THE EXPERIENCES OF SOCIAL WORKERS IN RENDERING PALLIATIVE CARE SERVICES: SUGGESTIONS FOR SOCIAL WORKERS

by

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DECLARATION

“The experiences of social workers in rendering palliative care services: suggestions for social workers”.

I declare that the above dissertation is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the dissertation to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

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ABSTRACT

Palliative care is one of the crucial services provided by social workers to improve the quality of life of people suffering from life-threatening illnesses. It is an inter-disciplinary medical care giving approach which focuses on relieving symptoms and stress of life-threatening illness. To my knowledge there is limited guidelines on how social workers should intervene in providing palliative care services.

Therefore, this study will the explore experiences of social workers in rendering palliative care services to people faced with life-threatening illnesses. The study will follow a qualitative research approach. Purposive and snowball sampling will be employed to frame the sample of social workers who render palliative care services. Ethical issues regarding informed consent, confidentiality/anonymity and management of information will be considered and attended to. Data will be collected through semi-structured interviews and analysed in terms of Tesch eight steps. The Guba and Lincoln's model will be employed for data verification (Lincoln and Guba in Schurink, Fouché and de Vos 2011:419-421).

Keywords: *life-threatening illness, quality of life, relief of symptoms, palliative care, hospice, palliative care services, the role of the social worker, interdisciplinary team, intervention, death*

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CHAPTER 1

GENERAL OVERVIEW OF THE STUDY

1. GENERAL INTRODUCTION

This chapter presents a general overview of the study, as initially planned and subsequently adopted by the researcher. Although the chapter touches on the research methodology, amongst others, it is worth noting that a detailed discussion of the qualitative social work research employed for this study is presented in Chapter 3. In this section, a general introduction and problem formulation, as well as the rationale for the study, will be presented.

1.1 Introduction and background to the study

The hospice movement was started in the 1960s by Dame Cecily Saunders who was a professional nurse, social worker and medical doctor (Lutz 2011:305). Her philosophies quickly spread to the USA and the rest of the world (Lutz 2011:305). These philosophies, also known as hospice philosophies, include the belief that each person has the right to live and die, free from pain and with dignity and that their families should receive the necessary support to allow them to do so (Lutz 2011:305).

The ‘hospice approach’ is an approach that recognises that there are healthier and less painful means of negotiating, not only the final days of one’s life but also the grieving period for the remaining loved ones (Buss, Rock & McCarthy 2017:281). Moreover, hospice care is often provided in the patient’s home or in most clinical settings (for example, in a nursing home, hospital or separate hospice centre) depending on which environment best serves the patient’s interests and allows them to die comfortably surrounded by their loved ones (Buss et al 2017:281). Usually, the patient is managed by an interdisciplinary team which may consist of health care professionals including, for example, a nurse, chaplain, medical doctor, dietician and a social worker (Kaplan 2010:42).

According to McAteer and Wellberry (2013:11), most studies reveal that admission to a hospice or early hospice care consultations, can improve the quality of life compared to cure-directed care.

This has been attributed to the fact that patients feel more in control of their situation and thus experience less depression (McAteer & Wellberry 2013:11). In addition, patients are also able to avoid the risks associated with treatment and hospitalisation, and there is a clear decrease in healthcare costs. Lastly, in some circumstances, life is lengthened (McAteer & Wellberry 2013:11).

As such hospice care is a distinct type of palliative care, used when patients are terminally ill and curative treatment is no longer beneficial or desired, thus it is a specific subset of palliative care (Sekse, Huskar & Ellingsen 2017:2). According to Yu and Stander (2016:2), hospice care and palliative care share the same philosophy, yet they are not the same.

Although palliative care is closely linked to hospice care, the latter is a team-based type of care to the family, patient and caregivers and not necessarily a place (Wordingham & Swetz 2015:31). Palliative care begins at any stage of an illness, you do not have to be terminally ill to receive palliative care (Yu & Stander 2016:2). Palliative care is given together with active treatment for example chemotherapy and radiation. Palliative care support will involve regular visits, as well as family and care team meetings to evaluate the patient's status to ascertain if all the needs are being met (Wordingham & Swetz 2015:31). A table showing the differences between hospice and palliative care is provided in detail in Chapter 2, Table 1 under section 2.3.2.

Palliative care is, therefore, an approach that seeks to improve the quality of life for people facing the problems associated with life-threatening illnesses, as well as that of their families (Ojimadu & Okwuonu 2015:87). This is done through the prevention and relief of suffering through the early identification, assessment and treatment of pain, be it physical, psychosocial or spiritual (Wordingham & Swetz 2015:31). Just like hospice care, palliative care is a multidisciplinary speciality that is delivered to all people with complex life-threatening illnesses and it may be given concurrently with treatments delivered with curative intent (Lutz (2011: 307).

It is important to note that as part of hospice care, palliative care looks at how the disease is affecting the whole person (Shippee, Shippee, Fernstron & Britt 2018:105).

Palliative care also aims to give the patient options and allows them and their caregivers the opportunity to take part in the planning of their care (Shippee et al 2018:105). The main goal of including palliative care in hospice care is to help the patient be comfortable while allowing them to enjoy the last stage of their life (McAteer & Wellberry 2013:13). Further, McAteer and Wellberry (2013:13), state that by helping to relieve the symptoms, the pain, stress and discomfort associated with the disease palliative care help patients to feel as good as possible. This includes alerting the patients on how to enjoy the people around them and make their own important decisions during the final stage of their lives (McAteer & Wellberry 2013:13).

The need for palliative care is expanding due to ageing of the world population and the increase in the incidence of terminal diseases such as cancers in both developed and developing countries (Reville & Foxwell 2014:29). A study of 234 countries conducted in 2010 revealed that only 33% of these countries have well-integrated palliative care services, while 42 % had no palliative care services at all and a further 32% had isolated palliative care services (Connor & Bermedo 2014:62). In general, high-income nations have comprehensive, government-supported palliative care programs (Connor & Bermedo 2014:62). Examples include the United Kingdom which has integrated palliative care into its national health services and also boasts a strong hospice movement. Together with other rich European countries, they dominate the top 20 countries with comprehensive palliative programs (Connor & Bermedo 2014:62).

On the contrary, less wealthy countries are unable to provide basic palliative care services due to limitations in staff and basic infrastructure (Economist Intelligence Unit 2015:7). However, there are some countries with lower incomes that have proven to be exceptions as they demonstrate the power of innovation and individual initiative (Economist Intelligence Unit 2015:7). Examples include Panama, which has successfully built palliative care into its primary care services, Mongolia, which has seen rapid growth in hospice facilities and teaching programmes and Uganda, which has made huge advances in the availability of opioids. Regardless, the Economist Intelligence Unit (2015:7), reflects that income levels remain a strong indicator of the availability of quality palliative care with wealthy countries clustered at the top of the index for good palliative care services.

It is important to note, however, that most of the studies to date are primarily from developed countries (Gardiner 2016:5). Despite the high number of people dying in low to middle-income countries, very little is known about how palliative care and end-of-life care are being structured and delivered in these developing countries (WHO 2019). In addition, the available statistics are inconsistent and research into palliative care in Africa is under-resourced and under-developed (Downing et al 2012:3).

The ‘Atlas for palliative care in Africa’ is a resource which provides the most up to date information on palliative care development in nearly all the countries in Africa (Rhee, Luyirika, Namisango, Powell, Garralda, Pons, de Lima & Centeno 2017:21). It makes use of indicators derived, rated and chosen by in-country African experts and was published in 2017. The fact that it was the first comprehensive publication on African palliative care in 10 years goes to show that palliative care research is in its infancy in Africa (Rhee et al 2017:21).

John Weru (2017) writing in the ‘The Conversation’, states that in Africa there seems to be a lack of awareness among policymakers, health professional and the public about what palliative care is and the benefits it can offer patients and the health system. On the other hand, Lutz (2011:308) states that the efforts of the International Association of Hospice and Palliative Care have resulted in the formation of more than 8 000 hospices worldwide in over 100 countries. However, most African countries do not have highly developed and comprehensive services and this is mainly due to lack of enough resources to develop formal hospices and palliative care programs (Rhee et al 2017:21). In other words, palliative care services are seriously lacking in Africa because only 19% of African countries have recognisable palliative care services, of which 71% of these are concentrated in Uganda, South Africa and Kenya (Rhee et al 2017:21).

In African countries where palliative care services have been developed, this has been driven mostly by programmes and interventions linked to the HIV epidemic (Rhee et al 2017:22). The initial funding in HIV has helped to boost hospices and palliative care services on the continent (Lentsoane, Meyer, Schellack & Cameron 2014:421). However, a decrease in funding, as well as a move away from vertical, disease-specific, funding to horizontal health system funding has negatively affected palliative care services delivery in many countries across the continent (Lentsoane et al 2014:421). This means that dwindling budgets will continue to disrupt the necessary end-of-life and palliative services for patients in Africa (Lentsoane et al 2014:421). This is evidenced by many programs having been forced to scale back due to reduced foreign aid budgets (Rhee et al 2017:22).

South Africa has been active in providing palliative care since the 1980s and is home to a very strong palliative care community (Gwyther, Krause, Cupido, Stanford, Grey, Crede, de Vos, Arendse & Raubenheimer 2018:86). Though focussed initially on cancer, palliative care organisations mobilised responses to the growing HIV pandemic in the 1990s, providing critical services to adults dying of HIV (National Policy Framework and Strategy on Palliative Care 2017-2022).

Although it is recognised that palliative care is an approach to care that can be provided in any care setting, most palliative care in South Africa is provided by Non-Governmental Organisations (Gwyther 2011:291). According to the Hospice Palliative Care Association of South Africa (2019), there are currently 150 hospices providing palliative care in South Africa and 40 of these also provide palliative care to children. They further estimate the need for palliative care using only mortality data is 0.52% of the population in any year. Since only eight hospitals provide hospital palliative services, there is a clear need for community-based and home-based palliative care programs (Drenth, Sithole, Pudule, Wust, Gunnclark & Gwyther 2017: S171).

Table 1 below shows the number of Hospices per province in South Africa.

Table 1: Number of hospices per province in South Africa

Province	No of Hospices
Western Cape	15
Free state	9
Eastern Cape	8
Gauteng	21
Northern Cape	13
Mpumalanga	9

Province	No of Hospices
North West	8
KwaZulu-Natal	19
Limpopo	2

In South Africa, care is provided mainly within the patient’s home and the professionals, comprising of nurses, caregivers, doctors and social workers, normally visit the patients and their families and provide physical, psychosocial and spiritual care (Drenth et al 2017:171). The palliative care team identifies people who require palliative care while they are admitted in, or have been referred to, hospital (Gwyther, et al 2018:86). Such patients are then discharged from hospital with post-discharge home-based care. In other words, they are discharged “to hospice” (Gwyther, et al 2018:86). With no doubt, the social worker’s role in the provision of palliative care is an important component in improving the quality of life of people and their families with life-threatening illnesses, particularly, in being able to provide this specialised palliative care treatment (Bomba, Morrisey & Leven 2010:75).

Social workers have many tasks in palliative care, these include conducting patient and family end-of-life education, providing a link and referrals to resources and services (Head, Peters, Middleton, Friedman & Guman 2019:17). Social workers are also involved in planning and preparing patients for advances in the disease, offering counselling and supportive therapies which help patients to manage and cope with psychosocial symptoms related to end-of-life transition (Head et al 2019:17).

The University of Cape Town is the only University in South Africa offering a post-graduate diploma in palliative medicine (Ens, Chochinov, Gwyther, Moses, Jackson, Thompson & Harding 2011:42). The post graduate diploma in palliative medicine launched in 2000, aims to equip experienced healthcare professionals, including doctors, nurses, social workers, and other disciplines, with knowledge and skills to provide palliative care in their work settings (Drenth et al 2018: 173). However, because it is delivered through distance learning, the course lacks a practical component, which means that there is no application of theory in a practical setting which is a vital component in higher learning (Ens et al 2011:43).

According to Hughes, Firth and Oliviere (2015:39), the inclusion of social workers in this innovative and important training means social workers are an integral component of the multidisciplinary team but the question that comes to mind is, are social workers well equipped to provide this specialist service? In a study conducted by McCormick, *et al* (2010:29), social workers in medical settings reported that they had not received adequate training in end-of-life care, palliative care, or the ethical dilemmas that they were confronted with daily. However, it is not proven that palliative care training equips social workers with how they should intervene when providing palliative care (Rubischko 2016:18). It is further argued that specialised education, experience in hospice and palliative care, rigorous and well-conceptualized studies that fully incorporate social work values, ethics, knowledge, skills and attitudes are needed to enhance social work practice. In addition, these may also serve to address gaps in end-of-life care research and ensure the highest quality of palliative and end-of-life care (Rubischko 2016:18).

According to Head et al (2019:16), social work has provided essential services as a component of hospice and palliative care, however, the field has had a more difficult time than their medical counterparts in clarifying, documenting, explaining and justifying their role on the interdisciplinary team. Coupled to this, social workers in palliative care often suffer from burn out and anxiety because they regularly function in a high stress, high loss environment (Christ, Messner & Behar 2015:778). A social worker must, therefore, be well equipped to be able to flourish in their role. However, this is made difficult by the seemingly inadequate training available to social workers to fully execute their duties in this specialist service (Rubischko 2016:18). Therefore, there is a pressing need to understand the experiences of social workers rendering palliative care to people faced with life-threatening illnesses.

1.2 Problem statement

Palliative care is one of the most important services rendered by social workers to people faced with life threatening illnesses (Bomba, Morrisey & Leven 2010:75). This service is very important for people who are faced with a life-threatening illness because they are overly anxious and experience depression (Niedzwiedz, Knifton, Robb, Katikireddi & Smith 2019: 2). Moreover, post-traumatic stress disorder (PTSD) has been noted to occur among those faced with life threatening illnesses (French-Rosas, Moye & Naik 2015:2). Amongst others, it is therefore the duty of the social worker to prepare the family on complex decision-making responsibilities but also to provide the necessary support required (McCormick *et al* 2010:297).

Palliative care is recognised as an important service to those faced with life threatening illness and as such social work is considered essential and valuable service in this regard however, there seems to be a lack of research within the South African context (McCormick, et al 2010:297). This is despite the developing nations accounting for a major percentage of people with life-threatening illnesses (Mohanti 2011:4). Research has shown that most studies on palliative care are mainly concentrated in the developed nations and focus is on medical personnel that include nurses and doctors and the interdisciplinary team (Spruyt 2011:3). This is further highlighted by the fact that the South African government adopted a policy paper on palliative care only as recently as in 2017 (Harding, Downing, Bristowe, Gwyther, Luyirika, Meiring & Ratshikana-Moloko 2018:5). This means that at national government level, palliative care is still a new phenomenon on which little or no research has been conducted moreso in relation to social work practice in palliative care (Gwyther et al 2018:87).

Currently, the University of Cape Town is the only institute of higher learning that offers a palliative care course in South Africa and it is a post graduate diploma in palliative medicine (Ens, Chochinov, Gwyther, Moses, Jackson, Thompson & Harding 2011:42). Although this diploma is offered to all healthcare workers, its focus is on a multi-disciplinary approach to palliative care services with a medical bias (Ens et al. 2011:42). There is very little, if any, content on social work practice in the course when rendering palliative care services and therefore, social workers are often left clueless on how to intervene in palliative care (Wang, Chan & Chow 2018:2). Further, this is exacerbated by the fact that their training at university is generic (Wang *et al* 2018:1)

Therefore, the problem statement reads as follows: ***although there are studies conducted on palliative care, there is still a knowledge gap in the existing***

literature on social work practice and methods of intervention in providing palliative care to people suffering from life-threatening illnesses.

1.3 Rationale for the study

The researcher was placed at St Luke's Hospice to conduct the practical work during her 4th level of study for a bachelor's degree in Social Work. She was later employed at the same organisation, as a community social worker from April 2017 until October 2018, her main responsibilities included the provision of psychosocial support to people suffering from a life-threatening illness. During her day to day operations, the researcher established that there were no clear guidelines in place regarding how social workers should intervene, as well as guidelines on social work practice on how to work collaboratively with other professionals. As a result, this created confusion and challenges with other members of the interdisciplinary team.

The researcher is convinced that this study added value to the field of social work especially in a palliative care set up where social workers work with people suffering from life-threatening illnesses daily and within an interdisciplinary team. This study was also intended to assist social workers with suggestions regarding social work practice. Research has been conducted on the topic as highlighted in the problem statement, however, it failed to focus on any suggestions for social work practice in a palliative care set up where social workers specifically deal with people faced with life-threatening illnesses. The following sections discuss the research questions, goals and objectives of the study as initially proposed and subsequently adopted.

1.4 Research questions

A research question is a question that the research is designed to answer (Bailey 2016:245). Research questions are essential for defining the nature and scope of research (Blaikie & Priest 2019:74). Further, it is stated by Denscombe (2012:74) that the research question is a crucial early step that provides a point of orientation for an investigation and it helps to link the researcher's literature review to kinds of data that will be collected. The research question is a statement about what the researcher needs to go out and find out, and it comes out from a challenge that has been experienced.

For this study, the research questions were formulated as follows:

- What is the nature of palliative care services provided by social workers working with people facing life-threatening illnesses?
- What do social workers encounter while providing palliative care services to people faced with life-threatening illnesses?
- What suggestions would social workers give to enhance social work practice in palliative care?

1.5 Research goal

The overall aim of the research is the goal of the research (du Plooy-Cilliers, Davis & Bezuidenhout 2014: 98). Furthermore, Bailey (2018:7) states that goals are your reasons for embarking on a study, whereby a researcher seeks to go on a journey to learn new things that they did not know about, the overall aim being to explore volumes of knowledge as the research progresses (Kumar 2011:204). This means that the research goals are as a result of the research project and these goals are achieved at the end of the project.

The goal of this study was to develop an in-depth understanding of social workers experiences while providing palliative care services to people facing life-threatening illnesses and suggestions that may enhance social work practice.

1.6 Research Objectives

The illustrations of what a researcher intends to explore, describe and explain are defined as research objectives (Maree 2012:32). Furthermore, du Plooy-Cilliers et al (2014:98), state that research objectives are the specific tangibles the researcher intends to achieve. Through research objectives, the researcher gets the direction in which the research will go and further provides an indication of the scale and scope of the proposed investigation (Denscombe 2012:20). This means that research objectives are what the researcher expects to achieve with the research project.

The following research objectives were adopted and employed for this study:

- To explore and describe the experiences of social workers providing palliative care services to people faced with life-threatening illnesses within the from the perspectives of social workers.
- To conceptualise the experiences of social workers rendering palliative care services to people faced with life-threatening illnesses within the context of ecosystems theory and a strength-based approach.
- To explore and describe the strengths and challenges experienced by social workers who render palliative care services to people suffering from life-threatening illnesses in Cape Town and to ascertain how these challenges can be addressed to enhance social work practice and offer effective services.

In addition to the above-mentioned objectives the following task objectives were adopted and employed: -

- To obtain a sample of social workers in the employ of organisations that render palliative care services in Cape Town. Western Cape Province.
- To conduct semi-structured interviews facilitated by open-ended questions in an interview guide to explore the experiences of social workers rendering palliative care services to people facing life-threatening illnesses in Cape Town, Western Cape Province.
- To sift, sort, and analyse the data obtained according to the eight steps of qualitative data analysis constructed by Tesch (Creswell, 2009).
- To draw conclusions and make recommendations which would enhance the social work practice for social workers rendering palliative care services to people faced with life-threatening illnesses in Cape Town, Western Cape Province.

The following section discusses the research methodology, research approach, and the research design.

1.7 Research methodology

According to Bailey (2018:70), research methodology refers to the steps a researcher has to follow in order to conduct research. In other words, it is the researcher’s map and plan for the study. Punch (2016:65) explains further that research methodology is a description of the methods and the data to be collected. It includes a description of the specific methods/techniques employed as well as the research method, research design, method of data gathering, and the type of data analysis utilised by the researcher (Denscombe 2012:93). This means that research methodology is a clear road map on the journey the study takes until its completion.

In this section, the research approach underpinning this study as well as the research design will be presented. It is worth noting that the application of the qualitative research methodology, research approach, and design will be comprehensively discussed in detail in Chapter 3 of this research report, and, therefore, will only be briefly touched on here.

1.7.1 Research approach

The researcher adopted a qualitative research approach for this study. Qualitative research is research that believes in multiple realities, and not just a single reality (Dudley 2011:26). Further, Bailey (2018:3) states that qualitative research uses textual and non-numerical data and is designed to scientifically explain events, people and matters associated with them. Summing it up, du Plooy-Cilliers et al (2014:173) state that qualitative research deals with the underlying qualities of subjective experiences and the meanings associated with phenomena. Qualitative research is research that believes in understanding meaning from how people see the world and how they experience it.

The following are the features embedded in qualitative research as outlined in Creswell (2014:235).

- Qualitative researchers are interested in meaning – how people make sense of their lives, experiences and their structures of the world.
- The qualitative researcher is the primary instrument for data collection and analysis.
- Qualitative research involves fieldwork.
- Qualitative research is explorative by nature.

- Qualitative research is descriptive in that the researcher is interested in the process, meaning and understanding gained through words or pictures.
- The process of qualitative research is inductive in that the researcher builds abstracts, concepts, hypotheses, and theories from the words or narratives from the participants.

Denzin and Lincoln (2014:11) on the other hand see qualitative research as a process that is committed to naturalistic perspectives and places importance on understanding the human experience. Further, Denzin and Lincoln (2014:11), state that the context in which qualitative research occurs in a controlled environment and the assumption is it is stable.

The qualitative research approach was applicable in this study because it enabled the researcher to use different participants to get different views on the experiences of social workers rendering palliative care to people faced with life-threatening illnesses.

1.7.2 Research design

Research design is the plan that has to be followed logically to enable the researcher to navigate from point ‘a’ to point ‘b’ of the study (Blaikie & Priest 2019:33). It is further defined by Gerring (2014:434) as the gathering of evidence to conduct an appropriate empirical test and may be contrasted with data analysis. Similar sentiments are echoed by du Plooy-Cilliers et al (2014:93), who define research design as the step by step plans that the researcher adopts so that they can provide answers that are objective, valid, economic and accurate. Thus research design is the link between research questions, empirical data and research conclusions.

For this study, a qualitative research approach was utilised to explore, describe, and contextualise the phenomenon under study. The researcher was able to explore the magnitude of the problem to be studied and systematically explore and describe the perspectives of social workers who render palliative care services to patients suffering from life-threatening illnesses.

For this research, the following research techniques were adopted and used for data collection.

1.7.2.1 Exploratory design

The purpose of the exploratory design is to attempt to explain and account for descriptive information (Punch 2016:67). In other words, it aims to simplify things so that they can be understandable and provides reasons for showing why and how things are the way they are (Denscombe 2012:102). Further, de Vaus (2013:8), explains that exploratory research is often conducted in new areas of inquiry with the aim being to discover a new phenomenon, behaviour or problem to generate initial ideas about the phenomenon. This means that exploratory designs are designs that are used to gain new insights in an unknown area. In the present study, as shown above, a knowledge gap exists in the experiences of social workers engaged in palliative care. There are no previous comprehensive studies in South Africa and, therefore, the researcher has embarked on a journey to explore and study the problem, so that significant insights can be gained on the subject.

As little is known about social workers experiences in rendering palliative care services, this study aimed to explore the experiences of social workers in rendering palliative care services from the perspectives of social workers in Cape Town Metropole region. An exploratory research design was employed to elicit more information about the phenomenon under study. The researcher asked open-ended questions and used semi-structured interviews with the assistance of an interview guide to explore the experiences of the participants. This enabled the participants to share information. Through self-reflection, the researcher was able to avoid being judgemental and biased as to the values and beliefs about the phenomenon in question.

1.7.2.2 Descriptive design

Descriptive designs allow the researcher to describe the characteristics and relationships of phenomena as accurately as possible (du Plooy-Cilliers et al 2014:75). Similarly, Mc Milan & Schumacher (2010:324), point out that the purpose of the descriptive design is to gather knowledge about a particular area where little is known about the area under study/phenomenon. Furthermore, Punch (2016:67), explains that descriptive designs are geared at collecting, organising and summarising information about the matter under study. This means that descriptive designs are designs that focus on getting enough information on a phenomenon, such as, the characteristics, trends, relations and categories of a problem under study.

The semi-structured interviews helped the researcher to describe the experiences of social workers rendering palliative care services to people faced with life-threatening illnesses in Cape Town.

1.7.2.3 Contextual design

The context refers to considering all factors that exist in and around the situation (McMilan & Schumacher 2010:320). Furthermore, Babbie (2010:94), states that the intrinsic interest that phenomena generate is the reason why we embark on a study. In addition, a contextual design seeks to give a rich description of the phenomena within the context of the unique setting and territory of the phenomena. In addition, Maree (2016: 82), concurs that contextual studies focus on specific events in “naturalistic settings.” These are settings that are uncontrolled real-life situations sometimes referred to as field settings. This means that contextual designs are specific designs that focus on understanding phenomena in the environment.

The researcher intended to gain an in-depth understanding of the experiences of social workers working with people suffering from life-threatening illnesses and suggestions for practice or solutions to enhance practice from the perspectives of social workers. Only social workers involved in rendering palliative care services to people faced with life-threatening illnesses formed part of the interviews. Furthermore, only organisations providing palliative care services in Cape Town metropole formed part of the study. The participants were to be interviewed in their natural settings, namely in their offices based at the organisations where they are employed.

1.7.3 Population, sampling and sampling methods

In this section, the population, sampling and sampling methods will be introduced.

1.7.3.1 Population

The population is that group of people who we ought to study so that we can draw conclusions about the phenomenon under study (Babbie 2016:116). Furthermore, a population is the total sum of all cases that we draw so that they conform to some sought of criteria (Blaikie & Priest 2019:166). Similar sentiments are echoed by Wiid and Diggines (2013:186), who describe the population as the number of people from whom we have to get information. A population refers to an entire pool where study participants will be selected from. The population for this study comprised of all social workers working with people faced with life-threatening illnesses in the Cape Town metropolitan region.

The following common denominators were found to be of interest to the researcher:

- Participants were employed and practising in organizations that render palliative care services to people faced with life-threatening illnesses in the Cape Town metropole region.
- Participants were registered with the South African Council of Social Services Professions (SACSSP) as social workers.
- Participants had between two- and five-years' working experience.

1.7.3.2 Sampling and sampling methods

The sample is a part of the study population that we will vigorously subject to examination (Gerring 2012:75). The sample is usually smaller than the actual population hence the name sample. In some instances, the entire population is studied, for example, the national census (Gerring 2012:75). Furthermore, Krathwohl (2009:159), explains that a sample is an economical way of studying a population where cases are taken from a population and ought to represent accurately the variable interests in that population. In summing it up Blaikie & Priest (2019:167), defines a sample as a selection of element members of units from a target population and from there conclusions are drawn about the population, with all the relevant features of the population included in the sample in the same proportions. A sample is a smaller set of participants we choose from the greater population using a selection method the researcher chooses.

The type of sampling that was used in this study was the non-probability sampling method. According to Maree (2016: 10), in non-probability sampling, the probability of being chosen is not the same for each entity. Similarly, non-probability sampling refers to the case where the probability of including each element of the population in a population is unknown and it is not possible to determine the likelihood of the inclusion of all representative elements of the population into the sample (Krathwohl 2009:163). Regardless, non-probability sampling is very useful and mostly used when there are time and financial constraints, and the entire population is difficult or impossible to access (Maree 2016: 10).

In this study, purposive sampling and snowball sampling were employed, whereby the names of the welfare organizations in Cape Town that provide palliative care services to people suffering from life-threatening illnesses were selected. The researcher then requested for referrals from these organisations. Purposive sampling and snowball sampling are explained below.

Purposive sampling

Purposive sampling is a method used to deal with situations where it may be challenging or impossible to study the whole population (Blaikie & Priest 2019:173). Further, Babbie (2016:187), define purposive sampling as a type of non-probability sampling where the researcher's judgement is used to select units to be observed. Similarly, Krathwohl (2009:171), describes purposive sampling as a method of sampling that relies on the wisdom and judgement of the researcher in choosing the units to be observed. This means that purposive sampling involves selecting participants based on one's expert knowledge. In this study, purposive sampling was deemed appropriate because it enabled the researcher to judge who would provide the best information about the problem under study in order to meet the objectives of the study.

Snowball sampling

The snowball sampling technique relies on participant referrals to increase the sample size (Babbie 2016:188). Similar sentiments are echoed by Blaikie & Priest (2019:173), who state that snowball sampling makes use of networks, referrals and chains. Snowball sampling is used to find members of a population who would, otherwise, not be visible, or easily identified, for example, crime groups, or people involved in sensitive activities e.g. sex workers or drug users (Krathwohl 2009:173). Snowball sampling is a technique that uses the participants to nominate others who might be willing to participate also. This technique was deemed suitable in this study because of the uniqueness of palliative care service providers who are not easily accessible and are rare to find. In this study, the researcher was referred by participants to other organisations that she was not aware of that provided palliative care services.

The following was the inclusion criteria for the study:

- Social workers from Cape Town in Western Cape Province, who provide palliative care services to people faced with life-threatening illnesses.
- The social workers with working experience of two years and more in providing palliative care services were deemed to have more practical experience in the challenges and effectiveness of providing palliative care services to people faced with life-threatening illnesses.
- Social workers who were able to converse in English, which is the language the researcher was familiar with.
- The social workers who formed part of the study were to be all registered under the Social Service Professions Act (Act 110 of 1978).
- Participants should voluntarily consent to participate in the study.

Since a sample was drawn the principle of data saturation applied in this study. According to Bailey (2018:245), data saturation is the point at which data collection can cease. This point is arrived at when the information that is being shared with the researcher becomes repetitive and contains no new ideas such that the researcher can be reasonably confident that the inclusion of additional participants is unlikely to generate any new ideas (Bailey 2018:245). Similar sentiments are echoed by Kumar (2011:213), that data saturation as a point where one cannot get any new information. Likewise, Maree (2016:84), refers to data saturation as a point where all the themes in a category have been saturated and no new data are generated. This means that data saturation is the point where interviews do not bring any new information to the surface.

1.7.4 Data collection methods

The process of collecting evidence is called data collection. Examples of methods of data collection are surveys, interviews, ethnography, archival research and non-reactive measures (Gerring 2012:419). Furthermore, data collection is the process that enables the researcher to obtain richness and depth of data gathered from complex and multifaceted phenomena in a specific social context (du Ploy-Cilliers et al 2014:173). Leedy and Ormrod (2010:145) also explain that data collection is the process of thoroughly, accurately and systematically recording data of the observations the researcher as well as jotting down of notes about these observations. This means that data collection is a process of getting evidence matter from the participants.

1.7.4.1 The process of gaining entry

When preparing for data collection the first step is usually to identify the gatekeepers who control access or entry into the population under study. Gatekeepers are the individuals at the study site who provide access to the site and allow or permit the research to be done (Creswell 2014:188). Sometimes a brief proposal might need to be developed and submitted to the gatekeepers for review or consideration (Creswell 2014:188). Similarly, Maree (2012:122), states that gatekeepers are the people or organisations that need to be approached and who approve a study at a site (Maree 2012:122). Furthermore, Creswell (2013:94), define gatekeepers as one or more individuals in the group who will allow the researcher in. This means gatekeepers are the regulators that give access to researchers to the organisation.

According to Gerring (2012:419), the most common ways of collecting qualitative data are research interviews and group discussions. There are three main types of interviews, namely structured, semi-structured and in-depth interviews.

In this study, the researcher utilized a semi-structured interview. According to Bailey (2018:245), semi-structured interviews are interviews that make use of both pre-planned and unplanned questions. These questions are found in the interview guide, which stipulates the topics to be covered and the direction or line of inquiry to be followed (Holloway & Wheeler 2010:89-90). Similarly, Maree (2016:5), defines semi-structured interviews as interviews that have questions that are prepared in advance by the researcher and the line of inquiry includes probes and clarifications as a way of getting further clarity and information. Semi-structured interviews are interviews that follow a structure but are flexible in that follow up questions and probes can be added to the structured questions. A tape recorder was used with the permission from the participants to record the information and field notes were be taken as a back-up.

The following requests and open-ended questions were formulated, and these were stipulated in the interview guide, corresponding to the overall goal and objectives of the study, to obtain data from the social workers as service providers for people faced with life-threatening illnesses:

1. What is your experience of working with people faced with life-threatening illnesses?

2. What is the nature of palliative care services you provide to people faced with life-threatening illnesses?

3. What is your role within the interdisciplinary team that provide palliative care services?

4. What is your intervention strategies in working with people faced with life-threatening illnesses?

5. What challenges do you often encounter in rendering palliative care services?

6. How do you cope or deal with the challenges experienced in rendering palliative care services?

7. Are you satisfied with the kind of palliative care services you provide to people faced with a life-threatening illness? Please substantiate.

8. What are your suggestions regarding the nature of palliative care services provided by social workers?

9. What are your recommendations regarding the role of social workers in providing efficient palliative care services to people faced with life-threatening illnesses?

The researcher made use of the following interviewing skills during data collection: -

1.7.4.2 Building rapport

To gather rich data, one must ease the participants into the main questions, therefore, sensitive and threatening questions should be avoided at the beginning of the interview session (Maree 2012:90). Similarly, Creswell (2013:173), state that it is important to create an environment where the researcher and interviewee get to a point of collaborative interviewing, where the participant and researcher approach equality in questioning, interpreting and reporting. Furthermore, McGrath, Palmgren & Lijedahl (2019:1003), sum it up by stating that building rapport and establishing comfortable interactions in the qualitative interview situation is important and even though it must preferably be done well in advance of the interview, it can also be done during the interview. This means that the researcher must approach participants with an open and curious attitude, stating specifically why they are interested in their specific point of view in an unthreatening manner.

1.7.4.3 Empathy

Empathy is the power of understanding and imaginatively entering another person’s feelings; attempting to understand that person’s world, it is the outwardly expressed by facial expressions, tone of voice and gestures but also by the use of vocabulary appropriate to the situation and the person being interviewed (Abrahams 2017: 255). Similarly, Creswell (2013:173) explains that empathy is achieved when participants can articulate the forces that interrupt, suppress or oppress them. They can articulate their history, approaches, cultural identity and the difficult aspects of their lives without fear of judgement. Prior (2017:6), concurs and states that empathy involves sharing the perceived emotion of the other, “feeling with” another and is an imaginative sharing of someone else’s experiences, it requires a high degree of relational and emotive involvement. Relational and emotive involvement enable interactants to reinforce their social solidarity, and therefore, can be a key means by which the researcher facilitates the gathering of personal information of the participants. This means that the researcher encourages participants to recount their experiences from their own frame of reference, with assurances that they would not be judged in any way.

1.7.4.4 Attending and listening.

In qualitative research, listening means the researcher should do as little talking as possible, instead, the participant must get to speak on the issue at hand as this enables better chances of rich data being uncovered (Maree 2012:103). Furthermore, listening also means not ignoring parts of what is being said, and not criticising or judging, arguing or counselling (Louw 2011:71). Abrahams (2018:254) sums it up by stating that active listening involves the “conscious discipline of setting aside one’s own preoccupations to concentrate as fully as possible on what the other person is expressing,” taking note of verbal cues, being conscious of participant’s non-verbal cues, as these may reveal significant information. This means that the researcher respects silence and identified silent moments as an opportunity for reflection. Researcher listened more, but also listened actively and made use of prompts probes and encouraging words such as “tell me more” “really” “uh” “why”. Attention was paid to verbal and non-verbal communication to understand participants experiential world.

1.7.5 Data analysis methods

Data analysis is the process when data collected is transformed to lead to substantive meaning (Bailey 2018: 243). On the other hand, Denscombe (2012:99), states that data analysis as bringing order, structure, meaning to the mass of data collected. Additionally, Creswell (2014:258) states that data analysis leads to identifying and describing patterns and themes from the perspective of the participants then attempting to understand and explain these patterns and themes. This means that data analysis is the process of bringing order and meaning to the mass of data collected.

In this study, the researcher compared and analysed the data following Tesch’s eight steps as cited in Creswell (2014:248) and this entails the following process applied:

i. the researcher transcribed the interviews and carefully read through all the transcripts and wrote down the themes as they emerge.
ii. the researcher picked up transcripts and read through thinking of the underlying meaning and wrote these down as they came to mind in the margin of the scripts.
iii. after repeating this exercise with more scripts, the researcher listed the themes that emerged. These themes were grouped according to their commonalities. These themes were written under the subheadings (a) major theme, (b) sub-themes, and (c) categories.
iv. the researcher then took the list of themes and revisited the data. The themes were abbreviated as codes and the codes were written alongside the appropriate portion of the text. The researcher then reviewed the coding scheme and observed if the new themes emerged.
v. the researcher found the most descriptive words for the themes and placed them into categories. This was done so that the categories were reduced and as many similar themes as possible were placed in the appropriate category. Linking lines were drawn between categories to show shared relationships.
vi. the researcher alphabetized the codes after making the final decision on the abbreviation of the codes.
vii. The data of each category was written up and the researcher was able to make a preliminary analysis of data.

In addition, the researcher provided the transcripts to an independent coder to conduct data analysis as a way of ensuring the trustworthiness of the study. Thereafter, the researcher compared her findings with the findings from the independent coder during the consensus discussion facilitated by the promoter.

1.7.6 Methods of data verification

1.7.6.1 Data verification

Research studies require that there be some mechanisms to verify the quality of the research (Guest, Namey & Mitchell 2013:298). Further, Gibson & Brown (2009:5), state that data verification is a systematic way of checking the certainty of the research. Additionally, Lincoln and Guba in Schurink, Fouché and de Vos (2011:419-421) concur that data verification refers to the quality of research. This means that data verification is the process of checking that data that has been collected is accurate and that human errors have been minimised.

In this study, Guba’s model (in Maree 2016:123), of ensuring the trustworthiness of qualitative data was applied in relation to the following four aspects to ensure trustworthiness: namely credibility, transferability, dependability, and confirmability (Maree 2016:123) as follows: -

1.7.6.2 Credibility

Credibility refers to the process of ensuring that participants viewpoints are recorded accurately (Schurink, Fouché & de Vos, 2011:419). Further Punch (2013:113), points out that credibility focus on establishing that the findings reflect what the participants articulated. Similarly, Gibson & Brown (2009:5), concur that credibility is all about the truthfulness of the researcher in analysis data appropriately as expressed by participants. This means that credibility is the ability of the researcher to mirror the findings according to the participants' viewpoints.

During the collection of data the researcher used an audio tape recorder to record the interviews. She also observed the reactions of the participants during the interview process and made notes based on their responses. After data collection, the researcher proceeded to transcribe the recorded information gathered from the individual participants and made comparisons of the transcripts with her notes to determine and verify the credibility of the data.

1.7.6.3 Transferability

Transferability is when data can be generalised and can be transferable to other situations (Schurink, Fouché & de Vos, 2011:420). Similarly, Guest (2013:298), states that transferability refers to whether a researcher can transfer and apply the research findings to a similar situation. Korstjens & Moser (2018:121), concur that transferability is the degree to which qualitative researchers can transfer their findings to other contexts. Transferability is when findings can be transferred to other similar contexts.

The researcher was able to assess the usefulness of the collected data which could contribute to the development of knowledge about the experiences of social workers rendering palliative care services to people faced with life-threatening illnesses.

1.7.6.4 Dependability

According to Elo, Kääriäinen, Kanste, Pölkki, Utriainen, Kyngäs (2014:2), dependability refers to consistency in the research process that is data collection as well as the reporting of the findings. Further, dependability required that the researcher prove that the study process checked, audited and the process followed a logical sequence (De Vos et al., 2011: 420). Dependability is the ability of findings to be stable over time (Korstjens & Moser 2018:121). Dependability refers to the ability of findings and outcomes coming out the same if the study is to be repeated.

The process of dependability in this study was established through the use of an independent coder. The researcher and the independent coder independently coded the data, a discussion followed and consensus was reached and discussed with the supervisor on the themes, subthemes, and categories presented as research findings.

1.7.6.5 Confirmability

Confirmability is the process at which research findings can be corroborated by other people (Whittaker, 2012:92)., Further, Biber and Leavy (2011:301), state that is the researcher’s concern regarding objectivity in the study process. Further, Korstjens & Moser (2018:121), concur that the confirmability is the extent to which research findings can be confirmed by other researchers. Confirmability considers the researcher’s own views and bias.

The researcher took all possible steps to ensure that her own beliefs and opinions did not sway or influence the outcomes of the interviews or the study. All the interviews were audio tape-recorded and audio recordings were immediately transcribed after each interview.

1.8 Ethical considerations

Ethics are rules and guidelines that govern the conduct of research (Bailey 2018: 18). This is echoed by (Blaikie & Priest 2019:52), who states that ethics are the norms and practices that are acceptable and required in conducting research, put differently, research ethics refers to those norms that are good, right or virtuous courses of action in research (Punch 2016:430). This means that ethics are the rules that govern our behaviour when conducting research. The researcher abided by the UNISA ethics rules and guidelines, including, but not limited to providing the participants with informed consent forms to sign, as well as any relevant information they may need to decide whether to participate or not.

1.8.1 Informed consent

Informed consent is when participants come to the research voluntarily, being aware of the risks involved (Babbie 2016:64). For example, in medical experiments, prospective subjects are presented with a discussion of the experiment and all the possible risks. Similarly, Bailey (2018:18), state that informed consent as getting permission from research participants, with knowledge on the nature of the research and their role in it which is voluntary. The researcher must inform participants about the research and get their approval before they are a part of the research. Furthermore, Denscombe (2012:128), defines informed consent as voluntary participation that is devoid of force, coercion, moral blackmail or pressure from the researcher.

This means that informed consent is as permission from participants to be included in the research. In this research, the researcher availed a consent form which participants were to sign before they undertook the research. The participants were allowed to draw back from the interviews should they wish to do so (see Addendum 1).

1.8.2 Confidentiality

Confidentiality is making it a point that the names of the participants will not be made public (Dudley 2011:430). This is the circumstances in which the researcher is aware of the names of their participants but does not disclose them to anyone (Dudley 2011:430. Similar sentiments are echoed by du Plooy-Cilliers et al (2014:267), that confidentiality is the researcher’s ability to protects the identity and sensitive information about the participants. This is summed up by Krathwohl (2009: 213), that confidentiality is controlling access to participants information. This means that participants are at ease and have a reasonable expectation that information they have availed in the study is being treated confidentially. During the research write-up, the researcher did not mention the names of participants or anything that might identify individual participants.

The researcher informed the participants formally through a letter and by signing the confidentiality forms that their personal details would be kept locked and that none of the information shared will be made available to other people or the public. They were also informed that the research results and report would be handed over to the supervisor for supervision purposes.

1.8.3 Anonymity

Anonymity is ensuring that participants cannot be identified with their responses (Blaikie & Priest 2019:55). Similarly, Bailey (2018:25), explains that anonymity is when the researcher is not able to identify the participants in the study. Furthermore, Krathwohl (2009:213), sums it up that anonymity refers to the process when the researcher cannot link data provided by the participants to the specific person.

