

A Prospective Cohort Study and Evaluation of an End-of-life Programme Intervention in a Primary Health Care Setting

By

Jennifer Mary Morgan

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Supervisors:

Elizabeth Gywther

School of Public Health and Family Medicine

University of Cape Town

Abdul Isaacs

School of Public Health and Family Medicine

University of Cape Town

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DECLARATION

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ABBREVIATIONS

ACD – Advanced Care Directive

AIDS – Acquired Immunodeficiency Syndrome

APCA – African Palliative Care Association

APCA African POS – African Palliative Care Association African Palliative Outcome Scale

ARV - Antiretroviral

CHC – Community Health Centre

CNP – Clinical Nurse Practitioner

COPD – Chronic Obstructive Pulmonary Disease

CVA – Cerebro-vascular Accident

DOTs – Directly Observed Treatment

EN – Enrolled Nurse

ENA – Enrolled Nursing Assistant

GFJ – GF Jooste Hospital

GPs – General Practitioners

GSF – Gold Standards Framework

GSH – Groote Schuur Hospital

HBC – Home Based Carers

HIV – Human Immunodeficiency Virus

HIV/AIDS – Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome

HPCA – Hospice Palliative Care Association of South Africa

HPO – Health Promotion Officer

IHD – Ischemic Heart Disease

IOELC – International Observatory on End of Life Care

KS – Kaposi's Sarcoma

LRTI – Lower Respiratory Tract Infection

MPCHC – Mitchells Plain Community Health Centre

MPDH – Mitchells Plain District Hospital

MDHS – Metro District Health Service

MVA – Motor Vehicle Accident

NCDs – Non-communicable Diseases

NGOs – Non-governmental Organisations

NHS – National Health Service

RN – Registered Nurse

SMS – Short Message Service

TB – Tuberculosis

UNAIDS – United Nations Programme on HIV/AIDS

WHO – World Health Organisation

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ABSTRACT

Context: Palliative care is the holistic care for patients, and their families, who are facing the end of their life due to a life-threatening illness. The Global burden of disease indicates that 65.5% of all deaths in 2010 were caused by non-communicable diseases. In South Africa, seven of the top ten causes of death in 2007 would benefit from palliative care.

Objectives: This study aimed to evaluate patient reported outcomes at a Community Health Centre (CHC) prior to an intervention and to evaluate the impact of an intervention involving a support group and focused care for people facing life threatening illness.

Method: This study was conducted in a primary health care clinic, over a period of six months. Initially the participants were recruited, by the programme coordinator, to a control group (Group A) and the African Palliative Care Association African Palliative Outcome Scale (APCA African POS) was applied to them weekly for six weeks. Thereafter the intervention began, consisting of a support group and an in-depth consultation with a doctor at the clinic. The intervention group (Group B) was recruited after the completion of Group A's data collection. Group B, like Group A, were asked to complete the APCA African POS questions, weekly for six weeks. Group A and Group B were invited to participate in the intervention. The participants still involved in the intervention at the completion of the study, and the staff at the CHC, completed an evaluation of the intervention.

Results: There were 46 participants recruited to the study, five participants were excluded as they were not mentally competent; 20 participants were recruited to Group A and 21 participants were recruited to Group B. The percentage of participants in the whole cohort who died was 43.9%, with 66.7% of Group B dying at some point in the study. All (100%) participants wanted the role of programme coordinator to continue, the support group to continue to meet, monthly and the programme to continue with few changes. Of the staff that completed the evaluation, 64.9% had referred patients to the study, 66.67% stated that the study had a positive impact on them as staff members and 96.9% stated that they wanted the programme to continue.

Conclusion: The participant and staff evaluation showed that both parties found the programme beneficial and recommended that the programme continue, with few changes. However, due to the attrition rate and poor participation in the intervention among Group B participants, the APCA African POS results could not be used to show a change in patient reported outcomes. Recommendations include: a permanent palliative care programme, a study over a longer period of time, active reminders to refer patients to the programme timeously, palliative care training for the staff in the facility and more opportunities for staff to be more involved in future palliative care programmes within the clinic.

CHAPTER 1: INTRODUCTION

Health is defined as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity¹. If we desire holistic health care, we should aim for this ideal, despite the disease entities our patients may face. When considering patients who are nearing the end of their life as a result of chronic illness, although cure may not be possible, we as health care providers can still attempt to improve physical, mental and social wellbeing. This is the essence of palliative care².

The aim of this study was to evaluate patient reported outcomes at a Community Health Centre, in Cape Town, South Africa, prior to an intervention and then to evaluate the impact of an intervention, involving a support group and focused care, for people facing life threatening illnesses. We aimed to achieve this by meeting the following set of objectives. We planned to determine the prevalence of people with palliative care needs at Mitchells Plain Community Health Centre (MPCHC) and to assess the extent to which people with life-threatening illnesses seek medical attention prior to an intervention. We planned to assess the physical, psychological and spiritual concerns of people facing life-threatening illnesses, prior to an intervention and then to determine if there is a change in these patient reported outcomes with a palliative care programme in place. We planned to evaluate the effect of the programme on the participants and the staff of the MPCHC.

Palliative Care:

There are two main definitions of palliative care, one from the World Health Organisation (WHO) and the other from the European Palliative Care Association. Both encompass the principles of palliative care.

The WHO broadly defines palliative care as care that improves quality of life for patients and their families, who face the difficulties associated with life-threatening illness. This care includes pain and symptom control, as well as spiritual and psychological support. Beyond defining palliative care, the WHO recommends that: (a) all governments include palliative care in their primary health care policy development and (b) they integrate palliative care programmes into existing health care systems.²

According to the European Palliative Care Association, 'Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care –

that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.’³

While these definitions provide a clear explanation of palliative care, there are issues they do not address, for example, expanding on how important palliative care is and how many people would benefit from such health care.

Disease Burden and Palliative Care:

People who are dying from progressing chronic illnesses need care that is different to preventative primary health care therapy, because it is too late to prevent the illness. More emphasis needs to be placed on helping the person to accept their limitations (including the shortening of their life), facilitating communication with their family and assisting them to achieve spiritual wellbeing. Such patients specifically need palliative care (individualised to each patient), which is supportive in nature and seeks to improve quality of life and control symptoms.

The global and local burden of disease gives an indication of the scope of need for palliative care. The WHO Global Burden of Disease report from 2012 indicates that non-communicable diseases are the leading cause of death internationally, at 65.5% of all deaths in 2010⁴. In the report, the top 10 causes of death, globally were, in order of prevalence (with rates per 100 000 deaths given), ischemic heart disease (IHD, 105.7), cerebro-vascular diseases (88.4), chronic obstructive pulmonary disease (COPD, 43.8), lower respiratory tract infections (LRTI, 40.0), lung cancer (23.4), HIV/AIDS (21.4), diarrheal disease (20.9), motor vehicle accidents (MVA, 19.5), diabetes (19.5) and tuberculosis (TB; 18.0)⁴. Of these causes of death, IHD, cerebro-vascular diseases, COPD, lung cancer, HIV/AIDS and diabetes are considered to be chronic diseases, for which palliative care can be used and improve people’s quality of life. These data suggest that, internationally, there is thus a need for palliative care.

Sub-Saharan Africa has been devastated by the HIV (Human Immunodeficiency Virus) epidemic⁵. According to the Global Burden of Disease report, Southern sub-Saharan Africa has the top five causes of years of life lost as: HIV/AIDS, LRTI, diarrheal diseases, interpersonal violence and TB⁴. In seventh place is cerebro-vascular disease and in eighth place is diabetes mellitus⁴. HIV/AIDS continues to be a major burden of disease for sub-Saharan Africa. In 2012 the UNAIDS (United Nations Programmes on HIV/AIDS) report estimated that world-wide there are approximately 34 million people living with HIV⁶. In

sub-Saharan Africa the prevalence of HIV is 4.9%, with 69% of the world's HIV-infected people living in the area⁶.

In South Africa the leading cause of death in 2007 was pulmonary TB⁷. The other nine causes that constituted the top ten causes of death in the 2007 report are: LRTI, diarrhoeal disease, HIV/AIDS, cerebro-vascular disease, diabetes mellitus, trauma, heart failure, hypertension and IHD⁷. Of the top ten causes of death in South Africa, seven would benefit from palliative care: TB, HIV/AIDS, cerebro-vascular disease, diabetes mellitus, heart failure, hypertension and IHD⁷.

Much emphasis is placed on screening for chronic illnesses, as well as diagnosis and prevention of complications from chronic illnesses. However, once a person has a chronic illness and especially once they have irreversible complications, action must take place to provide care for them. This action should not be aimed at prolonging suffering, but rather at alleviating suffering from illness, and this should include appropriate pain management. This care needs to include preparation for the future: biologically, psychologically and socially. And so this indicates a need for palliative care, with broad inclusion criteria, providing care for all members of the community, and their families, who are facing life-threatening illnesses.

In the Western Cape, in 2009, HIV was the leading cause of death, followed by TB, IHD, cerebro-vascular disease, diabetes mellitus, interpersonal violence, lung cancer, LRTI, COPD and hypertensive heart disease⁸. In Mitchells Plain, a sub-district of Cape Town, where this study took place, the causes of death were very similar to that of the Western Cape, with a few differences. The causes of death, in Mitchells Plain, in 2006 were: homicide, HIV, TB, road traffic accidents, LRTI, diabetes mellitus, low birth weight, diarrheal diseases, IHD and cerebro-vascular disease⁹. Of all of these causes of death in Mitchells Plain, five out of the ten would benefit from palliative care: HIV-related illnesses, TB, diabetes mellitus, IHD and cerebro-vascular disease. Considering some of the symptoms people with the above listed illness may experience, palliative care aims to address the individual's needs for symptom control, to control their pain, breathlessness, anxiety, nausea, constipation and low mood. Palliative care would integrate the person's psychological and spiritual needs into their care. Most importantly, it would be geared towards assisting the individual to live as actively as possible and support their family in coping with the challenge of caring for them and managing the process of grieving. These are some ways that palliative care would benefit people dying of chronic illnesses, in their last months of life.

Call for Improved Palliative Care:

Globally, the palliative care community has recognised the need for improved palliative care in all countries¹⁰. In 2002, the Cape Town Declaration stated that palliative care is a human right, that appropriate drugs should be made available, that improved education on palliative care is necessary and that palliative care should be provided at all levels of health care¹⁰.

