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DISSERTATION

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In the field of

PALLIATIVE CARE

With the title

ASSESSMENT OF THE QUALITY OF CARE PROVIDED TO PATIENTS WHO DIED IN THE CARE OF TSHWANE DISTRICT HOSPITAL

FACULTY OF MEDICINE

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DECLARATION

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

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LIST OF ABBREVIATIONS and DEFINITION OF TERMS

AID's: Acquired Immune Deficiency Syndrome

BP: Blood Pressure

CHC: Community Health Centres (one of network of clinics staffed by a group of general practitioners and nurses to serve the people in a certain area)

COPC: Community Oriented Primary Care (refers to a continuous process of providing primary care to a defined community based on its assessed needs through planned integration public health with delivery of primary health care).

CRF: Chronic Renal Failure

CVA: Cerebral Vascular Accident

COPD: Chronic Obstructive Pulmonary Disease

EoL: End-of-life (End-of-life may refer to the last few days of life when a person is irreversibly dying (also known as the terminal phase); it may also refer to the final illness without a time frame)

GP: General Practitioner (physician who does not specialize in any particular area of medicine, provide routine assessment or health care for all, treat all conditions and illnesses).

GSF: Gold Standard Framework which refers to a comprehensive care programme that helps practitioners to identify patients who are in the last years of their life, assess their needs, symptoms and preferences, and to plan care to enable patients to live and die where they choose.[16]

HIV: Human Immunodeficiency Virus

IHD: Ischaemic Heart Disease

PHC: Primary Health Care Centre (centre established to provide accessible, affordable and available primary health care to people in accordance with the Alma Ata Declaration of 1978 by WHO).

SPICT: Supportive and Palliative Care Indicators Tool (internationally used tool to identify people at risk of deteriorating and dying with advanced conditions for Palliative care needs assessment and care planning)

WBOT: Ward Based Outreach Teams (outreach teams based in a primary health care centre or community health centre to offer integrated services to the households and individuals within its catchment area).

WHO: World Health Organisation (specialized agency of the United Nations concerned with international public health).

ABSTRACT

ASSESSMENT OF THE QUALITY OF CARE PROVIDED TO PATIENTS WHO DIED IN THE CARE OF TSHWANE DISTRICT HOSPITAL

Objective: To assess the quality of care rendered to admitted patients in need of end-of- life care at Tshwane District Hospital in Pretoria Central, Gauteng, South Africa.

Method: A combined retrospective review of the patient's folder and a descriptive qualitative study through interviewing the deceased patient's relatives was used. An after-death audit (ADA) tool, developed by the researcher and supervisor using the Gold Standard Framework ADA Tool, which is used in the UK was used as a reference as was agreed to be appropriate for this study. This explored the ability of healthcare workers at district hospital level to identify patients who were at end-of-life through noting and recording the end-of-life symptoms and signs and the interventions taken within the last 72 hours of the patients' life. An interview guide for the bereaved family members was developed using the family medicine principle of patient-centred care and management in order to investigate their perception of the quality of care rendered to their relatives whilst admitted at Tshwane District Hospital during their last days.

Results: 96 files were audited, revealing that patients between the ages of 21 years to 101 years were admitted. This confirmed the increase in number of older people with incurable chronic disease and multi-morbidity such as malignancy and HIV/AIDS, as compared to younger patients. Of those admitted, 55.2% were admitted from home and 15.6% were referred from a tertiary institution. 83% of these patients were admitted due to non-cancer diagnosis, of which about 36% of those admissions were HIV- related, followed by renal causes (10%), cardiac (10%) and COPD (3%). Cancer accounted for approximately 16.6% of the admissions. The duration of stay was between 4.3 to 4.7 days, with younger and white patients admitted for shorter periods compared to their older and black counterparts. The audited patient records recorded signs in their files (gasping - 51.04%, low BP, low pulse - 18.75%) and symptoms of end-of-life (confused, ill, weak - 18.75%) but patients were not identified or recognised as being close to end-of-life and were not referred for palliative care. The only recorded intervention that patients received was oxygen by mask (54.1%).

Record reviews and family interviews revealed poor patient involvement in decision-making as only about 9.3% were involved in their own care management. There was also a lack of family involvement in patient management (4.4%), poor multi-disciplinary /team involvement as only 29.2% were referred to the other members of the multi-disciplinary team, and a low referral to hospice (8.3%). According to the 18 consented family members' interviews conducted, there was lack of information with poor updates on patients' problems or prognosis. Only 58,8% felt that enough information was given and the members interviewed were not offered any additional services (76.5%). They indicated that they thought referral to hospice would have improved the quality of life and care of their loved ones at end-of-life. The majority of family members (88.24%) also reported little care for patients during the dying phase as their relatives (patients) had symptoms (23.53%) but nothing had been done to relieve these symptoms.

Conclusion: There is an increased need for palliative care and end-of-life care education and skills at district hospitals as most patients are admitted or down-referred for care to district hospitals at the end-of-life. When looking at interventions rendered, the study revealed poor quality of care rendered to patients at their end-of-life, poor patient and family involvement in management decisions, and a lack of multi-disciplinary approach of care. Helping or training of the healthcare workers at District Care level Hospitals to be able to recognise a patient in need of palliative care or have an ability in recognising those patients who require end-of-life care or are in their last 72hrs of life (which refers to the patients in the final hours or days of their lives, or those with a terminal illness that has become progressively advanced) is still a challenge in the District level hospital. The integration of palliative care at district hospitals would improve the quality of care for both patients and their families.

CONTENTS

CHAPTER ONE: INTRODUCTION

1.1 Background

Palliative care refers to an active, total or holistic form of care that focusses on improving the quality of life for patients and their families facing problems associated with incurable life threatening illnesses.[1] The main goals or principles of this form of care involve relief of suffering through early identification of the illness or disease, assessment and treatment of pain, other physical, psycho-social and spiritual problems in patients diagnosed with non-curable or life threatening illnesses and their families.[2] It is a form of care that regards dying as a normal process and offers support to the patient and family to help them cope during the patient's illness through death and the bereavement period.[3,4] This approach of care focusses on improving the patient's quality of life by providing relief of symptoms during their last stages of life.[2]

End-of-life may refer to the last few days of life when a person is irreversibly dying (also known as the terminal phase); it may also refer to the final illness without a time frame. For the purpose of this study, end-of-life is considered to be the last 72 hours of the patients' life. Caring for patients at this stage of life has always been at the core of palliative care practice. Palliative care goals during this stage are to minimise suffering and distress for the patient and family in any care setting, i.e. home, hospital, hospice or care home.[5] It is important that these principles are based on best practice models for end-of-life care.

However, there are serious deficits in the field of palliative care in many countries, especially in the sub-Saharan Africa region, and the need for palliative care has increased due to increasing numbers of older people with incurable chronic disease or illness and multi-morbidity which includes the consequences of the HIV/AIDs pandemic. The growing ageing populations are prone to an increased incidence of disease affecting the elderly such as chronic respiratory, cardiac, cerebral degenerative disease and malignancy.[5]

These patients require palliative care in the form of symptom control and emotional support. It is of vital importance that in all care settings, patients in need of palliative care are identified early in their illness, properly assessed and that care planning or management arranged.[5] Further developments in palliative care should therefore be seen as a public health priority especially at district health level.[4, 5]

Supporting people nearing the end-of-life and their families is just as important as promoting good health throughout life[5]. The World Health Assembly Resolution (WHA 67.19, 2014) on Palliative Care acknowledges this as an ethical responsibility of health systems. Brennan and Gwyther *et al* (2009) found that access to palliative care has been identified as a human right, thus all patients are entitled to this form of care. [6,12] Being aware of and recognising the value of palliative care has become a pressing issue, together with political commitment to our health care system (South Africa) to develop a comprehensive palliative care service as an integral part of mainstream health and social care systems, and a better and systematic knowledge base for planning and delivering effective palliative care services.[5]

It has been noted that most patients with a progressive or terminal illness who are in need of end-of-life care are increasingly likely to be admitted to a hospital towards their end-of-life.[5] This puts a lot of pressure on Family Medicine or primary health care systems, as most of these patients are referred to the Department of Family Medicine for end-of-life care or palliative care,[5] after being diagnosed by other specialist units in the field of medicine (who saw their main function as diagnosis and attempt to cure) such as Internal Medicine or surgical departments within the health or medical system.

As reported by StatsSA, most deaths in South Africa were found to occur in hospitals; for example, according to the death statistics at Tshwane District Hospital where the researcher is employed, approximately 65 patients die per month (approximately two deaths daily) as most patients tend to be admitted to hospital during their final year of life.[8,56] As clinicians in a specialised discipline, Family Medicine registrars are expected to exit their training with competencies in palliative medicine. This is unit standard 3 according to family medicine unit standards.[9] The question is whether we (especially family physicians or doctors working in Family Medicine departments or district health hospitals) are skilled enough to provide this form of care to patients and their families, even though providing palliative care is one of the outcomes for family medicine postgraduate training in South Africa.

It has been noted and observed by the researcher (through her 10-years' experience working as a family physician in the Tshwane District Hospital) that some doctors and other health care alliances working in the Family Medicine Department do not seem confident or competent enough to deal with or manage the situation or render this form of care. In order to scientifically substantiate this observation, it is practical to assess and evaluate the quality of end-of-life care rendered by health care workers and their alliances working in the Department of Family Medicine at Tshwane District Hospital.

Most published research indicates that high-quality end-of-life care results when healthcare professionals:

> "(1) Ensure desired physical comfort and emotional support.
>
> (2) Promote shared decision making.
>
> (3) Treat the dying person with respect.
>
> (4) Provide information and emotional support to family members.
>
> (5) Coordinate care across settings."[14]

Quality end-of-life care has been associated with six elements, including overall quality of life, physical wellbeing and functioning, psycho-social well-being and functioning, spiritual well-being, patient perception of care and family well-being and perceptions.[14] As found by Singer *et al* (1999) according to patient's perspectives, quality end-of-life care included receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving the burden on loved ones and strengthening the relationship with loved ones.[26]

Palliative care has also been recognised as an ethical obligation of health care providers and needs to be understood from both the patient and family perspective.[26] Patient and family satisfaction is also one of the vital measures of quality of care at end-of-life.[26]

End-of-life quality indicators consisted of four components:

"1) Structure (accessibility to end-of-life care services with healthcare workers who are skilled in providing it),

2) Process (which involves availability of resources, patient and family involvement in resources and how to access them),

3) Output (rates of service use and improvement of the patients' well-being), and

4) Outcome (What happened to the patient? Did they die at the place of their choice?)"[28]

If all health care professionals, especially those at district healthcare level, received training and gained adequate knowledge of palliative care, they would be better equipped to manage the symptoms of late-stage illness more effectively, and by knowing how to relieve physical and psychological symptoms, the distress of both patients and families faced with the end-of-life care needs would be eased.

