

# **A Needs Assessment for palliative care training in undergraduate students at the University of Stellenbosch**



**Dr AE Fourie**

**FRXANN007**

**Supervisor: Dr Liz Gwyther**

**University of Cape Town**

**MPhil Palliative Medicine**

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# Acknowledgements

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I hope that this research will benefit the undergraduate medical students of the future and ultimately the patient population that deserve a right to palliative care!

# Declaration

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

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## **Abbreviations**

WHA World Health Assembly

WHO World Health Organisation

EAPC European Association for Palliative Care

IAHPC International Association for Hospice and Palliative Care

WHPCA Worldwide Hospice Palliative Care Alliance

HRW Human Rights Watch

QOL Quality of life

HIV Human immunodeficiency virus

AIDS Auto-immune deficiency syndrome

TB Tuberculosis

APCA African Palliative Care Association

HAART Highly active anti-retroviral therapy

UNAIDS United Nations Programme on HIV/ Acquired Immune Deficiency Syndrome

PLHIV People Living with HIV/AIDS

GLOBOCAN Global burden on cancer

HASA Hospice Association of South Africa

HPCA Hospice Palliative Care Association

CANSA Cancer Association of South Africa

UK United Kingdom

US United States

ASCO American Society of Clinical Oncology

MDGs Millennium Development Goals

ESO European School of Oncology

AORTIC African Organisation for Research and Training in Cancer

OSCE Observed structural clinical examination

AAHPM American Academy of Hospice and Palliative Medicine

SEPC Self efficacy in Palliative Care Scale

MPhil Masters of Philosophy in Palliative Medicine

PCU Palliative care unit

PCIS palliative care inpatient service

NEOUCOM North Eastern Ohio Universities Colleges of Medicine and Pharmacy

PCQN Palliative Care Quiz for Nursing

TS Thanatophobia Scale

FATCOD Frommelt Attitude toward Care of the Dying

MFODS Multidimensional Fear of Death Scale

VAS Visual Analogue Scale

SD standard deviation

UCT University of Cape Town

## **Abstract**

**BACKGROUND:** The number of patients with cancer and other life-limiting diseases continues to increase. The WHO estimate that by **2050** there will be 24 million new cancer cases diagnosed annually. Seventeen (17) from the 24 million cancer cases in 2050 will come from developing countries. The vast majority of patients in the Third World Countries do not have access to modern diagnostic and therapy facilities and for them palliation is all they can hope for. Palliative care is a basic human right when curative care is no longer appropriate. The World Health Assembly (WHA) stated that each health care practitioner and health system has an ethical duty to relieve the pain and suffering of patients. This is only possible if the health care professionals are effectively trained to provide holistic, end-of-life care. The World Health Organisation (WHO) challenged training institutions to ensure that palliative care is compulsory and given high recognition. The 67<sup>th</sup> WHA (resolution A67.19) published a document in 2014 with nine recommendations to ensure effective palliative care delivery. There should be emphasis on palliative care teaching to all levels of health care workers and palliative training should be implemented as part of the curricula to all health care workers.

**PURPOSE:** To conduct a needs assessment for palliative care training in undergraduate students at the University of Stellenbosch.

**METHODS:** Two validated assessment scales were distributed via a questionnaire to all the fifth year medical students:

- The Self-efficacy in palliative care scale (SEPC) assesses the confidence/anxiety the student experience in performing certain tasks.
- The Thanatophobia scale assesses the student's attitudes towards caring for dying patients.

The results of the above two scales provided a valid measure of the impact of the current undergraduate palliative curriculum at the University of Stellenbosch.

**RESULTS:** A total of 135 from 179 students responded to the questionnaire (response rate of 75.4%) A minority (21%) of the students felt that their training and skills in palliative care was sufficient. Only 28% of students feel comfortable to discuss death with a patient. 52.7% of students felt anxious about their communication skills. Certain topics were highlighted as challenges: Discussing death with the patient and family, answering questions on pain and suffering and “How long will I live?”, as well as the knowledge and management of symptoms in palliative patients.

In 2013, the University of Stellenbosch dedicated six hours to the palliative care curriculum. Since 2014, palliative care training has been removed from the curriculum. The study indicated that communication and patient management skills were experienced as challenging by students and this correlated with the curriculum that focused only 15% respectively on these two concepts.

**CONCLUSION:** According to the literature, a lack of palliative care training can result in poor symptom control and inevitably a decrease in quality of care for the patients. The need for palliative care is increasing. To address the palliative care needs of the population, health care professionals should be effectively trained in palliative care. This study highlights the need for a dedicated undergraduate palliative care curriculum that should focus more on communication and patient management’s skills to empower the next generation of medical practitioners to care for dying patients with confidence and a positive attitude.

## Chapter 1: Introduction

**“Life is pleasant. Death is peaceful. It’s the transition that’s troublesome”**

**-Isaac Asimov**

**In May 2014, the World Health Assembly (WHA) unanimously adopted resolution A67.19 which urges each state and health care professional to alleviate the pain and suffering endured by patients and their families. With regard to palliative care training the resolution urges that basic palliative care training should be included into all undergraduate health care curricula. Health care workers that manage life threatening diseases should receive more in-depth training in palliative care. Feedback on the progress of the implementation of this resolution is due in 2016.<sup>1</sup>**

Every human being will experience death at some stage in their life. This is part of reality. Doctors work daily with patients living with chronic life-limiting diseases and progressive illness. The number of patients needing end-of-life care is rapidly increasing, especially in resource limited countries like South Africa.<sup>2</sup> The recognition of these patients as in need of special care should be taught, as well as the holistic care of these patients and their families. The management of these patients should become more integrated among different interdisciplinary groups to effectively address the needs of these patients along with their families.

Today the aim of holistic care in integrating the care of the emotional, social, spiritual and financial needs of each patient as part of treatment of their life-limiting disease is well recognized and practiced in developed world countries.<sup>3</sup> The aim of managing end-of-life care patients, has moved to improving quality of life as well as recognizing that each individual has a basic human right to live and to die with dignity.

Due to the current medical training given to health care professionals, newly qualified doctors do not know how to approach dying patients and their family and how to involve the multi professional team in the management of the patient.<sup>4,5</sup> The doctors feel uncomfortable to discuss dying with the patient and family members. The discipline of palliative care needs to be integrated and recognized as part of

comprehensive care delivered to the population. There is a growing need and recognition from the lay person about the right to deserve appropriate end-of-life care and medical schools need to review training of undergraduates to prioritise palliative care as an essential part of the medical curriculum.<sup>6</sup>

Only then will patients get effective management at the end of life and feel that they are still respected and cared for.

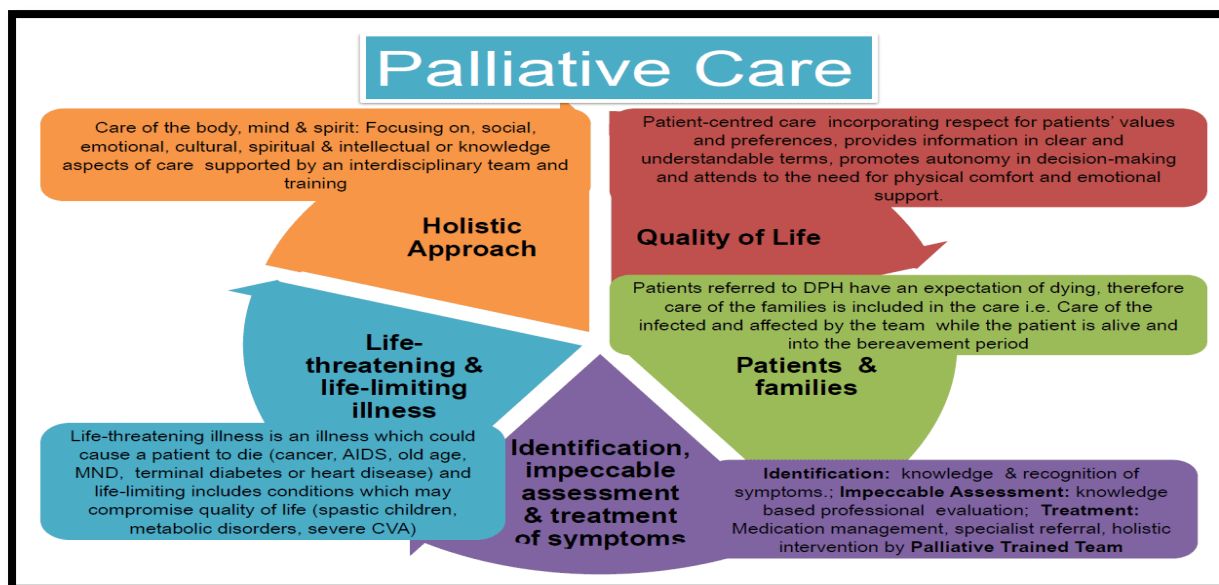
In this chapter the need for palliative care training will be emphasized and discussed under the following headings.

1. Defining Palliative Care
2. Palliative care needs
3. The background of palliative care in Africa and South Africa
4. Palliative Education
5. Conclusion

### **1. Defining palliative care**

Palliative care, defined by the WHO in 2002, is an approach that improves the quality of life of patients and their families facing problems associated with life threatening disease through the prevention and relief of suffering by means of an early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated. A very important aspect of the full definition is that palliative care applies early in the course of the illness and not just at the end of life.<sup>2</sup>

Figure one below describes the essential elements of palliative care.



**Figure 1: Elements of Palliative Care**

**a) Indicators for palliative care**

The Gold Standards Framework Prognostic Indicator Guide in 2011 provides specific criteria for the need for palliative care. This guide include cancer, organ failure (Chronic Obstructive Pulmonary Disease/ Heart Disease/ Renal Disease) and Neurological Diseases (Motor Neuron Disease/ Parkinson's Disease/ Multiple Sclerosis).<sup>7</sup>

**b) Benefits of palliative care delivery**

There have been numerous studies published on the benefit of palliative care for the patient. The benefits include effective addressing of the physical and psychosocial symptoms, improvement of quality of life,<sup>8,9,10</sup> better end-of-life management, a satisfied patient, cost-effectiveness in the care delivered and also reports of improved survival.<sup>11,12,13,14,15</sup>

There are also well documented benefits of palliative care delivery for the family. Jecker et al published a review article in 1995 where they report the benefit of addressing the fears of death for the family. If denial of death is explored, it can lead to a counselling process that result in the patient and family finding meaning in the dying process.<sup>16</sup>

There are also benefits of palliative care delivery for the health care professional. Cicely Saunders (The founder of the modern Palliative Care) once said: **“I believe we need our personal meetings with dying people if we are to remain human and true to the original commitments to openness to people and even new challenges to the balance of the scientific rigor of the mind with the sensitivity of the heart, and to the freedom of the spirit which is fundamental to us all”**.<sup>17</sup>

c) **Palliative care as a basic human right**

i) **Background on the human right movement**

Where did this principle actually started? A medical law student, Somerville, published a statement in 1992 that dying patients have the right to get proper management of their symptoms and pain.<sup>18</sup> Following this awareness, there were numerous organizations that played an important role in the advocacy of the implementation of palliative care as a “Human Right” One of these organizations included the WHO.

Over the past 25 years the WHO has acted as conductor and adviser to various countries worldwide for the recognition and implementation of Palliative Care as a “basic human right”. There were clear and distinct benchmarks during this period.

ii) **The role of the WHO**

The first benchmark in Palliative Care happened in **1980** when the WHO recognized that the majority of cancer patients worldwide suffer from uncontrolled pain. One of the factors that contributed to this poor pain control, was the unavailability of opioid drugs.<sup>19</sup> The next benchmark happened in **1990** when the WHO published guidelines for “Cancer Pain Relief and Palliative Care”. In **1998**, the next set of guidelines on “Symptom Relief in Terminal Illness” followed. In **2002**, the WHO again published guidelines for the implementation of “National Cancer Control Programmes”<sup>20</sup>

A set of guidelines has been published since 1990 that serve to provide a clear framework for implementing step-by-step an effective palliative care program within each country.<sup>21,22</sup> In 2002, the WHO adapted the definition of palliative care to become applicable from the time of diagnoses of any life limiting disease, the holistic approach included also the emotional and psycho-social and spiritual care of a patient. The family members and care givers are considered as part of the team with support to loved ones offered after death as part of the palliative care approach.<sup>3</sup>The

framework also stipulate guidelines to integrate palliative care for each countries' own resources.<sup>21</sup>

Since 1982, the commitment of the WHO in promoting awareness and implementation of palliative care as part of each countries health practice is clearly visible.

### **iii) The role of other organizations**

The WHO is not the only body that promote palliative care as a “human right”. There are numerous other organizations that unite together to promote palliative care as a “basic human right”. These institutions include the European Association for Palliative Care” (EAPC), the International Association for Hospice and Palliative Care (IAHPC), the Worldwide Hospice Palliative Care Alliance (WHPCA) and Human Rights Watch (HRW).<sup>6</sup>

Brennan in 2007 published an article “Palliative Care as an International Human Right”. In this article he discussed human rights law globally with emphasis on each country’s responsibility to ensure that basic palliative care as a human right gets delivered to each person throughout the world.<sup>23</sup>

The Prague Charter for Palliative Care as a Human Right was published in 2013. This statement challenged resource-limited, as well as countries with high resources to prioritize the integration of palliative care service at all levels of care towards patients. This is seen as a basic human right. <sup>6</sup> Subsequently a petition was started to urge all countries to adhere to the four pillars for effective palliative care delivery as recommended by the WHO in 1990 “The Public Health Palliative Care Strategy”.<sup>22</sup>

In 2014, the 67<sup>th</sup> World Health Assembly (WHA) published a document “Strengthening of palliative care as a component of comprehensive care throughout the life course”. The right of each individual to have access to basic palliation was again stressed. The WHA support the WHO’s “Global Action Plan for Prevention and Control of Non-Communicable Disease 2013 – 2020”. A part of this action plan is to include palliative care as part of service delivery.<sup>1</sup>

Since 1992 there has been an emphasis to deliver effective palliative care to provide in the demands of the rapidly increased burden of chronic life-limiting diseases. The

implementation however will depend on the commitment of each government towards the recognition and incorporation of palliative care in their country.

#### **d) Symptoms experienced in life threatening diseases**

##### **i) General symptoms**

The impact of pain and other symptoms (as part of the disease trajectory of each patient with life threatening disease) on the quality of life (QOL) has been recognized and described through various studies and the importance of this has already been stressed since 1960's.

Solano in 2006 published a review comparing the prevalence of symptoms in various life threatening diseases. The 3 most common symptoms experienced among the 5 life threatening diseases examined were pain, shortness of breath and tiredness.<sup>24</sup>

**Table 1: Prevalence of symptoms in life threatening diseases (Solano)**

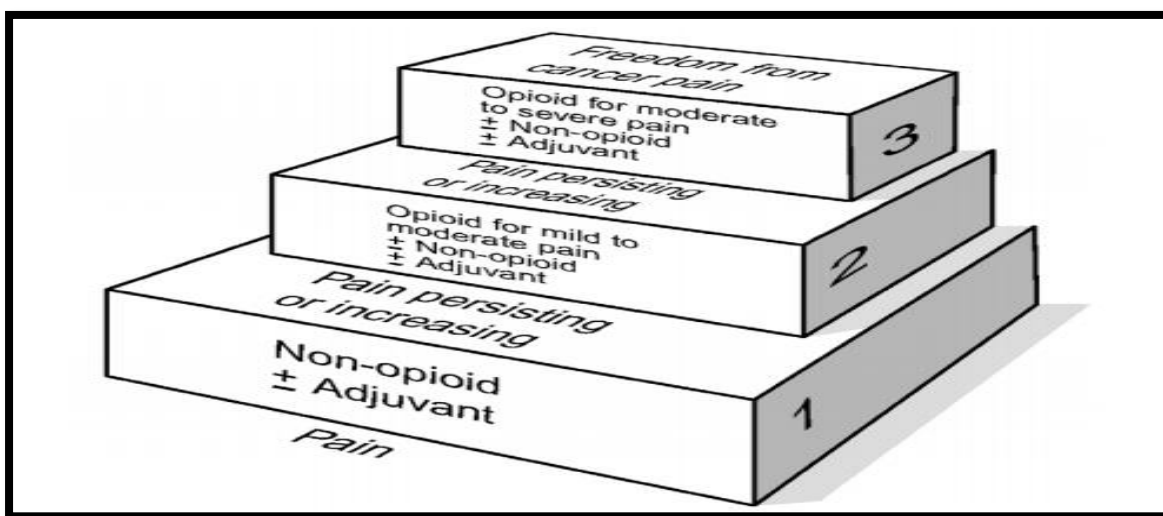
<b>Symptoms</b>	<b>Cancer</b>	<b>AIDS</b>	<b>Heart disease</b>	<b>COPD</b>	<b>Renal disease</b>
<b>Pain</b>	35-96%	63-80%	41-77%	34-77%	47-50%
<b>Depression</b>	3-77%	10-82%	9-36%	37-71%	5-60%
<b>Anxiety</b>	13-79%	8-34%	49%	51-75%	39-70%
<b>Confusion</b>	6-93%	30-65%	18-32%	18-33%	-
<b>Fatigue</b>	32-90%	54-85%	69-82%	68-80%	73-87%
<b>Breathlessness</b>	10-70%	11-62%	60-88%	90-95%	11-62%
<b>Insomnia</b>	9-69%	74%	36-48%	55-65%	31-71%
<b>Nausea</b>	6-68%	43-49%	17-48%	-	30-43%
<b>Constipation</b>	23-65%	34-35%	38-42%	27-44%	29-70%
<b>Diarrhea</b>	3-29%	30-90%	12%	-	21%
<b>Anorexia</b>	30-92%	51%	21-41%	35-67%	25-64%

A study done by Harding et al in 2011 has shown that patients with advanced cancer in South Africa and Uganda experience approximately 18 symptoms per patient. The 5 most common reported symptoms were pain (87.5%), asthenia (77.7%), depressed mood (75.9%), feeling sleepy (72.3%) and a sense of worry. (69.6%)<sup>25</sup>

## ii) Pain

In general, the prevalence of pain experienced by cancer patients due to the tumor itself or treatment given, can vary between 35-96%.<sup>26</sup>

In 1982 already, the WHO proclaimed that the insufficient treatment of cancer pain has become a global health problem.<sup>21,27,28</sup> This observation has led to the development of the WHO Pain Ladder in 1986.<sup>29</sup> Numerous studies have shown that the use of this validated instrument for pain management improves pain in 70% to 90% of cancer pain and can result in complete freedom from pain for the cancer patient.<sup>30,31</sup>



**Figure 2: WHO Pain Ladder**

In 1990, the WHO published The Public Health Palliative Care strategy with 3 recommendations to treat cancer pain effectively, namely to implement effective government policy that recognize the need and importance of effective palliative care management to address the need of the population, to improve the education of health care professionals as well as the lay person, and also to improve the access to drugs for better pain management.<sup>21</sup> This strategy was revised and updated in

2007 with the inclusion of a fourth recommendation that states the importance of the incorporation of palliative care into the health care systems.<sup>22</sup>

In 1992, Teoh et al (WHO Cancer pain relief program-Ten years on IASP) reported a 90 % prevalence of cancer pain.<sup>26</sup> These two reports are 19 years apart, with pain still causing most of the distress among cancer patients. In 1996, Stjernsward et al reported the poor access of opioid drugs as a major contributing factor to poor cancer pain management.<sup>19</sup>

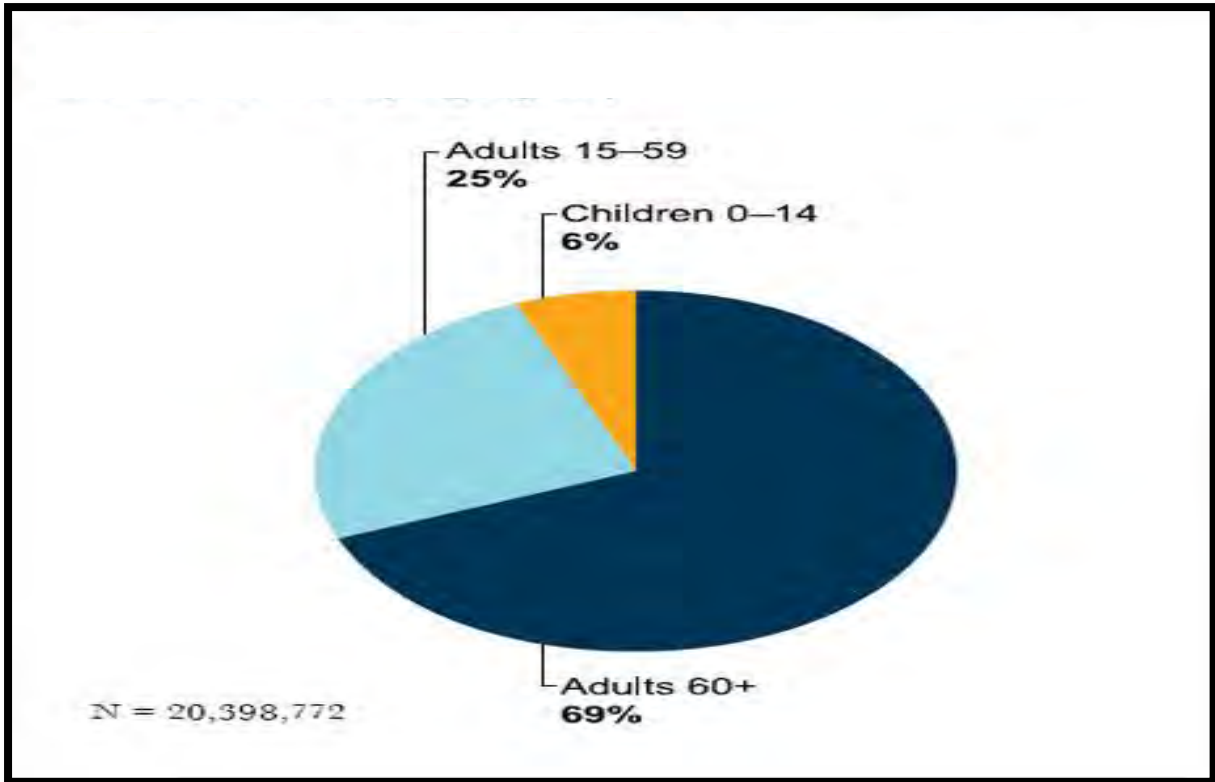
The above observations are shocking, if you take into account the fact that the WHO already in 1982 (almost 30 years ago) announced cancer pain as a worldwide problem and described effective management of pain.

## **2. Palliative care needs**

### **a) Palliative care needs globally**

The WHO Global Health report estimates that there were 54, 6 million deaths globally in 2011. Chronic diseases constitute 66% of the deaths.<sup>32</sup>

Globally, in 2011 the predicted number of people that required end-of-life care were 20,4 million, 94% were adults and 69% were >60 years of age. The 2 most common causes of death in the end-of-life care group were cardiovascular diseases (38,5%) and malignancies(34%). HIV/AIDS accounted for 5, 7% of deaths with 78% of these adults residing in the low- and middle-income countries.<sup>32</sup>



**Figure 3: WHO Global Health: Distribution for palliative care need in 2011 according to age**

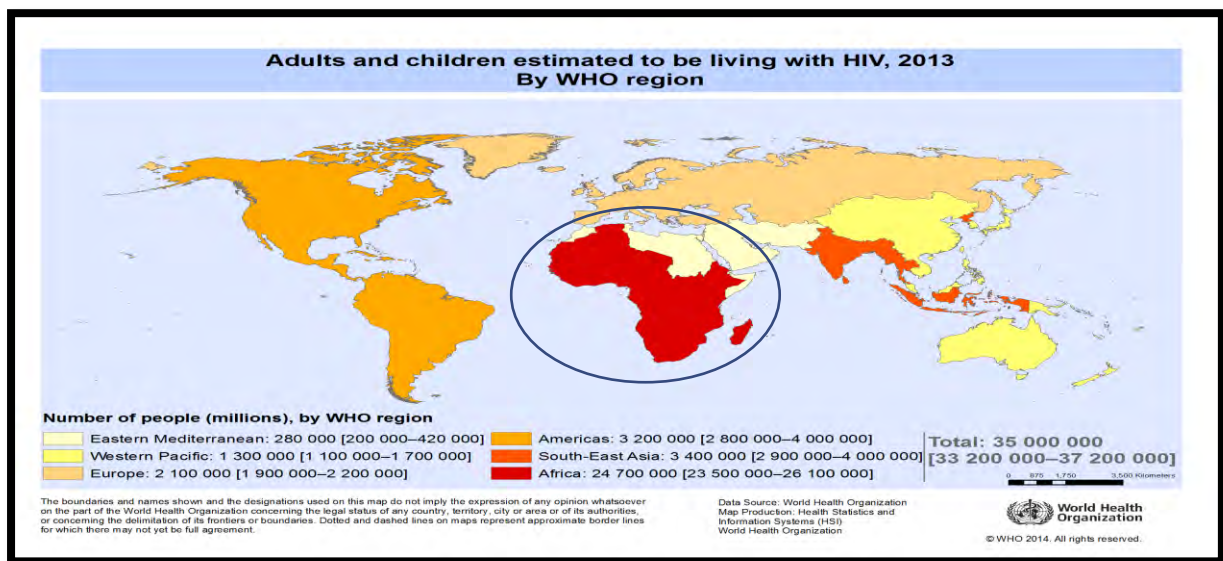
**b) Palliative care needs in Africa**

In Africa, HIV and other infectious diseases (TB and Malaria) have contributed to the burden of disease. Palliative Care is required for both communicable and non-communicable diseases. The African Palliative Care Association (APCA) estimated that in 2007, 1.8 million paediatric cases of HIV existed with an associated mortality rate of 240 000.<sup>33</sup> In **2009** an estimated 22.5 million people were diagnosed with HIV and AIDS in **Africa**.<sup>34</sup> The amount of newly diagnosed cancer cases in Africa for 2008 were more than 500 000, with 421 000 patients dying from cancer annually.<sup>35</sup>

In 2013, Merlin et al published on the role of palliative care in HIV. She report that people with HIV experience a lot of co-morbidities like renal and liver disease as well as non-AIDS-defining malignancies that can benefit from palliative care. HIV patients also experience a lot of symptoms associated with the disease itself as well as the highly active anti-retroviral therapy (HAART) being used for the HIV. These symptoms include pain, nausea, fatigue and mood disorders. There are numerous problems encountered during the HIV disease trajectory that necessitate the intervention of the palliative care team. The palliative care team should be involved

with the physical, psycho-social and spiritual aspects of care. Some of the physical needs include complications due to poor adherence to the HAART medication and late diagnosis.<sup>36</sup>

Another organization that supplies data on the incidence of HIV/AIDS in Africa is UNAIDS. UNAIDS reported an average life expectancy for adults in 2010 in Africa of 53 years.<sup>37</sup> The life expectancy of PLHIV has greatly improved with the advent of HAART and the scale-up of initiation of patients on HAART and improved adherence support.



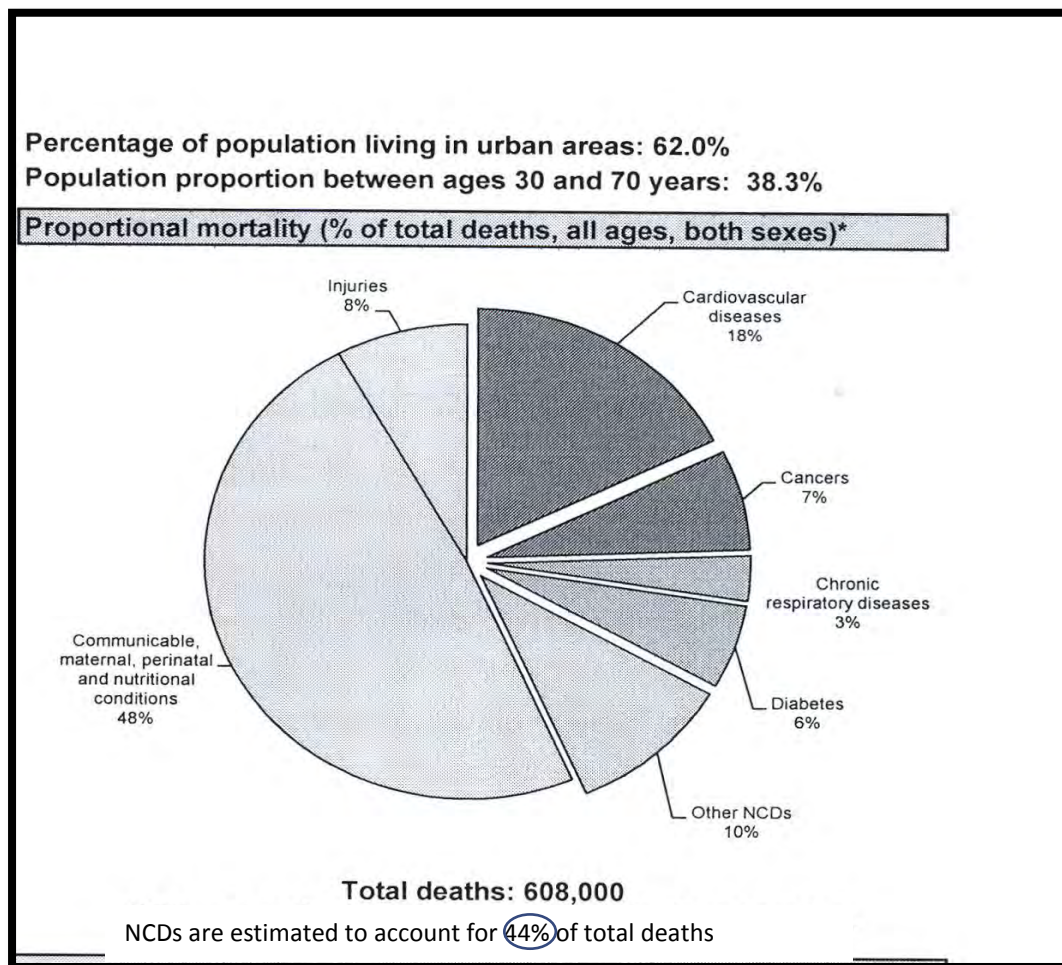
**Figure 4: The prevalence of HIV in Africa in 2013 (WHO)**

### c) Palliative care needs in South Africa

In **South Africa** specifically, the WHO in **2014** predicted that chronic life limiting diseases account for 44% of the deaths in the country, with cancer-related mortality being 7 %.<sup>32</sup> The real picture of the disease burden is probably much worse, as these statistics are based on estimations only. In South Africa the registration of cancer only became compulsory in 2011.<sup>38</sup> This will probably still not reflect the true incidence of chronic life limiting diseases among the population, as some of the rural areas do not have proper access to health care facilities.

