AN ASSESSMENT OF THE CURRENT STATUS OF INTEGRATION OF PALLIATIVE CARE INTO PRIMARY HEALTH CARE CENTERS IN ALEXANDRA COMMUNITY.

SCHOOL of PUBLIC HEALTH and FAMILY MEDICINE

THESIS SUBMITTED IN FULFILMENT FOR THE REQUIREMENT OF THE AWARD OF M. PHIL. DEGREE IN PALLIATIVE MEDICINE

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DECLARATION

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LIST OF ABBREVIATIONS

APCA	Africa Palliative Care Association
EAPC	European Association Palliative Care
EML	Essential Medicine List
EoLC	End of Life Care
HCPs	Health Care Professionals
GPG	Gauteng Provincial Government
HPCA	Hospice Palliative Care Association
HIC	High Income Countries
HRH	Human Resource for Health
IAHPC	International Association of Hospice and Palliative Care
LMIC	Low and Middle Income Countries
NDoH	National Department of Health
NGO	Non-Governmental Organizations
NHS	National Health System
NHI	National Health Insurance
NPFSPC	National Policy Framework and Strategy in Palliative Care
MOH	Ministry of Health
PC	Palliative Care
PCSS	Palliative Care Specialized Service
PDoH	Provincial Department of Health
PEPFAR	Presidents Emergency Plan for AIDS Relief
PHC	Primary Health care
PHS	Public Health Strategy
PPSG	Pain and Policy Study Group
UCT	University of Cape Town
UHC	Universal Health Coverage

UN	United Nations
USA	United States of America
USAIDS	United States Agency for International Development
WBOT	Ward Based Outreach Team
WHA	World Health Assembly
WHPCA	World Hospice and Palliative Care Alliance
WHO	World Health Organization

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ABSTRACT

Introduction-The WHA resolution in 2014 to strengthen PC as a continuum of health care service delivery mandated member states to incorporate PC into their NHS using the PHS. An assessment of a health system will only be complete when the four elements of the PHS that (entrenches palliative care) are assessed alongside preventative, curative and rehabilitative care.

Aim-To assess the current status of integration of PC into the PHC centers in Alexandra community in Johannesburg, South Africa.

Objectives - 1) to identify the existing policies including budgets available in the clinics relating to PC, 2) to identify the availability of PC essential medicines in the PHC and 3) to survey the HCPs training in PC.

Methodology- Each objective has different targets. Objective number 1) has clinic managers as its targets. Objective 2), HCPs and people involved in procuring and prescribing essential medications and objective 3), all the HCPS. Data was collected using structured questionnaires administered by the researcher and analyzed using statistical tables.

Results-The clinic mangers are not aware of NPFSPC, there is no provincial policy, budget or any existing policy on PC in any of the clinics. The essential medicines are available in the clinics, only recent graduates has undergraduate trainings in PC, no HCP has any post graduate training in PC at any level (Certificate, Diploma or Masters) as recommended by the WHA resolution to member countries. Skills in PC is close to zero in the PHCs.

Conclusion-The study confirm the findings in previous literature and highlights the needs for PC policies and continuous training in PC for HCPs, essential medicines for PC are in the clinics contrary to findings in other LMIC.

CHAPTER 1

1.0 INTRODUCTION

"The health care system in its fixation with diseases process, had forgotten that its mandate is to alleviate suffering and we as medical practitioners need to recapture that vision. There is a cruel irony in our care of the dying, although these are the sickest people in our health system, when medical technology doesn't know what to do, the quality and quantity of care falls away. How can we justify that? We can't shift the dying into another kind of ghetto of inadequate care because not having competent palliative care resources available in the 1990s is unethical and cannot be excused." BALFOUR MOUNT[1]

This chapter presents the elements of palliative care, palliative care need, development of palliative care internationally, regionally (in Africa) and South Africa in particular.

1.1 Palliative care overview

Palliative care(PC), as defined by the World Health Organization (WHO) "is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." It is a holistic approach that integrates and aims to alleviate physical, social and spiritual pain and existential discomfort so that patients may come to terms with their impending death as fully and constructively as they can, by providing relief from all types of pain and other worrying signs. PC upholds life and encourages dying as a normal process.

PC is a missing component of modern medical care. Modern medical care focuses on curative medicine,[2] dependent on the income bracket of a country. In High Income Countries (HIC) where curative treatments are often prioritized over PC, there is a need for early integration of PC with active treatment. In Low and Middle Income Countries (LMIC),[3] where there still needs to be strong advocacy for better access to curative care, cure may be very limited, or unavailable, PC is needed as an integral part of the healthcare systems and should be the minimum where curative services are not available at all.[2, 4]

PC "also offers a support system to help the patients live as actively as possible until death and the family to cope during the patients' illness and their own bereavement"[4] by "using a team approach to address the necessities of patients and their families, with grief treatment when specified." PC will improve patients' quality of life and may positively impact the progress of sickness.[4] It is appropriate early in the disease progression alongside other remedies for instance chemotherapy, radiotherapy and investigations needed to establish diagnosis and control upsetting symptoms.[4]

The objectives of PC are to attend and relief adult and pediatric patients throughout the trajectory of life limiting health conditions by continually evaluating, averting and getting rid of pain, and misery of any kind either physical, psycho social or spiritual using evidence based provision of patient and family -centered care that improves quality of life and enhances patients' dignity.[4] In promoting Universal Health Coverage (UHC), one the goals are to integrate PC with and to complement prevention, early diagnosis, treatment and rehabilitation of patients with life limiting health problems at primary, secondary and tertiary levels of healthcare so firming up health systems and improving continuity of care. Patients with longstanding life threatening illnesses will regularly need most of the components of good all-inclusive and integrated PC because these ailments usually have a trajectory laden with recurrent crises that requires care, and all available sources of relief.[2]

PC can be delivered to all patients with progressive life-threatening or limiting illness and should be presented at the diagnosis of life-threatening condition, not only End of Life Care (EoLC). PC can be delivered in all situations and settings (hospitals, PHC centers, old age homes in the community and patients' homes), in all areas of the world in High Income Countries (HIC) and Middle and Low Income Countries (MLIC), to care givers and families during grief and bereavement periods, to adults, children and all human vulnerable populations (refugees and asylum seekers, prison inmates, homeless and disabled).[2]

1.2 Palliative care need –International and National.

The Worldwide Hospice Palliative Care Alliance (WHPCA) estimate that worldwide over 40 million people will benefit from PC (20 million of these being at the end of life) however less than 10% of the global need is being met.[5] The bulk (69%) of people needing PC are adults over 60 years and only six percent (6%) are children, the highest percentage of adults requiring PC live in LMIC.[4] The highest illnesses in need of PC are cardiovascular disease then cancer, lung disease, HIV/AIDS, diabetes, renal disease, liver disease, dementias, drug-resistant TB, Parkinson disease, rheumatoid arthritis, and progressive neurological disorders. These ailments represent the bulk of adult PC needs and tend to occur in the older age group.[6]

In South Africa a crude estimate obtained from underlying causes of deaths (total death, natural and unnatural deaths) from National Department of Health (NDoH) indicates malignant neoplasm (8.2%), heart disease (16.8%), and renal disease (1.5%), liver disease (0.9%) respiratory disease (3.7%) neurodegenerative disease (0.1%) Alzheimer's dementia and senility (0.3%) HIV/AIDS (4.8%) TB (8.4%) diabetes mellitus (5%), in total (49.7%) of cases seen in palliative care.[7]

1.3 Palliative care developments international and national.

The Alma Ata declaration[8] in 1978 addressed key health problems in the local communities internationally, delivering health promotion, prevention, cure and rehabilitation services but excludes PC as PC had not been identified as a specialty until 1980s. The first hospices were opened over a century ago in Dublin.[9] Dame Cecily Saunders pioneering works opened St Christopher's Hospice in South London in1967, it was followed by other hospice initiatives in Europe and other parts of the world. In the USA hospice programs began in the 1970s and insurances started reimbursing costs in 1982 but requiring giving up of curative treatments.[9]

Island Hospice in Zimbabwe was established in 1979 as the first PC service in Africa.[10]The first South African hospice began in 1979 in Hurlingham, Sandton which became the Hospice Witwatersrand, St Luke's Hospice in Cape Town started in 1980. The Highway Hospice in Durban and St Francis Hospice in Port Elizabeth were opened in 1982 and 1986 respectively.[11]

The first hospital PC team was first established in Royal Victoria Hospital, Montreal by Balfour Mount[1] in 1976 followed by the St Thomas Hospital London, team in 1977. Tertiary Hospital PC teams in South Africa had been formed by the Gauteng Centre of Excellence for Palliative Care at the Chris Hani Baragwanath Hospital, Charlotte Maxeke Hospital under the University of Witwatersrand and in Cape Town at the Groote Schuur Hospital under the University of Cape Town (UCT). PC services are also available at the Victoria Hospital in Cape Town, Knysna hospital and Wentworth hospital in Durban.[11]

1.4 The World Health Organization (WHO) Public Health Strategy (PHS).

In integrating PC into national policies, it had been found and demonstrated that good policies forms the foundation for an active health care structure and delivery.[12] The World Health Organization (WHO) Public Health Strategy (PHS)[13] was one of the effective advocacy tools used in influencing governments all over the world in the adoption, development and implementation of PC, it provides practical implementation guide to integrate PC into a country's health care system,[14] this guideline for implementation of PC is the way the information in this dissertation will be presented. The PHS discourses applicable policies, essential medicines availability, HCPs and public trainings in PC and the PHS execution through PC services delivery at all levels of a country's health system.[13]

A public health approach means that the methods adopted must be valid scientifically as well as acceptable, sustainable and affordable at the community level.[13] It contains instructions and strategies to countries on the imports and how to execute National Palliative Care Programs and National Cancer Control Programs, where PC is one of the four important drivers of good cancer control which is prevention, early detection, treatments and palliation.[13]

Preferably PC is integrated as an important component of health care within all facets of each country's national health plan. National policies must reflect and represent needs in the society in a manner that all people with life threatening conditions could have their misery alleviated especially the vulnerable groups including children and the elderly. The PHS addresses the importance of PC medications, provisions and availability of inexpensive generic medications especially opioids and training of PHCs and the public in PC.

1.5 International & national advocacy influencing government policy

Palliative medicine was first recognized as a specialty in the UK in 1987. In the mid-1990s the International Association of Hospice and Palliative Care (IAHPC) was established in the USA and in 2000, the Latin American Association of Palliative Care was formed. In 2002 the Asian Pacific Hospice Palliative Care Network was formed. The first conference focusing on PC was in Hague 2003 and the same year the European Society for Medical Oncology officially recognize the discipline. In the year 2004, The African Palliative Care Association (APCA) was formed. The United States Agency for International Development (USAIDS) launched the Presidents Emergency Plan for AIDS Relief (PEPFAR), which allocated funds to the development of hospice and PC. The second conference on international PC was in Seoul in 2005 and the first Hospice and Palliative Care Day was observed the same year worldwide.[4]

As of 2014 only seven out of fifty-four African countries have anything approaching country wide network of PC services, namely South Africa, Kenya, Tanzania, Uganda, Zimbabwe, Zambia, and Malawi.[15] These countries and Rwanda are good examples of the LMIC in the world and Africa with a fully integrated PC services that had established all the foundation measures recommended by the WHO.[16] There are clear national policies, education and training in PC already integrated into the learning programs of student nurses and medical students. Pain relief trainings and PC are available to the public and (HCPs) at general and specialist levels.[16] Morphine is affordable and generically produced within the countries.[15] The Ministry of Health (MoH) in Uganda had published guidelines for handling morphine and other strong opioids in local languages, qualified nurses in PC can prescribe morphine to their patients.[14]

The Rwanda Human Resource for Health (HRH) Program is a major advance in PC development in the country. It is an “innovative global partnership initiative to increase the quality of health care and health professional education and decrease dependence on foreign aid over a 7-year strategic plan”[16] “formed between the Rwandan Ministry of Health (MoH) and a US-based consortium of academic medical centers and nursing, public health, and dentistry schools in August 2012. One of the substantive contributions of the HRH is the creation of the country’s inaugural 2years Master of Science in Nursing program at the University of Rwanda which provides a unique opportunity to integrate PC (among other courses) into the official educational preparation of HCPs in Rwanda for the first time."[16]

Good national policies enable the execution of PC program intended at providing care for all people requiring PC services and also ensure rightful contact with inexpensive drug and treatments.[13]

Integration of PC within different government health services in the few Africa[17] countries where PC had been integrated was achieved through agreed interventions being delivered concurrently. These include advocacy at National, provincial and district levels with training of health care professionals, budgets for clinical and support services, including essential palliative care medicines, and in partnership across hospitals, district and community services.

1.6 Palliative care Health policy

Individual and community beliefs around death and dying impact on the process of forming public policy on PC, and especially the EoLC component.[18]

A key challenge in the development of public policy that will actually have meaning in helping to shape the PC provided in communities is accommodating widely varying and opposed views.[18] The range of beliefs is wide, at one extreme there may be a belief that any life is sacred in and itself, even in a vegetative state; the other extreme is that life can only be enjoyed if there is little or no compromise to physical and psychological wellbeing.[18] The number of variations along this spectrum makes any public policy in PC incredibly difficult to generate in a way that will satisfy all people.[18]

The purpose and intent of a good policy is to ensure that the well-being of all people including the weak and voiceless is respected and protected.[18] This alone does not purely deliver policies that will necessarily please every lobby group, but it is a crucial principle around which to build strong public policy.

In a society, the basic values held by the groups, the fiscal strength of that society, and the existing health care structure in which the PC are being built into, are among other intrinsic factors which influence priorities between treatment and cure.[18] Priorities such as life prolongation or relief of symptoms at the EoLC, may be challenging for developing good EoLC policy because in many health systems, the drivers to invest in marginal life prolongations seems to be many with economic, marketing and professional pressures all influencing the ultimate policy decision.[18]

1.7 Lack of Patients' voices

The voice of the community in democratic societies helps to inform health policies including EoLC. A key challenge in PC settings is the lack of effective patient voices. Patients at the end of life can rarely find the sustained voice needed to truly influence public policy. The caregivers of the people at the end of life are working tirelessly to provide care for the person with the life limiting or threatening illness. After the patient dies, many caregivers are unable to devote any significant time and energy to advocacy. Often this leaves professional bodies in the role of social advocates, with the inherent concern that there may be an element of self interest in the requests being made by health professionals, seemingly on behalf of their patients.[18]

The almost absent voice of people with life limiting illness and their caregivers in service development means that in the public discourse of policy development, it is possible to drown out key views and values that are important to people with life limiting illness and their caregivers. Simply asking the well population what they would like at the end of life is unlikely to be sufficient and may lead to policy that is not congruent with the wishes of people actually facing advanced, progressive, life limiting illness. The almost absent voice of people with life limiting illness and their caregivers in PC service development (lack of advocacy) is likely to continue to be there and finding ways of interviewing people in PC about EoLC policy remains an ongoing challenge.[18]

1.8 International and national advocacy influencing Essential drugs

PC essential drugs are crucial for the provision of quality PC. The essential medicines concept was developed by the WHO[19] stating that there is a list of medicines required for basic health care delivery, including the most efficient, and cost effective medicines required for priority conditions. These lists of drugs fulfils the Primary Health Care (PHC) requirements of the population, hence these needed medicines should always be available, affordable and used appropriately.[19]

In 2007, the International Association of Hospice and Palliative Care (IAHPC) developed a list of essential palliative care medicines and practice guidelines[20] for PC through discussions with palliative care experts and using Delphi technique. The lists of essential medicines and practices for PC had since been adopted by the WHO.

In different reports the United Nations, Africa Palliative Care association (APCA), the European Narcotics Board and European Medical Oncology reports it had been stated "that in the public sector, generic medicines are only available in 38.1 % of facilities, and on average cost 250 % more than the international reference price. In the private sector, those same medicines are available in 63.3 % of facilities, but cost on average about 610 % more than the international reference price. High prices limit access to medicines with common treatment regimens, costing a significant portion of salary of workers in developing countries."[18]

An important component of PC is relief of pain and other symptoms. Access to opioid medication for pain control and its diversion and misuse remains a pressing big problem worldwide.[21] Many people suffering with chronic pain do not have access to effective pain management for a variety of reasons, including restrictions on availability and access, personal and cultural concerns.[22] The 1994 declaration of Florianopolis in South America raised awareness of barriers to the accessibility and availability of opioids in the region. The major focus is on control of criminal use of drugs with little emphasis on access for medical and scientific use. Advocacy for opioid availability and control culminated in the University of Wisconsin Pain and Policy Group proposal being adopted as a resolution, at the 53rd Session of The United Nations Commission on Narcotic Drug in 2010. This included "encouraging sufficient accessibility of internationally controlled medicines for medical and scientific purposes while preventing their diversion and abuse."[14]

Barriers to access to opioids can be divided into four factors namely; political, attitude, clinical and facility factors[2]. Political factors include little political will within government department of health, lack of PC policies and outdated policies and legislation concerning the use of opioids. Clinical factors include little knowledge of pain assessment and management by HCPs and inadequate training of HCPs. Attitude factors include little or no interest in PC, fear of potential side effects and potential abuse of opioids and no reimbursement for PC services by medical insurance schemes. Challenges at facility level are procurement difficulties, absence of skilled professionals in the use of opioids and concerns about addiction and misuse of opioids.

Diversion is defined as the "illegal moving of medicines from right use places to the outside market and directing medicines to persons for whom it has not been recommended.[21] The reasons of diversion encompass patients sharing or peddling opioid medicines, fake prescriptions, thefts from manufacturers and pharmacies, house burglaries, and multinational drug trafficking."[21] Diversion of opioids and its extensive impact has been a worldwide challenge for almost 30 years.[4, 21] "It has encouraged opioid dependence, violence/emergency department presentations, incarceration of people under drug effect, conflicts in health care settings and drug overdose deaths."[21]

Diversion is widespread because it can happen everywhere along the supply chain, "with the most common point at the physician–patient interface."[21] In USA, it was "detected that 55% and 11.4% of people aged 12 or older got opioids either free or bought, respectively, from a friend or family member; 4.4% bought from a drug dealer or stranger, only 17.3% had prescriptions from their doctors."[21] The elderly population was also observed to be a public source of diversion as they would mislead their doctors with pain complaints and appeal for prescriptions, patients with real pain trade portions of their medicines for money, the motivation to sell the medicines could be due to drug dealing maneouvers.[21]

Globally the International Narcotics Control Board and WHO have continually motivated countries to relax their opioid laws, import opioids adequate to the pain requirements of their populace, and guarantee opioids availability when needed for medical uses. 90% of the worldwide use of morphine, fentanyl, and oxycodone occurs among the United States, Australia, Canada, New Zealand, with some European countries.[21] The USA alone unduly uses 99% and 83% of the global supply of hydrocodone and oxycodone, respectively,[21] also in the USA the trade and circulation of opioids has enlarged from 96 mg morphine per person in 1997 to 710mg per person in 2010. Correspondingly, the trades of hydrocodone, methadone, and oxycodone have multiplied (3x), (13x), and (9x) from 1997 to 2010, respectively,[21] according to the Researched Abuse, Diversion, and Addiction Related Surveillance System (RADARS), "an associated increase in diversion and misuse occurred from 2002 to 2010 and a projected total of 10.89 million people consumed at least 430.61 million doses of opioids without prescription, which is about 1/25 of all opioids dispensed, in just a year between 2002 to 2003."[21]

Advocacy for improving access to pain relief medications for PC patients in South Africa had been led by the Hospice and Palliative Care of South Africa (HPCA),[11] in Africa, by the African Palliative Care Association (APCA)[16] and international supporters such as Worldwide Hospice Palliative Care Alliance (WHPCA) and the Open Society Foundations (OSF). These initiatives had received technical assistance from international Non-Governmental Organizations like Global Access to Pain Relief Initiative (GAPRI), clinical education programs such as the Pain and Policy Studies Group (PPSG) and international advocacy bodies such as Human Rights Watch.[18]

The WHO advocates for a balanced approach including education of HCPs in opioid use and "appropriate regulation and legislation to improve drug availability and government policy". In Rwanda Uganda for example, the law allows HCPs, including nurses, to prescribe morphine within the scope of their clinical practice.[16]

1.9 International & national advocacy influencing training in palliative care

The European Association for Palliative Care (EAPC) white paper on education[23, 24] noted that people with life threatening sickness apart from cancer face mutual trials in their illness and that emphasis may change worldwide. For instance, the long-lasting illness of an elderly populace in Europe relates to the HIV/AIDS epidemic in Africa. The commitment to PC principles however will deliver excellence care for all, irrespective of age, primary condition or phase of ailment. The EAPC white paper[24] therefore prescribes three levels of training in keeping with international standard. First level – PC approach planned as a way to incorporate PC approaches and methods in health care settings not dedicated to PC, the training is made accessible to general practitioners, staff in general hospitals, nurses and nursing home staff, the training can be done through undergraduate education or through ongoing PC training as part of continuous professional development.[24] Second level - generalist PC provided by PHC, HCPs and specialists handling patients with life threatening sicknesses who previously have good simple PC skills and knowledge, "the training is made accessible to HCPs who are involved more regularly in PC such as oncologists or geriatric specialists, but do not provide PC as the main focus of their work."[24] It can be taught in undergraduate or postgraduate level or through continuous professional development.[24] Third level is defined as Specialist PC to patients with complex and difficult needs. This therefore, requires a higher level of education, at post-graduate level and additional resources. this training is reinforced through continuing professional development.[24]

1.10 World Health Assembly (WHA) cosponsored by South Africa

Summary of WHA resolution 67.19 recommendations to governments[6].

WHA resolution 67.19

"Urges member states:

1) *to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems,*

2) *to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives,*

3) *to provide basic support to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals*

4) *to aim to include palliative care as an integral component of the on-going education and training offered to care providers in accordance with their roles and responsibilities*

    a) *basic training in undergraduate medical and nursing professional education, and in service training at primary health level*

    b) *intermediate training offered to all health care workers who routinely work with patients with life-threatening illnesses*

    c) *specialist palliative care training*

5) *to assess domestic palliative care needs, including pain management medication requirements*

6) *to review, and, where appropriate, revise national and local legislation and policies for controlled medicines*

7) *to update, as appropriate, national essential medicines lists*

8) *to foster partnerships between governments and civil society, including patients' organizations, to support, as appropriate, the provision of services for patients requiring palliative care*

9) *to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of non-communicable diseases 2013–2020"*

South Africa with other countries namely; Panama, Spain, Australia, Malaysia, Chile, Colombia, Ghana, Libya, Switzerland and USA were the co-sponsors of the WHA resolution. The 67th WHA resolution adoption was preceded by historical landmark activities, advocacy and accomplishments.