1.2 **End-of-Life Care**

End-of-life is defined as terminal phase or that period of time when the patient progressively deteriorates on a daily basis due to a life-limiting illness/disease, especially when it comes to his or her strength, appetite and awareness.[1]

End-of-life care forms an important part of Palliative Care and is that form of management referring to the management of patients towards their last few days, weeks or months of life from the point where it is clear that the patient is in a progressive state of life decline.[3] Relieving suffering through early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems, and the implementation of a support system to help patients and their families to live as actively as possible until the patients' death, are the main goals and principles involved in rendering palliative care.[2,3]

Relief of suffering has been identified as one of the processes that contribute to helping the patient achieve a sense of completion of life. Palliative care regards dying as a normal process and offers support to help the patient and family cope during the patient's illness and helps the family during the bereavement period.[2,3]

Dying is a natural and inevitable part of life that very often is not accepted at some point when the role of medicine in curing the disease, saving or prolonging life could no longer be achieved. Help to usher in death in a compassionate, merciful way, respectful of personal

3

autonomy and dignity is every person's right.[10] Diagnosing death can at times become a problem, especially in a hospital setting where the medical practitioners' role is focused on curing the disease. At times, this can include invasive procedures, investigations and treatments which may be continued at the expense of the patient's comfort. Therefore, it is important that medical officers (working in district hospitals where most patients in need of end-of-life care are admitted) have the ability to recognise signs and symptoms or diagnose that the patient is dying, in order to best manage the patients' care. [10]

According to Landman, every individual's moral right and obligation has to be recognised at end-of-life such as being freed from any unnecessary suffering (adequate management of pain and other signs and symptoms at end-of-life or comfort care),[43] the current medication being assessed and non-essential medications to be discontinued, subcutaneous drugs given as needed and according to protocol for pain, agitation, respiratory tract secretions, nausea and vomiting), and to clearly document "not for cardiopulmonary resuscitation".[11] Withholding and withdrawing potentially life-prolonging treatment is an appropriate decision if the treatment is no longer beneficial. At the end-of-life, some treatments may be inappropriate because they do not improve the disease process or benefit the patient and are therefore futile or non-beneficial. It is appropriate to reduce non-beneficial treatment and burdensome healthcare interventions and to offer a choice of place of care, especially if requested by patient and family.[11]

Death is the final stage of every person's life and the experience is unique to each person and their family or close friends. It is important that the dying person's comfort and choices are respected, especially their preferred place of death (which is usually not the hospital), and that quality of life is maintained so as to support their individuality and contextual aspect of life. Family and friends may need to be taken care of after the patient's death, as family members may develop complicated grief due to the impact of loss on their daily lives, problems such as dealing with AIDS-related loss and grief and how it personally affects them, and possibly stigmatisation.[5]

Respecting patient's choices or including the patient in decision-making at end-of-life tends to improve the quality of care and results in fewer unwanted treatment decisions reported. It has also been found by Hudson *et al* (2012) that caring for a loved one at end-of-life can have positive and negative effects on bereavement experiences for the family or care-givers. However, by improving communication at time of death and having effective follow-up approaches post-death, some of these issues could be addressed.[5]

Although palliative care is usually discussed in the context of end-of-life care for cancer patients, it is also appropriate to apply it in the earlier stages of any incurable disease, both malignant and non-malignant.[2] It is a major undertaking for health systems worldwide to deliver appropriate palliative and end-of- life care as it has become an important health concern due to the large number of people it affects.[3,4]

The highest percentage of deaths (as recorded in the most recent South African statistics for this subject in 2014) occurred in the age group 60 - 64 years (7.4%), followed by age group 35 - 39 years which accounted for 7.0% of all deaths. Age groups 40 - 44, 50 - 54, 55 - 59 years and 70 - 74 years each represented about 6.9% of all deaths.[56] The highest proportion of these deaths (43.9%) occurred within a health institution (hospital) according to the *Mortality and Causes of Death in South Africa, 2015: Findings from Death Notification.*[56] The largest single cause of death (25.5%) is HIV/AIDS and its related infections. Other causes of death include other chronic related illnesses such as IHD, stroke, diabetes, COPD, hypertensive related illnesses or complications.[56] This places a huge burden on the South African health system and the country as a whole. It is important to identify any gaps in the quality of care provided to those patients and their families who are in need of it in order to make any necessary improvements.[56]

Wherever patients with progressive illness die, they are increasingly likely to be admitted to the hospital towards the end-of-life. This has been confirmed by Gysel *et al* (2011)[5] Both the World Health Organisation (WHO) and the Joint United Nations Programme on AIDS (UNAIDS) list palliative care "*as an essential activity for care and support as well as an essential component of a public health system for those affected by life-limiting illness*". The provision of palliative care is also considered crucial within the framework of integrated community and home-based care services. Palliative care services need to be integrated and balanced within other services of care such as Family Medicine, in order to address the needs of patients and their families.

In developing countries like South Africa, it has already been noted through research that patients who are diagnosed with malignant diseases and/or HIV/AIDS initially seek treatment or management when their disease is already advanced.[5] Palliative care may therefore be a major form of therapy that could be provided to manage the patient's symptoms, support the patient and family, address their psychological, cultural and existential distress, and serve as a preventative intervention.[5, 6]

Palliative care is defined as active management which is also continuous.[1, 2] It helps the families and patients that are faced with terminal illness to deal with the physical, emotional, psychosocial and spiritual distress associated with end-of-life issues.[1, 2, 3, 4,] As noted by Gwyther *et al* (2007),[4, 21] the end-of-life is a period of time mostly associated with serious and distressing symptoms which require skill and expertise to control, as well as emotional and spiritual support to promote physical comfort and allow dignity during death.

According to the African Palliative Care Association's (APCA) strategic plan developed in Cape Town in November 2002, patients in sub-Saharan Africa (SA included) who died of HIV/AIDS-related illnesses or cancer were in pain and suffered severe symptoms which were inadequately alleviated.[15] They also experienced psychosocial distress and the illness affected their experience of dignity throughout the course of illness till death.[15] It was also stated that palliative care is an essential component of the healthcare system in the face of HIV/AIDS and increased instances of cancer and should be available/rendered at all levels of care.[15] Gwyther *et al* (2008) also noted that as palliative care is affordable and cost effective, it echoes the definition of family medicine principles.[18]

In the past, end-of-life care was associated with hospices only, but lately it has been integrated into acute-care hospitals at district level. There is a need for good quality palliative practises within these settings as they form part of primary health care. The World Health Assembly Resolution 67.19 of 2014 advocated for the integration of palliative care into health worker training and education at all levels. The question is are we skilled enough as medical practitioners (especially family physicians or doctors working in family medicine departments at primary healthcare level and district health hospitals) to provide this form of care to the patients and their families?

Temel *et al (2010)* found that the integration of early palliative care into patient management can improve quality of life and decrease the patients' chances of becoming depressed.[59] They also found that these patients required less aggressive management and fewer unnecessary interventions during end-of-life care and had longer survival rates.[59] This seems to confirm the effectiveness of referring and integrating palliative management as soon as the patient is diagnosed with a life-limiting illness/disease.

1.3 District Health System, Family Medicine and Primary Health Care

The district health system in South Africa has been a vehicle adopted to deliver comprehensive primary healthcare services which a district hospital then forms part of.[10] The district hospital plays an integral, pivotal role in supporting primary health care on one hand and being a gateway to more specialised care on the other.[9] For many South Africans, particularly in rural areas, district hospitals are the only hospitals they will ever get admitted into.[10]

The district hospitals play a central role between primary health care clinics (PHCs), community health centres (CHCs), and regional and tertiary hospitals. They provide level one or generalist services to in- and out-patients who have been referred from PHCs or CHCs, or down-referred from the tertiary level hospitals. Ideally, the hospital may have between 30 and 200 beds for admissions (adult male, females and paediatric patients), a 24-hour emergency unit, an obstetric unit and an operating theatre. [10] The district hospital should ensure that patients are treated at the appropriate level of care and receive continuity of care.[10]

According to WHO's functional definition, district hospitals should provide diagnostic treatment care, counselling and rehabilitation services.[10] It is interesting to note that this definition was developed prior to Universal Health Coverage (UHC) being identified as one of the health objectives of the Sustainable Development Goals. The WHO states that UHC "means that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship".[2] In addition, the National Health Insurance White Paper released in December 2015 identified palliative care as an essential service in the primary care setting.[52] A further development was the approval in 2017 of the *National Policy Framework and Strategy for Palliative Care* which identifies the palliative care services required at each level of health care.[54]

According to the District Hospital Service Package for South Africa (2002), the following clinical disciplines may be provided at generalist level: family medicine and primary health care, medicine, obstetrics, psychiatry, eye care, surgery, paediatrics, geriatrics and rehabilitation.[10]

The above is the minimum that could be covered but some services are shaped by the needs of the catchment population being served and there are many factors that could influence the capacity of hospitals to render the above-mentioned full range of services.[10]

The hospital is supposed to provide patients with out-patient and in-patient management in all life stages in accordance with National Standard Treatment Guidelines at primary care and hospital level. This would include the provision of acute, chronic, palliative and rehabilitative care. Terminally ill patients are provided with sufficient analgesia to prevent pain, receive appropriate counselling and are assisted in making decisions regarding their choice of a place to die in a district level hospital. In a district level hospital, family members and caregivers are involved in the care of their loved ones whenever possible and a close working relationship exists with all disciplines for holistic and comprehensive patient management, with recourse to community resources such as old age homes, social development, home-based care groups and hospices.[12]

District hospitals are usually serviced by family physicians or the Department of Family Medicine which is supposed to be a community-based discipline providing a patient-centred clinical service. It is defined by the population being serviced and where the patient-physician relationship is central to the role of the family physician. According to the NHI, everyone will have access to an affordable, appropriate, efficient and quality health service, of which palliative care services are a critical part. [11]

1.4 Family Medicine

Family medicine is a speciality concerned with providing individual/personalised, continuous and comprehensive care to all age groups and genders, suffering from all diseases (affecting all parts of the body) from first patient contact to end-of-life care/terminal care, with special emphasis on the care of the family as a unit. It is based on knowledge of the patient in the context of the family and community and emphasises disease prevention and health promotion. It is a medical speciality which integrates the biological, clinical and behavioural sciences, and is provided by family physicians (qualified medical doctors who have specialised in family medicine), generalists (qualified medical doctors), clinical associates and family nurse practitioners.

"The family physician is a skilled clinician, who sees the patient as a member of a community and puts patient-physician relationship as a priority.[24] The family physician is committed to the person rather than a particular illness which is part of the Batho Pele principle (being patient-centred and respecting patient's choices and decisions)." [24]

According to Mash (2006), Family Medicine may be defined as that group of individuals connected to the patient in all spheres of life by choice and from whom a patient can expect a

measure of support in all forms (food, shelter and emotional nurturing).[24] The principles of family medicine, as defined by McWhinney (1997), state that the physician sees the patient as a person who is sick, and is therefore committed to the patient not the disease. He/she seeks to understand the context of the illness according to the patient's experiences, sees the patient as part of a wider community and tries to network using all available resources to support the patient.[24] There is a significant overlap between palliative medicine and family medicine as they both provide holistic care, place an emphasis on patient-family involvement, professional teamwork and the importance of communication.[21, 24]

Interdisciplinary care with good, functioning teams has been found to be effective, especially when treating patients with chronic disease, showing better clinical outcomes, higher patient satisfaction and enhanced delivery of care. This is evidenced by effective patient management changes, particularly for end-of-life care patients.[24]

According to the Patients' Rights Charter of May 2008, every patient has the right to participate in decision-making regarding health issues affecting his or her health, as well as access to affordable and effective palliative care if affected by incurable or life-threatening illnesses.[51]

Quality of Care

Quality of care in health systems refers to the extent to which the organisation meets its clients' needs and expectations. Data must be analysed to understand, assess and improve the quality of the service delivered to the patient and community so that their expectations and needs are met.[5, 6] This system needs and encourages an approach where we meet as a team from different disciplines within the heath system, ensuring that the quality of patient care is met. Continuous assessment is required in order to identify gaps between the actual service delivered and the expectations of the service so that the quality of the service rendered can be improved. Efficient

and effective provision quality end-of-life care to the community as a whole will have a positive impact on patient, family, community and staff.[5, 6]

The principles or dimensions of quality healthcare are to be "1) Effective; 2) Efficient; 3). Accessible; 4) Acceptable/patient-centred; 5) Equitable and; 6) Safe." [5]

This affirms that palliative care is an ethical responsibility of health systems, that every patient has a right to access effective, accessible, cost-effective and patient-centred care, to be positioned at primary-care level where all patients have access to it, and where patients' needs are met across all age groups.

Dying at a preferred place of care is recognised as one of the defining indicators of good quality or meaningful end-of-life care. Ineffective communication about patient and relatives' wishes at end-of-life, ineffective pain and symptom control, or patients and their family members and carers feeling unable to cope at home, results in patients dying in hospital which at times is not the preferred choice.[30] It is therefore important to identify the needs of patients and their families at end-of-life, and to coordinate services to meet their expectations and needs, therefore improving quality of care at end-of-life.[30]

The 67th World Health Assembly 2014 (Resolution 67.19) "has acknowledged and recognised that palliative care when indicated is fundamental in improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' needs to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received".[12]

The resolution states that palliative care contributes to the realisation of the right to the enjoyment of the highest attainable standard of health and well-being and acknowledges that palliative care is an "ethical responsibility of health systems and that it is an ethical duty of healthcare professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care ".[12]

The resolution also realises the urgent need for palliative care to be integrated across the continuum of care, especially at the primary care level, recognising that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care.[12]

Thus, the World Health Assembly and all member states of the United Nations recognise the importance of palliative care and have committed to integrating palliative care into country health systems.

