

https://dspace.org/

Perceptions of terminally ill patients concerning the palliative care they receive in rural primary health care

Mahole, G L

2021
https://hdl.handle.net/10539/32681

Downloaded from a DSpace repository. https://dspace.org/

PERCEPTIONS OF TERMINALLY ILL PATIENTS CONCERNING THE PALLIATIVE CARE THEY RECEIVE IN RURAL PRIMARY HEALTH CARE

Dr G.L. MAHOLE
Student Number: 780729

A publishable article as research report submitted to the
Faculty of Health Sciences,
University of the Witwatersrand
in partial fulfilment of the requirements for the degree
of
Master of Medicine in Family Medicine (M.Med in Fam. Med)

Supervisor:
Dr C. Lion- Cachet
(Family Medicine University of Witwatersrand)

Co-Supervisor:
Mrs D. Pretorius
(Family Medicine University of Witwatersrand)

Johannesburg, 2020

DECLARATION

I, G.L. MAHOLE, hereby declare that this research is my own unaided work, except where due acknowledgement for assistance received has been made. It is being submitted for the degree of Master of Family Medicine at the University of the Witwatersrand, Johannesburg. It has not been submitted previously for any other degree or examination at this or any other University.

Signed ..... (Signature of candidate)

Date: 31 May 2021

Signed .....

Dr C. Lion-Cachet (Supervisor)

Date: May 2021

Signed .....

D. Pretorius (Supervisor)

ACKNOWLEDGEMENT

I would like to thank all my lectures and supervisors at the University of the Witwatersrand, Johannesburg and in particular my immediate supervisors Mrs Pretorius and Dr Lion-Cachet. Also, a special thanks to Prof Claire Van Deventer with whom I started this journey, but who retired from the service as time went by. The author extends sincere thanks to the patients who participated in this study, and also appreciates the help provided by the staff members at the Department of Oncology, colleagues who unfailingly told us whenever they come across a terminally ill patient whom they thought would qualify for the study. The author would also like to extend his gratitude to the research assistant and supervisors for their patience and for motivating the author when things got tough during the research process.

DEDICATION

I dedicate this research report to
My family
for their unconditional support and unfailing understanding of
the sacrifices required for the completion of this work.

TABLE OF CONTENTS

	Page
Declaration	ii
Acknowledgement	iii
Dedication	iv
Table of Contents	v
List of Tables	vi
Nomenclature	vii
Article: Perceptions of Terminally Ill Patients Concerning the Palliative Care They Receive in Rural Primary Health Care	1
Abstract	2
Introduction	3
Aim and Objectives	5
Research Method	5
Study Population and Sampling Strategy	6
Data Collection Tools	6
Data Analysis	7
Ethical Considerations	8
Strengths and Limitations	8
Results	9
Discussion	14
Conclusion	18
References	19
Article Requirements	24
Acknowledgements	24
Competing Interests	24
Authors' Contributions	24
Funding Information	24
Data Availability Statement	24
Disclaimer	24
Appendix I : Questionnaires	25
Appendix II : Consent Forms	30
Appendix III : Ethical Clearance Certificate	33
Appendix IV : Permissions	34
Appendix V : Turn-It-In Report	35
Appendix VI : Proofreading Certificate	36

Page

Appendix VII : Research Proposal..... 37

LIST OF TABLES

			Page
Table 1	:	Demographic Characteristics of Patients.....	9
Table 2	:	The Percentage of Patients Experiencing Needs versus Need for Professional Help.....	11
Table 3	:	Statistical Comparison between Demographic and Percentage of Responses Suggestive of a Need for Professional Help.....	12
Table 4	:	Statistical Comparison between Demographic Variables and Percentage of Responses Suggestive of a Need for Professional Help.....	13

NOMENCLATURE

QI	:	Quality improvement
QIP	:	Quality improvement project
PNPC-sv	:	Problems and needs in Palliative Care Questionnaire – short version
WHO	:	World Health Organisation

PERCEPTIONS OF TERMINALLY ILL PATIENTS CONCERNING THE PALLIATIVE CARE THEY RECEIVE IN RURAL PRIMARY HEALTH CARE.

An article submitted according to the style guide and requirements of the **African Journal of Primary Health Care & Family Medicine** (PHCFM).

The article name for publication will be ***Perceptions of terminally ill patients concerning the palliative care they received in rural primary care of Ventersdorp sub-district, North West Province.***

ABSTRACT (301 words)

Background: Terminal illness is an incurable medical condition that cannot be completely treated and is reasonably expected to result in the death of the patient within a certain period of time. The term is used more for progressive diseases; it will therefore include all the efforts aimed at providing a better quality of the remaining life of a terminally ill patient.

Aim: The aim of this study was to assess perceptions of patients regarding the quality of palliative care that they were receiving in the Ventersdorp subdistrict.

Setting: This study was conducted in the Ventersdorp subdistrict, with patients interviewed at their home, hospital, health centre and some at old age home.

Methods: A quantitative cross-sectional approach was used, including record reviews and an administered questionnaire; Records of patients who were already referred to oncology unit at our tertiary hospital from Ventersdorp were also accessed and patients traced for interviews. Descriptive statistical methods were used, and the Fischer-Exact test was done for associations.

Results: Forty patients were interviewed on the following domain, daily activities, physical symptoms, autonomy, social issues, psychological issues, spiritual issues, financial problems and need for information. For the study as a whole the listed activities (domains) were reported to be problematic in 1074 (81.0%) of the 1326 responses that were recorded. The need for professional attention was expressed in 988 (92.0%) out of the 1074 responses where problems existed.

Conclusion: Based on these results terminally ill patients notably expressed need for help regarding their condition in the Ventersdorp subdistrict. Low education level, poor socio-economic conditions of participants contributes to dissatisfaction with quality of services they receive. We are failing patients in rural areas if they do not receive good palliative care. As a manager of resources, the task of establishing community programmes is on the shoulders of family physicians.

Keywords: Palliative care; End of life care; Home based care; Patient needs; Rural health services.

INTRODUCTION

When the journey of life draws to an end, not everyone experiences a sense of fulfilment, a signal of satisfaction with a life lived to its fullest.[1] Some patients even feel they are a burden deserving solitary abandonment as opposed to the display of a heartfelt desire to spend their last moments in life, surrounded by the people they wish to be with at a place of their choice.

Anecdotally, hospitals are becoming dumping sites to provide palliative care for terminally ill patients.[1] According to the World Health Organisation (WHO), palliative care is defined as, 'an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness that is non-curable. Palliative care aims to provide a better quality of the remainder of life to patients who are terminally ill. Palliation has the focus on preventing, treating, reducing, or removing discomfort. Besides improving sharing information regarding palliative care, expels some myth around palliative care, the identification of palliative care patients palliative care can improve access to symptom and /or pain control, by minimising barriers to the service.[2] Removal of discomfort may be in the form of rendering physical assistance, providing adequate analgesia or alleviating anxiety as needed or indicated. In addition this type of care makes provision for both psychological and spiritual support. Palliative care services enable patients to deal with unfinished business and to help them communicate their last wishes.The patient can be assisted to arrange for prayer meetings with either members of the church, temple, synagogue, mosque or spiritual leaders and encourage rituals for the traditional believers if so desired. Psychological help in the form of emotional support, resilience coaching, and therapy for both patient and family can be offered. Couple counseling or family therapy as well as health education of caregivers form part of the social care activities in palliative care.[3] Legal help e.g., assisting patients with necessary information to finalise a will to distribute their assets amongst their nominated beneficiaries, and guardianship of minors must also be considered under social care. The care does not stop with the psychological and spiritual care of the patient; the family and even the community forms part of social care services..[3]

It has been estimated that approximately three million patients have died while receiving palliative care services. Allegedly, a proportion of 14% of patient mortalities

worldwide occur during palliative care.[4] While the global number of adults and children in need of end-of-life palliative care is about 20.4 million, Africa has 1.8 million terminal patients needing palliative care.[4] Based on mortality data from South Africa, it is projected that 0.52% of the population will require palliative care services yearly.[5] Out of the total number worldwide, well over 50% of terminally ill patients prefer to be cared for and die at home if circumstances allow it.[6]

The Ventersdorp Subdistrict has no programme dedicated to care or support terminally ill patients. While South Africa launched the National Policy Framework and Strategy for Palliative Care 2017-2022, integrating it into existing public health care is still in its infancy. Most patients still have poor access to palliative care, especially those living in rural areas.[7] A palliative care model for rural areas was initiated in the Western Cape, it has changed the way patients needing palliative care are managed and has restored some of the dignity and ethos of patient-centred care, which is a core principle of Family Medicine and of the provincial Health Care 2030 vision.[7]

Patients' perceptions of their care are important for the development of professional service as well as for the discipline of palliative care.[8] Most of the studies on palliative care focus on quality of life and not necessarily on the nature of the service and what patients think of it. Globally, research has found that patients expressed a need for improved communication, financial support and good symptom control.[8,9] In Africa and sub-Saharan Africa, patients expressed similar needs.[9] An intervention study of 60 patients with a mean age of 66 years in home based care in Poland, found that 73% of them no longer bathed or showered independently and were dependent on others to assist them; after a physiotherapy intervention, independence improved significantly to 53.3%.[9] Functional mobility is a common challenge faced by patients with end stage disease that can improve with sufficient intervention and assistance in a palliative care programme.[10,11]

A South African study conducted in Soweto found that when religious and spiritual needs of patients with an incurable disease were met, their quality of life improved.[3] The spiritual need of patients reflects aspects of hope, comfort, meaning, and purpose. Patients then also concluded that having their spiritual needs met, was just

as good as being relieved of physical pains.[3] Globally, studies postulated that psychological well-being and physical symptom relief contributed to patients' perceptions of quality of life.[12-14] An observational study by Winkelman et al showed that patients with cancer who had unmet spiritual concerns were more likely to have significantly worse psychological quality of life than those whose spiritual concerns were addressed.[15,16] In addition, a multisite cohort study involving 343 patients with advanced cancer showed that the patients whose spiritual needs were unmet were reported to have poor quality of life.[17,18] There is evidence in numerous palliative care studies that show patients receiving professional care, have more autonomy and therefore do not need long institutional care, and experience higher quality of life.[11,19,20] Literature consistently documents that families of patients with end of life challenges and the patients themselves report difficulties regarding access to information regarding their illness. These include difficulties in obtaining specific and straightforward information and answers that they can understand and therefore need quality of care to meet their needs.[21]

AIM AND OBJECTIVES

With this in mind, the aim of the researcher in this study was to know what opinions the patients held with respect to the quality of palliative car they were receiving in Ventersdorp subdistrict with the following objectives:

- To determine the sociodemographic and clinical profile of patients participating in the study;
- To determine the patients' perceptions of their problems and needs in palliative care; and
- To statistically associate the demographic variable with the patients' need for professional help.

RESEARCH METHOD

Study Design

This study was a quantitative cross-sectional design.

Study Setting

The study was conducted in the Ventersdorp subdistrict, situated in the Dr Kenneth Kaunda District Municipality, North-West Province, South Africa. The district is rural and people are dependent on mainly farming activities for employment. Patients receive specialist care at the tertiary hospital in Klerksdorp and then return to Ventersdorp for palliative care at the primary care clinics.

Study Population and Sampling Strategy

The study population was all the patients with terminal illness referred to the subdistrict for end of life care. Sampling was done using a convenience sample of patients referred to primary care for palliative care for a period of three months from May to July 2019. The patients were diagnosed at the tertiary hospital, namely the Klerksdorp Hospital Oncology Unit, with life threatening cancers. The hospital then alerted the researcher for the period of this study when these patients were referred to the health district. The list the hospital supplied had 46 names listed after three months. All the patients were approached to participate in this study. Three patients could not be traced and three declined. No patient was excluded.

DATA COLLECTION TOOLS

The measuring tools in this study were a demographic questionnaire and a palliative care questionnaire based on a Dutch study namely, the Problems and Needs in Palliative Care questionnaire – short version (PNPC-sv).[22] The questionnaire had high internal consistency (Cronbach's alpha > 0.70). [22] The PNPC-sv has 33 items and was developed for patients who were the recipients of palliative care, to describe their perceptions of the care they were receiving. Permission was obtained from the original authors of the questionnaires to use the PNPC-sv questionnaire. Permission was also granted to the researcher to translate the question verbally to a participant who was unsure about the meaning of the question. The researcher is multilingual and fluent in the indigenous languages of the area. The questionnaire was piloted on three terminally ill patients who did not have cancer and their results were not included in this study. Changes were only made to the demographic questionnaire after the pilot study. The questionnaire covered eight domains, namely: daily activities; physical symptoms; autonomy; social issues; psychological issues; spiritual issues; financial problems and the need for information.[22] The questionnaire

assessed whether the patient had experienced problems in any of the domains and if he or she needed to consult a professional.

The research assistant was trained to help the researcher to trace patients, and keep a list of patients' names that she had contacted to establish their willingness to give consent for participation in the study. Her training was a face to face session covering the study's technical, ethical and recruiting requirements. The patients' names and contact details, as well as diagnosis were obtained from hospital records for the purpose of tracing patients identified for the study. The inclusion criteria were adult patients living in Ventersdorp health subdistrict with end stage disease needing palliative care. Patients too sick or physically and/or mentally not stable enough to participate, were excluded. The researcher is a doctor and determined whether the patient's state of mind allowed participation in the research by checking orientation and overall physical health. No patient was excluded on mental unsuitability. The research assistant contacted the patients and asked to participate in the research; when they agreed to be interviewed, a home visit was arranged. The information sheet regarding details of the study was given to the patient to read, or it was read on his or her behalf if the patient was illiterate, and the consent form was then signed or thumb printed respectively after the patient was given ample time to consider participation in the study. The study was explained in the patient's first language if they requested it. The questionnaires were then administered in the comfort of the participants' homes by the researcher who is well versed in the local languages. The questionnaires did not contain any identifying information and the patients' privacy and confidentiality were protected for data capturing. Completed questionnaires were sealed in an envelope and captured later by the researcher. The questionnaires were kept by the researcher in a safe place. Data were kept on the researcher's own laptop and password protected. Data were also stored on a back-up system and statistically analysed with the support of a statistician.

DATA ANALYSIS

Data analysis was done using on SAS (SAS Institute Inc, Carey, NC, USA), Release 9.4. Descriptive statistics was done calculating frequencies. Associations between the PNPC-sv and demographic variables were done using Fischer Exact test. The different domains in the questionnaire had various items which added up to 1322

possible response options; therefore results were reported in percentages and not numbers. As it was a small sample, the researcher combined the 'yes' and 'somewhat yes' as a 'yes' for calculation purposes for both categories of 'experiencing a problem' and 'professional help needed'. The number of responses versus the number of participants was used as a denominator for the PNPC-sv as the domains assessed allowed more than one response and condensing the domain to the two main domains, namely 'problems and need for care' and 'need for professional attention', would have caused important results to be missed.