1.11 Palliative care (PC) in South Africa (1) policy (2) drug availability (3) education and (4) services.

The WHO and WHPCA did a mapping exercise of PC services development in the countries all over the world and South Africa was categorized into level 4A countries. Countries in this group have preliminary presence of PC integration into its health system.[25]

1.11.1 Policy

The South African government now has a national policy on PC approved by the National Health Council in 2017. The National Department of Health (NDoH) operates on the District Heath System (DHS) for its health care service delivery. The South Africa National Health System (NHS) was reformed in 2011.[26] The National Department of Health (NDoH)'s Strategic Plan for the Prevention and Control of Non-Communicable Disease 2013-17 emphasized the need for interaction around palliative services at all levels. South Africa now has health policies at the national, provincial levels with advisory committees to the Departments of Health at each level.[27]

Following the sponsorship of the WHA in 2014, a National Steering Committee For Palliative Care was formed in May 2016 by the Minister of Health with a mandate to create 1) "a revolution in health care through palliative care" and 2) "to provide expert guidance on the implementation, monitoring and evaluation of progress toward achieving the WHA resolution recommendations on integrated supportive and PC services throughout South Africa's heath system."[28]

Within the steering committee, seven task teams were formed to carve the National Policy Framework and Strategy for Palliative Care delivery in South Africa (NPFSPC) namely for policy, funding, support for families and healthcare workers, education and training, drug availability, vulnerable population and ethics to guide on the approach and considerations on End of Life decisions.

The National Policy Framework and Strategy For Palliative Care (NPFSPC)[28] 2017-2022 was approved in 2017 and describes what informs the NPFSPC, which are South Africa's burden of diseases, a crude estimate of PC need in South Africa and cost implications if PC is not implemented. Other contents describe the following:

- Evolution of PC in South Africa. A recognition of the contribution of hospice to PC in South Africa was evident in the implementation of integrated supportive and PC services and the NPFSPC's dependence upon the strong national network of hospices and NGOs who have led the provision of care and support services to patients and their families for several decades and in advancing education and training of HCPs.
- Why is a NPFSPC required as response to WHA Resolution? PC is a government responsibility as it is to correct the structural challenges in the present health system, namely inequitable access to health delivery and the social and economic costs of health. It address the specific needs of vulnerable groups, children, elderly, refugees and asylum seekers, patients in TB and psychiatric hospitals, prison inmates of correctional service facilities, homeless and disabled people. It recognises the social determinants of health, positions services within a context of human rights and United Nations' Sustainable Developmental Goals (SDGs).
- South Africa's response to advancing PC for the concepts of PC and continuum of care to be integrated throughout the National Health System.
- What will enable South Africa to deliver PC? Service delivery platforms, PC referral pathway, positioning of PC services.
- PC in South Africa's strategy-vision, mission, guiding principles, Goals and objectives.
- Monitoring and evaluation plan
- Implementation schedule with dates.

- Roles and responsibilities of National Department of Health (NDoH) and Provincial Departments of Health (PDoH).

Funding for PC and practices are incorporated into the main government health systems. Some community-based organizations, providing PC do receive subsidies from provincial governments but are largely dependent on donor funding. The provision of PC in the private sector is relatively low or non-existing compare to public sector and a big change is anticipated with the introduction of the National Health Insurance (NHI). The National Health Insurance (NHI) white paper of the South African government includes PC as an essential component in its service delivery with its policies and Essential Medicine List[29].

The NHI in South Africa pursues realization of the Universal Health Coverage (UHC) for South Africans. Universal Health Coverage was included in the third health goal of the United Nations' seventeen Sustainable Development Goals (SDGs). The SDGs with its 169 targets were adopted by member states in 2015 "to end poverty, protect the planet and ensure prosperity for all by the year 2030". The range of the Universal Health Coverage (UHC) contains promotive, preventive, curative, rehabilitative and palliative care (PC). PC as an important component of Universal Health Coverage necessitate inclusion in the National Universal Health Coverage Scheme. "This means that every South African will have a right to access comprehensive healthcare services" – including PC, "free of charge, at the point of use at accredited facilities such as clinics, hospitals and private health practitioners", and this will be achieved through the National Health Insurance card. Access is addressed through availability of services close to where people live or work. The National Health Insurance bill was passed in July 2018 and it includes PC within the plans for Primary Health Care.

1.11.2 Training

The University Of Cape Town (UCT) delivers an educational training program[30] to fill the vital requirement to assist African HCPs to develop the PC skills needed to care for an ever-increasing population of patients and families who were facing progressive life threatening diseases and the physical, emotional, psychological and spiritual distress associated with EoLC. PC courses are being incorporated into medical and nursing school curriculum in South Africa.[10, 30] The University of Cape Town (UCT) and the University of the Witwatersrand (Wits), the Hospice Palliative Care

Association of South Africa (HPCA) are actively involved in PC competency-based training up to generalist level of PC education.[31, 32] Currently the training packages from Palliative treatment for Children (Patch) SA, Paedspal and the Stellenbosch University, University of Cape Town and HPCA, meets the training recommendations of the Western Cape Government Department of Health.[28]

UCT had apportioned 46 hours, the University of the Witwatersrand 36 hours and University of KwaZulu Natal (KZN) had apportioned 36 to 40 hours to undergraduate trainings in palliative medicine training curriculum.[33]

1.11.3 Drug availability

In South Africa there are four essential medicines list documents issued by the NDoH. 1) The PHC level (green book)- Standard Primary Health Care Policies and Treatment Guidelines for Pediatric and Adults Patients for use at the clinics, Community Health Centers (CHC) and out patients at district hospitals. 2) The pediatric hospital level (purple book) - Standard Treatment Guidelines and Essential Medicine List (STG/EML) nationally for hospital use, 3) the adult hospital level Standard Treatment Guidelines (STG/EML) (yellow book) and the 4) Tertiary and Quaternary List. SA essential drugs list had been evaluated by the task team for drug availability in 2017 and 2018, it included most essential palliative medicines, and new chapters on pain and PC will be included in the new editions of the STG/EML.

The District Health System has the Standard Treatment Guidelines and Essential Drugs List (EDL) for South Africa[34] (which includes essential palliative medicines), as its guideline and policy on delivery of health care service. The existing policies and guidelines in clinical management and health service delivery were in the Essential Drug Lists for Hospital, Pediatrics and Primary Health Care.[34, 35] The Essential Drug List (EDL) for Hospital Level and Pediatrics contains a specific section on palliative care including the WHO Three Steps Analgesic Ladder for pain management. The EDL Primary Health Care Level does mention PC in context of certain conditions, such as cancer and HIV, It however contains all the essential medicines needed for PC. The procurement of these essential medicines is from the government central pharmacies to district pharmacies and local clinics. Medication prescription generally at the primary care levels (PHC) is by doctors, Primary

Health Care Nurses (PHCN) and Community Health Workers (CHW) except for control drugs (opioids) which only doctors can prescribe.

1.11.4 Services

The Hospice Integrated Community Based Home Care is one of South African government[36] best practice whereby highly trained and professionally supervised community care givers and community based volunteers provide a home based PC services. It started in KZN and replicated in other provinces.[11] The awareness of the people of South Africa and families for whom there is a need for PC is high as they are able to access PC through the hospices and district health systems.[5, 25]

The South Africa National Health System contains Community Based Services Outreach Services, School Based Health System, operative Referral System and upgraded Emergency and Planned Patient Transport Services and a Ward Based Outreach Teams (WBOT).[26]

1.12 Current Implementation of the NPFSPC in South Africa

All the stakeholders /constituency groups delivering different aspects of PC in South Africa have been identifying with the policy and questioning the policy for improvement. These stakeholders/constituency groups are the National Department of Health NDoH, Provincial Department of Health (PDoH), District Health Management Team, primary (district) and provincial hospitals, tertiary hospitals, PHC clinics and community health centres(CHC), community based organisations/nongovernmental organisations/faith based organisations, private hospitals, private specialists, general practitioners, National Department of Social Development (DoSD), Social Services and academic institutions.

In Gauteng province, the Tshwane Health District and Family Medicine Department of the University of Pretoria had formed a PC team of many professionals, undertaking collaborative and multi-disciplinary ward rounds with other specialities such as ENT, internal Medicine within the hospital, making appropriate referrals to social workers, spiritual members, physiotherapist and other members of the team (speech therapist, dietician) as needed.

An EoLC team within the hospital emergency unit comprising of clinical mangers, head of clinical departments as well as PC team (family physicians) was developed, this team's goal is to relief the challenges of the emergency and Intensive Care Units (ICU) of resources, such as bed availability and resuscitation machines availability. Using Supportive and Palliative Care Indicator Tool (SPICT),[37] they identify patients in need of PC, EoLC, discuss management with family members and patients and make appropriate referrals. This also help in reducing the number of investigations performed.

1.13 Alexandra Township

In the Alexandra Township (see appendix 9 for location and population details) health care delivery including PC is being provided by the private general practitioners in their surgeries, hospice, faith based and charity organisations with old age homes and traditional healers in the nongovernmental sector. The government community clinics are staffed with Health Care Professionals (HCPs) and Community Health Workers (CHWs) providing PHC according to the district system of the national health policy, ward based outreach teams (WBOT) and lay health workers, all active in the community implementing the national health system. A focus on Alexandra township district level PC programme could provide a blueprint for other health districts in South Africa.

CHAPTER 2

2 LITERATURE REVIEW

The literature review was conducted by using online search engines PubMed, Medscape and Google Scholar. Key words used as search terms are ‘integration palliative care,’ ‘hospice,’ ‘primary care,’ ‘primary health care,’ ‘community.’

2.1 Background of palliative care (PC) need

World Health Statistics[38] from the WHO in 2012 show that the life expectancy in the African region of the WHO is 20 years less than in Europe. Cardiovascular diseases, the leading cause of death worldwide, are three times as likely to be fatal in resource poor regions of the world, while the HIV prevalence in Africa is about 10 times higher than in Europe, the HIV mortality was 40 fold higher yet per capita government expenditure on health in US dollars is 170 times higher in Europe than in Africa. The amount of people living on less than one US dollar per day is 43 % in Africa and other LMIC of the WHO compared to zero % in Europe and other HIC of the WHO.

In the same World Health Statistics 80% of the 17.3 million annual deaths due to cardiovascular diseases and 70 % of the 76 million annual cancer deaths occurred in LMIC.[38] Twenty five million people have died of HIV in the last three decades, the vast majority in economically disadvantaged countries.[39]

Stjernsward et al.[13] In 2007 in his article on the Public Heath Strategy (PHS) for PC showed that worldwide, there is a notable unmet need for PC, of the 58 million people dying annually (45 million in LMIC, 13 million in HIC). “It is estimated that at least 60% (35 million) will have a prolonged advanced illness and dying and would benefit from PC”. They also noted that already there are 600 million persons 60 years of age or older, about two thirds of the dying patients would probably benefit from PC with a minimum of two family members engaged in each patient’s care, PC can increase the quality of life of more than 100 million people yearly globally and the only way for universal access to be achieved in resource poor countries will be by adopting a public health approach.[13]

The PC service models which have developed in the USA and UK are too expensive and if transplanted in low income countries, would not reach more than a small percentage of those in need.

The Lancet Commission on palliative care and pain relief[40] (2018) described the need to alleviate the access abyss in PC and pain relief. The report highlighted the imperative of universal health coverage (including palliative care) and the fact that poor people in all parts of the world live and die with little or no PC or pain relief because of poverty and inequity. The report also stated that denial of access to such an inexpensive intervention in LMICs is a medical, public health and moral failing and a travesty of justice.

The WHPCA[4] advised that service delivery patterns for the developing world will have to take into account the available resources and context such as, economic and culture within the developing world.

Emanuel et al. in their 2010 study on the Economic Impact of Illness and the Willingness to Change It, observed that patients‘ expenses for treatment, combined with absence of social security can have a domino effect on poor families with treatment related debt and the loss of a livelihood pushing families that are unpaid workforce in treating their relatives below poverty line and children leaving schools.[41]

Harding et al. reported in an international multi study centre in Africa in 2012, Prevalence, Burden, and Correlates of Physical and Psychological Symptoms among HIV Palliative Care Patients in Sub-Saharan Africa that 70% of HIV patients reported hunger as a symptom.[42] “The most common symptoms were pain in the physical dimension (82.6%) and worry in the psychological dimension (75.4%)”.

Harding et al.[43] in another article in 2003 had observed that in Africa the needs of hundreds of thousands of children orphaned by AIDS has severely stretched the timeline and boundaries of PC provision.[43] Many PC programmes collaborate with other agencies to provide nutritional assistance, safe housing, and income generating projects, PC programmes have to find resources to provide free medicines, to support the education of children, and find alternative source of livelihood for needy families.

According to Lynch et al.[25] in their study in 2006, Mapping Levels of Palliative Care Development: a Global Update, very few African countries have anything approaching a country wide network of PC services. These are South Africa, Kenya, Tanzania, Uganda, Zimbabwe and Malawi. In 2006 countries of the world were grouped into four groups: "Group 1 (no known hospice-PC activity) and Group 2 (capacity-building activity), but Groups 3 and 4" have been subdivided in 2011 "to produce two additional levels of categorization: 3a) Isolated PC provision, 3b) Generalized PC provision, 4a) Countries where hospice-PC services are at a stage of preliminary integration into mainstream service provision, and 4b) Countries where hospice-PC services are at a stage of advanced integration into mainstream service provision." In 2011, according to Lynch et al.[25] "136 of the world's 234 countries (58%) had at least one PC service an increase of 21 (9%) from 2006, with the most significant gains having been made in Africa."

Gomez-Batiste, Connor et al. in their 2018 publication on Building Integrated Palliative Care Programs and Services[2] also noted that regional analysis of PC progress between 2006 and 2011 shows that the most substantial advances have been made in Africa. "Although there are indications of interest in PC on the part of national governments and policy makers, advanced integration of PC with wider health services has been achieved in only 20 countries globally (8.5%). Despite increasing calls for PC to be recognized as a human right, there remains much to be done before PC is accessible equitably and globally.[2]"

Harding et al.[42] had shown in their 2012 study on Prevalence, Burden, and Correlates of Physical and Psychological Symptoms among HIV Palliative Care Patients in sub-Saharan Africa that in LMIC, there is often confusion about which life threatening illness fall within the remit of PC, in some African countries, more than 20 % of the adult population is HIV positive, twenty five million had died of HIV in the last three decades and the vast majority in economically disadvantaged countries. However where ARVs are provided HIV is no longer the killer it was.

Callaway, Currow et al. stated in their study; Funding for Palliative Care Programs in Developing Countries (2007),[12] that financial supports from the international donor community is often conditional and limited to people who are HIV positive and with the stipulation that the specialized PC units take on stable HIV patients just for support care. This impacts directly on available time and resources and therefore disadvantages many dying patient. People with severe chronic obstructive pulmonary disease may not be eligible for care, even though the suffering may be no less.[12]

Currow et al.[44]said in a study; Community-based Palliative Care: The Natural Evolution for Palliative Care Delivery in the US (2013), that cancer in Africa has doubled in incidence with the advent of HIV. Where oncology services and palliative radiotherapy are non-existent, there can be protracted suffering from pain and fungating wounds. Affluent people in Africa can access state of art technology for anti-cancer treatments, but not facilities for PC. Many centres with the latest machines and anti-cancer treatments do not stock oral morphine for home based care and their intensive care unit had become a place to admit the dying patient.[44]

The original definition WHO for PC as applicable when “the disease is no longer amenable to curative treatment” may have inadvertently caused suffering by sometime denying symptom relief and psychosocial support when anti-cancer treatment is still in progress according to Connor et al.[4]and that those trained in PC must be equipped to care for patients with life limiting illness, whether or not they require EoLC.

2.2 Families part in PC.

In traditional societies of Africa, according to Gwyther et al.[5] in their text book: Development of Palliative Medicine in Africa. Textbook of Palliative Medicine and Supportive Care. It is rare to find a patient dying alone in a hospital or nursing home and Rosa et al.[16] in their study on The Advancement of Palliative Care in Rwanda, describe the active role that family members play in providing care. Rajagopal et al.[18] describe that families provide an important resource to build on in PC – “willing hands” that can be trained in many aspects of physical care.[18] For this to work, PC services should develop simple nursing protocols, and respond thoughtfully and sensitively to care givers emotional and financial struggles and their concerns about contagion and address fears about addictive potential of opioids. In addition, truth telling and communication that is understandable by the family is an important consideration.[18]

Rajagopal et al. stated in Providing Palliative Care in Economically Disadvantaged Countries; Oxford Textbook of Palliative Medicine (2015 edition) that family involvement[18] has its negative aspects too, in societies where families can override the autonomy of the patient, relatives may demand the continuation of futile treatments, regardless of the wishes of the patient. On the other hand, a fatalistic attitude towards suffering and death may limit care. The health care team may have to negotiate with numerous relatives before they are allowed to discuss prognosis and options with the patients. Unsolicited advice from extended families, differences of opinions with the accusations about "not doing enough,"[18] and a lack of respect for privacy can also create problems for the patient.

In integrating PC into the health care system, Kamal et al.[44] in their 2013 study Community-Based Palliative Care: The Natural Evolution for Palliative Care Delivery in the US has highlighted the need for also integrating the out-of-hospital PC with the in-hospital PC. PC would extend through the full course of progressive chronic illness rather than concentrating only on EoLC and ultimately improve PC in the community.

2.3 "Public health approach to Palliative care"[13]

A public health approach to PC was the framework chosen by the WHO since 1996. It was developed by Stjernsward et al.[13]

The WHO Public Health Strategy has four components; "appropriate policies, adequate drug availability, education of healthcare workers and the public, and the implementation of PC services at all levels" in the society. The key elements of the WHO public strategy are government policy ensuring integration with and not separated from the mainstream of other health care services, an education policy including HCPs, volunteers and the public and a medication policy that assured the availability of essential medications.

According to the Global Atlas of Palliative Care at the End of Life,[4] these key elements are based on the work defining the greatest perceived need of people needing EoLC. The need for protocols, guidelines and standards are integral to successful PC programmes.

2.4 International & national advocacy and influencing government policy effects

2.4.1 Generating Adequate Policies

Clark et al.[9] in their 2000 article on Palliative Care History: a ritual process, had shown that PC developed in very different ways around the world due to local experts (and their network of colleagues), differing health and social systems, differing sources of funding, and different perceptions of needs by the communities served by these services. The development of these PC services around the world was outside the normal health system policy and planning processes of countries involved.[9]

They show further that, it is doubtful that any country in the world has commenced hospice or PC services in response to well-formed national policies with adequately funded planning and development phase. Rather South Africa like most countries have built PC services on the momentum of visionary clinicians and funders who have responded to perceived needs from HCPs, patients, families, and the communities which they live and according to Gwyther L. in her 2002 study, South Africa: The Status Of Palliative Care, South Africa.[11]

The Global Atlas of Care at the End of Life published by WHO and WPHCA and edited by Connor et al. indicated that without good policies backing the delivery of PC in a country, it is quite challenging for PC to grow in any country. There is no government support whatsoever for PC In some countries, in others, consent to operate has to be granted.

Stjernsward et al. in their 2007 article Integrating Palliative Care into National Policies[14] stated that "good policies lay the groundwork for an effective health care system and society. They facilitate the implementation of PC programs aimed at providing care for all people in need of these services, and they ensure equitable access to affordable medications and therapies". The lack of good policies according to Stjernsward et al.[14] "can lead to unnecessary suffering and costs for patients, families, and society". In the same article they wrote that 75% of cancer patients globally are incurable when identified and because the magnitude of the suffering accompanying cancer is significant, development of a National Cancer Control Policy is an operative access point to initiate incorporating PC into a Nation's Health Structure and to be complete, all cancer clinic must include PC.[14]

Policy is an important component, without appropriate policies other changes cannot be introduced. Types of policies needed according to Connor et al[4] include: "laws that acknowledge and define that PC is part of the healthcare system; national standards of care describing PC; clinical guidelines and protocols; establishment of PC as a recognized medical specialty/subspecialty; regulations that establish PC as a recognized type of healthcare provider with accompanying licensing provisions; a national strategy on PC implementation”.[4]

In South Africa PC works started with the establishment of hospice services, Wits Hospice (1979), Saint Luke’s Hospice and Highway Hospice (1980). The Hospice Palliative Care Association (HPCA) was formed in 1987according to Gwyther,[11] when there were 15 hospices in South Africa. This background is important in that it places in context the work that is being done on the national level to create effective policies that can further the effective delivery of good PC long after the services have commenced and often, after a large number of apparently local services have been well established.

Currow and Kassa [45] in their article, Policy in Palliative Care; Oxford textbook of Palliative Medicine (2015 edition) argue that national policy initiatives reflect the breadth of service provision, the diversity of health service delivery models (in response to local funding and broader health service provision models in health and social service) and the basic philosophies about life, death, and care in the communities in which the services had been built. In some cases policy generation and any accompanying legislation or regulation may also reflect specific political imperatives at particular time points in a jurisdictional environment examples given in the World Health Assembly legislation for all countries.

Currow and Kassa further stated in the same article.[18] that a fundamental aim of good government is to develop and implement policy that optimises the wellbeing of its citizens. Given the universal nature of death, and the increasing prevalence of expected death from chronic, progressive conditions, it should be expected that there are policies and even legislation that ensure good EoLC is given to people. Such policy must be informed by the best possible data, and to seek to understand explicitly the needs of people at the end of life and their caregivers in order to generate the best possible frameworks for care delivery and support.

According to Currow and Kassa,[18] the policy in health care delivery reflects complex political processes that substantiate priorities and the subsequent responses that may or may not include budgetary allocation and changes to legislation, regulations or both. In most settings around the world, formulation of health policies is shared between politicians, professional stakeholder organisations (medical and para medical societies) patient organisations, public servants and the general society. In some cases policy is driven by a political imperative and at other times by public servants or other bodies presenting key issues to their government, with proposals to prioritize a particular issue and on how to prosecute the issues in public policy. In most settings this makes for a dynamic process of tacit or overt negotiation between the political and operational arms of government.

Any policy is a series of compromises[18] according to Currow et al. there are always competing interest that will help shape the final results. The factors that influence policy are not always explicit and may relate at times, to policy initiatives that are seemingly unrelated. Tracing such processes is almost impossible. Changes in health care policy will often take time, and consistent work is often needed to generate and sustain any change in direction. At times there may also be differences in the approach between various level of government and public administration within the same country. This may lead to differences in policies and documents that may be difficult to reconcile. Vested interests abound in bringing together the wide variety of opinions that help to inform any societal policy, given the increasing plurality seen in many communities around the world.

