ATTITUDES OF PARENTS TOWARDS PAEDIATRIC PALLIATIVE CARE: A MEDICAL SOCIAL WORK INTERVENTION PERSPECTIVE IN THE LIMPOPO PROVINCE: SOUTH AFRICA

BY

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DECLARATION

I, Rudzani Noria Mogale declare that the dissertation hereby submitted to the University of Limpopo for the degree, Master of Social Work is my work in my design and execution. I also swear that this work has not been previously submitted by me or someone else for a degree at this or any other University and that all material contained herein have been duly acknowledged using complete references.

Signed: RN Mogale

Date: 07 August 2023

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DEDICATION

This dissertation is dedicated to the following important people in my life:

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ABSTRACT

Case study design was used to explore parents' attitudes towards paediatric palliative care in Limpopo Province, South Africa. Semi-structured in-depth face-to-face interviews were used as a main method of collecting data. Purposive sampling was used to select twenty (20) participants to be involved in the study which were ten (10) parents and ten (10) caregivers of children with cancer who were admitted in the Paediatric Oncology ward within the Polokwane hospital in the Limpopo Province. A Content analysis was used to analyse the data which encompassed ATLAS.ti software. The results showed that parents and caregivers of children suffering from cancer and admitted in Paediatric Palliarive ward at Polokwane hospital, had a generally positive attitude towards PPC. The participants' perspectives on their own emotional, social, financial, and psychological health because of caring for a child with cancer are mixed, with most parents reporting that they are striving to cope with the situation. In relation to challenges that temper with their coping, other participants made mention of their financial battle and losses incurred in their search for a cure for their child's illness. The study also revealed positive support received from health workers and family members. Regarding the knowledge of PPC, results indicate that parents do not have sufficient information regarding the meaning of PPC. The results also revealed lack of referrals by social workers for PPC and lack of cooperation between health workers and social workers. The researcher concluded that the support provided to parents improves their knowledge and awareness of PPC services, and consequently, changes their 'negative' attitudes towards PPC. Thus, they begin to trust the system being certain that their children will receive better treatment in PPC.

SUMMARY OF FINDINGS

This study found that parents have a positive attitude towards PPC services. Majority of parents also reported that they receive positive support from both health workers and family members. However, the research findings indicate that parents do not have sufficient information or knowledge regarding the meaning of PPC. Furthermore, the findings reveal lack of referrals by social workers for PPC, and that there is no cooperation between health workers and social workers, Lack of co-operation should equally affect social and health care workers.

LIST OF ACRONYMS

IPCC-	International Pallative Care for Children
WHO-	World Health Organisation
PPC-	Peadetric Pallative Care
NCI-	National Cancer Institute

CHAPTER ONE:

GENERAL ORIENTATION OF THE STUDY

1.1 Background and motivation

The standards relating to the care of children with cancer was developed through motivation by health professionals' consensus with the aim to identify pediatric palliative care as part of the essential standards of caring for children with cancer (Van Heerden & Kruger, 2021). In the year 2006, a meeting was held by the International Palliative Care for Children (IPCC) andthe focus was on Europe, Canada, the United States of America and Lebanon. The meeting adopted the standpoint of the World Health Organization (WHO) that defined palliative care for children as an active approach within the health care system whichis mainly concerned with the total or complete care of the patient's body, mind, spirit, and ensuring that proper support is given to the patient's family (Otoo, 2020).

Although Pediatric Palliative Care (PPC) services are increasing internationally, thereis evidence of challenges in terms of meeting the needs of many paediatric patients (Twamley, Craig & Kelly, 2014). There is a challenge of access to PPC services by a vast number of children, including in the most developed countries with established PPC programmes (Downing, Boucher, Daniels & Nkosi, 2018). Many countries experience problems which block them from trying to implement sufficient and meaningful PPC services. This includes "lack of both medical and financial resources, problems with access in PPC, lack of public knowledge and awareness of the benefits from services offered through PPC" (Knapp, Sberna-Hinojosa, Baron-Lee, Curtis & Huang, 2014:16).

In South Africa, paediatric hospice was established with the attention to increasingly focus on the needs of children suffering from illnesses that are regardedas life-limiting and life-threatening such as cancer (Connor & Bermedo, 2014). The Department of Health as well as several healthcare facilities, including hospices and nongovernmental organisations are already delivering and developing facets of palliative care for children (Campbell, 2011).

In South Africa, there are various organisations that are active in providing advocacy and education on matters relating to PPC. However, although there are currently limitations experienced within paediatric palliative care, the framework still maintains its comprehensive form that considers the provision of a holistic approach, whose aim is to achieve the child’s needs, including those of his/her family (Ivana, van der Geest, Anne-Sophie, Darlington, Isabelle, Streng, Pieters & van den Heuvel, 2015). Paediatric Palliative Care (PPC) programmes normally assist the family to consider taking decisions which will, always, put the needs of the child who faces a life-threatening illness. The programmes also facilitate communication about their fears and challenges (Weaver, Heinze & Bell, 2016). Furthermore, PPC programmes provide families and the child with ‘psychosocial support’, ‘pain and symptom management’, as well as ‘bereavement care’. Currently, there are many families receiving paediatric palliative care services, including those who have life-limiting as well as complex illnesses. In addition, parents may need education in relation to the coordination of care and support for medical complexity and relief (Cohen & Ezer, 2013).

This study explored attitudes of parents towards paediatric palliative care, especially in revealing and outlining reactions by parents when medical social workers recommend paediatric palliative care for their children. What influenced or motivated the researcher to undertake this study was because of her experience as a medical social worker in Mankweng Hospital, which exposes her to cases of children suffering from cancer and kept within the paediatric ward even though there is no further treatment administered to the said children. Her scope of practice includes providing counselling services to parents of children suffering from chronic illnesses that are mostly cancer related. She observed the rate at which parents become affected by their children’s conditions and the fear of losing them through death. She observed that at times there are reported cases of premature discharge of those children. Hence, the study explored the attitudes of parents with children diagnosed with cancer towards placing the said children in paediatric palliative care.

Negative attitudes towards palliative care are sometimes held by parents who are unfamiliar with it and who mistakenly believe that it is synonymous with death (Scott, Coombes, Braybrook, Haroardottir, Gaczkowska & Hardig, 2023). The same holds true for child palliative care; even in communities where the concept is well-known, knowledge and comprehension are limited. (Saad, Huijer & Noureddine, 2022) discovered that when parents are given accurate information about paediatric palliative care, their attitudes towards it improve. In a study conducted by Verberne et al. (2017) on parental experiences with a Paediatric Palliative Care Team (PPCT), several parents expressed uncertainty about what to anticipate from the palliative process and the new environment their sick kid would inhabit. Moreover, parents valued the PPCT members' competence since it allowed them to respond to their concerns and offer guidance on how to handle such circumstances in the future. Because of the PPCT's approachable demeanor, parents reported feeling no resistance while trying to get in touch with them, as indicated by Verberne et al. (2017). Furthermore, parents emphasised that the PPCT was a safe space where they could share their experiences and ask whatever questions they had without fear of being labelled as insensitive or naive (ibid).

1.2 Definition of key concepts

1.2.1 Palliative care

Palliative care is defined as a system that is centred around caring for the patient and concerned with the enhancement towards the quality of life. The system also provides services which are aimed at addressing all the needs of the patient throughout the experience of the illness to prevent unnecessary pain and suffering (National Consensus Project for Quality Palliative Care, 2016). Palliative care services begin at the point of diagnosis and continue throughout the entire course of the illness until death. This study focused its definition of palliative care from the perspective of the National Cancer Institute (2011) that sees it as an interdisciplinary approach that focuses on caring for an individual suffering from cancer with the purpose of reducing pain, and physical and mental stress at any stage of the illness. This definition was suitable to this study as the parents of cancer victims are likely to be grieved due to fear of losing their children.

1.2.2 Paediatric palliative care

The study defines paediatric palliative care as an active approach that provides a holistic form of service which intends to respond to the unique needs of each child who has been diagnosed with cancer. The type of service is applicable from the pre-natal and neo-natal period until the child either dies or becomes a young adult. According to Craig, Abu-Saad Huijer, Benini, Kuttner, Wood, Feraris & Zernikow (2008), paediatric palliative care refers to providing a complete care of the patient’s body, mind and spirit. PPC also prioritises the psychological and emotional wellness of the patient’s family through the provision of support to the parents and other family members. The overall goal of PPC is to improve the quality of life for children with cancer. These services are offered immediately when the child is diagnosed with the illness. Thereafter, continuous support is provided to the child until he or she succumbs to the illness and dies.

1.2.3 Hospice care

The researcher saw the importance of defining the concept because in most instances, it is not easy to distinguish palliative care and hospice and home-based care. A hospice is a type of care facility that focuses on the provision of accommodation to patients who are terminally ill. Such care begins when there is no more hope for life for the patient. According to Mendieta (2015), a hospice is a facility aimed at accommodating patients whose illnesses (i.e., cancer) have progressed to the point where the patient has fewer than six months to live.

1.2.4 Home-based care

Home-based care is a service rendered to patients within their home settings to assist them to take medication properly. This ensures that patients continue with their medical check-ups and are assisted to attend sessions aimed at enhancing their psychological and social care (Lazzarin, Schiavon, Brugnaro & Benini, 2018).

1.2.5 Paediatric patients

The paediatric patient represents a group in which the various techniques of sedation and general anaesthesia are frequently required, usually for behavioural management (Sedation, 2018).

1.2.6 Paediatric Palliative Care services

Paediatric Palliative Care Service provides physical, emotional, spiritual, and psychological support to children who have a life-limiting illness (www.childrens.health.qld.gov.au/service-paediatric-palliative-care.

1.2.7 Paediatric Palliative Care programmes

What is Palliative Care? **Hospice care**, sometimes referred to as palliative care, focuses on treating a person's symptoms to increase the quality of life when the disease no longer responds to treatment (www.vnane.org/hospice-bridge-program).

1.2.8 Paediatric hospice

Paediatric hospice care refers to services offered to children with life limiting illnesses. It focuses on treating children in need of end-of-life care (www.salushomecare.com).

1.2.9 Palliative care social work

The role of Social workers in Pallative care is to help children and families who are facing life limiting conditions. This can be achieved through providing counseling to the family and the children. (NSW,2023). Developments within palliative care which encompass intervention by social workers can be drawn from the establishment of 'specialist palliative care social work' and the history of services offered in a hospice (Small, 2001; Butler; Ratner; McCreedy, Shippee & Kane, 2014).

1.3 Research problem

The situation within families and among people who care for children suffering from life-limiting conditions such as cancer poses multiple threats, including losing a loved one (Carter & Mandrell, 2013). Furthermore, Carter and Mandrell (2013) indicate that other challenges experienced by families include a reduction of income whereas some parents encounter difficulties maintaining employment. Chronic illnesses create stress that can be related to finances, emotions, spiritual as well as physical difficulties that can affect both the patient and family members alike. On the other hand, there is also a need for emotional counselling to members of the family to understand their child’s illness for them to process the emotions that they are experiencing (Cook, 2011). Findings by the National Cancer Institute (NCI) indicate that there are other family responsibilities that parents are faced with other than taking care of their child with cancer. For example, they are expected to provide everyday care to their families, take decisions, support and manage finances, advocate for their children’s education and manage relationships (Family Caregivers in Cancer, 2018). Furthermore, service barriers relate to the time at which referrals are likely to be made.

According to Twamley et al. (2014), in the case where referrals are done late, this creates challenges towards the likelihood for patients and families to benefit from palliative care support. Losing a child through death puts parents at increased risk of developing psychological problems such as anxiety, multiple mental and emotional discomfort, and poor quality of life (Bergstraesser, Hain & Pereira,2013). Most of the children with chronic illnesses such as cancer and HIV & AIDS are reported to die daily at home in the care of their parents. The parents who provide carefor these children also have a responsibility to partake in other duties at home such as attending to the needs of other family members such as physical, emotional, social and spiritual (Caicedo, 2014). Lack of awareness from parents, caregivers, and other members of the family about the services offered within paediatric palliative care creates barriers towards the recommendation as well as the implementation of the services (Downing et. al., 2018). Some parents are unable to disengage from their children because they suspect and attach synonyms such as “ending one’s life” to placing the child in a palliative care facility. In 2016, the World Health Organization (WHO) revealed that access to palliative care is hindered by factors such as lack of knowledge regarding PPC. Downing, Boucher, Daniels and Nkosi (2018) highlight that PPC services are needed globally but there are some “challenges in accessing them”, especially in developing countries. The researchers cited, among others, “lack of trained health and social care experts as some of the challenges of developing effective palliative care in poor communities”.

South Africa has put in place a policy framework and strategy to ensure that children with chronic and life-threatening illnesses are provided with palliative care services. The problem is that many children who require PPC services still die without being provided with these services. This is despite numerous attempts by the government to provide proper care for these children. For example, a study by Scrimgeour, Marston& Boucher (2010) reveal that “many children in South Africa requiring PPC services die in inadequate conditions without adequate relief from distressing symptoms”. The other reason why children die without PPC services is the stigma associated withit. For example, many parents and care givers believe that PPC is for “dying cancer children”, and subjecting their children to such services means that they are ‘giving up’on them (Scrimgeour et al., 2010). The research gap showed that this study has not being done in the University of Limpopo.

1.4 Purpose of the study

1.4.1 Aim of the study

The aim of this study was to explore attitudes of parents towards pediatricpalliative care.

1.4.2 Objectives of the study

- To identify the current emotional, social, financial, and psychological wellbeing experienced by parents of children with cancer.
- To determine parents’ knowledge of palliative care services offered for their children who are diagnosed with cancer.
- To establish parents’ awareness of palliative care services.

- To establish the level at which social workers recommend and refer children with cancer for psychological and hospice care during the end of life.

1.5 Significance of the study

Parents' attitudes on PPC and hospice care for their terminally ill children were detailed in the study (LLD). This research contributes to the education of social workers about the perspectives, emotions, decision-making, and family and HCP communication of PPC-affected parents. The study also detailed the elements that influence Social Workers' ability to provide palliative care services despite government funding cuts. It shed light on the difficult setting that exists within palliative care, particularly regarding the services provided to clients by Social Workers and the resources required for them to perform optimally. As a result of this research, we may be better able to inform policymakers about potential factors that have a negative impact on the roles of social workers in the wards while trying to provide support and attend to the needs of patients and their families; reduce stigma, fear, and doubt among parents of children with cancer; promote public awareness to inform societies about the importance of PPC services; and more. Furthermore, the study makes important new contributions to our understanding of parental perspectives on PPC in South Africa.

1.6 Preliminary literature review

Palliative care has been developed to offer services to various patients who suffer from different life-threatening illnesses. These include, among others, communicable diseases such as HIV & AIDS and non-communicable diseases such as cancer, cardiac arrest, diabetes, respiratory failure, or multiple sclerosis (WHO, 2016). WHO (2016) further states that “palliative care is widely recognised as part of the comprehensive services required for the non-communicable diseases as stated in the WHO Global Action Plan (2013-2020) which focuses on the prevention and control of non- communicable diseases”. WHO (2016) has noted that “palliative care for children is perceived as distinct from palliative care for adults. The former begins when an illness is diagnosed and continues regardless of whether a child receives treatment directed at curing the disease”.

1.6.1 Policies of Paediatric palliative care in South Africa

(i)The National Policy Framework and Strategy on Palliative Care 2017–2022

The National Policy Framework and Strategy was implemented in 2017 to help "increase the life expectancy and enhance the quality of life for children and adults requiring PPC services". This came after the World Health Assembly resolved that all member states should "develop a policy which will strengthen palliative care services". This policy gives hope for both patients and caregivers to "live as actively as possible with good quality of life despite the diagnosis of life-limiting or life- threatening illness" (NPFSPC, 2017).

1.6.2 Palliative care and Social Work

Small (2001) and Butler, Ratner, McCreedy, Shippee and Kane (2014) indicate that palliative care, which encompass intervention by social workers, was developed during "the establishment of specialist palliative care social work as well as the history of services offered within a hospice. Palliative care social work as a specialised field emerged in the late 1960s. The pioneering work of Cicely Saunders in 1967 was influential to draw attention towards the need and care for patients with advanced life-threatening diseases such as cancer. Cancer is perceived as the most common cause of death even among diagnosed children. Therefore, PPC social work is required for these patients to deal with a wide range of life-limiting health and socially related problems".

Hallenbeck (2003) notes that PPC is complex and consists of experts from different professions. As a result, it gives patients an opportunity to develop a positive view of the condition of the patient (Smith et al., 2012). The services provided are aimed at ensuring that pain and symptoms are managed and that the patient and his/her family continue to receive social services, counselling, and bereavement services (Bona, Bates & Wolfe, 2011).

1.6.3 The role of Social Workers in palliative care

The discipline of palliative care focuses on emotional care, pain control and other services. It also assists patients who are terminally ill as well as provides support to their families so that they can understand and accept death as a natural phenomenon. Professionals who provide services within palliative care, such as social workers conduct assessment carefully and take into consideration the uniqueness of each individual patient and their situations, and thus come up with different plans which would address the individual needs of each patient (Jayita & Deodhar, 2015). According to the National Association of Social Workers (2003), the need for PPC services is vital, and their value is being recognised worldwide. Social workers are key stakeholders in this programme. The association further states that social workers arevested with the responsibility "to confront social problems affecting patients with life- limiting illnesses, performing multi-dimensional roles as counsellors, educators, advocates, mediators, facilitators, and researchers. This programme focuses on improving the care of patients at the end-of-life and promote societal change through raising public awareness on the importance of palliative care social work Palliative care social work is an important means of relieving and addressing situations that cause undue distress and frequent visits to the hospital or clinic by patients".

1.6.4 Palliative care

Palliative care refers to services that are offered to patients to provide support and relief to their illness. The emphasis is placed on the reduction of pain and the provision of relief as the illness cannot be cured (Phillips, Ajrouch, Hillcoat & Nallétamby, 2010). According to WHO (2002), palliative care is "an approach which improves the living conditions and situations of the patient including that of their family. Palliative care is a system of service delivery which prevents and relieves the patient's suffering by way of early identification, assessment and treatment of pain and other physical, psychosocial, and spiritual challenges". Palliative care provides the following:

- Pain relief;

- Assists patients and family members on stressful situations;

- Supports and encourages families to see death as a normal and naturalprocess;
- Taking into consideration the importance of the psychological and spiritualaspects of patients when providing care;
- Offers care by providing meaningful support so that patients can live as activelyas possible until death;
- Offers support to the family to assist them to cope during the patient’s illnessand in their own bereavement;
- Embraces a team approach to address the needs of patients and their families,including bereavement counselling; and
- Enhances the quality of life, and positively influences the course of illness.

1.6.5 The need for palliative care

The provision and need for palliative care is vital as it plays a significant role in the contribution of quality of life of patients and adults suffering from life-limiting diseases and illnesses. This care is needed and offered immediately after diagnoses, to the time when the patient dies (end-of-life) and time of bereavement. Primary healthcare workers provide PPC services to patients with cancer to reduce pain, unnecessary suffering and make trials to calm them so that they stay and live without complaints (World Health Organization, 2014).

1.6.6 Parents as caregivers

The importance of understanding the way parents assume the role as caregivers to their sick child may assist policymakers and healthcare workers to develop an approach that should be used by healthcare workers as an intervention strategy in PPC. There are three types of social support provided by caregivers, namely, instrumental, personal and emotional. Instrumental caregiving is the kind of support that allows an individual (in this case, achild suffering from a life-threatening illness such as cancer) to live and engage in other activities, including attending to school activities, communicating with peers or educators, and engaging in other family activities. These activities play a significant role in the social well-being of the child.

Furthermore, personal caregiving offered to the child suffering from a life-threatening illness includes tasks such as feeding, personal hygiene and dressing. Informational caregiving generally involves managingmedicines by the patient's caregiver. Emotional caregiving is an important part of the provision for support to parents or caregivers of children who suffer from life-limitingillnesses. Parents and caregivers of children who receive paediatric palliative care services are likely to be sad, hopeless, and fearful. These emotions are normal to parents and are a result of the parents' worry about their child's conditions.