ETHICAL CONSIDERATIONS

Ethical approval was obtained from the Human Research and Ethics Committee (HREC - **M170170**), University of the Witwatersrand, Johannesburg. Permission was also obtained from Ventersdorp subdistrict and Dr Kenneth Kaunda District (Dr KK District). The patients gave written consent. The completion of the questionnaires was anonymous and thus patient identifiers remained confidential. The researcher arranged for follow-up by the psychologist for patients who experienced emotional challenges. The researcher also arranged for a dedicated social worker to follow-up on the patients at home. Being a doctor, the researcher had the skill and capacity to determine and ethical obligation to ensure that the patient was at sound mind to give informed consent. There was no direct potential harm to the participants, as patient/participant in an unstable condition were excluded before any interview was conducted. Excluded patients received the medical care they needed.

STRENGTHS AND LIMITATIONS

The strength of this study is that it was the first palliative care study done in the health district. Due to limited number of known patients with terminal illness in the sub-district, the study had a small sample size and results may not apply to all terminally ill patients in the province or country. However, it gave a clear picture of the palliative needs in a rural setting at a specific time. The questionnaire was also not validated for South African use, but because of its high internal consistency and face validity the best option to assess the research objectives. Using a convenience sample of identified terminally ill cancer patients, could have contributed to sampling bias, and must also be considered a limitation in this study. These patients however

were all patients with baseline palliative needs at the time of the research and reflected previously unexplored needs in the health district.

RESULTS

Forty patients completed questionnaires. As shown in Table I, the sample consisted of 16 men (40%) and 24 women (60%) as follows: the patients' ages ranged between 39 years to 79 years; education level was rudimentary with 23 (57.5%) and 13 (32.5%) having obtained primary level education and only a Grade 1 qualification respectively; thirty patients (75%) were Tswana first language speakers; fifteen patients (37.5%) were living with their children and 11 patients (25.5%) with a spouse; eighteen patients (45%) were taken care of by their children, some 12 patients (30%) had a spouse as caregiver; and seventeen patients (42.5%) had a monthly income.

Table 1: Demographic Characteristics of Patient

	Men (n=16)		**Women (n=24)**	
Age				
Age range	39–75		47–79	
Age: Median	58		58	
Age: Mean	57		60	
	Number	**%**	**Number**	**%**
Marital Status				
Single	2	(12.5)	7	(29.2)
Married	7	(43.8)	8	(33.3)
Separated			1	(4.2)
Divorced	1	(6.3)		
Widowed	5	(31.3)	8	(33.3)
Cohabitated	1	(6.3)		
Education				
Grade 1– 4	10	(62.5)	4	(16.6)
Grade 5 – 7	1	(6.3)	8	(33.3)
Grade 8 –10	1	(6.3)	11	
Grade 12	4	(25.0)	1	(4.2)
Language				
Tswana	13	(81.3)	17	(70.8)
Xhosa	2	(12.5)	3	(12.5)

Afrikaans			3	(12.5)
Shona			1	(4.2)

	Number	%	Number	%
Employment				
Full time	3	(18.8)	1	(4.2)
Part time	1	(6.3)	5	(20.8)
Piece job	3	(18.8)	8	(33.3)
Unemployed	4	(25.0)	2	(8.3)
Pensioner	5	(31.3)	8	(33.3)
Household				
Lived alone	1	(6.3)		
Lived with spouse	7	(43.8)	4	(16.7)
Lived with parent	2	(12.5)	2	(8.3)
Lived with children	3	(18.8)	12	(50.0)
Lived with grandchild			3	(12.5)
Live-in facility for the elderly	3	(18.8)	3	(12.5)
Primary Caregiver				
Spouse	8	(50.0)	4	(16.7)
Child/children	5	(31.3)	13	(54.2)
Parent			2	(8.3)
Friend/neighbour			2	8(.3)
Professional care	3	(18.8)	3	(12.5)

The primary diagnosis of all the patients was cancer that varied between CA Cervix, Ca prostate, CA oesophagus, pancreas CA and Kaposi sarcoma. Twenty-one patients (52.5%) lived with hypertension or a combination of hypertension and diabetes as comorbidity (Table 2).

Thirty-two patients (80%) were of the opinion that the services they received from Ventersdorp subdistrict were not satisfactory, while the others did not expect better services (Table 2).

Table 2: Patient's Clinical Characteristics and Their Perceptions of the Quality of Palliative Care

	Men (n=16)		Women (n=24)
Illness			
Primary condition: Cancer	16 (100.0)	24	(100.0)
Comorbidities			
HPT	4 (25.0)	7	(29.2)
HPT & DM	3 (18.8)	5	(20.8)
HIV	3 (18.8)	1	(4.2)
HPT< CVA	2 (12.5)	3	(12.5)
MDD &RVD		6	(25.0)
COPD &HIV	2 (12.5)	1	(4.2)
Osteoarthritis, HPT / DM		1	(4.2)
COPD, HPT	1 (6.3)		
Perception of Quality of Care			
Not satisfied with services	14 (87.5)	18	(75)
Did not expect better	2 (12.5)	6	(25)

Out of the 1326 responses 1074 (81.0%) suggested that patients experienced problems with the nature of palliative care they received, and 988/1074 (92.0%) wanted professional help (Table 3). Despite patients having the least problems in the physical (61.7%) and financial (73%) domains, some 182/222 (82%) physical and 56/58 financial responses (96.6%) suggested they want additional help with it.(93.7%). All the patients had psychological challenges such as a depressed mood, fear of physical suffering and metastases, the unpredictability of the future, and difficulties to show emotions (Table 3). The biggest need was the need for information. Thirty-eight responses (95%) suggested problems around information and 97.4% wanted help.

Table 3: The Percentage of Patients Experiencing Needs versus Need for Professional Help

Patients' Problems and Need for Assistance	Experience a Problem		Need Professional Help
Domain and items	**Yes**	**No**	**Yes**
Daily Activities (n=119 responses)			
Daily activities such as body care, washing, dressing, toilet assistance, personal transportation and doing light housework	96 (80.7%)	23 (19.3%)	90 /96 (93.8%)
Physical Symptoms (n=360 responses)			
Pain, Fatigue, Sleeping problems, Shortness of breath, Cough, Itch, Sexual dysfunction Prickling or numb sensation, Night sweats or hot flushes	222 (61.7)	138 (38.3)	182/222 (82.0)
Autonomy (n=17 responses)			
Loss of control over one's life, being dependant of others, difficulty in delegating tasks, difficulty in continuing usual activities	144 (86.2)	23 (13.8)	133/144 (92.4)
Social Issues (n=174 responses)			
Relationship with life companion, Difficulties in talking about the disease, Not wanting to burden others, Others not receptive to talking, Difficulty in finding someone to talk to.	174 (87.0)	26 (13.0)	160/174 (92.0)
Psychological Issues (n=200 responses)			
Depressed mood, Fear of physical suffering, Fear of metastases, Unpredictability of the future, Difficulty in expressing emotions.	200 (100)	0	197/200 (97,0)
Spiritual Issues (n=142 responses)			
Difficult to be engaged usefully, Difficult to be of avail for others, Meaning of death, Difficult to accept the disease.	142 (88.8)	18 (11.2)	133/142 (93.7)
Financial Problems (n=58 responses)			
Extra expenditure and/or loss of income due to the disease.	58 (72.5)	22 (27.0)	56/58 (96.6)
Need for Information (n=38 responses)			
Insufficient information	38 (95.0)	2 (5.0)	37/38 (97.4)

When comparing need for professional help between men and women, the women expressed a statistically significant need for help in respect of physical symptoms ($p \leq 0.027$), as well as in respect of social issues ($p \leq 0.019$) (Table 4). Single patients expressed the least need for professional attention in respect of daily activities ($p \leq 0.002$). These single patients were mainly taken care of by either a parent or

children. Part-time workers and unemployed patients also seemed to have autonomy challenges (p≤0.002) and social issues (p≤0.008) (Table 4). Patients in professional care (old age home) did not express a need for professional help regarding autonomy or spiritual issues.

Table 4: Statistical Comparison between Demographic Variables and Percentage of Responses Suggestive of a Need for Professional Help

Sex and Need for Professional Help						
Domains where Patients Wanted Professional Help			**Men (%)**	**Women (%)**	**p-value**	
Daily activities			87.5	76.1	0.157	
Physical symptoms			68.8	56.9	0.027*	
Autonomy			90.6	89.6	1.000	
Social issues			80	91.7	0.019*	
Psychological issues			100	100		
Spiritual issues			89.1	88.5	1.000	
Financial problems			81.2	66.7	0.204	
Need for information			100	91.7	0.508	
Marital Status and Need for Professional Help						
	Single	**Married**	**Separated**	**Divorced**	**Widowed**	**p-value**
Daily activities	55.6	80.0	100	100	89.7	0.002*
Physical symptoms	63.0	60.0	55.6	72.2	61.2	0.887
Autonomy	75	88.3	100	100	100	0.002
Social issues	86.7	88.0	100	80.0	86.2	0.914
Psychological issues	100	100	100	100	100	
Spiritual issues	72.2	91.7	100	100	94.2	0.027*
Financial problems	77.8	73.3	100	100	61.5	0.489
Need for information	100	93.3	100	100	92.3	1.00
Caregiver and Need for Professional Help						
	Spouse	**Child**	**Grandchild**	**Neighbour/ Friend**	**Professional**	**p-value**
Daily activities	89.7	76.8	83.3	100	58.3	0,097
Physical symptoms	64.1	57.7	66.7	66.7	66.7	0.723
Autonomy	96.2	90.8	100	100	56.2	0,002*
Social issues	90.8	86.3	90.0	100	70.0	0.153
Psychological issues	100	100	100	100	100	n/a
Spiritual issues	94.2	89.5	J87.5	100	62.5	0.022*
Financial problems	65.4	79.0	75.0	25.0	87.5	0.149
Need for information	100	89.5	100	100	100	0.683

Employment and Need for Professional Help						
	Full Time	**Part Time**	**Piece Work**	**Unemployed**	**Pension**	**p-value**
Daily activities	91.7	76.5	66.7	72.2	94.9	0.015*
Physical symptoms	77.8	62.3	54.6	61.1	62.4	0.186
Autonomy	87.5	83.3	86.4	83.3	100	0,008*
Social issues	75.0	100	89.1	73.3	89.2	0.008*
Psychological issues	100	100	100	100	100	n/a
Spiritual issues	93.8	83.3	90.9	75.0	94.2	0.131
Financial problems	75.0	83.3	86.4	66.7	57.7	0.216
Need for information	100	83.3	100	100	92.3	0.817

DISCUSSION

The researcher set out to determine the profile of patients who qualified for palliative care in the Ventersdorp subdistrict, and their opinions on the quality of care they were receiving. Key findings were their dissatisfaction with their care, the lack of psychological support and need for information, and challenges with physical symptoms. The lack of education and employment could contribute to the patients having low expectations of care and not being informed on their rights.

The small sample of 16 men and 24 women indicated that all lived with different cancers and other comorbidities. Most of these patients were cared for by family members at their homes, and had primary school education levels with associated high unemployment rate. Several studies found that most patients with terminal disease and short life expectancy preferred to stay in their homes as long as possible, and eventually die at home surrounded by their family members, and that in-home palliative care significantly increased patient satisfaction while reducing use of medical services and medical care costs at the end of life.[23,24,25] In one study, a rudimentary educational level and low socio-economic status of participants were high on the list compiled in order of magnitude in relation to high/extremely important factors that contribute to patient's opinion regarding satisfaction with quality of care they receive.[26] Notably, the patients in this North West study were not satisfied with the care they received at the time this research.

The patients' perceptions of their problems and needs of palliative care, as measured with a questionnaire suggested an overall need for professional help. The

priority needs exposed by this research were psychological support and need for information. A systematic review aiming to describe the impact of a paucity of information on the lives of patients (unclear), found that those considered to have rudimentary levels of education apparently had intense fears and anxiety about their future with the illness. Inferences about the psychosocial morbidity are often linked to the scanty information given to patients as according to needs.[27] The researcher was given to speculation on whether patients' uncertainty stemmed from the lack of information, exacerbating their fears for their health and future with a general dissatisfaction.

Women had more challenges with physical symptoms than men. If one considers the broad definition of physical symptoms of the questionnaire (pain, fatigue, sleeping problems, shortness of breath, cough, nausea, itch, sexual dysfunction, prickling or numbness hot flushes that are the physical demands of the cancer), it is difficult to explain this result. One must not however, underestimate the socio-cultural perception around masculinity and the admission of pain; in other words, men may have the same symptoms as women but suffer in silence.[28]

Single patients had the least need for body care, washing, dressing, toilet assistance, personal transportation and doing light housework. The only explanation could be that the single patients were either taken care of by their parents or a child and that patients were, either afraid to be seen or regarded as ungrateful if they expressed a need for help rather than appreciation for being taken good care of or experienced that they were well taken care of in this domain. Another factor explanation could have been that most patients interviewed were ambulatory patients.

It was a surprise that low education levels and unemployment were both factors associated with the least need for professional attention. The level of education was rudimentary among the sample of study. The geographical context where this research was done, also offers few work opportunities to the entire population, and individuals with a rudimentarily education, are often unemployed.[29] All of this contributed that these patients may not have understood their rights in terms of demanding or accessing better care as it is clearly guaranteed by Section 27 of the

Constitution, on the South African Bill of Rights. Moreover, these patients were possibly had lower levels of expectations due to their rudimentary education caused them to be dependent on others, thus doubting their autonomy.[30]

This study adds to growing reports of the importance and needs for palliative care for patients with terminal illness.[31] Other earlier surveys for palliative care need assessment have reported similar results. A study categorized palliative care facility development in various countries available throughout the world, showing changes over time and development of palliative care hospitals. Although there is an increase in palliative care services in more than half of the world, these services continued to be grossly inadequate globally, mostly in Africa.[32] In a country where resources are scarce the primary care clinics are positioned to deliver supportive care on an outpatient basis to terminally ill patients. Primary care should be utilised towards delivering a comprehensive service incorporating support from the healthcare team in its totality. In palliative care the family physician is not allowed to provide a service segregated from other members of the team.[32] Participants in this study were generally of the opinion that their problems and needs demanded professional attention which was unavailable. The importance of regular assessment of the psychosocial burden, quality of life and supportive needs of patients with terminal illness in South Africa have become the responsibility of the family physician.

In a country like South Africa where resources are scarce, the primary care clinics are best positioned to deliver supportive care on an outpatient basis to terminally ill patients. Primary care should be utilised towards delivering a comprehensive service incorporating support from the healthcare team in its totality. In palliative care the family physician is not expected to provide advanced care planning and end of life care separate from the rest of the healthcare team. Linking the patient to community support will strengthen the health care support even further.

End of life discussions are best held early on in the course of the disease when the patient can participate actively. Documentation of these consultations enables the family physician to share the patient's wishes with whomever they allow, when they agree. Techniques of advanced communication, optimal pain and symptom management and psychosocial evaluation and care fall within the scope of practice

of the family physician. The family physician is part of the team who provides advanced care planning and end of life care. Close relatives and home-based carers should be included in discussions with the terminally ill index patient. Patient advocacy dictates that the drive behind organising these sessions should be the family physician.