Policy that relate to health service delivery will have significant pressure exerted on it, depending on the funding models that are used to pay for health care. Private practitioners operating on a fee for service basis may bring very different pressure to negotiations than a health system where payment is primarily through capitation. Financial gains and losses are powerful factors in influencing policy and hence referral from one clinical service to another.[18]

2.4.2 Strengthening Policy documents: Evidence based policy

Basch and Abernethy et al.[46] in their 2011 article on Supporting Clinical Practice Decisions with Real-Time Patient-Reported Outcomes, emphasized on evidence based public policy is as important as evidence based clinical practice, and where sufficient evidence is not available it is imperative that adequate research is done to understand the net effect (benefits and harms), not just with highly motivated clinicians who are willing to participate in such studies, but also in sites that are not particularly interested in the processes.

They postulated further that after implementation sufficient resources need to be invested in the ongoing evaluation of the training required, the uptake, and the outcomes using prospectively collected data with specific questions about performance of the programme as well as seeking signals of any untoward or unintended consequences, as part of a learning health care system.

Lomas et al.[47] in an article on Connecting Research and Policy concluded that, ideally good public policy is informed by the best available evidence not simply political expediency.

Gluckmann et al.[48] in a discussion on Towards Better Use of Evidence in Policy Formation added that a formal structure that is applied in other areas of medicine may also be applied in PC which consists of the following steps, literature reviews and review of best practice, international/ national guidelines, clinical care pathways, audit/assessment of outcome(s).

The literature review and review of best practice and national guidelines according to Gluckmann et al.[48] should ideally be endorsed by national and regional health care authorities in order to assure allocation of sufficient resources to implement the pathways and evaluate the pathways impact on health outcomes.

The assessment of policy documents must include the effectiveness of introducing these measures, level of adherence to the pathways, and reasons for non-adherence or poor uptake. Ideally the effect/outcomes on patient care before and after the introduction of the pathway should be prospectively assessed, this assessment can be conducted at patient level but also through pre-defined quality indicators at institutional, regional and or national level.

Rowett D et al.[45] emphasized that “access to affordable priority PC medicines needs to be informed by good clinical data from well-conducted clinical trials designed to address efficacy, cost-effectiveness, and safety” and that the “availability of priority PC symptom control medicines improves the provision of PC in the place of patient’s choice including the community”.

Stjernsward.J et al. in their works on Public Health Strategy (PHS) and PC development in Uganda[15] stated that successfully developing PC services require every level of government funders to develop and support policies that can ensure the widest reach of services and the most equitable distribution of limited resource. They also emphasize in another article from Jordan, Jordan Palliative Care Initiative: A WHO Demonstration Project that successful integration of PC requires the development and maintenance of close ties with the existing health and social policy makers and funders and in their work in Mongolia, Mongolia: Establishing a National Palliative Care Program that building on international, national, and sub-national initiatives is delivering improved access to palliative care services around the globe.

Murray et al.[49] demonstrated that lack of timely identification of palliative care patients is the greatest barrier to early palliative care, they suggested there should be routine and systematic consideration similar to screening for cardiovascular risk factors for diabetes especially at treatment reviews, hospital admission or discharge, and annual medical examinations in older people. Policies on how to identify who needs palliative care and who does not, what disease entity qualifies for palliative care and who gives it, are needed because there is a lot of confusion already in LMIC.

Previous definition of WHO defining palliative medicine as being limited to life limiting conditions or general beliefs that PC is only EoLC also makes it mandatory that HCP that are trained in PC delivers it, local job description for staff involved to avoid duplication of services and omission of important service are avoided are highly needed in adapting national policy locally according to Connor et al.[4]

Gwyther et al. in an article in 2008, Palliative care as a Human Right, stated that access to integrated palliative care is a basic human right.[50] South Africa is rich with lessons on human rights, it is of concern that in the past this rights had been violated both in South Africa and in many LMIC through neglect of PC as an integral part of continuum of care. Right to health is a human right.[50]Funding is a major determinant of policies, since right to health is a human right for provision of care and training needs to be available at all levels for the care of citizens and especially the vulnerable groups of which constitute a high percentage of palliative care patients.

Callaway et al. in their article, Funding for Palliative Care Programs in Developing Countries (2007), noted that “the funding necessary to cover essential PC services usually exceeds the financial means of many developing countries. Health care services may have to be complemented by nongovernmental organizations that are dependent on fund raising and voluntary donations from a variety of external sources. Coordinated action by international funding agencies is needed to ensure that the world's poorest people have access to essential medications and appropriate PC. To this end, international networking in the PC field is vital".

Stjernsward et al. also added in The Public Health Strategy for PC (2007) and Integrating Palliative Care into National Policies (2007) that motivation and training of health care professions for effective quality care delivery has to be included in budgets.[13, 14]

2.4.3 Planting Palliative Care; international collaboration

According to Connor et al.[4] The WHO through its collaborating centres, recognises that policy making bodies need individuals at beacon services as fulcra to initiate implementation. Lavy et al.[22] said that local pioneers can be empowered with advocacy tools, teaching curricula, clinical guidelines and policy documents developed by international organisations, associations, and academic centres without having to re-invent the wheel.

In a study on; What are the Essential Medications in Palliative Care? A survey of Australian palliative care doctors, good palliative policy has been shown by Good et al.[51] to influence health care delivery in other parts of health care system.

A study done by Marcus et al.[17]in 2017, which Primary Care Model? A Qualitative Analysis of Ward-Based Outreach Teams in South Africa, in some selected South Africa National Health Insurance (NHI) pilot sites support for the plan "to extend PHC services to people in their homes and communities." This recognises that an individual experiences health and illness with a family context. In addition, providing care in a person's home assists in reaching marginalised people. Community based PHC strengthens a health system, can address some of the problems associated with facility-based services and is viewed as a sustainable and affordable way of achieving public health goals, according to the results of a study done in Catalonia in 2001 by Serra-Prat et al. Home Care Teams for Terminal Cancer Patients allow for Savings to the Health Care System,[52] home PC is cost-saving. The cost of using resources other than patients' homes in EoLC was 71% higher when compared to home care.

2.5 International and national advocacy and influencing drug availability

2.5.1 Essential drug Availability

Gomez-Batiste et al. noted in Building Integrated Palliative Care Programs and Services[2] that the United Nations included access to essential medicines as part of the right to the highest attainable standard of health ("the right to health"), target 8E of the eight millennium Developmental Goal. In spite of all the efforts and commitments of the WHO and the UN, the vast majority of the global population still does not have access to essential medicines.

Although there are no specific reports according to Gomez–Batiste et al.[2] on access to essential medicines used in PC, many of these global reports include medication used in PC such as potent analgesics, antidepressants, laxatives and others. Of these, lack of access to opioids is a global problem which had been highlighted in many global and regional reports.[4]

The WHPCA in a recent (2018) article published by Connor et al. estimated that 80% of the world population, including tens of millions of people worldwide who suffer from moderate to severe pain, does not have access to adequate pain treatment.[6]

In 2009 according to the opioids consumption data of the Pain and Policy Study Group (PPSG) 83% of people who live in the low income countries only utilise 7% of the world medical morphine[4]. This include 5.5 million terminal cancer and 1 million end stage AIDS patients.

The WHPCA 2018 campaign, according to Gwyther et al.[6], highlighted a reality that 75% of the world's population (5.5billion) lacked "adequate access to pain relieving medications and about 18 million people die each year untreated pain while we have the knowledge to treat and medicines to relieve almost all moderate to severe pain."

Brenan, Gwyther et al.[50] argue that PC is a human right. Connor et al.[2] stated that "access to essential medicine as part of the highest attainable standard of health is well founded in international law and that the right to health first emerged as a social right in the WHO constitution and in the Universal Declaration of Human Rights. The binding International Covenant on Economic Social and Cultural Rights (ICESR) details the progressive realization of the right to health through four concrete steps, including access to health facilities, goods and services. The General Comment 14 further applies the principles of accessibility, availability, appropriateness and assured quality to goods and services" which include essential medicine as defined by WHO according to Connor et al.[2]

Gwyther et al. in two separate publications, Palliative care in chronic disease[53] (2014) and Development of palliative medicine in Africa. Textbook of Palliative Medicine and Supportive Care[5] (2015) stated that the care in the homes improves patient outcomes, is affordable, and improves access to care.

Connor et al. in their publication in (2017) Building Integrated Palliative Care Programs and Services,[2] stated that access to essential medicine is one of the six WHO leadership priorities for 2014- 2019 endorsed by WHO member states, the 2014 World Health Assembly (WHA) Resolution on Access to Essential medicine; the WHA Resolution on PC; the UN Global Action Plan on Non-communicable Diseases; and the 2011 WHO World Health Report on Universal Health Coverage.

The WHA "emphasizes the importance of access to PC and to essential medicines for medical and scientific purposes," including opioids analgesics such as morphine[54]. As described above, this resolution calls on "governments to ensure adequate domestic funding and allocation of human resources, supporting the availability and appropriate use of essential" medicines and to update national essential medicine list in the lights of the addition of "sections on pain and PC medicines to the WHO Model List of Essential Medicines and the WHO model list of essential medicines for children." Levy et al.[22] stressed that "having palliative medicines in the WHO list is critical and may contribute to their better use and raise awareness of access to medicines for PC." According to De Lima et al.[18] In 2013 the WHO model list was created containing a separate section include medicines for pain and PC in the model lists of for both adult and children, in previous editions of the WHO Model list, medicines for PC were a category under the oncology section.

Advocacy by many organisations including United Nations, bodies and non-governmental organizations to improve availability, increase awareness and knowledge of these essential medicines led the International Association of Hospice and Palliative Care (IAHPC) based on the WHO concept of essential medicines to develop an Essential Medicine List for Palliative Care[55] and the Opioids Essential Prescription Package (OEPP).[55] The main goal of these projects is to improve access to medicines and better patient care throughout the world. The OEPP is designed for moderate to severe chronic pain in adults who require initiation of strong opioids, further work is needed according to De Lima et al.[18] to examine "the effectiveness of the OEPP compared to usual care in reducing adverse effects and improving tolerability of opioid treatment, leading to better pain management."

De Lima et al.[55] published the IAHPC list of essential medicines in palliative care in 2006. It was developed from the WHO Model List Of Essential Medicines[20] published in 2005 which had a section called palliative care but was blank with no list of medications but a paragraph stating that all drugs mentioned in the WHO publication Cancer Pain Relief With a Guide To Opioids Availability[56] be considered essential. According to De Lima et al. this publication had since been revised and replaced by other publications including WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illness,[18] WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Adults with Medical Illness, and the WHO Guidelines on the Pharmacological Treatment of Acute Pain.[18]

The IAHPC List of Essential Medicines in Palliative Care[53] does not specify dosages or combination of treatments regimens such as those needing chronic pain treatment. The list does not recommend which opioid, laxative and emetic may be most safe and effective in the treatment of chronic pain in patients who require initiation of strong opioids.

According to the WHO[56], opioid medication are the mainstay of moderate to severe pain treatment. However, in A Review of Published Literature in Prevalence of Under Treatment in Cancer Pain, Deandra et al.[57] reported that an estimated 80 % of patients in need do not have adequate access to analgesics. Regulatory barriers and limited resources are among several causes of poor availability of medications. In addition they added that inadequate training of HCPs and poor communication between patients and physicians "often lead to undertreated pain and the presence of adverse effects that are preventable or treatable. "

Campora et al.[58] in their study on Narcotic-Induced Emesis (1991) postulated that nausea and vomiting occur in 14- 15 % of patients using opioids. Davies et al.[59] in their article, Treatment of Nausea and Vomiting in Advanced Cancer. (2000); stated that "adverse effects of opioids such as constipation and nausea may limit the dosing of opioids and lead to early discontinuation and inadequate analgesia."

Some HCPs suggest using antiemetic for the prevention of nausea and vomiting whenever opioids are prescribed, but there is limited evidence to support this recommendation. According to Davies et al.[59] Treatment of nausea and vomiting in advanced cancer (2000) Metoclopramide is generally recommended as first line therapy given that it has central nervous systemic effects as well as aiding gastric emptying. Medications with central nervous system effects, such as cyclizine, haloperidol, leavopromazine,[59] had been shown to be effective but also cause sedation and other adverse effects[42]. There are no studies to indicate the effectiveness of one anti-emetic medication over another in the management of opioids induced nausea.

Rowett et al.[45] in their 2009 article Using National Health Policies improve Access to Palliative Care Medicine in the Community said that "access to affordable priority PC medicines needs to be informed by good clinical data from well-conducted clinical trials designed to address efficacy, cost-effectiveness, and safety. Availability of priority PC symptom control medicines improves the provision of PC in the place of patient's choice including the community."

Hanks et al.[60] in their 2001 paper on Morphine and Alternative Opioids in Cancer Pain: The EAPC Recommendation, stated that the selection of the medication for the IAHPC list of essential medications for PC and the OEPP is consistent with different clinical guidelines and critical reviews in symptoms management.[60]

Joranson, Ryan et al.[61] in their 2007 study Ensuring Opioids Availability; Methods and Resources stated that the "challenges in the provision of pain treatment in many countries are complex and include poverty, illiteracy, language barriers, limited health care resources", lack of training and unnecessary "restrictive laws and regulations which limit the distribution, prescription dispensation and use of controlled medications". According to De Lima et al. in some countries, more expensive medication and formulations become available before cheaper medications or formulations and in response to this situation the IAHPC included a footnote in the list of Essential Medications for Palliative Care, stating that no government should approve modified release morphine, fentanyl, or oxycodone without also guaranteeing the availability of immediate release oral morphine.[20]

The IAHPC Lists of Essential Medicines in Palliative Care and the OEPP studies have several limitations, both studies have participants selected from convenient samples of a working group of international experts in the field and the final results are based on consensus opinion. Additional research to evaluate the safety and efficacy of these medications needs to be carried out. Moreover the two projects did not address cost and affordability issues and the list was developed for adults patients

2.6 International & national advocacy and influencing training movements

2.6.1 Training needs: Education in palliative medicine

The world health assembly (WHA)[54] mandates the training of all health practitioners in an on-going training in accordance to their roles and responsibilities on three levels, basic, intermediate and specialist.

Connor et al. in the Global Atlas of Palliative Care at the End of Life,[4] identified a lack of global information about education and training plans in PC all over the world. Only 20 % of countries have developed PC services and most countries do not have any specific national plan for PC. However, some of them have integrated PC proposals into other national plans. It is noted that education and training plans do not correspond to national health and strategies in PC, even though training programmes had been identified in this countries. Whilst there has been progress in providing and improving educational opportunities for physicians at all stages of their training, training deficits still lead to many patients receiving poor care at the end of life.

In 2016 Pivodic et al.[62] in a study in the United Kingdom (UK) on Home care by General Practitioners for Cancer Patients in the last 3 months of life: An Epidemiological Study of Quality and Associated Factors, 55% bereaved relatives reported excellent or very good home care by general practitioners, compared with 78% for specialist PC providers and 68% for district/community/private nurses. “The odds of high satisfaction (excellent/very good) with end-of-life care by general practitioners doubled if general practitioners made three or more compared with one or no home visits in the patient’s last 3 months of life and halved if the patient died at hospital rather than at home.”

2.6.2 Undergraduate teaching

The European Association for Palliative Care (EAPC) White Paper on Core Competences in Palliative Care Education,[23, 24] highlights the need for structural programmes of education incorporated into the training of all HCPs acknowledged the strategic shift in PC practice that most curricula had moved towards competency-based objectives. Competences are a set of observable and measurable behaviours encompassing the combined knowledge, skills, abilities and personal attributes that make someone able to carry out a given task or do a given job. In designing teaching, the desired learning objectives/outcomes, or competency statements for the students should be made clear. Objectives drive assessment and assessment drives learning. So objectives should be specific, measurable, achievable, relevant and timely (SMART) and particularly for competency – based assessment, should make explicit what the student needs to be able to do, under what circumstances, how well, and when according to EAPC.

Meekin et al.[63] developed the Palliative Education Assessment Tool to facilitate the mapping of palliative care education. They suggested that seven domains should be included in any undergraduate curriculum. These are PC, pain, neuropsychological symptoms, other symptoms, ethics and the law, patient/family /nonclinical caregiver perspectives on EoLC and clinical communication skills. In setting up or reviewing an undergraduate course, this tool could allow faculty to map existing provision, including, in an increasing multidisciplinary health care environment, teachings delivered by other HCPs, which might otherwise not be obvious. Alternative method of planning undergraduate teaching curriculum according to Meekin et al.[63] can be through a Delphi technique, focus groups of staff and students, previous student evaluations, or faculty opinion. Having identified gaps, teaching and learning experiences to address them can be designed and implemented.

A variety of approaches has been used to introduce PC experience. In some schools, teaching was not part of the core curriculum and students gain only optional PC experiences. Many school continues to deliver a small number of lectures and tutorials, others were more innovative. According to Marks and Bertman[64] in their 1979 article; Communicating with the Dead: An Ongoing Experience as expressed in Arts, Literature and Song , some schools introduce learning about death and dying during anatomy dissection sessions or communication skills teaching sessions.

Torke et al.[65] in their 2007 paper on Peer Guided Cooperative Learning Enhancing the Performance of Refresher Students; highlighted that as PC gains increasing popularity and credibility more diverse and teaching methods will be employed. Knowledge based learning objectives can be acquired through lectures, tutorials, and group discussions. Skills can be encouraged through problem based learning, role play consultations with simulated patients and supported hospice visits and clinical attachments.

Schillerstorm et al.[66] in their study in 2012 on Improving Student Comfort with Death and Dying Discussions through Facilitated Family Encounters postulated that more recent approaches include involving bereaved family members in teaching communication skills and the use of films, drama and literature to teach PC skills.

Ellman et al.[67] in 2012 in an article on - Using Online Learning and Interactive Simulations to teach Spiritual and Cultural Aspects of Palliative Care to Inter-professional Students highlighted on the use of e learning and simulation to teach spiritual and cultural aspects of care. The article noted that teaching about attitude is complex. Attitude was defined as a settled way of thinking or feeling. Professional attitudes are important in many areas of medicine, but perhaps particularly so in PC where attitudes such as seeing death as a failure, wishing to avoid dying patients, and fears about opioids can all influence patients care adversely.

Gibbins et al.[68] in a study in 2011, on - Why are Newly Qualified Doctors unprepared to Care for Patients at the End of Life? Suggests that end of life issues are not discussed within the culture of the working environment and so these attitudes may remain unaddressed. Studies also show that attitudinal change may occur with increased knowledge alone, but it may require also role modelling and facilitated discussion and reflections following clinical or educational encounters.

2.6.3 Postgraduate training

The EAPC in their white paper on training[23, 24] outlined three groups of health care practitioners (HCP) who requires training to improve their service to patients in their domain. First, staff who work in specialist PC and hospices. Second, staff who frequently deal with end of life care as a part of their role. For example, secondary care workers who work in the emergency department, "acute medicine, respiratory medicine, care of the elderly, cardiology, oncology, renal medicine, intensive care, and those who work with patients with long term neurological conditions". The third group are staff who work within other services do not often have to care for patients at the end of life.

The EAPC white paper[24] stated that all staff need training in communication skills, assessing patients' needs and preferences, advance care planning and symptom control. The first group will have their own specialist curricula while those in the third group will need mainly to be aware of PC issues and empowered to recognize that a patient might be approaching and need EoLC. Within the second group are the recently qualified doctors who are generally the clinicians who spend most of the time with patients with PC needs and according to the EAPC white paper,[24] their early post qualification period is, therefore an important time for them to put their undergraduate training into practice and to consolidate their PC skills.

In a Study by Charlton and Smith,[69] in year 2000 on Perceived Skills in Palliative Medicine of Newly Qualified Doctor in the UK, have shown that many newly qualified doctors report being unprepared to care for patients with PC needs. They lack confidence in breaking bad news, empathizing, discussing prognosis and symptom control and managing distress and social issues.

Bowden et al.[70] in their study of Medical Student Teaching in The UK: How Well are Newly Qualified Doctors Prepared for their Role Caring for Patients with Cancer in Hospital? They find out in a survey of all first year graduates in the UK that 71 % felt they needed more teaching about symptom control and 41 % in communication skills in caring for patients with PC needs. In the

USA, the authors surveyed 972 internists and family practitioners and concluded that although these physicians provide PC, they feel their skills are lacking.

From the literature considering the Training of Primary Health Care or Family Practice Doctors in South Africa, Gomes et al.[62] reported that the skills and training of these group of doctors are important as most patients who know they have life limiting illness wants to die at home.

Dickson et al[71] found that HCPs are poor judges of their own competence. A randomised control trial[71] was conducted to compare trainees' self-assessments communication skills with regard to end-of-life issues and the assessments by their patients, patients' families, and clinician-evaluators. There was no correlation between these quality scores assessed by patients, patient's 'families' and clinicians evaluators and doctors' perceived competence. More worrying was that there was correlations for "treatment discussion" only, and here the more the confidence of the trainee, the lower the families ratings were. The authors concluded that efforts to improve communications about EoLC should consider outcomes other than physicians' self-assessment to determine intervention success. The best evaluation for PC teaching according to Gibbins et al.[72] is to show that it improves patient care.

Ury et al.[73] in their 2002 study; Can a Pain Management and Palliative Care Curriculum improve the Opioids Prescribing Practices of Medical Residents? Examined pharmacy record and demonstrated improved prescribing practices for pain following an educational intervention, suggesting that attitudes towards opioids and fears about addiction had been changed by education. However whether patient's pain outcomes were improved was not examined.

Miller and Wee[17] suggested we may need to consider indirect indicators of effective PC teaching rather than patients' outcomes. For example, improvements in appropriate referrals from junior doctors to specialist PC or the inclusion of PC topics within their teaching by the wilder medical school teaching community, whilst these may be useful outcomes, they remain measurable proxy outcomes. Students need exposure to real clinical experience with PC patients despite the increase in their curriculum time in PC.

Bui[74] et al. in their 2012 article on Effectively Training the Hospice Staff and Palliative Medicine Physician Workforce for Improved End of Life Care in the United States and the UK Department of Health[75] in their 2008 circular on End of Life Care Strategy, has suggested that training deficits still lead to many patients receiving poor care at the end of life.