The researcher understood anonymity as the requirement that the researcher cannot tell those outside the research team the identity of the participants. To ensure anonymity, the names of participants were not written on notes and transcripts. Pseudonyms were allocated to participants to hide their identity. Tapes/recordings and transcripts should be destroyed after the completion of the research. In addition, participants’ records were kept anonymous using coding and by using the letters of the alphabet.

1.8.4 Management of information

Management of information is the process when information is collected, managed from one source and then distributed to one or more audiences (Creswell 2014:139). This sometimes involves those who have an interest or a right to the information

(Babbie 2010:101). Management of information is the act of organising, control, processing and delivery of information (Kumar 2011:221). Management of information is the process of acquiring data, its storage and distribution with other stakeholders in a study.

In the proposed research study, the researcher ensured that the process of data collection was done properly and ethically. The collected information was coded and kept strictly confidential. The audiotapes were coded to disguise any identifying information with the participants. Tapes were stored in a locked cabinet, to which only the researcher had access. The transcripts (with no names) were made available to the research supervisor and an independent coder for the sole purpose of assisting and guiding the researcher with this research undertaking. The researcher kept the research information on an encrypted personal computer which only the researcher had access. Also, all information will be destroyed by the researcher after the conclusion of the research (see Addendum 2).

1.8.5 Beneficence

According to Punch (2016:37), beneficence seeks to put the welfare of the research participant at the forefront and it should be the goal of any clinical trial or research study. It seeks to minimise risks of harm to the participant (Punch 2016:37). Similar sentiments are echoed by Kumar (2011:223), that beneficence is the art of ensuring that there is a balance between the benefits of research against the risks or harm to participants. Furthermore, Maree (2012:150), states that the safeguarding of the welfare and rights of the participants whom the researcher interacts with is important. This means that beneficence is safeguarding the welfare of participants, in other words, there should be no harm to participants.

In this study, the researcher observed the following principles: -

- respect the autonomy of participants.
- respect for decision making.
- respect the dignity of participants.
- respect communities protect their values and interests.

The researcher intends to share the findings of the research with the participants. This means that the participants will have access to the findings and suggestions that will help them in their rendering of palliative care services to patients with life-threatening illnesses.

1.8.6 Debriefing of participants

Debriefing is an important aspect of interviewing process where we ought to understand and learn the experiences of participants in the project, especially so if there has been harm in any way due to their participation (Babbie 2010:97),. Similarly, Kumar (2011:221), echoes the same sentiments that debriefing entails that the researcher has a back-up plan in case there has been harm to the participants because of their involvement in the study, participants should have an opportunity for intervention and counselling. This is summed up by Creswell (2014:139), that researchers should anticipate that harm may come especially after participants have shared intimate information during data collection. Debriefing is the act of providing support to participants at the end of the interview, in the event that the interview process has caused harm to them. The impact emotional and psychological harm may have is difficult to anticipate but debriefing soon after the interviews can point out the way the researcher can tackle this.

The researcher intended to conduct debriefing immediately after each interview, then refer participants to an identified social worker for further debriefing, whenever the need arose. This was important to the study because the participants were social workers who provide services to people with life-threatening illnesses. There always is, a possibility that research questions and the process of disclosing information during data collection could resurrect memories of the experiences and challenges they face daily and these could also negatively affect the social worker (see Addendum 3). Although participants were informed about the availability of the debriefing services, none of the participants sought debriefing after the interviews and thus debriefing services were not provided.

1.9 Theoretical framework

The theoretical framework of this study is based on a strength-based approach and the eco-system theory. The strengths-based perspective is a model that focuses on strengths but does not overlook or ignore challenges or does it convert struggles into strengths (Pattoni 2012:3). Gottlieb (2014:24), state that the strength-based approach believes that people are born with inherent strengths and resources in them and given an opportunity they are able to put them to use, thus the focus is on the inner being (intrinsic) and outer (extrinsic) strengths of the person. Further, a strengths-based approach allows people to identify and build on their strengths so that they can attain their goals and retain or regain some form of independence in their daily lives (Pulla 2017:100). This means that the strength-based perspective assumes that people have the capacity for growth and change even during periods of challenges, crisis and hardships. The approach was deemed appropriate for this study because, even though people are faced with life-threatening illnesses, they still possess strengths that they can tap into, these can include how they have navigated through difficulties in the past and strengths that they still personally possess which they can make use of.

The eco-system systems theory is a model of a man and society and it believes that all individuals do not operate in isolation but their physical and social environments which they live in and interact with influence them (Teater 2014:3). Its main concern is with people's interactions in real life and space and includes the whole web of life between systems and subsystems of people (Ettekal & Mahoney 2017:2). Similarly, Bridgen (2017:11), explains that the eco-systems system theory is thus a holistic approach which believes that challenges can never be separated from a person's relationships and interactions. This means that the ecosystem theory believes that no man is an island, his surroundings and interactions have an influence on his whole system. The ecosystem theory was deemed appropriate in this study because people with life-threatening illnesses are not seen as standalone entities but form part of a greater system which includes their families, hospitals, hospices and their places of employment.

To ensure the applicability of the strengths-based approach and the eco-system theory in the provision of palliative care services to people faced with life-threatening illnesses, the research questions were structured in such a way that research participants would realise the importance of identifying the strengths of the people who face life-threatening illnesses and thus receive palliative care services. In other words, the researcher structured the research questions in such a way that they helped participants in assisting their clients to identify their strengths and in the process bringing together or connecting an individual with the multiple resources or systems around him/her.

It is worth noting that the literature review pertaining to this study is comprehensively discussed in Chapter 2 of this research report.

1.10 Glossary of concepts

The following sections explain and clarify some of the key concepts that could be encountered regularly in this research report.

Experiences – experience is the practical knowledge, skill, or practice derived from direct observation of or participation in events or a particular activity (Oxford Dictionary 2016).

Hospice - A program that gives special care to people who are near the end of life and have stopped treatment to cure or control their disease. Hospice offers physical, emotional, social, and spiritual support for patients and their families (Marais 2016:140).

Hospice care – Care designed for people in the final stages of an incurable disease and focuses on comfort and quality of life, rather than cure (Lutz 2011:306).

Interventions - Interventions are ways of doing social work, and are sometimes called ‘methods’ or ‘practice approaches’ (Lomarpark, Jones, Leigh & Gay 2010:42).

Intervention methods - In social work, intervention methods are intentionally implemented change strategies which aim to impede or eradicate risk factors, activate and/or mobilize protective factors, reduce or eradicate harm, or introduce betterment beyond harm eradication; thus, social work intervention encompasses a range of psychotherapies, treatments, and programs. Interventions may be simple or complex (Sundell & Olsson 2017:1).

Life-threatening illness - Life-threatening illnesses are usually incurable diseases, which have the effect of considerably limiting a person's life expectancy. These include cancer, diabetes, neurological conditions, coronary heart disease and HIV/Aids. (*Life-threatening disease* 2019).

Methods – A method is understood to be an orderly way of procedure and therefore it is always carried out towards the achievement of a specific aim (Parmar 2014:303).

Palliative care - Palliative care is an approach that seeks to improve quality of life for people and their families facing the problems associated with life-threatening illnesses through the prevention and relief of suffering through early identification, assessment and treatment of pain be it physical, psychosocial and spiritual (Lutz 2011:306).

Social worker - A social worker is a change agent who is skilled at working with individuals, groups, families, organisations, and communities (Teater 2014:3).

Suggestion - an idea or plan put forward for consideration (Oxford Dictionary 2016).

1.11 Format of the research report

The research will be divided into the following four chapters: -

Chapter 1 – General Introduction

This chapter gives a detailed overview of the study and includes the general introduction of the study, problem formulation, rationale of the study, the research questions, goals and objectives of the study, research methodology, ethical considerations and the clarifications of the key concepts. This chapter concludes with the chapter summary.

Chapter 2 - Literature Review

This chapter reviews the literature on social workers' experiences in providing palliative care services to people faced with life-threatening illnesses. The chapter includes the following sub-sections, the historical perceptive of the hospice movement; An overview of Hospice and Palliative Care; An overview of Palliative Care Services; Social workers' role in Palliative Care; Challenges faced by social workers in providing palliative care services and the theoretical framework underpinning the study were presented. This chapter concludes with the chapter summary.

Chapter 3 - Research methodology

This chapter focuses on the researcher's description and application of the qualitative research process. The Chapter begins with the introduction of the research methodology, followed by a detailed discussion of the applied research methods. The chapter concludes with a summary of the chapter.

Chapter 4 – Research findings

The findings of this research study are reported here. The chapter begins with the presentation of the demographic particulars of the participants followed by a detailed discussion of the themes, sub-themes and categories. A summary of the chapter concludes the discussions.

Chapter 5 – Summary, conclusions and recommendations

This chapter presents the summary and conclusions of the research findings and recommendations. Recommendations made are based on social work practice, social work training and education and further research.

1.12 Summary of the chapter

This chapter presented a general overview of the study as initially proposed and subsequently adopted by the researcher. The chapter begins with the general introduction of the study, the problem formulation and rationale. In addition, the research questions; goals and objectives, research methodology; research method; preparation; methods used for data collection, data analysis and data verification; ethical considerations; and clarification of key concepts were discussed. The Chapter concluded with an outline of the study. The following chapter discusses the literature on the study.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

In this chapter, a historical perceptive of the hospice movement, as well as an overview of hospice and palliative care and palliative care services, will be presented. Also, the roles of social workers in palliative care and the challenges they face in the provision of palliative care shall be discussed. This shall be done within the context of the theoretical framework underpinning the study, which will also be presented in this chapter. The theoretical framework shall provide the reader with a holistic perspective about the topic under investigation emanating from the literature review.

2.2 The historical perspective of the hospice movement

Hospice has its roots in the Latin word “hospes” which seeks to describe a house as well as a guest (Hickman 2010:7). It is from this word that we have “hospitium” – a place that was designated for visitors. This is where they were received and entertained. Further origins are from the root of ‘hotel’, ‘hotel-dieu’, ‘host’, ‘hostess’, ‘hospital’, ‘hospitality’ and ‘hospice’ (Hickman 2010:7). It all began with the hospitality of the religious orders of the middle ages who were kind enough to offer abode to tired and exhausted travellers, who they then invited in and offered a place to refresh in the monastery’s “hospitium” (Breslin 2013:1). The medieval hospice was a place where pilgrims would rest, refresh, all were welcomed and sheltered until such a time when they were prepared to embark on their journey. It also cared for and tended to the sick and wounded (Breslin 2013:1).

Various religious sects were at the forefront of continuing this movement (Hickman 2010:8). Among them were the Daughters for Charity in France, the Servants for Relief of Incurable Cancer in the USA, the Anglican Church in Sydney, Australia in 1907. Also, the Religious Sisters of Charity opened Our Lady’s Hospice in Dublin in 1879 where they cared mainly for cancer and TB patients (Hickman 2010:8). In different parts of the world caring for the terminally ill was left to different groups of people, institutions and homes (Clark 2016:8). An example is in the USA were those with incurable infirmities were cared for in hospitals. It was reported that their deaths were unpleasant and they had symptoms that could not be managed (Clark 2016:8). They were labelled “incurable” or deemed “terminal” and as such were considered of less value and physicians steered clear of them, as such doctors were absent from their cot sides upon death (Clark 2016:8). The United Kingdom cared for its dying patients in hospitals but there were reports that the terminally ill were cared for badly (Thoresen, Wyller & Heggen 2011:260). In some instances, they were not given proper treatment and they were put away from sight, away from active parts of the hospitals. Even though they received some form of medical treatment, their distress was not attended to (Thoresen *et al* 2011:260*).*

In sub-Saharan Africa, before the advent of the modern-day hospices, the responsibility of taking care of the terminally ill in a household was often left to women even though most of these women had no expertise (Gysels, Pell, Straus & Pool, 2011:7). Also, women mostly were burdened with other domestic duties and responsibilities, including for income-generating roles as well as childcare duties (Gysels *et al* 2011:7). The landscape has since changed, however, because of the HIV/AIDS pandemic which can affect several family members at once, changing provider and dependency relations in unexpected ways. Gysels et al (2011:7), further state that the responsibility for informal care had in many cases shifted to the elderly and children. A previous review appraising the status of palliative care within sub-Saharan Africa identified a wealth of experience yet a dearth of evidence (Gysels et al 2011:7)

Despite the need for modern-day hospice, the idea had to wait for two major developments in the 1950s to gain the necessary momentum (Hickman 2010:9). Firstly, it was the establishment of the Marie Curie Foundation in England which set out to fight the consequences of malignant diseases and secondly, the death of David Tasma, a polish refugee from Warsaw, who died in 1948 in a London teaching hospital (Thoresen et al 2011:263). David had a close relationship while in the hospital with a social worker and they discussed his needs especially towards the end of his life (Clark 2016:259). Between them, an idea was conceived that a special kind of care in a home designed for the care of the dying was ideal. At his death, he left a gift of 500 Pounds for the social worker so that she could be a “window in her home” (Clark 2016:259). The social worker was Cicely Saunders who at that time had already qualified as a nurse. This relationship helped solidify Saunders’s ideas that terminally ill patients needed compassionate care to help address their fears and concerns as well as **palliative** comfort for physical symptoms (Clark 2016:259). Cecily Saunders left social work and went on to embark on a qualification in medicine and upon completion, she became the first full-time medical director of St Joseph's Hospital (Hickman 2010:9). In this role, she set about proving her prior conviction that pain for the dying was unnecessary (Hickman 2010:9).

Later, it was documented in her writings that Saunders had come to know of the anxieties and sorrows that accompany and surround death when she got to know David Tasma (Thoresen et al 2011:263). She had strong beliefs that terminally ill people felt deserted by their doctors at the end when, ideally, the doctors should have been at their sides to relieve the emotional and physical pain, to console and to keep a tag on the struggles that patients go through during those twilight moments of their lives (Clark 2016:27). Saunders also pointed to the conditions that the dying were left in, in the hospitals and the need for safe, home-like places and dedicated healthcare professionals who were skilled in taking care of the dying person (Thoresen et al 2011:261). Resources for the care of patients dying were minimal at the time and a few institutions provided "dedicated custodial care" virtually untouched by medical advances (Thoresen et al 2011:261).

According to Saunders, the topic of death was taboo in Western society and she called for a new openness about dying and death (Hickman 2010:10). Further, Hickman (2010:9), states that Saunders pointed to the necessity of including relatives in the lives of dying persons and the importance of total care, to relieve total pain. The concept of total pain is a key concept in hospice philosophy developed by Saunders because of something she learned from a patient (Thoresenet al 2011:263).

From this development of Cicely Saunders' ideas, a whole new system of a way of caring for the terminally ill was born and in it is the concept we call 'hospice' today (Hickman 2010:9). Cicely Saunders is, thus, widely regarded as the founder of the modern hospice movement (Al-Mahrezi & Al-Mandhari 2016:161). She founded the St Christopher's Hospice in London and this was due to a response in unmet needs of those patients dying in hospitals (Lutz 2011:305). Traditionally, hospices cared mostly for those incurable diseases such as cancer. However, there has been an increase in hospice care spreading to other patients as those with motor neurone disease and multiple sclerosis (Buck 2011:2).

Physicians the world over were inspired by Saunders' ideas and the opening of St Christopher's hospice marked a turning point that has influenced physicians all over the world to be trained in this new field and set up and establish palliative care units in their countries (Al-Mahrezi & Al-Mandhari 2016:161). The field of palliative care grew out of the hospice movement, which is commonly associated with Saunders (Baines 2011:225). Since then, palliative care has been developing worldwide and has shown that the basic principles demonstrated in those early years can be interpreted in various cultures and with different levels of resources (Baines 2011:226).

Globally, diverse cultures have different approaches to helping people who have reached the latter stages of their lives of which sub-Saharan Africa is no exception (Opoku 2014: 3). Further, the idea of modern palliative care is not well developed especially in sub-Saharan Africa (Opoku 2014:3). There has been slow development of palliative care in sub-Saharan Africa and this can be attributed to the diverse perceptions and attitude towards the dying especially in an African context (African Palliative Care Association 2016:6).

This diversity in perception is informed by several cultural and traditional factors which have interrupted the formal development of the concept of palliative care in this area (Opoku 2014:4). An example is the concept of facing the reality of one's death, it is not encouraged according to African customs, whether it is one's death or that of family members (Ekore & Lanre-Abass 2016:5). It is considered an abomination to think of or discuss one's death, hence no preparations are made, such as living wills or setting money aside for one's funeral while still alive (Ekore & Lanre-Abass 2016:5). This is in stark contrast to what is practised in Western culture. Further, the occurrence of death is seen as an enemy of life and the belief that life should be preserved at all cost even in hopeless situations is still prevalent among African cultures (Ekore & Lanre-Abass 2016:5)

The belief in traditional spiritual views still reigns supreme in Africa, this is evident by the use of traditional medicines and herbs and studies have reported that 80% of palliative care patients at least consult traditional healers (Selman, Harding-Swale, Agupio, Fox, Galimaka, Mmolendi & Higginson 2010:28). In some cases, there are African-specific factors such as the substantial linguistic diversity from the four main languages i.e. Arabic, English, French and Portuguese, to the immense variety of over 2,000 indigenous languages and a scramble for scarce resources in such resource-poor settings (Powell, Harding, Namisango, Katabira, Gwyther, Radbruch, Murray, El-Ansary, Ajayi & Mwangi-Powell. 2013:5). Additionally, Powell et al (2013:5) state that, in the African culture, people do not yearn or desire to find information about sickness or disease or understand the concept of death, they consider that to be a western cultural value or trait. They believe that everyone has a right not to know as they have the same right to know (Selman et al 2010:30). One explanation is that, in the African sense, death is not the end of life but a mere separation and transition to another realm (Powell *et al* 2013:5) In addition, African cultures, when it comes to ethnic groups, have different perceptions of death and dying matters depending on the degree of westernisation, evangelism and urbanisation, as a result, what you find applicable in Southern African societies might be perceived differently in West Africa (Selman et al 2010:30).

Despite the diversity in perception in African cultures regarding death and dying, there was a considerable interest to the care of the terminally ill towards the end of the 1970s in Southern Africa and this encouraged the visit which was a “lecture tour” by Cecily Saunders to South Africa in 1979 (Hickman 2010:18). Various participants were encouraged and inspired by the lecture and one such person was Maureen Butterfield who attended a lecture at the University of Witwatersrand and went back home and founded the first hospice in Africa (Sarbo, Dickson, Chifamba, Mastrojohn, Sisimayi & Williams 2010:1). Island Hospice opened its doors in 1980 in Harare, Zimbabwe, it was to be the pioneer in Sub-Saharan Africa (Khumalo & Maasdorp 2016:1). Despite the reservations in the medical community, the hospice movement spread and in 1987 the Hospice Palliative Care Association of South Africa was formed which birthed the Highway Hospice in Durban (Khumalo & Maasdorp 2016:1). Different other hospice organisations were then also founded in South Africa in a variety of settings (Hickman 2010:18)

These developments spread to other African countries such as the Nairobi Hospice in Kenya in 1990 (Kamonyo 2017: S50). Dr Anne Merriman founded Hospice Uganda

(HAU) and it started its operations in 1993 at a house specially loaned from the Nsambya Hospital (Baines 2011:226). Hospice Uganda has since grown and as from January 1998, they set up mobile clinics run by Hospice Mbarara (Campbell, Buyinza N & Hauser 2018:903).

As of 2006, Kenya, South Africa and Uganda were among 35 countries offering widespread, well-integrated palliative care and these programs adopted the United Kingdom model, but emphasise home-based care as backing support (Kamonyo 2017: S50). Because of South Africa’s extensive palliative care services, the region of Southern Africa has more advanced palliative care services when compared to the other regions (Lynch, Connor, Clark 2013:1095).

Hospice care was driven mainly by pioneering advocates and over the years it has advanced outside the mainstream department of health systems and it is prominent among the religious groups and secular based agencies (Grant, Brown, Leng, Bettega & Murray 2011:5). Positive advances have been witnessed over the last decade, there has been a considerable increase in the number of organisations providing palliative care services however when looking at the whole continent it can be noted that service provision is still inconsistent, where it is, it is centralised and restricted geographically instead of it being included in primary health care for easy access, it is still accessible to only a fraction of the population (APCA 2015:5).

The next discussion focuses on an overview of hospice and palliative care.

2.3 An overview of hospice and palliative care

In this section, an overview of hospice and palliative will be discussed specifically focussing on the understanding of the concept hospice care; palliative care; global perspective on palliative care; palliative care in Africa and palliative care in South Africa.

2.3.1 Hospice care

Hospice is an approach to care that is team-based and this team includes different professionals who are called an “interdisciplinary team” and they comprise a social worker, nurse, home aides, medical doctor, chaplains and volunteers (Buss, Rock &

McCarthy 2017:281). These professionals render levels of care that are routine home care, general inpatient care, continuous care and respite care, it is recognising the fact that there are healthier and less painful means of navigating the final days of one's life, as well as the mourning and grieving period for the remaining loved ones (Bus et al 2017:281).

Hospice is many things; it can be defined as a special home where care is made available in an inpatient backup facility (Buck 2011:1). It is nursing at a highly skilled level, it is a pastor (clergy) and medical doctor visiting a patient at home and summing it up hospice is putting a human face (humanisation) to the health care system (Buck 2011:1). According to Crawley (2017:5), hospice care is care thus focuses on the relief of symptoms, offering support to patients with life-limiting illnesses who are in the final stages of their life which can be in weeks or months. In most cases, hospice care is provided in the place which the patient feels most comfortable usually one's home or in other instances in freestanding hospices, an inpatient facility at a hospital or long-term care facility (Crawley 2017:5).

Hospice care is a distinct type of care, that is used when people who suffer from a life-threatening illness no longer find curative treatment beneficial and therefore seek alternative treatments that give better comfort and dignity to the dying and their families (Sekse, Huskar & Ellingsen 2017:2). According to Meier (2011:346), hospice is aimed at providing an all-inclusive, Interdisciplinary team-based palliative care in a place that is called home by the dying person this is after it is certified that the person has a poor prognosis. The aim is to support the loved ones throughout the time of the disease progression and at the passing on of the patient render bereavement counselling to the loved ones (Meier 2011:346). Hospice is applicable when patients and loved ones agree that treatment is of no use and they would want to focus on improving the quality of life and enhance comfort (Meier 2011:346).

The modern hospice has become a skilled community which aims to improve the quality of life left for the patient who may be frail and debilitating, the focal point is on the patient and their loved ones and hospice is concerned with the inclusion of the family as much as possible in the caring process and giving them supportive bereavement at the death of their loved one (Hickman 2010:15).

2.3.2 Palliative care

Palliative care is an approach that builds on many principles, one of the key principles being patient and family centred (Sawatzky et al 2011:5). It focuses on the person, is not only limited to the disease but also includes quality of life as a goal at the forefront of caring (Sawatzky et al 2011:5). Palliative care is a new way of caring for those dying that has evolved in the last five decades (Al-Mahrezi & Al-Mandhar 2015:161). Initially, the aim was to cater for patients dying from cancer and their families. This was amid growing concern from the public about their dissatisfaction with how the dying were being cared for in the 1960s and 1970s (Al-Mahrezi & Al-Mandhar 2015:161). Oncologists seemed to be preoccupied with cure directed interventions and were not concerned with end-of-life care, studies conducted then indicated there was no end-of-life care, or it was sub-optimal at best (Al-Mahrezi & Al-Mandhar 2015:161).

Modern palliative care is linked to the hospice movement, even though in the beginning the care was directed at cancer patients and it relied heavily on charitable funding which meant that this provision of care was thinly and inequitably spread (Dixon, King, Matosevic, Clark & Knapp 2015:3). A key characteristic of a palliative approach is the fact that it is an upstream orientation that puts the needs of patients and their families at the centre while addressing them early on and throughout the illness trajectory of people who have life-limiting illnesses (Sawatzyy et al 2011:5)

Therefore, palliative care can be defined as work at improving the quality of life of patients and their families facing many challenges that are associated with life-threatening illnesses (Lipman 2012:20). This is done through systematic prevention, relief of any pain and suffering through early identification, thorough assessment, treatment of pain and other problems be it physical, psychosocial and spiritual (Hall et al 2011:20).

Palliative care kicks in when one is diagnosed with a serious illness in which any medical intervention or a complete reversal of the illnesses and its processes is no longer possible (Krau 2016 :5). It involves controlling symptoms that have either an insidious onset and progression or rapid onset and progression (Krau 2016:5). Palliative care seeks to give assurance to the patient and their loved ones that the patient can experience an optimal quality of life. It involves managing symptoms, attending to social, spiritual and psychosocial needs, it involves care throughout the illness trajectory (Krau 2016:5).

Dr Balfour Mount coined the term palliative care which means "palliate" in French (Hawley-Kile, Osuji, Larsen & Lubkin 2014:493). This was because historically the term hospice was associated with "destitute" (Krame et al 2014:493). The renaming facilitated the development and spread of palliative care programmes in the latter part of the 20th century (Krame et al 2014:493). Originally the intention was to use a socially accepted word "palliative" but unfortunately, it has been misused to mean or be associated with dying (Hawley 2017:3). As the benefits of early palliative care have noted and recognised there might be a need to rename the language of palliative care (Hawley 2017:3). Palliative care outside hospice is offered independent of the patient's prognosis and simultaneously with life-prolonging and curative therapies for persons living with serious, complex, and life-threatening illness. Figure 1 below illustrates the concept of palliative care.

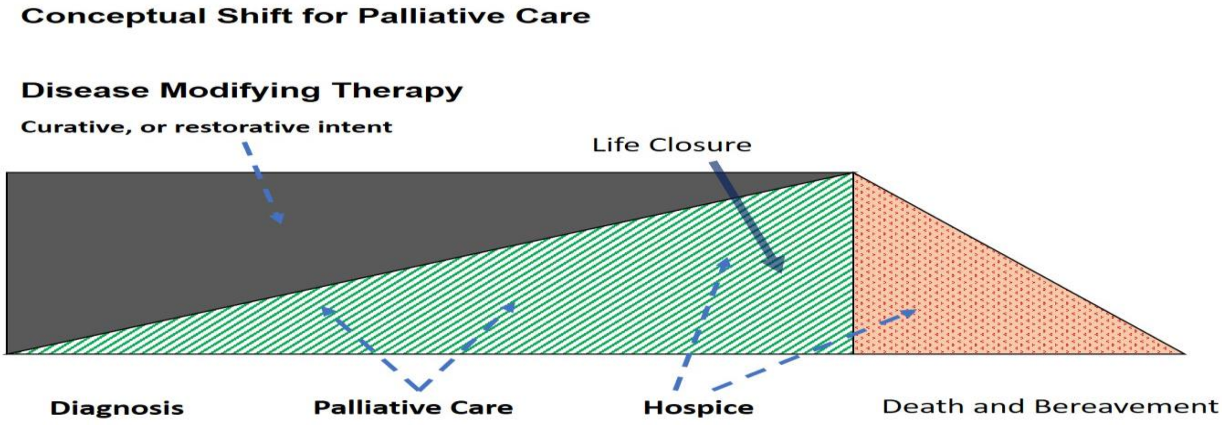

Figure 1: The Concept of Palliative Care Adapted from Meier (2011:346)

The WHO definition of palliative care is a "response to suffering" that includes physical, psychological, social, legal and spiritual domains of care and is provided by an interdisciplinary team of professional and lay health care providers (Reville & Foxwell 2014:129). The table below encapsulates the difference between hospice and palliative care.

Table 2: The differences between palliative care and hospice care

	Palliative care	Hospice care
Eligibility	This care happens at any time during the illness, you do not have to be near death to get this care	Eligible for hospice if physicians believe that you have no more than six months to live
Timing	Begins with the diagnosis of an illness or poor symptom or pain control. If a patient's serious illness becomes terminal with a prognosis of six months or less may be referred to hospice care	During the terminal phase of illness
Location	Provide symptom support and comfort care, concurrently with all other treatment, including curative care and disease-modifying treatments	Focus on comfort without seeking curative or disease-modifying treatment
Purpose	Can be given while the patient is having active treatment (it can be given at the same time as chemotherapy, radiation and immunotherapy)	Hospice care is given when there is no curative treatment being given for the serious illness
Teams	Palliative care teams are separate from the patient's medical team that is giving and managing treatment, but they communicate with the medical team.	The medical team is in charge and coordinates the majority of care of the patient

2.3.3 Global perspective on palliative care

The advances that have been made in medicine worldwide have resulted in the life expectancy increasing, more people are now able to live into their old age and this has led to more deaths being from serious chronic illnesses rather than acute illness (Sawatzky et al 2016:2). This has necessitated the need for high-quality care at the end of life hence the need for palliative care primarily focused on incurable diseases and these services have been delivered by specialist palliative care teams (Sawatzky et al 2016:2). Increasingly, it is being recognised that high-quality end of life care should be an integral part of the care provided for those with life-threatening illnesses who are being cared for in a variety of setting for example in the home, acute care, residential care and even hospitals (Sawatzky et al 2016:3).

Globally, a rise in cancers and other chronic diseases alongside the dreaded HIV/AIDS pandemic has increased the world’s population demand for palliative care services (LaVigne, Gaolebale, Maifale-Mburu, Grover 2018:1). Despite the global population’s demands for palliative care services, it has been reported that only three out of five continents have quality palliative care in place (Cruz-Oliver 2017:110) and these are Americas, Asia-Pacific and Europe (Line 2015:16).

Using the quality of death as a measurement tool, Figure 2 below, shows the ranking by income group across the regions.

The Global Atlas of Palliative Care at the End of Life, published by WHO and the Worldwide Palliative Care Alliance (WPCA), found that almost 80% of the global need for palliative services is in low- and middle-income countries (Opoku 2014: 5). On a global scale, the need for effective palliative care remains unmet. This is mainly because of the 58 million people dying every year (i.e. 45 million in developing countries, 13 million in developed countries). It can be estimated that 60% of them have a life-threatening and prolonged illness and would benefit from the provision of palliative care services (African Palliative Care Association, 2016:5).

On further scrutiny, it can be noted that palliative care services are not yet available to all patients with serious chronic illness, even in a high-resource system such as the United States (Crawley 2018:2). Some developing counties are now catering for cancer patients but only in urban areas with community hospitals and rural areas underserviced and people in those areas being less served and having poor access to specialist palliative care services (Crawley 2018:2).

Some government and global policymakers have concerns regarding the use of opioids and they continue to limit their use and access to these, despite long-standing policy statements and guidelines that highlight the advantages and benefits of relieving physical pain and suffering (Kopf & Patel 2010:10). Many in the low-income countries have fears and myth about opioids use, they choose to focus more on tolerance, dependence and addiction which should normally not prevent appropriate use of opioids (Kopf & Patel 2010:10).

Furthermore, barriers to effective palliative care and pain management have been identified as poor medicine supply systems that hamper the functioning of palliative care services, there is also the issue of unnecessary restrictive legislation and a general fear amongst health professionals on the legal sanctions if opioids are used (Lentsoane, Meyer, Schellack & Cameron 2014:421).

2.3.4 Palliative care in Africa

Africa has seen steady growth in the provision of palliative care services (Rhee, Garralda, Namisango, Luyirika, Lima, Powell, Robinson & Centeno 2018:2). Between 2006 and 2011, a total of 15 countries managed to move to higher levels of palliative care development (Rhee et al 2018:2). However, on the downside, half of the continent in 2011 had no identified palliative care services, as much as there is hope in the provision of palliative care services in Africa, many obstacles are impeding its progress. These include the high disease burden, high morbidity and mortality rates, and the lack of funding and other resources (Rhee et al 2018:2).

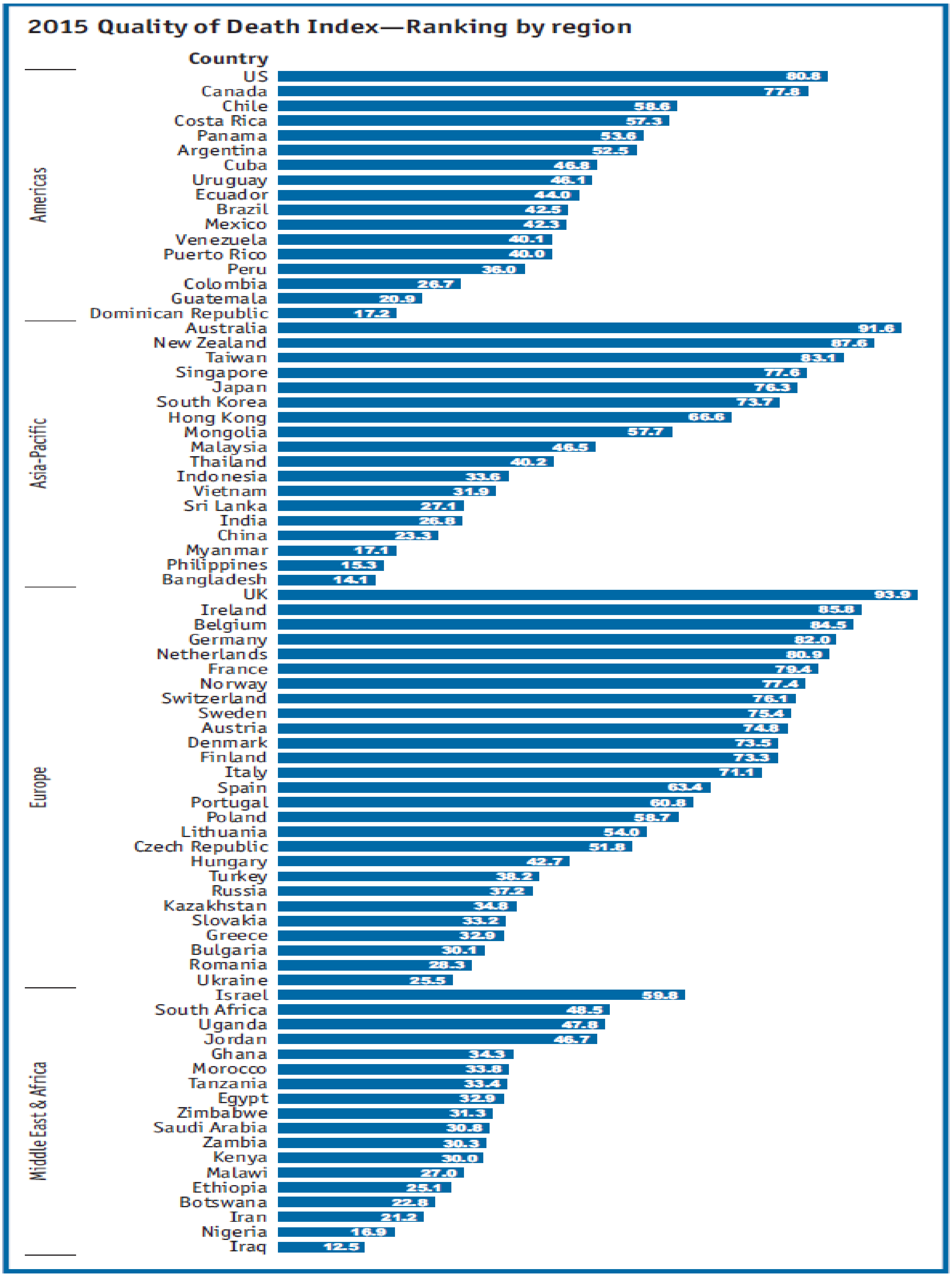

Figure 2: The Quality of Death Index (Adapted from the Economist Intelligence Unit 2015:18)

It can also be noted that indicators for palliative care development are unable to present the rich background of the cultural diversity, challenges and historical achievements of counties in Africa, for example, South Africa is held highly in terms of the development of palliative care programmes, it is ranked first in Africa but it did not have a standalone policy on Palliative care until 2011 whereas Mozambique did, despite not even being listed among those with palliative care programmes (Rhee et al 2018:2).

A lack of enough training for health professionals in developing countries both before and after they begin practice can be attributed as a major challenge to the widespread provision of palliative care services (African Palliative Care Association, 2012). There is a need for a systematic training programme for health professionals in the delivery of palliative care services, this training must be adapted to the care context, which in many regions, will be provided predominantly by volunteers working alone or with health professionals (African Palliative Care Association, 2012). It should also take into consideration local implementation challenges and potential solutions (African Palliative Care Association, 2012).

Studies from researchers on palliative care in sub-Saharan Africa bring to light numerous factors hampering the development of palliative care (Opoku 2014: 5). Key among these factors include little insight on palliative care (education), medical unavailability, financial, psychological, social and religious barriers (Opoku 2014: 5).

In addition to the burden of HIV, cancer and other non-communicable diseases are becoming urgent public health issues in Africa (O'Brien, Jenkins, Munnings, Grey, North, Schumann, De Klerk-Green, 2019:2). The constraints on the resources and infrastructure deficits mean that governments struggle to meet the burden of diseases which means survival rates are significantly poorer than those in developed countries and patient expectations for curative oncological treatment are low (Selman et al 2010:25). The situation is likely to worsen as the population ages, the number of people in Africa over 60 years old is projected to quadruple by 2050, with the lifetime risk of cancers and other incurable diseases expected to increase by 50–60%, and the annual number of cases to rise from 650, 000 to 2.2 million (Selman et al 2010:25).

There is a marked difference in Africa from the rest of the world when it comes to delivery of palliative care services, mainly due to the burden of specific diseases such as HIV/AIDS which predominates Africa and other malignant diseases and tuberculosis (WHPCA 2014; WHO 2014). In addition, Africa hosts the majority of children globally who need palliative care services, the balance in need of other different types of palliative care services are different from what their equivalent require in the rest of the world (Centeno & Rhee 2018:18)

The first hospice in Africa was started in Zimbabwe in 1979 and since then there has been significant growth in palliative care in Africa which accounts for most of the growth in palliative care globally from the year 2006 to 2011(Centeno &Rhee 2018:19). Topping the list of the countries with the most hospices and palliative care services are South Africa, Uganda and Kenya (Centeno &Rhee 2018:19)

It can be noted that the access of palliative care services in Africa is hindered by several factors such as the unavailability of pain medications (such as morphine and other opioids), a lack of treatment options, the exorbitant funds required to set up palliative care services in a hospital, lack of clinical guidelines for palliative care services and cultural beliefs that do not see the benefit of palliative care (Poudel, Shrestha & Nissen 2019:3).

In most African countries palliative care is not incorporated into the health care system except for a few exceptions (Poudel et al 2019:3), what this means is there is no budgetary allocation from the Governments. This lack of public funds for palliative care means the burden of care is left to the family which causes huge spending in health which leads to potentially catalysing poverty (Poudel et al 2019:3). Palliative care services need to be addressed at the same time with efforts geared towards the elimination of poverty so that they can also get support from global funders (Poudel et al 2019:4).

Home-based care models are common in-service provision in palliative care settings in many countries in sub-Saharan Africa, these are also divorced from the mainstream health care services and they centre around trained health practitioners and are more community based, run by volunteers and family carers who do not adhere to the

WHO's model of palliative care development (African Palliative Care Association 2015:6).

2.3.5 Palliative care in South Africa

South Africa boasts a strong palliative care community, though initially, it focussed on cancer only, the community managed to mobilise a response to the growing HIV pandemic in the 1990s providing critical services to adults dying of HIV (National Policy Framework and Strategy on Palliative Care 2017-2022). Palliative care services were started in the early 1980s and mainly provided by non-governmental (NGOs) who were caring for AIDS and cancer patients (Obrien et al 2019:2). The National Hospice and Palliative Care Association (HPCA) started in 1986 which oversees and supports more than 150 000 people with life-limiting conditions annually. It manages to service around 40% of those in need of palliative care. In 2015, at number 34 in the world, South Africa was the highest ranked African country on The Economist's 'Quality of Death Index'. O'Brien, et al (2019:2) assert that this a reflection that all hope is not lost for palliative care services in Africa.

Figure 3 below shows the most common life-threatening illness in the world afflicting most palliative care users.

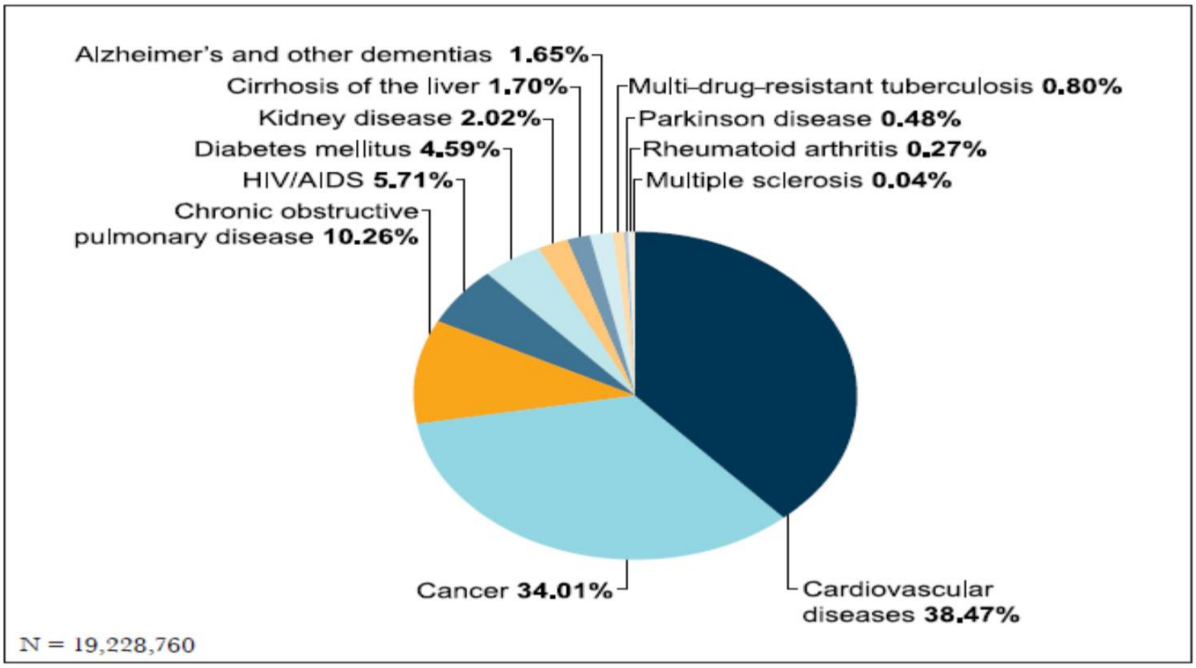

Figure 3: Common life-threatening illnesses in the world (Adapted from Kim & Choi 2017:5)

Even though studies reveal that the world over the most prevalent life-threatening illness is Cardiovascular diseases (38.47%) the situation is different in South Africa where 50% of patients during the period 2003-2004 were diagnosed with HIV/AIDS with the other half diagnosed with cancer (Drenth et al 2018: S171).

The growing HIV/AIDS pandemic has increased the need for palliative care services in South Africa (Lentsoane, et al 2014:421). However, the availability and access to well-resourced palliative care services are limited, in a review of hospices, it was found that only 37 of the 76 hospice and palliative care organisations in South Africa, make provision for in-patient hospice services, which means that the vast majority of patients experience moderate to severe pain during the course of the disease because they do not have access to affordable and effective pain medication (Lentsoane et al 2014:421).