As in this research, another study showed that families caring for a dying patient had the greatest need for information on symptoms associated with the physical condition, hygiene and nutritional care of terminal patients.[32] All the patients had psychological challenges such as a depressed mood, fear of physical suffering and metastases, the unpredictability of the future, and difficulty showing emotions. The biggest need was the need for information. Thirty-eight responses (95%) suggested problems around information and 97.4% wanted help. Patients required the following information: knowledge of the condition, information on medication, patient hygiene and nutritional care, contacts for emergency support and support options for the carer. An advanced care plan may be communicated to patients by way of a printed booklet. Sketching a clear roadmap of the availability of step-up or -down palliation services between district and subdistrict will inform patients of their right to professional care, even at the end of life in hospital, a hospice or even at home. End of life discussions are best held early on in the course of the disease when the patient can participate actively. Documentation of these consultations enables the family physician to share the patient's wishes with whomever they allow, when they agree.

This research indicated the urgent need to establish a palliative care service in the Ventersdorp health subdistrict. The family physician is ideally positioned to fulfil this task. Culturing awareness in health care professionals of the neglected needs that terminal patients present with during routine consultations, should be seen as a capacity building exercise for family physicians. Upskilling the ward based outreach teams' care through weekly teaching ward rounds hosted by palliative care specialists from Klerksdorp Hospital, will improve knowledge and integrate care between the primary and tertiary facilities in the Dr KK District. The family physician has an excellent opportunity to build the primary healthcare team by improving communication between the various tiers of palliative medicine. Technology could

be incorporated by the family physician to organise a link between the subdistrict and the multiprofessional team at the tertiary centre in the district. Discussion with the local Pharmacology and Therapeutics Committee will advocate for access to restricted medications for terminal care at subdistrict level to address pain, itching nausea and vomiting. Extending palliative care services has to be the focus of future quality improvement projects led by the family physician in Ventersdorp

As the focus of future quality improvement projects (QIPs) led by the family physicians in Ventersdorp, primary care as an entity can contribute to the upskilling of staff members at all health care levels and integrate care between primary, secondary and tertiary facilities. Part of the quality improvement (QI) can be the exposure of staff members working with these patients to the setting the patient came from and to provide follow-up. The primary care staff members can also meet the patients at the tertiary setting before they are referred for palliative services. Realistic expectations and familiarity with the setting will decrease anxiety and open communication lines.

Since the researcher became aware of these unmet needs, he immediately ensured that all newly diagnosed terminally ill patients are referred to the psychologist. Dedicated social workers still need to be identified. The researcher is also considering implementing the "Hoping is Coping" programme for patients and significant others such as spouse, family member or friend to attend a monthly morning session on information or ideas sharing to make life easier for the patient and the family.[33, 34] Hence, information can be shared and newly formed relationships can act as support network.

According to Health Professions Council of South Africa's Ethical guidelines for good practice in the health care professions, there is a professional requirement for a doctor to render palliative care services to patients, but is prohibited from doing this alone.[35] The lack of a policy in the subdistrict to assist the doctor to manage this task causes a gap in services and leaves the patient without comprehensive care.

CONCLUSION

Terminally ill patients in the Ventersdorp subdistrict notably expressed need for help regarding their care. A low education level, poor socio-economic conditions of participants contributed to dissatisfaction with quality of services they receive. Health services are failing patients in rural areas if they do not receive good palliative care. As a manager of resources, the task of establishing palliative care services in the community is on the shoulders of family physicians. The family physician must engage with policy makers in the health district to design policy regarding palliative matters in primary care.

REFERENCES

1. Morris SM, King C, Turner M, Payne S. Family carers providing support to a person dying in the home setting: A narrative literature review. Palliat Med. [internet]. 2015 Jun [cited 20 Sep 2018];29(6):487-95. Available from: https://pubmed.ncbi.nlm.nih.gov/25634635doi: 10.1177/0269216314565706

2. Gwyther L, Krause R, Stanford J, etl. The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa. S Afr Med J CITED ????2018;108(2):86-89. DOI:10.7196/SAMJ.2018.v108i2.12524

3. Grant L, Brown J, Leng M, Bettega N, Murray SA. Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. BMC Palliat Care. 2011 May 12 [cited 17 Aug 2020];10:8. Available from: https://pubmed.ncbi.nlm.nih.gov/21569423/ doi: 10.1186/1472-684X-10-8.

4. Kyota, A., Kanda, K. How to come to terms with facing death: a qualitative study examining the experiences of patients with terminal Cancer. BMC Palliat Care. 2019 [Cited 20 Aug 11]; 18; 33. Available from: https://doi.org/10.1186/s12904-019-0417-6

5. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database Syst Rev. 2013 Jun 6 [vited 20 July 12];(6):CD007760. Available from: https:// doi: 10.1002/14651858.CD007760.

6. Al-Mahrezi, Abdulaziz & Al-Mandhari, Zahid. Palliative Care: Time for Action. Oman Medical Journal. 2016 [cited 17 Aug 20]; 31. 161-163. Available from: https://www.researchgate.net/publication/301793010

7. Gwyther E. How is palliative care part of the right to health?: The South African evidence [thesis]. Cape Town; University of Cape Town; 2019 [cited 2020 Dec 11]. Available from: https://open.uct.ac.za/bitstream/handle/11427/30368/thesis_hsf_2019_gwyther_elizabeth.pdf?isAllowed=y&sequence=1

8. Cox-Seignoret K, Maharaj RG. Unmet needs of patients with cancer in their last year of life as described by caregivers in a developing world setting: a qualitative study. BMC Palliat Care [serial online]. 2020 [cited 2020 Oct 29]; 19(1):13. Available from: https://doi.org/10.1186/s12904-020-0516-4

9. Dhavale P, Koparkar A, Fernandes P. Palliative Care Interventions from a Social Work Perspective and the Challenges Faced by Patients and Caregivers during COVID-19. Indian J Palliat Care. 2020 Jun [cited 2020 Sep 22];26(Suppl 1):S58-S62. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7534999/ doi: 10.4103/

10. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X, Villanueva A, Espaulella J, Espinosa J, Figuerola M, Constante C. Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia. BMJ Support Palliat Care. 2013 Sep [cited 23 Oct];3(3):300-8. Available from: https://pubmed.ncbi.nlm.nih.gov/24644748/ doi: 10.1136

11. Selman L, Higginson IJ, Agupio G, et al. Meeting information needs of patients with incurable progressive disease and their families in South Africa and Uganda: multicentre qualitative study. BMJ. 2009 [Cited 12 Oct];338:b1326. Available from: https://doi.org/10.1136/bmj.b1326

12. Hudson P, Trauer T, Kelly B, O'Connor M, Thomas K, Zordan R, Summers M. Reducing the psychological distress of family caregivers of home based palliative care patients: longer term effects from a randomised controlled trial. Psychooncology. 2015 Jan [cited 20 Oct 17];24(1):19-24. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4309500/ doi: 10.1002/pon.3610.

13. Mitchell G, Nicholson C, McDonald K, Bucetti A. Enhancing palliative care in rural Australia: the residential aged care setting. Aust J Prim Health. 2011 [cited 20 Nov 12];17(1):95-101. Available from: https://pubmed.ncbi.nlm.nih.gov/21616032/ doi: 10.1071/PY10054. PMID: 21616032.

14. Goodridge D, Duggleby W. Using A Quality Framework to Assess Rural Palliative Care. Journal of Palliative Care. 2010 [cited 20 Nov 22];26(3):141-150. Available from: https://journals.sagepub.com/doi/10.1177/082585971002600302 doi:10.1177/082585971002600302

15. Kehl KA, Kirchhoff KT, Kramer BJ, Hovland-Scafe C. Challenges Facing Families at the End of Life in Three Settings. J Soc Work End Life Palliat Care. 2009 Jul 1 [cited 20 Oct 18];5(3 &):144-168. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles doi: 10.1080/15524250903555080. PMID: 20563315

16. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, Jackson VA, Block SD, Maciejewski PK, Prigerson HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA. 2008 Oct 8 [cited 20 Nov 12];300(14):1665-73. Available from: https://pubmed.ncbi.nlm.nih.gov/18840840/ doi: 10.1001

17. Zimmermann C, Swami N, Krzyzanowska M, Leighl N, Rydall A, Rodin G, Tannock I, Hannon B. Perceptions of palliative care among patients with advanced cancer and their caregivers. CMAJ. 2016 Jul 12 [cited 20 Nov 12];188(10):E217-E227. Available from: https://pubmed.ncbi.nlm.nih.gov/27091801/doi: 10.1503/cmaj.

18. Sandsdalen T, Grøndahl VA, Hov R, Høye S, Rystedt I, Wilde-Larsson B. Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes, and home care: a cross-sectional study. BMC Palliat Care. 2016 Aug 24 [cited 20 Dec 17];15(1):79. Available from: https:// doi: 10.1186/s12904-016-0152-1.

19. Bajunirwe F, Tisch DJ, King CH, Arts EJ, Debanne SM, Sethi AK. Quality of life and social support among patients receiving antiretroviral therapy in Western Uganda. AIDS Care. 2009 Mar [cited 20 Sep 19];21(3):271-9. Available from https:// doi: 10.1080/09540120802241863. PMID: 19280404.

20. Peltzer K, Phaswana-Mafuya N. The symptom experience of people living with HIV and AIDS in the Eastern Cape, South Africa. BMC Health Serv Res. 2008 Dec 22 [cited 20 Aug 11];8:271. Available from: doi: 10.1186/1472-6963-8-271. PMID: 19102765; PMCID: PMC2628894.

21. Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. J Am Geriatr Soc [serial online]. 2007 [cited 2020 Dec 23];55(7):993–1000. Available from: https://doi.org/10.1111/j.1532-5415.2007.01234

22. Osse BH, Vernooij-Dassen MJ, Schadé E, Grol RP. A practical instrument to explore patients' needs in palliative care: the problems and needs in palliative care questionnaire - short version. Palliat Med [serial online]. 2007 [cited 2020 Dec 23];21(5):391-399. Available from: https://doi.org/10.1177/0269216307078300

23. Wheatley VJ, Baker JI. "Please, I want to go home": ethical issues raised when considering choice of place of care in palliative care. Postgrad Med J [serial online]. 2007 [cited 2020 Nov 22];83(984):643-648. Available from: https://doi.org/10.1136/pgmj.2007.058487

24. Cruz-Oliver DM. Palliative Care: An Update. Mo Med. 2017 Mar-Apr [cited 20 Dec 28];114(2):110-115. Available from: https://pubmed.ncbi.nlm.nih.gov/30228556/ PMID: 302285569

25. Ullrich A, Marx G, Bergelt C, et al. Supportive care needs and service use during palliative care in family caregivers of patients with advanced cancer: a prospective longitudinal study. Support Care Cancer [serial online]. 2020 [cited 2020 Oct 10]. Available from: https://doi.org/10.1007/s00520-020-05565-z

26. Bluethmann SM, Mariotto AB, Rowland JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. Cancer Epidemiol Biomarkers Prev. 2016 Jul [cited 2020 Oct 10];25(7):1029-36. Available from https:// doi: 10.1158/1055-9965.EPI-16-0133.

27. Raybould G, Babatunde O, Evans AL, Jordan JL, Paskins Z. Expressed information needs of patients with osteoporosis and/or fragility fractures: a systematic review. Arch Osteoporos [serial online]. 2018 [cited 2020 Aug 22];13(1):55. Available from: https://doi.org/10.1007/s11657-018-0470-4

28. Samulowitz A, Gremyr I, Eriksson E, Hensing G. "Brave men" and "emotional women": A theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. Pain Res Manag [serial online]. 2018 [cited 2020 Jul 12];6358624. Available from: https://doi.org/10.1155/2018/6358624

29. Doku DT, Acacio-Claro PJ, Koivusilta L, Rimpelä A. Health and socioeconomic circumstances over three generations as predictors of youth unemployment trajectories. Eur J Public Health [serial online]. 2018 [cited 2020 Sept 18];29(3):517-523. Available from: https://doi.org/10.1093/eurpub/cky242

30. Musinguzi G, Anthierens S, Nuwaha F, Van Geertruyden JP, Wanyenze RK, Bastiaens H. Factors influencing compliance and health seeking behaviour for hypertension in Mukono and Buikwe in Uganda: A qualitative study. Int J Hypertens [serial online]. 2018 [cited 2020 Sept 18];8307591. Available from: https://doi.org/10.1155/2018/8307591

31. Gaertner J, Siemens W, Meerpohl JJ, et al. Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis. BMJ [serial online]. 2017 [cited 2020 Nov 8];357: j2925. Available from: https://doi.org/10.1136/bmj.j2925

32. Asthana S, Bhatia S, Dhoundiyal R, Labani SP. Garg R, Bhtnagar S. Quality of life and needs of the Indian advanced cancer patients receiving palliative care Assessment of the quality of life, problems, and needs of the advanced cancer patient receiving palliative care. Cancer Research, Statistics, and Treatment. 2019;2(2):138–144.

33. Germann JN, Leonard D, Stuenzi TJ, Pop RB, Stewart SM, Leavey PJ. Hoping is coping: A guiding theoretical framework for promoting coping and adjustment following pediatric cancer diagnosis. J Pediatr Psychol [serial online]. 2015 [cited 2020 Dec 14];40(9):846–855. Available from: https://doi.org/10.1093/jpepsy/jsv027

34. Kimball TG, Shumway ST, Austin-Robillard, H, Harris-Wilkes, KS. Hoping and coping in recovery: A phenomenology of emerging adults in a collegiate recovery program. Alcoholism Treatment Quarterly [serial online]. 2017 [cited 2020 Dec 24];35(1), 46–62. Available from: https://doi.org/10.1080/07347324.2016.1256714

35. HPCSA. Ethical guidelines for good practice in the health care professions: Ethical guidelines on palliative care (booklet 17) [homepage on the internet]. Health Professions Council of South Africa; 2019 [cited 2020 Dec 24]. Available from https://www.hpcsa.co.za/Uploads/Professional_Practice/Ethics_Booklet.pdf

36. Gwyther L, Krause R, Stanford J, etl. The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa. S Afr Med J 2018;108(2):86-89. DOI:10.7196/SAMJ.2018.v108i2.12524

ARTICLE REQUIREMENTS

Acknowledgements

The author extends sincere thanks to the patients who participated in this study, and also appreciates the help provided by the staff members at the Department of Oncology, colleagues who unfailingly told us whenever they come across a terminally ill patient whom they thought would qualify for the study. The author would also like to extend his gratitude to the research assistant.

Competing Interests

The authors declare that that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article.

Authors' Contributions

This article was submitted by GLM as a requirement for partial fulfilment of MMed (Family Medicine). GLM was the main author. CLC and DP supervised this research. CLC and DP commented on drafts of the article and approved the final version to submit for publication.

Funding Information

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Data Availability Statement

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Disclaimer

The views expressed in the submitted article are my own and not an official position of the institution

APPENDIX I

- **QUESTIONNAIRES**

Number:

CENTRE FOR QUALITY OF CARE RESEARCH

PROBLEMS and NEEDS in PALLIATIVE CARE questionnaire

version: PNPC-sv-engl 2005

© Centre for quality of care research, WOK, Radboud University Nijmegen

Instructions:

This questionnaire is designed to clarify what problems you experience, and for what issues you need (extra) attention or care.

