A qualitative study of the experience of primary caregivers of patients receiving end of life hospice care

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DECLARATION

I, …*Johanna Lubbe…………*, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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TABLES.

ACRONYMS

AIDS: Acquired immunodeficiency Syndrome
CANSA: Cancer Association of South-Africa
CBHW: Community based Health Workers
COPD: Chronic obstructive pulmonary disease
CSNAT: Carer Support Needs Assessment Tool
DALY's: Disability-adjusted life year
HIV: Human Immunodeficiency Virus
HPCA: Hospice and Palliative Care Association of South-Africa
HREC: Human Research Ethics Committee
IAHPC: International Association for Hospices and Palliative Care
IPU: In-Patient Unit
LMICs: Low- and middle-income countries
NCD: Non-communicable disease
NGO: Non-governmental organization
NNPC: Neighbourhood Network in Palliative Care
NPFSPC: The National Policy Framework and Strategy on Palliative Care
NPO: Non-profit organization
OT: Occupational therapist
PCC: Person-centered Care
PubMed: "Pub" Public/Publisher; "Med" refers to Medline database
TB: Tuberculosis
UCT: University of Cape Town
UHC: Universal Health Coverage
WHA: World Health Assembly
WHO: World Health Organization
WHPCA: World Hospice and Palliative Care Association

ABSTRACT

A qualitative study of the experience of primary caregivers of patients receiving end of life hospice care

Introduction.

A life-threatening illness impacts profoundly not only the patient but also the family. As the spouse or partner is often the primary caregiver for patients with a life-threatening illness it especially affects the couple as a unit, rather than isolated individuals.

The Aim of this study.

To explore and describe the experience of primary caregivers of patients at end of life receiving care from Hospice Bloemfontein.

Objectives.

1. To obtain an in-depth description of the experience of primary caregivers of patients within hospice care.
2. To explore and describe primary caregivers' coping mechanism while providing care.
3. To explore and describe support structures and resources that assist the primary caregiver.

Methods.

A qualitative study was conducted through individual semi-structured interviews, to explore the experiences of primary caregivers taking care of their partners with a life-limiting disease in hospice care in Bloemfontein, Free State.

Results.

The findings of this study reflect on the complex experiences and emotional responses of primary caregivers taking care of their partners with a life-limiting disease in hospice care. It also reflects on the demands that are placed on those caregivers to meet all the different and multidimensional needs of their ill partners, which include the effect it has on them financially, physically, and personally. The study further reflects on their emotional reaction to the illness, their caregiving and the impending death of their partners in a context where they are often isolated. Certain factors added to and others relieved caregivers' distress. Although there were common themes, the reactions and experiences of all participants were unique and individual. As a consequence of these demands some of the caregivers in the

study experienced exhaustion, physical complaints, isolation, sleeplessness, spiritual distress, and unmet needs.

Conclusions.

This study reflects on the importance of the role of caregivers as an active participant in providing care and comfort during the final stages of the illness of a patient, but also reinforces the critical need to provide the necessary and adequate support to those caregivers. A thorough assessment is necessary to respond holistically to the unique and individual needs, challenges, and concerns of families.

CHAPTER 1

Introduction

"There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver." ***Rosalyn Carter.***

1.1. Definition of primary caregiver

The primary caregiver is identified by the patient, in line with the definition of caregivers as: "...*unpaid, informal providers of one or more physical, social, practical and emotional tasks. In terms of their relationship to the patient, they may be a friend, partner, ex-partner, sibling, parent, child or other blood or non-blood relative"* (1). This research study investigated the experiences of the primary caregiver who was either a spouse or a partner of the patient, with the partner being the person who the patients identified as his/her partner.

1.2. Context of the study

The study was conducted in Hospice Bloemfontein, situated in Bloemfontein, Free State. The hospice has home-based adult palliative care patients from the state and private sector, of whom the majority are cancer patients but also include patients with organ failure, multiple-sclerosis, COPD and motor-neuron disease.

1.3. The impact of a life-threatening illness

A life-threatening illness impacts profoundly a whole family and not only the patient. Family caregivers, along with the patient, exist within a social unit that is affected by a serious illness, from the time of diagnosis, until end of life and into bereavement (2). A serious illness affects the role the patient had played in a family and becomes someone who needs a caregiver. As the spouse or partner is often the primary caregiver for patients with a life-threatening illness it especially affects the couple as a unit, rather than as isolated individuals (3).

The informal caregiving experience is complex and the relationship dynamic changes and evolves in both predictable as well as unintended ways (3). Especially with a more advanced illness, caregiving involves stress and higher levels of anxiety (3). As stated in literature the stresses include "*fatigue, emotional distress, diminished quality of life, social restriction and isolation, family conflict and financial difficulties"* (1, 4, 5). Among the listed stressors, the reported primary stressors can be categorized as *"patient illness-related*" and *"care demands"* (3). "Spill-over" effects of those primary stressors include *"role and relationship"*, *"self-concept"*, and *"employment and finance*" (3). Caregivers, especially partners or spouses, not only face the potential loss of their loved one (3), but may feel overwhelmed and inadequate to meet their loved one's practical and emotional end-of-life care needs or feel inadequate to advocate for those needs. They may experience guilt or resentment when other care providers become involved (such as hospice or hospital care, formal caregivers) (6). In their new unfamiliar role as a caregiver, the stresses involved as well as the critical importance of their caregiver role can create a situation where the caregiver becomes the "hidden patient" (7). In particular, "*passing from active treatment to palliative care represents a delicate and dramatic transition both on the clinical and the emotional levels",* which is true for both the patients and their families involved, especially those caring for the patient (8). Unless the caregivers receive sufficient and adequate support from the family and/or others, coping mechanisms will fail and the caregiver will run the risk of developing hidden or visible signs of illness (9).

1.4. Rewards of caring for someone at the end of life

Despite all these challenges, caring for someone at the end of life and mediating the process of dying can be rewarding as it can create an opportunity for healing for all who are involved (10). Caregivers have reported post-traumatic growth as a result of their loved one's diagnoses and caring for them (10). In the process of accepting the illness as a family matter they may gain a different and better perspective as well as newfound resilience (10). The illness may force them to reflect on the role of the loved one in the family, as well as the importance of their family member, and could also provide an opportunity for families to unite (10). The illness of a loved one can create an awareness of and an opportunity for family members to reflect on their own health, and motivate them to regular healthcare while they are still healthy (10). The awareness that everyone is vulnerable to illness could result in an appreciation of the mundane aspects of everyday life (10). Those experiencing satisfaction in their caregiving role, feel more confident that the care they provide is valuable and effective, but realizing their own limitations and needs, may also be more open to allowing the involvement of hospice, formal caregivers, and others without a sense of failure, guilt or resentment (6).

The knowledge of impending death can furthermore result in an opportunity for resolution and healing of possible personal and interpersonal conflicts (11). In this way, an opportunity to develop healing connections and cultivate compassion in the caring relationship can be created facing end-of-life of a family member (11). Providing this compassionate care to the loved ones is motivated by love, which is demonstrated by an altruistic motivation and continuous small acts of kindness (12). Caregivers often describe a sense of purpose and meaning, and mobilize coping mechanisms to help them overcome some challenges - which in return positively influence their self-confidence and sense of commitment (13, 14). The caregiver's confidence is shaped by how they perceive their ability to provide the needed care adequately to their loved ones (15). The levels of stress that family caregiving cause depends very much both on the actual work involved as well as the meaning and satisfaction they derive from the experience (16). To create an opportunity to experience meaning in the end-of-life care of their family member, families and primary caregiver need the best possible support - this support is in line with the definition of palliative care.

1.5. The role of Palliative Care in supporting primary caregivers in end-of-life care

To provide the best possible support, it is important to understand the experiences of caregivers and their perceptions they have about the end-of-life care they provide. This understanding can high-light areas where interventions are needed which may improve their caregiving experience and may also ultimately influence their own wellbeing and health positively, as well as the overall end-of-life care quality (6). Quality of life is a core element in palliative care, and to add to this quality one needs to recognize the burdens and difficulties associated with the role of caregiver, so as to provide appropriate support to those caregiver addressing the specific need of the caregiver (8). Palliative care has a holistic approach and takes many different dimensions of care into account including physical, mental, social, spiritual, and economic issues, with the aim to relieve suffering (4). As the different aspects of suffering are interdependent, "*untreated or unresolved problems relating to one cause of suffering may cause or exacerbate other aspects of suffering*" (17). Suffering or pain may be caused or aggravated by problems relating to other causes of suffering, such as caregivers feeling stressed and overburdened (17). Thus, palliative care requires attention to some or all of the other aspects of care and suffering. Holistic palliative care is intended for both the patient and his/her family members - especially when a family member is also the primary caregiver of the patient. This support to families of patients is present during illness, death, and even after patients' deaths.

1.6. The need for palliative care

Reports from families who have received home-based palliative care support confirmed that they experienced an increase in satisfaction and quality of life, both for them and their families (7). These reports demonstrate the importance of providing support to family caregivers during a time of extreme vulnerability. This supportive care may positively affect the mental health and stress levels of those caregivers. This support includes medical, psychological, social, and spiritual support to patients and their caregivers (8). However, the World Health Organization (WHO) and The Worldwide Hospice Palliative Care Alliance (WHPA) estimate that palliative care is provided to only 14% of 40 million patients who need palliative care. Around 78% of these patients live in LMICs (4).

The need to provide palliative care is especially important in developing countries where the incidence of cancer is also on the rise in addition to communicable diseases such as HIV and AIDS, but adequate palliative care is seldom available (17). Half of the world's new cancer cases and deaths happen in LMICs of which approximately 80% of those cases are already advanced at the time of diagnosis (17). Despite the increase in numbers, adequate palliative care is not available to 80-90 percent of those patients in these countries (17).

1.7. Providers of palliative care in Africa

In Africa particularly, the needs for palliative care are much higher than the limited resources that are available (4). Despite the limited palliative care development in Africa, there has been a growing number of countries with hospice and palliative care services over the last decade (18). Where there are no hospice and palliative care services, the demand for palliative care results in the over utilization of emergency services in large hospitals in urban areas (17). The majority of hospice care in Africa is provided by faith-based organizations and non-governmental and that often operate on inconsistent models of care (17). In developed countries families tend to be nuclear (parents and children), and rely on a health care system for the care of the sick and dying, to which they most often have easy access. The contrast in developing countries is that the responsibility of care often lies with the family (17). According to Clemens et al. the importance of the home as part of the African identity has been emphasized in different studies and the fact that when a member of the family is ill, the family provide the care (9). The extended family who tend to live together or who are not far away (grandparents, children, grandchildren, uncles and aunts) is the family structure, and the burden of care is the responsibility of the entire family (17).

Healthcare has therefore shifted strongly towards a home-based focus, and therefore, in order to determine optimal palliative care at the end of life, it is important to look at caregiver burden and the use of healthcare resources at the end of life (19, 20). To assume that in African caring systems, extended families have the inexhaustible capacity to withstand crisis is not valid (11). Although the cornerstone of care may be the family, family members may not have the capacity or may not want to provide the necessary care to the patient at times. To achieve end-of-life care of patients in their homes until death, the members of the family must be integrated into the care team, both as care providers and to receive the support they need to be caregivers (17). As outlined by literature (2, 3, 6, 8, 10, 21), those providing end-of-life care face a whole range of challenges which may be experienced differently by all families and individuals depending on factors such as the family's socio-economic status, and background. There are also cultural differences towards very sensitive issues such as the delivery of bad news, disclosure of the diagnosis, communication with the patient, patient autonomy and others (1, 9, 11). How people understand and perceive illness, death, bereavement and expressions of grief and bereavement differ across cultures and regions (9, 11). The influx of immigrants and refugees into more developed countries has changed the demography of those countries, which complicated the provision of health care tremendously. Adding to that, in most developed countries, there are sectors that are less privileged and where the support from the health care services is not adequate to safeguard families from the detrimental financial impact taking care of a family member has.

In addition to these above-mentioned factors, the Covid-19 pandemic as a global health emergency has added tremendous pressure on existing health systems. It has further caused people around the world to consider complex decision making, as well as death and dying as a new reality in everyday life (17). In a study conducted by Boufkhed et al. to assess the preparedness of African palliative care for the Covid pandemic, they found that urgent measures are needed to ensure infection control and safe provision of care especially in the community. Intensive care for patients with moderate to severe and distressing Covid-19 symptoms is scarcely available in weak health systems which are resource limited (22). It is recommended that the management of Covid-19 patients must include palliative care to "*relieve suffering, improve outcomes, and safe costs" (*22). This support from palliative care teams is particularly important when complex decision making for patients is needed (22, 23).

1.8. Palliative care in South Africa

In South-Africa the need for palliative care was estimated to be 1 in 143 people every year using mortality data for 2010 for conditions that require palliative care(12). However, only an estimated 18% of those needing palliative care received care during the year 2011 (12). Although it is evident that the need is great, the availability of palliative care services is insufficient to meet this need(9). The World Health Organization (WHO) Constitution stipulates that "*the highest attainable standard of health as a fundamental right of every human being*" and implies a clear set of ethical obligations on states and health care providers to ensure appropriate conditions for the use and access of health for all people without discrimination (24). In order to improve this care and quality of service in South Africa, relevant research is needed to provide necessary information for clinical decision making and service provision for palliative care patients and their family caregivers, including the consideration of culture differences (14). Without the perspective and understanding of the experience of patients and their family caregivers it is difficult to understand their needs and thus to develop interventions to meet those needs, or to know how to adjust interventions to provide better support.

1.9. Impact of interventions to reduce caregivers' burden

To draw attention to the need for interventions to caregivers, studies have been conducted to exam the specific needs of caregivers and document the impact interventions to reduce burden and strengthen benefits have on caregivers (3, 6, 25) . The results suggested that support interventions may have a positive and lasting impact on how caregivers perceive the end-of-life care they provide (6). Caregiver's perceptions of their experience (the burdens and benefit) may also shape - positively or negatively - how they evaluate their loved one's end-of-life care (26). This again may influence their grieving process (26). Bereaved family often experience mixed emotions evaluating their caregiving experience, but those members who evaluate the care they provided negatively may often experience some guilt or depression, whereas those who evaluate the care they provided positively experience satisfaction, believing that they did everything possible to support their dying loved one (6).

Bereaved family members whose loved ones died while receiving hospice services have reported higher levels of satisfaction with those services if certain important aspects of care were present and achieved(27). These aspects and processes of care involved "*regular and accurate communication about the patient s medical condition by the hospice team, provision of adequate amounts of emotional support by hospice staff, and the family s belief that hospice staff was knowledgeable enough about the patient s medical history to provide the best possible care*" (27).

1.10. Support programs for caregivers

There have been a variety of interventions and support to caregivers that have been implemented around the world, mainly in developed countries, that focus on the wellbeing of informal caregivers providing end-of-life care in response to their needs (25). These programs operate as a public health response to support informal caregivers providing end-of-life care where the patient and his/her family are considered to be the unit of care, rather than the dying individual alone (25). This approach implies that to enable adequate and responsive care for dying patients, public health measures must address the needs of the informal caregivers in addition to dying persons - as the health status of these caregivers is intimately tied to that of those who they care for (25). Those responses include individual grief counselling services, skill-building and educational workshops for family caregivers, and group session where family caregivers have the opportunity to share with others who are having a similar experience. Some countries also provide different kinds of financial support for end-of-life caregivers, including employment leave programs (25). The development of family oriented education programs to include both the family and the patient in the journey of caring for a patient have been recommended as well (10). There is also a need for a greater focus on proactive and preventative strategies that support and facilitate the positive aspects of caregiving. This means that there should be a bigger focus on the "*strengths, resources, and skill-building of caregivers to empower them in their role*" (10).

Developing countries may consider and copy systems and structures to develop palliative care services and support for caregivers that have been implemented in more 'developed' countries - with often disappointing results (17). Developing countries, like South Africa, need to be assisted in formulating systems addressing their specific their needs, and their experiences, and culture (17). The International Association for Hospices and Palliative Care has suggested some community education programs and strategies to adapt care delivery systems to create the necessary environment which is needed for palliative care to grow (17). The IAHPC program includes training of the caregiver to enable caregivers to perform basic caring tasks appropriately (17). It furthermore suggests adequate support to the caregiver to prevent frequent hospitalization of the patients, as well as measures, such as psycho-educational meetings for caregivers, are suggested to reduce the emotional load of caregivers (17).

The IAHPC suggests that the program should be adjusted to acknowledge and respect different communities, cultures and resources available to ensure that it is effective and sustainable (17). According to the IAHPC Palliative care "*can be provided using limited resources with minimal infrastructure support*" (9). One of the most remarkable examples is the Neighbourhood Network in Palliative Care (NNPC) in Kerala, India. Local communities identify patients in need of help, refer them to the NNPC, strategies are then planned to help them with active support from health care professionals (9). In certain areas of Kerala the coverage of patients in need of palliative care has reached approximately 60% compared to a national average in India of around 1%, covering a population in need of palliative care of more than 15 million people (9).

1.11. Providers of support to informal caregivers in South-Africa

In South Africa the support being provided to caregivers is limited and mainly available in urban centers. Based on personal inquiries and reports from patients and their family members, if there are no hospices present, support mainly comes from the families' communities, including their church communities, as well as Non-profit organizations (NPO's) such as the Cancer Association of South-Africa (CANSA)or support groups. There are websites for caregivers or support for caregivers that provide advice to caregivers or advertise respite care to family members of ill persons, but few focus specifically on end-of-life care. Where hospices are present, they mainly provide home-based care and support, with nurses visiting patients and their families to administer medication and to ensure that the family and caregivers are coping. Apart from those services many hospices also provide education and training to caregivers and health care workers, they facilitate grief counselling, and other support activities. The role hospices play in providing this valuable and necessary support is important. Unfortunately, many hospices are struggling financially as they rely mainly on donations or grants to fund their services, with the result that many hospices have closed their doors in the last few years. In the Free State alone, four hospices had to close recently due to financial strain (31).

The Covid-19 pandemic has added to the financial burden of families and caregivers all over the world (28). Existing socioeconomic disparities and access to resources have been exacerbated by the pandemic (28). At the same time, it has also led to an increase in the need of health care services and supplies, often causing deficiencies for patients and health care providers. In addition, palliative and hospice care workforce have been strained as it has provided increased services at a higher rate to patients and families (29). Social distancing measures have also impacted on the emotional well-being of patients, families, and staff, where the usual demonstration of compassion that hospice care are if known for, namely a comforting closeness, could not be practiced (29).

1.12. Hospice Bloemfontein

Hospice Bloemfontein was founded in 2017 after the need was identified for a hospice providing palliative care to patients with non-communicable diseases in need of end-of-life care. At that stage there were two other hospices in the Mangaung-area providing care to patients diagnosed with HIV/AIDS (Lesedi Centre of Hope) and to those patients with TB (Naledi Hospice). Since 2017 the Naledi hospice had to close its doors.

Hospice Bloemfontein is situated within the parameters of the city metropole which is surrounded by the bigger Mangaung area, which includes areas such as Heidedal, Bathu, Rocklands and Turflaagte. Based on its location and staff capacity, Hospice Bloemfontein mainly provides home-based palliative care to patients living within the metropole's parameters, but co-operating with other existing health care providers to care for patients outside of the city's parameters. The researcher in this study is the general manager and co-founder of the hospice, as well as a counsellor addressing needs and concerns of patients and specifically needs and challenges their loved ones are experiencing.

The hospice has adopted a combined model of care, which includes Home-based Palliative care as its core model of care, as well as a small inpatient palliative care facility. The in-patient unit (IPU) is situation in a separate wing of a Frail Care facility, making use of their staff, who are trained in palliative care, to provide care to the hospice patients. Admissions into the three room IPU are mainly for complicated pain and symptom management; to offer respite to family members; and to provide active end-of-life care. Admission is typically not longer than two weeks. These rooms offer a homely and dignified space for patients as well as family members. The home-based services are provided by a team of professional and lay caregivers in patient's home. The professional care is provided by a palliative care physician, professional nurses, counsellor, OT and clergy. A group of trained volunteers provide supportive care to families. Physical, psychosocial and spiritual care is provided. Essential palliative care medicines are used.

The hospice service is funded through donations, fundraising events as well as medical fund payments for admission of private patients. These payments subsidize patients without financial means to pay for admission to a room. Care that is needed for home-based patients in areas outside of Hospice Bloemfontein's service area, is organized on a contractual ad hoc basis. Nurses or caregivers from other service providers (Lesedi Hospice or the Sunflower Children's Hospice or other nursing agencies) are approached to provide care as needed. They are reimbursed for those services.

In-service training in palliative care is regularly provided to current hospice staff, other health workers, allied health workers and volunteers.

1.13. Importance of developing sustainable and effective support in South-Africa

The South African National Policy Framework and Strategy for Palliative Care (NPFSPC) has developed reasonable goals to "*ensure economic sustainability and cost effectiveness along with compassionate care*" (30). Unfortunately, according to report from the Hospice Palliative Care Association of South Africa (HPCA), funding for South African hospices has dropped drastically in the last few years (31). The HPCA further states that with the government's plan to change the healthcare sector in South Africa with the implementation of the National Health Insurance initiative, which include the provision of palliative care, it is important that hospices become a priority as they provide necessary and needed support to the healthcare industry (31). This creates an opportunity to bring more focus and relevance to hospices by setting up formal and structured relationships between hospitals and hospices and develop programs to provide more training for the home-based carers that hospices provide to families (31). Despite the crucial work hospices do in South Africa, there are no state-funded hospices. Hospices rely solely on grants, donations and claims from medical funds to continue the work that they do. The HPCA urges that "*while the government does provide some level of funding this is nowhere near sufficient to enable them to meet the needs of everyone who would require this kind of service and it is an issue that should be urgently addressed* "(31).

1.14. A model of care which aligns with palliative care

Person-centered care (PCC) has become prominent in discussions of quality provision of healthcare, which is the "*practice of caring for patients (and their families) in ways that are valuable and meaningful to the individual patient"* (32). PCC has moved away from a model where the patient is a passive recipient of medical intervention or care - to a more interactive model where "*the patient takes an active part in his or her care process"* (33). It highlights the importance of engaging the person as an active partner in his or her treatment - which means knowing the person as human being with needs, feelings, reason and will (33). Essential in PCC is the tenet that the patient's quality of life and experiences are constantly being assessed and acknowledged, which is also essential in palliative care (34). Common values in palliative care are autonomy, dignity, a holistic approach, and individual planning - which also comprise the core characteristics of PCC (34). The Institute of Medicine defines PCC as, "*Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.*" (32). The services provided need to be adapted to the expectations and preferences of the patient, not the other way around. Doing so enables patients to maintain their autonomy and dignity during an already difficult time (34). Some of the core principles of PCC are the involvement of family and friends in decision making, to further support those family members as caregivers, as well as recognizing the needs of family and friends. Patients and their family caregivers are better informed and understand their condition better, and would not unnecessarily use emergency services or choose expensive or invasive treatments when their condition deteriorates (34). Therefore, the value of the social network of each patient must be recognized, which is a strong tenet of both PCC and palliative care. Both approaches strongly include the family caregivers in the care plan, and the family caregivers could potentially play a big role in the management of and executing of the care for the patient. With individually focused support, adequate information and training in specific caregiving tasks, family caregivers and the patients can be better empowered to manage the care that needs to be provided (33).

This approach supports hospice's aim to "*relieve suffering and to improve quality of life of patients"* - which includes decreasing the burden on family caregivers. To achieve this a better understanding of the experiences and needs of those caregivers of patients is needed to provide healthcare professionals with needed information to develop interventions to prepare and support caregivers to care for their loved ones adequately (8).

1.15. Conclusion

This chapter has described the profound impact of a life-threatening illness on the patient as well as on the family (2). As the spouse or partner is often the primary caregiver for patients with a life-threatening illness it affects the couple as a unit, rather than isolated individuals(3). The caregiving experience is complex and includes stress and higher levels of anxiety, and the relationship dynamic changes and evolves in many ways. The need for the provision of palliative care, which are mainly provided by hospices, is especially pronounced in developing nations, but those needs are not met by the available resources. Support programs for caregivers have mainly been implemented in developed countries, and developing countries may need to consider systems specific to their needs, and their experiences, and culture (17). Therefore, a better understanding of the experiences and needs of those caregivers of patients is needed to provide healthcare professionals with needed information to develop person-centered, holistic palliative care interventions to improve the overall end-of-life care quality, and to prepare and support caregivers to care for their loved ones (8).

The next chapter provides a review of the current knowledge and background on the experiences of primary caregivers caring for patients at the end of life.

CHAPTER 2

Literature Review

2.1. Introduction

A systematic search was conducted to identify relevant literature on the experiences of primary caregivers of patients receiving end-of-life hospice care. The search was undertaken using the keywords listed below in a Boolean structure to search for literature in PUBMED, Clinical Key, Medline, CINHAL and Google Scholar. The keywords and phrases used to conduct a thematic search included: "' caregiver or caregiving", "experience of caregivers", "end-of-life care", "hospice care", "home-based care", "need of caregivers", "stress in caring", "burden of illness", "place of death" challenges", "Africa", "South Africa", "middle-income countries", "low-income countries", "resource-limited countries". Keywords were combined using Boolean operators AND, OR and NOT.