According to Charlton et al.[69] in their study; Perceived Skills in Palliative Medicine of Newly Qualified Doctors in the UK, many newly qualified doctors report being unprepared to care for patients with EoLC and PC needs, they lack confidence in breaking bad news, empathizing, discussing prognosis and symptom control, and managing distress and social issues. They often report having received little or no training in medical school, or that it was inadequate for their role and they want to learn more. In their survey of all first year graduates in the UK with 43 % response rate from (n=2062), 71% felt they needed more teaching about symptom control and 41 percent in communication skills in caring for patients with cancer.

Williamson et al. in their 1989 article, Health Science Information Management and Continuing Education of Physicians: a survey of US primary care practitioners and their opinion leaders,[76] a survey of 972 internists and family practitioners described that the clinicians were concerned that they lacked the skills for the provision of PC although they found that they were in the position of providing such care.

A telephonic survey[77] by Billings et al. in their 2010 study; Determinants of Medical Students' Perceived Preparation to Perform End-of-Life Care, Quality of End-of-Life Care Education, and Attitudes toward End-of-Life Care; of 1455 students, 296 junior doctors, and 287 senior clinicians from accredited medical schools with response rates of 62%, 56% and 41% respectively revealed that junior doctors do not have the opportunity to learn from care of dying patients as these patients are not perceived as being “good teaching cases”. The study also found that there was a lack of role models from whom they could learn palliative care skills. Students and juniors felt unprepared to provide PC, and senior and junior doctors felt unprepared to teach palliative care skills; only 17% of senior clinicians reported having taught some aspect of EoLC in the past year.

Forbes and Gibbins[72] in their article, Teaching and Training in Palliative Medicine in Oxford Textbook of Palliative Medicine said that junior doctors learn PC experientially that ‘learning by doing’ is an effective way to learn PC. Doctors who had more experience with situations involving PC had significantly higher PC competence scores than those with less experience.

Schulman-Green et al.[78] in their 2003 study in the USA, How do physicians learn to provide palliative care? 20 house –staff reported that formal education in PC was not a major source of learning. Staff learned mostly on the job, by observing attending physicians, and by making mistakes. Gibbin et al.[68] agreed with this point.

Schulman-Green et al.[78] in same article above reported that many senior consultants have received little or no training in PC as undergraduate but rather they learnt by observing others in practice, perhaps with professionals with less training.

Fitzsimons et al.[79] in their 2007 article on The Challenge of Patients' Unmet Palliative Care Needs in the Final Stages of Chronic Illness, qualitative interviews and focus groups reveals that even caring specialists physicians find it difficult to face their patients PC needs and to discuss EoLC issues with them.[79] This is significant, since these clinicians will serve as role models to students and junior doctors, potentially influencing them, indirectly that PC issues can, or should be avoided.

Ratanawongsa et al. in their 2000 article on, Third-year medical students' experiences with dying patients during the internal medicine clerkship: a qualitative study of the informal curriculum Whilst students for example acknowledge learning from end of life courses, they found patients care experiences guided by teams that acknowledge deaths, role modelled end of life care, and respected students' participation in patient care far more useful.[80]

An interesting document on continuing professional development from the Royal College of Physicians' working party in 2012, indicates that two thirds of physicians had not attended any end of life care educational event in the last two years. Respondents were very confident in their ability to recognise when a patient was approaching the end of life, discuss this with the patient and family, break bad news, control pain and withhold or withdraw treatment. (RCP Working party 2012). These results are surprising giving the ongoing reports of poor care, but are reports of self-rated confidence only, without any proxies for actual skills. It is likely that at least some of these physicians were unaware of their own incompetence. The working party recommended that all physicians caring for patients with PC need to attend at least one relevant training event every five years.

2.6.4 Developing the culture of care

Forbes et al.[72] in their article, Teaching and training in palliative medicine in Oxford Textbook of Palliative Medicine, argued that we still need to encourage and develop innovative clinical and research partnerships to design, deliver and evaluate educational packages to demonstrate how education in PC best benefits patients and their families.

2.7 Implementation of policy and services

Lavy et al. in Palliative Care Toolkit,[22] a resource for implementing and improving PC and adapting it to local environment and cultures from the roots up in resource-limited settings, stated that policy making bodies need individuals at beacon PC service centres to act as fulcra in initiating implementation and according to them "without the passion and willingness of people at service centres who take ownership of the programme there might be challenges to implementing the policies developed". The Palliative Care Tool Kit[22] is a good curriculum which had been adapted and translated to local languages in Africa and had been shown to improve patients outcomes.[2]

Clark et all[9] shows locals champion and their network of colleagues in response to systemic defects in health system had responded to PC needs of community in different ways.

Gomez-Batiste and Connor[2] recommend adapting national and provincial policies to local communities as being crucial so that pain and symptomatic management protocols can be translated into local languages for easy understanding of HCPs and caregivers.

Kamal et al.[44] in their article on Community-Based Palliative Care: The Natural Evolution for Palliative Care Delivery in the U.S, noted that with only a few exceptions, "PC is not incorporated within health care systems. As a result, there is no allocation of public funds or institutional resources, and no reimbursement for services rendered through health insurance programs. The levels of funding necessary to cover essential PC services are usually far beyond the financial means of developing countries. Governments may not have the economic ability or political will to implement PC policies, and services may have to be complemented by those provided by NGOs" and private practitioners.

They stated that “currently, considerable workforce, cultural, institutional, and financial barriers prevent widespread implementation” of Community oriented PC and that “these issues must become priorities for researchers, payers, and policy makers who share a commitment to improving continuity, quality, and outcomes of care for patients with serious, advanced, and/or life-limiting disease.” They further suggested that “as a first step toward ensuring coordinated and effective PC across settings, we must promote and broadly instil a new manifesto: ‘bringing PC to where patients are mentally, physically, emotionally, spiritually, socially, sexually, and geographically.’ ’’ Community oriented PC may be an effective model “that delivers on this mantra”.[44]

2.8 RATIONALE FOR THE STUDY

South Africa is one of the co-sponsors of the WHA resolution that recognized PC as an essential component of the continuum of care. Worldwide only a minority of governments especially in LMIC have been able to implement PC policies effectively. It is important to use the WHO framework to plan PC services delivery and development at the grass roots.

The rationale for this study is to investigate the integration of PC effectively into the PHC Centers in South Africa, making sure all the components of the WHO’s PHS are present and appropriately implemented, which is important in the delivery and sustainability of good quality PC services at the primary care level, so that the people who need PC can have access to this care. This study aims to also provide baseline preliminary data for further research in integration of PC as an essential component of Universal Health Coverage (UHC) such as the South African National Health Insurance (NHI).

2.9 AIM

To determine the current status of integration of palliative care into the primary health care centres in Alexandra community (-26°06'8.40" S 28°05'27.60" E).

2.10 OBJECTIVES

1. To identify the existing policies including budgets available in these clinics relating to palliative care.
2. To identify the availability of palliative care essential medicines in these clinics.
3. To conduct a survey of the health care professionals' training in palliative care.

CHAPTER 3

3.1 METHODOLOGY

3.2 STUDY DESIGN

This is a cross sectional, observational study. A cross sectional study is a type of observational study that analyses data from a population at a specific point in time. A focus on Alexandra township district level PC programme could provide a blueprint for other health districts in South Africa and the use of routinely collected data allows for large cross sectional study to be made at little or no expense for the whole country.

3.3 STUDY SITE

Alexandra as a township in the Gauteng province of South Africa, forms part of the city of Johannesburg. It is densely populated and located near the upper - class suburb of Sandton. Alexandra is bounded by Wynberg on the west, Marlboro and Kelvin on the north, Kew, Lombardy West and Lombardy East on the south. It is said to be one of the poorest township areas in South Africa and it is located on the banks of Juskei River. Alexandra has five PHC clinics and a Community Health Center (CHC) in addition to its well built houses, it has a large number of shacks. The research study sites were all the six PHC in Alexandra Township namely the 4th Avenue clinic, the 8th avenue clinic, Alexandra Community Health Centre, the East Bank clinic, River Park clinic and Thoko Mngoma clinic.

3.4 STUDY POPULATION

Health Care Professionals (HCPs) employed in the clinics and the facility managers. The three different objectives have three different target populations. The target population in identifying the existing policies and the budgets available for PC in the PHC centres are the facility managers involved in the corporate governance of each clinic.

All the PHC were the target for the data on training and their professional qualifications, their levels of training in PC and the perception of their clinical competence in PC were obtained in the Survey of training.

The pharmacists, the doctors, the professional nurses and other prescribing staff were the target for the data on availability of essential medicines.

3.5 SELECTION CRITERIA

All the available HCP and facility managers involved in the management of patients in the PHC centres in Alexandra Township were selected. There are no exclusion criteria.

3.6 SAMPLE SIZE

All consenting PHC and facility managers were invited to take part in the study, the sample size was therefore determined by the number of staffs employed in each clinic.

3.7 DATA COLLECTION.

Data collection tools

In developing the data collection tools, the researcher had consulted the literature, discussed the proposed tools with colleagues and with his supervisor. To identify the existing policies and budget relating to PC, the researcher consulted with family physicians managing district clinics, literature on survey of policies and polices in other countries, the South African NPFSPC and Palliative Care Toolkit. Questions were formulated to determine the managers' awareness of the South African government NPFSPC on the national, provincial and local levels; the policies relevance to their local clinic and on who qualifies for PC; who provides the PC services job training and recruitment policies; how they provide services such as pain management, referral services both to higher services and also from their clinic to other higher institutions; control of opioids such as purchase and prescription, training and motivation for continuous professional development in PC and budgets availability In the plans of the clinic for executing the services and trainings. The questions in a questionnaire were then arranged in a descending order from the national to the local level.

In developing the structured questionnaire used to interview the pharmacists the doctors and other HCPs involved in prescribing medications for the availability of essential medicines, the researcher explored the IAHPC/WHO Essential Palliative Care Medicines List and the National Palliative Care Steering Committee Task Team recommendation on drug availability to advise which WHO essential medicines are essential for South Africa. A list of essential medicines in PC to check for their availability in the clinic pharmacies was then drawn. The researcher also reviewed the procuring and prescribing practice of the clinics and issues around procurement of scheduled drugs. The 15 essential medicines were listed mainly because of their frequent daily use in PC and because some indications were different from the normal day-to-day indications in PHC. Most of the essential drugs are on the essential drugs list of the NDoH already.

The researcher reviewed the existing guidelines on pain management, opioid prescription, procurement and opioid management, from the NDoH. Standard Treatment Guidelines and Essential Medicines List for Primary Health Care, Community Health Worker's employment and deployment. Data extraction from human resources relating to staffing especially PC. Literatures and journals on the PHS.

The researcher reviewed the EAPC White Paper on Education and Core Competencies in Palliative Care,[23, 24] The IAHPC List of Essential Practices in Palliative Care (Appendix5) and The National Palliative Care Steering Committee Task Team Recommendations on Education and Training to formulate a structured questionnaire to ascertain the HCPs' level of training and competence in PC. The self-rating scale of confidence of HCP skills were assigned numerical scores as follows: 5 = High level of competence; 4 = Moderate level of competence; 3 = Average level of competence; 2 = Low level of competence and 1 = No level of competence.

The researcher piloted the questionnaire on identifying existing policies on the HCPs and the manager available in the Rosettenville clinic which is located in the southern suburb of Johannesburg. Their understanding of the questions were clear and they advised to adopt the questionnaire as it is. The piloting exercise had no effect on respondents from Alexandra as the clinics are very far from one another and on the opposite ends of Johannesburg town. Similar questions which produce similar answers, were asked in a standard way with the same probes and clarification for each manager and their verbal responses were recorded in a uniform way (YES, No and Don't know) by the researcher (see Appendix 1). This standardisation provided validity and reliability for the survey tool.

3.8 DATA COLLECTION PROCEDURE

With ethical approval letters obtained from UCT (Appendix 8) and Gauteng provincial government (Appendix 7), the researcher approached the clinic managers, introduced the research study and also arranged to meet with the HCPs in their clinics. At each site, the research study was introduced to the facility managers first, then the HCPs. The participants were assured that their participation was voluntary and if they chose not to take part in the research, it will not affect them in any adverse way. This was part of the consent process, those that agree to take part in the research were asked to sign the consent form. All consenting HCPs were recruited. All questions were responded to by all in a meeting at each clinic.

The researcher made all necessary appointments for data collection to be convenient for the participants. Data was collected over a period of four weeks. A week was dedicated to each clinic. The 4th Avenue clinic building at the 4th avenue in Alexandra is currently being repaired, also Thoko Mngoma clinic building in 19th avenue, the two clinics were temporarily operating from the newly constructed 18th Avenue Psychiatric Clinic building presently. All the questionnaires were interviewer administered and the researcher conducted all the interviews in a private confidential room provided by the clinic managers at each clinic. Appointments were made for doctors rotating between clinics and those that visits only on certain days.

The structured questionnaires with specific response questions were used to collect data from the HCPs. The data on budget allocation for PC was obtained from the facility managers.

The survey of training of the HCPs in PC was conducted using a structured questionnaire to obtain information on demographics, levels of training in PC (basic, intermediate and specialist) and the HCPs self-rating of their skills in palliative medicine using the IAHPC Essential Practices in Palliative Medicine List and EAPC Recommendations on Core Skills in Palliative Care.

3.9 DATA STORAGE AND CONFIDETIALITY

Copies of the data collected /research instruments were kept under lock and key in the researcher's office and all electronic data were kept in a password protected computer, for privacy and confidentiality to be maintained. No names were used and all possible identifiers from the data obtained were deleted. The interviews were conducted in places that confer privacy in the primary health care centres.

3.10 DATA ANALYSIS

With the assistance of a Biostatistician, the data collected were analysed and interpreted in line with the specific objectives of the study. The different answers were tabulated and analysed by descriptive statistics such as frequencies and tables. The study data captured in Excel sheets were imported into Statistical Analytical System (SAS). Comparative statistical analyses were performed, based on the mean and median values of the averages as measures of competence. Student's two-sample t-test was applied to test for differences between two mean values in the case of equal variances. Satterthwaite's t-test was applied in the case of unequal variances. The application of a t-test is based on the assumption of normality of the underlying distributions. The sample sizes achieved in the study are mostly too small to allow for reliable normality testing. Together with each t-test, the nonparametric Wilcoxon rank sum test, not depending on normality and allowing for moderate skewness, was applied to median values to test for differences in location. Comparisons of three mean values were performed by one-way ANOVA and lsmeans. Three median values were compared by the Dwass, Steel, and Critchlow-Fligner method. All the statistical analyses were performed on a suite of analytic software Statistical Analysis System (SAS). (SAS Institute Inc, Carey, NC, USA), Release 9.4, and p values ≤0.05 (5%) were considered significant.

3.11 ETHICAL CONSIDERATIONS

Ethics approval for this research was obtained from the UCT Faculty of Health Sciences Human Research Ethics Committee (HREC REF 728/2017) (appendix 8). With ethics approval, permission from the facility managers to use their clinic as research sites was obtained from the Johannesburg Health District Research Committee (GP 2017 10 034) (appendix 7).

The participants were reassured that their skills competences, training and professional development was not under investigation and will be maintained as confidential for the purpose of this study.

CHAPTER 4

4.1 RESULTS

The result from this study is presented under the following subheadings; demographic characteristics of the respondents, awareness and implementation of the PC policies, availability of essential medicines in PC and their indications, HCPs self-perceptions of abilities.

4.1.1 Demographic characteristics of the respondent at the six clinics

One hundred and twelve HCPs were interviewed in the course of this study. Majority of the HCPs (69; 62%) were at the Alexandra clinic and the least (6; 5%) each at the 4th Avenue and Thoko Mngoma clinics (Table 4.1). Out of the six clinics used for this study, only the Alexandra clinic had the full complement of the HCPs (74; 66%) that is expected at this level of healthcare delivery and as indicated in (Table 4.1). All the clinics had Professional Nurses with the highest of 34 (49%) at Alexandra clinic and the lowest of six each at the 4th Avenue and Thoko Mngoma clinics.

Table 4. 1 Occupation of the Health Care Practitioners at the six clinics.

	Number (%)						
Occupation	**4th Ave**	**8th Ave**	**Alexandra**	**East Bank**	**River Park**	**Thoko Mngoma**	**ALL**
Dental Therapist			1 (1.45)				1 (0.89)
Dentist			2 (2.90)				2 (1.79)
Dietician			1 (1.45)				1 (0.89)
Doctor		1 (7.14)	18 (26.09)		1 (12.50)		20 (17.86)
Occupational Therapist			2 (2.90)				2 (1.79)
Physiotherapist			2 (2.90)				2 (1.79)
Pharmacist			2 (2.90)				2 (1.79)
Professional Nurse	6 (100)	12(85.72)	34 (49.26)	9 (100)	7 (87.50)	6 (100)	74 (66.07)
Psychologist			3 (4.35)				3 (2.68)
Speech Therapist & Audiologist			1 (1.45)				1 (0.89)
Social Worker		1 (7.14)	3 (4.35)				4 (3.57)
TOTAL	6 (100)	14 (100)	69 (100)	9 (100)	8 (100)	6 (100)	112 00)

4.1.2 Year of Graduation of the HCPs

The time of graduation of the HCPs that participated in this study was between the 1966- 1970 period working at the East Bank and Thoko Mngoma clinics and more recently in the 2016 – 2020 period working at the Alexandra clinic. HCPs that graduated in the 2011 -2015 period are present in all the six clinics.

Table 4. 2 Year of graduation of the HCPs

year of graduation	Number (%)						
	4th Ave	8th Ave	Alexandra	East Bank	River Park	Thoko Mngoma	ALL
1966 – 1970				1 (11.11)		1 (16.66)	2 (1.79)
1971 -1975		2 (14.29)	2 (2.90)				4 (3.57)
1976 -1980	1 (16.67)		2 (2.90)			1 (16.67)	4 (3.57)
1981 – 1985			4 (5.80)				4 (3.57)
1986 – 1990			3 (4.35)			1 (16.67)	4 (3.57)
1991 – 1995		1 (7.14)	6 (8.70)	1 (11.11)		1 (16.67)	9 (8.03)
1996 – 2000	1 (16.67)	2 (14.29)	9 (10.14)	1 (11.11)			11 (9.82)
2001 – 2005	1 (16.67)	4 (28.57)	10 (14.49)	1 (11.11)	2 (25.00)		18 (16.08)
2006 – 2010	2 (33.32)		11 (15.94)	3 (33.34)	4 (50.00)	1 (16.67)	21 (18.75)
2011 – 2015	1 (16.67)	5 (35.71)	10 (14.49)	2 (22.22)	2 (25.00)	1 (16.66)	21 (18.75)
2016 – 2020			14 (2.030)				14 (12.50)
Total	6 (100)	14 (100)	69 (100)	9 (100)	8 (100)	5 (100)	112 00)

4.1.3 Age

The mean age of the health care practitioner varied from 35.3 years at the River Park clinic to 53.8 at the Thoko Mngoma clinic. Thoko Mngoma clinic is the oldest PHC center in Alexandra Township after Alexandra CHC. Thoko Mngoma clinic have two retired Nurses among staff members (Table 4.3, Figure 4.1).

Table 4. 3 Average Age of HCPs

Age	CLINICS						
	4th Ave	8th Ave	Alexandra	East Bank	River Park	Thoko Mngoma	ALL
	6	14	69	9	8	6	112
Mean	40,2	43	42,1	47,7	35,3	53,8	42,7
Standard Deviation	14,27	13,01	13,2	15,44	8,26	16,75	13,52
Median	37	41	42	43	34	53	41
IQR	30-42	34-48	30-53	32-60	29-40	41-70	31-53
Min/Max	29/67	27/71	23/70	31/70	26/51	30/74	23/74

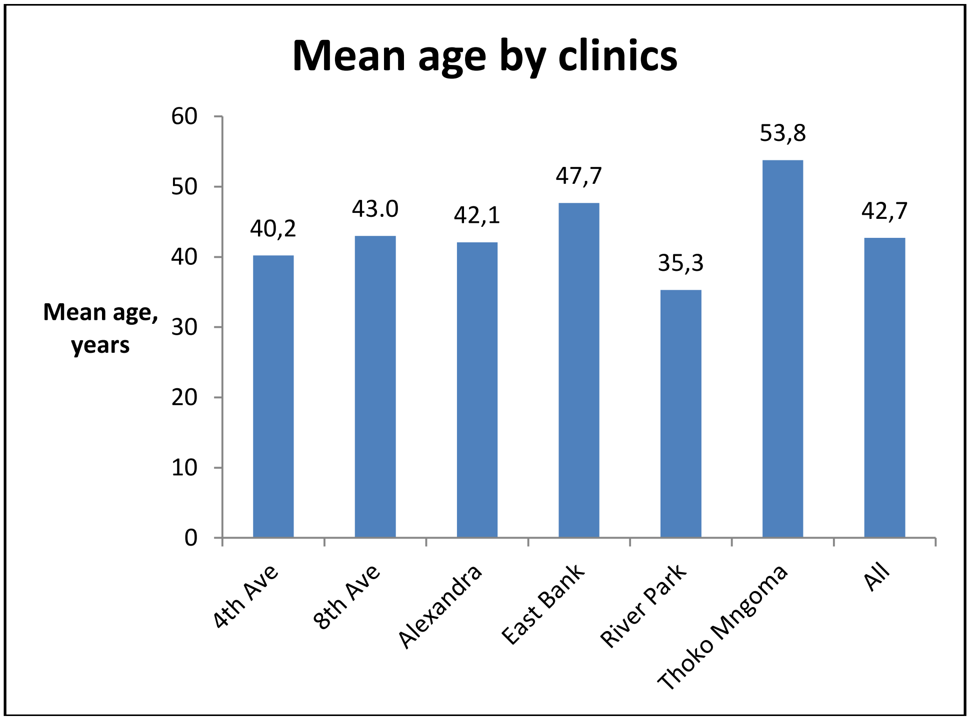

Figure 4. 1 The mean age of the health care practitioner at the six clinics.

4.1.4 Gender

Of the total respondents (n=112), 93 (83%) were females and 19 (17%) males. The distribution across the six clinics is shown in (Table 4.4). Alexandra clinic had the highest number of staff.