This was followed by the Korea Declaration, in 2005, which called on governments to improve policies on palliative care integration and education, as well as policies designed to improve access to appropriate drugs and make palliative care available to all citizens¹¹. In addition the Venice Declaration (2006), supported a call for more palliative care research¹².

Most recently, in January 2014, the WHO passed a resolution which supports all aspects of palliative care¹³. This resolution comprehensively covers all principles of palliative care in a practical manner. It requests that all members of the WHO comply with providing broad and integrative palliative care, to all people (adults and children) across all diseases, including non-communicable diseases and infectious diseases, including HIV and TB. This is a major step forward for all people who need palliative care and are not able to access quality care. It is also encouraging for those trying to implement quality palliative care around the world.¹³

Improved Palliative Care:

Each country has its own standard of palliative care and level of integration. In 2006, the International Observatory on End of Life Care (IOELC) undertook research in many areas of the world and mapped the level of palliative care that was available in each country¹⁴. More recently the World Wide Palliative Care Alliance has updated this research and improved on the classification that was originally developed by the IOELC¹⁵. There are four levels within the classification, stratifying the levels of integration of current palliative care in different countries. Currently South Africa holds a classification of 4a. Level 1 indicates that there are no palliative care services. Level 4 is the highest, but there are 2 components for level 4, namely 4a and 4b. Level 4a is assigned to countries where Hospice and palliative care organisations are in the preliminary stages of integration into mainstream service provision. Level 4b is assigned to countries where Hospice and palliative care organisations are advanced in their integration into mainstream service provision¹⁵. This classification indicates that South Africa still has improvements to make in the area of palliative care, more specifically in the integration of services. South African palliative care experts agree with this classification, as they feel there is a long way to go, before South African palliative care can compare with countries like the United Kingdom, Canada and the Netherlands¹⁶. In South Africa there are pockets of excellence, Non-Profit Organisations, religious-based

organizations and charities, where good integration is taking place. However there is very little structured palliative care offered in the primary health care setting or in hospitals.¹⁶

Harding and Higginson¹⁷ conducted a review, in 2003, that attempted to include all palliative care research and programmes in sub-Saharan Africa. They agree that, while there is some palliative care activity in South Africa, there is room for improvement. They highlighted some key points relating to the need for improvement of palliative care services in this region. Some important points include: structural and resource challenges, increasing coverage and evaluating services. They concluded that more work needs to be done in this region in order to improve palliative care.¹⁷

In the United Kingdom there is a national end-of-life programme, which is aimed at assisting health care professionals to improve the quality of care for all patients at the end of their lives and to enable patients to live and die where they choose to. To assist in the implementation of this improved care, the National Health Service (NHS) supports the use of the Gold Standards Framework (GSF), designed to assist primary health care services to improve the care given to the patients facing life-threatening illnesses. The GSF was first developed to assist with the care of patients dying from cancer, but has subsequently been adapted to assist in the management of patients suffering from any chronic illness which threatens their lives. The aim of the GSF is to provide a 'Gold Standard' of care for each patient who is nearing the end of his/her life and a primary health care registry of all 'Gold Standard' patients to ensure that they receive coordinated care at the time of greatest need. The processes of the GSF assist with the identification of all patients who are nearing the end of their lives, assessment of their needs, symptoms, and preferences, and the formulation of plans designed to manage their care, accordingly. The goals of the GSF are¹⁸:

1. To improve patients' symptoms
2. To enable patients to live and die at their place of choice
3. To provide security and support to enable better advanced planning and fewer crisis admissions to hospital
4. To empower and support care givers
5. To improve the confidence of staff administering palliative care
6. To improve the communication of medical staff with their patients and the patients' families.¹⁸

Current Palliative Care in the Western Cape:

The Abundant Life Palliative Care Programme¹⁹ was started in 2009 at Victoria Hospital in Wynberg, based on the GSF. Its aim is two-fold

1. To assist people living with organ failure and other non-communicable diseases (NCDs) to enable them to stay at home and continue to be a part of the household for as long as possible
2. To assist the people caring for terminally ill patients, to do so with confidence and competence.

The programme makes use of an interdisciplinary team, led by a physician and a palliative care trained nurse, with a part time social worker involved as well. The mainstay of the programme is individual assessment and optimisation of the person's medical care, with support of the patient and family, by means of a weekly support group. This programme has managed to reduce the number and length of hospital admissions, thus saving costs to the hospital and the individuals¹⁹. It has also helped more people to die at home, rather than away from their families, in hospital.¹⁹

St Luke's Hospice, a member of the Hospice Palliative Care Association of South Africa (HPCA), is active in the city of Cape Town, Western Cape. This organisation provides care at home and in the form of a small in-patient unit, for people suffering from any form of cancer, as well as some neurological conditions (e.g., Motor Neuron Disease). The members of the organisation have chosen to limit the extent of their care to certain diseases, as they feel that this enables them to continue to provide good care for certain patients, and avoid the risk of becoming over-burdened by trying to cover all diseases that require palliative care. They assist with providing training for health care workers and lay people, with regard to all aspects of palliative care. They are a Non-Profit, Non-Government Organisation (NGO), relying mainly on community donations to fund the service, which is provided free of charge to all patients, except those with medical insurance.

In the Western Cape there are various Home-Based Care organisations, which usually work in a small area, or have various branches in different suburbs. They consist of home carers, who visit several homes each week, carrying out various roles, from bed bathing and wound dressing, to directly observed treatment (DOTs), in the case of home-bound TB patients. Home carers are not nurses and have very basic nursing training. Ideally, these NGOs should have a registered nurse to oversee the carers and to assess clinical needs, such as the need for pain management and relief from other distressing symptoms. The presence of the registered nurse is not guaranteed and the nurse, if present, is overstretched and not able to

include patient assessment and management, in addition to her responsibilities of supervision of carers and management of the service.

There are a few facilities in Cape Town that can accommodate people needing short-to intermediate-term placement, for medical reasons. Examples of such facilities include Living Hope, Life Esidemeni and St Joseph's Home. St Joseph's Home provides care for children with palliative care needs. The Intermediate Care Policy of the Western Cape Department of Health, provides a platform for the development of intermediate care facilities which would provide care for people in need of post-acute care, rehabilitation, restorative and palliative care²⁰. Currently these facilities are often far from where the family may stay and do not offer a permanent solution for people who may survive for more than a few months, living with their illnesses.

According to the HPCA, there were 165 sites providing palliative care in South Africa in the years 2012 and 2013²¹. Of these, 25 sites were based in the Western Cape. These sites catered for people living with TB, HIV/AIDS and non-communicable diseases, such as cancer, organ failure and dementia²¹.

Palliative Care Research in Africa:

In general, there is less medical research done in Africa compared to other continents²². Within Africa, certain countries produce significant medical research and many produce very little or none. Volmink suggests that reasons such as political and economic differences may be responsible for this discrepancy²². Significantly, South Africa is one of the countries that is reported to produce significant medical research²². In the context of palliative care research, there has been a call, made in the Venice declaration, for more palliative care research, worldwide¹².

Most palliative care research coming out of Africa, at present, focuses on HIV-related illness and some attention is given to cancer related palliative care. Very little attention has been given to the non-communicable diseases, such as heart failure or renal failure. A shift in this trend is starting to emerge with the research from Abundant Life and a prevalence study of local palliative care needs in Cape Town, South Africa^{19,23}.

Tools for Research:

Because palliative care is about improving a patient's symptoms and emotional, spiritual and psychological wellbeing, proving that an intervention has been beneficial can only be based on a subjective response, from the patients themselves. It is difficult to use objective

markers to verify improved outcomes²⁴. There are no laboratory tests to validate outcomes. It is a difficult area in which to verify outcomes because there are many confounders. For example, one of the criteria for joining a palliative care programme is that a person is nearing the end of his/her life. Some people may get frailer during the study and may not be able to complete the study. Some people may not survive to the end of the study. Because palliative care relies on subjective markers to verify outcomes, the patient needs to be able and willing to contribute to the study, which he/she may not be able to do as the illness progresses or he/she passes away. Studies investigating the efficacy of palliative care methods, therefore, have high rates of attrition.

There are various tools available to assist with testing outcomes (e.g., testing symptoms and emotional wellbeing of the patient and the primary care giver) in palliative care interventions. The African Palliative Care Association African Palliative Outcomes Scale (APCA African POS) has been validated for use in Africa²⁵. It is a short, 10 question tool and quick to administer. It was developed in response to a need for quick, effective and efficient research in African palliative care facilities²⁶. With the aid of the APCA African POS, one can statistically analyse outcomes of symptoms and emotional wellbeing of palliative care patients. If an improvement in outcome can be demonstrated, this may support researchers advocating the need for palliative care and the programme it is testing.

Description of Study Population:

The population, from which the sample for this study was drawn, consisted of the residents of Mitchells Plain, a suburb and community within the city of Cape Town, in the Western Cape province of South Africa. Mitchells Plain covers a large area (43,76km²) and is inhabited by a large population (310 484 people)²⁷. The origins of the suburb date back to the implementation of the Group Areas Act, which resulted in the forced removal of coloured people from District Six and other areas, to Mitchells Plain. Prior to 1990, it was made up of only coloured people, both Cape Malay and coloured people of mixed ancestry, with a mix of Christianity and Islam as the two main religious groups. This suburb is seen as one of the lower socio-economic coloured communities in Cape Town.

Post 1990 and the abolishment of the Group Areas Act, Mitchells Plain has seen a change in the demographics with relation to ethnicity, but that change has been small. The culture of gangs, currently evident in the area, was present even before 1990 and it continues to play havoc with the peaceful nature of many of the inhabitants. This violence explains why the leading cause of death in Mitchells Plain is homicide and not a disease related death, as is evident in other parts of Cape Town⁹. At the last census (2011), the population was

estimated to be 310 484 (8.3% of the total population of Cape Town), with 91% falling into the ethnic group of coloured²⁷.

The site for this research study, Mitchells Plain Community Health Centre, was chosen for various reasons. This area has very little in the way of palliative care services. Those which do exist are poorly integrated and, the clinic in which the study was set, is a very busy primary health care clinic. It was felt that this programme could benefit the community at large.

