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INVESTIGATING HOW THE PALLIATIVE CARE POLICY WAS IMPLEMENTED IN THE SHISESLWENI REGION, SWAZILAND

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfillment of the requirements for the degree

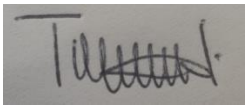
of

Master of Public Health

September 2016

DECLARATION

I, Teluleko Nhlonipho Maseko declare that this research report is my own work. It is being submitted in partial fulfillment of the requirements for the degree Master in Public Health at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



_____

22 day of September 2016

DEDICATION

This work is dedicated to my family thanks for your continued support and understanding. To my wife you must be so proud, I finally did it. To my daughter Sakhelo Maseko thanks for keeping me on my toes and for the unconditional love. To my partner thanks for being there during the challenging times and for always celebrating and appreciating the small and big achievements.

ABSTRACT

Background: Palliative care (PC) services in Swaziland were offered without policy guidance until in 2011 when a policy was enacted. This absence resulted in a fragmented approach to palliative care service delivery (Swaziland Ministry of Health, 2011). The absence of a PC policy resulted in the provision of PC services that lacked interdisciplinary collaboration.

Aim: To explore the understanding of the palliative care policy and experiences with regard to implementation amongst health care workers in the Shiselweni Region from November 2011 to March 2015.

Method: The study used a qualitative method using in-depth interviews with health workers and policy makers.

Results: A total of 17 health workers participated in this study. The study showed that there was lack of knowledge about palliative care, confusion as to where palliative care should be offered and by whom and the role of providing medication as part of palliative care. Fascinatingly, the health workers mentioned the importance of different actors, the importance of teamwork and some perceived successes of palliative care implementation. Several challenges were reflected which included availability of medicines, human resources, transport, infrastructure, and lack of coordination of RHMs. Suggested strategies for improving palliative care that were pointed out comprise of training, improving medicine supply, organizational issues and the development of guidelines and standard operating procedures.

Conclusion: Concerted action is needed to strengthen the availability of medicines and recruitment of human resources. Successful implementation of palliative care requires that local resources and customs are taken into account and that educational initiatives be undertaken to train health care professionals.

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I wish to start with my Supervisor Aziza Mwisongo who assisted, guided and supervised me from proposal development to the very end. I am very grateful to her. To, Colin Pfaff thanks for the guidance, commitment and professionalism and moreover your patience. Additionally, I appreciate the sacrifices you made to accommodate my complex work and study schedule and always willing to make compromises so that we completed this. I am indebted to the Human Ethics Committee of Swaziland for granting me permission to conduct the study. Thanks to the Regional Matron of Shiselweni for allowing me to collect the data from the research settings. I wish to express my appreciation to Dr. Sifiso Sithole for assisting with transcribing the interviews. Lastly and once more, I would not have done it without encouragement from my family.

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Abbreviations

APCA: African Palliative Care Association

ART: Anti-Retroviral therapy

CBOs: Community Based Organizations

CHW Community Health Workers

FBO: Faith Based Organization

HIV: Human Immunodeficiency Virus

NGO's: Non-Governmental Organizations

PC: Palliative Care

RHM: Rural Health Motivators

WHO: World Health Organization

Chapter 1: Introduction

This research report examines how the Palliative Care (PC) policy was implemented in the Shiselweni region in Swaziland. This chapter presents the background of the study, a situational analysis of the PC services in Swaziland, the literature review, problem statement, study justification, as well as the aim and objectives.

1.1 Background

1.1.2 Definition of Palliative Care

Palliative care is "an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2002). While the palliative care approach was developed in response to the plight of patients with cancer, other life threatening conditions, such as HIV, heart diseases, diabetics and stroke, were soon added. The focus is therefore on life threatening illnesses that are malignant and non-malignant (African Palliative Care Association, 2012)

1.1.3 Situational Analysis of Palliative Care Services in Swaziland

The need for palliative care in Africa, and in particular the sub-Saharan region is enormous as shown by the number of people infected and affected with HIV/AIDS. Indeed 67% of the global 33 million people living with HIV and 72% of all AIDS deaths in 2007 occurred in this region (Swaziland Ministry of Health, 2011).

Palliative care in Swaziland has historically focused on the end of life care provided in hospices and other facilities. However, it has expanded into an approach for delivery of treatment, care, support and follow-up services for delivery through all healthcare programmes. Palliative care services are currently provided in varying packages by health facilities and NGOs/ FBOs at facilities and in the communities. The care is provided on an inpatient, day care, outpatient and/or outreach basis depending on the patients' condition and availability of inpatient space (Swaziland Ministry of Health, 2011). In 1990 the Swaziland Hospice at Home pioneered

palliative care in the home setting as part of home based care (Swaziland Ministry of Health, 2009).

1.1.4 Review of palliative care services in Swaziland

Palliative care is a relatively new concept in Swaziland. There is evidence from the mid-eighties that some level of palliative care was offered which resulted in it being included as one of the elements of the Community Based Care and Support program (Swaziland Ministry of Health, 2011). In 2008 the Swaziland Ministry of Health trained 189 health workers including 169 nurses and 20 doctors in palliative care (Swaziland Ministry of Health, 2009) and later in 2009, undertook a review of palliative care services. They found that the number of palliative care patients seen by different health facilities and NGOs over a period of one year varied greatly.

The geographical reach of these services was limited. Some of the service providers were making attempts at national coverage with their services (Swaziland Ministry of Health, 2009), however activities were limited due to inadequate personnel, expertise, equipment and supplies.

The palliative care service package provided by service providers varied. Symptom control and pain management were the most commonly provided elements and effective communication was the least provided elements of palliative care (Swaziland Ministry of Health, 2009).

1.1.5 Swaziland National Palliative Care Policy.

The gaps identified in the 2009 review of palliative care services, led to the development of a national Palliative Care Policy in 2011. The National Palliative Care Policy was the product of widespread consultations and participation of institutions and individuals. The policy provided a broad guide for the implementation and management of PC interventions, programs and activities at various levels (Swaziland Ministry of Health, 2011). The policy was supported and launched by the Minister of Health and had a lot of public support (Swaziland Ministry of Health, 2011).

The purpose of the policy was to provide a framework for standardized implementation of palliative care services in Swaziland. This is because PC is a broad concept encompassing a range of activities undertaken by health workers. Furthermore the policy was a tool to ensure good management of patients needing palliative care, guide priority strategic orientations in

relation to palliative care, and secure resources (human, material and financial) (Swaziland Ministry of Health, 2011).

The Palliative care (PC) policy objectives were:

- To facilitate the integration of regulated, coordinated and decentralized palliative care in health care services delivery;
- To ensure that all persons have equal access to PC services by mobilizing adequate resources;
- To ensure that essential medicines (pain medications) are available to at all levels of health care services delivery;
- To ensure that PC services are available for children;
- To provide guidance for use in developing PC standards;
- To provide a framework for supporting PC integration into other service delivery programs;
- To stimulate awareness of human resource development and training in PC;
- To provide a mechanism for monitoring and evaluation of PC services;
- To promote PC service delivery by public sector, private sector players and civil society.
- "To stimulate the development of legislation for PC" (Swaziland Ministry of Health, 2011).

Strategies outlined in the policy include sections on capacity building, leadership, quality of care, referral, service delivery through decentralization of PC services, service accessibility and equity, client and community management, and monitoring and evaluation. Swaziland's priority interventions in implementing the policy include but are not limited to: human and institutional resources, integrating standardized services at all levels of the health system, both private and public; ensuring the availability and accessibility of comprehensive palliative care programs and the availability and regular supply of essential palliative care medicines particularly morphine; ensuring that patients in need can access essential medicines, including opioids; developing and strengthening legislation that promotes and protects the rights of palliative care beneficiaries and providers; incorporating palliative care into pre-service and in-service training of health workers; mobilizing needed resources to coordinate, implement and monitor palliative care services; and creating awareness and demand for palliative care for all those who need it (Swaziland Ministry of Health, 2011).

The policy has decentralization of palliative care as a specific objective and clearly outlines the services that are to be available at three levels - specifying that palliative care shall be delivered at 3 levels- community and clinic level; health centre level and hospital level.

The Swaziland National Palliative Care Policy promotes a holistic approach to patient care and outlines proposals for integrating PC into Swaziland's health care system.

The policy also aimed to put a human face to the end-of-life period through civilized and compassionate care for the patient and her/his family, ensuring that such care is available to all those in need, including children (Swaziland Ministry of Health, 2011).

1.2 Literature Review

1.2.1 Global need for palliative care?

Globally, there is a significant unmet need for palliative care; of the 58 million people dying annually (45 million in developing countries, 13 million in developed countries), it is estimated that at least 60% will have a prolonged advanced illness and would benefit from palliative care (African Palliative Care Association, 2012). For example, in 2008 there were 12.7 million cancer cases and 7.6 million cancer deaths; of these, 56% of the cases and 64% of the deaths occurred in the economically developing world. The global burden of cancer continues to increase largely because of the aging and growth of the world population alongside an increasing adoption of cancer-causing behaviors, particularly smoking (Snelling et al., 2007).

1.2.2 Need in Africa for palliative care

The need for PC in Africa is characterized by a significant burden of communicable and non-communicable diseases (NCDs), many of which will require palliative care. For example, by 2013, 24.7 million (m) people in the sub-region were living with HIV/AIDS. Cancer is also an emerging public health problem in the African region (Jemal et al., 2012). In 2008 there were 715,000 new cases and 542,000 cancer-related deaths in Africa and this is projected to nearly double by 2030 due to population growth and aging, (Ferlay et al., 2010).

Many patients in Swaziland present late to the health care system with advanced disease (Swaziland Ministry of Health, 2011). At that stage of their illness, therapies are frequently ineffective, associated with multiple side effects that cause increased suffering and are expensive. For those patients, at end stage of their disease where therapies are frequently ineffective palliative care would be of benefit to them (Gomez-Batiste et al., 2006).

Swaziland also reports high rates of cancer. In 2009, 700 patients with cancer were admitted to the country's hospitals. Earlier reports show cancer of the cervix accounting for 43.1% and cancer of the breast accounting for 10.2% of all cancers. Among men common cancers include skin cancers, cancers of the genital organs and of the oral cavity (Swaziland Ministry of Health, 2006). These statistics were one of the triggers in the development of the National Palliative Care policy.

1.2.3 Chronological account of the development of palliative care services

History of palliative care

Modern palliative care is believed to have commenced in 1967 with the opening of St Christopher's Hospice in London in response to the unmet needs of dying patients in hospitals. Traditionally, hospice care was reserved for those with incurable cancer. Increasingly, hospice care is now also provided for other patients such as those with AIDS and neurological disorders, including motor neuron disease and multiple sclerosis (O'Neill and Fallon, 1997).

In the past, hospices provided only inpatient care, and they were isolated from mainstream care. Most units now combine inpatient and home care services, and many independent home care teams also exist, working closely with general practitioners and other workers in primary care. Similarly, many acute hospital and teaching centres now have consultative, hospital-based teams (O'Neill and Fallon, 1997).

Palliative care declarations; internationally palliative care service delivery is guided by the following two declarations:

The Cape Town Declaration, (2002*)* which emphasizes that:

a. Palliative care is the right of every adult and child (accessibility, affordability)

b. Control of pain and symptoms is a human right (need to ensure pain medicines availability)

c. All members of health care teams and providers need training in palliative care

d. Palliative care should be provided at primary, secondary and tertiary levels.

The Korea Declaration, (2005) emerged from the 2nd Global Summit of National Hospice and Palliative Care Associations in 2005. It stated that governments must "make access to hospice and palliative care a human right." Specifically, it called on governments to include palliative care as part of health policy; integrate palliative care training into the curricula of health professionals; ensure the availability and affordability of all necessary drugs, especially opioids; and strive to make hospice and palliative care available to all citizens in the setting of their choice.