At each item you will be asked 2 questions:

- **Left:** Do you experience the item to be a **problem**?
- **right:** Do you need (extra) professional **attention** for the item?

So, please provide 2 answers at each item !!

Name:	*Date of birth:*
Date of completing:	
Address or institution:	

Is this a problem? Yes	Some what	No	Your problems and needs for care	Do you want professional attention for this? Yes, more	As much as now	No
			Daily activities			
☐	☐	☐	**Body care, washing, dressing, or toilet**	☐	☐	☐
☐	☐	☐	**Personal transportation** (cycling, driving a car, using public transportation etc.)	☐	☐	☐
☐	☐	☐	**Doing light housework** (tidying up, etc.)	☐	☐	☐
			Physical symptoms			
☐	☐	☐	**Pain**	☐	☐	☐
☐	☐	☐	**Fatigue**	☐	☐	☐
☐	☐	☐	**Sleeping problems**	☐	☐	☐
☐	☐	☐	**Shortness of breath**	☐	☐	☐
☐	☐	☐	**Cough**	☐	☐	☐
☐	☐	☐	**Itch**	☐	☐	☐
☐	☐	☐	**Sexual dysfunction**	☐	☐	☐
☐	☐	☐	**Prickling or numb sensation**	☐	☐	☐
☐	☐	☐	**(Nightly) Sweating or hot flushes**	☐	☐	☐
			Autonomy			
☐	☐	☐	**Difficulties in continuing the usual activities**	☐	☐	☐
☐	☐	☐	**Difficulty to give tasks out of hands**	☐	☐	☐
☐	☐	☐	**Being dependant of others**	☐	☐	☐
☐	☐	☐	**Experiencing loss of control over ones life**	☐	☐	☐
			Social issues			
☐	☐	☐	**Problems in the relationship with life companion**	☐	☐	☐
☐	☐	☐	**Difficulties in talking about the disease with life companion**	☐	☐	☐
☐	☐	☐	**Finding it difficult to talk about the disease, because of not wanting to burden others**	☐	☐	☐
☐	☐	☐	**Finding others not receptive to talking about the disease**	☐	☐	☐
☐	☐	☐	**Difficulties in finding someone to talk to** (confidant)	☐	☐	☐

Continued on the next page

© Centre for quality of care research, WOK, Radboud University Nijmegen

CENTRE FOR QUALITY OF CARE RESEARCH

Is this a problem? Yes	Some what	No	Your problems and needs for care	Do you want professional attention for this? Yes, more	As much as now	No
			Psychological issues			
☐	☐	☐	**Depressed mood**	☐	☐	☐
☐	☐	☐	**Fear of physical suffering**	☐	☐	☐
☐	☐	☐	**Fear of metastases**	☐	☐	☐
☐	☐	☐	**Difficulty coping with the unpredictability of the future**	☐	☐	☐
☐	☐	☐	**Difficulties to show emotions**	☐	☐	☐
			Spiritual issues			
☐	☐	☐	**Difficulties to be engaged usefully**	☐	☐	☐
☐	☐	☐	**Difficulties to be of avail for others**	☐	☐	☐
☐	☐	☐	**Difficulties concerning the meaning of death**	☐	☐	☐
☐	☐	☐	**Difficulties to accept the disease**	☐	☐	☐
			Financial problems			
☐	☐	☐	**Extra expenditures because of the disease**	☐	☐	☐
☐	☐	☐	**Loss of income because of the disease**	☐	☐	☐
			Need of information			
☐	☐	☐	**Insufficient information e.g. about the disease and its treatment, aids and agencies that can provide help, alternative healing methods, etc.**	☐	☐	☐
			Are important issues missing from this list? Please add your personal issues below!			
☐	☐	☐	_____	☐	☐	☐
☐	☐	☐	_____	☐	☐	☐
☐	☐	☐	_____	☐	☐	☐
☐	☐	☐	_____	☐	☐	☐
☐	☐	☐	_____	☐	☐	☐

Space for your remarks or questions

End of the questionnaire.

To be completed by the researcher

Demographic Questionnaire

Sex

- **Male**
- **Female**

Age .....

Educational level

- No school
- Primary school
- Middle school
- High school
- Tertiary level

Marital status

- Single
- Married
- Divorced
- Separated
- Widowed

First Language .....

Employment

- Full time
- Part time
- Piece jobs
- Unemployed
- Pensioner

Professional care

- Yes
- No

Household

- Husband and children
- Wife and children
- Wife
- Husband
- Husband and grandchildren
- Alone
- Grandchildren

Primary Carer

- Children
- Spouse
- Relative
- Grandchildren
- Neighbour

Primary illness.....

Co-Morbidity

- .....
- .....
- .....
- .....

APPENDIX II

- **CONSENT FORMS**

Study title: Palliative care in rural primary health care

Good day. I am Dr Lesley Mahole, a 2nd year postgraduate student at the University of Witwatersrand studying towards an MMed in Family Medicine.

Introduction

We are doing a research to assess the Perceptions of terminally ill patients concerning the palliative care they receive in rural primary health care. Terminally ill patients who are being taken care of at home or at the old age home, whose information has been accessed, will be visited if they consent to, interviewed using an administered validated questionnaire.

Invitation to participate: we are asking/inviting you to take part in the research project intended to assess perceptions of terminally ill patients concerning the palliative care they receive in rural primary health care.

What is involved in the study-?

An initial audit of the numbers of patients being treated will be done to assess the total number of patients. This will be done by retrieving information from the referral hospitals e.g. oncology department, renal department etc as well as the numbers at the 3 facilities being researched.

Recruitment of patients: A research assistant will be trained to identify the patients based on their clinical history at each of the 3 facilities in order to compile a recruitment list. WBOTs (Ward Based Outreach Team members) will also help to identify those who are classified as end stage illness but are unable to come to hospital and are mostly being cared for at home. The research assistant will take the patient to a private room and give or read the patient the information letter and obtain consent to participate in the study. It will be explained to the patient that the researcher will either consult the patient at the hospital when s/he collects medicine

or do a home visit. Those on the recruitment list and not traced at the facilities shall be telephonically contacted and consent for the visit be requested. The research assistant will mark the file of patients recruited with a green sticker, irrespective if they agreed to participate or not. This will prevent that patients feel pressurised to take part in the study.

Data collection: The researcher will administer the questionnaires at the three sites and for those who consented to home visits, administered it at their homes. Home visits is part of the family medicine principles as the home visit extends the boundaries and is thus of additional benefit to the research in palliative care. The questionnaires will be kept by the researcher in a safe place.

AIM OF THE STUDY

To assess perceptions of terminally ill patients concerning the palliative care they receive in rural primary health care

OBJECTIVES OF THE STUDY

1. To determine the social demographics and clinical profile of patients participating in this study.
2. To describe the patients' perceptions of their problems and needs in palliative care.
3. To statistically associate demographic and clinical variables and problems and need questionnaire variables for any significant associations.

Risk: There are no risks to participating in this study

Benefits: There are no direct benefits to the participants

Participation is voluntary, refusal to participate will involve no penalty, and the participants may discontinue participation at any time without penalty.

Ethical considerations. No patient's career particular's or identifying diagnosis shall be disclosed, all the information shall be treated as confidential, and the patients shall be coded to ensure anonymity. However no absolute confidentiality can be

guaranteed. A clear letter describing the research process will be given to each patient/carer which will be signed by them if they consent to be part of the study. Information will be made available in a simple sheet with the researcher name and contact details. This will also request written consent and will need to be signed by each respondent. Organizations that may inspect and/copy the research records for quality assurance and data analysis includes groups such as Research Ethics Committee of the university of the Witwatersrand health.

Contact details of researcher and research supervisor

Dr L Mahole: 0182642197

Prof Claire van Deventer: 018-2975060

Contact details of HREC administrator and chair

Prof Cleaton -Jones: 011-7171234

.....

Consent form

I .....hereby give permission to participate in the study to assess Perceptions of terminally ill patients concerning the palliative care they receive in rural primary health care. I have read the information sheet and understood well what the study entails, I also understand that I am not forced to participate in the study and if I agree to participate I can withdraw at any time without any negative implication on me.

There is no immediate personal gain from the study and the is potential harm that I may experience. The researcher has attended to my questions and explained the process to me.

.....

Signature

.....

Date

APPENDIX III

- **ETHICAL CLEARANCE CERTIFICATE**

R14/49 «Tit init name»

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M170107

NAME: (Principal Investigator)	Dr Lesley Mahole
DEPARTMENT:	Family Medicine JB Marks Health Centre, Ventersdorp Hospital
PROJECT TITLE:	To Assess Patients' Perceptions of the Quality of Palliative Care in the Ventersdorp Subdistrict
DATE CONSIDERED:	27/01/2017
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof C Van Deventer
APPROVED BY:	Professor P. Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	31/05/2017

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review in March and will therefore be due in the month of March each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX IV

- **PERMISSIONS**

Title:	A practical instrument to explore patients' needs in palliative care: the Problems and Needs in Palliative Care questionnaire — short version:
Author:	Bart H.P. Osse, Myrra J.F.J. Vernooij-Dassen, Egbert Schadé, Richard P.T.M. Grol
Publication:	Palliative Medicine
Publisher:	SAGE Publications
Date:	07/01/2007
Copyright © 2007, © SAGE Publications	

If you're a copyright.com user, you can login to RightsLink using your copyright.com credentials.

Already a RightsLink user or want to learn more?

Gratis Reuse

Permission is granted at no cost for use of content in a Master's Thesis and/or Doctoral Dissertation. If you intend to distribute or sell your Master's Thesis/Doctoral Dissertation to the general public through print or website publication, please return to the previous page and select 'Republish in a Book/Journal' or 'Post on intranet/password-protected website' to complete your request.

health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

3 Belfuro Building
Van Riebeck Street
Ventersdorp, 2710
Private Bag X1007
Ventersdorp
2710

Tel: (018) 264 3251
Fax: 018 264 2358
galebos@nwpg.gov.za

2030 NDP

VENTERSDORP SUB DISTRICT

Date: 17 May 2017

To: **Mr EN Lesupi**
PHC Manager

From: **Dr. L Mahole**

Request for permission to conduct a study

Study title: **To assess patient's perception of the quality of palliative care in the Ventersdrop Subdistrict**

Good day, I am Dr Lesley Mahole, a postgraduate student at the University of Witwatersrand studying towards an Mmed in Family Medicine.

Introduction
I am intending to do a research to find out how patients living with incurable disease feel about the treatment or care they receive in a rural primary health care.

What is involved in the study.
I would like to better understand how patients feel about the problems caused by their illness, and their need for help from medical staff. This will involve going through patient's files at Oncology department to identify patients eligible for the study. Patients will then be followed up and requested to participate in the study. If they agree Consent form will be issued for them to sign then questionnaire administered for them to complete.
Those who will be involved are patients with cancer, XDR TB, HIV, kidney and Lung diseases

There is no risks to participating in these study, however if it is found that patient is having social or psychological problem needing a social worker or psychologist, he or she shall be referred should they so wish. There is no direct benefit except that the researcher except that the researcher will try to understand problems so that we may look at ways of improving care. Participants are free to refuse to be part of the study or to leave at any time without this having impact on the care you will receive. Their names and diagnoses will be kept confidential.
I am therefore requesting to be granted permission to conduct the study

Healthy Living for All





DIRECTOR DHS: DR KENNETH KAUNDA DISTRICT

1

health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

TO: Dr GL Mabele
Fam Med Registrar
Student No. 780729
Email: Drlea@live.com

18 July 2018

Re: REQUEST FOR APPROVAL TO CONDUCT RESEARCH STUDY

This serve to confirm the approval for your request to conduct a research study in Ventersdorp Subdistrict and Klerksdorp/Tshepong complex, after your presentation of the study. This is based on the fact that as a post graduate student pursuing the Mmed studies at Witwatersrand University you must submit research report, and is also based on the provision that your research is granted ethical clearance.
Research study: **To assess patient's perception of the quality of palliative care in the Ventersdorp Subdistrict.**

The district hope you find this approval in order and wish you luck with your studies

Permission is provisionally granted by

Mr LM Molot
Director DHS
Dr Kenneth Kaunda District

1

Healthy Living for All

APPENDIX V

- **TURN-IT-IN REPORT**

780729:Mahole_780729_Turnitin _(2).docx

by Goitseone Mahole

Submission date: 13-Jan-2021 03:20PM (UTC+0200)
Submission ID: 1486847283
File name: 381b-2dca-48a5-9cb7-a2d1f54e5a27_Mahole_780729_Turnitin__2.docx (87.55K)
Word count: 5056
Character count: 27933

13%
SIMILARITY INDEX

10%
INTERNET SOURCES

8%
PUBLICATIONS

34

-

5%
STUDENT PAPERS

1%

1%

1%

1%

1%

1%

1%

1%

1%

780729:Mahole_780729_Turnitin_(2).docx
ORIGINALITY REPORT
PRIMARY SOURCES

docplayer.net
Internet Source

bmcpalliatcare.biomedcentral.com
Internet Source

phcfm.org
Internet Source

journals.sagepub.com
Internet Source

bmchealthservres.biomedcentral.com
Internet Source

hdl.handle.net

35

Internet Source
www.journals.ac.za
Internet Source
Submitted to Institute of Technology, Tralee
Student Paper
"Palliative Care for Chronic Cancer Patients in the Community", Springer Science and

<1%

<1%

<1%

<1%

<1%

<1%

<1%

<1%

Business Media LLC, 2021
Publication
N. Wearne, B. Davidson, T. Motsohi, M. McCulloch, R. Krause. "Radically Rethinking Renal Supportive and Palliative Care in South Africa", Kidney International Reports, 2020
Publication
Linda J Kristjanson, Samar Aoun. "Palliative Care for Families: Remembering the Hidden Patients", The Canadian Journal of Psychiatry,

36

2016
Publication
"EAPC Abstracts", Palliative Medicine, 2019
Publication
Submitted to University of KwaZulu-Natal
Student Paper
uclainnovates.org
Internet Source
Submitted to University of Maryland, University College
Student Paper
Submitted to Portage Northern High School
Student Paper
scholarsrepository.llu.edu
Internet Source

<1%

<1%

<1%

<1%

<1%

<1%

<1%

<1%

<1%

Submitted to University of Plymouth

37

Student Paper

T. Gross. "Multiple-trauma management: standardized evaluation of the subjective experience of involved team members", European Journal of Anaesthesiology, 09/15/2005

Publication

acds.co.za

Internet Source

uncdf.org

Internet Source

www.researchsquare.com

Internet Source

curationis.org.za

Internet Source

www.health.gov.za

Internet Source

R Harding. "Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence", Sexually Transmitted Infections, 2005

Publication

Bart H.P Osse, Myrra J.F.J Vernooij-Dassen, Egbert Schadé, Berna de Vree, Maria E.T.C van

<1%

<1%

<1%

<1%

<1%

38

den Muijsenbergh, Richard P.T.M Grol. "Problems to discuss with cancer patients in palliative care: a comprehensive approach", Patient Education and Counseling, 2002
Publication

Gbotemi Bukola Babatunde, André Janse van Rensburg, Arvin Bhana, Inge Petersen. "Stakeholders' perceptions of child and adolescent mental health services in a South African district: a qualitative study", International Journal of Mental Health Systems, 2020
Publication

"Public Policy in ALS/MND Care", Springer Science and Business Media LLC, 2021
Publication

B. H.P. Osse. "A practical instrument to explore patients' needs in palliative care: the Problems and Needs in Palliative Care questionnaire short version", Palliative Medicine, 07/01/2007
Publication

Minimally Invasive Bariatric Surgery, 2015.
Publication

doaj.org
Internet Source

Exclude quotes On
Exclude bibliography On
Exclude matches < 7 words

39

APPENDIX VI

- **PROOFREADING CERTIFICATE**

From the desk of
F. E. Meyer
P. o. box 885
2041 HOUGTON
e-mail: meyer.fe576@gmail.com
https://meyerfe576.wixsite.com/editormysite
(Note: two full stops: one after 576 and one after wixsite

December 28th, 2020

ENGLISH PROOF-READING/EDITING

To Whom It May Concern

The journal article titled, 'Perceptions of terminally ill patients concerning the palliative care they receive in rural primary health care' to be submitted by Dr G.L. MAHOLE et al has been proof-read and edited for proper English language, syntax, grammar, punctuation, British English/South African spelling and overall style by F.E. MEYER. As requested, document formatting such as Times Roman 12 and Unicodes was applied to the journal article according to the African Journal of Primary Health & Family Medicine's guidelines for authors: https://phcfm.org/index.php/phcfm/pages/view/submission-guidelines#part_1. The 35 references were checked according to the standard Vancouver referencing style (also see AOSIS) as per the journal's guidelines. The research content and/or the authors' intentions were not altered during the process.