1.6 Palliative Care in Primary Health Care

The Gold Standard Framework (GSF) aims to optimise primary palliative care provided by general practitioners for patients nearing the end of their lives.[16] It is more concerned with helping people who are at end-of-life to live well until death, irrespective of their diagnosis. This approach was introduced in the UK in 2001, and is centred on the needs of the patient and their families. Developed by Dr Keri Thomas, a GP with a special interest in palliative care, supported by multi-disciplinary reference group of specialists and generalists[16], encourages inter-professional team work and a multi-disciplinary approach to patient care.

The Gold Standard Framework refers to a comprehensive care programme that helps practitioners to identify patients who are in the last years of their life, assess their needs, symptoms and preferences, and to plan care to enable patients to live and die where they choose.[16] It has five goals that provide for patients with any terminal or life threatening illness such as the provision of consistent, high-quality care aligned with patients preferences, improved staff confidence and teamwork with more home-based care than hospital-based care, pre-planning and anticipation of needs.[16] The Gold Standard Framework characterises what ideal care might look like and describes the general processes that are required to achieve this.[16]

Due to its effectiveness in the primary care setting, the Gold Standard Framework has been endorsed nationally in the UK as a model of good practice in providing quality end-of-life care.[16] General Practitioner practices and community nursing teams are encouraged to implement the Gold Standard Framework through a stepwise approach to enhance communication, co-ordination, control of symptoms, continuity, continued learning, carer support and care of the dying.[15, 16]

Quality end-of-life care has been associated with six elements: overall quality of life, physical well-being and functioning, psychosocial well-being and functioning, spiritual well-being, patient perception of care and family well-being and perceptions. It has also been recognised as an ethical obligation of healthcare providers and needs to be understood by the patient and their family.[26] One of its main features is the need for better information about end-of-life care,

as it would be difficult to improve quality without any understanding of the current level. Although the study on patient perspectives of quality end-of-life care was undertaken in developed countries, and pain and symptom management was cited, inappropriate prolongation of dying was not mentioned. Instead, the study looked at achieving a sense of control, therefore relieving the burden on loved ones and strengthening relationships with them.[26]

Patient and family satisfaction is also one of the vital measures of quality of care at end-of-life. End-of-life quality indicators consisted of four components: structure (which is more about the accessibility of end-of-life care services provided by skilled healthcare workers), process (which involves the availability of resources, patient and family involvement regarding these resources and how to access them), output (rates of service use and improvement of the patients' well-being), outcome (what happened to the patient i.e. did they die at the place of their choice).[28] Factors considered significant for the delivery of high-quality end-of-life care in general practice or primary healthcare settings are: coordination and continuity care, communication with patients, the ability to meet preferences for places of care and death, and appropriate bereavement care.[27]

Gwyther *et al* (2004) concluded that if we can help with training and adequate teaching in palliative care for healthcare professionals, this could help to equip the healthcare system (especially district healthcare) to manage the symptoms of terminal illness effectively. By relieving physical and psychological symptoms, the distress of both patients and families faced with the terminal illness can be eased.[27]

1.7 Diagnosing a dying patient or patient in the final hours of life (last 72 hrs of life)

Crossroads Hospice and Palliative Care developed a guide for caregivers to better understand the emotional, physical and spiritual changes at end-of-life. The signs and symptoms usually observed are the following: confusion, coolness, sleepiness, incontinence, restlessness, congestion, decrease in urine output, a decrease in fluid and food intake, change in breathing patterns and commonly, an increase in temperature.[48] Within days or hours, the following signs may be noted: decreased blood pressure, weak pulse and irregular breathing, and within minutes, gasping and non-responsive.[47] According to this guideline, the signs and symptoms help the healthcare worker to understand end-of-life changes, and give an indication of the timeline; for example: months (loss of appetite, sleepy, withdrawal), weeks (confused, restless, weak, ill), days (change in breathing, weak pulse/BP), or minutes (gasping, non- responsive).[47]

During the final 72 hrs to 48 hrs of life there will be increase in body weakness, immobility, loss of appetite (losing interest in food as well as drinking fluids), difficulty in swallowing and drowsier. This is usually anticipated in an incurable or progressive illness but as it becomes sudden and very distressing it therefore means end of life or the final hours in life.[61] The diagnosis is important as to be able to control symptoms, avoid unnecessary interventions, review all drugs, maintain effective communication with patients, carers and family, ensure their support. [61]

Hospices as Providers of Palliative Care and End-of-Life Care.

Hospice is a style of care which aims to improve the lives of people who have an incurable illness, from the point they have been diagnosed as terminally ill and choose the care, to end-of-life, however long it may take.[50] Hospice care places a high value on dignity, respect, and the wishes of the person who is ill, and aims to look after their needs. It provides medical, emotional, social, psychological and spiritual support to the patient and their family and carers, and is therefore referred to as holistic care. This care extends into the bereavement period. Hospice care is provided mostly at the patient's home but can also be provided in a care home (in-patient), or as a day patient visiting the hospice. Hospice care is provided by a team of healthcare workers trained in controlling patients' symptoms such as pain and other distressing symptoms. The team includes doctors, nurses, social workers, physiotherapists, occupational therapists, counsellors and trained volunteers. Hospice care is not for dying patients but used

to control symptoms early in the patients' illness (e.g. patient admitted to a hospice then discharged home), or admitted to hospice as a relief for carers or family (respite care).[50] The family physician is seen as the primary caregiver and is usually the one who will identify that the patient is in need of palliative care. This includes recommending hospice care when appropriate.[51]

1.8 NICE (2004) Guidance on Supportive and Palliative Care for Adults with Cancer.

The National Institute for Health and Care Excellence (NICE) in the UK developed guidelines that define the service model required in order to ensure that cancer patients and their families or carers receive information, are well cared for and supported to help them cope with the disease.[44] It applies to dying people aged 18 or over, and covers the recognition of dying, communication, shared decision making and symptom management. Being aware and recognising the value of palliative care has become a pressing issue, together with political commitment to developing comprehensive palliative care as a service as an integral part of mainstream health and social care systems, and a better and systematic knowledge base for planning and delivering effective palliative care services.[44]

The key recommendations are: patient involvement, good communication (patient to be involved in decision making); information to be freely available and given to the patient and family; support offered in all aspects of life (physical, social, emotional and spiritual support); and patients and family or carers' needs to be met.[44]

1.9 After-death audit (ADA)

The ADA is a tool developed in the UK and used as a measure for improving care for people nearing end-of-life and has not been validated or used in South Africa. As it has been noted that end-of-life care is an international priority and also a difficult area to measure to assess progress, a tool had to be developed.[16] This tool has been recommended in the National End-of-life Care Strategy for use in primary care by the Royal College of General Practitioners.[16] The ADA is a web-based audit tool used to review end-of-life care services provided to the deceased patient, and an improvement tool based on the Gold Standard Framework. It provides a snapshot of the quality of care and allows for comparison over time, helps assess current quality and identifies gaps or areas for improvement.[16]

The use of the ADA tool would help local and national hospitals and departments of family medicine in South Africa to review their end-of-life care, make any necessary changes, help future patients in need of end-of-life care, and identify gaps in service provision; all of which should show improvement once the above have been addressed.

1.10 Bereavement

Bereavement care (supporting relatives after the patient's life has ended) has been described in published literature and research as a vital part of good-quality end-of-life care or the core function of palliative care. Ensuring that family caregivers are assessed after losing their loved one is one of the top ten quality markers for end-of-life care. Guidelines for the psychosocial and bereavement support of family members/caregivers of palliative care patients have been developed and approved for use.[37]

1.11 Record keeping

Good record keeping has been identified and proven to be one of the most important tools used in quality assessments. Records usually highlight the care provided and act as a form of communication between the healthcare providers, therefore helping to coordinate services or patient management.[45] Records generate data for research and act as source for data, quality measurement and management, therefore helping to improve the quality of healthcare. In the study by Bergen-Jackson *et al* it was confirmed that documentation is a key factor in supporting the consistency and quality of patient care, especially in a setting such as hospice.[45] Electronic record keeping has been found to be enormously beneficial,, not only in patient care but also for secondary analysis, and when linked with other health and social care datasets, for outcomes measurement, quality improvement, public health surveillance and research. Electronic records are also more accurate,[58] reducing the complications of lost paper records, the reading and translation of physicians' illegible handwriting and difficult-to-access records.[58]

RATIONALE FOR THE STUDY

Palliative care is an approach of care that improves the quality of life of patients and their families who are facing problems associated with life-threatening illnesses or life-limiting diseases.[4] According to the WHO fact sheet of July 2015, approximately 40 million people require palliative care annually, of which 78% live in low- and middle-income countries. Only 14% of those who need palliative care worldwide receive it.[5] The global need for palliative care continues to rise due to the burden of HIV/AIDS, cancer, and non- communicable disease. Due to an aging population, the incidence of cancer has increased.[5,35,36]

Although end-of-life care has been identified as an important aspect of quality of care, there are still methodological problems on how to measure it, therefore more research is necessary. There are no approved tools in South Africa that measure the quality of end-of-life care therefore researchers in this field have to use the tools approved in the UK such as GSF and Liverpool Care Pathway in part as audit tools.[16] These help to benchmark quality improvement and was also used in this research.

Best practice in end-of-life care focuses on supporting both patient and family, attending not only to the physical but also the psychosocial and spiritual concerns through to the bereavement period. It requires a very good communication and teamwork from healthcare workers.[3,5,41]

Many patients in need of end-of-life care are likely to be admitted to an acute care or district level hospital to die, and they are less likely to receive appropriate pain control and more likely to receive burdensome interventions.[26] Diagnosing an approaching death is an important clinical skill, and it has been noted that too many patients die an undignified death with uncontrolled symptoms. Empowering the generic healthcare worker to care for the dying by ensuring all relevant healthcare professionals, especially primary level workers, are adequately trained, could be pivotal.[39]

Identifying patients who are at end-of-life and in need of palliative care is a challenge for clinicians working in acute hospital settings.

The rationale of this study was to evaluate the quality of care rendered to patients in need of end-of-life care services who were admitted to a district level hospital.

This research addresses palliative care needs in the primary or district health care system (which is defined as accessible, acceptable, affordable, and with the patient's full participation) as this is the gateway to the healthcare system. It also motivates for the integration of quality palliative care training to improve the skills and care within our healthcare system.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

The literature search was undertaken by searching databases such as PubMed and Medline platforms on the University of Pretoria Medical Library website. Google Scholar and chapters in books were also manually searched. The main words entered into the search engines included: end-of-life, quality end-of-life care, assessment of end-of-life, palliative care, district hospital, primary healthcare and at times, these phrases were combined as a search strategy. The databases used or information got from the journals between the years 2012 to 2018. The oldest paper from The Hospice Journal. 1995;10(2):65-83 because it agreed with late access of dying patients to the healthcare system due to lack of primary cares and latest being (2016). Journal of Family Medicine and Primary Care. 5(2):234-237 as it also found that primary care doctors should be in a position to provide palliative care as they are at the gateway of medical system.

2.2 Hospital palliative care

End-of-life care needs amongst patients admitted in general or district hospitals

Van Niekerk and Raubenheimer (2014) reported an increase in the need for end-of-life care services in our public hospitals.[30] They found that patients with advanced organ failure or life-threatening illnesses found to be in need of end-of-life care services tend to be admitted to acute care or district level hospitals for management. The study, undertaken in the Western Cape, confirmed an increase in the prevalence of palliative care needs amongst patients occupying acute care beds (admitted to a general hospital). However, further research of other South African provinces is necessary to confirm the above as the study was only carried out in one metropole. The study concentrated on the prevalence of patients with life-limiting illnesses who occupied acute in-patient beds or were admitted to hospital. The patients were in need of end-of-life care services as based on the identification tool used (GSF). This made the research relevant to this dissertation. The cross-sectional study looked at patients' notes but did not include the study of the families' perception of care. It was noted that this tool is not yet recognised in South Africa.[30]

Jang and Lazenby (2013) confirmed an increased need for end-of-life care services within the hospital environment in sub-Saharan Africa and Africa. Their study showed an increased availability or distribution of opioids that were best accessed at in-patient level, hence the higher usage reported at hospital level than on an outpatient basis.[33] This supports an increased need for end-of-life care within the hospital environment, although the study does not specifically mention South Africa but was done in sub-Saharan Africa.