GLOBOCAN is an organization that attempt to give an indication of the incidence, mortality and prevalence of certain cancer types for 184 countries worldwide. The statistics come from the International Agency of Research on Cancer’s Database.

GLOBOCAN predicted in 2008 that 202 per 100 000 people in South Africa will develop cancer according to age specific adjustment. In South African men, prostate, lung, oesophagus, colo-rectum, liver and Kaposi sarcoma were the major six causes of cancer. In the South African women, breast, cervix, oesophagus, colo-rectum, lung and uterine corpus played a significant role in the cancer burden.<sup>39</sup>



**Figure 5: WHO estimated deaths in South Africa in need of palliative care in 2014**

**d) Predicted palliative care needs for the future**

The WHO estimate that by **2050** there will be 24 million new cancer cases diagnosed annually.<sup>40,41</sup> Seventeen(17) million of the 24 million cancer cases in 2050 will come from developing countries. The WHO also predicts a notable increase in elderly > 65 years in 2050, especially in the developing countries. This will result in an increase in

chronic life-limiting diseases as well as an increase in cancer patients. The increase is estimated to be from 0.2 billion in 2002 to 1.2 billion in 2050.<sup>2</sup>

Despite the available statistics reflecting the grave situation of the impact of chronic life limiting diseases in Africa and even in South Africa, there has been little attention paid to patients with progressive, advanced disease with these patients often being sent home to the care of their families and community – this at a time when patients have complex clinical problems and needs, requiring care of skilled professionals.

All of the above data emphasizes the enormous burden of life threatening diseases on the health care system as well as society.

### **3. Background of palliative care in Africa and South Africa**

The developed countries were the pioneers for the development and promotion of palliative care, but Africa as an underdeveloped continent did not lag far behind. In 1979, Island Hospice was the first African Hospice that started in Zimbabwe.<sup>42</sup> In South Africa, the provision of palliative care started in 1980 in Johannesburg, Cape Town and Durban. The Hospice Association of South Africa (HASA), now the Hospice Palliative Care Association (HPCA) was founded in 1986 to advocate palliative care, as well as to support the incorporation of certain standards within palliative care. Today there are more than 150 established hospices in South Africa.<sup>43</sup> In 2004 the African Palliative Care Association (APCA) was started with the explicit aim to promote the integration of palliative care into all African health systems.<sup>44</sup>

The slow but steady recognition and integration of palliative care services as part of patient management in South Africa has been described by Gwyther in 2002. The article states that palliative care services are not delivered as part of the health system. The health care workers involved with palliative service delivery are mostly volunteers and the facilities are non-governmental. The hospice palliative care movement started in the beginning of 1980, and 20 years later (2002) includes a postgraduate Diploma and Master Degree in Palliative Medicine at the University of Cape Town, a Palliative Medicine Institute in Johannesburg and a palliative care service at Pretoria Academic Hospital.<sup>43</sup>

Stefan report in 2013 on the existing cancer control plans in Africa. The article addressed South Africa, Egypt, Nigeria, Ghana and Rwanda. Over the past 20 years, South Africa has implemented the Tobacco Products Control Act, cervical cancer screening and the adoption of the CANSA National Cancer Control Program.<sup>45</sup> These are all small steps towards prevention of cancer. This may reduce the incidence of cancer in the future if applied efficiently.

Currently in South Africa the majority of patients present with advanced stages of disease. Due to limited resources to diagnose and manage these patients, with contributing factors such as HIV and malnutrition, there is a need for prompt revision of existing health care delivery. Strengthening of palliative care as a component of comprehensive care throughout the life course should be prioritized as recommended by the WHA (A67.19) from 2014.<sup>1</sup>

#### **a) Barriers to palliative care delivery in Africa/South Africa**

The African continent has a population of almost 1.1 billion people.<sup>46</sup> It consists of 50 countries, with South Africa being one of them. Africa is seen as the poorest and most under developed continent globally.<sup>46</sup> Limited resources such as locations in rural areas with difficult access to health centres can contribute to patients that present with advanced stages of their disease.<sup>47</sup> There are also constraints on diagnosis and treatment available due to resource-limited equipment and drugs.<sup>48,49</sup> In Sub-Saharan Africa, the outcome of most of the cancers tends to be fatal, with 60% of patients that will never see a health practitioner before they die.<sup>50</sup> Traditional healers are usually the first contacts for treatment of a patient's cancer<sup>51</sup> and HIV/AIDS.<sup>52</sup>

There are several articles that report on the status of palliative care delivery in Africa. These articles identify key factors that play a crucial role in the late presentation of many patients, as well as the unsatisfactory management of these patients. A lot of the barriers identified in Africa, can be extrapolated to the South African context as there are numerous similarities in the population of Africa and South Africa with the same challenges experienced in South Africa.

#### **i) Lack of education**

Poor knowledge has been linked to improper pain treatment and also unsatisfactory management of other symptoms experienced by terminally ill patients.<sup>53, 54, 55</sup>

Insufficient training of doctors in palliative care results in deficiencies in quality of care. This is experienced by the patient as (1) improper management of symptoms leading to a high symptom burden, (2) poor communication between the patient/family and doctor and (3) fragmentation of the care delivered.<sup>56</sup>

#### **ii) Unavailability of drugs**

Cleary published a report in 2013 where he indicated that only 15 of the 25 investigated African countries had morphine available. The two major barriers identified for effective cancer pain management were (1) poor access to opioids and (2) unavailability of opioids due to stringent regulations on opioid use. This report acted as a situation analyses for opioid availability in developing countries such as Africa.<sup>44</sup> There is a need for each countries' government to supply opioids as essential medicine in delivering palliative care to patients.

In South Africa, although opioids are available for use, poor access to opioids in the community clinics results in patients that have been discharged from hospitals on morphine not able to continue with their analgesia as prescribed. This results in poor pain control.<sup>54</sup>

#### **iii) Poor access and resource constraints**

In 2003 Kihara identified poor access to medical facilities due to difficult transport from the rural areas in Kenya as yet another factor that contribute to late presentation of patients for medical/ palliative care.<sup>47</sup> Soyannwo and Minja identified poor access to pain medication, and limited diagnostic and therapeutic equipment to also influence palliative service delivery.<sup>48,49</sup> Sebuyira also confirmed in 2003 the delayed presentation of cancer patients in the Sub-Saharan African population.<sup>50</sup>

In South Africa, access to health care facilities is also a problem. Most of the patients are depending on public transport, with overbooked transport facilities resulting in patients not getting timeous work-up and management for their disease and also missing out on their planned treatment regime. This results in ineffective management of the patient.<sup>47</sup>

#### **iv) Cultural differences**

Another factor for delayed presentations in both the cancer group and the HIV/AIDS population can be contributed to differences in the African Culture, such as the

involvement of traditional healers. Solanke and Harding published independently on the various similarities in practices and beliefs between the African and Sub-Saharan African population.<sup>51, 52</sup>

#### **4. Palliative Education**

##### **a) The status on undergraduate palliative care training**

As early as 1991, articles were published to report on individual palliative programs presented to undergraduate medical students. Merrman described in one of these reports the outcome on palliative teaching offered to medical students from the Yale University. The survey was done on 124 medical schools, 111 of the responding schools indicated that teaching on death and dying is provided.<sup>57</sup>

In 2002, Dickinson assessed undergraduate palliative training among the United States (US) medical schools from 1975 to 2000. Palliative care teaching has been integrated in 87 % of the undergraduate Medical School Curricula in 2000.<sup>58</sup> Dickinson also assessed the difference in undergraduate palliative training among the UK and the US medical schools. The UK Medical Schools had a response rate of 100 % and the US Medical Schools 92 %. Almost all the Medical Schools offered palliative teaching.<sup>59</sup>

Although teaching on the proper management of dying patients has been accepted and implemented in various universities<sup>59,60,61,62</sup> there are still studies that report that newly qualified doctors feel anxious to care for dying patients.<sup>4,5</sup>

##### **b) Need identified for improving palliative care training**

While palliative teaching was slowly integrated into undergraduate medical curricula over the past 40 years, a lot of studies still report on the lack of confidence of young doctors to manage terminal patients.

In 2001, Tiernan performed a study on 34 newly qualified medical doctors to assess their knowledge about pain and symptom management in their first year working as doctors. Six month training was given on pain and symptom management and the doctors evaluated with a multiple choice questionnaire before and after the training. The lack of knowledge suggest that the training at undergraduate level is not sufficient.<sup>61</sup>

There have been numerous studies published internationally that identified a need to improve the knowledge and skills of health care workers in palliative care.<sup>57</sup> Some of these studies include: The American Society of Clinical Oncology( ASCO) that conducted a survey 15 years ago to investigate palliative training as experienced through various oncological disciplines. It was evident that 65% of oncologists expressed poor training in symptom management.<sup>63</sup>

A National survey was done in the US in 2003 among medical students and also deans of faculties about confidence in palliative care. The survey illustrated a lack of confidence and skills in the management of palliative care as well as insufficient exposure in palliative care training.<sup>64, 65</sup>

### **c) The role of the WHO promoting palliative training**

The WHO Public Health Strategy for Palliative Care that was published in 1990 and updated in 2007, give clear guidelines to help countries to incorporate palliative care into their health systems. In this document, **education** of appropriate role players, such as **government leaders** and **health care workers**, is one of the major recommendations to improve palliative care access for patients.<sup>21, 22</sup>

Palliative medicine education is an important strategy in ensuring the needs of terminally ill patients are met.<sup>66</sup> The WHO challenged training institutions to ensure that palliative care is compulsory and given high recognition.<sup>67</sup>

### **d) Other organisations advocating palliative training**

Since the publication of the WHO Public Health Model in **1990**<sup>22</sup>, there has been various organisations globally that advocates the importance of palliative care training in health care workers. In South Africa, the need for education on pain management and palliative care has also been identified. This has led to the “Cape Town Palliative Care Declaration” in 2003. Sebuyira reported on this document that states that there should be an implementation of palliative teaching in undergraduate and postgraduate level to all health care professionals. Palliative care need to be practiced in the community, as well as in academic hospitals. Training of all health care workers needs to be prioritised.<sup>50</sup>

The Korea Declaration (**2005**) challenged leaders of countries to ensure that there is proper palliative care teaching in the Medical Curriculum.<sup>68</sup>

Mwangi-Powell (Chairperson of APCA) reported in 2011, that countries need to align themselves with the Millennium Development Goals (MDGs) to improve outcomes for patient delivery. No matter where palliative care is being delivered, the ultimate goal should be for patients to still feel that they have self-worth. She states that one of APCA's goals is to promote training of health care workers as recommended by the WHO.<sup>69</sup>

In 2004, Ahmedzai reported about the European School of Oncology (ESO) that developed recommendations to help countries worldwide to integrate palliative care delivery to patients. One of the major goals is the incorporation of palliative training in curricula of all health care workers. There should be a focus on prioritizing knowledge and skills of oncology workers in palliative care management. Any medical discipline caring for oncology patients should be able to attend to the basic palliative needs of their patients. This can only be achieved if there is proper training in palliative care. The oncology staff needs to assess when to refer to a specialized palliative team to manage more complex cases. Each health care worker should have the basic education to manage terminal patients. ESO divides palliative care training into basic standard of care education to all health care workers and then also the more specialized palliative care training to a subgroup of disciplines.<sup>70</sup>

The European Association for Palliative Care (EAPC) updated its recommendations "Curriculum in Palliative Care for Undergraduate Medical Education" in 2013. In this document, they emphasize that all doctors need to be trained in palliative care. The EAPC also provide a document on postgraduate palliative training that was published in 2009.<sup>71</sup>

The Prague Charter published recommendations in **2013** to encourage countries to provide proper teaching in palliative care and pain, starting with the undergraduate students.<sup>6</sup>

Downing reported on the APCA/HPCA conference held in **2013** that palliative care teaching needed to be implemented in the curriculum for **all** health care workers across Africa.<sup>72</sup>

At the last African Organisation for Research and Training in Cancer (AORTIC) conference held in **2013**, it was recommended that APCA need to aim towards integrating palliative care delivery within existing oncological services. This will ensure improvement in palliative care delivery.<sup>73</sup>

The 67<sup>th</sup> World Health Assembly (WHA) published a document “Strengthening of palliative care as a component of comprehensive care throughout the life course” in **2014**. This has led to nine recommendations to ensure effective palliative care delivery. This document stated that there should be ongoing teaching to all levels of health care workers in palliative care. Palliative training should be implemented as part of the curricula to all health care workers. There is a distinct emphasis on basic palliative training for all health care professionals at undergraduate level, more advanced palliative education for oncology workers and then also the recognition of palliative care as a speciality.<sup>1</sup>

#### **e) Recommendations to address palliative care training**

There are numerous trials that have demonstrated an increase in knowledge, skills and attitudes of medical students if palliative care training is integrated in to the undergraduate medical curriculum.<sup>74,75,76,77</sup> The increase in knowledge and skills resulted in medical students that feel confident to perform palliative activities. The increase in attitudes of the students resulted in positive feeling of care for dying patients.

The European Association for Palliative Care (EAPC) provides a framework that can be used as a guideline to implement palliative care training in the undergraduate medical curriculum.<sup>71</sup>

In this document, they emphasize that all doctors need to be trained in palliative care. Training in principles of palliative care should be started early in the course of the undergraduate curricula, with exposure to clinical situations later in the medical training. These set of guidelines provide a framework on seven topics that need to be addressed with the proposed importance of each topic given. The ultimate goal of these recommendations is to equip doctors with the basic essential knowledge, skills and attitudes to provide palliative care to the population.<sup>71</sup>

## **Recommendations from the EAPC to improve palliative care education: “Curriculum in Palliative Care for Undergraduate Medical Education”**

The EAPC promote teaching principles of palliative care that incorporate the WHO definition of Palliative Care (2002). The objectives of the palliative curriculum should aim to increase the knowledge and skills of the medical students to perform palliative care, as well as address the attitudes of the students to feel positive to care for dying patients.

The EAPC identified seven areas that are necessary to address as part of the palliative training to ensure basic competence in palliative delivery.

The EAPC recommends a total of 40 hours training, in different years of undergraduate medical education to achieve the goals of the Palliative Care Curriculum. A clinical experience in a palliative care setting is recommended. Assessment methods to evaluate the knowledge, as well as tools to measure attitudes and skills, need to be implemented.<sup>71</sup>

## **Recommendations from international studies to improve palliative care education**

Lloyd-Williams published in 2004 recommendations to improve palliative education. These recommendations suggest:

(1) Identify the best time to train palliative care to the undergraduates. Some studies suggest that ethical lectures should be given in the first year of training with the more formal lectures done later in the medical curriculum. Other studies recommend Focusing on attitudes in the pre-clinical years and then implementing formal palliative care teaching in the clinical rotation.

(2) Formulate the content and structure of the palliative curriculum upfront. Numerous guidelines exist to guide the implementation of an undergraduate palliative curriculum such as the EAPC medical curriculum for undergraduate palliative training. A clinical rotation, exposing the students to hospice, need to be included in the curriculum. Teaching methods need to incorporate reflective thinking. Assessment of the curriculum needs to be done and the assessment methods need to include an OSCE station, skills lab and a formal assessment like a written exam.

(3) Teaching should not just focus on knowledge and skills, but need to address the attitudes of medical students towards dying.

(4) Appoint a qualified lecturer in palliative medicine that needs to coordinate the teaching program.<sup>78</sup>

In 2010, the American Academy of Hospice and Palliative Medicine (AAHPM) published guidelines to assist universities to incorporate effective palliative care curricula. This publication stressed the responsibility of the Academic institution to take ownership of training and mentoring the students in improving their palliative knowledge and skills.<sup>56</sup>

#### **f) Assessment methods to evaluate the impact of palliative training**

##### **i) Why do you need to evaluate palliative care training?**

There are numerous reasons that necessitate the need to evaluate the palliative curriculum being taught at an institution.<sup>79</sup>This include:

- Assessing if the current curriculum is achieving the desired outcomes to improve the knowledge, skills and attitudes of the trained students
- To identify if there is unmet needs in the current curriculum
- To identify needs for improving the future curriculum

##### **ii) How to evaluate palliative care training**

There are various tools and instruments available for assessing the effectiveness of palliative care programs. Many of the tools used to evaluate the palliative care outcomes of a program rely on self-reporting of the students. This aspect does bear significance as it reflects on the theoretical knowledge acquired and also the change in the attitudes of the student. It does not however assess the behavioural competence that is needed in effective palliative care delivery.<sup>79</sup> The problem identified with self- assessment as an instrument used to assess the outcomes of training, is the fact that self-assessment is very subjective.<sup>80</sup> It is recognized that it is not sensitive enough to reflect the actual abilities of the student tested. This in turn does not really assess the effectiveness of the program being assessed. There have been studies done in health care that has shown a correlation between an individual's attitude and the behaviour. Behaviours on the other hand are influenced by numerous factors. Thus the tools that only measure attitude are not sensitive

enough to assess change in behavioural competence. The OSCE (observed structural clinical examination) is an assessment tool that has been used extensively to evaluate many different clinical competencies including palliative care.<sup>81,82,83</sup> This form of assessment, if added to the self-assessment done by the student, is a reliable and valid tool to provide information on the outcomes of a training program.

**iii) Specific instruments identified for evaluation of palliative care training**

- **The Self efficacy in Palliative Care Scale(SEPC): an instrument to assess knowledge and skills of palliative training in medical students**

## **Background**

Research studies have highlighted the effects of self-efficacy and outcome expectancies, key components in Bandura's social cognitive theory, on behavioural change in clinical training. "Self-efficacy" refers to the belief in one's ability to perform a specific behaviour or skill. The perceived consequence of performing a specific behaviour or skill relate to an "outcome expectancy".<sup>84</sup>

Bandura's social cognitive theory has led to different applications in health care. One of these applications included a study done by Parle in 1977. In this study the lack of knowledge and skills were identified as principal causes of poor communication with cancer patients. The outcome of this study resulted in suggested workshops to improve communication skills and therefore self-confidence in communication of health care workers with patients. Here the concept of self-efficacy is used to assess the outcome of the workshops attended in communication.<sup>85</sup>

Evidence suggests that aspects of attitudinal disposition, such as self-efficacy and outcome expectancy, affect the performance of target behaviours.<sup>86</sup> These robust scales that assess self-efficacy and outcome expectancies will provide a valid measure of the impact of undergraduate palliative care education programmes.<sup>87</sup>

## **SEPC Scale**

This scale had its origin in 1999, where Barrington and Murie wanted to evaluate a palliative care program introduced to Australian undergraduate medical students.<sup>87</sup>

In 2004, Mason assessed if self-efficacy can be used to determine the impact of an undergraduate palliative training program. He modified the initial SEPC scale that was developed by Barrington in 1999 and applied this modified SEPC scale in 4<sup>th</sup> year medical students before and after a two week palliative training program. The modifications included three areas to be evaluated: “communication, patient management and multidisciplinary team working”. The SEPC Scale has been tested for validity and reliability in 2004 and accepted to be used for the evaluation of the impact of palliative care programmes.<sup>86</sup>

### **Thanatophobia Scale**

This instrument evaluates a medical student’s attitude to care for palliative patients. The Thanatophobia Scale evaluate how positive or negative a student feel to manage terminal patients. This scale was described the first time by Merrill in 1998. It was designed and tested on American students and doctors with the goal of identifying reasons why some health care workers avoid terminal patients. This scale was initially tested in 1998 for reliability and validity among American students.<sup>88</sup> The Thanatophobia Scale was again tested for reliability and validity by Mason in 2004 among the UK students and also proofed to be an effective tool to assess the impact of undergraduate palliative curricula.<sup>86</sup> The Thanatophobia Scale is a recognized tool to aid in assessing attitudes of medical students to care for dying patients.

### **g) Factors that contribute to poor palliative training**

To identify why recently qualified physicians feel “unprepared” to attend to dying patients and their families despite better teaching on this topic, a systematic review was done in 2004 by Lloyd-Williams.<sup>78</sup> This review identified five problem areas in palliative care education: (1) a wide variations in the content taught to students<sup>62,65,89,90</sup>; (2) no clear structured palliative care curricula; and (3) a lack of proper recommendations on the qualifications required to teach palliative care<sup>87,89,91</sup>; (4) The outputs/outcomes of palliative care curricula are not evaluated properly and (5) palliative care curricula fail to address the attitudes of students towards caring for terminal patients.<sup>92,93,94,95</sup>

There were other studies that also identified the lack of qualified lecturers in palliative care as a major obstacle to deliver and implement high quality palliative care programs.<sup>96,97</sup>

Since 1990 there has been an emphasis on palliative care training for health care workers across the world. What is the status on palliative care training in South Africa?

#### **h) Status on palliative education in South Africa**

From my literature search, there are only a few authors that focus on palliative care and training in South Africa. Gwyther and Rawlinson published an article in 2007. In this article it is reported that palliative education started in 2001 at the University of Cape Town, where two programmes were introduced in Palliative Medicine Education, namely Postgraduate Diploma in Palliative Medicine and a Masters of Philosophy in Palliative Medicine (MPhil). The training of undergraduate students in palliative care was only introduced as part of the undergraduate curriculum in 2002.<sup>98</sup>

Although medical institutions in South Africa address some issues of palliative care during the undergraduate academic training, the concern is if the current training is sufficient in preparing “tomorrow’s doctors” with the necessary confidence and attitudes to completely care for the dying patient and their families.

There is no standard curriculum implemented for palliative medicine training in South Africa. The time allocated also varies widely between institution to institution as identified from this research data (for example between 3h to 46h). There is clearly a need to adopt a standardized palliative curriculum for undergraduate palliative care education.

#### **i) Status on palliative training at the University of Stellenbosch**

Due to my working capacity as a radiation oncologist at Tygerberg Hospital, one of the major academic hospitals in the Western Cape, I have been dealing with undergraduate medical students from the University of Stellenbosch. The need for more training in breaking bad news, symptom control and end of life care has been voiced by numerous students.

In 2013 (at the time the study was commenced), the Palliative Curriculum at the University of Stellenbosch was part of the Community Health, Family Medicine and Rehabilitation rotation. It was part of a four week rotation in the third year undergraduate medical training.

The palliative care time allocated for teaching existed of a two hour tutorial given by a general practitioner qualified in palliative medicine. The students also had a four hour visit to one of the local hospices. At the end of the four week rotation, the students had an assessment about general topics in palliative care of a question-answer format. They also gave feedback on their experiences on the local visit to the hospice.

The topics covered during the two hour tutorial included:

- (1) Introduction to palliative care
- (2) Palliative care in chronic illness and suffering,
- (3) The dying patient
- (4) The Syringe Driver and
- (5) The grieving process.

It is evident from the palliative curriculum at the University of Stellenbosch that the time allocated to training in palliative care is far less than the recommended forty hours suggested by the EAPC.

Since 2014, the palliative curriculum has been stopped. For the past two years there has been no formal training in palliative care at the University of Stellenbosch. This is the same year the WHO adopted resolution A67.19 recommending that “basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education”.

## **Conclusion**

The literature clearly indicates that there is a slow, but steady increase in awareness and implementation of palliative care as part of the undergraduate medical curricula at universities worldwide.

Over the past ten (10) years, palliative care teaching has been introduced at various levels and at many of the medical schools across South Africa. Unfortunately, there are no standardized undergraduate palliative care curricula in South Africa. This leaves the onus of palliative care training at the discrepancy of each individual

medical school. This, despite the South African Department of Health's Patients' Right Charter that clearly stated since 2007: "Everyone has the right of access to health care services...palliative care that is affordable and effective in cases of incurable or terminal illness."<sup>99</sup>

The question should not be: "Is Palliative care training necessary for health care workers?", rather "Why is there in 2015 still no standardized palliative care curricula for undergraduate medical students to equip them with the basic knowledge, skills and attitudes towards palliative care necessary to provide in the needs of our South African population?" **In 2016 what feedback will the South African government give at the next WHA meeting? What did the South African government do to integrate palliative training in the undergraduate medical curricula since 2014?**

The next chapter will focus on the research done over the past 40 years regarding palliative education. It will address the basic needs and principles for delivering, implementing and assessing palliative care programs for service delivery and education.

## Chapter 2: Literature Review

The previous chapter sketched the background of the evolution of this relative new discipline, namely Palliative Medicine. Over the past 50 Years, Palliative Medicine has evolved from the concept of hospice care to a well-recognized speciality. Numerous organizations recognize and advocate the integration of palliative medicine as part of the health system.

The need for palliative care in developed and developing countries is well recognized. However, effective palliative care as defined by the WHO can only be delivered to patients if the health care team is equipped to provide this holistic care. The only way to equip health care workers is to provide proper palliative care training that increase the knowledge, skills and attitudes of the health care team that need to care for patients with chronic life limiting diseases.

As part of my work as an oncologist in an academic, tertiary hospital, I have to deal with undergraduate students that visit the oncology unit for 1 day in their 4<sup>th</sup> year of medical training. During one of my interactions with this group of students, a lot of the students expressed a need for proper palliative care training. Many students voiced their lack of confidence to break bad news and also to manage pain and other palliative symptoms.

I also deal with referrals of patients managed by various disciplines as inpatients in the tertiary and secondary hospitals. The majority of these patients referred, had poor pain control with no application of basic principles of the WHO pain ladder. Many patients also express poor communication about their disease and associated future management plan. Palliative emergency situations such as spinal cord compression, hypercalcaemia and superior vena cava syndrome are neglected with delayed referral and management, resulting in unnecessary and many times irreversible consequences to the patient and their family.

I witness daily the insufficient palliative care delivered to our patient population. The consequences of this poor palliative management have devastating effects on family dynamics. The financial burden due to lack of palliative care on society and the health system is enormous.

A literature search was performed to gain information on palliative care training as part of the undergraduate curricula in medical students. The search also focused on guidelines/ frameworks/recommendations for a recognized palliative care curriculum for undergraduate medical students. Instruments/tools used to investigate gaps in current undergraduate palliative training were identified. The literature review included published research that related to the research question – A needs assessment for an undergraduate palliative care curriculum.

The literature was searched electronically using Medline, Pubmed, Google Scholar and Science Direct. Search words that were used included palliative care training, palliative care curriculum, undergraduate medical students, needs assessment, palliative medicine, tools/ instruments for evaluating needs assessment for palliative training, benefits, and barriers. Studies that used scientific research methods and articles that were published in peer reviewed journals were evaluated.

The literature articles were reviewed to support the need for this research and were considered in the following categories:

1. Status of Palliative Education in South Africa
2. Inadequate palliative training – the consequences
3. Effective Palliative delivery – The Benefits
4. Identifying a need for palliative training
5. Addressing the need for palliative training
6. Planning an Undergraduate Palliative Curriculum
7. Assessing the impact of the palliative training
8. Factors that contribute to poor palliative training

### **1. Status of Palliative Education in South Africa**

From my literature search, there are only a few authors that focus on palliative care and training in South Africa. Gwyther and Rawlinson published an article in 2007: “Palliative Medicine Teaching Program at the University of Cape Town: Integrating Palliative Care Principles into Practice”. This is a descriptive article that gives a background on the palliative education in South Africa at that time.