Blue highlighting will require the corresponding author's attention. The date on the footnote on this page corresponds with that of the attached proof-read and edited sections of the journal article. Any further proof-reading or editing required by the author(s), due to changes or amendments to this journal article will be accompanied by an updated covering page and will replace this covering page.

F.E. Meyer
F.E. MEYER
B.A. (UNISA)

Footnote: Proof reader's/Editor's covering page
Edited journal article *2020/12/28* *MAHO/01*

APPENDIX VII

- **RESEARCH PROPOSAL**

PERCEPTIONS OF TERMINALLY ILL PATIENTS CONCERNING THE PALLIATIVE CARE THEY RECEIVE IN RURAL PRIMARY HEALTH CARE

Mahole G.L

780729

MMedFamMed

Supervisor: Prof Claire Van Deventer

A research proposal to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements for the degree of
Master in Family Medicine

CONTENTS

1. Background of the study 2
2. Literature review 3
3. Aim and objectives 7
4. Method 8
   - 4.1 Design 8
   - 4.2 Site of study 8
   - 4.3 Population 9
   - 4.4 Sampling 9
   - 4.5 Data collection tools 9
   - 4.6 Reliability and validity 10
   - 4.7 Process 10
   - 4.8 Data analysis 11

5 Ethical consideration 11

6 Timing 12

7 Funding 13

8 Bias/limitation 13

9 References 14

1. BACKGROUND

Terminal illness is a medical condition that cannot be cured or completely treated and is reasonably expected to result in the death of the patient within a certain period of time. The term is used more for progressive diseases such as cancer or HIV than for trauma. In popular use, it indicates a disease that eventually ends the life of the sufferer. According to the World Health Organisation (WHO), palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritually"[1]. Palliative care will therefore include all the efforts aimed at providing a better quality of the remaining life of a terminally ill patient. In most cases that includes physical assistance (providing adequate analgesia regularly when needed or indicated), assisting with psychological or spiritual support e.g. helping the patient to arrange for prayer meetings with either members of the church or church leaders if so desired and legal help e.g. assisting patients with necessary information to finalise a will to distribute their assets amongst their nominated beneficiaries. There is a key role in all the above for palliative practitioners. A very good multidisciplinary team is also essential for these to be executed effectively.

The decision to conduct research on palliative care in a rural district hospital and community health centre was mostly influenced by the experience gained by the researcher, during a rotation in a palliative care block at an urban tertiary hospital. Based on this experience the researcher reflected on a few questions:

- Is the quality of palliative care given to the rural patients the best that can be given within the circumstances?
- Are there significant enough numbers of patients who need palliative care to warrant a programme being developed for them?
- Can similar services provided for terminally ill patients and their families in an urban area be transferred to this rural context?

Taking care of terminally ill patients was both a very emotional yet fulfilling experience. Palliative care ensured that the remainder of these patients' lives

were of a better quality and that the majority departed with a sense of being at peace.

With the above information in mind, the aim of this research is to assess patients' perceptions of the quality of palliative care in Ventersdorp sub district.

2. LITERATURE REVIEW

Introduction

According to WHO Global Health Estimates there were approximately 54.6 million deaths worldwide in 2011[2]. The great majority of deaths, 66%, are due to non-communicable diseases· it is further documented that globally, in 2011, over 29 million (29,063,194) people died from diseases requiring palliative care[2]. The estimated total number of people in need of palliative care at the end of life is 20.4 million according to the WHO global estimation and the number is divided into following percentages, 94% corresponds to adults of which 69% are over 60 years old and 25% are 15 to 59 years old. Only 6% of all people in need of palliative care are children[2].

The number of patients receiving specialised palliative care worldwide is unknown according to World Palliative Care Alliance, the only available record is of the United States where numbers of patients enrolled in the Medicare Hospice Benefit are tracked and documented[2]. However it is then estimated that the numbers of patients that die while receiving palliative care services are in the region of three million patients, or about 14% of those needing palliative care at the end of life worldwide [2]. According to the Non Communicable burden of disease, it is estimated that while globally the number of adult and child patients in need of end-of-life palliative care is 20.4 million, in Africa it is estimated that this figure is 1.8m, 346,203 of which are for cancer[3].

The following illnesses according to WHO/WPCA require palliative care[2]:

For adults: Alzheimer's and other dementias, cancer, cardiovascular diseases (excluding sudden deaths), cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, drug-resistant tuberculosis (TB).

From the above lists diseases requiring palliative care at the end of life were grouped in three categories namely: cancer, HIV/AIDS, and progressive non-malignant diseases in all the regions globally [3] Adults in need of palliative care for progressive non-malignant disease represent the highest proportion, HIV/AIDS predominates in the African Region[2]. By 2013, 24.7 million people in the sub-region were living with HIV/AIDS, 70.6 percent of the global disease burden[2]

There are already identified and documented barriers to formulations and implementations of effective palliative care programmes[3]. Psychological, social, cultural, and financial barriers have been some of the factors. Africa as a developing country has been lacking in palliative care due to socio-economic and cultural reasons[2].

In South Africa, the palliative care facilities are mainly managed by NGO groups e.g. the Hospice palliative care of South Africa[3]. According to The Hospice Palliative Care Association of South Africa, the US is the single biggest HIV/AIDS donor to South Africa, providing $3.2 billion since 2003 [3]. However, this annual funding to South Africa is expected to fall to $250 million by 2017 – roughly half the $484 million budgeted for 2012 and despite outside corporate funding, the association says they will be unable to secure sufficient donor support locally to make up the budget shortfall. Finances therefore are always under pressure, which impacts directly on care. The users of these facilities in South Africa are usually poor and terminally ill patients with HIV/AIDS [3].

Services Provided in Palliative Care

The aim of Palliative care as already mentioned earlier includes all the efforts aimed at providing a better quality of the remaining life of a terminally ill patient. And that includes physical assistance (providing adequate analgesia regularly when needed or indicated), assisting with psychological or spiritual support e.g. helping the patient to arrange for prayer meetings with either members of the church or church leaders if so desired and legal help e.g. assisting patients with necessary information to finalise a will to distribute their assets amongst their nominated beneficiaries. In already functional programmes all this are offered irrespective of a place where a patient is cared for at a particular time e.g.

admitted in a hospital or at a placement institution (hospice) or cared for at home. Those who are admitted in hospital and where no proper programme is established benefit mostly from the prescribed analgesia that is given according to a particular regimen. They are assisted with bathing, feeding and clothing if they are unable to do these themselves. So within our context basic nursing care is what palliative care with symptomatic relief of a patient's complaints. Those who are terminal will be admitted in the ward and this will be termed palliative care, whereas it will just be relief of their presenting physical complaints.

Three palliative care programmes were studied in Uganda, Kenya and Malawi[4]. Though constructed differently, all 3 programmes focused on delivering care which was culturally and contextually appropriate to the local conditions, and which attempted to deliver much more than pain relief, all on a limited budget. The programmes faced several key issues: how to provide effective palliative care in the face of poverty; how to encourage early identification of patients who would benefit; and how to develop effective and integrated referral systems. All programmes faced a new challenge of how to manage patients who would previously have died but are now surviving (due to antiretroviral therapy or successful amputations). In a study conducted in Canada in which a comparison of support needs between rural and urban family caregivers providing palliative care was done, it showed that rural caregivers experience greater unmet needs in receiving support for instrumental activities (tangible support) which has implications for the financial resources to run the programme. [5] However studies have shown that a holistic approach to palliative care can be rendered effectively in the face of poverty and that can be achieved with a good public health approach ensuring equitable provision of resources[4].

These experiences are similar to the program in the researcher's context, Ventersdorp. The challenges of the programmes is not the focus of this study, but results will have to interpreted against this background as these challenges directly link with the quality of service the program can render and the patients' perceptions of it.

Patients' Perceptions

Despite best efforts and policies, one-third or less of all deaths take place at home in many countries of the world.[6] There is also evidence that shows that when terminally ill patients are treated at home it reduces physical and emotional burdens and optimises resources e.g. less travel to and care at health facilities.[4] Evidence shows that well over 50% of people prefer to be cared for and to die at home provided circumstances allow choice.[6]Therefore good palliative care is needed, not only at institutions established to provide it, but at homes as well.

In programmes studied in Uganda, Kenya and Malawi, services brought essential pain relief to patients, reduced physical, emotional and spiritual suffering.[4] There was also increased support for family members to care for the patients in their home environments.[4] So patients' perceived palliative care to make a positive change to the quality of their remaining life.

A study done in Canada measured level of home palliative care services and quality of end-of-life indicators.[7] the result was that the government then increased spending on home care to promote better end-of-life care. Provision of home palliative care services remained limited in the province of Québec, but when present, they were associated with improved quality of end-of-life indicators, which meant amongst others improved levels of satisfaction among those receiving palliative care. This shows that with a good home-based palliative care programme, the remaining life of terminally ill patients can be made better.

Physical symptoms

A study conducted in rural Malawi identified a high prevalence of pain and psychosocial needs among patients with serious chronic illnesses[8]. In palliative care oral morphine was a vital and often new intervention in African programs which greatly benefited patients and helped staff to know they were providing effective care[4]. Within the researcher's context, staff is rendering health services on a very restricted budget, therefore with limited drug availability to patients.

Care giver support to ensure quality of care

As emotionally challenging as it can be taking care of a sick person, some do it without much professional knowledge or skills or support in the form of debriefing. A study was done in which a general health questionnaire was given to care givers of patients after a one-to-one psycho- educational intervention aimed at mitigating the distress of caregivers of patients with advanced cancer receiving home-based palliative care [9]. The results supported the existing evidence which demonstrates that relatively short psycho educational interventions can help family caregivers who are supporting a dying relative[9]. For every programme to run well, it must have skilled implementers. This means care givers who are involved in running the programme should receive adequate training to acquire necessary skills. Most patients who are terminally ill and cannot be accommodated in placement institutions are cared for at home. Family members, friends and relatives then become the custodians of the quality of the remaining life of that patient. This means sufficient information must be exchanged on the disease and the management of patient needs, what daily activities are realistic for the patient, e.g. bathing and clothing themselves, preparing meals, assistance with using bathrooms or nappy changes, applying and going to get their disability grants. And also how to deal with patient autonomy e.g. others even though would be physically unable to walk, may not prefer that pampers be used on them but rather be assisted to go to the bathroom. As it often cause conflict in the care giving situation, as well as the financial challenges and resources as assisting the patient to go use the bathroom when the need arise provided logistically is possible could save on the finances of purchasing sanitary pads. Finances currently are a major problem as donors from international institutions are no longer pledging same amount of funds to our local NGO'S as they used to before[13], and in South Africa most of the terminally ill patient are cared for in NGO's run facilities.

3. AIM AND OBJECTIVES

To assess patients' perceptions of the quality of palliative care in Ventersdorp sub district

1. To determine the social demographics and clinical profile of patients participating in this study.

2. To describe the patients' perceptions of their problems and needs in palliative care.
3. To statistically associate demographic and clinical variables and problems and need questionnaire variables for any significant associations.

4. METHODS

Design

This will be a quantitative cross sectional study including record reviews and an administered questionnaire.

Site of Study

Ventersdorp is a rural community. According to the local government handbook it is an area of 3764 km^2, situated within the Dr Kenneth Kaunda district municipality in the North West province, 45km away from Potchefstroom and 68km from Klerksdorp[10].

It has a population of about 56702, with 60.2% of the population being between the ages of 15 to 64. There are around 14562 households[10]. However there are also informal settlements that are not always captured statistically. There are five fixed clinics that are serviced on a daily basis by professional nurses, one community health care centre that operates for 24hours and a level one hospital which has just been downgraded to a community health care centre but still offers hospital services, one satellite clinic and one mobile clinic. An old age home/placement centre is available for those who cannot be taken care of at their homes, or for those who need palliative care. The centre is semi private with financial assistance from the government and NGO's.

The referral hospitals are Potchefstroom and Klerksdorp hospital, Klerksdorp hospital has a specialised Oncology department where Ventersdorp cancer patients receive treatment and are subsequently down referred when their oncology therapy e.g. radiotherapy is finished.

The national unemployment rate is 25.27%, whereas in the sub district it is 27%[10]. The economy of the area is mostly from the agricultural sector and many people are employed informally in the farms. Carletonville mines also employ a

number of community members. Indirectly, the farms and mining areas have been implicated in the rising numbers of HIV infections.[11] In the North West province, Dr Kenneth Kaunda district municipality (Dr KK)and Bojanala district are leading with HIV statistics, mostly due to their mining areas and informal settlements [11]. What is seen in these rural facilities as well are the high number of patients who default on their chronic treatments e.g. ARV's and as a result many of them progress quickly to end stages of disease e.g. end stage HIV, CVA's from uncontrolled hypertension and COPD. The three sites namely: JB Marks CHC, Ventersdorp CHC and Oncology department at Tshepong Hospital reflect both in-patient/bedridden patients and ambulatory patients.

Population

All patients with mainly cancer or terminal illness attending the three named clinics in Ventersdorp form part of the population.

Sampling

Purposive sampling will take place over a period of 3 months during which I will get information at our oncology units about the total number of patients who would currently be receiving treatment with them, together with those who will be coming as outpatients to collect treatment and or admitted.

Inclusion criteria: Patients over 18 with any malignancy; end stage HIV with debilitating illness e.g. TBM, XDR and end stage renal conditions. Patients living with chronic obstructive airway disease (COPD) patients on home oxygen will also be selected for the study. And also patients with complications of cardiovascular diseases e.g. CVA's .