Health Care Facilities in Mitchells Plain:

At the time this study was conducted, Mitchells Plain was serviced by many private General Practitioners and one private hospital. Government health care services consisted of 5 nurse-managed and nurse-run municipal clinics (open five days a week, from 8:00 am to 4:00 pm). There was also one 24-hour clinic, MPCHC, open seven days a week, where the study was conducted. The Mitchells Plain District Hospital (MPDH), which offered limited patient care for level-one medical patients and had no out-patient facilities, was the only district-level hospital in Mitchells Plain. The other district-level hospital that serviced Mitchells Plain was GF Jooste Hospital (GFJ), which was in Manenberg, 10 kilometres away. GFJ received surgical patients from Mitchells Plain. The tertiary hospital that serviced Mitchells Plain was Groote Schuur Hospital (GSH), which received patients for complicated surgery and secondary level Medicine. There was a tertiary Psychiatric hospital in Mitchells Plain, Lentegeur Hospital, which serviced the community (and a large part of the Western Cape) for specialty psychiatric services.

Prior to this study, the Western Cape Department of Health had started the building of a new district hospital in Mitchells Plain. The hospital only officially opened in the new building after completion of this study. At the time, MPDH was operational, but was located in two empty wards in the psychiatric hospital, Lentegeur Hospital. As mentioned above, it had capacity for a fixed number of in-patient beds, but no out-patient facility. Carnation Ward, one of the MPDH wards at Lentegeur Hospital, had palliative care trained staff. In 2013, after completion of the study, GFJ was closed and all services and staff were moved to MPDH in the new building. This new hospital caters for acutely ill people, including people in need of palliative care. It also makes use of Carnation Ward, still based physically at Lentegeur Hospital, but run and staffed by MPDH, as a step-down facility for those patients who are more stable but still in need of in-patient care.

Magnolia Ward used to be part of MPDH prior to the occupation of the new hospital. Since the opening of the new hospital, it has changed in its function and is now run through public-

private partnership by Life Esidemeni. It has been identified by the Western Cape Department of Health as an intermediate care facility for convalescent, rehabilitation and palliative care patients. HPCA is providing palliative care training to equip the ward to provide palliative care to patients needing this service. The University of Cape Town palliative care teaching staff are concerned that none of the doctors providing part-time medical services to Life Esidemeni are trained or experienced in palliative care (E. Gwyther, personal communication, 10 April 2014). So, although this has been labeled a facility providing palliative care, the reality is quite different.

Palliative Care in Mitchells Plain:

Other palliative care services in Mitchells Plain, at the time this study was conducted, consisted of community-based Hospice care, provided under the umbrella of the St Luke's Hospice in Kenilworth. This consisted of community nurses visiting patients, who suffered from any type of cancer, in their homes. These nurses worked together with the other health care workers involved in each person's care, but no formal link existed between St Luke's Hospice and the MPCHC.

There were two Non-government organisations that work in the community that offered home-based care. This service was provided by home carers, who provided simple nursing care and are accessed through the CHC, by referral letter. There was little interaction between the CHC and the NGOs at the time this study was conducted.

Palliative care is an important aspect of holistic health care. At the time this study commenced palliative care was practised in Mitchells Plain, but there was a lack of integration between services and very poor palliative care practised within government health care facilities. The aim of this study was to address this problem.

CHAPTER 2: LITERATURE REVIEW

Palliative care is a relatively young specialty within medicine. It became more formally recognised by the medical community as a result of the work Dame Cecily Saunders started in the United Kingdom, in the 1960s. Interest in the idea slowly spread to all corners of the globe, initially only in first-world countries and, more recently, in many third-world countries. From one country to the next, the model on which the palliative care programmes are based varies. They all focus on the management of pain and other symptoms, with the primary aim being to improve the quality of life for people in the last months of their lives. Within the field of palliative care, there are still many questions that need to be answered and there is still much research to be done. For example, with certain diseases, it is unclear when palliative care should be initiated and which model is best suited to the particular setting.²⁸

The search for this literature review was conducted using Medline, Pubmed and Africa-wide databases. The words “palliative care” and “chronic diseases” were initially used.

Thereafter, “APCA African POS” was searched for, to find research that made use of the tool that was used in this study. Lastly, local, South African published research was found by word of mouth.

Overview of the Research Available:

In 2004, a group of palliative care experts in the United Kingdom gathered to create evidence based guidelines for the care of people dying from cancer²⁹. As a result of this work, Higginson wrote an editorial outlining what types of research they found in palliative care to aid them in the formulation of the guidelines and to highlight where the biggest gaps in palliative care research were. She notes that palliative care research is quite different from other areas of research in medicine. For example, when evaluating services, the methods used need to be different from other research, like drug trials, as randomisation and controlling the dose or care administered is very hard. And outcomes of a service are more difficult to assess, when dealing with a frail population, which is the case in palliative care. The wealth of knowledge in palliative care comes from studies looking at the needs of the palliative care population, the importance of good palliative care and options for solutions to providing palliative care²⁹. There is very little evidence on finding the most effective solution to providing palliative care and suggests ways to address this.²⁹

With this overview in mind, in this literature review I aim to present a selection of the findings yielded by palliative care research conducted to date. I will focus on chronic illnesses, family carers and different programmes available within palliative care. I will

compare international research to research conducted in Africa and, more specifically, in South Africa.

Research Focusing on Elderly People:

When trying to look at the needs of a palliative care population, it could be deemed unethical to ask hard or difficult questions of a person who is dying. They have so much to handle and asking them questions that may upset them could be seen as unethical. There are several studies in which such questions are asked of older people³⁰⁻³³, because, although, they are may be near the end of their natural life, they are not necessarily ill with a life-threatening disease. Researchers assume that elderly, relatively healthy people are less likely to be upset by sensitive questions relating to ill health and death, but may have started to think about how they hope that their death will be handled, when the time comes³⁰. If these studies were conducted with younger people, who were not ill, it may be very difficult to get helpful answers, because the participants may never have thought about the issues of death and dying, nor their preferences for how the end of the lives should be handled by the people around them.

Clark *et al.*³⁰ performed a study where they invited older people, over the age of 60 years, to attend a focus group, where they were invited to share their stories or experiences of death. The themes which emerged from the sessions conducted with such focus groups included the following: having a desire to die with dignity, being involved in the decision-making processes associated with the end of their lives, not dying alone and not being in pain when they die. These are some of the core principles of palliative care and, while they might make logical sense and be taken as a given by those involved in palliative care³, these themes need to be validated by asking people who are facing the end of their life.³⁰

Arber *et al.*³¹ investigated preferences of older people with respect to how the end of their lives should be managed, by gender. In this study they approached older people in the United Kingdom who were not necessarily ill, but over 60 years old, and asked them questions relating to decisions that may affect them as they face death, if they were to be too ill to make the decisions themselves. This study found major gender-related differences in how the individuals anticipated they would want decisions to be handled in the end stages of their lives. Older women seemed more concerned with being a burden and not wanting life prolonging therapies, while men expressed the desire for the administration of life prolonging therapies and were less concerned about being a burden to anyone around them.³¹

Pierson³⁴ asked people who had Acquired Immunodeficiency Syndrome (AIDS) to comment on what aspects of their death they thought would make it a 'good death'. This study

confirmed that people who are facing the end of their lives worry about dying in pain, dying alone and having drawn out deaths. A theme from this study showed a split between people wanting to die with loved ones at home and others wanting to die in hospital, so as not to burden their families. Those who were spiritual had desires for certain rituals or ceremonies relating of their spiritual lives to be completed near their death, e.g. having their last rights performed.³⁴

Gott *et al.*³² performed a similar study with similar outcomes, validating that people want to die with loved ones around them and do not want to be a burden to their family³². In Singapore, a study was performed to assess what Singaporeans wanted at the end of their life³³. Singapore has a strong Asian influence with Asian culture. Their study implied that older people, in Singapore, rely on their families to make decisions for them as they get older³³.

In 2014, Downing *et al.*³⁵ conducted a study in Kenya, investigating the preferences and priorities people had towards death and dying. They conducted a street survey of Kenyans in Nairobi, asking people over the age of eighteen a selection of questions on death and dying. Although the mean age for this sample population was 27 years, 42% reported having cared for a family member or close friend in the last months of that person's life, indicating that these issues are not only pertinent for the elderly in Africa. Downing *et al.* found that, to the respondents, having a positive attitude and ensuring that family members were not concerned about them when they are dying was more important than relieving symptoms. Only half of the respondents wanted to die at home and 23% wanted to die in hospital, which indicates that the palliative care principle of choosing where to die is more relevant than necessarily dying at home, as some individuals would advocate. This study is a good start to looking at people in Africa's preferences for good palliative care. Unfortunately this study was not randomised nor generalised, in terms of geographical location and sampling, given that it was conducted in select parts of Nairobi, in areas of Nairobi that were deemed safer for researchers, at particular times of the day. It thus has a bias for unemployed urban people. People at work, with a potentially higher level of education and information on medical treatment and care, were excluded by virtue of the methodology. And people living in rural areas were not included. So, although this gives a good introduction to Kenyan residents' perception of death and dying, it is certainly not a comprehensive summary and needs broader inclusion criteria.³⁵

The studies considered in this section of the literature review highlight the importance of the themes of pain, dying alone, having drawn out deaths and decision making around the time of dying, to those who are facing death.

Patients and Family:

There is a significant body of research that has been conducted on patients, themselves. Some studies have aimed to assess the symptom burden that palliative care patients encounter, some have aimed to assess the needs of the patients or the success of a palliative care intervention. Palliative care acknowledges that the care of a person who is dying is best done in the context of their family, including the family and the primary caregiver in programmes for palliative care^{3,36}. There are studies that have been conducted on the families and caregivers of patients in an attempt to improve the understanding of what aspects of care best help the family in coping with the death of a loved one.

One area of palliative care that has been well researched and continues to be researched is the dying trajectory^{37,38}. The dying trajectory is a pattern of decline in health that occurs in a specific disease (e.g. pancreatic cancer or heart failure). Recognising what disease stage an individual has reached enables health care workers to predict when a person may die and, therefore, the ideal time is for a person to be referred to a palliative care programme. Idealists would say that a person qualifies for palliative care as soon as they have been diagnosed with a life-threatening illness. However, most palliative care programmes cater for people who are dying and not people who are still able to go to work and lead a fairly functional life. Thus, the need to identify when a person needs to be referred to palliative care is an important aspect in the initiation of palliative care. Much research has been done in patients with cancer, but there are still questions about other chronic diseases, which become a way of life for many people. For example, it is difficult to know when to initiate palliative care in the case of a patient diagnosed with heart failure and COPD. It is generally difficult to know what treatment modalities to implement in the palliative care of chronic diseases. Most guidelines for chronic diseases give advice on how to prevent progression and what medication prevents morbidity and/or mortality, not what medication or treatment improves quality of life in a person who is facing the end of their life.