1.6.7 Challenges experienced by parents of children with life-limiting illnesses.

Many parents experience burdens in childcare and rendering their responsibilities whereas at times those roles are complicated and create family dynamics such as struggles within the family, sleeplessness, financial burden and other stressful circumstances which may negatively affect care and decision-making. Parents who take care of children with cancer or life-limiting illnesses are likely to be vulnerable and prone to be negatively affected socially, psychologically, and financially. They are more likely to develop conditions that cause fatigue and problems with sleep. They run the risk of being socially isolated because of the tasks that they have (e.g., caring for a child with cancer). They often fear that their child might be exposed to lack of relief in pain and frequent hospitalisation. Hospitalisation is expensive. As a result, parents are faced with financial difficulties due to the accompanying costs. Sometimes they are forced to leave work to take care of their sick child.

According to WHO (2016), "life-limiting illnesses entail diseases marked by progressive deterioration which ultimately result in the death of the patient. Thus, palliative care has been developed from the need for services towards a wide range of patients who suffer from life limiting illnesses". An earlier study by Brotherton (2012) highlights that "life-limiting illnesses could be diseases at which there is no reasonable hope for cure and due to the condition suffered, a person is expected to die. This leads to severe conditions which may have enormous effects on both the patient suffering from the illness and the family. Patients affected by any type of life-limiting illnesses usually have contact with health professionals within a health care setting, including social workers within a palliative care facility".

1.7 Theoretical framework

This study focused on Kubler-Ross' theory of death and dying. The theory was propounded in 1969 and it outlines several stages that include grief, which are applicable to the study because cancer is a condition that raises mixed emotions to the parents as well as other members of the family (Anfara & Mertz, 2014). This emotional state further includes aspects relating to parents' attitude wherein they can become doubtful whether their child would survive if taken away from them and also worry of their survival without family care. On the other hand, family members may experience mixed emotions to accept the health condition of the child. Parents may also develop feelings related to denial (for example, there can be resistance from parents to admit the stage at which the disease has advanced), anger and bargaining (which defines the thought of blaming others and having self-blame), depression (the state of emotional strain and distressed) as well as acceptance (facing reality, willingness to get prepared about the forth coming death and getting prepared accordingly).

This theory was found to be suitable in this study as it seeks to probe the attitude of parents of children with life-limiting illnesses who are highly likely to develop one or all the above-mentioned feelings which are associated with the fear of death or dying. It is linked with the study because Elisabeth Kübler-Ross changed the way the West viewed, treated, and understood death. She humanized it and introduced palliative care. She taught us how to deal with death with her famous theory on the phases of mourning and also reminded us that this ending isn't so terrible for the one leaving. In fact, she set a trend and left us an indisputable legacy, one that's still present today.

1.8 Outline of chapters

CHAPTER 1 provides a brief overview and description of the background and motivation of the study e.g., the origin of PPC and why it is important in the care of children with life limiting illnesses. The chapter also identifies the research problem –

that is, the reasons why this study is undertaken. The aims and objectives, and significance of the study are also briefly discussed here.

CHAPTER 2 provides a brief discussion of polices in South Africa.

CHAPTER 3 provides a brief discussion of literature to assist the researcher in understanding the problem under investigation and to identify gaps thereof.

CHAPTER 4 gives a brief discussion of the methodology used in this study. The researcher discusses various research methods such as the research approach, research design, sampling, data collection and data analysis used in the study.

CHAPTER 5 gives a brief description of the discussion, presentation and interpretation of the findings of the study.

CHAPTER 6 discusses in detail the findings, recommendations, limitations and the conclusion of the study.

CHAPTER 2: POLICIES AND GUIDELINES OF PPC

2.1 Introduction

In this chapter, the researcher provides and discusses policies and guidelines that govern Paediatric Palliative Care (PPC) in South Africa. These are legal instruments implemented by the government to ensure that the rights of both patients and healthcareworkers (doctors, nurses, social workers, etc.) are protected. The policies are vital asthey also give guidelines and directions to be followed when providing PPC services in the wards to ensure that healthcare workers do not bring the name of the department into disrepute.

2.2 Policies and guidelines on Paediatric palliative care services

The World Health Organization's (WHO) definition of PPC for children includes the principles that are also applied to other paediatric chronic conditions. Hence, amongst others, it refers "to the child's body, mind and spirit as wellas giving support to the family". Furthermore, WHO (2016) points out that "the kind ofcare begins when the illness is diagnosed and continues regardless of whether or nota child receives treatment directed at the disease and the process where-in health providers have a responsibility to alleviate a child's physical, psychological and socialdistress".

2.2.1 The general principles attached to PPC guidelines for children.

The guidelines on the Integrated Paediatric Palliative Care services (2012) indicate that all directives and guidelines should be in line with the international agreement, which stipulates that all patients who require PPC services should be provided with such, and these services must preserve the principles that follow: "access to competent care; continuity of care that links local and specialist services and inter-sectoral services; care delivered over long illness courses and that addresses transitions of illness; care which aims at brining relief and caregiver support; care at the time of death; bereavement care; relief from pain and other distressing symptoms; care that meets developmental needs; emotional and spiritual support; help to live as normal a life as possible; help with decision-making; timely and truthful information; and family support that respects family choices, values, and cultural tradition as well as the consideration of family structure and support through the promotion of access to health care services at the time of need".

2.2.2 The Constitution of South Africa Act no 108 of 1996

The Constitution is the supreme law of the Republic of South Africa and was signed into law by parliament in 1996 to "heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights, and to Improve the quality of life of all citizens and free the potential of each person". Chapter two of the Constitution guarantees everyone the right to life and human dignity. Also, section 27 provides that "everyone has the right to access to health care servicesand the fact that no one may be refused emergency medical treatment". These include, as also stated by the Health Profession Council of South Africa (HPCSA) in 2019, "the provision of PPC, and not merely access to such care,as is the case with adults".

2.2.3 The South African National Health Act No. 61 of 2003 and Childrens Act No 38 of 2005

The South African National Health Act No. 61 of 2003 aims at providing "a framework for a structured uniform health system within the Republic of South Africa by taking into consideration all the responsibilities imposed by the Constitution and other relevant laws". This should be followed by the national, provincial, and local governments with special reference to the delivery of anadequate, proper and equal healthcare service. The Act is in line with Chapter 2 (Bill of Rights), Section 24(a) as per the Constitution of the Republic of South Africa, which states that everyone has the right to an environment that is not harmfulto their health or well-being. Section 27(2) of the same Act indicates that the state must take reasonable legislative and other measures within its available resources to achieve the progressive realisation of the right of the people of South Africa to have access to health care services, including reproductive health care. Again, Section 27(3) indicates that "no one may be refused emergency medical treatment" and Section 28(l)(c) refers to the fact that "every child has the right to basichealth care services".

The Childrens Act No. 38 of 2005 aims to set principles in relation to protection and care of children, and more specifically considering Section 11 (Children with disabilities and chronic illnesses) sub-section (2)(a)(b)(c).

2.2.4 The National Policy Framework and Strategy on Palliative Care 2017–2022

The National Policy Framework and Strategy on palliative care was implemented to help “increase the life expectancy and enhance the quality of life for children and adults requiring PPC services”. Due to widespread diseases such as HIV and AIDS, this policy “acknowledges the importance of integrating palliative care as an essential component of health service delivery” (Department of Health, 2019). The South African government introduced this policy after the World Health Assembly resolved that all member states should “develop a policy which will strengthen palliative care services”. This policy gives hope for both patients and caregivers to “live as actively as possible with good quality of life despite the diagnosis of life-limiting or life-threatening illness” (Department of Health, 2019). The National Policy Framework Strategy on Palliative Care, in line with the World Health Assembly resolution, addresses the following factors:

2.2.4.1 Structural challenges

- *Inequitable Access:*

South Africa has an ugly history which was marred by social injustice and racial inequalities. Historically, PPC services were only available to selected groups in South Africa. Most indigenous people had no access to such services. Furthermore, patients were only offered PPC services after the realisation that treatment had failed. There was no early intervention at all. This was very problematic as at this stage (after treatment has failed), “palliative care interventions would not be effective as the illness was too far advanced and the patient had already undergone significant suffering. It also meant that health services are often inappropriately utilised as families and health care workers fail to understand the illness trajectory. There is evidence that early palliative care, from the time of diagnosis of a serious condition, improves a patient’s quality of life, reduces depression, and may even have the capacity to prolong life" (Department of Health, 2019).

- *Social and economic costs*

Having a child with life limiting illness may affect parents and guardians socially and economically. For example, these children need to be cared for on a fulltime basis – that is, there must be someone close to care and provide for their needs and pay for hospital and medical bills. This may have a negative impact on the parent as he/she may be forced to give up professional or academic endeavors to take care of her sickchild. All this does not come cheap. It is expensive and may cause dire problems on family relationships (Department of Health, 2019).

2.2.4.2 Burden of Disease Demands

According to the Department of Health (2019), "burden of disease refers to mortality, morbidity, injuries, disabilities and other risk factors which impact the health of a population". Recent data from Statistics South Africa Mortality and Causes of Death in South Africa shows that "more than half of all natural deaths (55%) were due to non - communicable diseases, 33% to communicable diseases and 11% to injuries. TB was the leading underlying cause of natural deaths at 7.2% with diabetes mellitus the second most common cause of natural death at 5.4%. HIV was the fifth most common cause of death (4.8%) after, TB, diabetes mellitus, cerebrovascular disease, and other forms of heart disease" (Department of Health, 2019).

The results reveal that "most of the reported deaths are due to illnesses that require palliative care, either from diagnosis or at later stages of the illness trajectory, depending on the severity of the symptoms and suffering. Palliative care is required for neonatal conditions that are life threatening and may be indicated in the ante-natal period in some conditions where the outcome is expected to be distressing to the family. Palliative care for children is vital to support patients and their families while coping with the implications of their condition" (Department of Health, 2019).

2.2.4.3 Estimation regarding the Need for Palliative Care in South Africa

There is limited data regarding the estimation of needs. In terms of this policy, estimation is done in line with the study by Murtagh *et al,* who *"*studied the different methodologies for estimating need for palliative care and will serve as a basis for the estimation exercise for this document. Need is defined as the ability of the population to benefit from palliative care, utilising a normative (defined as a professional's perspective) approach. The Murtagh group used death registration data with both underlying and contributory causes of death to estimate the need for palliative care as a relatively simple method which did not require symptom information or hospital data" (Department of Health, 2019). Furthermore, the policy acknowledges that the following factors should be considered when assessing the need for palliative care: "the conditions that would benefit from palliative care for adults and children; and the prevalence and severity of symptoms for these conditions; and the intensity of care that would be required" (Department of Health, 2019).

2.2.5 Ethical guidelines on palliative care in South Africa

These guidelines seek to provide clarity and give directions as to: *"when palliative care should be provided, why palliative care should be provided, who provides palliative care, where palliative care services are provided, and how palliative care is provided and used"* (HPCSA, 2019)**.** According to the HPCSA (2019), palliative care services are offered to people with life-limiting illnesses. This refers to people whose illnesses are at an advanced stage, people who are dying due to their critical and incurable conditions regardless of their age or setting. Furthermore, the council states that palliative care should be providedimmediately after diagnosis until the end of life of a patient. Empirical research showsthat palliative care may reduce the costs of the healthcare system by reducing the chances of "unnecessary hospitalisation and use of health care services" (HPCSA, 2019).

Health practitioners in collaboration with other healthcare professionals are mandated with the responsibility of providing palliative care services to all people living with life-threatening conditions. These practitioners should be qualified to provide palliative care services – that is, they should have “the required knowledge, skills, and attitudes to meet the physical, psychological, practical, social and spiritual needs of their patients. It is the responsibility of healthcare practitioners to ensure that their possessed skills. Moreover, it is very important that all healthcare professionals play an advocacy role regarding the importance of palliative care services in the public health sector and for palliative care to be included in the curriculum of health practitioners” (HPCSA, 2019).

2.2.6 Regulations relating to cancer registration 2011.

These regulations were made in line with section 90 of the National Health Act no 61 of 2003, which gives the minister powers “to make regulations regarding anything which may or must be prescribed in terms of this Act” (National Health Act, 2003). The regulations were made to amend section 90(1)(q) on non-communicable diseases. For the health regulations, cancer registration refers to “the process of continuous, systematic collection and storage of a defined data set on the biographicalinformation of all persons diagnosed with cancer, and of the characteristics of cancer,including its treatment and outcome”. These regulations led to the establishment of the national cancer registry (NCR), which is aimed at ensuring that all information relating to cancer in South Africa is collected, validated, recorded, managed, analysed,interpreted, and reported (Department of Health, 2011).

2.3 Summary of chapter

This chapter discussed relevant acts, policies and legislations that govern PPC. These are the legal instruments which give directives as to who should provide PPC services, what to be considered when providing the services, how PPC services should be provided, when intervention programmes should start and where. These policies also ensure that the rights of both patients and healthcare workers are promoted and protected.

CHAPTER 3: LITERATURE REVIEW ON PALLIATIVE CARE AND SOCIAL WORK

3.1 Introduction

Madhavan, Sanders, Chou, Shuster, Boone, Dente, Shad and Hesse (2011:3) refer to Paediatric palliative care as “a comprehensive treatment regimen designed to relieve suffering and to improve quality of life for children facing serious illnesses. They argue that paediatric palliative care extends beyond merely pain alleviation, encompassing both management of symptoms and psychosocial support for the patient and their family”. The role of PPC is to assist patients with differing chronic illnesses which threaten the lives of those patients. This includes “communicable diseases such as HIV and AIDS, non-communicable diseases such as cancer, cardiac arrest, diabetes, respiratory failure or multiple sclerosis” (WHO, 2016).

3.2 Palliative care and Social Work

Developments within palliative care which encompass intervention by social workers can be drawn from the establishment of specialist palliative care social work and the history of Hospice and its services (Small, 2001; Butler; Ratner, McCreedy, Shippee & Kane, 2014). Social work and its role began to be recognised within palliative care in the late 1960s. The proponents of PPC include the work of Cicely Saunders in 1967. His work was influential and drew attention towards the need for PPC – that is, the need to care for patients with advanced life-threatening diseases such as cancer, which is responsible for the death of children who were diagnosed with the disease. Therefore, paediatric palliative care social work is vital to provide social and psychological support and services to patients with life-limiting illnesses and problems.

Since palliative care is a complex system of service delivery that involves a coordinated programme of care that involves numerous professionals among multiple disciplines (Hallenbeck, 2003), the process affords an opportunity “to the patient and family, especially Africans, to work towards developing a positive perspective of the patient’s health condition” (Smith, Temin, Alesi, Abernethy & Balboni, 2012). The services provided also concentrate on “the management of pain and symptoms while both the patient and the family continue to receive social services, counselling, and bereavement services” (Bona, Bates & Wolfe, 2011).

3.3 The role of Social Workers in palliative care

Palliative care is “a holistic approach which focuses on emotional care, pain control and services. It also assists the terminally ill patients and their families to come to grips with death. Professionals who provide services within palliative care such as social workers conduct assessment carefully considering the individual situations and develop plans that work best for each patient” (Jayita & Deodhar, 2015). As palliative care services continue to grow and spread, the role of the Social Worker within this care includes “confronting social problems of patients with life-limiting illnesses, performing multi-dimensional roles as counsellors, educators, advocates, mediators, facilitators, and researchers”.

Social work palliative care programmes seek “to improve the quality of care at the end-of-life and promote societal change through raising public awareness on the importance of palliative care social work. Palliative care social work is an important means of relieving and addressing situations that cause undue distress and frequent visits to the hospital or clinic by patients. Palliative care social workers also have the responsibility to contact local social work teams “to establish a route for people at end of life to access palliative care support” (National Association of Social Workers, 2003). Paul (2013) points out that “several important concepts seem to be apparent when looking at work tasks in relation to public health approaches to palliative care. Fundamental aspect of this approach involves challenging stigma with death, dying and bereavement.

Palliative care social workers unique position to effect change in attitudes simply through initiating engaging in such conversation. Although such practice necessarily social workers examining their own views on death and dying, theal value base and ethical framework of social work enables understanding of inequality, discrimination, and oppression”. Moreover, Paul (2013) indicates that “social workers are equipped with and training that may help them to address the taboo that surrounds death, dying and bereavementsensitively and appropriately. Second, public health approaches emphasise the importance munity engagement and development and relies on strengthening the capabilities of individuals and communities to control health. A core value of social work is 'understanding and valuing community networks as a source for support for individuals their families'. Social work has always been with the context of environmentjust as much as the relationship client. It has continued to employ systems-based approaches that value the individual within a broader social network and community context". In her study where she sought to understand social workers' role in palliative care, Hildebrand (2017) found that most social workers "strongly value establishing therapeutic rapport with palliative individuals and their family members, which serves as a tool to effectively perform their roles". The researcher also reveals that additional findings emerged which highlight "identified strengths that social workers bring to palliative care including social workers' ability to establish therapeutic rapport, and knowledge that social workers have pertaining to palliative care and using self- reflective practice. This research further suggests that social workers are unique in their ability to adapt in their roles to meet the individual needs of each palliative individual" (Hildebrand, 2017).

Furthermore, Hildebrand (2017) reports that many participants "identified strongly with being a case manager on palliative care interdisciplinary teams. Case management was frequently described as organising information collected from fellow interdisciplinary team members and arranging details related to the care of palliative individuals. Several of the participants reported they were familiar with details related to palliative individuals' care and therefore prioritized organizing required paperwork and meetings to keep members of the interdisciplinary team up to date".

3.4 Palliative care

Palliative care refers to services which are offered to patients to provide support and relief to their illness. The emphasis is placed on the reduction of pain and the provision of relief as the illness cannot be cured (Phillips, Ajrouch, Hillcoat & Nallétamby, 2010). According to WHO (2002), palliative care is "an approach which improves the living conditions and situations of the patient including that of their family. Palliative care is a system of service delivery which prevents and relieves the patient's suffering by way of early identification, assessment and treatment of pain and other physical, psychosocial, and spiritual challenges”. Palliative care provides the following:

- Pain relief;
- Assists patients and family members on stressful situations;
- Supports and encourages families to see death as a normal and natural process;
- Taking into consideration the importance of the psychological and spiritual aspects of patients when providing care;
- Offers care by providing meaningful support so that patients can live as activelyas possible until death;
- Offers support to the family to assist them to cope during the patient’s illnessand in their own bereavement;
- Embraces a team approach to address the needs of patients and their families, including bereavement counselling; and
- Enhances the quality of life, and positively influences the course of illness.

3.5 The need for palliative care

The provision and need of palliative care are vital as it plays a significant role in contributing to the quality of life of patients and adults suffering from life-limiting diseases and illnesses. This care is needed and offered immediately after diagnoses, to the time when the patient dies (end-of-life), and time of bereavement. Primary healthcare workers provide PPC services to patients with cancer to reduce pain, unnecessary suffering and make trials to calm them so that they stay and live without complaints (World Health Organization, 2014). Muckaden, Dighe, Balaji, Dhiliwal, Tilve, Jadhav and Goswami (2018) point out that “new advances in medicine have improved survival among children with any life- limiting illness”.

However, the researchers indicate that “approximately 25% of these children would still die of their disease even after many years. When the hope of cure and prolonged survival dwindles, families and care givers may face tremendous stress. Care at this stage requires a holistic approach to the patients’ and families’ physical, emotional, and spiritual needs. It should aim to achieve realistic goals. Such an approach improves clinical care and may also contribute to a sense of satisfaction and meaning that the physician can gain from the experience of caring for children at the end of life". Paul (2013) argues that "death, dying and palliative care are surrounded by confusion and ignorance, with specialist palliative care only available to the lucky few. A public health approach to palliative care has been recognised for the contribution it can make to meaningful end-of-life care. Such approaches have gained increased literature and policy focus and practice examples exist worldwide. In the UK, end-of-life care policy documents have highlighted the significance of a public health approach. They identify action to challenge stigma associated with death and dying to enable positive end-of-life care experiences". A British study by Paul (2013) reveals that "over 55,000 people die each year in Scotland, usually over the age of sixty-five and often following a period of, possibly prolonged, illness and/ or frailty. This figure is expected to rise, meaning that people will be increasingly living with a range of progressive illnesses, having significant implications for the range and amount of care that will be required".