It can be noted that people who have been diagnosed with life-threatening illnesses face many challenges (Stark, Tofthagen, Visovsky & McMillan 2012:16). These include physical symptoms of the disease, as well as pervasive and persistent treatments, irrespective of the type of illness, stage of disease or the type of medical intervention (Stark *et al* 2012:16*)*. The most common symptoms experienced by patients going through treatment are fatigue and pain (Stark *et al* 2012:16). Of these, fatigue is the most common distressing symptom reported as it can interfere with the performance of activities of daily living (Stark *et al* 2012:16). Even though there have been great advances in pain management, pain persists among patients with life-threatening illnesses for example, the pain incidence in cancer patients is estimated to range from 14% to 100 % (Ali & Soliman 2016:26).

Further, it has been reported that patients complain of a reduction in muscle strength, decreased lean body mass, decreased cardiorespiratory capability, lowered bone mass and exhaustion (Ali & Soliman 2016:26). Losses at every level, are also a common occurrence in patients with a life-threatening illness and these range from loss of physical health, independence, jobs and ability to earn an income, status, normal family life, future, motivation and meaning and these losses that the patient suffer are also experienced in parallel by the family (Hickman 2010:48).

The physical symptoms that people have to go through, cause a lot of distress in patients and some seek a hastened death (Schroepfer 2011:358). The motivation for such has been psychosocial factors such as a lack of enjoyment of life, the losses they have to go through, losing one's dignity, and feelings of powerlessness (Schroepfer 2011:358). In some instances, patients report that they have very little and often conflictual social support, in addition to social support needs, individuals also reported anxiety, depression and feelings of being useless (Schroepfer 2011:358). Psychosocial problems was prevalent especially over issues that included logistics, coping with their illness and treatment, and addressing the concerns of their partner and children (Schroepfer 2011:358).

The social workers' role in palliative care will be discussed in the section that follows.

2.4 Social workers' role in palliative care

The tasks of social workers in palliative care include educating the patient and family on end-of-life care, linkage to available resources, referring to other support services, advanced care planning in preparation for disease progression, supportive counselling and assisting with supportive therapies meant to help cope and manage psycho-social symptoms related to end of life transition (Head, Peters, Middleton, Friedman & Guman 2019:17).

Social workers see themselves as partners in the interdisciplinary team, recognising that palliative care is a team effort and its impact is unique in that it results from a combination of skills (Schroepfer 2011:361). It includes every approach that assists patients and families to find their own strength for a journey that is different for each person (Schroepfer, 2011:361).

People with life-threatening illness are faced with many fears that arise from the threat of the disease and it is the duty of the social worker to create a trusting relationship that helps the people to feel safe and be able to disclose and explore them (Hickman 2010:49). The social worker works from a point of neutrality to ensure that a balance is maintained and people feel they are part of the solution rather than being the problem (Hickman 2010:49).

Social workers in palliative care teams are responsible for mediating in solving social problems, planning and provision of supportive counselling (Sadauskas & Benošyte 2016:2). These functions are organized and performed by the social worker in collaboration with the other members of a palliative care team (Sadauskas & Benošyte 2016:2).

According to Watts (2013:200), counselling and providing information is a big part of palliative care social work. The key role in such instances is that of the implementor, organiser, counsellor, dialogue partner, coordinator and team member (Sadauskas & Benošyte 2016:2)

Social workers give attention to financial matters, no effective work can be carried out if patients and families are worried about the loss of income (Smith, et al 2014: e368). Identifying financial needs is essential, particularly with families who must deal with poverty, unemployment and poor housing (Smith et al 2014: e368).

Social workers generalist training in nature means they possess a broad and diverse theoretical based that uses different systems frameworks to assess using different intervention models (Trevithick 2012:8). Social workers can give guidance to individuals and their families with the use of problem-solving techniques (Blackledge 2017:24). Social workers plan different interventions at different stages of challenges because they understand that challenges can occur at different levels for individuals, families and community level (Blackledge 2017:24).

The next section discusses the challenges faced by social workers in palliative care.

2.5 Challenges faced by social workers in palliative care.

In the course of work social workers encounter complicated psychological conditions, that is having to face frequent pain, suffering and death of their patients, it is natural that social workers experience big emotional stress and experiences, as a result of which depression may occur (Sadauskas & Benošyte 2016:8).

Barck-Holst, Nilsonne, Åkerstedt and Hellgren (2019:2), state that the roles of social workers are specific activities, these roles are often problematic, causing major inner conflicts of the person of the social worker, thus social workers experience complex stress both on a personal and professional level as interacting with different systems can elicit emotional, psychological and physical overload and that leads to great stress and concerns.

According to Fink (2015:597), circumstances in palliative care systems often dictate that palliative care is often introduced to people with life-threatening illnesses late in the course of the disease after curative intent has been exhausted, this concern of late referrals is one that is common in palliative care teams, it often leads to suboptimal pain, increased suffering, failure to discuss or adhere to advance care planning and unplanned hospital deaths. To social workers this puts extreme pressure on their interventions, the situation resembles a major crisis and not much can be optimised from interventions, further, the desired outcomes are not achieved and certain preparatory work that is of paramount importance is not undertaken (Fink 2015:597), leaving the social workers questioning the effectiveness of their interventions.

The next section discusses the theoretical framework underpinning the study.

2.6 Theoretical framework

In this section, the theoretical framework underpinning the study will be discussed, particularly in relation to palliative care. For that reason, the researcher opted for the following theoretical work, namely: Strength-based perspective and eco-systems theory. Although other theoretical frameworks may seem relevant to the topic under investigation, the researcher found the above-mentioned theories more appropriate and relevant.

2.6.1 Strength-based perspective

The strengths-based perspective is a model that focuses on strengths, but it does not mean ignoring challenges or converting struggles into strengths, it believes that people do have strengths and resources and that they can put them to use (Gottlieb 2014:24). The focus is thus on the inner (intrinsic) and outer (extrinsic) strengths of the person (Gottlieb 2014:24). Furthermore, a strengths-based approach allows people to identify and build on their strengths so that they can reach their goals and retain or regain independence in their daily lives (Pulla 2017:100). This means that the strength-based perspective assumes that people have the capacity for growth and change even during periods of challenges, crisis and hardships.

According to Saleebey (2009:15), there are six principles inherent in the strength-based perspective. There are as follows: -

i) **Every individual has strengths.**

An absolute belief that every person has potential, and despite facing a life-threatening illness, people dying can still be useful and use their unique strength and capabilities to determine their evolving story as well as define who they are, not their limitations.

ii) **Trauma and abuse, illness and struggle may be injuries, but they may also be sources of challenge and opportunity.**

An absolute belief that every person can turn their limitations into opportunities. People facing life-threatening illnesses may be facing death, but this allows them to maintain healthy and good relationships with family and significant others as they are aware of the limited time they have left. This period may be a trying and painful time but there is an opportunity for everyone to gather and say goodbyes.

iii) **Assume that you do not know the upper limits of your clients' capacity to grow and change and take individual aspirations seriously.**

People frequently are bound by an assessment, diagnosis, or profile that has become a verdict or a sentence in their lives. By holding high expectations of clients and keeping an alliance with their hopes, values, aspirations, and visions, we make an obvious deal with their promise and possibility.

iv) **We best serve clients by collaborating with them.**

The strength-based perspective believes that it is important to value differences and underscores the essential need to collaborate. It acknowledges that effective change is a collaborative, inclusive and participatory process. For people who are facing life-threatening illness, it is important to let them lead the way as this is their journey. With guided support, they can share their pain, stories, hopes and fears without feeling helpless.

v) **Every environment is full of resources.**

The environment can be harsh and challenging but there are always positives or resources that can be found in that environment. When people are faced with life-threatening illnesses, resources that can be utilised are churches, who come in to pray and offer spiritual support, family members who take turns to take the patient for their hospital visits and the community who take turns to provide meals. Those are resources which no external person can bring to a community.

vi) **Caring, caretaking and context.**

The belief that positive change occurs in the context of genuine and authentic relationships underpins the strength-based perspective. This is especially true for people faced with a life-threatening illness who need helpers who care, who will be there unconditionally and who engage with them in their distress with respect and compassion.

When working with people with life-threatening illnesses social workers must know what clients have done, how they have done it, what they learned from their experiences and what resources they used in their struggle to surmount difficulties (Jones-Smith 2013:5). When helping the focus should shift from a person's diagnosis to the strengths that they possess, emphasis on sickness and diagnosis leads to discouragement and people with life-threatening illnesses will feel they are victims of a disease over which they have little control (Jones-Smith 2013:6). Further, the goal of helping should be to empower clients to discover their own individual and family strengths.

It is important when working with people with life-threatening illnesses to keep in mind that adversity, difficulties and suffering all offer the potential for learning and growing (Hughes, Firth & Oliviere 2015:157). Lessons learnt from life experiences will be applied in subsequent situations in future. This will help them build on their resilience and personal control, instead of focussing on failures and inadequacies, which can make a person with a life-threatening illness worse rather than better. Understanding the personal traits and virtues that people possess helps key in helping people with life-threatening illnesses restore some form of control and independence to their lives.

The strength-based perspective also affords the social worker an opportunity to help the patient and their family identify tools they already possess to cope with the life-threatening illness without ignoring the stressors that come with such an illness for the family (Metcalf 2013:14). Because the strength-based perspective focuses primarily on the quality of the relationship between the social worker and those being supported, it guides the social worker on the best methods of intervention to use at each time.

2.6.2 Eco-systems theory

The eco-system systems theory is a model of man and his society and it believes that individuals do not operate in isolation but are influenced by their physical and social environments in which they live and interact (Teater 2014:3). It is concerned with people's interactions in real life and space, and it deals with the whole web of life between system and subsystems of people (Ettekal & Mahoney 2017:2). Similarly, Bridgen (2017:11), explains that the eco-systems system theory is a holistic approach which believes that problems cannot be separated from a person's interactions and relationships. It maintains that any problems are fundamentally systematic in nature.

The eco-systems theory was developed based on the biological science of ecology, which views all living organisms within their social and physical environments and examines the exchanges of people with their environments (Teater 2014:3). One of the earliest references to social work and eco-systems theory goes as far back as the mid-1970s (Walker 2019:3). At that time, the theory was being articulated most notably in works seeking to provide social workers with a unitary model of practice one that could offer a holistic framework within which to place social work practice (Walker 2019:3). Social work as a new profession was evolving and experimenting with ideas from psychology, sociology and social policy to try to find an identity and set of skills based on solid theories Walker 2019:3). As a result, there was a lot of effort expended into creating a professional identity, value base and intellectual framework that could explain what social work was (Connolly & Harms 2011:48). This debate has continued ever since, mediated through changes in society, economic upheavals, population trends, legal and educational developments (Walker 2019:4).

Eco-systems theory offered more than the prevailing reductionist psychological theories that were concerned with behaviour and stimuli and that it could develop sociological theories that would place human behaviour in the context of a desire for equilibrium and maintenance of the social and economic status quo (Walker 2019:5). It was argued that systems theory could happily incorporate the concept of free will as well as self-determination and fit into Marxist-inspired conflict theory (Connolly & Harms al 2011:49).

And for the second half of the century eco-systems theory has helped us gain an appreciation of the multiple perspectives in response to complex needs (Connolly & Harms 2011:48). Eco-systems theory has nevertheless continued to be important to social work thinking and practice as it provides a foundation for much of social work understanding of human adaption and coping in the face of adversity (Connolly & Harms 2011:48).

According to Miley, O'Meila & DuBois (2009:32), the following principles encompass the eco-systems perspective: -

- It presents a dynamic view of human beings as systems interacting in context.
- It emphasises the significance of human systems transactions.
- It traces how human behaviour and interaction develop over time in response to internal and external forces.
- It describes current behaviour as an adaptive fit of "persons in [the] environment".
- It conceptualises all interaction as adaptive or logical in context.
- It reveals multiple options for change within persons and their social and physical environments.

According to Ettekal & Mahoney (2017:3), there are four interrelated types of environmental systems in Bronfenbrenner's classic rendition of ecological systems theory, namely the (1) micro, (2) meso, (3) exo, and (4) macrosystems. These levels range from smaller, proximal settings in which individuals directly interact to larger, distal settings that indirectly influence development.

Figure 4 below shows the various levels within ecological systems theory which are presented graphically as a series of four systems nested around a focal individual like a set of concentric circles.

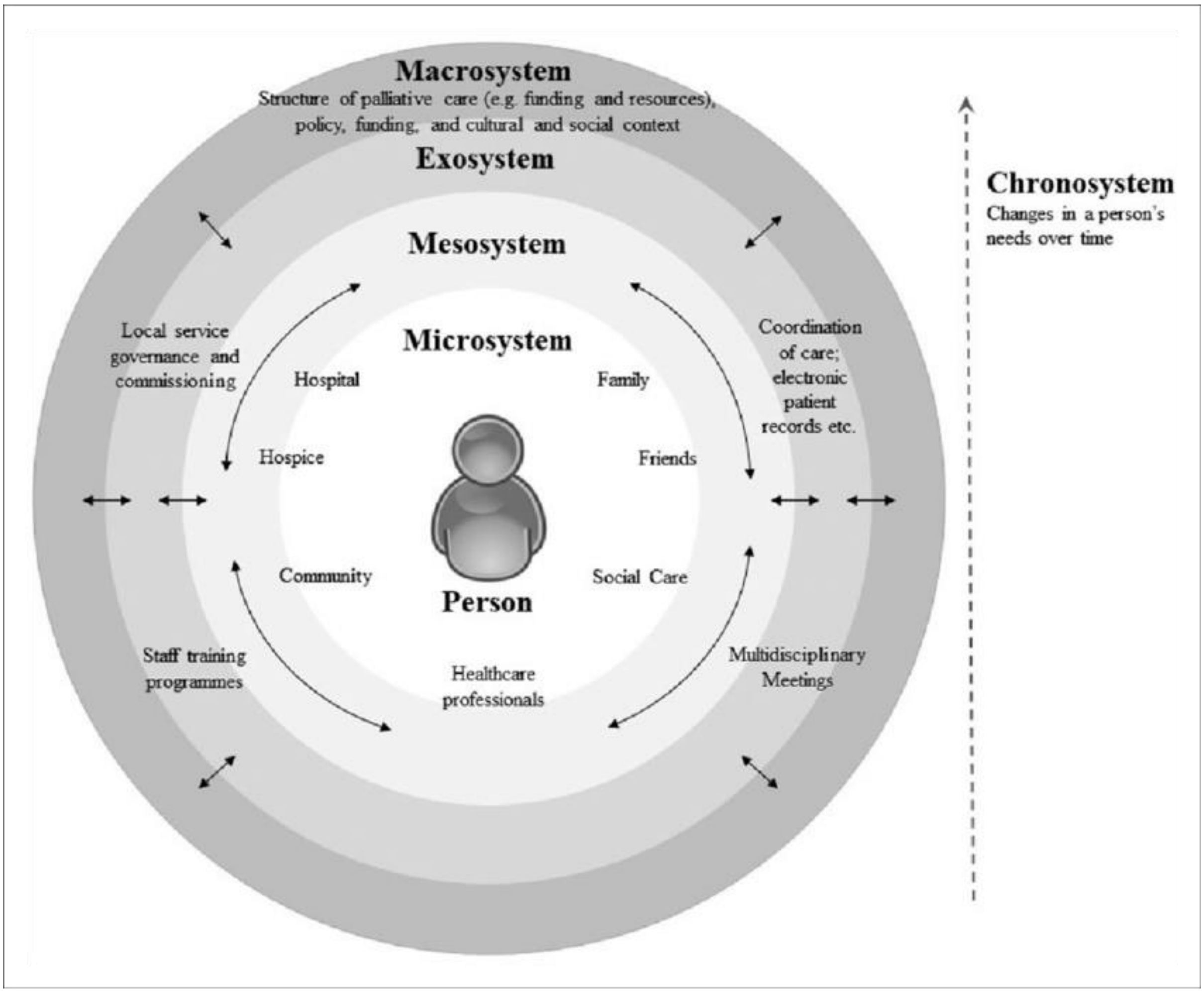

Figure 4: Levels within ecological systems theory (Adapted from Ettekal & Mahoney 2017:3)

The microsystem: the needs of a person faced with a life-threatening illness and their characteristics (Pask, Pinto, Bristowe, van Vliet, Nicholson, Evans, George, Bailey, Davies, Guo, Daveson, Higginson & Murtagh 2018:1082).

The mesosystem: this level represents the interactions between the person, (the main people) their family and health professionals and place of care (e.g. hospice, hospital and community). In palliative care, complexities can arise from interactions the patient has with family, healthcare professionals, spiritual connections and other support elements. However, these complexities can be reduced by strong supportive links (Pask et al 2018:1083).

The exosystem: service and system-level factors. In relation to palliative care, the exosystem comprises services and systems that the person is not directly part of, yet, which influence the care they receive. This refers to how multidisciplinary teams work/are structured (including provision or absence of staff training) and how palliative care is coordinated (Pask et al 2018:1084).

The macrosystem: population and society. The wider community is included in this system. This includes societal, cultural and other values. Within palliative care, the macrosystem includes, the system-wide structure of palliative care (funding), the structure and organisation of health care systems, end-of-life care policies and values in society (stigmas, beliefs and customs). (Pask et al:1084).

The chronosystem refers to changes in a patient's needs, circumstances and environment over time. In palliative care, this often reflects the prevailing uncertainty related to disease trajectory, care, long-term caregiving burden, late referral in non-cancer or shorter disease trajectory (Pask et al 2018:1082).

In other words, the eco-system theory is a system that brings together an individual and the multiple systems around him (Azhar & Bruera 2018:231). Each system has its own purpose and understanding these systems and functions can enable a person to alter and make the most of their system. People with life-threatening illnesses are generally seen as complex with multiple symptoms, psychological, existential and social concerns (Azhar & Bruera 2018:231). All physical illnesses, particularly life-threatening affect the family of the patient and the changed family circumstance, in turn, have an impact upon the physically ill patient, the imminent death presents a crisis and a challenge to the entire system (Azhar & Bruera 2018:231). These complexities in turn influence the models of interventions social workers will employ when working with people with life-threatening illnesses.

Furthermore, the main providers of psychosocial services in Hospice and palliative care settings in the community are social workers (Schroepfer 2011:358). These professionals possess significant knowledge of terminal illnesses, are aware of psychosocial issues that result from having a life-threatening illness and the intervention strategies for addressing such issues (Schroepfer 2011:358). First, the social work profession is distinctive in its use of a person-in-environment approach, which takes note of the reciprocal relationship between the person and his or her environment and how he or she is influenced by interactions with the environment (Schroepfer 2011:358). Social workers view individuals as being dynamically involved with systems in the environment that include family, friends, work, social service organizations, religions, health care, educational, government, and culture, to name a few (Schroepfer, 2011:358).

According to Schroepfer (2011:358), the person in his or her environment is a whole in which the person, the situation is both cause and effect in a complex set of relationships. This means that an assessment includes the person and his or her environment, treatment models are within the context of his or her environment, interactions are aimed at improving the interactions between the person and his or her environment, this approach in palliative care provides the social worker with assessment skills that “reflect a patient’s place in a broader environment of relationships, resources, and copying history available to him as he struggles to integrate his prognosis and meet the demands of treatment. Additionally, this resulting assessment “communicates that the social worker is interested in the patient as a person who has a valued life beyond treatment. Furthermore, it assists in creating and implementing interventions aimed at concurrently strengthening the client’s adaptation to being diagnosed with cancer, as well as strengthening the environment’s responsiveness to that individual’s needs.

2.7 Summary of the chapter

This chapter discussed a literature review concerning the historical perceptive of the hospice movement. It provided an overview of hospice and palliative care and a discussion of the role of social workers in palliative care. The challenges faced by social workers in providing palliative care services were also discussed, and lastly, the theoretical framework underpinning the study was explained.

The next chapter presents the application of the research methodology.

CHAPTER 3: APPLICATION OF RESEARCH METHODOLOGY

3.1 Introduction

This chapter focuses on the research methods that were employed in this study. It gives an overview of the qualitative research methods that were utilised to explore, describe and contextualise the experiences of social workers rendering palliative care services to people faced with life-threatening illnesses in Cape Town. In Chapter 1 of this report, the research plan outlining the research methodology as proposed by the researcher was discussed, and therefore, Chapter three gives an overview of how the research methodology was applied.

The research methodology used in the study is discussed in detail below.

3.2 Research methodology

Research methodology refers to the steps a researcher undertakes to conduct research (Bailey 2018:70). Punch (2016:65) state that the methodology is a description of the methods and data to be collected. Denscombe (2012:93), on the other hand, provides a more comprehensive definition of research methodology which is defined as a description of the specific methods/techniques that have been utilised as the research method, research design, method of data gathering and also the type of data analysis undertaken by the researcher. Therefore, research methodology refers to the specific techniques employed to identify, analyse and process information about a certain topic. In this study, the researcher employed the qualitative research approach which consisted of empirical research and literature study following an explorative, descriptive and contextual research design which will be discussed under section 3.2.

3.3 Research approach

The qualitative research approach is based on the belief that there are multiple realities, it focuses on the views of each participant and participants are regarded as experts while the researcher appreciated what he learns from the participants (Dudley 2011:26). This is further concurred with by Bailey (2018:3), who states that qualitative research uses textual and non-numerical data and uses the evidence of science to explain events, people and matters that are linked to them.

In this study, the researcher made use of semi-structured interviews with the individual participants of the selected sample. The advantage of this type of data-collection technique is that the focus is on the participant and it seeks to promote a culture of active participation by the participant. The researcher gave a voice to the participants in the study, that is social workers who render palliative care services to people faced with life-threatening illnesses. The disadvantage to this type of method is that participants can provide information filtered through their personal views; they can provide information in a designated place rather than in a natural field setting, or the mere presence of the researcher may cause the participants to answer with a bias or influence their responses, they may provide answers that they feel will please the researcher or meet her expectation (Hofisi, Hofisi & Mago 2014:62).

According to Creswell (2009:175), some characteristics of qualitative research are as follows: -

- Qualitative researchers focus on meaning, that is how participants make sense of their lives, their experiences and the world around them.
- The qualitative researcher acts as the primary instrument of data collection and analysis.
- Qualitative research involves fieldwork.
- Qualitative research is explorative by nature.
- Qualitative research is descriptive in that the focal point for the researcher is in the process and in how participants give meaning and understanding gained through visuals or words.
- The qualitative process is inductive, the researcher builds abstracts, hypothesis, theories from the words of the participants.

In this study, the researcher was able to interview social workers who render palliative care services to people faced with life-threatening illnesses in Cape Town. This involved the participants narrating their stories with regards to how they understand the provision of palliative care services because they are in the frontlines on a day-today basis in the provision of these services at organisations that render palliative care services. The researcher listened to the stories from their own perspective as palliative care social workers.

In other words, the researcher managed to listen to the participants’ stories from their point of view as palliative care social workers. Moreover, the researcher was able to acknowledge diversity, political and social identities that many ascribed to and ensured that self-reflection was a continuous activity on her own beliefs, values and perceptions. Therefore, the researcher listened with a non-judgemental attitude and made use of simple, clear and understandable language during the interview process with an aid of the interview guide to direct the questions.

3.4 Research design

Research design provides a link between research questions, empirical data and research conclusions, it is also the plan that has to be followed logically to enable the inquirer to navigate from point a to point b of the study (Blaikie & Priest 2019:33). It is further defined by Gerring (2014:434) as the gathering of evidence to perform a suitable empirical test and may be contrasted with data analysis. Similarly, du Plooy-Cilliers et al (2014:93), define research design as the step by step plans that the researcher adopts so that they can provide answers that are objective, valid, economic and accurate. The research design is the plan, structure and strategy for the investigation aimed at obtaining answers to research questions.

In this study, the researcher applied a qualitative research approach to explore, describe and contextualise the phenomenon under study (Kumar 2011:204). The researcher explored the magnitude of the problem, and systematically explored and described the perspectives of social workers who render palliative care services to people faced with life-threatening illnesses.

The following section discusses in detail the research designs that were used for this study, namely: explorative, descriptive, contextual and phenomenological research designs.

3.4.1 Exploratory research design

According to Punch (2016:67), an exploratory design's main goal is to explain and account for the descriptive information. In other words, it seeks to make complicated things understandable. The aim, therefore, is to find the reasons for things, giving answers as to why and how they are (Punch 2016:67). Furthermore, Denscombe (2012:102), explains that exploratory designs are used to discover new and under-researched topics, to describe and discover new things. Moreover, de Vaus (2013:8), explains that exploratory research is often set out in new areas of inquiry where the aim is to discover the depth of a particular phenomenon, problem or behaviour to generate initial ideas about that phenomenon. They are useful for more persistent phenomena as they are essential when breaking new ground and they are known to yield new insights into a topic of research.

Because little is known about the experiences of social workers providing palliative care services to people faced with life-threatening illnesses this study explored the experiences of social workers rendering palliative care services from the perspectives of social workers providing this service in Cape Town. For that reason, the researcher made use of an exploratory research design to get information from 10 participants about the phenomenon under study. The researcher embarked on this study because the area of social work and palliative care is under-researched, especially in a South African context (McCormick, et al 2010:297).

Therefore, the researcher made use of open-ended questions by using semi-structured interviews guided by an interview guide, to explore the experiences of social workers. According to DeJonckheere and Vaughn (2019 :1), semi-structured interviews allow the researcher to gain a detailed picture of participants beliefs, perceptions of a particular topic at the same time give the researcher and participant flexibility.

3.4.2 Descriptive research design

Descriptive designs assist the researcher to describe the characteristics and relationships of phenomena as accurately as possible (du Plooy-Cilliers et al 2014:75). Similarly, Mc Milan and Schumacher (2010:324), point out that we use descriptive designs to enquire about phenomena where little is known about the subject. They can be used to discover themes in the meaning expressed by participants. Punch (2016:67), explains that descriptive design sets out to collect, organise and summarise information about the matter being studied. This means that they enable researchers to gain a better understanding of the phenomenon under investigation. In addition,

The descriptive research design with the use of semi-structured interviews allowed the participants to describe the experiences of social workers rendering palliative care services to people faced with life-threatening illnesses. In so doing, the participants were able to describe the challenges they are faced with, in the provision of these services, from their own frame of reference and made suggestions on how to overcome such impediments to formulate practice guidelines.

3.4.3 Contextual research design

Context refers to the taking into consideration factors that exist in or around the situation (Mc Milan & Schumacher 2010:320). Furthermore, Babbie (2010:94), explains that when it comes contextual research design, phenomena are studied because of the intrinsic interest that they generate. Additionally, contextual designs aim to produce an extensive description of the phenomenon within the context of the unique setting and domain of the phenomenon (Babbie 2010:94). Maree (2016: 82), concurs that contextual studies emphasise specific events in “naturalistic settings.” Where the settings are uncontrolled, it is real-life situations, sometimes referred to as field settings.

In this study, the researcher used the contextual research design. Babbie (2010:94), emphasise that when contextualising the research design, the phenomena are studied because of their intrinsic interest and because contextual design aims to produce an extensive description of the phenomenon within the context of the unique setting of the domain of the phenomenon. Therefore, the researcher considered the unique context under which the social workers render palliative care services.

The focus of this study therefore was on social workers who render palliative care services to people faced with life-threatening illnesses. Social workers who are employed by organisations that provide palliative care services in Cape Town formed part of the study. Eight participants were interviewed at the participants' respective offices with a specific focus on how they provide palliative care services, whereas two interviews were conducted via video call in adhering to Covid-19 regulations.

3.4.4 Phenomenological research design

A phenomenological design allows the participant to delve into how they understand a particular issue from their own perspective and social realities, it concerns itself in giving answers to "what is it like to have a particular experience? (Maree 2012:83). In addition, Maree (2016: 77), states that all phenomenological research efforts in human sciences are explorations into the structures of the human lifeworld, the lived world as experienced in situations of everyday life and how people relate. Similar sentiments are echoed by Creswell (2014:78), who states that phenomenology refers to an approach to qualitative research that focuses on common themes of a lived experience with particular groups, with the end goal being to get at a description of the nature of the particular phenomenon (Creswell, 2014:79). The researcher was able to construct a universal meaning from the experiences of the social workers rendering palliative care services and arrive at an understanding of these experiences from the perspectives of the participants.

3.5 Population, sampling and sampling methods

In this section, research population, sampling, pilot testing, data collection, methods of data verification ethical considerations and limitations of the study will be introduced.

3.5.1 Research population

The population for a study is the group of people about whom we want to draw conclusions (Babbie 2016:116). A population is further explained as the total sum of all cases that conform to some designated set of criteria (Blaikie & Priest 2019:166). Similar sentiments are echoed by Wiid and Diggines (2013:186), who describe a population as the total number of people within a group from whom we need to gather information. It can be summed up as the larger large collection or group of people whom the focus of the study will be on.

The population for this study consisted of all social workers who render palliative care services to people faced with life-threatening illnesses in Cape Town. Due to time, money and other logistical constraints, the whole population could not be included in the study, and therefore a sample of 10 participants was drawn.

3.5.2 Sampling

Sampling is the process of selecting observations that will be vigorously subjected to examination (Gerring 2012:75). Further, Blaikie and Priest (2019:167) define a sample as a selection of element members of units from a target population and from there, conclusions are drawn about the population. Krathwohl (2009:159), explains that a sample is an economical way of studying a population where cases are taken from a population and ought to represent accurately the variable interests in that population. Sampling is when you make your own choice of who you want to interview. The size of the sample could not be decided beforehand and it should be noted that the sample reached capacity when we reached data saturation. According to Kumar (2011:213), data saturation is a point where one cannot get any new information from participants. Further, Maree (2016:84), state that data saturation is the point where interviews do not bring any information to the surface. Similarly, data saturation is a point when nothing new is being heard in interviews (Sutton and Austin 2015:16).

The researcher understood that data saturation had been reached when the information she received from the participants became repetitive and when no new information came to light. To determine saturation, the researcher identified any gaps in the data by employing a system of continuously analysing the data and deducing themes and subthemes concurrent with the data-collection process. The participants were able to present information that was the same although they were from different metros, which was able to convince the researcher that data saturation had been reached. In relation to the research study, 10 participants were interviewed.

3.5.2.1 Non-probability sampling

The type of sampling method used in this study is non-probability sampling method. Non-probability sampling refers to the case where the probability of including each element of the population in a population is unknown and it is not possible to determine the likelihood of the inclusion of all representative elements of the population into the sample (Maree (2016: 10). Further, Krathwohl (2009:163), state that nonprobability sampling is sampling where the probability of being chosen is not the same for each unit. Additionally, non-probability sampling is very useful and mostly used when there are time and financial constraints, and the entire population is difficult or impossible to access (Maree 2016: 10). Non-probability sampling is sampling that is dependent on the researcher's subjective judgement and it is not random. In this study, non-probability sampling was employed because it enables responses to be obtained faster and more cost-effectively since the sample is known to the researcher. It also enabled the participants to provide answers much more quickly, when compared to participants that are selected randomly and the fact that they are motivated to participate.

3.5.2.2 Purposive Sampling

In this study, the researcher made use of purposive sampling. Purposive sampling is a method used to deal with situations where it may be challenging or impossible to study the whole population (Blaikie & Priest 2019:173). Furthermore, Babbie (2016:187), define purposive sampling as a type of non-probability sampling where the researcher's judgement is used to select units to be observed. Similarly, Krathwohl (2009:171), describes purposive sampling as a method of sampling that relies on the wisdom and judgement of the researcher in choosing the units to be observed. Purposive sampling is when the researcher chooses the best sample that will serve the purpose.

Purposive sampling was used to select the participants, and this enabled the researcher to judge who would present the best information about the phenomenon in order to meet the objectives of the study. The researcher employed purposive sampling as this presented the researcher with accessibility to Social workers employed in organisations that care for people with life-threatening illnesses in the Cape Town Metropole. Further, purposive sampling was suitable because it enabled the researcher to select a sample based on the purpose of the study and knowledge of the population. Purposive sampling was considered because it is flexible and meets multiple needs and interests.

The following criteria were employed for social workers who provide palliative care services to people faced with life-threatening illnesses:

- Social workers based in Cape Town in Western Cape Province, who provide palliative care services to people faced with life-threatening illnesses. The region was accessible, and the researcher could therefore spend more time in conducting the interviews.
- The social workers who had working experience of three years and more in providing palliative care services were deemed to have more practical experience in the challenges and effectiveness of providing palliative care services to people faced with life-threatening illnesses.
- Social workers who were able to converse in English. They were all South African citizens/permanent residents and were familiar with the mandate of palliative care services for people faced with life-threatening illnesses. The interviews were conducted in English and all the social workers were comfortable with this arrangement.
- The social workers who formed part of the study were all registered as such under the Social Service Professions Act (Act 110 of 1978).
- All the social workers who the researcher approached were willing and available to be interviewed.

The section below describes how the pilot test was conducted.

3.6 Pilot testing

Pilot testing is trying out a procedure or instrument to determine problems before it is employed in its intended use (Krathwohl 2009:588). Similar sentiments are echoed by Maree (2012:101) who defines pilot testing as selecting a few interviews and coding the responses to measure the appropriateness of the questions and processes before the actual interviews are done as well as ascertain if there will be problems in the coding process. Furthermore, pilot testing is a process aimed at receiving feedback from an interview conducted with someone who is part of the study and its purpose is to improve the interview process (Bailey 2018:245).

For this study, two social workers were identified to participate in the pilot test. The researcher wrote letters to the organisations providing palliative care services and the participants informing them of the purpose of the study and requested permission to conduct the interviews at their organisation. The researcher also travelled to those participants in the selected organisation and again explained the purpose of the study and reminded them of the consent form they had to sign. The participants gave their consent voluntarily.

As such two interviews were conducted as part of the pilot testing with two social workers in English and the interviewing skills of probing, reflecting, paraphrasing and summarising were used by the researcher to gather information. The researcher was able to build a relationship with the participants. The pilot test enabled the researcher to re-assess her skills in research interviewing with the aim of collecting information. The data that was collected as part of the pilot test was not included in the main research process.

The interviews were conducted at the organisations that render palliative care services where the participants felt more comfortable and relaxed. It was conducted in a safe, private and protected environment devoid of disruptions. Pilot testing assisted the researcher to modify and rephrase the research questions in the interview guide where necessary and this was done in consultation with the supervisor.

3.7 Data collection

Data collection is a technique of collecting evidence from participants and this data is collected using surveys, interviews, ethnography, archival research and non-reactive measures (Gerring 2012:419). According to du Ploy-Cilliers et al (2014:173), data collection enables the researcher to obtain richness and depth of data gathered from complex and multifaceted phenomena in a specific social context. In addition, Leedy and Ormrod (2010:145), explain that data collection includes the thorough, accurate and systematic recording of data, including the jotting down of notes about the researcher observations.

In this research study, the research collected data using semi-structured interviews with the social workers who render palliative care services to people faced with life-threatening illnesses in Cape Town. The methods of data collection expounded in section 3.6.2 of this report. In the following section, the researcher discusses aspects of data collection and the methods employed to collect data.

3.7.1 Preparation for data collection

The researcher made the decision to undertake the study. She identified herself to the participants first and foremost as a researcher (Creswell 2014:188). The Departmental managers/Counselling Service Managers those who are in charge of counselling at various organisations providing palliative care services are referred to as gatekeepers. Gatekeepers regulate access to the various organisations. Gatekeepers are the respective persons at the study site who provide access to the site and allow or give permission for the researcher to conduct their study (Creswell 2014:188). Similarly, Maree (2012:122), states that gatekeepers are the power holders at organisations that need to be approached and who approve a study at a site (Maree 2012:122). Furthermore, Creswell (2013:94), defines gatekeepers as the people with the power to let researchers into the organisations.

In preparation for data collection, the researcher wrote letters, which were sent via electronic mail, to the respective Managers and Head of Departments, who are responsible for counselling at various organisations providing palliative care services in Cape Town, informing them of the study and its purpose. She also requested their permission to conduct interviews with the identified individuals at their organisations (Addendum 1).

The researcher followed this up by writing letters which were sent via electronic mail to the individual participants informing them of the purpose of the study and how they could participate. She explained what would happen when the research was completed and requested participants to volunteer their participation in the study (Addendum 2).

Visits were made by the researcher to the participants to inform them of the study and the participants were requested to complete the consent form once they had agreed to participate in the study. This was done so that the participants would be aware of their importance in the whole process and to dissolve any feelings of superiority they might have towards the researcher, that is to remove the threatening nature of the researcher and be less threatened by the position of the researcher (Addendum 2).

The researcher drafted a consent form for the participants to voluntarily sign if they wished to be provided with debriefing (Addendum 3). The venue, dates and time of the interview were outlined in the letter. The inclusion criteria and purpose of the study were also explained to the participants. The purpose and value of the research findings, and how the results would be disseminated, were also explained to the participants. Issues regarding ethics were also clarified and participants were assured of confidentiality.

While preparing for data collection, the researcher acknowledged her ongoing relationship with participants and the impact and influence this might have on the outcome of the study. The researcher was aware of the possible influence that she might exert in the data-collection process and inspected her relationships with the participants and how the dynamics of these relationships could affect their responses to her questions. Self-reflection was employed on the researcher's powers of observation and amongst others, the methodological aspects of her research and her actions when conducting these interviews. The researcher continuously exercised self-reflection to identify her own bias, different views, experiences in the heavy loss environment, responses to the questions and her position in the palliative care industry.

3.7.2 Methods of data collection

Qualitative research customarily makes use of interviews as a method for data collection and there are different types of interviews namely structured, focus group, participant observation, unstructured and semi-structured interviews (Maree 2012:89). Semi structured interviews were used to collect data in this study. According to Bailey (2018:245), semi-structured interviews are interviews that combine questions that are pre-planned with those that are not, the questions are contained in an interview guide with a focus on the issues or topic areas to be covered and the lines of inquiry to be followed (Holloway & Wheeler 2010:89-90). Similarly, Maree (2016:5), defines semi-structured interviews as interviews that follow a line of inquiry developed by the researcher in advance of the interview and this line of inquiry is followed by further probing and clarification. Summing it up Hofisi et al (2014:62), state that semi-structured interviews combine a list of questions and topics to be covered referred to as an “interview guide” but the questions give the interviewee freedom in answering the questions. Semi-structured interviews are structured interviews guided by an interview guide but offer flexibility for the researcher and interviewee.

The application of the semi-structured interviews helped to keep the discussions focussed on the goal of the study. The formulated requests and open-ended questions corresponded to the overall goal and objectives of the study.

In collecting data, the researcher prepared herself by reading documents relating to the particular organisations, their constitutions, policies, reports, newsletters, and guidelines so that she could have an understanding on the roles and responsibilities of the organisation, the way they operate, their achievements and challenges they encountered in the process of rendering services to people faced with life-threatening illnesses as well as their highlights and best practices. During the interview sessions, the researcher made use of interview techniques such as paraphrasing, clarification, and probing to ensure an effective interview (Louw 2011:71). The interviews were conducted after the process of the research had been explained once again to each participant. The participants were informed of the benefits of being part of the research, as they would be assisting in providing recommendations that would be applied to improve the rendering of palliative care services to people faced with life-threatening illnesses.

During the interviews, the researcher observed the participants’ verbal and non-verbal communication. All the interviews were conducted in English and each interview lasted between 45 minutes and 60 minutes and this allowed the participants time to share more of their experiences, challenges they encounter and suggestions they had in offering palliative care services to people faced with life-threatening illnesses. The researcher used an audio recorder to record the interviews after permission had been granted by the participants. The participants were informed on the need to record the interviews and it was explained that the purpose of the audio recording was to complement what the researcher had been writing and the recording will assist her in during the process of transcribing the exact words that were spoken by the participants. The ethical considerations, confidentiality and the storage of the tape recordings were explained. Participants were informed that tape recordings would be placed in a lockable cabinet at the researcher’s home. When the research had been approved the tape recordings would be destroyed.

Eight of the interviews were conducted in the offices and board rooms at the respective organisations and two interviews were conducted via video call due to Covid-19 pandemic. All precautionary measures for COVID-19 -19 were adhered to by both researcher and participant. The researcher ensured that the required social distancing was observed, the participant ensured that the room was well ventilated and masks were worn at all times during the interview.

3.7.3 The role of the researcher

The authority of the researcher refers to the knowledge the researcher possesses and the number of years she has been working in the field of the phenomenon under study (Creswell 2009: 181). According to Creswell (2014:237), qualitative research is interpretative in nature, the inquirer is typically involved in a sustained and intensive experience with the participants. The same is summed up by Pandey and Patnaik (2014:5752), who also argue the background and position of the researcher will affect what they choose to investigate, the areas of interests, the techniques they choose to employ, the findings they deem most appropriate as well as how they will frame and communicate their conclusions.

The researcher used the following interviewing skills to collect data from social workers: -

3.7.3.1 Building rapport

Building rapport is defined as establishing comfortable interactions with participants (McGrath, Palmgren & Liljedahl 2019:1003). Further Prior (2017:3), state that building rapport is the sense of requiring a pleasant attitude on the part of the researcher more so creating closeness between interviewees and researcher (Prior 2017:3). Similarly, Zakaria and Musta’amal (2014:3), concur that rapport is aiming to have a good relationship with your participants which helps with getting rich data while at the same time ensuring respect. Rapport is the art of listening attentively and engaging with your participants in a pleasant and non-threatening manner.

A good rapport was established with the participants and a positive atmosphere, conducive to trust and cooperation was created. The researcher was authentic and open at all times. She described the importance of conducting the research and how their participation was of paramount importance. This assisted in dispelling any preconceived notions participants had about research and lessened anxiety and participants felt comfortable and they were able to speak openly and freely regarding their experiences in rendering palliative care services to people faced with life-threatening illnesses. A summary of the research project was drafted in simple easy to understand terms and sent to participants before the interviews as a way of giving them information about what to expect in the interview and why it was important for the topic to be studied.

3.7.3.2 Asking relevant questions

Asking relevant questions will allow the researcher to elicit responses that will allow the researcher to explore issues brought forward by the interviewee (McGrath et al 2019:1003). Further, when relevant questions are asked it guides the researcher and directs the type of search for the information needed, how the information should be collected and the definition of the corpus data (de Souza, de Souza & Costa 2016:7). Similarly, Fox (2009:18), concurs that asking relevant questions is important because it helps to keep your interview focused on the research questions and It helps to avoid being side-tracked (Fox 2009:18). Asking relevant questions acts as a road map in research, to avoid being swayed, side-tracking, and getting lost.

The researcher was guided by the interview guide when asking relevant questions. She also added more questions after reviewing the interview guide and from the feedback she got from the pilot study conducted. The researcher asked brief and easy to understand open-ended questions. The interviews started with easy-going questions so that the participants could relax and be comfortable. Then at the end, the researcher would ask, “Is there anything else?” to continue the comfortable environment created at the beginning. In some instances the participants did continue on matters they felt had left out.

3.7.3.3 Showing empathy

Empathy has been described as offering situational understanding from another's perspective (Baker 2017:78). Additionally, empathy involves sharing the perceived emotion of another or feeling with another (Prior 2017:6). Josselson (2013:80) describe empathy as the process of entering the world of another and trying to understand how it looks and feels from the participants' point of view (Josselson 2013:80). Empathy means understanding the perspectives and experiences of others experiencing first-hand what it's like to be the person you wish to understand.

The participants were encouraged to retell their experiences from their own frame of reference and the researcher maintained and assured them that they would not be judged in any way.