In 2011 Kheirbek *et al.* conducted a study of the dying trajectory of heart failure patients³⁷. A previous study (conducted in 2007) had determined that it is very difficult to predict the dying trajectory for heart failure³⁸. However, Kheirbek *et al.* discovered that, although it is not easy to determine the dying trajectory of heart failure, there are some indicators which allow a reasonable analysis to be conducted³⁷. Kheirbek *et al.* found that twenty percent of deaths attributed to heart failure are unexpected deaths³⁷. In the other 80% of such cases, the patients show a gradual decline in functioning over their last six to twelve months of their lives. The authors recommend that clinicians should consider two key points in caring for heart failure patients. Firstly, when considering the dying trajectory, they should take into account other comorbidities which often co-exist with heart failure. Secondly, mortality is

more dependent on the change in prognosis with time, as opposed to with the value of an index.³⁷

An in-depth, qualitative study of COPD patients³⁹ reported that the healthcare workers found it difficult to know when to initiate palliative care for people living with COPD, as the disease is slowly progressive and there is no clear point when palliative care should be started.³⁹ There are guidelines about when to initiate palliative care in heart failure and COPD but clear research to support this is not evident⁴⁰.

Some studies combine the patient's and the family's perceptions of the service they have received⁴¹. In a study of people who had suffered an acute stroke, the patient's wishes, as well as the family's perceptions, were explored. All parties wanted better communication with their doctors. Families wanted to know the prognosis, although some patients did not want to know. Many of the family members did not associate death with a stroke and so having that discussion was deemed helpful and they did not regret being told that the patient was nearing the end of their life.⁴¹ These findings confirm the need for timely palliative care.

In palliative care, qualitative research helps to broaden our understanding of dying. Pinnock *et al.*³⁹ conducted in-depth interviews with people with severe COPD and attempted to understand the complex nature of the disease. This study highlighted the fact that there is no clear point when people with COPD become palliative and people with COPD see their symptoms as a way of life, not a sign that their life is near the end. This study highlights the need to ensure good symptom control and emotional support throughout the illness with an increase in the palliative care component as the disease progresses. There is difficulty in deciding when to start treating a person suffering from COPD as palliative, as mentioned above³⁹. Unlike cancer, when there clearly comes a point when it is appropriate to withdraw anti-cancer treatment, optimal treatment of COPD should be continued in conjunction with palliative measures.³⁹

When dealing with people, individual personalities of patients and families surely play a part in how they cope with this life event, that of dying. Gilbar *et al.*⁴² investigated the coping styles of people with end stage renal disease, in a study conducted in Israel. They found that different people have different coping styles; some cope with stress better than others. And these coping styles play a big part in coping with a terminal disease. Understanding one's own patient's coping style can help in caring for them, as a healthcare worker. Different strategies of care are needed for different types of coping styles.⁴²

Given that personalities play a role in coping with facing the death of a family member, or of oneself, one must surely consider to what extent the disease itself may play a role in how a person copes. Steinhauser *et al.*⁴³ investigated patients with cancer, heart failure and a debilitating stroke. They found that the disease itself does not have an influence on functional status, but it is rather the severity of the illness, that determines the life experience, along with emotional and social factors. Patient outcomes, depression and anxiety were most strongly associated with socio-demographic details like gender, education and perceived financial security. They conclude that non-biomedical factors affect the overall experience of life-threatening illnesses.⁴³

Garlo *et al.*⁴⁴ and Burton *et al.*³⁶ support the findings of Steinhauser *et al.*⁴³ Burton found little difference on the burden of carers across different diseases, but found that the burden on carers was more related to coping styles and the amount of support they had. They conclude by recommending that programmes provide support to the carers and consider their psychosocial support in the overall service of providing palliative care.³⁶

The title “Advanced Care Directive” (ACD) is used to refer to the consideration given to planning for the future, within the context of palliative care. This is where the patient and family, together with their doctors, talk through issues that may arise close to their death and consider what everyone’s wishes are. Thus, when the time comes, the issues have already been discussed and the patients’ desires can be taken into account. Two studies present the discussions that the researchers had with older people, talking about ACDs^{45,46}. Both studies’ results show mixed responses, as some people want their wishes carried out and others seem to want their families to make decisions for them when the time comes.^{45,46}

Two South African studies investigated professionals involved with palliative care’s perceptions on ACDs, advanced directives or living wills^{47,48}. Stanford *et al.*⁴⁷ started her focus groups by introducing the concept of an ACD and asking about perceptions of an ACD. Their results show that professionals do think it is a good concept, but there was some reluctance to initiate this discussion within ones’ own family as result of the stigma associated with death and dying in some cultures. The participants felt that a discussion around an ACD should be held prior to a health crisis. Within the methodology, there was a range of professionals invited to the focus groups and the reason each group was invited was not made clear. Inviting hospice staff and spiritual care providers is understandable. However, including primary school teachers, who are not routinely involved with palliative care, was a perplexing choice. Had they been trying to investigate a range of professional people’s opinion, then I would have expected a wider range of professionals to have been included.⁴⁷

Bull *et al.*⁴⁸ restricted their study to healthcare workers involved in caring for elderly people, in a small rural town, in South Africa⁴⁸. All participants knew of the concept of an advanced directive or living will, but most felt that it was not their place to suggest that a patient should formulate one. Rather, they felt their role was to be the custodian of the advanced directive or living will. The author suggests that healthcare workers should meet their patients halfway, by introducing the topic and being available to talk about an ACD, not waiting for the patient to raise the topic. This study only included healthcare workers who are involved with caring for the elderly, so there is a bias, as they are likely to have come across this concept in their work. This study was also conducted in a small rural area, comprising, mostly, of retired middle to upper class white people. This is not a true reflection of South Africa's population and cannot be generalised to most parts of the country.⁴⁸

A study, from the United States, looked at the effect of using ACDs on the patients and caregiver stress levels. It showed that it does reduce the stress but not completely⁴⁹. There is a substantial amount of stress evident around the time a person dies and, knowing what the person dying would prefer, does not necessarily make choices easier.

Identifying People in need of Palliative Care:

Clinicians find it difficult to anticipate when a person may die from a chronic illness and Glare⁵⁰ states that when clinicians use, what he calls, temporal predictions, i.e. their personal judgment, they are overoptimistic. Glare suggests using probabilistic predictions, using concrete signs and symptoms, along with laboratory results, to determine a person's prognosis⁵⁰. One such model is the prognosis in palliative care study predictor model, which is complex and time consuming⁵¹. The Gold Standards Framework: Prognostic Indicator Guide formulated in conjunction with a number of palliative care experts and using many different prognostic models, is used throughout the United Kingdom and is the prognostic indicator guide that has been chosen for this research project⁴⁰.

The Gold Standards Framework: Prognostic Indicator Guide⁴⁰ suggests three triggers to palliative care. These are the surprise question: 'Would you be surprised if this patient were to die in the next 12 months?'; patient choice or need; and clinical indicators for palliative care such as significant weight loss, physical decline and reduced physical activity, recurrent hospital admissions for the particular chronic illness.

Palliative Care Programmes:

There are a variety of palliative care programmes around the world; most involve in-hospital programmes and out-patient programmes to varying degrees. Some programmes are predominantly in-patient and others are predominantly out-patient, home-based palliative care.

Francke and Kerkstra⁵² expand on the different types of palliative care services that are available in The Netherlands⁵². Many countries have similar services, with some being well-integrated, as in The Netherlands, and others still striving for that integration. Francke and Kerkstra's study aimed to describe the services available in The Netherlands and to ascertain to what extent there is integration of the services within the national health care system. They found services that specialise in palliative care and other services that are relevant to palliative care but not specialists in palliative care. The specialised palliative care services included hospices, palliative care units in homes for the elderly, palliative care units in nursing homes, palliative care units in a general hospital, a palliative care unit within a specialist oncology unit and a children's home that specialises in care for children in need of palliative care. The other services involved in palliative care included: professional home-based carers, volunteer carers for patients staying at home, almost-home-houses, nursing homes that take an interest in palliative care patients (but have no specialised unit), hospitals with no specialised palliative care unit, but with an interest in palliative care, services for pain alleviation and services for psychological support.⁵²

With regard to the integration of palliative care services in parts of The Netherlands, Francke and Kerkstra propose that the integration is satisfactory. One major reason for this is that the Dutch government discouraged private initiatives within the health sector, allowing for good integration of the palliative care services, as they are mostly interconnected in the National Health Service. This has resulted in better integration than would be typical of a more fragmented health care system, which may develop if more private initiatives were encouraged.⁵² The idea that private initiatives cause fragmented care is valid. However, in Africa and most low income countries, it is almost impossible for the government in each country to fully cater for peoples' every need. Most low income countries rely on international aid or non-government organisations to assist in providing health and social care for their people. Thus it is not a viable solution to place all palliative care programmes within the government health care system in South Africa. But this article does give a good overview of the different types of palliative care that can be offered. African palliative care services are usually home care programmes using community care workers as the primary carer with professional staff providing supervision and support of care workers.

The article described above shows the range of palliative care programmes that exist. Do palliative care programmes make a difference? Some research shows the impact of actual programmes for palliative care:

Temel *et al.*⁵³ enrolled people with cancer, suffering from metastatic non-small cell lung cancer, into a palliative care study and compared the outcomes with people not enrolled in the palliative care programme. The outcomes showed that patients who were integrated early into a palliative care programme had a two-month prolonged survival and clinically improved quality of life and mood, compared to the patients not in the programme.⁵³ This supports the need for palliative care programmes. This study also showed the cost saving when a palliative care programme is in place. The programme results in less hospital admissions, shorter stays in hospital and less investigations while in hospital.⁵³ However, this study was with conducted with a very narrow subset of participants and cannot necessarily be generalised to all areas of palliative care.

Hanratty *et al.*⁵⁴ studied people who were diagnosed with either cancer, heart failure or a stroke and were transferred between two or more facilities of care in the previous three months. This study took place in Northern England. The researchers showed that the support across different settings is lacking and the system is too rigid for people who are dying – there needs to be flexibility. The patients felt that communication was not satisfactory and they were not being heard. Their dignity was not upheld. The researchers concluded that transitions of care, near the end of a person's life, bring much upheaval and discomfort for those concerned, and should be avoided as much as possible.⁵⁴ This kind of research can aid in guiding carers implementing palliative care programmes in their work and direct their focus when managing a patient and their family.