In a study undertaken in the United Kingdom, Reyniers *et al* (2014) found that the majority of patient's hospital admissions at end-of-life could be clinically justified due to the patient's preferences or their families' inability to care for their loved one due to acute medical situations or emergencies occurring at home.[33]This resulted in an increase in number of admissions of patients who are in need of end-of-life care to acute hospitals or primary level hospitals. The study looked at the perceptions of the family physicians and nurses of patients who are at end-of-life and required hospital admission.[33]

Within the same study, Reyniers *et al* (2014) also found end-of-life hospital admissions to be associated with poor quality of life and burdensome for both the patient and their relatives. The family physician has a limited ability to prevent end-of-life admissions, which at times may be inappropriate and is patient/family dependant.[33] Most patients tend to be admitted to hospital at end-of-life, requiring specialised services in palliative care, but due to the shortage of these services, are more often than not treated in general hospital wards. This confirms that general hospitals do play a major role in end-of-life care.[33]

Over the past years, dying has become increasingly institutionalised. In the early 1900's, most people died at home, but by the middle of the 20th century, the majority of deaths in industrialised nations occurred in healthcare institutions, even though the preferred choice would have been to die at home.[17, 30]

Nursing homes and hospitals have increasingly become the site of death, yet no national studies have examined the adequacy or quality of end-of-life care in institutional settings compared with deaths at home in South Africa.[29]

Burt *et al* (2006) and Arnold *et al* (2013) noted that hospital deaths are usually predictable, yet rarely effectively managed.[14,30] In developed countries, it has been found that only 10% die unexpectedly, but that most deaths occur from chronic or progressive diseases and after a period of illness.[14]

According to Burt *et al* (2006), hospitals are not the most preferred place of care or death at end-of-life for patients with a progressive illness, but death usually takes place in hospitals (especially district or community hospitals that are managed by family medicine doctors.)[14] The above views were shared by patients' families and many doctors and nurses in the same study.[14] Their views may have been influenced by the fact that in-hospital care for people at the end-of-life has been criticised over many years, in many case reports and in descriptive and evaluative studies.[14] Studies have demonstrated a considerable unmet need for symptom control, psychological and social support, and communication amongst patients and their families.

DesRosiers *et al* (2013), in their study of patients with advanced organ failure being treated on an out-patient basis in urban South Africa, found that out-patient palliative care services reduce in-patient admissions, increases home death rates and is cost effective. In the study, the patient and the family were informed of the diagnosis, made aware of the prognosis and were part of the decision making and any intervention.[32]

2.3 Training in Palliative Care

A study conducted by Oneschuk *et al* (2000) acknowledged that practicing physicians were uneasy about caring for terminally ill patients due to limited exposure to palliative care during medical school years.[20] Gwyther *et al* (2007) confirmed that it is essential to enhance the skills and knowledge of previously-qualified healthcare professionals in palliative care even if the programme is developed for undergraduates.[21] This would greatly impact the quality of patient care, especially at primary health care level as this is where most patients are first seen.

Ramanayake *et al* (2016) found that family physicians (often the clinician or healthcare worker closest to the patient or community and thus easily accessible) have been perceived as having a major role to play in providing palliative or end-of-life care but felt uncomfortable when confronted with dying patients because they felt that their palliative care knowledge was poor.[40]

According to a study of the role of the family physician in palliative care,[40] conducted by the Department of Family Medicine at the University of Kelaniya in Sri Lanka, patients were quite satisfied with the care provided by their family physician as they communicated more information about the disease so the patient felt involved.[40] The consensus was that the broad knowledge and long-standing relationship of the family physician with patients and their families, the ability to carry out home visits, and communicate and co-ordinate with other

healthcare resources place the family physician in an ideal position to address the complex issues experienced by patients.[40] The study suggested that in order to develop palliative care models, doctors would benefit from improving their skills by learning sound palliative care principles in order to meet the increased need for palliative care.[40] This could be compared to the South African family physician that is person-centred and relational (ensuring that the relationship and care of the patient includes good communication, effective collaboration, patient participation, trust and confidentiality).[60]

2.4 The role of the General Practitioner

Burt *et al* (2006) agreed in his study that general practitioners deliver the majority of palliative care to patients in their last year of life but expressed discomfort about their competence in performing it adequately as they tend to omit symptoms which are not treatable by them or common to their practice.[14] Patients and their relatives appreciate being managed by a general practitioner who is accessible, takes the time to listen, allows the patient and carer to vent their feelings and is seen to be making an effort to relieve symptons.[14] It was encouraging that most responding general practitioners saw palliative care as a central part of their role.[14,19,21,22] However, the uncertainties expressed by some general practitioners about their palliative care skills and expertise set an important challenge to change their assumptions about their future responsibilities.[22] Traditionally, in the national health system in the United Kingdom, general practitioners have retained a pivotal position in palliative care for three key reasons:

- "Firstly, they are the initial point of contact for all patients and frequently gatekeepers to further services.
- Secondly, general practitioners often play a key role in issues of continuity affecting patients and families; especially where there are other co-morbidities.
- Finally, general practitioners usually hold responsibility for their patients' prescribing.[14]This also occurs in South Africa, where the role of a family physician or general practitioner is often the first medical practitioner that the patient consults and becomes the point of contact for every patient's entry into the healthcare system.

General practitioners increasingly encounter patients who require palliative care.[21] Medical developments, an ageing population and a primary care-oriented government policy all contribute to the growing need for palliative care in primary practice.[14,21,22] General practitioners value the care provision highly; "some even describe it as the epitome of their work."[21]

Pivodic *et al* (2016) in the United Kingdom confirmed that the general practitioner (known in South Africa as a medical officer or primary care physician usually employed in district level hospitals) is perceived to be central to palliative care but often has limited training and experience in the field.[39]The study also suggested that medical officers had limited skills and confidence in managing pain and other symptoms, and that their knowledge of end-of-life care, the availability of specialist home-care services and out-of-hours district nursing homes can be improved.[39] Although this study concentrated mostly on out-of-hospital care, it also looked at non-specialist doctors as well as general practitioners who are the primary carers of patients in need of end-of-life care i.e. medical officers. The study also took into consideration bereaved relative's perceptions and perspectives to assist with comparing the findings. This study may also explain the increase in the number of patients in need of end-of-life care services who are admitted to hospital, rather than being managed on an out-patient basis.

2.5 Assessment of end-of-life care/diagnosing dying

Acquiring the skill of recognising that the person is at end-of-life can improve the patient and their families' experience of death, and increases the job satisfaction of the involved healthcare worker.[27] This is an important clinical skill that develops over time. A key aim of specialist palliative care is to empower generic healthcare workers to take care of dying patients. Clinical signs (such as reduced level of consciousness, respiratory changes and cardiovascular changes) are common and therefore, there is a need for care workers to recognise these signs earlier so that family/patient can express their preferences for end-of-life care. This is vital if palliative care is to be practised properly.[34]

Joan *et al* (2004) confirmed that research studies indicated that high-quality end-of-life care resulted when healthcare professionals ensured good physical comfort and emotional support, promoted shared decision making, treated the dying person with respect, provided information and emotional support to family members and coordinated care across all settings.[28]

In the UK, end-of-life care forms an important part of primary care, where general practitioners and district nurses deliver the bulk of care and form part of an important network for referral to specialist services.[28] It has been noted that these practitioners face significant challenges due to limited or no training in end-of-life care, and have few opportunities to extend their skills due to competing priorities and barriers to inter-professional working.[21,28]

2.6 The Gold Standard Framework

Within the end-of-life environment, the Gold Standard Framework (GSF) has been an important resource for organising end-of-life care services.[16] Recurrent evaluation of the use of GSF within primary care shows evidence that GSF is an effective programme, facilitating the introduction and consistent improvement of practice-based processes and organisational structures to support end-of-life care.[16] Practises participating in evaluating GSF also reported improvements in the quality of the care delivered to patients and their carers.[16,17]

According to the review paper written by Shawn *et Al* (2010), the Gold Standard Framework has considerable potential to improve end-of-life care, but further work needs to be done to support the uptake and consistency of its implementation.[13] Recent data has shown that most practices in England fulfil enough of the GSF criteria to claim quality and outcomes framework points for palliative care.[13] According to the review paper, GSF has made a significant contribution to end-of-life care and has not only helped to shape the current UK approach to best practice in primary care, but has also improved the quality of care for patients in need of end-of-life care at district level hospitals.[13]

The following are the key tasks and evidence required from primary care physicians caring for end-of-life patients, as described within the Gold Standard Framework.[13]: "Communication (C1): to monitor patient care such as identification of the patient as having end-of -life-care needs. This should be a multi-disciplinary decision; coordination (C2): to have a nominated coordinator for patient care; control of symptoms (C3): patient's symptoms (physical, psychological, social, practical and spiritual) and concerns are assessed and managed accordingly; continuity (including advance care planning) (C4): following protocols to ensure continuity of care delivered by inter-professional teams and out-of-hours care; continued learning (C5): for health care providers to meet the patients' or individuals' identified learning needs, and have meetings to reflect on past patient care to improve quality, carer support (C6):

providing care and support for families (bereavement support and support for staff and; care of the dying (C7) : appropriate end-of-life care protocol to be implemented in order to prevent non-essential interventions, consider comfort measures (psychological, religious or spiritual), bereavement planning, communication and care after death".[13]

After identifying the patient in need of end-of-life care, the GSF process assesses their needs, symptoms, preferences and issues important to them, in order for care to be planned accordingly.[17]

The primary goal of GSF is to provide high-quality care for people in the final months of life by: "Ensuring that their symptoms are controlled, enabling patients to live and die at a place of their choice, encouraging security and support by better and advance care planning involving both patient and family, empowering carers through increased communication, listening and addressing issues proactively, educating - thus developing increased competence and confidence of staff".[17]

There are three programmes of work within the GSF.

These are the Primary Care Programme, the GSF for Care Homes Programme and the GSF End-of-Life Support Programme.

There are seven tasks within the primary care programme:

"Level 1: Communication and coordination of care. (C1, C2)

Level 2: Control of symptoms and assessment, continuity of care with out-of-hours providers

and continued learning and reflective care in the dying phase. (C3, C4, C5)

Level 3: Carer support and care in the dying phase. (C6, C7)

Level 4: Sustainability of improvements made in end-of-life care through implementation of GSF."[17]

The principles of palliative care services include the following:

"Holistic care: Services should be viewed holistically, with physical, emotional, spiritual, and social aspects equally weighted.

Interdisciplinary: Services should be provided by interdisciplinary teams to address the diversity of needs.

Family Centred: The unit of care is the family, as defined by the client or patient, and includes adults, children, and family caregivers.

Dignity and Respect: All services should be provided with respect for the individual's wishes and culture, and with dignity.

Continuum of Care: Comprehensive and linked care, treatment and support services should be provided at all levels, from health facility to community to home. Services should be provided by a combination of providers from various sectors: government, non-governmental, community- and faith-based, people living with HIV (PLHIV), and family members."[1,2]

According to the National Health Plan for South Africa; prepared by the ANC with the technical support of WHO and UNICEF in May 1994: "Relief of chronic pain and care of people with terminal illness or life threatening disease forms an important component of healthcare that has been seriously neglected in South Africa." Although some cancers are curable, most are not. 80% of people with advanced cancer suffer from pain, with or without other major symptoms. Cancers are becoming more common and are now the fourth most common cause of death. AIDS is another incurable disease which is increasing significantly.

If South Africa is to become a more caring society, people with these diseases must receive high-quality care, including active and effective management of pain and other symptoms and this has to be easily accessible, affordable and effective.[10]

SPICT (Supportive and Palliative Care Indicators Tool), (April 2017), is a tool used by healthcare workers to identify people whose health is deteriorating, assess them for unmet palliative care needs and plan for their care. The indicators include unplanned hospitalisation, poor performance and persistent symptoms despite optimal treatment. The healthcare workers, in consultation with the patient's family, can then review, coordinate and plan patient management.[47]

AIM AND OBJECTIVES

AIM:

The aim of this study was to evaluate the quality of care rendered to patients in need of end-of-life care admitted to Tshwane District Hospital, Pretoria Central, Gauteng, South Africa.

OBJECTIVES:

1. To conduct a record review as an after-death audit assessing documented care provided to patients who died whilst admitted to the hospital.

