who take care of women with advanced or terminal womb cancers.

To be able to participate:

- You need to be the primary caregiver of a woman receiving treatment for womb cancer (cancer of the cervix, ovaries, uterus, vagina or vulva)
- You must be taking care of the patient for at least one month or longer
- You must be 18 years or older
- Speak English or Afrikaans
- You must not get paid for taking care of the patient

You will be asked to take part in an interview. In the interview, you will be asked about your experience of being the patient's caregiver. This interview will be 60-90 minutes long. The interview will be audio-recorded with your permission.

Participants will receive a token of appreciation from the researcher for attending the interview.

If you are interested in learning more about this study, please feel free to contact me.

This study is conducted under the guidance of the Department of Psychology at Stellenbosch University. Ethical clearance was granted by Stellenbosch University's Health Research Ethics Committee and permission to conduct this study was granted by the Western Cape Department of Health.

Principal Investigator

Chantè Odendaal

20758960@sun.ac.za

0848267036

Appendix C

Consent form

TITLE OF RESEARCH PROJECT:	
Exploring the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancers	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Ms. Chante Odendaal	Ethics reference number: S21/04/075
Full postal address: Psychology Department, Wilcocks Building, Ryneveld Street, Stellenbosch, 7600	PI Contact number: 0848267036

We would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the investigator (Chante Odendaal) any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary**, and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you or the patient negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

The Health Research Ethics Committee at Stellenbosch University has approved this study. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

- This research aims to explore the experiences of people who take care of women with advanced or terminal womb cancer. Womb cancer can be cancer in the cervix (neck of the womb), ovaries (female glands), uterus (womb), vulva (external genital organs) or vagina.
- You will be asked to take part in an interview. In the interview, you will be asked to share what it is like to care for someone who has terminal or advanced womb cancer. The interview can be face to face, online or on the phone. If you choose to do your interview through a phone call, then I will phone you on a day and time that suits you. If you choose to do your interview online then you can decide if you want to do the interview on WhatsApp, Microsoft Teams, Skype or Zoom. You will be given data for the interview on the day that you choose to do the interview. The online interview will also be done on a day and time that suits you. If there is no surge (huge increase) in Covid-19 cases and the country remains (stays) in level 2, then you can choose to do your interview face-to-face. You will be able to choose to do your interview in one of four places namely, your home, a private office at your workplace, in a private office at the radiation oncology clinic (this is the clinic where the patient is receiving treatment) or in a private office in the psychology department of Stellenbosch University. If you choose to conduct your interview in one of the offices in the department of psychology at Stellenbosch University or at the radiation oncology unit on a day that the patient is not having treatment, you will be reimbursed for your travelling expenses. This means that I will pay back the money that you spent on travelling costs. However, if there is a surge (huge increase) in Covid-19 cases in the Western Cape then face to face interviews will not be an option. Similarly, if South Africa moves to level 3, 4 or 5 of lockdown regulations then face to face interviews will also not be an option. This means that online or telephonic interviews will be done.
- There are two ways to be asked to be part of this study. The cancer patient will give you a leaflet that tells you that the study is about sharing your experiences of being the caregiver of the patient. If you are interested to learn more about the study, you can contact me via SMS, WhatsApp or phone call. I may also ask the patient if I can speak to you about the study if you are waiting for her outside the clinic. You could also be asked to take part in the study online on the Instagram, Facebook, Twitter or LinkedIn pages of the Cancer Association of South Africa (CANSA).