Palliative care delivery models – the public health approach

The World Health Organization has mandated countries to adopt the public health approach for effective delivery of palliative care. It emphasizes that all countries should use a public health approach and have a Palliative Care policy, which will guide palliative care delivery (African Palliative Care Association, 2008). The policy is an umbrella to thematic areas such as; drug availability, education and implementation. The call has been adhered to by several countries in Africa including Uganda, Kenya, Ethiopia, South Africa and Swaziland (African Palliative Care Association, 2012).

The WHO Public Health Model contains four thematic areas: 1) appropriate policies, 2) adequate drug availability, 3) education of health care workers and the public, and 4) implementation of palliative care services at all levels throughout society (see Table 1.1 below). The process is to be implemented within the context of the culture, disease demographics, socioeconomics, and the

health care system of that country. For each component there are short, intermediate, and long-term outcomes that must be measured (Stjernsward et al., 2007). Table 1 below shows a detailed explanation of the WHO public health model approach.

Table 1.1 WHO Public health model approach.

Specific Area / Strategies	Areas of focus
Policy	Palliative care policy as part of the national health plan, and service delivery models and ensuring the availability of essential medicines.
Drug availability	Prescribing, distribution, dispensing and administration
Education	Media and public advocacy, family caregiver support, courses for professionals and expert training
Implementation	Trained manpower, strategic plans, resources and infrastructure

Source: (Stjernsward et al., 2007)

The current challenges associated with implementing all four components of palliative care are extending coverage while ensuring quality (African Palliative Care Association, 2008). Downing (2008) states that some challenges in its delivery include; availability of drugs and other resources, logistics and infrastructure, the immense need for such services and negative attitudes of health workers who provide palliative care.

The World Health Organization has a strategic document in regard to palliative care. The section below discusses each of the four strategies of the WHO public health approach in detail.

1.2.4 WHO strategy 1 – Palliative care policy as part of a National Health Plan

Palliative care policy internationally

Access to palliative care is dependent on its integration into national policies and on the overall strengthening of the health care delivery systems (African Palliative Care Association, 2012). However, only 20 of 234 countries globally have achieved high-level integration of palliative care into mainstream health service provision (Lynch et al., 2013). Although it is encouraging that there was a 9% increase between 2006 and 2011 in the number of countries in which individuals have access to at least one palliative care service, this increase is primarily related to the HIV/AIDS epidemic in Africa, rather than to care of patients with cancer (Knapp et al., 2011). The successful integration of palliative care into mainstream health care is facilitated by national policies for palliative care or at least the embedding of palliative care within other national health policies; leadership to pursue advocacy and to sensitize policymakers is also needed to achieve this goal (Stjernswärd et al., 1996).

However, palliative care for patients with cancer is most likely to be implemented when it is incorporated into national cancer control policies, as a fourth pillar, alongside primary prevention, early detection, and curative treatment (Stjernswärd et al., 2007) This approach is consistent with the 2014 resolution of the World Health Assembly that palliative care be included in all national health policies and budgets and integrated across all health care levels, especially in community and home-based care settings (De Lima and Radbruch, 2014). Indeed, a primary care model for palliative care is typically more feasible to finance and implement in low to middle income countries than a specialist model based on tertiary care (Downing et al., 2010).

A study conducted in China indicates that palliative care is not yet supported by a national policy or governmental funding in China or India, which together accounts for one third of the world's population (Kumar, 2013). However, it has been reported that there are now more than 200 privately funded hospices and palliative care units in China and more than 10,000 professionals working in the field of palliative care (Li et al., 2011). Palliative care is still unavailable to most people in India, although the Indian state of Kerala has become a model for the integration of palliative care into the public system of health care (Kumar, 2013). The government of Kerala in 2008 integrated palliative care into primary health care and established a cohesive, community-based system of palliative care. Community volunteers in palliative care provide care in clinics and at the homes of patients, and palliative care units in communities provide food for starving families, educational support for children, and financial support and advocacy. This model has achieved remarkable success; approximately 90% of all palliative care services in India are now reportedly provided in Kerala, although this region represents just 3% of the country's population (Kumar, 2013).

There have been a variety of other successes in low middle income countries in Latin America in the integration of palliative care into health care systems. For example, Costa Rica has integrated palliative care into the public health system, achieving a ratio of palliative care services to the general population that is comparable to that in high income countries (Lynch et al., 2013). In low middle income countries programs include home based care which is facilitated by health workers and volunteers. This strategy works for these countries. This works because the

programs are community driven. The only challenge they have is the issue of insufficient medicines.

Palliative care policy in Africa

In Africa, three of 54 countries (Mozambique, Rwanda, and Swaziland) have established a stand-alone national implementation plan for palliative care services, (African Palliative Care Association, 2012) whereas seven countries (the Democratic Republic of Congo, Kenya, Mauritius, Namibia, South Africa, Tanzania, and Uganda) have integrated palliative care into public health care policy or into a strategic plan focusing on cancer treatment (Mwangi-Powell and Dix, 2011). Malawi has published national palliative care guidelines, whereas other countries, including Botswana, Ethiopia, Nigeria, Zambia, and Zimbabwe, are drafting their national palliative care policies (Ferrell et al., 2014).

The stand alone implementation plan, in the three countries has seen the palliative care program viewed as an important service on its own whereas when integrated, PC services are viewed as a complimentary service to HIV/AIDS. In addition the stand alone plan encompasses a broad spectrum of diseases. The challenge of both policies is monitoring the implementation of them.

In Uganda, palliative care is integrated into the government's Strategic Health Plan, with civil society organizations working with the Ministry of Health to implement it (Radbruch et al., 2013). Community-based palliative care programs involving volunteers and paid staff in Kenya, Malawi, and Uganda have been shown to improve access to services; control of physical, emotional, and spiritual symptoms; and community attitudes toward the dying (Grant et al., 2011). However, extreme poverty and a lack of such basic resources as nutrition continue to have a profound impact on the wellbeing of those who are dying and their families.

In Swaziland, the palliative care policy which was developed in 2011 and both documents palliative care and considers palliative care as a human right. Swaziland currently has no national strategies for cancer or other NCDs, but does have a strategy for home-based care that includes palliative care (Swaziland Ministry of Health, 2009). The country has a dedicated budget line for

palliative care in its health budget, a palliative care desk and a dedicated palliative care officer in the Ministry of Health.

1.2.5 WHO strategy 2 - Access to opioid medication

In 1986, the WHO published the analgesic ladder to encourage the appropriate use of oral morphine for cancer pain, and morphine has been on its Model List of Essential Medicines since 1977 (Duthey and Scholten, 2014). The appropriate use refers to the correct use of opioids to all patients who have life limiting illnesses. Nevertheless, more than 70% of the world's population, mainly in low and middle income countries, still has little or no access to opioids (Seya et al., 2011). In fact, the aggregate morphine consumption in low middle income countries is less than 10% of aggregate global consumption, even though low middle income countries compose more than 80% of the world's population (De Lima et al., 2004).

The unavailability of medications that most effectively treat cancer pain in low middle income countries is a result of multiple factors, including their financial cost (often inflated because of over-regulation); lack of the infrastructure required to store and distribute them (Duthey and Scholten, 2014); inadequate training of physicians and other health care professionals to prescribe opioids; cultural and attitudinal barriers; global and national regulatory controls related to concerns about abuse, dependence, and diversion; and insufficient governmental commitment to purchase opioids and to finance educational initiatives (De Conno et al., 2005). The availability of morphine within a country is also linked to the degree to which palliative care is integrated into its health care system and to its attainment of health, education, and income (Gilson et al., 2013).

Governmental and global policymakers' concerns about the abuse of opioids continue to limit appropriate access to these medications, despite long-standing international policy statements and guidelines to make them available to relieve physical pain and suffering (Cassileth and Gubili, 2010). The 1961 Single Convention on Narcotic Drugs, implemented by the International Narcotics Control Board, obliges governments to ensure opioid availability for medical purposes, while simultaneously addressing potential abuse and diversion (Cassileth and Gubili, 2010). Further, guidelines published by the WHO in 2000, updated in 2011, highlight the so-called quadruple imperative (legal, political, public health, and moral) to make controlled drugs accessible and available to prevent unnecessary suffering (Hastie et al., 2014).

However, these international guidelines have failed to shift many nations from current unbalanced restrictions. Initiatives must be undertaken within low middle income countries to educate policymakers about the need for opioids in palliative care and about the safeguards that can be instituted to prevent their diversion and abuse. Morphine (sustained release tablets) and other essential drugs for palliative care are intermittently available, and research has shown that some health professionals have continued fears about prescribing opiates (Woolf et al., 1999).

There have been some improvements in global access to morphine in recent years, with successful initiatives being undertaken in Costa Rica, India, Malawi, Panama, Romania, Serbia, and Uganda (Duthey and Scholten, 2014). Uganda was the first African country to adopt the WHO pain management guidelines and to develop model regulation guidelines for the authorization, documentation, storage, and distribution of morphine. Until 10 years ago, opioid prescription in Uganda was limited to registered physicians, dentists, and veterinary surgeons under the National Drug Policy and Authority Statute of 1993. An amendment in 2004 allowed specialized health workers to prescribe morphine, after successful completion of a 9-month training course (Jagwe and Merriman, 2007). This change increased accessibility to morphine, particularly for the more than 85% of patients in Uganda who live in remote or rural areas with limited access to physicians. This initiative in eastern Africa made oral morphine freely available to those in need in districts with specialist palliative care nurses and clinical officers and abolished limits to the dose and number of days that morphine could be prescribed within the hospice setting (Logie and Harding, 2005). This change came about because Uganda had trained rural health workers on palliative care and further gave authority to these health workers to administer oral morphine. Whereas in countries like Swaziland only doctors are allowed to administer oral morphine which turns to be a huge setback in terms of access to oral morphine.

Positive steps have also been taken to improve opioid availability in other low middle income countries. For example, in Ethiopia, a government owned company formulates and distributes oral morphine solution in various concentrations, and a National Pain Management Guideline has been developed. In Jamaica, guidelines have been developed for the safe transportation of opioids from distributors to health care facilities (Gilson et al., 2013). Critical reforms to the systems for prescribing and dispensing opioids were announced in Mexico in 2014, and one of

that country's largest health insurance programs has added a number of palliative care interventions to its packages for the first time. Previously restrictive complex prescription requirements (including the need to use both a special prescription form and a bar-coded sticker, accessible only in-person by the prescribing physician and at a limited number of sites in each state) will be replaced with a more user-friendly system aimed at encouraging more widespread prescription of appropriate opioids (Harding et al., 2013).

Swaziland has developed initiatives to change regulations that may restrict physician or patient access to pain relief and promote attitudinal change relating to 'opiophobia' (Swaziland Ministry of Health, 2009). Swaziland has initiatives that consider access to essential medicines as a legal or human right. In the last three years morphine powder has been imported and there is a more favourable policy environment for the availability of, and access to, opioid analgesics (African Palliative Care Association, 2012). The African Palliative Care association has rated the availability of non-opioid essential palliative care medicines and patient access to non-opioid essential palliative care medicines as good but the collaboration between the country's opioid prescribers and regulators as mixed, and the availability of oral morphine in the country and patient access to oral morphine were also rated as mixed (African Palliative Care Association, 2012). They found that although the Ministry of Health has made oral morphine available, it is only available at level 2 and level 3 health facilities, due to the unavailability of doctors at the lower level. Currently doctors are ethically and legally eligible to dispense morphine

1.2.6 WHO strategy 3 - Palliative care training and education

The insufficient training of health professionals in developing countries, both before and after they begin practice, is a major obstacle to the widespread provision of palliative care. Systematic approaches are needed to train these caregivers in the delivery of palliative care and in pain management. This training must be adapted to the care context, which, in many regions, will be provided predominantly by volunteers working alone or with health professionals. It should also take into consideration local implementation challenges and potential solutions (African Palliative Care Association, 2012).