Only peer reviewed articles were selected. Besides electronic searches, the reference lists of the identified studies were also hand-searched for further relevant studies, after which the publications of the prominent authors in this area were searched for relevant articles.

2.2. Burden of disease

The global burden of disease is increasing, with cancer alone as a leading cause of death globally (35). The World Health Organization (WHO) estimates that 8.8million people died of cancer in 2015, up from 7.6 million in 2005 (35). Seventy percent of all cancer deaths (approximately 5.7 million) and 40% of all new cancers worldwide occurred in low- and middle-income countries (LMICs) (35). Statistics South Africa reported that in 2015, neoplasms caused 41799 deaths which account for 9.1% of all adult deaths in South Africa (35). As palliative care focuses on "*providing quality of life to all patients and their families throughout the course of a life threatening illness*", it is necessary to measure the burden of disease in terms of morbidity and impact on individuals as well as families, support structure, and communities, besides mortality data (36). A metric for measuring burden of disease is the DALY (Disability Adjusted Life Years), which measures the "*healthy years of life lost due to each incident case of, disease or injury*", by adding together "*years of life lost*" (YLLs) due to premature mortality, and "*years of life lived with disability*" (YLDs) (36). The five leading causes for premature mortality (YLL) in 2012 in South-Africa were HIV, cerebrovascular disease, lower respiratory tract infections, TB and interpersonal violence (36).

The Lancet Global Health which reported on the burden of non-communicable diseases in the Sub-Sahara region stated that although the burden of diseases in this region is still mainly caused by infectious diseases, there has been an increasing prevalence in non-communicable diseases (NCD's) due to a demographic transition leading to this change (37). Gysels et al. further state that adding to the current disease burden of HIV in the sub-Saharan Africa is the additional burden of disease of cancer and other non-communicable diseases, which is predicted to grow with an aging population (38). These NCD's subsequently pose an increase challenge for health systems in the Sub-Saharan region as they have up to date mainly focused on and treated infectious diseases (37). In South Africa more than half of all natural deaths (55%) were due to non-communicable diseases in 2015, according to the data from Statistics South Africa Mortality and Causes of Death report (2017) (30).

2.3. Need for palliative care

"The Global Atlas of Palliative Care" states that despite the fact that palliative care is recognized as an essential part of health care systems, there still is not adequate access to hospice and palliative care worldwide, apart from North-America, Europe, and Australia (39). They further state that the demand will continue to increase as the world population is aging and will therefore live and die with more complex conditions (39). According to the WHPCA, 37.4% of all deaths from causes worldwide need palliative care (30), and "The Global Atlas of Palliative Care" estimates that over 56.8 million people worldwide require palliative care, of which the majority of adults live in LMIC's and the highest proportion are in low income countries (39). In Africa it is estimated that 353 in 100,000 adults and 160 in 100,000 children need palliative care at the end of life (30). The estimated need for palliative care in high income countries was 69 – 82% of all persons who died (30), with the estimated need for palliative care in SA in 2014 about 45% – 50% of all deaths (38). This is also within the range of estimates reported for middle to high income countries (39). The indicated need from the Quality of Death Index Report 2015, estimates "*that South Africa has a high demand for palliative care, similar to that of other high-income countries, possibly because of our unique quadruple burden of disease with a mix of non-communicable diseases, HIV and TB*" (39).

Universal Health Coverage (UHC) has been identified as a Health Goal of the United Nation's (UN) Sustainable Development Goals (38). The aim is that "*all people should have access to the health services they need, when and where they need them, without financial hardship, including the provision of palliative care*" (38). Currently, around 50% of the people in the world do not receive the health services they need, and about 100 million people are forced into poverty annually because of out-of-pocket spending on health (36). Despite the fact that palliative care and pain relief are core elements of the UHC, it has been largely ignored, even for the most vulnerable population (36). In a report by the Lancet Commission that was published in 2019 it was stated that access to opioids is not available to most patients in low-income and middle-income countries (LMICs) and more particularly to poor people - including poor or vulnerable people in high-income countries (40).

"The Global Atlas of Palliative Care" states that recently the need for palliative care for other chronic diseases has been acknowledged apart from cancer patients, such as congestive heart failure, neurodegenerative disorder, drug-resistant tuberculosis, cerebrovascular disease, kidney failure, and disease of older people (39). The importance of palliative care in all health care systems has also been highlighted recently with the emergency of Covid-19. The need for relief from suffering, difficult decision making and the complicated grief due to the pandemic are challenges and problems palliative care can help to address (39).

2.4. Where is palliative care provided?

As stated by "The Global Atlas of Palliative Care" palliative care development has been very uneven over the world (39). Without supportive policies for palliative care, and inadequate funding, growth is limited to those pioneers and champions creating hospice and palliative care services in their communities (39). However, to address the need for palliative care, further integration into existing health care systems is necessary (39). In South-Africa this *ad hoc* development has resulted in palliative care not consistently provided within South-African health facilities with subsequent significant sustainability issues (30). Palliative care services in South Africa are provided by a few known hospitals (36). Those services provided by these facilities may include an inpatient consultation service, palliative care wards, some provide an outpatient service, or an emergency palliative care service (36).

The" Global Atlas of Palliative Care" states that home based care is especially important to reach the huge numbers of people with palliative care needs (39). In South-Africa palliative care and home-based care have been provided in the public health care sector by Home and Community-Based Carers (CBHWs), although what their roles are in terms of provision of palliative care is not certain and there is no clarity on the extent of their responsibility (36). A need for better training to those CBHWs was identified, as well as reasonable reimbursement and more support with regards to the prevention and treatment of psychosocial suffering (30).

Non-governmental organizations (NGOs), for example the Hospice Palliative Care Association (HPCA) of South Africa, provide a wide range of palliative care services, including training, across the country (36). Hospices provide palliative care services in the community throughout South Africa through mainly home-based care models as well as some in-patient services and day care services (30).

2.5. Availability of palliative care

According to "The Global Atlas of Palliative Care" there were approximately 25 000 hospice or palliative care service units world-wide in 2020 (39). They further state that only 14% of the global population has access to palliative care at the highest level, and this percentage is concentrated in European countries (39). It is estimated that with the increasing need, palliative care is not available to at least half of the global population (39).

In a comparative analysis conducted by Rhee et al. who mapped out palliative care development in Africa, they concluded that although there is limited palliative care development in Africa, there has, however, been an increase in the number of countries with hospice and palliative care services over the last ten years (41). Sepulveda et al. state that in Africa particularly, the available resources cannot meet the huge need for palliative care (4). In a research article by Clemens et al. reporting on the issues in palliative care in developing countries, the authors reflect that the vast majority of hospice care in Africa is provided by non-governmental and faith based organizations that operate on inconsistent models of care (9). The authors also emphasize the importance of the home as part of the African identity based on their research (9). In a systematic review on qualitative literature on end of life care in sub-Sharan Africa, Gysels et al. supported these findings of Clemens that healthcare has shifted strongly towards a home-based focus (38). The authors further state that it is therefore important to look at caregiver burden and the use of healthcare resources at the end of life in order to determine the optimal setting for palliative care at the end of life (38).

In South-Africa the need for palliative care was estimated to be 1 in 143 people every year using mortality data for 2010 for conditions determined a priori to require palliative care (12). The estimated number of patients who received care during the year (2011) was approximately 18% of the those needing palliative care (13). The need for palliative care is substantial, but the services are insufficient to meet this great need (9). The "Global Atlas of Palliative Care" reflects on this situation, stating that in the efforts to expand palliative care the focus "*needs to be on bringing relief of suffering and the benefits of palliative care to those who do not have easily have access to health care and have little resources*" (39).

2.6. The impact of caring for loved ones at the end of life on primary caregivers

Primary caregivers play an important part in providing care to patients at end of life, but they, along with patients, exist within a social unit that can be negatively impacted throughout the illness continuum (2). In a descriptive, longitudinal study by Grant et al. describing burden, skills preparedness, and quality of life for caregivers of patients with cancer, they concluded that caregivers experience "*high levels of caregiver burden and reported deteriorations in psychological well-being and overall quality of life*" (2). They further state that a diagnosis of a life-threatening disease profoundly impacts not only the patient but the whole family - from diagnosis to end of life (2). In their article they furthermore refer to current literature recognizing the multidimensional needs and experiences of caregivers throughout the continuum of the illness experience, but those needs are still addressed inadequately by most healthcare providers who are focused primarily on the physical needs of the patient (2). In a literature review of spouses' experience of caregiving for cancer patients, Li et al. emphasized as well that "*cancer and its treatment affect not only the patient but also their family caregivers, leading to the description of cancer as a 'we-disease'* " (3). The psychological well-being of informal caregivers and their cancer patients is closely related - which is particularly true when the caregiver is the patient's spouse (3). In their review they stated that cancer affects the couple as a unit, rather than as isolated individuals (3). In a comparative study that was conducted by Spatuzzi et al. where the burden in family caregivers of patients with advanced cancer in active treatment settings and hospice care were studied, they concluded that the wellbeing of the patient correlates strongly with the wellbeing of the caregiver who provides care to the patient (8). They added that especially the transition from active therapy to palliative care represents a very fragile and dramatic period in the treatment trajectory, both on the clinical as well as the psychological and emotional levels, for both the patients as well as their caregivers (8).

In an article by Harding the author explores the informal caregiver experiences and needs in home palliative care, referring to international survey data that had confirmed the preference of the public to die at home (1). He points out that to achieve home death the presence of a family caregiver is needed to provide care (1). This implies that with more patients being cared for at home at end-of-life, more primary caregivers will be involved in providing care (15). The Global Atlas of Palliative Care also acknowledges the importance of caregivers, stating that not only patients but family members and carers can also benefit from palliative care where the focus is not only on the patients but on providing quality of life to both the patient and the family members (39). Grant et al. adds to this when they state that the caregiving role can be associated with physical, psychological, social, and functional distress and could add to the spiritual burden for informal caregiver (2). They further state that "*caregiver burden is influenced by characteristics of the patient, caregivers, and the care environment*" (2).

In a validation study Ewing et al. in which they assessed the Carer Support Needs Assessment Tool (CSNAT) for use in Palliative and End-of-life care at home, it was concluded that providing care does come at a cost - the scores of the assessment tool (CSNAT) provided clear indication that strain added to distress, and preparedness for caregiving contributed positively to overall health (16). Caregivers often experience stress, fatigue, emotional distress, diminished quality of life, social restriction and isolation, family conflict and financial difficulties (16). Congruent to this study, Hricik et al. looked at the changes in caregiver perception over time in response to providing care to patients, and added negative psychological effects like hopelessness, stigmatization and isolation that prevail in home care of the end-of-life patient (42). In addition to that, Soroka reported a high incidence of loneliness, and feelings of social isolation, as the caregivers and patients are being separated from the community and lacking in support (43).

Findings furthermore suggested that primary caregivers are not always equipped to address the spiritual and psychosocial needs of both themselves and their loved ones, which, according to Soroka, could also affect the caregivers confidence negatively (43). In addition to this statement, Jang and Lazenby also pointed out that evidence has shown that education in the specific challenges of the illness and caregiving skills has an impact on the way professional and family caregivers are able to tolerate their stressors (11). They found that family caregivers are not properly educated and informed about symptoms related to their loved ones' illnesses they are caring for (11). Congruent to their statement, Rhodes concludes that a lack of disease knowledge and accurate communication about the patient's medical condition is a major factor influencing the caregiving experience (27). According to him many patients *and* their caregivers experience a strong need for clear communication about the implications of advanced disease and the need for advance care planning, including informed preferences for place of death (27).

The term "hidden patient" has been used in 1996 by Charles Emlet in a study assessing informal caregivers, exploring whether the caregiver is a team member or a hidden patient (15). He concluded that the serious challenges and deficits caregivers may experience are not always acknowledged (15). The roles, stresses and critical importance of family caregivers can create a situation where their needs become more than those of the patient (15). The overall care they provide and time and energy it consumes are often invisible to the rest of the support network (15). Congruent with this theory, Harding also found that the caregiver can be seen as an extension of the patient, holding a unique position of both providing and needing support - creating a situation where it is sometimes unclear who "the patient" is (1).

2.7. Benefits of caregiving

It is well recognized by a number of the studies that there are levels of both negative and positive experiences in caregiving (1,2,3,8). Thus, despite the fact that caregivers face many challenges, there are benefits in taking care of a loved one. Han et el. acknowledged that despite all these challenges, "*caring for someone at the end of life and negotiating the process of dying can also be rewarding as it can create an opportunity for healing for all who participate*" (10). Caregiver burden and benefit often operate alongside one another (10).

The authors further state that caregivers have reported posttraumatic growth as a result of their loved one's diagnoses and caring for them (10). The presence of an illness gave them a better perspective and newfound resilience in the process of accepting the illness as a family matter (10). The authors explain that the caregiver's and family's situation and experience of the illness forced them to reflect on the importance of their family member, including the role of the loved one in the family (10). Han et al. further state that caregivers also came to appreciate the normal aspects of everyday life and forced them to realize that everyone is vulnerable to illness (10). This is also reflected in a literature review by Li et al. of twenty-five articles looking at spouses' experience of caregiving, they reported that most of the spouses reported personal growth, particularly in relating to others, appreciation of life, personal strength and spiritual change (3).

In a study comparing the state of palliative care in home care and inpatient units Jang and Lazeby concluded that the knowledge of impending death can facilitate resolution of possible personal and interpersonal conflicts, and can create an opportunity to resolve those conflicts (11). This is in line with the findings of the study by Han et al. where they stated that an illness could create an opportunity for families to reunite (10). Jang and Lazeby further state that facing end-of-life of a family member can not only potentially create healing connections but it can also cultivate compassion in the caring relationship (11). In addition to this statement, Aoun et al. found that providing compassionate care to the loved ones is then motivated by love, which is demonstrated through small acts of kindness (14). Caregivers often describe a sense of purpose and meaning, and mobilize coping mechanisms which help them overcoming some of the challenges they may face, which positively influence their self-confidence and sense of commitment (14). This statement is in line with Soroka's findings that the caregiver’s confidence is shaped by how they perceived their ability to provide adequate needed care to their loved one (43). Those experiencing satisfaction in their caregiving role, feel more confident and may more easily include end-of-life care, for example allowing the involvement of hospice or formal caregiver without guilt or resentment (43). The stress caregivers experience depends as much upon the meaning and satisfaction derived by their experience, and how they perceived themselves as an adequate caregiver as it depended on the actual work involved (43). Luth et al. added to this viewpoint in an article "Do Caregiver Experiences Shape End-of-Life care Perceptions?", where they suggested that caregivers often experiences both dimensions simultaneously in different degrees, both burden and benefits (6). How they perceive these burden and benefits may influence their caregiving experience as well as how they perceive the quality of the end-of-life care they provide to their loved ones (6). Therefore, interventions reducing burden and increasing perceived benefit simultaneously may result in more positive end-of-life care assessments.

2.8. Effect of hospice care and palliative care on caregiving experience

In a comparative study conducted by Spatuzzi et al. that aimed to assess the quality of life and burden in family caregivers of patients with advanced cancer in active treatment settings and hospice care, they concluded that the stress levels and mental health of a caregiver may be positively influenced by the supportive palliative care hospices provide (8). This support includes medical, psychological, social, and spiritual support to patients and their caregivers (8). This finding is confirmed by a study conducted by Hendrix et al. reviewing supportive care in cancer (7). The authors found that families receiving home-based palliative care support have been reported to experience an increase in satisfaction and quality of life, and added that their grieving process has subsequently been influenced positively (7) . In a study by Sinclair et al. interviews were conducted to better understand the experiences of patients and their families receiving palliative care, especially their perspectives of sympathy, empathy and compassion (44). Compassionate care, a core dimension in palliative care, is increasingly considered by patients, family members, and policymakers as a core dimension of quality care (44). Sinclair et al. concluded that enhancing compassionate healthcare may positively influence patient and family-reported outcomes (44).

In a qualitative study that was conducted in England by Jack et al. where twenty caregivers were asked about their perceptions and experiences of a hospice at home service, all participants reported personal positive impact of the service (45). The study concluded that the impact of an individualized, home-based palliative care service provided by palliative trained staff is perceived positively by family caregivers (45). The carers especially commented that "*the service provided a valued presence, that they felt they were in good hands, and it aided in supporting normal life*" (45). This study also emphasized the value of respite care, especially during the terminal phase (45). This respite was particularly valued by those family members who had other caring responsibilities in the family, or work commitments (45).

In a case-controlled study conducted by Voisine et al. where early versus late referrals to hospice care have been compared, it was suggested that when hospice services are offered too late in the course of an terminal illness it could limit patient comfort and quality of life (46).

2.9. Support to address the needs of caregivers

In a comparative study that was conducted by Spatuzzi et al. to determine quality of life and burden in family caregivers of patients with advanced cancer, it was concluded that early identification of family caregivers is necessary to support the specific needs of the caregivers (8). Early identification of burdened caregivers is important to intervene proactively (8). In a study conducted by Han et al. exploring the experiences of primary caregiver who provided care and support for female family members with cancer, they concluded that family support is crucial to help patients adjusting successfully to life with treatment routines (10). They recommend family-oriented education programs to include and support both the family and the patient in the long journey of cancer (10).

Han et al. concluded that "*while evidence shows that palliative care improves outcomes for patients, and that caregivers have higher levels of satisfaction with care, caregivers unmet physical, emotional, and social needs persist"* (10). What adds to the challenge is that professionals have a very limited time and opportunity to improve outcomes for caregivers of patients in home palliative care (10). The researchers continue stating that effective and tailored interventions need to be delivered in a very challenging time when "*patient and caregiver wellbeing are fluctuating, and caregivers are facing their own anticipatory grief* " (10). They suggest that in order to develop suitable and tailored interventions, it is important to first understand the experiences and needs of caregivers providing care at end-of-life (23). Sinclair et al. further state that "*this understanding will enable the provision of effective, compassionate, and cultural sensitive care to patients and their primary caregivers which is increasingly considered by patients, family members, and policy makers as a core dimension of quality care*" (44). This is also is also in line with the World Health Organization's (WHO) definition of palliative care which include the relief of suffering also of family members and caregivers (47). Governments do focus on providing more care and support in the community, partially driven by a need to save hospital costs, however good care of the dying at home requires excellent nursing and/or hospice care and social support (47). Few studies have been conducted in a South-African context that focus on the experience of caregivers in hospice care, knowledge which is necessary to provide the best possible and culturally sensitive support to those caregivers.

"The Global Atlas of Palliative Care" also states that home based care is especially important to reach the huge numbers of people with palliative care needs (39). Congruent with this view Jang et al. state that families and caregivers providing end-of-life care need to be assisted by the formal health system as they face a whole range of challenges (11). They are expected to provide care, but are not always equipped with adequate knowledge, resources and receive no remuneration for the service they provide (11).

2.10. Conclusion

As the global burden of disease is increasing, the need for and importance of palliative care is also expanding in all health care systems. The development and provision of palliative care have been unequitable globally, and in many areas hospices with limited resources are the only providers of palliative care in the health system. To reach the huge number of people in need of palliative care, home based care is especially important to deliver care in the homes of people. Therefore, not only patients but family members and carers can also benefit from palliative care where the focus is not only on the patients but on providing quality of life to both the patient and the family members.

2.11. Rationale for the study

Documenting the experiences of primary caregivers of patient receiving hospice care in Bloemfontein in addition to a review of the literature, will illustrate the particular needs of those caregivers in their specific social environment. The unique and often under-estimated challenges experienced by this group, which could directly influence the well-being of the patients they care for, ask for further research. Understanding the personal experiences of these participants, is important for developing effective support programs. This study results may contribute to the development of specific support programs and integrated palliative care strategies, interventions and policies for primary caregivers, to adequately address the needs of patients as well as their loved ones and provide better quality of life outcomes for both.

Regarding what this support needs to look like, more knowledge is required on the experience, preferences, needs and values of the primary caregiver.

2.12. Research question

What are the experiences of primary caregivers of end-of-life patients receiving hospice care regarding their coping mechanisms and support systems and how can these guide provision of effective palliative care and support to caregivers?

2.13. The Aim of this study:

To explore and describe the experience of primary caregivers of patients at end of life receiving care from Hospice Bloemfontein.

2.14. Objectives:

1. To obtain an in-depth description of the experience of primary caregivers of patients within hospice care.
2. To explore and describe primary caregivers' coping mechanisms while providing care.
3. To explore and describe support structures and resources that assist the primary caregiver.

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CHAPTER 3

Methodology

3.1. Introduction

This chapter will discuss the system of methods that was utilized to implement the study.

3.2. Study design

A qualitative cross-sectional study design was conducted through individual semi-structured interviews. This method was used to get an understanding and in-depth information on the experiences of informal caregivers of patients in hospice care, and how they make meaning of their experiences. The decision for this research design was guided by research studies where the aim was to explore and explain the experiences of participants (42,43). Hricik et al. looked at changes in caregiver perceptions over time in response to providing care to loved one with cancer (42). This was a descriptive, qualitative design using open-ended questions addressing various aspects of the care situation Soroka et al. used the same study design to explore caregivers' experiences of caring for patients under hospice care at home (43). This was a qualitative research design involved semi-structed, in depth interviews. The semi-structured interviews allowed a more structured and systematic approach while it still allows to explore, clarify, and understand the participant's experiences. In this way, detailed and in-depth information regarding the thoughts, feelings and experiences of participants was discovered.

3.3. Study site

Hospice Bloemfontein, Bloemfontein.

The study was conducted in Hospice Bloemfontein, situated in Bloemfontein, Free State. The hospice has a small IPU and home-based palliative care patients from the state and private sector, of which the majority are advance cancer patients but also include patients with end-stage organ failure, multiple-sclerosis, COPD and some neurodegenerative disorders like motor-neuron disease or multiple-sclerosis.

The researcher is the general manager and co-founder of the hospice, as well as a counsellor addressing needs and concerns of patients and specifically the needs and challenges their loved ones are experiencing. The researcher wanted to explore and better understand these experiences of family caregivers so as to offer better support and care to them.

3.4. Study participants

3.4.1. Selection criteria:

Primary caregiver to be identified by the patient, in line with the definition of caregiver: "...*unpaid, informal providers of one or more physical, social, practical and emotional tasks. In terms of their relationship to the patient, they may be a friend, partner, ex-partner, sibling, parent, child or other blood or non-blood relative.*" For the purpose of this study, the primary caregiver will be either a spouse or a partner of the patient, with the partner being who the patient identifies as his/her partner. The patient being diagnosed with a life-limited disease receiving care or support from Hospice Bloemfontein.

3.4.2. Inclusion criteria:

- Unpaid, informal providers of one or more physical, social, practical and emotional tasks. In terms of their relationship to the patient, a partner or spouse.
- The patient was receiving hospice care from Hospice Bloemfontein.
- Participant had to be older than 18 yrs.

3.4.4. Exclusion criteria:

- If there was a professional full-time caregiver involved in the daily care of the patient, the primary caregiver (partner / spouse) will not be considered for the study.
- Adult children of patients.

3.5. Sampling

3.5.1. Sample size

The intended sample size was 10 - 16 participants as described by Marshall (48) with the goal to attain data saturation. Saturation occurs when "*adding more participants to the study does not result in obtaining additional perspectives or information*" (48, 50). Codes or themes emerged from the data, and when no new codes emerged with new data, the data was considered saturated. Therefore, the number that is required for data saturation corresponded to the number of participants in this study.

Other studies which have adopted similar designs with similar research problems were used as guidance (42, 43, 48, 51). In a study by van der Watt et al. where the experiences of children living with congenital heart defect were explored and described, the sample consisted of 9 participants (23). This was similar to another study by Hricik et al. where changes in caregivers' perceptions over time in response to providing care for a loved one with a primary malignant brain tumour was studied, with a sample size of 10 (24). Guided by a publication by Marshall et al, with recommendations for sample sizes in qualitative studies the range of the sample size will be 10 - 16 (48).

3.5.2. Sampling method

Purposive sampling was used to generate a study sample that was large enough to adequately describe the phenomenon of interest, as well as to address the research question at hand. Therefore, the sample size was not linked to a fixed number of participants. The participants were purposefully selected to adhere to the inclusion criteria.

3.6. Data collection

3.6.1. Data collection tools

A Semi-structured interview guide to help guide interviews (Appendix) was developed by the researcher and refined through discussion with the supervisors. The formulation of the questions were based on recognized assessment tools and other research studies with similar questions, for example the Carer Support Needs assessment Tool (CSNAT), and the Caregiver Burden Inventory (15, 16, 44, 52). The **CSNAT** is an evidence-based tool that "*facilitates tailored support for family members and friends (carers) of adults with long term life-limiting conditions*". The CSNAT comprises 14 domains in which carers commonly say they need support. The Caregiver Burden Inventory is a 24 item Likert-format scale that "*measures five dimensions of caregiver burden: time dependence, developmental, physical, social, and emotional burden*". Although the questions were developed in accordance with the researched objectives, they remain open-ended which is an important aspect of a qualitative study, as it allows elaboration if necessary (52, 53). The fact that the questions are open-ended allowed the participants to describe their experiences freely, which provided rich data. The questions selected focused on the physical, emotional, social, and spiritual aspects of the participants' *experience*, and explored *coping mechanism* and their *support structures* and *resources* while caring for loved ones in hospice care. The research question was adequately addressed by the questions and they were arranged in the most logical sequence.