- A sample of 20-30 participants will be asked to take part in this study
- To be included in this study, you need to be the main person taking care of the patient with womb cancer. This can be any womb cancer. For example, cancer of the cervix (neck of the womb), ovaries (female glands), vulva (the external genital organs), uterus (the womb) or vagina. You need to be caring for the patient for at least one month or longer before you can do the interview. You have to be 18 years old or older. You cannot be getting paid (money) for taking care of the patient.
- The interviews will be in either English or Afrikaans depending on your preference. This means that you can choose to do your interview in either English or Afrikaans. The interview will be 60-90 minutes long.
- The interviews will be audio-recorded using two digital audio-recorders. This is to make sure that I have two recordings of the interview in case one recorder is not working properly. I need your permission to record your interview. This means that I will not record your interview without asking your permission before we start the interview. The interviews that are recorded will be stored on my laptop with a password. It will also be stored on my university linked OneDrive and only me and my supervisors (Dr Roomaney and Prof Simonds) will have access to it. This means that no one else will be able to hear or get the interviews that are recorded. This means that no one will know that it is you who have taken part in the study.
- You will also need to fill in a demographic questionnaire that will ask you short questions about yourself, your relationship with the patient, how long you have been taking care of the patient and what womb cancer the patient has.
- In this study, your name will be replaced with a unique study number. I will save your personal information and the recording with a study number so that no one knows it was you who took part in the study. I will also give you a fake name when I report on your story.

Why do we invite you to participate?

- As research exploring the experiences of informal primary caregivers of women with advanced or terminal womb cancers patients are limited in the South African context, we would like to fill this gap as it may be influential in bringing awareness to the needs of gynaecological cancer caregivers. In addition, this research may help people create interventions for individuals who take care of women with advanced or terminal womb

cancers. This study may also help the public and doctors understand what it is like for as the caregiver to take care of a woman with advanced or terminal womb cancer.

What will your responsibilities be?

- As someone taking part in this study, you will be responsible for sharing your experiences with me in an honest manner. If there is no surge (huge increase) in Covid-19 cases and the country is on level 2 of the lockdown regulations then you can choose to do a face-to-face interview but then you will have to follow strict rules such as wearing a mask and sanitising your hands (I will have hand sanitizer for you to use).

Will you benefit from taking part in this research?

- You will help researchers, the public and medical professionals (doctors, nurses and psychologists) understand what it is like to be a caregiver for a woman with advanced or terminal womb cancer in South Africa.

Are there any risks involved in your taking part in this research?

- There are physical and emotional risks that is involved with taking part in this study. The physical risk is the potential of getting the Coronavirus if you decide to do a face-to-face interview with me. However, I will put safety measures (rules) in place such as wearing masks, sanitizing hands and sanitizing the office space that we will use. We will also be sitting at least 1,5 metres apart from each other. In addition, since you will be sharing your personal experiences with me, you will receive (get) the contact details of a counsellor at Welgevallen Community Clinic. The sessions at the Welgevallen Community Clinic are online and free. You can contact the clinic if you need to speak to someone about your struggles, emotions or experiences. You can also contact me or Dr Rizwana Roomaney if you are experiencing distress (struggling with your emotions or challenges or you just want to talk to someone about what you are going through) after the interview. We will then get you a counsellor that will give you counselling sessions for free. You will also get the contact details of the South African Depression and Anxiety Group (SADAG) as well as the contact details of Lifeline Western Cape which are two free counselling helplines. In addition, should you feel the need to withdraw from the study, you will be free to do so. This means that if you do not want to be part of the study anymore, then you can decide to leave the study. Nothing bad will happen if you do not want to be part of the study anymore.

- The contact details of the Welgevallen Community Clinic (Welgevallen House, Suidwal Street, Stellenbosch) are:

Phone: 021 808 2696

Email: WCPC@sun.ac.za

- The contact details of South African Depression and Anxiety Group are:

Phone: 011 234 4837

- The contact details of Lifeline Western Cape are:

Phone: 021 461 1113

- You can contact the research supervisors, Dr Rizwana Roomaney by email at rizwanaroomaney@sun.ac.za or by phone at 0218083973

- You can contact me either by email at 20758960@sun.ac.za or by phone at 0848267036.

Who will have access to your medical records?

- No one associated with this study will have access to your medical records.