A variety of educational initiatives within developing countries and with international partnerships have developed in response to the need for more training in palliative care. For example, the University of Cape Town in South Africa offers a multidisciplinary master's course (Ferrell et al., 2014). Postgraduate training for palliative care nurses and special clinical officers in Uganda is available through a 9-month Clinical Palliative Care course, which includes clinical placements and training to prescribe morphine. This program is the only one of its kind in Africa to allow health care professionals other than physicians to prescribe morphine (WHO, 2012). A master's program has been developed to supplement this training, through collaboration between Hospice Africa Uganda and Makerere University.

In Mexico, recently passed legislation clearly states that all health care personnel must have adequate training in palliative care and that health care institutions must "guarantee the training and continued education of human resources in health care in the area of palliative care and attention to patients in the terminal phase" (Harding et al., 2013). Active steps are currently under way there to identify how best to integrate palliative care into undergraduate curricula and to ensure the timely up skilling of current staff (Harding et al., 2013).

A study conducted in South Africa indicated that the lack of palliative care knowledge among health care providers was a major barrier to adequate care in the rural provinces of South Africa. This study aimed to: (1) to identify palliative care learning needs of community health workers (CHWs) working in a non-governmental organization (NGO) in Mpumalanga province, (2) to develop a training session based on the needs identified by the CHWs, and (3) to describe CHWs' perceptions of the usefulness of the training content. Data were collected from 29 CHWs in focus group interviews. Eight palliative care learning needs were identified. These included HIV/AIDS, palliative care, TB, sexually-transmitted illnesses, debriefing, care of bedridden patients, and other chronic diseases. Based on three of the most salient learning needs, a training session was planned and delivered. Future program development should consider interventions to provide emotional support for CHWs and how to evaluate the quality and impact of care provided on the community (Campbell and Bearnholdt, 2016).

In Swaziland there is has no accredited palliative care training course – but it does have an "in-service introduction to palliative care training" developed and implemented by the Ministry of

Health – five palliative care physicians but no medical schools (Swaziland Ministry of Health, 2009). The training course is based on a national curriculum for introductory training, adapted from APCA's core curriculum. The country has a very limited number of health care workers with diploma-level training in palliative care (Swaziland Ministry of Health, 2009).

1.2.6 WHO strategy 4 – Implementation

Models of Palliative Care in Africa

Recent analysis of different models used within Africa has highlighted benefits and challenges of each model(Mwangi-Powell and Dix, 2011). Integrated PC models can be positioned in different ways throughout the continuum of care and may address generalist, intermediate or specialist palliative care needs; often in combination. Examples of models of PC provision include:

1. Specialist palliative care services: Specialist services may be provided across the continuum of care at tertiary, secondary and primary levels of care. Such services provide an element of leadership, training, mentorship and supervision, in addition to directly addressing complex needs for patients and families.

2. Hospital-based palliative care teams: These provide palliative care services within a hospital context and can offer generalist, intermediate or specialist functions. This may include both inpatient and outpatient services.

3. Home-based care: This may be provided through specialist PC teams that visit patients and support them directly in the home, or generalist or intermediate care delivered through home-based care services provided by community-based programmes. These may utilise trained volunteers and may have a clear partnership with specialist palliative care services.

4. *Outreach services:* Some PC providers have outreach services that support other organizations to provide PC, or provide roadside and mobile clinics (Mwangi-Powell and Dix, 2011).

1.2.7 Palliative Care Perception

The evolving nature of palliative care is apparent in the varying interpretations of what is meant by the term. Many nurses and other health care professionals, as well as the general public, have difficulty distinguishing between palliative care and hospice care, which are not synonymous (Gómez-Batiste et al., 2006).

The specialty of care grew out of the hospice movement in the 1970's and as such has been associated with care for "dying" patients, particularly those with cancer. Furthermore, hospital-based palliative care has been supported by administrators largely based on the expectation of cost-savings accrued by decreasing length of stay or reducing per-diem resource use among terminal hospitalizations. Thus, for many, palliative care is synonymous with dying (Rodriguez et al., 2007).

While there are some studies of how patients view palliative care services, few studies have explored how physicians and other health care providers in acute care hospitals perceive and utilize these services (Gore et al., 2000). A better understanding of provider perceptions could inform efforts to broaden the use of palliative care by its proponents.

In a study conducted in Pennsylvania hospitals, most participants perceived palliative care to be a type of care that focuses on terminal pain and symptom management and on facilitating decisions to stop life-sustaining treatments. Some viewed palliative care as reserved for patients with terminal cancer, and some viewed it as care for "actively dying" patients (i.e., during the last days or hours of life) (Seidlitz et al., 1995).

In other cases, the participants were worried that other individuals (physicians, patients, and patients' family members) viewed the institution or consideration of palliative care as a signal that health care workers had abandoned all hope for a specific patient. For health care providers, the options are sometimes viewed as "doing everything or doing nothing," and palliative care is essentially viewed as "pulling the plug" or "doing nothing." A number of participants viewed palliative care as incompatible with the hospital goals of saving lives, and some surgeons perceived instituting palliative care as being "soft" or "giving up (Seidlitz et al., 1995).

Although physicians rarely discuss palliative care as a supportive service that could be useful 6–12 months before death, nurses tend to believe that it should be available to all patients, not just as an option after disease-oriented care fails or becomes too burdensome and not just when patients reach the end of life. Further, nurses emphasize the role of palliative care in facilitating discussions and decision making about goals of care and quality of life; issues that they felt other treating physicians frequently neglect (Rodriguez et al., 2007)

In another study conducted in the Northeastern United States, health workers expressed varying perceptions about the meaning of palliative care and how it differs from hospice care. Some heath workers believed that palliative care was intended only for cases in which death was imminent. Most health workers equated palliative care with end-of-life care when palliative care services became involved in the acute care setting. Both palliative and hospice care services were perceived as valuable resources when a patient could no longer benefit from curative treatment. Three subcategories became evident: confusion regarding the differences between palliative and hospice care, the timing of referral to palliative care as a key issue, and the need for further education in palliative care (O'Shea, 2014). The general perception of PC in the studies above is that health workers and the population perceive PC as a service that is offered to dying people. Their perception is rooted in this because they believe that once a patient is enrolled for PC it means that patient is approaching end of life.

1.3 Problem Statement

Although some form of palliative care has been available in Swaziland since 1990, a review in 2009 showed that PC services in Swaziland were being offered in an unstructured and poorly coordinated manner leading to a fragmented approach to service delivery (Swaziland Ministry of Health, 2011). This resulted in many terminally ill patients receiving compromised care while others remain unserved (Swaziland Ministry of Health, 2011). The review also indicated that PC services providers lack the capacity to offer care. There was thus poor coordination nationally (Swaziland Ministry of Health, 2009) with many services being provided in varying packages by various providers (Swaziland Ministry of Health, 2009). In response to this, a palliative care policy was developed in 2011 but its implementation was not subsequently reviewed. The previous inconsistent and non-uniform service delivery of palliative care in Swaziland highlighted the need, to explore how palliative care services have been delivered in the Shiselweni Region after the palliative care policy was established.

1.4 Justification for the Study

The researcher has worked in palliative care at a hospice level for the past five years. The mandate of the hospice is to offer palliative care to all patients with life limiting conditions. The

researcher was part of a training team which provided introductory training in palliative care. During this process it became clear that morphine and other palliative care services were not available. It was observed that although the National Palliative Care Policy called for decentralization of PC it is mainly offered from regional hospitals. It was thus necessary to review ways in which the PC policy has been implemented. The results of the study may further inform the development of palliative care programs in Swaziland.

1.5 Aim of the study

To explore the understanding of the palliative care policy and experiences with regard to implementation amongst health care workers in the Shiselweni Region from November 2011 to March 2015.

1.6 The study had the following objectives

1. To describe the understanding of health care workers on the content of the PC policy.
2. To understand the role of actors in the implementation of PC services.
3. To explore health care worker's perceptions on how PC is implemented including, successes and challenges.
4. To explore health care workers coping strategies in delivering PC services

Chapter 2: Research Methodology

2.1 Introduction

The study design, study setting, target population, sample size and sampling procedures are discussed in this chapter. The data analysis plan and ethical principles used to protect the integrity of the study are also discussed.

2.1 Study Design

A qualitative exploratory design using in-depth interviews was used. A qualitative method was used because in depth information was required on the implementation of the policy, for instance information about the challenges and successes in the implementation of the PC policy. Such information is expected to enable policy makers, partners and MOH PC coordinators to better address the policy implementation gap.

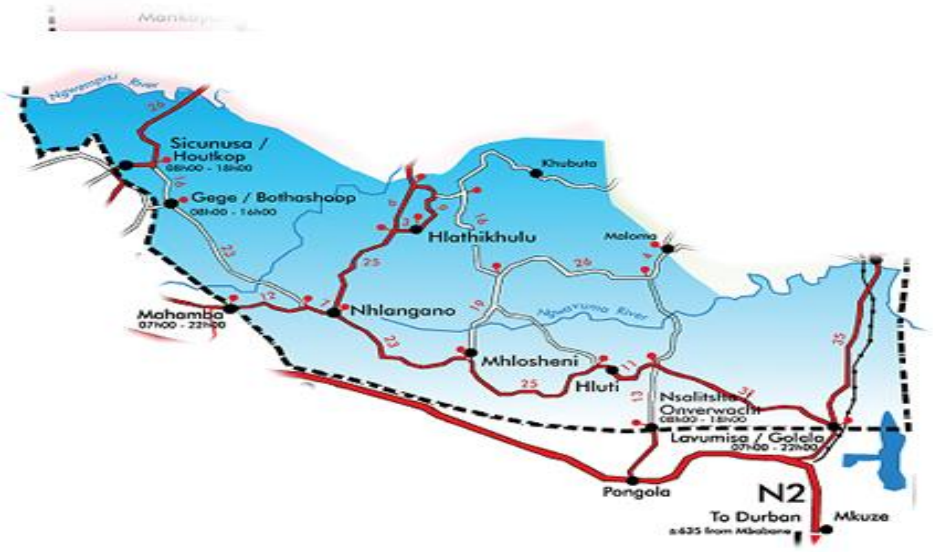
2.1.1 Study site

The kingdom of Swaziland is a small landlocked country in southern Africa, and borders both South Africa and Mozambique, with an area of 17, 364km square. The kingdom's population in 2007 was 1,018449, with 52% being under the age of 20 years, and 78% residing in rural areas (SPHC 2007). It had an estimated nominal gross domestic product per capita of US$2,994 in 2007 (Central Bank Quarterly Review June 2010, SPHC 2007) and is classified as a lower middle income country. The country includes four administrative regions namely: Manzini, Hhohho, Lubombo and Shiselweni Region.

The study was conducted in the South Western Shiselweni Region which is a, lowveld ecological region that is furthest away from the capital Mbabane, and adjoins the KwaZulu-Natal Province of South Africa to the south. It was selected because it is the most rural district in Swaziland. It has an area of 3,786.71 km² and a population of 208,454, and is divided into 14 tinkhundla, its administrative center being Nhlangano (population census, 2007). The region has one referral hospital, two health centres, 17 clinics and several NGO's providing health services (Swaziland Ministry of Health, 2007). The region has three small towns Nhlangano, Hlatikulu and Lavumisa with the referral hospital being found in Hlatikulu and one health centre being in Nhlangano. The

Swaziland health system has an acute shortage of health-care staff, which is complicated by the burden of disease due to HIV and AIDS, and migration of skilled health workers.

Figure 2.1: Shiselweni Region in South Western Swaziland



2.2 Study Population and sample

The population for this study involved health-care workers in Shiselweni Region, from five facilities; one regional hospital (Hlatikulu), health centre (Nhlangano), and three rural clinics which were purposefully selected by the researcher. The health workers who were interviewed included: chief medical officer, matron, doctor, policy makers, pharmacist, sister in-charge, physiotherapist and registered nurse at each site.