3.7.3.4 Listening

Listening is the act of paying attention to someone to hear and understand what they are saying (Yin, 2011:26). Further, Josselson (2013:66), state that listening is an important component to successful interviewing and involves attending to all aspects that include, verbal and non-verbal cues that may supplement the interviewee's verbal responses. Similarly, Louw (2011:3), describe listening as an activity of listening with a purpose. Listening is giving your undivided attention while someone speaks, at the same time noting their non-verbal cues and using this to make meaning of their words.

The researcher listened attentively to the words spoken by the participants and a recorder was used to record the interviews. Moreover, the researcher paid attention to their verbal and non-verbal communication to understand their experiential world.

The process of data analysis commenced as soon as data had been collected and it is expounded in the next section.

3.7.4 Methods of data analysis

Data analysis is the process of transforming data in ways that lead to substantive meaning (Bailey 2018: 243). On the other hand, Denscombe (2012:99), states that data analysis brings order, structure and meaning to the mass of data. Additionally, Creswell (2014:258), points out that data analysis is the process of identifying and describing patterns and themes from the perspective of the participants then trying to understand the meanings of the patterns and themes.

The researcher made use of Tesch’s eight steps for qualitative data analysis as cited in Creswell (2014:248) to analyse data which entailed the following: -

- The researcher had to get a sense of the whole by going through the transcripts meticulously, aided by notes that were jotted down on the margins for some ideas as they came to mind concerning the topic.
- The researcher chose the transcript on top of the transcribed interviews, read through the transcript with questions on what he was reading. The process involved thinking about the hidden meaning rather than the substance of the information.
- The researcher repeated the process until a list of themes or topics was acquired. The themes were then grouped into clusters that had labels major theme, sub-theme and excess.
- The researcher revisited the interviews with the list and abbreviations for each topic were made using codes and these codes were written alongside the text. This enabled the researcher to see the emergence of new categories and codes.
- The researcher looked for the most descriptive words and turned them into categories. In the process researcher aimed to reduce the categories by group similar topics together. The researcher drew lines between categories to show interconnectedness.
- The researcher made a final decision on the abbreviations for each category and these were alphabetized.
- Data that belonged to each category was assembled in one place preliminary data analysis was performed.
- Methods of data verification were applied (this is discussed under section 3.7)
- The utilized codes and the descriptions from the textual data were taken as a source of evidence to justify the nominated themes. The report of the results was then presented in a descriptive and narrative form.

The researcher proceeded to transcribe and code the data into themes to identify common elements and well as unique themes. The transcribed interviews were checked again with the taped interviews and comparison was made with the field notes to ensure that data had correctly been transcribed.

The researcher went through the interviews to try and understand the meanings behind the information that was provided. This process enabled the researcher to identify common themes and patterns that emerged. This was done to all transcripts until a point where the researcher was able to formulate a clear and complete picture of the data. Themes were then summarised into a condensed form and similar themes were grouped. It was from these themes that the researcher formulated sub-themes and categories. These findings are presented and discussed in Chapter 4.

3.8 Data verification

Data verification involves the processes of checking, confirming, making sure and being certain (Spiers 2015:17). It is a mechanism that is inbuilt to prevent errors before they are locked into the developing model where they may subvert the analysis (Spiers 2015:17). Further, Carlson (2010:1103), state that data verification refers to the techniques that are employed by researchers to increase the trustworthiness of the research they conduct. They determine how much trust can be given that the researcher did everything possible to ensure data was appropriately and ethically collected, analysed and reported. Similarly, Lietz & Zays (2010:191), explain that data verification is a process where different types of data are checked if they are accurate and consistent after data migration had taken place, the goal being to determine whether data were accurately translated when transferred from one source to another, whether the data were complete and support processes reflected in the new system.

Guba’s model states that the four criteria that should be followed by researchers in pursuit of a trustworthy study are, credibility, transferability, dependability, and confirmability (Maree 2016:123). Researchers need to establish trustworthiness in a study in order to validate the research findings and conclusions. In this study, Lincoln and Guba’s model (Maree 2016:123) for ensuring the trustworthiness of qualitative data was applied in relation to the following five aspects:

3.8.1 Truth value (credibility)

The truth value refers to the credibility of data and includes factors such as the significance of results and their credibility for participants and readers (Maree 2012:140). Credibility, therefore, corresponds to the concept of internal validity, since it seeks to convince that the findings depict the truth of the reality under study and that they make sense (Bless & Achola 2013:236). Similarly, Glaser & Strauss in Corbin & Straus (2015:345), used the term credibility, to mean is it believable or is it rather valid? In other words, can we believe the findings as a true reflection of the experiences of the participants in the study? Data needs to be rich and representative of the participants for it to be credible.

During the collection of data the researcher used an audio tape recorder to record the interviews, she also observed the reactions of the participants during the interview process and made notes based on their responses. After data collection, the researcher proceeded to transcribe the recorded information gathered from the individual participants and made comparisons of the transcripts with her notes to determine and verify the credibility of the data.

3.8.2 Applicability (transferability)

Applicability refers to the extent to which results apply to other similar situations. It requires that the researcher provides detailed descriptions of the context in which the data was collected, of the researcher as a person and the relationships formed with the participants (Bless & Achola 2013:238). Further, Maree (2012:141), explains that applicability in research refers to the extent to which the study results can be “exported” and generalised to other contexts. Additionally, applicability is explained as the degree to which the findings can be applied to other contexts, settings, or groups and this is established through a strategy of transferability (Kumar 2011:181). For transferability to be achieved, the researcher must provide a dense description of the research methodology used and how the research methodology was proven to be best applicable in other similar or related contexts that were not part of the study (Kumar 2011:181).

The researcher was able to assess the usefulness of the collected data which could contribute to the development of knowledge about the experiences of social workers rendering palliative care services to people faced with life-threatening illnesses

3.8.3 Consistency (dependability)

Consistency can be described as the stability and consistency of the research process and techniques over time and influences the degree of control in research (Maree 2012:140). It answers the questions “can we obtain the same results if we could observe the same thing twice? (Kumar 2011:181). Similarly, Bless and Achola (2013:238), describe ‘consistency’ as a concept similar to reliability, though different Consistency demands that the study must thoroughly describe, precisely follow a clear and thoughtful strategy. Further, when a researcher precisely describes the way how data was collected, recorded, coded and analysed and has good examples to illustrate this process, one will start to trust that the results are dependable (Bless and Achola 2013:238).

The process of consistency in this study was established through a strategy of dependability by using an independent coder. The role of the coder entailed analysing and coding of 10 transcripts and compiling a report consisting of the themes, sub-themes and concomitant storylines from the interviews. The researcher and the independent coder independently coded the data followed by a discussion between them after which the themes, subthemes, and categories to be presented as research findings were discussed with the supervisor.

3.8.4 Neutrality (confirmability)

When research findings are found to be neutral, fair and free from bias and are divorced from the researcher’s perception, their background, position, conditioning and circumstances then neutrality has been achieved (Maree 2012:141). Bless and Achola (2013:238), point out that the process of neutrality requires that other researchers or observers be able to obtain similar findings by following the same research process in a similar context. This is summed up by Kumar (2011:181), who concurs that neutrality is the degree to which the results could be seconded or corroborated by others.

The researcher took all possible steps to ensure that her own beliefs and opinions did not sway or influence the outcomes of the interviews or the study. All the interviews were audio tape-recorded and audio recordings were immediately transcribed after each interview. The researcher jotted down notes and the notes enabled the researcher to later substantiate the information garnered from the participants during the analysis process.

3.8.5 Peer examination

Peer examination is the process of evaluating scientific work by other experts and these provide feedback and make recommendations on whether the work is suitable (Koshy, Fowler, Gundogan, Agha 2017:1). Trietsch (2019:3), state that it is the process of verifying a research paper by other experts in the field, they check for mistakes potential problems and gaps in the research. Similarly, Kelly, Sadeghieh & Adeli (2014:1), concur that it is the process of subjecting one's research work to the scrutiny of others who may be experts in that field. Peer examination is the evaluation of the quality of one's research by colleagues in the field.

The researcher was able to solicit input from her colleagues who were well-versed in qualitative research and who could lend veracity to the study by asking questions, generally shedding light on aspects of the research and making suggestions. The researcher also had her supervisor, an expert in qualitative research as study leader. The researcher acknowledged the role of the Supervisor as someone who would not interfere with the data collection promise or compromise the integrity of the data collected or influence the research findings.

The tape recordings and the transcripts were handed over to a colleague to identify any discrepancies and to verify accuracy in the recordings. The transcripts were sent to the supervisor for input and guidance.

3.8.6 Reflexivity

Reflexivity can be defined as an ongoing process of looking at our own beliefs, underlying perceptions and knowledge as we interact with other and talk experiences in research (Haynes 2012:1). Further, it is described as a process that concerns itself with the effect of the person of the researcher on the research (Attia and Edge 2017:35). Similarly, Barrett, Kajamaa & Johnston (2020:10), concur that reflexivity is when the researcher engages with and spells out the place of the research and the context of the research. Reflexivity is the examination of one's beliefs and practices that may influence the research.

The researcher practised reflexivity through the use of a field journal and this was to ensure that the researcher's background, perceptions and interests did not influence the reliability of the data. The researcher also embarked on a self-reflective exercise to check her pre-conceptions of the research.

The researcher assumed an objective position since she had worked with some of the participants when she was employed as a Hospice Social Worker. The researcher reflected on the nature of her involvement in the study process and the way it could shape its outcome. The researcher applied reflexivity throughout the research process and any questions that arose that had an impact on the research were clarified and this the researcher did in their capacity as a researcher and not as a colleague.

3.8.7 Authority of the researcher

The authority of the researcher refers to the position of privilege the researcher occupies because of their expert knowledge of the subject under study (Raheim, Magnussen, Sekse, Lunderm, Jacobsen & Blystad 2016:1). Further, Johnson (2017:41), state that the authority of the researcher refers to the researcher's personal, educational, and professional experiences that inform their viewpoints on a host of issues and problems. The authority of the researcher is the researcher's knowledge and experience in working in the field of the phenomena under study. The researcher is a social worker who used to work as a Hospice social worker for a Hospice. She has an extensive network of relationships with the professionals in the palliative care field. The researcher throughout the study employed a process of self-reflection and was aware of her authority and knowledge about the topic at hand and she remained objective throughout the process of conducting her research by remaining honest and exercising ethical maturity.

3.9 Ethical considerations

Ethics are rules and guidelines that must be followed when conducting research (Bailey 2018: 18). This is echoed by (Blaikie & Priest 2019:52), who explains that ethics are the accepted principles and practices that researchers are required to adopt in the design, conduct and use of their research. Arguably, research ethics refers to the study of what is good, what is right or virtuous courses of action in research (Punch 2016:430).

The researcher should at all times endeavour to establish supportive, respectful relationships with the participants without being judgemental or stereotyping them because it will be the voices of the participants that will be represented in the final study. Ethical approval for the study was granted by the Department of Research and Ethics Committee from the University of South Africa (Addendum 9).

The following ethical considerations were considered to ensure that the researcher remained ethical in her conduct at all times: -

3.9.1 Informed consent

Informed consent is a norm in which participants in a study base their voluntary participation in research projects on a point of having fully understood the possible risks involved (Babbie 2016:64). An example is in medical experiments where prospective participants are provided with information about the experiment and all the possible risks. Similarly, Bailey (2018:18), states that informed consent refers to the permission that research participants give when they are fully informed about the nature of the research and their voluntary role in it. Participants must be told, informed about the research and give their approval that is consent before they can be included in the research. Further, Denscombe (2012:128), defines informed consent participating voluntarily and no force, coercion, moral blackmail, or other means of putting pressure on someone to take part in research against their will.

The researcher drafted the consent form, which the participants voluntarily signed without coercion. The form included information on the purpose of the study, duration of the study and what the role of participants in the study would be, also what would happen to the research results and the benefits of the study to the participants. All administrative work about the research was done from the researcher’s home. This included making telephone calls, checking electronic mail. The researcher sent an explanatory letter (Addendum 1) to the identified organisations and presented an outline of the research.

The participants completed and signed the consent forms and voluntarily consented to participate in the study (Addendum 2). They clearly understood the objectives of the study. The researcher was able to travel to eight organisations (with the exceptions of two participants that were video called), where the interviews were conducted and where the participants felt more comfortable and relaxed in a safe, protected and private environment, with limited disruptions.

3.9.2 Confidentiality

Confidentiality refers to the researcher’s assent to handle, put away and share research data to ensure that what has been obtained from and about participants is not inappropriately divulged (Dudley 2011:430). Further, du Plooy et al (2014:267), state that confidentiality is the process of removing or making advancement to data of any personal, identifying information provided by participants, this is in circumstances in which the researcher knows the names of the participants but promises not to disclose the names to anyone outside the research (Dudley 2011:430). Similar sentiments are echoed by Krathwohl (2009: 213), that confidentiality also includes controlling access to the participants’ information.

A confidentiality clause was drafted by the researcher as part of the consent form, explaining to the respondents the aspect of confidentiality and the duration of the interviews. The researcher also informed the participants that their personal details would be kept in a private lockable cabinet at the researcher’s home and would not under any circumstances be revealed to other people. The researcher informed the participants that the final report and research results would be handed over to the supervisor. The researcher kept the participants’ records anonymous by coding them, using the letters of the alphabet (A - J).

3.9.3 Compensation

Babbie (2013; 2009) argues that in some research, it is fairly common practice to pay experimental and focus group subjects for their participation. This compensation can be in the form of gift certificates, contributions to charities, and other gifts. Creswell (2014; 2010) emphasises that the researcher must endeavour to avoid the exploitation of participants. There should be reciprocation and participants should be commended for their involvement in the study.

Letters of appreciation were sent to all the participants who participated in the study for their contributions and willingness to avail themselves (Addendum 6). The researcher remained conscious and mindful her influence in the whole process as well as her position in this respect. The researcher’s position was that of researcher and social worker during the research process.

3.9.4 Debriefing of participants

According to Babbie (2010:97), debriefing affords the participants an opportunity to learn about their experience of participating in the project, this is especially important if there has been harmed in any way due to that participation. Similarly, Kumar (2011:221), states that that debriefing is the process that ensures that the involvement of participants does not cause harm and if it does, the researcher must ensure that the risk is minimal and where necessary addressed through intervention or counselling. This is summed up by Creswell (2014:139), that it is the responsibility of the researcher to anticipate the possibility of harmful, intimate information being disclosed during the data-collection process.

The researcher had made provisions that debriefing would be conducted immediately after each interview if there was a need and where necessary the researcher would refer participants to an identified social worker for further debriefing. Two social workers were on standby in case the need arose. This was a critical aspect of the study since all the participants were social workers who care for people with life-threatening illnesses, who face challenges associated with helping people facing their mortality daily. There always is, a possibility that research questions and the process of disclosing information during data collection could resurrect memories of the experiences and challenges they face daily and these could also negatively affect the social worker. However, despite this having been made clear to the participants, none of them needed debriefing or counselling services.

3.9.5 Management of information

The management of information can be defined as collecting and managing information from different sources and the distribution of that information to one or more audiences this sometimes involves those who have an interest in it or a right to that information (Kumar 2011:221). Further, Creswell (2014:139), states that the management of information means the organisation and control over the structure, processing and delivery of information. Babbie (2010:101) concurs that the process of data management is designed to arrange, classify and file data materials to make them easily accessible and duplicable.

The researcher ensured that the process of data collection was properly and ethically carried out. The data collected were coded and kept strictly confidential. The researcher kept all transcripts without any identifying information, these were made available to the independent coder and research supervisor with the sole purpose of seeking assistance and guidance. The audiotapes were given codes to conceal any identifying information and these were stored in a locked cabinet at the researcher's home and only the researcher had access. When the research is completed and approved, the audiotapes and other confidential information will be destroyed.

3.10 Limitations of the study

There were several limitations with the sample that could have influenced the study. The fact that all participants were female social workers created an imbalance in terms of gender as social work is a female-dominated profession and very few male participants were available. This study was conducted only in Western Cape Province and as such a relatively small sample was taken which means that the findings could not be generalised. As this study was explorative and descriptive, further research is needed to verify the findings.

3.11 Summary of the chapter

This chapter addressed the research methodology and its application to the study. It also focused on the research method and the sampling procedures that were followed in the study. Further, this chapter provided details regarding the data-collection method employed in the study. It also discussed extensively the research methods used and lastly limitations of the study is presented.

CHAPTER 4: PRESENTATION AND DISCUSSION OF THE RESEARCH FINDINGS

4.1 Introduction

This chapter presents the research findings of the study about the experiences of social workers in rendering palliative care services and suggestions for social work practice. These research findings emerged from the process of data collection and analysis with the participants', namely, social workers and are presented, discussed, and compared with the existing literature related to the topic of the study.

This study followed a qualitative research approach and the goal of the study as discussed in Chapter 1 (section 1.4.1) was to develop an in-depth understanding of the experiences of social workers in rendering palliative care services and suggestions for social work practice in Cape Town, Western Cape. Thus, the objectives of this research study as discussed in Chapter 1 (section 1.4.2) were to explore, describe, and conceptualise the experiences of the social workers and suggestions that could enhance the provision of palliative care services to people faced with terminal illnesses. It worth noting that there was a consensus discussion on the research findings between the researcher, the independent coder and the supervisor/promoter.

4.2 Profile of the participants

The following are the specific characteristics of the respondents that were extrapolated during the study and will be outlined in Table 3 below. The profiling of participants is done to give clarity to the data collected. This is an essential part of the study as the participants' backgrounds and personal experiences affect how the participants respond to the research questions from their perspectives and context.

For this study, the researcher conducted ten semi-structured interviews with individual participants and eight of these interviews were conducted face to face and the last two were conducted virtually in adherence to the national lockdown and Covid-19 regulations. It should be noted that all ten participants were registered with the South African Council for Social Service Professionals (SACSSP). Participants were all female between the ages of 29 and 65. Three are in private practice and seven are employed by different organisations including Hospices that are non-governmental organisations as well as privately owned medical facilities providing oncology services to people faced with life-threatening illnesses. All the participants have between three and thirty years of working experience (Table 3).

Table 1: Biographical information of the participants

Participant (pseudonyms)	Age	Gender	Language	Race	Organisation	Work Experience
A	46	Female	English	White	Cancer Care	20
B	51	Female	English	Coloured	Drakenstein Hospice	13
C	65	Female	English	White	Private Practice	30
D	37	Female	English	White	Helderberg Hospice	12
E	42	Female	English	Coloured	Helderberg Hospice	5
F	29	Female	English	White	Netcare Haemalife	3
G	53	Female	English	White	Hermanus Oncology	27
H	50	Female	English	White	Overstrand Hospice	8
I	33	Female	English	White	Private Practice	9
J	45	Female	English	Black	Private Practice	12

The section below discusses the biographical information of the participants.

4.2.1 Race of the participants

The participants were from three different racial groups: namely white (seven), two were coloured (referring to the South African classification of people from mixed backgrounds) and black (one).

4.2.2 Years of experience as a social worker

Three of the participants work in private practice providing grief and bereavement counselling. On the other hand, four of the participants work as hospice palliative social workers and three of them work at private oncology facilities. Years of experience ranged from three to 30 years.

4.2.3 Gender of the participants

All ten participants were female social workers who provided palliative care services to people faced with life-threatening illnesses. Only the female social workers were available and willing to take part in this study.

4.2.4 Age of the participants

The participants' ages ranged between 29 and 65 years and seven of the participants were between the age of 40 and 65, while three where between the ages of 29 and 37.

4.2.5 Home language

All participants were comfortable to be interviewed in English. Five of the participants' home language was Afrikaans. This is attributed to the geographical location of the participants which is in Cape Town in the Western Cape where Afrikaans is a home language to 35.7%.

4.3 Discussion of findings

In this section, the findings are presented. This overview encapsulates the themes, sub-themes and categories that emerged from the interviews with the social workers providing palliative services. The findings were subdivided into nine themes.

1. Social workers' accounts of their experiences of working with people faced with life-threatening illnesses.
2. Social workers' descriptions of the nature of the palliative care services they provide to people faced with life-threatening illnesses.

3. Social workers' descriptions of their role within the interdisciplinary team that provides palliative care services.
4. Social workers' descriptions of their intervention strategies when working with people faced with life-threatening illnesses.
5. Social workers' accounts of the challenges they often experience when providing palliative care services.
6. Social workers' descriptions of how they deal with the challenges experienced when providing palliative care services.
7. Social workers' level of satisfaction with the kind of palliative care services they provide to people faced with life-threatening illnesses.
8. Social workers' suggestions regarding the nature of the palliative care services provided by social workers.
9. Social workers' recommendations regarding the role of social workers in providing palliative care services to people faced with life-threatening illnesses. An overview of the above nine themes, subthemes, and categories are presented in Table 4.

Table 2: An overview of the themes, sub-themes and categories

SUB-THEMES	CATEGORIES
Theme 1: Social workers' accounts of their experiences of working with people faced with life-threatening illnesses	
1.1 Work daily with people faced with life-threatening illnesses. 1.2 An unknown experience and difficult 1.3 1.3 Positive but challenging	
Theme 2: Social workers' descriptions of the nature of the palliative care services they provide to people faced with life-threatening illnesses	

SUB-THEMES	CATEGORIES
2.1 Assess and address needs of patients and families. 2.2 Provide support and information. 2.3 Provide counselling. 2.4 Assist with practical issues. 2.5 Identify and mobilise community resources. 2.6 Plan and discuss with patient and family. 2.7 Facilitate communication between role players	
Theme 3: Social workers' descriptions of their role within the interdisciplinary team that provides palliative care services	
3.1 Team members are equally important 3.2 Provide the psycho-social perspective 3.3 Liase with and communicate with available resources 3.4 Advocate for patients	
Theme 4: Social workers' descriptions of their intervention strategies when working with people faced with life-threatening illnesses	
4.1 First build relationship and gain trust 4.2 Follow at patient's pace 4.3 Practise various social work methods and approaches 4.4 End of life counselling and support	
Theme 5: Social workers' accounts of the challenges they often experience when providing palliative care services	
5.1 Late referral of patients 5.2 Resistance and denial 5.3 Stigma linked to hospice and palliative care 5.4 Patients' conditions 5.5 Family related issues 5.6 Interdisciplinary team members do not always understand or accept the role of the social worker 5.7 Emotionally challenging 5.8 Inequality between public and private healthcare	• 5.2.1 from patients • 5.2.2 from family members
Theme 6: Social workers' descriptions of how they deal with the challenges experiences when providing palliative care services	

SUB-THEMES	CATEGORIES
6.1 Peer support and supervision 6.2 Debriefing 6.3 Attending training opportunities. 6.4 Proceeding at patient's pace. 6.5 Patients' satisfaction 6.6 Self-Care 6.7 Know yourself and be comfortable	
Theme 7: Social workers' level of satisfaction with the kind of palliative care services they provide to people faced with life-threatening illnesses	
7.1 Not satisfied 7.2 Satisfied in general and proud	
Theme 8: Social workers' suggestions regarding the nature of the palliative care services provided by social workers	
8.1 Training 8.2 Skills development 8.3 Work more in-depth 8.4 Know and use community resources 8.5 Change attitudes	• 8.1.1 At graduate level • 8.2.2 Specialisation
Theme 9: Social workers' recommendations regarding the role of social workers in providing palliative care services to people faced with life-threatening illnesses	
9.1 Promote social worker's role in palliative care. 9.2 Communicate/consult with others. 9.3 Supervision and training 9.4 Self-care and debriefing	

In the next section of this discussion, each one of the main themes and accompanying sub-themes and categories (where applicable) will be presented and confirmed or endorsed by direct quotes from the transcripts of the interviews. The identified themes and sub-themes, with their supporting storylines from the transcripts, will be compared and contrasted with the body of knowledge available, namely a literature control will be undertaken.

4.3.1 Theme 1: Social workers' accounts of working with people faced with life-threatening illnesses.

This theme emerged from the responses of social workers to the initial question to describe their experiences of working with people faced with life-threatening illnesses. Their responses are given in 3 sub-themes, namely work daily with people faced with life-threatening illnesses; an unknown experience and difficult; and positive but challenging.

4.3.1.1 Sub-theme 1.1: Work daily with people faced with life-threatening illnesses.

Many of the social workers who participated in this study responded by explaining how they work daily with people faced with life-threatening illnesses. This perception was articulated by participant A, C and F as follows:

"*I am an Oncology Social Worker, so I work with patients that have been diagnosed with a life-threatening illness of cancer, various different types of cancers and…that is what I do on a daily basis…and many of them are no longer able to receive treatment anymore so they are palliative care, their treatment intent changes from curative to palliative"* [Participant A 5-11]

"I have been an Oncology Social Worker now for 21 years and all through my career starting at the Cancer Association right to where I worked in a private oncology practice to where I am now working in my own private practice, I have been involved with dealing with people in end-of-life care planning but also care during that phase and I looked after patients as well as the family's needs. So I have had many years of experience 25, 30 years of working experience within the oncology field. I haven't worked a lot with other terminal illnesses…but I have now in the current state of COVID been confronted with the reality of how COVID is impacting the palliative care patients that are now not able to have treatment, not able to go easily to hospital and stuff like that. So that has quite been an interesting different angle of experience I have had during this time" *[Participant C 11-22]*

“I started working at Haemalife in July 2017 so it’s almost three years…our patients all get diagnosed with a life-threatening illness. Every single one of our diagnoses if it is like leukaemia, if it’s lymphoma, multiple myeloma, all of them are life-threatening. We hope that with our bone marrow transplant…that the patient’s life expectancy gets extended with five to 10 years. Sometimes the patient gets really cured and that is what we hope for, but multiple myeloma…it is more a chronic cancer…You will live with it for the rest of your life and you will die of that cancer so you can never be cured. You will be constantly receiving chemotherapy maybe two to three bone marrow transplants but the patients…where it is the final stage of life and…we need to prepare and put everything in place for the family and for the patient to empower everyone. It is a very difficult road because sometimes it’s very quickly, you do not really have much time to prepare the family like you would like to and the type of death is a very cruel death…the patients…they really suffer in the end…I have built up a lot of experience over the almost three years and…sometimes it is something you would not like to deal with because you work so much with a lot of death, I mean you are confronted with it constantly” [Participant F 14-31]

The above statements are supported by Hennessy, Lown, Landzaat and Porter-Williamson (2013:78) who state that when you work in a palliative care setting death and dying are everyday activity, the provision of care to patients is daily, it is a consistent everyday exercise. Similarly, Sadauska and Benosyte (2014:3) assert that palliative care teams that include social workers encounter the subject of death and dying as a daily routine. The NASW (2010:2) support this and allude that hospice and palliative care social workers witness daily the struggles to find meaning in the face of serious illness and death.

4.3.1.2 Sub-theme 1.2: An unknown experience and difficult

Some participants focused on their responses to the experience of patients and families. According to Sadauskas and Benosyte (2016: 3), palliative social workers are faced with the deaths of their patients daily, experiences of fear, hopelessness and guilt are common, further, psychological readiness is of paramount importance and even those considered the strongest workers break down and suffer from many stressors. At the end of the day, it is a physical and emotional journey. Additionally, Cheung (2018:3) states that social workers in palliative care are faced with intrinsic challenges during death work, the likelihood of them being overwhelmed by emotions and seeing their patients suffering is greater, they have to watch the meaning they place on life and deaths being shattered. Sadauskas (2016:2), concurs that the dying process of a patient is an emotionally hard experience for a particular social worker, just like their other counterparts on the palliative care team they experience different intense emotions when their patients die.

The following quotations highlight the views of social workers.

***"I think for most of the people it is a first-time experience when a loved one has a life-threatening illness…and what I experience from them is that they do not know what to do and the people are scared and it's things that they don't know if they are behaving this way if it is the best way for helping the patient. And also the family gets impacted as well as the patient. So, it is a new experience for people when it is a first-time experience and even if you are used to death that everybody is going to die it is still something difficult to experience when it actually happens and it happens to a loved one of yours*"** [Participant B 11-18]

"*…it can be very devastating experience. But again, people are different I think that depends on personality, on the stage of their life where they are at. But it is not a very easy experience all overall whether you are losing a younger person it's very distressing because the whole dream is lost when you are in our mid-life early adulthood or maybe you are more having to focus, maybe you're starting a family. If you are older, the children are still devastated by the news. So, overall, the very common sense that I have experienced working with people with life-threatening diseases is it is a very difficult time for the patient as well as for the families"* [Participant J 17-25]

"…*being conscious of entering somebody's world or experiences that is unique to that specific patient…"* [Participant G 12-13]

4.3.1.3 Sub-theme 1.3: Positive but challenging.

Social workers also reported that their work can be both positive and challenging.

The following quotations highlight the experiences of the social workers.

"…it's quite a wide variety in terms of experiences because like every patient and family is so different and so diverse…so for me, it is a positive experience. Mostly because you get to really walk in the journey or space that is very sacred in people's lives. It is a space not a lot of people are comfortable to go into and to talk about. So, the experience for me is positive because you see change happens…people are grateful for the service you deliver which is not like other sectors of social work so, you have a much higher degree of job satisfaction, I think. It is very challenging and yes, it's positive because you feel like you are making a difference. It is challenging, you have to be able to think on your feet, you have to be able to be flexible, your day will never go as planned of course you know you just got to go with the way the day takes you" [Participant D 16-27]

"…*I am a palliative care social worker for the last five years. Before, I was working in child protection for 13 years, so you can imagine the shift from being a child protection social worker to being a social worker working in a set-up like hospice or palliative care social worker. Five years down the line I think I am where I am now. I am confident in doing my job. It was a learning curve and I mean you learn every day. You are working with people who are coming from different backgrounds…you learn, if it's new you feel like that I don't know where I am, but we have a good team and excellent support from our manager* " [Participant E 13-21]

"I think we learn as much from the patients and within their journey as what we provide to them as found in our support. For me, the focus is firstly, it is patient-centred and we do not force ourselves on the patients. So, if the patient is willing and accepting the support that we provide and they buy into, then we grant it. So the patient needs to open emotionally their space up, open it for us to enter. For me, it is standing with the patient in their end-of-life phase. Supporting them and their family members is holy ground for me, it is their sacred private space and it's for us to enter with their permission. It is not to force ourselves on them, ticking the boxes of what needs to be done. I think we never must lose the focus

***of the person with the illness and not so much the outcome…not all people want social work intervention but when they are open to the support of the holistic of hospice then I think we are one of the few organisations that know what palliative care is about and understand the value of it within the context of the patient, within their culture, within their beliefs system, within their support system. It is a two-way thing; we learn from one another. I always say I learnt from my patients how I need to die and not to die…*"** [Participant H 15-33)

"*My experience I would summarise has been very challenging and rewarding. I have always felt that it is a huge honour to be allowed in, to be with people and with their families and walking alongside them during their journey of their illness. It is obviously very challenging in the sense that you are watching the deterioration of somebody; you are walking a very emotionally straining journey on their families and that, especially as an outsider, trying to fit in and provide and ascertain what the best support is and trying to meet them at their needs every step of the way and this can change rapidly"* [Participant I 12-19]

The above statements are supported by Quinn-Lee Olson McBride and Unterberger (2014:223), who state that while engaged in hospice social work, one gets a sense of it being a privilege, a challenge, including a sense of purpose and commitment as a result of the journeying with the patient on their last stretch of life. Similar views are shared by Go-Coloma (2018:30) palliative care social work can be challenging but it can also be rewarding as you get to make deep connections with patients and help them celebrate their life stories and leave a positive impact on them and their families. However, Murray (2015:8) argues that even though there have been many studies on the negative impact of palliative social work on social workers recent studies have explored the positive factors and it has been found that compassion satisfaction, resilience and personal growth can come out social work interactions with dying patients.

4.3.2 Theme 2: Social workers' descriptions of the nature of the palliative care services they provide people faced with life-threatening illnesses.

The social workers were then asked to describe the nature of the palliative care services they provide to people faced with life-threatening illnesses. Their responses are given in seven sub-themes that range from assessment and addressing the unique needs of patients and families to facilitate communication between role players.

4.3.2.1 Sub-theme 2.1: Assess and address the needs of patients and families.

The social workers first explained how they assess and address the unique needs of patients and families and below are some of the quotations from participants B, E, H and J:

Participant B explained: **"*…we walk the journey with the patient; we are not walking the journey for them. So whatever need that arises on the path is what we address and stuff that usually comes up depending on if it is a free patient or paid patient. It's usually SASSA grants when people is the breadwinner and they lose their job…or if there is things that are going to be left behind like a car or a house. There is always friction between families, so we do family meetings with them and we look at wills, living wills. But we as the social workers do specifically…advanced planning because we do not have directives, it's not legal in South Africa yet, but we do advanced care plan where we discuss stuff with them like where they would they want to die, if they want to be resuscitated, would they want to go to hospital or do they want to be at home. Do they have somebody that can make decisions for them when they are not able to do that anymore? does somebody have power of attorney for them if there are decisions that need to be taken? So, according to what the need of the patient is, we will address it according to that because everybody is unique and everybody's circumstance is different and although all people…have lung cancer or breast cancer or prostate cancer they handle it differently and you need to take it in their different way*"** [Participant B 24-41]

"*Firstly, we work with the patient, the patient is the most important person and of course the family. So, often we do assessment with our patient to see what the needs are". Sometimes you don't have that opportunity because people come and…I can just give an example. A patient was admitted on Monday afternoon and what we usually do we won't go in immediately because if he is in the in-patient unit there is lots of attention they need to do…And so we let the patient settle in first and like the next morning you go in, introduce yourself.*

***Just explain your role to the patient, if the patient can still talk or is compos mentis…then the Monday the patient was admitted…he passed away the Tuesday. It wasn't expected so yeah sometimes you have time with the patient, it all depends. I mean the earlier the diagnosis, the patient can be referred to us…the better, but we don't always have that opportunity*"** [Participant E 25-37]

"*My focus for me would be the patient's understanding of their diagnosis. I think that must be, is one of the key things to confirm. What do you understand; what is communicated to you about your illness?…was it clinically explained to you by the health care sister, if it's a State patient or if it's a clinic patient or if it's a private patient. It is what is your understanding of your illness and then the focus would be (what) is the impact of the diagnosis on your current emotional state*" [Participant H 40-47]

"…*I work as a social worker in the ward as well as in the community. So the nature of my work really depends on where the people are…(the) specific needs they have at that specific period of time. So, you might be working with a client who just lost an income and you need to facilitate a social grant application, you might be working with someone who is facing denial and you have to break the bad news*" [Participant J 30-35]

The above-mentioned quotations from the participants are supported by Reigad, Ramos and Aguirred de Carcer (2015:6), who state that a proper and thorough assessment is one of the skills which social workers are trained to do. This sentiment is supported by Middleton, Head and Remke (2020:3), who agrees that it is the responsibility of the social worker to assess and address patient and caregiving needs of the patient and family. Similarly, Go-Coloma (2018:30), postulates that it is the duty of palliative care social workers to conduct psychosocial assessments of patients and their families so that they can determine their needs so that these can be addressed. This is supported by Moriarty, Baginsk and Manthorpe (2015:8), who state that social worker's major role thrust upon them is the assessment of needs and risks over a number of clients.

4.3.2.2 Sub-theme 2.2: Provide support and information.

The second sub-theme that emerged was that social workers provide information and support as part of their palliative care services.

Equally, Reigad et al (2015:6) are of the view that that social workers in palliative care support their patients and the interdisciplinary team and ensures there is a good flow of information between the patient and the team considering client autonomy and good clinical practice. On another hand, Middleton, Head and Remke (2020:1) share a similar view that the social worker fulfils the role of providing patients and their families information regarding how they can cope with the illness and ways to normalise stressors and available palliative care options in the community for example hospice services. Furthermore, social workers teach patients and their families the process of dying, communication with the family and clarification of rights regarding the end of life, this duty extends to enhancing good communication with healthcare providers and empowering the patient by informing them of their available supportive options (McInnis 2014:8).

Below are some of the extracts from the participants G and C:

"*…my main focus is information, so that's where I start. Information and then support and creating a safe environment for people to show or express their vulnerability…that is summarising the nature of the way I approach and the focus points"* [Participant G 18-21]

"…*supporting the family dealing with unresolved issues, dealing with the crisis as the illness progresses and then working with the other members of the multidisciplinary team in terms of dealing with the needs of the patient and family all through that*" [Participant C 45-47]

4.3.2.3 Sub-theme 2.3: Provide counselling.

Counselling was identified as one of the important services the social workers provide to people faced with life-threatening illnesses. This is supported by Sadauskas and Benosyte (2016:2), who state that social workers in palliative teams in most cases provide activities of counselling and informing the patient and family. Additionally, they also help to support their patients who may be facing conflict, anger, frustration in a helpful manner with the goal being to strengthen and sustain relationships (Paul 2016:15). Similar sentiments are echoed by the NASW (2010:2), who state that social workers are providers of counselling and psychotherapy to individuals, couples and face with incurable diseases.

This is also confirmed by the following extracts from participants A, C and I: -

"*Basically, the actual services would be that I would need to counsel them around their feelings of about now no longer being able to have further active treatment like chemotherapy or radiation. They also need to speak about what it means to them to now have a life-threatening illness where there is no cure and then to give information around what to expect. A lot of patients are very fearful of pain; when they are going to die; they do not know how long they have. A lot of patients want to know how much time do I have left. We need to talk about those feelings and what are their fears, their concerns and very importantly physically; what is going to happen to their bodies and what support is there?"* [Participant A 14-23]

"*I would have contact with their spouse or caregiver and then support them emotionally as well as with information and then when the person does die I would often see, depending on the relationship that I have established with the caregiver and family, I would then see the caregiver for bereavement counselling*" [Participant A 28-32]

***"I just deal with the family issues, patient issues and couples issues… so I do quite a lot of in-depth counselling during the terminal phase as part of my palliative care service*"** [Participant C 66-67]

***"I would say that it's social and emotional, very much working therapeutically with them. What are their concerns, fears, that sort of thing…*"** [Participant I 23-25]

4.3.2.4 Sub-theme 2.4: Assist with practical issues.

The participating social workers also talked about how they must often assist people and their families with practical issues resulting from being faced with a life-threatening illness.

“We also assist patients with disability grants, old age pensions depending on what the age of the patient is, assisting with the process, we also follow up; we also assist with UIF applications. Say, for instance, a patient had to leave work due to the illness, I do documents. Sometimes we get people that the birth was never registered…that’s the dilemma on its own, but we support where we can. And we also take them through the process of when it comes to the point where the patient passes away or the patient’s wishes, because as I said it’s always patient first and what patient wants and we will let the patient guide us. So, as I say if sometimes you have a relationship with a patient it’s good in a good way but when you don't have the time it is like in a day or two the patient passes away…but afterwards we (are) still there to offer support for the family after the patient pass away” [Participant E 45-57]

“…there is also very practical side of things, that is helping people get the practical things sorted so that essentially so they can actually live the last of their lives, so that those things can be put aside because they are making sure IDs are sorted, making sure that there is a will if the person wants a will. So very big practical side but then a large therapeutic side as well. But then through the practical side you get to develop relationships which helps on the therapeutic side again…so it’s variable, a lot of practical, a lot of emotional support” [Participant D 36-43]

“Sometimes I need to arrange oxygen; I need to arrange the hospital beds; I arrange all of those things that need to be at home, so I look at the practical side as well” [Participant F 44-46]

“…it’s the support on what are your practical patient needs? Do you need a simple thing like a wheelchair? Do you need a toilet seat raised? So it’s besides emotional, it’s also being aware of what is the practical needs of the patient. Is there enough food in the household? What resources in the community can I use to provide Eat pap or nutrition or food parcels or soup kitchens? Because

hospice cannot provide that necessarily but you can network within the community so that would also be the nature of the palliative care. It would be in assisting the patient with the information of how to apply for a disability grant" [Participant H 71-78]

According to Otis-Green (2020:6), a number of psychosocial and social issues arise during palliative care and it is the duty of the social worker to address these, this can include issues to do with finances and the social worker has to assist with the provision of practical advice around income and debt, retirement and housing issues and access to advocacy services and support groups. On the same note, McInnis (2014:9) states that the social worker has a wealthy of experience regarding community resources and services, financial aid programmes, organising home nursing services, advocacy for older persons regarding their right to care and this can involve telephone calls and personal contacts that are considered difficult for a patient ravished by disease. Similarly, social workers work with dying patients to determine their final wishes, communicate aspects of health care in periods of incapacity, this can be done through written or verbal expressions. They also assist in the drafting of simple forms and these can include living wills, refusal to unwanted invasive treatments and proxies as well as the power of attorney (Wang, Chan & Chow 2018:2).

4.3.2.5 Sub-theme 2.5: Identify and mobilise community resources.

The social workers and their employers are not always able or in the position to directly meet all the various needs of people faced with life-threatening illnesses. Consequently, one of the social workers' services is to identify and mobilise community resources to assist the patient. This is confirmed by the following extracts:

"So, I will also often need to refer to other community-based resources like hospice or a homecare agency. So, I would apply via the medical aid with a letter of motivation so that we can arrange for them to get a carer and so that way I would also manage the palliative care service and then what it would also involve…If the patient is admitted in hospital I would go and visit them in the ward" [Participant A 23-28]

“***…and then obviously resource development, so engaging the nurses agency, preparing and helping them access hospital bed, helping them get stoma therapy help or even dieticians”*** [Participant C 69-71]

***“So it is to give the information of what resources are available in the community so that their needs can be addressed. And then palliative care also focuses obviously…for the families and we refer because our hospice social workers don’t work with childcare law so we refer them to the services in the area that do work (with children). If there needs to be a foster placement or that sort of placement that so we network with that organisation but we will always communicate that with the parents and the children obviously and future care planning for the children is always part of the conversation*”** [Participant H 86-93]

***“Our patients deteriorate very quickly so you do not always have time to prepare the family like you would want to…including the community resources, community hospice everything and everyone that can be of help. I try to arrange and coordinate for the family at home if the patient wants to die at home*”** [Participant F 48-52]

According to Hughes, Firth and Olivier (2014:43), palliative care social workers are involved in capacity building activities with the aim being to be a catalyst between social and community networks while supporting dying patients. Equally, Reckrey, Guttenberg, Ross, Kopke, Soriano and Ornstein (2016:4), state that social workers act as a liaison between patients, local resources and agencies. An example can be social workers in oncology unit assisting with hospice placement to an undocumented immigrant dying of cancer or social workers facilitating family reconciliation despite complicated dynamics. In addition, social workers must work in partnership with the people they offer support while they work alongside other professionals as part of a wider community in the areas they are based. Social work expertise complements the knowledge of other professions such as Physiotherapists, advocates, nurses including the wisdom that is available in the community (Paul 2016:8).

4.3.2.6 Sub-theme 2.6: Plan and discuss with patient and family.

Planning and discussing with the person faced with a life-threatening illness and the family were described as part of the social workers' services in palliative care.