Table 4. 4 Gender

Gender	Number (%)						
	4th Ave	8th Ave	Alexandra	East Bank	River Park	Thoko Mngoma	ALL
Male	1 (16,7)	3 (21,4)	12 (17,4)	1 (11,1)	1 (12,5)	1 (16,7)	19 (17,0)
Female	5 (83,3)	11 (78,6)	57 (82,6)	8 (88,9)	7 (87,5)	5 (83,3)	93 (83,0)
Total	6 (100)	14 (100)	69 (100)	9 (100)	8 (100)	6 (100)	112 (100)

4.2 Training in Palliative care medicine

Only 23 (20.54%) of all the participants had received any training in undergraduate palliative medicine while the remaining 89 (79.46%) never received any training in undergraduate palliative medicine.

None of the participants had received - postgraduate training in palliative medicine.

4.3 Awareness and knowledge of Palliative care Policies and Allocation of resources for palliative care

The results presented here represents the clinic managers' knowledge of national policy and strategy on PC, provincial policy and strategy on PC and the local clinic policy and strategy on PC. The budget allocation for PC and training of HCPs in PC at these clinics is also presented. The data here is based on the entire respondents and not based on individual clinics

Five of the six managers at the six clinics responded in the negative pertaining to their knowledge of the development and implementation of PC policies at the national, provincial and local clinic level. NO manager has identified the elements of the national strategy that applies to the clinic. All the respondents could not identify with the existing policies at the provincial level. Majority of the responses (91.7%) on identification and implementation of the PC policies at the local clinic level were negative. All (100%) of the managers indicated that there was no budget/funding allocation to PC and no budget for training of HPCs in PC this year in their clinics. The weighted average in all ten questions 60 (100%) responses, showed a 93.3 percent negative response. Only 6.7% of the managers of PHCs can identify with the existing palliative care policies.

Table 4. 5 Managers' knowledge of palliative care policies

Policy and strategy on palliative care	**Percentage**	
	Yes	**No**
National	8.3	91.7
Provincial	-	100
Local clinic	8.3	97.7

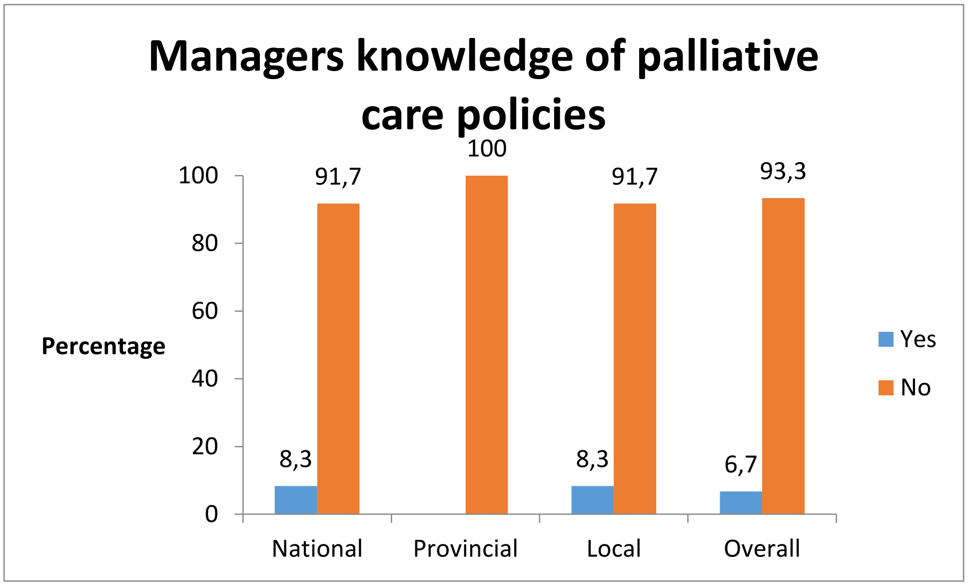

Figure 4. 2 Managers' knowledge of palliative care policies

4.4 Palliative care essential medicines

The survey on the PC essential medicines was to establish which ones are available at these six clinics, how the medicines are procured, who prescribes the controlled drugs and the average quantity of morphine use per month till January 2018.

In summary as in the table below 56.2% of all the essential medications in PC were available while 43.8 % are not in the six PHC centers in Alexandra community (Table4.6). All the clinics procured their medicines especially the opioids from the Medical Supply Depot (MSD) in Oaklands Park, Johannesburg.

Only doctors prescribe control drugs in the 8th Avenue, Alexandra and River Park clinics.

Between December 2016 to January 2018, 100 ampoules of 10 mg injectable morphine were used. One hundred and sixty (160) ampoules of 50mg injectable pethidine was used and 290 ampoules of 100mg pethidine was used in the Alexandra community health center. No morphine syrup or tablets used.

Table 4. 6 Availability of essential medicines in palliative care and their indications across all clinics

Medication	**Indication**	**Percentage**	
		Available	**Not available**
Amitriptyline	Depression	100	
Dexamethasone	Anorexia		100
Diazepam	Anxiety	98.0	2.0
Docusate sodium	Constipation		100
Fluoxenthine	Depression	10.8	89.2
Gabapentin	Neuropathic pain		100
Haloperidol	Delirium	67.7	32.3
Hyoscine buytylbromide	Respiratory tract secretions	100	
Ibuprofen	Pain (mild to moderate)	100	
Loperamide	Diarrhea	100	
Lorazepam	Anxiety	9.8	90.2
Metoclopramide	Nausea and vomiting	99.0	1.0
Morphine	Pain (moderate to severe)	58.8	41.2
Senna	Constipation	99.0	1.0
Sodium picosulfate	Constipation		100
Weighted overall percentage		**56.2**	**43.8**

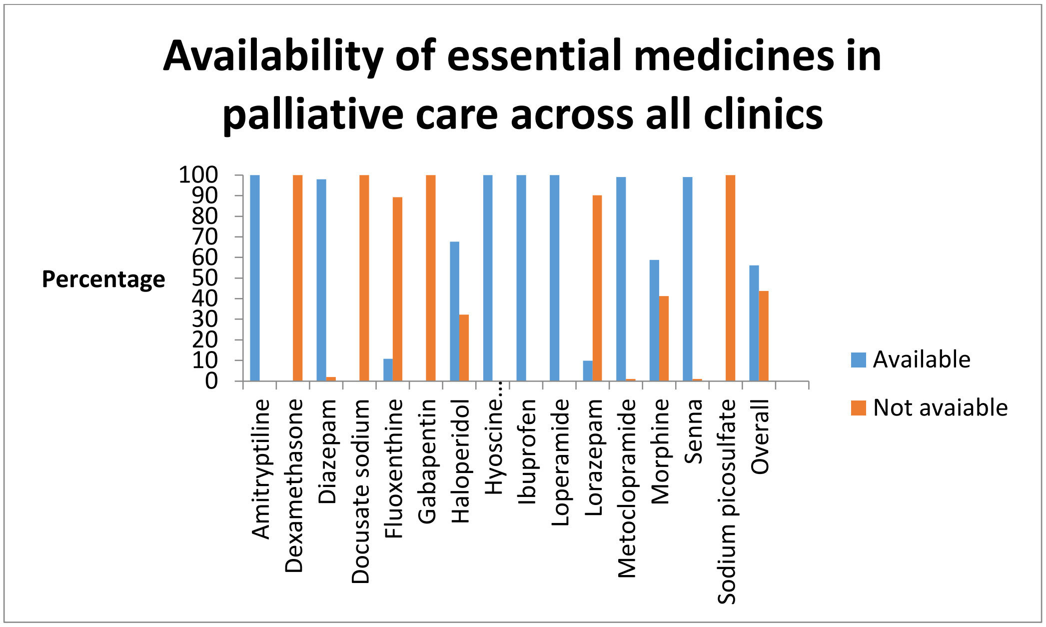

Figure 4. 3 Availability of essential medicines in palliative care across all clinics

4.5 IAHPC Essential skills set for level of ability in managing palliative care needs

The IAHPC Essential Skills List was used to investigate the perception of the ability of the HCPs in assessing the level of competence in identifying and managing the physical care needs, management of psychological/emotional/spiritual care needs, the care planning and coordination and communication skills require in PC in the six clinics. It serves as a global assessment of the levels of ability in the management of PC needs.

While there was relative high and moderately high level of skills in the management of the “physical care” needs and the “psychological /emotional/spiritual care” need, the ability to manage “care planning and coordination,” and “communication issues” seems to be wanting, (see Table 4.7, fig 4.4). The Table below was compiled by counting all the responses (1, 2, 3, 4, and 5 see appendix 3) collectively and converting to percentages for each category of the four essential skills set.

Table 4. 7 Summary of overall HCP self-perception of ability and competence

Management of	**Self-perception of level of ability: Overall percentage responses**				
	High	**Moderate**	**Average**	**Low**	**None**
Physical care needs	28.3	28.8	17.4	12.1	13.4
Psychological/emotional/spiritual	12.9	24.8	25.7	16.2	20.4
Care planning and coordination	8.7	7.8	10.8	26.7	46.0
Communication issues	7.9	10.1	14.0	24.8	43.2
Weighted overall percentage	**19.0**	**22.4**	**18.0**	**16.9**	**23.7**

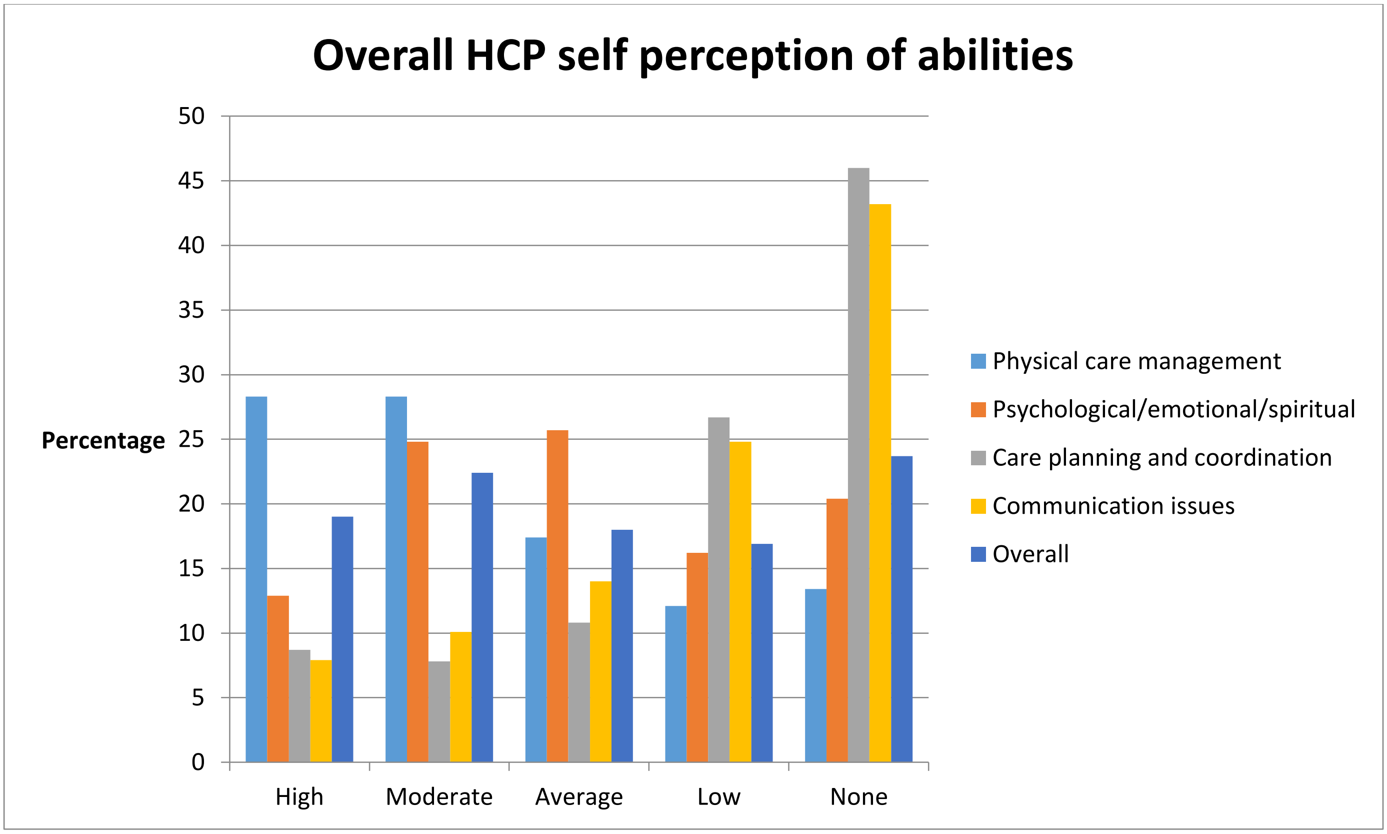

Figure 4. 4 Overall HCP self-perception of level of abilities

4.5.1 Management of the physical care needs

The physical needs that are prevalent in these clinics that the HCPs can manage are constipation, cough, dyspnea, pain, wound ulcers and anemia (Figure 4.5) with high and moderately high level of competence in the skills area.

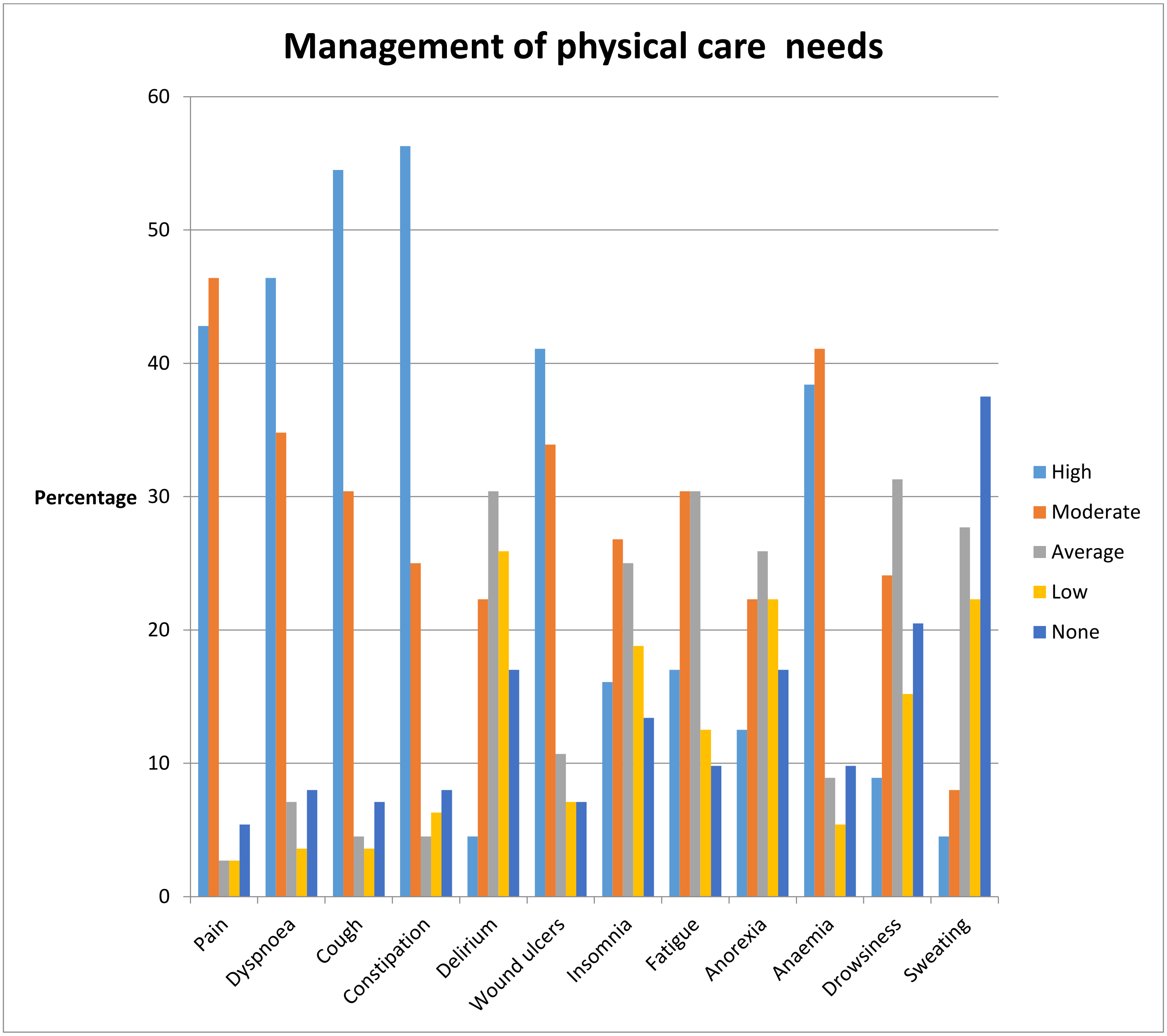

Figure 4. 5 Management of the physical care needs

4.5.2 Management of psychological, emotional and spiritual care needs

There is a moderately high level of competence in the skills area-management of psychological distress, "suffering of the relative and/or care giver," "anxiety" "family grief and bereavement issue" then "depression," "spiritual needs and existential distress," in a descending order (Figure 4.6).

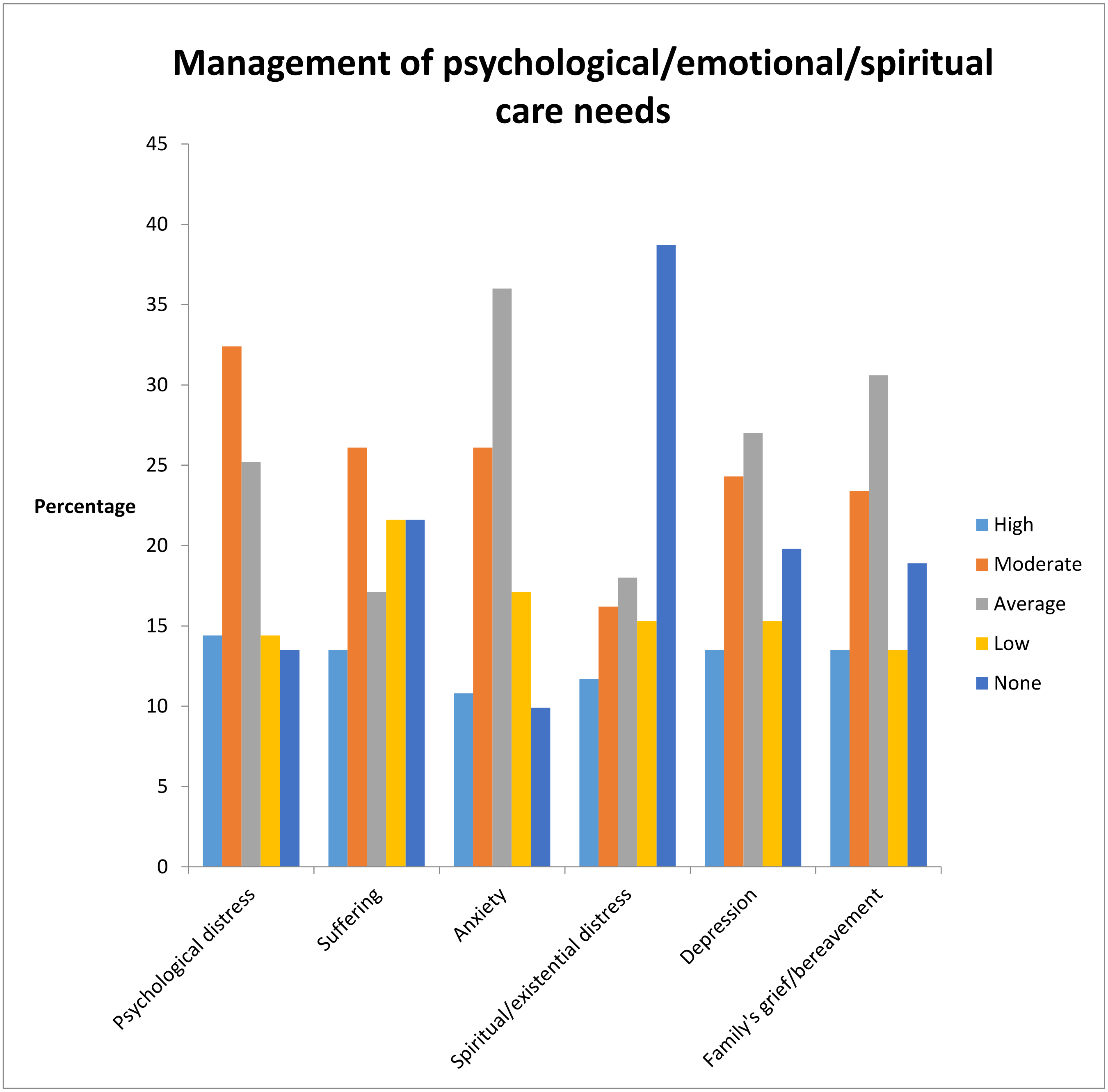

Figure 4. 6 Management of psychological, emotional and spiritual care needs

4.5.3 Care planning and coordination

It is evident that level of competence in this domain of the essential skills set is lacking among the HCPs in the clinics in the Alexandra community (Figure 4. 7)

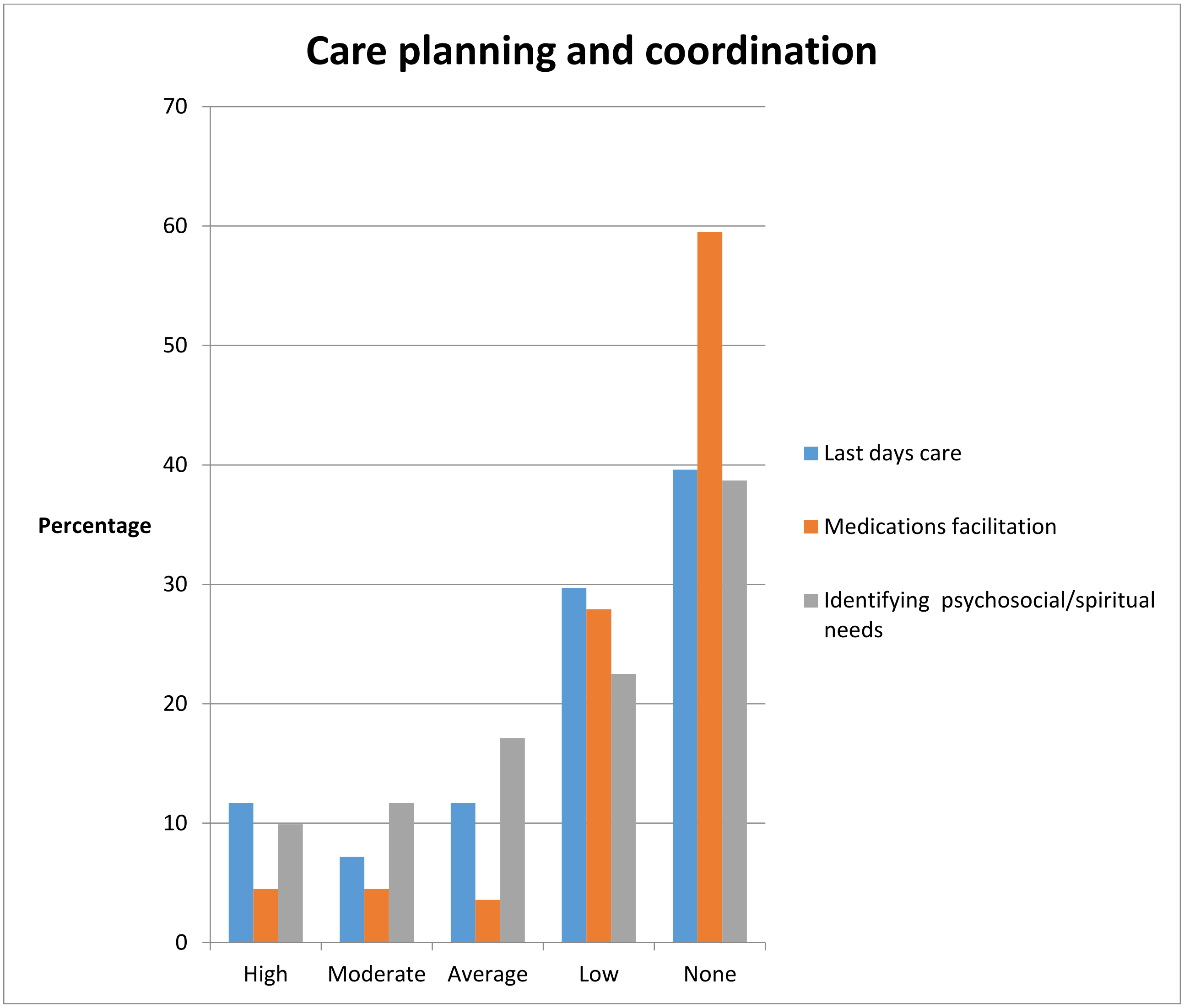

Figure 4. 7 Care planning and coordination.