After the first two interviews the first question asking the participant, some personal background was refined to asked more specifically about their relationship: "How old are you?", "How long have you been a couple?" and "How long have you cared for your partner?". A question referring to their spiritual experience was added: "What motivates you in taking care of your partner?" This question was included as both the first participants refer to what they experience as a motivation or reason to carry on with their caregiving responsibilities.

See **Interview Guide** (Appendix 11).

7. Data collection process

3.7.1. Recruitment of research assistants

Prior to the recruitment of participants research assistants were recruited and appointed. The assistants were recruited based on their roles in the hospice, their familiarity with hospice work, communication skills, their language skills, and the fact that they were available for the duration of the data collection period. The two assistants were both part of the hospice team, with the one assistant a professional nurse, and the other a volunteer and by profession an ordained minister in the Anglican church. The research assistants were informed of the aim of the study and the questionnaire. One of the assistants was responsible for the recruitment of potential candidates, the explanation of the study, and to obtained consent from the participants (professional nurse), and the other assistant was on standby to conduct the interviews in Sesotho if that would be necessary. The researcher trained the two assistants simultaneously. During the session comprehensive information was provided regarding:

- Research ethics (both of them) - it was important for the research assistants to fully understand the issues of voluntary informed consent as well as to be sensitive and attentive to the vulnerabilities of the potential participants, including continued care and support if they would wish to not take part.
- How to conduct an interview (for the person who will do the Sesotho interviews). This included a revision of interview techniques using open-ended questions. To obtain rich and valuable data an explorative approach needed to be practiced during the interviews. The use of prompts was also explained and explored.
- Exercises to improve interviewing skills and interpersonal communication.
- All uncertainties to be clarified, and questions to be answered.

Before data collection started, the research assistant(s) felt confident and prepared to conduct the individual interviews.

3.7.2. Recruitment of participants

Approval from the Human Research Ethical Committee (HREC) of the Faculty of Health Sciences (FHS) at the University of Cape Town (Ref.586/2020), and further approval from the

Ethics Committee of the Hospice and Palliative Care Association of South Africa (HPCA) were obtained prior to the onset of the study (Ref. 03/20). (Appendix 1 + 2)

The researcher and research assistants had access to personal contact details and background information of patients and their caregivers who were in hospice care, and those potential participants who met the inclusion and exclusion criteria for the study were approached by the research assistant for potential participation. Those potential participants were contacted telephonically or in person and had the research project explained to them, including the context and the purpose of the study. The researcher was not directly involved in the recruitment process. It was made clear to the potential participants that their willingness (or not) to take part in the research project would not in any way influence the care they received from Hospice Bloemfontein. Participation in the research project was completely voluntarily. Each candidate who demonstrated interest and was willing to participate following this discussion, was referred to the researcher who contacted them directly to schedule a Zoom or telephonic interview with them as stipulated by the HREC requirements.

The purpose and objectives and methods of the study were explained to all participants in Afrikaans, English or Sesotho, depending on the language they preferred. If the participants had any questions or if they were uncertain, there was enough opportunity to clarify those uncertainties to ensure that they fully understand what the study entailed. Confidentiality was assured as well as the fact that they could choose to not participate or withdraw from the study at any stage (including if they became distressed). They were further assured that if they should choose to not participate or withdraw it would not influence the quality of care they receive. They also received an informed consent document explaining this. (Appendix 7).

Written informed consent was obtained by the professional nurse doing the recruitment from each participant prior to the interview, as well as consent from the patient, if possible. All the participants received detailed information in writing as well as verbally regarding individual interviews, including audiotaping of the interview. The information was provided in a language which the potential participants preferred. Recruitment of participants continued until data saturation was reached.

During the recruitment process, six potential participants' partners who were identified by the researcher and assistants, had sadly passed away before the interviews could take place, which excluded their potential participation. This illustrates a general problem of late referrals that the hospice is experiencing. (See further discussion in the Conclusion chapter.)

3.7.3. Data collection process

Semi-structured, individual interviews were conducted with participants. These interviews lasted between 30 - 60 minutes and had an explorative, open-ended approach. The participant could choose which language the interview had to be conducted in and took place over Zoom or as a telephonic conversation due to the infection risks involved during the COVID-19 pandemic, and as stipulated by the HREC. During the interviews the researcher was in a private and quiet space to minimize interruptions or ensure that conversations could not be overheard by anybody else. Before the interviews started, the researcher gave a short description of the research aims again and indicated that the interview will be audio-recorded. Before the start of the data collection the researcher provided more opportunity for the participants to ask questions if needed.

The researcher conducted the interviews with the participants who preferred to speak in English or Afrikaans. Conducting interviews herself also enabled the researcher to familiarize herself with the data. For participants who would have preferred to speak in Sesotho, a trained Hospice staff member would have conducted these interviews in Sesotho.

The interviews were audio recorded, after which the researcher transcribed those recordings verbatim after each interview to ensure an accurate transcription and to reduce memory bias and the possibility of researcher interpretation. Any interview that was conducted in Afrikaans, was transcribed verbatim in Afrikaans and then translated into English by the researcher and checked for accuracy by a professional translator. Interviews conducted in Sesotho would first be transcribed verbatim in Sesotho and then translated into English by a professional translator. But all participants chose to have the interview in either English or Afrikaans.

To ensure confidentiality the researcher undertook to only listen to the recorded material in privacy, or over headphones, to ensure that no other person was able to overhear any of the information that was shared during the interview so that a third party was not able to recognize the voice of an interviewee.

To further ensure confidentiality the translator was asked to sign a confidentiality statement.

3.8. The collected data

Prior to analyzing the data, the participants were asked if they would like to add anything to the information or would like to edit what they said. This enhanced credibility of the study results.

3.9. Distress Protocol

A Distress Protocol was developed before implementing the research study. It was important to act in the participants' best interest without inflicting any physical or emotional harm on them during data collection. All participants were fully informed as to the nature of the issues to be explored in the interview. All participants were explained clearly that during the interview the researcher will only conduct the interview to explore the participant's experience and, although she is also the counsellor, she would not provide counselling during the interview. If the participants demonstrated any emotions during conversation where sensitive issues were discussed, it was acknowledged. Those participants who seemed emotional were asked if they would like stop, or they were offered the option to continue later on when they were comfortable - either after a short break, or later on.   As the questions referred to a sensitive and emotional issue, namely their experience as caregiver to their ill partner/spouse, participants could become very upset and emotional. The participants were offered support when upset, and enough time to settle. Ongoing counselling from the hospice counsellor, or alternatively from other professionals, was offered - if they would choose that.

All participants who did become emotional chose to continue with the interview.

As stipulated and explained by the distress protocol (Appendix 14), If a participant would have demonstrated high levels of stress and anxiety (more than only emotional) and would become upset due to financial problems as a result of the illness of their loved one (lack of income, continual medical expenses, etc.), the participants would be asked if they would like to stop the interview. If they wanted to stop, the researcher would have offered bringing him/her in contact with social services for financial advice and support after the interview. The interview would have only been continued when/if they chose to do so. Or if such high levels of depression or desperation were being detected that there would be a fear that the participant would harm him/herself or the patient, or if an imminent danger is signaled, the interview would have been stopped. He/ she would have been advised that the researcher would need to contact his or her general practitioner, mental health care provider, or other medical health professional on his/her behalf in view of the potential danger posed; or the services of the counsellor would have been offered, as well as a visit by the hospice care team to discuss measures to bring relief (for example to arrange for patient to be admitted to an in-patient facility, and to arrange for additional support from family members/ carers).   Follow-up would have taken place to ensure that the caregiver was safe and well.

None of the participants demonstrated such high levels of distress, anxiety or desperation that any of the above-mentioned measurement had to be considered and no participant required urgent referral. It was not necessary to implement the distress protocol.

One participant who mentioned the fact that they are struggling with finances and getting enough food, was brought in contact with a local church organization who started to support them with regular food parcels.

3.10. Reflection

The researcher in this study was also the counsellor of the hospice where the study was conducted. The researcher was not involved in recruiting participants. The recruitment, explanation of the study and getting consent from participants were conducted by the professional hospice nurse of the hospice. All participants were clearly informed that participation is voluntary, and that the care they were receiving from the hospice would not be affected or influenced by their willingness to participate. During the interviews the researcher only conducted the interviews to explore the participant's experience and did not provide counselling during the sessions.

As the hospice counsellor is working as part of a team her role is to guide and support patients and their family members / loved ones through the final stages of the patient's life. Good counselling follows the concept of good bonding between the counsellor and the patient, which is based on trust and good rapport. These two attributes, trust, and rapport are also important to have meaningful interviews that provide rich qualitative data, and as the researcher already knew most of the participant before the interview trust and rapport were already established.

Furthermore, the researcher has normally applied the Rogerian person-centered therapy principles (54) in her interaction with patients and their families, which are congruence (genuineness), unconditionally positive regard and acceptance, and accurate empathic understanding - all attributes that would contribute to creating a positive atmosphere for a successful interview. This counselling approach creates a space for clients to share their experience, without the counsellor enforcing any of his/her views on the clients. During the research interview the experience did differ from a normal counselling session, though, as listening and prompting were used to get information from the participants and not to offer counselling.

The researcher had to be able to intentionally reflect on and be vigilant about the influence her background, position and interactional behavior had on interactions with participants. Given her role in the research project and as counsellor in the hospice, the researcher could have access to information to the situation prior to the interview which could introduce bias to the interview or could lead to her attributing certain meaning to answers based on her knowledge and not on the shared answers of participants. Careful and intentional reflection were crucial to identify those influences. Furthermore, the participants had be assured that what they share was confidential and would not negatively impact counselling care or any care in general they received from the hospice.

3.11. Data storage and confidentiality

All the questionnaires and transcripts were anonymized to maintain strict confidentiality. No unauthorized person had access to the data. The master copy which identifies participants, as well as the electronic (audio recordings, transcripts and all documentation of the participants) and hard copy data (consent forms), were kept secure by using both password protection (electronic data) and keeping the hard copies in a locked cabinet that only the researcher has access to. The same functionality ensuring security and privacy for recordings were allowed for sharing access to the recordings with the translator and transcriber. As per HREC requirements all research data including paper documents will be stored for five years and kept in a locked cabinet in the researcher's home that will be protected from water damage or any damage that could be caused by extreme weather conditions or fire hazards. Electronic data will be cloud-based stored on Google Drive.

3.12. Data analysis

As new data was collected, the transcribing and analyzing of the data occurred simultaneously, which led to either formulating new questions or to adjusting some of the questions slightly for subsequent participants. The researcher carried out the analysis procedure, which included the transcribing and translation.

Data analysis followed the six phases of **thematic analysis** (55), which was structured yet flexible, allowing adequate interpretation of data. NVivo, a qualitative data analysis computer software package for qualitative research was initially considered to be used as the tool for coding of the data, but as the interviews were only 10 the researcher did the coding manually. The six steps of thematic analysis included (i) "*familiarisation with the data, namely, the transcription of the data, reading and re-reading the data, and noting down initial ideas; (ii) generating initial codes, specifically coding of systemically interesting features of the data and organising data relevant to each code; (iii) moving closer to definite themes by organising potential themes and gathering all data relevant to each potential theme; (iv) reviewing the themes, such as checking the work in relation to the coded extracts and the entire data set, and generating a thematic map of analysis; (v) defining and naming the themes; and (vi) the final analysis of selecting vivid, compelling excerpt examples*" (13). These excerpts were related back to the research question and literature to ensure that the research question was answered appropriately.

Results of the data analysis are described in Chapter four.

3.13. Ethical considerations

The study was undertaken to fulfil requirements for the University of Cape Town (UCT) Master of Philosophy in Palliative Medicine. As the study involved human participants it had to adhere to ethical standards in all circumstances. Ethical approval had to be obtained from the Human Research Ethics Committee (HREC), and the HPCA (the Hospice and Palliative Care Association of South-Africa) Research Committee, and permission from the Board of Hospice Bloemfontein. The research proposal was submitted the HREC in November 2020 and formal approval was granted on the 2nd of December, and to the HPCA in December 2020 and the formal approval was granted on the 26th of February 2021. (Appendices 1 + 2)

Adhering to ethical guidelines, helped the researcher to weigh the value of improved knowledge against the value of non-interference in the lives of research participants. The fact that participants are vulnerable could potentially place them at risk as it could influence their decision-making ability negatively as well as understand the consequence of those decisions. Per definition participants in a palliative care environment are vulnerable - they find themselves in an uncertain and very emotional situation (56). Therefore ethical guidelines must protect these vulnerable groups (53). The informed consent process made it clear that the interviews were voluntary and if they decided not to participate, it would not change the care they receive. The Distress protocol explains how the researcher would support a participant at the time of distress, according to the palliative care principles. The participants had access to debriefing or counselling sessions. In addition, the participants were offered follow-up counselling - either by the hospice counsellor or someone else, if that was necessary or preferred.

To be listened to could be experienced by the participants as being beneficial. Some of reported benefits that patients and families have experienced when they contributed to a study are a sense of altruism and personal gain (13). It gives them a sense of altruism to know that, if not themselves, at least future patients or their families can benefit from their data which could lead to new or adapted practices or policies (57).

Although purposive sampling was used to ensure a fair selection of all available participants who met the study requirements and criteria, the number of potential participants were limited by very late hospice referrals. Many suitable participants' partners died within days after referrals before interviews could take place. No incentives were offered to participants during their participation in the study.

Bias was minimized by following the principles and process of a thematic analysis as it was described earlier. Bias was further minimized by the researcher's awareness of her role as primary researcher through self-reflection.

A checklist for the Standards for Reporting Qualitative Research (SRQR) was used to ensure that all steps were taken to ensure the reporting complies with the standards (74). (Appendix 18).

- See **Information Sheet + Consent Forms** (Appendices 4 - 10).

- See **Distress Protocol** (Appendix 14).

Permission to conduct these interviews was granted by the Hospice Bloemfontein Board of Directors. (Appendix 3).

The research adhered to the Declaration of Helsinki.

CHAPTER 4

Results

4.1 Introduction

Chapter 4 describes the experiences and challenges in their own words of primary caregivers taking care of their partners with a life-limiting disease. Ten participants were interviewed in the period of March 2021 - November 2021.

4.2. Participant demographics and characteristics

The mean age of participants was 64 years (range 26 - 80 years). Seven of the participants were females and three male, and 9 of them Afrikaans speaking, none were Sesotho speaking. One of the participants spoke English as a first language. Nine of the participants were taking care of the partners in their private homes, and one participant lived in a residence for low-income adults where she shared a small room with her husband. Seven of the partners of the participants were diagnosed with advanced cancer of whom one also had additional dementia, and three participants had heart failure, one of whom also had dementia. The duration of the time they had taken care of their partners at the time of the interview varied from two years to a few weeks.

Table 1. Participant demographics and characteristics:

PARTIPANTS	AGE	GENDER	YEARS TOGETHER & DURATION OF CARE	PUBLIC OR PRIVATE HEALTHCARE	PARTNER'S DIAGNOSIS
Participant 1	47	Female	20 yrs. Durations of care: 1-2yrs.	Public	Spinal cancer
Participant 2	26	Male	8 yrs. Duration of care: 1-2yrs.	Private	Brain cancer
Participant 3	79	Female	66 yrs. Duration of care:< 1yr.	Private	Prostate cancer and Heart failure

Participant 4	44	Male	19 yrs. Duration of care: 1-2yrs.	Private	Childhood osteosarcoma, adult metastatic breast cancer
Participant 5	72	Female	50 yrs. Duration of care:1-2yrs.	Public	Prostate cancer and Dementia
Participant 6	74	Male	51yrs. Duration of care: 1-2yrs.	Private	Heart failure and dementia
Participant 7	77	Female	53 yrs. Duration of care: <1yr.	Private	Heart failure
Participant 8	75	Female	52 yrs. Duration of care: <1yr.	Private	Prostate cancer with metastases
Participant 9	69	Female	43 yrs. Duration of care: 1-2yrs.	Private	Heart failure and Alzheimer's
Participant 10	80	Female	61 yrs. Duration of care:<1yr.	Private	Pancreatic cancer

4.3. Findings

The data from the in-depth semi-structured qualitative interviews with primary caregivers about their experiences of taking care of their spouse or partner at the end of their life in hospice care were categorized into three main themes using the process of thematic analysis, as outlined in the previous chapter. The first theme dealt with the personal costs and/or gains of taking care of their loved ones. The second theme dealt with factors that were either distressing and / or supporting in their caregiving experience. The third theme focused on the emotional responses of the caregivers to different aspects of their caregiving role:

TABLE 2: Table of themes and sub-themes developed in data analysis:

THEME 1	**THEME 2**	**THEME 3**
PERSONAL COSTS / GAINS OF CAREGIVING	**DISTRESSING AND SUPPORTING FACTORS**	**EMOTIONAL RESPONSES TOWARDS ILLNESS AND CAREGIVING ROLE**
Physical demands	Communication	Coping with the caregiving responsibilities
Financial burden	Involvement / support from others	Coping with the illness and changes.
Personal implication	Personal coping mechanisms	
Social implication	Spiritual / belief system	Coping with impending death
Impact on the Relationship	Love / Commitment	Coping with uncertainty about life after partner's death.

THEME ONE: PERSONAL COSTS AND GAINS OF TAKING CARE OF A LOVED ONE.

Taking care of a loved one has an enormous impact on a person’s life, with the effect noticeable and felt across different domains. Although the impact can be experienced negatively and can come at a cost, it can also create an opportunity for growth and contentment. The sub-themes of the impact of taking care of a loved one were: the physical demands, financial burden, how taking care has impacted them personally, as well as the social impact, and how their relationship has been affected by the illness.

1.1. Physical demands.

All of the participants that were interviewed were actively involved in taking care of their partner, all to a different extent depending on additional support. Three of the participants hired carers who provided basic physical care such as washing, dressing, feeding, and changing of nappies. The support these carers provided varied from a few hours a day to occasionally staying over for the night or over weekends on request. The rest of the participants were reliant on help and support from family members or friends to help with basic caring tasks, such as those that were mentioned above. Regardless of additional support, all participants mentioned that the physical demands of taking care of their loved ones were exhausting, took up most of their time, and had an impact on their bodies.

> *"Until about two weeks ago I set my alarm for every hour and a half to go and check on her. But now I have just realized that I cannot any more. I am exhausted." [P4]*
>
> *"The hardest thing for me is to take her to the toilet as she cannot walk anymore. It is very, very hard for me. My back is really hurting." [P6]*

One participant mentioned that she herself got ill a few times, but could not afford to focus on herself as her husband needed care:

> *"I get so exhausted. There's been a few times where I also got ill, and just had to get up and carry on. I cannot just stay in bed just because I am ill. I have to get up and continue taking care of him. I can feel that my body has been drained, is tired, but I carry on... I just have to." [P1]*

Two participants also mentioned that they have gained weight because their diets have changed and they are house-bound and have less time to exercise.

> *"I am also a bit overweight now, because I sit so much and cannot get out" [P6]*
>
> *"We just have to eat what we get from people as we cannot afford the food we used to buy. For example, we get a lot of bread now, and Pilchards, and I can see it on my body, I have gained a lot of weight."[P1]*

One participant mentioned that the physical demands of taking care of his wife has had no big effect on him as caring was part of their relationship form the beginning as she is disabled:

> *"Physically - I am just walking so much more, really! But remember, I've been married to a disabled woman from the start. So, the physical thing is not an issue for me. It is second nature for me." [P4]*

Only one participant (age 26) has reflected that he has become stronger and fitter since taking care of his wife, and has taken up a healthier life-style.

> *"What is interesting is, that in this time I have actually done quite a lot to NOT feel physically drained. I cut down tremendously on smoking, and I'm exercising every day. So, that's given me already more energy, and I feel more focused, more energetic and do not feel as lethargic as I used to." [P2]*

1.2. Financial burden

All participants reported that their loved one's illness has had a financial impact on their lives. The impact depended on their financial situation prior to the diagnosis, how much they have saved before the illness, and on the support, they receive from friends and the community. Two of the patients had home-based carers that were paid for by their medical aid, and one participant had to pay himself for the home-based carers.

> *"If there is one thing I need to make it easier, is money. Financial support. If you don't have money, you cannot buy food, electricity or water. This whole thing is about money." [P1]*
>
> *"The other day at the hospital they wanted to get social services for me to organize someone to help me with him. But I said, no, because then I also have to pay R400 out of my pension for that help. That takes away from what I can spend on nappies. It costs me R1400 per month for nappies, and I just don't have R400 left to pay them." [P5]*

One participant stated that her husband was the breadwinner, and without his salary they are now only living from a small investment:

> *"His illness has really affected us financially very, very badly. Going from R30 000 per month to nothing was a very big adjustment. We have sold a lot of things to pay for the things we need now." [P1]*

One participant stated that they were both earning salaries prior to her diagnosis, and that they had to make adjustment without an income:

> *"You know, she's lost her job, obviously, and I was also retrenched the beginning of the year. That is hard. We have to stay with my parents now, and I am very grateful for that." [P2]*

Despite having medical funds, those participants could also feel the financial burden as many of the occasional cost are not covered by a medical fund:

> *"Our pharmacist knows her ID by heart, that's how big our bill is there. Our bill there only the last two weeks is already over R1200, and that is only what the medical aid doesn't pay! And then I'm not even mentioning Energade, Rehydrate, nappies, and so on! And petrol driving to all the pharmacies! And parking - all the money you spend on hospital parking fees!" [P4]*

A few of the participants had to use savings or retirement funds, or make alternative plans:

> *"I am fortunate, with help from a broker friend, we could arrange for all her policies to be paid out already. So, preparation is everything. [P4]*
>
> *"At the moment we are still coping financially because her whole pension is used to pay for the carers. But maybe I'll have to sell my house to move to a smaller place where there is care." [P6]*

Only one participant stated that they are not experiencing any financial worries:

> *"We are really fortunate that we really have everything we need. And if he needs something, we can get it for him. I know how fortunate we are. " [P3]*

1.3. Personal implication

Taking care of their partners also affected the participants in a very personal way in terms of how they relate to other, and how they perceive themselves. They reflected on their needs, their limited capacity to be there for any other personal relationship with friends or colleagues, or how they sacrifice their time, energy, career, to take care of their partner. They put their lives "on hold" while they focus on their partners.

> *"You know, you don't live for yourself anymore. You live for him, and you live his life, according to his time. You have to do what he wants to, to eat when he wants to. In a way you live a second life." [P1]*
>
> *"I think that is the worst part, I feel I cannot be socially or emotionally involved in my friends' lives anymore. Because I am drained, I'm really drained. And I have no idea what I need. " [P2]*

One participant has reflected that she has grown emotionally stronger because of her experience:

> *"I am stronger now. One pushes the reality away, out of sight, initially... but slowly it does catch up with you." [P3]*

One participant reflected on his desire to also be a recipient of attention and love:

> *"Emotionally you get to a point...I don't think I would like to marry again one day. But I would just like to have a friend again who checks in on me every now and then. And let it be about me - because I'm not OK. I don't know how it feels to receive love back, because so much is just about caring now that one loses the meaning of what love is." [P4]*

This participant also mentioned that while he took care of his wife, he could not prioritize his career as his focus was on caring for his wife. It was difficult to travel and visit clients elsewhere, or make appointments as, depending on her condition, he often had to rush home, or pick up their daughter from school:

> *"For four years I have played the butler at home, and now, soon, I will not be butler anymore. I am looking forward being able to plan my day ahead again, because I could not do it with her illness. I can then focus on my career again. [P4]*

Some participants reflected that they have realized that some form of self-care or support is important to be able to continue with the responsibilities of taking care of their loved one:

> *"It really takes the whole day to help him and to take care of him. But I also know, to be able to take care of him, I really need to look after myself as well. I swim on a Wednesday, and that is good for me, and my mood is also so much better!" [P7]*
>
> *"My doctor told me if I collapse now, she will also collapse. But it is hard. I know I also have to look after myself." [P6]*

One participant expressed his desire to get away from his caring responsibilities and the emotional impact it has on him, even just for a short while:

> *" I've always been an introvert, but I must say there has been a few times where I just wanted to get away. To visit a friend, or go on a camping trip, or a music thing, or something. Just go and leave the guilt behind. But that is just not happening." [P2]*

1.4. Social implication

The majority of the participants very strongly pointed out that their partner's illness has had a tremendous effect on their social life, their interaction with others, and their ability to go out and see other people. The illness often isolated them and restricted them to their homes where they take care of their loved ones.