The article discussed the postgraduate course for palliative medicine that started in 2001 at the University of Cape Town. The course was designed for doctors to teach and equip them on the concepts of holistic care, multidisciplinary teamwork, the family as part of the team and effective symptom management<sup>98</sup>

## **2. Inadequate Palliative Training - The Consequences**

Suffering from pain is one of the major fears of most patients. Patients that report poor pain control, usually have inadequate pain assessment and management. Bernabei in 1998 reported on the pain management of older patients in different nursing homes in the USA. This was a retrospective, cross-sectional study that included 1492 nursing homes in 5 different states. A total of 13 625 patients with cancer older than 65 years were included. A significant proportion of patients (38%) complained of pain each day. From this group 26% received no pain medication. If patients were > 85 years, only 13% were given morphine. It was noted that patients older than 85 years were not given any pain medication. The strength of this study is the large amount of patients included and also across different nursing homes and in five different states. The weakness however is that the study is retrospective.<sup>100</sup>

Cleeland commented on Bernabei's study in 1998 and identified insufficient training in pain control as the main factor contributing to unsatisfactory pain management of patients.<sup>101</sup> This article is however only a review of literature already published. Susan Beck investigated in 1998 the prevalence and management of cancer in South Africa. Of the 263 selected patients, 35.7% reported cancer-related pain. The prevalence of pain was 56.1% among black patients versus 29.4% among white patients. During the second phase of the study, nearly 30% of 426 patients reported "worst pain" in a questionnaire that included the brief pain inventory. Only 21% of patients actually mention a complete pain relief. Recommendations from this article suggest improving the training of health care professionals in pain management and also to improve the delivery of health care services. This study consisted of two phases. Phase 1 consists of epidemiology and Phase 2 involved the use of a questionnaire to determine the severity of pain experienced. The total amount of patients included (426) were also representative of the public and private sector and represent cancer pain over a spectrum. This method decreases the possibility of bias. The study however still remains an observational study.<sup>53</sup>

In 2000, Beck conducted an “ethnographic field study”. Various methods of data collection were used including review of documents, observation and interviews. The study population consisted of 33 participants. This study also highlighted a lack of education as one of the obstacles to poor pain control among patients<sup>54</sup>.

The above two studies confirm that poor pain control of patients reflect on inadequate training on pain management of health care workers.

### **3. Effective Palliative delivery – The Benefits**

Casarett et al did a study in 2008 to evaluate the impact of palliative consultations. The study consisted of a retrospective telephone survey among 524 family members caring for terminal patients. Nine aspects of palliative care were assessed. The study confirmed that family members of terminal patients that received palliative care were more satisfied with the health service received than those members without any palliative consultations. If palliative care were introduced early in the course of the disease, it translated to improved outcome. This study indicated the increase in quality of care associated with implementing palliative care. The weakness of the study was again in the retrospective nature with possible recall bias and the observation from a family member and not the patient.<sup>8</sup>

In 2003, Higginson et al conducted a systematic review to evaluate the benefit of palliative and hospice care versus “conventional” care, evaluating 44 studies. Many mistakes were identified in the methods used for the studies and, publication bias was also identified. Despite the latter, meta-regression of 26 studies did show a small benefit of palliative and hospice care on the outcomes experienced by patients. Meta-analysis of 19 studies indicated a minimal benefit, especially towards pain (OR 0.38, 95 % confidence interval, CI: 0.23 0.64). The review concluded that palliative and hospice care showed a trend towards improvement in quality care and also reducing the cost of care.<sup>9</sup>

A study conducted by Manfredi in 2000, also demonstrated the benefit of palliative care consultations for hospital inpatients. A total of 408 patients were referred over a 15 month period for consultation by the palliative care team. Only 325 patients were included in the study. Discussions about prognosis and the aim of treatments resulted in 88.6% of patients that reported an increase in understanding of prognosis. In 74.8% specific symptoms were addressed. The study reported that palliative care

involvement resulted in a reduction in hospital stay and this translates in financial saving for the hospital. This is the results of better communication leading to better understanding of the disease<sup>10</sup>.

The financial gain of implementing palliative care has been demonstrated in 48 studies. Smith in 2003 conducted a case control study to assess if palliative care unit (PCU) admission will influence the cost of care. A total amount of 237 patients were admitted during a six month period. A reduction of 66% in overall costs and 74% in medication and investigations were noted in favour of admission in a PCU.<sup>11</sup>

Another study that confirmed the cost-effectiveness of an outpatient palliative care service was published in a South African context by DesRosiers et al in 2014. The study evaluated patients with “advanced organ failure” exposed to a hospital palliative care service and the impact of this service on hospital admissions place of death. The study indicated that a palliative care service reduce admissions to hospital and also resulted in more patients dying at home.<sup>102</sup>

Back investigated in 2005 resources used in the final two months of a patient’s life who received palliative care as compared to patients that receive conventional medical care. This was a retrospective non-randomized comparison of resources. 265 patients were evaluated – 82 patients received palliative care and 183 received conventional medical care. The involvement of a palliative care team for the last two months prior to death resulted in less admissions in an acute care hospital for dying patients. The patients that received PCS died mostly at home.<sup>12</sup>

Elsayem reviewed retrospectively in 2004 the financial implications of admissions of patients in the palliative care inpatient service (PCIS) at the MD Anderson Cancer Centre. A total of 328 patients were admitted. The main indication for admission was pain in 44%of patients. The patient stayed approximately 7 days in the hospital. The daily cost of the PCIS was 38% less than the rest of the hospital. The study concluded a financial gain for PCIS.<sup>13</sup>

#### **4. Identifying a Need for Palliative Training**

Harding undertook a systematic review in 2005 to assess if application of palliative care in HIV/AIDS patients impacted on the outcome of symptoms experienced. A total of 34 services delivering palliative care were included. Pain and other

symptoms experienced, were improved if a patient was managed in an inpatient hospice or at home. Anxiety, understanding of disease and spiritual aspects were all affected positively through palliative interventions. The systematic nature of this publication can detect flaws and bias within the studies and this can be seen as a strength in the study. This systematic review support the need for improving the knowledge and skills of health care workers in palliative management of patients with HIV/AIDS.<sup>103</sup>

In 1998, the American Society of Clinical Oncology (ASCO) conducted a survey among its 3227 members that consisted of various oncologists. The majority (90%) expressed that their palliative care knowledge and skills was as a result of working with dying patients. A distressing incident with a patient contributed in 38% of the members to their palliative education.<sup>63</sup>

A paper published in 2001 by Hilden reported that 81% of 228 paediatric oncologists that responded to a survey conducted by ASCO in 1998, felt ill-equipped to discuss poor prognosis with patients and 65% expressed a lack of training to manage symptoms of patients.<sup>104</sup>

In 2007, Buss published an article that reported 120 physicians specializing in oncology that participated in a survey done in 2004 at the annual ASCO meeting. The doctors clearly expressed a lack of training in palliative care and 31% of the group had inadequate knowledge about creating end-of-life issues.<sup>105</sup>

Another survey done in 2007 by Baker among paediatric residents regarding palliative care teaching, demonstrated that only 38.2% of the residents felt competent to deliver palliative care. This again highlights the need to improve palliative care training.<sup>106</sup>

Sullivan et al published two consecutive articles in 2003 and 2004 regarding end-of-life care teaching in medical curricula and the feedback of deans from various medical faculties on the status of palliative training. Both articles illustrate a lack of confidence and skills in palliative care among the medical students and deans. There was also feedback on limited exposures to practical palliative care scenario.<sup>64,65</sup>

## **5. Addressing the Need for Palliative Training**

Von Gunten published an article in 2012 on the results of a prospective longitudinal study done on 593 third year medical students at the University of California, San Diego School of Medicine between the periods of July 2002 to December 2007. The study assessed the knowledge, skills and attitudes of the medical students towards palliative care after a 32-h palliative curriculum was introduced with exposure to home and inpatient hospice care. The students were assessed with the use of 3 validated instruments applied before and after exposure to the palliative curriculum. There was a 100% response rate.

The study indicated an improvement of 23% in the knowledge of the student, 56% increase in their skills and also a 29% decrease in their concerns. This study used a large sample size, and also used validated tools to assess the 3 main outcomes needed in assessing palliative care education.<sup>(17)</sup> The assessment was focused on self-assessment of the students which may be seen as a weakness of the study.<sup>74</sup>

Schulz et al also reported in 2013 on their findings after conducting a prospective quasi-experimental study on 37 medical students (third and fourth year) at the University Witten in Germany between September 2006 to April 2007. The students were tested before and after exposure to the palliative curriculum. The study indicated an increase in competence in communicating, knowledge and skills reported by the students. The weaknesses of this study lies on the small sample size and assessment done via self-estimation of the students. However, the instruments used were known and validated instruments to test self-efficacy in palliative care training.<sup>75</sup>

Morrison et al published an article in 2012 about their experience after introducing a palliative care workshop to third year medical students (total 157). The student's palliative pain knowledge and end-of-life attitudes were assessed before, during and at the end of the workshop. The study showed that there was an increase in the knowledge and attitudes ( $p < 0.001$ ) following the training and this was especially associated with time of exposure. Thus the knowledge and attitudes assessed were the best at the end of the training.<sup>76</sup>

Again the study did not address the palliative skills training and assessment. The assessment of knowledge and attitudes were again student self-estimation.

Another study that confirmed the benefit of implementing an undergraduate palliative curriculum in medical school was done by Radwany et al in 2011 as part of the North Eastern Ohio Universities Colleges of Medicine and Pharmacy (NEOUCOM) requirements. A four-year palliative care curriculum was introduced as part of the undergraduate medical training. The benefit of experience in hospice rotation and small group discussion were highlighted.<sup>77</sup>

It is clear from the above literature that implementation of an undergraduate palliative curriculum can address the knowledge, skills and attitudes of medical students towards palliative care. Thus addressing the medical students needs for palliative care training.

## **6. Planning an Undergraduate Palliative Curriculum**

Kristen et al published in 2014 the results of a National Survey that was done in the United States to determine the basic palliative care skills required for medical students and doctors working in Internal Medicine and Family Medicine.

The required competencies were derived from recommendations of a survey done among 68 palliative care specialists. Palliative care competencies were identified as communication skills and managing pain and other palliative symptoms as the two most important competencies. The other three areas identified as essential for palliative care training included: principles of palliative care, psychosocial, spiritual and cultural aspects of palliative care and also terminal care and bereavement.<sup>107</sup>

In Europe however, the European Association for Palliative Care (EAPC) that was started in 1988, recommend seven competencies that need to be addressed as part of the training of the undergraduate curriculum. These competencies include the knowledge about basic principles in palliative care, pain and other symptom management, ethics and law in palliative care, psychological and spiritual aspects of palliative care. It should also include training in communication skills. (The discussion of prognosis with family and patient)

Training of all health care professionals in palliative care is their main objective as well as the implementation of a standardized undergraduate palliative curriculum across all European Medical Schools. The proposed guidelines for an

undergraduate medical palliative curriculum has been updated in 2013 and reviewed by 30 palliative care specialists.

The undergraduate palliative curriculum should change the attitude of medical students towards end-of-life care, address knowledge about symptom management and address skills in multi-disciplinary team work.

Teaching and training the undergraduate palliative curriculum should involve different members of the multi-disciplinary palliative team.

The EAPC recommend a total of 40h for palliative training to achieve the required objectives. Training of the basic principles of palliative care should be done in the early medical curriculum, with the application of clinical aspects later in the medical training. A clinical rotation is recommended.

The outcomes of the palliative training should be evaluated. Evaluation methods need to assess knowledge, skills and attitudes of the students towards palliative care.

It is apparent that from the EAPC guidelines, pain and symptom management should get the most attention in the palliative curriculum (55%), with psychosocial and spiritual aspects weighted as the second most important aspect of training (20%).<sup>71</sup>

The recommendations of the United States National Survey published by Kristen et al in 2014 however reflect communication as the most important competency required, followed by pain and symptom management. From the five areas identified as essential competencies for palliative training, psychosocial and spiritual aspects were rated as less important.<sup>107</sup>

The EAPC and the United States National Survey recommend the use of problem based learning, small groups, formal lectures and role play to address the knowledge of medical students in palliative care.<sup>71,107</sup>

The teaching methods that improve the skills of the medical students in palliative care include: the exposure to practical/clinical scenarios under supervision, role play and reviewing the students' skills/managing of patient with the use of audio or visual tools.

The methods that address the attitude of medical students to care for palliative patients should focus on: the discussion on patients/family issues after practical exposure, role play and the discussion of palliative cases on an individual basis or in small groups. This method applies reflective teaching.<sup>71</sup>

## **7. Assessing the Impact of Palliative Training**

### **The significance of palliative training assessment**

Frey published in 2013 a systematic review on the instruments used to measure the effectiveness of palliative care education at undergraduate level. In this review the main indications for assessing palliative training included: the identification of any unmet needs in the palliative curriculum, to address the barriers and improve the outcomes of the palliative care training and also to evaluate if the objectives (knowledge, skills and attitudes) of the palliative curriculum are met.<sup>79</sup>

### **Methods used for assessing palliative training**

Frey identified numerous tools designed and used to identify the “gaps” in a palliative curriculum. The lack of a standardized assessment tool resulted in difficulties to interpret and compare the data published. From the literature, numerous aspects of palliative training have been identified as a predictor of effective palliative education. Frey identified thirteen questionnaire-based instruments that evaluate the effectiveness of undergraduate palliative education.<sup>79</sup>

Arber published an article in 2001 that measured knowledge as an indicator of proper palliative training. The instrument used to assess the knowledge of the students, was the Palliative Care Quiz for Nursing (PCQN) questionnaire. This instrument focuses on testing the principles of palliative care, symptom management, as well as the psychosocial and spiritual care of patients. The study was designed for assessing palliative training on nursing students. The instrument only assessed the knowledge of training (not attitudes and skills) and was not applied to medical students. It is also subjective and relies on self-reporting of the students. Arber reported issues on how the questions were formulated. The PCQN instrument has been tested for reliability using the Kuder-Richardson (KR-20) formula for dichotomous variables. Test-retest reliability was also shown. Structural validity was also shown through principal component analysis. Content validity was

tested in the questionnaire about concerns on caring for dying patients. Response rates were > 60%.<sup>108</sup>

Kwekkeboom published an article in 2005 assessing the impact of a Palliative Care Companion program on the knowledge and attitudes of nursing students. The PCQN instrument was used to assess knowledge, as well as a 12-item scale to evaluate attitudes about end-of-life care. Another 6-item scale evaluating specifically nursing students' concern regarding care of dying patients were included in the study. Again this study assessed nursing students (not medical students) and only evaluated knowledge and attitudes and not skills. The PCQN instrument has been tested for reliability using the Kuder-Richardson (KR-20) formula for dichotomous variables. Test-retest reliability was shown. Structural validity was shown through principal component analysis. Content validity was tested in the questionnaire about concerns on caring for dying patients. Response rates were > 60%.<sup>109</sup>

Velayudhan assessed in 2004 the knowledge of third year nursing students and 4<sup>th</sup> year medical students after a palliative care training program has been implemented in Bangalore, India. There has been an increase in knowledge detected after the palliative training. The tool applied, consisted of multiple choice questionnaires. The response rate was > 60%. Pre-test and post-test questionnaires were applied. There was no mention given about testing of reliability and validity.<sup>110</sup>

Kumar evaluated in 2011 the knowledge, attitudes, beliefs and experiences of physiotherapy students exposed to a palliative care training program in India. There was an increase demonstrated in all the domains tested after exposure to the palliative program. The instrument used was "Physical Therapy in Palliative Care – Knowledge, Attitudes, Beliefs and Experiences". The response rate was > 60%. Test retest reliability was mentioned for 24 students. There was a lack of validity noticed.<sup>111</sup>

Mason and Ellershaw used the Self-efficacy in Palliative Care Scale (SEPC) to evaluate self-reported efficacy and outcomes for caring for patients dying. The first article was published in 2008 and assessed 4<sup>th</sup> year medical students at the University of Liverpool in the United Kingdom. A pre- and post-test questionnaire was applied after the introduction of a short-program in palliative care. The SEPC Scale consists of three categories, namely communication, patient management and

multi-professional teamwork.<sup>112</sup> Mason and Ellershaw applied the SEPC Scale in 2010 on undergraduate nursing students at the University of Liverpool, United Kingdom. The results were similar as the 2008 article. This instrument specifically assessed the students' confidence to perform certain tasks relating to palliative care. The Thanatophobia Scale (TS) was also applied as part of the two studies to measure anxiety related to death. The tool specifically assessed the attitudes and outcomes for caring for dying patients. Both the two scales were validated in 2004 in the United Kingdom among 4<sup>th</sup> year medical students. Reliability was demonstrated with the use of Cronbach's alpha that showed an internal consistency. There were > 60% response rates reported in both studies of 2008 and 2010.<sup>113</sup> A group of students submitted incomplete questionnaires in both studies (2008 and 2010). This may highlight some questions that may provide difficulties to decide on what to do.

Three studies reported on the use of the Frommelt Attitude toward Care of the Dying (FATCOD) tool to evaluate attitudes towards death and caring for dying patients.<sup>114,115,116</sup> Barrere published an article in 2008 after applying the FATCOD tool to assess changes in nursing student's attitudes after introduction of end-of-life education at Hamden, United States. There was a positive change in attitudes noted. The response rate was > 60%. Content validity was mentioned and test-retest reliability in 18 students as first and then 30 students as second sample noted internal consistency reported.<sup>114</sup>

Frommelt also published an article in 2009 on the attitudes assessed with the FATCOD tool of undergraduate students after exposure to end-of-life care training. There was a dramatic positive change in attitude measured after palliative training. The response rate was not mentioned. Content validity, as well as test-retest reliability were reported. The sample group was very specific and could there for have resulted in selection bias. The study only assessed attitude as an outcome of the palliative training. The trial did show a clinical significance increase in attitudes after the intervention.<sup>115</sup>

Mallory also used the FATCOD tool to assess the attitudes of nursing students after introduction of palliative training. The study was published in 2003 and it was performed at 2 state universities in North Carolina, United States. Positive change in attitude was noted after training with a response rate > 60%. Test-retest reliability

was measured and internal consistency reported. This trial only assessed attitudes. The sample groups were represented by two different Universities and thus decrease the possibility of selection bias. The trial showed clinical significance in attitudes after the palliative training given.<sup>116</sup>

Schwartz reported in their study published in 2005 on the outcome of nursing students' attitudes after the "Concept of a Good Death Measure" was used as an instrument to measure attitudes. Three aspects were tested: "Closure, personal control and clinical criteria". The response rate for the inter-clerkship group tested was > 60%. Item frequency distributions and Cronbach's alpha were reported.<sup>117</sup>

Another tool used to measure change in death anxiety experienced by medical students and health care workers is the "Multidimensional Fear of Death Scale" (MFODS). Hegedus published the result of their article in 2008. There was a reduction in fear of death measured after introducing end-of-life care training. Response rate was > 60%. Cronbach's alpha and test-retest reliability was reported.<sup>118</sup>

From the above literature it is apparent that the numerous tools available to measure the outcomes of a palliative program have limitations. Assessment of a palliative curriculum needs to incorporate an objective method of assessment as well. All the above instruments rely on self-reporting of the students assessed. This is a subjective method of assessment, and usually reflects the individuals' perceived effectiveness of the palliative training.<sup>80</sup>

The assessment of the outcomes of palliative training needs to incorporate more than one method. Weissman published in 1998 recommendations to evaluate palliative education. They suggest the inclusion of Objective Structured Clinical Examination Stations (OSCE's) to evaluate the outcomes of palliative programs.<sup>119</sup>

The above method (OSCE) has been used by Chipman (2007)<sup>81</sup>, Gessaroli in (1994)<sup>82</sup> and also by LaDuca in (1980)<sup>83</sup> in various studies to test palliative care objectives.

### **Aspects that need to be assessed in palliative training**

Frey identified in her systematic review of 2013 a few criteria that can be used to assess if the palliative training is effective. These criteria need to be assessed to determine if the outcomes of the palliative care curriculum has been achieved.<sup>79</sup>

Medical knowledge (especially focusing on pain and symptom management) has been used as a predictor of successful integration of palliative teaching in four studies respectively. These studies include Arber (2001)<sup>108</sup>, Kwekkeboom (2005)<sup>109</sup> and also Kumar (2011)<sup>111</sup>. Velayudhan (2004)<sup>110</sup> addressed symptom management, ethical and legal applications in palliative care, communication and teamwork.

Attitudes towards caring for the dying had also been identified as an important factor that determines effective palliative care training. Seven (7) studies confirmed the above observation. Barrere (2008)<sup>114</sup>, Mallory (2008)<sup>116</sup> and Frommelt (2003)<sup>115</sup> assessed the attitudes of the students towards the patient and family. Thompson (2005) evaluated the nursing students' perception to care for dying patients and also if they can cope emotionally.<sup>120</sup> It is not clear from Schwartz (2005)<sup>117</sup>, Kumar (2011)<sup>111</sup> and Kwekkeboom's (2005)<sup>109</sup> studies what exactly they assessed.

Reported efficacy/confidence of the student in performing certain palliative activities has also been identified to reflect the effectiveness of the palliative training given. This has been reported by Mason and Ellershaw in two separate studies as described above. (2008 and 2010)<sup>112,113</sup>

The increased exposure to practical scenarios of palliative care (hospice rotation, home based visits) has been linked to improved palliative care education as reported by Kumar in 2011.<sup>111</sup>

**Two instruments were identified for assessing the outcome of the palliative training**

**The Self-efficacy in Palliative Care Scale (SEPC):**

**A tool to assess the knowledge and skills of medical students**

Mason and Ellershaw from the University of Liverpool in the United Kingdom published in 2004 the results of their study where they have tested if self-efficacy can be used to determine the impact of an undergraduate palliative training program. They applied the modified SEPC scale in 4<sup>th</sup> year medical students before and after a palliative training program. The SEPC Scale specifically measured changes expressed in a student's confidence associated with palliative care activities. The SEPC Scale consists of 23 items measured. The items are divided into three categories, namely communication, patient management and also multi-professional teamwork. The scale consists of a 100 mm Visual Analogue Scale (VAS).

The perceived efficacy and outcomes are measured in caring for dying patients. The medical students rate their confidence in delivering certain palliative care activities on this VAS. Expression of anxiety relates to a lack of confidence and this again can influence negatively the ability of the student to perform palliative activities. The SEPC Scale was tested for reliability and validity in 2004. Internal consistency was demonstrated using Cronbach's alpha, with a score of 0.84 – 0.85 noted for the SEPC scale, this is highly indicative of reliability. Structural validity was tested with Varimax rotated principal components analysis that identified the three factors of communication, patient management and multidisciplinary teamwork. High factor loading of 0.45 – 0.89 were reported at pre- and post-test.<sup>86</sup>

In 2008, Mason applied the SEPC scale among 4<sup>th</sup> year medical undergraduates before and after a short program on palliative care training. There was a statistically significant increase detected in communication, patient management and multidisciplinary teamwork after palliative training.<sup>112</sup>In 2010, Mason published another article where the SEPC scale was used on undergraduate nursing students at the University of Liverpool, UK. Similar results were demonstrated.<sup>113</sup>

## **The Thanatophobia Scale:**

### **A tool to assess attitudes of medical students toward caring for the dying**

Mason and Ellershaw assessed anxiety to death with a scale that evaluated attitudes and outcomes for delivering palliative care. The Thanatophobia Scale consists of a 7-item Likert Scale. The students express how much they agree or disagree to specified negative attitudes in the questionnaire. The higher the score, the more negative attitudes are experienced. Again reliability is confirmed with Cronbach's alpha of 0.92 – 0.95. Validity was tested with principal components analysis with recorded factor loadings of 0.60 – 0.81 at pre- and post-testing.<sup>86</sup>

### **8. Factors that contribute to poor palliative training**

In 2004, Lloyd-Williams published a systematic review on: "Teaching and learning in palliative care within the undergraduate medical curriculum."<sup>78</sup>

From the 88 articles identified, only 49 were included. The review searched databases from 1966 until 2001. There was no randomized controlled trial regarding undergraduate palliative teaching, only descriptive studies.

The **first factor** that results in ineffective palliative training includes the **inconsistency** with which the palliative training is presented to the medical students. The content of the curriculum taught varies widely between the different medical schools. This result in a lack of uniformity on the palliative content taught to the medical students.

Ury conducted a needs assessment for a palliative curriculum in the United States in 1995. The study was done among doctors, nurses, staff from the university as well as families and patients. Methods used included questionnaires, focus groups and one-to-one interviews. In 1995 there was no palliative teaching done. The newly qualified doctors specifically expressed a need for adequate palliative training. The three most important topics included: management of symptoms, communication skills and also to address ethical issues associated with palliative care.<sup>121</sup>

An article published by Schonwetter in 1994 specifically assessed the objectives that need to be taught as part of the palliative curriculum. The study consisted of a questionnaire done among the members of the Academy of Hospice Physicians. A Delphi type approach was used. The first part of the study consisted of a small

group that identified 30 important topics that cover knowledge, skills and attitudes in palliative care.<sup>62</sup>

These topics were sent to other doctors that ranked the significance as inappropriate/ unsure or appropriate. From 39 objectives identified initially, 34 were validated using the congruence analysis. Skills as an objective of palliative training were rated as most important. Topics that address skills training included: multidisciplinary teamwork, communication and ethical issues.

Topics addressing knowledge included the management of physical symptoms. Attitude training should specifically address death as part of life.

The **second factor** that hinders palliative training includes the **fragmentation** of the palliative training across the various disciplines with no dedicated timeslot identified in the undergraduate medical curriculum for palliative education. This results in the palliative training not getting the high recognition of importance that it should deserve, with the risk of the training given by unskilled lecturers.

Lloyd-Williams comment that there are very few articles that address the best time to introduce palliative training.<sup>78</sup>

Weisman published an article in 1998 about the integration of a palliative care curriculum at the University of Wisconsin in the United State. The palliative curriculum is integrated throughout the undergraduate curriculum including the acute and community-based setting. The curriculum is taught as a program in the 2<sup>nd</sup> year. Palliative teaching is offered to the 3<sup>rd</sup> and 4<sup>th</sup> year medical students as optional. The house staff was trained in palliative principles through lectures. Unfortunately assessment of the impact of this palliative curriculum is not documented.<sup>122</sup>

The **third factor** contributing to poor palliative training results from the **lack of skills, knowledge and expertise of the lecturer involved with palliative training.**

Lloyd-Williams reported that palliative medicine is a small discipline, resulting in few doctors that can teach this discipline with passion. The few skilled doctors in palliative care are usually working as clinicians and doing research (as all the other disciplines), this result in almost no time available for teaching activities.<sup>78</sup>

MacLeod did his Master's Thesis in 1992 on teaching postgraduate palliative medicine. In his thesis he evaluated the training received by hospice physicians to equip them to be able to teach students. The finding revealed no formal training of physicians in health education.<sup>89</sup>

Barrington published an article in 1999 about an education model used in Australia. Nursing staff are allocated as the primary educators. Pre-selected nursing staff will be allocated with medical students. The medical student will be "shadowing" the nurse for the duration of her shift. The impact of this model was assessed with a Visual Analogue Scale to test the medical students' perceived confidence regarding communication, symptom management and teamwork work. The medical students reported a positive experience.<sup>87</sup>

The **fourth factor** that contributed to poor palliative training is the fact that the **palliative training** given to the medical students is **not formally assessed** to determine if the students have met the stipulated outcomes of the palliative curriculum. This results in students not realizing the importance of the palliative training and thus neglecting this discipline.

Lloyd-Williams identified only one article that reported on their experiences of evaluating the palliative program at the Queen's University in Belfast. This article was published by Irwin in 1984. In his article, the members of the multidisciplinary team involved with the palliative teaching consisted of the Department of Family Medicine, Geriatrics, Oncology and Psychiatry. All the members of the team received the objectives of the palliative course. A group of 50 students were selected as a study population. Teaching included topics such as attitudes towards dying patients, knowledge about managing symptoms and also psychosocial issues that address multidisciplinary teamwork.

The palliative training was evaluated at the end of the three month program. The methods used consisted of short questions. The students that failed the written exam were assessed with an oral examination. The results of the examination were included as part of the student's final examination<sup>123</sup>

MacDonald published the Canadian Palliative Care Undergraduate Curriculum in 1993 and in this document he highlighted the importance of examining students on

the palliative training received. He stated that the assessment of the palliative module will convey to the students that this part of the curriculum should be recognized as very important.<sup>4</sup>

The **last factor** that can contribute to poor palliative training is the fact that the attitudes of the students towards caring for dying patients need to be addressed. If the palliative training **neglects the attitudes** of the students and only focuses on the knowledge and skills' objectives of the palliative curriculum, then the end result of that palliative training was ineffective and it did not meet the 3 objectives of a palliative curriculum required.

Rappaport conveyed a questionnaire based study in 1993 to evaluate the attitudes of the 3<sup>rd</sup> year medical students on their palliative training received. The results of the questionnaire confirmed that > 50 % of the students experienced their training as insufficient to care for dying patients. This highlighted that there is a lack in the undergraduate palliative curriculum to address the attitudes of medical students for caring for palliative patients.<sup>94</sup>

### **Rationale for the Study**

The above observations made me question why patients are not getting appropriate holistic palliative management. I realized that health professionals cannot deliver proper palliative care, if they do not know how to practice good palliative principles.