4.5.4 Communication issues

The communication skill “breaking bad news” seem to be the main communication issue that these HCPs do undertake to a certain extent with some element of advance care planning with the patient family and care givers. The other communication issues are still at infancy stage of development at these clinics (figure 4.8).

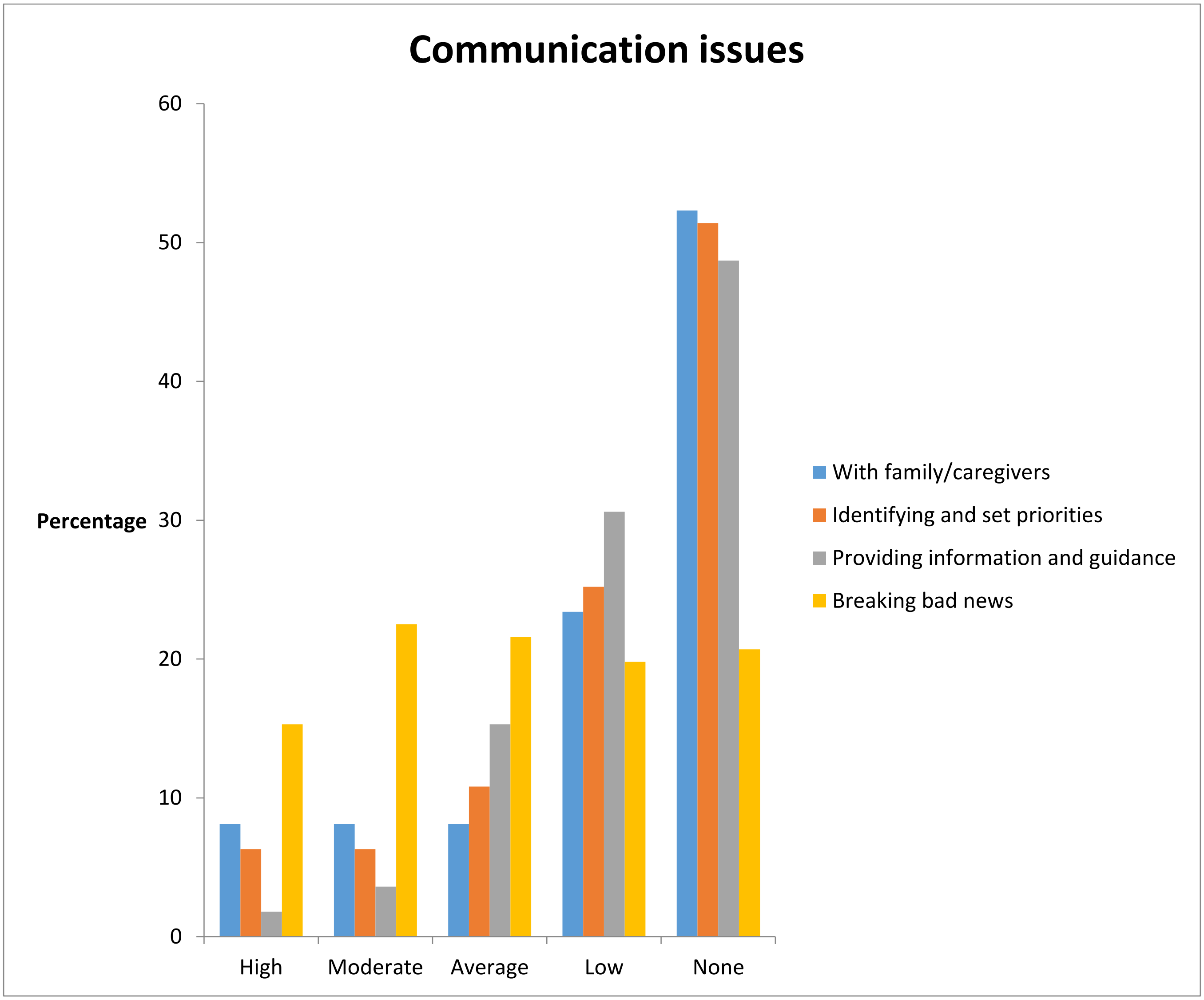

Figure 4. 8 Communication issues

4.6 Inferential statistics

The relationships between the participants' demographic characteristics and their self-assessment of HCPs skills were analyzed statistically. The analyses is based on the numerical scores which were assigned to the self-rating scale of confidence of HCP skills as follows:

5 = High level of competence; 4 = Moderate level of competence; 3 = Average level of competence; 2 = Low level of competence and 1 = No level of competence.

While the scores have no numerical meaning, they were used in comparative statistical analyses of subgroups of participants as indicated in the tables that follow hereafter. As per the Study Questionnaire (see Appendix 3) the following skills sets were considered: Management of physical care needs (12 items), Management of psychological / emotional / spiritual needs (6 items), Care planning and coordination (3 items) and Communication issues (4 items).

Each participant in the study rated each item in each skills set on the above 5-point scale. For each participant the **average item score** was calculated per skills set, which was then considered to be the participant's measure of competence for the particular skills set (e.g. for Management of physical care needs, the average score of the 12 items was calculated as a measure of the participant's competence in this field). The higher the item scores of a participant in a skills set, the higher the average and the better the competence.

Table 4. 8 Gender

Skills set	**Average item score per skills set**		
	n	Mean	Median
Management of physical care needs			
Males	19	3.33	3.58
Females	93	3.49	3.67
p value*		0.477	0.595
Management of psychological/ emotional / spiritual needs			
Males	19	3.16	3.17
Females	93	2.89	2.83
p value*		0.319	0.295
Care planning and coordination			
Males			
Females	19	2.02	2.00
p value*	92	2.08	2.00
		0.827	0.777
Communication issues			
Males	19	2.22	2.00
Females	92	2.13	2.00
p value*		0.714	0.560

* t-test for difference between mean values; Wilcoxon rank sum test for difference between medians

No statistically significant differences of mean, as well as median, scores were found between males and females. Thus, no gender differences were demonstrated in respect of the average levels of competence for the different skills sets.

Table 4. 9 Year of graduation

Skills set	**Average item score per skills set** **n**	**Mean**	**Median**
Management of physical care needs			
≤2000	38	3.81	3.83
2001-2010	39	3.62	3.83
≥2011	35	2.92	3.00
p value* ≤2000 vs 2001-2010		0.296	0.767
≤2000 vs ≥2011		**<0.001**	**<0.001**
2001-2010 vs ≥2011		**<0.001**	**0.001**
Management of psychological/emotional/ spiritual needs			
≤2000	37	3.00	3.00
2001-2010	39	3.12	3.00
≥2011	35	2.67	2.67
p value* ≤2000 vs 2001-2010		0.635	0.893
≤2000 vs ≥2011		0.184	0.324
2001-2010 vs ≥2011		0.071	0.246
Care planning and coordination			
≤2000	37	2.23	2.00
2001-2010	39	2.16	2.00
≥2011	35	1.78	1.33
p value* ≤2000 vs 2001-2010		0.766	0.944
≤2000 vs ≥2011		0.070	0.109
2001-2010 vs ≥2011		0.121	0.288
Communication issues			
≤2000	37	2.36	2.25
2001-2010	39	2.19	2.00
≥2011	35	1.88	1.75
p value* ≤2000 vs 2001-2010		0.451	0.713
≤2000 vs ≥2011		**0.043**	0.125
2001-2010 vs ≥2011		0.187	0.346

* One-way ANOVA for difference between mean values; Dwass, Steel, Critchlow-Fligner test for medians

For the management of “physical needs” the mean as well as the median values of the average item scores were significantly lower, i.e. on average a lower level of competence, for participants who graduated since 2011, compared to participants who graduated before 2011. The year of graduation had no significant influence on the average levels of competence in respect of the management of “psychological/emotional/spiritual” needs and on “care planning and coordination.” For “communication issues” one significant p value was found which could be probably just a chance outcome. Except for this p value, the year of graduation showed no significant influence on the average level of competence in respect of communication issues.

Table 4. 10 Occupation

Skills set	**Average item score per skills set**		
	N	**Mean**	**Median**
Management of physical care needs			
Professional nurse	74	3.74	3.79
Other	38	2.93	3.17
p value*		**<0.001**	**<0.001**
Management of psychological/ emotional/ spiritual needs			
Professional nurse	74	2.97	3.00
Other	37	2.87	2.67
p value*		0.646	0.590
Care planning and coordination			
Professional nurse			
Other	74	2.13	2.00
p value*	37	1.94	2.00
		0.366	0.551
Communication issues			
Professional nurse	74	2.19	2.00
Other	37	2.05	2.00
p value*		0.495	0.608

* t-test for difference between mean values; Wilcoxon rank sum test for difference between medians.

Both the mean and median average item scores for management of physical care needs were significantly greater among professional nurses, i.e. indicating a significantly greater level of competence, compared to other occupations. The occupation showed no significant influence on the average levels of competence in respect of the management of "psychological/emotional/spiritual needs," on "care planning and coordination," and on "communication issues."

Table 4. 11 Age

Skills set	Average item score per skills set		
	N	**Mean**	**Median**
Management of physical care needs			
<35	36	3.03	3.17
36-50	43	3.66	3.83
>50	33	3.69	3.67
p value* <35 vs 36-50		**0.002**	**0.001**
<35 vs >50		**0.002**	**0.004**
36-50 vs >50		0.879	0.711
Management of psychological/emotional/ spiritual needs			
<35	36	2.77	2.67
36-50	42	2.92	2.83
>50	33	3.14	3.17
p value* <35 vs 36-50		0.554	0.813
<35 vs >50		160	0.235
36-50 vs >50		0.377	0.601
Care planning and coordination			
<35	36	1.82	1.67
36-50	42	2.14	2.00
>50	33	2.23	2.00
p value* <35 vs 36-50		0.186	0.515
<35 vs >50		0.111	0.181
36-50 vs >50		0.716	0.792
Communication issues			
<35	36	1.94	1.50
36-50	42	2.10	2.00
>50	33	2.43	2.25
p value* <35 vs 36-50		0.469	0.552
<35 vs >50		**0.041**	0.108
36-50 vs >50		0.155	0.427

* One-way ANOVA for difference between mean values; Dwass, Steel, Critchlow-Fligner test for medians.

For the management of “physical needs” the mean as well as the median values of the average item scores were significantly lower, i.e. on average a lower level of competence, for participants under the age of 35, compared to participants older than 35 years. Age had no significant influence on the average levels of competence in respect of the management of “psychological/emotional/spiritual” needs and on “care planning and coordination.” For “communication issues” one significant p value was obtained which was probably a chance outcome. Except for this p value, the age of participants showed no significant influence on the average level of competence in respect of communication issues.

CHAPTER 5

DISCUSSION

5.1 Introduction

This chapter will be discussing and interpreting the data collected using the research tools.
To effectively integrate PC into a society and change the experience of patients and families, all four components of the WHO Public Health Strategy (PHS) must be addressed which are appropriate policies, adequate drug availability, education of HCPs and the public and implementation of PC services at all levels throughout the society.

The 67th WHA resolution[54] in 2014 to strengthen PC as a component of comprehensive care advised member countries to develop policies which integrate PC into health structures, guarantee ample internal capital backing for PC, incorporate PC teaching into all the HCPs curricula, evaluate internal PC requirements, appraise and review medicine regulation laws and add PC drugs to all indispensable drug lists. The findings of this study will therefore be discussed under the following headings: the existence of a national, provincial and local policy on palliative care and its implementation, the availability of essential PC medicines and the level of training and competence of HCPs in PC skills.

5.1.1 The existence of a national, provincial and local Policy on Palliative Care and its implementation

South Africa has a policy on PC that is not yet integrated into the existing national health system but according to this study most managers (93.3%) in the Alexandra Township PHC are not aware of it. While there is a little awareness (6.7%) of the National policy on PC, the identification of the elements of the national policy and strategy applicable to the local clinic level is not existing. Interestingly, the knowledge of the elements of the Gauteng Provincial Policy on PC is non-existent at these clinics, though the NPFSPA exists it has not been accessed by the clinic managers because they are not aware of it. This will become one of the highlights of the findings of this present study such that clinics in communities such as Alexandra will become sites for monitoring and evaluating integration of PC into the continuum of health care in South Africa.

Stjernsward et al. had shown that where there is no policy on ground in PC, the WHO Public Health Strategy (PHS) had proven effective in integrating palliative care (PC) into their National Health System[13]. It had also been established by the WHO that it is important that PC should be integrated as a full functioning component of a health system and should be the fourth component of National Cancer Programmes, other components being prevention, early identification and curative treatments. Every cancer centre must have PC in order for the services to be comprehensive.[14]

Policy is seen as an important component of PC service delivery because without it other changes cannot be introduced. Connor et al.[6] in a recent report on the World Hospice and Palliative Care Association (WHPCA) established that it is very challenging for any PC to grow without national policy backing it up and that persuading national leaders that political will and funds are required to amend policies and institute PC is one of the current challenges of the WHPCA. The types of policies needed, according to the Global Atlas of Palliative Care,[4] include National Regulations and Plans to smoothen incorporation of PC into existing health structures, legislations that recognise and describe PC as a crucial portion of the health care structure, countrywide protocols of care outlining PC, PC clinical plans and procedure, formation of PC as a known medical domain, procedures that establish PC as an accepted type of HCP with associated authorising requirements and a National Policy Framework and Strategy for Palliative Care.

There is no provincial policy on PC at all in Gauteng Province, lack of good policies according to Stjernsward et al.[14] “can lead to unnecessary suffering and costs for patients, families, and society.” In the same article they wrote that 75% of cancer patients globally are incurable when diagnosed, because the magnitude of the challenges and suffering accompanying cancer is big, formulation of a National Cancer Control Policy is an active access point to initiate incorporating PC into a Nation’s health care structure and to be complete, all cancer clinic must have PC. Currow and Kassa.[18] had stated that an ultimate goal of good government is to develop and implement policy that optimises the wellbeing of its citizens, given the prevalence of expected death from chronic, progressive conditions, it should be expected that there are policies and even legislation that ensure good EoLC is given to people. Currow and Kassa also noted that at times there may also be differences in the approach between various level of government and public administration within the same country. This may lead to differences in policies and documents that may be difficult to reconcile. Vested interests abound in bringing together the wide variety of opinions that help to inform any societal policy, given the increasing plurality seen in many communities around the world.

They postulated further that after implementation sufficient resources need to be invested in the ongoing evaluation of the training required and Lomas et al.[47] concluded that ideally good public policy is informed by the best available evidence not simply political expediency. The literature review and review of best practice and national guidelines according to Gluckmann et al.[48] should ideally be endorsed by national and regional health care authorities in order to assure allocation of sufficient resources to implement the pathways and evaluate the pathways impact on health outcomes. Effective policy making according to the 2018 Lancet Commission[40] report requires better evidence and priority-setting tools to adequately measure the whole need for PC, to implement policies and programmes, and to monitor progress toward alleviating the burden of pain and other health related suffering.

Stjernsward et al.[81] reiterates that successful integration of PC requires the development and maintenance of close ties with the existing health and social policy makers and funders. This research still demonstrate the further needs of the Gauteng Provincial Government (GPG) in ensuring that the national policy and strategy are available and implemented in Gauteng province, at the local clinics and communities. There is a necessity for individual roles for each level of health service facility in implementing PC to be described.

There is no policy on how to identify who needs PC, this is because PC had not been recognised in the clinic. Lack of identification of PC patients had been identified by Murry et al.[49] as a barrier to integration of PC. There are guidelines available for use on identification of patients with PC needs, SPICT[37] guidelines can be used and is recommended by the National and Western Cape Governments.

Clear designation of certain members of staff to provide PC improves PC deliveries into communities according to Lavy et al.[22] This is to avoid confusion and duplication of services. According to the WHO PHS there supposed to be a clear policy on who provides what care interventions in PC[13] to avoid duplication of services and to promote accountability. This will be addressing section 2 of the World Health Assembly (WHA) resolution[54] which emphasizes PHC, "community /home-based care, and Universal Health Coverage Schemes."

There is no policy in the local clinics on referrals to or from PC, though there are other referral systems to and from district and tertiary hospitals operational in the clinic but PC was not included. This is probably because PC had not been incorporated into the public health services in the township. An operative Referral System and upgraded Emergency and Planned Patient Transport Services are part of the existing South Africa National Health System, it also have Community based Services Outreach Services,[26] incorporating PC policies into the existing referral system is addressing the WHA resolution 3 which encourages provision of basic referral support system and multi sectorial partnerships to community based organisations and all stake holders in the PC implementations. Ward based PHC is progressively being documented as an indispensable portion of a robust health care provision structure.[26] The World Health Assembly resolution advocates close working relationship between stake holders in the community, with the different models of care available at home, local clinics, community health centres, hospitals and care homes, there should be a clear policy on referral pathway both to higher centres of care and to lower care centres of care throughout the country.

PC had not been recognised as part of the continuum of heath care as it had not been included in the job description of the staffs of the clinics. The WHA resolution in section 4 admonishes governments to include PC as an essential part of the continuing teachings and preparations presented to HCPs in harmony with their current jobs and duties.

There is an existing policy or guideline on pain management. Half of the managers are aware of the WHO three steps ladder guide on pain management in the green book (EML) which is the written policy for PHC. This is because pain is one of the reason for encounters in a PHC centre. Integrating and implementing PC will correct the deficiency in the knowledge and awareness of the HCPs as had been shown by Good et al.[51] that executing good PC policy will influence other portions of the existing health care structure. The WHA resolution[54] in section 5 admonishes countries to evaluate internal PC requirements especially pain control medicine requirements, the WHO guideline on pain management had been proven to solve 90% of all the pain that will be encountered at the PHC level.[20]

There is no policy on controlled medicine especially morphine, its procurement and its prescription in the clinics. This is also because PC programmes is still in its infantile stage. The PHS advocates clear policy at every level of the health system on the procurement and prescribing of opioids especially morphine. Access to morphine had been shown by Connor et al.[6] to be one of the major barriers to delivery of PC, and according to the Global Atlas of Palliative Care[4] a clear policy on its procurement will ensure availability in the local clinics. A clear policy on its prescription, guidelines on its use both at the hospital and community level and with families at home will ensure access and availability to the patients who need them.

There is no policy or memo on training /continuous professional development in PC in the clinics. Lavy et al. indicated that local champions are needed to provide and promote PC services, also lack of Monitoring and Evaluation policies had been shown by APCA[16] to be one of the barriers to the development of PC in LMIC.

There is no encouragement, motivation or requirements for staff to be trained in palliative medicine at the clinics this is because PC is just beginning at the clinics. Studies have shown that to develop and sustain PC at any level there needs to be a policy on motivation, encouragement of people to be trained in PC. WHA resolution recommendations to governments in the section 4 emphasized "including PC as a component of the on-going education and training offered to HCPs in accordance with their roles and responsibilities."

No funding was allocated to funding PC services or training in PC, also because managers are not aware of the policy and because currently there are no PC services in the public health sector in Alexandra Township. WHA resolution[54] recommends in its directives to governments to ensure adequate domestic funding and allocation of resources as appropriate for PC. The NHI financing system is intended in future to take care of the existing model in PHC and PC delivery.[26]

National policies, protocols and clinical guidelines educational pamphlets, motivating advocacy materials are recommended to be adapted to local languages and possible models are described in the Palliative Care Toolkit[22].

The South Africa NPFSPC was informed by need of the people among other factors, it include how to identify patients that need PC and the characteristic and designation of who provides PC, which according to WHA should be all HCPs at the clinic level.[54] The NPFSPC is a government responsibility as it is to correct the structural challenges in the present health system it recognises the social determinants of health and position health care services within a context of human rights and sustainable developmental goal. It answers the question of what enables South Africa to deliver PC.

These are different service delivery platforms ranging from tertiary hospital to secondary and district hospitals down to the PHC centres and homes in the community with appropriate PC referral path way which is also embedded with the present health system and emergency services. The awareness and accessibility and implementation of the NPFSPC will correct the deficiencies. Goodet.al.[51] have shown that implementing PC policies in a national system helps to correct the deficiency of the existing system.