2. To interview bereaved family members about their perception of the quality of care rendered to their relative during his/her last days in hospital.

3. To assess whether the patient at end-of-life (the last 72 hours of life) was recognised as such.

Research Question

Can an audit of quality of care be used to improve the care of people in the last 72 hours of life in district level hospitals in South Africa?

CHAPTER THREE: METHODOLOGY

Study design:

The study was a combined retrospective review of the patient's folder and a cross-sectional, descriptive, qualitative study through interviewing bereaved family members.

Study site or setting:

The study was conducted at Tshwane District Hospital in Central Pretoria, Gauteng Province, South Africa.

Study population:

The targeted population were the deceased patient's records and interviews with bereaved family members.

Sample size:

The sample size required for the study was 96 files and participants. This was based on an expected outcome of 50% with a precision rate of 10% worked around a 95% confidence interval. With the help of a statistician, the margin for error and bias that we could tolerate for this study was considered and the above method was decided upon. The qualitative sample size was estimated to be approximately 14-20 participants or until data saturation was reached.

Sampling method:

A simple random sampling method was used as it allowed the records of all adult patients who died whilst admitted to adult medical wards during the period January 2012 to June 2012 an equal chance to be chosen and included in the research. In the deceased record office, 96 files were randomly selected. An in –depth interview was recommended and used instead of Focus group discussion as it seemed as appropriate i.e. we were dealing with emotional topic and respondent is key to the outcomes generated from each interview.

1. **For patient's files:**

   Records of adult patients who died whilst admitted to general medical wards at Tshwane District Hospital between January 2012 and June 2012 were randomly sampled from the record-keeping office for use in this research.

2. **For Relatives:**

   Adult next-of-kin of the patients whose records were randomly sampled were contacted telephonically and informed of the research. They were asked if they were willing to participate in this study, and those who had functioning telephones and consented to participate were part of the research. (Convenience sampling method was used).

Selection criteria:

Inclusion/exclusion and the process involved in selection:

1. Folder/Record:

   Files of adult patients who died whilst admitted to the hospital between the months of January to June 2012.

2. Adult relatives of selected deceased patients' records. There were no children involved in the study (either as next-of-kin or participants); only files of adult patients were audited. The participants had to be least six months' post-bereavement before partaking in the interview.

Research assistant recruitment:

The researcher recruited a research assistant and trained her in research ethics and research study protocol. The research assistant is a qualified social worker who was informed of the project and voluntarily agreed to be an assistant. She also agreed to interview the bereaved patient's relatives about their perceptions and perspectives on the quality of care their relatives received whilst in hospital during their last days. No financial reimbursement was promised, but she is recognised as a partner in this research project as part of hospital-patient quality improvement.

Pilot study:

A pilot study was conducted using three files in order to establish the feasibility of the questionnaire. These files were not used as part of this research. The pilot was conducted by the research assistant in a district hospital in a different province. The bereaved family member interview was not piloted as it was considered as a flexible interview guide.

Ethical considerations:

Before the commencement of the study, ethical clearance was obtained from the Human Research Committee of the University of Cape Town (see attached letter of approval - **HREC REF: 584/2012**). Permission was granted by the Department of Health Gauteng District (see attached letter of approval). As the researcher considered the vulnerability of the participants, the in-depth interviews were carried out six months after bereavement. This time period proved to be fruitful as relatives could still recall details, and voluntary consent was given.[48] Those who were still not emotionally stable were afforded post-bereavement counselling within the Family Medicine Department at the University of Pretoria, by the interviewer who is a qualified social worker. The post-bereavement needs of the family were discussed for follow-up services and involved the district hospital as part of a patient care quality improvement study.

Data collection tool:

1. After-death audit Tool:

The researcher used an exploratory form of questionnaire that was developed using the GSF (Gold Standard Framework) as part of an after-death audit of the randomly selected files. This tool was developed in the United Kingdom and has not been validated in South African population, but after discussion with the supervisor and colleagues, it was agreed that the tool is relevant to the South African setting and appropriate for this research study. The after death audit tool explored the ability of health workers at district level hospitals (primary healthcare setting) to identify patients who are at end-of-life (terminally ill) by recording end-of-life signs and symptoms, and the interventions carried out during the last 72 hours of the patients' life.

2. **Interview guide for relatives**:

The researcher developed the interview guide for the bereaved relatives using family medicine principles of patient care/management. The questionnaire investigated the relative's perceptions and perspectives about the quality of care (management) rendered to their relatives whilst admitted to Tshwane District Hospital during their last days. It focused on whether: 1) the patient was provided with the desired physical comfort and emotional support, 2) The patient was supported in shared decision making, 3) the dying person was treated with respect, 4) the families' emotional needs were attended to and 5) the care of the patient was well co-ordinated. The researcher used one-on-one, in-depth interviews instead of a group discussion, as the bereaved family members are regarded as vulnerable people, and death and illness can sometimes be a sensitive topic.

Stroebe *et al* (2003) found that although this form of interview was time consuming and many bereaved relatives often declined to take part in such studies, certain designs, methodologies and ethical concerns should be considered, especially the fact that bereaved people may be in a state of acute grief during the time of study, and therefore bias selection and a limit on generalization should be taken into account.[57]

Data collection:

Data was collected by the researcher and her assistant using the developed and approved standardised questionnaire from the randomly selected patient files.

Qualitative interviews were then conducted with the consenting bereaved family members of those patients who were admitted and died at Tshwane District Hospital between January and June 2012. The interviews were conducted by the social worker (assistant researcher) in a language that the patients were comfortable with (assistant is multilingual).

Data collection process:

1. Audit of files:

The researcher audited the randomly selected files of adult patients who died whilst admitted to Tshwane District Hospital (in medical wards which included adult male and

female patients) between January 2012 and June 2012. The researcher reviewed the healthcare professionals' notes (doctor's, nursing care and allied healthcare team members within the ward who were involved in patient's management) to evaluate the care given to the patient and to determine if the quality of care was optimised or below the level that a district hospital (as defined in the introduction/background) is supposed to render. All management or interventions undertaken during the patients' last 72 hours at the district hospital were recorded on the developed audit form. Only the interventions or data recorded in the patients file was taken as performed. Missing records or unrecorded information was not included in the file audit.

Recruitment of Participants and Interview of Relatives of the Deceased:

After randomly selecting patient's records, the researcher contacted the relatives of the deceased telephonically and invited them to attend an interview to discuss the care of the deceased. Those who accepted the invitation were informed of the research aim and process, were encouraged to ask questions about the research and requested to complete an informed consent form. The participants were informed of their right to withdraw from the study at any time. Participants who consented to participate in the research project were offered reimbursement of travelling costs if any were incurred during the project. If the potential participants indicated that they were not ready to take part in research for emotional reasons, bereavement counselling was offered if needed. Some of the relatives could not be reached due to malfunctioning phone numbers recorded on the audited files, some refused due to their emotional state and were offered post-bereavement counselling. There were 17 relatives of deceased patients who came to the study site to hear about the research and 16 agreed to partake in the project after being fully informed.

Data Collection

The consenting relatives were interviewed by a qualified social worker (trained research assistant) using the interview guide. Participants were asked about their perceptions of the quality of care received by or offered to their relatives at end-of-life, as well as their own experience of care as the family of the deceased during that time (last days in hospital). The interview was audio-taped for quality data collection purposes with the consent of the participants. The research assistant then transcribed the audio-recordings of the interviews from the language of the participant into English for research purposes.

Data storage and confidentiality

All files were randomly coded from 101 to 196 for anonymity and privacy, and no private or personal details were used. The records and data collected are kept for three years in a locked cabinet in a private record office within the hospital. The audio recordings are kept for five years, also locked in a private office, for future use by the research team.

Data analysis

The data was examined by the researcher with the help of a bio-statistician from the University of Pretoria, and analysed the age and race of the patients admitted, the disease patients were admitted with and died from, duration of stay in hospital after admission, diagnosis of death signs and symptoms, and the interventions carried out. The data was collected using Excel 2003. This was exported into Stata 14 for statistical analysis. The analysis undertaken was initially a descriptive summary of statistics presenting frequencies of the characteristics of the samples. This was followed with presentation of proportions, standard errors and associated 95% confidence interval for the characteristics that are in categories (death notification clarity) while Means, standard deviations as well as the 95% confidence intervals were presented for continuous measurements (Age and duration). Proportions were compared between racial groups where necessary.

This was followed with presentation of proportions, standard errors and associated 95% confidence interval for the characteristics that are in categories (death notification clarity) while Means, standard deviations as well as the 95% confidence intervals were presented for continuous measurements (age and duration). Proportions were compared between racial groups where necessary.

Thematic analysis of qualitative data

For the qualitative analysis, the researcher used the transcripts and participant's responses to familiarise herself with the main issues in order to create codes for the data, develop and describe themes to represent the findings and interpret the data. After collecting the after-death audit transcripts from the deceased patient's records, she coded them deductively using the Gold Standard Framework as a theoretical framework for the study.

The researcher then identified relevant and specific themes of the study through the analysis of the transcripts of the interviews held with the bereaved family members. The data was organised, coded and categorised into themes using the manifest analysis according to Morse and Field (looking at issues and perceptions expressed by the bereaved relatives interviewed).

CHAPTER FOUR: RESULTS ANALYSIS

4.1 Introduction

This chapter is presented in two parts; first, the audit findings of patient files and secondly, the qualitative analysis of interviews with bereaved family members.

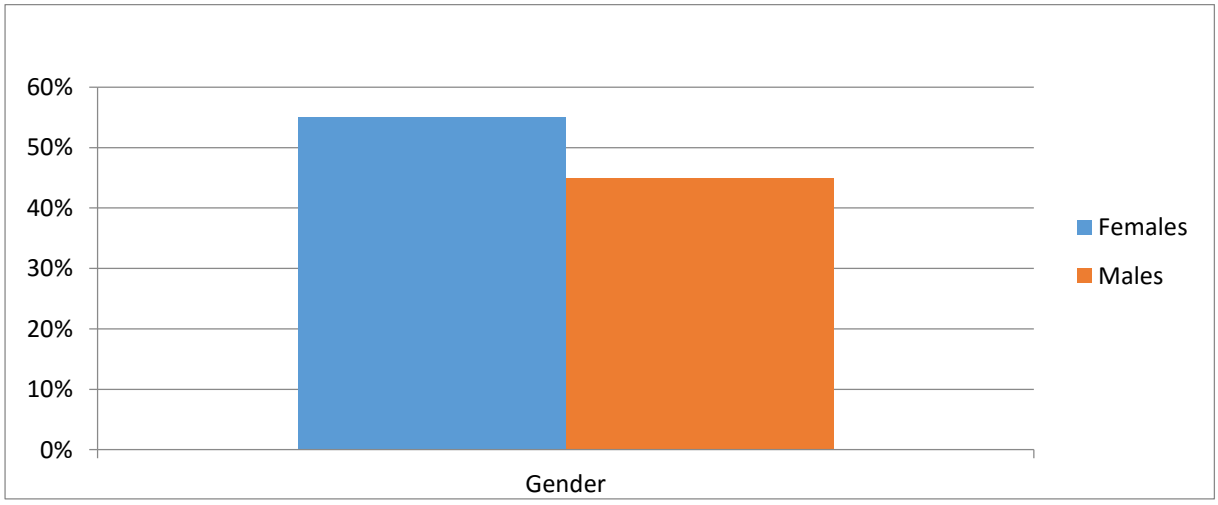
The audit was conducted on 96 files of deceased patients who were admitted to Tshwane District Hospital during the six-month period from January 2012 until June 2012. These files were randomly selected as described above and an after-death audit was conducted using the standardised spreadsheet developed by the researcher. Of the 96 files audited, there were no missing questionnaire forms, although the medical records were sometimes incomplete. Therefore, not all fields could be completed according to the spreadsheet.

4.2 Assessment of patient records

Demographics of patients admitted at Tshwane District Hospital at end-of-life.

4.2.1 Race and Age

Of the 96 audited patient files, the statistics showed that the age range of patients admitted was 21-101 years with p50 of 60.5. 61.5% of the audited patient records were of black patients, with 35.4% being white and 0.02 % being coloured. The p50 was 60.5, with mean of 60.8.



Graph 1: Females (55%) and Males (45%)

4.2.2 Place of referral

Of the 67.71% of the patients admitted, 55.21% came from home from an old age home (11.46%) or were homeless (1.04%).