The most obvious explanation why doctors do not know how to apply palliative principles is due to ineffective or no palliative care training and exposure during their undergraduate medical training.

I have realized that we are dealing with a serious deficit in our medical training. The only way to identify this gap was to investigate it with a reliable and validated research methodology.

If this gap is proven, the results can be used to motivate for an improvement in the palliative training offered to the undergraduate medical students.

## **Chapter 3: Methodology**

From all the published data, the importance of undergraduate palliative training starts with addressing the self-efficacy/ confidence of the medical students in providing effective palliative training. This however can only be determined with the evaluation of the training given to assess if the training given is meeting the objectives of improving the knowledge, skills and attitudes of the students towards caring for the dying. This chapter describes how the research has been conducted.

### **Aim**

A needs assessment for palliative care training among undergraduate students at the University of Stellenbosch, with comparison to other South African medical schools' palliative curricula.

### **Objectives**

1. Assessing the self-efficacy/ confidence of the undergraduate medical students
2. Assessing the undergraduate student's attitudes towards caring for palliative care patients, thus measuring outcome expectancies of caring for dying patients.
3. Assessing and comparing current undergraduate palliative care training at other South African medical schools.

### **3.1: Research design and methodology**

#### **3.1.1: Study design**

This is a cross-sectional, descriptive study.

#### **3.1.2: Study site**

The University of Stellenbosch's medical school was the primary site. All the other medical schools in South Africa (University of Kwazulu-Natal, University of Pretoria, Walter Sisulu University in the Eastern Cape, University of Cape Town, University of Limpopo {Medunsa}, University of the Free State, University of Witwatersrand and the University of Stellenbosch) were contacted to provide details on their undergraduate training in palliative care.

#### **3.1.3: Study population**

**There were two target groups for this study:**

- a. At the University of Stellenbosch's medical school, the study population included fifth year medical students.
- b. The convenors of the MBChB undergraduate curricula in all the eight medical schools in South Africa formed the study population for part two of the study.

#### **3.1.4: Selection criteria**

##### **a. Inclusion criteria**

All the fifth year medical students were invited to participate in the questionnaire.

All the medical schools in South Africa were contacted to provide details on their undergraduate training in palliative care.

##### **b. Exclusion criteria**

All undergraduate medical students not in their fifth year of training at the University of Stellenbosch.

#### **3.2: Sampling**

**3.2.1:** The whole population of fifth year medical students was included in the study.

**3.2.2:** Course convenors of undergraduate curricula at all South African medical schools were included in the study.

#### **3.3: Data Collection**

##### **3.3.1: Data collection tools**

During my literature review, a theoretical framework was hallmarked for successfully evaluating teaching programs. This framework was based on social cognitive theory. To test this cognitive theory, two scales were found that can be used as assessment tools. The SEPC scale was initially developed in 1999 by Barrington to evaluate 4 subscales: diagnosis, prognosis, management and continuous care in palliative medicine training at the University of Western Australia among medical students. This scale was not tested for reliability and validity. In 2004, Mason then adapted the initial scale to test 3 expected outcomes of palliative training (communication, patient management and teamwork). The Thanatophobia scale however started in America from the acute care set-up.

The reliability and validity of the 2 scales were statistically measured with 2 tests: factor analysis and Chronbach's alpha. Factor analysis is done on each of the individual subscales. This produce data that is called factor loadings or correlation

coefficients that again identify certain groups that correlate together to form a cluster, for example the subscale of communication. The Chronbach alpha on the other hand measures the intercorellation between the individual subsets. If the Chronbach alpha is high ( $>0,07$ ), this is a good indication that each subscale measure the same thing. This reflects internal consistency. Mason and Ellershaw published an article in 2004 that confirmed the reliability and validity of these scales to test the impact of a palliative curriculum in medical students.

The questionnaires used for this study were identified after consultation and permission from Dr S Mason. It was compiled on the research already done internationally on the use of the SEPC and Thanatophobia scales for objectively testing the undergraduate palliative curriculum at an institution.

The questionnaires distributed to the fifth year medical students included an explanation on the aim of the study as well as three sections for completion. The first section consisted of general questions that evaluated demographics and basic knowledge on palliative care. Section two consisted of the first scale used: Self-efficacy in palliative care scale (SEPC). Section three consisted on the second scale used: the Thanatophobia scale.

The scales evaluate the medical students' knowledge, skills and attitudes in palliative care respectively.

**a. Part 1: Demographics and General questions:**

Section one of the questionnaire specifically evaluated the sex, age and previous experience with dying. These demographic questions were part of the questionnaire designed by Mason and Ellershaw in 2004. Other general questions to assess knowledge/training on palliative care were identified by the researcher as important through extensive reading on the topic. The questions were not piloted. The general questions included: WHO 3 step ladder, route of administration of morphine, syringe driver use, morphine prescription, morphine addiction, managing of the 'death rattle', intravenous fluids or nasogastric feeds in a dying patient. The students were asked if they had enough knowledge and training to provide palliative care, if they had enough education and skills in palliative care and also to express how they feel to discuss dying with a patient.

## **b. Part 2: SEPC and Thanatophobia scales**

### **b1: SEPC**

This section consisted of the first scale used: **The Self-efficacy in palliative care scale (SEPC)** that evaluated the confidence or anxiety of the medical student in 3 subsets:

- i. Communication
- ii. Patient management
- iii. Multidisciplinary team work

The SEPC scale had 23 items. A visual analogue scale (VAS) of 100mm was used with extremes of 'very anxious' and 'very confident'.

### **b2: Thanatophobia scale**

This section consisted of the second scale used. This is a 7-item Likert scale that evaluated the medical students' attitude to manage a palliative care patient. The students' rate how positive or negative they feel towards caring for the dying.

## **c. Part 3: Evaluating and comparing the undergraduate palliative care curriculum at the medical schools in South Africa**

The European Association for palliative care in 2007 developed a framework to guide institutions on how to implement an undergraduate palliative curriculum. This document recommends that seven topics need to be included in a palliative curriculum to provide the necessary skills, knowledge and attitudes for palliative training. The document also recommends that at least 40 h are needed for palliative training and it provides guidelines for evaluation of the outcome of an undergraduate palliative curriculum.

Based on these recommendations, I structured a questionnaire that assesses all these core areas highlighted for effective palliative training. The questionnaire was sent to the respective convenors of the undergraduate MBChB curriculum of the 8 medical schools in South Africa. The questionnaire consisted of the following: the content of the palliative curriculum, the time allocated to palliative care education, the assessment used to evaluate the students and also the qualifications of the persons responsible for the training of the undergraduate medical students in palliative care.

The main role of the questionnaire was to collect data on each medical school's approach to palliative teaching and to get an idea of the amount of time spent on palliative training for each medical school. The questionnaire was not tested statistically for reliability or validity as the purpose of the questionnaire was for descriptive purposes only. The questionnaire was not tested in a pilot study to evaluate for content validity as this was not one of the objectives of the study to compare the significance of the different undergraduate palliative curricula. Thus no statistical conclusions can be made from the different questionnaires. The questionnaire gives an indication on each medical school's palliative training and how South Africa's palliative training compare to the European guidelines. The questionnaire also highlights the major differences in palliative training for undergraduate medical students in South Africa.

### **3.4: Data collection process**

#### **3.4.1: Part 1 and Part 2**

Before the documents could be sent to the fifth year medical students, permission was obtained from Prof B van Heerden, the Head of the MBChB undergraduate curriculum at the medical school of the University of Stellenbosch.

Two documents (the questionnaire and the informed consent) were e-mailed to the 179 fifth year medical students. The importance of the study was explained, as well as the fact that participation in the study was entirely voluntary with the questionnaire being anonymous. The informed consent form also needed to be signed by each student on participation. A reminder e-mail was sent again 1 month later to each of the students.

The 135 questionnaires received, were each allocated with a study number. The data were stored under lock and key with a secured computer password to safeguard the data.

#### **3.4.2: Part 3**

The convenors of the individual undergraduate curricula in palliative training at the 8 medical schools were identified after an e-mail to the different Heads of the undergraduate MBChB curricula. They were contacted via e-mail. The aim of the dissertation was explained with the accompanied questionnaire for completion.

A reminder e-mail was sent 1 week later. An attempt was made to contact the individual convenors via telephone consultation, but due to logistical reasons (busy clinical activities and not having a dedicated person that can follow up on telephone calls), this method was abandoned.

### **3.5: Data analysis**

**3.5.1:** The response rate was calculated to exclude the possibility of selection bias. The results of the questionnaires were assessed in three parts. All quantitative data were collected from the coded questionnaires and then translated into a spreadsheet and subsequently analyzed using SPSS version 20.0 statistical software. All data were presented as descriptive statistics. Applicable data were analyzed descriptively by means of the following:

#### **3.5.1a: Continuous data**

- Means and standard deviations were used if data were normally distributed
- Medians and interquartile ranges were used for non-normally distributed data
- A p-value of  $<0,05$  were indicative of statistical significance
- Pie charts, bar graphs, linear graphs and/or histograms were used to present data graphically

#### **3.5.1b: Categorical data**

- Frequency distributions were presented to show absolute counts and percentages for categorical variables
- 95% confidence intervals were presented for binary variables
- Pie charts, bar graphs, linear graphs and/or histograms were used

#### **3.5.2: Part 1: Demographics and General Questions**

The **first part** evaluated gender ratio, age of the respondents, as well as if the students had previously encounter a dying patient. General questions evaluating basic principles/ knowledge of palliative care were examined to identify certain 'gaps' in the training.

### **3.5.3: Part 2: SEPC and Thanatophobia scales**

Reliability analysis was conducted by calculating Cronbach's alpha for each subset of the SEPC Scale and also for the Thanatophobia scale. An increased calculated value translates to different aspects tested within a subset, measuring the same principles, thus internal consistency.

The mean scores and the standard deviations (SD) of the different subsets of the two scales were examined. The t-test analysis was also calculated for the three subsets of the SEPC and the Thanatophobia scale. This in turn generated a p-value for each subset, which indicates the areas of statistical significance. These specific areas could then be further investigated. Means of the current sample were compared against literature means by using one-sample t-tests. SEPC Scales were compared between different groups using one-way ANOVA. Fisher least significant difference (LSD) testing was used for post-hoc testing.

A comparison was made between the three identified variables (gender, age and previous exposure to a dying patient) with the SEPC scale subsets and the Thanatophobia scale respectively. The responses from two of the general questions evaluated in Part 1 of the questionnaire were also compared against the SEPC subsets and the Thanatophobia scale.

Differences in the means within each subscale were also assessed to identify tasks which the fifth year students were more comfortable with, and those areas which they perceived as more challenging. This will be linked to the content of the undergraduate palliative curriculum at the University of Stellenbosch.

### **3.5.4: Part 3: Undergraduate palliative care curriculum at the 8 medical schools in South Africa**

The response rate of the 5 medical schools that participated out of the 8 medical schools invited, was calculated. The third part of the study was to assess the current undergraduate palliative curriculum at the University of Stellenbosch. The other medical school's palliative curricula were also assessed. The differences in the

palliative training for each of the medical schools were noted, as well as the amount of time spent on palliative teaching. This was done to identify the university that spent the least amount of time on palliative teaching versus the university with the most hours of dedicated palliative training.

### **3.6: Ethical considerations**

The proposal of the study was submitted to the research ethics committee at the University of Cape Town and approved (HREC ethics no. 265/2013) The University of Stellenbosch accepted the ethics approval given by the University of Cape Town. However, before the study was commenced, institutional permission was obtained from the University of Stellenbosch. The Head of the undergraduate MBChB curriculum (Prof B van Heerden) at the University of Stellenbosch's medical school was asked for permission to approach the fifth year medical students to take part in the study.

Informed consent was taken for each medical student that participated in the study. The potential risk of confidentiality was ameliorated by the use of a study number and password protection.

The questionnaires that were sent to the fifth year medical students were anonymous. All data were de-identified on chart abstraction and handled/stored under lock and key with a secured computer password to safeguard the data. All data collected were treated with utmost confidentiality.

## Chapter 4: Results

The previous chapter described the instruments that were used to measure the outcomes of the undergraduate palliative curriculum at the University of Stellenbosch, namely to measure the knowledge of the students, to assess how confident the students perceive their abilities to perform palliative tasks and lastly to evaluate the attitudes of the medical students towards caring for dying patients. The other medical schools in South Africa's palliative training were also assessed.

In this chapter the results of the questionnaires will be interpreted and assessed if there are significant findings.

### 4.1: Response rate

The questionnaires were sent to 179 undergraduate fifth year students. A total of 135 students returned their questionnaires. (Response rate ~ 75.4%)  
(Table 1 below)

**Table 1:** Response rate

<b>Students</b>	<b>Total</b>
Invited	179
Responded	135
Response rate	75,4%

### 4.2: Incomplete questionnaires

The 135 returned questionnaires were assessed and 14 (10.3%) had missing data in some of the sections. The latter were excluded from the analysis, leaving 121 (89.6%) valid for interpretation. The demographics of all 135 were evaluated. (Table 2 below)

**Table 2:** Questionnaires for Analysis

<b>Questionnaires</b>	<b>Nr. and percentage</b>
Total received	135
Missing data	14 (10, 3%)
Valid for analysis	121(89, 6%)

### **4.3: Demographics**

#### **Gender ratio**

Of the 135 students that responded, 41 (30%) were male and 94 (70%) female (1:2.3).

#### **Age**

The majority of the students (116/87%) were  $\leq 25$  years and 17 (13%) of the students' age ranged from 26 to 30 years. Only one (1%) student was  $\geq 31$  years of age.

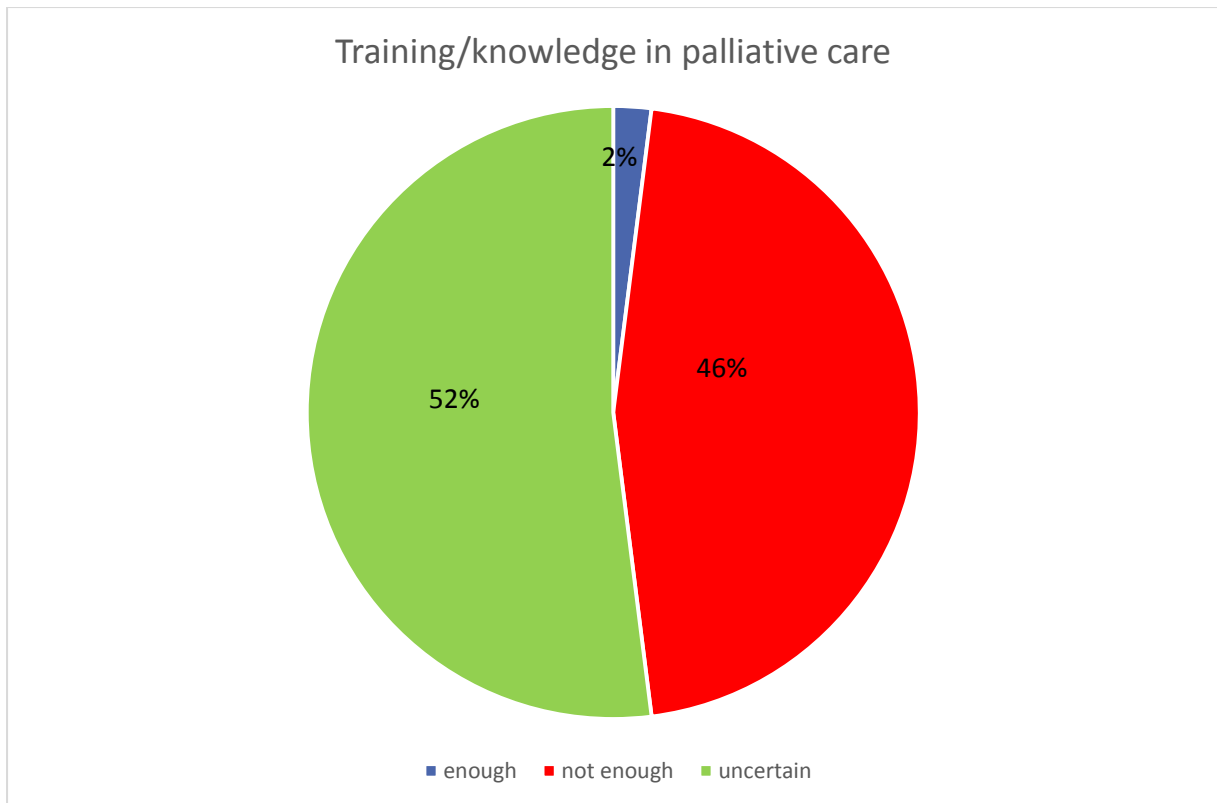
#### **Previous experience with dying**

128 students expressed that they had already encountered the dying process. From this group of 128 students, the majority (70 students = 52%) had their first experience of the dying process linked to patient care, 53 (39%) students lost a family member and only five (4%) students lost a friend. There were however seven (5%) students from the 135 respondents that had never experienced the dying process.

### **4.4: General questions**

#### **Knowledge/training of Palliative care**

Only three (3) students (2%) felt that they had enough knowledge and training to provide palliative care. The remainder of the 135 respondents agreed that they do not have enough knowledge (62 ~46%) or some knowledge. (70 ~ 52%) (*Figure 6 below*)



**Figure 6:** Feedback about palliative training

### Knowledge of pain management

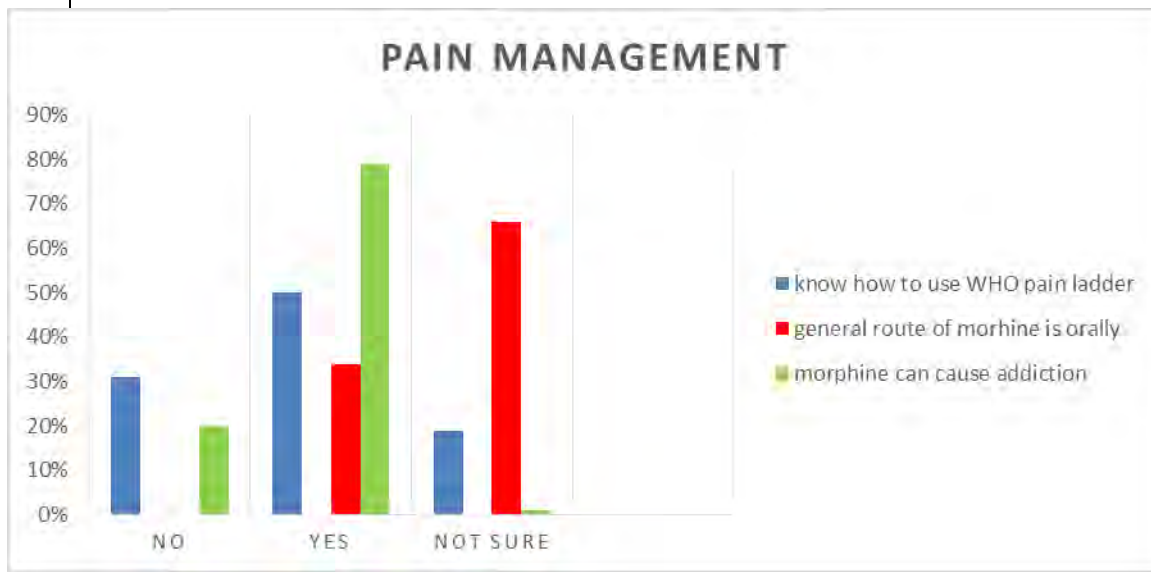
Sixty-eight (68) students (50 %) know how to use the WHO 3 step ladder for pain relief, 31% of students do not know how to use the WHO step ladder and 19% of students were uncertain.

Only 34% of the students express that the preferred route of morphine should be orally. The rest of the group (66%) was uncertain about the ideal route of administration of morphine and felt that morphine need to be given by intramuscular or intravenous route.

Thirty-four (34) students (25 %) did not know what a syringe driver was.

Only 46 (34 %) students knew that morphine syrup need to be prescribed 4hourly, while there were 35 (26 %) students that would prescribe morphine as necessary. The remainder of 53 (40 %) students would prescribe morphine 6h or 8h.

A total of 106 (79 %) students felt that morphine can cause addiction with regular administration for pain relief. Twenty-seven (27) students (20 %) did not feel that morphine can cause addiction with 1 (1 %) student being uncertain. (*Figure 2 below*)



**Figure 2:** Pain management

### Management of distressing symptoms

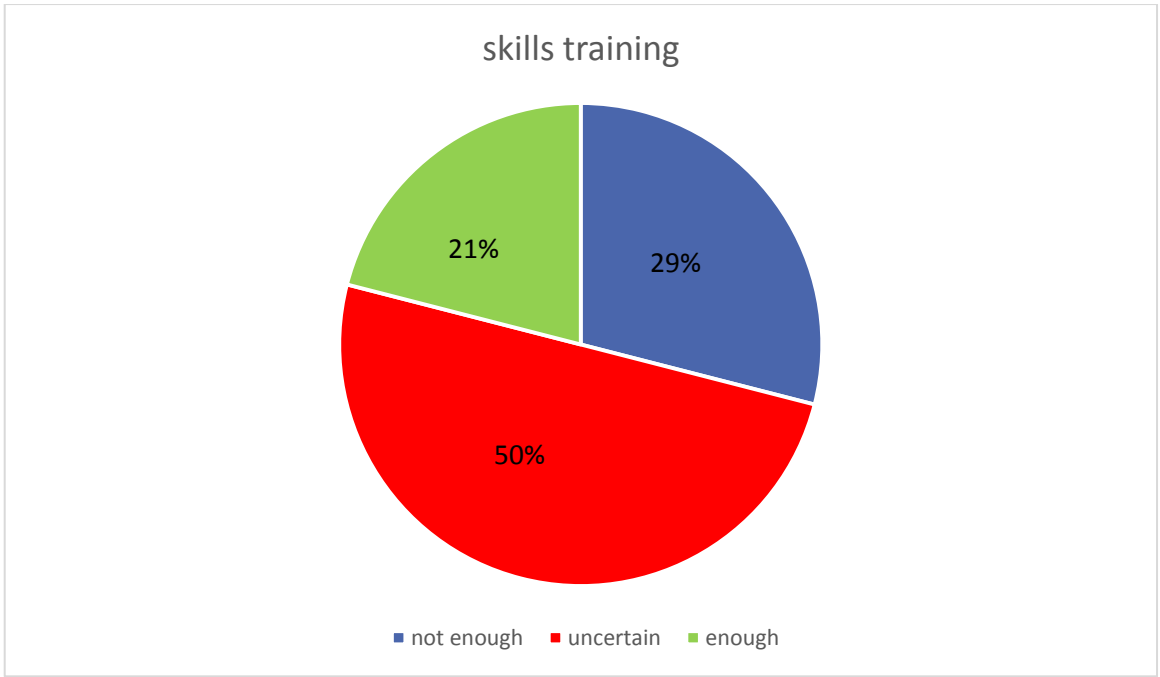
Only 8 (6%) students knew the term “death rattle” and the use hyoscine butylbromide in the management of this symptom.

### Knowledge of legal and ethical issues

Fifty-eight (58) students (43 %) would use IVI fluid and NG-feeds in a dying patient, while 31 (23 %) students were uncertain and only 45 (34 %) students agreed not to use the above interventions in a dying patient.

### Skills training

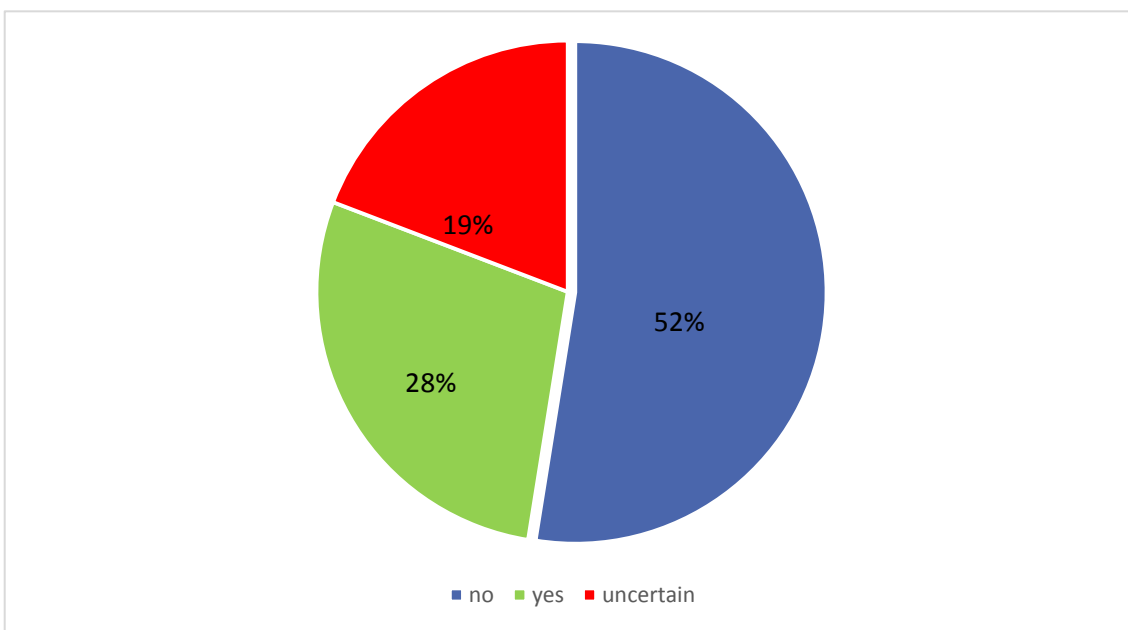
Thirty-nine (39) students (29 %) expressed a lack of education and skills training in palliative care. The majority (67) of the students (50 %) felt uncertain about their skills and training in palliative care. (*Figure 3 below*)



**Figure 3:** Training in skills

**Attitudes**

Ninety-six (96) students (71 %) do not feel comfortable to tell a patient that he/she is dying. (Figure 4 below)



**Figure 4:** Discussing death with a patient

#### **4.5: The Self efficacy in Palliative Care (SEPC) Scale**

The SEPC scale is a well recognised instrument that is used to assess the outcome of a palliative care curriculum. It specifically assesses the student's knowledge and skills to perform certain palliative tasks. The SEPC scale had 23 items that evaluated the confidence or anxiety of the medical student in 3 subsets:

- I. Communication
- II. Patient management
- III. Multidisciplinary team work

##### Communication subset consists of the following 8 questions:

- Discussing the likely effects of cancer with the patient.
- Discussing the likely effects of cancer with the patient's family.
- Discussing issues of death and dying.
- Discussing the patient's own death (with the patient)
- Discussing the patient's death (to occur) with the family.
- Discussing the patient's death with the family upon treatment.
- Answering the patient's question: How long have I got to live?
- Answering the patient's question: Will there be much suffering or pain?

##### Patient management subset consists of the following 8 questions:

- Your ability to assess the patient's needs.
- Your knowledge of the etiology of common symptoms experienced by palliative care patients.
- Your ability to manage common symptoms experienced in palliative care patients.
- Your ability to prescribe appropriate and adequate pain control medication.
- Your knowledge of the therapeutic and side-effects of analgesic agents.
- Your ability to provide psychological care for the palliative care patient and his or her family.
- Your ability to provide social care for the palliative care patient and his or her family,
- Your ability to provide spiritual care for the palliative care patient and his or her family

Multidisciplinary & team working subset consists of the following 7 questions:

- Working within a multi professional palliative care team
- Appropriately referring palliative care patients for physiotherapy.
- Appropriately referring palliative care patients for occupational therapy.
- Appropriately referring palliative care patients for complementary therapies.
- Appropriately referring palliative care patients to a lymphedema service.
- Appropriately referring palliative care patients for psychiatric evaluation.
- Appropriately referring palliative care patients to a spiritual adviser.

The SEPC scale is a well recognised instrument that is used to assess the outcome of a palliative care curriculum. It specifically assesses the student's knowledge and skills to perform certain palliative tasks.

### Reliability Analysis

The Cronbach alpha ( $\alpha$ ) for each subset of the SEPC Scale was calculated. The Cronbach  $\alpha$  for communication was 0.92 (ranging from 0.6 to 0.84 across the subscales).

The Cronbach  $\alpha$  for the subset of patient management was 0.89 (ranging from 0.51 to 0.77).