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

- You will receive R100 Checkers voucher or R100 which will be sent via an electronic funds transfer (eft) as a token of appreciation.
- You will also be given R100 data one hour before the interview if you decide to do an online interview via WhatsApp, Zoom, Skype or Microsoft Teams. If you decide to do you interview on the phone, then I will phone you. This means that you will not get R100 data, but you will not have to use your own airtime as I will be phoning you.
- If there is no surge (huge increase) in Covid-19 cases and the country is on level 2 of the lockdown regulations, then you can decide to do a face-to-face interview with me. If you decide to do the interview in an office in the psychology department of Stellenbosch University, then I will give you R100 for travelling costs. If you decide to the interview at the radiation oncology clinic (the clinic where the patient is having treatment) on a day that the patient is not having treatment, then I will give you R100 in travelling costs. However, if you decide to do the interview at the radiation oncology clinic on a day that the patient is having treatment at the clinic, then I will not give you R100 in travelling costs. You will also be given snacks if you attend the face-to-face interview after the interview.

- You will not be asked to pay for anything.

Is there anything else that you should know or do?

- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed.
- You can contact the research supervisors, Dr Rizwana Roomaney by email at rizwanaroomaney@sun.ac.za or by phone at 0218083973 as well as Prof. Hannah Simonds by email at hsimonds@sun.ac.za or by phone at 0219384727.
- You can contact me either by email at 20758960@sun.ac.za or by phone at 0848267036.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled exploring the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancers.

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary**, and I have not been pressurised to take part.
- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (place) on (date) 2021.

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

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document in a simple and clear manner to

- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as
 discussed above.
- I did/did not use an interpreter.

Signed at (place) on (date) 2021.

.....
Signature of investigator **Signature of witness**

Permission to have all anonymous data shared with journals:

Please carefully read the statements below (or have them read to you) and think about your choice. No matter what you decide, it will not affect whether you can be in the research study, or your routine health care

When this study is finished, we would like to publish results of the study in journals. Most journals require us to share your anonymous data with them before they publish the results. Therefore, we would like to obtain your permission to have your anonymous data shared with journals.

Tick the Option you choose for anonymous data sharing with journals:

I agree to have my anonymous data shared with journals during publication of results of this study

Signature_____

OR

I do not agree to have my anonymous data shared with journals during publication of results of this study

Signature_____

Appendix D

Ethics Approval



Approval Notice

New Application

12/07/2021

Project ID :22105

HREC Reference No: S21/04/075

Project Title: Exploring the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancers.

Dear Miss CM Odendaal

The **New Application** received on 08/07/2021 was reviewed by members of **Health Research Ethics Committee** via **expedited** review procedures on 12/07/2021 and was granted **full approval**.

Please note the following information about your approved research protocol:

Protocol Approval Date: 23 June 2021

Protocol Expiry Date: 22 June 2022

Please remember to use your Project ID 22105 and Ethics Reference Number S21/04/075 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/22105>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Melody E Shana

Coordinator

HREC1

Appendix E

Western Cape Department of Health Approval



TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG**
Marinus
TELEPHONE: **021 938 5752**

Project ID: 22105

Ethics Reference: S21/04/075

TITLE: Exploring the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancers.

Dear Miss Odendaal

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Tygerberg Hospital Health Research Policy and Protocol of **April 2018**, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital for a year based on your HREC approval.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

A handwritten signature in black ink, appearing to read "GG Marinus", is written over a rectangular stamp. The stamp contains the following text: "Dr GG Marinus", "MB, MPA", "FRM", "RP0370665", and "Western Cape Medical Services".

Dr GG Marinus
MB, MPA,
FRM
RP0370665
Western Cape Medical Services

DR GG MARINUS
MANAGER: MEDICAL SERVICES

Date:

30/01/2021

Administration Building, Francie van Zijl Avenue, Parow, 7500
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505
www.capegateway.gov.za

Appendix F

Amendment



10/06/2022

Project ID: 22105

Ethics Reference No: S21/04/075

Project Title: Exploring the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancers

Dear Miss CM Odendaal

We refer to your amendment request received 30/05/2022.

The Health Research Ethics Committee (HREC) reviewed and **approved** the amendment through an expedited review process.