Only14.58% were referred from a tertiary institution closer to the district hospital and the remainder were referred from the local clinic (9.38%) or general practitioner (7.29%).

4.2.3 Reason for admission/diagnosis on admission.

83% of patients were admitted due to a non-cancer diagnosis. The diagnoses included HIV (36%), CRF/renal disease (10%), cardiac disease (10%) and COPD (3%). Cancer accounted for 16.6% of total admissions during the period January 2012 to June 2012.

4.2.4 Diagnosis on death notification.

The statistics revealed at a 95 % confidence interval of between 0.28 to 0.47, that most patients died from LRTI-related causes (37.50%), followed by cancer-related causes at 13,54%, gastric diseases (13.5%), renal disease (11.45%), cardiac disease (9.38%), cerebrovascular disease (7.29%) and other neurological diseases at 7.29%.

4.2.5 Duration of stay in hospital

The record audits showed that older patients (usually 60.8 years of age) are admitted for a duration of 4.3 days. Younger patients are usually admitted for a lesser duration of days. This is also affected by race, with black patients (at a mean of 51.7 at p50) staying for a duration of 4.7 days), longer than for white patients (at a mean of 75.8 at p50) who stay for a duration of 3.8 days.

Variable	OBS	Mean	Std. Dev.	Min	Max
Age	96	60.27083	22.67411	21	101
DURATION	96	4.33333	4.141362	0	19

Table 1: *Summary of age/duration of hospital admission*

4.2.1 Quality of end-of-life care provided as per patient's records

Symptoms of end-of-life recorded.

According to the audited records, the most recorded symptom of end-of-life was confusion (18.75%). Approximately 6.25% of the patients were recorded to be confused, ill and weak, 20.83% of patients experienced shortness of breath and only 5.21% were recorded to be in pain. No comment can be made about the completeness of the records with regards to symptoms.

Signs of end-of-life recorded.

The end-of-life signs that were recorded on patient's files were low pulse, low BP, and gasping. 18.75% had all signs recorded and about 51.04% were recorded as gasping with frequency of 49%. No comment can be made about the completeness of the records with regards to signs of end-of-life.

Management of patients at end-of-life from patient's records

4.2.6 Interventions carried out at end-of-life

According to the audited patient's files at end-of-life, the interventions mostly carried out when patients were in need was oxygen by mask (54.17%) at a frequency of 52%. None of the patients' records documented the use of intravenous fluids or naso-gastric tubes.

4.2.6.*1* ***Team involvement (multi-disciplinary team involvement).***

According to the record review, some patients were referred for multi-disciplinary team management as part of quality care management, although about 70.83% of them were not referred at all. Only 29.2% showed an indication of team involvement.

4.2.6.2 ***Hospice referral***.

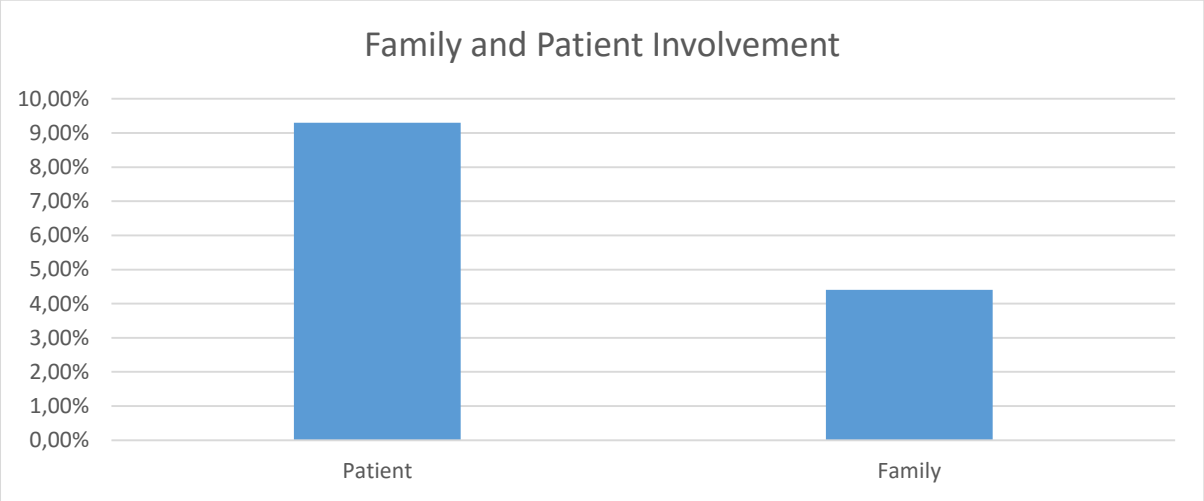
Only 8.3% of patients were referred for hospice management according to the record review with 95% confidence interval of 0.04 to 0.15 at a frequency of 8%.

4.2.6.3 ***Patient involvement***.

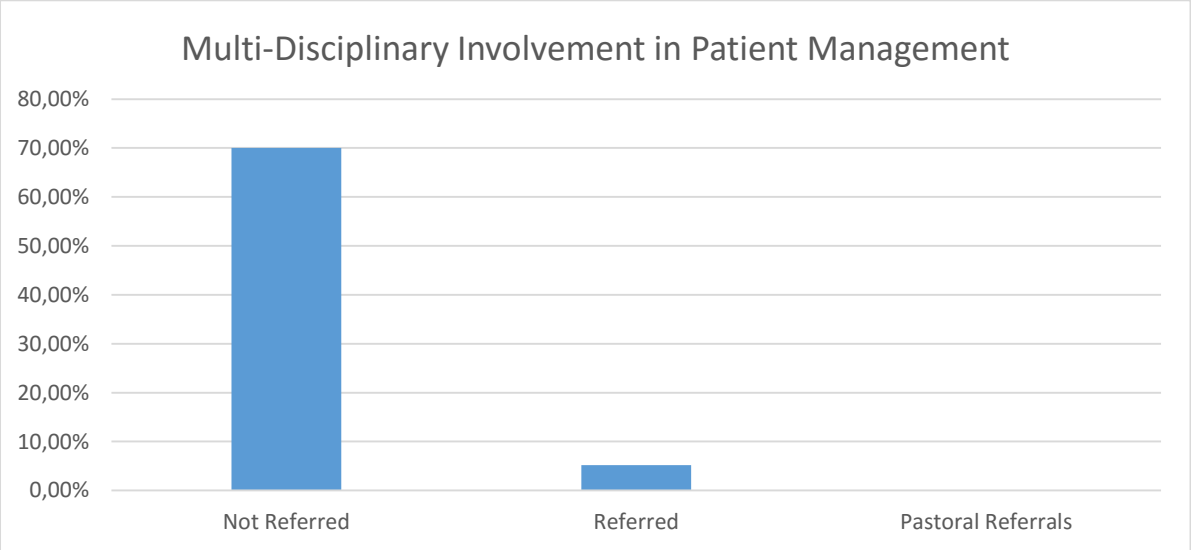
About 9.3% of patients were involved in their management according to the record review with 95% confidence interval of 0.04 to 0.17.

4.2.6.4 ***Family involvement.***

According to the record audit, only 4.4% of family were involved in patient management with 95% confidence interval of between 0.17 to 0.34



Plot 1: Patient and Family Involvement (see above)



Plot 2: Multi-disciplinary involvement in Patient Management

- 70.0% - not referred to any additional service or health care professional.

- 5.2% - referred to dietician, physiotherapy, occupational therapist or speech therapist.
- 0% - pastoral or religious referrals recorded.

4.3 Qualitative data analysis

4.3.1 In-depth interviews

Most of the relatives approached were eager to discuss their family member's illness and care and consented to be part of the study. There were 17 participants in this part of the study of which 16 agreed to participate. Table 2 provides a summary of the themes that emerged during analysis to guide the reporting of thematic analysis.

Table 2: Table of themes and sub-themes from relative's interview results analysis

THEME ONE	**THEME TWO**	**THEME THREE**	**THEME FOUR**
Communication and coordination of care (C1,C2)	**Services offered by the hospital at end-of-life (control of symptoms, continuity of care. (C3, C4, C5)**	**Quality of end-of-life care at district level hospital (carer support and care at dying phase) (C6,C7)**	**Hospice knowledge by family or relatives and referral (C7)**
1.1 Understanding of relatives problem through information (C1)	**2.1 Control of symptoms and interventions performed when relatives were in distress (C3)**	**3.1 Perception of family members care at end-of-life (C6)**	**4.1 Understanding and knowledge of hospice**
1.2 Enough information given (C1)	**2.2 Follow-ups if discharged, any referrals to other carers (C4)**	**3.2 Any bereavement support (C5)**	**4.2 Referral to hospice care (C1,C7)**
1.3 Referral to the multi-disciplinary team within the hospital such as social workers (C2)			

The themes identified during the interviews were as follows: understanding information; services, good quality, nurses and doctors which then was categorised as follows: understanding of their relative's problem, being informed by doctors and nurses or health care workers, good quality of care, services offered and therefore ended up being themed into communication with the family, quality of end-of-life care at district level hospitals, services offered by the hospital, hospice knowledge by the family or relatives according to the GSF levels in the primary care level. These themes were then used as the theoretical framework. [1]

THEME ONE

Communication and coordination of care

Participants reported that they were aware of or informed of their relative's problem and prognosis. They knew the diagnosis and the prognosis and a further management decision plan was taken with their involvement.

1.1 Understanding of their relative's problem through information.

Participants reported that they received useful information from the hospital staff.

"Yes we knew he was going to die and they were quite honest about the condition." (110)

"Nurses and Doctors gave information to understand more" (178)

1.2 Enough information provided.

Although some of the family members felt that too little information was given and they had to ask or probe for more information and understanding and other related services towards their relative's illness or prognosis, 58.8% of the interviewed family members felt they were given enough information by the attending doctors.

"Enough information was given by attending medical officer". (106)

"Not enough, no updates voluntary from doctors until asked". (102)

"No information was given as patient was taken in casualty to the ward for observation." (174)

"They gave us lacking information for better understanding." (196)

1.3 Referral to multi-disciplinary team.

All the family members interviewed felt that their relatives had not been offered any additional services or were referred to any other multi-disciplinary team members for further patient management. They would have appreciated referral or further information on what additional resources were available at that stage of the illness. With respect to coordination of care, about 76.5% of the interviewed relatives did not think there was good coordination of care, compared to 17.7% who thought that the care was well co-ordinated.

"No additional information about available services was given" (171
"No additional services as it was her last days." (177)

THEME TWO

Services offered by the hospital

2.1 Control of symptoms and interventions offered to relatives with distressing symptoms

According to the relatives interviewed, only about 17.7% of the patients did not experience any distressing symptoms, meaning that the rest were in distress and needed intervention. According to their relatives, patients were in pain (17.7%), experiencing catheter problems (5.88%), were tired (5.88%) or gasping (17.65%). About 23.5 % of the patients had symptoms, according to family perceptions or interviews.

"Was sleeping, then gasping had no idea was the last day, oxygen mask was given then doctors took it out and patient was taken out of the ward, put in isolation." (102)

2.2 Follow-ups if discharged, any referrals to other carers.

No patients were discharged or any recorded follow up notes on patient's files.

"no additional information given about available services" (171)

THEME THREE

Quality of end-of-life care at District Level Hospital

3.1 Perception of their family members care at end-of-life.

3.1.2: Bad perception.

Although some participants had a good experience at the hospital (see 1.1 & 1.2), other participants observed poor quality of end-of-life care as patients were placed in a side ward without much information, reasons for their isolation or explanations being provided to the family members, or updates given about their relatives' prognosis. According to family perceptions there is no care in the dying phase. About 81.3% experienced poor care as nothing was done at end-of-life for their loved ones

"No additional services were given as it was her last days." (177)

"Not good quality of care as only young people given preference, patient care to be done by family, family does hygiene to own patient, nurses oral care not done, not bath given." (102)

3.1.2: Good perception:

There were also those who felt that the patient had received good quality of care as they were kept up to date concerning their relative's progress, and attention was provided to them and their loved ones by the healthcare workers involved in the patient's management. About 64.7% of the family responded positively with respect to continuity of care, compared to 11.7% who felt otherwise.

76.4% of the participants also responded positively for the carer and 11.7% testified that care was provided in the dying phase.