> *"I have no social life anymore. The only time that I do get some social interaction is when I go and play drums for the church. So, when there is a band practice, it's just like YES, I'll go! [P2]*
>
> *"I cannot go anywhere with her, I am housebound, except for Fridays when I visit some friends." [P6]*

Some participants also mentioned the inability of people to deal with and respond to the illness in a helpful and supportive way towards them:

> *" The one friend she has, WhatsApp-ed me the other day and said she cannot visit anymore because the situation is too hard for her, and she doesn't know what to do. I wrote back that she should just come and visit her friend! She said, yes, maybe next week... Needless to say, the woman just never came!" [P4]*

Two participants said that they are being supported and visited by friends, the illness did not affect their social life negatively at all:

> *I really admire our friends. They still come and visit." [P7]*
>
> *"There are some friends, or people, who are afraid to come, but I really don't mind. There are so many other people that want to come and support." [P8]*

1.5. Impact on the relationship

The illness of the partner has had a big impact on most of the participants' relationships. The majority of the participants expressed a deep sense of loss, acknowledging that they miss the person the partner used to be, and miss activities they used to share. The illness forced them to play different roles towards each other, and taking over some of the roles the partner used to perform. Some participants expressed their need to be loved, to receive attention, and to feel less alone:

> *"You know, he's not the man he used to be. There are the small little things, like hugs from your husband I miss. There's not really anything left that we can share, we do not have anything to say anymore." [P1]*
> *"His illness really has had a huge impact on our relationship. There is a big distance between us that has never been there before. We used to share all the chores and responsibilities, but now I do all on my own." [P7]*

Two candidates reflected on their intimacy in their relationship and expressed their longing to experience closeness with someone again:

> *"Her illness put a lot, a lot of strain on our relationship, even though it is hard to admit it. I feel more like a caretaker than a husband. Obviously, intimacy is not something that s very big in our relationship anymore. So, I get very frustrated." [P2]*
> *"Our sex life has been chaotic the last few years, and I have a huge need for physical intimacy. I really miss the closeness of someone." [P4]*

One participant expressed the fear of their partner being left alone:

> *"We have been together for nearly 50 years now, and that is why we love each other so much. He cried the other night and said I shouldn't leave him alone. I told him that I won't leave him, I am with him!" [P5]*

Only three participants said that caring for the other has brought them closer, or has brought a positive change in their relationship:

> *"Taking care of him has brought us even closer together. He is like a baby in my arms now, he is close to me." [P8*]
> "*You know, I think his illness just brought us closer, really. He is so grateful for what I am doing. " [P10]*
> *"I've always felt as if I wasn't on his level, and he wasn't on my level. We haven't understood each other all the time. But now it feels as if I can mean something to him. And I do it with so much love". [P9]*

THEME 2: DISTRESSING AND SUPPORTING FACTORS

A few themes emerged from the data that either added to the distress of the caregiver's experience, or were experienced as supportive and encouraging. The sub-themes are communication; involvement and support from others; the role their spirituality and belief system play; what personal coping mechanisms are helpful and constructive; and how love for and commitment to their partners motivate them to carry on.

2.1. Communication

Six of the participants mentioned communication as a factor that either added to their distress, or requested specific communication to aid them in their caregiving. Most of the participants reflected on the fact that it was easier to talk to hospice staff, and felt that things got clearer and easier once hospice got involved:

> *"And look, this is the situation. The doctors are basically saying that everyone runs the risk of dying. Ha-ha! What a dumb observation!" [P2]*
> *"The information we receive from the hospice, helps us so much in preparing us for the future." [3]*

Three participants expressed their need to receive clearer practical guidance, explanations and instructions:

> *"I was sometimes not sure how to proceed with things, where to go next. One needs information, practical advice, where to get things, for example oxygen. I feel so uncertain and ignorant." [P3]*
> *"I would like specific information regarding his medication. I would like to understand that better". [P9]*

Two participants referred to inappropriate comments and inquiries from friends or family, or expressed their frustration with people's lack of understanding of their situation:

> *"You know, I just sometimes want to tell people to f*ck off! Sometimes people will WhatsApp you at 7 in the morning asking how she is doing today. My God, it is 7 in the morning! I haven't even been to the toilet; how should I know" [P4]*
> *"To talk to people... You know, I don't think that if anybody even told me that they understand what I m going through that would help, because - I just don't believe anybody will understand. Maybe if they just listen..." [P2]*

The same participant as above also expressed his frustration with people telling him to be positive:

> "*You're making assumptions, tell me to be positive. Please just don't give me advice when you've got no f*cking idea what I'm dealing with!*" [P2]

2.2. Involvement / Support from others

The second sub-theme dealt with the involvement and support they receive, or not, from friends and family. Most of the participants experienced isolation to a certain extent, and only three participants said that they receive enough support and do not feel alone at all. Those not receiving adequate support or visits from friends and family experienced more distress. Some of the participants reflected on how much the support they received from the hospice had helped them in coping with their situation and reduced their anxiety. All participants were reliant on some kind of support to perform all the tasks and carry out all the caregiving responsibilities:

> *"I don't see or meet anyone at the moment. But I need support to get through this. People just come over less and less. " (emotional). [P1]*
> *"I am so grateful for some of the other residents in this house that sometimes check-in on me and see how they can help. Because I don't really have anybody from outside who supports me, everyone has their own stuff to do." [P5]*

2.3. Spiritual / Belief system

All but one participant experienced their spirituality and their faith as a source of strength and encouragement that helped them and supported them in coping with the illness of their loved one. Some of the responses:

> *"But I say that the Lord has brought it on my way, and I have to make it work. He will help me to get through every day."[P1]*
> *"I've always had a struggle with spirituality, trying to figure out what the purpose is of my life. But after she was diagnosed the last time, I had this clear message from the Lord that I have to stay for a reason. Since then, I am calm. The message said: Stop asking what your purpose is. You are where you have to be to help this woman, and to raise this child. There will be an end to this, and something new will come from it. Relax." [P4]*

Only one participant expressed his deep distress and spiritual crisis:

> *"I've had existential crisis upon existential crisis, and I really cannot make any sense out of any of this. The purpose of all of this I've lost. It feels like, this is the way now. It's something that I just have to accept. But, what's the point of life if this is the way it's going to go. What am I even doing here?" [P2]*

2.4. Personal coping mechanisms

All participants had some kind of ritual or habit which helped them in coping with their situation. The habits included exercise, reading, knitting, visiting friends, exercising, and gardening. Some of the responses:

> *"Generally, the exercise is good, because it feels like I cause my body pain in the socially acceptable way (laughing). And it is a way to cope. It feels I have time for myself. Exercising is a different pain, but it kind of feels good. "[P2]*
> *"My garden motivates me. I really enjoy it so much working in the garden." [P7]*

2.5. Love / Commitment

Despite all the challenges, hardship and in certain circumstances suffering the participants were experiencing, they all had a strong sense of commitment and gratitude to their partner and their role of caregiver, and did not see any other option as to do what they do - to care until the end. Some of the participants not only feel committed to taking care of their partner, but were acting out of a deep and strong sense of love:

> *"What I do, I do with love." [P1]*
>
> *"I think it is simply love that keeps me going. I love my wife's smile every now and then - THAT's what keeps me going." [P2]*
>
> *"The love one has for the person you care for gives me all I need to go on. I am so grateful for all we have, and for the life we've had together." [P3]*
>
> *"I continue taking care of her because I love her. It's as simple as that." [P4]*

THEME 3: EMOTIONAL RESPONSES TOWARDS ILLNESS AND CAREGIVER ROLE

The third theme that emerged from the data dealt with the emotional responses towards different aspects of the illness, including the impending death of the loved one, as well as the responsibilities that taking care of a loved one entail. As it had been a while already since the initial diagnosis and the shock, most of the participants had already had time to adjust to the illness and had made some changes in their lives. Being referred to hospice care moved them into a new phase of the illness and more into the reality of an impending death. The participants did not only face the death of their loved ones, which brings with it a wide range of emotions, but also struggled to cope with the practical tasks and responsibilities that caring for a person bring. Caring is time consuming and exhausting, which adds to feeling of being overwhelmed and helpless.

Although all participants mentioned reactions that fall under the three sub-themes of the emotional responses, the intensity, focus and experience were very individual. The first sub-theme is dealing with how they cope with the responsibility of and the tasks involved in taking care of their loved one; the second sub-theme is how they handle and react to the illness and the subsequent changes, and how they try to process and deal with those changes. This theme is dealing with their thoughts, reactions and emotions about facing the death of their loved one.

3.1. Coping with the caregiving responsibilities

Apart from one participant, all the other participants felt some sense of frustration, desperation, or an overwhelming sense of helplessness facing the daily tasks and responsibilities of taking care of their loved ones.

> *" She's sick, and I have this sense of helplessness, of I don't know what to do to help you!" [P2]*
>
> *"You know, it is as if something inside of you is just taking over. You do what is necessary, without thinking about it too much." [P3]*

The practical tasks, often perceived as never-ending and time consuming, proved to be a challenge and exhausting:

> *"So, it is cleaning up vomit, making more food, filling water bottles, making sure she's taking her medication. And then my son comes home from day school, and then it's just chaos!" [P2].*
>
> *"I have to do everything here. I don't know if I will be able to take care of her is she gets worse." [P6]*

One participant mentioned that the practical tasks of caring do not come naturally to her, even though she chooses to do it:

> *"I am a compassionate and caring person, but not really a nurse. That really doesn't come naturally to me." [P7]*

One participant mentioned how the never-ending responsibilities made him feel helpless, frustrated and drained, which is reflected in his response towards her:

> *"I'm snapping a lot lately, my patience is kind of run thin, and it is not her fault. I just don't know what else to do, it just never stops." [P2]*

Only one participant mentioned that the caregiving responsibilities had not changed that much lately, due to the fact that his wife had been disabled since a child due to childhood cancer. He was used to that role of caregiving and support since the beginning of their relationship:

> *"Her illness didn't change that much for us as it wasn't really anything new to me, because with her disability, her leg was amputated as a child due to osteosarcoma, I have been helping her from the beginning of our relationship and has been the caretaker of our daughter since her birth. " [P4]*

3.2. Coping with illness and changes

Seeing the impact of the illness on a loved one confirms the fact that they are ill, and that it is a progressive illness. They have to deal with multiple losses daily, while facing the responsibility of caring and taking over many other roles in the relationship and household. They often reflect on lost dreams, on how things used to be, needing to process the image of a weak, changed and ill partner. Their reactions range from efforts to carry on, worry, sadness, exhaustion, desperation, anger, hopelessness, feeling insecure - especially when witnessing their pain.

> *"It's been very hard for me seeing how he gets weaker...(emotional)." [P3]*
>
> *"It is hard coping with her illness emotionally. I've been to a psychiatrist and am taking anti-depressants." [P6]*

> *"I'm very insecure a lot of the times, and I tend to think I do a terrible job. I cannot make her feel better. I do my best, and that's all I can do." [P2]*

Some participants reflected on the changes in their partner's mobility and their loss of performing tasks independently:

> *"He's spending more and more time on his own, and does not want to have people visiting him that much anymore, he's tired. And I really have to help him with everything. He is also on nappies now... (emotional" [P3]*
>
> *"I have to help with washing her. I washed her hair - she got very emotional, because she never used to let me touch her hair. I laughed, and she cried. It was hard for her, but for me it was an absolute privilege. She doesn't see it like that, I know, because for her it is another thing that she has lost that was important to her." [P4]*

Two of the participants also have to witness their partner's changes towards their small children, as well as the children's reaction:

> *"She was angry with our daughter when she got breast cancer, because the doctor told her the pregnancy caused the cancer. So, it's always been a rocky road." [P4]*
>
> *"She does not really have any interaction with our son anymore. She tries, but cannot anymore, really. It's eating her inside. " [P2]*

Concerns and uncertainties about their future role:

> *"My emotions are changing the whole time. What kept me awake last night was what will I do when our daughter turns 16, and she starts with her periods, and she's going to ask me about sex and boyfriends, and all those things? What am I going to do?" [P4]*

Reflecting on how things used to be:

> *"It sometimes makes me so sad if he is so grateful for what I do, because he used to do it all himself... He used to make us breakfast every morning and bring it to bed. Breakfast in bed with coffee... But now I am doing it, and he doesn't really eat anymore" [P8]*

3.3. Coping with impending death

All participants mentioned the possibility or inevitability of death of their loved ones, but their engagements with, concerns and thoughts about their death differ. Some participants reflected that they have no control over what is going to happen, or have made peace with what is coming:

> *"I very soon made peace with the fact that she is going to die, because I realized I would otherwise struggle." [P4]*
>
> *"I've asked him if he is afraid of dying. And then he always says no, not of dying, but he is concerned about what will happen to me after his death. But this gave us time to talk about all of it and get everything in place". [P10]*

Some mentioned the fact that their partners are also aware of the fact that they are dying, with different emotions, ranging from contentment and peace to anxiety:

> *"He is not afraid, and says that God has sent his angels to take care of him." [P3]*
> *" She knows she is dying. She is actually restless because she cannot die sooner..." [P4]*
> "*You know, everybody says that they want to go to heaven, but they don't want to die. I see he is anxious. I've asked him what he is afraid of, but he doesn't know*." [P7]

One participant very clearly described his anticipation of his wife's nearing death, and how he tries to prepare for when death happens:

> *"When I get up in the mornings, I go to her room to see if she is still alive. I know it sounds hard, but I prepare myself for what is awaiting me in her room from 5:30 in the mornings. And if I open the door - and I know it will sound weird - but there is a smell. And I've learnt now to know what to expect by the smell that is in the room. If she is better, the smell is gone. When I opened the door this morning, the smell was there again. Death is coming closer. So, it is this challenge every morning to get myself ready: will I find her dead or not in the room." [P4]*

Death is not always feared, as was reflected by one participant whose wife has been struggling for a long time from brain cancer. He rather sees death as a relief, and fears any effort or possibility to prolong her suffering:

> *"I know she is dying, but honestly, my biggest concern at the moment is that, if my wife has the opportunity to fight or let go, is that she'll choose to fight. That's my concern." [P2]*

One participant admitted her own fear regarding her husband's death:

> *"I'm worried and anxious about death, you know. But I try to hide it from him, I don't want to upset him. I don't know how I will react when he dies." [P7]*

3.4. Coping with uncertainty about what will happen after the partner's death

What will happen after the partner's death, was a concern that was mentioned by four participants. The concern included what will happen to them after the death of their loved one, as well as some practical aspects, including funeral and living arrangements:

> *"I worry about being on my own after his death. We have been together for so long, that I don't know how I will cope on my own. I am afraid of being alone after his death." [P8]*
> *"I have struggled for a long time with the idea that a part of me will die with her. I was afraid that I won't know myself without her. You define yourself so much as part of a thirty-year relationship. People don't really know me on my own. I would need to get to know myself again! [P4]*

One participant has found comfort in what he plans to do after her death:

> *"I know this will give it all meaning - to give back after her death. That will give meaning to her life, and especially to her death." [P4]*

4. Conclusion

This chapter provides a clear reflection of the complex experiences and emotional responses of primary caregivers taking care of their partners with a life-limiting disease in hospice care. It also reflects on the demands that are placed on those caregivers to meet all the different and multidimensional needs of their ill partners, which include the effect it has on them financially, physically, and personally. The study further reflects on their emotional reaction to the illness, their caregiving and the impending death of their partners in a context where they are often isolated. Certain factors added to and others relieved caregivers' distress. Although there were common themes that emerged from the data, the reactions and experiences of all participants were unique and individual. As a consequence of these demands some of the caregivers in the study experienced exhaustion, physical complaints, isolation, sleeplessness, spiritual distress, and unmet needs.

The findings of this study will be further interpreted in Chapter 5.

CHAPTER 5

Discussion

In this qualitative study, the aim was to explore and describe the experiences of primary caregivers taking care of their partners with a life-limiting disease in hospice care in Bloemfontein, Free State. The richness of this data gave a comprehensive reflection on their experiences, and responses as demonstrated by three key themes. The implications of these findings will be further discussed in this chapter.

5.1. Personal cost or gains of caregiving

In the findings of this study, the physical demands of caregiving as well as the financial impact of their partner's illness have contributed significantly to their experience of distress. This was often exacerbated by the fact that they were isolated from their normal social interactions with others, while their caregiving role and the illness not only affected them personally but also their relationship with their partner.

5.1.1. Physical demands

The labour of caregiving is defined in the literature as "*the ongoing cognitive, emotional, and physical work of caregiving*" (58). *Labour* means "*physical and mental exertion, often without recognition or adequate compensation, which also connotes suffering or the existence of some burden*" (58). *Taking care* is defined in the literature as the "*guiding, giving and doing for the ill person to meet his or her needs"* (58). The physical demands of caregiving had a huge impact on most of the participants in this study. Physical complaints they had due to caring (labouring) ranged from sore backs and shoulders, exhaustion, and lack of sleep. For some participants coming to know their own strength and limitations was a turning point in their caregiving role as they realized that they had to ask for additional help. Most of the participants, especially those who had been married to their partner for many years, wanted to be with their loved ones as much as possible throughout the illness as being with their loved one's side was central to their experience. It was often difficult to contemplate additional help, but they had also come to realize that caring for their loved one is exhausting and physically draining. They have consequently learned that to be able to continue with the care they provide, they had to look after themselves and had developed competencies in negotiating what they need (from neighbours, family members or caring agencies). Despite the challenges and poor health due to their caregiving responsibilities, some of the caregivers in this study continue to provide care mainly on their own and describe a great overall satisfaction with the caring experience. The distress other participants were reporting was significant, and as Spatuzzi et al. pointed out: "*could affect their ability to care for the patient, and may also influence their ability to provide emotional support, to support activities of daily living, and to deal with other aspects of care*" (8). Once the caregivers' mental and physical condition has been affected, the care they provide to their ill family member could be compromised (8).

5.1.2. Financial burden

Some of the participants in this study experienced great financial hardship as they had given up their jobs to take on a full-time role as caregiver to their partners. In addition to that they also had to manage without the income of their partners, in some cases only with the support of a small grant. Those participants living only from state grants could feel the impact the hardest, being dependent on support from others, also for food donations. Those participants who experienced less of a financial burden are those who had a medical fund as well as enough savings to support them, but even those with medical funds could feel the strain and impact of extra expenses and some had to access additional savings to cover all expenses. Some literature suggests that there are opportunities in lower to middle income countries (LMICs) to improve the welfare of poor people at modest cost involving public funding, but those opportunities have not typically been realized (59). Knaul et al. suggested using cost-effective models of providing essential services and packages of essential commodities to people in need, that need, and that should be integrated into the national health systems as part of universal health coverage (59). Social support for patients and their families are essential to ensure that families are not further forced into poverty while caring for a loved one. Participants in this study who were in need of support, received essential goods, for example food, nappies, and vouchers, from some local community centers, like churches.

5.1.3. Personal implication

Becoming a caregiver had a profound impact on the lives of caregivers and required and caused significant changes, ranging from personal changes and adjustments to how their friendships and social interactions had been impacted, as well as how their relationship with their partners had been affected. The rhythm of daily life was dependent on the ill person's health situation and abilities, findings that are also reflected in the literature (3, 26). They often feel that their own life had been put on hold and had been indefinitely interrupted by the illness, with insufficient time to attend to their jobs or life (3). This was also true for some the participants of this study who had to give up their work to take care of their partners. They felt that their caregiver role was grueling, depriving them of strength and energy. Those caregivers in this study who witnessed a greater deterioration of their loved ones and had experienced a long and exhausting end-of-life trajectory with symptoms and distress that increased in severity, had experienced more difficulties with their caregiver role. These findings correlate with findings in a comprehensive review done on home-based family caregiving by Stajduhar et al. (60). But, as the illness progressed, the caregivers had also acquired some skills in managing the illness, including the provision of physical care, comfort and the monitoring and administering of symptoms and medications.

5.1.4. Social implication

Most of the participants stated that they hardly had a social life left, feeling isolated, either not able to leave their house or too afraid to leave their loved ones alone. Some participants pointed out that friends came for support initially, but that gradually, over time, that support became less. Chiu et al. in a study to identify determinants of complicated grief in caregivers who cared for terminal cancer patients, pointed out that lower levels of social activities and smaller social networks over months of caregiving as well as lower satisfaction with social support were factors that were predictors of higher post-loss depression (61) . Spatuzzi et al. also state that the presence of an adequate social support network which the caregivers also perceived as adequate, could act as a buffer against stresses he or she may face (8). Knaul et al. add to this in stating that social support for patients and their families are essential to promote dignity at the end of life, as caregiving can exacerbate poverty and isolation for the caregiver (59). Most of the participants in this study would also have benefited from support that include minimum social support and provision of supplies, for example the provision of nappies, bandages and other basic medical necessities; and access to a well-developed community-integrated programs for patients and families, as suggested by Knaul et al.(59), which include access to community based health care facilities, support groups, and more.

5.1.5. Impact on the relationship

The illness and the change of roles towards each other also had an impact on the quality and character of their relationship. A life-limiting illness does not affect only an individual, but rather the couple as a unit, as also stated in the literature (3). Terminal illness adds stress to an intimate relationship, with caregivers and their ill spouses experiencing a range of physical interferences and emotional distress (3) , as was confirmed by many of the participants. During their caregiving experience some of the participants longed for the person their loved one was and the life that they had lived together. They reflected on the quality of their relationship, and although some of them reflected that their relationship had grown stronger, other participants, especially those who are younger, stated that they feel lonely and longed for intimacy. It may be difficult for couples to find a sense of partnership again and reciprocity in a relationship that illness has changed irreversibly, but there are components in a relationship that are not physical (62). Some of the participants reflected on how their relationship got stronger, which is in accordance with findings from Tie and Poulson, where concepts of intimacy were referred to and how there are many facets, most of which are emotional (62). Emotional intimacy, as suggested by Tie and Poulson (62), can be fostered by "*helping couples to face and express their deepest fears and desires with one another*" (62). This was also demonstrated by some of the participants where they mentioned the fact that they could discuss the nearing death of the ill partner with each other and could reflect on the life they had together. Those participants were open for discussion and there was a willingness and space to build a feasible life around the illness and time they had left with one another. These couples demonstrated some flexibility in finding new ways to connect with one another, depending on the level of inability and the nature of the illness. Furthermore, talking about the inevitability of their partner's death as a couple gave them the unique opportunity to grieve together, share memories and emotions together, even though they sometimes wanted to spare the other one from witnessing their emotions too often. Sharing these emotions gave them the opportunity to express not only the emotions of guilt and regret, but also messages of love, appreciation and goodbye. Despite physical decline an emotional partnership of equals can be formed as opposed to just a caregiver and a patient. This could contribute to a less complicated post-death grieving process (62), and as Elizabeth Kübler Ross stated: "*If they (the spouse) had been helped before the death of their partner to bridge the gulf between themselves and the dying one, half the battle would have been won* "(63, 64). Some of the participants in the study reflected on the fact that the support and guidance they had received from the hospice team reduced their anxiety and enabled them to focus on meaningful conversations with their partners, an act that brought them closer to their partners.

5.2. Distressing and supporting factors

A few factors were identified in the experience of caregivers that either added to their distress or contributed to some sense of relief. Factors that added to distress were inadequate medical information provided by physicians or frustrating efforts of communication between clinician and patient, or with family and friends, or inadequate formal or informal support from professionals and/or social networks. All participants demonstrated some coping mechanisms and/or internal belief systems as a way of motivation, distraction, or self-regulation.

5.2.1. Communication

One of the factors that were reflected on was communication, or especially the lack of adequate and effective communication that contributed to the caregivers' sense of distress and frustration, regardless of whether the communication was between clinician and family, or communication with family and friends. Lack of information and feelings of inadequacy contributed to feelings of uncertainty about the future and what would be expected of them. These findings were in line with findings of Gysel et al. when stated that "*…poor information supplied by healthcare personnel working in EoL care led to high levels of* *distress amongst patients and their carers*" (38). Some explicitly expressed a wish to receive clearer guidance from the clinicians who were involved before they were referred to hospice care, in terms of certain administration of medication and information about the illness which would help them in their caregiving tasks. Having this information would have consequently boosted their confidence. Some of the participants stated that they felt responsible to gather more information about the illness and prescribed medication, not only for themselves but also for their partners. They felt that the information they needed was not always readily available or shared by health care professionals. However, receiving the information they needed gave them a sense of control over the situation. Rhodes et al. confirmed these statements by stating that family members were more likely to experience more satisfaction if regular and accurate communication about the patient's medical condition took place by the hospice team (27). Some participants reflected that the communication and guidance they received from hospice was supportive, reduced anxiety, and prepared them for the way forward.

5.2.2. Involvement / support from others

Two participants expressed their frustration with attempts of friends or family members to advise them to stay positive, this resulted in the participant experiencing a sense of not being heard properly, and of not acknowledging the depth of their experience. These statements are consistent with findings of Sinclair et al. who stated that "*empathy expressed as an effective response acknowledging and attempting to understand individual's suffering through resonance* is *important"* (44). Assessing patients or people's needs involves more than the application of techniques, it also involves actively listening to patients, as was also confirmed by Sinclair (44). Studies have highlighted the fact that people have consistently identified that having someone to listen to them fulfills one of the greatest needs at the end of life (44). Listening is a core element of communication, and it presents one of the most important skills patients desire from their health care professionals, as confirmed by some of the participants.