The following amended documentation was reviewed and **approved**:

1. MODS_Protocol_20220530
2. MODS_Informed consent form_20220530
3. Amendment of Physical leaflet_11March2022
4. Amendment of Online Leaflet_11March2022

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your project ID 22105 and ethics reference number S21/04/075 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Melody E Shana
Coordinator: Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1) REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1) IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition)

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix G

Interview Schedule

I am going to ask you a few questions about your experiences as a gynaecological cancer caregiver. Please take your time to answer the questions, providing as much or as little information as you feel comfortable sharing. The information that you share will be treated as confidential. If at any time you would like to end this interview you are free to do so.

1. Can you please describe how you became the patient's primary caregiver?
2. Can you please describe a typical day in your life as a caregiver?
Prompt: what are some of the tasks that you help the patient with? / are there any tasks that you have difficulty helping the patient with?
3. What are the challenges that you experience being a cancer caregiver?
4. Do you have other responsibilities that you also need to fulfil other than being a caregiver?
Prompt: Are you employed? Do you have children? / How has being a caregiver affected your responsibilities? / Are you overwhelmed/stressed? How has stress affected your other responsibilities?
5. How has providing care affected your physical well-being?
6. How has providing care affected you financially?
7. How has providing care affected your social life?
8. How has providing care affected your personal relationships?
9. What are some of the emotions you experience while providing the patient with care and assistance?
10. Can you describe the support available to you?
Prompt: Who provides you with support? /Who do you speak to when you need someone to talk to? / Can you describe how you feel when you experience support (or no support)/Are you able to be completely honest about how you feel when you are venting to someone? Do you feel that you are being supported enough?
11. What are your experiences with the patient's doctor and the healthcare system?
Prompt: Are there any challenges that you experience in the hospital? How do you and the doctor/ nursing staff communicate? How does the communication with the doctor/nurses affect your role as the patient's caregiver? If there were any things that you would change between the relationship with the patient's doctor, what would it be? What

emotions do you experience at the hospital or when speaking to doctors or nurses? How often do you communicate with doctors or nurses?

12. How has providing care to the patient affected your relationship with the patient?

Prompt: What are some of the challenges you experience when communicating with patient? What are some of the emotions your experience when communicating with the cancer patient? Do you experience any conflict with the patient? If so, what causes conflict in your relationship? What happens when conflict arises and how is it resolved?

13. What are some of the lessons you have learnt while providing care?

Prompt: if there were any positive or meaningful experiences during your time as the patient's caregiver, could you please describe these?

14. How has the Coronavirus affected your role as a cancer caregiver?

Appendix H

Welgevalen Community Psychology Clinic



WELGEVALLEN COMMUNITY PSYCHOLOGY CLINIC

Department of Psychology, Stellenbosch University

Tel: 021 808 2696 Email: wpcpc@sun.ac.za Web: www.sun.ac.za/wpcpc

20/04/2021

RE: Free Psychological Services

The Welgevalen Community Psychology Clinic (WCPC) is a clinic offering free psychological services. The clinicians delivering the service at WCPC are student psychologists in training, all working under the supervision of registered independent practicing Clinical/Counselling Psychologists. WCPC is offering online therapy sessions during the Covid-19 pandemic.

This letter serves as confirmation that the clinic services are available to provide support to any research participants who may experience psychological distress during or due to participation in the research being conducted by Chante Odendaal.

The abovementioned student is conducting this research in fulfilment of her Masters in Psychology (Thesis) under the supervision of Dr Rizwana Roomaney from the Department of Psychology at Stellenbosch University.

Her research title is: Exploring the experiences of informal primary caregivers of patients with palliative gynaecological cancers.

The researcher agrees to provide the clinic details to all research participants to ensure that they are aware of the support available and are thus able to access the necessary support should the need arise.

Please do contact me for further information

Megan Snow

*Lecturer: Psychology Department
Clinical Psychologist
Clinic Manager
Welgevalen Community Psychology Clinic*