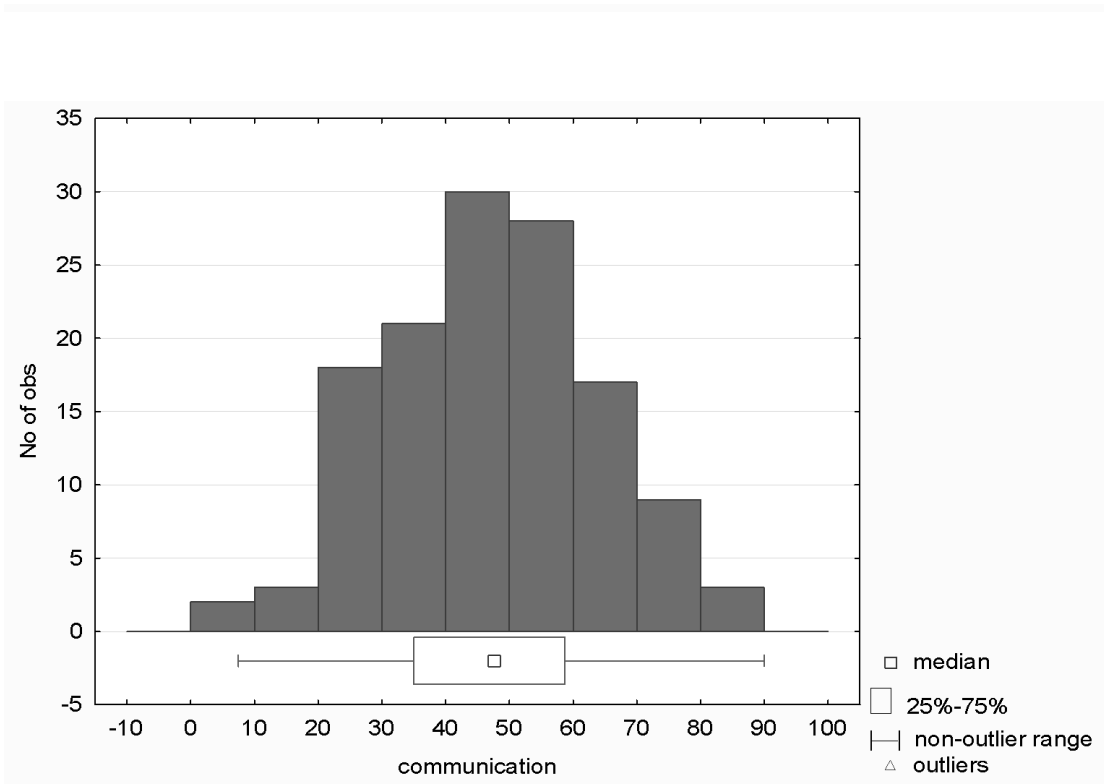
The Cronbach  $\alpha$  for the subset of teamwork was 0.86 (a range from 0.41 to 0.77). (*Table 3 below*)

**Table 3:** Cronbach  $\alpha$  as an indicator of reliability

Cronbach $\alpha$	Score
SEPC-communication	0.92 (0.6-0.84)
-patient management	0.89 (0.51-0.77)
-teamwork	0.86 (0.41-0.77)
Thanatophobia	0.87 (0.57-0.75)

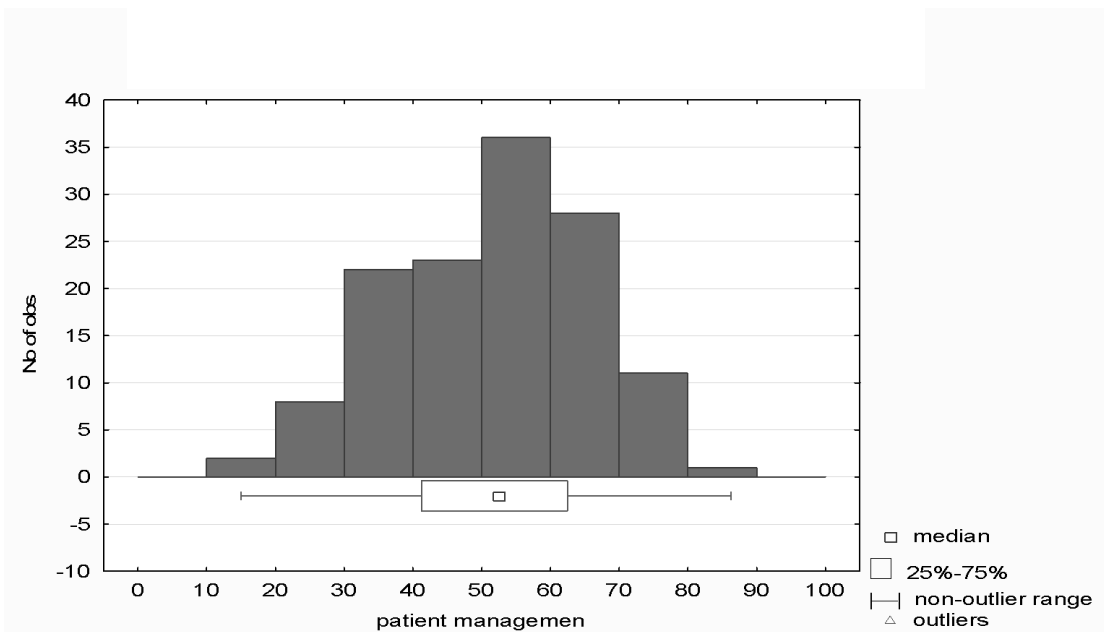
### Mean scores

The mean scores for each subset of the SEPC Scale were analyzed. The subset of communication had a mean score of 47.27 (the standard deviation (SD) was 17.3). This indicates anxiety perceived by the students. (*Figure 5 below*)



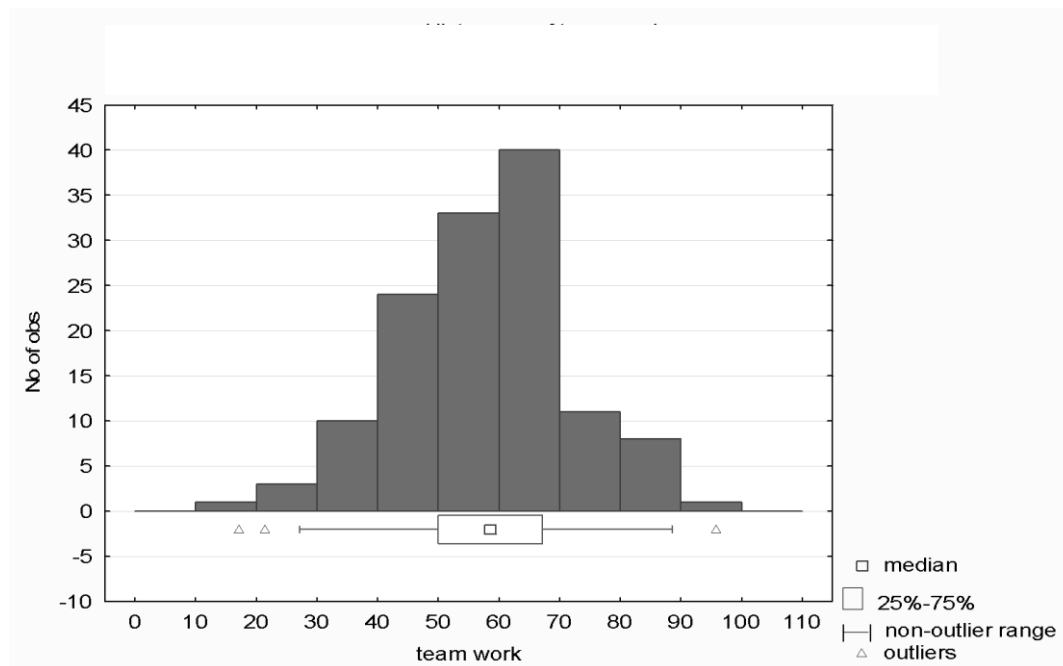
**Figure 5:** Mean score of SEPC-communication

The patient management subset however had a mean score of 51.68 (SD 14.5). This translates to the majority of students expressing confidence in communication. (Figure 6 below)



**Figure 6:** Mean score SEPC- patient management

Finally, the teamwork subset revealed a mean score of 58.17 (SD 14.2). The majority of students' confidence in patient management is expressed by this score. (Figure 7 below)



**Figure 7:** Mean scores for SEPC-teamwork

### Analysis of the SEPC subsets versus anxiety or confidence

The communication subset indicated that 52.7 % of the students experienced anxiety versus 47.3 % of the students feeling confident. The patient management subset had 42 % of students experiencing anxiety versus 58 % feeling confident. The teamwork subset revealed 24 % of students feeling anxious and 75.6 % feeling confident. (Table 4 below)

**Table 4:** Percentages of anxiety versus confidence in each subset

Breakdown of subsets for anxiety/confidence		Count	N %
SEPC-communication	anxiety	69	52.7%
	confidence	62	47.3%
	Total	131	100.0%
SEPC-patient	anxiety	55	42.0%

management	confidence	76	58.0%
	Total	131	100.0%
SEPC-teamwork	anxiety	32	24.4%
	confidence	99	75.6%
	Total	131	100.0%

### T-test analysis

The t-test analysis were performed for all three subsets of the SEPC Scale. The communication subset had a calculated t-value of -1.80 ( $p < 0.07$ ), the patient management subset had a t-value of 1.33 ( $p < 0.18$ ) and the teamwork subset had a t-value of 6.56 ( $p < 0.01$ ). (Table 5 below)

**Table 5:** Evaluate for statistical significance among the subset

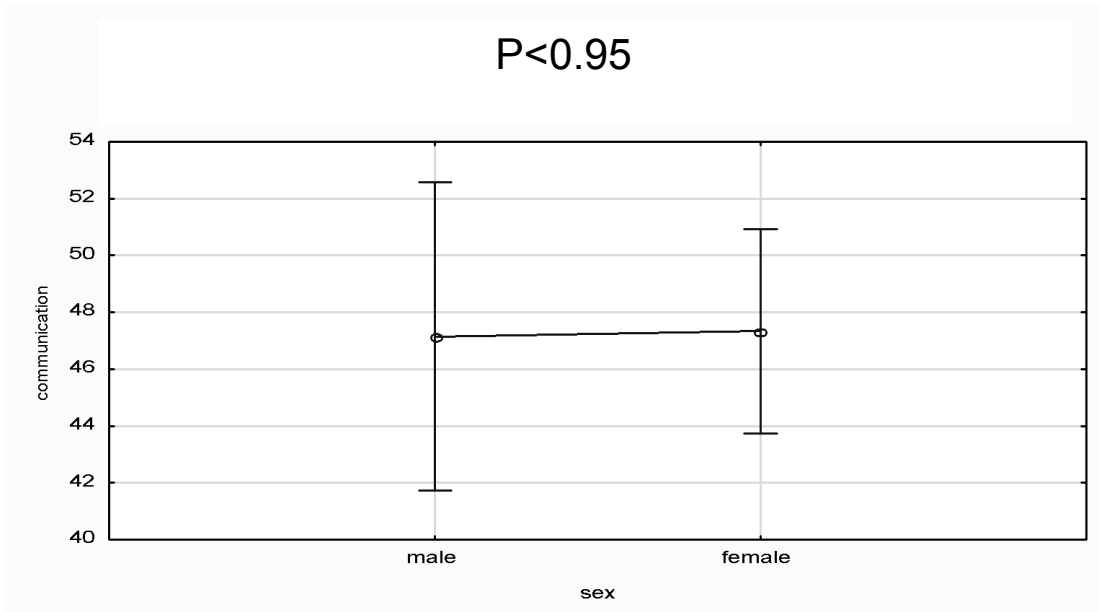
Subset	t-value	p-value
SEPC-communication	-1.80	P<0.07
SEPC-patient management	1.33	P<0.18
SEPC-teamwork	6.56	<b>P&lt;0.01</b>
Thanatophobia	3.85	<b>P&lt;0.01</b>

### Comparison between three identified variables (gender, age, previous exposure to a dying patient) and the SEPC Scale subsets

#### Gender

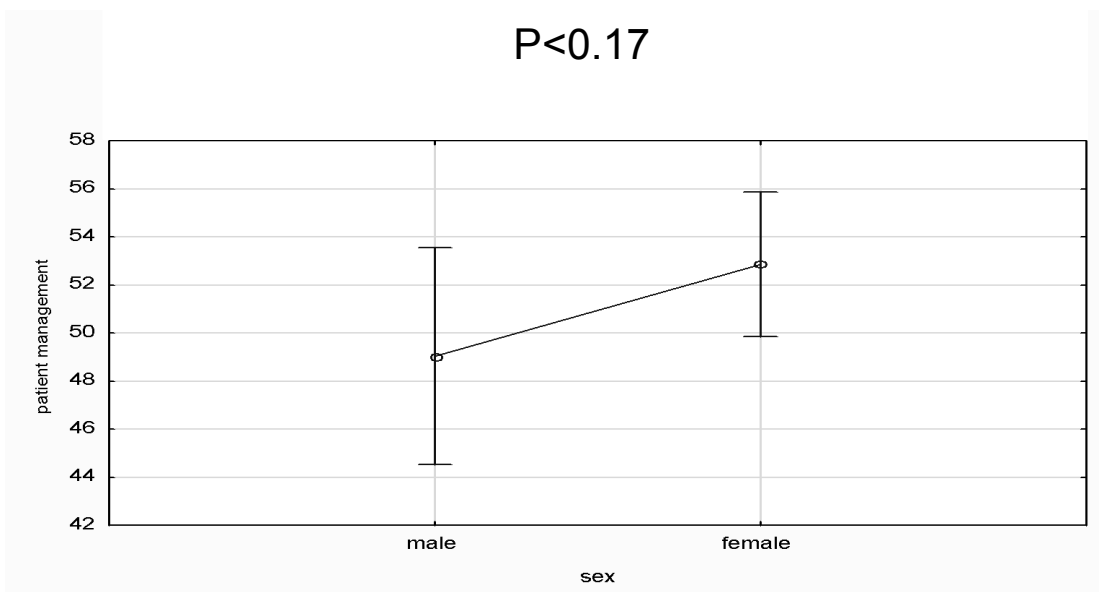
Comparison between the SEPC subset of communication and gender (male versus female) revealed a non-significant p-value of 0.95. A graph was used to display the association between gender and the subset communication. (Graph 1 below)

**Graph 1:** Association between gender and communication



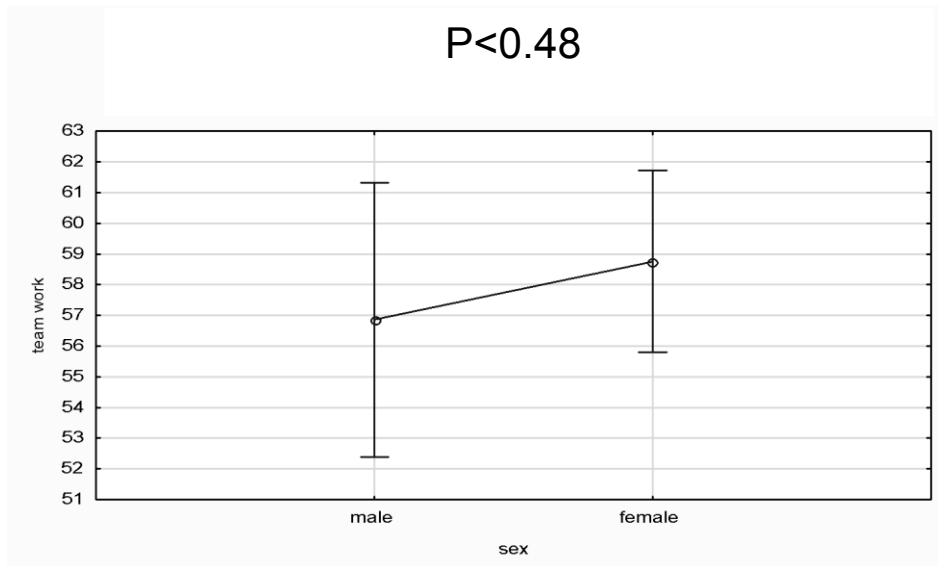
A p-value of 0.17 were calculated when the patient management subset was compared with gender. This was also non-significant. (Graph 2 below)

**Graph 2:** Association between gender and patient management



The comparison of the subset teamwork with gender also showed a non-significant p-value of 0.48. (Graph 3 below)

**Graph 3:** Association between gender and teamwork



### Age

The SEPC subset communication, patient management and teamwork compared with the two age groups revealed a non-significant p-value of 0.15/0.14 and 0.26 respectively.

### Previous exposure to a dying patient (no/ family member/ patient)

Comparison between the communication subset, patient management subset and teamwork subset dealing with a dying patient revealed a non-significant p-value of 0.51/0.64 and 0.70 respectively.

### Analysis of the mean scores of the SEPC subsets compared to the variable of previous exposure to a dying person

The communication subset had a mean score of 44.9 associated with a family member's death as the previous exposure. This indicates anxiety in communication skills as perceived by the students. The mean score was 44.1 if there was no previous exposure to death and 48.4 if a patient's death was the previous exposure to death. Both of these observations also indicate anxiety in communication skills measured. The mean score was 65.6 if the previous exposure to death was due to a friend dying. This translates to confidence in communication skills as perceived by the students. (Table 6 below)

**Table 6:** Association between mean scores and previous exposure to a dying person

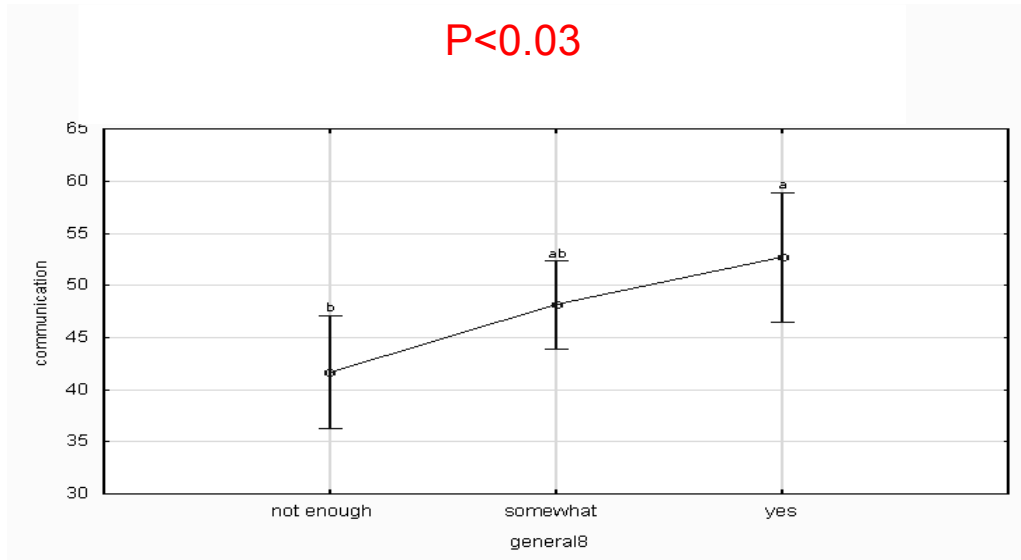
Previous exposure to a dying person	Family	Friend	No	Patient
	Mean	Mean	Mean	Mean
<b>SEPC-communication</b>	44.9	65.6	44.1	48.4
<b>SEPC-patient management</b>	50.1	61.6	49.8	52.5
<b>SEPC-teamwork</b>	59.3	59.6	58.6	57.1
<b>Thanatophobia</b>	3.6	3.1	3.6	3.6

**Comparing the responses from 2 of the general questions in Part 1 of the questionnaire to the SEPC subsets and Thanatophobia Scale**

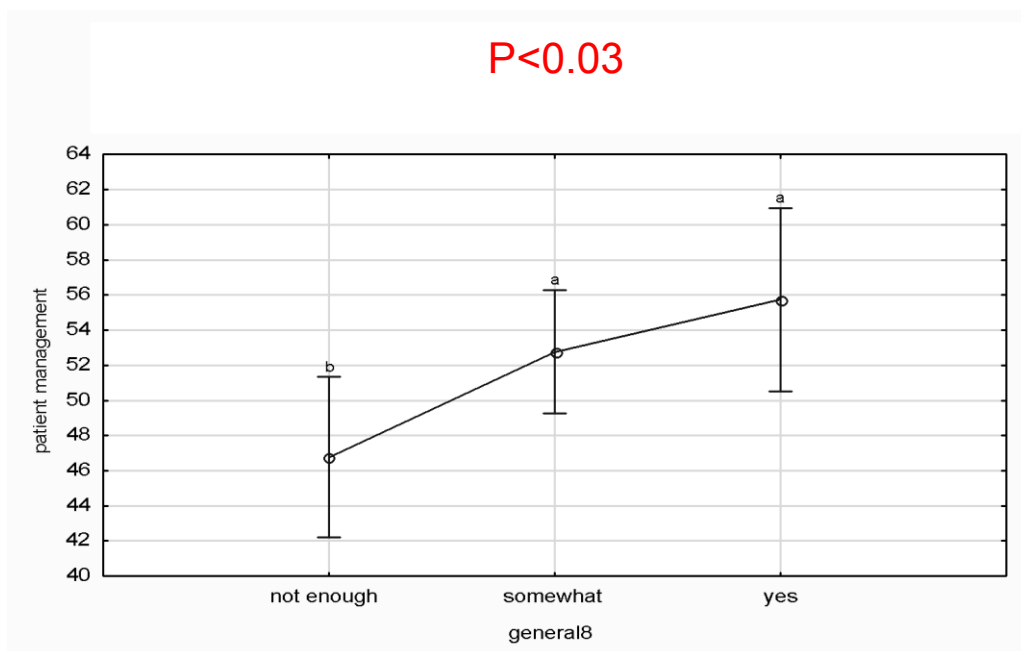
**“Does the student feel that they got enough education and skills in palliative care during their training”**

There were 3 responses to the above question, namely yes, somewhat and not enough. The majority of students expressed that there were a lack of education and skills in palliative care during their medical training. The lack of education and skills in palliative care had a statistical significant effect on the student’s confidence regarding their communication skills ( $p < 0.03$ ), on their confidence to manage patients ( $p < 0.03$ ) and also on their confidence to work in a multidisciplinary team ( $p < 0.01$ ). (Graph 4, 5 and 6 below)

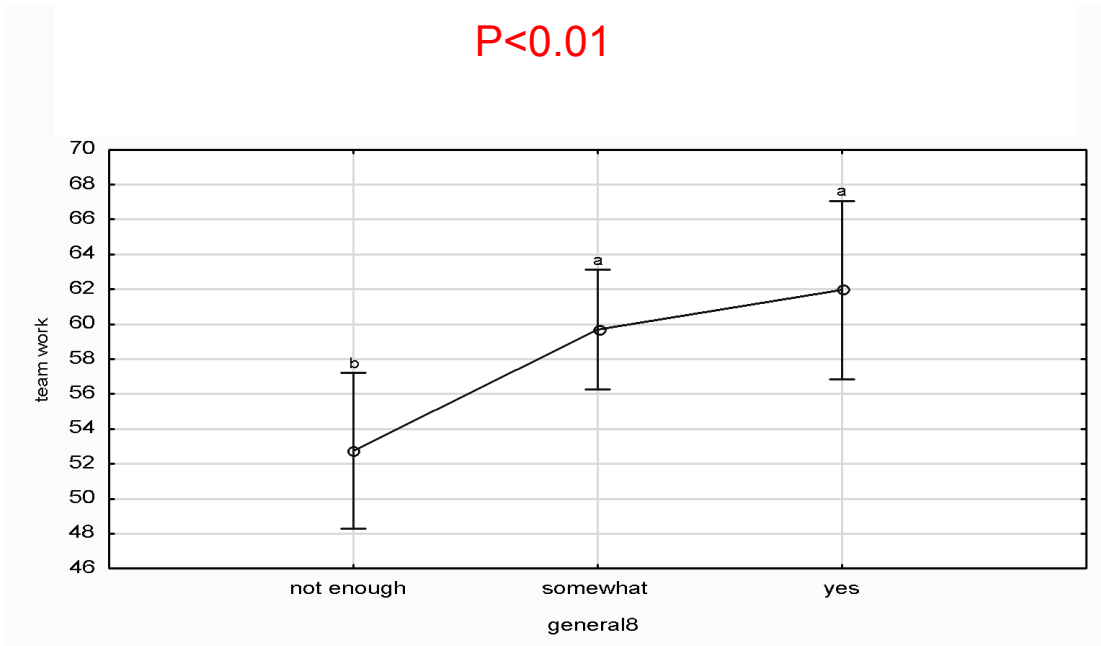
**Graph 4:** Student's response on palliative education versus communication



**Graph 5:** Student's response on palliative education versus patient Management



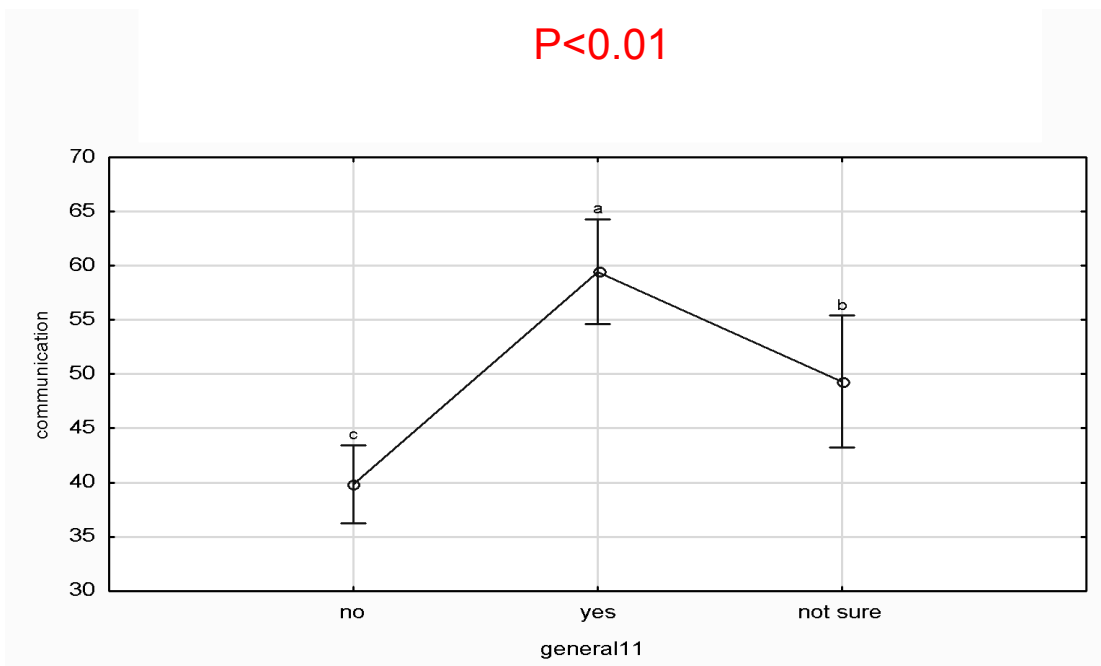
**Graph 6:** Student's response on palliative education versus teamwork



The question: **“Do you feel comfortable to tell a patient he/she is dying?”** had 3 responses (yes, no or not sure).

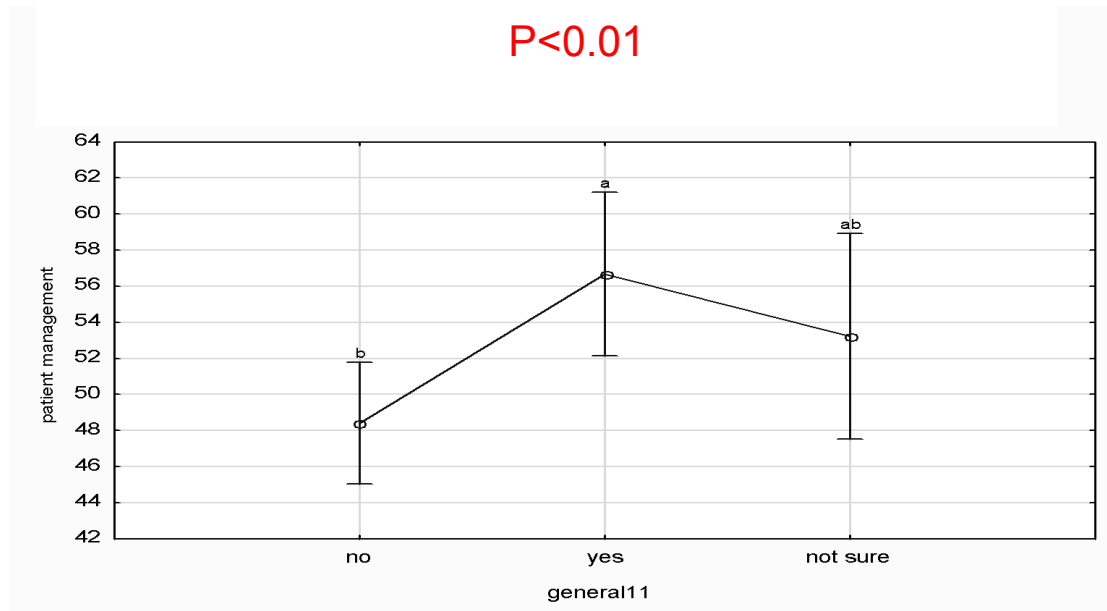
These 3 responses were compared with the communication subset and calculated a significant p-value < 0.01. (Graph 7 below)

**Graph 7:** Student's feel comfortable to talk about death versus communication



The comparison with the patient management subset indicated a significant p-value of 0.01. (Graph 8 below)

**Graph 8:** Student's feel comfortable to talk about death versus patient management

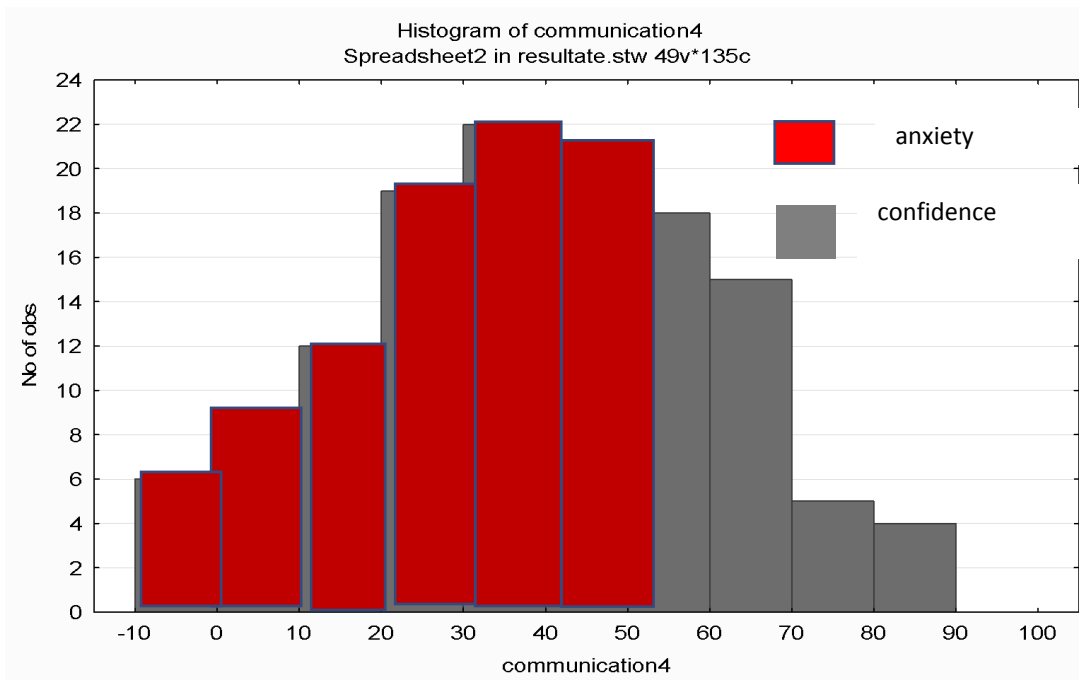


The teamwork subset comparison showed a non-significant p-value of 0.12.