According to Paul (2013) furtherreveals that "current palliative care service provision will not be able to meet this growing demand and developing capacity to provide equitable care and support for this population is necessary. This challenge is exacerbated by the taboo that surrounds death and dying in Western societies. For example, prior to the middle of the twentieth century, death was considered a community affair; it was visible,frequent, and managed by family and church". Moreover, Paul (2013) indicates that many deaths recorded occurred at home due tovarious infectious diseases which affect both children, parents, and elderly people. As a result, death was considered inevitable and seen as a natural thing which is part of a human journey. The researcher further states that currently, "developments in medical practices have meant that people live longer, with many deaths in Scotland being due to organ failure, several cancers, chronic heart disease, respiratory diseases, and dementia. Most people now die in institutions such as hospitals, care homes and hospice" (Paul, 2013).

3.6 Parents as caregivers

The importance of understanding the way parents assume the role of caregivers to their sick child may assist policymakers and healthcare workers to develop an approach that should be used by healthcare workers as an intervention strategy in PPC. There are three types of social support provided by caregivers, namely: instrumental, personal and emotional. Instrumental caregiving is the kind of support that allows an individual (in this case a child suffering from a life-threatening illness such as cancer) to live and engage in other activities, including attending to school activities, communicating with peers or educators, and engaging in other family activities. These activities play a significant role in the social well-being of the child.

Furthermore, personal caregiving offered to the child suffering from a life-threatening illness includes tasks such as feeding, personal hygiene and dressing. Informational caregiving generally involves managingmedicines by the patient's caregiver. Emotional caregiving is an important part of the provision for support to parents or caregivers of children who suffer from life-limitingillnesses. Parents and caregivers of children who receive paediatric palliative care services are likely to be sad, hopeless, and fearful. These emotions are normal to parents and are a result of the parents' worry about their child's conditions.

3.7 Conditions eligible for children with palliative care

Scrimgeour, Marston and Boucher (2010), in their International Children's Palliative Care Network (ICPCN) document, argue that more than "360 conditions have been identified as eligible for the provision of palliative care to children". The following categories apply in South Africa:

a) Life-threatening conditions:

This includes those illnesses with curative treatment that is feasible but can fail (Scrimgeour, Marston & Boucher, 2010). The category of illness covers cancer,organ failure of heart, infections of the liver or kidney as well as infections suchas malaria and Tuberculosis (TB).

b) Conditions requiring long periods of intensive treatment:

This category of treatment and care seeks to prolong life. However, patients can still die prematurely (Scrimgeour, Marston & Boucher, 2010). Therefore, it includes sicknesses such as HIV/AIDS, cardiovascular anomalies, severe renalconditions, and severe respiratory diseases (those that are non-TB).

c) Progressive conditions without curative options:

These include a situation where a patient is diagnosed and found to have a condition requiring palliative care e.g., “neuromuscular, or neurodegenerative disorders, progressive metabolic disorders, chromosomal abnormalities, advanced metastatic cancer, complex or severe cardiac disease, multiple congenital abnormalities where therapy has little to offer” (Scrimgeour, Marston& Boucher, 2010).

d) Irreversible, non-progressive conditions

These are illnesses with “severe disability causing extreme vulnerability to health complications e.g., severe Cerebral Palsy with recurrent infection, genetic disorders, congenital malformations, prematurity with significant neurological complications, severe CNS sequelae of infectious diseases, acutesevere meningitis, severe spinal cord injury and severe hypoxic brain injury” (Scrimgeour, Marston & Boucher, 2010).

e) Support

These include children who only require support than being placed under palliative care. For example, children who are victims of HIV/AIDS, who lost their parents to this pandemic and need support regarding their future and planning. After it has been determined that they no longer need palliative care and intervention, they are referred to other support organisations (Scrimgeour,Marston and Boucher, 2010).

3.8 Access to palliative care

An earlier study by Liben, Papadatou and Wolfe (2008) reveal that “paediatric palliative care (PPC) is focused on ensuring the best possible quality of life for children whose illness makes it likely that they will not live to become adults. Such care includes the family and extends into the domains of physical, psychological, social, and spiritual wellbeing. The frequency and circumstances of childhood mortality are geographically and socio-economically dependent, with some children having full access to the newest and costliest treatments and others little access to even basic medical care, food, and clean water. Applying the principles of PPC to a particular child and their family will thus vary depending on the availability of local resources and training. While recognising the need to improve access for the many children worldwide that lack basic medical care, we contend that all children facing the possibility of death would benefit from the application of basic, low-cost principles of PPC". White (2017) indicates that families and their children deserve excellent care at the end of life; they deserve the right to choose where they spend their last days together, to be comfortable, and to die with dignity. The researcher further states that "these children suffer from severe symptoms at the end of life – ranging from anxiety to painto dyspnea and require the expertise of a dedicated hospice or palliative care teamto minimise their suffering and the toll it takes on their families. As much as we know that paediatric palliative care improves children's quality of life and their families' quality of life, many children do not have access to this necessary level of care".

According to White(2017) further states that while over 70% of families would prefer their child to die at home, only 15-30% of children do. There are many factors leading to low paediatric enrolment, but one of the main causes is low access to end-of-life care. Few existing hospice programmes have dedicated paediatric teams even though paediatric patientshave unique needs at the end of their lives, and providers report feeling inadequatelytrained to care for these children. Twamley, Craig, Kelly, Hollowell and Mendoza (2014) argue that referrals to children'spalliative care services typically occur late in the illness trajectory, with many childrenwho would benefit not referred at all. Previous studies report healthcare professionals'assessment of various parent-related factors as barriers to referrals. Survey respondents evidenced good knowledge of the principles of palliative care in closed questions, but their attitudes expressed in open-text questions and reported reasons to refer to a palliative care service demonstrated an association between palliative care and death and dying. We suggest that the association between palliative care and end of life may be a modifiable factor relevant to late and non-referral and deserving of further investigation and attention in education and training.

Twamley et al (2014) further indicate that “only a minority of children who would benefit from palliative care services are referred, and few of those in a timely manner. For example, a large UK-based paediatric tertiary care hospital with its own specialist palliative care unit reported that only 21% of children who died in the hospital were known to the palliative care team. In studying parental experiences of their child’s death in the hospital, the authors noted that some parents would have appreciated earlier preparation on the possibility that their child was going to die. Similarly, low rates of referral to hospice and palliative care services have been observed in the United States”. A study by Balkin, Kirkpatrick, Kaufman, Swetz, Sleeper, Wolfe and Blume (2017) found that “Sixty percent of respondents felt that palliative care consultations occur too late, and the majority (85%) agreed that palliative care consultations are helpful. Barriers to requesting palliative care consultation were most frequently described as referring to palliative care services too early will undermine parents’ hope (45%) and concern that parents will think I am giving up on their child (56%). Only 33% of cardiologists reported feeling very or moderately competent in prognosticating life expectancy while over 60% felt competent caring for children with heart disease around end of life, and nearly 80% felt competent discussing goals of care and code status”.

Balkin et al (2017) highlight that these findings “underscore the need for further training in palliative care skills for pediatric cardiologists. Enhancing palliative care skills among cardiologists and facilitating partnership with subspecialty palliative care teams may improve overall care of children with advanced heart disease”. According to Taylor, Booth, Beresford, Phillips, Wright and Fraser (2020), to access “a specialist paediatric palliative care is associated with less intensive care at the endof life, more advanced care planning and fewer in-hospital deaths. However, the researchers argue that current evidence cannot tell us whether these services improvechildren’s symptom burden or quality of life. Nine studies reporting provider or family views identified uncertainties about what specialist paediatric palliative care offers, concerns about involving a new team, association of palliative care with end of life and indecision about when to introduce palliative care as important barriers to access. There was evidence that children with haematological malignancies are less likely to access these services. Current evidence suggests that children and young people with cancer receiving specialist palliative care are cared for differently. However, little is understood about children's views, and research is needed to determine whether specialist input improves quality of life". Taylor et al (2020) further state that "access to paediatric palliative care is associated with less intensive care at the end of life, more advanced care planning and fewer in- hospital deaths for children and young people with cancer". On the other hand, "there is no robust evidence to tell us whether these services lead to improvements in quality of life or symptom management".

Furthermore, "children with haematological malignancies are less likely to receive specialist palliative care than children with other cancer, whereas uncertainty about when to introduce palliative care services to families, what it comprises and the added value of specialist input was identified as a key barrier to access, and perceptions that paediatric oncology teams already meet the palliative care needs of their patients". Taylor et al (2020) conclude that "evidence is still needed to determine whether specialist paediatric palliative care improves the quality of life and symptom management for children and young people with cancer. Exploration of why children with certain cancers are less likely to receive specialist palliative care at the end of life may help address this inequality in access. A core outcome set study including the views of children and families would help improve future aggregation of evidence in this area".

3.9 Challenges experienced by parents of children with life-limiting illnesses.

A British study by Norman and Fraser (2014) reveals that data is lacking in the number of children requiring palliative care services. The researchers report that the number of children with life limiting illnesses has more than doubled in England. The prevalence is found to be higher for children younger than one-year old. Time trends show no increase for younger children but significant increase for older children. This increase is caused by a decrease in all causes of mortality for children, suggesting improved survival. Rates are highest in poor communities and those typified by multicultural populations (Norman & Fraser, 2014). Another study by Balkin et al (2017) reports that “key medical and surgical advances have resulted in a growing population of children with advanced heart disease (AHD), and paediatric cardiovascular clinicians now routinely care for these children. Among those children with AHD who die in the hospital, a majority occur during the first year of life in an intensive care unit after a prolonged hospital stay”. Balkin et al (2017) argue that “bereaved parents perceived that their children experienced suffering around end of life and that quality of life in the last month of life was poor related study of parents and physicians revealed a discrepancy between expectations regarding prognosis and quality of life at time of diagnosis, suggesting gaps in parent–physiciancommunication. Inconsistent communication also occurs in counselling families, especially around discussion of diagnoses. Palliative care consultation for children with other diagnoses, such as cancer, can help to improve quality of life, reduce burdenof disease, provide decision-making support, and bring goals of care conversations tothe forefront”.

3.10 Communication challenges in palliative care

Collins (2014) refers to communication as the exchange of meaningful information from one person to the other. However, Collins (2014) notes that communication is a complex and multi-level process. For example, the physical environment, the availability and attentiveness of participants, their emotional responsiveness and cultural biases are part of communication, as are numerous other verbal and non-verbal components. Moreover, Collins (2014) identifies goals of communication in palliative care which include, among others, the establishment of a positive working relationship between the family and health professionals involved; the development of an accurate understanding of the family and of the messages they are attempting to communicate;enabling the family to understand the information communicated by the health professionals; and understanding the communication styles and processes that occurnaturally within the family, and using this to facilitate manageable communication for the child, family and all involved. Madhavan et al (2011) highlight that paediatric palliative care is faced with many challenges such as unnecessary pain from insufficiently personalised treatment,doctor–patient communication breakdowns, and a paucity of usable patient-centric information. The researchers further state that paediatric palliative care has distinct communication challenges, as care must be coordinated through various stakeholders including the child, family, healthcare professionals, chaplains, social workers, bereavement counsellors, and school staff. The seamless flow of information among different parties involved is critical to enable personalised care for the child. Madhavan et al (2011) conducted an interview with patients, and identified several communication challenges and needs in paediatric palliative care. The researchers argue that these gaps are related to 'existing or emerging cyberinfrastructure'. They believe that adoption and adaptation of appropriate technologies could improvepatient–provider communication, behavioural support, pain assessment and education, all through integration within existing workflows. Findings by Madhavan et al (2011) are in line with existing literature reporting the importance of communication and showing the complex nature of communication in PPC.

3.11 Empowering the family

Collins (2014) indicates that "health professionals do not control or 'own' the children and families that they work with. However, these professionals "are a resource for families to use in finding their place in the very broad spectrum of adaptive coping and grieving. An empowering culture is one in which the family is enabled to have maximum control over the resources, information, decision making, and relationships that affect them. Such a culture respects the reality that each family has their own resources and information, and can make decisions, and of maintaining and contributing to relationships (including their relationships with palliative care providers). Within this culture, families are trusted to manage their own lives. They are not perceived as passive recipients of professional services but as competent and leading partners in their child's palliative care".

Collins (2014) further argues that families that are caring for a child with a life-threatening illness may feel “an enormous loss of power and control in their lives. The

The psychosocial value of assisting them to regain or increase their sense of power and control whenever possible cannot be over emphasised. Empowerment can be facilitated by the health care team listening to the family’s needs, offering encouragement and advice, being advocates for them and their child, and by ensuring they have access to skilled health professionals and practical assistance, including home care equipment”.

3.12 Referring children for paediatric palliative care

Harrop and Edwards (2012) argue that paediatric palliative care is “a new area of paediatrics, and the interface with other disciplines can occasionally pose challenges for referrers due to lack of information about the diverse services available. They point out that although services vary on a regional basis, there are common principles which may be used to guide and support referrals. Children may be referred to palliative care services via several routes from community-based primary care to regional tertiary centres. Identifying those most likely to benefit from the finite resources available can be a challenge, and healthcare professional’s negative attitudes to palliative care have been further identified as a potentially modifiable barrier. To identify children who are likely to benefit from paediatric palliative care can pose a significant challenge. Referrals typically occur late in the illness trajectory with many children who would benefit not referred at all. Recent research from a tertiary hospitalin the UK with a well-established paediatric palliative care team has shown that other healthcare professionals’ association of palliative care only with death and dying may be a modifiable factor relevant to late and non-referral (Harrop & Edwards, 2012).

3.13 Parents attitude towards palliative care

Historically, parents reported negative attitude towards palliative care. An earliest study by Delight and Goodall (1988) sought to investigate parents’ attitude towards palliative care. The participants included those parents whose children were cared for in hospital and those who took their children home for parental care, support and treatment. The study reveals that 44 babies had died before their first birthday, and only a quarter of them had required treatment for, for example, analgesics and anticonvulsants though half had been given drugs terminally. Six of the 18 babies taken home had died there, the remainder having been admitted terminally because of worrying symptoms. The researchers report that of the “38 babies who had died in hospital, 25 had never been home at all and 29 had died without a member of the family present, though four of these had spent time at home. The six who had died at home had been ill and causing concern, but each death had been peaceful and, with one exception, both parents had been present” (Delight & Goodall, 1988).

Furthermore, a study by Delight and Goodall (1988) established that parents whose children were kept and remained in hospital were sadder than those who hadtaken their children home when they looked back at their experiences, and they also considered that their baby's life had been of poor quality. Most of those who had taken their baby home had a more positive view of their child's life. The figures suggest that the bereavement process after a baby's death is longer than has been thought, but despite residual sadness just over half of the parents interviewed thought that something positive had come out of their experience (Delight and Goodall, 1988). However, a lot has changed, and our health systems have been improved significantly. For example, children who are very sick due to chronic illnesses, “including extremely premature infants who may have previously died, now survive due to rapid technological progress in medicine and improvements in intensive care over the past few decades. Nonetheless, most of these children will face the risks and burden of prolonged hospitalisation and a future with severe and permanent disabilities.

Therefore, resuscitating and providing life-sustaining treatments to very sick neonates have become issues fraught with ethical dilemmas for both parents and healthcare workers” (Tang, 2013). Kirk and Pritchard (2011) explored the perspectives of parents and young people regarding hospice support. The researchers found that “families were highly satisfied with the support provided in terms of quality of care; interpersonal qualities of the staff; the individualised, family-focused approach; accessibility of support and involvement in decision making. For parents, the provision of a break from caring was the main way in which they were supported although they felt they wanted more of this form ofsupport. A consistent theme in relation to support for young people and siblings was the need to develop facilities, activities, and bereavement support specifically for teenagers/young people. The researchers conclude that parents value a model of carethat provides holistic, family-focused support that is responsive to individual needs, and which promotes control and active involvement in decision making”. The effects of having a sick kid on families have been the subject of a great deal of study. Aoun (2004:26) found that parents caring for a terminally sick child face challenges including family disruptions, social isolation, and physical and mental suffering. The parents of a sick child live in an atmosphere with little support and frequent arguments. They also experience significant levels of sadness. According to McGrath (2001), parents need both practical help and emotional support to get through the difficulties of caring for their child throughout the lengthy invasive treatment. How to deal with terminal illness, mortality, societal stigma, and talking about worries are all things that worry some people.

The disease of their child becomes the context that defines what it means to be a parent for parents of children with life-limiting illnesses (Bluebond-Langner 2010). The study included parents from the United States and Great Britain. It was discovered that parents' role and responsibility, as they understood and performed them, was to exhaust all options in order to help their children with cancer when normal therapy had failed, and a cure was not likely (Bluebond-Langner 2010). Parents have an essential role in promoting communication between themselves, their children, and health care experts, as was made obvious by the literature review on children's participation. How their children turn out is mostly dependent on the parents (Rajagopal, 2015).

Children have a voice in shaping their palliative care strategy. Understanding how parents view their children's involvement in palliative care is crucial for social workers who work with families whose children are receiving this type of treatment. In India, where the notion of palliative care has only been around since the mid-1980s, just one percent of the population, which includes a small percentage of children, has access to this type of care (Rajagopal, 2015). Given the current state of affairs, it is quite clear that there is a dearth of corpus money and inadequate access to paediatric palliative care facilities for children (Mathews & Kumar, 2012). Given Indian parents' scepticism of western medicine, where they may prefer alternative treatments and put off making crucial life-saving decisions out of fear for their children's disfigured appearances, paediatric palliative care in India would require significant cultural adaptation (Seth, 2010). This also implies that the general public has a low level of knowledge of child palliative care. When faced with the prospect of making life-altering choices for the sake of their children, parents and carers may experience extreme emotional distress, which can lead to paralysis in the decision-making process and even denial (Feudtner, 2007). This could impede crucial decision-making, such as when deciding between actively continuing treatment despite knowing there is no cure and shifting focus to comfort care or palliative care. Major obstacles to end-of-life care and decision making include not just socio-cultural but also psychological and socio-economic aspects (Mack et al., 2012). Even though paternalism in medicine, a lack of adequate training in communication skills, knowledge of the grieving process, special issues related to caring for children, and cultural barriers have all been observed in paediatric palliative care, the need for and lack of proper communication for carers has emerged as a central theme in India's paediatric hospice care (Mack et al., 2012). Clearly, therapy guidelines are needed to bridge these communication gaps (Mack et al., 2012).

A communication tool like Ariadne Labs' Serious Illness Conversation Guide (SICG) could potentially be helpful (Bernacki et al., 2014, 2019). The SICG, created by Ariadne Labs, a Joint Centre for Health Systems Innovation (Boston, MA, USA), is a structured communication tool that equips clinicians with psychologically informed language to evaluate patients' grasp of their illness and their preferences for receiving information about it; to tailor prognosis to those preferences; to inquire about patients' values, goals, and care preferences; and to make recommendations in line with those values, goals, and preferences (Bernacki et al., 2019). The SICG has a paediatric version, SICG-peds, that can be used in conversations with people responsible for the care of children. In addition to the afore mentioned technologies, there are more that can facilitate dialogue and group decision making (Bernacki et al., 2019). However, these tools may need substantial adjustments to be suitable for use with the Indian community, given the diversity of the Indian people and the impact of cultural factors on decision-making and communication. Clinicians and carers alike would need to contribute to the creation of a communication quality improvement tool that is culturally sensitive.

It is challenging to provide for a child who has been diagnosed with a terminal disease and requires palliative care treatments. Multiple studies have shown that parents of terminally ill children experience extreme exhaustion, emotional and physical distress, and a lower-than-average quality of life (Price et al., 2016). Before any counselling guideline or communication tool could be put to use, special attention may need to be paid to these concerns, issues, and needs; in fact, these tools should be made so keeping in mind the perspectives of parents. So, it is theorised that knowing the parent's perspective is crucial when developing a communication tool or a counselling guideline (Price et al., 2016). Accordingly, we argue that a better understanding of the needs and concerns of Indian parents would be facilitated by conducting a comprehensive analysis by conducting a systematic review of the literature on parental perspectives in the context of paediatric palliative care in India (Bernacki et al., 2019).