5.1.2 The availability of essential palliative care medicines.

Essential medicines in PC are available in the clinics, this because more than half of the medicines listed were available. Essential medicines (EM) are the least medications for the effectiveness of a simple health structure,[2] this is comprising the most effectual, safe, and affordable medicines for importance conditions that satiate the PHC requirements of all the populace. EM must constantly be accessible, obtainable and used sufficiently.[2] The IAHPC List of Essential Medicine for Palliative Care is consistent with diverse clinical protocols/course of actions and important appraisals in signs and symptom control.[4]

The Global Atlas Of Palliative Care[4] stated that availability of essential medicines in PC is a challenge worldwide especially in LMIC.[16] However availability of medicines is not a problem in South Africa. The government had made a significant effort here. Though some of the EM are used currently for a different indication from that of PC they are still available for example, hyoscine for respiratory tract secretions, and lorazepam for anxiety.

According to Connor et al.[2] availability and accessibility to important medications especially PHC medicines is one of the six WHO management concern for 2014 -2019 validated by WHO participant countries with the following resolutions, the 2014 WHA resolution on access to EM, the WHA resolution on PC, the United Nations Global Action Plan on Non Communicable Diseases and the 2011 WHO World Health Report on Universal Health Coverage altogether highlights the significance of access and availability of essential medicines in PC. However according to De Lima et al.[4] "having strong controlled analgesics on the shelf does not ensure that patients will receive these medications for symptom control."

Gomez-Batiste, Connor et al.[2] noted that explicit accounts on access to EM used in PC are not available, numerous worldwide accounts contain medicine used in PC such as laxatives, antidepressants, potent analgesics, and others, "Of these, lack of access to opioids is an international problem which had been emphasized in many international and local reports." Analgesics for mild to moderate pain and laxatives were available in all the clinics. Antidepressants were available only at the Alexandra Community Health Centre and the East Bank Clinic which attends to psychiatric patients. Morphine was only available in the Community Health Centre, no other clinics has morphine. This study supports the existing findings in literature of laxatives being available.

Dexamethasone for anorexia and gabapentin for neuropathic pain was not available.

Pain constitute about 60% of the burden of symptoms presentation[37] at the primary care level in PC and the mainstay of treatment recommendation by the WHO is opioids.[61]

Opioids availability knowledge among the HCPs is about 60 percent and it is concentrated in the Community Health Centre however The WHA recommends adequate supply of EMs in PC including pain medicines.

In 2013 the WHO Model Lists of Essential Medicines for Adults (EML) and for Children (EMLc) included section with medicines for pain and PC. The SA EML committee has agreed to include new chapters on pain and PC in the next edition of South Africa EML, the green book.

There is no procurement policy for opioids in place in all the clinics, this is partly because there are no pharmacists in all the clinics except the CHC to procure the opioids, also because (80%) of the HCPs don't use opioids or prescribe them and PC had not been recognised and integrated into the practice of the clinics. The most senior pharmacist in charge of procurement of opioids in the CHC claims he procures from the Government Medical Depot. The reason he advanced for this was because this is where the provincial government dispense medication to local clinics, and the amount procured is dependent on doctors' prescriptions.

The WHA resolution in section 5 advises governments "to evaluate their country PC needs, with pain control medicine requirements and in section 6 advises government to review, evaluate and revise national and local laws and guidelines for control medicines."

Procurement difficulties, absence of skilled HCPs in the use of opioids, morphine in particular, little or no interest in PC what previous studies have shown and is also revealed in this study in Alexandra, and with most drugs available at these clinic absence of skilled professionals in the use of morphine, stands to be another major highlight of this study. In South Africa all the palliative medicines are already in the EDL though the indications that they were meant for might be different, pharmacist in the township can be encouraged to procure and stock medicines that PC needs. The WHA resolution in section 8 encourages fostering of partnerships between governments and community based organisations to support the provision of services for PC patients.

All the respondents says doctors prescribe controlled drugs, this is in line with the current legislation in the country this is however limiting the access of users to the available opioids, as doctors constitute only 20 % of HCPs.

According to Wee Jun Yan et al.[21] access to opioids and opioids diversion and misuse had been the two greatest barrier to the delivery of good PC worldwide. Lack of policies on procurement and prescription, outdated policies were factors associated with it, couple with clinical issues like little knowledge of pain assessment and management, fear of opioids use, inadequate training of HCPS.

Ryan et al.[61] of Human Rights Watch stated that the "problems of pain management provision in many countries are complex and include poverty, illiteracy, language barriers, and limited health resources, teaching deficiency and needless deterring legislations and policies which limit the delivery, preparation and use of controlled drugs," however the legislation in South Africa is not overtly restrictive as in other LMIC to constitute a barrier.

There is a need in updating the laws and legislation on prescribing to allow nurses that are trained in PC to prescribe morphine. Rwanda,[16] Uganda,[13] kenya,[2] are examples of countries in Africa that has upgraded their prescribing laws and legislation to allow trained nurses in opioids pain managements to prescribe. WHA resolution 5, 6, 7, also speaks to these.

This study also show that the Knowledge, Attitude And Practice of the doctors are inadequate, injectable formulations are the only form of opioids the doctors prescribe, No tablets for slow or normal release was used. The knowledge base is inadequate for two reasons, 1) according to WHO[22] morphine is the preferred opioid in the management of moderate to severe pain and the oral route is the most preferred route this is because of the cost and ease of use, patient, family members and the public can be trained on how to use it effectively. 2) Two types of opioids are being used in the Alexandra Community Health Centre, morphine and pethidine. The amount of pethidine used was about three times that of morphine used. Pethidine use and indication is only in Obstetrics in South Africa,[82] it is a very short acting, highly addictive medication and the build-up of its metabolites can result in convulsions. Thus it should not be used for chronic pain.

Attitude is poor because doctor are hesitant to prescribe opioids especially morphine, in total an average of 8 ampoules of morphine is used every month, this is a very low usage of morphine. Opioids diversion and misuse may be a serious concern in Alexandra Township, also addiction and death from over dose. Hence the poor disposition of the prescribing doctors to morphine. According to Wee Jun Yan et al. (2018) paper have shown that the most common place of diversion is the doctor patient interphase, with elderly patients pretending to have pains and real patients with pain selling their medications to drug dealers who are very skilled in their brokerage.[21]

Poverty and hunger might be motivation for this. Interestingly hunger had been reported by Harding et al.[42] as a symptom in LMIC. Availability and training of HCPs in the use of oral morphine is particularly important for Alexandra Township because most people prefer to die at home in LMIC[16] and Gwyther et al. had shown that care in homes improves patient outcomes and it is affordable, and improves access to care.[5, 53]

Ury et al. [73] had demonstrated improved prescribing practices for pain following an educational intervention, suggesting that attitudes towards opioids and fears about addiction had been changed by education.

5.1.3 The level of training and competence of Health Care Professionals in Palliative Care.

Most of the HCPs did not have any undergraduate training in palliative medicine, this study shows that recent graduates are the one that are trained in PC. This is a demonstration of the results of the advocacy activities that the PC groups had been doing to incorporate PC topics into the curriculum of medical schools.

This study highlights the magnitude of the need for training among the HCPs, because no HCPs had postgraduate training in PC at any level whether certificate, diploma or masters also because PC had not been recognised as a specialty and integrated into jobs description of HCPs and also because there is no motivation, encouragement or policy to demand the skills.

The WHA resolution in section 4 mandates governments to have on an ongoing basis a continuous training of all HCPs in PC in basic, intermediate and specialist level of training in PC in harmony with their present jobs and duties.

The EAPC in their white paper[23, 24] on Core Competencies of PC recommend that all HCPs be trained in PC and the core competencies, they identified "three groups of HCPs who require training to increase their services to patients in their domain: 1) staff who work in specialist PC and hospices; 2) staff who frequently deal with EoLC as a part of their role for example HCPs who work in the emergency department, acute medicine, respiratory machine, care of the elderly, cardiology, oncology; and 3) staff who work within other services and who have to deal with EoLC infrequently."

The need for training and continuous training was reemphasized with no budget being available for continuous medical education (CME) in PC in any of the clinics. The document on continuing professional development from the Royal College of Physicians' working party, indicates that two thirds of physicians had not attended any end of life care educational event in the last two years. The working party recommended that all physicians caring for patients with PC need to attend at least one relevant training event every five years. It is certain that the HCPs at the clinics in Alexandra will benefit from such periodic trainings.

The competences of the HCPs were surveyed under four general headings according to the EAPC List of Essential Practices in Palliative Care,[24] 1) "their ability to identify, evaluate, diagnose, treat and apply treatment and solution measures for physical care needs," 2) "the HCPs ability to identify and evaluate – provide support and when possible, refer for diagnosis, treatment and solution for psychological/emotional/spiritual care needs." 3) "The HCPs ability to do care planning and coordination issues" and 4) "communication issues."

Many of the HCP perceived themselves to be having extensive experience to good experience in the management of physical care needs especially the common problems such as pain, respiratory problems- dyspnoea and cough, GIT problems -constipation, vomiting and diarrhoea, wounds, ulcers and anaemia, this is because these are symptoms they see frequently in nonlife threatening conditions in PHC though they can also be associated with life threatening / chronic conditions of PC. The HCPs also perceived themselves to be with no or little experience in unusual symptoms like sweating, drowsiness and delirium and anorexia and fatigue which are less common symptoms encountered in the PHC but frequent symptoms in PC patients. The HCP skills level were based on self-perception, studies by Dickson et al.[71] had shown that HCPs overestimates their abilities, Gibbins et al.[72] show that families rate HCPs competence lower than the way they rate themselves. It is possible that the HCPs are not aware of the big gaps in their training that this study is highlighting.

The core competencies in PC from "IAHCP List of Essential Practices in Palliative Care" is very essential in a place like Alexandra to monitor and evaluate training. it emphasizes the competence of "HCPs to identify, evaluate, diagnose, treat and apply treatment and solution measures the following physical care needs, pain (all types), respiratory problems (dyspnoea, cough), gastrointestinal problems (constipation, nausea, vomiting, dry mouth mucositis, diarrhoea), delirium, wounds ulcers, skin rash and skin lesions, insomnia, fatigue, anorexia, anaemia, drowsiness or sedation and sweating."

The HCPs skills in the management of "psychological/emotional/spiritual care" was generally reported as lacking because these are not what is seen as the HCPs role in PHC clinics. However, the patient needs for these skills is still encountered at PHC level and HCPs should be able to identify and manage these symptoms. The EAPC List of Essential Practices in Palliative Care emphasized the competence of HCPS to "identify, evaluate, diagnose, treat and apply treatment and solutions measures for psychological/emotional/ spiritual care needs such as psychological distress, suffering of the relative and /or caregiver, and anxiety, spiritual needs and existential distress depression family/caregivers grief and bereavement issues."

The HCPs had no experience in care planning and coordination of care, more than 70% said they "cannot provide care in the last days /weeks of life," more than 87% has no ability to "facilitate the availability and access to medications (especially opioids)" and more than 62% said "they have little or no ability to identify the psychosocial /spiritual needs of self and others professional involved in the care." The level of competence in this skill is low or lacking. These group of symptoms are core skills in PC that may distinguish the palliative medicine approach out from other disciplines.

The IAHPC List of Essential Practices in Palliative Care listed the competences required for this skill to be; 1) "ability to identify the resources and support available and develop and implement a plan of care based on patient needs." 2) "Provide care in the last days/weeks of life," 3) "identify, evaluate and implement solutions to facilitate the availability and access to medications (with emphasis on opioids)" and 4) "identify the psychosocial /spiritual needs of self and others professionals involved in the care." This competence involves skill in addressing issues on death and dying, and death and dying brings carers and HCPs to the reality of their own mortality too.

Schulman-Green et al.[78] in two different studies in 2003 reported that many senior consultants have received little or no training in PC as undergraduate but rather they learnt by observing others in practice, perhaps with professionals with less training.[83] Qualitative interviews and focus groups focusing by Fitzsimons et al. in 2007 reveals that even caring specialists physicians find it difficult to face their patients' PC needs and to discuss end of life issues with them.[79] According to Marks and Bertman[64] some schools introduce learning about death and dying during anatomy dissection sessions or communication skills teaching sessions.

Gibbins et al.[68] noted that end of life issues are not discussed within the culture of the working environment and so these attitudes may remain unaddressed, their studies also show that attitudinal change may occur with increased knowledge alone, but it may require also role modelling and facilitated discussion and reflections following clinical or educational encounters.[68]

According to Fitzsimons et al.[79] even caring specialists physicians find it difficult to face their patients PC needs and to discuss end of life issues. This is significant, since these clinicians will serve as role models to students and junior doctors, potentially influencing them, indirectly that PC issues can or should be avoided. Whilst students for example acknowledge learning from end of life courses, they found patients care experiences guided by teams that acknowledge deaths, role modelled end of life care, and respected students' participation in patient care far more useful.[79]

Torke et al.[65] suggested that skills can be encouraged through problem based learning, role play consultations with simulated patients and supported hospice visits and clinical attachments. Schillerstorm et al.[66] postulated that more recent approaches include involving bereaved family members in teaching communication skills and the use of films, drama and literature to teach PC skills.

To teach spiritual and cultural aspects of care, Ellman et al.[67] stressed on the use of electronic learning and imitation. The article noted that teaching about attitude is complex. Attitude was defined as a settled way of thinking or feeling.[67] "Professional attitudes are important in many areas of medicine", but perhaps particularly so in palliative medicine where attitudes such as "seeing death as a failure, therapeutic nihilism" in patients with cancer or other end stage disease, "wishing to avoid dying patients, and fears about opioids" can result in sub-optimal patient care.[67]

All staff need to be trained in communication skills, assessing patients' needs and preferences advance care planning and symptom control. This is because 75% of HCPs said they have little or no experience on communication with patient and family and care givers, more than 76% have low or little experience in identifying and setting priorities with patients and caregivers, more than 80% have little or no experience in providing information and guidance to the patient and care givers. Skills in breaking bad news seems to be both equally high and moderate (38%) and also low or no level of competence (42%) while (22%) of the HCPs are average.

The IAHPC List of Essential Practices in Palliative Care listed the skills needed in communication issues to be; 1) "ability to communicate with patient family and caregivers about diagnosis, prognosis, condition treatment ,symptoms and their management , and last days /weeks care issues." 2) "Identify and set priorities with patients and caregivers," 3) "provide information and guidance to patients and caregivers according to available resources, sensitize other health care professionals and workers about PC."

The HCPs had some high and moderate scores in breaking bad news and communication issues with family and care givers about last days /weeks care issue advance care planning because of the burdens of HIV disease in South Africa which is high, they have been involved in the diagnosis and management. This involves breaking bad news to the patient and family, but generally the communication skills are still very low. This study shows a general deficiency in the core skills of PC which is prevalent among HCPs as shown in the Global Atlas of Palliative Care.

The outcomes of this study stressed the need for training of HCPs in PC at PHC centres.

This study correlates with the finding that HCPs that have been working longer are more experienced in management of physical care needs than recent graduates since 2011. This is expected as the longer you work the more experienced you become in the practice. This study highlights the role of hands on experience than didactic teaching, studies has shown that practical experience and continuous mentoring makes HCPs better practitioners. The year of graduation has no significant influence in the average levels of competence in the other 3 domains.

This study correlates with the finding that the nursing profession has a more significant relationship with competence in caring for physical needs of patient than any other occupation listed ($p<0.0001$). Understandably so as the Nurses constituted 66 % of the HCP at all the six clinics. Also the Nurses constituted the highest number of the HCPs at each of these six clinic in Alexandra. The occupation show no significant influence on the average levels of competence in other 3 domains.

In the management of physical needs this study also correlates with the findings that on average a lower significance in competence for participants under the age of 35 years compared to participants older than 35years, Age had no significant influence on the other 3 domains. This also has to do with experience in the field which may be proportional to the age of graduation, further studies are needed to proof whether age brackets has to do with responsibility of caring. Charlton and Smith et al.[69] (2000), Bowden et al.[70](2013) have shown that newly qualified doctors report being unprepared to care for patients with PC needs, they lack confidence in breaking bad news, empathizing, discussing prognosis and symptom control and managing distress.

Connor et al.[4] in the Global Atlas of Palliative Care at the End of Life recognized a dearth of PC knowledge worldwide. They noted "that education and training plans do not match up to national health strategies in PC, though training delivery had been recognised in some nations."[2]

Bui et al.[74] advocate that it is essential for doctors to be equipped with the knowledge, skills and attitudes and behaviours necessary to look after patients who need PC at the end of life. While there had been progress in providing and improving educational opportunities in PC for physicians at all stages of their training, it had been shown that training deficits still lead to many patients receiving poor care at the end of life,

5.1.4 Implementation

This study finds lack of implementation of the NPFSPC in Alexandra township PHC clinics. This is because clinic mangers have no knowledge of and are not aware of the existing NPFSPC, there is no provincial policy on PC, PC had not been incorporated into the job descriptions and delegations of staff furthermore there had been no funds available for training and implementation of PC in all the clinics.

In order to implement NPFSPC, there has to be a Gauteng provincial policy on PC including its funding mechanisms as resourcing is key to delivery. The WHA resolution on palliative care identifies the need for domestic funding and allocation of human resources for the development of palliative care policies, for palliative care training and to ensure access to essential palliative care medicines[53].

Connor et al.[2] published "steps to implement and actions to improve PC approach at PHC and other health care services."[2] These are: 1) "Establish and document a formal policy for enabling a palliative approach for all people." 2) "Identify patients in need with validated tools: this would identify needs, stratify the population at risk, and determine prevalence."3) "Establish protocols, registers and tools to assess patients' needs and respond to most common situations." 4) "Train professionals and insert principles of PC training and review into the conventional training process." 5) "Increase accessibility to continuing and emergency care, home care, (if primary care services), access to families (in hospitals)." 6) "Identify the care givers of patients and give them support and care, including for bereavement needs and their own medical needs." 7) "Increase team approach to jointly assess, plan, and implement care." 8) "In- services with high prevalence; devote specific times and professional with advanced training to attend PC patients (possibly with specific times in outpatient settings, specific dedicated area in inpatient settings)." 9) "Coordination and integrated care in the area: Establish links and criteria for intervention and access to Palliative Care Specialised Services (PCSS) in the area and with all specialities." 10) "Evaluate the results of the palliative approach." 11) "Address the ethical challenges of over and under early identification." 12) "Involve patients and society in the design and evaluation."

This study has created an awareness of the NPFSPC and the need for PC policy in Gauteng. A good model of PC that could be implemented in the Alexandra clinics is the Proposed Model for the Implementation of the Palliative Care Policy in the Western Cape September 2018. With its twinning model of implementation.

Implementation of the existing policy is very limited now because of the awareness, however issues of poverty, drug addiction, hunger might affect implementation in future. Lack of identification had been the greatest barrier so far. Emmanuel et al.[41] and studies from Rwanda[16] had noted that combined poverty with lack of social security can have domino effects on poor families accruing treatment related debt and the loss of livelihood especially as these family are not paid as they work and stay at home caring for families. Harding et al.[42] reported on orphans finding alternative source of livelihood.

When funding from government becomes available and NHI instituted nationwide, implementation of PC polices is expected to be smoother. Studies in different countries Mongolia, Uganda, Rwanda other African countries Malawi, had shown that ultimately successfully developing PC services require every level of government funders to develop and support policies that can ensure the widest reach of services, and close ties with existing health system.

5.2 LIMITATIONS OF THE STUDY

Method of data collection

Quantitative data tools did not make provision for some probes for example in developing the questionnaire on skills, a lot of concepts had to be condensed together from the IAHPC list of essential practice in PC also there are instances where probing could have provided in depth data for this study for instance the manager who claimed to have knowledge of the national policy could have provided more insights into her knowledge.

Being a student and a medical practitioner did not give time enough to do in depth study as one would have wanted to.

The non-inclusion of Ward Based Outreach Team (WBOT) members among the Health Care Professionals, the WBOT team is usually led by professional nurses but largely made up of auxiliary nurses, auxiliary social workers and auxiliary community health workers visiting patients at homes, they are a rich source of data for integration and evaluation of PC into communities.

The fourth objective could have been measurement of implementation and services on ground as an assessment of status of integration but because the PC integration into the system is still at infancy, or close to zero it can’t be measured for now. This will be a baseline study to evaluate further interventions.

5.3 CONCLUSIONS

All the managers of the six clinics were available for data collection exercises and 120 HCPs so the results obtained could be used to generalize for the case study of Alexandra townships.

In general, there are no existing policies relating to PC provincially and locally, no budgets available in the PHC centers of Alexandra Township, managers are not aware of the existing national palliative care policy and strategies on palliative care.

In general, 56 % of essential list medications are available in the primary health centers and 44% not available. The essential medicines are available in the country including opioids but not locally for various reasons such as limited doctors at clinics in Alexandra and their knowledge and attitude to prescribe same.

Morphine is available only in injectable form and only in the Alexandra clinic, prescribed only by doctors.

In general, only 20% of the health care professionals had undergraduate training in palliative medicine and these are recent graduates, no HCP has any training at the post graduate level whether at certificate, diploma or masters level. Training in, motivation and encouragement to learn PC is nonexistent among the health care practitioners at the clinics serving Alexandra community.

This study brought awareness of the NPFSPC and PC to the clinic managers and highlights the need for recognition of PC as a specialty needed in the community, the need for regular ongoing and continuous training for HCPs and their managers.

Palliative care had not been integrated into the PHC centers in Alexandra Township. There are existing policies on PC in the country nationally, and in the Western Cape Province adapted locally to district levels.

5.4 RECOMMENDATIONS

Policy

There need to be a Gauteng provincial policy informed by need of PC in Gauteng province adapted to the NPFSPC. An evidenced based steps to follow in improving PC at the local clinics developed by Connor et al. is already listed above.

The twinning model of Implementation strategy of the Western Cape Policy 2018 can be adapted to Gauteng Province where by hospitals are linked to the Gauteng Province Palliative Care Center in Soweto, University of Wits and University of Pretoria.

Adaptation and use of the Palliative Care Tool Kit[22] at the community level will help in forming the local policy at the clinics. The local policy will among other things recognize PC requirements in the community/clinic structure-Who and what the problems are? It will also help HCPs ascertain the relief they are getting currently and what could be added to expand their PC to be more comprehensive?[22] Levy et al. explained that "numerous effective PC ventures started very small, when somebody saw a group of people who needed help".[22]

The local policy should encourage working in teams, teams formed locally in each clinic comprising of local champions of PC in the clinics (staffs) communities (volunteers) needed to be encouraged and formation of PC teams comprising of HCPs, spiritual counsellors volunteers from different fields for continuous monitoring of the integration and implementation of policies.

The government should make funds available for awareness campaign on PC, training of and encouragement of HCPs to engage in continuous professional development.