### **Evaluation of individual subscales to identify tasks perceived as challenging for the students**

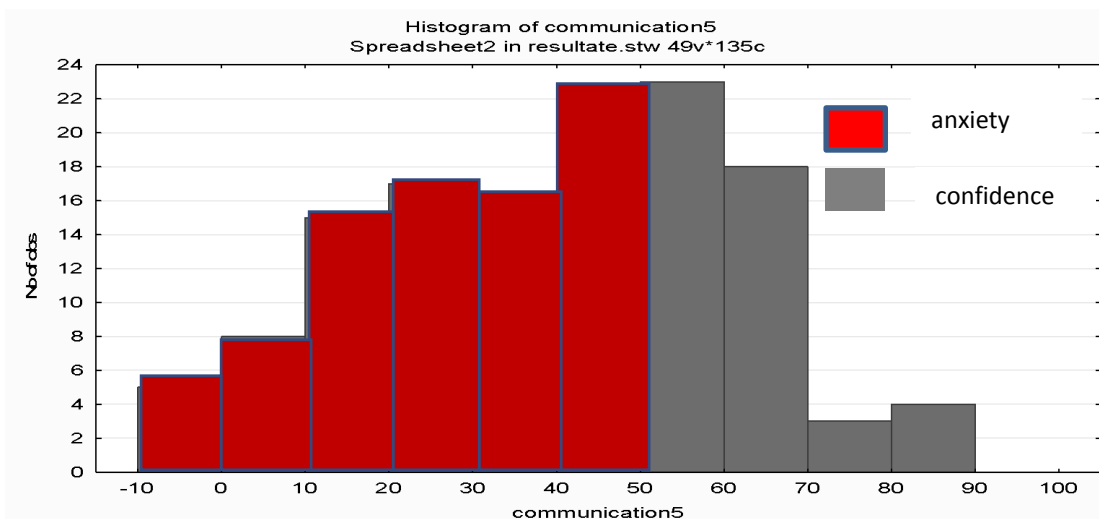
#### **SEPC : Communication**

92 from the 131 students did not feel comfortable to discuss the patient's own death with him. This correlates with the anxiety measured by the SEPC scale. (Figure 8 below)



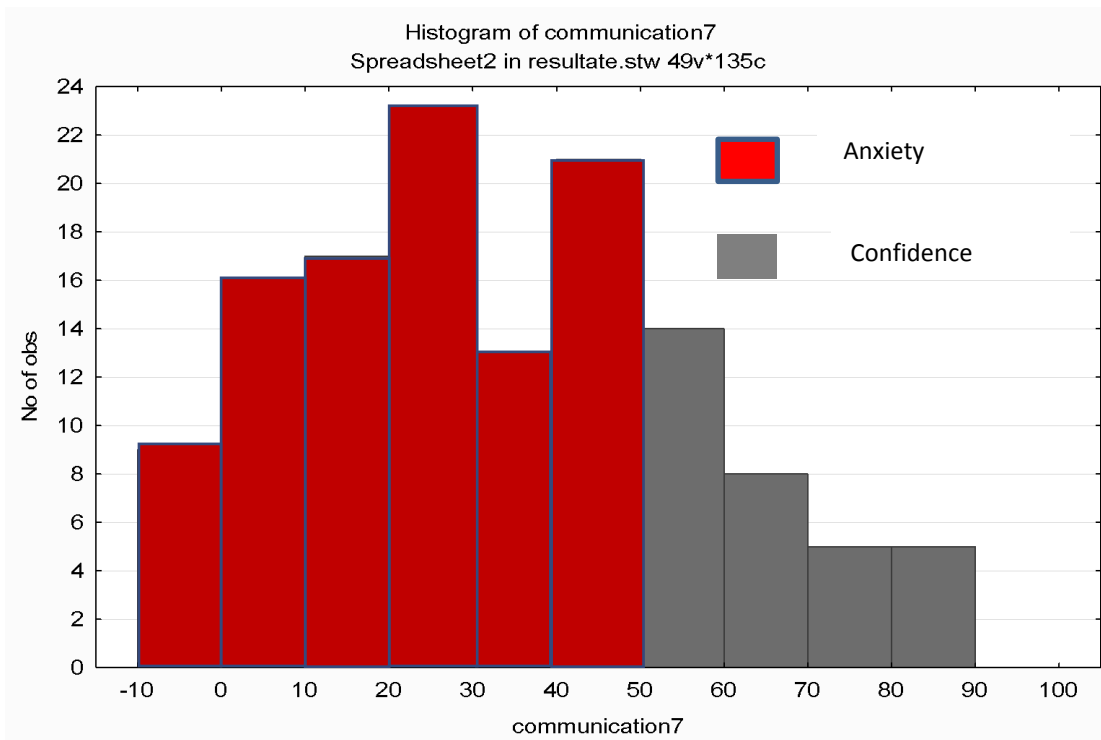
**Figure 8:** Reflection of the student’s discomfort to discuss death with the patient

To discuss the patient’s death with the family upon treatment generated anxiety in 86 of the 131 students. *(Figure 9 below)*



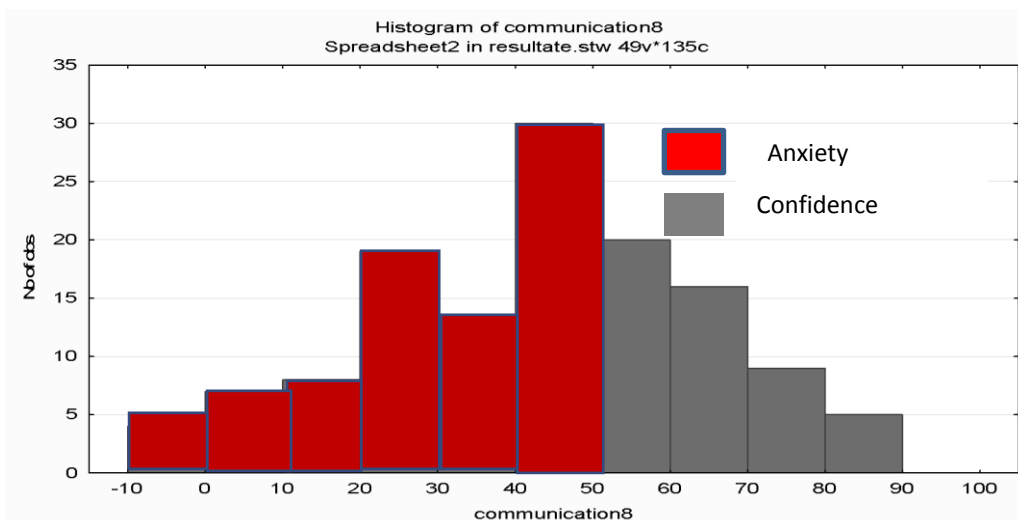
**Figure 9:** Reflection of the student’s discomfort to discuss death with the family

To answer the question: “**How long do I have to live?**” were experienced with a lot of anxiety in 102 of the 131 students. *(Figure 10 below)*



**Figure 10:** Reflection of the student’s discomfort to answer the question: “How long do I have to live?”

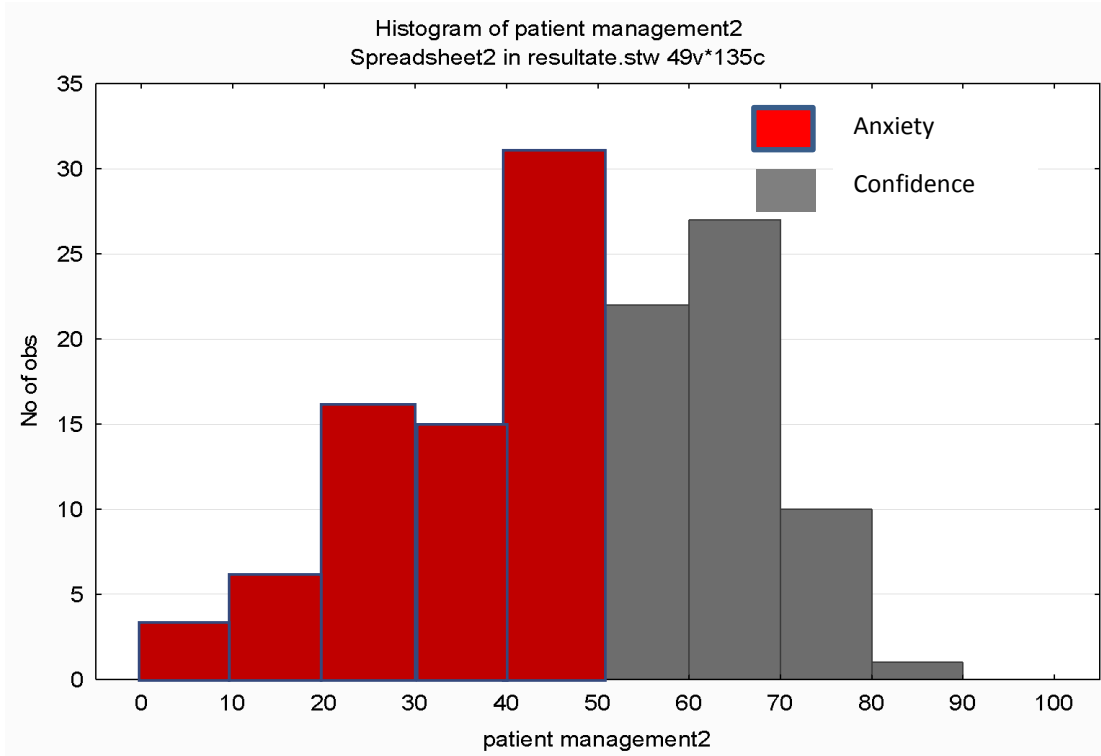
83 students did not feel comfortable to answer the patient’s question: “Will there be much suffering or pain?” (Figure 11 below)



**Figure 11:** Reflection of the student’s discomfort to answer the question: ” Will there be much suffering or pain?”

### SEPC : Patient management

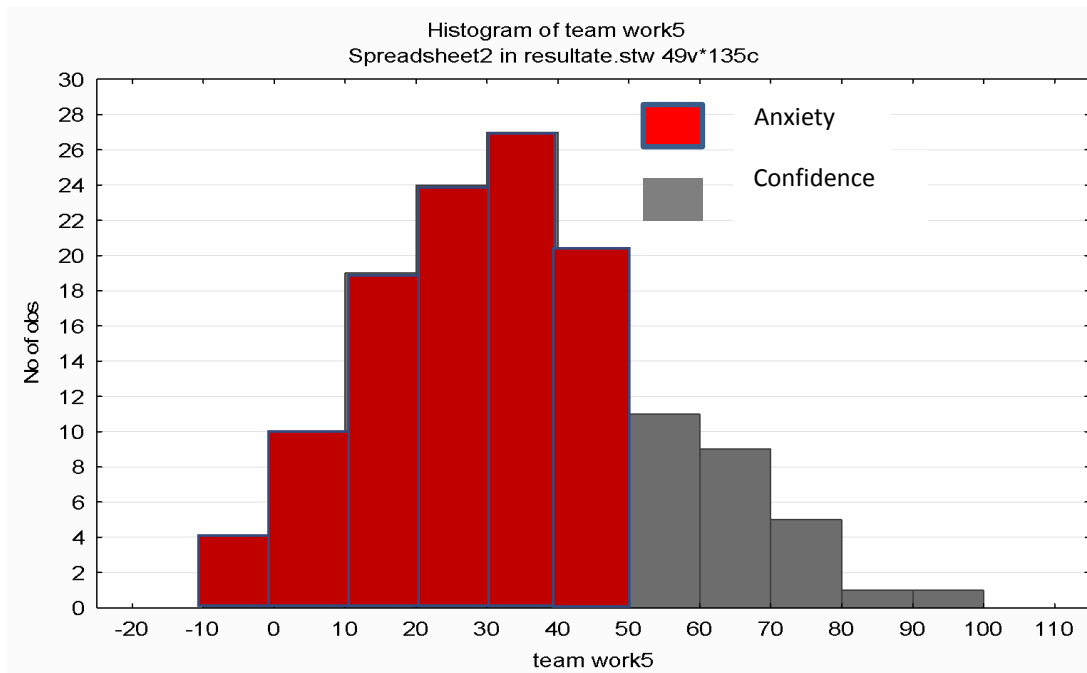
74 from the 131 students expressed anxiety about their knowledge of the etiology of common symptoms experienced by palliative care patients. ( *Figure 12 below* )



**Figure 12:** Reflection of the student’s anxiety about their knowledge on palliative care

### SEPC : Multidisciplinary and teamwork

94 from the 131 students felt anxious to refer palliative care patients to a lymphedema service. ( *Figure 13 below* )



**Figure 13:** Reflection of the student's anxiety to refer to a lymphedema clinic

#### 4.6: The Thanatophobia Scale

This scale is used to assess the outcome of a palliative curriculum by measuring the **attitudes** of the students towards **caring for the dying**. This is a 7-item Likert scale that consists of the following 7 questions:

- Dying patients make me feel uneasy.
- I feel pretty helpless when I have terminal patients on my ward.
- It is frustrating to have to continue talking with relatives of patients who are not going to get better.
- Managing dying patient's traumatises me.
- It makes me uncomfortable when a dying patient wants to say goodbye to me.
- I don't look forward to being the personal physician of a dying patient.
- When patients begin to discuss death, I feel uncomfortable.

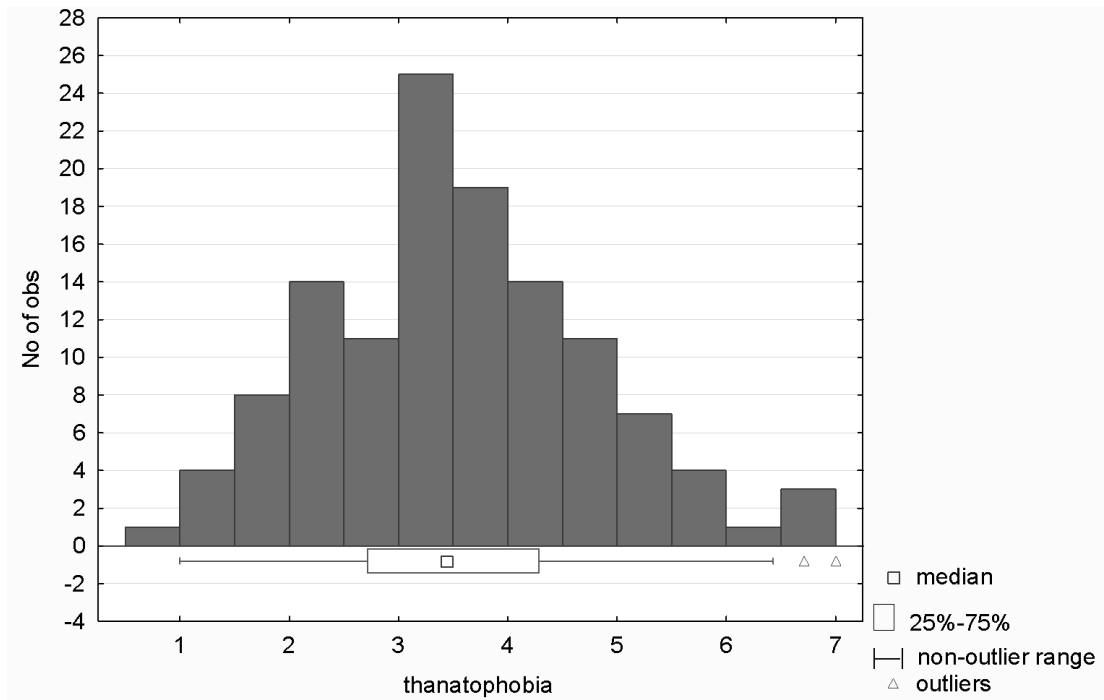
This scale is used to assess the outcome of a palliative curriculum by measuring the **attitudes** of the students towards **caring for the dying**.

#### Reliability Analysis

The Cronbach  $\alpha$  for the Thanatophobia Scale was calculated at 0.87 (ranging from 0.57 to 0.75).

### Mean scores

The Thanatophobia Scale had a mean score of 3.56 (SD 1.2). The score is <4 and this indicates a positive attitude. (Figure 14 below)



**Figure 14:** Mean score Thanatophobia

### Sub-Analysis of the Thanatophobia Scale

The Thanatophobia Scale indicated that 63.1 % of students had positive attitudes versus 36.9 % with negative attitudes. (Table 7 below)

**Table 7:** Percentages of anxiety versus confidence

Thanatophobia	Positive attitudes	77	63.1%
	negative attitudes	45	36.9%
	Total	122	100.0%

### T-test analysis

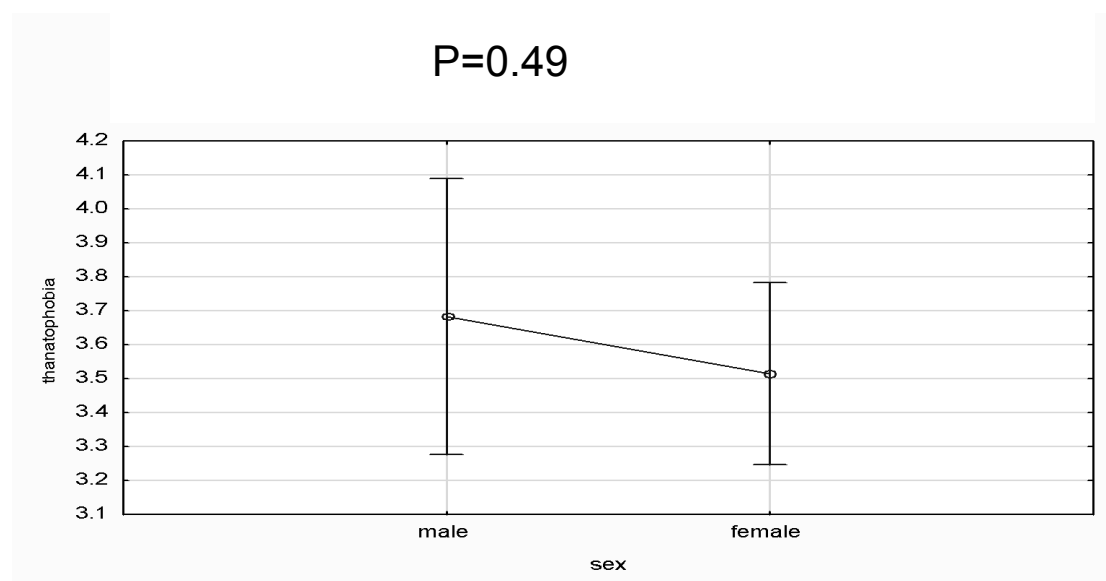
The Thanatophobia Scale had a calculated t-value of -3.85 ( $p < 0.01$ ). This was statistically significant.

### Comparison between three identified variables (gender, age, previous exposure to a dying patient) and the Thanatophobia Scale

#### Gender

The Thanatophobia Scale was compared to gender and this resulted in a non-significant p-value of 0.49. (*Graph 9 below*)

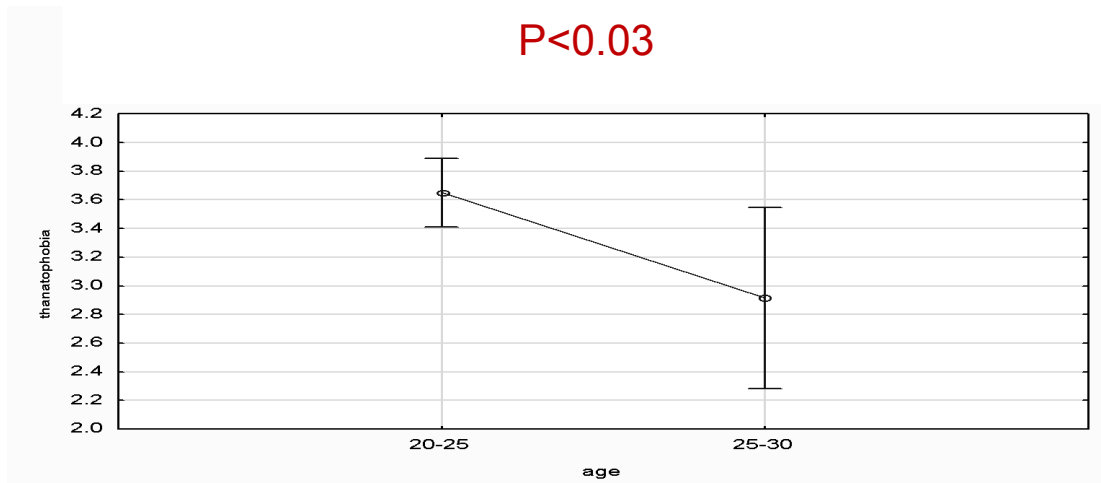
**Graph 9:** Association between gender and the Thanatophobia scale



## Age

The Thanatophobia Scale compared with the 2 age groups however resulted in a significant p-value of 0.03. (Graph 10 below)

**Graph 10:** Association between age and the Thanatophobia scale



### Analysis of age versus the Thanatophobia Scale

An analysis of the age groups versus the Thanatophobia Scale (positive versus negative attitudes) showed that there were 105 (86 %) students from the 121 between the age-range 20 to 25. Of this 105 students, 62 (59 %) had positive attitudes and 43 (41 %) had negative attitudes. There were 15 (12 %) students in the age group of 25 to 30 years. From this 15.14 (93 %) students had positive attitudes and one (6.7 %) had a negative attitude. (Table 8 below)

**Table 8:** Positive versus negative attitudes in age groups

<b>Age versus Thanatophobia</b>				
<b>age</b>		<b>positive attitudes</b>	<b>negative attitudes</b>	<b>Total</b>
<b>20-25</b>	Count	62	43	<b>105</b>
	%	59.0%	41.0%	100.0%
<b>25-30</b>	Count	14	1	<b>15</b>
	%	93.3%	6.7%	100.0%
<b>30-35</b>	Count	1	0	<b>1</b>
	%	100.0%	0.0%	100.0%
<b>Total</b>	Count	77	44	<b>121</b>
	%	63.6%	36.4%	100.0%

**Previous exposure to a dying patient (no/ family member/ patient)**

The Thanatophobia scale compared to previous exposure to a dying patient revealed a non-significant p-value of 0.99.

**Comparing the responses from 2 of the general questions in Part 1 of the questionnaire to the Thanatophobia Scale**

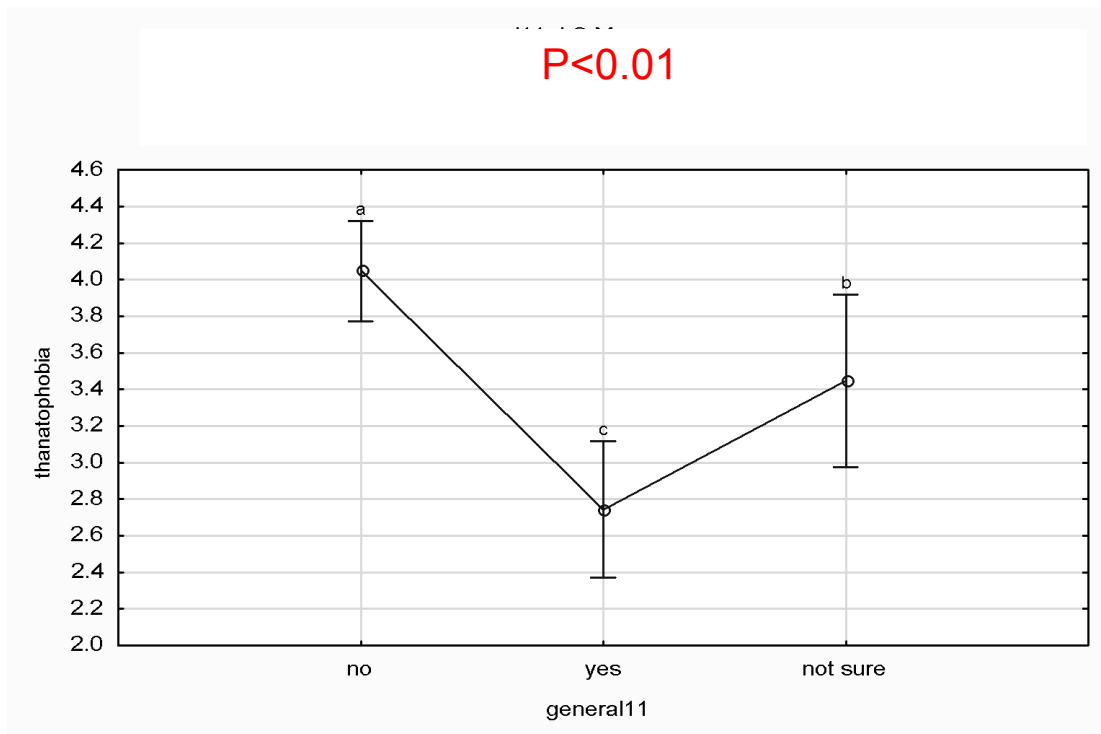
**“Does the student feel that they got enough education and skills in palliative care during their training”**

There were 3 responses to the above question, namely yes, somewhat and not enough. The 3 responses were compared to the Thanatophobia Scale and showed a non-significant p-value of 0.74.

**The question: “Do you feel comfortable to tell a patient he/she is dying?” had 3 responses (yes, no or not sure).**

The 3 responses were compared to the Thanatophobia scale and showed a significant p-value < 0.01. (Graph 11 below)

**Graph 11:** Student's feel comfortable to talk about death versus the Thanatophobia scale



**Evaluation of individual subscales to identify tasks perceived as challenging for the students**

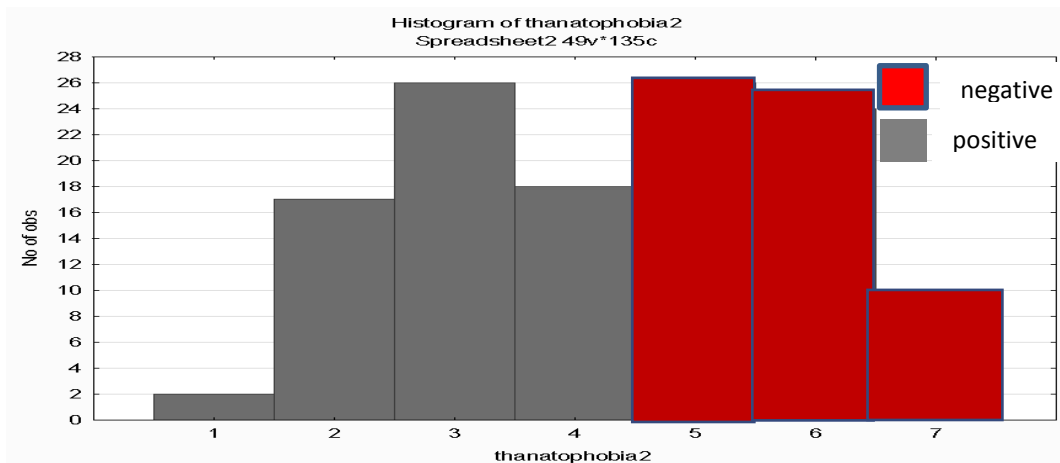
**Thanatophobia**

The statement “**dying patients make me feel uneasy**” generated a negative attitude in 60 students vs. 63 positive attitudes. (Figure 15 below)



**Figure 15:** Negative attitudes to “dying patients make me feel uneasy”

There were 60 students that expressed negative attitudes to the statement: “I feel pretty helpless when I have terminal patients on my ward” (Figure 16 below)



**Figure 16:** Reflection on the student’s attitude when they have a terminal patient in their ward

#### **4.7. Palliative training in other medical schools in South Africa**

##### **The Response rate of the medical schools in South Africa**

The questionnaires were sent to all 8 medical schools in South Africa. Only 5 of the medical schools responded. (Response rate 62.5 %) The other 3 medical schools,( University of Kwazulu Natal, University of Pretoria and the Walter Sisulu University in the Eastern Cape) did not reply to any e-mail requests.