"he was clean, food and water, lunch and supper, ward was clean." (106)

"Excellent every time I called information was given, I would call seven times." (175)

"Information was given by managing doctors and nurses" (188).

THEME FOUR

4.1 Hospice knowledge by the family or relatives

Many family members were not informed about hospice care. From the interviews, it seemed that patients were not referred to hospice for further management. The relatives interviewed indicated that they would have appreciated the services and information as they think it would have made the passing on of their relative and care of their relatives at end-of-life much easier and better.

> ***"I know nothing about hospice." (101)***
> ***"It is an old age home, I'm not sure, if more information was given it would have helped." (102)'***
> ***"It is a place where terminally ill are cared for but not for my father." (106)***

4.2 Referral to hospice care.

Some of the family members had an idea of what hospice services are and 50.0% of the interviewed relatives would have appreciated a referral to a hospice.

"I have knowledge of hospice care, it is where patients are given proper care and if proper referral and information was given; it would have helped my family to deal with our relatives care and we would have agreed." (171)

Summary of the qualitative results analysis:

Communication with family members was identified as an important issue, both with regards to how much information was shared and the understanding of that information, as it was often above their level of understanding. Additional support or referral to a multi-disciplinary team for further patient management was felt to be lacking. Families would have appreciated referral or further information about available additional services that could have been offered at that stage. A high proportion of participants observed poor quality of care shown toward their relatives as the patients were placed in isolation without much information,

reasons or explanations being provided to the family for this. However, many participants also observed good quality of care as they were kept up-to-date concerning their relative's progress, and attention was provided to them and their loved ones by the healthcare workers involved in the patients' management. About 50% of the participants knew about hospice and would have appreciated a referral as they think it would have made the passing on and care of their relatives at end-of-life much easier and better.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

The researcher assessed the quality of care rendered to patients in need of end-of-life care (last 72 hrs) who were admitted to the Tshwane District Level Hospital, Gauteng, South Africa, as recorded in patient files as well as per their relative's perceptions. This was done through retrospectively auditing the deceased patients' records and through qualitative interviews with bereaved relatives about their perceptions of the quality of care that family members received whilst admitted to the hospital.

5.2 Discussion

5.2.1 End-of-life care needs in South African District Hospitals

The after-death audit results revealed and confirmed an increase in number of younger and older people being admitted to an institution or hospital towards their end-of-life. The increase of patients who are admitted for end-of-life or palliative care are either above 60.5 years of age years with maximum age 101 years, or around 21 years of age. An increase in elderly patients with age-related, chronic, life-threatening diseases, cancers or malignancies (CVA CRF, COPD) was noted. Whilst the prevalence of HIV also influenced the increase of most patient admissions as per the record audit, the majority of patients had a cancer diagnosis. The research undertaken in Cape Town by Van Niekerk *et al* (2014) also confirmed that patients with advanced organ failure or life-threatening illnesses tended to be admitted to acute hospitals or district level hospitals for management and were in need of end-of-life care services.[30]

However, when extracting the cause of death, most patients died from lower respiratory tract infections (LRTI).

This was also supportive of prior studies done in sub-Saharan Africa which showed an increased need for end-of-life care due to the prevalence of age-related illnesses and HIV-related problems.[5, 28, 31] Gysels *et al* (2011) noted that **"**There is an increasing number of older people with incurable chronic disease or illnesses and multi-morbidity which includes consequences of the HIV/AIDs pandemic."[5]

The researcher also noted that patients who are close to end-of-life or have palliative care needs are likely to be admitted to a district level hospital (primary level facility) usually run by the Family Medicine Department, family physicians or general practitioners. It was evident from patient records and the after-death audit that patients were admitted from home, down-referred from a tertiary institution or came from an old age home and none of them were from a hospice. It has been noted that patients with a progressive illness are increasingly likely to be admitted to the hospital towards end-of-life and are therefore likely to die in hospital.[5] These patients were indeed in end-of-life, as confirmed by the number of days they spent in hospital. Patients were admitted for a duration of 4.3 days to 4.7 days. It is also of concern that younger patients spend fewer days in hospital than older patients, and more studies are necessary in order to find the reasons behind this. It may be that the patient does not fell well-supported in hospital, or they may still be in denial, only going to the hospital once they are already terminal or understand their condition better, and understand that it is time to receive care. It was also noted that black patients were admitted for longer periods than white patients. The researcher needs to revisit her findings, as this may be related to socialisation or be cost-related.

5.2.2 Diagnosing or recognising patients in need of end-of-life care or in their last 72hrs of life and in need of Palliative Care

According to patient management, the after-death audit sheet of the patient revealed that patients experienced symptoms such as confusion (18.75%), pain (5.21%), shortness of breath (20.83%) and weakness (6.25%), indicating that they were close to death. In addition, signs were recorded that are indicative of the end-of-life stage of an illness. These signs were slow pulse (18.75%), low BP (18.75%), gasping (as identified by Crossroads guidelines and recorded in the patients' files). The description of gasping (51.04%) may have been Cheyne-Stokes breathing, a recognised indicator of a person being close to death. The only clinical intervention done by healthcare workers within the institution was the administration of oxygen by mask.

The researcher noted that although the signs and symptoms had been recorded, there was no indication that patients had been identified or acknowledged, assessed or diagnosed as being at the end-of-life or last 72 hrs/48hrs of life and managed as such. This relates to the study objective to the objective as to whether patients are recognised as being close to the end-of-life. The study results raise the question of whether healthcare workers within the district level

hospital are able to manage patients who need palliative care or are able to identify who are at end-of-life.

The qualitative assessment also revealed that family members perceived that patients had experienced distressing symptoms, reporting pain and gasping, and the family felt that not much had been done for the patient. Although pain was reported by few family members, it remains a critically important symptom requiring attention and good management. Pain is recognised as a distressing end-of-life symptom and adequate pain control is an essential component of palliative and end-of-life care. Therefore, healthcare workers need to know how to assess and manage pain adequately. Other physical signs and symptoms to be anticipated at end-of-life include delirium, agitation, dyspnoea, increased respiratory secretions, mouth and skin dryness, and poor bladder and bowel control.[1] Pain and symptom management, good communication and quality care for terminally ill patients is vital, but it has been noted that at times, healthcare workers are inadequately equipped to diagnose dying effectively or discuss it with the patient and their family.[40]

Many patients in need of end-of-life care are likely to be admitted to an acute hospital or district level hospital where they are less likely to receive appropriate pain control and more likely to receive burdensome interventions.[25]

The family members interviewed also felt there was not much care given in the dying phase as the patients were placed in isolation or a side ward and family members felt they were ignored and not involved in their management. The family members of end-of-life patients need to be a part of patient management and involved in every management decision made. In addition, patients also need to be part of management through being involved in decision making. Decision making is perceived by both patients and their families to be a key feature of management, especially during end-of-life care in an acute hospital setting. End-of-life care should include the thorough exploration of the patient's wishes regarding death and dying before they reach their final 24 hours and the family should be part of these discussions. It has been found that family and patients gain great comfort in knowing that they made the most of precious moments and had the opportunity to resolve any issues important to them at the time. According to the GSF tool, care for the dying should include implementing the following appropriate measures: stopping non-essential interventions and drugs, considering comfort measures, offering psychological, religious or spiritual support, bereavement planning, communication and after-death care.[16]

Diagnosing patients in need of palliative care and recognising those who require end-of-life care or 72hrs of life (which refers to the patients in the final hours or days of their lives, or those with a terminal illness that has become progressively advanced) is still a challenge, especially in old age (geriatrics). There is currently no approved or validated protocol to identify patients in need of palliative or end-of-life care in South Africa, although the National Palliative Care Policy suggests the use of SPICT (Supportive and Palliative Care Indicators Tool) or GSF (Gold Standard Framework). SPICT looks at the individual general status of the patient and to establish if there is any deterioration in health or any advance of the diagnosed clinical condition, and reviews supportive and palliative care for the patient. As previously described, GSF has four levels of care adopted within primary care which include "Level 1: communication and coordination of care, Level 2: control of symptoms and assessment, and continuity of care and reflection, Level 3: carer support and care during in the dying phase, Level 4: sustainability of improvements made in end-of-life care through implementation of GSF ".[16] Timely identification and management of patients at this stage of life is vital and helps prevent unnecessary interventions. As described previously, GSF, Crossroads and SPICT are widely-used international tools which are invaluable when identifying patients in need of palliative care. When used effectively, these tools help to identify patients with multiple unmet needs who would benefit from holistic advanced care planning, a needs assessment and a review of care goals.[46]

5.2.3 Multi-disciplinary involvement in improving quality of end-of-life care.

The multi-disciplinary involvement (as part of intervention or patient management) was revealed to be poor, with few referrals to other members of the healthcare team within the hospital such as social workers, psychologists, pastoral care and occupational therapy, with very few referrals to hospice. Multi-disciplinary care is an approach of care that establishes a collaborative effort, and is a patient-centred approach to care planning and provision, leading to the achievement of care goals that are unlikely to be achieved by healthcare professionals working in isolation. This approach of care leads to the patient feeling that their care is being managed by a team, increased patient satisfaction, a greater likelihood of delivery of care according to national standards, access to information and psychosocial support for patients. The group of healthcare workers from different disciplines or with varied skills work together towards the common goal of providing optimal care to the patient. An effective multi-disciplinary team depends on recognising that the patient and their family are at the core of everything they do. The multi-disciplinary team focusses on being respectful and

understanding of the patients' values, and communicates clearly to other professionals and to their patients.[1]

Family members reported poor coordination of care between the health care workers within the system or hospital. As described in the results chapter, almost all of the interviewed family members felt their members were not offered any additional or referred to other multi-disciplinary team members for further patient management, they would have appreciated referral or more information on available additional resources or services that would have been offered at that stage of life.

The family members also felt their relatives' care was not well-coordinated within the hospital team (multi-disciplinary management), and were disappointed by this. Coordination of care within palliative care is vital in management as it keeps the patient and family at the centre of communication, helps the healthcare system and social environment to work together to support the patient at end-of-life. It prevents duplication of services, and creates an environment of trust and security around the dying person. As also confirmed by an independent evaluator reporting on the Royal Trinity Hospice (September 2016), a well-coordinated end-of-life care service reduces unnecessary hospital or institutional admissions at end-of-life. This means that there will be fewer hospital deaths and quicker discharges from the institution, thus making it more cost effective. Coordination of care and having a preventative attitude, managing resources effectively and being part of the community, places the family physician as the first contact for patient care. This expedites the coordination of patient care as well as the referral to relevant members of the healthcare team and community resources.

As with general healthcare, quality indicators for end-of-life care can be defined by four components: Structure (describing accessibility to end-of-life care services with healthcare workers skilled in palliative care); Process (the availability of resources, patient and family involvement about use of these resources and how to access them); Output (service use and patient improvement of their well-being), Outcome (what happened to the patient, improved symptoms, psychosocial support and preferences for care such as, to die at the place of their choice) ."[26]

Interventions provided

The only intervention noted and found to be effective was that of administering oxygen by face mask when patients were noted as 'gasping'. There is some question as to whether offering oxygen by mask is the only appropriate treatment or management at the time. Dyspnoea or shortness of breath is one of the most common symptoms experienced during end-of-life, and healthcare workers at district healthcare hospitals need to understand this and be able to assess the patient at this stage of life, so as not to misuse the resource (oxygen therapy)**.** It is unlikely that oxygen therapy will make a difference when a patient is actively dying. In addition, an oxygen mask may be uncomfortable and restrictive, limiting possible interaction and communication with family and/or staff.

The interventions that are important in the dying phase are symptom control, avoiding unnecessary interventions, reviewing all symptoms and drugs regularly (their need and route of administration dependent upon the individuals' situation), and ensuring support for family or carers on how they are coping. This also includes effective communication.

Communication with patient and family

This study did not evaluate communication with patients - a key element of all healthcare, including palliative care. However, there was a mixed response by family members participating in the research study as to the adequacy of information provided to them. Many reported that they were given enough information by the attending healthcare worker. Some participants reported that they had little understanding of what was happening and a few stated that they were not informed of what was happening.