It is valuable to have palliative care programmes, but the benefit of these programmes needs to be supported by economic evidence that shows it is cost effective to support programmes such as this. In Johannesburg, South Africa, Hongoro *et al.*⁵⁵ analysed the cost of running a palliative care programme based at a hospital, with outreach into the community. This is a sound basis for most palliative care programmes in Africa. They found that it was more cost effective to run an outpatient programme than only an inpatient programme. Their biggest expense was personnel and they concluded that, if they did not have teaching, advocacy and policy making responsibilities, they could cut costs even more.⁵⁵ This supports an outpatient programme in Africa. A limitation of this study is that all patients involved in the programme were HIV-positive. The study did not give broad consideration to a range of people facing the end of their life with various illnesses.

Spirituality:

Two studies, conducted by Elliot *et al.*⁵⁶ and Cobb *et al.*⁵⁷ investigated the impact spirituality has in palliative care. Elliot *et al.*⁵⁶ performed their study in the United States among people with end-stage renal disease. Their study highlighted the issue of spiritual pain. It seems that, although it was not explicitly stated, most of their cohort were Christian⁵⁶. Cobb *et al.*⁵⁷ performed a systematic review of research on spiritual issues within the context of palliative care. The data set was difficult to assess, but it shows the breadth of research on spiritual issues, mostly coming out of the United States and the United Kingdom, mostly among Christian and Jewish people⁵⁷. These studies highlight the need to include spiritual issues in a good palliative care programme.

Family Caregivers:

Several studies have considered family caregivers of people in need of palliative care. Grant *et al.*⁵⁸ conducted a systematic review, looking at research on family carers of COPD patients. They found that 40 –70 % of family carers of COPD patients have clinically significant symptoms of depression. Isolation and lack of support result in a higher burden on the family carer.⁵⁸

Wright *et al.*⁵⁹ performed a study to look at the effect of end-of-life care and discussions on family caregiver bereavement. They found that end-of-life discussions are associated with less aggressive medical care and earlier palliative care referrals. Aggressive end-of-life care is associated with worse patient quality of life and family carer bereavement adjustment afterwards.⁵⁹

Harding *et al.*⁶⁰ performed a literature review of research addressing programmes for carers. They found programmes that included respite care, social networks and activities, one to one interventions and group work, all of which attempted to alleviate the stress and burden that carers face.⁶⁰

Streid *et al.*⁶¹ conducted a study in Uganda and South Africa, investigating the stressors experienced by, and recourses available to, caregivers. Their study included 37 participants, of which 31 were female and most were relatives of the patient. They found that some of the biggest stressors were around feelings of isolation and lack of support from the extended family, as Grant *et al.*⁵⁸ had found. Stried *et al.*⁶¹ also found that carers were physically exhausted and found it agonising watching their family member suffer, because they felt helpless and frustrated. The carer is often the confidant of the patient, and this can be a burdensome responsibility. There were financial stressors, as the patient was often the

breadwinner, there were often children of the patient, that needed to be cared for, and this care fell to the patient's carer as well. This study went on to look at resources the carer used to cope with this burdensome task. They seemed to rely on internal resources, such as spiritual beliefs and confidence. Externally, they relied on family and friends for support; many found the patient-carer relationship rewarding and a source of strength. The stressors and resources that carers use to cope with their role are complicated and interwoven. Programmes aimed at assisting carers in these stressful aspects of their role and empowering their use of internal and external resources would be beneficial to carers.⁶¹

There are a wide variety of ways to support family carers. And these studies highlight the need to provide family carer support within a palliative care programme and into the bereavement stage. Palliative care is not only about the person who is dying, but about the family and community as well.

In Africa:

In Africa, the level of palliative care, the government support of palliative care and the amount of research on palliative care varies greatly between different countries and in some countries these elements are non-existent¹⁴. Palliative care in South Africa is a recent development; the first hospice was founded in the early 1980's¹⁶. Since then, the HIV epidemic has grown exponentially and the need for palliative care has become vitally important²⁶.

HPCA reports that, from April 2012 to March 2013, they cared for 82, 681 patients who were dying²¹. Of those patients, 59% had a diagnosis of HIV, 33% were diagnosed with chronic diseases and 8% had a diagnosis of cancer²¹. This shows the range of people in our country currently being cared for by a non-governmental organisation aimed at providing palliative care.

In Africa, there is a range of published research, some looking at palliative care programmes^{62,63}, the patient outcomes of improved programmes⁶⁴, the cost effectiveness of palliative care programmes^{55,65} and the barriers to producing palliative care research⁶⁶⁻⁶⁹.

Ddungu⁷⁰ discusses the obstacles which inhibit palliative care in Africa and offers possible solutions to providing good palliative care in Africa. Much of what is known about palliative care comes from research in developed countries and it is difficult simply to apply a framework that is successful in a developed country to Africa. Firstly, the level of healthcare is vastly different and availability of medication is not reliably consistent in Africa. The most important difference, in patient-centred medicine, is that the culture of the

people of Africa is different and we need palliative care that is culturally acceptable and sensitive. One of Ddungu's suggestions is the implementation of appropriate services. He finds the idea of care in the home, by home-based carers (HBCs) highly appropriate for Africa⁷⁰. It is not feasible to have inpatient care centres and it is more economical to make use of HBCs. It is also culturally acceptable, in Africa, for a patient to be cared for by his/her own family, in the comfort of the patient's own home.⁷⁰

Home-based carers are found all over the world, none more so than in Africa¹⁷. Some are from formal community home-based care organisations and have formal training, while others are informal carers, who have had little to no training. Even within the organisations where carers have had training, ongoing support and training is needed. Defilippi and Cameron⁶⁴ published a research project that undertook to give ongoing training and support to home-based carers, from a professional nurse, trained in palliative care. Difilippi and Cameron describe the intervention in a clear and simple manner. Using the APCA African POS, the authors showed that support of the home-based carers improved the patient outcomes (patient perceptions). All components of the outcome scale improved with each visit. This study supports community palliative care, but underlines the need for ongoing training and support of the community home-based carers, by a trained professional.⁶⁴

In Malawi, Francis *et al.*⁷¹ looked at the treatment of Kaposi's Sarcoma (KS) and the efficacy of different treatment options. The research team also applied the APCA African POS to their cohort of patients, in order to assess the feasibility of using the outcome scale in HIV-positive people suffering from KS. It is not clear what their palliative care programme entailed, so the change in patient outcomes is difficult to evaluate. The results of the APCA African POS show that symptoms did improve, but the feeling of their life being worthwhile and feelings of peace did not improve. As the details of the programme are not indicated, it is not clear if these aspects were addressed in the programme or not. It is not clear whether this is indicative of a problem with the tool, with the programme or with the population being studied. The population is that of a young African population, mostly unemployed and facing the end of their life. This research seemed to focus on the treatment of the KS, and the outcomes of that, more than the overall palliative care outcomes, as the title of the article may suggest. The authors state that they experienced difficulty with the use of the APCA African POS, because the participants found the numerical rating difficult to use, which would point to a problem with the tool.⁷¹

Selman *et al.*⁷² investigated the APCA African POS in more detail, in South Africa and Uganda, with regard to being able to pick up spiritual concerns. They hypothesised that the questions on feeling at peace and feeling that life was worthwhile are related to each other and give an indication of spiritual wellbeing. They used the two questions from the APCA

African POS in conjunction with the Spirit 8 tool, which has only been validated for use in Uganda. They found that these two questions do relate to spiritual wellbeing and although they do not get to the heart of the matter for the patient, they do give an indication of potential unresolved concerns. This study highlighted that the question on feeling at peace was interpreted, by their participants, as being prepared for death, having forgiven people, accepted their own mortality, and on a more practical level, socioeconomic stability and symptom control. Some participants interpreted feeling that life was worthwhile as more of an attitude of hope and gratitude, while others interpreted it as being able to work and contribute to the family, being of value to people around them and being helpful or useful.⁷² This study validates the use of certain questions in the APCA African POS to indicate spiritual wellbeing in participants.

In Johannesburg, South Africa, there is a palliative care project that is based at Chris Hani Baragwaneth Hospital in Soweto⁵⁵. This project started in 2003 and is a hospital-based programme with an inpatient consultation component, a large outpatient service including home visits and a drop-in centre, as well as a training and advocacy aspect.⁵⁵

Hongoro conducted a cost analysis of their programme⁵⁵. He showed that their programme is more cost effective than an inpatient programme. The programme saw each patient, on average, twice in hospital and nine times at home. The biggest cost saving relates to HIV patients in need of palliative care who are not yet on treatment for their HIV, as they tend to have a longer stay in hospital per admission and this can be reduced by being seen at home. This study supports the need to have an outpatient based palliative care programme. The limitation with this study is that all patients had either HIV or cancer. In keeping with many palliative care programmes in South Africa, no patients with other life-threatening chronic diseases were cared for.⁵⁵

In this study, the APCA African POS was used to determine the effect of their palliative care service and researchers found that there were significant changes in the patient outcomes relating to family worry, symptoms and pain, all improving by more than 50%. While all other areas improved, they were not as significant.⁵⁵

The authors admit to some limitations in their cost analysis. An interesting concern was raised by the authors with regard to the people that they serve. They noted that, with increasing poverty, many people live in cramped environments, sharing a bed, and the home may have more than one person who is ill, making it very difficult to care for someone who is dying. So, their conclusion is that, although palliative care supports the idea of people dying at home, with their family, it might not be practical for all palliative care patients.⁵⁵

DesRosiers *et al.*¹⁹ describes a palliative care programme in a government hospital in Cape Town, in South Africa. This programme has the objectives of providing good palliative care, reducing hospital admissions and assisting people to die at home rather than far from their loved ones. They showed that their programme can meet these objectives. Their cost analysis was very simple, looking only at days admitted, not taking into account personnel, investigations or medication that might differ between a control group and the intervention group. However, with the limitations in mind, they were able to demonstrate a reduction in number of days in hospital and number of admissions in the intervention group.¹⁹

A study conducted in Cape Town, South Africa, in 2012 investigated the prevalence of patients in hospital, who would qualify for palliative care²³. Van Niekerk and Raubenheimer studied admissions to adult acute care beds in all hospitals in Cape Town, in a three-month period. Depending on its size, each hospital was sampled over a period of one to two days. They used the GSF Prognostic Indicator Guide as an indicator of qualifying for palliative care. The study included 11 hospitals, with 1443 patients reviewed. The average age for patients sampled was 48 years. The overall prevalence of palliative care in this study was 16.6%, with a range between hospitals of 7.1% to 28.7%. Within medical wards, the prevalence was found to be 20.3%. This implies that one fifth of medically ill patients, admitted to hospital, are in need of palliative care. One limitation of their methodology is that they conducted their data collection from November to February. Many people live and work in Cape Town, but travel home to rural parts of the country, from where they originally came, for Christmas. They travel home from mid-December and return from mid-January to March. It is possible that a person who knows they are dying may choose not to return to Cape Town in the New Year and rather stay in their family home, far from Cape Town. This indicates that the true prevalence of palliative care may in fact be higher than this study suggests. Van Niekerk and Raubenheimer conclude that there is potential for improved care of patients, a potential to reduce costs and improve communication between facilities with palliative care programmes in place. They recommend palliative care programmes in primary health care.²³

The first three studies discussed above show a range of interventions and approaches to palliative care research. However, all studies were conducted on patients with HIV or cancer (with the acknowledgment that one study was specifically on patients with an HIV related disease). No mention is made of any patients being cared for with chronic diseases. The last study discussed points out the need for palliative care across the disease spectrum.