##### **The undergraduate Palliative care curriculum at the University of Stellenbosch**

The curriculum forms part of the Centre for Health Professions Education and Family Medicine. Training is given in the 2<sup>nd</sup> year (2h) and 3<sup>rd</sup> year (4h) respectively. A total of six hours is dedicated to palliative care. The curriculum consists of:

- Basics in Palliative Care 15 %
- Pain and Symptom Management 15 %
- Psychosocial and Spiritual Aspects 15 %
- Ethical and Legal Issues 10 %
- Communication 15 %
- Teamwork and Self Reflection 30 %

Training is given by a general practitioner with a MPhil (Palliative Medicine) as well as a professional nurse. The educational methods used include small groups and lectures. There are practical exposures to local hospices.

The progress is assessed with a multiple choice questionnaire in an exam format and group work which includes reflection on their hospice exposure

##### **Comparison between the undergraduate training in palliative care among the medical schools in South Africa**

## University of Limpopo (Medunsa)

- Subdivision of: Practice of Medicine Integrated Programme
- Training in: 3<sup>rd</sup> and 6<sup>th</sup> year
- Total hours for teaching: 20 hours
- Curriculum: Basics Palliative Care ✓
  - Pain/symptoms ✓
  - Psychosocial/spiritual → limited training
  - Ethical/Legal → not covered
  - Communication ✓
  - Teamwork ✓
- Qualification of lecturer: Doctor (MBChB) with four year experience in Primary Healthcare
- Practical exposure: Yes (2 - 3 hospices)
- Educational methods: Problem based learning
  - Small groups
  - Lectures
- Assessment: MBChB III: → Case assignments  
→ Theory test
  - MBChB VI: → Family Medicine OSCE
  - Breaking bad news

## University Witwatersrand

- Subdivision of: Wits Center for Palliative Care
- Training in: MBChB III / IV / V / VI
- Total hours for teaching: 26h 30min ± 3h extra for some
- Curriculum: Basics Palliative Care 100 %
  - Pain/symptoms 16h / 62 %
  - Psychosocial + spiritual 14h / 54 %
  - Ethical/legal 16h / 62 %
  - Communication 18h / 69 %
  - Teamwork 19h / 73 %
- Qualifications of lecturer: Doctor with MPhil (Palliative Medicine)/ Diploma Palliative Medicine
- Practical exposure: Yes
- Educational Methods: Problem based learning
  - Small groups
  - Lectures
  - Role plays
- Assessment: Short answer case scenarios  
End of block exams MBChB III - V

Case portfolio + case study + personal reflection (MBChB IV/VI)

## **University of Free State**

- Subdivision of: Dept Internal Medicine  
Surgery
- Training in: MBChB III  
MBChB IV  
MBChB V
- Curriculum: Not separate teaching (part of theory + clinical system)  
All aspects covered in general
- Qualifications of lecturer: Any consultant do training
- Practical exposure: Yes
- Educational methods: All used

Assessment: In theoretical and clinical assessments during block, end of block and final exams.

## **University of Cape Town**

- Subdivision of: Dept Public Health and Family Medicine
  - Training in: MBChB II, III, IV, VI
  - Total hours for teaching: 42 Hours
  - Curriculum: All topics covered
  - Qualifications of lecturer: Doctor with Diploma in Palliative Medicine/ MPhil (Palliative Med) and clinical social worker with MPhil Pall Med and hospice experience
- Practical exposure: Yes
- Educational methods: Problem based learning
- Small groups
  - Lectures
  - Role plays

Assessment: MBChB IV: Assignments

Summative

Exam on identification of problems and  
writing a comprehensive plan

Holistic management

MBChB VI: Summative

Patient study

Written short questions

**Total time spent on Palliative Education**

**Table 9:** Differences in total time spent on palliative training for each of the medical schools

<b>Medical schools</b>	<b>US</b>	<b>UCT</b>	<b>Wits</b>	<b>Medunsa</b>	<b>Free State</b>
<b>Tot. hours for training</b>	<b>6h</b>	<b>42h</b>	26h 30min	20h	Not given

The least time spent for undergraduate palliative training is 6h at the University of Stellenbosch compared to 42 hours at the University of Cape Town. (*Table 28 above*)

The University of Free State did not provide the time spent on their palliative care curriculum.

All 5 medical schools included a practical exposure to hospice as part of the palliative care curriculum.

The University of Stellenbosch focuses the training of palliative care in the 2<sup>nd</sup> and 3<sup>rd</sup> year only. The University of the Witwatersrand however gave training to the 3<sup>rd</sup>/4<sup>th</sup>/5<sup>th</sup> and 6<sup>th</sup> year medical students.

## **Chapter 5: Discussion**

The need to investigate the status of palliative care training on undergraduate medical students at the University of Stellenbosch originated from the researcher's exposure to medical students during their academic rotations. The students indicated a lack of confidence to perform palliative care activities. The poor management of symptoms related to end-of-life care delivered by physicians in different disciplines at Tygerberg Hospital also provoked the question about the palliative training offered to health care professionals.

To my knowledge, this is the first study that investigates a needs assessment for palliative care training in undergraduate medical students done in South Africa.

In this chapter the results of the study will be discussed under the following headings:

1. Background of the target population
2. Demographics
3. General questions
4. SEPC Scale
5. Thanatophobia Scale
6. Palliative care training in undergraduate medical schools in South Africa
7. Limitations
8. Conclusion

The above will be discussed in the light of current knowledge of palliative care training and training needs locally and internationally.

## **1. Background of the target population**

During the fifth year (middle clinical rotation) of medical training at the University of Stellenbosch all the theoretical aspects of training and lectures are completed and the students are doing clinical rotations in different disciplines. In the middle of the fifth year the students start with the final clinical rotation that ends at the end of the sixth year. During the final clinical rotation the students have no more theoretical blocks. The first part of the survey that formed the basis of this research was conducted amongst 5<sup>th</sup> year medical students at the University of Stellenbosch. There was a good response rate which enhanced the validity of the study. This response rate is comparable to the response rate of the studies published by Mason et al in 2008 and 2010 that also applied the SEPC and Thanatophobia scale in undergraduate students. The missing data in incomplete questionnaires may indicate that some of the questions in the two scales (SEPC and Thanatophobia Scale) are unclear and this may result in difficulties to formulate a response to it, even though both scales have been tested for validity.

The section that included general questions in the first part of the survey, was chosen by the researcher to assess the knowledge of the students on some basic principles used in palliative care. These questions were not tested for reliability and validity and the results from these can only be used as informative. Results of these questions should be further investigated in future studies.

The second part of the survey compared the undergraduate palliative curricula of the different medical schools in South Africa.

## **2. Demographics**

### **a) Gender ratio**

There were 94 female respondents versus 41 male respondents. (70:30) There was no association seen between gender and the three subsets of the SEPC scale. This implies that there is no difference detected between the male and the female students' confidence towards palliative care. There were no association seen between gender and the Thanatophobia scale. This also implies that there is no

difference detected between the male and the female students' attitudes towards palliative care.

### **b) Age**

The majority of the students were younger than 25 years old and there was 1 student older than 30 years. Students usually start with tertiary training immediately after completing grade 12 of high school. (Average age of 19 years) The sample group consisted of 5<sup>th</sup> year medical students. If the above observation is true, then the average age of students in their 5<sup>th</sup> year of medical training would range between 23-24 years. This will explain the majority of the sample group being  $\leq 25$  years of age. Mason et al did not comment on the age of the students that were tested in his two studies. There is no literature that addresses the ideal age of introducing palliative care training. The literature only comments that palliative care training should be introduced already in the pre-clinical years to address principles of palliative care, as well as the ethical and legal concepts associated with end-of-life care.

The age of the students were divided into "younger" ( $\leq 25$ ) and "older" (25-30) groups. There was no difference detected between the younger groups of students versus the older group with regards to confidence expressed to perform palliative activities. There was a statistically significant difference detected in the attitudes measured between the younger groups of students versus the older group of students.

Further analysis showed that the majority of the students were in the "younger" group ( $\leq 25$  years). There were however not a huge difference between the positive and the negative attitudes detected in the "younger" group. The "older" group (25-30 years) of students represents the minority of the group. Almost all the older students had positive attitudes towards palliative care. This may be due to the fact that the older students had more "life-experience" and due to their emotional maturity they are feeling more comfortable with their own feelings of death and dying.

### **c) Previous experience of palliative medicine**

The majority of students reported exposure previously to palliative medicine. This was either linked to the care of a patient or associated with the loss of a family

member. There was no difference in confidence detected in the group of students that were previously exposed to death versus the group of students that had never experienced death before. This is of interest, as one would expect to see a difference (positive or negative) due to previous death experienced. The result of the difference will depend on the experience of the death as positive or negative.

This lead to further analysis to identify if there were any associations between personal experiences of death versus an experience linked to a patient dying versus no experience of death. If exposure to death was related to a family member, the students felt anxious about their communication skills. The latter was also seen if the experience of death was related to a patient dying. The above could indicate that experiences of death related to a family member and/ or a patient were perceived as an abnormal negative experience and thus could explain the anxiety associated with this subset of communication. It is interesting to note that if the previous exposure to death was a friend, the students were more confident in their communication skills. Another observation came from the group of students that lost a friend. This group of students also felt more confident in their patient management skills.

The undergraduate medical curriculum at the University of Stellenbosch consists of a pre-clinical phase (theory), followed by a clinical phase (practical). The latter is introduced during the fourth year of medical training. From the data presented above, it is apparent that >50% of the students reported their first encounter with palliative care linked to patient care, thus during their fourth year or fifth year of medical training. This indicates that >50% of the students were exposed to palliative medicine from their fourth year of medical training. The questionnaire did not evaluate if this exposure has been perceived by the students as positive or negative. There was no difference in attitude detected in the group of students that were previously exposed to death versus the group of students that had never experienced death before.

The EAPC recommend that the basic principles of palliative care should be covered in the early medical curriculum, with the application of clinical aspects later in the medical training. In the Stellenbosch University setting, this will translate to introducing the undergraduate palliative curriculum during the first 3 years of the

undergraduate medical curriculum which consist of the theoretical phase of the undergraduate curriculum. This will equip the students with the basic concepts of palliative care and also address the attitudes of the students before the clinical exposure to patients happen in the fourth to six year of training.

Lloyd-Williams et al also recommend from their systematic review published in 2004 that ethical issues regarding palliative care should be taught during the 1<sup>st</sup> year of the medical curriculum with the integration of palliative training in all the years of undergraduate medical curricula.

It is of concern that seven students reported no previous exposure to palliative medicine. The questionnaire was done among 5<sup>th</sup> year medical students, this group has already been exposed to patients for 3 years at their training. This group of students had palliative training in their 3<sup>rd</sup> year. As part of the Palliative Curriculum, a 4 hour visit to one of the local hospices was recommended. An explanation for the response of these students can be that they did not attend the hospice visit or that they did not understood the question or perhaps even forgot the hospice visit.

### 3. General Questions

The EAPC recommend that **undergraduate palliative training** should **focus** on the **knowledge** of students regarding palliative care, addressing the **skills** of the students to **deliver** palliative care and also to provide an empathetic **attitude** of medical students towards end-of-life care.

#### a) Knowledge/training of Palliative Care

Almost the whole group of students reported a lack of knowledge and training to provide palliative care. This response is of concern, as this group of students has almost completed their medical training and will be caring for palliative patients within the next 12 months as newly qualified doctors. According to the EAPC, palliative training should address the knowledge on palliative care. One of the key competencies that need to be taught in an undergraduate palliative curriculum is the assessment and management of pain and other symptoms. The palliative

curriculum should include pain and symptom management comprising 55% of the course.

### **Knowledge of pain management**

Only half of the students reported that they knew the 3 steps of the WHO Pain Ladder. There were also gaps in the students' knowledge with regard to route of administration of pain medication, knowledge of opioid prescribing and the beliefs with regard to morphine addiction. Teoh reported the prevalence of pain experienced by cancer patients as high as 70%.<sup>26</sup> Ventafridda and Zech had shown that the use of the WHO Pain Ladder for pain management improves pain in 70% to 90% of cancer pain.<sup>30,31</sup> Numerous studies have shown that there is a link between poor pain management and lack of palliative training. The lack of knowledge reported by the students surveyed is likely to result in poor pain management and consequently poor quality of care for the patients.

The WHO guidelines for pain control explain the use of the pain ladder and also the correct prescribing of pain medication. This recommends the administration of analgesics orally and at regular intervals. Pain medication should be prescribed according to the severity of pain experienced by the patients. This will call for good assessment of the patient's pain experience in order to apply the most appropriate management plan.

It should be emphasized that the majority of the students that took part in this survey had poor knowledge of pain management, although the SEPC could not differentiate between anxiety or confidence in patient management. If this survey is viewed objective and accurate, according to the literature reviewed this observation indicated poor palliative training in pain control and with the observation that pain control generally receives more focus than control of other distressing symptoms, it is of concern that this result implies poor training in symptom control.

These results can be explained by the lack of emphasis given to pain and symptom management (only 15%) as part of the Palliative Curriculum at the University of Stellenbosch. The palliative curriculum is only 6 hours which is 0,0006% of the total medical curriculum!

More focus should be given to the assessment and management of pain and other symptoms. Pain and symptom management training is grossly inadequate and needs to be given more attention throughout all disciplines. The EAPC recommend that pain and symptom management should comprise 55% of the undergraduate palliative curriculum of 40 hours to be able to deliver adequate pain management. There is a need to re plan the structure of the palliative curriculum at the University of Stellenbosch and to integrate palliative medicine training into other disciplines.

### **Management of the terminal phase**

The minority of the students knew the term “death rattle” and the use of hyoscine butylbromide as part of the management. Students need to be trained to recognize the terminal phase of the disease process to be able to inform the family and also to effectively treat the patient to provide the ability to die with in comfort and with dignity. Again this indicates a lack of knowledge in palliative assessment and symptom control, as well as the management of a dying patient. Poor knowledge results from poor palliative training. This is of great concern as students should be competent in providing care to patients who are dying.

The questionnaire used fluid and feeding in the terminal phase as a proxy to measure knowledge on legal, ethical and clinical challenges. The majority of the students responded that they would use intravenous fluid and nasogastric feeds in dying patients. There is definitely a place for intravenous fluid if a patient is experiencing hypercalcaemia due to dehydration and also the side-effects of the morphine metabolites in the body. The role of intravenous fluids in these scenarios are to relief symptoms experienced due to dehydration that can cause discomfort. Thus the intravenous fluids will improve symptoms and therefor quality of life and not to prolong suffering.

The WHO definition of palliative care clearly states that palliative care aims to improve quality of life and regards dying as a normal process. In which case care of dying patients should be part of medical student training.

Another core competency recommended by the EAPC as part of an undergraduate palliative curriculum is the education on the principles and application of ethics and the law associated with palliative care. The ethical and legal aspect should comprise at least 5% of the curriculum as suggested by the EAPC. There are a lot of moral dilemmas associated with end-of-life care such as decisions regarding the discontinuation or withdrawing of treatment, consent, to share information, conflict between family and patient regarding treatment, the use of a living will and issues associated with quality of care. These challenges are part of the daily practice of palliative care and medical professionals need to be equipped to understand and apply the principles around end-of-life care ethics and also the law.

The University of Stellenbosch's palliative curriculum devoted only thirty-six minutes of the curriculum to training on ethical and legal issues.

#### **b) Communication skills**

The majority of students do not feel comfortable to tell a patient that he/she is dying. Being able to discuss death with a patient and family is regarded as part of communication skills. Discussing death with patients/family is very challenging to most health care professionals, but through effective training in communication skills and the confidence acquired during the training process, health care professional realize the benefit for the relationship between doctor and patient if open and honest discussions is part of the management of the patient. It is always a difficult task to discuss death & dying with a patient but skills in managing difficult conversations can be learnt and practiced to gain competence in this task even if the doctor will never find it 'comfortable'.

The EAPC recommend training in communication skills as one of the seven core competencies that need to be part of the undergraduate palliative curriculum. According to the EAPC communication should comprise at least 10% of the curriculum taught. The teaching method recommended by the EAPC to improve skills in palliative care is to expose the students to clinical scenarios/practical cases under supervision.

The National survey done in the United States to determine the basic palliative care skills required for medical students, recommended that communication skills are the most important competency required as part of palliative training. Improved communication result in a reduction of hospital admission and this result in a reduction of health cost <sup>10,11,12,13</sup>

The responses of >50% of students that they do not feel comfortable to discuss death with a patient indicate a lack of palliative training to address the attitudes and communication skills of the students. In the current undergraduate palliative curriculum at Stellenbosch University, communication comprised less than one hour (0.9 hours) of the curriculum and teamwork/self- reflection consist of less than two hours. 30%.The EAPC suggest four hours of training in communication.

The Palliative curriculum at the University of Stellenbosch consisted of **only 6h** in total training. From this, 2h was spent giving formal tutorials by only 1 general practitioner. It is apparent from the above that the teaching methods applied to address the outcome of skills training and providing a change in the attitudes of the students could not be properly met due to the limited exposure to palliative cases and limited time to discuss the patient cases individually or even in small groups. There were a lack of resources (only 1 doctor) to provide in the needs of the students to effectively address skills and attitude training. The involvement of local hospices in palliative care training helped with the scarce resources and also provides valuable services such as counselling from the social worker. Many times the social worker/nursing staff plays a crucial role in teaching communication skills to the students.

Schonwetter reported that palliative care training in skills should include the multidisciplinary team approach, communication between doctor and patient/family and also addressing ethical issues as part as skills training.

### **c) Attitudes**

Attitudes of students towards caring for dying patients influence their ability to discuss death and prognosis with a patient/family. The desired attitudes that each medical student should be taught include an empathetic doctor that can take time to

listen to the patient and family. They should be advocates for the patients to demand palliative care as part of service delivery. They should respect the wishes of the patient and have compassion towards the patient. This can only be taught if the student is exposed to practical patient cases and under supervision and guidance learn to be sensitive towards the patient and family. This also necessitates excellent communication skills as part of the attribute to discuss death and dying.

The teaching methods recommended by the EAPC to address the attitudes of students include the discussions of a holistic management plan that involve the patient and family after being exposed to a practical palliative case. This should be done individually or in small groups to allow for reflective thinking. The benefit of reflective thinking as part of a teaching method applied in palliative training has been highlighted by Schon (1987), MacLeod (2001 and 2003) and also by Lloyd-Williams (2004)

Seligman reported in 1999 that exposing students to practical palliative cases resulted in an increase of positive attitude towards caring for the dying in 71% of students. When medical students experience practical palliative cases such as family meetings and discussing death with the patient and family, the knowledge taught during the palliative training will make more sense and the students thus reflect on their perceived ideas with a result in change in attitudes towards caring for dying patients. If a medical student develops a positive attitude towards caring for dying patients, the quality of care delivered to the patient will also increase.

Even though the majority of the students at Stellenbosch University had been exposed to palliative medicine via practical cases, they still expressed that they felt that they had received insufficient training in palliative care. This indicates that there is a need for training to assist students to develop more positive attitudes students towards providing palliative care.

The measured mean score of the Thanatophobia Scale is  $< 4$  in this study and this indicates that the students at the University of Stellenbosch have a positive attitude towards palliative care. This score contradicts the response of the students in the general questions. There is thus inconsistency in the results of these two data

collection methods. The individual questions in the Thanatophobia Scale should be evaluated and the possibility of a validation study of the Thanatophobia scale among South African medical students should be considered. These questions could have been unclear, resulting in responses that do not reflect the true situation. It is difficult to explain this discrepancy noted.

#### **4. The Self efficacy in Palliative Care (SEPC) Scale**

The SEPC scale is a recognised instrument that is used to assess the outcome of a palliative care curriculum. It specifically assesses the student's confidence to perform certain tasks.

##### **Reliability of SEPC and Thanatophobia scale in this study**

By calculating Cronbach's Alpha it is clear that the different questions within each subset are measuring the same underlying concept. Each subset of the SEPC Scale, namely **communication**, **patient management** and **teamwork** demonstrated high Cronbach's Alpha. The Cronbach's Alpha of the Thanatophobia Scale also demonstrated a high Cronbach's Alpha. The survey carried out for this study at the University of Stellenbosch compares well with the initial reliability testing of these two scales done by Mason and Ellershaw in 2004.

##### **Communication**

There was a definite decreased confidence in communication skills as measured by the SEPC scale. The most challenging tasks identified by the students were discussions about death with the family and patient, discussions on prognosis as well as discussions on the expected course of the disease in terms of suffering or pain. This result confirms the response of the general section where the majority of the students expressed a lack of education and **skills** during their training. The above challenges are addressed through clinical training to acquire competence in clinical skills and in particular communication skills training. According to the EAPC, the methods needed to strengthen communication skills include experience to patient cases under supervision and simulation as part of training. This will be observed if the student gets exposed to family meetings held by a trained palliative professional and also observations in the multidisciplinary team meetings held to

discuss patient/family concerns. The once-off exposure of the Stellenbosch's students to a hospice, as well as the limited time spent on palliative training is clearly not enough to address these identified needs of the students. The palliative curriculum only spent 15% time of the two hour lecture on communication training. There is a correlation between the amount of time spent on teaching in palliative care and the confidence experienced, as well as the attitudes measured.

Mason has demonstrated that students receiving >4 weeks of palliative training, showed more confidence in all 3 subsets of the SEPC scale, as well as positive attitudes towards caring for the dying patient.

### **Patient management**

This subset indicates the knowledge of the students. The results measured from the scale do not differentiate between anxiety or confidence of the students about their perceived knowledge. The most challenging task identified by the students under patient management included a gap in knowledge about etiology of symptoms as experienced by the patient. The general section of the survey however identified a definite lack on pain management and ethics in palliative care. Again the majority of the students did voice a lack of education in palliative care. Knowledge need to be addressed with formal lecture on principles and application of symptom and pain management and also ethical application in palliative care. This requires dedicated time slots and trained palliative staff to teach the students the concepts and then to test their knowledge in application with problem case studies. The limited time of two hours for lectures are way too little to effectively convey the knowledge about palliative care and during those two hours only 15% of the time was spent on pain and symptom management and basics in palliative care.

### **Teamwork**

This subset indicates that the students feel confident with the concept of a multidisciplinary team approach. Teamwork was part of the 'hidden curriculum' in the teaching provided by hospices showing the interdisciplinary team in action. Teamwork and self-reflection also consisted of 30% of the Palliative curriculum at the University of Stellenbosch. This can explain the confidence expressed by the students. Multidisciplinary team work is also practised in a lot of other disciplines. The student could have been exposed to this skill throughout their undergraduate

medical training. The confidence of the students in teamwork does not depend only on the palliative education and should be interpreted with caution. The only major challenge experienced under the teamwork subset, included the concept of referral to lymphedema service. The obvious explanation for this can be the lack of lymphedema clinics that exist in our setting. Thus the students probably does not know about this type of service, and due to the fact that there is a lack of this type of service in our setting, do not correlate with lack of training.

The majority of students expressed that there were a lack of education and skills in palliative care during their medical training. The lack of education and skills in palliative care had a statistical significant effect on the student's confidence regarding their communication skills, on their confidence to manage patients and also on their confidence to work in a multidisciplinary team.

Numerous studies have proven that the introduction of a structured undergraduate palliative curriculum can increase the knowledge, skills and attitudes of medical students towards delivering palliative care. The EAPC suggest teaching methods to increase knowledge should include problem-based learning, small group activities, formal lectures and role play. The teaching methods that improve skills should include exposure to practical cases under super-vision, role play and review of the student's skills with the use of audio/visual tools. The EAPC also suggest at least 40h palliative training should be offered. A dedicated (palliative-trained) person should give the training (preferably multiple members of the multidisciplinary palliative team). Exposure to practical cases is imperative. Assessment of the palliative curriculum is mandatory and should include tools to assess knowledge, skills and attitudes, but also objective measures such as an OSCE exam. Reflective teaching should be supported.

It is clear that palliative care teaching at the University of Stellenbosch is inadequate and that time and resources should be found to improve the situation.

Training is given in the 2<sup>nd</sup> year (2h) and then in the 3<sup>rd</sup> year (4h). Pain and symptom management accounts for 15% of the curriculum (again far less than the recommended 55% from the EAPC). Communication form 15% of the curriculum

(EAPC recommend 10%). Team work and self-reflection form 30% of the curriculum (EAPC recommend 5%). The training at the University of Stellenbosch is given by a trained doctor and nurse. The teaching methods used include small groups and formal lectures. There was practical rotation to a local Hospice. The palliative training was assessed with multiple choice questionnaires in an exam format and group work which included reflection on their Hospice exposure.

The lack of education and skills expressed by students from the University of Stellenbosch can be explained: training in symptom management only form 15% of the current palliative curriculum. The total of 6h palliative training does not allow for effective palliative training.

There was a statistically significant difference between negative attitudes expressed and the lack of confidence tested in the communication subset of the SEPC scale. This trend was also seen when negative attitude was compared to lack of confidence in patient management.

The above observation correlates with the literature. If a medical student feels uncomfortable about palliative care, they will feel anxious to communicate with palliative patients and also feel anxious to manage palliative patients' symptoms. This again highlights a decrease in attitudes, a decrease in knowledge and a decrease in skills of palliative care which in turn reflects an ineffective palliative training of the medical students at the University of Stellenbosch.

Schonwetter in 1994 specifically discussed the 3 objectives of palliative care training. He reports that skills training include concepts of multidisciplinary team work, communicating with patient/family and ethical issues of end-of-life. According to him knowledge training includes management of physical symptoms. Attitude training focuses on discussing death with a patient/family.

According to the above literature, the medical students at the University of Stellenbosch's lack of confidence in communication reflect a lack of skills in palliative care. The lack of confidence in patient management reflects poor knowledge training.

## 5. The Thanatophobia Scale

The Thanatophobia Scale can be used to assess the outcome of a palliative curriculum by measuring the **attitudes** of the students towards **caring for the dying**.

### Mean score

If the score is  $< 4$ , this indicates that the students have a positive attitude towards palliative care. The measured mean score of the Thanatophobia Scale is  $< 4$  and this indicates that the students at the University of Stellenbosch have a positive attitude towards palliative care.

There is a significant difference in favour of the positive attitudes measured in the Thanatophobia Scale. The lack of education and skills expressed by the students did not affect their attitudes towards caring for the dying. The literature indicates that insufficient palliative training is associated with negative attitudes of the students towards palliative care. The fact that there are no association between poor education and attitudes may be due to the fact that the format of the questions asked in the questionnaire were difficult to understand and therefore evoked a wrong response. In the general questions, almost three quarter of the students voiced that they do not feel comfortable to tell a patient he/she is dying. This indicates a negative attitude to discuss death. This is however contradictory to the score measured in the Thanatophobia Scale that calculated a positive attitude towards palliative care.

The negative attitude did not test statistically significance against confidence in teamwork as measured by the SEPC Scale. This can be explained partially as medical students are exposed to the concept of teamwork throughout their medical training. If they feel uncomfortable towards dying patients, in a multidisciplinary team approach the student do not feel as if he needs to manage the patient alone. The concept of the team may give the student some security.

### **Challenges experienced by students**

When the challenges experienced under the Thanatophobia Scale were assessed, it revealed that almost half of the students feel “uneasy” with a dying patient as well as feeling helpless if a patient is dying.

The above 2 challenges are part of attitude training. It can also be seen as part of skills training. If the student/doctor knows what to do next, there will be less uneasiness. The EAPC suggested three methods to improve attitudes, namely discussions regarding death of a patient should be done individually under supervision, the use of role play to simulate case scenarios and also the practical exposure to dying patients.

## **6. Palliative care training in undergraduate medical schools in South Africa**

The final part of the survey consisted of feedback from the other medical schools in South Africa on their palliative training offered to undergraduate medical students.