Purposive sampling was used, as the researcher wanted to ensure the sample drew on participants who are informed and involved with the routine implementation of palliative care. A total of four health care workers from each facility were supposed to be interviewed, which would have resulted in 20 respondents. Facilities were purposively sampled in order to ensure that the sample

covered a full range of possible characteristics of interest these included providing ART services and remoteness of clinic. The following health workers were interviewed : chief medical officer, matron, doctor,, pharmacist, physiotherapist or sister in-charge, and registered nurse Purposive sampling was used, as the researcher wanted to ensure the sample drew on participants who were informed and involved with the routine implementation of palliative care. The researcher only managed to recruit 17 respondents because they were engaged in their daily duties and could not participate in the study.

2.3 Data Collection Tools

In-depth interviews were conducted for all participants, with all four objectives being addressed by each person.

Table 2.1: Interview Guide

	Major issues	Probes
1.	The understanding of health care workers of the content of the PC policy	- Enquire on the key features of Palliative Care Policy * Probe about the system, the interaction between actors in the system, personal interests and benefits. Ask why and how these key features have influenced the implementation of the Palliative Care Policy
2.	How the PC policy was implemented including successes and challenges?	- How is palliative care offered in this setting, if at all - Enquire about the **main actors** involved in the process (include private actors too) - Ask about the role and opinion of each actor and its influence on the implementation of the policy Enquire about factors that affect the performance or action of these actors and their interests - Enquire about the opinions of each actor - Probe if these opinions have influenced the implementation process, how and why - Enquire about the interaction and relationship between these actors
3.	The role of actors in the implementation process	- Enquire about the **main actors** involved in the process (include private actors too) - Ask the role and opinion of each actor and his/her influence on the implementation of the policy - -Enquire about factors that affect the performance or action of these actors and their interests - Probe if these opinions have influenced the

		implementation process, how and why - Enquire on the interaction and relationship between these actors.
4.	Health care workers coping strategies in delivering PC services	- Enquire on the key features of Palliative Care Policy * Probe about the system, the interaction between actors in the system, personal interests and benefits. - Ask why and how these key features have influenced the implementation of the Palliative Care Policy
5.	Recommendations	- Ask him/her to state three key issues and why they should be strengthened in order to affect future Palliative Care Policy implementation - Ask him/her to mention other key people to talk to in regard to the implementation of the policy, probe for reasons for each person mentioned.

2.3.1 Data Collection Process

Once the health facilities for inclusion in the study had been identified, the managers were contacted telephonically and the study explained. After the telephonic communication, meetings were scheduled, and the selected participants were introduced. Prior to the interviews appointments were made with participants and a reminder was sent one day before.

All participants were provided with an information sheet providing a brief description of the study (Appendix 2). Consent was obtained before proceeding with any interview. All participants were given the choice to refuse to be interviewed without prejudice. They indicated that they understood the purpose of the study and gave consent to be interviewed. Demographic data were obtained through in-depth interviews. An interview guide was utilized to direct the discussion and to enable additional input from the participants (Table 2.1).

The in-depth interviews on average lasted for between 30 and 60 minutes. The interviews were done by the researcher using audio recording. Permission for audio recording was requested from the study participants (see Appendix 4). The study participants signed a recording consent form before the researcher commenced with the interview. The researcher ensured that during the interviewing process disturbance or interruptions were minimized by conducting the interview in a conducive environment. The interviews were conducted in English because the respondents

were of mixed nationalities and all respondents used English as their professional working language.

2.3.2 Data Management

The data collected from the audio recording were transcribed into Microsoft word documents. Information was checked for accuracy after transcription by playing back the recorded interview and adding information from the written notes. The transcripts were de-identified for confidentiality using a code She_PC_R. where She: Shiselweni, PC: palliative care and R: respondent. Facilities Regional Hospital: RH, Health Centre: HC and Rural clinics: RC1, RC2, RC3; the R number related to each participant, being assigned in the order in which they were interviewed

2.3.3 Data Analysis

Verbatim transcripts of the interviews were analyzed using the student version MAX QDA software. The transcriptions were de-identified and participant's names were substituted by codes for confidentiality. The transcripts were then exported to MAXQDA software for qualitative data analysis. Subsequently, the researcher familiarized himself with the transcripts by reading and re-reading them to enable clear understanding of data and to facilitate the development of codes. The coding process was based on key themes which were constructs that were identified before data collection-from the literature review and from the experience of the researcher. For quality control in coding an inter coder agreement was achieved through the supervisor reading transcripts that had been coded by the researcher. Through the inter-coding reliability process the definitions were refined as needed for better clarity.

2.4 Ethical Considerations

The study was granted ethical clearance by the, Human Research Ethics Committee of the University of Witwatersrand in South Africa (Certificate No: M 141039) and also the Human Scientific Ethics of Swaziland under the Ministry of Health in Swaziland (REF:MH/599C/ FWA 00015267/ IRB 0009688).

Chapter 3: Results

This chapter presents the findings of the study, with the first section reviewing the participants' socio-demographic characteristics. The succeeding sections present the results according to each of the objectives.

A total of twenty potential interviewees were approached. However it was only possible to interview 17 respondents because they were engaged in their daily routine tasks and could not participate in the study. The participants (both females and males) were from a range of nationalities, most of them used Siswati and Shona as a medium of communication in their homes. All interviews were conducted in English. Table 5 below shows the demographics of the study population.

Table 3.1: The demographics of study population (n=17)

Occupation	Number of participant	Level of facility	Nationality	M/F	Years of service	Age range
Policy maker	3	National	Swazi	F	3	35- 45
		Stakeholder	Swazi	M	4	40-45
Chief Medical Office (head of facility)	1	Regional Hospital	Non-Swazi	M		40- 50
Doctor	1	Health centre	Non- Swazi	F	5	25- 35
Matron (Head of facility)	1	Health centre	Non- Swazi	F	6	45- 55
Nurses	8	Rural clinic 1	1 Swazi 1 non Swazi	F	4	35- 45
		Rural clinic 2	4 Non Swazi 1 Swazi	F	3	35-45
		Health centre	1 Swazi	F	3	35-45
Physiotherapist	1	Regional Hospital	Non- Swazi	M	3	45- 55
Pharmacist	1	Health Centre	Non-Swazi	M	4	35- 40
Pharmacist	1	Regional Hospital	Swazi	M	4	30-35

Table 3.2: Themes and Sub Themes

Themes	Sub Themes
Objective # 1	
The understanding of health care workers on the content of the PC policy.	Lack of knowledge about palliative care
	Confusion as to where palliative care should be offered and by whom
	The role of providing medication as part of palliative care
Objective # 2	
To understand the role of actors in the implementation of PC services.	Different actors in the team
	The importance of teamwork
Objective # 3	
To explore health care workers perceptions on how PC is implemented including, successes and challenges	Perceived success of palliative care implementation
Challenges in implementing palliative care	Availability of medicines
	Challenges in human resources
	Challenges in transport and infrastructure
	Lack of coordination of RHMs
Suggested strategies for improving the implementation of palliative care	Training
	Improving the medicine supply
	Organizational issues
	Developing guidelines and SOPs

Objective 1: The understanding of health care workers on the content of the PC policy.

3.1.1 Lack of knowledge about palliative care

In general, most of the health workers, including the policy makers, understood the concept of palliative care. They were aware of the scope of work with respect to PC and of the available guidelines that were designed to assist with providing standards and norms for managing life limiting and threatening conditions.

> *"Palliative care is taking care of those with long illnesses so that we provide them with the support they need until the die"* ***(Nurse, Health Centre, female).***

Most health workers were aware that there was a policy with regards to PC but the content of the policy was not clear to them. Some did not know that a policy existed at all. Others felt that the policy was a good document, and wanted to know how it could best be implemented.

> *"I am aware but I have not seen it. I know that there is a policy for that"* ***(Nurse, rural clinic, female).***

> *"Policies are documents given to the matron and they are kept in their offices, I personally don't know any PC policy"* ***(Nurse, rural clinic female).***

> *"I personal feel the policy is okay, I think we need the necessary equipment to implement it. Otherwise it is a good policy which we can be implemented. It can be of good use to the people out there"* ***(Nurse, rural clinic 2, female).***

Some health care workers specifically expressed a lack of knowledge about the content of palliative care and said that this was common to the health workers in rural clinics whose primary role was to provide primary health care.

> *"I am blank on palliative care. I have minimal knowledge about it. I can't really say much about it, unlike the other services we offer"* ***(Nurse, rural clinic, female).***

"I am yet to attend that policy workshop, because right now I am still blank on how it's functioning" ***(Nurse, health centre, female).***

One respondent believed that some training in the policy would assist her in understanding how to implement it and to know what is expected from her, saying:

*"Unfortunately no, I am not aware. I have not attended any workshop or any in-service training on palliative care and it is not something that is taken so seriously" (****Nurse, rural clinic, female).***

Thus it seems that although the general concept of palliative care was understood, there were significant gaps in knowledge of the content of the policy and knowledge about providing palliative care.

3.1.2 Confusion as to where palliative care should be offered and by whom.

The interviewed health workers and policy makers presented different views about the level of services where palliative care should be offered. The policy maker believed that PC was mainly offered in hospitals as it was a service offered to patients who had cancer. Respondents who worked at health centers had different descriptions from this, describing PC as offering services to patients at home.

*"It's actually a holistically approach, I think it is offered to a dying patient or a cancer patient, whatever the case maybe but you actually find that being in the hospital setting with clinicians"****(National Policy maker, MOH, female).***

"I think it is taking care of sick people at home, not at hospital or long term illness like cancer, something that is not curable" ***(Nurse, regional referral hospital, male)****.*

"It's giving care to people who are about to die, where we want them to die peaceful regardless of where they are. Palliative care can be offered at home and hospitals"

The policy itself though clearly stated that palliative care should be offered at all levels. This concept was understood by some respondents. For example one health worker wanted more sensitization for the community to be aware that palliative care was available at every level.

> *" What I understand about the policy, is that, they are trying to decentralize the palliative care to all areas of the country, especially the peripheries, where we were having some of the clients going to a central point to collect their medication and get the care they need"* ***(Senior Matron, Head of facility, female).***

> *"We are achieving but I think there is a lot still needed to be done especially in terms of sensitizing some health workers and the community at large to be aware that they can access medication for palliative care at the nearest health facility should they be prescribed for them"* ***(Nurse, rural clinic, female).***

It was also not clear to some respondents as to who should be offering palliative care services. Nurses working in the rural clinics perceived PC as being offered by Non Governmental Organization (NGOs) and mainly in urban areas.

> *"I think Palliative care is offered by NGO's and in urban areas not in rural clinics"* ***(Nurse, rural clinic, female).***

> *"In my opinion I think the Palliative care policy was developed for NGO's to implement it not us"* ***(Nurse, rural clinic female).***

3.1.3 The role of providing medication as part of palliative care

There was a variety of opinion in regards to how medical or holistic palliative care was viewed. Many respondents mentioned the important role of providing medication. This also included counseling on how to take the medication. The importance of morphine was specifically mentioned including the advantage of various preparations. The importance of preventing stock outs was mentioned. The fact that morphine was not available at health centres and patients had to be referred for this was also mentioned.

> *"So in my job I have to make sure that I explain and discuss with every patient as to why they are taking that medication, how that medication is going to help them and the importance of that medication"* ***(Senior Matron, health center, female).***

"I can speak for myself as a pharmacist as a pharmacist I have I to make sure that the drugs they are using they are always in stock...and make sure that they are given in the right dosages, and so that they are not toxic to the patient" ***(Pharmacist, regional hospital, female.***

"We usually provide panado only. We send them to hospital for physiotherapy and others" ***(Nurse, rural clinic, female).***

"Tablets are rather heavy while the syrup seems a little bit lighter and does not make them too drowsy. I'm not sure but that's my perception. The patient must not be flat out but have his or her pain controlled" ***(Senior Matron, health center, female).***

However not only medication was needed but also other medical supplies as well.

"I am also talking about providing material resources such as diapers, artificial dressings that you discard. So our role is to see that all these things are available" ***(Senior Matron, Health center, female).***

Other respondents had a more holistic view of palliative care services beyond medication and supplies. They mentioned the role of counseling and also of other team members.