5.2.3. Personal coping mechanisms

In this study a series of coping mechanisms to reduce caregiver stress and a way to handle daily life were identified by the participants which also acted as a way to self-regulate. Some participants sought relief in gardening, playing bowls, or reading. Some also sought support through visiting friends and family as a distraction and a short break-away and respite from their caregiving responsibilities. It allowed them to rest and recuperate by engaging in pleasurable activities. These findings are congruent to a study by Carlander et al. describing the experiences of family caregivers of dying family members at home (26). Most of the participants were aware of their limits and need to find some way to compensate for their physical and emotional effort of caring for their loved one, in order to reduce caregiver stress, a need that is also confirmed by Coelho et al, in a study about family caregivers' anticipatory grief (65). This resonates with the findings of Calander et al. stating that "*caregiving is a relationship that makes the caregivers face their own limits, shortcomings, and loss of control*" (26). Brown described three primary coping strategies for caregivers, and those are: "*being oriented in the present (taking one day at a time); retelling the reasons for caregiving (validating their actions); and establishing a routine (structuring ways to get help and respite from others)* " (58) . These kinds of strategies increase a sense of control and mastery for the caregiver, which were reflected in the participants' experiences in this study (58). Some participants reflected on "*the time we have left*", stating that every day counts. Most of the participants stated their love and commitment as the main reason for caring for their loved one, and had worked out a daily routine of caregiving, which included asking or accepting support from others, as well as rituals of respite (reading, gardening, sport, and so forth).

5.2.4. Spiritual / belief system

Most of the participants mentioned their faith as a source of strength and motivation, as well as adding meaning to their experience. One should, however, take into consideration that all participants in this study were Christians and regular church goers, and these results might not be generalized to caregivers of different religious and spiritual backgrounds. What was evident in this study is that the participants wanted to talk about their religious and spiritual beliefs and the role it played in their experience. The moderating effect of spirituality and religion on their caregiving experience was evident, as was also reflected in other studies (3, 66). Dumont et al. furthermore states that religious beliefs could have a positive influence on the grieving process (66). Those participants who could not attend church anymore because they were not being able to leave their loved one alone, expressed their longing to be in church again and be part of a congregation. This desire to be part of a congregation could be twofold: to take part in and express faith rituals that were meaningful to them; as well as experiencing the comfort and benefit of being among others. These statements of participants are in accordance with literature reflecting that religion and spirituality may contribute to patients' well-being and could have a positive impact on adjustments to bereavement (66, 67). Therefore communication about spirituality and religion is a core element of comprehensive palliative care as patients and their loved ones facing the end of life often want to discuss those needs with health care professionals (68). Holistic care to a dying patient and his or her family members includes physical, psycho-social, and spiritual care (4). Sinclair and Chochinov acknowledge the importance of this communication, but also point out that health care professionals often find it challenging to fully address these issues, especially when they are faced with an existential and spiritual crisis, as demonstrated by two participants in this study (68). Traumatic experiences can be important motivation for religious reflection and action, but on the other hand it can also cause fundamental challenges to religious meaning systems (69). A traumatic event, like the illness of a loved one, suddenly appears into life and changes the way we see the world, and the process of trying to make sense out of it can be a painful and difficult process, and for health care professionals difficult and overwhelming to support. To provide clinical guidance for health care professionals in assessing and supporting patients and their loved ones, Sinclair and Chochinov presented a clinical framework to effectively communicate with patients about their existential and spiritual needs (68). The framework they presented is the pneumonic SACR-D (68) *: "S - self-awareness, A - assessing the patient, C - compassionate presence, R - referring for additional spiritual support, and D - dialogue"*. They continue to state that patients have consistently expressed a desire to have these needs addressed, especially approaching the end of life (68). Clinicians and health workers have to exhibit sensitivity to the influence of patients' and their loved ones' spiritual beliefs and experience within their health care (44). This includes the bereavement care before and after the death of a loved one. The two participants in this study who demonstrated intense spiritual distress were referred to professionals for additional support.

5.2.5. Love / commitment

The emotional connection as well as the historical relationship between the caregiver and the recipient of care influence the experience of labour in an essential way. For many of the caregivers in this study choosing to care and becoming caregivers was a natural or expected role because of their relationship with the ill person, congruent to the findings in a review by Stajduhar et al. about home-based family caregiving at the end of life (60). Most of them assumed the role of caregiver automatically because of commitment and their loyalty towards their partner. Taking care of the ill person was inherent in their role. A few participants also expressed the lack of any alternative option as a reason for caregiving - they felt as if they had no choice. Some participants in this study, especially those who have been married for a long time, described caring for their partner as a deeply felt will to care for him or her, mainly out of love, but also out of feelings of responsibility. This is consistent with findings of Carlander et al. where caregiving can be seen as "*something that naturally belongs to life, and living*" (26). They further state that caregiving can be described as an practice of "*empathy, imagination, responsibility, witnessing and solidarity with those who are suffering*" (26).

5.3. Emotional responses towards illness and caregiving role

5.3.1. Coping with caregiving responsibilities, and coping with illness and changes

Caring for a dying loved one can be hard and challenging, and as D'Antonio stated: " *grief is often a constant companion"* (70). Grief is defined as the "*internal experience of a person to the loss of something loved and valued*," but the grief of caregivers is complex and therefore often more intense than the grief experienced after the death (70). The literature defines that caregivers often feel uncertain and out of control, especially when they have noticed distinct changes in their partners' condition caused by the illness (65, 70). They are furthermore often challenged with the reality of their situation which include dealing with a range of emotional responses (65, 70). The findings in this study confirms this statement as the participants often mentioned the patient's progressive decline, referring to their frailty, extreme thinness, loss of ability to help themselves as a reminder and confirmation of the seriousness of their illness. In response to seeing these changes the participants also experienced a sense of sadness, saying that it is "hard" witnessing this progressive decline. Their physical decline acted as a message that helped the caregiver to prepare for death, as was also described by Melin-Johansson, et al. (71). This physical decline forms an image of deterioration resulted in a change which is completely the opposite of who the person was previously (71). Even though the caregivers in this study were informed about the possible changes and trajectory of the illness, it was very upsetting to see their loved ones so frail. Not only were they aware of the impending death of their loved one, they also grieved and mourned losses that had already occurred because of the illness. As the disease progressed, and the patient's suffering became increasingly difficult to manage, some of the caregivers began to experience feelings of uncertainty and exhaustion. What helped many of the caregivers was to focus on what they could do, such as focusing on their caregiving tasks.

5.3.2. Coping with impending death, and coping with uncertainty about life after partner's death

In this study, nearly all participants had briefly considered and mentioned the possibility of their partner's death or imagined themselves and their situation after that event. Some participants spoke about confronting an unknown future which awaits them after the death of their partner, mainly in terms of how they will cope emotionally, especially of being on their own after years of marriage. Some compared the thought of being without their partner with having to continue in a body with some parts missing. Some participants also reflected that they did not know who they are without their partner and would have to redefine themselves again. Those participants who did discuss their partners' nearing death as a couple, had found comfort in the fact that they could have that conversation, and that they could prepare for life after the partner's death and arrange for necessary documentation and arrangement to be in place. This not only comforted the healthy partner, but also provided some sense of comfort to the patient.

Most of the participants had not witnessed death before and spoke about how unprepared they felt emotionally as well as practically. This is congruent with the findings of Brown et al. where he states that caring for a loved one at the end of life, and anticipating death is often a traumatic experience, regardless of the degree of suffering the ill person is experiencing or the amount of control the caregivers feel they have (58). Some of them were anxious about what to do when death occurs and had been waiting in anticipation for death to happen for a period of time already. Their waiting was filled with feelings of helplessness as well as trying to cope, and trying to manage their partners' pain and other symptoms. They found caring and waiting for death as an intense and exhausting experience.

As highlighted by Bouchal, et al. "*family members live in a complex tension of the duality of holding on and letting go throughout the illness and continued into bereavement*" (72). They are hoping for the suffering to end soon for their loved ones, but are also holding on to hope that their loved one will be there for another while (72). Participants in the study also expressed occasional feelings of guilt when they either wished for their partner's suffering to end, or when they wished for something good for themselves, or when they expressed a sense of frustration with their situation. They often struggled with contradictory reactions: trying to be with the loved one in the present, longing for and missing the person as he or she was, and at the same time planning for a life without their loved ones. Coelho et al. refers to this process as an *approach* and *avoidance* pattern (65). An *avoidance* orientation protects the caregivers from anxiety-arousing stimuli, where an *approach* orientation, in contrast, allows for appropriate action by noticing the threat stimuli and making it more controllable (65). This was demonstrated in this study when caregivers notice the decline of their partners, initially with shock and sadness, but after some initial procrastination (avoidance or holding on) arranged for what was needed to make the situation more controllable (letting go), for example additional caregivers, or specific medical equipment, such as a commode.

Families grieve many different losses when confronted with a terminal illness of a loved one while they are still involved in their caregiving tasks and attending to their loved one's needs. Therefore, grieving starts during an illness and has an effect on post-death grief (72). This grief that is already present before death happens, is referred to as anticipatory grief -*" a reaction to the threat of death rather than death itself" (*72). Bouchal et al. state that "*anticipatory grief includes coping, interaction planning, and psychosocial reorganization*" (72). According to Kübler-Ross, "*anticipatory grief is the process whereby terminally ill patients prepare for their final separation from this world*" (64). Kübler-Ross' five classic stages of grief are shock and denial, anger, bargaining, depression, and acceptance - which are normal reaction to separation and loss (64). Caregivers also experience these emotions in reaction to the impending death of their loved ones, although all the stages are not always present and do not follow a particular order. This grief and painful aspects of their experiences are often covered under a blanket of caregiving activities and, therefore caregivers themselves as well as outsiders are not always aware of the process of grief they are experiencing. Literature also refers to this "hidden" grief as holding grief inward (72). In this study, it was also a way of protecting their loved ones from their emotions. According to Coelho et al. this covering up of emotions is also an effort to "*manage both the threatening circumstances of end-of-life caregiving as well as the anticipated loss"* (65).

Literature indicates that caregivers express a huge sense of relief and release once hospice gets involved (27, 43). The support families receive from Hospice Bloemfontein is provided by different members of the hospice teams, which include a physician, nurses trained in palliative care, counsellor, occupation therapist, and clergy, as well as a group of trained volunteers that act as "Companions" to families. The support includes pain and symptom control, conversations around goals of care, and emotional support. Reports from participants in this study confirmed findings of these mentioned studies, they could let go of the intensity of the physical demands of caregiving as well as the intense responsibility of medication administration. This gave them an opportunity to focus more on just being a family member, and potentially finding the opportunity to become aware of and express their own anticipatory grief.

5.4. Researcher's reflection

"She used to be singer and she used to be a dancer
But everything changed when she was diagnosed with cancer.
There's really only so much silence I can take,
God
Where the hell are you now?
Why won't you answer?"

"I'm royalty in the land of desolation
I've found a throne in this wasteland
I'm numb from the silence of
the wise
And drowned in the
cacophony of the foolish.

No one left to hear my cries
No one to hear my
screaming."

This poem was written by one of the participants, age 26. His wife was diagnosed with brain cancer nearly two years ago. They have a three-year-old son. After his interview for the study, he started to write a few poems which he shared with me. He expressed his relief in being able to share his feelings of isolation, frustration, anger, and depression without guilt or fearing judgment.

I was not prepared for the brutal honesty of some of the participants and how these truths would affect me. Their sincere reflections cut through all pre-conceived conceptions, understanding and ideas I had about the lived experiences of caregivers caring for their loved ones, and left me with an adjusted, broader view that includes the terrible isolation and sacrifices, desperation, exhaustion, and frustration they are experiencing. Listening to their experiences, however, also left me with images of strong loving bonds and commitment and made me a witness of the incredible source of strength and motivation love can be.

Participants in the study reported that being listened to had a positive and beneficial effect on them. Not only did they feel heard, but it also gave them a sense of validity which, in turn, boosted their confidence to ask for what they needed. The impact of listening to their voices and stepping into their word of caring for a loved one, will forever sensitize me for those who are 'hidden' behind the patient.

Although I attempted to the best of my ability to describe participant experiences and so reduce the number of quotes required to convey a clear, honest, and distilled representation and reflection of all the participants' experiences, I could not help but feeling as if I had failed those participants who entrusted me with their experiences and feelings, but whose voices were directly not included in the results chapter. To give acknowledgment to all those voices, I have attached an appendix with all the quotes. In this way, all of these quotes are acknowledged.

5.5. Limitations of study

The study aimed to explore the experiences of primary caregivers who care for their spouses or partners in hospice care. Hospice Bloemfontein care for all patients who fit the hospice's admission criteria, regardless of ethnicity, socio-economic background, religion, or language, and participants were selected by purposive sampling (partners of end-of-life patients in hospice care). Hospice Bloemfontein's admission criteria are patients with advanced cancer, patients with end-stage organ failure or COPD, and patients with advanced neurodegenerative disorder, like motor neuron disease. However, none of the participants recruited for the study was Sotho speaking, and nine of the ten participants were Afrikaans speaking. There were three potential participants identified who were Sotho speaking, but before an interview could be conducted, their partners had died. Consequently, the experiences of caregivers from diverse ethnic and cultural backgrounds are not included in this study. To explore possible reasons for this lack of diversity of participants could be valuable in identifying possible differences in health risks and needs of populations.

Another limiting factor which influenced the availability of potential participants was late referrals to hospice care. During the recruitment stage there were seven partners of hospice patients who were identified as potential candidates, but unfortunately their spouses passed away before they could be approached, all within days after hospice referral. Schockett et al. suggest that *" family members of patients that were referred too late reported lower satisfaction with hospice services, a higher rate of unmet needs for information especially about what to expect at time of death, and less confidence in taking part in patient care at home"* (73). Those family members reported a lower overall satisfaction (73). The concern is that those patients that are being referred too late also suffer from pain and other symptoms unnecessarily where hospice care and palliative care could bring earlier relief. A possible reason why patients are not referred to hospices earlier is physicians not informing patients and their families about hospice care or waiting too long before referral (73). Physicians need to be informed as how they could facilitate earlier hospice admission (73) .

Lastly, as the primary researcher conducted the thematic analysis, the perspectives and views of the researcher may have influenced and limited the research findings. However, this influence was minimized and limited by the guidance and objective input from the supervisors throughout the analysis process.

5.6. Conclusion

This work has provided a very honest and valuable view on the experiences of primary caregivers who are caring for their partners with a life-limiting disease in Bloemfontein, Free-State. It reflects on the complex experiences and enormous demands that are placed on informal caregivers to meet all the different and multidimensional needs of their ill partners. These demands include treatment monitoring, assisting with or performing physical care, emotional, financial, and spiritual support. It also reflects on their emotional reaction to the illness, and the impending death of their partners in a context where they are often isolated and exhausted. There were certain factors that either added to or relieved their distress. Although there were common themes, the reactions and experiences of all participants were unique and individual. As a consequence of these demands some of the caregivers in the study experienced exhaustion, physical complaints, isolation, sleeplessness, spiritual distress, and unmet needs, reactions that were also reported in other studies (3, 26) . This study further reflects on the importance of the role of caregiver as an active participant in providing care and comfort during the final stages of the illness of a patient, but also reinforces the critical need to provide the necessary and adequate support to those caregivers. A thorough assessment is necessary to respond holistically to the unique and individual needs, challenges, and concerns of families.

CHAPTER 6

Conclusions and Recommendations

6.1. Conclusion

This study contributes to a better understanding of spouses or partners' experiences of caring for their loved ones at the end of life in all its complexity to help professionals to intervene in a preventative way to support them and to relieve suffering. Primary caregivers play an important role as an active participant in providing care and comfort during the final stages of the illness, therefor it is imperative that family caregivers need to be supported to maximize their potential, recognize and develop their strengths and abilities to enable them to handle the demands of everyday life with a dying family member at home.

The aim of the study was to evaluate the experience of primary caregivers of patients at the end of life receiving hospice care, with the objectives to obtain an in-depth experience of those caregivers, to identify coping mechanisms while providing care, and to finally identify support structures and resources that assist those caregivers. The study successfully achieved the objective of giving an in-depth and rich description of participants' experiences as caregivers, reflecting a broad range of emotions, burdens they are experiencing, and the implications caring for their loved one had on different aspects of their lives. The study furthermore identified coping mechanisms participants applied to reduce caregivers' stress and to help them to handle their daily life. Finally, the study achieved the objective to identify structures and factors that were experienced as supportive to their caregiving experience, as well as those factors that added to the distress of caregivers, often highlighting the lack of adequate support to caregivers.

One striking observation from this work is that regardless of whether participants were receiving care form the public or private health care systems, all of them could feel the financial implication and burden of caring for their loved ones, albeit all to a different degree depending mainly on additional resources and savings. Those participants in the public health system reported the biggest burden, and often had to make ends meet with only a small grant. The whole families suffered due to the illness of the patients.

The multidimensional but also individual needs of caregivers in this study would benefit from Brown et al.'s suggestion that policy changes need to be made to provide real family-focused care to allow families to be the recipient of care (58). Whole families experience illness, and not only the ill patient (58). This approach to support families resonates strongly with the person-centered-approach stating that professionals cannot assume that needs of families are known, but need to carefully listen and hear what the needs are, as well are their fears, concerns, challenges, and struggles (34). It is important to create a safe environment and space where caregivers can express their thoughts and feelings, especially those forbidden thoughts which often fill them with guilt (66). Knowing their specific needs, caregivers, can then be empowered to actively take part in the care team with appropriate support (66). This person-centered approach is also in line with the The National Policy Framework and Strategy on Palliative Care 2017–2022(NPFSPC) recommendations that " *patients and families should engage in the planning of their care, act as full partners and take responsibilities for self-management, with the assistance of other home -and community-based support."(30).*

It is advisable that this care needs to be provided not only by a palliative care team but also with support and involvement from the community, as was the case with how one family in the study was supported by a church community. The hope is that this kind of community support will be duplicated in other churches and communities. This church, in collaboration with the hospice, 'adopts' families that are identified by the hospice in need of essential support that cannot be fully addressed by the hospice team. This support may vary from essential "packages", which include for example food, airtime vouchers or nappies, but can also be social support with professionals providing their services on a voluntary basis, for example psychologists, dietitians, or other complementary services. This approach is in accordance with Knaul et al.'s view that LMIC's have "*opportunities to improve the welfare of especially poor people at modest cost"* (59). They suggest the integration of an Essential Package of essential goods and services that are publicly financed into the health system (59). In this way, the accessibility of essential support and care becomes possible for all, in both the public and private health sectors. This is in accordance with the WHO's view that strong health systems are rooted in the communities they serve, and that *"universal health coverage should be based on strong people-centered care to assist and improve well-being and quality of life"* (5).

The Global Atlas of Palliative Care states that the need for palliative care has increased rapidly due to the aging of the world's population, increases in cancer and other non-communicable diseases, and the emergence of COVID-19 (39). Therefore, families would increasingly need more assistance and support in providing care for family members. The recommendation they provide, which would also have benefited the participants from this study are individually tailored support for family carers, respite for family carers, and ongoing regular assessment of family carers (39).

6.2. Recommendations

6.2.1. Research implications and recommendations

- As recommended by the World Health Assembly resolution 2014 (WHO 67.10), it is imperative to train more healthcare professionals in palliative care. Governmental health services and departments should fund training for undergraduate students across disciplines.
- Basic training in "total pain" and the ongoing support relating to this concept as well as the important role it plays in palliative care needs to be implemented. This needs to be done on a tertiary, secondary and primary nursing level. This may lead to an awareness towards patients' and their family members holistic care needs. In addition, students from allied health care professions, for example occupational therapists, physiotherapist, social workers, should all be informed and trained in the concept and management of “total pain”, to be sensitive towards those needs and skilled to address them.
- Providing adequate and clear communication to patients and families regarding the illness and its trajectory is essential to empower them in taking an active role in managing the illness and their caregiver role. This communication needs to take place from the time of diagnosis, and especially when the focus of treatment shifts from curative to palliative care. Training in effective communication should take place on a secondary and tertiary nursing level, as well as training to medical students and for specialist trainees.
- As this study demonstrated that religious beliefs are one of the strongest sources of motivation and support for caregivers, it is recommended involving local religious communities and to equip them to address the specific spiritual needs of patients and their loved ones. This can be achieved through education and training in palliative care principles in different church and religious institutions, and ensuring that enough resources are available to support those caregivers. Local hospices or palliative care training centers can provide this training.
- The involvement of churches as described in the previous point, could also lead to the establishment of community support centers that can provide Support Packages for families that are in need of essential support. These centers can be based in different areas and suburbs of a city or municipalities focusing on families in their immediate vicinity. Again, as religion plays a big role in many people's life, churches can be initially approached by palliative care or hospice centers to set up these centers.
- In accordance with the person-centered approach professionals need to create a safe space where patients and families can express their needs, fears and struggles and the appropriate care that specifically address those unique needs of every family need to be developed and implemented. This patient-centered care may increase professionals' sensitivity and contribute towards a compassionate and respectful

approach towards patients and families. Educators could promote this patient-centered approach in order to develop and implement it more successfully.

- In order to understand each patient and caregiver's unique challenges the approach to provide palliative care needs to be individualize - to provide care that is dignified, comprehensive, compassionate, and patient-centered. Health-care providers should be made aware of this approach.
- Hospice-based interventions which include support and guidance programs should be developed that target the mental and emotional aspects of caregivers' health. Funders to support the operational costs of hospices and the implementation of programs supporting patients and their families need to be approached.

6.2.2. Further research

- South-Africa has a cultural and ethnical diverse population, and to acknowledge this diversity future studies are recommended to deeper explore the experiences of primary caregivers from different backgrounds. A better understanding and awareness of the unique beliefs, traditions, and values of families could improve healthcare workers' ability to provide care that is respectful and culturally sensitive and would help them to address emotional and spiritual pain in more adequate ways.
- It would be interesting to do a follow-up study of the same participants who took part in this study to not only explore their perception of their caregiving experience in retrospect, but to also explore their ability to find and make meaning of their experience of caregiving and coming to terms with their loss.
- Further studies are recommended that focus on the analysis of differences in the experience of different age groups facing end-of-life care of their partners. Different age groups may have varying levels of emotional maturity, coping styles and unique needs.
- A further need is to conduct studies that focus on the analysis of experiences of couples facing a life-limiting illness of one of the partners after varying years of being a couple. Couples who are together for a shorter period of time (regardless their age) may experience the challenges of facing a life-limiting disease of their partner differently than couples that have been together for much longer.

6.2.3. Dissemination of Findings

- The findings of this study will be reported back to the participants, as well as Hospice Bloemfontein’s management and the Hospice Palliative Care Association of South Africa (HPCA).

- Participants will receive a short one-page summary of the research findings. A written report will be submitted to the hospice management and HPCA. A presentation of the study (Power Point) will be presented to the Hospice Bloemfontein’s management, staff members and volunteers, and participants will be invited to attend this presentation.

- An abstract will be submitted to relevant conference/s, as well as a publishable article will be submitted to a peer-reviewed scientific journals.

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APPENDIX 1

HPCA
CARE & SUPPORT
Hospice Palliative Care Association of South Africa

25th February 2021

Ms H Lubbe Bloemfontein Hospice info@hanneke.co.za

Dr Lindsay Farrant

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Associate Professor L Gwyther

liz.gwyther@uct.ac.za

Dear Ms Lubbe

PROTOCOL Title: Ref.: 03/20 - A qualitative study of the experience of primary caregivers of patients receiving end of life hospice care. H Lubbe, Bloemfontein Hospice.

The above protocol was reviewed by the Hospice Palliative Care Association Research Ethics Committee at its meeting held on the 19th November 2020. The majority of concerns have been adequately addressed.

The study has been formally approved, subject to the following:

1. The REC feels that there is not sufficient justification for face-to-face interviews, especially given the current second wave and the high level of vulnerability of the people receiving care from the potential participants in this study. The study is approved for remote interviews only at this stage. Should you struggle with recruitment as the study progresses, you are at liberty to come back to the REC regarding the need for face-to-face interviews.
2. In addition, the COVID-19 Indemnity Form absolves the researchers from any “wrongdoings” by the employee. The National Guidelines and GCP are very clear that it is the responsibility of the PI to ensure the safety of the staff/employee/research team and patients during the course of the research study and must by “any means necessary” ensure the safety of the above and not “absolve” one’s self of that responsibility.
3. Please could proof of ethics training be provided for all the researchers associated with research including those in direct contact with patients, interviewers and or recruiting officers. A free on-line ethics training course is available at TRREE (for Training and Resources in Research Ethics Evaluation) at http://elearning.trree.org.

Please note the following:

- An original signed copy of the amended protocol and supporting documentation (as approved) must be submitted to the HPCA offices in Cape Town.

- Ethics approval is valid for one year only, until 28th February 2022. no end to caring

  Palliative Care is an approach that improves the quality of life of patients and their families facing life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

  Hospice Palliative Care Association of South Africa NPC. Reg no.1986/001887/08. NPO no.003-462 Founding patron: Archbishop Emeritus Desmond Tutu Patrons: Professor JP van Niekerk and Justice Edwin Cameron

1st Floor Eagle Park, Corner of Bosmansdam and Omuramba Road, Milnerton, 7441. Cape Town

PO Box 38785, Pinelands 7430
Tel: 021 531 0277 | Fax: 021 531 1706 Email: info@hpca.co.za | www.hpca.co.za

- Application for recertification of the protocol should be submitted a few months prior to February 2022 to ensure continuous approval.

- ANY changes to an approved protocol must be reviewed by the Research Ethics Committee.