Drug availability

Awareness that most medicines are available needed to be raised, awareness of the efficacy and use opioids to the public and patients using local pamphlets, also dispel fear of abuse. Public and private partnership with local pharmacy for dispensing medications especially after hours and during public holidays. Training of HCPs especially the prescribing doctors in the use of other forms of Morphine especially oral syrups and tablets.

Education / training

Levy et al said “If people feel unprepared or unsupported, they will not work well and may leave the team” and recommends “ training and supervision which can be done in teaching sessions and on-the-job, working alongside a mentor.”[22] mentoring and continuous training of HCPs is recommended.

Motivations to the staff in terms of remuneration and recognition of training in PC had to be encouraged on a continuous basis.

Public private partnership can be encouraged more where private practitioners are being remunerated by doing locums in government hospitals and hospices.

Service delivery.

Designation of certain HCPs to provide PC, with PC clearly written in their job description and designation of certain area or space in the local clinic to PC service daily.

Volunteers[22] including family members are a great help for PC delivery and are needed in PC teams. They should be encouraged, involved and trained.

Emotional support for families

Financial support in form of Governments grants to allay poverty and ongoing emotional support is very important and recommended.

Implementation studies and post intervention research are needed, Monitoring and Evaluation of Implementation studies are needed. The impact of PC on family and house hold in the communities are needed in monitoring the efficacy of the national policies.

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APPENDICES

Appendix 1: DEVELOPMENT AND IMPLEMENTATION OF PALLIATIVE CARE POLICIES, ALLOCATION OF RESOURCES FOR PALLIATIVE CARE

Instruction: Tick (x) your most appropriate response for each question

		Yes	**No**	**Don't know**
	National policy and strategy on palliative care			
1	Are you aware of the National policy and strategy on palliative care?			
2	Have you identified elements of the National policy and strategy that apply to your clinic?			
	Provincial policy and strategy on palliative care			
3	Is there a provincial policy in your clinic on how to identify who needs palliative care?			
4	Is there a provincial policy on which members of staff provide palliative care at your clinic?			
	Local clinic policy and strategy on palliative care			
5	Is there a policy in this clinic on referrals to or from palliative care?			
6	Is palliative care included in the job description of the staffs of the clinic?			
7	Is there any policy or guideline on pain management in this clinic?			
8	Is there any policy on controlled medicines especially morphine, its procurement and prescription in this clinic?			
9	Is there any policy or memo on training/ continuous professional development (CPD) in palliative care in this clinic?			
10	Is there any encouragement, motivation or requirement for staff to be trained in palliative medicine in this clinic?			
	Budget allocation			
11	What funding is allocated to palliative care this year in this clinic?			
12	What funding is allocated to palliative care training this year?			

Appendix 2: QUESTIONNAIRE ON PALLIATIVE CARE ESSENTIAL MEDICINES[20]

1) Checklist of essential medicines in palliative care and their indications.

	MEDICATION	INDICATION	AVAILABLE	NOT AVAILABLE
1	AMITRYPTILINE	Depression		
2	DEXAMETHASONE	Anorexia		
3	DIAZEPAM	Anxiety		
4	DOCUSATE SODIUM	Constipation		
5	FLUOXENTHINE	Depression		
6	GABAPENTIN	Neuropathic pain		
7	HALOPERIDOL	Delirium		
8	HYOSCINE BUYTYLBROMIDE	Respiratory Tract Secretions		
9	IBUPROFEN	Pain (mild to moderate)		
10	LOPERAMIDE	Diarrhea		
11	LORAZEPAM	Anxiety		
12	METOCLOPRAMIDE	Nausea and Vomiting		
13	MORHPHINE	Pain (moderate to severe)		
14	SENNA	Constipation		
15	SODIUM PICOSULFATE	Constipation		

2) How do you procure your medicines especially the opioids? (Explain)

____

____

____

____

____

3) Who prescribes controlled drugs in your clinic?

____

____

4) What was the **average** quantity of morphine used <u>monthly</u> last year (Syrup, tablets and injectable)? (Please quantify)

Syrup:

____

Tablets:

____

Injectable:

____

Appendix 3 Questionnaire on demographic characteristics & palliative care competencies

Participant number:

1. Age (years): ____
2. Sex: Male [ ]   Female [ ]
3. Occupation: ____
4. Year of Graduation: ____
5. Do you receive any training in undergraduate palliative medicine? YES or NO.
6. Do you have any postgraduate training in Palliative Medicine? YES or NO.
7. If yes to Question 10, at what level? (postgrad certificate); (postgrad diploma); (masters)
8. Is there any budget for continuous medical education in palliative care? YES or NO

Please indicate your perception of your level of ability in each area using the following scale.

5 = High level of competence - extensive experience in the skill area
4= Moderately high level of competence -good experience in the skill area
3= Average level of competence -some experience in the skill area
2 = Low level of competence -little experience in the skill area
1= No level of competence -no experience in the skill area

		IAHPC ESSENTIAL SKILLS SET	**5**	**4**	**3**	**2**	**1**
1		Physical care needs. management of -					
	a	Pain					
	b	Dyspnea					
	c	Cough					
	d	Diarrhea					
	e	Delirium					
	f	Wounds and ulcers					
	g	Insomnia					
	h	Fatigue					
	i	Anorexia					
	j	Anemia					
	k	Drowsiness or sedation					
	l	Sweating					
2		Psychological/emotional/ spiritual care needs. Management of -					
	a	Psychological distress					
	b	Suffering of the relative and /or caregiver					
	c	Anxiety					
	d	Spiritual needs and existential distress					
	e	Depression					
	f	Family's grief and Bereavement issues					
3		care planning and coordination					
	a	Provide care in the last days/weeks of life					
	b	Facilitate the availability and access to medications (with emphasis on opioids)					
	c	Identifying the psychosocial /spiritual needs of self and others professionals involved in the care					
4		**communication issues**					
	a	With patient family and caregivers about last days /weeks care issue ADVANCE CARE PLANNING					
	b	Identify and set priorities with patients and caregivers					
	c	Provide information and guidance to patients and caregivers according to available resources, sensitize other health care professionals and workers about palliative care.					
	d	Breaking bad news to patient and family.					

Appendix 4: PARTICIPANT INFORMATION SHEET

AN ASSESSMENT OF THE CURRENT STATUS OF INTEGRATION OF PALLIATIVE CARE INTO PRIMARY HEALTH CARE CENTERS IN ALEXANDRA COMMUNITY

Dear Facility manager/doctor/ pharmacist

I am Dr Soji Soogun and I am undertaking a research study as part of the degree of MPhil in Palliative Medicine. There is no funding source for this research.

WHAT IS THE PURPOSE OF THIS STUDY?

This study is to determine the current status of integration of palliative care into the Primary Health Care centres in Alexandra community.

Its objectives are to identify the existing policies including budgets available in these clinics relating to palliative care, to identify the availability of palliative care essential medicines in these clinics and to conduct a survey of the health care professionals' training in palliative medicine.

DO I HAVE TO TAKE PART?

No, you don't have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. Whether or not you take part will not affect you in any way. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part, and you may want to talk it over with your family, friends or someone in your care team.

WHAT WILL HAPPEN IF I TAKE PART?

You have been chosen as one of the study participants because you are working in this clinic either as manager or /and a healthcare professional.

As a manager, the researcher will ask you questions in a questionnaire about policies and budgeting, and as a health care professional the researcher will ask you questions about delivering palliative care and your training in palliative medicine.

As the pharmacist in charge the researcher will ask you questions in a questionnaire about dispensing and procuring essential medicines especially opioids in this clinic.

This information sheet is for you to keep.

BENEFITS OF THE STUDY.

There are no direct benefits to the study for participants. The anticipated benefits are the successful integration and delivery of good quality/ sustainable palliative care services at the primary care level throughout the country, and data provision for further intervention in this area.

WHAT ARE THE RISKS OF THE STUDY?

There are no risks in this study.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

All the information which we collect during the interview will be kept strictly confidential. You will not be identified in any way, and your personal details will be kept separately from the information you give us we will use a number and not your name on any info you gave us. No one outside the study will have access to the information you give us.

HOW WILL I KNOW ABOUT THE RESULTS OF THE STUDY?

At the end of the study a report will be sent to the clinic and to the people who took part in the study.

WHO IS ORGANISING THE RESEARCH?

If you have any questions about this research, you can contact the following people.

If you have any questions about the study:

The researcher: Dr Soji Soogun. Gauteng Department of Community Safety.Tel 0112423028, cell 0839908090, email address sojisoogun@yahoo.com

Research supervisor & PI: DR LIZ GWYTHER. University of Cape Town: Tel 021 4066707, email address Liz.Gwyther@uct.ac.za

If you have any questions about your human rights of any ethical issues about the study:

UCT Research Ethics Committee:

Mrs Lamees Emjedi

Research Ethics Committee

E52 Room24, Old Main Building, Groote Schur Hospital, Observatory.

Telephone: 021 406 6338

(Appendix 5).

CONSENT FORM FOR: AN ASSESSMENT OF THE CURRENT STATUS OF INTERGRATIONOF PALLIATIVE CARE INTO PRIMARY HEALTH CARE CENTERS IN ALEXADRA COMMUNTY

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

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

3. I agree to take part in the above study

Name ______________________________

Signature ____________________________ Date ____________________

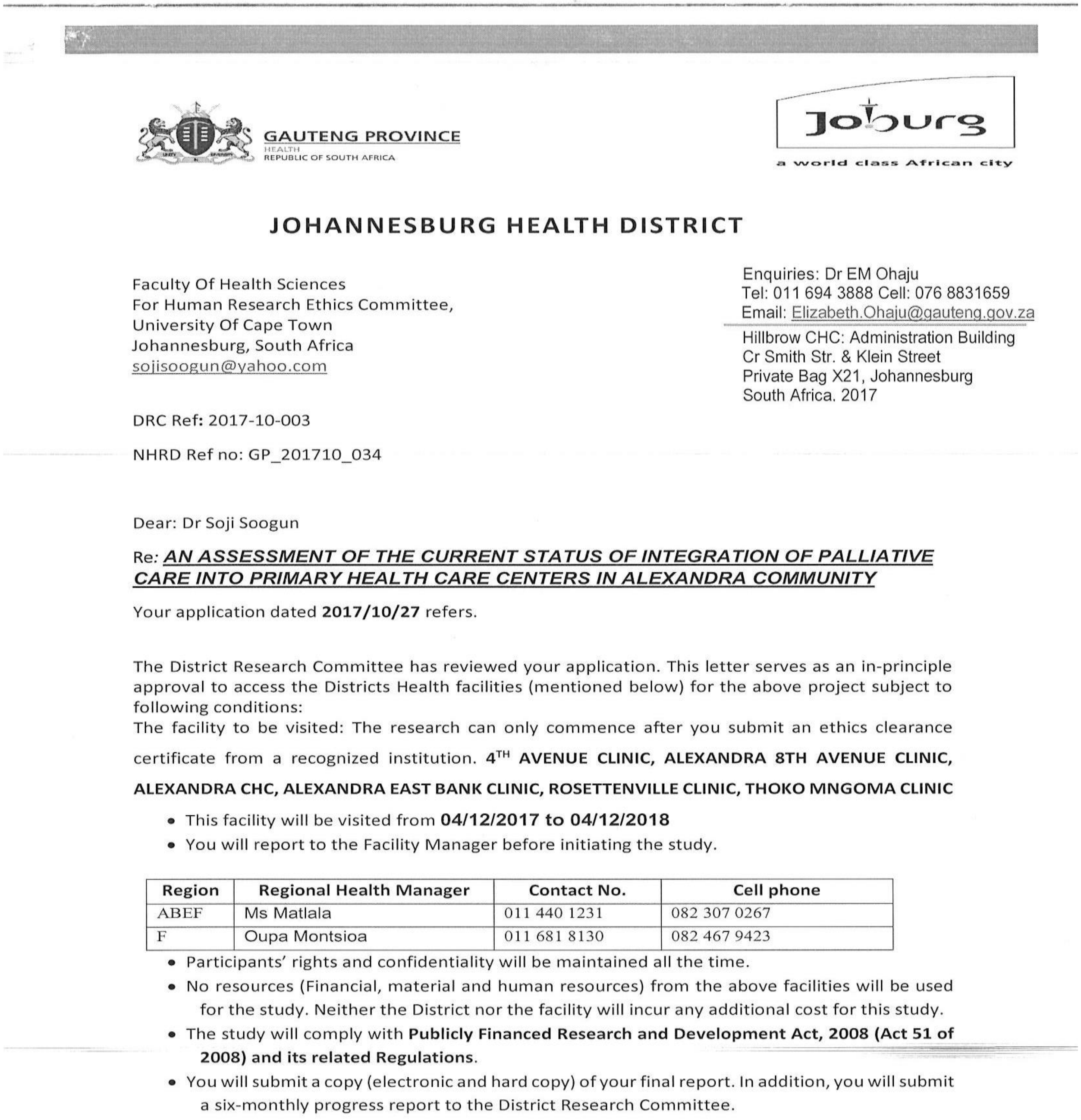
Researcher: Signature ____________________ Date ____________________

Signature ____________________________ Date ____________________

(Appendix 6) The IAHPC List of Essential Practices.

identify, evaluate, diagnose and apply treatment and solution measures for
physical care needs
pain (all types)
respiratory problems (dyspnea, cough)
gastrointestinal problems (constipation, nausea, vomiting, dry mouth, mucositis, diarrhea
Delirium
wounds ulcers, skin rash and skin lesions
Insomnia
psychological/emotional/spiritual care needs
psychological distress
suffering of the relative and /or caregiver
Anxiety
identify and evaluate-provide support and when possible, refer for diagnosis, treatment and solution measures for
physical care needs
fatigue
Anorexia
Anemia
drowsiness or sedation
sweating
psychological/emotional/spiritual care needs ;
spiritual needs and existential distress
Depression
family/caregivers grief and bereavement issues
Other
care planning and coordination
identify the resource and support available and develop and implement a plan of care based on patient needs
provide care in the last days/weeks of life
identify, evaluate and implement solutions to facilitate the availability and access to medications (with emphasis on opioids)
identify the psychosocial /spiritual needs of self and others professionals involved in the care
communication issues
communicate with patient family and caregivers about diagnosis ,prognosis, condition treatment ,symptoms and their management, and last days /weeks care issues
identify and set priorities with patients and caregivers
Provide information and guidance to patients and caregivers according to available resources sensitize other health care professionals and workers about palliative care.

Appendix 7: GPG Ethics approval letter.



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Joburg
a world class African city

JOHANNESBURG HEALTH DISTRICT

Faculty Of Health Sciences
For Human Research Ethics Committee,
University Of Cape Town
Johannesburg, South Africa
sojisoogun@yahoo.com

Enquiries: Dr EM Ohaju
Tel: 011 694 3888 Cell: 076 8831659
Email: Elizabeth.Ohaju@gauteng.gov.za
Hillbrow CHC: Administration Building
Cr Smith Str. & Klein Street
Private Bag X21, Johannesburg
South Africa. 2017

DRC Ref**:** 2017-10-003

NHRD Ref no: GP_201710_034

Dear: Dr Soji Soogun

Re*:* ***AN ASSESSMENT OF THE CURRENT STATUS OF INTEGRATION OF PALLIATIVE CARE INTO PRIMARY HEALTH CARE CENTERS IN ALEXANDRA COMMUNITY***

Your application dated **2017/10/27** refers.

The District Research Committee has reviewed your application. This letter serves as an in-principle approval to access the Districts Health facilities (mentioned below) for the above project subject to following conditions:
The facility to be visited: The research can only commence after you submit an ethics clearance certificate from a recognized institution. **4TH AVENUE CLINIC, ALEXANDRA 8TH AVENUE CLINIC, ALEXANDRA CHC, ALEXANDRA EAST BANK CLINIC, ROSETTENVILLE CLINIC, THOKO MNGOMA CLINIC**

- This facility will be visited from **04/12/2017 to 04/12/2018**
- You will report to the Facility Manager before initiating the study.

Region	Regional Health Manager	Contact No.	Cell phone
ABEF	Ms Matlala	011 440 1231	082 307 0267
F	Oupa Montsioa	011 681 8130	082 467 9423

- Participants' rights and confidentiality will be maintained all the time.
- No resources (Financial, material and human resources) from the above facilities will be used for the study. Neither the District nor the facility will incur any additional cost for this study.
- The study will comply with **Publicly Financed Research and Development Act, 2008 (Act 51 of 2008) and its related Regulations**.
- You will submit a copy (electronic and hard copy) of your final report. In addition, you will submit a six-monthly progress report to the District Research Committee.

- Your supervisor and University of South Africa will ensure that these reports are being submitted timeously to the District Research Committee.
- The District must be acknowledged in all the reports/publications generated from the research and a copy of these reports/publications must be submitted to the District Research Committee.

We reserve our right to withdraw our approval, if you breach any of the conditions mentioned above.

Please feel free to contact us, if you have any further queries. On behalf of the District Research Committee, we would like to thank you for choosing our District to conduct such an important study.

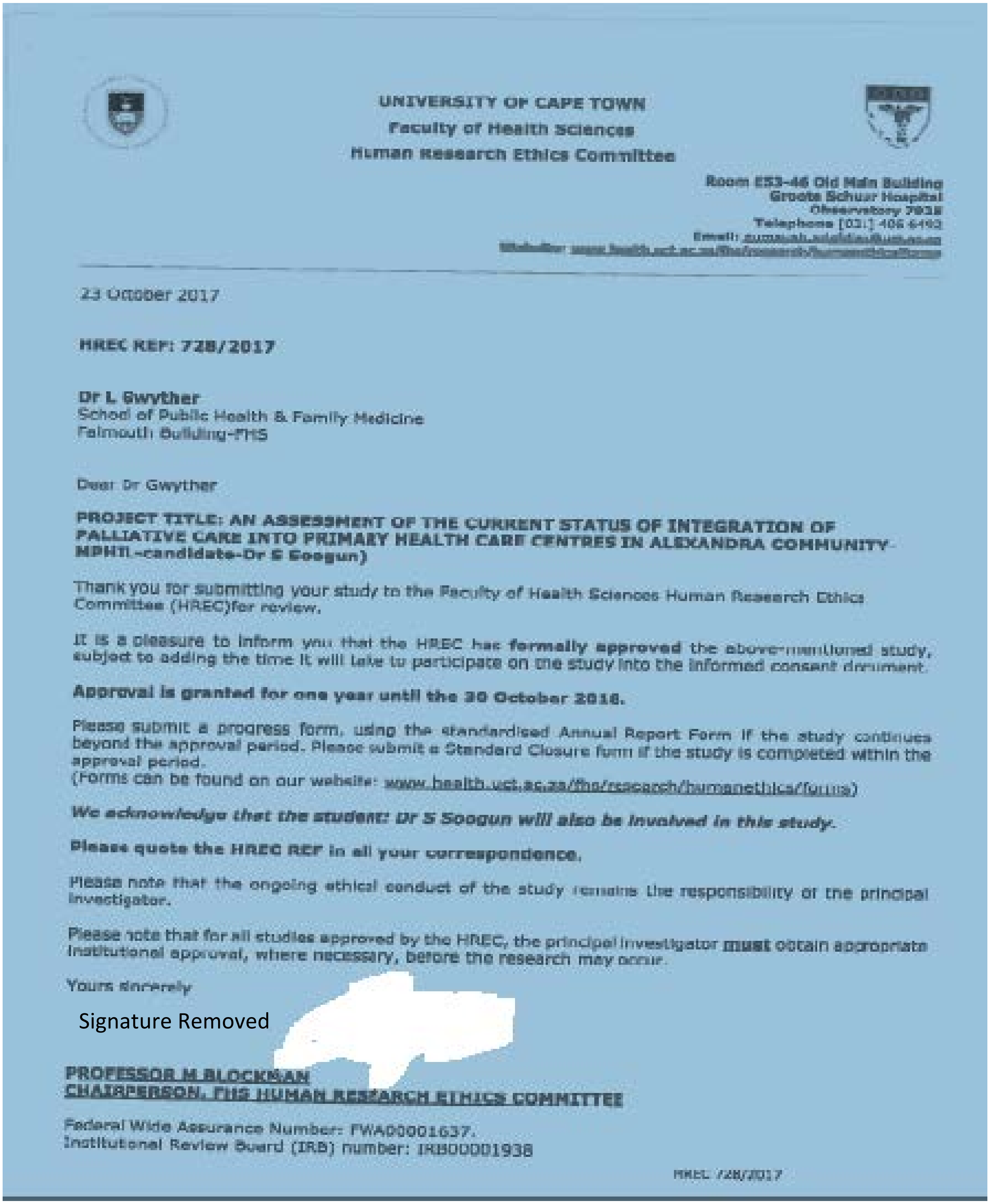
Regards,

Signature Removed

Dr EM Onaju
Chairperson: District Research Committee
Johannesburg Health District
Date 7/12/2012

Mrs M. Morewane
Chief Director
Johannesburg Health District
Date:

Appendix 8; UCT HREC letter of approval.



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: [illegible]
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

23 October 2017

HREC REF: 728/2017

Dr L Gwyther
School of Public Health & Family Medicine
Falmouth Building-FHS

Dear Dr Gwyther

PROJECT TITLE: AN ASSESSMENT OF THE CURRENT STATUS OF INTEGRATION OF PALLIATIVE CARE INTO PRIMARY HEALTH CARE CENTRES IN ALEXANDRA COMMUNITY-MPHIL-candidate-Dr S Soogun)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC)for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study, subject to adding the time it will take to participate on the study into the informed consent document.

Approval is granted for one year until the 30 October 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Dr S Soogun will also be involved in this study.

Please quote the HREC REF in all your correspondence.

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

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 728/2017

Appendix 9: Map, population details and time zone of Alexandra township, Gauteng, Republic of South Africa.

Alexandra

● Show map of Gauteng
○ Show map of South Africa
○ Show all

Coordinates: 26°6.23'S 28°5.77'E

Country	South Africa
Province	Gauteng
Municipality	City of Johannesburg
Established	1912
Area[1]	
• **Total**	6.91 km² (2.67 sq mi)
Population (2011)[1]	
• **Total**	179,624
• **Density**	26,000/km² (67,000/sq mi)
Racial makeup (2011)[1]	
• **Black African**	99.0%
• **Coloured**	0.4%
• **Indian/Asian**	0.1%
• **White**	0.1%
• **Other**	0.4%
First languages (2011)[1]	
• **Zulu**	26.3%
• **Northern Sotho**	23.1%
• **Tsonga**	11.3%
• **Xhosa**	9.6%
• **Other**	29.6%
Time zone	UTC+2 (SAST)
Postal code (street)	2090
PO box	2014