"In terms of what as each role is very important, nurses will do their nursing part, including monitoring adherence to taking medications, giving injections, the physiotherapist will give physical treatment through non pharmacological means" ***(Physiotherapist, regional hospital, male).***

"I give patients medicine, I also provide counselling" ***(Nurse, rural clinic, female).***

"In as much as a lot of drugs are used to manage patient's pain we believe that their pain can also be managed through physical therapy. Therefore, we try to assure that

physiotherapy is accessible to the chronically ill patients" ***(Physiotherapist, regional hospital, male).***

"I feel like it's one part of health care provision that is really lacking especially for I am a trained community nurse. That is one part that is lacking. It's like now we are focusing more on the curative, we are leaving behind rehabilitation because PC is the rehabilitation part of health care" ***(Nurse, rural clinic 1, female)***

Objective 2: To understand the role of actors in the implementation of PC services.

3.2.1 Different actors in the team

The respondents' views indicated that PC is offered by different actors at different levels of care. Actors involved in implementing the policy ranged from rural health motivators, rural nurses, nurses in the health centre and doctors in the hospitals.

"Basically, it's the nurses. We do have the RHMs, sometimes they do come and request some things for clients that they have in the community but basically it's the nurses" ***(Nurse, rural clinic, female).***

"I would say basically its first the nurses who are taking care of the patients. Basically, the doctors are just there to prescribe their drugs" ***(Nurse, health centre, female).***

Rural Health Motivators (RHMs) were mentioned as being as an important linkage to the community. However, it was felt that some had a knowledge gap regarding issues in PC and that this was because their training package (content of trainings) was not clearly defined. One nurse believed that RHMs were not assisting the rural clinic sufficiently when it comes to PC compared to other services, and highlighted this notion in this statement:

"I am not sure because we are not involved in their training, during they are being trained" ***(Nurse, Health centre, female).***

Collaborative efforts whereby different disciplines form a team and support each other to achieve the best possible outcome for the patient were said to be important. Even relatives and support staff could be part of that team.

> *"Provision of PC is team work. No one person can do this job. You need the nurses, you need the RHMs, and relatives too are supposed to be involved (but must be equipped with the necessary or relevant skills). In essence it's a team work approach"* ***(Matron, regional hospital, female).***

> *"Support staffs such as cleaners because they are first people patients talk to, so there are very helpful"* ***(Nurse, rural clinic, female).***

> *"We send them to hospital for physiotherapy and others are referred to Cheshire Homes"* ***(Nurse, rural clinic, female).***

Some actors played a more socially orientated role in that they provided transport for patients who were referred or who are socially challenged in regard of transport fees.

> *"Some patients don't have transport or transport fees, we then request transport from MSF"* ***(Nurse, rural clinic, female).***

While stakeholder engagement was seen in a positive light it had its own challenges. The respondents were worried because there was no support from other stakeholders. This was expressed by one respondent who said:

> *"There is nothing on the ground and even if you are to phone hospice sometimes you don't get that much interaction"* ***(Nurse, rural clinic, female).***

3.2.2 The importance of teamwork

In general, respondents described the importance of a team approach and mentioned that they related to each team member frequently, as is evident in that from one respondent:

"Like here in our Hospital we have a doctor, a physiotherapist, the nutritionist, we have nurses and we involve relatives also in order to be an effective team in terms of quality" ***(Physiotherapist, Regional Hospital, male).***

*"We have a close working relationship where we can help each other because we have different expertise and that different expertise when we put them together we can achieve the best possible outcome for the patient who is undergoing PC" (****Nurse, health centre, female).***

The importance of communication in the team was mentioned

"Well, in that case you have to communicate. I am a drug specialist, they are the medical officers, so when we have a disagreement we have to sit down and discuss pros and cons" ***(Pharmacist, regional hospital, female).***

Objective 3: To explore health care workers perceptions on how PC is implemented including, successes and challenges.

3.3.1 Perceived success of palliative care implementation

Although there were reports of challenges in implementing palliative policy, some successes were shared by respondents. One respondent was grateful that the country had a guiding document which would see palliative care being implemented in a coordinated approach.

"Having the policy itself, includes the guidelines, we have good palliative care guidelines, we have a strategy which we have implemented almost fully and we have a training manual, we have commitment from government, currently government is the one buying us morphine" ***(National Policy maker, MOH, female).***

Additional further success was mentioned by a policy maker related to human resource development. This included training staff and the deployment of staff solely for the purpose of palliative care.

"We have also trained people in palliative care and the other success is that the policy has allowed us to have a doctor, a palliative care doctor with whom we think we are going to push the palliative care agenda" ***(National Policy maker, MOH, female).***

One respondent said that the policy brought about the availability of medicines and human resources for the palliative care program. The respondent further mentioned that patient care had been improved.

"The successes are that the availability of doctors, nurses and medications. It is very rare for a patient to be written up for morphine and he/she does not receive it. Most of the time everything it is there" ***(Chief medical Officer, regional hospital, male).***

3.3 Challenges in implementing palliative care

3.3.1 Availability of medicines

Respondents pointed out the issue of resource limitations, which impacted negatively on their efforts of implementing the policy. Stock -outs were a major challenge at all facility levels and the health workers felt that the issue was not dealt with appropriately. They mentioned that stock outs were very common and that workers felt disempowered to influence issues related to the supply chain of the medicines. The medicines were kept centrally and distribution was also decided upon centrally.

"If the Central Medical Stores say we don't have this in stock then it means I am also affected, the client is also affected" ***(Nurse, Health centre, female).***

"Sometimes you want to an adjuvant to treatment it s not there. Amytryplines are not there and they are not there most of the time" ***(Nurse, Health centre, female).***

Other interviews though revealed a more complex situation with some drugs available at central level but not being distributed to the peripheral level. The pharmacist at the regional hospital said medicines were kept up to the point at which the medicines expire.

"Our pharmacy keeps the narcotics and in the meantime they expire and must be returned" ***(Pharmacist, regional hospital, female).***

Some health care workers did however express a sense of agency in being able to improvise in the event of some items not being available.

"Constraints are that some of the drugs are usually out of stock and we have to improvise with what we have and this may not necessarily the exact drug that is needed for that particular patient but we manage to improvise with what we currently have in order to maintain the patient's" ***(Chief Medical Officer, regional hospital, male)***

"In some cases if there are items that we require and probably the Central Medical Stores (CMS) does not have them, we source from other stakeholder. The client must leave the institution satisfied" ***(Nurse, health center, female).***

3.3.2 Challenges in human resources

The issue of human resource was a huge concern both at rural clinics and higher levels of health facilities. One respondent in the rural clinic spoke about the workload and limited personnel. The respondent said:

"Currently the work that we do here, there are a lot of patients whom we are seeing these days, and we are short staffed" ***(Nurse, rural clinic, female).***

"The facility has expanded but its personnel are still as it was in 1986 when it was opened. I came here in 2005 and there is no change in personnel now from then. Another contributing factor is the turnover especially with nursing assistants" ***(Senior Matron, Health center, female).***

These sentiments were echoed by another respondent who cited issues of power saying they have nothing to do with the issue of human resource it's beyond their control and she angrily said:

"There is nothing we can do. It is beyond our control. As I said, we are short staffed and they know we short staffed but there is nothing they are doing" ***(Nurse, rural clinic, female).***

"It's becoming unbearable really the number of patients, sometimes you find that there are only a few nurses and this makes our work difficult" ***(Nurse rural clinic 1, female).***

One the respondent explained that a lot of programs are being introduced at the facility, but that the personnel complement had not increased over the past 5 years. She also mentioned the issue of staff turnover, and concerns about human resources:

"There are 40 patients to 2 nurses per night. In this facility there is that MDR unit that has just been open and each patient occupies their own room and being catered for by 2 nurses per night" ***(Senior Matron, health center, female).***

With challenges such as high workloads, a respondent believed that the standard of service they are offering was sub standard. The respondent said:

"I don't feel its quality because it could be better" ***(Nurse Health center female).***

3.3.3 Challenges in transport and infrastructure

Other contextual challenges that were noted, included infrastructure and transport.
Several respondents mentioned the issue of transport being a major challenge when they want to provide palliative care, specifically to patients who were not close to the facility.

"As I have said, we are short staffed, we cannot go out there. The issue of transport, we don't have transport to go to the community. Sometimes there are places, which are too far away and we cannot get there because they are unreachable" ***(Nurse, rural clinic, female).***

"The major constraints are lack of access to services as patients are not mobile. As a result they tend to send their relatives for refills of medications instead of them coming to

us personally. That is why there is need for a PC team which goes to the patients" ***(Chief Medical Officer, regional hospital, male).***

Infrastructure was also noted as a key challenge.

"The infrastructure is also contributing. There is need for wards to accommodate those who are in desperate need of care. That will be so lovely. It would be easier then to assign an registered nurse and an nursing assistant to look after those patients, assess them and discharge them home" ***(Nurse, health center, female).***

3.3.2.4 Lack of coordination of RHMs

The lack of interdisciplinary teamwork as well as poor leadership and management with regards to RHMs was mentioned.

"I don't know but I think its lack of cooperation between the offices that looks at RHMs is the regional office...so if that office and the clinic are not working together there won't be any relationship with the RHMs" ***(Nurse, rural clinic, female).***

3.3 Suggested Strategies for improving implementation of palliative care

3.3.1 Training

Health workers reported positively on the value of the skills they had acquired and expressed the desire for more training opportunities. The views indicated that they wished to be more self - sufficient and not rely on managers for other tasks

I don't know but I think its lack of cooperation between the offices that looks at RHMs is the regional office...so if that office and the clinic are not working together there won't be any relationship with the RHMs" ***(Nurse, rural clinic, female)***

"I think it can be better if some people come to train us here at our institution" ***(Nurse, rural clinic, female).***

They should provide refresher training on palliative care ***(Nurse, rural clinic, female).***

"Maybe if there can be an in-service training or if a workshop that can be conducted or guidelines be given to us so that we really help and know what are we talking about and what is expected of us" ***(Nurse rural clinic female).***

The above sentiments were echoed by another policy maker who wanted palliative care to be introduced in nursing schools.

"I wish there was a training curriculum for nursing students on Palliative care" ***(Policy maker, female).***

One policy maker referred to the speed that training was conducted

"I've said, government has been training so many nurses especially on introduction to palliative care and pain management and other bits and pieces, though I would say, that it's not going at a pace you would appreciate" ***(Policy maker, female).***

3.3.2 Improving the medicine supply

The respondents raised issues of medicines being readily available and the need to capacitate health workers with the required skills. A policy maker said:

"To make medications available and accessibly making sure that the people are treated and also conduct trainings" ***(National policy maker, MOH, female).***

"I would love to see us have a more variety of drugs and medicines that can help alleviate some of the pain" ***(Doctor, health centre, female).***

The above view was supported by another respondent who suggested that advocating for palliative care and the development of palliative care essential medicines list would be very

important. The respondent said this because he believed the Ministry of Health is doing it, but at a low speed. As the Chief Medical Officer comments:

> *"I don't know, you know once you start advocating at times people think otherwise of you but I think it's high time that we know about palliative care in the country, we need to advocate because government is working at a snail pace advocate that at least we have the essential medicine list for palliative care that was there developed"* ***(Chief medical Officer, regional hospital, male).***

3.3.3 Organizational issues

To effectively implement the policy one respondent mentioned the approach of a dedicated department that would focus on palliative care issues. The respondent had this to say:

> *"We need to identify a special room where we identify them; they have their own special forum where they come direct to do their fill up"* ***(Chief Medical Officer, regional hospital, male).***

Another respondent added by saying there is a need for good leadership and management for good implementation of the policy and a working plan. The nurse said:

> *"Some matrons who understand PC and support it, others do not or are less interested in PC. We need a structure"* ***(Nurse, health center, female).***

3.3.4 Developing guidelines and SOPs

One policy maker was of the view that the policy should develop Standard Operational Procedures (SOP's) to be used to effectively implement the policy. They believed that the SOP's would improve the quality of palliative care and said:

> *"Another strategy is where you will have your documents that are talking about issues of quality for instance the standards, the SOP's, in all of this, so they also*

form part of the strategy, so we making sure that the palliative care, or rather the policy, is being implemented" ***(National policy maker, MOH, female).***

Another view that was expressed by the respondent here believed that guidelines would be more effective in implementing the policy and the guidelines would assist in implementation. The respondent said that the policy is at a macro level thus making it difficult for street level bureaucrats to implement it, as a policy maker puts it:

"We need to start operationilizing the policy, it's at a higher level but we also needed to come up with a guideline as to how we are going to implement it" ***(National policy maker, MOH, female).***

From the interviews the issue of sensitization was seen as a strategy to implement the PC policy. As policy makers commented:

"Definitely we flag the key statements that are on the policy, so it's kind of sensitizing so that they can see that what is in the policy is also operationalized in terms of the strategies and in terms of the activities" ***(Policy maker, male).***

Objective 4: To explore health care workers coping strategies in delivering PC services.