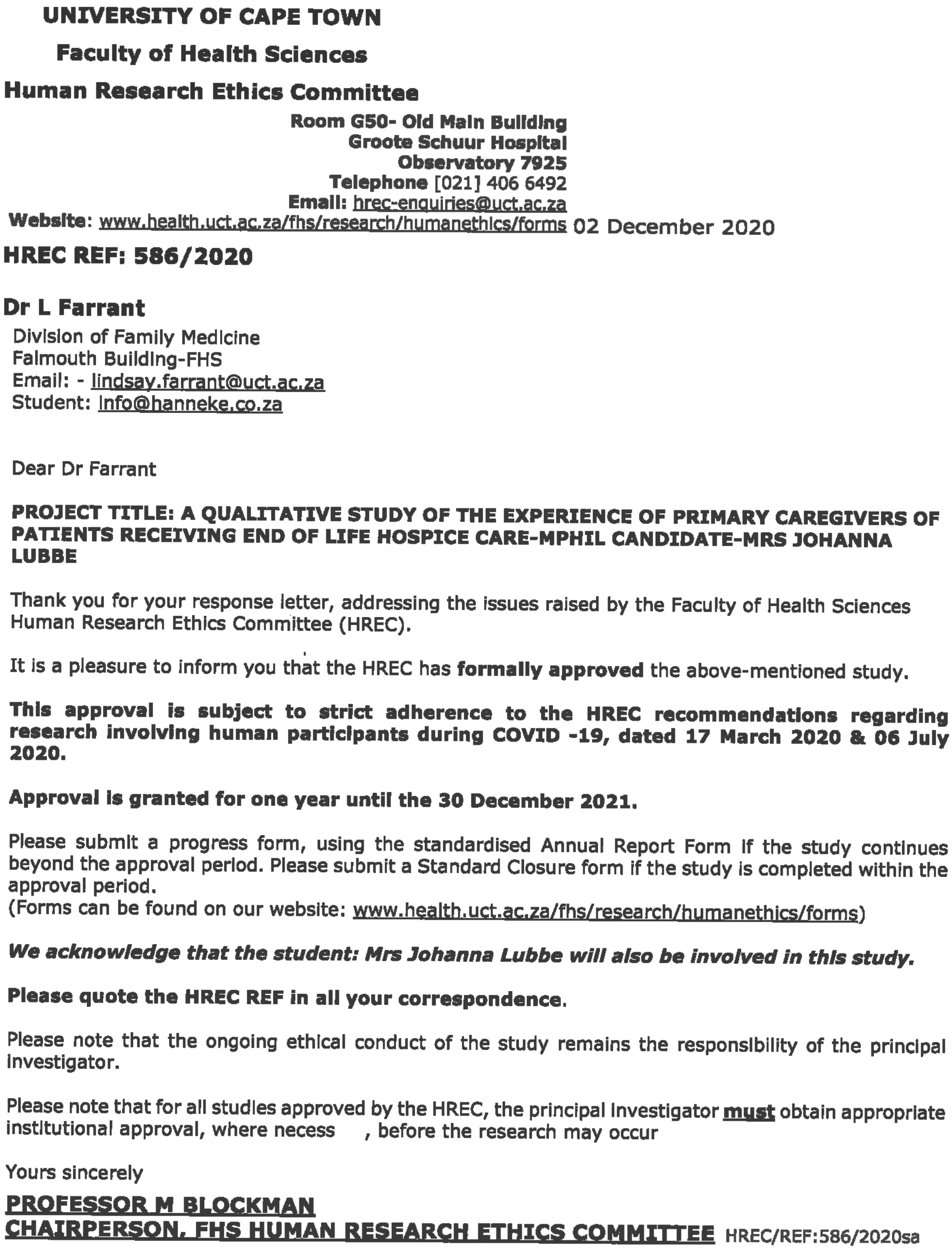
  It would also be appreciated if, once the study has been completed, the End of Study Report be completed and submitted to the Research Ethics Committee together with a summary of the results for inclusion on the HPCA website.

  I would like to take this opportunity to wish you well with your research. Yours sincerely

  T L BURGESS (A/Professor)
  HPCA REC Chairman
  (REC Registration No. : REC-250408-00-RA)

...

APPENDIX 2



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee
Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

02 December 2020

HREC REF: 586/2020

Dr L Farrant
Division of Family Medicine
Falmouth Building-FHS
Email: - lindsay.farrant@uct.ac.za
Student: info@hanneke.co.za

Dear Dr Farrant

PROJECT TITLE: A QUALITATIVE STUDY OF THE EXPERIENCE OF PRIMARY CAREGIVERS OF PATIENTS RECEIVING END OF LIFE HOSPICE CARE-MPHIL CANDIDATE-MRS JOHANNA LUBBE

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Approval is granted for one year until the 30 December 2021.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Mrs Johanna Lubbe will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necess , before the research may occur

Yours sincerely

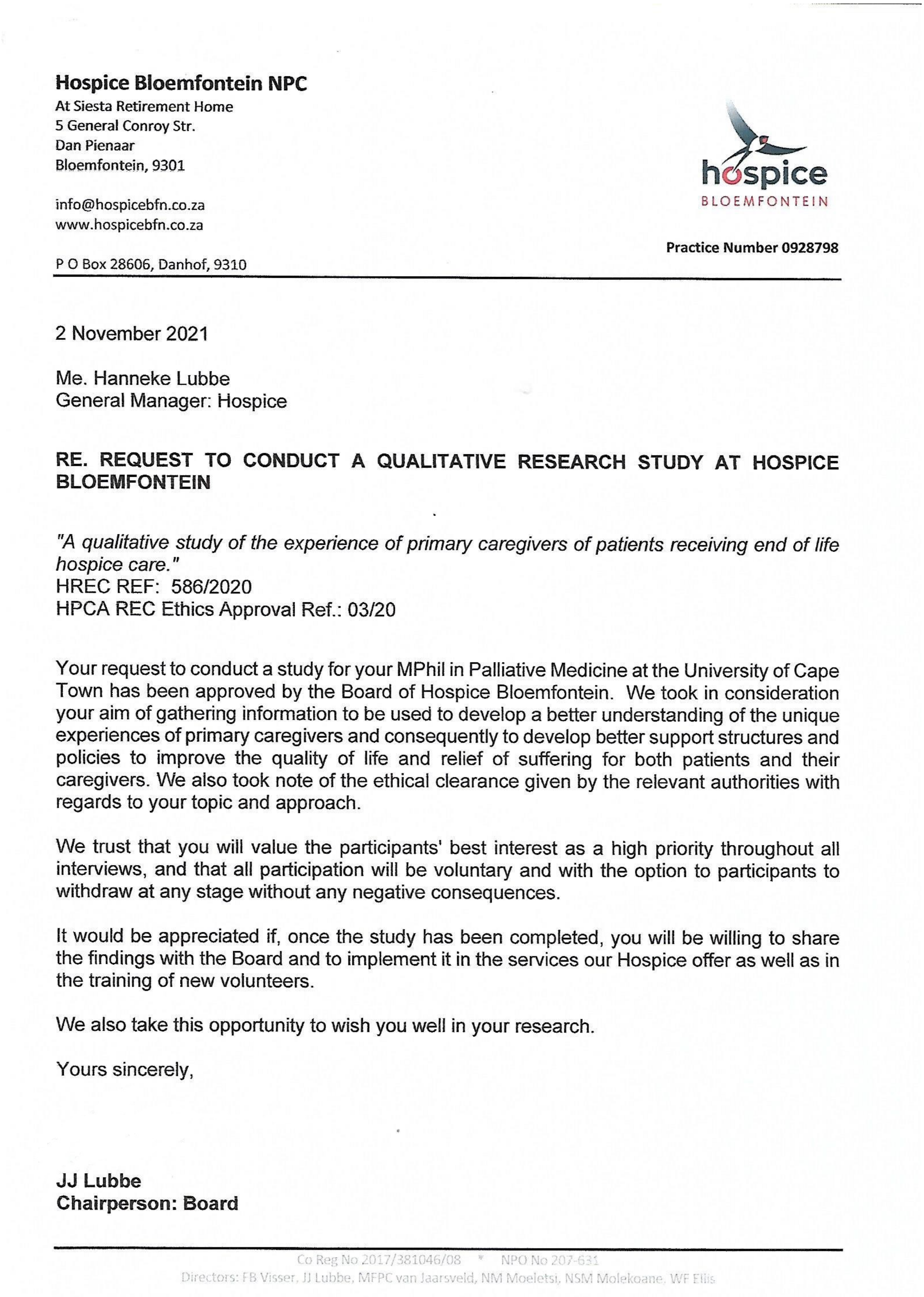
PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE HREC/REF:586/2020sa

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC/REF:586/2020sa

APPENDIX 3



Hospice Bloemfontein NPC
At Siesta Retirement Home
5 General Conroy Str.
Dan Pienaar
Bloemfontein, 9301

info@hospicebfn.co.za
www.hospicebfn.co.za

P O Box 28606, Danhof, 9310

hospice
BLOEMFONTEIN

Practice Number 0928798

2 November 2021

Me. Hanneke Lubbe
General Manager: Hospice

RE. REQUEST TO CONDUCT A QUALITATIVE RESEARCH STUDY AT HOSPICE BLOEMFONTEIN

"A qualitative study of the experience of primary caregivers of patients receiving end of life hospice care."
HREC REF: 586/2020
HPCA REC Ethics Approval Ref.: 03/20

Your request to conduct a study for your MPhil in Palliative Medicine at the University of Cape Town has been approved by the Board of Hospice Bloemfontein. We took in consideration your aim of gathering information to be used to develop a better understanding of the unique experiences of primary caregivers and consequently to develop better support structures and policies to improve the quality of life and relief of suffering for both patients and their caregivers. We also took note of the ethical clearance given by the relevant authorities with regards to your topic and approach.

We trust that you will value the participants' best interest as a high priority throughout all interviews, and that all participation will be voluntary and with the option to participants to withdraw at any stage without any negative consequences.

It would be appreciated if, once the study has been completed, you will be willing to share the findings with the Board and to implement it in the services our Hospice offer as well as in the training of new volunteers.

We also take this opportunity to wish you well in your research.

Yours sincerely,

JJ Lubbe
Chairperson: Board

APPENDIX 4

Information Sheet for:
The experience of primary caregivers of patients at the end of life in hospice care.

Thank you for giving your time to hear about our study.

This information sheet tells you about a study that you may wish to take part in. The study is undertaken for the purpose of Mrs. H. Lubbe completing the MPhil. Degree in Palliative Care at UCT. Participants will not be renumerated for taking part in the study, but the researcher, Mrs. H Lubbe, will reimburse any costs incurred taking part in the study.
You may have some further questions to help you decide whether you want to take part. You can ask any further questions from your hospice team, from the researcher, or using the telephone numbers at the end.
The researcher is also the counsellor of the hospice, but whether you agree or not to take part, will in no way affect the quality of care and access to counselling support or any other support from the hospice.
Thank you for thinking about whether you want to take part. Please take your time to make a decision.

What is the purpose of the study?

We are looking at the experience of primary caregivers of patients who are in hospice care to determine how to support them effectively.

Do I have to take part?

No, you don’t have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. Whether or not you take part, the care and support your partner / spouse and you receive from the hospice will NOT be affected in ANY WAY.
If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part, and you may want to talk it over with your family, friends or someone in your care team.

What will happen if I take part?

Depending on the situation regarding the COVID-19 pandemic, interviews will take place either face to face, or via Zoom or Skype. A researcher will speak to you and ask you questions about you and your experience of taking care of your ill loved one. It will take around 40 minutes for the interview. This information sheet is for you to keep. The interview will be audio recorded whether it will happen over Skype or Zoom, or face to face.

Benefits of the study

There are no direct benefits of taking part in the study for participants although people who have been interviewed using these questionnaires find that they are good points for discussion with care providers. The anticipated benefits are in identifying people's care needs and in trying to meet those needs of participants and future caregivers and families.

What are the risks of the study?

There are few study risks. Answering some questions might cause an emotional response. If the questions cause an emotional response, you become too upset to continue with the interview, the interview will be stopped and assistance / counselling will be available to you, should you need and desire that.

Will my taking part in this study be kept confidential?

All the information which we collect during the interview will be kept strictly confidential, except in the situation of the patient's or family's safety being at risk, in which case the information may be acted upon and you will be informed on this. You will not be identified in any way from the audio recording, and your personal details (for example name and address) will be kept separately from the information you give. We will use a number and not your name for any information you give us. No-one outside the study will have access to the personal information you give us.

How will I know about the results of the study?

At the end of the study a report will be sent to the hospice and to the people who took part in the study.

Who is organizing the research?

If you need to talk to anyone about this research, you can contact the following people.
Hanneke Lubbe: 076 9129490.

If you have any questions about the study:
Dr. Lindsay Farrant, University of Cape Town: Tel 021-4066707.
Hanneke Lubbe, Hospice Bloemfontein: Tel: 076 9129490.

If you have any questions about your human rights of any ethical issues about the study:
UCT Faculty of Health Sciences
Human Research Ethics Committee.
E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory
Telephone: 021 406 6338

HPCA REC. contact details:
TL Burgess. HPCA REC Chair Person.
Tel: 021 531 0277

APPENDIX 5

Inligtingsblad vir:
Die ervaring van primêre versorgers van pasiënte aan die einde van hul lewe in hospice-versorging.

Dankie dat u tyd neem om te luister waaroor hierdie studie gaan.

Hierdie inligtingsblad gee inligting oor 'n studie waaraan u dalk belang sou stel om aan deel te neem. U sal dalk verdere vrae het wat hulpsaam sal wees in die besluit om deel te neem of nie. U kan enige verdere vrae aan die hospice span vra, of aan die navorser, of u kan enige nommer skakel wat aan die einde verskaf word.
Die navorser is ook die hospice-berader, maar die kwaliteit van versorging, of toegang tot berading, of enige ander ondersteuning van die hospice-span sal geensins beinvloed word deur u keuse nie - of u sou deelneem aan die studie of nie.
Dankie dat u u deelname aan die studie oorweeg. Neem asseblief u tyd voor u 'n besluit neem.

Wat is die doel van die studie?

We are looking at the experience of primary caregivers of patients who are in hospice care to determine how to support them effectively.

Moet ek deelneem?

Nee, u hoef nie deel te neem nie. As u sou instem om deel te neem, kan u nogsteeds ook enige tyd onttrek uit die onderhoud, sonder om ons enige rede te vereskaf. Of u sou besluit om deel te neem, of nie, sal GEEN invloed op die versorging hê nie. Indien u instem om deel te neem, sal u gevra word om 'n toestemmingsvorm te teken wat aandui dat u wel toestemming gegee het om deel te neem. U kan u tyd neem om die besluit te neem, en dalk wil u dit eers bespreek met vriende of familie, of 'n lid van u versorgingspan.

What gaan gebeur as ek deelneem?

Afhangende van die situasie aangaande die COVID-19 pandemie, sal onderhoude óf in persoon plaasvind, óf oor Zoom of Skype. 'n Navorser / assistent sal met u praat en vrae vra oor u en u ervaring as versorger van u siek geliefde. Die onderhoud sal ongeveer 40min. duur. Die inligtingsbrief kan u hou. Daar sal 'n klankopname van die onderhoud gemaak word, of dit in persoon plaasvind, of oor Zoom of Skype.

Voordele van die studie.

Daar is geen direkte voordele vir deelnemers om deel te neem aan die studie nie, alhoewel persone wat voorheen ondervra is het gevind dat die vraelys goeie punte verskaf om te bespreek met hulle gesondheidspan. Die verwagte voordeel lê daarin dat die behoeftes van versorgers geidentifiseer kan word, en in die toekoms daardie behoeftes van pasiënte en hul families effektief te kan aanspreek.

What is die risiko's verbonde aan die studie?

Daar is baie min risiko's verbonde. Sommige vrae mag dalk 'n emosionele reaksie uitlok. Indien dit wel gebeur, en u te emosioneel is om met die onderhoud voort te gaan, sal die onderhoud onderbreuk word en ondersteuning / berading sal beskikbaar wees, indien u dit sou aanvra.

Sal my deelname aan die studie vertroulik wees?

Al die inligting wat gedurende die studie ingesamel word, sal streng vertroulik hanteer word, tensy die veiligheid van die pasiënt of familie in gevaar is, waar die inligting wel gebruik sal word om op te tree - maar u sal daaroor ingelig word. U sal geensins geidentifiseer word in die opnames nie, en u persoonlike inligting (bv. naam en adres) sal apart gestoor word as die inligting wat u verskap gedurende die onderhoud. Ons sal 'n nommer gebruik om u te identifiseer, en nie u naam nie. Niemand buite die studie sal toegang tot u inligting hê nie.

Hoe sal ek weet wat die resultate is van die studie?

Na die voltooiing van die studie, sal 'n verslag aan die hospice en almal wat deelgeneem het, gestuur word.

Wie beplan die studie?

As u met enigiemand wil gesels wat oor hierdie studie, kan u die volgende persoon kontak Hanneke Lubbe: 076 9129490.

As u enige vrae het oor die studie:
Dr. Lindsay Farrant, University of Cape Town: Tel 021-4066707.
Hanneke Lubbe, Hospice Bloemfontein: Tel: 076 9129490.

Indien u enige vrae het oor u menseregte of enige etiese probleme wil bespreek:
UCT Faculty of Health Sciences
Human Research Ethics Committee.
E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory
Telefoon: 021 406 6338

APPENDIX 6

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Info Sheet:

LEGHEPHE LA TSEBISO BAKENG SA LEHAE LE HLOKOMELANG BAKUDI BA MAHLOKO A HLOKOLOSI.

Rea leboha ha o iphile sebaka sa ho utlwa ka thuto ya rona.

Leghephe tsebiso lena le ho jwetsa ka thuto yeo o ka lakatsang ho nka karolo ho yona. O ka bana le dipotso tse ka hofang monyetla wa ho nka qeto ya ho nka karolo thutong ena. O ka botsa dipotso ho batho ba mokgatlong ona wa bahlokomedi kapa ho mofupodi kapa wa sebedisa fono ka dinomoro tse hlabhang qetellong ya leqephe tsebiso lena.

Mofupodi ebile ke mothobi wa maikuthlo lehaeng lena. Empa ho dumela le ho hana ho kenela mokhotlo ona ho ke ke ha theola boleng ba tlhokomelo kapa ho thoba maikutlo ho teng lehaeng lena.

Rea ho leboha ka ho nahana ho nka karolo kapatjhe. Rea kopa nka nako ya ho etsa qeto.

SEPHEO SA THUTO ENA KE SEFE?

Re shebile tsebo ya behlokomedi ba bakudi lehaeng lena re shebile le tshehetso e ka bang molemo.

NA KE LOKELA HO NKA KAROLO?

Tjhe ha watshwanela ho nka karolo empa ha o dumela ho nka karolo ona le bolokoluhi ba ho ikqula dipotsong tsena ntle le ho fana ka mabaka - o dumela kapa osa dumele ho nka karolo. Tlhokomelo ya hao ekeke ya fetola, tlhokomelo ya hao hohang. Ha o dumela ho ikakhela ka setotswana o tla lokela ho saena foromo ya ho totobatsa hore o dumetse ho kena. O ka nka nako ho etsa qeto. Ka mohlomong o kabatla ho buwa le baleloko le metswalle kapa ho setho sa mokgatlo ona wa tlhokomelo.

HO TLA ETSAHALA ENG HA KE DUMELA?

Mofuputsi o tla bua le wena a ho botse ka boiphitlelo ba hao tebang le tlhokomelo ya hao ho bakudi bao o ba ratang. Ho tla nka metsotso e kabang 40 bakeng sa dipotso. Leghephe tsebiso lena o ka inkela lona.

MENYETLA KAPA MELEMO YA THUTO ENA.

Ha hona melemo e otlolohileng bakeng sa ho nka karolo thutong ena. Leha hole jwalo batho ba qetileng leqhephe-phupotsonglena, ba fumana no na le karolo tla tse ntle tsa puisano ho ba hlokomedi ba bakudi. Melemo e ka lebellwang e ho hlwayeng ditlhoko tsa bakudi le ho leka ho fumana ditlhoko tsa ba nka kaarolo ditlhokong le bokamoso ba bahlokomedi le ba leloko.

HO IPEHA MENYETLENG KAPA KOTSING YA THUTO ENA?

Ho ipeha menyetleng kapa kotsing ya thuto ena ho hongata.
Karabong ya tseding tsa dipotso ho ka kgwapola karabo ya maikutlo. Ha dipotso di kqwapolo karabo e susumetswang ke maikutlo, o lahlehelwa ke takatso ya ho tswella pele ka ho araba dipotso. Dipotso di tla ema mme thuso ya ho thoba maikutlo e tla tholahala, ebang o ehloka kapa o lakatsa jwalo.

A HO NKA KAROLO HAKA DIPOTSONG TSENA HO TLA BOLOKWA E LE SEPHIRI?

Tlhahiso leseding e tla utolwa dipotsong tsena e tla bolokwa e le sephisri kapa lekunutu le tghekolotsi haholo. Tghe feela ha maemo a mokudi kapa ba leloko a ka pepesa kotsi kapa monyetla o itseng tebang le polokeho. Maemona a jwalo, tlhahiso leseding e ka etsa ho nkuwe mehato mme o tla tsebiswa ka hona. O keke wa hlwauwa ka mokgwa ofe kapa ofe kgatisong ya puisano ena. Boitsebiso ba hao (mohlala lebitso le adrese ya hao) di tla behelwa ka thoko ho tlhahiso leseding yeo o entshitseng. Re tle sebedisa nomoro e seng lebitso la hao. Leseding le leng le le leng le hlahiswang ke wena. Ha ho motho ya kantle ho thuto ena ya tla tseba tlhahiso le seding e ntshitsweng ke wena.

KE TLA TSEBA JWANG DIPHOLO TSA THUTO ENA?

Ka mora thuto ena pheletsong raporoto e tla romelwa mekgatlong le ho bohle ba nkileng karolo thutong ena.

PHUPUTSO E E HLOPHISITSWE KE MANG?

Ha o lakatsa ho buwa le motho ka phuputso ena o ka ikopanya ka mohala le:
Hanneke Lubbe: 076 9129490.

Ebano na le potso tebang le thuto ena letsa mohala ho:
Dr. Lindsay Farrant, University of Cape Town: Tel 021-4066707.
Hanneke Lubbe. Hospice Bloemfontein: 076 9129490.

Ebang o ka ba le potso tebang le ditokelo tsa hao tsa botho le boitshwaro ka thuto ena:
UCT Faculty of Health Sciences
Human Research Ethics Committee.
E 52 Room 24, Old Main Building, Grootte Schuur Hospital, Observatory.
Telephone: 021-406 6338

APPENDIX 7

Consent form for:
The experience of primary caregivers of patients at the end of life in hospice care.

UCT HREC REF No: ....
HPCA REC REF No: ....

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.

2. I understand that my participation is voluntary, and I am free to withdraw at any time, without giving a reason, and without my care being affected.

3. I agree to take part in the above study.
4. I agree to the audio recording of the interview.

Name ___________________________________
Signature ________________________________ Date _________________

Researcher:
Signature ___________________ Date: ________________

APPENDIX 8

Toestemmingvorm vir:
Die ervaring van primêre versorgers van pasiënte aan die einde van hul lewe in hospice-versorging.

UCT HREC REF No: ....
HPCA REC REF No: ....

5. Ek bevestig dat ek die inligtingstuk gelees en verstaan het, en die geleentheid gehad het om vrae te vra.

6. Ek verstaan dat my deelname vrywillig is, en dat ek vry is om enige tyd te onttrek sonder om 'n rede te gee, en sonder dat my versorging enigsins beinvloed sal word.

7. Ek gee my toestemming om deel te neem aan die bostaande studie.
8. I gee toestemming dat die onderhoud opgeneem sal word.

Naam: ________________________________

Handtekening: _____________________________ Datum: ________________

Navorser:
Handtekening: __________________ Datum: _______________

APPENDIX 9

FOROMO YA BOITLAMO:
BOIPHITLE LO BA BAHLOKOMEDI BABAKUDI PHELETSONG YA BOPHELO NTLONG YA HLOKAMELO YA BAKUDI.

UCT HREC REF NO: ____

HPCA REC REF NO: ____

1. Ke netefatsa hore ke badile mme ke utlwisisa foromo ya tlhahiso leseding mme ke ile ka fuwa monyetla wa ho botsa dipotso.

2. Ke utlwisisa ho nka karolo hwa ka ke boithaupi ba ka, mme nka ikqula nakong efe kapa efe, ntle le fana ka mabaka, le hore tlhokomelo ya ka ekeke ya ameha.

3. Ke dumela ho nka karolo thutong ena e kahodimo.

4. Ke dumela kgatiso modumo ya ka dipotsong tsena.

Lebitso: ____

Signature ya ka: _________________________ Letsatsi: _________________________

Mofuputsi: ____

SIgnature: ______________________________ Letsatsi: _________________________

APPENDIX 10

Patient Consent Form.

Patient Consent form for:
The experience of primary caregivers of patients at the end of life in hospice care.

UCT HREC REF No: ....
HPCA REC REF No: ....

Thank you for agreeing that your partner / spouse can take part in the above research project. This consent form is necessary for us to ensure that you understand the purpose of the project and the conditions of your partner / spouse's involvement. Please would you therefore read the accompanying **information sheet** and then sign this form to certify that you approve the following:

9. I confirm that I have read and understand the information sheet that my partner / spouse has received and have had the opportunity to ask questions.