The social workers had the following to say: -

"*…we work with people…coming from different backgrounds, lots of social issues but we cannot fix everything, and you can only work with what you have. As you know, there is always lots of family dynamics you know, it is lots of involvement of the family but one can only work with what the patient tells you even if you know something is happening. If it is not coming from the patient, it is not like you do not address what the family is saying you can listen to them, being an ear to their concerns but if the patient is not comfortable to go there then you do not go there*" [Participant E 38-45]

"*…some patients that want to talk about death, want to talk about…how is it going to happen, when do I need to come back to hospital…Those difficult topics regarding when do we stop treating an infection because in our cases with our patients they do not usually die from the cancer, they die from the infection because the immunity is so compromised. So it's usually an infection so you need to make sure that you make that decision when do we stop treating with antibiotics because then the patient deteriorates very quickly. So I do discuss very difficult topics as well and the family members sometimes…we talk about the will, we talk about what is going to happen afterwards, what is going to happen to my family. Some patients…have that concern. So, it depends absolutely on the family and the patient regarding what extent of palliative care I can render*" [Participant F 54-65]

"*…helping them tell their children about death because sometimes parents they do not know how to address the difficult topics. So there is a lot of educating as well that goes along with that while they are here and sometimes I need to see the young kids and just assess where they are at regarding the understanding of death. So, it's a lot of preparation and education*" [Participant F 79-83].

According to Wang et al (2018:2), social workers are involved in a leading role to assist the patients and their families in the planning and decision-making processes around end-of-life care, they also help ensure that the psychosocial and spiritual needs of the dying patient and family are addressed, and this includes planning around care at the end of life and discussing it with the family. In addition, Metcalf (2013:6), state that social workers tasks in hospice care include conducting patient and family end of life education, providing referrals and resources as well as planning care with disease progression and offering supportive counselling, as well as complimentary therapies meant to assist and manage the stressors and assist with coping with psychosocial symptoms related to end of life care. Hospice social workers help their patients and significant others with navigating the end-of-life process, educate them about treatment plans, empowering them to be vocal about their needs and managing the stress that comes with a debilitating disease (Go-Coloma 2020:30)

4.3.2.7 Sub-theme 2.7: Facilitate communication between role-players.

The social worker is also in the position to facilitate communication between role players on the multidisciplinary team as highlighted in the following responses by participants F and A.

"*My role is to facilitate mostly, the communication between doctor, patient and also hospice, hospice social workers. So I would say my basic rule is communication at this stage and empowering everyone. Doctors will come to me when they want me to start with referrals for home-based care and arranging all of that. So I know sometimes…what the need is, what is the family…(I) can empower doctor with information on what is necessary and (who) does not want to continue with treatment. So patient will discuss…some of the things with me…my biggest role is to be the facilitator between the doctor, between patient and hospice, between doctor and hospice, between palliative doctors to give feedback to them, to give medical history so that they can treat patient at home with the necessary support"* [Participant F 68-78].

"*My role would be to liaise and network with the different…available services that can help the patient and their family and then to also give feedback. Often the pain is not managed, so I would need to liaise with the sister or the doctor in the team and ask for advice or request that they contact the patient's family urgently in terms of management of pain and so it would be a referral role. It*

***would also be a role of educating so that the family knows who is in the interdisciplinary team and then it will be mostly counselling so just helping them to cope with the reality that this is somebody that is going to die and often then also information…A lot of people want to know what's going to happen? Why isn't my father or mother eating anymore? So, I would need to explain to them that the body no longer needs the food and that the organs are slowly shutting down. So, the role I play is very much a liaison role but also largely a coordinator and facilitator with…the other services that are available*"** [Participant A 36-49].

According to Paul (2016:16), palliative care social workers do not work in isolation, they collaborate with other professions, organisations and agencies, their contribution is in the spirit of collaboration with an awareness of confidentiality with confidence in the professional standpoint. Facilitative communication is at the core of these collaborations among the dying patient, the families and those who are close to them, carers and friends and people providing health and social care services (Paul 2016:16). Additionally, social workers provide insight and help prepare other interdisciplinary team members in palliative care, they play a key role in providing insight and preparing other members of the Interdisciplinary team of health care professionals, they are also guides for advanced care planning (Go-Coloma 2018:30). Similarly, Hill-Jones (2015:28), states that social workers uniquely play a vital role in direct intervention, but they also indirectly help other team members with interpreting meanings of behaviour, their responses and how they can respond professionally during the team process of discovering reasons for troubling behaviours in patients and social workers are in a place to offer valuable insights on human behaviour.

4.3.3 Theme 3: Social workers' descriptions of their role within the interdisciplinary team that provides palliative care services.

The social workers were asked to describe the role they play in the interdisciplinary team that provides palliative care services to people faced with life-threatening illnesses. Their responses are given, namely, the interdisciplinary team are equally important; provide the psycho-social perspective; facilitate and liaise with available resources, and advocate for patients.

4.3.3.1 Sub-theme 3.1: Team members are equally important.

Two of the social workers when responding to the question emphasised that in the interdisciplinary team, no member is more important than another member. Participants B and H shared the following extracts: -

***"…everybody in the team is equal because everybody's role is as important as the other ones…sometimes people come in and their focus is on physical pain and then the patient actually experiences emotional pain. So, we're there to help each other to give the best care to the patient. It's not about the social workers doing more or is doing better than what the nurses is doing or the carers are doing more because they see the patient more when they do full washes and wound care and stuff like that. But we need to be respectful that we are all in it for the patient, and to give the best care to the patients*"** [Participant B 63-66].

"…*I am very lucky that in our hospice…each member has equal superiority. So it is not like a multidisciplinary team…I am very fortunate that I was the first social worker at the Overstrand Hospice appointed and I was welcomed with open arms in the IDT. There is no hierarchy. I think not all hospices can say that…I know that can be a problem. That you have the voice but you need to fight for your voice in order to be heard within the interdisciplinary team...*" [Participant H 96-103].

According to Youngwerth and Twaddle (2011:650), the interdisciplinary model is primarily based on synergistic and interdependence interaction of team members who each possess particular expertise. Additionally, the interdisciplinary team is composed of professionals who share their expertise, knowledge and skills to impact on client care and this is accomplished through open communication and shared decision making with the understanding that no single team member can meet all the patient and family needs (Albers, Bonsignore & Webb 2018:256). Similarly, the interdisciplinary team need to have a common ideal and understand the role and importance of each team member and that they contribute specific skills, experience, attitude, and values to the whole to achieve successful team outcomes (Spruyt 2011:517).

4.3.3.2 Sub-theme 3.2: Provide the psycho-social perspective.

A major role played by social workers in the interdisciplinary team relates to how they provide the psycho-social perspective in the palliative care services through various means. The following extracts from the participants confirm this:

"*…it will be mostly counselling. So just helping them (patients and family) to cope with the reality that this is somebody that is going to die and often then also information…"* [Participant A 42-44].

"…*usually when I introduce myself to a patient I will explain to them my role on the team. And I will (say), sister does symptom control; the medical things, doctor does that; and I do everything else. So here where I work the role of the palliative social worker on the team is counselling to patients and families and it's spiritual support"* [Participant D 60-64]

"…*I think we (social workers) work a lot with narrative therapy. Part of our strategy is narrative therapy because if you can hear the story then you can understand what the patient and family's perception is, where they are at and where they have come from and where think they are going…it is very much a person-centred approach.-. So trying not to generalise but looking at each patient in their own unique needs in their process and their own unique perceptions of what is happening and how they cope…it's not an intervention as much as journeying alongside, rather than trying to make things change in a short period of time. But it's rather realising that we go with where the patient is and just journey alongside them not ahead of them or behind them. Really be where they are at and just be present with them through their processes"* [Participant D 89-101].

"I bring the psycho-social side to the team. So when we have our interdisciplinary team meetings then it's the social workers, it's the nurse, it's the doctor and it's the home-based carers and we all give our specific input as to what we have done and this is (the) platform where we share. Where they will tell you something that maybe you didn't pick up or missed out or that you need to look at but specifically the psycho-social things and sometimes also the spiritual…spirituality for us is important and we do not see it as religion because you can still have religion and not be spiritual…it is more important for me for

you to be spiritual and not religious. So if there is, then we address it, if people at the beginning tell you that they have their own people that address that then we are respectful of that" [Participant B 48-61].

"…*I am a Clinical Social Worker…A lot of the meaning I derive from my work comes from in-depth psycho-therapeutic intervention and I use (the) eclectic approach in terms of my intervention. I use a lot of narrative therapy in the work that I do, so really looking at restoring this phase of your life, teaching them how to live until they die. Not dying while living and really kind of doing a new…personal mission statement for this phase of their life…what values do they have and how do they want to live out those values in this situation? Making a list of dreams that they want to achieve before they die and teaching them. How to celebrate life instead of just giving up on life…the focus is psycho-social adjustment of the patient and the family and obviously unlocking resources as may be needed"* [Participant C 75-92].

"*...our voice is to address the social, the spiritual and the emotional pain that includes the total pain and the cultural pain"* [Participant H 105-106].

"…*the role would be to provide social and emotional support for the family and then it usually links up to usually being notified by medical professionals…working alongside them in finding what the best way is to support patients and their families. And discussing, being part of the decision-making processes and assist, for example, if a person needs at home to be cared for at home or needs to be placed somewhere then we will be called in to be a part of that discussion"* [Participant I 29-35].

"*The role of the social worker on that team is mainly to provide psycho-social support to the patient and the client but over and above that you might have to take a little bit of a lead especially when there is a discrepancy in expectation of different roles. In a normal ideal situation because we are interdisciplinary team we are supposed to complement each other. However, from time to time…as a social worker you are expected almost to be this magician who can just find a solution to anything if I may put it that way. So half of the time you have to undo those expectations"* [Participant J 84-91].

According to Hughes et al (2014:42), the social worker’s inclusion on the interdisciplinary team is to ensure that psychosocial care is at the core of care provision, social workers bring a psychosocial perspective to interdisciplinary education through a collaborative process. Additionally, social workers use their skills to educate, train and support other team members in the psychosocial aspects of palliative care (O’Callaghan 2014:209). Further, Otis-Green (2020:60), states that social workers have the ability to bring a systems perspective to their work and they can contextualise the concerns that patients and their families have, they are able to assist the team to understand the complex family dynamics and ensure the needs of the patient and caregiver are not overlooked.

4.3.3.3 Sub-theme 3.3: Liaise with and communicate with available services.

The social worker plays an important role in the inter-disciplinary team of facilitating contact and liaising with available services so that the needs of patients and families can be met. The following statements represent the views of the participants:

“*My role would be to liaise and network with the different…available services that can help the patient and their family and then to also give feedback. Often the pain is not managed, so I would need to liaise with the sister or the doctor in the team and ask for advice or request that they contact the patient's family urgently in terms of management of pain and so it would be a referral role. It would also be a role of educating so that the family knows who is in the interdisciplinary team*” [Participant A 36-42].

Over and above counselling, Participant D explained how she facilitates and liaises with available services as the social worker in the multidisciplinary team: *“…**facilitating spiritual support for patients and families…So facilitating spiritual care support whether we need to do it ourselves or whether we refer it to the person’s existing spiritual support network but we don’t have spiritual care volunteers here so we do that ourselves. Connecting patients with volunteers is part of our role**…”* [Participant D 64-69].

*“**introducing other service providers” in order to address the patient’s needs.*** [Participant G 30-31]

According to Hopp, Comp and Parry (2015: 201), the social work profession has the potential to play a significant role in providing palliative care services and support to people faced with incurable illnesses. Social workers assist other health providers to recognise the need to provide more explanation on disease and education as well as facilitate access to community resources (Hopp et al 2015:201). Similarly, Watts (2013:199), points out social workers act as the liaison between the patient, family and other health care providers, this work involves complex ethical dilemmas related to end of life care decision making. Additionally, social workers have diverse roles in palliative care, they include advocacy, liaison, assessment, care delivery, care planning, community capacity, confirmation and decision making (Bosma, Johnston, Cadwell, Wainwright, Ngairer, Feron & Nelson 2010:82).

4.3.3.4 Sub-theme 3.4: Advocate for patients

Social workers also identified their role as being one of advocating for the patient.

This view is supported by the NASW (2010:2), that hospice social workers spend a considerable time advocating on behalf of the patient and family. Similarly, Go-Coloma (2018:30), states that social workers are specially trained professionals who act as advocates for their patients and their families and bring a depth of knowledge about available resources, whether palliative hospices are delivered in a hospital setting. Further, Moriarty, Baginsk and Manthorpe (2015:8), concurs that social workers in the advocate role give, assist and support individuals, groups and families.

A few quotations below demonstrate the participants' viewpoint on advocacy for their patients:

"We (social workers) must be the advocates for our patients and I think what helps a lot is when the social worker and the nurse go together to a patient, because only then you can have layered information and layered assessments… you can actually only show the social worker in action when you visit with the nurse, so that they can actually see what we do. Because we pick up on phrases or what is not being said and I don't think nurses have the skill to assess that. But with reading body language and reading between the lines we can pick up something that is not said and you can ask the right questions to open up a

completely different conversation…within the interdisciplinary team we must be professional and owning our role within the team with authority…you need to voice in the IDT when a matter is addressed and you see that colleagues are getting thrown by family dynamics…so you call and make an appointment or…you go together. And I think in that way you also support your colleagues and that they don't have to deal with the stress of the family dynamics because that is our forte that we are comfortable with that and I think there is kind a lot of tension by handling the family matters at the visit and sister can just do the clinical stuff' [Participant H 107-134].

"***Sometimes you have to do a bit of advocacy work for the families or for the client. A perfect example will be say if you see the patient maybe is neglected. It could easily take more (the) form of trying to set up a family meeting to see if there are other resources that can be used. You could easily draw a faith community"*** [Participant J 52-56].

4.3.4 Theme 4: Social workers' descriptions of their intervention strategies when working with people faced with life-threatening illnesses.

Participating social workers were asked to describe what intervention strategies they used when working with people faced with a life-threatening illness. From their responses, four sub-themes emerged, namely first build relationship and trust; follow patient's pace; practice various social work methods, and end of life counselling and support.

4.3.4.1 Sub-theme 4.1: First build a relationship and gain trust.

Some social workers identified that their first intervention strategy is to build a relationship with the patient and develop trust. The following are some of the quotations from the participants about the need to build relationships and trust:

"…*before the intervention strategies can actually be applied, I really believe in the importance of building relationships with the patient and their family. Often my relationship is very much with the caregiver because some patients when they are referred to the practice, they are actually so ill they do not actually have*

***the energy to communicate. They do not have the energy to build relationships…then I focus on…the caregiver and the family members that are closest with looking after the patient. So, I really believe to build a positive relationship you have to apply the values of respect and non-judgement and also to take a non-directive approach in dealing with a patient's family and the patient*”** [Participant A 54-63].

“...*when I first meet the patient or go to a patient again, I explain my role why I am here because sometimes the patient gives consent to the home care sister for the social worker to get involved but when you get there…then it's totally something different. Maybe the patient was not ready, was under pressure or whatever, so what the need is as I already mentioned the patient needs you…to build the relationship, to build trust and whatever comes from there then we work out this is (my) way and my experience with working with patients is if the trusting relationship is there…then patient will feel comfortable to share some certain stuff with you and you contract with your patient”* [Participant E 91-104].

“…*my approach would be to build a trustworthy relationship because if you do not have a relationship people will not give their deepest of emotions or fears, or uncertainty or their vulnerability so that is so important; that would be my first thing. When I meet a patient…who is already in a palliative phase and I have not really seen them before that because…often we do have patients that come here that already are very ill and therefore I need to build that relationship but also respecting their pace, so what they are ready…the more they trust you, the more they feel safe, they are prepared to hear even the not-so-good news. So that's my approach and to have openness the whole time for them to know that they can ask whatever they can but also saying to me I do not want to hear this…”* [Participant G 49-59].

Palliative care social work interventions must start at relationship building, the focus must be on building relationships, gaining trust and practitioners will be able to have meaningful and productive interventions, trusting relationships enable patients to seek support and guidance freely (McMullin 2017:20). Similarly, Kennedy (2019:2), points out that social work to a much greater extent than many other professions is founded on a belief in the value of human relationships, it is a profession highly dependent for its impact on the establishment and maintenance of effective relationships with patient, families and communities. Research has proven that the development of a good quality helping relationship between a social worker and clients is significant in influencing the effectiveness of interventions (van de Merwe & Marais 2016: 52). Furthermore, Spray and Jowett (2012:56), state that support can only be offered when social workers have built trust and created a platform from which support can be offered, this encourages clients to disclose difficult information.

4.3.4.2 Sub-theme 4.2: Follow at the patient's pace.

It was emphasised by most of the social workers that it is important to intervene at the patient's pace as explained in the following storylines.

"…*for me, before I start the psycho-social is for me to know where they are? What do they understand about the illness? Where is this going to? So that we are on the same page and then start introducing the services and giving the emotional support with that…I often hear I am going to fight this cancer, I am not going to stop fighting."* *[Participant G 34-42].*

"Because a lot of patients struggle to come to terms with the fact that they are palliative so they use denial as a way of coping. So, I believe in going with where (the) patient is at and to ask them what did they feel they are needing to cope or what would be best? And when I do give them information in terms of resources." [Participant A 63-65].

"…*with life-threatening illnesses it is so important that one realises that everyone copes differently, everybody is different even if the cancer is the same. That particular person is going to deal with the news differently and so it is also that I am not their expert. I cannot let them feel that I know what they should be doing and how they should be managing it. I can really be the person that can listen and empathise. Some people cope really well with a lot of information and others do not want to know what to expect. They prefer not to know so it is also being aware how each person differs you know and to do a very good assessment in terms of needs."* [Participant A 74-82].

"…*you never know what you are going to expect when you arrive at the patient and…I try to read what is going on before even trying to start a conversation and what they allow me to be part of I take and I run with it. If they put a stop to something…it's a unique situation. Sometimes people open stuff for you and then you intervene in a specific way."* [Participant B 75-79].

"…*it's pretty (much) meeting that patient where they are at. Sometimes you are able to do quite a great deal of intervention, sort of dealing with where they are at, what is happening."* [Participant I 47-49].

According to Sjoberg and Farsner (2020:2), person-centred care suggests that patients should not be classified in terms of their illness but should be integrated and accorded the opportunity to claim an active role in their care as contractual partners in every step. In other words, patients should be a part of the process every step of the way. Similarly, Ramsey and Montgomery (2014:1), concurs that the field of social work has long been identified as a profession that emphasises that the client must be at the centre of any helping relationship. Respecting and promoting the right of clients to self-determination and assisting them in their efforts to identify and clarify their goals is a prerequisite to the helping process (NASW 2018:7).

4.3.4.3 Sub-theme 4.3: Practice various social work methods and approaches

The social workers also spoke of the various social work methods and approaches that they use in their intervention strategies to meet the needs of people faced with life-threatening illnesses and this is expressed in the following storylines.

"*We are not there to replace the clinic sister; we are not there to replace the home-based carers. We are the support within the other networking systems that are in place…my strategy is individual work, I love individual work but I am also very comfortable with family meetings that is actually then our group, the old element of group work to practise that and especially important for me that, everyone in the family must have a voice.*" [Participant H 160-164].

"So sometimes on the extent of my involvement I would do the therapy of the children myself because I have done play therapy as well. I sometimes I refer them out to a specialist play therapists." [Participant C 64-66].

In terms of the approaches used by the social workers, specific mention was made of the person-centred approach and narrative therapy.

"…*I use eclectic approach in terms of my intervention. I use a lot of narrative therapy in the work that I do, so really looking at restoring this phase of your life, teaching them how to live until they die, not dying while living and really kind of doing a new…personal mission statement for this phase of their life.*" [Participant C 77-81].

"*So I think we work a lot with narrative therapy, part of our strategy is narrative therapy because if you can hear the story then you can understand what the patient and family's perception is where they are at and where they have come from and where think they are going…it is very much a person- centred approach…trying not to generalise but looking at each patient in their own unique needs in their process and their own unique perceptions of what is happening and how they cope."* [Participant D 89-95].

"…*I have a therapeutic approach. Obviously I use a person-centred approach but with a lot of focus on the narrative of their own life. So I would move away from the victim narrative to…how can we embrace this phase where you are in? What are the things that are hampering you to get on and to move on and what are the things that you would like to do about that? What are some of the dreams? ...also legacy work…where you really encourage people to do videos or I do it for them or write letters for their children or for their husbands or for the people where there is unfinished business - facilitating conversations to resolve the unfinished business…*" [Participant C 86-94].

Middleton, Head and Remke (2020 3), highlighted that it is the duty of the palliative social worker to provide supportive information through legacy work, including dignity therapy, acceptance and communication therapy. Additionally, Kyle (2015:8) states that it has been found fitting that narratives strategies are important in social work practice. Its focus and emphasis on the client stories are important to palliative care. Miley and Du (Bois 2010: 316) share similar views that that narrative therapy is a model that focuses on language and places emphasis on client's stories. It allows the clients to speak for themselves and to give voice to their own experiences, struggles, problems and hopes for change.

4.3.4.4 Sub-theme 4.4: End of life counselling and support

An integral part of providing palliative care services to people faced with life-threatening illnesses is to provide end of life counselling and support. Some of the participants made the following statements:

"…a lot of it is end of life, right at the end of life so a lot of our work is helping people to adjust to somebody who is actively dying, making sure the person is emotionally and spiritually comfortable. We do a lot of discharge planning from here and future care planning so a lot of patients that come in here cannot go home and be independent again. So a lot of our in-patient work is either facilitating care amongst the family and helping to train the family up to care for the patient or assisting with placement at frail care facilities and then a lot of our care outside is more the emotional support…helping people to cope within their home circumstances…" [Participant D 74-82].

"So because I cannot go out to their homes to do home visits I focus a lot on telephonic support when a patient does come in and also coordinate everything, making sure that everything is in place because at that moment…sometimes the patient says he wants to die in hospital but then there comes a point when the patient says I want to go home. And because the patient was not ready before now you need to do everything. You need to get authorisation from the medical aid; you need to make sure that there is a hospital bed; you need to make sure that the ambulance can take them; there is oxygen…my biggest role or my intervention strategy is once again communicating, listening to the needs. That is the biggest focus, addressing their needs regarding that last phase of their life." [Participant F 86-97].

"So, if the patient is willing and accepting the support that we provide and they buy into then we grant it. So the patients' needs to open emotionally their space up, open it for us to enter, for me it is standing with the patient in their end-of-life phase. Supporting them and their family members is holy ground for me, it is their sacred private space and it's for us to enter with their permission." [Participant H 18-22].

When patients are nearing the end of their life social workers play a very important role, they are involved in assisting patients with legacy building, they provide additional support, education to the patient and family, anticipatory guidance and to aid advance care planning and bereavement (Otis-Green 2020:7), Further, Glajchen, Berkman, Otis Green, Stein, Sedgwick, Bern-Klug, Christ, Csikai, Downes, Gerbino, Head, Parker-Oliver, Waldrop and Portenoy (2018:889), state that social workers are involved in educating patients and their families on the meanings of palliative and hospice care as well as learning and respecting culturally diverse end of life rituals and providing anticipatory bereavement as well as referrals for complicated grief. Moreover, social workers are positioned to address the psychosocial challenges of patients and assist those with life-threatening illnesses deal with the uncertainty brought by illness and be a guide while planning end-of-life issues (Hopp et al 2015:202).

4.3.5 Theme 5: Social workers' accounts of the challenges they often encounter when providing palliative care services.

After describing the services they provide, and their intervention strategies, the participating social workers were asked to describe the challenges they often encounter when providing palliative care services. Eight sub-themes emerged from their responses, ranging from the late referral of patients to inequality between private and public health care.

4.3.5.1 Sub-theme 5.1: Late referral of patients

All of the social workers identified and described the challenge of patients being referred to palliative care late as often being encountered. They also described the impact this has on the services they provide, some of the participants made the following statements:

"*So, we have learnt through the years to just go on and patients will come around and when they are ready then we will address the things that they did not want to speak about…nurses will come and say Mr Dangaz does not want to speak about this…But you know at a certain time they get to a point when they are now ready to open up. So, I will never force that, but it is sometimes challenging because of late arrivals of patients at our doorstep*." [Participant B 112-118].

"*…the one challenge is often times the oncologists or hospitals or state hospitals especially do not refer the patient for palliative care soon enough…that is the biggest challenge so that you land up…doing crisis management, getting everything organised and there is not enough time to build and have the meaningful discussions that you should have. So, in my ideal world the planning phase of palliative care, the difficult conversations, the expectations of what care should be like and adjusting to the palliative care concepts should receive more attention and the fact that it does not get done that way is a big challenge…it actually stops the efficacy of the kind of impact that palliative care can have, if you had time to do it properl*y." [Participant C 117-126].

**"*…the sister in the unit phoned me to say it looks like the patient is terminal and I don't know this person…I don't know the family… (I tried to) make contact…it went straight to voicemail, try other numbers, eventually got hold of a family member that must still come from Stellenbosch and by the time…the family member got here the patient had passed away. So now you have to break that bad news to a family member who just brought in that patient the previously day. It was not expected; there were no goodbyes, no nothing. So there was no closure so that's…really a challenge for me…If it's like a patient that we have a relationship with the patient and family, then you can walk that journey with them and it's much easier…it also depends on your contact with the family. If it's like weekly or two weekly then you can see the patient is going down. So*

you can start preparing the family members. I mean one will never be prepared when it comes to death but you can see that this patient is going down, he is not eating and losing weight, more in bed, the physical symptoms is there…the biggest challenge is to break the bad news when family members are not prepared.” [Participant E 142-160].

“*…or they (the oncologists) will just avoid not saying that it’s actually that your cancer is not curative, because…it’s too difficult for them to say it…so they give false hope without doing so intentionally, unintentionally and of course everybody that has a cancer diagnosis wants to believe that they will get better…So that topic often gets avoided and I think it’s definitely something (that should be looked at)…tertiary level…a whole module should actually be around palliative care (for) the doctors and how to talk to patients about the fact that this is not going to be cured but this is just buying you time and it’s your choice whether you want treatment or not*.” [Participant A 189-200].

“…*sometimes contact is made quite too late were in some cases there has been no opportunity to get a social worker involved earlier. So I find that part and sometimes I will be contacted the last minute and then there is not much I can do. I feel like I have failed because I have a minute to* provide *everything and it’s almost offensive. What is the point of having these sessions? So I find that very difficult that we could be included more or that we are made to sort of feel part of the team at the same time with other health professionals. It sort of comes like a package.”* [Participant I 65-74].

Efforts have been made to have early referrals to palliative care, however, despite the increasing rhetoric, patients with advanced diseases continue to be referred to as hospice-based palliative care very late in the illness trajectory (Allsop, Ziegler, Muley, Russel, Taylor & Bennett 2018:15).. This results in a missed opportunity to do better for the patient and their family and to optimize the use of health services (Allsop et al 2018:15). Further, Baek, Shin, Choi, Kong, Kim, Sohee, Won Juang, Joo and Park (2011:693), concur that early referrals make it possible to detect unfulfilled needs at the beginning of the end-of-life care, control symptoms, and reinforce the emotional connections between patients and family. However, late referrals continue to be the norm in palliative care, interfering with the optimal provision of the necessary services, this in turn leads to lower satisfaction with palliative care services, brief use of palliative care services and places a financial burden on the healthcare services (Baek et al 2011:693). It is also disruptive to the interdisciplinary and comprehensive nature of palliative care services (Baek *et al* 2011:693). Similarly, Diamond, Russell, Kryza Lacombe, Bowles, Applebaum, Jeanne, De Angelis and Prigerson (2015:78) postulate that late referrals are common in palliative care, patients are severely debilitated by the time they reach hospice and therefore derive little benefits from the interdisciplinary care services.

4.3.5.2 Sub-theme 5.2: Resistance and denial

Another challenge identified by the social workers was resistance and denial. Resistance and denial of the situation and the patient's condition can be shown by both the patient and family members. Therefore, this challenge is given in 2 categories, namely from patients and family members.

- From patients

When patients resist and deny their condition of having a life-threatening illness, this presents a challenge for the social workers providing palliative care services.

"*Definitely the resistance and denial that people have in not recognising and or accepting that they no longer can have treatment; that they are no longer able to be cured; that their time is limited. And that denial makes it really hard to help someone because I cannot talk to someone about a carer or hospice or give them information as to what to expect because they are very resistant to hearing that information….*" [Participant A 85-90].

**"*…for me even though I know that this patient is not going to make it, but this patient is telling you that you know I am going to walk out of this hospital by the end of this week. Then I cannot tell that patient No, you cannot. I need to keep that hope alive so I cannot…disagree with the patient…that is difficult because you know what is going to happen but the patient is not at a place where he or*

***she accepts that. So that is sometimes the difficult part…*”** [Participant F 280-283].

“*Patient and family does not want to talk about end-of-life journey and this is one thing I have experienced from the time I was here. That they cling to any form of treatment as that is giving them hope and that is helping them to fight this cancer. So that is quite challenging…It’s as long as I get treatment, I am okay, there is a possibility for recovery, although there is not. Although doctor has told them this is not going to cure you but the treatment is their anchor. That makes it difficult because you do not want to rob them of their hope and you want them to have a good life still but at the same time you cannot let them carry on in a world with unrealistic expectations. Because then it is a bigger shock to the family as well.*” [Participant G 64-73].

“*…as you work with humans there is always hope. So one of the biggest challenges that I have found is that…much of the time, there is a denial. I think denial can come in a different forms but I feel also denial is not necessarily a bad thing because it could easily be your coping mechanism…*” [Participant J 116-120].

Denial in cancer patients is a mechanism by the patient, or family members, or both, to avoid the reality of the illness, in many instances, the patient may refuse to talk openly about the disease or avoids using certain words associated with cancer (Onyeka 2010:8). Further, a patient may also delay seeking medical help, skip treatment and refuse further medical intervention or even defaulting on treatment (Onyeka 2010:8). This is further supported by Siemerink, Jaspers, Plukker, Mulder and Haspers (2011:66), who state that denial in cancer patients is a common phenomenon in clinical practice, it is a defence mechanism against painful or threatening diseases. Denial of diagnosis mostly takes place early in the process and decreases over time, although it sometimes increases due to disease progression (Siemerink et al 2011:66). Summing it up Rossi, Giorgi, Baiard, Giuntoli, Balestroni, Cerutti, Monera, Gabanelli, Solora, Fornora, Luisetti, Omarin, Omarin and Vidotto (2017: 910), assert that the onset of a terminal illness or disruption can cause psychological distress and trigger the emergence of defence mechanism to contain it, denial preserves a person from something that they are not yet ready to face.

- From family members

Family members also demonstrate resistance and denial with respect to the patient's condition. This is confirmed through the following extracts from the participants:

"*Another challenge yes is when the family is in denial and they do not want to acknowledge that this person is not going to live much longer… Another challenge is when patients or family members are non-compliant and so in other words the doctor will give them a script and tell them how to use the morphine for pain, adequate pain management but they do not follow the script as prescribed and then they have pain and then they phone and they are in distress but they haven't actually, when we further investigate, we realise that they did not take the medication as prescribed so that is also difficult.*" [Participant A 99-106].

"*…sometimes I feel it is just really difficult because once you are at that point where you cannot do anything then it goes very quickly and although you need to start preparing the family before that…the family does not want it. So it is not that doctors do not refer earlier because they forget to do it or they don't think about it. It's because they also need to focus on where the family is at…this type of cancer is just very aggressive and things go wrong very quickly so it is challenging to do it from our side if the family and patient is not ready for it."* [Participant F 132-138].

"…*but where families are too in denial to understand the seriousness of the illness and the fact that they will not be around to see their children get older and not actually engaging with the children to have a proper separation and preparation for death, it is very traumatic, very, very traumatic for the patient, as well as for the family and for the children especially."* [Participant C 59-63].

A cancer diagnosis causes trauma on both the patient and caregivers, caregivers make use of various coping strategies to minimise the anxieties caused by the disease and these can either be positive or negative and denial is one of them (Aydogan, Doganer, Komurcu, Ozturk, Ozet & Saglam 2016). Further, Olson (2011:908), asserts that the way carers of cancer patients have responded to a cancer diagnosis has been at the centre of psycho-oncology, some of the literature state that the maladaptive coping strategy denial is prevalent amongst carers. Additionally, a cancer diagnosis does not only affect the family but also the caregivers, caregivers are confronted with a lot of physical and emotional challenges during the illness of a loved one (Olson 2011:908). However, they have hope and sometimes they refuse to accept the diagnosis. In certain instances, they encourage the patient to take fewer meds than prescribed so that they can be awake for longer, and they hope for a miracle, these behaviours have been described as denial (LeSeure & ChongKhom-ong 2015:407).

4.3.5.3 Sub-theme 5.3: Stigma linked to hospice and palliative care.

The social workers also mentioned that the stigma linked to hospices and palliative care is a challenge they often encounter. The following statements were provided by the participants regarding stigma:

"*…the challenge I would say is the stigma regarding palliative care, because I try to implement it from diagnosis and some patients are very open and they accept that type of care at home. So I make that hospice referral right at the beginning and they meet the family and help with the transition when they are in the hospital, going back home. You know those patients do incredibly (well) because they have that support at home too, not just here at hospital or via telephone. So the stigma is a big challenge…*" [Participant F 110-116].

"*…then the other thing is the stigma that is around a hospice because if your car is parked in front of my house, someone is ill and I do not want the community to know that someone is ill or that someone is dying and I actually do not want anyone in the community to know that someone is dying…the barriers that we need to break down about the stigma of, oh but hospice means dying or the fact that I am going to start using morphine is dying…*" [Participant H 172-178].

"…and there is also a lot of stigma I think from patients or families as to what that means and why social workers would need to be involved in this kind of process." [Participant I 67-68].

Palliative care is crucial to managing symptoms, pain and transition to end of life care among those that are faced with serious illness and even though it is often underutilised, contributors to underutilisation may be due to stigma associated with palliative care representing giving up one's illness (Johnson Shen & Wellman 2019:378). Further studies have shown that patients with life-threatening illness perceived (at least initially) palliative care as being associated with death, giving up and reliance on others (Johnson Shen & Wellman 2019:378). On the other hand, hospice has a potent stigma attached to it, it is viewed as the last walk towards death and an option when all medical interventions have failed and hospice is often associated with giving up and giving in to the inevitability of death (Botek 2019:1).

4.3.5.4 Sub-theme 5.4: Patient's condition

Patients' conditions and the stage in which they impact service delivery and can present challenges for social workers. The following statements demonstrate the participants' viewpoints:

"Our patients get tired really easily at times so…you say to yourself this is what we are going to do for today and I have an hour but after 10 minutes the patient is tired…our job at times it's challenging, it's difficult you can't really plan like today I'm going to see…three, four patients. I mean it is like for instance in the afternoon your patient was talking. Before you go home you go into the support centre and greet the patient and say I will see you in the morning…the next morning when you pass the room then the bed is empty…so you work with what you have at that moment." [Participant E 120-128].

"…comfortable in the sense I feel secure to a certain extent and then they get the news but the cancer didn't respond the way that we thought it would and I am sorry but we cannot carry on with treatment and that is the next peak and the trauma and anxiety…and the people the first thing they would ask me is what

can I expect, how long and what will be the symptoms that I will need to cope with? So it is a difficult one." [Participant G 82-87].

Patients diagnosed with a terminal illness face many anxieties and uncertainties, the diagnosis can create extreme disruption in the life of almost any individual, a cancer diagnosis can create a threat to one's general sense of security and orderliness in life, no day is predictable and waves of emotions that are intense similar to grief reaction with periods of calmness are common (Williams & Erlank 2019:6). Additionally, Garman (2018: 15) asserts that weakness, confusion and fatigue are common in advancing cancer and these make it impossible to maintain control of the environment and what is happening to them. Aspects of the self are lost, as the patient can no longer maintain everyday skills, interests and relationships (Garman 2018:15). Approaching the end of one life, coupled with a progressive disease can bring a lot of stressors to the patient and family, there are uncertainties and these make it difficult for healthcare professionals to plan any meaningful interventions, there is little time left for therapeutic processes, even where arrangements are made patients cannot finish the sessions due to fatigue (Cavallo 2014:2). Summing it up Sanders and Swails (2011:129) are of the view that social work values are grounded in equality and the belief that patients regardless of the disease can benefit from therapeutic services, this involves a two-way communication and client's involvement during the therapeutic process for terminally ill patients (Sanders and Swails 2011:129). This is a challenge given their inability to engage in this type of relationship, they face fatigue, confusion, tiredness, fall asleep easily and this leaves social workers asking themselves if their involvement had any purpose at that stage.

4.3.5.5 Sub-theme 5.5: Family-related issues

The social workers indicated that family-related issues can also present them with challenges. Some of the participants pointed out the following as challenges they encounter: -

"Now when you have a close family that's great but when you have a family where there has been a lot of dysfunctionality and a lot of baggage. I find it quite challenging and sometimes sad because you cannot come to a good

termination in the sense, the patient dies without sometimes that business being done, so that has been quite challenging.” [Participant C 48-52]

“*…there are also a lot of people that do not have funeral policies. And then it is a struggle for the family to get along and they get cross and you cannot do like this (snaps fingers) and there is a funeral policy. So we try as soon as the patient arrives and there is work then start working and need to get the application then the social auxiliary workers run with it.”* [Participant B 105-109].

According to Onyeka (2010:8), family relationships and their interconnectedness can affect chronic disease management outcomes, the psychological mechanism involved in the disease process can be influenced by the general calm and harmony in the family or the disruptive effects of family enmity and criticism. A cancer diagnosis affects the whole family and brings about great degrees of psychological distress to everyone involved (Onyeka 2010:8). All parties involved have needs that need to be met. Additionally, Reigad et al (2015: 6) articulate that social workers in palliative care endeavour to stabilise the anxiety faced by the patient and family and the whole palliative team. Hill-Jones (2015:28), adds that challenges may arise then the patient family members disagree, examples include family members demanding inadequate medication so that clients remain alert or family members wanting patients to continue receiving full baths when it has become painful for them. Sometimes patients are afraid to make decisions or fear disagreeing with family members.

4.3.5.6 Sub-theme 5.6: Interdisciplinary team members do not always understand or accept the role of a social worker.

According to Glajchen et al (2018 891), social workers identify knowledge and clinical deficits among frontline clinicians, there is widespread confusion about palliative care terminology and the role of social work in the fields. Similarly, Sanders, Bullock and Broussard (2012:11), point out that some challenges to social work collaboration with other members of the interdisciplinary team include the fact that social workers have huge caseloads, a heavy focus in hospice care on the medical model and sometimes limited social work visits. It has been noted in previous studies that social workers have difficulty articulating their role and often feel that they get involved at the requests of the nurse and thus roles are not clearly defined as there is role overlap with other members of the team (Sanders et al 2012:11). Further, Parker-Oliver (2012:2) shares the sentiments that that hospice social worker’s role on the team and the role with patients are often confused and blurred with nurses and chaplains, it is therefore evident that the collaborations among the interdisciplinary team which often require disciplinary responsibilities to overlap, make the challenge of defining social work perhaps greater. This ambiguous nature of the role of social work in hospice care is due to in part to the lack of standardized assessment across hospice settings (Parker-Oliver 2012:2). This is what participants D and J have to say:

“*So for social workers in palliative care, I think it is very challenging because hospices are very nurse driven or have been historically been nurse driven. So we constantly have to advocate for our role and I think there is this general consensus that everyone can do counselling even though they do not understand the in-depth nature of how we are trained to do our work. So it’s challenging on a professional level for the profession as a whole.”* [Participant D 105-110].

“*Another challenge that I have encountered in rendering palliative care services is that we, being social workers Hospice movement is more medically driven. There is always those hierarchy obstacles, a doctor say, nurse say, much of the time you are on the back (foot)…Even if you look at our health system, people if they have a headache or sore throat, they are more likely to seek treatment. But sometimes we are also a little bit down and you are not feeling yourself but the emotions are usually not the first thing that are taken care of. So I think me working as a social worker my role is not always seen as an essential service. It is a complementary but it takes the last, it is not the first on the list…hospice movement is still more medically driven in its nature.”* [Participant J 128-138].

It is evident from the quotations above that social workers while working in an interdisciplinary team sometimes they experience the challenge that their team members do not always understand or accept the social worker’s role.

4.3.5.7 Sub-theme 5.7: Emotionally challenging

The social workers referred to the services they provide as being emotionally challenging. The participants voiced their experiences in the following terms:

"*The other challenge I encounter is just really having to myself come to terms with the fact that this person is going to die and I have now established a connection with the person. So emotionally it is draining and it is sad for me. The impact it also has on the rest of the person's immediate family, it is hard because then you are looking at the teenage daughter, the teenage son of the patient and the effect it is having on them and how do I support them, so it's a ripple effect."* [Participant A 106-112].

"…*what is difficult and challenging part is the family and what their state of mind is, what they want and what they do not want and what they're thinking about palliative care. That is the most difficult part and also supporting the families during that last part you know. You don't have the words that are going to make anything better although you specialise maybe in palliative care, even though you are a palliative care social worker. I do not think we want to do something, we want to help but there are no words. I think that is also one thing that is so challenging for me and I must say palliative care personally for me is difficult for me to do. It is one of the biggest roles I need to fulfil here…*" [Participant F 277-291].

Palliative care professionals are exposed to recurrent distressing events daily, this exposure to death and dying and witnessing the physical pain and suffering in patients, results in social workers and others absorbing negative emotional responses (Portoghese, Gattetta, Larkin, Sardo, Compagna, Finco & D'Aloja 2020: 2). These healthcare professionals are at risk of reduced psychological wellbeing as a result of inadequate organisational strategies related with these demands (Portoghese et al 2020:2). Further, studies have revealed that professionals working in end-of-life care are at risk of stress, burnout and mental ill-health, they may exhibit chronic stress symptoms which include being emotionally exhausted (Franco, Tesio, Bertholet, Gashier, Gonzalez del Portillo, Bibault, Borst, Elmpt, Thorworth, Mullaney, Redalen, Dubois, Chargari, Perrryck, Heukelam, Petit, Lybeer & Castelli 2020: 7). Frequent deaths and burnout in palliative care settings may inhibit the ability of social workers and other Healthcare professionals to completely perform job-related responses hence feeling of emotional exhaustion (Pessin 2015:2).

4.3.5.8 Sub-theme 5.8: Inequality between public and private health care

The inequality between public and private health care was raised as a challenge that the social workers encountered.

"I am very, very, much concerned about the inequality of service delivery between the private and public health sector. The total lack of awareness about the importance of palliative care… but that lack of resources for state patients in my mind is a human rights issue…I often got a call from people from the State hospital saying that they sent me home and said there is nothing more I could do and they even didn't give me any pain medication. So they were sent home to rural areas without morphine, without a note to the clinic saying this is the situation…they were sent back just get out and it often left them feeling very, very vulnerable and abandoned and the primary health care clinics are not equipped to deal with palliative care…" [Participant C 127-141].

"…*I don't think there is time to spend with people, enough time to help them, those that are palliative. I think that there are so many needs out there that I would say there needs to be more posts available specifically to help patients come to terms with palliative care. I think often those patients are…once they are out and they're no longer receiving active treatment it's like now you can go home that's that and now look after yourself.*" [Participant A 242-248].