Exclusion criteria: Patients living further than 15 km away from the hospital, patients that need translators e.g. unable to communicate well (e.g. Venda, Shona) and cannot speak any of the local languages commonly used e.g. English, Sotho, Zulu/Xhosa and Afrikaans. Patients who at the time of the interview will not be physically or mentally stable e.g. delirious patients and those who will be having acute exacerbations of their illnesses at the time of the research.

Data Collection Tools

Firstly a demographic and clinical questionnaire covers the following aspects, age and gender of the participant, level of literacy, employment history, parity and area of residence.

On the questionnaire aspects of daily living e.g., self-bathing, clothing, home chores, facilitation with taking treatments, doing administrative work e.g., going to the bank and shopping, shall be covered and also indications where additional or professional help is needed.

To explore the above, a questionnaire used in a similar study in Holland will be used. [12] The Problems and Needs in Palliative Care questionnaire (PNPC-sv) was developed for patients who were the recipients of palliative care to describe their perceptions concerning care they were receiving. [12] Quality of care is a social construct that takes different forms influenced by age, gender, social circumstances and state of health, it is therefore multi-dimensional and is highly personalised in how it is experienced[15]. Permission will be obtained to use their questionnaire to assess problems and needs of patients in palliative care. The questionnaire covers eight domains, namely: Daily activities; Physical symptoms; Autonomy; Social issues; psychological issues; Spiritual issues; financial problems and Need for information. The questionnaire assess firstly any needs and the eight domains and then if the patient needs intervention for it.

Reliability and Validity

Questions asked on the questionnaire are clear are clear and easy to understand, layout is easy to read and pleasant to the eye. They are easily explainable to anyone who may not be able to read. The questions used do measure what the research intend to measure or find out, and they are in relation to the objectives of the study.

The original Problems and Needs in Palliative Care questionnaire (PNPC)instrument is a comprehensive checklist of problems and needs for palliative care, and has shown validity and reliability[12]. It originally has 90 items, however it is not logistically always practical to use all of the items, and

it was abridged to a short version with 33 items. The validity and reliability are established with its item response, its internal consistency, and with its correlations with the original PNPC and with European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 and COOP/WONCA quality-of-life measures. A secondary analysis was done with data from 94 patients with metastatic cancer who had completed the long version and results were as follows: Each item in the PNPC represents a problem relevant to 25% of the patients or more. High correlations of PNPC-sv and PNPC domains demonstrate construct validity. The dimension reliability was satisfactory (Cronbach's of 0.70), while two problem-aspect domains were less coherent. The PNPC-sv domains show convergent validity with corresponding health-related quality-of-life domains.[12]

Process

An initial audit of the numbers of patients being treated will be done to assess the total number of patients. This will be done by retrieving information from the referral hospitals e.g. oncology department, renal department etc as well as the numbers at the 3 facilities being researched.

Recruitment of patients: A research assistant will be trained to identify the patients based on their clinical history at each of the 3 facilities in order to compile a recruitment list. WBOTs (Ward Based Outreach Team members) will also help to identify those who are classified as end stage illness but are unable to come to hospital and are mostly being cared for at home; they will the assist with getting consent from the patients to be visited for interview. The research assistant will take the patient to a private room and give or read the patient the information letter and obtain consent to participate in the study. It will be explained to the patient that the researcher will either consult the patient at the hospital when s/he collects medicine or do a home visit. Those on the recruitment list and not traced at the facilities shall be telephonically contacted and consent for the visit be requested. The research assistant will mark the file of patients recruited with a green sticker, irrespective if they agreed to participate or not. This will prevent that patients feel pressurised to take part in the study.

Data collection: The researcher will administer the questionnaires at the three sites and for those who consented to home visits, administered it at their homes. Home visits is part of the family medicine principles as the home visit extends the boundaries and is thus of additional benefit to the research in palliative care. The questionnaires will be kept by the researcher in a safe place. Data capturing will be done by the researcher as the data is collected. Data will be on the researcher's private laptop and password protected. Data will also be stored on backup system. Data will be statistically analysed.

Data Analysis

1. Descriptive statistics will be used for demographic and clinical data. This includes the following variables (e.g. gender, age, and race). Chi-square test will be used to compare variables of the three questionnaires (To statistically associate demographic and clinical variables and problems and need questionnaire variables for any significant associations.) for statistical significance. A statistician at Wits Research Support office will be consulted.

5. ETHICAL CONSIDERATIONS.

- Consent to the research will be obtained from the different settings, North West Province and Wits HREC. Completion of the questionnaires will be anonymous and thus will patient identifiers remain confidential. The patient will receive an information sheet and sign consent (See Annexure 1).

- Potential harm: there is no direct potential harm to the participants, however if patient/participant will be found in a not stable condition at the time of interview necessary referral shall be made.

6. **TIMING**

Research Gantt chart

	June	July	August	September	October	November	December	January	February	March	April	May
Submission of protocol to review P G committee	X											
Re Submission of corrections to PG		X										
Submission to Ethics Committee			X									
Turn Around time from Ethics						X						
Collection of Data							X	X				
Meeting with Supervisor prior to research									X			
Actual Research									X			
Meeting with supervisor										X		
Analysis of Data										X		
Compiling Research finding											X X	
Meeting with supervisor and making of recommendations												X X

7. FUNDING

The researcher will apply for funding from Wits and what is not covered, use personal funds to cover the costs for this research.

ITEM	Unit price	Cost
Duplication of information sheet	100 x 50c	50.00
Duplication of consent forms	100 x 50c	50.00
Duplication of questionnaires	5 pages x 50c each x 100 questionnaires	250.00
Gift for WBOT for recruitment	R250 x3	750
Compensation for research assistant	R500	
Travelling	500 km x R3.35	1675.00
Language editor	R2000	2000.00
TOTAL COST		**4725**

8. BIAS/LIMITATIONS

- As a structured questionnaire is used, bias to elicit information will be limited. Inter recruiter bias may exist as different WBOT team members will approach the patients as well as a research assistant in the different settings. The researcher will limit this bias by training the WBOT and research assistant on the inclusion criteria and ethical approach of a patient to take part in research. The researcher will also teach the recruiters how to deal with questions and to respect the patient wish if the patient declines to take part.

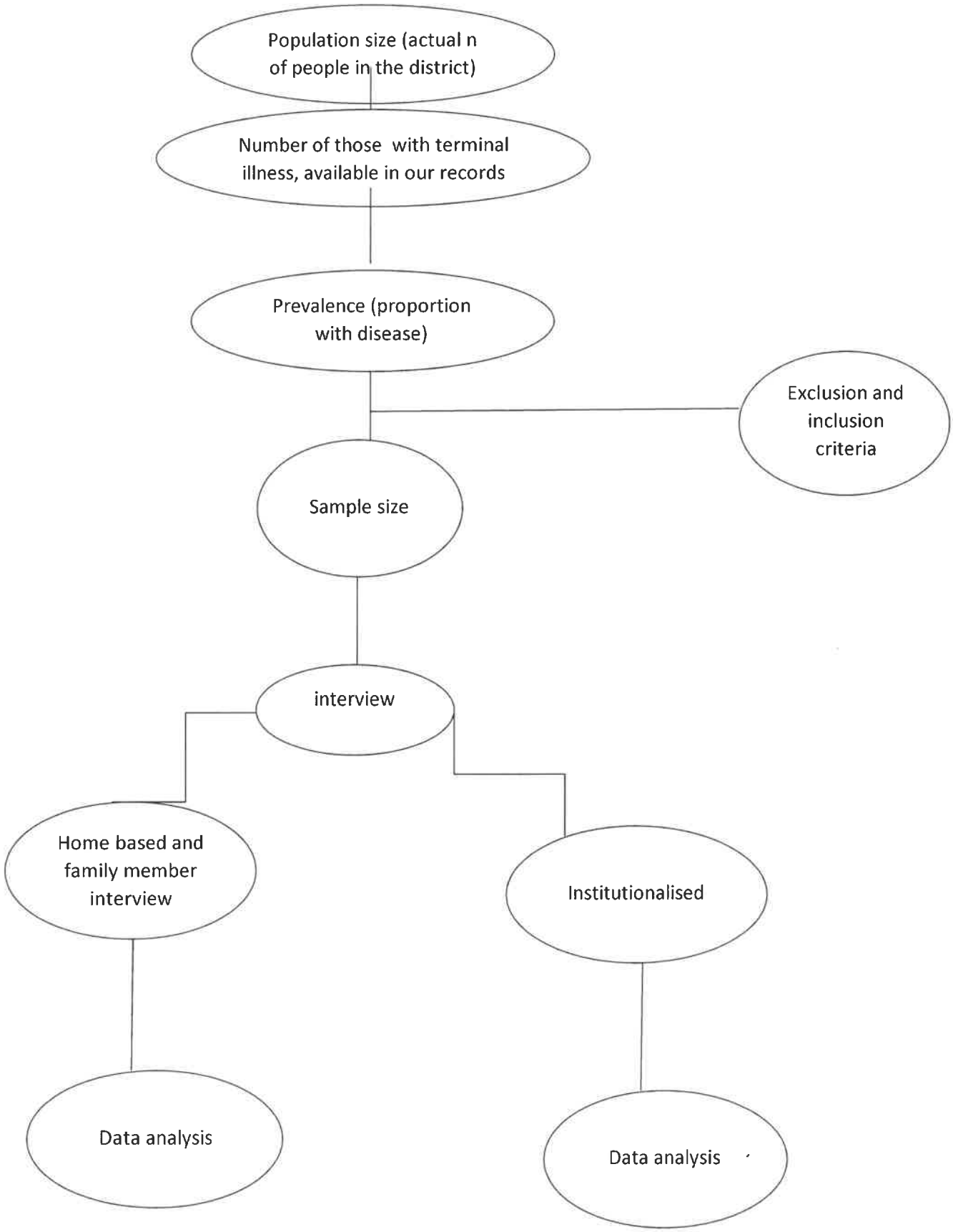
- One of the limitations in this study is limited resources e.g. availability of drugs and the logistics of supplying drugs to those patients who are unable to fetch their medications. Patients may have problems with it not so much as a patient factor, but as a system factor. The researcher will not assess system factors that contribute to problems patients' experience.

REFERENCES

1. WHO definition World Health Organization
   Available: http://www.who.int/cancer/palliative/definition/en/ [Accessed on the 9 June 2016]
2. Connor SR, Bermedo MCS. Global Atlas of Palliative Care at the End of Life. World Health Organization / Worldwide Palliative Care Alliance, Geneva / London, 2014.
   Available: www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf [Accessed on the 8th August]
3. Joint United Nations Programme on HIV/AIDS. The Gap Report. Geneva. UNAIDS, 2014.
   Available:
   www.unaids.org/.../unaids/.../unaidspublication/2014/UNAIDS_Gap_rep
   [Accessed_on the 8th August 2015]
4. Grant L, Leng J, Bettega M, Murray N, Scott A.2011. Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. *BMC Palliative Care.,*10:8
5. Gomez-Batistel X, Martinez-Munozol M, Blay C, Amblas J, Costa X, Villanueva A,et al. 2013. Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia. *BMJ Support Palliat Care.,* 3(3):300-8
6. Gomes B, Higginson IJ, McCrone P. Effectiveness and cost effectiveness of home palliative care services with advanced illness and their caregivers.2009. *Cochrane Database of Systematic Reviews.,*2: 32-33
7. Gorgon B, Nadeau L, Scott S, Dumont S, Macdonald N.2015. Association between home palliative care services and quality of end of life care indicators in the province of Quebec. *J Pain Symptom Manage.,*1(50): 48-58
8. Grant L, Mhoira B, Nadia M, Scott A.2011. Assessing and Responding to Palliative Care Needs in Rural Sub-Saharan Africa: Results from a Model Intervention and Situation Analysis in Malawi. *BMC Palliative Care.,* 10:8
9. Hudson P, Trauer T, Kelly Bl. 2013. Reducing the psychological distress of family caregivers of home based palliative care patients: short term effects from a randomised controlled trial. *Psycho oncology Journal.,* 22: 1987-1993

10. The local government handbook: A complete guide to municipalities in South Africa.
11. Available: http://www.localgovernment.co.za/locals/view/195/Ventersdorp-Local-Municipality [Accessed on the 15th July 2016]
12. South Africa: Miners facing Huge HIV/AIDS Challenge from CDC National Prevention Information Network. It is a part of the publication *HIV/Hepatitis/STD/TB Prevention News Update*. November 17, 2008. [Accessed on the 10/09/2016]
13. http://www.thebody.com/content/art49484.html
14. Bart O, Vernooij-Dassen MJFJ.2007. A practical instrument to explore patients' needs in palliative care: the Problems and Needs in PalliativeCare questionnaire – short version. *Palliative Medicine.,* 21: 391–399
15. PROFMED. Improved funding for South African hospices crucial to the stability of local healthcare system. 2013
16. Available: http://www.profmed.co.za/News-Blog/Blog/Profmed-Improved-Funding-for-SA-Hospices [Accessed on the 10th August 2016]
17. Hudson L P, Remedios C, Thomas K.2010. A systematic review of psychosocial intervention for family carers of palliative care patients. *BMC Palliative Care.,* 9: 17
18. Mitchell G, Nicholson C, McDonald K, Bucetti A.2011. Enhancing palliative care in rural Australia, the residential aged care setting. *Australlian Journal of Primary Health.*, 17(1): 95-101
19. Goodridge D, Duggleb W.2010. Using a quality framework to assess rural palliative care. *Journal of Palliative Care.,* 26: 141-15

Flow diagram of proposed study



Title:	A practical instrument to explore patients' needs in palliative care: the Problems and Needs in Palliative Care questionnaire — short version:	If you're a copyright.com user, you can login to RightsLink using your copyright.com credentials.
Author:	Bart H.P. Osse, Myrra J.F.J. Vernooij-Dassen, Egbert Schadé, Richard P.T.M. Grol	Already a RightsLink user or want to learn more?
Publication:	Palliative Medicine	
Publisher:	SAGE Publications	
Date:	07/01/2007	
Copyright © 2007, © SAGE Publications		

Gratis Reuse

Permission is granted at no cost for use of content in a Master's Thesis and/or Doctoral Dissertation. If you intend to distribute or sell your Master's Thesis/Doctoral Dissertation to the general public through print or website publication, please return to the previous page and select 'Republish in a Book/Journal' or 'Post on intranet/password-protected website' to complete your request.

Copyright © 2016 Copyright Clearance Center, Inc. All Rights Reserved. Privacy statement. Terms and Conditions.
Comments? We would like to hear from you. E-mail us at customercare@copyright.com

Number:

CENTRE FOR QUALITY OF CARE RESEARCH

PROBLEMS and NEEDS in PALLIATIVE CARE questionnaire

version: PNPC-sv-engl 2005

© Centre for quality of care research, WOK, Radboud University Nijmegen

Instructions:

This questionnaire is designed to clarify what problems you experience, and for what issues you need (extra) attention or care.

At each item you will be asked 2 questions:

- **Left:** Do you experience the item to be a **problem**?
- **right:** Do you need (extra) professional **attention** for the item?