3.14 Palliative care challenges in South Africa

3.14.1 Service delivery

Although South Africa has implemented PPC programmes, currently, there is no consistency regarding the provision of PPC within South African health facilities. The sustainability of palliative care in South Africa is faced with many challenges. One of the major factors was due to lack of policy governing palliative care. PPC services are offered by a few hospitals in the country. Some hospitals only offer “inpatient consultation service, while others have palliative care wards, some offer emergency palliative care service, and others provide an outpatient service” (Department of Health, 2017). By 2017, the “Gauteng Centre of Excellence for Palliative Care was the only facility funded by the Department of Health in South Africa responsible for providing service delivery. The facility was responsible for among others, providing consultative service, an outpatient clinic, as well as a community outreach palliative care service; in addition to teaching and research in an academic institution” (Department of Health, 2017:5).

3.14.2 Health workforce

The shortage of qualified home healthcare workers is one of the major problems affecting the effective provisioning of PPC services in South Africa. There is also "an absence of curricula, limited formal training and resources, and no clear definition of roles and responsibilities pertaining to the different cadres of health care workers. As a result, health care workers are unable to identify persons in need of care, assess their symptoms or alleviate their suffering through adequate management. There is lack of adequate training offered to nurses and other health care workers working within the multi-disciplinary team to enable them to recognise the needs of individuals seeking assistance for palliative care. Courses relating to palliative care are offered by organisations such as the Health Profession Council of South Africa (HPCSA), for different experts within health care such as nurses, doctors, social workers and spiritual counsellors" (Department of Health, 2017).

3.14.3 Medical products and Technologies

The provision of effective pain management in South Africa is hampered by a lack of knowledge regarding the vital or important need of medicines for palliative care. For example, "the morphine allowance in South Africa is currently calculated on prior usage and this does not mean that the need is met; especially when medicines are not easily accessed because of disruptions within supply chain and lack of adequate prescribers and pain assessment by health care providers. There are challenges regarding the continued supply of medicines to patients without interruptions either at supply chain management level or in the simple delivery of medicines to immobile patients in their homes" (Department of Health, 2017:6).

3.14.4 Governance and Financing

The commitment to successful palliative care services in South Africa should not be the responsibility of the health ministry alone, healthcare providers should also be involved to ensure that PPC services are effectively implemented. The difficulty in realising and achieving this collaboration is that palliative care has not yet been determined as a health service module. This means that there are not enough funds allocated to ensure the effective delivery of care. There is currently no model to determine costs in South Africa and the subsidy for service providers from government is not enough to meet the need of PPC services. Majority of service providers in South Africa survive through “donations or donor-funding, making them particularly vulnerable to changes in donor patterns” (Department of Health, 2017).

3.15 Parents awareness of palliative care services

Literature has revealed that parent’s awareness of palliative care services is related to palliative care. A recent study by Zawistowski, Black, Spruill & Granowetter (2018) was conductedto “ascertain awareness and understanding of palliative care among parents whose children are placed in paediatric palliative care”. To "ascertain awareness and understanding of palliative care among parents whose children are placed in paediatric palliative care," Zawistowski, Black, Spruill, & Granowetter (2018) recently conducted a study. According to the study's findings, "41% of parents had understanding about palliative care." They state that the parents' educational background has a significant impact on how well they understand palliative care. For instance, although 11.5% of high school dropout parents were aware of palliative care, 50% of college educated parents were familiar with it. White parents were more likely to know the phrase than parents of colour, according to a study by Zawistowski et al. (2018). In addition, the word was more commonly known by parents over the age of forty than by those under the age of forty.

Palliative treatment was not foreign to the majority of parents whose children were diagnosed with a 'hematologic' or 'oncologic' condition. "Parents agreed that palliative care can make children feel better, and most indicated they would consider it for their own child in the case of a serious illness," yet many still confused it with hospice care. To effectively integrate palliative care into their practise and inform parents of the options available for the care of their child, physicians and other critical role players need to get a deeper comprehension of parents' knowledge and perspectives (Zawistowski et. al., 2018). The researchers found that “forty-onepercent of parents had knowledge of palliative care. They argue that the parents’ levelof education was strongly associated with the knowledge and familiarity of palliative care. For example, fifty percent of parents with college education had heard of palliative care, compared with 11.5% of those with high educational level”.

Zawistowski et al (2018) further state that “Caucasian parents were more likely to be familiar with the term compared with parents from minority race of ethnic groups. Also, parents over forty years of age were more likely to be familiar with the term compared to parents younger than forty years. Most parents who had a child with ‘hematologic’ or ‘oncologic’ diagnosis had knowledge and understanding of palliative care”. Of all those who had knowledge of palliative care, “parents agreed that palliative care can make children feel better and most indicated they would consider it for their own child in the case of a serious illness, but many still equated it with end-of-life care. If physicians and key role players can achieve better understanding of parents’ knowledge and views, they will be well-equipped to include palliative care into their practice and be able to inform parents of the options available for the care of their child” (Zawistowski et. al., 2018).

3.16 The experiences of parents of children with cancer

The effects of pediatrics palliative care on long-term parental grieving were examined in a study by Van der Geest, Anne Sophie, Drlington, Isabelle, Streng, Pieters & Van den Heuvel, 2014). Researchers claim that "parents highly rated communication, continuity of treatment, and parental participation during the palliative phase. Among the physical and mental symptoms that parents reported their children experiencing during the palliative phase were exhaustion, pain, isolation anxiety, and anger. This significantly impacts parents’ attitudes in several ways. Lower levels of long-term parental sadness related to higher parent assessments of communication and continuity of care. Long-term parental sadness was correlated with the severity of the child's dyspnea, anxiety to be alone, anxiety about the future, rage, and uncontrolled pain. Long-term parental grieving was found to be significantly affected by both communication with healthcare providers and symptom treatment in multivariate models.

3.17 The level of support provided to parents of children with cancer

Van der Geest et al (2014) report that "approximately 25% of children diagnosed with cancer eventually die. This loss of a child puts parents at increased risk for developing psychological problems". According to Collins (2014), the passing of a young child can have "a lifelong impact on a family, and they need recognition, acceptance, and validation of their experience". Families will always remember their child and what kind of a person he/she would have been if he/she had survived. Life events such as watching other kids playing, attending school, and graduating, finding jobs, and getting married, etc., may remind parents of their loss and thus worsen and prolong their grief as they keep wondering what their child could have become if he had lived. Collins (2014) indicates the importance to "understand that all people, adults, and children react to the sickness or death of a family member differently. Health professionals develop relationships with the dying child and the family". This, as Collins (2013) points out, "requires acknowledgement of the personal impactof caring for the family. As professionals who have known the family and the child whohas died, we can assist families to acknowledge and live with their experiences. This can be achieved by being available to listen to their feelings of helplessness, anger, guilt, regret, relief, and sadness, and by exploring lost hopes, dreams and their searchfor meaning.

Throughout the course of their child's life, parents will have developed important relationships with staff and other families in the health care setting. Parentsmay wish to revisit the hospital and talk with people who knew them and their child and shared a part of their journey". Furthermore, Collins (2014) requests health professionals to pay attention and to carefully listen to parents and attend to the needs of all family members who are bereaved. The researcher highlights that a 'mere' general advice is not enough, and that "each family's grief is a unique and deeply personal experience requiring the flexible support from carers. It is helpful to avoid some words and phrases such as moving on, closure and we know how you feel. Once again listening is often more healing than talking".

3.18 Parents willingness to place their children under paediatric palliative care

Dighe, Jadhav, Muckaden & Sovani (2008) conducted a study to investigateparental concerns in children requiring palliative care. The researchers found that“parents showed varying degrees of anticipatory grief. Most families were financiallystrained. Most parents were reluctant to discuss disease and dying with the child. Siblings were rarely told or directly involved in care. There was resistance to allowing the palliative care team to communicate with the patient. Patients did not receive any formal support. Parents identified family and neighbours as the main sources of support”. The researchers conclude that “the attitudes of parents affect open communication with dying children and that there is a need for research to explore the concerns of families of children with fatal illness” (Digne et al., 2008). In other studies, parents reported that they no longer want their children to continue receiving treatment under paediatric palliative care and requested medicalpractitioners to withdraw the treatment. For example, Bos, Gevers, Gevers, Seeber, Vos & Willems (2015) argue that “sharing end-of-life decisions with parents is a more important duty for physicians than protecting parents from guilt or doubt.

Moreover, a request from parents on behalf of their child to discontinue treatment is, and should be, hard to over-rule in cases with significant prognostic uncertainty and/or in cases with divergent opinions within the medical team”. A recent study by Levine, Mandrell, Sykes, Pritchard, Gibson, Symons, Wendler & Baker (2017) found that many of those parents who reported suffering indicated substantial suffering severity from specific symptoms, including nausea, loss of appetite, constipation, pain, anxiety, depression, and diarrhoea. The researchers further reveal that “few parents expressed opposition to early palliative care involvement or perceived any detrimental effects on their relationship with their oncologist, and loss of hope, or therapy interference, respectively. Significant differences in patient-parent attitudes toward aspects of early palliative care includedchild participants being more likely than their parents to indicate that palliative care would have been helpful for treating their symptoms” (Levine et. al., 2017).

3.19 The involvement of parents in decision-making concerning withdrawal of treatment.

A Dutch study by Bos, Gevers, Gevers, Seeber, Vos & Willems (2015) points out that the decision to withdraw or discontinue treatment for children with severe acquiredbrain damage is never simple. The researchers argue that this is because there is limited research in this patient group. For example, there "is lack of scientific research on the knowledge about the correlation between type and degree of damage, on the one hand, and duration and level of recovery. Accordingly, physicians' opinions aboutthe period during which substantial neurological recovery may occur and treatment should be continued can be quite diverse" (Bos et. al., 2015). Bos et al (2015) further state that "physicians' views also vary on what may be considered a substantial level of recovery and an acceptable quality of life. An uncertain prognosis complicates end-of-life decision-making for medical teams and forparents. It confronts physicians with the question as to what extent parents should beinvolved in the decision-making process.

The guidelines published by national paediatric societies give contradictory advice about how to best involve parents. Some recommend that all decision-making authority should be referred to parents as the child's main representatives, thereby favouring an informed approach, others recommend that physicians should retain the final authority, thereby favouring a paternalistic approach". The Dutch Paediatric Society "recommends a semi-shared approach in which parentsshould be actively involved in the decision-making process while the physician in charge is responsible for making the final decision. Ultimately, the discussion how bestto involve parents comes down to one central dilemma: how can physicians best fulfilthe 'double ethical duty' of sharing end-of-life decisions with parents while protecting them from too much responsibility and later regrets. This balancing act becomes evenmore delicate when physicians and parents disagree. And while most literature centre on the situation in which parents demand (allegedly) futile care for their child, the opposite situation, though by no means uncommon, is much less discussed" (Bos et.al., 2015).

Bos et al (2015) further reveal that there is a time when some parents want treatment to be withdrawn and discontinued. The situation becomes worse to an extent that parents see the withdrawal of treatment as the only solution. For example, one parent had this to say:

> *"We had understood that he would be extubated today. We don't see any improvement now and we didn't last Tuesday. So we thought: today it will all be over.But now we hear that his treatment will be continued. It becomes harder and harderto retain a little hope. It is like a roller coaster."*

Bos et al (2015) highlight that "the parents' exhaustion intensified their feelings of confusion, anger and grief. These feelings were revealed during the meetings with the nursing staff. Some members had the impression that the parents' despair was caused by the prospect of having to take care of a son who would not recognise them anymore, who would be unable to make any contact and who could not be fed becauseof extreme unrest and epileptic seizures. To others it seemed as if the parents were already in mourning and had given up hope that their son would survive".

3.20 The role of religion and spirituality in influencing parents' attitudes towards palliative care.

Ai, Becker, Camp, Hopp, McCormick & Schlueter (2015) argue that "the complexityof illness and care needs at the end of life often include religious and spiritual issues. Religion and spirituality can be important coping mechanisms for meeting these challenges. However, although many people may want spirituality incorporated as a component of their care, spiritual needs are not always recognised or supported by the existing social care and medical system". But this cannot rule out the important role religion and spirituality play in people's life, especially towards the end of life. Parents put their trust in a supreme and spiritual being to protect them and probably save them and their loved ones from death. This unconditional trust in the supreme being may cause them to be more hopeful in believing that their child will be saved. Consequently, they may easily develop negative feelings towards the role of palliative care staff and experts when their child does not seem to get well as they have expected.

In relation to Ai et al (2015) it is indicated that “the end of life is marked by variety and complexity.For example, some individuals will die early in life, while others may die in old age. The family context of illness is also a salient consideration, as many dying persons prefer to make decisions to avoid creating a burden for family members. Regardless of the circumstances and setting at the end of life, the goal is to die in a comfortable manner with one's wishes honoured. Some individuals are particularly sustained by their spiritual beliefs”. Spirituality is one of most significant “dimension among biological, psychological and social considerations to assess in maintaining quality of life and quality of dying. Moreover, religion and spirituality have been the centre of maintaining a sense of continuity of self and a sense of belonging for many persons faced with serious illness.This may be the case for both older adults and their immediate families. Today, the role of religion and spirituality has become increasingly recognised in end-of-life issues” (Ai et. al., 2015).

An Australian study by Collins (2014) reveals that “death, dying, grieving and funerals often highlight religious, spiritual and cultural differences, and may give rise to new spiritual awareness as people search for meaning in response to life changing events”. The researcher further indicates that “culturally sensitive palliative care requires the health professional to develop an understanding of a family’s cultural needs and a willingness to ensure these needs are met. These needs and experiences may be very individual and fall outside formal cultural or religious expressions. They may also be unique for each member of the family, and in particular, the spiritual experience of children may be quite different to that of adults. It is important to provide opportunities for everyone to explore and express their spiritual and cultural needs and experiences” (Collins, 2014). Why do we need children’s palliative care in Africa? In Africa, it is often said that palliative care is ‘salvage work’ and not worth investing precious time and money into. But even a moment’s thought shows this to be nonsense. Our role as health workers is primarily to relieve suffering and to protect life. Of course, in children’s palliative care, children have diseases that can no longer be cured. In that sense, children’s palliative care cannot claim to protect the quantity of a child’s life. But children’s palliative care can claim to protect the quality of a child’s life, and of course to relieve suffering. There can be few things more important or more valuable in life than to relieve the suffering of a child and to help the child live the life they have as fully as possible.

Why do we need children’s palliative care in Africa?

In Africa, it is often said that palliative care is ‘salvage work’ and not worth investing precious time and money into. But even a moment’s thought shows this to be nonsense. Our role as health workers is primarily to relieve suffering and to protect life. Of course, in children’s palliative care, children have diseases that can no longer be cured. In that sense, children’s palliative care cannot claim to protect the quantity of a child’s life. But children’s palliative care can claim to protect the quality of a child’s life, and of course to relieve suffering (Kirk & Prichard, 2011). There can be few things more important or more valuable in life than to relieve the suffering of a child and to help the child live the life they have as fully as possible.

Some people might ask why we need another palliative care textbook. After all, there are now numerous general palliative care texts available, and even some focused on Africa. There are also now a few books specializing in children’s palliative care. These are good questions, but we think the answer is clear. African children’s palliative care is different to children’s palliative care elsewhere. And African children’s palliative care is different to adult palliative care in Africa. These differences are significant and not covered elsewhere . Every child or young person shall have access to education and wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.

The child and the family shall be given the opportunity to consult with a paediatric specialist with particular knowledge of the child’s condition where possible, and shall remain under the care of a paediatrician. The child and the family shall be entitled to a named and accessible key worker whose task is to build, co-ordinate and maintain appropriate support systems which should include a multi-disciplinary care team and appropriate community resources (Kirk & Prichard, 2011). The child's home shall remain the centre of care whenever possible. Treatment outside of this home shall be in a child-centred environment by staff and volunteers, trained in palliative care of children. Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child's family shall be available for as long as it is required.

3.21 Summary of chapter

This chapter presented a summary of the review of literature to allow the researcher to have a better understanding of parents' attitude towards paediatric palliative care. The researcher discussed in detail literature on PPC from 1.1 Why do we need children's palliative care in Africa? In Africa, it is often said that palliative care is 'salvage work' and not worth investing precious time and money into. But even a moment's thought shows this to be nonsense. Our role as health workers is primarily to relieve suffering and to protect life. Of course, in children's palliative care, children have diseases that can no longer be cured. In that sense, children's palliative care cannot claim to protect the quantity of a child's life. But children's palliative care can claim to protect the quality of a child's life, and of course to relieve suffering. There can be few things more important or more valuable in life than to relieve the suffering of a child and to help the child live the life they have as fully as possible. various studies across the world to investigate the phenomenon under study.

CHAPTER 4: RESEARCH METHODOLOGY

4.1 Introduction

This chapter discusses the research methodology applied in this study. The research methodology includes the research design, study site, study population, sampling method, inclusion and criteria used in the hospital. The chapter further discussed the qualitative research approach as well as the ethical part of the study. The said approach assisted the researcher to outline and understand attitudes as well as perceptions of participants (Lobiondo-Wood & Harber, 2014), with reference to parents of children who are at the last stages of cancer regarding the recommendation of placing their sick children in a paediatric palliative care. Nevertheless, it is important to note that not all children who have cancer are placed in palliative care, rather those that have severe conditions are given preference.

4.2 Research design

This is a qualitative study which adopted case study design since this allowed the researcher to capture a range of perspectives apart from focusing on a one-sided view of an individual. Therefore, multiple research designs were adopted, and it allowed the researcher to gather information from various participants to have an understanding of the differences and similarities of their experiences (Baxter & Jack, 2008). The use of face-to-face interviews was adopted, and the process allowed the researcher an opportunity to gain a greater understanding of the subject in hand, thus, this reduced the potential for any biasness. On that note, since the study employed a case study research design, this enabled the researcher to perceive relationships between occurrences amongst participants (Yin, 2017). On the other hand, the design allowed the researcher to capture the context of lived reality of participants and also created flexibility to collect data through face- to- face interviews. According to Creswell (2013: 485); Merriam and Tisdell (2015) a case study research design is based on extensive data collection. Therefore, this design became relevant to the study since the researcher managed to study the links between the personal, social, behavioral, psychological, organisational, cultural, and environmental factors that contributed to the attitudes of parents with children admitted in a paediatric onology ward that could warrant their placement in a paediatric palliative care facility.

4.3 Population

The population of this study constituted parents of children with cancer and who were admitted at Polokwane hospital in Oncology Paediatric ward. The researcher's focus was in a Paediatric Oncology ward at Polokwane hospital with the admission capacity of 30 patients only. Admission in the ward is a mixture of all races, gender, religion as well as any background. Therefore, children who are found in the ward are expected to be in the presence of a respective adult who is either closely related or known to the patient. Therefore, in the process of receiving treatment and care in the ward, there would be cases that may require referral or transfer to a paediatric palliative care. On that note, the researcher found 26 admissions during her administration of the study and a total of 20 participants were accessed. The said participants were ten (10) parents, and ten (10) caregivers where- by an in-depth face-to face interview was conducted with each participation.

4.4 Sampling

A purposive sampling was employed to select participants, and, on this part, the researcher considered the view by Bryman (2012) that, they said sampling method constitute the selection of participants since they possess characteristics that enhance the exploration and understanding towards the aims and objectives of the study. According to Bryman (2012), a sample should be enough to sufficiently describe the phenomenon of interest and address the research question at hand. Considering that the number of participants who were accessed was limited, which constituted twenty (20) individuals, ten (10) parents and ten (10) caregivers. Even though the said number was engaged, the researcher considered the risks attached to the size and ended up having repetitive data. Therefore, the goal of a qualitative research based on the attainment of saturation was noted.