According to Gordon, Booysen and Mbangaba (2020:2), the South African healthcare system is tiered with the least advantaged heavily dependent on the under-resourced public sector, while the wealthy many of whom have private insurance use the private sector. Additionally, in South Africa, better off individuals make use of private health care while those who cannot afford and are worse off depending on the public sector. The private sector serves just 16% of the population while absorbing almost half of the country's health expenditure (Maseko & Harris 2018:22). Further, South Africa boost a strong private health care sector allowing access to care for just 16 % of the population and an inefficient, poorly managed state healthcare system which is the reality of the day for poor South Africans (Dhai & Veriava 2012:520).

4.3.6 Theme 6: *Social workers' descriptions of how they deal with the challenges experienced when providing palliative services.*

After having explained the challenges they encounter when providing palliative care services, the social workers were asked to describe how they deal with the challenges they highlighted. Their responses are given in six sub-themes that range from peer support and supervision to know yourself and be comfortable.

4.3.6.1 Sub-theme 6.1: Peer support and supervision.

Most of the participating social workers identified peer support and supervision as the means by which they deal with the experienced challenges. The following are extracts from the participants:

"*In terms of individual challenges, I always ensure I have good support for myself in terms of preventing burnout. I go for regular supervision…But I do belong to professional organisations the Proprac where we have like this afternoon…a case discussion around palliative care patients so I do a lot of things academically to enhance that skill…"* [Participant C 161-170].

"*We meet three times a week as a full team, so there you can also talk about your experiences with a specific case, or perhaps frustrations, perhaps celebrations. You know you have got to look at the positives as well. So we are faced a lot with what people would call negative discussions, depressing things. We have a large sense of humour here that probably other people will think is abnormal…we have moments where we can laugh about things. Yah It's important to have a brighter side as well."* [Participant D 143-150]

"…*I think team support is important because your social workers in palliative care are isolated - it may be one social worker for a hospital or an organisation…*" [Participant D 199-201].

“…as a team, I mean we check in every morning, how is everybody doing?...before we end our day here how was your day, what was challenging?...we talk about stuff ok I am going to see this patient I really don’t know; it’s a new thing for me whatever, and you come back, how was it? Are you okay? what can one do for you so, that regular check-in it helps…because it’s really challenging…you go on a home visit you have like three visits for the morning you must go in there you open yourself up to that patient and family.(then you) get in the car and must get yourself ready for the next one…after the day the office is just that, your safe space where you can debrief and you know that your colleagues are there.” [Participant E 220-233].

“…I am part of the social worker forum in the community so the social workers within the…area is my support and…we provide forum discussions and peer group sessions so that’s good and obviously within the HPCSA there are social workers forums that we attend.” [Participant H 222-225].

“I think one of the best ways for me to cope is just to talk about it. if I have a difficult case or a very sad case where somebody’s pain is unmanageable irrespective of what medical interventions because that I find hard. When I see someone suffer, you see a lot of suffering with palliative care and then I need to talk, I need to debrief. So, I will perhaps have supervision, I will talk to my fellow staff members on the team…” [Participant A 116-121].

“…we do have monthly supervision. If I have to be truly honest I don’t get much support from there, simply because it’s more caseload driven, it is all about management of the caseload… However, much of the support comes from the peer support…if you do have a good working relationship with your other interdisciplinary team it’s very helpful because the burden does not lie with you alone. You get to share, you get to be provided with an opportunity or platform to express your difficulties and people are most likely to offer different suggestions on how they manage maybe a similar experience or sometimes even sharing and knowing that you are not alone…(in) experiencing difficult similar situation.” [Participant J 157-167].

"…we are three social workers…and when it comes to that point where you know that…you have to break the news (to family members) you have the support of your colleagues and they will come in. It's not like I am now alone with five family members, I have to break the bad news. This one screams, this one shuts the door, this one just stares at you, so who do you attend to now? So that is where we have our colleagues and support who step in and support us…because you cannot control like five people at the same time." [Participant E 160-168].

Learning from Supervision is an important component of the education and training of social workers, supervision allows social workers to seek and receive emotional support for undertaking what can often be a demanding and stressful role (Moriarty, Baginsk & Manthorpe 2015:17). Moreover, Harr (2013:73), points to "support" as a crucial strategy for increasing compassion satisfaction. Support can and should come from many places, from management within the organisation, administration, line managers, colleagues and family members. To add, palliative care social workers highlighted the benefits of external peer support whereby they were engaged in a network of palliative care social workers practising within other settings (O'Callaghan 2014:212).

4.3.6.2 Sub-theme 6.2: Debriefing

Social workers identified debriefing as a way to deal with the challenges they encounter in practice. A few quotations below demonstrate participants views on debriefing:

"…you can also go for three debriefing sessions a year with an outside psychologist or therapist." [Participant A 134-136].

"*We have somebody that we can contact if we need to debrief or need to speak. We used to have group sessions but if we want a one-on-one then we are allowed to contact her for one-on-one.*" [Participant B 145-147].

"…we debrief a lot in the office…I am the Manager of the Department. I do formal supervision but we have a lot more informal supervision than formal

***supervision because we need to debrief on a day-to-day basis. So we have a very much open-door policy in the office…if you have had a challenging moment or you are frustrated or whatever it is, you can actually come in and offload for a few minutes and we move on. So we try to take it as immediate. If you need to talk, get it off your chest now because we got to get to our next patient.*”** [Participant D 128-135].

“…*I take my work home a lot, especially emotional side. So I need to see my psychologist once a month for debriefing to help me deal with difficult situations; how to have difficult conversations with families; and how to help them through trauma. So my psychologist is the person who I go to but not enough at this stage…you do not get time but you need to make time for it and then you actually need someone. I actually need a Supervisor who is in this field who understands the dynamics of this field.”* [Participant F 334-341].

“…*debriefing especially in the ward when we have had like a very difficult death from time to time we do have a debriefing session and that has proven to be very helpful.”* [Participant J 168-170].

An approach that helps reduce the various symptoms of post-traumatic stress in palliative care social work is debriefing (Williams & Erlank 2019:3). This is supported by Keene, Hutton, Hall and Rushton (2010:185), who states that debriefing is one of the approaches that can be employed with the aim to providing emotional support and increase one’s ability to be able to manage the end-of-life processes in palliative care especially grief and death. Moral distress is a common occurrence in high stake health care settings that include hospice and palliative care settings. In such settings employees may benefit from brief interventions called debriefing when exposed to traumatic events (Keene et al 2010:185). The affected members come together to acknowledge shared distress, accept responses to that distress, to affirm the group’s human suffering to help the group cope (Danna & Romon 2007: 39). In summing it up (Kelley 2014:5), contends that’s debriefing is not therapy but allows staff to acknowledge their grief and loss at their own pace. It is an opportunity to share experiences among peers around grief and loss. It’s a time to reflect and support each other.

4.3.6.3 Sub-theme 6.3: Attending training opportunities.

The social workers expressed how attending training opportunities helps considerably in dealing with the challenges presented by their work. Some of the participants had the following to say about attending training opportunities:

"…also what I wanted to say with coping with challenges where the organisation also links in is with training. I find that going to training on palliative care or just training in general professional development as an Oncology Social Worker that helps me as well…" [Participant A 139-141].

"*I do quite…a lot of extra training so that I equip and renew myself.*" [Participant C 163-164].

The above-mentioned quotations are supported by Ostadhashemi, Maliheh, Khalvati, Eghlima and Reza (2019:3), who state that social workers reported that due to the existing academic limitations they use strategies of self-learning and participating in in-service training to increase their special capacity, as well as attend conferences and workshops where possible. Similarly, Yi, Kim, Akter, Molloy, Kim and Frozier (2018:9) assert that if social workers are to be competent in palliative care, they need to embody the professional social work values, acquire the necessary knowledge and continually enhance and update their knowledge and skill to ensure that the practice is of the highest standard (Hughes et al 2014:305). The use of ongoing assessment and training of staff and the development of programs that encourage appropriate engagement activities are some of the ways to support palliative care practitioners (Cross 2019: 27).

4.3.6.4 Sub-theme 6.4: Proceeding at the patient's pace.

The social workers acknowledged that allowing the patient to lead the process helps them considerably in dealing with the challenges presented by their work. A few quotations below demonstrate the participants view:

"…*I don't have a lot of ways that I have or that I can mention and tell you this strategy works or I have done this to address this kind of issue or challenge…If I know the prognosis it's easier to have a conversation and say you know we*

***have had patients with similar diagnosis and with this prognosis. They had questions about what is going to happen, how will my body deteriorate, what type of support will be necessary, when do we start this? And then I will ask them, do you have similar questions or thoughts about that to try and…start a conversation regarding that sort of thing. Some patients will shut down immediately. They do not want to talk about death, because no one wants to talk about that but then our other patients do and then I have the opportunity to go further and have that discussion that's very necessary.*"** [Participant F 151-161].

"…I always say to myself it's not my responsibility at the end to make it lighter for them - it's their decision. My main thing is that I tried to take small steps and not leaps…if we only touch one issue in a conversation then it's ok because this is this is traumatic not for all…there (are) patients that have total peace, they actually knew that this was coming, they had a good life, good relationships that have got strong faith so there are patients would really say to you I am okay with the road ahead. But others not so….and I think exploring statements like I've got to hope. So what is this hope for, what does that mean to you? Hope for curing, hope for being amongst my family in this time, hope that I'm not going to be suffering severely at the end…what does it mean? So I explore these statements of I'm going fight the cancer, I'm not going give up, I'm having faith and what does it mean?" [Participant G 90-100].

"…*if there is conflict…clear it up. We have to talk and to maintain the focus on the patient the whole time. So if you always come back to the patient and the best interests of the patient that can usually help to resolve the conflict because then everybody is working towards the same goal and if we have to remind people that we are working towards this but yes there are moments and sometimes you have to also recognise it for what it is.*" [Participant D 160-166].

According to Levil, Bologh, Nass and Ganz (2013:94), the crucial elements in patient-centred care are effective communication and shared decision making, these components require informed participation from patients and family and should be supported by accessible well organised and responsive health care system. These components enable the concerned patient to follow their own pace and self-manage

(Levil et al 2013:94). Additionally, Etkind, Daveson, Witt, Kwok, Higgison and Murtagh (2014: 618), state that an important principle of palliative care is to meaningfully engage patients and their families and allowing them the choice to lead the way and control as much as possible over their care so that they can have a voice to describe their experiences across the continuum of care.

4.3.6.5 Sub-theme 6.5: Patients' satisfaction

The social workers also spoke of how patients' satisfaction with their services enabled them to deal with the challenges they encounter in their work.

"But the biggest reward in this work are the people who we work with; the meaning that you derive from making good death possible. For me, that is the most gratifying and even if it is that little bit, that's enough. So I take a lot of solace from that." [Participant C 164-167].

"…*we have got the passion to do this. People often say to me really do you like your work? And then I say to them…patients encourage me often because they are the strong ones, the positive ones, the ones with a smile on their faces even if they feel terrible, the ones that are so encouraging to me. Sometimes when I walk away from an interview then I think I have been more uplifted I think more than they have been…you realise the thankfulness also and the outlook on life."* [Participant G 176-183].

This is supported by Pessin, Fenn, Hendriksen, Derosa and Applebaum (2015:5), who state that there is evidence that social workers find meaning and purpose from providing palliative care services and this, in turn, acts a protective factor and helps them diminish burnout. Sanso, Galiana, Oliver, Pascual, Sinclair and Benito (2015: 201), add that most palliative care team members have reported a high level of satisfaction and meaning in their work acknowledge that caring for the patients facing the end of life can be enriching and beneficial. Furthermore, Murray (2015:8) postulates that compassion satisfaction is derived from a sense of satisfaction that comes from helping others and giving your all in your work rather than having a negative effect, practitioners report It as a positive motivator.

4.3.6.6 Sub-theme 6.6: Self-Care

Some of the participants added that they also were mindful of self-care when dealing with the challenges they meet when providing palliative care services.

"…*also just looking after myself. Like I know for myself I have got to exercise often. I've got to have time for me to just do my own thing you know and timeout where I am not busy with anything. I need to have something to look forward to in the weekend where I switch off from work, do not read anything about death or dying, do not look at my computer. So also, just looking after myself, it helps to cope and I think also because I work 8 until 2pm that definitely also helps in dealing with challenges emotionally because I am not busy 8 hours a day just counselling.*" [Participant A 125-131].

"*My coping strategies at home are my pets, uhm so they are kind of my go-to. I like nature so spacing out to but I make sure that we take lunchtime, we space out, I make sure that when I am on leave my phone is off so I am on a break am not working on a weekend am off. Uhm so you have to have that break, you have to be able to try and switch off and like when I drive away from here I leave my work here or I try to, it is not always possible…*" [Participant D 137-142].

***"We have got a gym just three minutes' drive from my work. So when it's lunchtime I'll get into my gym class and I go and do a workout and I shower, get into my car. When I get back and start my head is open again, I have got some more energy for the rest of the day" She added: "…after hours I like nature, reading, animals. My faith is really I can't do this with without my faith in God and trusting Him for guidance and wisdom.*"** [Participant G 166-174].

According to Miller, Lee, Niu, Grise-Owens and Bode (2019:3), self-care is a purposeful engagement in strategies that promote healthy functioning and enhancement of wellbeing, they can be spiritual, social, physical or psychological. Further, Haley (2018:89), state that self-care is a crucial exercise for social workers who wish to maintain a healthy balanced life, it is argued that those who do not engage in self-care practices are not able to provide the best possible services to clients.

McGarrigle and Walsh (2011), describe self-care as a spiritual act that requires one to be self are and love themselves which also points out to the values of christian living.

4.3.6.7 Sub-theme 6.7: Know yourself and be comfortable.

A common response to the question of how they deal with the challenges they encounter in their work was that the social workers said that they know themselves and are comfortable in that knowledge.

"*I think very important, for all the team players that the nurses and social workers is you must be content with your own personal being…You must be grounded, you must be comfortable with your belief system and you must be comfortable with who you are. You must be grounded to absorb the impact of the families and the dynamics of patients and I think some patients trigger certain personal experiences and some patients are more comfortable with just managing on an empathetic professional way and I think we need to be honest with ourselves and acknowledge that this certain patient is ticking points that I experienced in my own losses maybe or my own fears or whatever…*" [Participant H 190-199]

"…*a lot of the time I feel some of the things are out of my hands, as frustrating as they are. To me it is about looking at my own process and reflections on a case by case. So you know if there is something more I could have done or is this one of the situations where I was kicked out or called in too late or something like that. So I think it's case by case but a lot of time I think it's sort of out of our hands.*" [Participant I 80-84]

"…*I also had a conversation with one of my friends…and she said how was your day? I said it was good…but a patient passed away earlier and so the response immediately from my friend's side was I'm so sorry to hear about that. So I said that is part of life it's reality. When you are faced with death or when you work in a setup like hospice, death becomes reality…I am not cold when it comes to death, I am still human and I still have feelings. But it just shows you that like it's about there is a time to be born and there is a time to go. I think that is more*"

reality. But sometimes…I also struggle like I said I am human…” [Participant E 197-207].

“*For me it is a calling to work. I do not think any social worker is …comfortable with death and dying. That is the reality of palliative care. Patients that are going to be referred to you are not going to get healed…you as a social worker you must be comfortable with seeing people frail and seeing people not able to walk or seeing people bedridden, with wounds…you can see yourself comfortable within a role in an interdisciplinary team focusing on palliative care. I think that is something that you need to be comfortable with. That comes to the point of knowing who you are, know what works for you*.” [Participant H 289-303].

According to Bennet, Zubrzycki and Bacon (2011:25), social workers need to know who they are and be reconciled with themselves, they should know the knowledge they possess and their identity because the identity of people impact practice. Additionally, Kaushic (2017:23), state that therapists need an awareness of the self, including their identity, cultural perspectives, personal goals, dreams, their needs, strengths and weaknesses, his knowledge and understanding enables you to facilitate the same kind of awareness to clients. Lastly being aware of one’s identity is a crucial element to the successful therapeutic use of self (Sabo & Vachon 2011:584), it is a combination of self-knowledge and developing ability of dual awareness a stance that allows social workers to attend to the needs of the patients, the work environment and own subjective experience.

4.3.7 Theme 7: Social workers’ level of satisfaction with the palliative care services they provide to people faced with life-threatening illnesses.

The next question that the social workers were asked was about how satisfied they were with the palliative care services they provide. The social workers’ responses ranged from not satisfied; satisfied in general and proud.

4.3.7.1 Sub-theme 7.1: Not satisfied.

A few of the social workers said outright that they are not satisfied with the services they render.

"*…sometimes I am and most of the time I am not because of the lack of enough trained professionals, is not enough to render proper palliative care services… there is not enough home nursing - patients cannot afford home nursing because it's too expensive. A lot of the medical aids do not have the palliative care benefit. Discovery has the advanced illness benefit but a lot of them do not have that. So we have done a lot of advocacy around that, but that's not enough*." [Participant C 173-181].

"*No definitely not because I would like to have more time. I would like to be able to render this service to all our patients but because there are so many patients, some patients you know they fall through the cracks and that is so sad to say out loud. I feel very guilty on a daily basis. I feel guilty because I feel like I am not giving to every single patient and family and if I am rendering services to one patient and family…I know exactly all the different types of needs that they have and I know that every single patient and family is struggling and they cannot cope with this on their own. So no, I am not satisfied…*" [Participant F 164-172].

According to McCormick *et al* (2010:297), prior studies have suggested that having many cases at a particular time may be an obstacle to delivering effective services and high caseload has been associated negatively with social worker satisfaction with meeting family needs, heavy caseloads limit the amount of time a social worker allocates per family and greatly reduces their ability to meet the needs of the patients. Additionally, it has been noted that in South Africa problems in healthcare are worsened by inequalities in the distribution of healthcare professionals between private and public health and this impacts the effective delivery of end-of-life care services as well (Maphumulo & Bhengu 2019: 2). Kritsotakis, Koutisa Alegakis and Koukaili (2012:91) state that patient satisfaction has emerged as a powerful determinant and outcome of health care quality.

4.3.7.2 Sub-theme 7.2: Satisfied in general and proud.

Moreover, some participants indicated that they were generally satisfied and proud and this is confirmed from the extracts that follow:

"***I think yes, I am satisfied but I often think, this is what makes it hard…People need to…make use of the services earlier, but what makes it difficult for them is they are not ready to accept that they are palliative now, that the treatment is no longer curative. We are now looking at the best supportive care which is palliative care…one can always look at a case and go I could have done more follow-ups you know; I could have rather given them the information earlier or broached the topic earlier. So yes, I am satisfied, because I think the service here is free for patients, they do not pay for it, it's part of being a patient at our organisation…*"** [Participant A 151-164].

"***I think working in private practice places…I am satisfied with my services that I offer and I am confident that I can ascertain sort of individually case by case, meet people where they are at and just be able to be with them and maybe their own pace. And I am comfortable with my knowledge of palliative care and how to be sensitive enough and be supportive, using the necessary skills...But if I was to be in a team, I think there is the possibility to be inhibited by members of the team so I think I feel confident in my abilities on my own in a way than what I would be in a team."*** [Participant I 98-105].

"***Yes, I am very proud of my place, I am very proud of what we do, and knowing where it's coming from what we are doing. I really believe we are doing our best. We are not perfect we will never be perfect. We all make mistakes everybody will not accept you, will be pleased with what you do but we really try and if we did something wrong we are big enough to go and say sorry. So I do not have any doubt that the care we give is the best care that we can give.*"** [Participant B 152-158].

"***…there is no other organisation that renders the service we do…I think people are appreciative of what we do…and we work with people that stay in the squatter camps and people that stay high up in the mountain so there is no differentiation when it comes to our services so we won't treat someone different if he stays on the ground compared to someone that stays up in the air…just to…care for a patient in our unit it costs us money because we are a five-star hospice and that says something about us, and we try to keep it there,***

not to say that we can't improve but we try to improve…we're on Facebook…and the community can say what they want…or comment…if there is something negative that happened…But I think the community that we serve they do have respect for us... " [Participant E 236-251].

Hospices make use of interviews and surveys with families of patients who have passed away to evaluate the level of services with hospice and their programs (Doten 2020:7). This has been done for over 20 years by mailing questionnaires 2-4 months after their loved ones have passed away (Doten 2020:7). Additionally, when patients report that they are satisfied with the services, this is used as an ultimate validator of quality care and its quantification is an important aspect in assessing the health care system. These surveys assist in improving the quality of health care, maintain and improve the image of the healthcare profession in terms of empathy, willingness to listen to patients and improving communication with the patient) and to provide a comfortable environment for the patient (Obrocnikova & Ludmilla 2017;22). Similarly, it has been noted that satisfaction with services is often selected as an outcome of social welfare programs, satisfaction has continued to be used as a measuring tool, the reason being if recipients of services are satisfied services are considered at least in part successful (Fraser 2013: 11). Partinico, Cora, Ghisi, Quimet and Visentin (2014:299), supports this and states that an important aspect in the evaluation of palliative care is the assessment of clients and caregivers reported satisfaction.

4.3.8 Theme 8: Social workers' suggestions regarding the nature of the palliative care services provided by social workers.

After describing their level of satisfaction with the palliative care services they provide, the social workers were asked whether they had any suggestions regarding the nature of the palliative care services provided by social workers.

Their responses are given in 5 sub-themes that range from training to change attitudes.

4.3.8.1 Sub-theme 8.1: Training

The issue of training for social workers in palliative care was suggested by many of the social workers. This sub-theme is divided into 2 categories, namely undergraduate level; and specialisation.

- Undergraduate level

Many of the social workers suggested that palliative care should receive more attention at the undergraduate level of social work training.

"*When I was at University…we did not have a module on death and dying or palliative care. We had perhaps a chapter or two in books, but there was no focus on palliative care. I have had to gain this knowledge through experience in working with patients that have been diagnosed and also just in my own training…I would say definitely palliative care needs to be more focused on at tertiary level in your social work degree.*" [Participant A 209-216].

"*…a lot of us are also trainers. What is important is that you need to do a course in Psycho-social palliative care to have an understanding of the type of work that we do because…we are not really trained into this field. This is something new if you come into this field and you actually grow as you go along, but there is definitely literature…and courses…that you can actually get…to upskill yourself, to deliver the best service that you can deliver…I have experienced…with the students it's an eye opener because they have never seen this type of work and do not know what to do. They cry with the patients the first time…because they don't know how to deal with it. They never received any training in that specific field so I think for me really if they can put something out there for social workers…even if it is just a short course.*" [Participant B 181-197].

**"*…has done a lot to help facilitate the development of social work skills even on an undergraduate level because all social workers work with loss and grief. So palliative care should be part of the curriculum of doctors, of nurses, of social workers much earlier, not only at the end as a specialisation but as part of the*

***curriculum. I think that is one of the challenges that we need to look at*.”** [Participant C 149-154]

“…*I know there has been a lot of advocacy for education within your degree training…it’s really important and I know they have started integrating that in the medical courses but there is not really anything in Social Work. Like if I look back we did a short course on HIV and AIDS…we never did anything about grief…so this is a completely new field and you actually have to learn from experience, so I would certainly advocate that there would be better education done on the degree level…because quite frankly it is something social workers have to deal with a lot out in the field…Grief and loss not only death and dying.*” [Participant D 190-199].

“*I think social workers can be more prepared to do this type of service and render this type of service and this needs to be while you are busy studying during undergraduate level. You actually need to have practice education, in a setting. I know we do have hospices and the hospitals they do not take any students really for practical work, so I would say I think social workers can be more equipped.*” [Participant F 230-235].

This is supported by McCormick et al (2010:297), who state that social workers who work in medical settings report that they have not received adequate training in palliative care services and end of life care process as well as on ethical dilemma they confront. Further, Krause (2018:16), report that there seem to be gaps in palliative care training and these affect service delivery as such it must also be ensured that medical officers, social workers in palliative care are being upskilled or training in continuous professional development is made available, it is also recommended that basic palliative care training should be taught to all undergraduate medical, nursing and social workers. Similarly, Otis-Green (2020:10), state that social workers in palliative care services reported that they felt not prepared enough by their social work education.

- Specialisation

Other social workers suggested that palliative care should be a specialisation within social work which is at a post-graduate level.

"I think it will be absolutely amazing if social workers can do a palliative course like a master's specifically in Palliative Care…it is a specialised field definitely…you cannot go in green. With that, I am saying you need life experience. I do not think it is fair to put a 24-year-old Social Worker just in palliative care because it is with death and dying. People who are 60 sometimes cannot cope with death and dying. It's a specialised field and must look through the hospice philosophies, you must put the glasses on of hospice philosophies and the hospice ethos and the hospice approach to go into that assessment and to be supported with that. So I think definitely there must be extra training in palliative care if that is what you are doing and if you are appointed, the organisation must provide that and support for the social worker in palliative care…" [Participant H 243-255].

"*…in our Social Work curriculum I can recall only seeing a very small segment of the work…there was a little bit of bereavement that was touched on…I think palliative care should really be considered as a specialisation for social work because you are dealing with people at the vulnerable state of their lives. It needs one with a special level of sensitivity, it needs someone with a little bit of wisdom and when I talk about wisdom it is not knowledge."* [Participant J 210-223].

This is supported by Glajchen et al (2018:891), who state that most social workers report that they are uncomfortable with certain roles expected of them especially in providing end of life care because their generalist training does not cover them. For social workers in health settings to survive they rely on the job learning from other team members, this includes leading in family meetings, addressing sexual functioning and managing complicated grief, Further, McCormick *et al* (2010:297), report that some school of social work have begun to provide specialised courses and practice training in the end life care. In addition to these undergraduate level progress, continuing education programs which are critical in palliative care are beginning to play an important role in preparing experienced social workers for new challenges in palliative care social work (McCormick *et al* 2010:297). Additionally, Otis-Green (2020:10), states that if social workers are to be effective in palliative care there is need for passion in lifelong learning, that goes beyond the generalist training they receive at the undergraduate level.

4.3.8.2 Sub-theme 8.2: Skills development

Linked to training, but somewhat different, it was suggested that skills development should receive attention. The following are some of the extracts from the participants on skills development:

"...*definitely more training…looking at on-going ways of improving services and what exactly we as social workers can do better when it comes to that. And especially helping somebody come to terms or managing denial you know or maybe some more creative ways of coping with that."* [Participant A 203-207].

"*I am dealing with 16-year-olds that are facing life-threatening illnesses. How do you prepare a 16-year-old for death?...I would love to…attend a conference around…palliative care with someone who is 16…what are your needs as a 16-year-old versus somebody who is 82 and has lived a long full life, how different is it? Is it different? I would love to kind of hear about helping those more in detail, more intensive. I find it is very general out there…I still need to learn. I have learnt a lot and find those that cope best with palliative care or their diagnosis…are the ones that actually talk about it; the patient that can actually verbalise their fears, verbalise their concerns, verbalise their anger that they are dying and that are able to actually debrief about it…the ones that are in denial are the ones that really actually in the end really struggle to get a sense of peace and closure.*" [Participant A 222-239].

"…*we don't have a lot of experience with this kind of work while you study so I think you learn a lot while you are actually physically doing this kind of work. So, you need really, good supervisors to guide you, to help you have conversations about these difficult topics. I think there needs to be more workshops regarding palliative care and how to implement different strategies, how to talk about these topics, how to support the family, how to stay strong*

***while you are inside actually crying as well…It's good to show emotions in front of the patient and family because, they appreciate that as well but you need to know where and when.*"** [Participant F 221-229].

It has been reported that competency-based training may reduce compassion fatigue in social workers, coupled with improved training may also help address a serious workforce shortage by enhancing the quality of generalist level care and encourage large numbers of social workers to seek specialist level training and qualifications (Glajchen *et al* 2018:890). Similarly, Otis-Green, *et al* (2014:503) note there is an urgent need to prepare the current crop of social workers so that they can be able to meet the demands of a diverse and ageing population. It has been identified that there are challenges to the provision of continuing education for psychosocial skills and insufficiency specifically in accreditation and licensing and the curriculum on psychosocial care (Otis-Green *et al 2014:503)*. Additionally, there is need for mandatory training in all palliative care professionals if we are to achieve a good death for all, this can be in the form of internal training programmes in the organisation or as part of workshops and conferences for palliative care teams (Artioli, Bedini, Bertocchi, Ghirotto, Cavuto, Contantini & Tanzi 2019:2).

4.3.8.3 Sub-theme 8.3: Work more in-depth

Participants also suggested that social workers should work in-depth and focus on the patient.

***"So I think more honesty, more authenticity, and professionals need to learn how to do it. Medical doctors need more communication skills, nurses need more communication skills and social workers need to learn to work more in-depth, not just on the superficial level. If I ask a social worker in the interview tell me what is your theoretical models of work they say client-centred model, outcomes-based. And I say how would you apply? - that they can't tell me. So, the depth of knowledge is not integrated, it is not part of that, the practical and theory are not done enough.*"** [Participant C 253-260].

"*If you stick to the basics and I think that is the most important that…we don't lose the patient within the system because we are so busy sometimes with a lot*

of those elements that need ticking the boxes…we don't spend the time next to the patient's bed and that's where we are needed…keep the focus on patients and family and providing them with the best service emotionally, practically within their community, what you can do for that family and patient and to respect their belief system, to respect their approach of cultural understanding because I think that goes back to patient-centred…we must never lose the patient in paperwork." [Participant H 275-287].

This is supported by de Saxe Zerden (2019:144), who state that the time has arrived for social workers to effectively articulate their role and to demonstrate the benefits of their interpersonal, interpersonal and organisational skills they possess and take their place as professionals who can effectively address the complex needs of patients in a rapidly transforming healthcare environment. Additionally, social workers need to prevent the further marginalisation of their clients who are vulnerable because of serious illness, by ensuring accessibility, breadth and depth in the provision of psychosocial services. Creativity and flexibility need to be the core of the helping process (Chi & Ruden 2019:235). Peres (2016:186), points out that if the quality of death in palliative care is to increase in patients there is a need for momentum and opportunity for change to happen, social workers need to deliver the range of biopsychosocial care that patients and families so desperately need. There is need for creativity so that new innovative solutions to problems, that align with the times, fresh ideas and doing things differently that assist social workers to meet the needs of the diverse clients (Calitz, Roux & Strydom 2014:159).

4.3.8.4 Sub-theme 8.4: Know and use community resources.

Knowing and using community resources to assist patients and families was suggested as essential in palliative care services.

"…*and the social worker also needs to make sure they have good relationships with the other resources in the community that can be of assistance. It is kind of also make enquiries, a lot of communities do not have resources and a lot of people do not have the access to home carers, private home care nursing because it's too expensive*." [Participant A 280-284].

"Know your resources, think, plan ahead, direct the patient to also get to the place where they start planning so that when there is a sudden deterioration that they are calm and everything is in place and that they know where to reach out or already have met the resources and that it doesn't cause an extra stress factor…sometimes, not patients, but the family or the carer because the wife or the husband starts getting anxious knowing so, doctor said no cure, can't do anything anymore just come for a follow up every month when there are symptoms. And now they start thinking so oh my goodness so my responsibility is to care for this patient now and I can't, I don't have knowledge or expertise. So they are often more open to listen to all the options and to know what to expect so they can prepare themselves." [Participant G 137-151].

"I also ran a cancer NGO called People Living with Cancer and I ran a buddy system. I believe very strongly in other cancer survivors supporting people with cancer. And I think the one thing that came to mind for me during that was that people who have been through the experience can mean so much more to people that are in the situation, especially when a diagnosis newly diagnosed but also when if you have like your bereavement teams. Often a lot of those people on the bereavement teams would have been people that have suffered bereavement and they can be a buddy for somebody that is going through bereavement." [Participant C 130-133].

The above is supported by Hughes, Wintz, Carbonell, Hall, Hodge, Mulvoney, Nelson Beckett, Soo, Sormant and Stepney (2018:7) who state that social workers have a unique opportunity of collaborating with board-certified chaplains to address the spiritual needs of patients and families, provide support and relieve suffering, particularly by referring a patient to the chaplain when spiritual distress is identified. Also, according to Reckrey et al (2016:2). people who seek medical treatment require guidance beyond their diagnosis and treatment of a medical problem, social workers can pick on the unmet needs in patients with serious illness and assist them in navigating the complex healthcare system and attaining optimal levels of functioning. They are also able to refer to other community resources for example nursing agencies and complementary therapists (Reckrey et al 2016:2). Social workers are trained and posed to deliver a variety of social and support services to diverse groups, however, direct access is a challenge sometimes in private and tight communities such as working with traditional religious groups as the orthodox Jews, in instances like these social workers use their contacts to have indirect access through working with the Rabbis to meet the needs of their patients and families (Sytner 2018:210)

4.3.8.5 Sub-theme 8.5: Change attitudes

Social workers also identified the need to change attitudes regarding hospices, palliative care and death in the community and also amongst social workers themselves.

"*I would say that the biggest thing is to promote, sell palliative care…completely get that out of people's minds that it is not, it is not just death. Palliative care is about symptom control, it's about improving quality of life at home, it's about addressing needs at home knowing when to call the doctor and when not. To get them in control about the situation at home…redefining palliative care as a different kind of support. It is not just supporting the last phase of life; it is supporting throughout the whole process of diagnosis, moving on to two three four lines of chemotherapy up until the end*." [Participant F 184-194].

"I think social workers are also scared to talk about death. It is also a difficult topic because you are being confronted with your own mortality so we need as social workers to be comfortable to be talking about that topic. If you are comfortable with your own death then it is easy to talk about death with others…" [Participant F199-203].

"*...there has to be some kind of different model of funding that will make palliative care more affordable across the board and I would like to see every community in fact having a palliative care team…right down to rural areas. I would like to see traditional healers and leaders becoming more involved in palliative care, speaking about death and there is a lot of cultural practices that impact death and dying very profoundly. I know with a lot of our black patients we cannot use the word dying because it's seen as an omen and that you are inviting death*." [Participant C 200-207].

"So there is a lot of stigma still around dying and so on and…there is this movement where they had these death cafes where people would talk about kind of normalising death in a sense. Death has become very clinical; it happens in the hospital. I would like to see people die more at home and death becoming part of the family again and I think COVID has done that to some degree which has been very refreshing for me…" [Participant C 211-220].

The diversity and depth of challenges, the vast range of social work roles and the need for wider collaboration among professionals are constantly expanding, these challenges will require complex thinking from a social worker (Kreiviniene & Rimkus 2016:91). As a result, the social workers have to develop from just action or work to become reflective, critical based activity involving practical skills, knowledge, thoughts and emotions (Kreiviniene & Rimkus 2016: 91). Further, Haworth, Miller and Schaub (2018:7), argue that the social work profession is not a simple choice between two options anymore, it is a search for alternative solutions based on inclusive and critical thinking, leading to positive change. This means orientation in social work needs a paradigm shift for social workers. Similarly, in palliative care social work, there is a need for the greater society to change its attitudes towards dying, death and bereavement if we are to ensure a good death for our patients. We need a fundamental shift of emphasis we must thrive to ensure that a good death is an expectation not the exception in all settings (British Medical Journal 2010:2).

4.3.9 Theme 9: Social workers' recommendations regarding the role of social workers providing palliative care services to people faced with life-threatening illnesses.

Social workers were asked to make recommendations regarding the role of social workers providing palliative care services to people faced with life-threatening illnesses.

Their responses are given in four sub-themes, namely, promote social worker's role in palliative care; communicate/consult with others; supervision and training; and self-care and debriefing.

4.3.9.1 Sub-theme 9.1: Promote social worker's role in palliative care.

The social workers all expressed the valuable role social workers play in palliative care and recommended that the role of social work in palliative care should be promoted.

"*…the most important thing is that the role of social workers involved in supporting people and families with life-threatening illnesses…I think it is something that should be almost made known and people made aware...that this is something social workers do or can do…people just see it so very medically…I think there is so much stigma attached to social workers particularly in this country which is so problematic in itself…"* [Participant I 129-137].

"*There's a big need for people in this field but because people are scared and don't have the right information on what a hospice does. They do not want to get in there but I must say if you put your foot in hospice then you are actually forever be part of what do because then you see and yes they are looking at…this as a specialised field, health social work and it would be nice to have more social workers that actually want to go within this field because it's just as needed as the other fields that is available."* [Participant B 229-235].

"*…more credibility could be given to the social workers… palliative care is still medically driven. You can easily increase the Panado and the pain goes away. But that very same people will still sleep with a sense of hopelessness knowing that they have got a very short life span, knowing that their dreams are gone. So I feel that social workers should be more respected…especially in the interdisciplinary relationship so that they are not seen as complementary right at the back of the wagon but are right at the forefront. They are the ones who are negotiating with the families, the ones who are educating, who are reinforcing family responsibility to take care of their loved ones. But half of the time their role is overlooked or undermined."* [Participant J 237-245].

"*…I think the role of the social worker needs to be respected number 1 and seen as valuable part of the team…I would certainly recommend that there would be more social workers fulfilling that role that perhaps from six medical people you*

need 6 social workers so that you can actually fulfil the need…" [Participant D 233-237].

According to Twohig and Strong (2020:1), social workers are standing united that their role in the palliative care team is misunderstood and undervalued, there is need for clarity on the definition of their role, both as a national concept and in practice and of differences between generalist social work and those who provide specialist palliative care. There is need for or metrics that demonstrate the financial benefits versus the non-financial benefits of social work in the community of palliative care programs, if this is not done the role of social workers in palliative care will remain confusing and undervalued in the absence of viable ways to measure its effectiveness and outcomes. O'Callaghan (2014:216), argues that role ambiguity is a big challenge facing social workers in end-of-life care, more emphasis should be placed on the means and measures employed to overcome such challenges, it is important to focus on the broader objective of promoting the social worker's presence and voice and ensuring they take their rightful position within the palliative care teams. Zebrack (2018:1) states that the misconceptions about the role social work plays in health care are vast, some assume that it is not evidence-based and there is a lack of insurance reimbursements for social work services, there is a stigma about using social work services despite evidence supporting its efficacy and the many benefits to patients and families. Therefore, there is a need for advocacy for the unique positioning of social work in palliative care teams to assist in addressing the psychosocial care of palliative care patients and their families (Zebrack 2018:1).

4.3.9.1 Sub-theme 9.2: Communicate/consult with others.

The social workers also recommended that social workers should communicate or consult with others working in the field of palliative care.

"…definitely do not be afraid to ask other experts for help, to make use of identifying other role players and access them. Do not work alone. Palliative care should be a holistic approach, there is a team involved. And then also for social workers to constantly look at being cognisant of where the gaps are and trying to see how those can be addressed…" [Participant A 252-256].

"…communicate with your doctor so that you as a social worker are well informed and know when to have the end-of-life conversations." [Participant G 161-162].

This is supported by Mills et al (2019:7), who state that from conversations with social workers regarding formal supervision it was found that supervision is not necessarily helpful for everyone and many find informal debriefing with peers effective, it also strengthens the team knowing that colleagues can depend on each other, it is also a sign of healthy teams. Similarly, it was noted that healthcare workers who take care of others in the course to time expand their resources of positive emotions, their organism become frail and incapable to withstand stress, as a preventive measure for their professionals, palliative care teams should openly communicate with each other and not to be afraid to unburden their minds and if necessary, seek help (Sadauska & Benosyte 2014:4). Further, Sadauskas (2016:4), recommends that after the death of a patient, team members are required to discuss their own feelings and emotions openly and freely, this is also an opportunity to seek help from the other team members especially if it was a difficult death.

4.3.9.1 Sub-theme 9.3: Supervision and training

The importance of supervision and training was emphasised in the recommendations made by the social workers. A few quotations below demonstrate the importance of supervision to the participants:

"…I was asked to do supervision work by hospice social workers in Robertson and that is for me very important, because if new people come in (they) need to get the basics so that they can know what they are doing when they go out and see patients…during supervision you can also give them literature, you can also help them with examples of stuff that they are struggling with and you can see what their experiences are…and like I said training and more training. They need to do the psycho-social course; they need to do the bereavement course" [Participant B 212-220].

"Yes, I think there is also a lack of formal supervision in hospices…particularly smaller hospices. There will be a manager but if you look at the social work

***actual practice there is not really a structured supervision process. That's important as well and I think a lot more training courses, CPD training courses…they would have an opportunity to professional development in palliative, group loss, spirituality that kind of thing that would help them…*"** [Participant D 213-219].

According to Cammy (2020:1), meaning centred supervision aims to enhance the meaning in one's work while also validating struggles in the work. Additionally, Pessin et al (2015:6), state that engaging in formal supervision helps address the large issues around caring for the dying and their families to buffer distress. Supervision and other interventions that attend to existential distress and promote self-care are necessary for assuring that social workers working in end-of-life care remain healthy and engaged in the field Sanso *et al 2015:206).* Also, continuous training, training in work abilities and other work interventions help the healthcare professions cope in their high stakes environment (Sanso et al 2015:206). Further, it has been noted that formal supervision an essential building block in social work practice, if effectiveness, personal growth and agency accountability are to be achieved. If done properly, it is a key factor in job satisfaction and results in high-quality service delivery in social work (Pelon 2015:12).

4.3.9.1 Sub-theme 9.4: Self-care and debriefing

Social workers recommended that self-care and debriefing are important for social workers in the field of palliative care services.

***"…and to continually look at self-care which is important and debriefing*."** [Participant A 257-258].

***"A social worker needs to look after herself that's actually more important because you cannot look after yourself you cannot care for the patient and the family so yah I mean you need to emphasise that as well I mean social workers tend to give and give because that's what we do and cannot help ourselves*."** [Participant F 354-256].

According to Sanso et al (2015:206), it is important to identify specific tasks that help social workers cope in caring for the dying patients, these tasks can include community support, continuous training in work abilities and practising self-awareness exercises. Further, Pessin et al 2015:6), emphasized the need for self-care, it is imperative when working with people who are dying. Health care professionals should seek support from colleagues, take time off work or engage in activities that are informal and that addresses the larger issues around care for the dying, this will ensure that social workers in end-of-life care remain healthy and engaged in the field (Pessin et al 2015:6). Jones (2009:38), state that to prevent burnout in hospice social work, social workers must develop a plan of self to balance their own needs with the needs of their clients.

4.4 Summary of the Chapter

This chapter presented the research findings that emerged from the data collection and analysis with the participants, namely, social workers. The findings of this study represent nine themes together with the accompanying sub-themes and categories. The themes, sub-themes, categories and complementing storylines from the transcripts were subjected to literature verification. The demographic information of the social workers who participated in this study was provided first by the researcher.

The **first theme** expounds on social workers' accounts of working with people faced with life-threatening illnesses. Three themes were introduced in this theme, namely, work daily with people faced with life-threatening illnesses; an unknown experience and difficult; and positive but challenging.

The **second theme** presented the social workers' descriptions of the nature of the palliative care services they provide to people faced with life-threatening illnesses. Seven themes emerged from this theme namely, assess and address needs of patients and families, provide support and information, provide counselling, assist with practical issues, identify and mobilise community resources, plan and discuss with patient and family and facilitate communication between role-players.

The **third theme** presented social workers' descriptions of their role within the interdisciplinary team that provides palliative care services. Under this theme, four sub-themes emerged and discussed, namely, team members are equally important, provide the psycho-social perspective, liaise with and communicate with available services, and advocate for patients.

The **fourth theme** described social workers' intervention strategies when working with people faced with life-threatening illnesses. Four themes were discussed under this particular theme, namely, first, build a relationship and gain trust, follow at patient's pace, practice various social work methods and approaches and end of life counselling and support.