10. I understand that my partner / spouse's participation is voluntary, and is free to withdraw at any time, without giving a reason, and without my care being affected.

11. I understand that any information he / she shares about me or our situation will be audio recorded and will be kept strictly confidential. No-one outside the study will have access to the personal information that was shared during the interview. My personal details will not be identified or identifiable in any reports or publications resulting from this study.

Name: _________________________________

Signature: ______________________________ Date: _________________

Researcher: _____________________________

Signature:______________________________

APPENDIX 11

Interview Guide: Semi-structured interview.

Opening statements:

Thank you for agreeing to take part in this research interview. My name is _______ and I am a member of the team from Hospice Bloemfontein. Today we will have a conversation about your partner's / spouse's illness, how it affects you, about your experiences of the care you are providing, and the support you are receiving. I am interested in hearing your thoughts so please do feel free to openly tell me what you think. The interview should take about 40 minutes. I will record our interview, but I will not start recording until we are ready to talk and I will tell you when I am switching it on.

We may cover some sensitive topics during the interview. You can pause or stop the interview at any point or skip any questions should you wish to. If anything I ask isn't clear, or you would like time to think about your answer, or you would like to raise something that you think is important, then please do tell me. I would like this to be a conversation so that I can find out what you think and what matters to you as someone caring for a spouse / partner with a serious illness.

What we talk about will not be shared directly and I will take out any names or places so that when I describe or discuss what you have told me about your experiences, neither you nor your partner/ spouse or any other person, will be identifiable.
Also, I will not share anything directly about you with your care team. However, if I am worried about your safety or anyone else's safety then I will let your care team know and I will let you know that I am doing that.

Could I please just confirm that you have signed consent form and read the information sheet? And are you happy for the interview to be audio recorded today? Do you have any questions before we start?

Ok, I am turning on the recorder -

(START RECORDING)

1. **Could you tell me a bit about yourself and your spouse/partner?**
2. **Tell me more about his/her illness and how the two of you are managing / struggling?**

3. Tell me about how a typical day looks like?

4. Could you tell me how much taking care of your spouse/partner has affected your life? Time wise / socially / emotionally / physically / spiritually?

5. What are your needs and concerns?

6. How do you see yourself as caregiver?

General probes:

What does *[concept that arises/term they have used e.g., 'respect', 'dignity']* mean to you?

Could you tell me a bit more about how _____?

How does/would that happen?

How does/would that affect you?

How did/would you feel about that?

Would you make any changes or add anything to this interview?

Closing statements

If there is anything you would like to add about your experiences of caring for your spouse / partner or anything we have missed out/not spoken about, you can always contact me afterwards. I'd like to thank you for taking the time to be interviewed today, I really appreciate it and your views will be a great help to us.

(END RECORDING)

APPENDIX 12

Onderhoudgids: Semi-gestruktureerde onderhoud.

Openingsverklaring:

Dankie dat u ingestem het om deel te neem aan die onderhoud. My naam is ____________ en ek is 'n lid van Hospice Bloemfontein. Ons gaan vandag 'n gesprek hê oor u man/vrou/lewensmaat se siekte en hoe dit u raak, ook oor u ervaring as versorger, en die ondersteuning wat aan u verskaf word. Ek sal graag u mening en gedagtes wil hoor, so deel asseblief u ervaring met vrymoedigheid met my. Die onderhoud behoort ongeveer 40 minute te duur. Ek gaan 'n klankopname van ons onderhoud doen, maar sal nie met die opname begin voor ons reg is nie, en sal duidelik sê wanneer ek dit aansit.

Ons mag moontlik sensitiewe onderwerpe aanraak gedurende die onderhoud, maar u mag enige tyd vra dat die onderhoud gestop word indien u dit sou verkies. As enige-iets onduidelik is, of as u tyd nodig het om oor 'n vraag na te dink, of as u iets wil opper wat u as belangrik ag, is u welkom om my te sê. My hoop is dat dit 'n gesprek is waarin ek kan uitvind wat u dink en wat vir u belangrik is as 'n versorger van 'n lewensmaat met 'n ernstige siekte. Die inhoud van ons gesprek sal nie met ander gedeel word nie, en ek sal enige name en plekke verwyder wat dit sou moontlik maak om hulle te kan identifiseer wanneer ek weergee wat u vertel het. Verder sal ek niks wat u vir my sê, deel met u versorgingspan nie. Alhoewel, wanneer ek bekommerd is oor u veiligheid, of oor die veiligheid van enigiemand anders, sal ek u versorgingspan inlig, maar sal ek u ook inlig as ek dit doen.

Kan ek net weer bevestig dat u wel die toestemmingsvorm onderteken het en dat u die inligtingstuk gelees het? Is u tevrede dat 'n klankopname van die onderhoud vandag gedoen word? Het u enige vrae voor ons begin?

Goed dan, ek gaan die bandopnemer aanskakel -

(BEGIN MET DIE KLANKOPNAME)

1. **Vertel vir my 'n bietjie oor uself en oor u lewensmaat.**
2. **Vertel vir my oor sy/haar siekte en hoe julle twee dit hanteer / daarmee worstel.**
3. **Vertel vir my hoe 'n tipiese dag by julle lyk?**
4. **Kan jy my vertel hoe die versorging van jou lewensmaat jou lewe beïnvloed het? Hoe het dit jou geraak in terme van jou tyd / sosiaal / emosioneel / fisiek / spiritueel?**

5. Wat het jy nodig / jou behoeftes, en waaroor bekommer jy jou?

6. Hoe sien jy jouself as 'n versorger?

Algemene aanmoediging:

Wat beteken [begrip wat na vore gekom het gedurende die gesprek, bv. “respek”, “waardigheid”] vir jou?

Kan jy my 'n bietjie meer vertel hoe ________?

Hoe gebeur so iets ?

Hoe sal dit jou affekteer?

Hoe sal jy daaroor voel?

Wil u enigiets verander of nog byvoeg tot die onderhoud?

Afsluitingsverklaring:

As daar enigiets is wat u nog wil byvoeg oor hoe u dit ervaar om u lewensmaat te versorg, of as u dink ons het iets uitgelaat, of nie oor gesels nie, kan u my altyd na die tyd laat weet.

Baie dankie vir die tyd wat u bestee het om met my te praat, ek waardeer dit opreg. Die deel van u ervaring is vir ons waardevol.

(BEËINDIG OPNAME)

APPENDIX 13

Interview Guide. Tsamaiso ya dipotso: Tlohopiso esa fellang.

Selelekela:

Rea ho leboha ka ho dumela ho nka karolo Dipotsong tsena tsa phupotso. Lebitso la ka ke _____________ mme ke setho mokgatlong wa ho Wokomela bakudi ba hlokolosi timing ya Bloemfontein.

Kajeno re tla ba le puisano ka ho kula ha molekane wa hao, hore ho ho ama jwang le boiphitlelo bahao tlhokomelong yeo o mofang yona. Le tshehetso yeo o e fumanang. Ke na le thahasella ya ho utlwa ka mooi o nahanagn ka teng, mme kea kopa lokoloha ho mpolella ka moo o nahanang ka teng. Dipotso tsena di ka nka bonyane metso tso e 40. Ke tla hatisa puisano ya rona, empa nke ke ka hatisa pele o re eba malala a laotswe ho bua, ke tla ho hlokomedisa ha kgatiso e qala.

Re kanna ra ama dihloho tse hlokolosi puisanong ya rona. O ka kgefutsa le ho emisa puisano neng kapa neng kapa wa tlola potso tse itseng e bang o lakatsa jwalo. Ha o sa hlakelwa ke potso, kapa o batla honahanisa karabo, kapa o batla ho hlahisa ho hong hoo o nahanang e le ba bohlokwa ka kopo mpolelle. Ke lakatsa hore hona ebe puisano, hore ke fumane monyetla wa ho tseba kamoo o nahdnang ka teng le ho fumana tse hlokolosi ho wena jwaloka ha a le mohlokomedi wa molekane wa hao, ka bohloko bo hlokolosi.

Hoo re tlo bua ka hona. Ho re tla bua ka hona ho keke ha phatlala tswa ka kotloloho. Ke tla tlosa mabitso le dibaka ele hore ha ke hlalosa sea lesoko kapa metswalle. Ha bana ho tseba hore ke buile le mang. Ebile ha ke tlo arolelana le mang kapa mang le ha ele timing ya hao ya tlhokomelo. Mme ke tla ho tsebisa hore ke etsa jwalo. Na nka netefatsa hore o saenile foromo ya boitlami le hore o badile legephe la boitsebisi, le hore o tla thabela ho hatiswa lentswe puisanong ena kajeno? A na o na le dipotso pele re qala puisano? Ho lokile jwale ke mathisa sehatisa mantswe.

(QALEHO YA HO HATISA MANTSWE)

1. A ko mpholelle ka wena le molekane wa hao?

2. A ko mpolelle ha holwanyane ka bohloko ba hae le hore le bo maneng jwang ako mpolelle ka?

3. A ko mpolelle letsatsi la hae le ikgethang le jwang?

4. A ko mpolelle ho mohlokomela ho ama jwang bophelo ba hao?
Ke tjho nako, kamano le batho / maikuthlo / hameng / semoyeng?

5. Ditlhoko tsa hao le dingongore ho ke dife.

6. O ikutlwa jwang ka ho fana ka tlhokomelo ha hao?

Ditlhwedimelo ka kararetso:

Ho wena mantswe mohlala 'tlhompho', 'seriti', di bolela eng ho wena?
O ka mpholella hanyane jwang?
Hoo ho ka etsahala jwang?
Hoo ho ka ho ama jwang?
O ka ikutlwa jwang ka hoo?

Na o ka etsa phetoho kapa wa kenya ho hong dipotsong tsee?

Statemente tse kwalang.

Haeba ho ena le ho hong hoo o ka ho kenyang ka boiphitlhello ba hao ka ho hlokomela molekane wa hao kapa eng fela yeo re e tlotseng kapa re sa buang ka yona. O na le bolokolohi ba ho ntjwetsa ka morao.
Ke batla ho ho leboha ka honka karollo dipotsong tsena. Ke lakatsa ho ho leboha ho nka nako ya hao ho araba dipotso tsena mme mehopolo ya hao ekaba thuso e kgolo ho rona.

PHELETSO YA KGATISO MANTSWE

APPENDIX 14

Distress protocol

The *Distress Protocol* for data collection is as follows. All participants will be fully informed as to the nature of the issues to be in the interview. All participants will have it explained clearly that during the interview the researcher will only conduct the interview to explore the participant's experience and, although she is also the counsellor, she will not provide counselling during the interview. Any person who appears to become distressed will be offered the opportunity to stop the interview and either abandon or restart when they are comfortable. As the questions refer to a sensitive and emotional issue, namely their experience as caregiver to their ill partner/spouse, participants may become very upset and emotional. If so, they can stop the interview, and only continue if they feel ready, and choose to do so. The participant will be offered support when upset, and enough time to settle. Ongoing counselling form the hospice counsellor, or alternatively from other professionals, will be offered.

If a participant demonstrates high levels of stress and anxiety and become extremely upset due to financial problems as a result of the illness of their loved one (lack of income, continual medical expenses, etc.), the interview will be stopped. The researcher can offer bringing him/her in contact with social services for financial advice and support after the interview. The interview will only continue when/if they choose to do so.
Or if such high levels of depression or desperation are being detected that there is a fear that the participant would harm him/herself or the patient, or if an imminent danger is signaled, the interview will be stopped. He/ she will be advised that the researcher will need to contact his or her general practitioner, mental health care provider, or other medical health professional on his/her behalf in view of the potential danger posed; or the services of the counsellor will be offered, as well as a visit by the hospice care team to discuss measures to bring relief (for example to arrange for patient to be admitted to an in-patient facility, and to arrange for additional support from family members/ carers). Follow-up will take place to ensure that the caregiver is safe and well.

APPENDIX 15

Noodprotokol

Die noodprotokol (*distress protocol*) vir die insameling van data is soos volg: Alle deelnemers sal volledig ingelig wees oor die aard van die onderwerpe wat in die onderhoude aangeroer word. Al die deelnemers sal deeglik ingelig wees daaroor dat die navorser die onderhoud slegs sal voer om inligting te bekom oor die deelnemer se ervaring as versorger, en alhoewel sy ook 'n berader is, sal sy nie berading verskaf gedurende die onderhoud nie. (Dit is indien die onderhoudvoerder die berader is). Enige persoon wat ontsteld blyk te wees, sal die geleentheid gegun word om die onderhoud te stop, en óf heeltemal op te hou, of eers daarmee voort te gaan wanneer sy/hy gereed voel daarvoor. Omdat die vrae betrekking het op 'n sensitiewe onderwerp, naamlik hulle ervaring as die versorger van hulle ernstige siek lewensmaat, mag dit wees dat hulle baie ontsteld en emosioneel word. Ondersteuning sal aan die ontstelde deelnemer gebied word, asook genoeg tyd om te kalmeer. Opvolgberading deur die hospice-berader sal aangebied word, of alternatiewelik deur 'n ander professionele persoon.

Indien 'n deelnemer hoë vlakke van stres en angstigheid toon as gevolg van finansiële probleme wat ontstaan het as gevolg van die siekte van hul geliefde (wegval van 'n inkomste, gedurige mediese uitgawes, ens.), sal die onderhoud gestop word. Die onderhoudvoerder kan aanbied om die deelnemer in verbinding te bring met maatskaplike dienste vir finansiële raad of ondersteuning na afloop van die onderhoud. Die onderhoud sal slegs voortgesit word wanneer / indien hulle dit so wou hê.

Verder, as daar hoë vlakke van depressie of wanhopigheid bespeur word en 'n vrees ontstaan dat die deelnemer 'n gevaar vir hom-/haarself of die pasiënt mag wees, of wanneer dit blyk dat 'n gevaar op hande is, sal die onderhoud gestop word. Die deelnemer sal ingelig word dat die navorser onomwonde met haar of sy geneesheeer, sielkundige, of enige ander professionele mediese personeel in aanraking sal kom om die dringende situasie te bespreek. Alternatiewelik sal die ondersteuning van die berader aangebied word, asook 'n opvolg besoek van die hospice-span wat met die gesin in gesprek sal tree om planne te beraam om die nood te verlig (bv. om die pasiënt in 'n hospice-eenheid op te neem en sodoende ruskans vir die versorger te reël, of om addisionele hulp en ondersteuning te reël van familielede of vriende. Opvolg besoeke sal gereël word om te verseker dat die versorger veilig is.

APPENDIX 16

Distress Protocol. Tlhotlomiso ya kagtello ya maikuthlo.

Yona e ka mokqwa o latelang. Banka karolo bohle ba tla tsebiswa ka botlalo mokwa wa dintlha tse ba tla botswa ka tsona. Banka karolo ba tla hlalosetswa hantle hore nakong ya dipotso mofupudisi o tla laola dipotso feela ho fumana boiphitlello ba bankakarolo mme le ena le ha ele mothobi maikutlo a batho a ke ke a sebedisa ho thoba maikuthlo nakong ya dipotso. Mang kapa mang ya bonahalang maikutlo a hae a hloka ho thobiwa o tla fuwa sebaka sa ho kgaotsa ho araba kapa ho tlohelo le ho kqutla a tswella ha a ikutlwa a photholohile.

Ha dipotso di ba hlokolosi maikutlong tje ka boiphitlelo ba bona tjeka ba fani ba tlhokomelo ho bakudi ba bona, ba ka iphumana ba tshwenyaha markuthlo. Ha hole jwalo ba ka kgaotsa ho tswela pele. Ba nkakarolo ba tla tshetswa ha ba ferekana mme ba fuwe nako e ntle ya ho iphumana. Thobo maikutlo e ka tswa ho bathobi maikotlo kapa ba fuwe thuso ho tswa ho ditsebi tse phahameng.

APPENDIX 17

Confidentiality Agreement.

Confidentiality Agreement / Non- disclosure Agreement.

Study Title:
A qualitative study of the experience of primary caregivers of patients receiving end of life hospice care.

MPhil Pall Med candidate: J Lubbe
Supervisors: Dr L Farrant and Prof L Gwyther

Name: ....
Description of role:...
Date:..

With regards to transcription work on any audio-recorded material or the translation of any transcribed material relating to the above study, that contains personal information or any other confidential information that has been discussed during the research interviewing process:

I agree to the following:

1. I will keep all information provided to me for the purpose of .... (Translation or transcribing) in strict confidence.

1. I will not disclose or share any of the information or content of the material with any third party, either verbally or in any written form or in audio recording format.

Name:
Signature:
Date:

Researcher name:
Signature:
Date

APPENDIX 18
Standards for Reporting Qualitative Research (SRQR)

Checklist:

Title and Abstract.
Title: Yes
Abstract: P9
Introduction
Problem formulation: P11 / P30
Purpose or research question: P30
Methods
Qualitative approach and research paradigm: P 31
Researcher characteristics and reflexivity: P37
Context: P31
Sampling strategy: P.32
Ethical issues pertaining to human subjects: P.39
Data collection methods: P35
Data collection instruments and technologies: P/33
Units of study: P32
Data processing: P38
Data analysis:P.38
Techniques to enhance trustworthiness:P.39
Results/findings
Synthesis and interpretation: P41 -
Links to empirical data: P41 – (quotes)
Discussion
Integration with prior work, implications, transferability, and contributions(s) to the field: Chapter 5.
Limitations: P66
Other
Conflicts of interest: None
Funding: self

APPENDIX 19

Results

THEME ONE: PERSONAL COSTS AND GAINS OF TAKING CARE OF A LOVED ONE.

Taking care of a loved one has an enormous impact on a person's life, with the effect noticeable and felt across different domains. Although the impact can be experienced negatively and can come at a cost, it can also create an opportunity for growth and contentment. The sub-themes of the impact of taking care of a loved one were: the physical demands, financial burden, how taking care has impacted them personally, as well as the social impact, and how their relationship has been affected by the illness.

1.1. **Physical demands.**

All of the participants that were interviewed were actively involved in taking care of their partner, all to a different extent depending on additional support. Three of the participants received hired professional carers who provide daily supportive care such as washing, dressing, feeding, and changing of nappies. The rest of the participants were reliant on help and support from family members or friends to help with basic caring tasks, such as those that were mentioned above. Regardless of additional support, all participants mentioned that the physical demands of taking care of their loved ones were exhausting, took up most of their time, and had an impact on their bodies.

> *"Until about two weeks ago I set my alarm for every hour and a half to go and check on her. But now I have just realized that I cannot any more. I am exhausted." [P4]*
>
> *"I had to accept the pain now of my arm that had broken three years ago. My sadness of this morning was because I had so much pain again trying to lift him. Somebody had to come and help me." [P5]*
>
> *"The hardest thing for me is to take her to the toilet. She cannot walk anymore, so I have to help her onto the toilet, back into the wheelchair and into the bed again. It is very, very hard for me. My back is really hurting." [P6]*
>
> *"He is heavy! He is nearly 100kg and I am only 50kg. So, I cannot lift him on my own anymore. Taking care of him has really had a huge impact on my body. Some days it just feels as if I cannot go on anymore. That's why I just cannot lift him anymore." [P7]*

One participant mentioned that she herself got ill a few times, but could not afford to focus on herself as her husband needed care:

> *"I get so exhausted. There's been a few times where I also got ill, and just had to get up and carry on. I cannot just stay in bed just because I am ill. I have to get up and continue*

> *taking care of him. I can feel that my body has been drained, is tired, but I carry on... I just have to." [P1]*

Two participants also mentioned that they have gained weight because their diets have changed and they are house-bound and have less time to exercise.

> *"I am also a bit overweight now, because I sit so much and cannot get out. I make the food, and I don't know if it is always so nutritional." [P6]*
> *"We just have to eat what we get from people as we cannot afford the food we used to buy. But I am grateful. For example, we get a lot of bread now, and Pilchards, and I can see it on my body, I have gained a lot of weight."[P1]*

One participant mentioned that the physical demands of taking care of his wife has had no big effect on him as caring was part of their relationship form the beginning as she is disabled:

> *"Physically - I am just walking so much more, really! But remember, I've been married to a disabled woman from the start. So, the physical thing is not an issue for me. It is second nature for me." [P4]*

Only one participant (age 26) has reflected that he has become stronger and fitter since taking care of his wife, and has taken up a healthier life-style.

> *"What is interesting is, that in this time I have actually done quite a lot to NOT feel physically drained. I cut down tremendously on smoking, and I'm exercising every day. So, that's given me already more energy, and I feel more focused, more energetic and do not feel as lethargic as I used to." [P2]*

1.2. **Financial burden**

All participants reported that their loved one's illness has had a financial impact on their lives. The impact depended on their financial situation prior to the diagnosis, how much they have saved before the illness, and on the support, they receive from friends and the community. Two of the patients had home-based carers that were paid for by their medical aid, and one participant had to pay himself for the home-based carers.

> *"If there is one thing, I need to make it easier, is money. Financial support. If you don't have money you cannot eat. If you don't have money, you cannot buy food, electricity or water. This whole thing is about money. And about groceries, the basic things we really need." [P1]*
> *"The other day at the hospital they wanted to get social services for me to organize someone to help me with him. But I said, no, because then I also have to pay R400 out of my pension for that help. That takes away from what I can spend on nappies. It costs me R1400 per month for nappies, and I just don't have R400 left to pay them." [P5]*
> *"My biggest worry is where would we go if our money runs out. Where will we stay?"[P1]*

One participant stated that her husband was the breadwinner, and without his salary they are now only living from a small investment:

> *"His illness has really affected us financially very, very badly. If I can just refer to the salaries, going from R30 000 per month to nothing was a very big adjustment. And since his diagnosis we have sold a lot of things to pay for the things we need now. It is a challenge every day, but you do get used to that." [P1]*

One participant stated that they were both earning salaries prior to her diagnosis, and that they had to make adjustment without an income:

> *"You know, she's lost her job, obviously, and I was also retrenched the beginning of the year. That is hard. But, that in a way gives me an opportunity to take care of her, but we have to stay with my parents now, and I am very grateful for that." [P2]*

Despite having medical funds, those participants could also feel the financial burden as many of the occasional cost are not covered by a medical fund:

> *"Our pharmacist knows her ID by heart, that's how big our bill is there. Our bill there only the last two weeks is already over R1200, and that is only what the medical aid doesn't pay! These are only over the counter medicine. And then I'm not even mentioning Energade, Rehidrate, nappies, and so on! And petrol driving to all the pharmacies! And parking - all the money you spend on hospital parking fees!" [P4]*

A few of the participants had to use savings or retirement funds, or make alternative plans:

> *"I am fortunate, with help from a broker friend, we could arrange for all her policies to be paid out already. So, preparation is everything. [P4]*
>
> *"At the moment we are still coping financially because her whole pension is used to pay for the carers. But maybe I'll have to sell my house to move to a smaller place where there is care. But it still is very expensive then. I cannot put myself into a financial difficulty." [P6]*
>
> *"Our pension funds are not enough to cover all our expenses; we have to use some savings too. That is a big worry..." [P7]*

Only one participant stated that they are not experiencing any financial worries:

> *"We are really fortunate that we really have everything we need. And if he needs something, we can get it for him. I know how fortunate we are. " [P3]*

1.3. Personal implication.

Taking care of their partners also affected the participants in a very personal way in terms of how they relate to other, and how they perceive themselves. They reflected on their needs, their limited capacity to be there for any other personal relationship with friends or colleagues, or how they sacrifice their time, energy, career, to take care of their partner. They put their lives "on hold" while they focus on their partners.

> *"You know, you don't live for yourself anymore. You live for him, and you live his life. You have to live according to somebody else s time, you have to do what he wants to, you have to eat when he wants to eat. In a way you live a second life." [P1]*
>
> *"I think that is the worst part, I feel I cannot be socially or emotionally involved in my friends' lives anymore. I feel I cannot put any more emotional strain on myself than what I'm already going through. And that sucks. Because I am drained, I'm really drained. And I have no idea what I need. " [P2]*

One participant has reflected that she has grown emotionally stronger because of her experience:

> *"I am stronger now. One pushes the reality away, out of sight, initially... but slowly it does catch up with you." [P3]*

One participant reflected on his desire to also be a recipient of attention and love:

> *"Emotionally you get to a point...I don't think I would like to marry again one day. But I would just like to have a friend again who checks in on me every now and then. And let it be about me - because I'm not OK. I don't know how it feels to receive love back, because so much is just about caring now that one loses the meaning of what love is." [P4]*

This participant also mentioned that while he took care of his wife, he could not priorities his career as his focus was on caring for his wife. It was difficult to travel and visit clients elsewhere, or make appointments as, depending on her condition, he often had to rush home, or pick up their daughter from school:

> *"For four years I have played the butler at home, and now, soon, I will not be butler anymore. I am looking forward being able to plan my day ahead again, because I could not do it with her illness. I can then focus on my career again. [P4]*

Some participants reflected that they have realized that some form of self-care or support is important to be able to continue with the responsibilities of taking care of their loved one:

> *"It really takes the whole day to help him and to take care of him. But I also know, to be able to take care of him, I really need to look after myself as well. I swim on a Wednesday, and that is good for me. And since my daughter has organized help, I can sleep so much better - and my mood is also so much better!" [P7]*
>
> *"My doctor told me if I collapse now, she will also collapse. But it is hard. I know I also have to look after myself." [P6]*

One participant expressed his desire to get away from his caring responsibilities and the emotional impact it has on him, even just for a short while:

> *" I've always been an introvert, but I must say there has been a few times where I just wanted to get away. To visit a friend, or go on a camping trip, or a music thing, or something. Just go and leave the guilt behind. But that is just not happening." [P2]*

1.4. **Social implication**

The majority of the participants very strongly pointed out that their partner's illness has had a tremendous effect on their social life, their interaction with others, and their ability to go out and see other people. The illness often isolated them and restricted them to their homes where they take care of their loved ones.