4.5 Data collection

The main form of data collection in the study was the use of Semi-structured, one-on-one in-depth interviews with an individual (Esin et al., 2014). This type of data collection method was opted because open-ended questions allowed the participants an opportunity to express and elaborate on their experiences (Bamberg, 2012). The researcher was able to take field notes which recorded the information from the interviews, observations gathered about situations and interactions (Esin et al., 2014) as well as the inclusion of relevant details for the purpose of a transcription process. The participants were recruited in the Peadeatric Oncology ward Polokwane hospital through Purposive Sampling. People who were interviewed were parents and Caregivers of children living with cancer. The information gathered and obtained from participants assisted the researcher to achieve insight and further explore their views, experiences, beliefs, and knowledge with regards to paediatric palliative care. The data collection process took three months and the interviews took at least two hours. The data collection process achieved saturation as indicated by Hennik & Kaiser (2021), it is the point in a research process where enough information has been collected to draw necessary conclusions which is without the researcher's personal added insights. The researcher challenges was that some parents used to be emotional and the interviews used to be stopped, some had to attend to their children emergency complications.

4.5.1 Data analysis

To accomplish a relevant analysis of data, the researcher considered facts laid by Yin (2017) that there is a need to choose from various methods of content analysis of specific aspects. In this study, data was analysed through Thematic Content Analysis (TCA) using ATLAS.ti software by Friese (2019). According to Bardin (2011), TCA can be used with different theoretical approaches as well as multiple data analysis processes. On the other hand, (Liamputtong, 2019; Bryman & Bell, 2011) outline the process to construct the meaning of the story, by including a transitions between themes, provide interpretations that brings about a narrative analysis which connects thematic ideas in order to develop a narrative from case-by-case comparisons.

Furthermore, Braun & Clarke (2006) define TCA as a method used to identify, analyse and report patterns in the data. In this study, the researcher conducted TCA by breaking down the information collected into themes, identified trends and patterns that developed from the data collected and coded as well as classified them into different categories that were used to analyse the attitudes of parents and caregivers towards paediatric palliative care at Polokwane hospital.

Furthermore, the researcher was guided by the following steps of content analysis as described by Luo (2019):

i. Select the content to be analysed

Guided by the study's research questions and objectives, the researcher "chose the texts to be analysed".

ii. Define the units and categories of analysis

The researcher defined "the units of meaning that were coded and the set of categories used for coding". For example, the researcher recorded participant's responses from the data collection instrument used.

iii. Develop a set of rules for coding

The researcher clearly defined the rules such as "what had to be included or excluded in order to ensure that all texts are coded consistently for the purpose of ensuring that the method should be more transparent and reliable".

iv. Code the text according to the rules

The researcher did carefully "check each text and ensured that all relevant data was recorded in the appropriate categories".

v. Analyse the results and draw conclusions

When the coding process was complete, the researcher "examined the collected data to find patterns and draw conclusions in line with the research questions".

4.6 QUALITY CRITERIA

In a qualitative study, trustworthiness is all about creating credibility, transferability, conformability and dependability of the findings. Reliability and validity are concerned with trustworthiness. Reliability is about ensuring that data and observation are trustworthy, whereas validity is about the trustworthiness of interpretations or conclusion.

4.6.1 Trustworthiness

The most common procedures to increase research trustworthiness was followed together with the concept of evaluating trustworthiness to determine the quality of qualitative research; which will be adjudicated on the basis of four concepts: (Nowell,2017.)The researcher assured participants about trust and that their information will never be shared with anyone.

4.6.2 Credibility

Strategies to ensure credibility can include, amongst others, aspects such as prolonged engagement, persistent observation and triangulation (O'Brien, Harris & Beckman, 2014). In every study, researchers determine which of these strategies will be suitable because not all strategies might be suitable. Credibility refers to the regularity of measurement and the range at which the results are similar over the forms of the same instrument of the data collected. In other words, the same outcomes are achieved each time the researcher applies several techniques of assessing the collected data (Babbie, 2007). For this study, the patients' personal perspectives prior to viewing the model of the study and their specific feedback after being provided. An overview of the model will be used to confirm the credibility of the results.

For the conformation to be done, the data collected will be available for peer review in order to provide external verification of the research process. The researcher will persistentlyobserve data and scrutinise the reference adequately as a way of checking preliminary findings and interpretations against raw data from the respondents.

4.6.3 Transferability

Transferability is the level to which findings of a study may be conveyed to another context or with other participants (Neuman, 2009; O'Brien et al, 2014)). The researcher will ensure that the study findings are available and applicable to other contexts. The researcher will ensure that the questions asked to the respondents are similar and transparent irrespective of the respondents' demographic characteristics.

4.6.4 Dependability

Dependability requires that there should be appropriate selection of a methodological framework in order to describe and carefully follow the strategy of the study (Bless, Higson-Smith & Sithole, 2013). It is the responsibility of the researcher to ensure that results are consistent and verifiable so that the process of analysis and the selected research design go together. The researcher will ensure that there is consistency in the findings, and that there is enough information from the research report so that if someone wants to replicate the study, they can do so. The researcher will be accountable in the research process by producing a logical, clear and traceable document. She will keep the documents in a lockable locker and submit it for editing purposes to an external person to review the research process to ensure that the findings are regular and can be reproduced.

4.6.5 Conformability

Confirmability is concerned with aspects of neutrality (Moser & Korstjens, 2017). The researcher will ensure that the findings of the report are unbiased and are based on participants' responses and not on the personal motivations of the researcher. Confirmability addresses the objectiveness of the study, which defines that the researcher's personal characteristics will not affect the findings of the study (De Vos, 2011). The researcher will submit the raw data, transcripts and field notes to an auditor in order to provide the rationale for the decisions made.

4.7. ETHICAL CONSIDERATIONS

Ethical considerations are ethical issues, principles and guidelines to be followed by the researcher in the field to ensure that the rights of participants are protected. These principles of research remind the researcher of his/her professional duties and responsibilities. The researcher will ensure that she abides by the following ethical issues when conducting the study: Ethical considerations relate to moral that the researcher should consider throughout all stages of the study. This forms part of a major study on paediatric palliative care which was conducted at the Polokwane Provincial hospital hospital within an Oncology Peadiatric ward. The hospital is in the Limpopo Province. Ethical clearance for the study was obtained from Turfloop Research and Ethics Committee (TREC) as well as the Department of Health Ethics Committee.

4.7.1 Consent to participation

The researcher asked for consent from participants and explained the aims and objectives of the study as well as how she is planning to achieve them. The researcher gave the participants a written consent form where they had to sign as proof that they are consenting to participate in the study. Interviews were conducted in a private and organised setting. Information collected will be kept in a safe and lockable place. No names of the participants were required to ensure that data is not linked to any ofthem. The participants were given freedom and an opportunity to withdraw from participating whenever they feel like doing so. On the issue of the duration of the interview, each case was treated as unique considering that people react to situations differently and since the aspect under discussion required more sensitivity, the student gave it the attention it required.

4.7.2 Permission to conduct.

The researcher requested for permission to collect data from parents of children admitted at paediatrics wards through the Department of Health management based in the Polokwane hospital. Furthermore, the researcher obtained ethical clearance from the Turfloop Research and Ethics Committee (TREC) for approval to collect data. Furthermore, another approval was obtained from the Department of Health Ethics Committee. A consent letter for voluntary participation was also provided to the individual participants who in turn, completed the said form as an agreement for voluntary participation.

4.7.3 Avoidance of harm

According to Wagner and Weeden (2012), the primary responsibility of the researcher is to make sure that participants are in no way harmed because of their participation in the study. Since this study carries a lot of emotional and psychological aspects, the researcher was guarded against creating trauma or further emotional distress towards participants. The researcher also considered that; the parents might be going through a lot of emotional as well as psychological stress caused by the health conditions of their children. Since the researcher is a qualified Social Worker, who has the experience of working within paediatric wards, she was in the best position to observe any discomfort caused by the interviews and engaged participants about the importance of undergoing therapy and seeing a therapist. She furthered ensured that the participants whose experiences reveals trauma, referral to the relevant office or therapist for assistance was discussed and once permission was granted, such referral was done. It helped to prevent their situations from escalating the emotions to be worst level.

4.7.4 Informed consent

In this study potential participants was informed about the aim, objectives, possible risks and benefits of the study. Moreover, they were allowed an opportunity to ask any questions of clarity and were given a consent form to sign before participating in the study. The participants were informed about the processes which were followed. Participants were familiarised with the entire procedure and were assured of their safety when working with the researcher. Hence, the researcher was prepared to assist them in dealing with any situation that may unfold in the process of the interview.

4.7.5 Confidentiality

The researcher ensured confidentiality by distinguishing the identity of the participants through use of the alphabet. Participants were assured that information will remain confidential. The researcher furthered ensure that all data gathered were sealed and the recordings was be kept in a safe place. To ensure confidentiality, the researcher explained to the participants that all data collected was be used for research purposes only, and that the information provided by them will remain confidential – that is, the data will not be given to third parties without their permission. This will help the researcher to avoid the physical or psychological harm of the participants. The researcher will display the highest level of fairness to ensure that participants' rights are protected.

4.7.6 Rights to privacy

It is the role of the researcher to ensure that the dignity and privacy of the participants are respected. Privacy refer to the state of keeping private information as a secret (Bryman, 2015) as well as a way of making the participants' identity unknown. The principle of privacy and confidentiality was assured in the study. Interviews were conducted in a private and organized setting with moderator and recorder. Information collected was kept in a safe and lockable place. Participants was allowed to withdraw from participation without penalty. The researcher ensured that the identities of the participants was not revealed. No names was requested to protect the dignity and privacy of the participants.

4.7.7 Release or publishing of findings.

On completion of the study, the researcher compiled an accurate and objective research report on factors that hinder the utilisation of intermediary services to alleged child offenders by probation officers. The researcher acknowledges that the findings of the study will be released for public consumption in a written form. The results will be made available to the university's School of Social Work, and the library. The outcome of the research as well as the recommendations will be stated.

4.8 Conclusion

This chapter concentrated on the study's research methodology. The research methodology included the hospital's research design, study site, study population, sampling method, inclusion and criteria. The chapter also went over the data collection method, data analysis, and ethical concerns. The study took a qualitative approach. The aforementioned approach aided the researcher in outlining and comprehending participants' attitudes and perceptions regarding the recommendation of placing their sick children in a pediatric palliative care facility.

CHAPTER 5: Results

5.1 Introduction

This chapter presents the qualitative findings of the study which aimed to explore the attitudes of parents and caregivers towards paediatric palliative care (PPC). Face to face interviews were conducted from a total number of twenty (20) participants who constituted of ten (10) parents and ten (10) caregivers with children suffering from cancer and admitted in Paediatric Oncology ward within Polokwane hospital in the Limpopo Province. Purposive sampling was used to select participants and data was coded and categorised into subthemes using ATLAS.ti software which according to Friese (2019), can be used with different theoretical approaches as well as multiple data analysis processes. In this study, the Content analysis by Bardin (2011) was adopted as an approach which was found to be useful since the study is qualitative. The demographic characteristics of the participants are outlined below and are followed by the themes and subthemes obtained from the views of participants concerning paediatric palliative care.

5.2. Demographic profile of participants

The table below outlines the demographic characteristics of participants who were interviewed on paediatric palliative care showing the gender of parent, race, age of child admitted, relationship ,name of the hospital and duration of admission .

TABLE: Demographic profile of participants

Participant No.	Gender of Parent	Race	Age of the Child	Relationship	Name of Hospital	Duration of Admission
1	Female	Black	6-10 years	Parents	Polokwane	0-5 months
2	Female	Black	6-10 years	Parents	Polokwane	0-5 months
3	Female	Black	11-15 years	Parents	Polokwane	6-11 months
4	Female	Black	0-5 years	Parents	Polokwane	0-5 months

5	Female	Black	11-15 years	Parents	Polokwane	0-5 months
6	Female	Black	11-15 years	Parents	Polokwane	0-5 months
7	Female	Black	0-5 years	Parents	Polokwane	0-5 months
8	Female	Black	0-5 years	Parents	Polokwane	0-5 months
9	Female	Black	6-10 years	Parents	Polokwane	0-5 months
10	Female	Black	0-5 years	Parents	Polokwane	0-5 months
11	Female	Black	11-15 years	Caregivers	Polokwane	0-5 months
12	Female	Black	0-5 years	Caregivers	Polokwane	0-5 months
13	Female	Black	11-15 years	Caregivers	Polokwane	6-11 months
14	Female	Black	11-15 years	Caregivers	Polokwane	6-11 months
15	Female	Black	6-10 years	Caregivers	Polokwane	0-5 months
16	Female	Black	11-15 years	Caregivers	Polokwane	1 years and Above
17	Female	Black	0-5 years	Caregivers	Polokwane	0-5 months
18	Female	Black	0-5 years	Caregivers	Polokwane	0-5 months
19	Female	Black	0-5 years	Caregivers	Polokwane	0-5 months
20	Female	Black	0-5 years	Caregivers	Polokwane	0-5 months

Twenty (20) participants were interviewed for the study, comprising 20 females (consisting of mainly mothers, a grandmother, aunt, and sister). They were all recruited from Polokwane Hospital. Majority of the participants (16) had children who had been admitted for a period between 0 to 5 months, three (3) had children that had been admitted for a period between 6 and 11 months and one parent had a child that had been admitted for over 1 year.

5.3 Themes and sub-themes of the study

The data from the twenty (20) interviews was analysed. The results of the study are presented below using themes and subthemes that emerged from the data in line with the objectives of the study, as outlined in the table below:

TABLE: THEMES AND SUBTHEMES OF THE STUDY

Themes	**Subthemes**
Theme 1. Parents' awareness of paediatric palliative care	1.1. Parents' view and knowledge of PPC 1.2. Lack of knowledge of PPC 1.3. Mixed beliefs of the benefits of PPC
Theme 2. Parents' current support and coping mechanisms	2.1. Positive and negative family support 2.2. Positive and negative health worker support 2.3. Positive and negative coping mechanisms 2.4. Perceived parents' role when the child is placed in PPC
Theme 3. Losses encountered due to the child's condition	3.1 Financial loss due to initial private and/or alternative treatment 3.2. School set back 3.4. No losses experienced
Theme 4. Level of parent's readiness to consent for paediatric palliative care	4.1. Parents' positive attitude and interest towards utilisation of PPC 4.2. Parents' negative attitude and disapproval of utilisation of PPC 4.3. Fears associated with PPC and

Themes	Subthemes
	child’s condition
Theme 5. Level of referral by social workers to paediatric palliative care	5.1. Intermittent to lack of referrals for PPC by social workers. 5.2. Absence of social worker visits in the Wards

5.3.1 Theme 1. Parents’ awareness of palliative care services

Under this theme, parents expressed their views which showed the differences in the level of awareness of parents and relatives on paediatric palliative care services. Data shows that some of the participants had a positive view towards PPC; had knowledge of PPC and where to receive it; some lacked knowledge of paediatric palliative care and others believed that PPC could benefit their children with some supporting any benefits if the services were offered in a hospital setting only or with similar hospital staff.

5.3.1.1. Subtheme 1: Parents’ view and knowledge of PPC

Knowledge of PPC

Shirinda-Mthombeni (2014) defines PPC as “an approach that improves the quality of life of patients and their families facing the problems associated with a terminal illness. It is a combination of active and compassionate, long-term treatment intended to comfort and support individuals and families who live with a life-threatening illness”. Knowledge of what PPC is and what it entails is very important, especially to parents of children with cancer. This sub-theme was interesting in that very reason – determining whether parents know what PPC is. The data highlights that some of the participants indicated that they were aware of PPC. They explained that they had received an explanation on PPC from the health workers (nurses and doctors) on admission and/or in the ward. Some of the responses provided by the participants are stated below: *Yes, during my admission the sister explained everything. (P4)*

I wish I came to provincial hospital early; their service is good. When I arrived in the ward, a nurse sat down with me and explained everything concerning my child condition, elaborated more about palliative care…. In the ward they told me they provide services, and they also told me about the specialised areas with refence to palliative care and hospice care. (P10)

This is the service that can really assist cancer children. When the doctor explained this to me, I already had hope that my child is going to be healed. This hospital is doing the best service ever…. I am fully aware when I was admitted all this was elaborated. (P15)

I know basic from what the nurses highlighted (P20)

These positive views are closely related to findings by McIlfatrick et. al. (2013), which revealed that participants were "more aware of palliative care and the availability of different palliative care services".

In the same scope, participants confirmed that they knew where to receive PPC as had been explained to them by the nurses and doctors. This is supported by some of the statements below when the participants were asked the question: "Do you know where to receive PPC?"

The sisters explained that I can receive the services in the hospital or private sector. They also told me that they provide those services in the ward. (P2)

In the ward they told me they provide the service, and they also told me about the specialised areas including palliative care and hospice care. (P10)

Yes, I do, provincial hospital provide basic care, some have a specialized field which deals full time with this service. (P13)

Yes, in the hospital the nurses explained everything to me about their provision of basic services which are the core services. (P18)

PARENTS VIEW REGARDING PPC

Some of the participants highlighted their positive view of PPC, describing it as a good service that assists parents, helps to understand the child's condition and provides hope to the families. This is indicated by some of the responses to the question: "What is your view with regard to PPC?" as highlighted by the statements below:

Palliative care is the best service any parent can ask for am telling you. (P18)

It is good because you get the chance to go through all the stages with your child, you also understand the illness better. (P1)

I think is a good program that will assist most parents. (P6)

To me yes, I do not know about his parents, people who are doing palliative care aretrained, they know what they are doing. (P9)

5.3.1.2. Subtheme 2: Lack of knowledge on PPC

In contrast to the above, there was also a significant number of participants who indicated that they were uninformed of paediatric palliative care. They explained that they were not informed about PPC. Some had just been in the ward for a short period and others only knew about it after they had been admitted. This is supported by the quotations below from the participants:

I can't talk much about palliative care because I don't know what is it all about, I can't talk much about because I was not told anything about this programme. (P12)

I don't want to talk more about the programme I was not told about, maybe let them talk to me first. (P14)

I don't know anything about this programme, I just have two weeks here and I am waiting for the results (P17)

I don't know anything about this, to be honest. (P19)

To be honest am just the grandmother I really don't know much. (P3)Not until the child was admitted. (P4)

I really don't know, Mam. (P8)

No, I don't but am willing to learn for the sake of the child. (P9)

I don't, nobody explained to me. (P16)

I don't know anything mam, I have two weeks here what is exactly palliative care, maybe explain better to me. (P17)

I am not even sure whether the service they are providing is palliative care because they never explained anything to me. (P14)

This lack of knowledge of PPC was further supported by some of the participants, who mentioned that they were not sure of the benefits of PPC, and that they were new in the ward, as expressed by the statements below:

I am not sure. (P7)

I don't know but, in this ward, I think the doctors are trying all their best. (P3)

Eish I really don't know. (P16)

Mam, please let them explain this service first to me then will talk about the rest. I can't talk about something I am not aware of I don't want to be rude my child needs me. (P14) I don't know,

Maybe if I experience it for now, I cannot talk much about it. (P17)

As result, most of the participants indicated that they were unaware of the differences between PPC, hospice and home-based care, including those who indicated that they knew about PPC. This is supported and expressed by some of the responses below:

No, I was not aware and am willing to learn more. (P5)

No, I was not aware of the differences, no one told us as a family. (P6)

No, I was not aware, I only know that if my child is sick, I have to take her to the hospital. (P1)

No, I was not aware, nobody explained anything to me. (P2)No,

I was not aware, no one told us as a family. (P3)

No, I was not aware of the differences, no one told us as a family. (P4)

No, I was not aware of these services. (P7)

No, maybe you can explain to me (P8)

No, am not fully aware. (P9)

I am not aware; I am willing to learn more. (P10)

I am not aware, (P11)

What is that now, you see I don't know these things. (P14)

Contrary to the responses in sub-theme 1 above, it appears that some of the participants, which are in higher number, are not aware of the PPC despite benefits of PPC. Considering that studies (Gilmer et al, 2012) above indicated that parents' knowledge about PPC is important to parents giving consent and their views about PPC, this should be a point of concern. The study by McIlfatrick et. al. (2013) proved that there is a limited knowledge about the PPC and the above responses are confirmed by this mentioned study. Parents' lack of knowledge about PPC can lead to parents being reluctant to giving consent to PPC for their children living with cancer and life limiting diseases (Downing et. al., 2018). This was first identified by the World Health Organization (2016) that lack of knowledge is the leading factor that hinders access to PPC. However, this could be justified with reference to Harrop and Edwards (2012), that PPC is still new in many countries developing countries like South Africa and might be worse to underdeveloped countries as compared to developed countries (Downing, 2018). Therefore, this can lead to reluctant manner of giving consent by parents despite researches revealing that PPC improves the quality of life and reduces psychological distressin patients with cancer and caregivers (Yoo et. al., 2017).