In **theme five,** social workers' accounts of the challenges they often experience when providing palliative care services were expounded. The presentation was made according to the eight sub-themes which emerged for this theme, namely, late referral of patients, resistance and denial, stigma linked to hospice and palliative care, patients' condition, family-related issues, interdisciplinary team members do not always understand or accept the role of a social worker, emotionally challenging and inequality between public and private health car. Moreover, the two categories which emerged for this theme were also expounded, namely, form patients and from family members.

Theme six presented social workers' descriptions of how they deal with the challenges experienced when providing palliative care services. Seven themes which emerged under this theme were also discussed, namely, peer support and supervision, debriefing, attending training opportunities, proceeding at patient's pace, patients' satisfaction, Self-Care and know yourself and be comfortable. The **seventh theme** presented on social workers' level of satisfaction with the kind of palliative care services they provide to people faced with life-threatening illnesses. Three sub-themes that emerged from this theme were also expounded, namely, not satisfied, satisfied in general, and satisfied and proud.

Theme eight expounds on social workers' suggestions regarding the nature of the palliative care services they provide. Five sub-themes and categories emerged in this theme, names, training, skills development, work more in-depth, know and use community resources, and change of attitudes. The two categories are undergraduate level as well as specialisation. Finally, **theme nine** presented social workers' recommendations regarding the role of social workers in providing palliative care services to people faced with life-threatening illnesses. These recommendations include the promotion of social workers’ role in palliative care, communication with others, supervision and training, as well as Self-Care and training.

The summary, conclusions and recommendations based on the findings are presented in Chapter 5.

CHAPTER 5: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

In Chapter 4, the findings of this qualitative study that emerged from the process of data collection and analysis supported by participants' storylines and complemented by the literature control, were presented. Therefore, the focus of this chapter is to summarize and draw conclusions. Subsequently, the limitations of the study followed by the recommendations will also be presented.

The summary and conclusions will be presented in terms of the chapters of the study and what each of these chapters entails, for example, general introduction, literature review, applied research methodology adopted for this study, the research findings based on themes, sub-themes and categories that emerged from the process of data analysis.

5.2 Summary of the study

The summary of the study is given through expounding a summary of the relevant chapters of this study, namely, general introduction, a deliberation on the goals and objectives of the study and an exploration of the research question, literature review, and the research findings.

Summary of the research chapters

This research report is comprised of five chapters, namely, Chapter 1 (General Introduction); Chapter 2 (Literature Review); Chapter 3 (application of the research methodology adopted for this study); Chapter 4 (Presentation of the research findings) and Chapter 5 (Summary, Conclusions and Recommendations)

1. Chapter 1: General Introduction

This chapter detailed an overview of the general introduction and background of the study, the theoretical framework that was employed to guide the study, the research question, the goals and the objectives of the study, the ethical considerations, limitations of the study and clarification of key concepts. The summary and conclusions of the goals and objectives of the study are presented in section 5.2.2 of this research report.

2. Chapter 2: Literature Review

In this chapter**,** a literature review comprised of the historical perceptive of the hospice movement; An overview of Hospice and Palliative Care; An overview of Palliative Care Services; Social workers' role in Palliative Care; Challenges faced by social workers in providing palliative care services and the theoretical framework underpinning the study was presented.

3. Chapter 3: Application of the research methodology

In this chapter, the researcher expounded on the research methodology that was employed to undertake the study. The summary of the implementation of the research methodology adopted for this study is presented in detail in section 5.2.3 of this research report.

4. Chapter 4: Presentation and discussion of the research findings

The research findings of the study together with the literature control were presented in this chapter and this was done in terms of the themes, sub-themes and categories. The conclusions of the conclusions of the research findings are summarised in section 5.2.4.

5. Chapter 5: Summary, Conclusions and Recommendations

The summary emanating from the study, together with conclusions and recommendations are presented in this final chapter of the research report. Based on the research findings, the researcher put forward the following recommendations for education, practice and future research and they are comprehensively presented in section 5.5 of this research study.

5.3 Summary and conclusions of the research goal and objectives

The goal of the study as discussed in Chapter 1 (section 1.4.1) was to develop an in-depth understanding of the experiences of social workers in rendering palliative care services and suggestions for social work practice in Cape Town, Western Cape. In other words, this study sought to explore the experiences of social workers in providing palliative care services to people faced with life-threatening illnesses.

Therefore, the researcher concludes that the study was able to achieve the above-mentioned goal in that it was able to gather the information that was able to explain and describe the experiences of social workers who provide palliative care services to people faced with life-threatening illnesses. The findings on the aforementioned goal are presented in chapter four of this report as evidence that the research goal was achieved.

Moreover, the objectives of the study were set out as follows: -

- To explore and describe the experiences of social workers in providing palliative care services to people faced with life-threatening illness and suggestions made for social work practice.
- To conceptualise the experiences of social workers rendering palliative care services to people faced with life-threatening illnesses with regard to the eco-system theory and the strength-based perspective.
- To find out the respective strengths and challenges that social workers face when rendering palliative care services to people suffering from life-threatening illnesses in Cape Town and to ascertain how these challenges can be addressed to enhance social work practice and offer effective services.
- To draw a sample from social workers in the employ of organisations that provide palliative care services in Cape Town in the Western Cape Province.
- To carry out interviews (semi-structured) that are aided by open-ended questions contained in an interview guide so that the experiences of social workers rendering palliative care services to people facing life-threatening illness in Cape Town can be explored.
- To carry out the data analysis process aided by Tesch (Creswell, 2014).
- To draw conclusions and recommend strategies that can improve social work practice for social workers rendering palliative care services to people faced with life-threatening illnesses in Cape Town in the Western Cape Province.

Based on the above-mentioned research objectives, the researcher concludes that the objectives were useful as they assisted in achieving the research goal.

5.4 Summary and conclusions of the applied research methodology

A qualitative research method was employed for this study with an exploratory research design after access had been granted and participants had been prepared for the process. The qualitative research method and design were chosen as it allows the participants an opportunity to tell their stories from their own perspective without the researcher imposing his own ideals, beliefs and assumptions and it enables the process to be non-directive (Creswell 2014:235; Dudley 2011:26 &Creswell 2009:175. Because of the non-directive nature of this research method participants can be flexible in their interactions with the researcher (Bailey 2018:3, Creswell 2014:235)

The researcher identified the particular research population and a sample was recruited using a non-probability, purposive and snowball sampling. The sample was enlisted using the researcher's existing knowledge of the population. The researcher undertook 10 semi-structured interviews with social workers in the employ of different organisations providing palliative care services in Cape Town as well as from social workers providing Grief and Loss services privately. Semi-structured interviews allow flexibility, and the researcher was able to make follow up questions or statements to elicit more information (DeJonckheere & Vaughn 2019:1; Bailey 2018:245; Hofisi et al 2014:62; Holloway & Wheeler 2010:89.

The researcher made use of the eight steps described in Tesch's model (cited in Creswell 2014:248) for data analysis. Nine themes with their sub-themes and categories were identified from the interview transcripts. The themes were as follows: -

- Social workers' accounts of their experiences of working with people faced with life-threatening illnesses.
- Social workers' descriptions of the nature of the palliative care services they provide to people faced with life-threatening illnesses.
- Social workers' descriptions of their role within the interdisciplinary team that provides palliative care services.

- Social workers’ descriptions of their intervention strategies when working with people faced with life-threatening illnesses.
- Social workers’ accounts of the challenges they often experience when providing palliative care services.
- Social workers’ descriptions of how they deal with the challenges experienced when providing palliative care services.
- Social workers’ level of satisfaction with the kind of palliative care services they provide to people faced with life-threatening illnesses.
- Social workers’ suggestions regarding the nature of the palliative care services provided by social workers.
- Social workers’ recommendations regarding the role of social workers in providing palliative care services to people faced with life-threatening illnesses.

Therefore, the researcher concludes that the research methodology adopted and applied for this study assisted in attaining the goal of the study.

5.5 Summary and conclusions arising from the research findings.

The section that follows involves the presentation of the summary and conclusions derived from nine themes (see Chapter 4, section 4.3). A summary of the themes, subthemes and their categories that emerged from the data analysis together with the researcher’s conclusions are presented below.

Theme 1: Social workers’ accounts of their experiences of working with people faced with life-threatening illnesses.

Based on the participants accounts of their experiences of working with people faced with life-threatening illnesses, the following themes emerged, namely, they work daily with people faced with life-threatening illnesses; the work is unknown experience and difficult; and that the work they do is positive but challenging. The participants' accounts of their experiences resonate with the assertion that working with people faced with life-threatening illnesses is a challenging and difficult task (Sadauska & Benosyte 2014:3; Hennessy, Lown, Landzaat & Porter-Williamson 2013:78, NASW 2010:2).

Based on the participants' extracts, the researcher, therefore, concludes that working with terminally ill patients involves a variety of duties for social workers. It is a varied job where social workers have to have multiple skills in order to meet the needs of the patients. Furthermore, it is also quite a challenging and difficult job for the social workers as it is hard to for one to navigate towards their own death. It is an experience that cannot be predetermined beforehand and social workers have to follow the lead dictated by the patient and their loved ones. Social workers have to dig deep to find an approach that works for each particular patient as each individual is unique and each one has their own way of dealing with the impending death. However, some of the participants highlighted how the work is difficult and challenging but drew positives from the fulfilment they get after helping patients come to a good death. Based on the aforementioned statement, the researcher concludes that working with dying patients is in some instances is a fulfilling job and leads to job satisfaction.

Theme 2: Social Workers description of the nature of the palliative care services they provide to people faced with life-threatening illnesses.

After being asked to describe the nature of the palliative care services they provide to people faced with life-threatening illnesses, the participants reported that social workers provide the following services: -

- They are a link between the patients and the various resources, this includes service providers, government agencies, for example, SASSA, Department of Labour, banks, community resources, medical aids, attorneys and their respective employers.
- They journey with the patients on this path.
- They are involved in future care planning.
- They provide patient-centred work.
- They provide guidance regarding financial matters.
- They are responsible for psychosocial assessments and supportive counselling and this is a major part of the work.
- They also refer patients to other support services, complementary therapists, physiotherapists and other services the patients might require.
- They provide information to the patients on various issues.

- They also facilitate communication and fulfil the role of mediator when they are disagreements in families.

The above responses from the participants correlate with the assertion that social workers major role thrust upon them is the assessment of needs and risks over some clients and their families in order to address patient and caregiving needs. (Middleton, Head & Remke 2020:3: Go-Coloma 2018:30; Moriarty, Baginsk & Mathorpe 2015:8; Reigad et al 2015:6).

Therefore, the researcher concludes that it is evident that the role of social workers is crucial in palliative care. Social workers are an important resource within palliative care. Social workers provide that safe space to patients at a very difficult time. Also, because of their resourcefulness, they are able to provide much-needed information and links that help patients make better decisions regarding stressful matters at such a time for example, where a patient has lost a job, they might need guidance with claiming their UIF benefits and start the process to get a SASSA disability grant if they qualify. Also, because the social workers in palliative care have a wealth of experience and because of relationships built with other service organisations, they are able to give guidance regarding the steps to be followed by their patients.

Theme 3: Social workers' descriptions of their role within the interdisciplinary team that provides palliative care services.

When asked to describe their role as social workers within the interdisciplinary team aimed at providing care services, the participants had this to say:

They reported that their understanding is that all team members are equal and each member's contribution to the team is equally important.

- They also reported that social workers are responsible for the psychosocial perspective and attend to spirituality matters on the interdisciplinary team.
- Moreover, they confirmed their role on the team is that of liaison and facilitating with available resources so that the needs of the patients and their families can be met.

- Finally, they pointed out that their role on the interdisciplinary team is to advocate for the patient and their families.

The above statements tally with the assertion that the inclusion of social workers on the interdisciplinary team is to ensure that psychosocial care is at the core of care provision (Otis-Green 2060:60; Hughes et al 2014:42; O'Callaghan 2014:209). Based on the participants' responses, the researcher concludes that the social workers on the interdisciplinary team are responsible for attending to the psychosocial and spiritual needs of the patients, and, in some instances, they take on the facilitation and liaison role which includes advocacy on behalf of the client.

Theme 4: Social workers' descriptions of their intervention strategies when working with people faced with life-threatening illnesses.

In their response to the question asked on social workers intervention strategies when working with people faced with life-threatening illnesses, the participants reported the following:

- Social workers first build a relationship and trust before they commence and interventions.
- They follow the pace set by the client. Any interventions that they employ are led by the client. In this, they listen to what the patients communicate and this guides them.
- They practise various social work methods and these include narrative therapy and the person-centred approach.
- Lastly, they reported that they make use of end-of-life support and counselling.

The above statements tie in with the assertion that social workers first, work on building a relationship and gaining trust before they employ other helping approaches (Kennedy 2019:2; McMullin 2017:20; van de Merwe & Marais 2016:52). It is only when trust has been established that other interventions can be implemented (Otis-Green 2020:7; Head & Remke 2020:3: Sjoberg & Farsner 2020:2; Kyle 2015:8; Hopp et al 2015:202; Ramsey & Montgomery 2014:1).

Based on the extracts from the participants, the researcher concludes that building a safe and trusting relationship is important if social workers in palliative care are to be successful with their interventions. When clients feel safe and can trust the helpers it leads to deeper and meaningful relationships that enable the patient to share their anxieties and fears and this can enable better exploration and benefit the patients. It is also important to be guided and follow the pace set by the patients, coupled with the ability to listen attentively to the needs of the patient and their families. The researcher also noted that the use of various approaches that are centred on the patients also aids social workers in their work with patients with life-threatening illnesses. Moreover, the researcher noted that patient-centred approaches were more effective than those centred on the diagnosis or the disease.

Theme 5: Social workers' accounts of the challenges they often experience when providing palliative care services.

The following points highlight the challenges often experienced by social workers when providing palliative care services.

- All of the social workers identified and described the challenge of patients being referred late as often being encountered.
- Another challenge identified by the social workers was resistance and denial from patients and their families.
- The social workers also mentioned that the stigma linked to hospices and palliative care is a challenge they often encounter.
- Participants also pointed out that patients' conditions and the stage in which they impact service delivery and can present challenges for social workers.
- The social workers indicated that family-related issues can also present them with challenges.
- Social workers mentioned that interdisciplinary team members do not always understand or accept the social worker's role.
- Participants confirmed that this type of work is emotionally challenging.
- Some of the social workers reported that there are also inequalities between public and private health care was raised as a challenge that the social workers encountered.

The above responses correspond with the assertion that social workers in palliative care face several challenges which impact the delivery of their services. The challenges range from personal, organisational and environmental challenges (Gordon et al 2020:2; Franco et al 2020:7; Johnson Shen & Wellman 2019:378; Botek 2019:1; Allsop et al 2018;15; Rossi et al 2017:910; Aydogan et al 2016; Diamond et al 2015:78; LeSeure & ChongKhom-ong 2015:407; Hill-Jones 2015:28; Baek et al 2011:693; Siemerink 2011:68).

The researcher, therefore, concludes that social workers in palliative care face many challenges, some are more on a personal level. For example, the emotional pain that comes with facing the death of your patients, some are to do with our different cultures and values that we place on the subject of death especially when it comes to stigma and denial in patients and their families, some are organisational for example the dynamics that are found in interdisciplinary teams and how the medical team is modelled and finally the some are on a national level where there are inequalities between the private and public sector.

Theme 6: Social workers' descriptions of how they deal with the challenges experienced when providing palliative care services.

After having explained the challenges they encounter when providing palliative care services, the participants described how they deal with the challenges as highlighted below.

- Social workers reported that they make use of peer support and supervision.
- They also identified debriefing as a way to deal with the challenges they encounter.
- They expressed how attending training opportunities helps considerably in dealing with the challenges presented by their work.
- They also stated that they proceed at the patient's pace as a way of coping.
- They also spoke of how patients' satisfaction with their services enabled them to deal with the challenges they encounter.
- Finally, they reported that knowing themselves and being comfortable in that knowledge helped them cope.

The above statements correlate with the pronouncement that, in order to function and perform at their optimum best when faced with a myriad of challenges, social workers in palliative care employ a variety of exercises for their mental wellbeing (William & Erlank 2019:3; Yi et al 2018;9; Frozier 2018:9; Moriarty et al 2015:17; O'Callaghan 2014:212; Harr 2013:73; Keene et al 2010:185). Also, they derive comfort from the satisfaction of their patients and engage in personal self-care exercise as well as being aware of their identity (Miller et al 2019:3; Haley 2018:89; Kaushic 2017:23; Pessin et al 2015:5; Benito 2015:201; Murray 2015:8; McGarrigle & Walsh 2011; Bennett et al 2011:25).

Based on the participants' statements the researcher concludes that peer support, supervision and debriefing are important for social workers working with people faced with life-threatening illnesses. It is not a one size fits all strategy but the social workers make use of one of the above mentioned, this is depended on the type of institution they work in and support structures that have been put in place for them. The researcher further noted training opportunities are important in this field as one has to be kept abreast of new approaches and relevant information to be equipped for service. Where social workers find themselves in difficult situations researcher noted that it is important to always revert to the pace dictated by the patient. The ability to know what you can do and cannot do and knowing yourself is also noted as an essential quality in working in this field.

Theme 7: Social workers' level of satisfaction with the kind of palliative care services they provide to people faced with life-threatening illnesses.

Participants expressed how they are satisfied with the palliative care services they provide:

- Some of the social workers were not satisfied with the services that they provide.
- On the other hand, there are social workers' whose responses can be categorised as satisfied in general but they also had certain reservations.
- Other participating social workers expressed their satisfaction and pride in the services they provide.

The above statements relate with the contention that some social workers are satisfied and proud with the services they provide while others are not satisfied (Doten 2020:7; Maphumulo & Bhengu 2019:2; Obrocnikova & Ludmilla 2017:22; Partinico et al 2014:299; Kritsotakis et al 2012:91; McCormick et al 2010:297).

Therefore, the researcher concludes that social workers are satisfied personally with the services they offer. They, however, have reservations regarding some challenges that are more institutional. For example, one participant was unhappy with the workload versus the staff compliment. There is also a participant who reported to be happy with the service she renders to one patient, though she wished she could do more for other patients.

Theme 8: Social workers' suggestions regarding the nature of the palliative care services provided by social workers.

Below are the suggestions made by the participants regarding the nature of the palliative care services provided by social workers.

- The issue of training for social workers in palliative care was suggested by many of the social workers. In other words, many of the social workers suggested that palliative care should receive more attention at the undergraduate level of social work training.
- There are some of the social workers who suggested that palliative care should be a specialisation within social work which is at a post-graduate level.
- Some of the social workers suggested skills development should receive attention.
- There were also suggestions given that social workers should work in-depth and focus on the patient.
- Moreover, some of the social workers stated that knowing and using community resources to assist patients and families was suggested as essential in palliative care services.
- Finally, Social workers also identified the need to change attitudes regarding hospices, palliative care and death in the community and also amongst social workers themselves.

The above statements tie in with the assertion that the issue of the training of social workers in palliative care should receive attention, coupled with skills development, and learning to work more in-depth as well as the ability to identify and make use of available community resources (Otis-Green 2020:10; de Saxe Zerden 2019:144; Artioli et al 2019:2; Chi & Ruden 2019:235; Sytner 2018:10; Glajchen et al 2018:891; Krause 2018:16; Reckrey et al 2016:2; Peres 2016:186; Calitz et al 2014:159; McCormick et al 2010:297).

Based on these statements the researcher concludes that there is a need to incorporate palliative care in the undergraduate social work training. It was evident from the participants' extracts, that they feel there is not adequate preparation for them for this type of work in their undergraduate studies. The researcher also noted that there is a need for skills development for those social workers who are already in the field. If the above statement regarding the undergraduate studies is taken into consideration, training and skills development should be prioritised for those already in practice. Additionally, the researcher noted that there is a need for a change in attitudes in the communities regarding end-of-life care, death and hospice. It was also noted that among hospice staff, there was a desire to work more with those social workers already in practice.

Theme 9: Social workers' recommendations regarding the role of social workers in providing palliative care services to people faced with life-threatening illnesses.

When asked to put forward their recommendations regarding the role of social workers in providing palliative care services to people faced with life-threatening illnesses, this is what the participants had to say:

- The social workers expressed the valuable role social workers play in palliative care and recommended that the role of social work in palliative care should be promoted.
- They also recommended that social workers should communicate or consult with others working in the field of palliative care.

- The importance of supervision and training was emphasised in the recommendations made by the social workers.
- Finally, the social workers recommended that self-care and debriefing are important for social workers in the field of palliative care services.

Based on the above statements the researcher concludes that the role of the social worker on the palliative care team needs to be promoted. The researcher also concludes that supervision and training are crucial exercises that must be put in place for the emotional and mental wellbeing of social workers in palliative care. These, together with self-care and debriefing, must be practised by all social workers working with patients with life-threatening illnesses engages in.

5.6 Limitations of the study

The limitations of this study are noted below:

- Participants were all female social workers which created an imbalance in terms of gender as social work is a female-dominated profession and very few male participants were available.
- The study was conducted only in the Western Cape Province and as such a relatively small sample was taken which means that the findings could not be generalised.

5.7 Recommendations

Based on the research findings, the researcher has made the following recommendations for education, social work practice and future research.

5.7.1 Recommendations for education and training

- The topic of palliative care should form part of the training at the undergraduate level in order to strengthen the knowledge base of social work graduates. Based on the findings of the study most social workers reported that they have received inadequate training when it comes to the subject of death and dying. They reported that the amount of material that is specifically allocated to the subject is not enough to prepare them for this type of work. In some instances, it is provided for in the curriculum but limited.

- Training institutions /colleges and NGOs that provide palliative care services should conduct additional training and workshops for social workers who are already practising continuously. In so doing, it would enable them to learn more about palliative care and this should also include social workers who are not in healthcare settings. Social workers should be continually conscientized on the subject as death is inevitable and that clients often suffer losses in the different spheres of life.

5.7.2 Recommendation for social work practice

The recommendations for social work practice include late referrals, supervision, self-care practices, debriefing and peer supervision and advocating for the role of the social worker.

5.7.2.1 Late referrals

Social workers should take a leading role in the education of patients, to allay any fears or stigma associated with referral to hospice or for palliative care services. One of the key findings for this study was that social workers struggle with later referrals. It was pointed out that patients often arrive at the doorsteps of the hospices a little too late and this makes the preparatory work that is supposed to be done months or weeks ahead impossible. The social workers pointed out the various reasons they think contribute to patients being referred late and they pointed out that they have even engaged with those responsible for the referrals but to no avail. Social workers need time with patients and their families to be able to work efficiently and achieve the ultimate goals of palliative care. Social workers need to advocate for the early referrals of their patients, this means that there is need to work collaboratively with healthcare professionals in acute care facilities, hospitals, radiologists and the patients themselves so that information on the advantages of having hospice and palliative care services included at the point of diagnosis can be discussed.

It was noted that late referrals are not entirely the fault of healthcare professionals, but patients and their families also play a part because of stigma, denial, a lack of knowledge and fear. This is was found more prevalent in public health settings.

5.7.2.2. Supervision

Social workers reported that working in palliative care settings, where one is faced with the pain suffered by the patients and all the stresses that come with death, is emotionally, mentally and physically exhausting.

It is recommended that for social workers to cope well, social workers should have formal supervision structures in place in their different settings. However, in cases where the circumstances are unique and the departments have only one social worker available supervised by other medical personnel, provision should be made to have supervision outside the organisation with a supervisor involved in the same type of work, who understand the challenges and dynamics of the field.

5.7.2.3 Self-care practises

Social workers mentioned various self-care practises they engage in as coping strategies and it is, therefore, recommended that social workers should practise self-care exercises and, where possible, the organisations should provide an environment for pursuing such practices.

5.7.2.4 Debriefing and peer supervision

Participants specified debriefing and peer supervision as a good way of coping especially after traumatic experiences with patients and **it is recommended that informal debriefing and peer supervision be incorporated into the day-to-day routine of social workers**. Time should be set out for such activities as this is important for the mental wellbeing of social workers.

5.7.2.5 Advocacy for role of the social worker

One of the findings reflected that the field of palliative and hospice care has historically been medically driven and social workers are in an ambiguous position when it comes to asserting and executing their role. Their roles and inclusion on the team are often questioned by the medical team and patients. **It is thus recommended that social workers should take a leading role in advocating and educating their medical counterparts and patients on what their role entails.** Education on the importance of giving attention to and attending to the psychosocial needs of the patients. This would mean social workers should be activists who are confident, knowledgeable and are willing to take the stand and educate others on what it is that they do. Social workers need to come in armed with knowledge, facts and a willingness to practically demonstrate their worth on the team.

5.7.3 Recommendations for further research

Based on the findings of this study, it is important that the following should be considered for further studies:

- This study took place in the Western Cape Province and focused on Cape Town Metropole regions. The study only had female social workers as there were no male social workers that could be identified in the field. It is therefore recommended that further studies be conducted in other provinces and these should include both female and male social workers to gain a deeper understanding of the problem under study but also to broaden the scope.
- Further studies should be undertaken to determine the various models of supervision and self-care strategies that are employed by social workers working with patients faced with life-threatening illnesses.
- Finally, there should be research studies conducted aimed at exploring the subject of denial and resistance faced by people with life-threatening illnesses.

5.8 Conclusion

This chapter presented a summary and conclusions of this study in terms of the chapters, how the research goal and the objectives were achieved, research findings according to the themes, sub-themes and categories, limitations of the study and recommendations. The study findings were corroborated with literature control. From this discourse, recommendations on the education and training, social work practice and further research were formulated. The researcher believes that the findings of this study will contribute immensely to the understanding and improvement of the provision of palliative care services by social workers to people faced with life-threatening illnesses.

REFERENCES

Al-Mahrezi, A & Al-Mandhari, Z. 2016. Palliative Care: Time for Action. Department of Family Medicine & Public Health, Sultan Qaboos University, Muscat, Oman. *Oman Medical Journal*. Vol. 31 (3): 161–163.

African Palliative Care Association. 2016. Review of the status of palliative care in ten southern African countries. Kampala: African Palliative Care Association.

Agnew, A., Manktelow, R., Haynes., T & Jones, L. Bereavement assessment practice in hospice settings: challenges for palliative care social workers. *The British Journal of Social Work,* 41(1): 111–130.

Albers, A., Bonsignore, L & Webb, M. 2018. A team-based approach to delivering person-centred care at the end of life. *NC Medical Journal.* 9 (4) : 256-258. Accessed 13 August 2020.

Allsop, MJ., Ziegler, LE., Muley, MR., Russel, S., Taylor, R & Bennett, MI. 2018. Duration and determinants of hospice-based specialists palliative care. A national retrospective cohort study. *Palliative Medicine.* 32 (8) 1322-1333. Accessed 2 September 2020.

Ali, WGM & Soliman, HMS. 2016. Effects of walking exercise program on chemotherapy-induced fatigue, physical functional status, and symptoms distress among cancer patients. *Journal of Nursing and Health Science*. Volume 5 (1): 25-33.

Ambrose-Miller, W & Ashcroft, R. 2016. Challenges faced by social workers as members of interprofessional collaborative health care teams. *Health and Social Work.* 41 (2). Oxford University Press.

Artioli, G., Bedini, G., Bertocchi, E., Ghirotto, L., Cavuto, L., Constantini, M & Tanzi, S. 2019. Palliative care training addressed to hospital healthcare professionals by palliative care specialists: a mixed-method evaluation. *BMC Palliative Care* **18,** 88.

Aydogan U., Doganer YC., Komurcu, S., Ozturk, B., Ozet, A & Saglam, K. Coping attitudes of cancer patients and their caregivers and quality of life of caregivers. *Indian Journal of Palliative Care*. 22:150-6.

Azhar, A & Bruera, E. 2018. Outcomes measures and complex physical, psychosocial and spiritual experiences of death and dying. *Annals of Palliative Medicine,* 7(3): 231-243. Accessed 10 September 2020.

Babbie, E. 2010. *The practice of Social Research*. Boston. Cengage Learning.

Babbie, E. 2016. *The practice of Social Research*. 14th ed. Boston. Cengage Learning.

Baek, Yj Shin., DW, Choi., Jy, Kong, J., Kim, YH., Sohee, K., Won Juang, K., Joo, J & Park, EK. 2011. Late referral to Palliative care services in Korea. *Journal of Pain and Symptom Management* 41 (4): 692-699. Accessed 28 September 2020.

Bailey, CA. 2018. *A guide to qualitative field research*. 3rd ed. Los Angeles. Sage Publications.

Baines, M. 2011. From pioneer days to implementation: Lessons to be learnt. *European Journal of Palliative Medicine.* 18(5) :223-227. Accessed 28 August 2020.

Barck-Holst, P, Nilsonne, A, Åkerstedt, T & Hellgren, C. 2019. Coping with stressful situations in social work before and after reduced working hours, a mixed-methods study, *European Journal of Social Work*. Accessed 03 March 2020.

Bennett, B., Zubrzycki, J & Bacon, V. 2011. What do we know? The experiences of social workers working alongside Aboriginal people. *Australian Social Work.* 64 (1). Accessed 19 October 2020.

Blackledge, J. 2017. Social worker perceptions on education for generalist and specialist roles. https://sophia.stkate.edu/msw_papers/711. Accessed 02 January 2020.

Blaikie, N & Priest, J. 2019. *Designing social research*. Cambridge. Polity Press.

Bless, C & Achola, P. 2013. Fundamentals of social research methods: An African perspective. Cape Town. Juta and Company Ltd.

Bomba, P., Morrisey, M & Leven, D. 2010. Key role of social work in effective communication and conflict resolution process. Medical orders for life-sustaining treatment (MOLST) Program in New York and shared medical decision making at end of life. *Journal of Social Work in End of Life and Palliative Care,* 7(1): 56-82.

Bosma, H., Johnston, M., Cadwell, S., Wainwright, W., Ngairer, A., Feron, NF. 2010. Creating social work competencies for practice in hospice palliative care. *Palliative Medicine.* 24(1), 79-87. Accessed 13 August 2020.

Botek, AM. 2019. Why Family members wait too long to call Hospice. *Aging Care.* September 2019.

Bridgen, S. 2017. Using systems theory to understand the identity of academic advising: A Case Study. *Nacada Journal,* 37 (2): 9-20.

British Medical Journal. 2010. Attitudes must change if we are to achieve a good death for all. “Science Daily”.

Buss, MK., Rock, LK & McCarthy, EP. 2017. Understanding palliative care and hospice: a review for primary care providers. *Mayo Clinic,* 92(2): 280-286.

Buck J. 2011. Policy and the Re-Formation of Hospice: Lessons from the Past for the Future of Palliative Care. *J Hospice Palliative Nursing*. 13(6): S35–S43.

Calitz, T., Roux, A & Strydom, H. 2014. Factors that affect social workers job satisfaction, stress and burnout. *Social Work Maatskaplike Werk*. 50 (2). Accessed 10 October 2020.

Cammy, R. 2020. Meaning centred supervision. A structured self-reflection model to reconnect with personal and professional meaning in palliative care work. Sidney Kimmel Cancer Centre. Thomas Jefferson University Hospital.

Campbell, J., Buyinza, N., & Hauser, J. 2018. Perspective on care at the end of life at Hospice Africa Uganda. *Journal of Palliative Medicine*, *21*(7). Accessed 10 October 2020.

Canadas-De la Fuente, GA., Vargas, C., San Luis, C., Garcia, I., Canadas, GR &De la Fuente EI. 2014. Risk factors and prevalence of burnout syndrome in the nursing profession. *International Journal of Nursing Studies,* 52(1): 240-249. Accessed 12 February 2020.

Carlson, JA. 2010. Avoiding traps in member checking. *The Qualitative Report,* 15(5): 1102-1113. Accessed 19 June 2020.

Cavallo, J. 2014. The role of psychosocial supportive services in palliative care*. The Ascot Post.*

Centeno, C & Rhee JY. 2018. Organization of Palliative Care in Different Parts of the World. In: MacLeod R., van den Block L. (eds) *Textbook of Palliative Care*. Springer, Cham.

Cheung, JTK., Au, DWH., Chan WCH., Chan, JHY., NG, K & Woo, J. 2018. Self-competence in death work among health and social care workers: a region-wide survey in Hong Kong. BMC Palliative Care. 17 (11) :65. Accessed 10 October 2020.

Chi, M & & Ruden, MH. 2019. Introduction to “best practises in psychosocial healthcare: complexity compromise and innovation. *Clinical Social Work Journal.* 47: 233-235. Accessed 01 October 2020.

Christ, G., Messner, C & Behar, L. 2015. *Handbook of oncology social work: psychosocial care for people with cancer.* New York. Oxford University Press.

Clarke, D. 2016. To comfort always: A history of palliative care medicine since the nineteenth-century origins. London. Oxford Press.

Clark, J., Gardiner, C. & Barnes, A.2016. International palliative care research in the context of global development: a systematic mapping review. *BMJ Supportive and Palliative Care*. Accessed 12 January 2021.

Connolly, M & Harms, L. 2014. Ecosystems theories in social work: From theory to practice. London. Cambridge Press.

Connor, RS & Bermedo, MCS. 2014. *Global atlas of palliative care at the end of life.* World Palliative Care Alliance. London.

Corbin, J & Strauss, A. 2015. Basics of qualitative research: techniques and procedures for developing grounded theory. Sage Publication Inc.

Creswell, JW. 2014. Research design: qualitative, quantitative and mixed methods approaches. London. Sage Publications.

Cross, LA. 2019. Compassion fatigue in Palliative care nursing. *Journal of Hospice and Palliative Nursing.* 21 (11) 21-28. Accessed 11 June 2020.

Cruz-Oliver, DM. 2017. *When to start palliative care?* US National Library of Medicine National Institutes of Health. Continuing Medical Education. 29(7): 291. Accessed on 08 January 2020.

Danna, D & Roman, M. 2007. Debriefing after a crisis: what is the best way to resolve moral distress: don't suffer in silence. *Nursing Management* 38 (8): 38-47.

Dugan. DO. 2019. Appreciating the legacy of Kübler-Ross: One clinical ethicist's perspective. *The American Journal of Bioethics* 19 (12):5-9.

Denscombe, M. 2012. *Research proposals: A practical guide.* Open Skills. Berkshire England: Open University Press.

Denzim, NK & Lincoln, YS. 2014. The Discipline and practice of qualitative research. London. Sage.

Department of Health. 2017. White paper on policy framework and strategy on palliative care: 2017-2022. Pretoria, South Africa.

de Vaus, D. 2013. Social Research Today: Surveys in Social Research. London. Routledge.

Dalphon, H. 2019. Self-care techniques for social workers: Achieving an ethical harmony between work and well-being. *Journal of Human Behaviour in the Social Environment.* 29. 85-95. Accessed 11 June 2020.

Diamond, EL., Russell, D., Kryza Lacombe, M., Bowles, KH., Applebaum, AJ., Jeanne, D., De Angelis, LM & Prigerson HG. 2016. Rates and risks for late referral to hospice in patients with primary malignant brain tumours. *Neurology Oncology.* 18 (1): 78-86.

De Saxe Zerden, L., Lombard, BM & Jones, A. 2019. Social work in integrated healthcare: Improving care throughout the life courses. *Social work in healthcare*. 58 (1): 142-149.

Dhai, A & Veriava, Y. 2012. Health inequality in South Africa a by-product of injustice. Australian and New Zealand Journal of Public Health. 36 (6). Accessed 11 October 2020.

Dixon, J., King, D., Matosevic, T., Clark, M & Knapp, M. 2015. *Equity in the provision of palliative care in the UK: Review of the evidence.* London School of Economics. Personal Social Services Research Unit.

Doten, KM. 2020. Patient and caregiver satisfaction with end-of-life care: a need for instrument validity. University of Toledo. Digital repository.

Downing, J., Simon, ST., Mwangi-Powell, FN., Benalia, H., Daveson, BA., Higginson, J., Harding, R & Bausewein, C. 2015. Outcomes “out of Africa”: the selection and implementation of outcome measure for palliative care in Africa. *BMC Palliative Care*. 11 (1).

Downing, JD., Marston, J., Selwyn, C & Ross-Gakava, L. 2013. Developing children’s palliative care in Africa through beacon centres: lessons learnt. *BMC Palliative Care* 12 (8).

Downing, J., Atieno, M., Debere, S., Mwangi-Powell, F & Kiyange, F. 2010. *Palliative care: A handbook of palliative care in Africa*. African Palliative Care Association.

Drenth, C., Herbst, AG & Strydom, H. 2010, ‘A complicated grief intervention model’, *Health SA Gesondheid,* 15(1).

Drenth, C., Sithole. Z., Pudule. E., Wust. S., Gunnclark. N & Gwyther. 2017. Journal of Pain and Symptom Management. 55 (2): S170-S177. Accessed 14 January 2021 du Plooy-Cilliers, F., Davis, C & Bezuidenhout, M. 2014. *Research matters*. Cape Town. Juta

Dudley, JR. 2011. Research methods for social work: being producers and consumers of research. London. Pearson.

Duffin, J. 2014. Palliative Care: The Oldest Profession? *Canadian Bulletin of Medical History.* 31(2) :205-228. Accessed 03 February 2020.

Economist Intelligence Unit. 2015. The 2015 quality of death index: Ranking palliative care across the world. A Report of the Economist Intelligence Unit. LIEN Foundation. Accessed 18 August 2019.

Ekore, RI & Lanre-Abass, B. 2016. African cultural concept of death and the idea of advance care directives. *Indian Journal of Palliative Care.* 22:369-72.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K & Kyngäs H. 2014. Qualitative Content Analysis: A Focus on Trustworthiness. SAGE Open.

Engelbrecht, L. 2010. A strengths perspective on supervision of social workers: An alternative management paradigm within a social development context. Department of Social Work. Stellenbosch University. South Africa.

Ens, CD., Chochinov, HM., Gwyther, E., Moses, S., Jackson, C., Thompson, G, & Harding, R. 2011. Postgraduate palliative care education: Evaluation of a South African programme. SAMJ: *South African Medical Journal,* 101(1), 42-44.

Etkind, SN., Daveson, BA., Witt, J., Kwok, W., Higgison, IJ & Murtagh, FEM. 2014. Capture, transfer and feedback of patient-centred outcomes. Data in palliative care populations: Does it make a difference. A systematic review. *Journal of Pain and Symptomatic Management.* 49 (3).

Ettekal, AV & Mahoney, J. 2017. The SAGE Encyclopedia of Out-of-School Learning.' In K. Peppler, *Ecological Systems Theory*. Thousand Oaks: SAGE Publications, Inc.

Fink, RM. 2015. Review of a study on late referral to a palliative care consultation service: Length of stay and in-hospital mortality outcomes. *Journal of Advanced Practice Oncology*. 6(6):597-601. Accessed 12 October 2020.

Franco, P., Tesio, V., Bertholet, J., Gashier, A., Gonzalez del Portillo, E., Bibault JE., Borst, G., Elmpt, V., Thorworth, D., Mullaney, L., Redalen, CL., Dubois, L., Chargari, C., Perrryck, S., Heukelam, J., Petit, S., Lybeer, M & Castelli, L. 2020. Professional quality of life and burnout amongst radiation oncologists: The impact of alexithymia and empathy*. Radiotherapy and Oncology.* 147: 162-168*.* Accessed 18 June 2020*.*

Freeman, RJ. 2017. Social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses: a qualitative study among social workers in primary care settings in Namibia, University of South Africa, Pretoria, http://hdl.handle.net/10500/24340. Accessed 18 September 2020.

French-Rosas LN, Moye J & Naik, AD. 2011. Improving the recognition and treatment of cancer-related posttraumatic stress disorder. Journal for Psychiatric Practice. 17(4):270-6. Accessed 13 January 2021.

Glajchen, M., Berkman, C., Otis-Green, S., Stein, S., Bern-Klug, M., Christ, GL., Csikai., E., Downes, D., Gerbino, S., Head, B., Park-Oliver, D., Waldrop, D & Partenoy, K. 2018. Defining core competencies for generalist level palliative care social work. *Journal of Pain and Symptom Management. 56 (6) 886-892.*

Gerring, J. 2012. *Social science methodology. 2nd ed*. United Kingdom. Cambridge. University Press.

Gibson, W & Brown, A. 2009. *Working with qualitative data*. London: SAGE Publications Limited.

Go-Coloma, R. 2018. Long term care: The role of social workers in end-of-life care. *Today's Geriatric Medicine.* 11 (6) 30

Gordon, T., Booysen, F & Mbangaba, J. 2020. Socio-economic inequalities in the multiple dimensions of access to healthcare: the case of South Africa. *BMC Public Health.* 20: 289. Accessed 13 September 2020.

Gottlieb, L. 2014. Strengths-based nursing: A holistic approach to care grounded in eight core values. *The American Journal of Nursing.* 114 (8): 24-32.

Gouda, H., Charlson, F., Sorsdahl, K., Ahmadzada, S., Ferrari, A., Erskine, H., Leung, J., Santamauro, D., Lund, C., Aminde, L., Mayosi, B., Kengne, A., Harris, M., Achoki, T., Wiysonge, C., Stein, D & Whiteford, H. 2019. Burden of non-communicable diseases in sub-Saharan Africa, 1990-2017: results from the Global Burden of Disease Study 2017. *The Lancet. Global health.* 7. e1375-e1387.

Grant L., Brown J., Leng M., Bettega N & Murray SA. 2011. Palliative care making a difference in rural Uganda, Kenya and Malawi: Three rapid evaluation field studies. *BMC Palliative Care*. 10(8). 19. Accessed 12 August 2020.

Green, S. 2017. Making it right in the end: Conflict on the hospice interdisciplinary team. https://Sophia.stkate.edu/msw_papers/744. Accessed 24 July 2019.

Guest, G., Namey, E & Mitchell, Marilyn. 2013. Collecting qualitative data: A field manual for applied research. London. Sage.

Gwyther, L. 2011. When to start palliative care. *Continuing Medical Education*, 29 (7): 291. Accessed 30 Oct. 2019.

Gwyther, L., Krause, R., Cupido, C., Stanford, J., Grey, H., Crede, T., de Vos, A., Arendse J & Raubenheimer, P. 2018. The Development of hospital-based Palliative Care Services in Public Hospitals. *The South African Medical Journal.* 108 (2). Accessed 07 March 2019.

Gysels, M., Pell, C., Straus L & Pool, R. 2011. End of life care in sub-Saharan Africa: a systematic review of the qualitative literature. *BMC Palliative Care*. 10(6). Accessed 03 September 2019.

Lipman, A. 2012. Palliative care for older people: Better practices palliative care for older people: better practices. Geneva, Switzerland, WHO Press.

Harding, R., Bristowe, K., Downing, M, Gwyther, L & Luyirika, E& Meiring, M & Ratshikana-Moloko, M. 2018. Policies on Palliative Care in Different Parts of the World. in R. D. MacLeod, L. Block (eds.), *Textbook of Palliative Care*. 1-16. Springer.

Harr, C. 2013. Promoting workplace health by diminishing the negative impact of compassion fatigue and increasing compassion satisfaction. *Social work and Christianity.* 40 (1) 71-88. Accessed on 29 August 2020.