There were interesting personal views and feelings regarding implementation of the policy. The respondents coped with the delivery of palliative care services in different ways.

For one health care worker, palliative care had become her passion and she was very motivated by the training.

" I really feel good and that this is the right work for me. I am happy with PC and I love it. I once attended a palliative care workshop and I became more motivate by knowing that I could do better when caring for such patients" ***(Nurse, health centre, female)***

Other health care workers were demotivated as they felt that they had less power to change the weaknesses of the system.

Chapter 4: Discussion

These are the new headings in the discussion section

Objective 1: The understanding of health care workers on the content of the PC policy.

1.1 Lack of knowledge about palliative care

1.2 Confusion as to what level of care palliative care should be offered and by whom**.**

1.3 The role of providing medication as part of palliative care

Objective 2: To understand the role of actors in the implementation of PC services.

2.1 Different actors in the team and importance of teamwork

Objective 3: To explore health care workers perceptions on how PC is implemented including, successes and challenges.

3.1 Challenges in implementing palliative care

3.1.1 Availability of medicines

3.1.2 Challenges in human resources

3.2 Suggested strategies for improving implementation of palliative care

3.2.1 Training

Objective 1: To describe the understanding of health care workers on the content of the PC policy.

1.1 Lack of knowledge about palliative care

In Swaziland, a palliative care policy and strategy was developed in 2011 in which palliative care was considered a human right (Swaziland Ministry of Health, 2009). The development of this policy had a number of factors in its favour: palliative care in Swaziland had a long history and the policy enjoyed the public support of influential policy actors including the health minister. Since that time there has been a dedicated budget line for palliative care in the health budget, a palliative care desk and dedicated palliative care officer in the Ministry of Health. According to

the results of this study, the policy did translate into increased levels of palliative care provision, although it did not produce greater geographic equity.

The study findings show that PC was generally understood by health workers and policy makers. They were aware of their scope of work with respect to PC and of the available guidelines that were designed to assist with providing standards and norms for managing life limiting and threatening conditions. The health workers did however present a view that they were unclear about the kind of services they should render under Palliative Care.

Lack of clarity as to the exact nature of palliative care services is a common problem in many settings. For example, in the North Eastern United States, health workers expressed varying perceptions about the meaning of palliative care. There was confusion regarding the differences between palliative and hospice care, the timing of referral to palliative care was a key issue, and there was the need for further education in palliative care (O'Shea, 2014). The physician's perspective saw palliative care as a supportive service to be given to patients that have been diagnosed with a few months remaining to live. However, other health workers tended to believe that it should be available to all patients, not just as an option after disease-oriented care fails. Further, nurses emphasized the role of palliative care in facilitating discussions and decision making about goals of care and quality of life; issues that they felt other treating physicians frequently neglected (Rodriguez et al., 2007). Others saw palliative care as a signal that health care workers had abandoned all hope for a specific patient. A number of participants viewed palliative care as incompatible with the hospital goals of saving lives, and some surgeons perceived instituting palliative care as being "soft" or "giving up (Seidlitz et al., 1995)

1.2 Confusion as to where palliative care should be offered and by whom

The Swaziland National Palliative Care Policy promotes a holistic approach to patient care and outlines proposals for integrating PC into the Swaziland's health care system. The policy has decentralization of palliative care as a specific objective and clearly outlines the services that are to be available at three levels - community and clinic level; health centre level and hospital level. However health workers seemed not to understand or fully implement this because of lack of resources and other working materials at the lowest levels of care. In addition health workers

understood palliative care differently at different levels thus causing confusion at all levels of care.

In many African countries, palliative care has been implemented using a combination of models at many levels in the health care service. These countries include Uganda and Kenya. The following models have been explored:

1. ***Hospital-based palliative care teams:*** These provide palliative care services within a hospital context and can offer generalist, intermediate or specialist functions. This may include both in-patient and out-patient services.

2. Home-based care: This is frequently provided through specialist PC teams that visit patients and support them directly in the home, or generalist or intermediate care delivered through home-based care services provided by community-based programmes. These may utilize trained volunteers and may have a clear partnership with specialist palliative care services.

3. *Outreach services:* Some PC providers have outreach services that support other organizations to provide PC, or provide roadside and mobile clinics. In Uganda outreach services are used in cases, whereby a team of different health workers do outreach services to those who need palliative care services. In most cases are referred by the hospitals that have discharged them.

This study shows that implementing palliative care services is a complex task particularly for rural clinics, especially because certain policies prevented opioid medication to be kept on site. The unavailability of morphine in rural clinics greatly affected the decentralization of palliative care services.

The issue of regulations around morphine storage and use has been a barrier in many African countries, to decentralizing palliative care services at a community or primary health care level. Uganda has led the way in this area and was the first African country to adopt the WHO pain management guidelines and to develop model regulation guidelines for the authorization, documentation, storage, and distribution of morphine. Until recently, opioid prescription in Uganda was limited to registered physicians, dentists, and veterinary surgeons under the National Drug Policy and Authority Statute of 1993. This was amendmended in 2004 to allow specialized

health workers to prescribe morphine after successful completion of a 9-month training course (Jagwe and Merriman, 2007). This amendment increased accessibility to morphine to a large population of the community, especially in the rural areas.

1.3 The role of providing medication as part of palliative care

While there are some studies of how patients view palliative care services, few studies have explored how physicians and other health care providers in acute care hospitals perceive and utilize these services (Gore et al., 2000).

In a study conducted in Pennsylvania hospitals, most participants perceived palliative care to be a type of care that focuses on terminal pain and symptom management and on facilitating decisions to stop life-sustaining treatments. Some viewed palliative care as reserved for patients with terminal cancer, and some viewed it as care for "actively dying" patients (i.e., during the last days or hours of life) (Seidlitz et al., 1995).

However palliative care is "an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2002). While the palliative care approach was developed in response to the plight of patients with cancer, other life threatening conditions, such as HIV, heart diseases, diabetics and stroke, were soon added. The focus is therefore on life threatening illnesses that are malignant and non-malignant (African Palliative Care Association, 2012).

Palliative care is thus not only about providing medications as most health workers perceive it to be, but is a holistic approach that goes beyond physical aspects only. This is evident in that different health workers who form part of the PC team that offers palliative care. One such example in this study was the physiotherapist who used non-pharmacological interventions when dealing patients with life limiting conditions.

Objective 2: To understand the role of actors in the implementation of PC services.

2.1 Different actors in the team and importance of teamwork

The study showed that several actors were involved in providing of palliative care, including, organizations such as Doctors without Borders, Cheshire Homes, Hope House and Hospice at Home. These actors were considered to be complementary actors by the lower level health workers who were employed by the Swazi government. However PC was delivered in an uncoordinated manner in the country by these actors, which was a deficiency that the policy was intended to address.

Palliative care is a field that frequently involves a multitude of actors and service providers and coordination is a key issue. A description of palliative care in Ireland showed similar findings with many actors involved including, central government, Department of Health and Children, local government, healthcare workers, voluntary and community groups, educators and the Irish Hospice Foundation (IHF) (Radbruch et al., 2013).

In many African settings, community health care workers (CHWs) have been an important part of the PC team and enabled delivery of services to the community level.

In Swaziland, Rural Health Motivators are part of the PC team but this study found that their role was not well coordinated and there was uncertainty about their training which caused some discredit of their roles. Other African countries have demonstrated that volunteers are an important human resource, which need to be utilized appropriately. In a study in Rwanda, community health workers were integral members of the palliative care multidisciplinary team and had a significant impact on the lives of people and their families accessing care. Health providers, people accessing care and their families agreed that a person trained in the community as a source of information and/or orientation reduced wasted time and unnecessary expenses. Community health workers were reported to have brought the humanity and dignity expected by the patients and their families which was sometimes neglected by health providers during the management of serious illness (De Lima and Radbruch, 2014).

In order to be successful, basic training and clear systems for referral and discharge of patients must be developed and given to the community volunteers. In this study, participants were aware of the important role of community health workers but expressed concern about the content of their training.

Other studies have looked at the training needs of community health workers for palliative care services. In focus groups involving 29 community health workers-in South Africa, eight palliative care learning needs were identified: HIV/AIDS, TB, sexually-transmitted illnesses, debriefing, care of bedridden patients and other chronic diseases. It was also recommended that future programs should consider interventions to provide emotional support for CHWs and how to evaluate the quality and impact of care provided in the community (Robertson et al., 2015).

In Swaziland, PC is nurse led, although a multidisciplinary team is involved. This is similar to the situation in countries such as Uganda; however in Uganda, unlike in Swaziland, nurses who are trained in PC are allowed to prescribe morphine.

Objective 3: To explore health care worker's perceptions on how PC is implemented including, successes and challenges.

3.1 Challenges in implementing palliative care

3.1.1 Availability of medicines

3.1.2 Challenges in Human Resource

3.2 Suggested strategies for improving implementation of palliative care

3.2.1 Training

3.1.1 Availability of medicines

The unavailability of morphine was a frequent complaint of health workers in this study. There are many factors responsible for the unavailability of medications that most effectively treat cancer pain in low middle income countries. These include drug prices (often inflated because of over-regulation); inadequate storage facilities, poor drug distribution systems (Duthey and Scholten, 2014); low level training and exposure of physicians and other health care professionals to prescribe opioids; cultural and attitudinal barriers; global and national regulatory controls related to concerns about abuse, dependence, and diversion and insufficient governmental commitment to purchase opioids and to finance educational initiatives and unfavorable government policies (De Conno et al., 2005).

The availability of morphine within a country is depends on the degree to which palliative care is given attention and integrated into its health care system and to its attainment of health and education goals in comparison to her income (Gilson et al., 2013).

The accessibility to and use of opioids , despite long-standing international policy statements and guidelines to make them available to relieve physical pain and suffering, is limited because of the fears and concerns of Governmental and global health policy makers (Cassileth and Gubili, 2010). The 1961 Single Convention on Narcotic Drugs, implemented by the International Narcotics Control Board, however obliges governments to ensure opioid availability for medical purposes, while simultaneously addressing potential abuse and diversion (Cassileth and Gubili, 2010). Further, guidelines published by the WHO in 2000, updated in 2011, highlight the so-called quadruple imperative (legal, political, public health, and moral) to make controlled drugs accessible and available to prevent unnecessary suffering (Hastie et al., 2014).

However, many nations have failed to adopt these international guidelines, and thus have remained with unbalanced restrictions of opiods. New strategies must be undertaken within low middle income countries to educate policymakers about the need for opioids in palliative care and about the safeguards that can be instituted to prevent their diversion and abuse. Morphine

(sustained release tablets) and other essential drugs for palliative care are only intermittently available, and research has shown that some health professionals have continued fears about prescribing opiates (Woolf et al., 1999).