RATIONALE FOR RESEARCH

Much research is being done in the developed world on chronic diseases. However, in Africa, most palliative care research is carried out on patients with HIV and there is limited research on patients with cancer. In South Africa, chronic diseases are the leading cause of death in people over the age of 65 years, but there is a lack of research into the care of these people at the end of their lives. The programme described by DesRosiers *et al.*¹⁹ is a good example of what can be achieved in our setting. Van Niekerk and Raubenheimer show the extent of the need for palliative care across the disease spectrum²³. Higginson advocates for more research evaluating palliative care services²⁹. We need specific research to evaluate patient outcomes in patients involved in a Government healthcare facility-based palliative care programme, and we need to give consideration to patients facing a broad spectrum life-threatening illnesses.

In South Africa there is poor integration of palliative care services with the government-provided healthcare sector, which most of the population accesses. It is possible to integrate palliative care services and we need researchers to evaluate how to implement this service in the primary health care setting. We need to find good palliative care that is simple to administer and has been shown to improve patient outcomes. This research has evaluated a palliative care programme in the primary health care setting, in an attempt to determine its effectiveness on patient outcomes.

AIMS AND OBJECTIVES

Aim:

To evaluate the patient reported outcomes at a Community Health Centre prior to an intervention and to evaluate the impact of an intervention involving a support group and focused care for people facing life threatening illness.

Objectives:

- Determine the prevalence of people with palliative care needs at Mitchells Plain Community Health Centre.
- Assess the physical, psychological and spiritual concerns of people facing life-threatening illnesses, prior to an intervention.
- Assess the extent to which people with life-threatening illnesses get admitted to hospital or seek urgent medical attention, prior to an intervention.
- Determine whether or not there is a change in patient reported outcomes experienced by people facing life-threatening illness when an Abundant Life programme is implemented in the Community Health Centre.
- Determine whether or not there is a change in the number of admissions to hospital or frequency with which patients seek urgent medical attention when an Abundant Life programme is implemented at the Community Health Centre.
- Conduct an audit of care according to the patient reported outcomes.
- Evaluate the effect of the Abundant Life programme on the participants in the programme and the staff at Mitchells Plain Community Health Centre.

CHAPTER 3: METHODS

Overview:

This study was conducted in a primary health care clinic, over a period of six months. A research assistant was employed to run the programme and collect the data. Patients were referred from the clinic and recruited to the programme by the researcher. Initially, eligible participants were recruited to Group A. The research assistant applied the APCA African POS tool to them, weekly, for six weeks. After recruitment to Group A was complete, recruitment to Group B commenced. At this point in time a support group was started for all the participants who had been recruited. Each participant was invited to attend a doctor's consultation. Thereafter the patients and their families were invited to attend the support group sessions. After six months, the entire programme was terminated. Figure 1 shows the programme structure in schematic format along a timeline from May 2012 to November 2012.

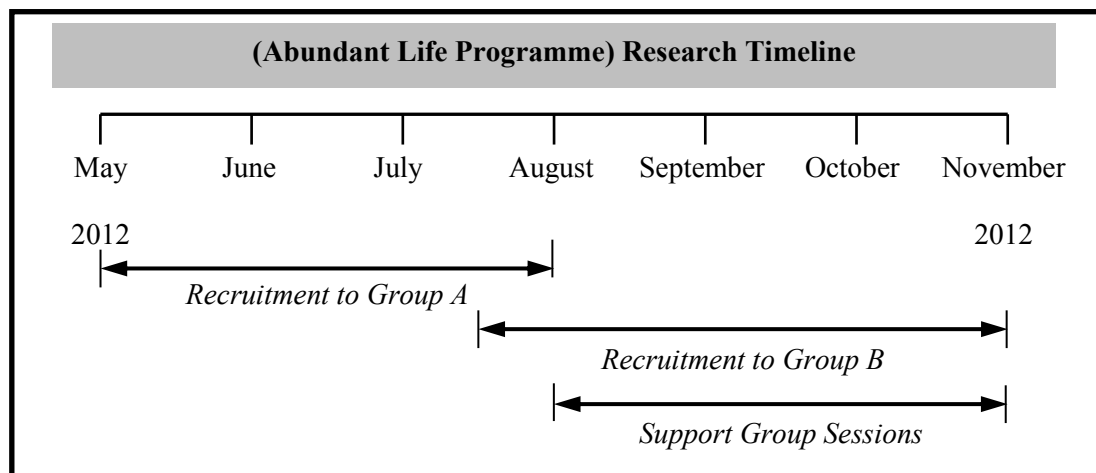


Figure 1: Schematic representation of study programme timeline

Study Design and Setting:

This study used a prospective cohort design. Data collection was conducted at Mitchells Plain Community Health Centre (MPCHC), based in the Mitchells Plain/Klipfontein Substructure of the Western Cape Metro District Health Services (MDHS), Cape Town, South Africa.

Study Population:

The study population consisted of patients attending MPCHC for medical management. Using an adaptation of the Gold Standards Framework: Prognostic Indicator Guide⁴⁰ (Appendix A), clinicians identified patients who qualified for palliative care and invited them to join the study.

Selection Criteria:

All patients were over the age of 18 years and met the criteria for palliative care based on the Gold Standards Framework: Prognostic Indicator Guide⁴⁰. A family member of each patient was invited to be included in the study, provided the patient gave consent for their inclusion. The family member was also over the age of 18 years. If there was no family member to join the study, or if the patient or family member did not consent, the patient was not excluded from the study. Mental competence of the patient was not formally tested. Any participant who had the diagnosis of dementia, was not included in the selection for Group A or B (see below for a description of Group A and Group B), as their neurological diagnosis may have compromised the accuracy and validity of their responses. If a participant was found to be confused during the informed consent process, they were not invited to join Group A or Group B. Participants, who were excluded from Group A or Group B, on the basis of mental competence, were still included in the collection of demographic information and in the intervention by, being invited to attend a consultation with a doctor and then being invited to join the support group. Allocation to Group A or Group B is explained in the section on Sampling. Only people speaking English, Afrikaans or isi-Xhosa were included in the study. Some patients were referred to the study, but contact was lost prior to them giving consent to join the study. Regaining contact with them was attempted twice, before it was assumed that they did not want to consent to the study or that it was impractical to contact them.

Sampling:

All patients identified as being palliative care patients, during the study, were asked to join the study and provide information. Of that cohort of patients, the sampling for two groups was convenience sampling. The first patients, who consented to the research, were asked to join Group A, until more than 16 participants had been recruited. From the commencement of the recruitment of Group B, all participants, who were eligible to join Group B, were invited to join Group B, until the conclusion of the programme.

Sample Size and Duration:

The estimation of sample size was calculated based on a two-sample means test. The requisite sample size for the test was calculated assuming $\beta = 0.1$ and $\alpha = 0.05$ ($SD = 1$, two tail). This test indicated that the minimum number of patients required to perform an analysis with these power- and significance parameters was 32, 16 in each group.

We recruited 20 participants to Group A and 21 participants in Group B. The reason for recruiting more than 16 patients to group A, was convenience and to allow for loss to the study. We continued recruiting patients until the end of the week in which we had recruited the 16th participant to Group A. When recruiting patient to Group B, we continued recruiting patients until the completion of the programme, as we suspected that there would be attrition and we may need more patients at the outset, to compensate for this attrition and allow reliable statistical analysis in spite of it.

From an initial survey of the patients attending the MP CHC, it was estimated that a time period of six months would be sufficient time for completion the study.

Data Collection Tools:

Demographic Data:

The researcher developed the Demographic Data Collection Sheet (Appendix B) in collaboration with the clinicians of MPCHC, to ensure that all relevant personal data were collected. The Demographic Data Collection Sheet was used to collect information about recent admissions to hospital or visits to the MPCHC Trauma Unit. These data were used in the analysis of the APCA African POS data and comparison of patient outcomes. For those patients who were not invited to join Group A or Group B, or who, after giving consent for the overall programme, did not wish to be more involved in either Group A or Group B, this information will be used to provide more insight into the demographics of the population in need of palliative care in MPCHC.

Research Tools:

African Palliative Care Association African Palliative Outcome Scale (APCA African POS)

The Palliative Outcome Scale was developed by the Department of Palliative Care and Policy, at the King's College School of Medicine and Dentistry, and Saint Christopher's Hospice, New Medical School, Bessemer Road, London²⁴. The Palliative Outcome Scale was adapted for use in Africa by the African Palliative Care Association (APCA) in 2007⁷³ (Appendix C). It has been validated for use in South Africa, in English, Afrikaans, Isi-Xhosa, Zulu and seSetho²⁵. This research tool has been used to collect data on a patient's perception of his/her symptoms, feelings of anxiety and future planning. It was also used to collect data on the care giver's knowledge on the patient's problem, his/her confidence in caring for the patient and his/her own feelings of anxiety.

Evaluation Form

The researcher designed the evaluation form (Appendix D), in collaboration with the research assistant. The evaluation form allowed participants to give feedback on the research assistant and her role as programme co-ordinator, the extra visit to the doctor (which was part of the intervention), the value of the support group and the an overall impression of the programme. The last question on the evaluation form asks for the participant's opinion on the continuation of the programme and similar future initiatives (programmes with a focus on end-of-life care).

In addition to this, MPCHC staff was asked to complete an evaluation form which the researcher designed for them (Appendix E). This evaluation form aimed to assess the extent to which the staff in the clinic knew about the programme, their involvement in the programme, whether the programme made any difference to their daily work in the clinic and to what extent they thought it should continue, or alternatively be terminated (and, if so, why). Permission to conduct this evaluation was obtained from the facility manager, operational manager and resident family physician. Evaluation forms were given out to as many staff as were present at the clinic at the conclusion of the programme.