5.3.1.3. Subtheme 3: Mixed beliefs of the benefits of PPC

A few participants believed and had an understanding that PPC can benefit their children positively because of the progress their children were making in their wards and the encouraging service and information provided by the health workers. This is confirmed by some of the statements below from the participants:

Yes, I see progress already. (P4)

> *Mine is benefiting already; most children can benefit from it. (P1)*
>
> *Yes, a lot, he can improve in the recovery processes. (P10)*
>
> *Yes, the way the sisters explained it to me yes. I already see progress with my son, and I am happy. (P2)*
>
> *Yes, too much, am already benefiting with the knowledge they are providing in the ward. (P5)*

These findings are supported by McAteer and Wellbery (2013), who highlight that many studies have found that "patients who receive PPC care have improved quality of life, with less depression and symptom burden; feel more in control". This shows that there are indeed benefits associated with PPC. Patients who have access to PPC services are likely to receive better and improved treatment compared to those who do not.

However, some parents had the belief that PPC could benefit their children if provided in hospitals only or by similar staff to those in the hospital as expressed by the quotations below:

Yes, I think if it is provided in a hospital setting because I am not sure of the other places. (P5)

Yes, it but if it is provided in the hospital not hospice. (P2)

Yes, if it is the staff that I always see in this hospital I can say yes, they show all the love and care 24 hrs. (P4)

One of the participants felt that it would benefit only those who believed in the services, as expressed by the response below:

For those who believe in the services. (P3)

The benefits of the PPC were outlined by Yoo et al, (2017) that PPC improves the quality of life and it further reduces psychological distress in patients with cancer and caregivers. However, the study also sought to investigate if there are people with controversial opinions about the benefits of the PPC. For example, the theory of Kubler-Ross' theory of death and dying to prove that certain health care methods such as PPC can trigger different emotions and perspectives about their benefits. The theory provides different stages, including grief which is more relevant to patients suffering from severe condition of cancer which often gives rise to mixed emotions to parents and family members as whole (Anfara & Mertz, 2014). For example, An Australian study by Collins (2014) reveals that death, dying, grieving and funerals often highlight religious, spiritual and cultural differences, and may give rise to new spiritual awareness as people search for meaning in response to life changing events. This implies that even the use of PPC is received with mixed thoughts. However, majority of the participants indicated that they see the benefits of PPC although one participant outlined that PPC benefits those who believe in it. This is due to the theory of Kubler-Ross' theory of death and dying creating a perception that even parents and some family members may have missed thoughts about the benefits of the PPC and some may look at it as mechanism with benefits and some may consider it otherwise.

The mixed beliefs are grounded by various factors which are deeply embedded in people's view of life. For example, Collins, (2014).spiritual, cultural, societal and religious beliefs as factors which can affect people perceptions about life and death and which thus may consequently affect people's perception about PPC. In relation to Ai et al (2015) it is indicated that the end of life is marked by variety and complexity. For example, some individuals will die early in life, while others may die in old age. The family context of illness is also a salient consideration, as many dying persons prefer to make decisions to avoid creating a burden for family members. Regardless of the circumstances and setting at the end of life, the goal is to die in a comfortable manner with one's wishes honoured. Some individuals are particularly sustained by their spiritual beliefs. Spirituality is one of most significant dimension among biological, psychological and social considerations to assess in maintaining quality of life and quality of dying. Moreover, religion and spirituality have been the centre of maintaining a sense of continuity of self and a sense of belonging for many persons faced with serious illness. This may be the case for both older adults and their immediate families. Today, the role of religion and spirituality has become increasingly recognised in end-of-life issues (Ai et. al., 2015).

5.3.2. Theme 2. Parents’ current support and coping mechanisms

Darlington, Korones & Norton (2017) highlight that “supporting parents in understanding and exploring their emotions in the face of the possible death of a child should be considered an integral part of professional practice”. Findings under this theme show the positive, negative support and coping mechanisms that parents experienced when dealing with their children’s condition. Participants also described their perceived role in supporting their children in paediatric palliative care.

5.3.2.1. Subtheme 1: Positive and negative family support

Under this subtheme, participants expressed their positive and negative experiences of the support that they receive from family members such as their spouses and parents.

Positive family support

Some participants explained that they receive positive support from their spouses at home, parents and friends, which assists them in dealing with their child’s condition and to accept it. They went on to mention that the support was adequate. The statements below highlight this positive family support:

At home they give me lot of support, they told me to be patient and accept what i can’t change. (P2)

I have great support system from my mother. (P13)

I got support from family members, I support myself with my mother… Yes, we support each other, I think it is enough p16

I also get support at home. The dedication for me makes me hope there isnothing that you will report and they don’t attend. (P6)

From my family I can say yes, am grateful. (P12)

I do, friends, doctors and family members. My partner is also very supportive. (P15)

Caring for a child with a life limiting illness may require parents to adopt different strategies to help them cope with this chronic illness. Such strategies may include relying on the assistance of other family members. If that fails, parents may have to deal with the problem alone. A study by Darlington, Korones and Norton (2017) reveals that parents may have to adopt multiple roles such as “nurse, child advocate, and detective – while trying to be a good parent, to ensure that the child is well and has a good life”.

Negative family support

In contrast to the positive support received by other participants, some of the parents experienced negative support from their spouses and family members because of different views of the child’s condition and treatment. Participants mentioned that family members did not accept that the disease was natural. The following quotations indicate some of the responses which show the negative and inadequacy of the family support by some of the participants:

From the hospital it is enough but from home there is no support. (P4)

As for my partner we always fight so I can’t talk much about him…I think from thefamily is not enough, I wish I can have loving partner who will always be there for me no matter what but is like believes made us fight, he doesn’t believe that this is nature. (P13)

I don’t want to talk about family, friends because no one is showing me support, the child ‘s father is worse he blames me for everything just imagine. (She started crying) …Nothing is helping me instead this people are causing more pains to me, it hurts. (P14)

To me no, cause I never had any support from staff or family members, my husband is worse. (P17)

I don’t get any support from the family since I am an orphan and I believe the hospital is part of my family now. (P7)

5.3.2.2. Subtheme 2: Positive and differential health worker support

According to WHO (2018), “it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured”. Research has found that friendly, caring and understanding staff who explain children’s conditions to parents were most helpful (Brooten, Youngblut, Seagrave, Caicedo, Hawthorne, Hidalgo and Roche, 2012). Participants mentioned both positive and differential support that they experience from the hospital staff. Some participants described the positive support that they received which helped them to deal with the child’s condition. Others expressed the differences in treatment by the health workers depending on the staff on duty.

Positive support from health workers

Responding to the questions of support from the hospital and if the support was enough, helpful and constructive, majority of the participants explained that they receive positive support from health workers, which was adequate to support them in dealing with their child’s condition and gave them hope. This is in line with findings by Kirk & Pritchard (2010), who reported that “participants were highly satisfied with the support provided in terms of quality of care; interpersonal qualities of the staff; the individualized, family-focused approach; accessibility of support and involvement in decision making”. The following responses confirm this support:

> *The support I get from the hospital for me I think it is enough and I am satisfied. (P6)*
>
> *To be honest the sisters and doctors makes us feel at home and we forget our problems at home, they are also giving me support at home…Yes, it is enough, I am no longer feeling stressed or hopeless, the hospital support is great, and I am satisfied. (P1)*
>
> *Yes, it is enough, and I am very happy to be honest. The sisters and doctors are always available not forgetting my beautiful family. (P2)*
>
> *To be honest the sisters and doctors respond fast and am happy with their service… Yes, it is enough, I am just concerned about his condition but the support in the hospital is more than enough. (P3)*

> *Yes, it is enough, helpful and satisfied, I can encourage by nurses to stay positive and whatever results will come up I should accept. (P7)*
>
> *To be honest I started at Mankweng hospital, and I waited for results and immediately when the results came back, nurses and doctors played an important role of understanding my child condition and ii can say I am a better parent today…This condition is scary and unreliable, Jo but the way the doctors are determined to assist my child, I fear not he is already healed. (P8)*
>
> *I get full support from nurses, doctors in the hospital, they are always there to provide information and to explain better in case of complications. (P5)*
>
> *The whole year that I spent in the ward I can attest that I received the best care and support to my child, from the nurses, doctors and family. (P18)*
>
> *Cancer ward has the best support anyone could ask for. (P20)*

These positive results are in line with the findings by (Verberne, Kars, Schouten-van Meeteren, Van den Bergh, Bosman, Colenbrander, Grootenhuis & Van delden, 2019), who argue that parents reported positive experience and healthy relationship with healthcare workers who are experienced and knowledgeable regarding PPC services. Parents also had positive experience with healthcare workers who aligned their care with their child's and own needs – that is, healthcare workers who were sympathetic and stroveto meet and address the needs of their patients.

However, some of the participants did not feel supported because they experienced differential treatment from the health workers such as negative attitude and what they considered favouritism depending on the staff who were on duty. This made them feel that the support was not enough, and, in some instances, this resulted in negative emotions such as pain and hurt. Some of the responses from the participants are highlighted below:

> *To me at the hospital due to the attitude I feel lost not supported…Is this research confidential, please promise me not to tell these nurses I will feel bad. Some treat us bad some are very nice, they are some nurses who are very harsh, very rude, please do not tell them.my family also support me. (P10)*

> *Nothing is helping me instead this people are causing more pains to me, it hurts. (P14)*
>
> *Professionals eish I think it depends on who is on call to be honest. (P13)*
>
> *I can talk more about family support, nurses it depends on the one who is on duty their personalities differ. (P12)*
>
> *No, these nurses is like they have favouritism am telling you. (P14)*
>
> *I don't have support, doctors and nurses are always busy, they don't have time to support. (P11)*

Brooten et. al. (2012) found several factors which made parents of children with cancer feel neglected and not supported. They included, among others, "insensitive, non-supportive staff; conflict between providers and parents; lack of communication problems after the death of their child; inexperienced nurses and doctors; parents not understanding child's disease, care, complications, etc." Furthermore, another study by Monterosso & Kristjanson (2008) argued "parents whose children died from cancer live within a context of chronic uncertainty and apprehension. Parents construed palliative care negatively as an independent process at the end of their children's lives rather than as a component of a wider and continuous process where children and their families are offered both curative and palliative care throughout the cancer trajectory". Paediatric palliative care services should conduct regular assessment of "parents' support needs to anticipate early and tailored supports including partnerships with the community" (Aoun et. al., 2020).

5.3.2.3. Subtheme 3: Positive and negative coping mechanisms

Positive coping

Closely linked to support, some of the participants mentioned that their religious beliefs such as praying, accepting the child's condition and talking to family, friends and health workers help them to cope with the child's condition and to motivate others. These views are supported by the findings in a study by Misko, dos Santos, Ichikawa, de Lima and Bousso (2015), who found that "hope, perseverance and spiritual beliefs are determining factors for the family to continue fighting for the life of their child in a context of uncertainty, anguish and suffering, due to the medical condition of the child". This is what some of the participants had to say:

> *I don't fear anything I accepted my child condition and I have hope he will recover in Jesus name. I have faith and it keeps me going. (P6)*
>
> *Yes, I can say I am a motivator now.*
>
> *As a family we update each other because every day there is a new thing, but we are very strong, we accepted what we cannot change. (P8)*

A few mentioned that they are open to talk to family, friends and health workers about their child's condition, and one mentioned that they motivate other parents. This is confirmed below.

> *I do, friends, doctors and family members. My partner is also very supportive…I usually talk to the parents, I encourage them to be strong, accept and be better for the sake of the children. (P5)*
>
> *Yes, I do. (P19)*

The above findings show how parents are coping and how they deal with the illness of their children. Another study by Verberne et. al. (2019) was conducted to investigate parents' experiences and strategies used to cope when caring for children placed or receiving treatment at paediatric palliative care unit. The researchers identified several coping strategies such as "suppressing emotions by keeping the loss of their child at bay, seeking support, taking control to arrange optimal childcare, and adapting to and accepting the ongoing changes". The researchers concluded that professional and trained healthcare workers who "understand and carefully handle the worries and losses of parents, parent-child relationship, and coping strategies are needed" (Verberne et. al., 2019).

However, a few expressed that they were not coping because of the seriousness of their child's condition, the pain they feel towards it, and the lack of support from family even as they tried to support their child. This is related to findings by Verberne et. al. (2019), who found that parents were experiencing "daily anxiety of child loss, confrontation with loss and related grief, ambiguity towards uncertainty, preservation of a meaningful relationship with their child, tension regarding end-of-life decisions and engagement with professionals". The following statements from some of the participants confirm this:

> *It is not easy at all although I accepted but emotionally, I am not coping. (P1)*
>
> *I don't want to talk about family, friends because no one is showing me support, the child 's father is worse he blames me for everything just imagine. (She started crying)…I don't manage because I feel I also need help. (P14)*
>
> *My mom is not coping at all I don't think she will cope with all this situation, am trying hard to be strong for my mom. (P16)*
>
> *Jo < is painful to see young children being so sick, no parent can wish this to happen to their children. (P7)*

Some of the participants showed a withdrawal from society because of their child's condition with reduced socialisation, unable to talk to people or they spoke to selected people about it and got stressed, as confirmed by the statements below:

> *Socially-I am no longer socialising before with friends I am focusing more on my child, sometimes I just talk to few women in the ward that's all… Jo other people or no I only talk to my family and her father. I do not want people to get more involved with my family business. (P1)*
>
> *Socially-I do socialise with my child am no longer socialising like before with friends and family but in the ward am trying… I only talk to my family and friends. When another child passes on then I stress a lot. (P2)*
>
> *Yes, I only talk to the doctors, or sisters' other people will not assist me with anything. (P3)*
>
> *I am an orphan with lack of family support, I don't have anyone I share information with, I only share with nurses in the ward. (P7)*
>
> *I only talk to my family because friends will not assist me with anything, I have hope that all will be well, faith keeps me going. (P6)*
>
> *Yes, I only talk my brothers they make me feel better. (P4)*

I share with my mother, child ‘’s father and feel better I don’t have many friends. (P10)

I have a problem sharing, I only share with family with others now, they have stereotype. (P11)

It depends on the person am talking with. I believe not everyone will understand my pain. I talk to my mother friends will not help me with anything just to be honest. (P13)

I only talk to my close family, friends will not be able to assist me with anything, just gossips only, I will rather keep quiet. (P12)

I do not talk to my friends, but I update the child ‘s parents and they are very grateful. (P9)

Two participants mentioned that they are closed people and do not interact much. This is highlighted below:

I am a very closed person, I am not a talkative person. (P17)

I am a very close person, I don’t like sharing my personal thing seven from my boyfriend. (P16)

5.3.2.4 Subtheme 3: Parent’s effort to provide emotional, social and educational support to their child

Verberne, Kars, Schouten-van Meeteren, Bosman, Colenbrander, Grootenhuis & van Delden (2017) argue that most parents strive to be the best parents to their sick children. This is a counter response to the suffering caused by chronic disease and the vulnerability which parents think their children are. The researchers identified several tasks performed by parents to ensure that their children are well taken care of, namely: “providing basic and complex care, organising good quality care and treatment, making sound decisions while managing risks and organising a good family life” (Verberne et. al., 2017). In this study, most participants also identified similar strategies and efforts to be the best parents to their children. For example, when asked if parents provide adequate emotional, social and educational support to their children, there were different views which highlighted efforts parents make despite the difficult circumstances, and some of them not coping with the situation. The following quotations confirm this:

> *I try my best to be there for my child, emotionally when he is not coping, I support, socially am no longer doing too much since this child was sick. (P5)*
>
> *Emotional-The family is playing the biggest role supporting me and the child, the child has days some are better, and some are worse. (P3)*
>
> *I am trying to give full support to my child, emotionally and socially. (P4)*
>
> *Some days is better some bad, the child cries sometimes but am here for support although I am not strong but am trying. (P7)*
>
> *I do but he is still young just imagine all this trauma, oh God (sobbing). (P8)*
>
> *I do talk to her she now understands although she is worried about school sometime. (P9)*
>
> *Emotionally am strong now I can be able to support my own child or even educate other women about cancer. (P18)*
>
> *My child is 1 year still young she does not understand what is happening to her. She was not going to crèche and am here to her full support. (P10)*

‘

5.3.2.5 Subtheme 4: Perceived parents' role with regard to PPC and when their child is placed in PPC

Majority of participants felt that parents should play a full supportive role, with love to the child. Others mentioned the role of prayer when the child is in PPC. This was confirmed by responses from some of the participants, as follows:

> *My role can be of a supportive parent, loving at all times. (P4)*
>
> *Above all love and prayer. (P8)*
>
> *In whatever programme my child will be in I think loving my child, supporting himin both ways it can be the best decision I can do. (P10)*
>
> *My role as a caregiver is acceptance and have more hope…To be a parent, to love my child with regard to any circumstance. (P5)*

> *My role can be of a supportive parent, loving and praying for the best…Parents should give full parental support for their children and full care. (P6)*
>
> *To be a parent, to love my child regarding any circumstance. (P7)*
>
> *As an aunt I have to be there, parents are working the best thing is to allow this child to recover. (P9)*
>
> *Every parent should give parental support and accept what you couldn't change. (P10)*
>
> *Although is difficult but I think is best for every parent to support their children, love and support their children, to be honest this the most difficult moment I came across, am trying to be strong even though is tough… Love is all about being there, loving and giving full parental support. (P13)*
>
> *Being a parent is tough, the most painful part is that you have to be there for your child regardless of what the situation might be. (P12)*

These findings show that parents care about their children who are receiving PPC services. They have a meaningful role to play in PPC. Leemann, Bergstraesser, Cignacco & Zimmermann (2020) argue that to make sure that parents are actively involved and that their needs are met in PPC, "both mother and father of a child must be given special attention, and their unique and different caregiving roles should be identified because these roles might influence their needs in this exceptional situation". For this reason, healthcare workers need to "identify how parental dyads mutually navigate care for their sick child to best meet their needs in support. Moreover, mothers and fathers should be supported in their individual coping strategies".

5.3.3 Theme 3. Losses encountered due to child's condition

This theme highlights the description of parents' different experiences of losses they faced seeking treatment for their child's condition or caring for them. Such losses included financial losses due initial private care, seeking alternative treatment from traditional doctors or prophets, losing a job, time off work, school set back and dropping out of school.