> *"There is no social life anymore. I'm not even going to town anymore." [P1]*
> *"The only time that I do get some social interaction is when I go and play drums for the church. So, when there is a band practice, it's just like YES, I'll go! [P2]*
> *"Initially our friends still came and visited often, but we haven't seen them that much lately." [P3]*
> *"I cannot go anywhere with her, I am housebound, except for Fridays when I visit some friends. You can basically say that we have no friends anymore, it really has gotten very bad." [P6]*
> *"I really do not get anywhere. I rush to the shops, and rush back as quickly as possible because I am so afraid that he would need me in that time." [P10]*

Some participants also mentioned the inability of people to deal with and respond to the illness in a helpful and supportive way towards them:

> *"You know, you then get a day like today when my brother-in-law just showed up and said, hey, let's go and have a coffee. But - he has not supported us in any way! Then I just want to tell him to fuck off! But I sit and listen to him...and I do it because what does it help to be aggressive?" [P4]*
> *" The one friend she has, WhatsApp-ed me the other day and said she cannot visit anymore because the situation is too hard for her, and she doesn't know what to do. I wrote back that she should just come and visit her friend! She said, yes, maybe next week... Needless to say, the woman just never came!" [P4]*

Two participants said that they are being supported and visited by friends, the illness did not affect their social life negatively at all:

> *I really admire our friends. They still come and visit. He is quiet now, but some days are better than others and he'll still participate in a conversation." [P7]*
> *"There are some friends, or people, who are afraid to come - like one of our neighbours - but I really don't mind. There are so many other people that want to come and support." [P8]*

1.5. Impact on the relationship

The illness of the partner has had a big impact on most of the participants' relationships. The majority of the participants expressed a deep sense of loss, acknowledging that they miss the person the partner used to be, and miss activities they used to share. The illness forced them to play different roles towards each other, and taking over some of the roles the partner used to perform. Some participants expressed their need to be loved, to receive attention, and to feel less alone:

> *"You know, he's not the man he used to be. There are the small little things, like hugs from your husband. And like when your husband would come back from work and tell you about his day... And you can tell him about your stuff. There is nothing like that anymore. There's not really anything left that we can share, we do not have anything to say anymore." [P1]*
>
> *"He used to do everything for himself, but now he is allowing me to take over more and more of those tasks. It is as if he is handing it over to me. That is a big change in our relationship."[P3]*
>
> *"His illness really has had a huge impact on our relationship. There is a big distance between us that has never been there before. It's hard. Our roles have changed completely. It is a nightmare doing all the things he used to do before. We used to share all the chores and responsibilities, but now I do all on my own." [P7]*

Two candidates reflected on their intimacy in their relationship and expressed their longing to experience closeness with someone again:

> *"Her illness put a lot, a lot of strain on our relationship, even though it is hard to admit it. I feel more like a caretaker than a husband. Obviously, intimacy is not something that s very big in our relationship anymore. So, I get very frustrated." [P2]*
>
> *"Our sex life has been chaotic the last few years, and I have a huge need for physical intimacy. The last time we were intimate she told me that she's only doing it out of a sense of duty. That's when I told her we re done. And now I have this big sexual desire. I just want someone to hold me, to just love me and cuddle with me, and just kiss me. I really miss the closeness of someone." [P4]*
>
> *"I do long for emotional closeness. Because, you know, my father can hug me, or a friend... F*ck, I told a friend the other day to just hold me so I can cry. It was so good to just be held. To just let your shoulders, relax and rest your head against someone, to not press your tongue against your palate from worry... Just to be in someone's arms. And they tell you it is all OK."[P4]*
>
> *"I have realized that I have a need for love, because that is one thing that has been neglected. Caring and caressing are things that I haven't received at all from her the last four years (since her last diagnosis). It was all about her illness and treatments...For four*

> *years it was: "Bokkie, go to the pharmacy to get this, and go to the pharmacy to get that ..." That was literally my shit for four years. [P4]*

One participant expressed the fear of their partner being left alone:

> *"We have been together for nearly 50 years now, and that is why we love each other so much. He cried the other night and said I shouldn't leave him alone. I told him that I won't leave him, I am with him!" [P5]*

Only three participants said that caring for the other has brought them closer, or has brought a positive change in their relationship:

> *"Taking care of him has brought us even closer together. He is like a baby in my arms now. I miss the way it was before, of course, but now I am so grateful to still have him so close to me." [P8*]
>
> "*You know, I think his illness just brought us closer, really. He is so grateful for what I am doing, and he stays a gentleman. " [P10]*
>
> *"I've always felt as if I wasn't on his level, and he wasn't on my level. We haven't understood each other all the time. But now it feels as if I can mean something to him. I want to mean something for him. When his illness came, I had the opportunity to do something meaningful for him in my own house: to take care of him. And I do it with so much love". [P9]*

THEME 2: DISTRESSING AND SUPPORTING FACTORS

A few themes were identified that either added to the distress of the caregiver's experience, or were experienced as supportive and encouraging. The sub-themes are communication; involvement and support from others; the role their spirituality and belief system play; what personal coping mechanisms are helpful and constructive; and how love for and commitment to their partners motivate them to carry on.

2.1. **Communication**

Six of the participants mentioned communication as a factor that either added to their distress, or requested specific communication to aid them in their caregiving. Some participants reflected on the fact that once hospice got involved, things got easier and clearer for them. Two participants shared that they have received vague communication from medical staff they were involved with before hospice referral:

> *"The doctors just told us that it is cancer and that he won't walk anymore. It was really such a big shock. We didn't know what to do." [P1]*
>
> *"Initially the doctors did not take us seriously, you know. They just said she should change her diet, have more antibiotics... When it still didn't work, we went to another doctor, and then after that again another doctor. And with every doctor a different opinion. " [P2]*

> *"And look, this is the situation. The doctors are basically saying that everyone runs the risk of dying. Ha-ha! What a dumb observation!" [P2]*

Three participants expressed their need to receive clearer practical guidance, explanations and instructions:

> *"I am sometimes not sure how to proceed with things, where to go next. One needs information, practical advice. For example, with oxygen - where to get it, and so on... I feel so uncertain and ignorant." [P3]*
>
> *"The information we've received from you helps us so much in preparing us for the future." [3]*
>
> *"Sometimes it would be nice if someone could explain to me how certain medication needs to be taken, or what to do in certain situations." [P8]*
>
> *"I would like specific information regarding his medication. Like why he feels a certain way in the morning after taking his medicine, and in the afternoon, he would feel completely different after taking the same medicine. I would like to understand that better". [P9]*

Two participants referred to inappropriate comments and inquiries from friends or family, or expressed their frustration with people's lack of understanding of their situation:

> *"You know, I just sometimes want to tell people to f**ck off! And I'm not saying it's right to tell them that, it is just... Sometimes people will WhatsApp you at 7 in the morning asking how she is doing today. My God, it is 7 in the morning! I haven't even been to the toilet; how should I know?! What should I say? I have no words left, because everyone is asking!" [P4]*
>
> *"To talk to people... You know, I don't think that if anybody even told me that they understand what I m going through that would help, because - I just don't believe anybody will understand. Maybe if they just listen..." [P2]*
>
> *"I sometimes avoid my friends, because when they ask me how I'm doing, I always have bad news. So, it is very difficult to talk to friends sometimes, because I feel I don't want to burden anybody else with what is happening in my life and bring them down. " [P2]*

The same participant as above also expressed his frustration with people telling him to be positive:

> "You're making assumptions, tell me to be positive. Please just don't give me advice when you've got no f*cking idea what I'm dealing with!" [P2]

2.2. Involvement / Support from others

The second sub-theme dealt with the involvement and support they receive, or not, from friends and family. Most of the participants experienced isolation to a certain extent, and only three participants said that they receive enough support and do not feel alone at all. Those not receiving adequate support or visits from friends and family experienced more distress. All participants were reliant on some kind of support to perform all the tasks and carry out all the caregiving responsibilities:

> *"I don't see or meet anyone at the moment. But I need support to get through this. People just come over less and less. " (emotional). [P1]*
>
> *"Look, I still have a lot of friends who care deeply for me, but unfortunately it's something I've realized, but nobody understands what I am going through. It is so difficult, so very difficult." [P2]*
>
> *"I am so grateful for some of the other residents in this house that sometimes check-in on me and see how they can help. Because I don't really have anybody from outside who supports me, everyone has their own stuff to do. Apart from the hospice there is not really anybody else." [P5]*
>
> *"You know, apart from the carers, nobody helps us. We get no support." [P6]*
>
> *"My friends are really supporting me amazingly. I can be on the phone now with one and say that I need something. And even if they're busy, they will drop everything to help. So no, I don't feel isolated or alone."[P4]*
>
> *"To be able to carry on doesn't just come to you, you have to make plans to let things happen. So, I ask people to help, and I sometimes arrange with the carer to stay a little bit longer. Else you'll just sit in the corner and cry. The support I get from the neighbours and my children make it possible for me to continue" [P9]*
>
> *"I cannot say it enough how much you have helped us. If it wasn't for the hospice, I don't know how we would have coped!" [10]*

2.3. Spiritual / Belief system.

All but one participant experienced their spirituality and belief as a source of strength and encouragement that helped them and supported them in coping with the illness of their loved one. Some of the responses:

> *"But I say that the Lord has brought it on my way, and I have to make it work. Every single day. He will help me to get through every day."[P1]*
>
> *"I've always had a struggle with spirituality, trying to figure out what the purpose is of my life. But after she was diagnosed the last time, I had this clear message from the Lord that I have to stay for a reason. Whatever the reason was, I don't know, just that I had to stay. Since then, I am calm. This whole process of caring for her, I've just realized and remember the voice again that said: "Stop asking what your purpose is. You are where you have to be to help this woman, and to raise this child. Stop asking. There will be an end to this, and something new will come from it. Relax." [P4]*
>
> *"My faith is very important to me. I know there is a higher Hand that protects me and supports me." [P9]*

> *"What keeps me going is Strength that comes from above." [P10]*

Only one participant expressed his deep distress and spiritual crisis:

> *"I've had existential crisis upon existential crisis, and I really cannot make any sense out of any of this. The purpose of all of this I've lost. When it comes to spirituality, I ve been asking God the same kind of question a year and a half now, and to no avail. It feels like, this is the way now. It's something that I just have to accept. But, what's the point of life if this is the way it's going to go. What am I even doing here?" [P2]*
> *"I believe God has a time and place and purpose for everything, but I just don't see it, and I just don't get it. How is there any purpose in this? I see my wife every day, and she is tortured." [P2].*

2.4. Personal coping mechanisms

All participants had some kind of ritual or habit which helped them in coping with their situation. The habits included exercise, reading, knitting, visiting friends and gardening. Some of the responses:

> *"I have a chat with my mother in the mornings, and that actually does fill my cup quite a bit." [P2]*
> *"Generally, the exercise is good, because it feels like I cause my body pain in the socially acceptable way (laughing). And it is a way to cope. It feels I have time for myself. Exercising is a different pain, but it kind of feels good. "[P2]*
> *"I realized that I have done many things on my own the last four years, while I was caring for her. I did a 55km mountain trail run, I climbed mountains, I did all the trail runs in the city. I actually started to realize that I cannot stand still, cause our daughter sees a mother that is just in bed, therefore she cannot also see a dad that is doing nothing. So, I do what I enjoy." [P4]*
> *"You know, I have my Christian books I ready every day, and I do needlework. I do that if my arm is not too sore." [P5]*
> *"Fridays I can quickly go and visit some friends. That's the only time I get out." [P6]*
> *"My garden motivates me. I really enjoy it so much working in the garden." [P7]*
> *"He goes to sleep early in the evening. But I still read, I love my reading." [P8]*

2.5. Love / Commitment

Despite all the challenges, hardship and in certain circumstances suffering the participants were experiencing, they all had a strong sense of commitment and gratitude to their partner and their role of caregiver, and did not see any other option as to do what they do - to care until the end. Some of the participants not only feel committed to taking care of their partner, but were acting out of a deep and strong sense of love:

> *"What I do, I do with love." [P1]*
>
> *"I think it is simply love that keeps me going. I love my wife's smile every now and then - THAT's what keeps me going. If my wife just smiles or laughs at a stupid joke I'm making, I'm good. That's what I need. My love for my son and my wife, that's what's keeping me going." [P2]*
>
> *"The love one has for the person you care for gives me all I need to go on. Just the love for him. I'll try to make the best of what we have. I am so grateful for all we have, and for the life we've had together." [P3]*
>
> *"I continue taking care of her because I love her. It's as simple as that." [P4]*
>
> *"We have been together for nearly 50years now, and that is why we love each other so much. I won't leave him. I feel so sorry for him." [P5]*
>
> *"What will happen if I just stop taking care of her? Do you understand, what will then happen to her? I just have to carry on." [P6]*
>
> *"I carry on because I have no choice. And I try to do it with joy. There is no escape, just going forward. The time that we still have left, that is what is good now." " [P7]*
>
> *"And so much love. We love each other terribly. I am his life at the moment, and cannot let him go anywhere else." [P10]*

THEME 3: EMOTIONAL RESPONSES TOWARDS ILLNESS AND CAREGIVER ROLE

The third theme that was identified dealt with the emotional responses towards different aspects of the illness, including the impending death of the loved one, as well as the responsibilities that taking care of a loved one entail. As it had been a while already since the initial diagnosis and the shock, most of the participants had already had time to adjust to the illness and had made some changes in their lives. Being referred to hospice care moved them into a new phase of the illness and more into the reality of an impending death. The participants did not only face the death of their loved ones, which brings with it a wide range of emotions, but also struggled to cope with the practical tasks and responsibilities that caring for a person bring. Caring is time consuming and exhausting, which adds to feeling of being overwhelmed and helpless.

Although all participants mentioned reactions that fall under the three sub-themes of the emotional responses, the intensity, focus and experience were very individual. The first sub-theme is dealing with how they cope with the responsibility of and the tasks involved in taking care of their loved one; the second sub-theme is how they handle and react to the illness and the subsequent changes, and how they try to process and deal with those changes. This theme is dealing with their thoughts, reactions and emotions about facing the death of their loved one.

3.1. Coping with the caregiving responsibilities

Apart from one participant, all the other participants felt some sense of frustration, desperation, or an overwhelming sense of helplessness facing the daily tasks and responsibilities of taking care of their loved ones.

> *" She's sick, and I have this sense of helplessness, of I don't know what to do to help you!" [P2]*
>
> *"You know, it is as if something inside of you is just taking over. You do what is necessary, without thinking about it too much." [P3]*

The practical tasks, often perceived as never-ending and time consuming, proved to be a challenge and exhausting:

> *"So, it is cleaning up vomit, making more food, filling water bottles, making sure she's taking her medication. Then when it comes to bathing and showering... Well, at the moment she is too weak for that. And then my son comes home from day school, and then it's just chaos!" [P2].*
>
> *"I have to do everything here. I don't know if I will be able to take care of her is she gets worse. But that's my problem, I don't think I can just take her to a caring facility, therefor I just have to carry on taking care of her." [P6]*
>
> *"I took care of him on my own, but realized I cannot look after him day and night. I've lost 10kg's in that time! I couldn't really sleep during the night, as I had to constantly take care of him. I have got somebody now who helps me during the day." [P7]*

One participant mentioned that the practical tasks of caring do not come naturally to her, even though she chooses to do it:

> *"I am a compassionate and caring person, but not really a nurse. That really doesn't come naturally to me. I will clean the wounds and so, but it isn't easy." [P7]*

One participant mentioned how the never-ending responsibilities made him feel helpless and drained, which is reflected in his response towards her:

> *"I'm snapping a lot lately, my patience is kind of run thin, and it is not her fault. I just don't know what else to do, it just never stops. I'm just lost, you know, I'm helpless. I just cannot do everything." [P2]*

Only one participant mentioned that the caregiving responsibilities had not changed that much lately, due to the fact that his wife had been disabled since a child due to childhood cancer. He was used to that role of caregiving and support since the beginning of their relationship:

> *"Her illness didn't change that much for us as it wasn't really anything new to me, because with her disability (*her leg was amputated as a child due to osteosarcoma*) I have been*

helping her from the beginning of our relationship and has been the caretaker of our daughter since her birth. " [P4]

3.2. Coping with illness and changes

Seeing the impact of the illness on a loved one confirms the fact that they are ill, and that it is a progressive illness. They have to deal with multiple losses daily, while facing the responsibility of caring and taking over many other roles in the relationship and household. They often reflect on lost dreams, on how things used to be, needing to process the image of a weak, changed and ill partner. Their reactions range from efforts to carry on, worry, sadness, exhaustion, desperation, anger, hopelessness, feeling insecure - especially when witnessing their pain.

"You cannot stay weak, you just have to be strong all the way, even though life is difficult now" [P1]
"Even despite the fact that she's been ill for more than a year now, the news is still kind of sinking in heavily on us." [P2]
"I am extremely drained. My emotional cup isn't necessarily being filled. It's me pouring out, pouring out as much as I can, where I can. It doesn't feel as if that cup will get filled up ever again. Yeah, I am empty." [P2]
"It's been very hard for me seeing how he gets weaker...(emotional)." [P3]
"It is hard coping with her illness emotionally. I've been to a psychiatrist and am taking anti-depressants." [P6]
"I sometimes cry when I look at him, and he looks back with these watery eyes. Then I think I just don't want him to suffer." [P5]
"I cry easily, but I try not to cry in front of him as I don't want to upset him. The same with my children - they are far away and I don't want them to know I'm crying". [P10]
"She vomits every day, she is emotional, I cannot have a conversation with her. It's like, what's the point of this? It's like how is this of use for any greater purpose? Yeah, there's a lot of anger around that." [P2]
"It's just every day's routine of getting up and doing what we have to do. There used to be dreams...what we're going to do the next year, or us planning next year's things. But now there's nothing really to talk about anymore. '[P1]
"I'm very insecure a lot of the times, and I tend to think I do a terrible job. I cannot make her feel better. I do my best, and that's all I can do. My wife seems to think I am taking good care of her. But I don't actually know if I'm helping at all. I cannot make things better, and because I can't make things better, I do feel as if I'm failing." [P2]

Some participants reflected on the changes in their partner's mobility and their loss of performing tasks independently:

"He's spending more and more time on his own, and does not want to have people visiting him that much anymore. I realize it is because he does not have the energy anymore...

> *And I really have to help him with everything. He is also on nappies now...(emotional). He was reluctant about it initially, but I just told him to save his energy for other things. It was easier for him" [P3]*
> *"I have to help with washing her. And I washed her hair - she got very emotional, because she never used to let me touch her hair. I laughed, and she cried. I laughed because I was never allowed to do it although I've always been doing our daughter's! It was hard for her, but for me it was an absolute privilege. She doesn't see it like that, I know, because for her it is another thing that she has lost that was important to her." [P4]*

Two of the participants also have to witness their partner's changes towards their small children, as well as the children's reaction:

> *"She was angry with our daughter when she got breast cancer, because the doctor told her the pregnancy caused the cancer. And she was angry with me as well, because I wanted kids, and she never wanted to. So, it's always been a rocky road." [P4]*
> *"She does not really have any interaction with our son anymore. She lies in bed most of the time. She tries, but cannot anymore, really. It's eating her inside. It really is. You can see how distraught she is. " [P2]*

Concerns and uncertainties about their future role:

> *"My emotions are changing the whole time. And every night you lie awake worrying about something else. What kept me up last night is what will I do when our daughter turns 16, and she starts with her periods, and she's going to ask me about sex and boyfriends, and all those things? What am I going to do?" [P4]*

Reflecting on how things used to be:

> *"We always used to go to the Saturday Farm market... And sometimes I still take him, in his wheelchair and with the carer. It's different, but we still try to go." [P7]*
> *"It sometimes makes me so sad if he is so grateful for what I do, because he used to do it all himself... He used to make us breakfast every morning and bring it to bed. Breakfast in bed with coffee... But now I am doing it, and he doesn't really eat anymore" [P8]*

3.3. Coping with impending death

All participants mentioned the possibility or inevitability of death of their loved ones, but their engagements with, concerns and thoughts about their death differ. Some participants reflected that they have no control over what is going to happen, or have made peace with what is coming:

> *"His illness...I put that in God's hands. There is nothing that I can do about that. It is all in His power." [P1]*
> *"I very soon made peace with the fact that she is going to die, because I realized I would otherwise struggle." [P4]*

> *"I told her the other day; we knew all along that she won't get old (because of her childhood cancer). And now we've had our life together. It doesn't help regretting things now that we haven't done, or the choices we have made - the good ones and the bad ones. It's all over now, in the past. Our line together has been drawn. So, I have made up that in my mind very quickly that I won't have another year together with my wife. but I know something good will come out of this." [P4]*
>
> *" I often look at my husband and ask him: "What are you thinking of now?" I've asked him if he is afraid of dying. And then he always says no, not of dying, but he is concerned about what will happen to me after his death. But this gave us time to talk about all of it and get everything in place". [P10]*

Some mentioned the fact that their partners are also aware of the fact that they are dying, with different emotions, ranging from contentment and peace to anxiety:

> *"He is not afraid, and says that God has sent his angels to take care of him. He says that he has peace, and that he is not afraid... We are truly filled with gratitude." [P3]*
>
> *"She was awake for a long time yesterday, and we chatted for a long time. We spoke about how much time she has left, more or less - just as the doctor told me. And she was calm about it. She knows she is dying. She is actually restless because she cannot die sooner..." [P4]*
>
> *"He doesn't want to walk this path on his own, but then I tell him that this is not an alone road, I am with him. Then he asks if God comes to get him, if I will go with him... Shame, I feel so sorry for him. " [P5]*
>
> "You know, everybody says that they want to go to heaven, but they don't want to die. I see that anxiety also with him. I've tried to talk to him, asking him what he is afraid of, but he doesn't know." [P7]

One participant very clearly described his anticipation of his wife's nearing death, and how he tries to prepare for when death happens:

> *"I know this will sound strange now, but when I get up in the mornings, I go to her room to see if she is still alive. I know it sounds hard, but I prepare myself for what is awaiting me in her room from 5:30 in the mornings. This tension is starting to build up before I enter her room, because I wonder what I will get. And if I open the door - and I know it will sound weird - but there is a smell. And I've learnt now to know what to expect by the smell that is in the room. She has a smell on her. If she is better, the smell is gone. When I opened the door this morning, the smell was there again. Death is coming closer. So, it is this challenge every morning to get myself ready: will I find her dead or not in the room." [P4]*

Death is not always feared, as was reflected by one participant whose wife has been struggling for a long time (brain cancer.). He rather sees death as a relief, and fears any effort or possibility to prolong her suffering:

> *"I know she is dying, but honestly, my biggest concern at the moment is that, if my wife has the opportunity to fight or let go, is that she'll choose to fight. That's my concern." [P2]*

One participant admitted her own fear regarding her husband's death:

> *"I'm worried about death, you know. It does make me anxious. But I try to hide it from him, I don't want to upset him. I don't know how I will react when he dies. But the Lord's time is always the right time, I am just holding on to the Lord." [P7]*

3.4. Coping with uncertainty about what will happen after the partner's death

What will happen after the partner's death, was a concern that was mentioned by four participants. The concern included what will happen to them after the death of their loved one, as well as some practical aspects, including funeral and living arrangements:

> *"I worry about being on my own after his death. We have been together for so long, that I don't know how I will cope on my own. I'm not afraid for his illness getting worse, but I'm afraid of being alone after his death." [P8]*
>
> *"We have known each other for so long, it is as if a part of my body is slowly disappearing. I cannot explain to you, but it is as if he is a part of my body. That part will be gone when he dies, and that will be very hard for me." [P5]*
>
> *"I have struggled for a long time with the idea that a part of me will die with her, she's been part of my life for 30 years already. I was afraid that I won't know myself without her. You define yourself so much as part of a thirty-year relationship. People don't really know me on my own. I would need to get to know myself again! [P4]*

One participant has found comfort in what he plans to do after her death:

> *"I know this will give it all meaning - to give back after her death. That will give meaning to her life, and especially to her death." [P4]*

4. Conclusion

This chapter provides a clear reflection of the complex experiences and emotional responses of primary caregivers taking care of their partners with a life-limiting disease in hospice care. It also reflects on the demands that are placed on those caregivers to meet all the different and multidimensional needs of their ill partners, which include the effect it has on them financially, physically, and personally. The study further reflects on their emotional reaction to the illness, their caregiving and the impending death of their partners in a context where they are often isolated. Certain factors added to and others relieved caregivers' distress. Although there were common themes, the reactions and experiences of all participants were unique and individual. As a consequence of these demands some of the caregivers in the study experienced exhaustion, physical complaints, isolation, sleeplessness, spiritual distress, and unmet needs.