Harris, B & Maseko, L. 2018. People centredness in Health system reform. Public perceptions of private and public hospitals in South Africa. South Africa Journal for Occupational Therapy. 48 (1): 22-27

Hawley. P. 2017. Barriers to Access to Palliative Care. Pain & Symptom Management/Palliative Care Program. 12: 1–6. Accessed 09 August 2020.

Hawley-Kile, ML., Osuji, JC., Larsen, PD & Lubkin, IM. 2014. Chronic illness in Canada. Impact and Intervention. USA. Jones & Bartlett Learning.

Haworth, S., Miller, R & Schaub, J. 2018. Leadership in social work (and can it learn from clinical healthcare). University of Birmingham.

Head, B., Peters, B., Middleton, A., Friedman, C & Guman, N. 2019. Results of nationwide and palliative care social work job analysis. *Journal of Social Work in End of Life and Palliative Care,* 15(1): 16.33.

Hennessy, J., Lown, BA., Landzaat, L & Porter Williamson, K. 2013. Practical issues in Palliative Care and quality of life care. *Journal of Oncology Practice.* 9 (2): 78-80. Accessed 27 August 2020.

Hickman, R. 2010. To say thank you and serve. The story of St Luke’s Hospice. St Luke’s Hospice, Cape Town.

Hill Jones, S. 2015. Managing difficult behaviours in Hospice clients. *Social Work Today. 8 (5) :28.* Accessed 23 August 2020.

Hopp, HP., Comp, JK, & Parry, TE. 2015. Addressing heart failure challenges through illness – *Informed Social Work Health and Social Work.* Vol 40 (3) 201-208.

Hughes, F., Wintz, S., Carbonell, E., Hall., E, Hodge, DR., Mulvoney, E., Beckett, N., Soo, S., Sormant, M & Stepney, L. 2018. Spiritual care and social work. Integration into practice. Spiritual Care Association. in the Western Cape South Africa. *The South African Medical Journal,* 108 (2): 86-89.

Hughes, S, Firth, P & Oliviere, D. 2014. Core competencies for palliative social work in Europe: an EAPC White Paper- Part 2. *European Journal of Palliative Care. 21 (6): 1-44.* Accessed 19 June 2019.

Hughes, F., Wintz, S., Carbonell, E., Hall, E., Hodge, DR., Mulvoney, E., Beckett, N., Soo, S., Sormant, M & Stepney, L. 2018. Spiritual care and social work. Integration into practice. Spiritual Care Association. in the Western Cape South Africa. *The South African Medical Journal,* 108 (2): 86-89. Accessed 18 April 2019.

Holloway, I & Wheeler, S. 2010*. Qualitative research in nursing and healthcare*. 3rd ed. MPG Books.

Hospice Palliative Care Association. Palliative Care Standards. HPCA. Cape Town. 2019.

Johnson Shen, M & Wellman, JD. 2019. Evidence of palliative care stigma. The role of negative stereotypes in preventing willingness to utilise palliative care. Palliative Support Care. 17 (4) 374-380. Accessed 15 September 2020.

Jones, SH. 2009. A self-care plan for hospice workers. American Journal of Hospital Palliative Care 1 (2) 38. Accessed 19 March 2019.

Jones-Smith, E. 2013. Strength-based therapy. Connecting theory, practise and skills. Sage Publications Inc.

Kaplan, BW. 2010. Comfort care for cancer patients: Exploring distinctions between hospice care and palliative care. *Oncology Nurse Advisor*, 5 (1): 42-43.

Kamonyo, ES. 2018. The Palliative care journey in Kenya and Uganda. *Journal of Pain and Symptom Management*. 55 (2) S46-S54.

Kaushic, K. 2017. Use of self in social work: Rhetoric or reality. Journal of Social Work Values and Ethics. 14 (1).

Keene, EA., Hutton, N., Hall, B & Rushton, C. 2010. An intervention to support Health care professionals in managing their grief after the death of a patient. *Paediatric Nursing Journal.* 36 (4) 185-189.

Kelley, ML. 2014. Peer-led debriefing toolkit. Guidelines for promoting effective grief support among frontline staff. Quality Palliative Care in Long term Care Alliance.

Kennedy, J. 2019. The importance of relationship in social work. Care knowledge. Pavilion Publishing and Media Ltd.

Khumalo, T & Maasdorp, V. 2016. The Island Hospice model of palliative care. *Ecancermedicalscience*. 10: 654. Accessed 10 October 2020.

Kim, DJ & Choi, M. 2017. Life-sustaining treatment and palliative care in patients with liver cirrhosis - legal, ethical, and practical issues. *Clinical and Molecular Hepatology.* 23. Accessed 18 September 2020.

Knapp C., Woodworth L., Wright, M., Downing, J., Drake, R., Fowler-Kerry, S., Hain R & Marston, J. 2011. Pediatric palliative care provision around the world: a systematic review. *Pediatric Blood Cancer*. 57: 361-368.

Kopf, A & Patel, NB. 2010. Guide to pain management in low-resource settings: Educational material written for general distribution to health care providers by a multidisciplinary and multinational team of authors. International Association for the Study of Pain.

Korstjens, I & Moser, A. 2018. Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing, European Journal of General Practice. 24:1, 120-124. Accessed 12 January 2021.

Koukali, S., Kritsotakis, G., Koutis, A & Alegakis, T. 2012. Social capital and patient satisfaction with cancer care. A cross-sectional study in Greece. *Archives of Hellenic Medicine.* 29 (29): 91-9991. Accessed 02 August 2020.

Krathwohl, DR. 2009. Methods of educational and social science research: the logic of methods. 3rd ed. USA. Waveland Press, Inc.

Krau, SD. 2016. The difference between palliative care and end of life care: more than semantics. *Nursing clinics of North America.* 51 (3): ix-x

Krause, R, Gwyther, L, Holding, L & Venter, M. 2018. *Gaps in palliative care training affect* service delivery. Report.

Kreivinience, B & Rimkus, VT. 2016. Positive social work approach “work” towards “social”. *Tiltai.* 73 (1). Accessed 01 August 2020.

Kumar, CR. 2011. Research methodology: a step-by-step guide for beginners. Singapore: Sage Publications.

LaVigne AW., Gaolebale B., Maifale Mburu G & Grover S. 2018. Palliative care in Botswana: current state and challenges to further development. *Ann Palliative Medicine.* 7(4):449-454.

Leedy, PD & Ormrod, JE. 2010. *Practical research: Planning and design.* 9th ed. New Jersey. Pearson.

Lekganyane, MR & Alpaslan, N. 2019. Suggestions by home-based caregivers caring for people living with HIV and AIDS on how social workers could support them in managing their work-related challenges. *Social work (Stellenbosch. Online)* 55 (2): 140-157. Accessed 03 May 2020.

Lemoine M., Girard PM., Thursz, M & Raguin, G. 2012. In the shadow of HIV/AIDS: Forgotten diseases in sub-Saharan Africa: Global health issues and funding agency responsibilities. *Journal of Public Health Policy*. 33: 430-438.

Lentsoane, P., Meyer, J., Schellack, N & Cameron, D. 2014. Challenges in the provision of palliative care at resource-limited South African hospice settings: *Palliative and Chronic Care. African Journal for Physical Health Education, Recreation and Dance. 20*: 420-432.

Levil, L., Bologh, E., Nass, S & Ganz, PA. 2013. Delivering high-quality cancer care. Charting a new course for a system in crisis. The National Academies Press. Washington DC.

Lietz, C & Zayas, L. 2010. Evaluating qualitative research for social work practitioners. *Advances in Social Work*, 11: 88-202.

Life-threatening Disease. 2019. Available from: https://www.omicsonline.org/scholarly/life-threatening-disease-journals-articles-ppts-list.php. Accessed on 20 June 2019.

Line D. 2015. *The 2015 Quality of Death Index: Ranking palliative care across the world*. The Economist, Intelligence Unit, Accessed 02 March 2019.

Lomarpak, R., Jones, K., Leigh, S & Gay, C. 2010. *Surviving your social work placement*. New York. Palgrave, Macmillan.

Louw, S. 2011. Active listening in qualitative research. *International Conference: Doing Research in Applied Linguistics*, King Mongkut's University of Technology Thonburi. Bangkok. Thailand. Accessed 10 October 2019.

Lutz, S. 2011. The history of hospice and palliative care: Current problems in cancer. *US National Library of Medicine National Institutes of Health,* 35(6): 304–309.

Lynch T., Connor S & Clark D. Mapping levels of palliative care development: a global update. J Pain Symptom Management 2013; 45: 1094-106. 20.

Maphumulo, WT & Bhengu, BR. 2019. Challenges of quality improvement in the healthcare of South Africa, post-apartheid: A critical review. *Curations*. 42 (1) e1-e9. Accessed 28 August 2020.

Marais, J. 2016. Navigating your own cancer journey: a handbook for cancer patients and caregivers by an oncology nurse navigator. Indianapolis. Dog Year Publications.

Maree, JG. 2012. Complete your thesis or dissertation successfully: Practical guideline. Cape Town. JUTA.

Maree, JG. 2016. *First steps in Research 2.* Hatfield. Pretoria. Van Schaik Publishers.

Mc Milan, J, & Schumacher, S. 2010. *Research in education*. New Jersey. Pearson Education Inc.

McAteer, R & Wellberry, C. 2013. Palliative care: benefits, barriers, and best practices. *US National Library of Medicine National Institutes of Health*, 88(12):807-13.

McCormick, AJ., Curtis, JR., Stowell-Weiss, P., Toms, C & Engelberg, R. 2010. Improving social work in intensive care unit palliative care: Results of a quality improvement intervention. *Journal of Palliative Medicine,* 13(3): 297–304.

McGrath, C., Palmgren, PJ & Lijedahl, M. 2019. Twelve tips for conducting qualitative research interviews. *Medical Teacher*, 41(9):1002-1006. Accessed 02 March 2019.

McGarrigle, T & Walsh, C. 2011. Mindfulness, self-care, and wellness in social work: effects of contemplative training. *Journal of Religion & Spirituality in Social Work: Social Thought*. 30. 212-233. Accessed 11 July 2020.

McInnis-Dittrick, K. 2014. Social work with older adults. Pearson. London

McMullin, M. 2017. Doing relationship-based social work. Jessica Kingsley. London.

Meier DE. Increased access to palliative care and hospice services: opportunities to improve value in health care. *Milbank Q*. 2011;89(3):343-380.

Metcalf, J. 2013. Hospice social work methods and intervention for terminally ill patients experiencing anticipatory grief. Available from: httpps://Sophia.stkate.edu/msw_papeers/232. Accessed on 18 September 2019.

Middleton, A., Head, B & Remke, S. 2019. Role of Hospice and Palliative Social Worker. Journal of Palliative Medicine. 23: 573-574. Accessed 6 August 2020.

Miller, J., Lee, J., Niu, C., Grise-Owens & Bode, M. 2019. Self-compassion as a Predictor of Self Care. A study of Social Work Clinicians. *Clinical Social Work Journal.*

Miley, KK & Du Bois, BL. 2015. Generalist social work practice. An empowering approach. Boston. Pearson

Mills, J., Wand, T & Fraser, JA. 2019. Exploring the meaning and practice of self-care among palliative care nurses and doctors: a qualitative study. *BMC Palliative Care.* 17 (63). Accessed 11 October 2020.

Mohanti BK. Research focus in palliative care. *Indian Journal of Palliative Care*. 2011;17(Supplementary): S8-S11. Accessed 20 January 2021.

Moriarty, J., Baginsk, M & Manthorpe, J. 2015. *Literature review of roles and issues within the social work profession in England.* Social Work Workforce Research Unit. Kings College London.

Murray, KP. 2015. Experiencing joy: Personal narratives of hospice and palliative care social workers. Retrieved from Sophia. The St Catherine University Repository website. Htpps://Sophia.stkate.edu/msw_papers/501.

Mwangi-Powell FN., Downing J., Powell RA., Kiyange F & Ddungu, H. 2015. Palliative care in Africa. In: Ferrell BR & Coyle N (Eds.) *Textbook of palliative nursing, 4th Edition.* New York: Oxford University Press, pp.1118-1129.

Nancarrow, SA., Booth, A., Ariss, S., Smith, T., Enderby, P & Roots, A. 2013. Ten principles of good interdisciplinary teamwork*. Human Resources Health*. 11 (9). Accessed 8 September 2020.

NASW Centre for Workplace studies and social work practice. Social Workers in Hospice Care and Palliative Care. Occupational profile. Accessed on 26 August 2020.

Niedzwiedz, CK., Knifton, L., Robb, KA., Katikireddi, SV & Smith, DJ. 2019. Depression and anxiety among people living with and beyond cancer: a growing clinical and research priority. *BMC Cancer* **19,** 943. Accessed 10 January 2021.

Niekerk, JV. 2008. Palliative care – from dream to mainstream. South African Medical Journal. 93.

Ngwenya**,** N, Ambler J & Archary M. 2019. Qualitative situational analysis of palliative care for adolescents with cancer and HIV in South Africa: healthcare worker perceptions. *British Medical Journal Open,* 9 (1): e023225.

O'Brien, V., Jenkins, LS., Munnings, M., Grey, H., North, Z., Schumann, H & De Klerk-Green, E. 2019. Palliative care made visible: Developing a rural model for the Western Cape Province, South Africa. *African Journal of Primary Health Care & Family Medicine.* 12: 1-12.

Obrocnikova, A & Ludmila, M. 2017. Patient satisfaction with health care in an oncology setting. *Nursing in the 21st century.* 15 (1).

O'Callagan, S. 2014. Social workers coming to voice within multi-disciplinary palliative care settings: an exploration of practitioners views and experiences. 6: 204-224. *Critical Social Thinking.* School of Applied Social Studies. University College Cork. Ireland.

Onyeka, TC. 2010. Psychosocial issues in Palliative Care. A Review of five cases. *Indian Journal of Palliative Care*. 16 (3) 123-128.

Opoku. JK. Health and care development; An exploration of factors that hamper better palliative care in Sub-Saharan Africa. *European Journal of Biology and Medical Science Research* 2 (4): 1-16. Accessed 03 March 2020.

Ostadhashemi, L., Maliheh, A., Khalvati, M., Eghlima, M, & Reza, K. 2019. Preventing burnout and compassion fatigue in pediatric oncology. *International Journal of Cancer Management.*

Otis-Green, S. 2020. Passion, purpose and preparation. The power of social in palliative care. Shirley Institute for Palliative Care. The California State University.

Otis-Green, S., Jones, B., Zebrack, B., Kilburn, L., Altito, JA & Ferrell, B. 2014. ExCEL in social work: Excellence in Cancer Education and leadership. An Oncology social work response to the 2008 Institute of Medicine Report.

Oxford Dictionary of English. 2016. 2nd ed: Oxford University Press

Pajka, SE. 2017. "Doctors, Death, and Denial: The Origins of Hospice Care in 20th Century America". MSSA Kaplan Prize for Yale History.

Palliative Care Competence Framework Steering Group. 2014. *Palliative care competence framework*. Dublin: Health Service Executive.

Pandey, C & Patnaik, S. 2014. Establishing reliability and validity in qualitative inquiry: A critical examination. *Jharkhand Journal of Development and Management Studies XISS, Ranchi*, 12(1): 5743-5753.

Parker-Oliver, D. 2012. Problem-solving. An opportunity for hospice social workers to better meet caregiver needs. *Journal of Social Work End of Life Palliative Care.* 8 (11) :3-9

Parmar, A. 2014. Methods of social work and its role in understanding team climate and team effectiveness for organisational development. *Journal of Sociology and Social Work,* 2(1): 303-318.

Pask, S., Pinto, C., Bristowe, K., van Vliet, L., Nicholson, C., Evans, CJ., George, R., Bailey, K., Davies, JM., Guo, P., Daveson, BA., Higginson, IJ & Murtagh, FEM. 2018. A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. *Palliative Medicine.* Vol. 32 (6): 1078–1090.

Pattoni, L. 2012. Strength-based approaches for working with individuals. *Institute for Research and Innovation in Social Sciences*. 5(16): 3-13. Accessed on 03 February 2020.

Partinico, M., Cora, A., Ghisi, M., Quimet, JA & Vissentin, M. 2014. A new Italian questionnaire to assess caregivers of cancer patients satisfaction with palliative care. Multicentre validation of post-mortem questionnaire short form. *Journal of Pain and Symptom Management.* 47 (2).

Paul, S. 2016. The role of social workers in palliative care, end of life and bereavement care. British Association of Social Workers Report.

Peres, JA. 2016. A time and place. The role of social workers in providing end of life care. *Journal of Social Work End of Life Palliative Care*. 12 (3). Accessed 06 August 2020.

Pessin, H., Fenn, N., Hendriksen, E., Derosa, PA & Applebaum. 2015. Existential distress among healthcare providers caring for patients at end-of-life care. *Cur Opin Support Palliative Care*. 91 (10): 77-86. Accessed 03 October 2020.

Portoghese, I, Gattetta, M, Larkin, P, Sardo, S, Compagna, M, Finco, G & D'Aloja , E. 2020. Compassion fatigue watching patients suffering and emotional display rules among health professionals. A daily diary study. *BMC Palliative Care.* 19 (23). Accessed 03 May 2020.

Poudel, A., Kc, B., Shrestha, S & Nissen, L. (2019). Access to palliative care: discrepancy among low-income and high-income countries. *Journal of global health*, *9*(2), 020309. Accessed 3 July 2020.

Powell, RA., Harding R., Namisango, E., Katabira, E., Gwyther, L., Radbruch, L., Murray, S., El-Ansary, M., Ajayi, IO & Mwangi-Powell, F. 2013. Palliative care research in Africa: An overview. *European Journal of Palliative Care*. 20: 162-167. Accessed 02 February 2019.

Pulla, V. 2017. Strengths-based approach in social work: A distinct ethical advantage. *International Journal of Innovation*, *Creativity and Change*, 3: 97-114.

Punch, KF. 2016. Developing effective research proposals. London. Sage.

Quinn-Lee, L., Olson-McBride, L & Unterberger, A. 2014. Burnout and death anxiety in hospice social workers, *Journal of Social Work in End-Of-Life & Palliative Care*, 10(3), 219-239.

Ragesh, G., Zacharias, L & Thomas PT. 2017. Palliative care social work in India: Current status and future directions. *Indian Journal of Palliative Care*, 23(1): 93–99.

Ramsey, AT & Montgomery, K. 2014. Technology-based interventions in social work practice. A systematic review: mental health intervention. *Social Work Health Care*. 53 (9) 833-899. Accessed 10 May 2019.

Reckrey, JM, Gettenberg, G, Ross, H, Kopke, V, Soriano, T & Ornstein, K. 2016. The critical role of social workers in home-based primary care: *Social Work Health Care*. 53 (4) 330-343.

Reigad, C, Ramos, P & Aquirred de Carcer, A. 2015. The social work competencies in palliative care: A case study. *BAOJ Palliative Medicine* 1 1-6.

Reville, B & Foxwell, AM. 2014. The global state of palliative care-progress and challenges in cancer care. *Ann Palliative Medicine,* 3(3): 129-38.

Rhee, J, Gerralda, E, Namisango, E, Luyiruka, E, De Lima, L, Powell, R, & Centreno, C. 2018. The African Palliative Care Association (APCA) Atlas of Palliative Care Development in Africa: a comparative analysis. *The Lancet Global Health.* 6. S21.

Rhee, John & Garralda, Eduardo & Namisango, Eve & Luyirika, Emmanuel & De Lima, Liliana & Powell, Richard & Robinson, Carole & Centeno, Carlos. (2018). Factors Affecting Palliative Care Development in Africa: In-Country Experts' Perceptions in Seven Countries. Journal of Pain and Symptom Management. 55 (5)

Vega, R., Bayon, B., Perez, C., Palaotarrero, A., Fernandez, LA l & Ferdosi, F. 2019. Mindfulness-based Narrative Therapy for Depression in Cancer Patients. Clinical Psychology and Psychotherapy. 21: 411-419

Rossi, FS., Giorgi, I., Baiard, P., Giuntoli, L., Balestroni, G., Cerutti, P., Monera, M., Gabanelli, P., Solora, V., Fornora, R., Luisetti, M., Omarin, P., Omarin, G & Vidotto, G. 2017. Illness denial questionnaire for patients and caregivers. *Neuropsychiatric Disease Treatment.* 13 909-916. Accessed 22 November 2019.

Rubischko, K. 2016. *Medical Social Worker Perception of Competence in Palliative Care Consultations*. Retrieved from Sophia, the St. Catherine University repository website: https://sophia.stkate.edu/msw_papers/661. Accessed on 17 August 2019.

Sabo, BM & Vachon MLS. 2011. Care of professional caregivers. Supportive oncology. 575-589. In Bruera, E., Higgison, I., von Gunten, CF & Morita, T. Oxford Textbook of Palliative Nursing. CRC Press.

Sadauskas J & Benosyte 2016. Experiences of Social Workers providing Palliative Care for dying patients in the institutions of Palliative Care and their ways to overcome stress. SHS Web Conference 20 00022.10/1051/SHSConf/20163000022.

Saleebey, D. 2009. Strengths, perspectives in social work. USA. Pearson.

Sanders, S, Bullock, K & Broussard, C. 2012. Exploring professional boundaries in end-of-life care: considerations for hospice social workers and other members of the team. *Journal of Social Work in End of Life and Palliative Care. 8(1): 10-28.*

Sanders, S & Swails, P. A quest for meaning: Hospice social workers and patient with end-stage dementia. *Journal for social work. 56 (2) 129-140.*

Sanso, N., Galiana, L., Oliver, A., Pascual, A., Sinclair, S & Benito, E. 2015. Palliative Care Professionals inner life: Exploring the relationship among awareness, self-care, compassion satisfaction and fatigue, burnout and coping with death. *Journal of Palliative Medicine.* 50 (2): 200-207.

Sarbo, PG., Dickson, D., Chifamba, D., Mastrojohn, J., Sisimayi, CN & Williams, SH. The Zimbabwe Rural Palliative Care Initiative: PCI-Z. *Journal of Pain and Symptom Management*. 40 (19). Accessed 18 September 2020.

Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Roberts, D., Tayler, C., Voth, J & Stajduhar, J. 2016. Conceptual foundations of a palliative approach: a knowledge synthesis. BMC Palliative Care. 15:5 :1-14.

Schroepfer, T. 2011. Oncology Social Work in Palliative Care. Current problems in cancer. 35. 357-64. Accessed 10 June 2020.

Schurink, W, Fouche, CB & De Vos. 2011. Qualitative data analysis and interpretation, in *Research at grassroots: For all the social science and human service professions,* edited by AS de Vos, H Strydom, CB Fouche and CSL. Delport. Pretoria: Van Schaik Publishers.

Sekse, RJT., Hunskar, I & Ellingsen, S. A nurse's role in palliative care: A qualitative meta-synthesis. *Journal of Clinical Nursing,* 27(1-2): e21. Accessed 10 June 2019.

Selman, L., Harding, R., Agupio, G., Fox, P., Galimaka, D., Mmoledi, K., Higginson, IJ. The Spiritual Care in sub-Saharan Africa Advisory Group: *Spiritual care recommendations for people receiving palliative care in sub-Saharan Africa*. 2010.

Selman, L. E., Harding-Swale, R., Agupio, G., Fox, P. T., Galimaka, D., Mmolendi, K., Higginson, I. J., & Spiritual Care in sub-Saharan Africa Advisory Group, T. 2010. *Spiritual care recommendations for people receiving palliative care in sub-Saharan Africa: With special reference to South Africa and Uganda*. Cicely Saunders International.

Shippee, ND, Shippee, TP, Fernstrom, K & Britt, HR. 2018. Effect of a whole person model of care on patient experience in a patient with complex chronic illness in late life. *The American Journal of Hospice and Palliative Care*, 35(1): 104-109.

Siemerink, EJ, Jaspers, JP, Plukker, JT, Mulder, NH & Haspers, GA. 2011. Retrospective denial as a coping method. *Journal for Clinical Medical Settings. 18 (1) 65-69.*

Sjoberg, V & Forsner, M. 2020. Shifting roles: Physiotherapists perceptions of person-centred care during a pre-implementation phase in the acute hospital setting - A phenomenographic study. *Physiotherapy Theory and Practice.* 1:11.

Smith, SK, Nicolla, J & Zafar, SY. 2014. Bridging the Gap Between Financial Distress and Available Resources for Patients with Cancer: A Qualitative Study. *Journal for Oncology Practice*. 10(5): e368–e372. Accessed 13 October 2020.

Spray, C & Jowett, B. 2012. *Social work practice with children and families*. Sage Publishers. London.

Snyder. H. 2019. Literature review as a research methodology: An overview and guidelines. *Journal of Business Research*. 104: 333-339.

Spiers, J. 2015. *Verification strategies*. University of Alberta.

Spruyt O. Team networking in palliative care. *Indian Journal of Palliative Care*. 2011;17(Supplementary): S17-S19.

Stark, l., Tofthagen, C., Visovsky, C & McMillan. C. 2012. The Symptom Experience of Patients with Cancer. 14(1): 61-70. Accessed 13 October 2020.

Sundell, K & Olsson, T. 2017. *Social intervention research*. Oxford Bibliographies. Accessed from 21 October 2019.

Teater, B. 2014. Social Work practice from an ecological perspective. In LeCroy C.W. (Ed.). *Case studies in social work practice.* 3rd ed. Belmont, CA: Brooks/Cole.

Thoresen L, Wyller T, Heggen K. The significance of lifeworld and the case of hospice. *Medical Health Care Philosophy*. 2011;14(3):257-263. doi:10.1007/s11019-010-9296-6

Trevithick, P. 2011. The generalist versus specialist debate in social work education in the UK. In J. Lishman (ed.) *Research highlights: Volume on social work education*. London: Jessica Kingsley: 233-254.

Twohig, JS & Strong, J. 2020. The social worker's role in community palliative care: insights from the field. Centre to advance Palliative care (CAPC and social work Hospice and Palliative care network (SWHPN) Seminar.

van der Merwe & Marais, C. 2016. Relationship building in the initial phase of social work intervention with child clients in a rural area. *Social work (Stellenbosch Online).* 52(1): 145-166.

van Westrhenena & Fritz E. 2013The experiences of professional hospice workers attending creative arts workshops in Gauteng. *Health Education Journal*.;72(1):34-46.

Walker, S. 2012. Effective social work with children, young people and families: Putting systems theory into practice. London. Sage Publications.

Watts, JH. 2013. Considering the role of social workers in palliative care: reflectors from the literature. *Journal of Palliative Care.* 20 (4): 199-201. Accessed on 08 January 2020.

Wang, C, Chan, CLW & Chow AYM. 2018. Social workers' involvement in advance care planning: a systematic narrative review. *BMC Palliative Care 17 (5).* Accessed 23 August 2020.

Weru, J. 2017. Most people in Africa do not have access to palliative care. *The Conversations* 6 July 2017. Accessed 12 October 2019.

Wiid, J & Diggines, C. 2013. *Marketing research*. 2nd ed. Cape Town. Juta.

Williams, HM & Erlank, EC. 2019. Traumatic incident reduction. A suitable technique for South African social practice settings. *Health SA Gesonndheid*. 24.

Wordingham, SE & Swetz, KM. 2015. Overview of palliative care and hospice services. *American Association for the Study of Liver Diseases*. 6(2): 30-32.

World Health Organization & World Hospice Palliative Care Alliance. 2014. *Global Atlas of Palliative Care at End of Life.* Geneva: World Health Organization & World Hospice Palliative Care Alliance.

World Hospice Palliative Hospice Palliative Care Alliance. 2019. Accessed 28 August 2019.

Worldwide Palliative Care Alliance. Mapping levels of Palliative Care Development: A global update. London: Worldwide Palliative Care Alliance, 2011.

Wu, S & Fraser, M. 2013. Satisfaction with social welfare services – a review. Socialstyrelsen Press.

Yi, J, Kim, J, Akter, J, Molloy, JK, Kim, MA & Frozier. 2018. Pediatric oncology social work experience of compassion fatigue. *Journal of Psychosocial Oncology.*

Youngworth, J & Twaddle, M. 2011. Cultures of interdisciplinary teams. How to foster good dynamics. *Journal of Palliative Medicine (14 (5) 650-654.*

Yu, QT & Stander, PE. 2016. Differentiating Palliative Care and Hospice Care. *University of Arizona Health Sciences*. Accessed 08 January 2020

Zebrack, B. 2018. Oncology social workers play an important role in cancer care. Health well foundation.

ADDENDUMS

Addendum 1: A preamble to an information and informed consent document for a participant

Dear Participant

I, Tendayi Nyamndaya, the undersigned, am a part-time master's student in the Department of Social Work at the University of South Africa. In fulfilment of requirements for a master's degree. I have to undertake a research project and have consequently decided to focus on the following research topic:

THE EXPERIENCES OF SOCIAL WORKERS IN RENDERING PALLIATIVE CARE SERVICES: SUGGESTIONS FOR SOCIAL WORKERS

Since you are well-informed about the subject under study, I hereby approach you with the request to participate in the study. For you to decide whether or not to participate in this research project, I am going to give you information that will help you to understand the study (i.e. what the aims of the study are and why there is a need for this particular study). Furthermore, you will be informed about what your involvement in this study will entail (i.e. what you will be asked/or what you will be requested to do during the study, the risks and benefits involved by participating in this research project, and your rights as a participant in this study).

The ultimate goal of this study is to develop an in-depth understanding of the experiences of social workers in rendering palliative care services: Suggestions for social work practice. Should you agree to participate, you would be requested to participate in a face-to-face interview(s) that will be conducted at your office at a mutually agreed time for one hour per interview. The following questions will be directed to you:

With your permission, the interviews will be audiotaped. The recorded interviews will be transcribed word-for-word. Your responses to the interview (both the taped and transcribed versions) will be kept strictly confidential. The audiotaped(s) videotape(s) will be coded to disguise any identifying information. The tapes will be stored in my locked office at my home in Cape Town and only I will have access to them. The transcripts (without any identifying information) will be made available to my research supervisor(s)/promoter(s), a translator (if they need to be translated into English), and an independent coder with the sole purpose of assisting and guiding me with this research undertaking. My research supervisor(s)/promoter(s), the translator and the independent coder will each sign an undertaking to treat the information shared by you in a confidential manner. The audiotapes and the transcripts of the interviews will be destroyed upon the completion of the study. Identifying information will be deleted or disguised in any subsequent publication and/or presentation of the research findings.

Please note that participation in the research is voluntary. You are not obliged to take part in the research. Your decision to participate, or to not participate will not affect you in any way, now or in the future and you will incur no penalty and/or loss to which you may otherwise be entitled. Should you agree to participate, please sign the information and informed consent documents contained herewith as proof of your willingness to participate. Please note that you are not signing your rights away.

If you agree to take part, you have the right to change your mind at any time during the study. You are free to withdraw this consent and discontinue participation in the study without any loss of benefits. However, should you withdraw from the study; you would be requested to grant me an opportunity to engage in an informal discussion with you so that the research partnership that was established can be terminated in an orderly manner.

As the researcher, I also have the right to dismiss you from the study without regard to your consent if you fail to follow the instructions or if the information you divulge is emotionally sensitive and upsetting you, to such an extent that it hinders you from functioning physically and emotionally in a proper manner. Furthermore, if participating in the study at any time jeopardises your safety in any way, you will be dismissed from the study. Should I conclude that the information you have shared left you feeling emotionally upset, or perturbed, I am obliged to refer you to a counsellor for debriefing or counselling if you agree.

You have the right to ask questions concerning the study at any time. Should you have any questions or concerns about the study, you can contact me on 0738051044 (any time of the day) or **0217155420**. My supervisor, Dr RP Mbedzi is also available at **0124298629** should you need clarity.

Please note that this study has been approved by the Research and Ethics Committee of the Department of Social Work at Unisa. Without the approval of this committee, the study cannot be conducted. Should you have any questions and queries that have not been sufficiently addressed by me as the researcher, you are more than welcome to contact the Chairperson of the Research and Ethics Committee of the Department of Social Work at Unisa. His contact details are as follows: Prof AH (Nicky) Alpaslan, telephone number: **012 429 6739**, or email: **alpasah@unisa.ac.za**.

If, after you have consulted the researcher and the Research and Ethics Committee in the Department of Social Work at Unisa and their answers have not satisfied you, you may direct your question/concerns/queries to the Chairperson, Human Ethics Committee, College of Human Science, PO Box 392, Unisa, 0003.

Based upon all the information provided to you above, and being fully aware of your rights, you are asked to give your full consent in writing should you want to participate in this research study by signing and dating the information and consent forms provided herewith and initialling each section to indicate that you understand and agree to the conditions contained herewith.

Thank you for your participation.

Kind regards

Researcher

Tendayi Nyamndaya

Contact details: (H) 021 715 5420.
073 805 1044
tendy.81@gmail.com

Addendum 2: Information and informed consent document

INFORMATION AND INFORMED CONSENT DOCUMENT

THE EXPERIENCES OF SOCIAL WORKERS IN RENDERING PALLIATIVE CARE SERVICES: SUGGESTIONS FOR SOCIAL WORKERS

REFERENCE NUMBER: **50076981**

PRINCIPAL INVESTIGATOR/RESEARCHER: **TENDAYI NYAMNDAYA**

ADDRESS:**5 EDGEWARE CLOSE. DIEP RIVER. 7800**

CONTACT TELEPHONE NUMBER: **021 715 5420**

DECLARATION BY OR ON BEHALF OF THE PARTICIPANT Initials

I, THE UNDERSIGNED , ________________________ (name), ID No ___________________________] of the participant [ID No _______________________] of

____

____

_______________________ (address)

A. HEREBY CONFIRM AS FOLLOWS:

1. I/the participant was invited to participate in the above research project which is being undertaken by (name) Tendayi Nyamndaya of the Department of Social Work in the School of Social Science and Humanities at the University of South Africa, Pretoria. South Africa.

2. The following aspects have been explained to me/the participant:

Initials

2.1 Aim: The investigator (s)/researcher (s) are studying.

The information will be used to/for

2.2 I understand that. Initials

2.3 Risks Initials

Possible Benefits: As a result of my participation in this study Initials

Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the investigator/researcher	Initials
Access to findings: Any new information/benefit that develops	Initials
Voluntary participation/refusal/discontinuation: my participation is voluntary. My decision whether or not to participate will in no way affect me now or in the future.	Initials
3. The information above was explained to me/the participant by _______________________________________ (name of relevant person) in Afrikaans/English/Sotho/Zulu/Xhosa/Other ____________ (indicate other language) and I am in command of this language/it was translated to me satisfactorily by ____________________ (name of translator). I was given the opportunity to ask questions and all these questions were answered satisfactorily.	Initials
4. No pressure was exerted on me to consent to participate and u understand that I may withdraw at any stage from the study without penalty.	Initials
5. Participation in this study will not result in any additional cost to me	Initials
B. I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE PROJECT.	Initials

Signed/confirmed at ____________________on _________20______

____

Signature or right thumbprint of participant Signature of witness

IMPORTANT MESSAGE TO PARTICIPANT/REPRESENTATIVE OF PARTICIPANT

Dear Participant /Representative of participant

Thank you for your/the participant's participation in this study. Should at any time during the study

- an emergency arises as a result of the research, or
- you require any further information with regard to the study, or
- the following occurs.

____

____

____

(indicate any circumstance which should be reported to the investigator), kindly contact DR RP Mbedzi 021 4298628

CONSENT FORM REQUESTING PERMISSION TO PUBLISH PHOTOGRAPHS, AUDIOTAPES AND/OR VIDEOTAPES OR VERBATIM TRANSCRIPTS OF AUDIOTAPE/VIDEOTAPE RECORDINGS

As part of this project, I have made a photographic, audio and/or video recording of you. I would like you to indicate (with ticks in appropriate blocks next to each statement below) what uses of these records are you willing to consent to. This I completely up to you. I will use the records only in	Place a tick. [✓] next to the use of the record you consent to

ways that you agree to. In any of these records, names will not be identified.

1. The records can be studied by the research team and photographs/quotations from the transcripts made of the recordings can be used in the research report.
2. The records (i.e. photographs/quotations from the transcripts made of the recordings) can be used for scientific publications and/or meetings.
3. The written transcripts and/or records can be used by other researchers.
4. The records (i.e. photographs/quotations from the transcripts made of the recordings) can be shown/used in public presentations to non-scientific groups.
5. The records can be used on television or radio.

__________________________ _________

Signature of participant Date

Addendum 3: Consent form for social worker for debriefing

IMPORTANT MESSAGE TO PARTICIPANT/REPRESENTATIVE OF PARTICIPANT

Dear Participant/Representative of participant

Thank you for your/the participant's participation in this study. Should at any time during the study

- an emergency arises as a result of the research, or you require any further information with regard to the study, kindly **021 4298628** at the Department of Social Work at the **University of South Africa**

Addendum 4: Letter of approval/permission to conduct the study.

HaemaLife
SPECIALIST PHYSICIANS & CLINICAL HAEMATOLOGISTS

Dr Pieter de Witt
MBChB, FCP (SA), MMedSc (Critical Care),
Cert Clin Haematology (SA) Phys

Dr Hannes Koornhof
MBChB, FCP (SA), Dip HIV Man (SA)
Cert Clin Haematology (SA) Phys

25 June 2020

Dear Ms Nyamndaya

RE: RESEACH STUDY PERMISSION

This letter serves as confirmation that permission has been granted to carry out your research studies on "**the experiences of social workers in rendering palliative care services: suggestions for social work practice" at** Haemalife.

We hope that your research will benefit social workers who work with people facing life threatening illnesses in the future and enhance social work practice in palliative care.

Best wishes

Lizette Gillespie
Practice Manager

Suite 4G, Netcare Kuils River Hospital, 33 Van Riebeeck road, Kuils River, 7580 | Tel: 021 900 6277 | Fax: 021 900 6323 | E-mail: admin@haemalife.co.za
Practice number: 018 001 0568082 | Reg no: 2015/035976/21 | VAT no: 4840269056

Addendum 5: Letter of approval/permission to conduct the study.

helderberg
hospice

25 June 2020

Dear Ms Nyamndaya

RE: RESEARCH STUDY PERMISSION

This letter serves as confirmation that permission has been granted to carry out your research studies on **"the experiences of social workers in rendering palliative care services: suggestions for social work practice"** at Helderberg Hospice.

We trust that your research will benefit social workers who work with people facing life threatening illnesses in the future and enhance social work practice in palliative care.

Best wishes

SW Manager

T: +27 (21) 852 4608 • F: +27 (21) 851 7426
E: info@helderberghospice.org.za

P.O. Box 1640, Somerset West, 7129 • 21 Old Stellenbosch Road, Somerset West, 7130
004-372 NPO • Reg. No. 1987/000465/08 • Prac. No. 7900058
www.helderberghospice.org.za

Addendum 6: Thank you letter to participants:

Enquiries: Ms Tendayi Nyamndaya

Tel No: 021 715 5420

Cell No: 0738051044

Date: 20 October 2020

Dear Participant

Re: Thank you letter for voluntary participation in the research study

Thank you for your participation in this study. Your cooperation is highly appreciated. Once the study report has been approved, I will send you a copy of the report.

Yours sincerely

Ms Tendayi Nyamndaya

Cell No: 0738051044

Addendum 7: Declaration of the independent coder

Margaret Grobbelaar

Die Opstal 589 Opstal Street

The Willows Pretoria 0041

Tel: (012) 807 1249

E Mail: mwmrg@iafrica.com

CODING OF TRANSCRIPTS: TENDAYI NYAMNDAYA

This is to confirm that I have acted as the independent coder for Tendayi Nyamndaya's research study entitled ***"The experiences of social workers in rendering palliative care services: suggestions for social workers".***

This entailed analysing and coding of 10 transcripts and compiling a report consisting of the themes, sub-themes and concomitant storylines from the interviews.

Yours sincerely

M Grobbelaar

M Grobbelaar

24 October 2020

Addendum 8: Letter from the editor

ENVIROSTAT CONSULTING (PTY) LTD

| 85 Olifant Street | Makhado | 0920 |

envirostatconsulting@gmail.com | +27746865819 | +27662995195

19 January 2021

TO WHOM IT MAY CONCERN

This is to certify that I have edited the Dissertation by Tendayi Nyamndaya entitled,

"THE EXPERIENCES OF SOCIAL WORKERS IN RENDERING PALLIATIVE CARE SERVICES: SUGGESTIONS FOR SOCIAL WORKERS"

submitted for the MASTER OF SOCIAL WORK degree at the University of South Africa.

Kindly contact me should you have any

queries. Yours sincerely

James Chapangara Mugabe Pr.Sci.Nat.

Lead Consultant

Envirostat Consulting (Pty) Ltd

Addendum 9: Ethical clearance letter

ADDENDUM 9: ETHICAL CLEARANCE LETTER

SOCIAL WORK RESEARCH ETHICS COMMITTEE (SWREC)

Date: 13 April 2020

Dear Ms T Nyamndaya

DECISION:
Ethics approval from 13 April 2020 to 13 April 2021

SWREC Reference #: 2020-SWREC-50076981
Name: T. Nyamndaya
Student #: 50076981
Staff #: N/A

Researcher(s): Name: Ms T. Nyamndaya
Contact details: 50076981@mylife.unisa.ac.za

Supervisor(s): Name: Dr RP Mbedzi
Contact details: mbedzrp@unisa.ac.za, 012 429 8628

Title of research:
The experiences of Social Workers in rendering Palliative Care services: Suggestions for Social Workers.

Qualification: Master of Social Work (MSW)

Thank you for the application for research ethics clearance by the Social Work Research Ethics Committee (SWREC) for the above-mentioned research. Ethics approval has been granted effective from **13 April 2020.**

The following are standards requirements attached to all approval of all studies:

1. Approval will be for a period of twelve months from of the date of issue of the certificate. At the end of this period, if the study has been completed, abandoned, discontinued or not completed for any reason you are required to submit a report on the project. If you complete the work earlier that you had planned, you must submit a report as soon as the work is completed. Reporting template can be requested from the SWREC administrator on radebn1@unisa.ac.za
2. However, at the **end of twelve months' period** if the study is still current, you should instead submit an application for renewal of the approval.
3. Please remember that you must notify the committee in writing regarding any amendments to the study.

4. You must notify the committee immediately in the event of any adverse effects on participants or any unforeseen event that might affect continued ethical acceptability of the study.
5. At all times you are responsible for the ethical conduct of your research in accordance with the SWREC standard operating procedures, terms of references, National Health Research Council (NHREC) and university guidelines. Yours sincerely

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Dr KJ Malesa: Chairperson of SWREC

Email: maleskj@unisa.ac.za

Tel No.: (012) 429 4780

Addendum 10: Interview guide

1. What is your experience of working with people faced with life-threatening illnesses?

2. What is the nature of palliative care services you provide to people faced with life-threatening illnesses?

3. What is your role within the interdisciplinary team that provide palliative care services?

4. What is your intervention strategies in working with people faced with life-threatening illnesses?

5. What challenges do you often encounter in rendering palliative care services?

6. How do you cope or deal with the challenges experienced in rendering palliative care services?

7. Are you satisfied with the kind of palliative care services you provide to people faced with a life-threatening illness? Please substantiate.

8. What are your suggestions regarding the nature of palliative care services provided by social workers?

9. What are your recommendations regarding the role of social workers in providing efficient palliative care services to people faced with life-threatening illnesses?