Only five of the eight medical schools replied. The three medical schools that did not respond include: University of Kwazulu-Natal, University of Pretoria and the Walter Sisulu University in the Eastern Cape. There is a wide variation in the Palliative curriculum taught among the five medical schools that responded.

The differences include: The palliative curriculum is usually slotted as part of different other disciplines (Ranging from Family Medicine, Palliative Care and Internal Medicine), this results in palliative training not getting the appropriate high recognition as it should be given. The training is not structured across all the years of the undergraduate medical curriculum to implement and re-enforce the various outcomes of the palliative curriculum. There is a wide variation in the structure of the different medical schools to expose the medical students to palliative training, this ranges from teaching in the 2<sup>nd</sup> year to 6<sup>th</sup> year of the undergraduate curriculum. The times allocated for palliative training vary widely from 6h to 26h and the objectives of the palliative curriculum are vague in some of the medical schools. (University of Limpopo and the University of Free State). There is also inconsistent weighting

given to the various objectives among the medical schools. Another difference is the qualification of the lecturer as can be seen from the University of Free State and Limpopo that only stipulate a doctor with MBChB as the required qualification. This again results in a lack of expertise in the palliative medicine discipline. The last difference detected includes the evaluation methods used to assess the outcome of the curriculum which also vary widely among the 5 medical schools.

From the above observation, it is clear that there is no structured, standardized palliative curriculum taught to undergraduate medical students. This will result in discrepancies in the knowledge, skills and attitudes of the qualified doctors.

The main barriers against palliative education as published by Lloyd-Williams in 2004 in their systematic review, are also identified in South Africa. These include: Inconsistent content taught to students, fragmentation of the palliative training among the 6 years of medical training, a lack of qualified specialists to teach palliative care, a variation in the assessment methods used to evaluate the outcome of the palliative training and none of the five medical schools comment on the use of OSCE in their assessment. The literature has indicated that an OSCE method of examination is more objective and will give a better indication of the outcome of the palliative curriculum. This needs to be combined with methods to assess the knowledge and skills of the students.

In future applying the instruments at the other medical schools with the same population (5<sup>th</sup> years) will provide valuable information regarding the knowledge, skills and attitudes of those medical students. This can be compared to the time spent on palliative training and investigated to test if there is an association between the time allocated for training and the outcome tested.

Of great concern is the fact that the University of Stellenbosch has stopped palliative training for medical students in 2014 after this study was initiated. Currently there is no time or lecturer allocated to train the medical students in knowledge, skills and attitudes towards end-of-life.

The lack of palliative training can have a devastating effect on the quality of care of the patient population. The resource constraints of the health system already hamper the management of many patients with advanced cancer.

## **7. Limitations of the study**

The two questionnaires used were subjective and relied on the students self-reporting. An objective method of evaluation needs to be included to properly assess palliative training.

The questionnaires were not tested for validity in a South African context. Although it have been accepted to be recognized tools that can be used globally to assess undergraduate palliative curriculum. Some of the questions, especially from the Thanatophobia Scale, contained ambiguity and resulted in difficult interpretation of the results, but this is an internationally validated scale that have not been formally tested in a South African context for reliability and validity.

It would be interesting to assess the other seven medical schools with the same instruments to compare the results and thus see if there is an association between the amount of time spent on palliative training and the outcomes of the training as reported in the literature. A medical school offering >20 hours palliative training can even be compared with the Stellenbosch University to assess the influence of time allocated for palliative training and the outcomes measured for palliative training.

Despite the limitations in the study, it still provided valuable information regarding the palliative training given at the University of Stellenbosch and this has resulted in awareness of role players to address the current situation and focus on a better structured palliative curriculum for the future group of medical students. The University of Stellenbosch is currently working on an undergraduate palliative curriculum for medical students for 2017.

## **8. Conclusion**

In this chapter the results of the study were discussed and compared to the literature. The findings of the assessment tools used in the study were interpreted and this has led to an indication of the effectiveness of the undergraduate curriculum at the University of Stellenbosch. It is evident that palliative care does not need a lot

of expensive technology and drugs. The core of palliative care is the holistic approach of the patient. This will ask for time from the treating physician to assess the patient properly and as part of a multidisciplinary approach address all the symptoms identified.

Time spent to properly discuss the disease and future management with the patient and family will improve communication and decrease anxiety of family and patients. This again will result in a content patient that will not demand unnecessary admission and investigations.

The ultimate goal for the patient and the family is the feeling of importance as a human being until the end. To die with dignity is the least that our medical profession can offer the patient and this principle does not require money, just knowledge, skills and positive attitude from the health care professional.

This however can only be achieved if there is adequate education of the medical doctors in palliative medicine.

There is enough emphasis given by the WHO on the significance of under graduate palliative training. The literature supports this imperative in numerous articles published on the benefits of palliative care training.

It is time that the governing health bodies in South Africa insist on a compulsory palliative training to undergraduate medical students, but also to all health care workers working with palliative patients.

Only when palliative training gets high recognition, will the patient population needs be addressed. The various medical schools need to get together to identify and implement a standardized palliative curriculum across South Africa.

The next chapter will discuss the conclusion of this study and also assess if the objectives of the study was. The recommendations that resulted from the study will also be highlighted.



## **Chapter 6: Conclusion and recommendation**

The previous chapter discussed the relevant findings of this study and also compared the findings with international literature. This chapter will summarize the end result of the study and provide recommendations for future applications.

In reviewing the objectives of the study, the first objective was to determine the self-efficacy of the Stellenbosch students. Self-efficacy is determined by the knowledge of the students as well as the skills to deliver palliative care. The SEPC tool that was used in the study measured communication, patient management and also teamwork as indicators to determine the confidence of the medical students to deliver palliative care. SEPC scale with specific areas highlighted as problematic to the students. The most obvious challenges under communication skills were discussions about death with patients and family members, discussing the prognosis with the patient and also discussions on the expected course of the disease in terms of pain and suffering. This lack of confidence in communication skills was confirmed by the general question part of the survey where the students also voiced their concern about a lack of training in skills. The second subset of patient management did not measure a definitive anxiety or confidence as measured by the SEPC scale. The most obvious challenges however identified by the students were the management of pain and symptoms. This was also confirmed with the general questions answered by the students in the first part of the survey that clearly showed a lack of knowledge on specifically pain management and ethics. The third subset of teamwork measured by the SEPC scale showed confidence in teamwork. Considering all of these results, the self-efficacy of the medical students at the University of Stellenbosch indicates towards a lack of confidence in knowledge and skills to deliver palliative care. Thus the first objective of the study has been met.

The second objective was to determine the attitudes of the medical students at the University of Stellenbosch to deal with dying patients. The Thanatophobia scale was used and this scale measured positive attitudes of the students towards caring for dying patients. The literature recommends that discussions on death should be part of palliative training to address the attitudes of the students to care for the dying patient. Discussions regarding death and dying are also a component of communication skills and this in turn can result in difficulties to interpret the

Thanatophobia scale. The students expressed the following challenges within the Thanatophobia scale, namely the feeling of discomfort and helplessness when confronted with dying patients. In the first part of the survey the majority of the students expressed discomfort to discuss death with the patient. This can be interpreted as lack of confidence in communication skills or a negative attitude of the students to care for dying patients. A conclusion regarding the attitudes of the medical students at the University of Stellenbosch to care for dying patients is there for difficult to interpret. Despite the inconsistency between the data collection methods, the second objective of the study has been met.

The third objective of the study was to evaluate the undergraduate palliative curricula at the other medical schools in South Africa and then compare the University of Stellenbosch's palliative training with the other medical schools. This objective has been met.

The World Health Organization identifies "palliative care as a component of comprehensive care throughout the life course" Training in palliative care at the undergraduate level will ensure that health care practitioners are competent to deliver such comprehensive care.

An undergraduate palliative curriculum should aim to address the knowledge of medical students about basic principles pertaining palliative care, assessment and management of pain and other symptoms associated with life-limiting diseases and provide sufficient knowledge on the principles and application of ethics and law in palliative care. The study illustrates that there is a lack of knowledge as perceived by the medical students regarding their confidence about pain and symptom management, treating the terminal phase of dying and also a lack of confidence to apply ethical and law principles in end-of-life care.

Palliative training should also equip medical students with the necessary skills in teamwork, communication and ethical decision making. The study highlights a lack of confidence in communication skills and ethical decision making as perceived by the medical students at the University of Stellenbosch.

The last main objective of a palliative curriculum should focus on fostering empathetic attitudes of medical students to discuss death with the patient and family

involved. The study reveal that the medical students showed positive attitudes towards end-of-life care as tested by the Thanatophobia scale, although the first part of the survey contradicts this finding and the medical students expressed a negative attitude to discuss death with patients/family.

Undergraduate palliative training at medical schools throughout South Africa varies widely in terms of content taught, structure of the palliative curricula, qualification of the lecturer involved in palliative training and also the time allocated for the palliative training.

An undergraduate palliative curriculum should address all three of these objectives to provide effective palliative training and to equip medical students to be a holistic-centred, palliative inclined health care professional that strives to provide quality care to the patient.

The study indicates that there is a need for a well-structured, dedicated undergraduate palliative curriculum that needs to specifically address the knowledge and skills of the Stellenbosch medical students.

## **Recommendations**

The University of Stellenbosch's medical faculty should prioritize palliative training as part of the undergraduate medical curriculum. A qualified, dedicated person should be identified that can plan and implement a well-structured palliative curriculum. The outcomes of the palliative curriculum should be defined upfront and the appropriate time should be negotiated for the curriculum. To compensate for limited time in the already overloaded undergraduate curriculum, options such as flipped classroom and blended learning should be considered. The palliative curriculum should be formally assessed to convey the message of importance to the students and need to be passed to be able to graduate. The structure of the curriculum should include practical exposure to palliative cases, case studies in small groups, exposure to interactions of multidisciplinary teamwork and also training in understanding the cultural and religious differences in the society. Ethical and law principles need to be reinforced with practical encounters of palliative cases and also case study discussions.

The palliative training should at least encompass 40 hours of the undergraduate medical curriculum and the palliative training need to be incorporated in all the years of the medical curriculum even if it entails patient portfolios and cases as part of the different other disciplines of training. The concept that palliative care is not an isolated discipline should be emphasized with this mind shift towards patient care should be assessed in each year of medical training.

Since the study was conducted, the University of Stellenbosch has terminated any theoretical and practical exposure to palliative care. There is an urgent call upon the Faculty of Health Sciences at the University of Stellenbosch to re-plan the medical curriculum especially in the forefront of the next WHA meeting to be held in 2016. Currently the University of Stellenbosch's Health Science faculty cannot proclaim that they are training health care professionals that can deliver to the needs of our patient population.

**“What we will learn here comes through the patient’s themselves. When we look back we remember not what death has done to them, but what they have done to our thoughts about it.”**

**Cicely Saunders (1967)**

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# **A NEEDS ASSESSMENT FOR PALLIATIVE CARE TRAINING IN UNDERGRADUATE STUDENTS AT THE UNIVERSITY OF STELLENBOSCH.**

## **Fifth year medical students:**

You are asked to participate in a research study conducted by Dr AE Fourie( MMed Radiation Oncology, MBChB, Dipl Palliative Medicine) from the Department of Family Medicine at the University of Cape Town. I am doing my MPhil in Palliative Medicine and the results of the study will be used as part of my dissertation. You were selected as a possible participant in this study because you are almost at the end of your medical training to become the next generation of practicing doctor's. The topic of Palliative Care was addressed in your third year rotation as part of Family Medicine.

The study want to assess if you covered different topics/issues during your Palliative Care curriculum. It will assess your knowledge, as well as if you feel equip to manage a dying patient.

### **1. Purpose of the study**

The study aims to investigate if there is a need for better training in Palliative Care at the University of Stellenbosch.

### **2. Procedures**

If you volunteer to participate in this study, I would ask you to do the following things:

A questionnaire will be given to each fifth year medical student. You will be given 15 minutes to complete the questionnaire. It is anonymous and voluntary.

### **3. Potential risks and discomforts**

No foreseeable risks, discomfort or inconveniences is anticipated.

### **4. Potential benefit to subjects and/or to society**

You as fifth year medical students will not benefit directly from participation to the study. The aim is to evaluate a need for a better training in Palliative Care and then incorporate the training in future for undergraduate medical students to equip them for managing a dying patient and the family.

### **5. Payment for participation**

No remuneration will be given for participating in the study.

### **6. Confidentiality**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of the questionnaire being anonymous.

**7. Participation and withdrawal**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study.

**8. Identification of investigator**

If you have any questions or concerns about the research, please feel free to contact Dr AE Fourie at Department Radiation Oncology, Tygerberg Hospital at 021 938 6014.

**9. Rights of research subjects**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

**Signature of research subject**

The information above was described to *[me/the subject/the participant]* by *[name of relevant person]* in *[Afrikaans/English/Xhosa/other]* and *[I am]* in command of this language or it was satisfactorily translated to *[me]*. *[I/the participant/the subject]* was given the opportunity to ask questions and these questions were answered to *[my]* satisfaction.

*[I hereby consent voluntarily to participate in this study]* I have been given a copy of this form.

\_\_\_\_\_

**1. Name of Subject/Participant**

\_\_\_\_\_

\_\_\_\_\_

**2. Signature of Subject/Participant**

**Date**

**Signature of investigator**

I declare that I explained the information given in this document to \_\_\_\_\_ *[name of the subject/participant]*. *[He/she]* was encouraged and given ample time to ask me any questions. This conversation was conducted in *[Afrikaans/\*English/\*Xhosa/\*Other]* and *[no translator was used]*.

\_\_\_\_\_

\_\_\_\_\_

**Signature of Investigator**

**Date**

## Evaluating Palliative care education

This is a questionnaire that forms part of a research study required for MPhil (Palliative Medicine): Evaluating the training of Palliative Medicine in the undergraduate medical curriculum. The Questionnaire is anonymous and voluntary. After analysis of the results, feedback will be provided to the participants and the Head of the undergraduate medical curriculum.

### Please provide the following:

#### Demographics:

Sex:                      Male                                            Female                     

Age:                      20-25                         25-30                         30-35                         35-40                         >40  

#### Have you ever had to deal with a dying patient?

Yes                                            No                     

If yes:  Family                       Friend                       Patient  
(work)

#### General questions:

1. Palliative Care already start when diagnosis is made.

Yes                     

No                     

2. Where do you think the majority of patients are treated?

In patient                     

Outpatient                     

Hospice

3. In palliative care, the most common symptoms (according to you) encountered in order of frequency are?

Pain

Depression

Cachexia

4. Do you have enough knowledge and training to provide palliative care to patients and their family?

Yes

Somewhat

No

5. Codeine is step 2 of the WHO step ladder for pain relief?

No

Yes

Cannot say

6. Route of administration of pain medication in general pain management?

Intravenous

Subcutaneous

Oral

7. What is the proportion of cancer patients requiring palliative care:

10-25%

30-50%

Up to 70%

8. During your training, education and skill about palliative care has been imparted?

Yes

Somewhat

Not enough

9. Do you read a palliative care journal at least once a month?

Yes

No

Not required

10. Do you know what a syringe driver is?

Yes

No

Not sure

11. Do you feel comfortable to tell a patient he/she is dying?

Yes

No

Not sure

12. How frequently should morphine syrup be prescribed?

prn

4h

6h

8h

13. Do you agree with this statement regular administration of Morphine for pain relief can cause addiction?

Yes

No

Not sure

14. What medication is useful to treat a patient's noisy breathing known as the "death rattle"?

Morphine

Midazolam

Oxygen

Buscopan

15. Is it important to provide nasogastric feeds in a dying patient?

Yes

No

Not sure

## Section 2

Please answer the following questions by placing an 'X' on the line between 'very anxious' and 'very confident' in relation to how you think you would feel about:

### Communication:

- Discussing the likely effects of cancer with the patient.

0 10 20 30 40 50 60 70 80 90 100  
Very Anxious Very Confident

- Discussing the likely effects of cancer with the patient's family.

0 10 20 30 40 50 60 70 80 90 100  
Very Anxious Very Confident

- Discussing issues of death and dying.

0 10 20 30 40 50 60 70 80 90 100  
Very Anxious Very Confident

- Discussing the patient's own death (with the patient)

0 10 20 30 40 50 60 70 80 90 100  
Very Anxious Very Confident

- Discussing the patient's death (to occur) with the family.

0 10 20 30 40 50 60 70 80 90 100  
Very Anxious Very Confident

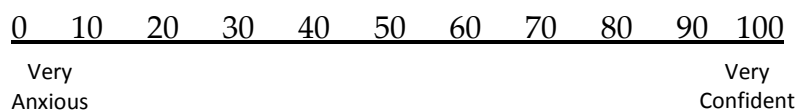
- Discussing the patient's death with the family upon treatment.

0 10 20 30 40 50 60 70 80 90 100  
Very Anxious Very Confident

- Answering the patient's question: How long have I got to live?

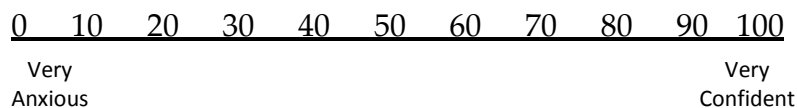
0 10 20 30 40 50 60 70 80 90 100  
Very Anxious Very Confident

- Answering the patient's question: Will there be much suffering or pain?

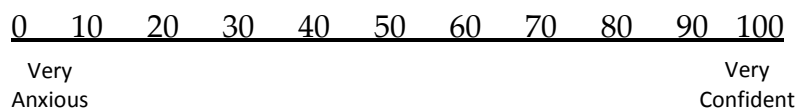


**Patient management**

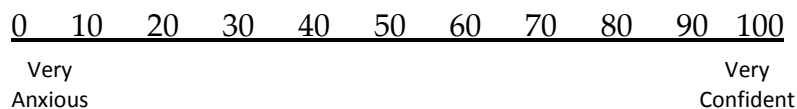
- Your ability to assess the patient's needs.



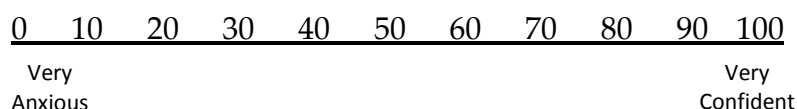
- Your knowledge of the etiology of common symptoms experienced by palliative care patients.



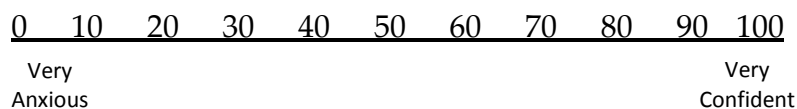
- Your ability to manage common symptoms experienced in palliative care patients.



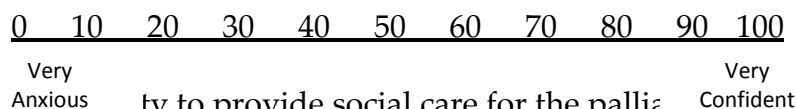
- Your ability to prescribe appropriate and adequate pain control medication.



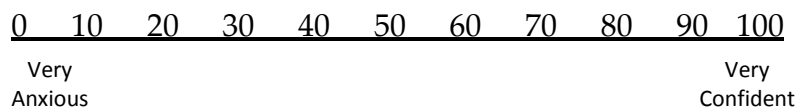
- Your knowledge of the therapeutic and side-effects of analgesic agents.



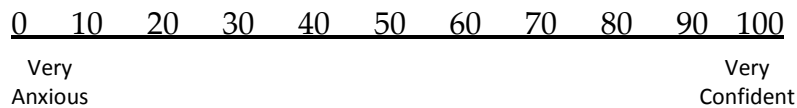
- Your ability to provide psychological care for the palliative care patient and his or her family.



- Your ability to provide social care for the palliative care patient and his or her family,

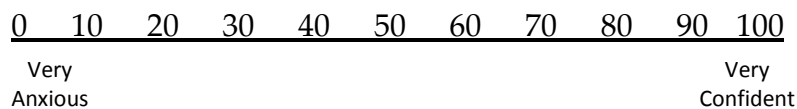


- Your ability to provide spiritual care for the palliative care patient and his or her family.

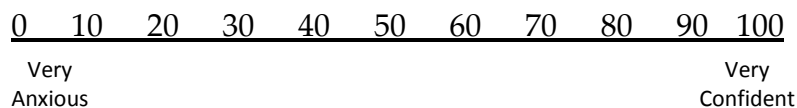


**Multidisciplinary & team working**

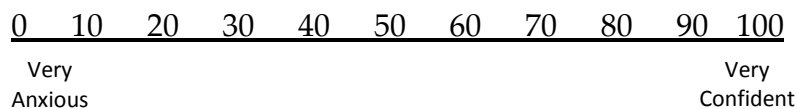
- Working within a multi professional palliative care team



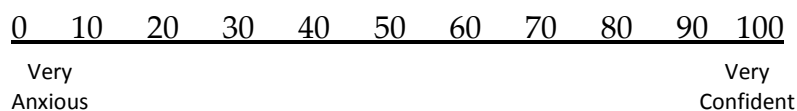
- Appropriately referring palliative care patients for physiotherapy.



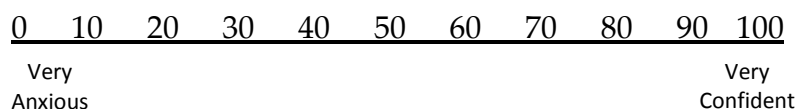
- Appropriately referring palliative care patients for occupational therapy.



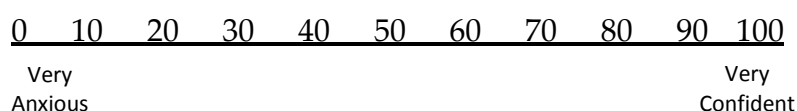
- Appropriately referring palliative care patients for complementary therapies.



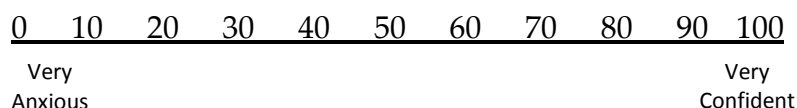
- Appropriately referring palliative care patients to a lymphedema service.



- Appropriately referring palliative care patients for psychiatric evaluation.



- Appropriately referring palliative care patients to a spiritual adviser.



### **Section 3**

Please circle the number that corresponds to how strongly you agree or disagree with the following statements. Answer according to how you think you would feel regarding the issues and situations presented below.

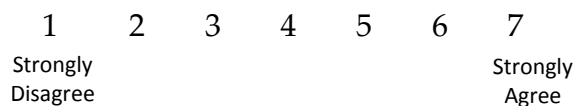
- Dying patients make me feel uneasy.



- I feel pretty helpless when I have terminal patients on my ward.



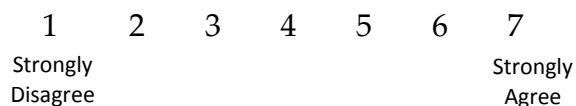
- It is frustrating to have to continue talking with relatives of patients who are not going to get better.



- Managing dying patient's traumatises me.



- It makes me uncomfortable when a dying patient wants to say goodbye to me.



- I don't look forward to being the personal physician of a dying patient.





### **The Head of the undergraduate MBCHB curriculum:**

You are asked to participate in a research study conducted by Dr AE Fourie( MMed Radiation Oncology, MBChB, Dip Palliative Medicine) from the Department of Family Medicine at the University of Cape Town. I am doing my MPhil in Palliative Medicine and the results of the study will be used as part of my dissertation. The WHO challenged training institutions to ensure that palliative care is compulsory and given high recognition.

Although medical institutions in South Africa address some issues of palliative care during the academic training, the concern is if the current training is sufficient in preparing “tomorrow’s doctors “with the necessary confidence of skills to competently care for the dying patient and their family. There is no standard curriculum implemented for palliative training in South Africa. The time allocated also varies widely between institutions to institution. There is clearly a need to adopt a standardized palliative medicine curriculum to standardize undergraduate palliative care education.

The study wants to assess and compare the palliative care training in each of the 8 medical schools in South Africa, including the University of Stellenbosch.

#### **10. Purpose of the study**

The study aims to investigate if there is a need for better training in Palliative Care at the University of Stellenbosch.

#### **11. Procedures**

If you volunteer to participate in this study, I would ask you to do the following things:

A questionnaire will be sent via e-mail to all of the Heads of the undergraduate MBCHB curriculum of all the 8 medical schools in South Africa. You will be given 1 week to respond to the questionnaire. I will be phoning you at the end of the week to have a telephonic interview with you and get feedback of any comments.

#### **12. Potential risks and discomforts**

No foreseeable risks discomfort or inconveniences is anticipated.

#### **13. Potential benefit to subjects and/or to society**

You as Heads of the undergraduate MBCHB curriculum will not benefit directly from participation to the study. The aim is to evaluate a need for a better training in Palliative Care at the University of Stellenbosch and then incorporates the training in future for undergraduate medical students at the University of Stellenbosch to equip them for managing a dying patient and the family.

#### **14. Payment for participation**

No remuneration will be given for participating in the study.

### **15. Confidentiality**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

### **16. Participation and withdrawal**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study.

### **17. Identification of investigator**

If you have any questions or concerns about the research, please feel free to contact Dr AE Fourie at Department Radiation Oncology, Tygerberg Hospital at 021 938 6014.

### **18. Rights of research subject**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

**Signature of research subject**

The information above was described to *[me/the subject/the participant]* by *[name of relevant person]* in *[Afrikaans/English/Xhosa/other]* and *[I am]* in command of this language or it was satisfactorily translated to *[me]*. *[I/the participant/the subject]* was given the opportunity to ask questions and these questions were answered to *[my]* satisfaction.

*[I hereby consent voluntarily to participate in this study]* I have been given a copy of this form.

---

### **3. Name of Subject/Participant**

---

### **4. Signature of Subject/Participant**

**Date**

**Signature of investigator**

I declare that I explained the information given in this document to \_\_\_\_\_ [*name of the subject/participant*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/\*English/\*Xhosa/\*other*] and [*no translator was used*].

---

**4.1. Signature of Investigator**

---

**Date**

## **Participant information**

The Head of the undergraduate MBChB curriculum information regarding study:

### **A needs assessment for palliative care training in undergraduate students at the University of Stellenbosch.**

Dear Lecturer,

I would like to ask you to read this information sheet very carefully. It contains important information about this study.

The WHO stresses the importance of Palliative Care in their definition of 2002. Palliative care addresses physical, psychological, social and spiritual needs and it improves the quality of life of patients and families. It implies early in the course of any life-threatening disease.

The vast majority of patients in the Third World Countries do not have access to modern diagnostic and therapy facilities and for them palliation is all they can hope for. Palliative care is a basic human right when curative care is no longer appropriate.

The WHO challenged training institutions to ensure that palliative care is compulsory and given high recognition.

Although medical institutions in South Africa address some issues of palliative care during the academic training, the concern is if the current training is sufficient in preparing “tomorrow’s doctors” with the necessary confidence of skills to competently care for the dying patient and their family.

There is no standard curriculum implemented for palliative medicine training in South Africa. The time allocated also varies widely between institution to institution. There is clearly a need to adopt a standardized palliative medicine curriculum to standardize undergraduate palliative care education.

I am doing this study as part of my MPhil in Palliative Medicine.

### **Study procedure**

A questionnaire will be sent via e-mail to all of the Heads of the undergraduate MBChB curriculum of all the 8 medical schools in South Africa. You will be given 1 week to respond to the questionnaire. I will be phoning you at the end of the week to have a telephonic interview with you and get feedback of any comments.

### **Aim of the study**

To conduct a needs assessment for palliative care training in undergraduate students at the University of Stellenbosch.

To assess and compare current undergraduate palliative care training at other South African medical schools, including the University of Stellenbosch.

### **Structure of the study**

All the fifth year medical students of the University of Stellenbosch will be asked to participate in the study. A questionnaire that contains demographic data, evaluates knowledge of palliative care and assesses the student's self-efficacy and attitudes towards caring for palliative care patients will be distributed. The questionnaire is voluntary and anonymous.

The Heads of the undergraduate MBChB curriculum at all the 8 medical schools in South Africa will also be asked to respond to a questionnaire about the palliative care curriculum in each institution, including the University of Stellenbosch.

The University of Stellenbosch's palliative care curriculum will be compared to the other 8 medical schools.



04 July 2013

HREC REF: 265/2013

Dr A Fourie  
c/o Dr L Gwyther  
Public Health & Family Medicine  
Falmouth Building  
FHS

Dear Dr Fourie

**PROJECT TITLE: A NEEDS ASSESSMENT FOR PALLIATIVE CARE TRAINING IN UNDERGRADUATE STUDENTS AT THE UNIVERSITY OF STELLENBOSCH**

Thank you for your letter dated 28 June 2013, addressing the issues raised by Human Research Ethics Committee.

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

**Approval is granted for one year till the 15 July 2014.**

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

However, please include the contact details of the UCT FHS HREC in the informed consent documents, in case participants have any questions or concerns about their rights or welfare as research participants.

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

**Please quote the REC. REF in all your correspondence.**

Yours sincerely

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, HSF HUMAN ETHICS**

Federal Wide Assurance Number: FWA00001637.

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