5.3.3.1 Subtheme 1: Financial loss due to initial private care and/or alternative treatment

Some of the participants mentioned that they had initially sort treatment for their child's condition from private services such as private doctors, traditional healers and prophets because of different family views concerning the child's condition. This led them to losing a lot of money to pay for the services offered, which in many instances is expensive and results in strained relationships. This is confirmed by some of the following quotations from participants:

> *I lost money, I was in the department, I thought it was miracle I went there until I startedgoing to the hospital. I did not lose any job. (P2)*
>
> *Doctors' fees were too much before the child was admitted even transport fees were costing but after the child was admitted all was well. His parents lost a lot of money. (P3)*
>
> *You know what the relationship is very strained I lost a lot of money; you know at home not all will believe in the medical care somewhere referring me to traditional doctors (P4)*
>
> *Jo money, from traditional healers, prophets, private doctors until the hospital. (P15)*
>
> *Before the child was diagnosed, I spent lot of money with private doctors at home but since the child was admitted I see lot of improvement and I regret taking time not to bring this child in a government setting. (P5)*
>
> *Ja eish, sobbing, I lost my job because my child comes first, I had to sacrifice. Before I brought him in the hospital, I was spending more money on private DR fees but since the child was admitted in the ward I didn't lose much. Public hospitals know their staff. (P1)*
>
> *I do have financial loss, I used private doctors too much until the doctor I consulted encouraged me to go to public setting where she is working. I am happy so far although am still paying depts. But am happy so far. (P13)*
>
> *Yes, I spent a lot with private doctors, and I now regret because my child is now receiving the service free of child. (P12)*

> *Finances, work am taking incapacity leave my child comes first. (P20)*

The above findings are in line with Du Plessis' (2017) argument that families suffer financial loss due to their child being diagnosed with cancer. Families spend a lot of money trying to find better institutions which may help their child. However, it is not all parents who reported financial losses. For example, some of the participants argue that they had not encountered any losses yet, or did not consider that they had any losses, as highlighted by the statements below:

> *I never encountered any loss am not working and I depend on children grant for survival. (P7)*
>
> *I don't have any loss, (P9)*
>
> *I am a lecture, is exam time, they understand at my workplace, I don't have any loss. They are paying me full salary. (P11)*
>
> *I never experienced any loss; I was just referred to this hospital. (P17)*
>
> *Not now (P19).*

5.3.3.2. Subtheme 2: School set back

Some of the parents argued that some of the children who were admitted were held back from school because of the illness and their efforts to reassure them. This is what some of them said:

> *He gets worried about his schoolwork; he is doing grade 6 but I always assure him education comes first. (P6)*
>
> *My child was doing grade 2 and I explained everything, and she does not give me problems her health come first, and she will go next year she is still young. (P1)*
>
> *With education is a loss this year, this child is too weak to go to school. (P3)*
>
> *At home they are giving me full support, my child is worried about schoolwork, he just wants to go back to school. (P11)*
>
> *At school they understand, I also spoke to him, he understands, and he does not mind repeating the course. (P13)*

Moreover, one of the parents had to drop out of school to take care of the child, and another was anxious that she might lose her job since it was early stages. This is what one of the participants said:

> *I was unemployed I was still going to school studying security, my loss is that I dropped out, but my child school comes first. (P10)*

5.3.4 Theme 4. Level of parents' readiness to consent for PPC

Another interesting discovery from the data were different views of parents and relatives about their positive and negative attitude towards PPC. Their fears associated with the child's condition and barriers for uptake of PPC. This indicated their level of readiness to consent to PPC for their child, with some being ready and others not ready.

5.3.4.1. Subtheme1: Parents' positive attitude and interest towards utilisation of PPC

Some of the participants were interested in their child using PPC because of the knowledge of PPC that they had received or perceived benefit that it could have for their child. When asked "Have you ever thought of utilising the services for your child?", participants were positively open to the use of PPC as pointed out by some of responses below:

> *Yes, after their explanation. (P5)*
>
> *Of course, it's already assisting me. (P1)*
>
> *Yes, I think is the best service that can help me also as a parent. (P10)*
>
> *Sometimes to be honest I do (P20)*

Closely connected to the interest in using PPC was the responses of some of the participants to the importance of placing a child in PPC. The statement belowhighlights participants' view of the importance of placing a child in PPC, agreeing to the recommendation and that it would be in the child's best interest:

Yes, I can't manage alone with all these complications… I don't have any problem as long as my child can get help…100 percent, I do believe, these people where trained to offer services like this. (P10)

Yes, I don't have any problem, this service seems to be working… I can agree, I don't have any problems I think this service can be the best…I think so if my child can be admitted to this service all will be well. (P11)

Oh yes obvious, this is a good service that Most parents should know about, awareness campaigns should be done so more parents can be reached out, I was lucky because I could afford to pay private doctor who told me about this service. (P13)

Yes, these nurses are well trained alone I can be more confused. (P15)

I really don't have any problem; I can take the challenge and see the results…If they recommend, I will go (P18)

I will agree if the doctor talk about it… I already saw the manner which my child is being treated in the ward so it is an obvious case for me I definitely agree. Please assist these children, they do not deserve all this please. (P15)

When participants were asked on the timing of placing a child in PPC, very few responded at the last stage.

Before his final stage of death not for ever I cannot allow that. (P13) Until

the final stage but family should also be allowed for closure. (P15)Till the

last stage (P19)

Connected to their beliefs that PPC should be offered in hospitals only, some of the participants were only interested in the services if they were delivered at the hospital. The following is a response from one of the participants:

Yes, but only if this service is provided in the hospital under the parents' supervision,I believe no one will allow the child to be far we are not white people we are Africans. (P2)

Participants also expressed their positive perspective of PPC yielding positive results. This is confirmed by the responses below:

I really do, this is the best programme. (P13)

Yes, it does, I have hope with this programme I believe is going to change my child 's life forever.

I think if it is provided in the hospital setting it can yield positive results rather than in area where the child will be with strangers. (P5)

> *Yes, if it is the staff that I always see in this hospital I can say yes, they show all the love and care 24 hrs. (P6)*
>
> *Yes, because I see lots of changes when the child is in the ward. (P10)*

In contrast, one participant expressed their concern about PPC yielding positive results related to fears of the young age of the child and the belief of better care at home. One participant had the following to say regarding PPC:

Oh no I really do not think so these children are very young, and they deserve better do you think whoever is taking care of them will do good I don't think so is better when they are at home. (P1)

Participants' positive attitude towards PPC is in line with findings by Levine et. al. (2017), who found that most participants had positive attitude towards the utilisation of PPC services – only very few parents had negative attitudes toward early palliative care. The researchers suggested that PPC patients and families might benefit from early palliative care integration. As indicated above that some parents have no knowledge about PPC and some may have negative perception of PPC. The study of Bos et al (2015) reveals that some parents even have willingness to withdraw the PPC treatment for their children especially when parents see no benefit from PPC and the situation becomes worse to an extent that parents see the withdrawal of treatment as the only solution.

5.3.4.2. Subtheme 2: Negative attitude and disapproval of utilisation of PPC

Some of the participants did not agree to the utilisation of PPC or placing their child in PPC because of various issues such as the stage of the child's condition, age, lack of knowledge, attachment to the child and fear of different care. This is also supported by Yoo et. al. (2017), who argue that "negative attitude toward PPC services is related to disagreement between health care workers and caregivers or parents regarding the following: “(a) death as the ending of life, (b) death is painful and therefore to be feared, and (c) people should be remembered”. This shows that some parents have negative views regarding placing their children under PPC. Here are some of the responses:

> *For now, no but maybe in the future, I don’t think my child is in the final stage yet. (P15)*
>
> *I don’t have any interest of this programme. I think this programme is designed for people who have good hearts. (P16)*
>
> *Eish I do not know because my child will never go to the facility…I don’t believe in utilising those services outside the hospital or at home not any other placement facility. (P1)*
>
> *I do not want my child to be placed anywhere rather than the hospital setting. (P2)*
>
> *Not my child, I can’t approve that, it’s either hospital or home. (P8)*
>
> *I think the hospital is the better place to keep these children they respond fast and as a parent you will be able to monitor your child. (P5)*
>
> *Not at all not to my child…I don’t think, I can ever place my child at that facility. (P11)*
>
> *I can’t comment much, my child will never go there…It’s a no no for me. P12*
>
> *Not at all, this child is my younger brother. I won’t allow anyone to take him away from me. P16…He is my younger brother am not sure what mom thinks but to me I will never allow it. P16…As sister also advocating for m younger brother is a no no for me. (P16)*

Furthermore, Barriers associated with lack of uptake or interest in PPC were described. This included culture, fear, mostly lack of information on PPC, denial and undermining government facilities. The quotations below confirm these barriers:

> *Culture and beliefs also play a role. (P15)*
>
> *Fear (P16)*
>
> *Fear of unknown P19*
>
> *Lack of information can make you take harsh decisions. (P12)*

I think lack of knowledge contributes to this if they are aware of these programmes, I don't think they will refuse. (P15)

Lack of knowledge. (P18)

I think is lack of knowledge, what our home hospitals are doing are not providing any information. (P5)

It depends on not accepting and also undermining the government setting. (P10)

A recent study by Shah, Qaisar, Azam and Mansoor (2020) agrees with the above findings and reveals that "limited knowledge of the concept of palliative care and misconceptions about it are barriers to meaningful utilisation of palliative care programs. As caregivers play an integral role for patients with terminal illness, it is necessary to assess their perceptions and attitudes towards the palliative care approach".

5.3.4.3. Subtheme 3: Fears associated with PPC and child's condition.

Research has shown that "children with cancer who have access to PPC services have "improved symptom burden, pain control, and quality of life with decreased intensive procedures, increased completion of advance care planning and resuscitation status documentation, and fewer end-of-life intensive care stays with higher likelihood of dying at home. Family impact included satisfaction with PPC and perception of improved communication" (Kaye et. al., 2021). Under this subtheme, participants expressed their mixed views of what they wanted at the end of life of their child, and fears associated with the child condition. When asked where they would prefer the child to die, some parents mentioned that they would prefer that their child dies at the facility with the family around, and others at the hospitals.

At a placement facility surrounded by family and friends. (P10)

I think the hospital is the better place with the parents around than with strangers. (P5)

I think the hospital is the better place with the parents around than with strangers. (P3)

> *I can’t let my child die at home; I think where there is medical team is better. (P4)*
>
> *Facility and holding my hands. (P15)*

In contrast, others did not agree for their children to die at facilities but at home with the family around. They disapproved for the child to be placed in PPC at the end of life, as supported by some of the responses below:

What, my child can die in my hands…Not at all, not to my child (P11)

My blood should die in my hands; I can’t allow someone to tell me about the death of my child. (P13)

> *Jo jo, in my hands, I want see his last breath… No. let my child close his last eyes with me. (P12)*
>
> *My child is my child, I will rather go home and monitor each moment. (P14)*
>
> *I believe being at home close to the family is the best decision ever…To me no I want to be there during each moment, I cannot cope if she is placed in the facility, I want to be there during each moment, I cannot cope if she is placed in the facility. (P1)*
>
> *Giving birth is the most traumatic fear, for every woman but this is worse than that, I will rather spend his last days at home. (P8)*
>
> *My mom will prefer we spend time with him at home. (P16)*
>
> *Before the end of life, the child should go home. (P18)*

One participant did not mind either home or facility as long as the parents are there as expressed below:

Both is fine for me as long as they allow parents (P20)

Concerns of the age of placing the child in PPC

Participants had different views when asked what age was appropriate to place a child in PPC. Due to the severity of the child’s disease, most of the participants were not worried about the age of the child when placed in PPC than the condition itself. This is confirmed by some of the responses below:

> *I used to worry too much but when I look at other children now, I see age does not matter at all. (P5)*
>
> *To be honest, when I discovered that my son has cancer, I was very worried, I cannot say maybe the age is appropriate but when I came in the ward and I discovered most children has cancer it broke my heart and I accepted because some where younger than him. (P1)*
>
> *Sicknesses of these days do not check age, only God knows some children are dying with two weeks. (P8)*

However, some of the participants felt that it is better to place older children in PPC than when they are young.

I think if my child got sick at the age of 14 it would be better but at her age now is too soon.(P2)

Maybe 17 and above, they will understand. (P11)

Maybe from 16, they will be able to understand now is a big problem. (P15)

From 17 maybe not these young ones they are really lost. (P20)

Mitchell et. al. (2019) conducted interviews with parents where they shared poignant accounts of how their children died. The researchers indicate that the experiences were shocking and traumatic. However, despite the traumatic experiences that they were exposed to, “parents valued the reassurance provided in PPC that all possible treatment options had been explored for their child. Being in PPC and having more days of life than might have been possible in other clinical settings was also highly valued”.

However, some of them had fears of the care they would otherwise receive in PPC, and that the children were still very young or deserved better than being placed in PPC.

No, I don’t agree my child is very young I can’t do that. (P6)

They are still young, and I do not think there is anyone who will take care of my child more than me. (P1)

They are still young, and they deserve the best parents love not to be thrown away. (P2)

They are still young, and I do not think there is anyone who will take care of my child more than me. (P3)

> *My child is so young I can't think of the best age to place the child under PPC… They are still young, and do you think there is anyone who will take care of my child more than me. P4…No, I don't agree my child is very young I can't do that. P4*

> *My child is too young to understand everything which is happening this side. (P17)*

Most of the participants described the fears that they had of their child dying, being barren or experiencing relapse because of the cancer, and sometimes the symptoms that they would see their children experiencing. Some feared death as highlighted below:

Yes, I fear death this condition is very scary. (P9)

Fear of death always come to my mind, this condition is unpredictable, is very scary, some days is better. Some is worse but I accepted that my child will be well. (P10)

I have big fear when the child is fitting, I fear death but with cancer all is well. (P3)

I do especially when my child is weak, I fear death but the way they respond in the hospital they give me hope. (P7)

The most painful fear is death, on a daily basis. (P13)

I do fear death oh no (crying) my child, my child what did he do I cannot accept this to be honest, is too much for me. (P14)

Yes, especially relapsing and death, I received enough counselling, and I accepted my child condition. P15

> *When he complicates, I fear death, he is the only brother I have. (P16)*

> *When someone is sick be honest who doesn't fear death. (P19)*

> *Yes, I fear that will he have kids or will he live…(P2)*

It is normal for parents to develop fears regarding the possible death of their children. This is supported by Mitchell, Spry, Hill, Coad, Dale and Plunkett (2019), who highlight that "parents experience wide-ranging, intense emotions towards the end of their child's life, which impact on their ability to take part in end-of-life care decision-making. They described a range of conflicting emotions related to a hope that their child would not suffer, and a simultaneous fear that their child was going to die. These emotions created stress, anxiety, a state of inner conflict and cognitive dissonance. Parents felt intensely vulnerable as their children approached the end of life".

Other parents expressed their fears of being separated from the child, care from strangers, and the bond with the child.

> *No, I don't have any fears but sometimes when I am far from her but when I am near her, I am okay…There are still young, and I do not think there is anyone who will take care of my child more than me. P1*
>
> *Fears of strangers taking care of your child. (P6)*
>
> *Do you have children? I think motherhood bond hinders everything. (P8)*
>
> *Can you take the child away from you? No, I don't think so, how will you feel being separated with your own child. (P17)*
>
> *I think extra care; some parents are over-protective. They want to spend most of their time with their children. (P11)*
>
> *The bond of your child (P20)*

However, there were a few who indicated that they did not fear at all when it came to their child, as expressed below:

> *Bo, I have no fears I don't want to lie. P17*
>
> *Jo death I used to fear it to be honest. But now no more I believe my child is healed and soon will be going home. P18*

Despite their differing and mixed views, all parents want what is good for their children. This is related to findings by Verberne et. al. (2017), who felt that it was very important for them "to reach controlled symptoms and controlled disease of their ill child. They mentioned that controlling symptoms was of major relevance for maximal comfort for their child or at least those inconveniences were minimised as much as possible. Additionally, they mentioned that controlling the disease was a matter of preventing loss of their child or maximally prolonging their child’s life”. According to Mack et al., (2012), it is normal for parents to develop fears regarding the possible death of their children. This is supported by Mitchell et at, (2019), as they authors highlight that parents experience wide-ranging, intense emotions towards the end of their child’s life, which impact on their ability to take part in end-of-life care decision-making. This could be due to range of conflicting emotions related to a hope that their child would not suffer, and a simultaneous fear that their child was going to die. These emotions created stress, anxiety, a state of inner conflict and cognitive dissonance. Parents felt intensely vulnerable as their children approached the end of life.

5.3.5 Theme 5. Level of referral by social workers to PPC

Social workers’ role in paediatric palliative care includes informing and recommending patients and parents about paediatric palliative services. Under this theme, parents described their experiences of receiving other services from social workers and the intermittent or lack of referrals for PPC as well as the absence of social worker visits in the wards.

5.3.5.1. Subtheme 1: Intermittent to lack of referrals by social workers

There was only one parent who mentioned that they had received a recommendation for PPC by a social worker, but they were not yet ready to utilise the service, as confirmed by the statement below:

> *The social worker tried her best to explain that this programme is just that am not ready.(P16)*

In contrast, most of the participants articulated that they had not received any explanation from a social worker or recommendation for PPC. This is supported by the statements below from participants:

> *She never came or explained anything this is the first time today I see a social worker in the ward, are you working here? (P5)*

> *No social worker explained this service for me. You are the only social worker I have seen so far. (P6)*

I was not seen by a social worker, so nothing was explained to me. (P8)

No one even nurses, no one explained to me, you are the first social worker I have seen. (P12)

There was no interview done by the social worker. (P10)

I have never received any counselling; I always see the social worker attending to others not me. (P13)

These views show how inactive social workers are in PPC programmes. Taels, Hermans, Van Audenhove, Boesten, Cohen, Hermans and Declercq (2021) suggest that social workers should be involved earlier to afford them an opportunity "to facilitatethe early introduction of palliative care during multidisciplinary discussions. Theresearchers acknowledge the fact that physicians have the final say in PPC but highlight that a social worker may help to make the situation of a client negotiable if they are involved at an early stage". For this reason, "social workers must be assigned toclients shortly after diagnosis to inform them and their relatives on the options during the illness trajectory. This allows clients to further discuss these options with their physicians. The inclusion of social workers shortly after diagnosis is important as'the lack of inclusion of the social worker in initial diagnostic conversations' forms a barrier to the implementation of holistic social work practices in the later palliative trajectory" (Taels et. al., 2021).

However, Harrop and Edwards (2012) argue that paediatric palliative care is a new area of paediatrics and therefore many social workers and medical practitioners may not be that much fond of it or not even quite knowledgeable about it to prescribe it to their patients. This could serve as the motive behind poor rate of PPC referrals. A few of the participants mentioned that they had received services from social workers such as counselling and therapy but had not received any referral or recommendation for PPC. This is highlighted by the statements below:

Yes, I received counselling, but she never mentioned anything about this programme. (P15)

I saw her but for therapy only (P18)

Yes, I saw her, but it was not about palliative care it was more about therapeutic support (P20)

5.3.5.2. Subtheme2: Absence of social worker visits in the wards

The lack of referral or explanation was supported by some of the participants, who indicated that they had never had any social worker visits in the wards. This is confirmed by the statements below:

> *I haven't seen any social worker in the ward ever since I was admitted. (P5)*
>
> *Do they have social workers in the ward I haven't seen any? (P8*
>
> *I was never interviewed by a social worker maybe his parents. (P9)*
>
> *I have never seen any social worker. (P11)*
>
> *No one saw me, I was not aware there is a social worker in the ward too, this is for the first time. (P14)*
>
> *Not at all, is there a social worker in the ward. (P17)*
>
> *I never consulted a social worker. (P19)*

Taels et. al. (2021) suggests that both social workers and health care workers must work together to develop a positive relationship so that social workers can be more involved in palliative care and play a significant role and be influential in practice. The findings above show that social workers are currently taking a back seat – they are not hands-on. Social workers must be empowered with a clear role description in palliative care. This will be very important and helpful in multidisciplinary cooperation and will assist social workers to be active and competent in their PPC roles.

CHAPTER 6: FINDINGS, CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

6.1 Introduction

The previous chapter presented and outlined the findings of the study. In this chapter, the researcher provides the findings and conclusions regarding parents' attitudes towards paediatric palliative care. The chapter also covers the recommendations for further research, and the limitations and implications of the study.

6.2 The findings

The main findings of the study regarding parents' attitudes towards paediatric palliative care are discussed in line with the objectives of the study. Therefore, in summary, the findings include the following:

6.2.1 Parents and caregivers who were interviewed have a positive attitude towards PPC and its accompanied services. Our finding was in correlation with a study done by (Kirk & Prichard, 2011) in the United Kingdom. Kirk & Prichard, 2011 concluded that parents value a model of care that provides holistic, family-focused support that is responsive to individual needs, and which promotes control and active involvement in decision making.

6.2.2 The success of PPC services is more dependent on the support provided to parents and in order for it to succeed, efforts need to be made before and during admission and after the passing of the service user. This is very crucial as it was shown by a recent study done in Lebanon by (Rassam, Huijer, Noureddine, Smith, Wolfe, Fares & Abboud, 2023), who showed that only 18/105 participants (17.1%) had heard about PPC and 2% had accurate information about it. When given a brief description, more than 90% endorsed PPC and recommended its integration upon the child's diagnosis.

6.2.3 The interviewed participants indicated their interest in recommending PPC to other parents and friends in their communities.