Communication with the patient and family after the patient has been diagnosed with a serious or life-threatening illness is fundamental. Beckman (2000) affirms that effective symptom control is impossible without effective communication. Poor communication at end-of-life causes a lot of stress, and has a negative impact on post-bereavement outcomes. Poor communication at this time of life was also highlighted by Sleeman (2013) as being responsible for much controversy and unhappiness surrounding the care of the dying.[49]

The results of the current study indicated that participants felt there was no care in the dying phase. Their perception was that the healthcare workers knew the patient was dying, yet

nothing was done. In particular, family members were not asked about their expectations nor were they involved in decisions about care.

The records audit during the family interviews also revealed that respondents felt there was poor patient or family involvement in decision making, and that they were given too little information. They also reported that they perceived poor patient involvement, with few patients being part of decision making.

After being diagnosed with a life-threatening illness or disease, patients and their families preferred to be part of decision making with the involvement of the multi-disciplinary team. . Studies have found that communication at this stage of life is vital and beneficial, involving the patient by informing him/her of the prognosis, knowing his preferences and expectations and discussing them openly.[15]

Quality of care in healthcare systems refers to the extent to which the organisation meets its clients' needs and expectations. How does the Tshwane District Hospital meet the needs and the expectations of patients and their families who are at end-of-life.[5] The principles or dimensions of quality healthcare are to be: 1) Effective; 2) Efficient; 3) Accessible; 4) Acceptable/patient-centred; 5) Equitable; and 6) Safe. [5]

The family members felt that their involvement could have improved their relative's quality of care at end-of-life. They would have appreciated being informed of their relative's illness, prognosis and alternatives as this would give them a choice as a family of how to spend their last days with their loved ones.

This really shows how close the district healthcare or primary healthcare workers could become to the patient and the family. This also relates to the study done by Ramanayake *et al* (2016) which concluded that attending to the palliative care needs of a community is the responsibility of the primary care doctor due to their unique position of being easily accessible and closer to the patient, allowing the patient to remain at a place of comfort (home with family). The primary care doctor is usually well-skilled. [39]

Referral to Hospice

As confirmed by both quantitative and qualitative data, most participants were not informed about hospice care. They expressed the view that they would have appreciated the hospice

services and information about this option of quality care. There is a lot of information available to communities about hospice care but public awareness of this important care and much-needed approach to care is still limited.[48,49]

The National Health Service in the UK identifies the family physician, who is closest to the community, to be the one to extend such a referral or invitation (hospice care services) to the patient and family when appropriate.[49] It is imperative for family physicians to be skilled in palliative care, and knowledge of hospice service care and the ability to refer the patient to community resources such as hospice means that the family physician should undertake training in the discipline of palliative care. The researcher agrees that palliative care should be part of all family medicine registrar training. According to Gordon *(*1995), hospice and hospice care refers to a philosophy of care rather than a building, and could therefore be provided or delivered anywhere where the patient and family is comfortable, characterised by a continued, regular and ongoing access to team of healthcare workers. [50,51]

Limitations of the Study

Poor record keeping, note taking or documentation by the healthcare workers at the Tshwane District Hospital was a great limitation to data collection as most of the procedures or management done might not have been recorded, and some records/patient files had been lost. This has resulted in incomplete data but has assisted in identifying an area for quality improvement in record keeping at the hospital.

It was difficult to reach some family members due to malfunctioning or non-existent contact numbers. Some of the participants or audited files were of homeless patients with no relatives or friends to contact. This also affected the data on care perception.

Some of the family members were not emotionally stable enough to partake in the interview as they were still going through the bereavement period and not received any post-bereavement counselling.

The researcher did not include the demographics of the relatives. This may have provided additional insight when analysing the interviews.

Recall bias was possible as this was a retrospective study interviewing participants at least six months' post-bereavement. In addition, there may have been recall bias due to the emotional

experience of caring for a sick relative and the experience of bereavement affecting participants' perceptions and recall.

CHAPTER SIX: Conclusions and Recommendations

The objectives of the study were to evaluate the quality of care rendered to patients admitted at the hospital in need of end-of-life care at Tshwane District Hospital through record review as an after-death audit and interview with bereaved relatives; and to assess whether the patient at end-of-life (the last 72 hours of life) was recognised as such. The researcher found that patients who are in need of end-of-life care are most likely to be admitted at a district or primary level hospital but there is poor recognition of the fact that patients are at the end-of-life so they do not receive appropriate care. There is therefore a need for the integration of palliative care services within District Hospital Services.

District Hospital Services are usually serviced by family physicians, general practitioners or healthcare workers who had not specialised been trained in palliative care medicine. This was revealed by the results of the study where patients were not identified or diagnosed as requiring end-of-life care. The healthcare workers at this level of care were unable to assess or diagnose patients in need of palliative care, including those who were actively dying.

The World Health Assembly Resolution (67.19) on palliative care states that "*palliative care is an ethical responsibility of health systems, and that it is the ethical duty of healthcare professionals to alleviate pain and suffering"* and recommends that healthcare professionals who care for patients with life-threatening illnesses should undergo intermediate (post-graduate) training in palliative care.

Recommendations

- Integration of palliative care into district hospitals and the primary healthcare system as planned in the South African National Health Insurance and described in the National Policy Framework and Strategy for Palliative Care (NPFSPC).
- Using a palliative care indicator tool (as described in the NPFSPC) during ward rounds to identify patients who need these services.

- A palliative care specialist to train and mentor the healthcare workers at primary care level to identify, assess and plan further management of the patient as early as possible, as well as working as a team. This could help in early coordination of care and referral of patients to hospice services (inpatient/outpatient/home-based care) within the community. This would ensure fewer unplanned hospital admissions, better involvement of the family in patient management, and that the patient is comfortable at a place of their choice.
- Improving primary care health workers' skills, knowledge and confidence in providing palliative care through making palliative care education a part of the family medicine curriculum for post-graduate and under-graduate degrees would benefit the district healthcare system and medical education as a whole.
- Palliative care policies and protocols for district hospitals on early identification of patients and the planning of their care using the approved indicator tools and protocols would help the primary care workers to manage palliative care patients.
- Healthcare workers could also attend mortality meetings as part of a reflection and record review or audit on improving the quality of management of patients who died within the institution.
- Improvement in communication between the healthcare workers, patients, and their families, understanding the importance of patient and family involvement in care, especially at end-of-life.
- The healthcare workers at this level of healthcare will also understand the comprehensive, interdisciplinary, holistic approach of patient care (physical, psychosocial and spiritual aspects) at this stage of life, including the bereavement period for family members left behind.
- The palliative care skills or education at this level of healthcare will also increase the healthcare workers' knowledge so that they can help in the coordination of care by identifying patients at end-of-life, and advising the patient and family about patient management and the use of hospice care (for those who have access and have consented).
- Provision of palliative care to patients not only improves patient and family satisfaction but also reduces the length of stay for admitted patients. It reduces admission rates, thus decreasing the cost of care, and lessens the burden of the healthcare workers in the hospital by improving the quality of care to patients (an improved patient-healthcare worker ratio in public hospitals).

- Further, follow-up research into the perceptions of healthcare workers at district or primary care level about their confidence in managing patients who are in need of end-of-life care. The National Policy and WHA Resolution 67.19 found that all general practitioners are expected to be able to manage patients who require end-of-life care services without having received expert training in palliative care. Integrating care education into the medical curriculum within undergraduate medical studies or postgraduate (Masters) studies in Family Medicine would be of great benefit to South African hospitals.
- Considering the importance of rational prescribing during end-of-life care, it would be beneficial to include a medicines review in the tool. It may also be useful to consider the level and experience of the attending doctor; was it a family physician, registrar, medical officer or intern, and was there any discussion with a consultant?
- A final suggestion would be to check whether a DNAR (Do Not Attempt Resuscitation) form was completed.
- Helping or training healthcare workers at District Care level Hospitals to be able to recognise a patient in need of palliative care or have an ability in recognising those patients who require end-of-life care or are in their last 72hrs of life (which refers to the patients in the final hours or days of their lives, or those with a terminal illness that has become progressively advanced) is still a challenge in the District level hospital.

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Appendix 1

Information Sheet and Consent Form

ASSESSMENT OF QUALITY PROVIDED TO PATIENTS WHO DIED IN THE CARE OF TSHWANE DISTRICT HOSPITAL.

Researcher: DR N.P ZELE

Supervisor: DR L. GWYTHER.

Research Assistant: MISS B MOHALE

AIM: The aim of the study is to look at the quality of care rendered to admitted patients in need of end-of-life care in Tshwane District hospital.

This is a research done by one of the doctors working in TDH as part of furthering her studies in taking care of patients diagnosed with life-threatening or incurable disease and those terminally ill or dying. She is studying how we take care of our patients and their families when faced with terminal illness and death. This study will help identify any gaps in our care so as to improve our quality of care at end-of-life. You are therefore invited to participate and help improve the quality of our healthcare system. If you agree to participate, please be assured that your name will not be mentioned, so feel free to answer the questions as honestly as you can. You are asked to give consent and I (research assistant) will sign on your behalf. There is no reimbursement for participating on the study. If you feel that you do not wish to participate, this will not affect you or your family in future visits to our hospital.

If you have understood the above information, and agree to participate, may I sign on your behalf and we continue with interview?

Agree/ Disagree (just cross the relevant)

SIGNATURE OF RESEARCH ASSISTANT AND NUMBER OF PARTICIPANT

…….

Consent form for: Assessment of Quality of Care of patients who died in the care of Tshwane District Hospital.

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

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

I agree to take part in the above study.

I agree to the interview being audiotaped.

Name _____ Date_____

Researcher Assistant: Signature_____ Date: _____

Witness: Name

Appendix 2

ASSESSMENT OF QUALITY OF CARE PROVIDED TO PATIENTS WHO DIED IN THE CARE OF TSHWANE DISTRICT HOSPITAL.

QUESTIONNAIRE FOR THE RELATIVE OF THE DECEASED

Participant Number:

1. Were you informed of your relative's problem, diagnosis and prognosis? Elaborate or say it as you understood it.	
2. Were you given information that you did not understand?	
3. Was it enough? If not what you think was lacking or should have been added?	
4. Were you referred to a social worker?	
5. Were you referred to HospiVision (free pastoral and counseling services at THD dealing with patients and families at end-of-life or with life-threatening illnesses)	
6. Were you involved in the decisions taken concerning your relatives' treatment or management?	
7. Did your relative ever complain of pain but was not given pain medication? Please elaborate?	
8. Any other problems he/she complained of that were not taken care of? Please tell me more.	
9. Do you think your deceased relative and family were treated with great care at that period of time? Elaborate.	
10. Any comments concerning the quality of care you received in our hospital and were you offered any referral to hospice care?	

Appendix 3

ASSESSMENT OF QUALITY OF CARE PROVIDED TO PATIENTS WHO DIED IN THE CARE OF TSHWANE DISTRICT HOSPITAL.

FILE AUDIT SHEET:

File no:

Gender:

Age:

Race:

Date of admission to the hospital:

Was the patient from home, referred from healthcare centre, general practitioner or down-referral from a tertiary institution?

Date of Death:

Diagnosis on admission:

Diagnosis on death notification form:

Registered symptoms 24-72hrs before death from nursing and doctors' files or diagnosis that the patient is at terminal phase:

Were there signs of end-of-life or dying recorded?

Interventions recorded i.e. treatment or management done:

Referral to multi-disciplinary team (pastor, social worker):

Referral to hospice/specialist palliative care team:

Patient involvement in care i.e. consent forms for interventions made:

Any family discussion reported /noted or notification regarding the terminal phase and end-of-life care experienced:

Appendix 4

DR N.P ZELE

81 JACQUELINE STREET

THE REEDS

CENTURION

0157

10/01/2012

The Management

Tshwane District Hospital

P/BAG X 179

PRETORIA

0001

Re: Permission to conduct research in your institution.

Sir/Madam

I, Dr N.P. ZELE request your permission to conduct research in your institution as part of my studies towards M. Phil with the University of Cape Town. The research will look at the quality of care that we as healthcare workers in your institution render to patients and their relatives at end-of-life.

The proposal for the study will be submitted to the Ethics Committee of the above university for approval prior to commencing any research, both for your protection and that of the patient. You will be furnished with a letter of approval from the Ethics Committee for your records as soon as it is available. At the end of the study, you will be informed of the findings and the recommendations thereof. Please see the attached information sheet and consent form for the research participants.

I hope that my request will receive your favorable consideration.

Yours truly,

DR N.P. ZELE

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