Research assistant:

The research assistant, Ms Yvonne Peterson, was not a healthcare professional. She was a trained palliative care home-based carer. She had completed the volunteer course at Saint Luke's Hospice and had cared for her mother in the final stages of her life. She thus had some experience in palliative care. She had lived for many years in a community that makes use of the MPCHC as their primary healthcare facility, so she came from the same broad community as the patients in the study. Her responsibilities included taking consent from the patients and their families, collecting the data as described above and convening the support groups. The researcher trained the research assistant in the use of the data collection tools and explained to her the ethics of the research. In her training, she was briefed on issues such as privacy and confidentiality, security of data and sensitivity in interacting with a vulnerable research population. She was responsible for keeping records of the participants and keeping documentation locked in a cupboard at the facility. Her position was funded by Hospice Palliative Care Association South Africa (HPCA).

A desk was made available to Ms Peterson for the duration of the study. The Health Promotion Officer's room, where her desk was, was shared by a group of support staff in the clinic, who spent most of the week working in the community. She was able to be in the same room and at the same desk each day for the duration of the study. This room, although

shared by other staff members, was big enough that confidentiality could be ensured, by the appropriate use of screens. Ms Peterson was easily accessible to staff and participants alike. The funding from HPCA covered the use of a cellular telephone, which Ms Peterson could use to make the telephone calls to collect data. This telephone also allowed her to collect data after hours, if it better suited a particular participant. She was able to make use of the short message service (SMS) to remind participants of a pre-set time for a conversation. She was available to call participants during office hours on the cellular telephone, thereby not placing any extra burden on the CHC's telephones. This cellular telephone number was used by participants to contact her, if they had a problem that she, as programme co-ordinator could address.

Ms Peterson assisted the participants in accessing healthcare in the facility. At times she assisted in collecting their folders, occasionally keeping them company, while they waited for an appointment. At other times she assisted them by organising help from the various health professionals in the CHC (e.g. by arranging an occupational therapy appointment for a patient with a stroke).

Recruitment:

Prior to the recruitment of participants, the clinicians (doctors and clinical nurse practitioners) at MPCHC were educated on the use of the Gold Standards Framework: Prognostic Indicator Guide, by the researcher. At the time of the study there were five fulltime doctors and five temporary doctors completing their community service, all ten doctors were trained in the use of the Gold Standards Framework: Prognostic Indicator Guide. In the same time period there were five full time clinical nurse practitioners, who were included in the training and recruitment of patients. An amended version of the Gold Standards Framework: Prognostic Indicator Guide was used to identify patients who qualified for palliative care (Appendix A). A copy of the amended version of the Prognostic Indicator Guide was placed in each consulting room and each clinical area of the CHC, to remind clinicians of the referral criteria. The clinicians were asked to continue with their routine care and management of the patient. Upon completion of their consultation, the clinician would inform the patient and care giver of the research study, then refer the patient and their family to the research assistant, who would provide them with the Information Letter (Appendix F) and be available to answer any questions they may have had. Potential participants were assured that they could choose not to take part in the study or choose to withdraw from the study at any time. Some participants gave consent immediately, while others decided to take the letter home, to talk to their family about participating, before

giving informed consent. The research assistant took consent from all participants and family members. If a patient took the letter home, the research assistant would arrange a time to call telephonically to follow up on their potential participation in the study. The consent forms were returned the next time someone from the family was at the clinic. Once consent was given, each participant was asked for personal information and some information on their recent illnesses. All patients identified as needing palliative care during the study were invited to join the study. The demographic information gave an indication of the extent of the need of palliative care in MPCHC and allowed the research assistant to invite all participants of the study to the support group.

The researcher used convenience sampling to identify participants. Recruitment for Group A commenced at the onset of the study (May 2012) and continued until more than 16 participants were recruited. The researcher chose to continue to recruit patients to Group A after 16 participants were recruited, to ensure that, despite potential dropout, there would still be sufficient participants to ensure that validity of the study. Patients were recruited until the end of the week in which the 16th patient was recruited. Participants who were approached for recruitment to Group A or Group B were given a second letter, which detailed the requirements of consenting to join Group A or Group B (Appendix G). Each participant in Group A and Group B was asked to consent to the inclusion of a family member with their consent to join Group A or Group B. Once the patient had given consent to involve the family member, the consent of the family member was also sought by the research assistant (Appendix H). Signed consent forms were kept confidential by the research assistant, separate from the data which was collected.

Data collection - Method:

For six weeks, the research assistant applied the APCA African POS (Appendix C) to the participants and their family member (if consent has been granted), weekly. The weekly interviewing of the patient and the interviewing of the family member were conducted separately from each other. These interviews took place over the telephone or at the CHC, if the patient was at the facility. No special visits to the clinic were required of the patients. Each patient was thanked, in person, after the collection of all the data, each week, and sincere gratitude and appreciation were expressed at the end of the six-week period. After the completion of the programme, a folder review was conducted of all patients referred to the study. This review was used to verify the information given by the participants, with regard to their diagnosis and their number of visits to the facility.

Distress Protocol:

In anticipation of the fact that participants may become too distressed to continue with data collection, during the course of the study, a distress protocol was put in place. This involved the intervention of the social worker and clinical staff at the CHC, as required. The distress protocol was never implemented, because the need for it did not arise.

Abundant Life Programme Intervention:

The programme was based on the Abundant Life Programme, at Victoria Hospital, in the suburb of Wynberg, which was then adapted for use in the primary healthcare setting. After two and a half months of recruitment, 20 participants were recruited into Group A and data collection was close to completion. At this point in time the intervention was initiated.

With specialist input, it was decided that the intervention would consist of a regular support group and a specific consultation with a senior doctor to explain the patient's prognosis and optimize their medical care. The intention of the support group was to educate the participants and create a forum for information sharing, thus improving their health literacy regarding their conditions. This was to be done with specialist input as described below.

A support group met fortnightly at the facility from 1 August 2012 until 7 November 2012. A suitable room was found at the community resource centre in the neighbouring City Health Clinic, adjacent to the CHC. The meeting of the support group was convened by a social worker, who was to be supported by a clinician, with invited professionals experienced in palliative care. The support group was open to all members of the study population (i.e. patients identified with palliative care needs), not only participants of Group A or Group B. The support group only commenced at the onset of recruitment for Group B. Members of Group A had already completed their data collection and were invited from the initiation of the support group. The research assistant invited participants of the study to join the support group and reminded them of dates and time of the support group.

Meetings of the support group were convened from 14:00 to 15:00 on each of the following dates: 1 August 2012, 15 August 2012, 29 August 2012, 12 September 2012, 26 September 2012, 10 October 2012, 24 October 2012 and 7 November 2012. The meetings were held in the community resource centre, in a separate room from the City Health Clinic, behind closed doors, to ensure that no interruptions were experienced. There were chairs and tables in the room, which were moved into a circle configuration for each meeting. There was a kitchenette attached to the room, so tea and coffee could be served. It was the research assistant's responsibility to ensure that the room was booked for the meetings, that the room

was prepared for the meetings and that it was cleaned after the meetings. Guest speakers were from St Luke's Hospice, Kenilworth. They included Ms Christilina Francis, a social worker, Sister Sharon Southerland, a palliative care nursing sister, Doctor Rene Krause, a palliative care specialist and the Reverend Peter Fox, a palliative care spiritual counsellor. A guest speaker did not attend every support group meeting. The sessions that were not attended by a guest speaker were used as an opportunity for the patients to share their experiences and difficulties with each other. Each support group meeting was attended by between seven and eleven participants. The composition of the groups varied over the course of the study, with between one and six patients present and between three and nine family carers present at any particular session.

Group B participants were only recruited after most members of Group A had completed their data collection. Group B patients were recruited from the newly referred palliative care patients in MPCHC. They were not members of Group A, but were recruited from the same study population, so that had similar characteristics, as is shown in the Results chapter. From the point at which recruitment for Group B commenced, all patients referred to the research assistant were asked to join an intensive research group, Group B. This recruitment of Group B continued until the end of the programme. Once the patient had consented, they were asked if a family member could be included in the study and then the family member's consent was sought. Initially the patient and their family were given an opportunity to discuss their illness and problems with a clinician. This consultation was not compulsory. Follow-up appointments with the clinician could be made as needed, or the patient was seen as normal in the CHC, by the various clinicians. For six weeks from the date of recruitment, the research assistant applied the APCA African POS to the participants and their family members in Group B each week. The weekly interviews of each patient and his/her family member were conducted separately from each other. These were conducted over the telephone or at the CHC, if the patient was at the facility. No special visits to the clinic were required of the patients. The patients and their families were also invited to join the support group. However, attendance at support group meetings was not compulsory for inclusion in Group B.

The consultation and attendance at the support group were not compulsory, but the lack of attendance to both these aspects of the intervention impacted on the ability to compare the control group with the intervention group, as was the aim of this study. Initially Group A was to be used as the control group and comparisons would have been analysed with the intervention group, Group B. However, no participants from Group B attended the support group and only three participants visited the doctor as a part of the programme. Participation in the intervention should have been part of the inclusion criteria for recruitment to Group B.

Due to the lack of participation of Group B in the intervention all the participants (patients in group A and group B) were analysed as one cohort, to assess the baseline palliative care needs in the study population and the change in these needs over time.

At the end of six months, the study was terminated. This time period had been estimated to be sufficient time to implement the programme and complete data collection. By the time the study was terminated all of Group B's data were collected. As the study neared its' completion, the researcher realised that there could be no comparison of the results of the APCA African POS between the intervention group and the control group, as the intervention group had not attended the intervention. Thus assessment of the impact of the intervention could not be ascertained by means of the APCA African POS. Another method of analysis was used, that of an evaluation of the programme, by participants and staff. At the conclusion of the study, the evaluation forms were distributed (Appendix D). The participants still in the programme at this point in time were asked to complete the form and return it to the research assistant. The evaluation aimed to assess the effect that the programme had on participants and family members.

The patients who had participated in the study were integrated back into the CHC, appropriate follow-up dates with clinicians were made and they continued to attend the CHC as they had before. They were thanked for their time and involvement in the research.

At the time that the participants were completing an evaluation form, the staff in the clinic were also asked to complete an evaluation form (Appendix E). Permission for this evaluation was granted by the Facility Manager and Operational Manager of the clinic. Evaluation of the programme was entirely voluntary. The researcher asked as many staff members as possible to complete the forms and did not intrude on their work schedules. The evaluation was conducted in an attempt to determine how the staff in the clinic perceived the programme and to ascertain the extent to which the programme had assisted them in their care of patients with advanced chronic illness.