So, please provide 2 answers at each item !!

Name:	*Date of birth:*
Date of completing:	
Address or institution:	

© Centre for quality of care research, WOK, Radboud University Nijmegen

CENTRE FOR QUALITY OF CARE RESEARCH

Is this a problem?			Your problems and needs for care	Do you want professional attention for this?		
Yes	Some what	No		Yes, more	As much as now	No
			Daily activities			
☐	☐	☐	**Body care, washing, dressing, or toilet**	☐	☐	☐
☐	☐	☐	**Personal transportation** (cycling, driving a car, using public transportation etc.)	☐	☐	☐
☐	☐	☐	**Doing light housework** (tidying up, etc.)	☐	☐	☐
			Physical symptoms			
☐	☐	☐	**Pain**	☐	☐	☐
☐	☐	☐	**Fatigue**	☐	☐	☐
☐	☐	☐	**Sleeping problems**	☐	☐	☐
☐	☐	☐	**Shortness of breath**	☐	☐	☐
☐	☐	☐	**Cough**	☐	☐	☐
☐	☐	☐	**Itch**	☐	☐	☐
☐	☐	☐	**Sexual dysfunction**	☐	☐	☐
☐	☐	☐	**Prickling or numb sensation**	☐	☐	☐
☐	☐	☐	**(Nightly) Sweating or hot flushes**	☐	☐	☐
			Autonomy			
☐	☐	☐	**Difficulties in continuing the usual activities**	☐	☐	☐
☐	☐	☐	**Difficulty to give tasks out of hands**	☐	☐	☐
☐	☐	☐	**Being dependant of others**	☐	☐	☐
☐	☐	☐	**Experiencing loss of control over ones life**	☐	☐	☐
			Social issues			
☐	☐	☐	**Problems in the relationship with life companion**	☐	☐	☐
☐	☐	☐	**Difficulties in talking about the disease with life companion**	☐	☐	☐
☐	☐	☐	**Finding it difficult to talk about the disease, because of not wanting to burden others**	☐	☐	☐
☐	☐	☐	**Finding others not receptive to talking about the disease**	☐	☐	☐
☐	☐	☐	**Difficulties in finding someone to talk to** (confidant)	☐	☐	☐

Continued on the next page

Number:

CENTRE FOR QUALITY OF CARE RESEARCH

PROBLEMS and NEEDS in PALLIATIVE CARE questionnaire

version: PNPC-sv-engl 2005

© Centre for quality of care research, WOK, Radboud University Nijmegen

Instructions:

This questionnaire is designed to clarify what problems you experience, and for what issues you need (extra) attention or care.

At each item you will be asked 2 questions:

- **Left:** Do you experience the item to be a **problem**?
- **right:** Do you need (extra) professional **attention** for the item?

So, please provide 2 answers at each item !!

Name:	*Date of birth:*
Date of completing:	
Address or institution:	

© Centre for quality of care research, WOK, Radboud University Nijmegen

CENTRE FOR QUALITY OF CARE RESEARCH

Is this a problem?			Your problems and needs for care	Do you want professional attention for this?		
Yes	Some what	No		Yes, more	As much as now	No
			Daily activities			
☐	☐	☐	**Body care, washing, dressing, or toilet**	☐	☐	☐
☐	☐	☐	**Personal transportation** (cycling, driving a car, using public transportation etc.)	☐	☐	☐
☐	☐	☐	**Doing light housework** (tidying up, etc.)	☐	☐	☐
			Physical symptoms			
☐	☐	☐	**Pain**	☐	☐	☐
☐	☐	☐	**Fatigue**	☐	☐	☐
☐	☐	☐	**Sleeping problems**	☐	☐	☐
☐	☐	☐	**Shortness of breath**	☐	☐	☐
☐	☐	☐	**Cough**	☐	☐	☐
☐	☐	☐	**Itch**	☐	☐	☐
☐	☐	☐	**Sexual dysfunction**	☐	☐	☐
☐	☐	☐	**Prickling or numb sensation**	☐	☐	☐
☐	☐	☐	**(Nightly) Sweating or hot flushes**	☐	☐	☐
			Autonomy			
☐	☐	☐	**Difficulties in continuing the usual activities**	☐	☐	☐
☐	☐	☐	**Difficulty to give tasks out of hands**	☐	☐	☐
☐	☐	☐	**Being dependant of others**	☐	☐	☐
☐	☐	☐	**Experiencing loss of control over ones life**	☐	☐	☐
			Social issues			
☐	☐	☐	**Problems in the relationship with life companion**	☐	☐	☐
☐	☐	☐	**Difficulties in talking about the disease with life companion**	☐	☐	☐
☐	☐	☐	**Finding it difficult to talk about the disease, because of not wanting to burden others**	☐	☐	☐
☐	☐	☐	**Finding others not receptive to talking about the disease**	☐	☐	☐
☐	☐	☐	**Difficulties in finding someone to talk to** (confidant)	☐	☐	☐

Continued on the next page

THESIS SUBMISSION FORMS

APPLICATION FOR CHANGE OF TITLE OF APPROVED RESEARCH REPORT, DISSERTATION OR THESIS

Student Surname and Initials: Mahole G.L_ Student Number: 780729

Degree: Mmed Family Medicine__ Department: Family Medicine_ Telephone: 0182642197_ E-mail: Dries@live.com

Current Title:

Perception of terminally ill patients concerning the palliative care they receive in rural primary health care _____

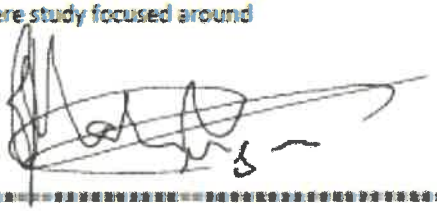
New Title:

Perception of terminally i patients concerning the palliative care they received in rural primary health care, Ventersdorp Subdistrict

Motivation / Reason for title change:

New title seemed more appropriate and was changed as research study unfolded to emphasize the specific rural primary health care where study focused around

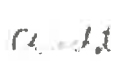
Approvals / signatures:

Student Signature:  Date: 31-12-2020

Supervisor 1 – Name & Surname: Dr C. Lion-Cachet_

Department: Family Medicine

Supervisor Telephone: _0833957376 Supervisor E-mail: _____carienlc@koshcom.co.za_____



Supervisor Signature: _____ Date: 31-12-30

Supervisor 2 – Name & Surname: _____

Department: _____

Supervisor Telephone: _____ Supervisor E-mail: _____

Supervisor Signature: _____ Date: _____

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG | FACULTY OF HEALTH SCIENCES

CERTIFICATE OF SUBMISSION FOR EXAMINATION SIGNED BY SUPERVISORS OF HIGHER DEGREES CANDIDATES

Full name	Goitseone Lesley Mahole
Student number	780729

Candidate for the degree of: Mmed Family Medicine

has submitted his/her thesis/dissertation/research report

ENTITLED: PERCEPTIONS OF TERMINALLY ILL PATIENTS CONCERNING THE PALLIATIVE CARE THEY RECEIVE IN RURAL PRIMARY HEALTH CARE.

Contact no	0783351531	E-mail	Dries@live.com

Mark with an X on appropriate box	Yes	No
Has this thesis/dissertation/research report been submitted with the acquiescence of the supervisor?	x	
To the best of your knowledge are you able to verify that this is the candidate's work, except as otherwise stated by the candidate?	x	
The substance (nor any part of it) has not been submitted in the past nor is being submitted for a degree in any other university?	x	
The candidate has acknowledged wherever any information used in the thesis, dissertation or other work has been obtained by him/her while employed by, or working under the aegis of, any person or organization other than the University or its associated institutions?	x	
Have examiners been nominated and approved?	x	

I certify that this thesis/dissertation/research report has the approval of the Animal Ethics Committee / Committee for Research on Human Subjects and the Number of the Certificate of Approval is:

M170107

List all publications, which your student has published in peer-reviewed journals from his/her postgraduate research report/dissertation/thesis during the course of his/her studies in the Faculty of Health Sciences (Include authors, year, title of paper, name of journal, volume number and page numbers). This information is mandatory.

N/A

1

Name of Supervisor 1: H.C. Lion-Cachet

Telephone: 0833957376 Email: carienlc@koshgcom.co.za

Signature: Date: 30 Dec 2020

Name of Supervisor 2: _____

Telephone: _0825553597 Email: ____deidre.pretorius@wits.ac.za

Signature: ___ _____ Date: __30 Dec 2020

==========

IMPORTANT NOTICE WITH REGARD TO THE SENATE STANDING ORDERS:

A.22 Submission against advice of Supervisor

If the Supervisor is not prepared to agree to the submission of a thesis, the candidate shall still be entitled, if he or she wishes, to submit it for examination. When a thesis is submitted against the advice of the Supervisor, this should be recorded in the minutes of the Faculty Graduate Studies Committee. In such a case, no internal examiners are appointed but a Supervisor's report will still be required. After the examination process, the external examiner(s) will be advised by the Chairperson of the Faculty Graduate Studies Committee that the thesis was submitted against the advice of the Supervisor.

A.24 *Nomination of Examiners*:

Nomination of examiners should take place at least six weeks before submission of the thesis or dissertation. (The Postgraduate Office will not accept any submission for examination without the confirmed appointment of the nominated examiners.)

A.25 Confidentiality of names of examiners (both external and internal)

The names of the examiners should be confidential during the examination process and may only be revealed to the candidate with the acquiescence of the examiner once the final version of the thesis has been submitted to the Faculty and the process has been completed.

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

Dr Goitseone Lesley Mahole (780729)
PO Box 615
Setlagole
2772
North West

13 April 2021

Dear Dr Mahole

RESEARCH EXAMINATION OUTCOME – Master of Medicine (Family Medicine)

We have received feedback from the examiners for your research report entitled: "***Perceptions of terminally ill patients concerning the palliative care they receive in rural primary health care.***"

The recommendation is to pass this research subject to substantial amendments as outlined by the examiners, done to the satisfaction of your supervisor/s and to the approval of the Head of Department/Head of School. Please discuss with your supervisor/s the actions that should be taken, before submitting the final research. The examination reports have been sent to your Supervisor/s and the final submission should reach Faculty within six weeks of receipt of this letter.

SUBMISSION REQUIREMENTS: FINAL RESEARCH

1. Candidate must be enrolled in order for a submission to be accepted;
2. Electronic copy of the Research (PDF): **(the abstract must be submitted as separate document)**
    a. Cover sheet should reflect current date and not the date the research was first submitted for examination;
    b. Declaration must be signed by the student;
    c. If ethics was required, a copy of the ethics clearance certificate must be included;
3. The signed supervisor submission form;
4. The HoD/HoS approval letter;

Please note that an electronic submission of your final research will be accepted.

NB: Candidates who have submitted final work for inclusion in a Graduation Ceremony should ensure that all fees are cleared at least six weeks before the ceremony to which they are linked. The next graduation will take place in July 2021.The graduation office encourages candidates to refer to their webpage for more information: **https://www.wits.ac.za/graduations/**

Rule 9.8 (Faculty of Health Sciences, Rules and Syllabuses) must be noted: **Acknowledgement of conferment of degree if material is published subsequently** – "*A candidate upon whom a degree of Master has been conferred by the University and who subsequently publishes or republishes her/his Dissertation or Research Report in whole or in*

part, must indicate on the title page or in the preface or, if this is not appropriate, in a footnote, that such Dissertation or Research Report has been approved for that qualification by the University."



Mrs Modie Maumela

Senior Faculty Officer: Postgraduate – Faculty of Health Sciences
Tel: +27 (0)11 717 2075; Email: modie.maumela@wits.ac.za
Room 210, 2nd Floor, Phillip V Tobias Building, 29 Princess of Wales Terrace, Parktown, Johannesburg, 2193, SOUTH AFRICA

PERCEPTIONS OF TERMINALLY ILL PATIENTS CONCERNING THE PALLIATIVE CARE THEY RECEIVE IN RURAL PRIMARY HEALTH CARE

Dr G.L. MAHOLE
Student Number: 780729

A publishable article as research report submitted to the
Faculty of Health Sciences,
University of the Witwatersrand
in partial fulfilment of the requirements for the degree
of
Master of Medicine in Family Medicine (M.Med in Fam. Med)

Supervisor:
Dr C. Lion- Cachet
(Family Medicine University of Witwatersrand)

Co-Supervisor:
Mrs D. Pretorius
(Family Medicine University of Witwatersrand)

Johannesburg, 2020

DECLARATION

I, G.L. MAHOLE, hereby declare that this research is my own unaided work, except where due acknowledgement for assistance received has been made. It is being submitted for the degree of Master of Family Medicine at the University of the Witwatersrand, Johannesburg. It has not been submitted previously for any other degree or examination at this or any other University.

Signed  (Signature of candidate)

Date: 31 May 2021

Signed .....

Dr C. Lion-Cachet (Supervisor)

Date: December 2020



Signed .....

D. Pretorius (Supervisor)

DEPARTMENT OF FAMILY MEDICINE
UNIVERSITY OF THE WITWATERSRAND

25th May 2021

The Postgraduate Office,
Faculty of Health Sciences

Confirmation of corrections on MMed (Family medicine) publication-ready research report:
Dr Lesley Mahole, Student number 780729

This serves to confirm that the above student has satisfactorily completed the corrections required by the examiners on the research report titled **"Perceptions of terminally ill patients concerning the palliative care they received in rural primary health care"** to the satisfaction of both the supervisors and is hereby permitted to submit the corrected version to the postgraduate office.

Dr L Mahole has also passed the FCFP(SA) part A exit examination of the Colleges of Medicine of South Africa, and is therefore also recommended for graduation at the next convocation ceremony, subject to fulfilling any other requirements for the award of the MMed (Family medicine) degree.



Prof OB Omole
Academic Head: Division of Family medicine

4th Floor, PV Tobias Building, 29 Princess of Wales St, Parktown
Faculty of Health Sciences, 7 York Rd, Parktown, 2193, South Africa
☎ +27 (0)11 7172758 / 7172092, 🖹 +27 (0)11 7172558

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

CERTIFICATE OF FINAL SUBMISSION FOR GRADUATION SIGNED BY SUPERVISORS OF HIGHER DEGREES CANDIDATES

Full name	Goitseone Lesley Mahole
Student number	780729

Candidate for the degree of: _____*MMED (FAMILY MEDICINE)*_____
has submitted his research report

Entitled: *PERCEPTIONS OF TERMINALLY ILL PATIENTS CONCERNING THE PALLIATIVE CARE THEY RECEIVE IN RURAL PRIMARY HEALTH CARE*

Contact no	0783351531	E-mail	ddedrles@live.com. Arles@live.com

Mark with an X on appropriate box	**Yes**	**No**
Has this thesis/dissertation/research report been submitted with the acquiescence of the supervisor?	X	
To the best of your knowledge are you able to verify that: This is the candidate's work except as otherwise stated by the candidate?	X	
The substance (nor any part of it) has not been submitted in the past nor is being submitted for a degree in any other university	X	
The candidate has acknowledged wherever any information used in the thesis, dissertation or other work has been obtained by him/her while employed by, or working under the aegis of, any person or organization other than the University or its associated institutions	X	

I certify that this thesis/dissertation/research report has the approval of the Animal Ethics Committee / Committee for Research on Human Subjects and the Number of the Certificate of Approval is: HREC - **M170170**

List all publications, which your student has published in peer-reviewed journals from his/her postgraduate research report/dissertation/thesis during the course of his/her studies in the Faculty of Health Sciences (Include authors, year, title of paper, name of journal, volume number and page numbers). This information is mandatory.