6.2.4 The researcher revealed that there is a need to get support from key stakeholders such as nurses, doctors, family members and social workers; and the findings indicated that support which was provided to parents and care-givers improved their knowledge and awareness of PPC services and it also led to changes towards their attitudes to accept and allow their children to receive treatment in PPC. This finding was in relation to studies by (Bluebond-Langner, 2010) in the United States of America and United Kingdom. In the study by Bluebond-Langner 2010), they also found out it was parents' role and responsibility to exhaust all options in order to help their children with cancer when normal therapy had failed, and a cure was not likely (Bluebond-Langner 2010).

In addition to the above findings, the objectives are concluded as follows:

6.3 OBJECTIVES

6.3.1 Objective 1

- To identify the current emotional, social, financial and psychological wellbeing experienced by parents of children with cancer.

This objective revealed different views regarding the emotional and psychological well-being of parentsof children with cancer. For example, some parents reported that they are coping andmaking efforts to stay happy despite the difficult circumstances and painful experiences that they endure due to their child’s critical condition. However, some reported that they are not coping with the situation. They must leave other activities so that they can be there for their child. Regarding the financial well-being of parents,some parents reveal that they lost and wasted a lot of money consulting with various practitioners (medical, traditional, and spiritual), trying to find solution and healing for their child.

6.3.2 Objective 2

To determine parents’ knowledge of palliative care services offered for their children who are diagnosed with cancer.

The results revealed that most parents only became knowledgeable with the PPC services after their children were admitted in the hospital. This indicated that, prior to the admission, parents and caregivers had no idea of PPC including it's purpose as well as services rendered. This means that one can conclude that participants did not have sufficient information regarding the meaning of PPC. Therefore, the researcher concludes that parents' knowledge of PPC is poor and that a lot still needs to be done to improve parents' knowledge of PPC services.

6.3.3 Objective 3

To establish parents' awareness of palliative care services.

The parents and caregivers who were interviewed were found to be aware of the palliative care services available for children living with cancer. The results indicate positive attitudeand awareness of PPC services. Although there were mixed reactions regarding theirawareness of PPC services, most participants reported that they were aware ofthe PPC services. Health workers such as nurses and doctors were cited as key stakeholders in terms of disseminating PPC related information to parents of children with cancer. They are always available to provide parents with all the necessary information in the wards.

6.3.4 Objective 4

To establish the level at which social workers recommend and refer children with cancer for psychological and hospice care during the end of life. The results from the objective revealed that there is lack or minimal referral by social workers for PPC. The results also show that social worker services required in the Paediatric Oncology ward are rendered actively and those services are hardly available in the wards to assist those in need. Again, the findings also indicated lack of partnership or cooperation between health workers and social workers. This situation leads to social workers' activity regarding the provision of PPC services in the wards not to be viewed as active.

6.4 Recommendations

- The study recommends that government use all available methods (imbizos, media, billboards, etc.) to create and promote awareness of PPC to all citizens in South Africa.
- The study recommends that effective measures or strategies be introduced and put in place to support parents/guardians of children who are receiving treatment in PPC to help them cope with their child's critical condition.
- The study recommends that all health workers in PPC section be trained to enable them to provide the best support and services to parents of children with cancer.
- The study recommends that parents be involved in all decision making regarding their children so that they can be more willing to utilise PPC services.
- The study recommends that public education be promoted to improve parents' knowledge of PPC and its services.
- The study recommends that social workers be empowered and be given a more active role in PPC services.

6.5 Conclusions

It is evident from the research findings that parents have positive attitude towards PPC and its accompanied services. The success of PPC services is more dependent on the support provided to parents before and during admission, and after the child has died. This may result in parents recommending PPC to other parents and friends in their communities. Parents need support from key stakeholders such as nurses, doctors, family members and social workers. The findings of this study have shown how the support provided to parents improve their knowledge and awareness of PPC services, and how it changes their attitudes to accept and allow their children to receive treatment in PPC either at home, hospice, or in the hospital. For this reason, the national department of health must take into consideration parents' needs and support to promote PPC and change their attitudes regarding its utilisation in the future.

6.6 Limitations of the study and recommendation for future research

The study only focused on the attitudes of parents and did not consider the attitudes and views of key stakeholders such health workers and social workers. Future research should be aimed at investigating parents, health workers and social workers' perceptions towards PPC services. This will ensure that the researcher presents rich data and analysis regarding the phenomenon under investigation.

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APPENDICES

APPENDIX A: INVITATION TO PARTICIPAATE IN THE STUDY

University of Limpopo (Turfloop Campus)
Faculty of Humanities
School of Social Sciences
Department of Social Work

REQUEST FOR YOUR PARTICIPATION IN THE STUDY

Dear Participant

I am a Masters' (M.A.) student in Social Work (SW) at the University of Limpopo, Turfloop Campus. You are invited to form part of the research study which forms part of my MA (SW) degree. As part of the study, I am supposed to collect data from identified participants, including you. The research study is titled "Attitudes of parents towards paediatric palliative care: A Medical Social Work intervention perspective in the Limpopo Province".

You are assured that the session will take approximately thirty (30) minutes to one hour. You are further requested to provide your honest responses to the questions asked in the tool provided. You are also requested to read and sign the informed consent provided to you.

Thank you for your participation.
Mogale R N
Date: 2019/03/31

M.A. Social Work student

APPENDIX B: CONSENT LETTER FOR PARTICIPANTS

TOPIC OF THE STUDY: Attitudes of parents towards paediatric palliative care: A Medical Social Work intervention perspective in the Limpopo Province.

DECLARATION OF CONSENT (PARTICIPANT)

I……………………..(initials and surname) being the participant in this study, hereby give permission to voluntarily participate in this research study with the following understanding:

- The researcher conducting the study is a student at the University of Limpopo (Turfloop Campus).
- The research forms part of the requirements for student’s Master’s degree in social work.
- Data will be collected by means of semi structured interview.

My rights as a participant:

- I am aware that my participation in this study is not forceful.
- I have the right to withdraw from the study at any given time.
- I have the right to refuse to give responses to any question(s) when I feel that I am not comfortable.
- I acknowledge that I have been assured that my personal information in this study will remain anonymous and my name and identity will be kept from public knowledge.
- I grant permission for any information that I will reveal during the interview process, with the understanding that data collected will be utilised for the sake of this study.

- I ,... (participant),

agree to take part in this study.

________________________ ________________________

SIGNATURES

Participant: **Mogale R N**

M.A. Social Work

APPENDIX C – DATA COLLECTION TOOL (INTERVIEW GUIDE)

DATA COLLECTION TOOL (INTERVIEW GUIDE)

SECTION A: DEMOGRAPHIC INFORMATION

1. Gender of the participant

Male	
Female	

2. Age the child

0 – 5 years	
6 – 10 years	
11 – 15 years	
16 and above	

3. Name of hospital

Polokwane	
Pholoso Netcare	

4. Duration of admission

0 – 5 months	
6 – 11 months	
1 year and above	

Section B: INTERVIIEW SCHEDULE GUIDE

THEME 1: To establish the parent awareness of Paediatric Palliative Care (PPC)

1. What is you view with regard to PPC?
2. Do you know where to receive PPC?
3. Have you ever thought of utilising the services for your child?
4. Do you think your child can benefit from PPC services?
5. What can be your role with regard to PPC?
6. Which age range do you think is proper to place a child in a PPC?

THEME 2: Parent' current support and coping mechanisms

1. Since your child was diagnosed with cancer, what kind of support services did you have?

2. Is the support enough, helpful, proper and constructive?

3. Are there any losses that you have encountered (example, work, finances, relationships etc)?

4. Do you manage provide adequate emotional, social and educational support to your child?

5. Do you have any fears of relapse, death, acceptance or doubts about any aspects relating to your child's future?

6. Are you able to talk to other people about your child's health?

THEME 3: Level of parent's readiness to give consent for placing their children in a hospice facility.

1. Which role do you think parents should play when children are placed in a PPC?
2. Do you think that it is important to place children in a PPC during end of life?

3. Do you think the child should die at home or at a placement facility?

4. How will long do you think children should be placed in a PPC?

5. What concerns do you think parents have that hinder them from having interest in the placement of their children in a PPC hospice care during end of life?
6. Do you think paediatric palliative care can yield positive results in caring for your child?

THEME 4: The level of referral by social workers to PPC by Social Workers

1. Did you ever have any recommendation from a social worker about placing your child in a PPC during end of life?
2. Were the services and benefits of placing your child in a PPC (hospice care) explained?
3. Are you aware of differences between PPC, hospice and home-based care?
4. Did you agree or will you agree to the recommendation of placing your child in a PPC?
5. Do you think the utilisation of PPC services will be in the best interest of the child?

Thank you for your participation

APPENDIX D: LETTER FOR PERMISSION

The Head of Department Department of Health Limpopo Provincial office
Polokwane
0700

Sir/Madam

Request for permission to conduct research with parents of children who are admitted within paediatric ward.

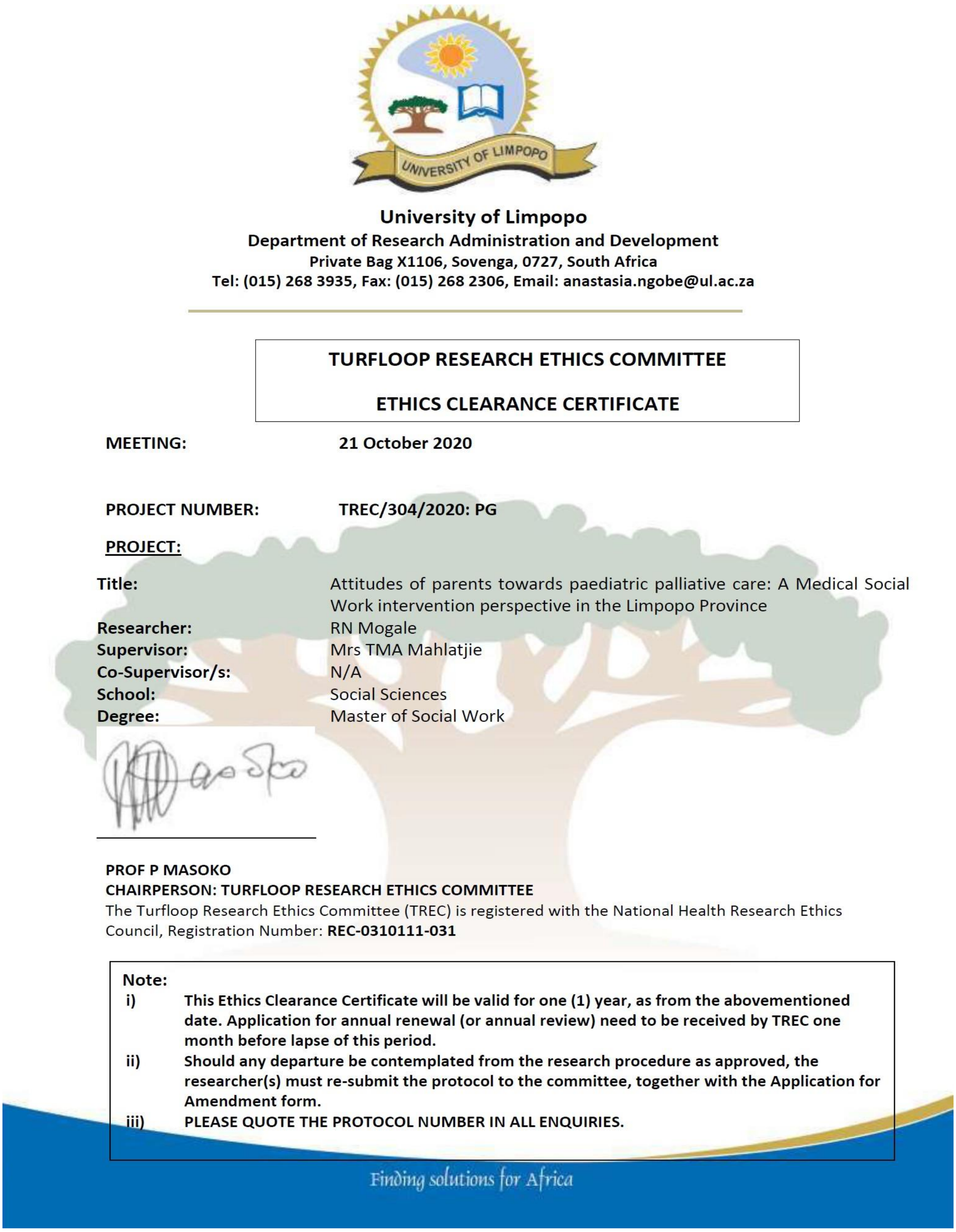
I Mogale Rudzani Noria hereby request permission to conduct research amongst parents of children who are admitted at paediatric ward at Mankweng and Polokwane Hospitals. The study is titled “Attitudes of parents towards paediatric palliative care: A Medical Social Work intervention perspective in theLimpopo Province”. I am currently registered with the University of Limpopo doing a master’s degree in social work, student number 201827932, supervisedby Mrs. Mahlatjie TMA who is a Lecturer in the Department of Social Work at theUniversity of Limpopo.

Attached please find my study proposal.

Thank you in anticipation of your consideration of this request.

Mogale RN

Researcher



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

TURFLOOP RESEARCH ETHICS COMMITTEE

ETHICS CLEARANCE CERTIFICATE

MEETING: **21 October 2020**

PROJECT NUMBER: **TREC/304/2020: PG**

PROJECT:

Title:	Attitudes of parents towards paediatric palliative care: A Medical Social Work intervention perspective in the Limpopo Province
Researcher:	RN Mogale
Supervisor:	Mrs TMA Mahlatjie
Co-Supervisor/s:	N/A
School:	Social Sciences
Degree:	Master of Social Work

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

Note:

- i) **This Ethics Clearance Certificate will be valid for one (1) year, as from the abovementioned date. Application for annual renewal (or annual review) need to be received by TREC one month before lapse of this period.**
- ii) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee, together with the Application for Amendment form.**
- iii) **PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.**

Finding solutions for Africa

APPENDIX F APPROVAL FROM DEPARTMENT OF HEALTH.

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA
DEPARTMENT OF HEALTH
PIETERSBURG HOSPITAL

Date: 14 July 2021

To whom it may concern,

RE: PERMISSION TO CONDUCT RESEARCH INTERVIEWS AT PIETERSBURG HOSPITAL: WARD L

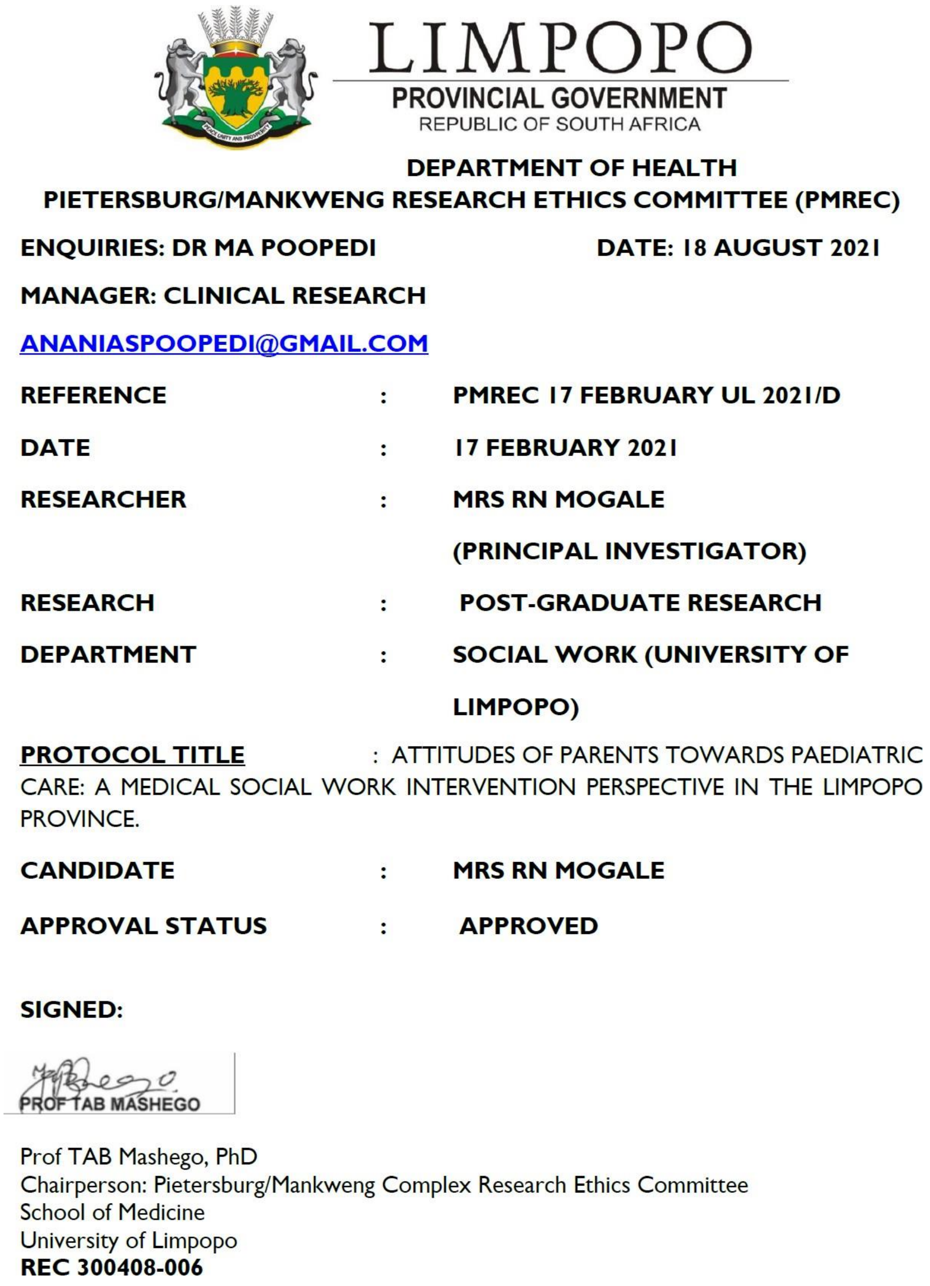
This letter serves as confirmation that Ward L is aware and have granted permission to RN Mogale Mrs being supervised by TMA Mahlatjie from school of Social Sciences doing Master of Social Work. The study is entitled: Attitudes of parents towards paediatric palliative care: A Medical Social Work intervention perspective in the Limpopo Province.

A critical condition would be that all participants (parents/guardians) must be asked to give their written or verbal consent before the research begins. Their responses must be treated confidentially, and personal information must be anonymous unless otherwise expressly indicated. Individual privacy must be maintained in all published and written data resulting from the study.

Please let me know if you require any further information.

Yours sincerely,

Dr V Netshituni
Head of Clinical Unit Paediatric Oncology
Cell Number: 0822939739



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
PIETERSBURG/MANKWENG RESEARCH ETHICS COMMITTEE (PMREC)

ENQUIRIES: DR MA POOPEDI **DATE: 18 AUGUST 2021**

MANAGER: CLINICAL RESEARCH

ANANIASPOOPEDI@GMAIL.COM

REFERENCE	**:**	**PMREC 17 FEBRUARY UL 2021/D**
DATE	**:**	**17 FEBRUARY 2021**
RESEARCHER	**:**	**MRS RN MOGALE** **(PRINCIPAL INVESTIGATOR)**
RESEARCH	**:**	**POST-GRADUATE RESEARCH**
DEPARTMENT	**:**	**SOCIAL WORK (UNIVERSITY OF LIMPOPO)**

PROTOCOL TITLE : ATTITUDES OF PARENTS TOWARDS PAEDIATRIC CARE: A MEDICAL SOCIAL WORK INTERVENTION PERSPECTIVE IN THE LIMPOPO PROVINCE.

CANDIDATE	**:**	**MRS RN MOGALE**
APPROVAL STATUS	**:**	**APPROVED**

SIGNED:

PROF TAB MASHEGO

Prof TAB Mashego, PhD
Chairperson: Pietersburg/Mankweng Complex Research Ethics Committee
School of Medicine
University of Limpopo
REC 300408-006