In assessments conducted in Mozambique and Congo, collaboration between the country's opioid prescribers and regulators, the availability of oral morphine in the country, patient access to oral morphine, the availability of non-opioid essential palliative care medicines and patient access to non-opioid essential palliative care medicines were all rated as very poor.
In Lesotho the situation was better where collaboration between the country's opioid prescribers and regulators and patient's access to oral morphine was rated as good, while the availability and patient's access to non-opioid essential palliative care medicines was rated as excellent (..).

Swaziland has developed initiatives to change regulations that may restrict physician or patient access to pain relieving medicines and promote attitudinal change relating to 'opiophobia' (Swaziland Ministry of Health, 2009). In the last three years morphine powder has been imported and there is a more favourable policy environment for the availability of, and access to, opioid analgesics (African Palliative Care Association, 2012). The African Palliative Care association has rated the availability and patient access to non-opioid essential palliative care medicines as good but the collaboration between the country's opioid prescribers and regulators as challenging. Although the Ministry of Health has attempted to make oral morphine available for all in need, this study revealed that oral morphine was only available at level 2 and level 3 health facilities, due to the unavailability of doctors at the lower level and the fact that currently, doctors are the ones who are ethically and legally eligible to dispense morphine.

A more puzzling finding in this study was that morphine was available in some facilities, not available in others whilst the regional hospital that reported that at times morphine expired on the shelf. The study did not explore this contradiction in depth, but doing so may yield important ways to improve morphine supply. It would appear that the entire morphine supply chain of morphine from ordering to deliver needs to be re examined.

Health workers displayed strong negative views about working in under-resourced hospitals where there is constant unavailability of medicines. However, PC implementation continued

regardless of the challenges the health workers encountered and some health workers showed high levels of commitment to providing palliative care to all needing the service, by developing workable strategies.

3.1.2 Challenges in human resources

A complaint expressed in this study was that the human resource compliment had not changed in the past decade despite new programs having been introduced.

The capacity to provide comprehensive palliative care in low- and middle-income countries is frequently constrained by a shortage of health care workers. The challenge to health-care human resources in low middle income countries encompasses all levels of the health-care work force, and innovative models to increase the capacity and capability of the health-care work force based on each region-specific conditions and are fundamental to any palliative care program (Grant et al., 2011).

In many African countries, attracting health care workers to rural areas is a challenge. Employing foreign workers is one strategy that many countries have adopted and this is reflected in the demographics of the study population (Table 6) where more than half of the respondents are not Swazi nationals.

3.2 Suggested Strategies for improving implementation of Palliative care.

3.2.1 Training

Training and education

The results suggest that the issue of training is important across all the different disciplines of health workers for effective implementation of programs and should be taken into consideration when formulating policies in the public sector.

In low and middle income countries, in-order to overcome the challenge of limited and inadequate wide spread and sufficient provision of PC to their citizens, systematic approaches

are needed to train these caregivers in the delivery of palliative care and in pain management. This training must be adapted to the care context, which, in many regions, will be provided predominantly by volunteers working alone or with health professionals.

New developments have emerged in developing countries in order to respond to the quest for a need to train more hands capable of providing PC. For example, the University of Cape Town in South Africa offers a multidisciplinary master's course (Ferrell et al., 2014). Postgraduate training for palliative care nurses and special clinical officers in Uganda is available through a 9-month Clinical Palliative Care course, which includes clinical placements and training to prescribe morphine. This program is the only one of its kind in Africa to allow health care professionals other than physicians to prescribe morphine (WHO, 2012). A master's program has been developed to supplement this training, through collaboration between Hospice Africa Uganda and Makerere University. In Kerala, India, there are several palliative care training programs for physicians and nurses, including 1-year residential or distance learning fellowships, an 8-week certificate course in essentials of palliative care, and 4- or 6-week residential training programs (Kumar, 2013). In Bangladesh and Myanmar, the Lien Collaborative for Palliative Care nurses are enrolled on a palliative care course for 12 weeks. This training helped to ease the knowledge gap and offer good palliative care services (Steedman et al., 2014).

Although Swaziland has not developed a fully accredited palliative care training course, the Ministry of Health has developed "in-service introduction to palliative care" training. The in-service introduction training is only one week. The training has been criticized by local training institutions to be very short and not offered by the appropriate personnel (Swaziland Ministry of Health, 2009). The training course is based on a national curriculum for introductory training, adapted from APCA's core curriculum. The country has trained 9 health care workers with this diploma-level training in palliative care (Swaziland Ministry of Health, 2009).

The Ministry of Education and the Nursing Council of Swaziland recommends that PC training should be carried out at both basic, intermediate and specialist levels. The basic training should include a clinical placement in a hospital with well-developed PC services. A range of cadres should be trained, including doctors, nurses, pharmacists, social workers, physiotherapists and

other allied professionals. Staff should be strategically deployed, in high-need wards following training, particularly intermediate and specialist training. Trained staff should be mobilized in a multi-disciplinary team. For PC to become a normal part of service delivery, a "critical mass" of staff should be trained: around 25% of all hospital staff (De Lima and Radbruch, 2014). Training and sensitization needs to become part of practice for this to be possible in most hospitals. Staff should be equipped with trainer of trainees' skills and resources to implement ongoing training, and training should be endorsed and supported by hospital management, including being provided with space and resources to carry out the training and ensuring trainees are strategically selected and instructed to attend. PC should become an integrated part of the performance management system and annual staff appraisal (Duthey and Scholten, 2014).

Modeling of integrated PC is an important part of capacity building. The modeling can be internally provided: from trained staff within the hospital to recent trainees. It can also be provided through mentorship provided at national level, through regional centres of excellence and by international networks. Mentorship is about enabling staff to embed what they have been taught into practice. Face-to-face mentorship provides the best opportunity for modeling PC, but mentorship can also be carried out remotely, following a first face-to-face session. Opportunities should also be provided, where appropriate, for sharing within countries and outside of the country.

Issues around prescribing morphine need a particular emphasis in training. The Ministry of Health has recommended that hospitals introducing PC services build staff confidence in prescribing and dispensing PC medications through mentorship and modeling. Pharmacists and senior doctors should be trained in PC together, in addition to other members of the multidisciplinary team, as this enables them to all become clear about the appropriate and effective utilization of medications such as oral morphine. Training should focus not only on prescribing, but should include supply chain mechanisms, including ordering processes and strategies to avoid stock-outs, particularly for newly introduced medications. It is important to train enough people, the right people and strategic individuals, who influence and manage procurement as well as clinical leadership.

Conclusion

There are unique challenges and opportunities to achieve comprehensive PC in low middle income countries related to the integration of palliative care into cancer control, investment in health systems and infrastructure, improved access to opioid medication, the training of health professionals and volunteers, the generation of region-specific research, and shifting attitudes about palliative care and death and dying.

Successful implementation of palliative care requires that local resources and customs are taken into account and that educational initiatives be undertaken to train health care professionals and volunteers. In many regions, community-based volunteer programs are an essential component of palliative care delivery, particularly in remote or rural areas where access to specialized health facilities is an additional challenge. Advocacy and public education are also essential to counter stigma and myths that hinder the availability of palliative care.

Chapter 5: Conclusions and Recommendation

5.1 Conclusion

Palliative care is a major but often neglected public health issue requiring national and international policy responses. In 2011 Swaziland published a dedicated national palliative care policy. This development occurred in the context of a long history of care, a rising profile for provision, political patronage and economic growth. Services expanded following policy publication but the policy struggled to achieve full generalist healthcare workers and public and voluntary sector bodies are vital to ensure support for any national plan, but this is challenging to achieve. The policy did not make any significant change in terms of access to PC services.

The findings in this study have indicated a range of issues that contributed to implementing the palliative care services among health workers in the Shiselweni Region of Swaziland. The issues included their lack of understanding of the role of the PC, its impact on the rural clinics, and the challenges in human resources. Other factors highlighted include training, and unavailability of medicines. The importance of capacity development opportunities was also raised, although there are no concrete examples of strategies on how to improve this aspect within the Swaziland health workers community. Therefore, this PC needs to be strengthened by providing training for the health workers. Other areas requiring attention include supervision and reassessing, and addressing the issue of the lack of adequate human resources and unavailability of medicines.

Several positive aspects are mentioned about the success of implementing the palliative care policy and health care professionals' experiences working in the public sector such as improved recognition, and the inclusion of palliative care in policy documents which are often overshadowed by some of the challenges they encountered like the issue of insufficient opioids. However, even with the study participants citing challenges, they were optimistic these could be addressed if their role in providing PC was acknowledged and they proposed solutions on how to address them.

5.2 Study Limitations

The study was done in one region of the country. More than two thirds of the respondents were not Swazi nationals and the interviews were conducted in English. English is not the home language of any participants. Another limitation is the short length of service of the respondents.

5.3 Recommendations

The following recommendations are made based on the findings of this study:

5.3.1 Capacity building

With no accredited palliative care training course, and no medical schools, there is a need to utilize the five palliative care physicians to create in-service training opportunities. Consequently, there is potential in investing in more specialized palliative care training, which will require necessary resources. Furthermore establishment of palliative care courses and partnering with educational institutions in other countries would be a long term strategic goal.

Palliative care education is one of the components which need to be addressed to effectively implement palliative care. Training at different levels, of various cadres need to occur to, support the implementation of palliative care services, as well as to access the performance of trained personnel following their attendance on such courses.

There should be an effort made by health workers to improve and maintain their competency and skills and to understand what palliative care policy consists of, for appropriate implementation of PC services. A dialogue should be initiated on how health workers and their supervisors could work together to address this gap in knowledge. Some of the practices used at tertiary level hospitals could be implemented in rural clinics with some mentoring and coaching. These activities can be adopted or explored at lower levels to motivate and support the process of implementation.

5.3.2 Working environment: multidisciplinary teams and working conditions

The working relationships between health workers, other health professionals and organizations should be strengthened. The suggested strategies to achieve this include proactive information sharing among them, participation in joint projects, including research opportunities. There should be multidisciplinary palliative care teams that would be responsible for implementing the

palliative care holistically. Palliative care should be treated as a discrete program, not as a complementary service for ART therapy.

There should be more recruitment of health workers with special focus on implementing palliative care so too easy the workload among health workers, though this exercise comes with a cost.

5.3.3 Leadership and Management

Given the strong Government ownership of palliative care in the Swaziland, it is important to strengthen the Ministry of Health structures for national palliative care coordination and implementation. In this respect, the Ministry of Health should form, via the Swaziland National AIDS Program, a palliative care technical working group or national palliative care committee to advocate for, facilitate and integrate palliative care into the health system at all levels.

The leadership and management of palliative care programs should be strengthened. This is because if there is a defined way of leading and managing the palliative care program better health outcomes can be achieved. The proposed strategy to achieve this is through appointment of key personnel at facility level who would make sure that palliative care is implemented appropriately. The key individual will be responsible for making sure that working materials are available and that the palliative care service is accessible to all patients who are terminally ill.

5.3.4 Advocacy

There should be an advocacy plan which will enable the Government of Swaziland to disseminate information to health workers. The advocacy plan will enrich health workers in the latest development of palliative care. Furthermore through advocating a large number of health workers are reached. With a palliative care policy and a national palliative care strategy, both of which include the discipline as a human or legal right, no national strategies for cancer / NCDs, and a national strategy for home-based care that includes palliative care, there is a need for a programme on cancer / NCDs to include palliative care. To ensure the effective implementation of these policies and programs, it is imperative to advocate for a dedicated budget line for palliative care in the national health budget.

Different strategies of advocating can be used including print media, debriefing sessions and through radio. When advocating there is a sense of involvement which can be a positive sign in implementing palliative care because health workers can develop some ownership.

5.3.5 Availability of Medicines

Given the positive elements surrounding the availability of, and access to, opioid and non-opioid medicines, it is critical that the amounts of morphine requested by the government reflect the quantity of need and collaboration between the country's opioid prescribers and regulators is systematically improved.

5.3.7 Research

In Swaziland it would be important to extend the research study to other regions and also to include patients or other relatives or support persons as the patients are terminally ill.

There is a need for further research on PC services. With no dedicated research group (and no sites experienced in international research), and no dedicated research resources, funding should be provided to forge connections with other researchers within and outside Africa.