SUBMISSION UNDER REVIEW

Name of Supervisor 1: Deidré Pretorius Telephone: 0825553597

Signature: E-mail: deidre.pretorius@wits.ac.za

Date: 2021.05.25

Name of Supervisor 2: _____H.C. Lion-Cachet____ Telephone: 0833957376

Signature: HC Lachet E-mail: carienlc@koshcom.co.za

Date: _____26/05/2021_

Name of Supervisor 3: _____ Telephone: _____

Signature: _____ E-mail: _____

Date: _____

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FINAL SUBMISSION OF THESIS, DISSERTATION OR RESEARCH REPORT/PROJECT
(Bound and Electronic Copies)

Faculty of HEALTH SCIENCES

School of CLINICAL MEDICINE

Submission of M_____**Dissertation or M** MED **Research/Project or PhD Thesis**
(Note: This form should only be completed at final submission of Dissertation or Research/Project or Thesis)

Payment and submission are for submissions, which have research weighting of 50% or more – so reports where the weighting in relation to the rest of the course work is less than 50% do not have to submit the document.

PLEASE WRITE CLEARLY IN BLOCK LETTERS (If completing form by hand)

1. Name (in full): MOITSEONE LESLEY MAHOLE
2. Person Number:
3. Present mailing address: P. O. Box 613, SETLAGOLE

   Postal code: 2772 Fax:

   E-mail: Arlei@live.com Cell: 0783351531

   Home tel: Work tel: 018 264 9000

4. If you are likely to move in the next 6-12 months please provide the mailing address and effective date of a change in address:

   Effective date:

   Contact telephone numbers:

5. I hereby submit my M_____dissertation or M MED research/project report or PhD thesis.
   (Delete whichever is NOT applicable)

   5.1 If this is research for a Masters by Dissertation or PhD thesis, please provide your ORCID number:
   https://orcid.org/0000-0003-1338-8828.

   (Open Research and Contributor ID (ORCID) – is an alphanumeric code to uniquely identify academic authors and contributors, it is highly recommended that you register and provide this ID. To register or read more see http://orcid.org)

6. Number of unbound copies:_____
   (Ensure that you have signed and dated all copies)

"Number of CDs: (Please note: an electronic version must be supported by a copy on CD for submission into the Electronic Theses and Dissertation System (ETD): *ETD Submission Form*

A payment of **R200** must be made at any one of the two beneficiaries below:

Wits University Cashiers Office	**First National Bank** (A copy of the payment receipt must be submitted to the Faculty with the thesis/dissertation)
Account Code: 001.152.4221103.5122609	Branch: Braamfontein Account number: 51360056499 Branch Code: 251905 Swift Code: firnzajja950

7. Declaration:
   - **7.1** I have checked all copies of my dissertation or research/project report or thesis and no pages are missing or poorly reproduced;
   - **7.2** All revisions have been completed in accordance with the recommendations of the examiners and such revisions have been duly approved;
   - **7.3** The electronic copy is identical to the printed copy approved by the Faculty;
   - **7.4** The dissertation or research/project report or thesis complies with the rules relating to abstract and style, copies and formal declaration, duly signed by me, as shown in the General Rules of the University;
   - **7.5** Where any document of which I am not the owner is included in my work, I have obtained and attach hereto the written consent of the holder of the intellectual property rights in such a document allowing distribution as specified in 7.5.1 below;
     - **7.5.1** In the event of copyright permission not being obtainable for visual images or other works, I will not include the full works(s) in my online thesis/dissertation/research report on the ETD system, but undertake to point only to the source (by URL or other means) for such work(s);
   - **7.6** I confirm that I have not used any confidential information in my work without the required permission;
   - **7.7** I have properly acknowledged all sources; and
   - **7.8** I have noted the rules relating to intellectual property and acknowledgement of the award of the programme as shown in the General Rules of the University and the University's Intellectual Property Policy. Insofar as I hold intellectual property rights in my dissertation or research/project report or thesis, and to that extent only, I agree that the University and its agents may archive and make accessible to the public, upon such conditions as the University may determine, my dissertation or research/project report or thesis in its entirety in all forms of media, now or hereafter known.

8. Title of submitted dissertation/research report/thesis:
   PERCEPTION OF TERMINALLY ILL PATIENTS CONCERNING THE PALLIATIVE CARE THEY RECEIVE IN RURAL PRIMARY HEALTH CARE

   (*Please note: if due to unforeseen circumstances, the above title has changed from your previously approved title, no further action can be taken by the Faculty Office until the amendment has been approved by the Faculty).*

   8.1 Keywords:

9. Acknowledgement:

I acknowledge that my dissertation or research/project report or thesis may be placed in the archive of electronic theses and dissertations. I acknowledge that it may be made electronically available in its entirety on the ETD system from four months after the date of submission unless permission for further embargo has been approved by Senate and communicated in writing by myself to the University Research Office, Library and Central Records Office.

The following files are on this CD (*please specify format*):

_____

_____

The following parts of the work may be released immediately for electronic access worldwide:
(Only if an official embargo has been agreed to in terms of General Rule G19 will your abstract not be made available for the agreed period).

Abstract and key bibliographic data (i.e. from submission form)

I acknowledge that I am not entitled to the return of the copies of the dissertation or research/project report or thesis or other work I have submitted for the programme.

10. Did your research involve animal experimentation or the use of human subjects, human tissue or other material, or patient records?

☐ Yes
☒ No

If yes, please certify that clearance was obtained from the relevant, approved, University ethics committee:

Clearance number(s): _____

11. I understand that I will not graduate unless my University fees have been paid in full.

12. I understand that if I am in material breach of any of the rules, term and conditions governing the submission of a dissertation or research/project report or thesis at the University I may not graduate or it may result in the revocation of the awarded award.

13. The University is not responsible for the safekeeping of the information constituting a dissertation or research/project report or thesis. Should a student use the University ETD system for keeping of a dissertation or research/project repot or thesis in progress responsibility for the maintenance, security and back-up of such work lies with the student. The student absolves the University of any liability whatsoever for any loss or damage to a dissertation or research/project report or thesis and/or information contained in them howsoever it occurs. The student indemnifies and hold the University harmless against any claims or liability whatsoever for any loss or damage to a dissertation or research/project report or thesis and/or information gathered for that purpose or contained in any dissertation or research/project report or theses howsoever it occurs.

14. Candidate:

14.1 The candidate must attach an original "Certificate to Accompany Higher Programmes Research Report" from his/her supervisor(s).

14.2 Is this dissertation or thesis supported by funding from *(please tick):*

☐ DST – NRF (e.g. CoE's; SARCHi Chairs; Innovation; African Origins Platform; Knowledge, Interchange and Collaboration; etc.) [*Please underline the programme that applies]*

☐ DST – CSIR (e.g. NEPTTP e-Research; etc.)

☐ Other (*Please list the full name of the funder*): _____

Signature of candidate: _____ Date: 31/05/21

15. Supervisor(s):

I confirm that I provided academic oversight as supervisor during the completion of the degree

Name of supervisor: _____

Discipline: _____

School: _____

Signature of Supervisor: _____ Date: _____

I confirm that I provided academic oversight as supervisor during the completion of the degree

Name of second Supervisor (*if more than one*): _____

Discipline: _____

School: _____

Signature of Supervisor: _____ Date: _____

FOR FACULTY OFFICE USE

- ☐ Retain one unbound copy
- ☐ Field of study and biographical information confirmed
- ☐ Two unbound final, corrected copies, as well as final, corrected copy in electronic format, of dissertation or research/project report or thesis submitted and forwarded to Central Records Office (refer to section 6)
- ☐ An electronic copy of the abstract of the dissertation or research report or thesis and receipt for the ETD payment submitted and forwarded to CENTRAL Records Office (refer to section6)

Note: 1. *Only abstracts of awards with 50% more as a research component must be submitted for uploading onto the ETD system*

2. Please tick the appropriate box below to indicate the percentage of the research component award:

   ☐ 50% or more research

   ☐ Less than 50% research

- ☐ Signed formal declaration submitted (refer to section 7.4) and included as part of dissertation or research/project report or theses
- ☐ Written consent of holder of intellectual property rights included in the work attached – if applicable (refer to section 7.5)
- ☐ Embargo notification attached – if applicable (refer to section9)
- ☐ Ethics Committee clearance number indicated – ifapplicable (refer to section 10)
- ☐ Copy of this submission form and attachments included with copies sent to Central Records Office – for forwarding to Library. **Originals placed on student file.**

Faculty Officer:_____ Date:_____

FOR CENTRAL RECORDS OFFICE USE

- ☐ One unbound final, corrected hard copy of dissertation or research/project report or thesis forwarded to Library
- ☐ Final corrected copy in electronic format and receipt for ETD payment forwarded to Library
- ☐ Copy of this submission form included with dissertation or research/project report or thesis forwarded to Library
- ☐

Central Records Office:_____ Date:_____

FOR LIBRARY USE

- ☐ Electronic version of dissertation or research/project report or thesis abstract activated on ETD

Library ETD Administrator:_____ Date:_____

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

CERTIFICATE OF FINAL SUBMISSION FOR GRADUATION SIGNED BY SUPERVISORS OF HIGHER DEGREES CANDIDATES

Full name	GOITSEONE LESLEY MAHOLE
Student number	780729

Candidate for the degree of:
MMED (FAMILY MEDICINE).
has submitted his/her thesis/dissertation/research report

Entitled: PERCEPTION OF TERMINALLY ILL PATIENTS CONCERNING THE PALLIATIVE CARE THEY RECEIVE IN RURAL PRIMARY HEALTH CARE

Contact no	0783351531	E-mail	Arles@live.com

Mark with an X on appropriate box	Yes	No
Has this thesis/dissertation/research report been submitted with the acquiescence of the supervisor?		
To the best of your knowledge are you able to verify that: This is the candidate's work except as otherwise stated by the candidate?		
The substance (nor any part of it) has not been submitted in the past nor is being submitted for a degree in any other university		
The candidate has acknowledged wherever any information used in the thesis, dissertation or other work has been obtained by him/her while employed by, or working under the aegis of, any person or organization other than the University or its associated institutions		

I certify that this thesis/dissertation/research report has the approval of the Animal Ethics Committee / Committee for Research on Human Subjects and the Number of the Certificate of Approval is: _____

List all publications, which your student has published in peer-reviewed journals from his/her postgraduate research report/dissertation/thesis during the course of his/her studies in the Faculty of Health Sciences (Include authors, year, title of paper, name of journal, volume number and page numbers). This information is mandatory.

_____
_____
_____
_____
_____
_____

Name of Supervisor 1: _____ Telephone: _____

Signature: _____ E-mail: _____

Date: _____

Name of Supervisor 2: _____ Telephone: _____

Signature: _____ E-mail: _____

Date: _____

Name of Supervisor 3: _____ Telephone: _____

Signature: _____ E-mail: _____

Date: _____

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FINAL SUBMISSION OF THESIS, DISSERTATION OR RESEARCH REPORT/PROJECT
(Bound and Electronic Copies)

Faculty of ~~FAMILY MEDICINE AND~~ HEALTH SCIENCES

School of ~~MBI~~ CLINICAL MEDICINE

Submission of M ~~ED~~ **~~Dissertation or M~~** _____ **Research/Project or PhD Thesis**

(Note: This form should only be completed at final submission of Dissertation ~~or Research/Project~~ or Thesis)

Payment and submission are for submissions, which have research weighting of 50% or more – so reports where the weighting in relation to the rest of the course work is less than 50% do not have to submit the document.

PLEASE WRITE CLEARLY IN BLOCK LETTERS (If completing form by hand)

1. Name (in full): GOITSEONE LESLEY MAHOLE
2. Person Number: 780729.
3. Present mailing address: Orles@live.com

   Postal code: _____ Fax: _____

   E-mail: _____ Cell: _____

   Home tel: _____ Work tel: _____

4. If you are likely to move in the next 6-12 months please provide the mailing address and effective date of a change in address: _____

   Effective date: _____

   Contact telephone numbers: _____

5. I hereby submit my M_____dissertation or M_____research/project report or PhD thesis.
   (Delete whichever is NOT applicable)

   5.1 If this is research for a Masters by Dissertation or PhD thesis, please provide your ORCID number:
   https://orcid.org/0000-0003-1338-8828.

   (Open Research and Contributor ID (ORCID) – is an alphanumeric code to uniquely identify academic authors and contributors, it is highly recommended that you register and provide this ID. To register or read more see http://orcid.org)

6. Number of unbound copies: _____
   (Ensure that you have signed and dated all copies)

"Number of CDs: (Please note: an electronic version must be supported by a copy on CD for submission into the Electronic Theses and Dissertation System (ETD): *ETD Submission Form*

A payment of **R200** must be made at any one of the two beneficiaries below:

Wits University Cashiers Office	**First National Bank** (A copy of the payment receipt must be submitted to the Faculty with the thesis/dissertation)
Account Code: 001.152.4221103.5122609	Branch: Braamfontein Account number: 51360056499 Branch Code: 251905 Swift Code: firnzajja950

7. Declaration:
   - **7.1** I have checked all copies of my dissertation or research/project report or thesis and no pages are missing or poorly reproduced;
   - **7.2** All revisions have been completed in accordance with the recommendations of the examiners and such revisions have been duly approved;
   - **7.3** The electronic copy is identical to the printed copy approved by the Faculty;
   - **7.4** The dissertation or research/project report or thesis complies with the rules relating to abstract and style, copies and formal declaration, duly signed by me, as shown in the General Rules of the University;
   - **7.5** Where any document of which I am not the owner is included in my work, I have obtained and attach hereto the written consent of the holder of the intellectual property rights in such a document allowing distribution as specified in 7.5.1 below;
     - **7.5.1** In the event of copyright permission not being obtainable for visual images or other works, I will not include the full works(s) in my online thesis/dissertation/research report on the ETD system, but undertake to point only to the source (by URL or other means) for such work(s);
   - **7.6** I confirm that I have not used any confidential information in my work without the required permission;
   - **7.7** I have properly acknowledged all sources; and
   - **7.8** I have noted the rules relating to intellectual property and acknowledgement of the award of the programme as shown in the General Rules of the University and the University's Intellectual Property Policy. Insofar as I hold intellectual property rights in my dissertation or research/project report or thesis, and to that extent only, I agree that the University and its agents may archive and make accessible to the public, upon such conditions as the University may determine, my dissertation or research/project report or thesis in its entirety in all forms of media, now or hereafter known.

8. Title of submitted dissertation/research report/thesis:

_____

_____

_____

(Please note: if due to unforeseen circumstances, the above title has changed from your previously approved title, no further action can be taken by the Faculty Office until the amendment has been approved by the Faculty).

8.1 Keywords:

_____

_____

_____