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Appendix 1 - Swaziland Ethics Clearance



Telegrams:
Telex:
Telephone: (+268 404 2431)
Fax: (+268 404 2092

MINISTRY OF HEALTH
P.O. BOX 5
MBABANE
SWAZILAND

THE KINGDOM OF SWAZILAND

March 2nd, 2015

Mr. Teluleko Maseko
Principal Investigator
MBABANE

REF: MH/559C/ FWA 000 15267/ IRB 000 9688

Dear Mr. Maseko

RE: INVESTIGATING THE IMPLEMENTATION OF THE PALLIATIVE CARE POLICY IN SHISELWENI DISTRICT IN SWAZILAND .

The committee thanks you for your submission to the Swaziland Scientific and Ethics Committee, an expedited review was conducted.

In view of the importance of the study and the fact that the study is in accordance with ethical and scientific standards, the committee grants you authority to conduct the study. You are requested to adhere to the specific topic and inform the committee through the chairperson of any changes that might occur in the duration of the study which are not in this present arrangement.

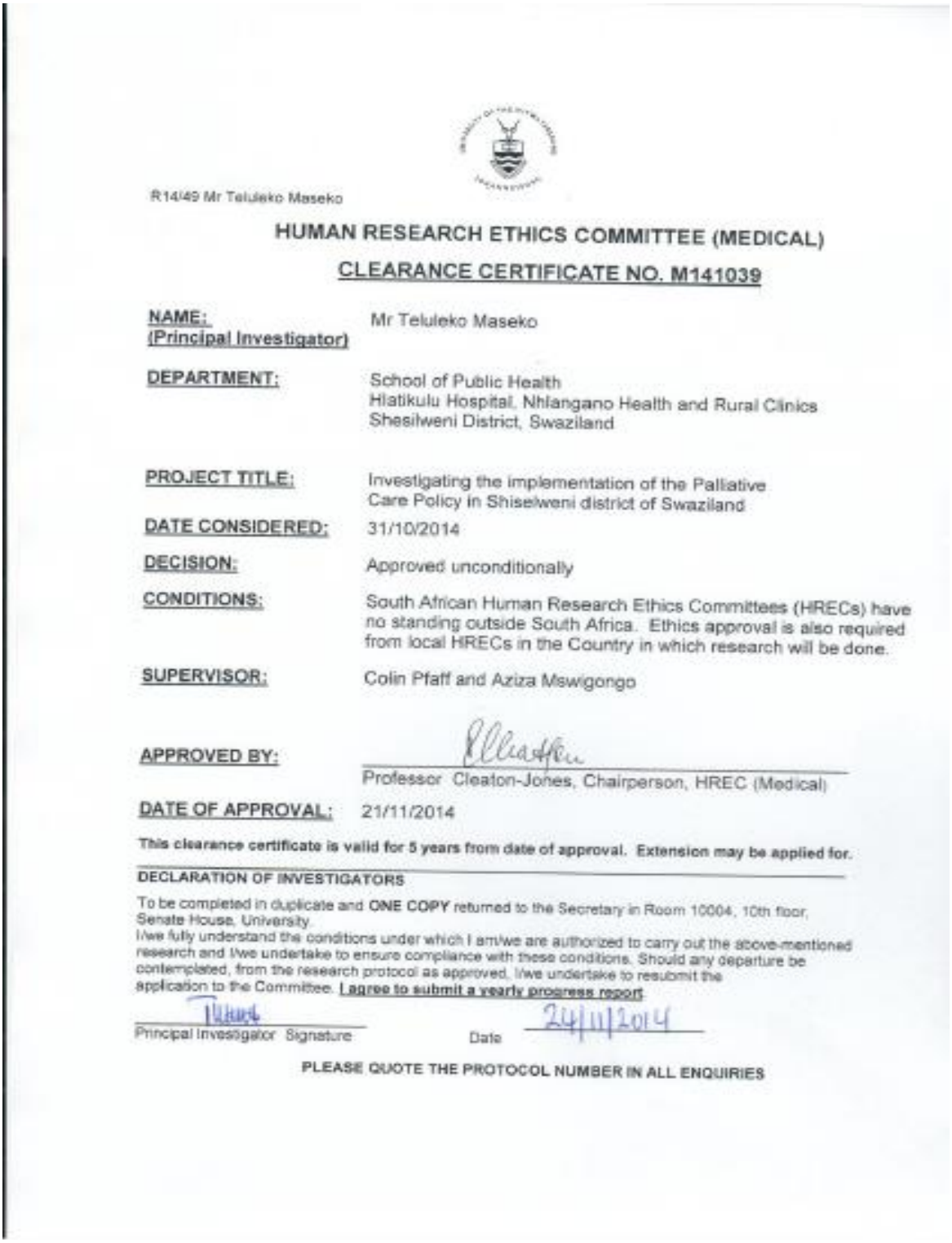
The committee requests that you ensure that you submit the findings of this study (Electronic and hard copy) and the data set to the Secretariat of the SEC committee.
The committee further requests that you add the SEC Secretariat as a point of contact if there are any questions about the study on 24047712/24045469.

Yours Sincerely,

RUDOLPH T.D. MAZIYA
THE CHAIRMAN, SEC

cc: SEC members

Appendix 2 – Witwatersrand University Ethics Clearance



R14/49 Mr Teluleko Maseko

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M141039

NAME: (Principal Investigator)	Mr Teluleko Maseko
DEPARTMENT:	School of Public Health Hlatikulu Hospital, Nhlangano Health and Rural Clinics Shesilweni District, Swaziland
PROJECT TITLE:	Investigating the implementation of the Palliative Care Policy in Shiselweni district of Swaziland
DATE CONSIDERED:	31/10/2014
DECISION:	Approved unconditionally
CONDITIONS:	South African Human Research Ethics Committees (HRECs) have no standing outside South Africa. Ethics approval is also required from local HRECs in the Country in which research will be done.
SUPERVISOR:	Colin Pfaff and Aziza Mswigongo
APPROVED BY:	Professor Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	21/11/2014

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature

Date 24/11/2014

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 3

INFORMATION SHEET

Good Day,

My name is **Teluleko N. Maseko** I am a student at the University of Witwatersrand studying my master's in public health. I am conducting a research to investigate the context, perceptions of content and process influencing the implementation of the Palliative Care Policy in rural health settings in Shiselweni district in Swaziland among health workers.

I would like to invite you to participate in this a study in order to understand the implementation of Palliative care. The researcher conducting this study is in partial fulfilment of the requirements for the degree Master of Public Health. We would be most grateful if you would agree to participate in this study.

Why am I doing this?

The study is motivated by the Palliative care policy which was lodged in November 2011 and the researcher wants to understand the effectives of the policy since its inception.

What do we expect from the participants in the study? After I explain the purpose of this research, you will be asked some questions related to Palliative care and the policy. This consent form (displays the form) confirms that I have explained the study to you and that you have voluntarily agreed to participate in this study. The first section of the will deal with your demographic information (e.g. age, gender, marital status) while in the follow up sections would deal with issues of the Palliative care policy and its implementation.

Are there benefits to the participants? No. There are no direct benefits to you, but your participation in this research will have long lasting rewards because at the end of the study, the findings will help to improve quality of services and care at the clinic and assist us as public health professionals with new knowledge on Palliative care.

May I withdraw from the study? Certainly, you may do this at any time without having to give a reason. Your responses will be confidential and you will not be victimized in any way by not participating or by withdrawing from the study, that is, your treatment for future clinic visits will not be affected. During the interview your answers will be recorded on a tape recorder, which only I will have access to. You are not required to mention your name so no one will be able to trace the recordings back to you. In addition, should you experience any physical, emotional or psychiatric discomforts that require counselling or psychiatric intervention; you will be re-referred to the clinic.

What about confidentiality? Confidentiality will be maintained at all times. No names are required at any stage during the research. At the top of the interview guide, which only the researcher and myself will have access to, will be a study number to help us order and identify the interview but this will not be linked back to you as the participant. They and the tape recorder will be kept in the researcher's locker that will be locked at all times. In addition, the findings will be reported as group and not individual results, in order to protect any identifying information.

If you require any further information or have any questions / complaints on the study please contact the research supervisor, Dr. Colin Pfaff on 256 (0) 1-11-739-469 or the chairperson of the University of the Witwatersrand Human Ethics Committee on 011 717 2230.

Should you wish to participate, please read and sign the attached consent form and complete the questionnaire and return it to the assistant who will be receiving the questionnaires.

Thank you

Teluleko Maseko

Appendix 4

Name of Health Facility_____

Postal address of Health Facility_____

INFORMED CONSENT

I agree to participate in the study entitled: _____as outlined in the information sheet.

The goals, methods and the purpose of the study have been explained to me and are clear. I understand that the study will involve participating in an in-depth interview _____. I understand that I have the right to refuse participation in the study.

I agree to participate in the study on condition that:

1. I can withdraw from the study at anytime voluntarily and that no adverse consequences will follow on withdrawal from the study.
2. I reserve the right not to answer any/or all questions posed in the survey.
3. The Human Research Ethics Committee at the University of the Witwatersrand has approved the study protocol and procedures.
4. My name will not appear anywhere on this interview guide. All results will be treated with the strictest confidentiality.
5. Only group results, and not individual results, will be published in the final report, scientific journals and in any presentation related to this study
6. The Researcher is committed to treating participants with respect and privacy throughout the procedure.

I, ……..herewith confirm that I have been fully informed about the nature, conduct and benefits (service delivery improvement) of the study, entitled _____outlined in the information sheet. I agree to participate in the above-mentioned study.

RESEARCHER:

Printed Name	Signature/Mark or Thumbprint	Date and Time

PARTICIPANT

_____

Signature/Mark or Thumbprint Date and Time

Appendix 5

Consent form for audio recording

I_____ consent that I am fully aware that the researcher is going to use audio recording for his interview. He has explained to me the purpose of the study and the procedures involved, risks, benefits and my rights as a participant in the study.

Participant's name_____

Participant's signature_____

Date_____

Researcher's name_____

Researcher's signature_____

Date_____

Appendix 6

Interview guide

Good morning/Good afternoon/
I would like to first thank you for volunteering your time to answer some few questions related to Palliative care policy. Your inputs to this pertinent study are important in recommending effective implementation of Palliative care policy in the future. I assure you that there is complete confidentiality in the information and your name will never be revealed.
Brief demographic questionnaire

Position or Occupation_____

Level of education_____

Urban or rural setting_____

Age_____

	Major issues	Probes
1.	The understanding of health care workers on the content of the PC policy	- Enquire on the key features of Palliative Care Policy * Probe about the system, the interaction between actors in the system, personal interests and benefits. Ask on why and how these key features have influenced the implementation of the Palliative Care Policy
2.	How the PC policy was implemented including successes and challenges?	- How is palliative care offered in this setting, if at all - Enquire about the **main actor's** involved in the process (include private actors too) - Ask about the role and opinion of each actor and its influence on the implementation of the policy Enquire about factors that affect the performance or action of these actors and their interests - Enquire about the opinions of each actor - Probe if these opinions have influenced the implementation process, how and why - Enquire on the interaction and relationship between these actors
3.	The role of actors in the implementation process	- Enquire about the **main actor's** involved in the process (include private actors too) - Ask the role and opinion of each actor and his/her influence on the implementation of the policy - -Enquire about factors that affect the performance or action of these actors and their interests

		- Probe if these opinions have influenced the implementation process, how and why - Enquire on the interaction and relationship between these actors.
4.	Health care workers coping strategies in delivering PC services	- Enquire on the key features of Palliative Care Policy * Probe about the system, the interaction between actors in the system, personal interests and benefits. - Ask why and how these key features have influenced the implementation of the Palliative Care Policy
5.	Recommendations	- Ask him/her to state three key issues and why they should be strengthened in order to affect future Palliative Care Policy implementation - Ask him/her to mention other key people to talk to in regard to the implementation of the policy, probe for reasons for each person mentioned.