Storage, Safety and Confidentiality of Data:

While the programme was running, documentation was stored at the facility, in a locked cupboard. Since the termination of the programme, the documentation has been stored in a locked cupboard.

The research assistant conducted each session with the patients and their care givers in private. Each session's data collection sheet bears only a number as identification. The numbers correspond to codes assigned to the participants, recorded on a list kept separately

from the data collection sheets. Only the researcher and the research assistant had access to the key to the codes, used for identification. The data was been entered into the researcher's personal computer, which was protected by means of a password.

Data Analysis:

All data was entered on a Microsoft Excel spreadsheet. StataIC 12 was used to analyse all data. As Group B did not participate in the intervention, the whole cohort was analysed together and there was no comparison of two separate means. The APCA African POS data first underwent cross-sectional multivariate analysis. P-values were derived from Chi-squared tests or Fishers exact test if the expected frequency was below 5. Multivariate analysis was used for large groups and T-tests were used to derive a P-value. Cross-section time dependent regression analysis was applied to the data. The evaluation forms were not statistically analysed, only reported on.

Ethical Considerations:

Ethical approval was obtained from the University of Cape Town (Appendix I – reference number 006/2012). Permission to conduct this research study was obtained from the relevant managerial staff at the facility at which the research was conducted (i.e. MPCHC) and the MDHS Research Committee. Informed consent was obtained from each participant and his/her care giver. Consent was obtained in the patient's first language. Refusal to participate did not subject patients to a standard of care lower than that which they had received previously at MPCHC.

The researcher (a potential care provider at the facility) could not take the consent for this research. This may have resulted in patients feeling an obligation to consent, even if they were assured that they could withhold consent. The researcher wished to ensure that consent was given freely, not given under duress. In the event of not consenting to participate in this study, the patient was still entitled to receive good medical care. If the researcher had taken consent, patients may have felt that they would not receive the best medical care and so may have been pressured into giving consent. The research assistant took consent for the study and collected the data.

As this research involved a vulnerable sector of the population, it was taken into account that some patients may be more advanced in the stage of their illness than others. If they did not wish to join the study, they still received good health care. If, at any point in the study, they or their family members felt that they would like to withdraw from the study, they were free

to do so, without incurring the risk of suffering any negative consequences. If the researcher or the research assistant felt that the participant was too ill to continue in the study, they would have been reminded that they were free to withdraw from the study. However, at no point in this study did the research assistant, nor the researcher, feel the need to remind a participant that they could withdraw from an illness point of view.

Some experts have debated the ethical validity of research in palliative care, as the people who need to be enrolled in such research are, by definition, nearing the end of their lives and hence their time is precious to them and their families⁷⁴. It has been agreed that, if evidence-based medical practice for patients with palliative care needs is to be improved, research needs to take place. However, there are some issues with research that should be taken into account.⁷⁴

In palliative care research, researchers are asking people who are near the end of their lives to be involved in a study that may or may not benefit them directly, and which will most likely take up valuable time and energy. So, when designing such a study, researchers need to ensure the study has the potential to be of good value. Researchers should be sensitive to the fact that they should not waste patients' time and they should thus ensure that any study is comprehensive enough to have the potential to allow them to draw valid conclusions. Many people who are identified as needing palliative care and then invited to participate in such research may not survive long enough to experience the benefits of the study. This is unavoidable, but measures can be put in place to ensure they enjoy some of the potential benefits of the study. It is worth remembering that not all research will have potential benefits, but it is hoped that this particular study will yield some benefits. In palliative care research, researchers should endeavour to minimise the burden and risk to the patients who consent to participate in studies.⁷⁴

In this study, the researcher aimed to analyse a sample large enough to give credibility to the conclusions that would result from the analysis of the data. However, the researcher was only able to recruit a few more participants than required, from a statistical analysis perspective. The whole study population was invited to join the support group, so the intervention was not restricted to the intervention group. The researcher made allowances for the collection of data telephonically, to reduce the need for participants to attend the clinic. The research tool was relatively quick to administer and therefore it was deemed not to be a major intrusion into the lives of the participants. A distress protocol was formulated and put in place, to allow participants to withdraw from the study with the assurance that any patient or family member who became distressed would be offered counselling. Consent to participate in this study was made freely, with no coercion, and the patient needed to be mentally competent to answer the APCA African POS questions. Thus ethical issues

relating to consent were decreased. Each time more data was collected, a verbal affirmation of continued consent was taken by the research assistant.

As this programme involved the implementation of alternative care, not previously available at the MPCHC, consideration was given to what would / should happen at the facility once the study ended. One of the outcomes of this project will be the compilation of a report (to be presented to the facility and the MDHS), which will outline the perceived benefits of this programme and recommend options for the provision of ongoing support for palliative care patients, either at the facility or facilitated by community or faith-based organisations. All patients who participated in this study were integrated back into the facility, and it was ensured that they had a follow-up date with a clinician, as well as optimised medication. Through the MPCHC, a report on the outcomes of this study will be made accessible to the participants.

CHAPTER 4: RESULTS

This results chapter is divided into three sections. In the first section, the results collated from the demographic information sheet are presented, and the study population is described. In the second section, the responses to the APCA African POS questions are presented and analysed. The last section reports on the data gathered from the evaluation of the participants and the staff.

DEMOGRAPHIC INFORMATION:

This is the first section of the results chapter. In this section, all information obtained from the demographic information sheets (Appendix B) is presented.

Sample Characteristics:

During the six months over which the study was conducted, 74 patients were referred from MPCHC and invited to consider participation in the study. Of those, 46 (62.16%) consented to participate in the study.

Demographic information for all participants included in the final sample is summarised in Table 1. Overall, for the entire sample, the ages were not normally distributed (Shapiro Wilk $p = 0.017$). The median age and the age ranges are therefore provided (mean age = 60.21 years). Individual age ranges, by sex, were normally distributed. The mean age of the female patients was 60.92 years. The median age and the range in ages are reported in Table 1 (Shapiro Wilk $p = 0.24$). The mean age of the male patients was 59.21 years. The median age and the range in ages are reported in Table 1 (Shapiro Wilk $p = 0.09$). When asked about ethnicity, all respondents (100%) classified themselves as “coloured”.

Table 1: Demographic Characteristics of Participants

Sex	
Female	27 (58.7%)
Male	19 (41.3%)
Mean Age (in years)	61 (29-78)
Female	61 (36-78)
Male	61 (29-77)
Diagnoses	
Cardiac Failure only	7 (15.22%)
*COPD only	5 (10.87%)
**CVA only	7 (15.22%)
Cancer only	12 (26.09%)
Cardiac Failure and a CVA	2 (4.35%)
Cardiac Failure and Cancer	3 (6.52%)
COPD and Cancer	3 (6.52%)
Dementia	2 (4.35%)
#HIV positive	1 (2.17%)
Renal Failure	3 (6.52%)
COPD, Renal failure and a CVA	1 (2.17%)
Caregiver	
Yes	42 (91.3%)
No	4 (8.7%)

*COPD – Chronic obstructive pulmonary disease

**CVA – Cerebro-vascular accident or stroke

#HIV – Human immunodeficiency virus

Participants reported their medical diagnoses. These were then cross-checked against the folder review findings and the cross-checked results are reported above in Table 1. The largest groups of different diagnoses were cancer only, cardiac failure only and one or more previous strokes only. The most commonly occurring diagnoses were cancer only, cardiac failure only and one or more previous strokes only. Of the 46 participants, 37 had only one diagnosis. These participants had either cardiac failure, COPD, a previous stroke, cancer, dementia, HIV or renal failure. Of those who had cancer (18), the specific types of cancers were lung cancer (3), gastric cancer (1), colon cancer (2), bone cancer (1), liver cancer (1), cervical cancer (2), prostate cancer (1), ovarian cancer (1), breast cancer (1) and pancreatic cancer (1). There were 4 participants who did not state which type of cancer they had, and their folders could not be found in the folder review to verify the diagnosis or type of cancer. Participants who stated that they had cardiac failure and COPD were investigated in the folder review. If their folder stated that, in fact, they did not have a diagnosis of heart failure, but rather a diagnosis of cor pulmonale, which is a complication of COPD and not left-heart failure (which is commonly referred to as heart failure), they were not added to the group in this study of cardiac failure participants, but only to the group of COPD participants.

Table 2: Demographic Characteristics of Caregivers by Gender

	Female	Male	Total
Number of Caregivers	35 (83.33%)	7 (16.67%)	42
Mean Ages	55 (25-81)	58 (41-74)	56 (25-81)
Relationship of Caregiver to participant			
Child	11 (91.67%)	1 (8.33%)	12 (28.57%)
Parent	3 (100%)	0	3 (7.14%)
Relative	5 (100%)	0	5 (11.9%)
Spouse	16 (72.73%)	6 (27.72%)	22 (52.38%)

With regard to gender, female caregivers were in the majority (83.33%), as indicated in Table 2. In this study all care givers were family members and not paid carers.

All caregivers, described as relatives, were siblings and, as shown in Table 2, they were all female and therefore they were sisters of the patients. For the remainder of this dissertation, caregivers will be referred to as “the family carer”. In each case, the family carer was the person who consented to answer APCA African POS questions.

Interactions with Health Care Facilities in the Preceding Six Months:

Questions were asked of each participant about recent admissions (in the last six months) to a hospital in Cape Town, as well as visits to doctors or healthcare workers in Mitchells Plain. This information was cross-referenced with the folder review and comprehensive results are reported below.

Visits to other clinics or outpatient departments in the last six months:

Of the 46 patients who participated in this study, seven attended an outpatient appointment at a hospital in the last six months, all of which took place at GSH. The mean age of those who attended GSH was 58 years, with the ages ranging from 29 to 77 years. Of those who visited GSH, one participant had cardiac failure only, one had COPD, two (28.57%) had cancer, one had cardiac failure and a previous CVA, one had dementia and one had renal failure.

The results shown in Table 3, for ages, institutions, diagnosis and family carer, all refer to those patients who were admitted in the last six months (56.52%). The number reported under each institution is the number of participants admitted to that particular institution. Of those who were admitted (26) compared to those who were not admitted (20), when compared by different diagnoses: Fisher’s exact: $p = 0.57$, which indicates that this difference between those admitted and those who were not admitted is not statistically significant.

Admissions to any hospitals in the last six months:

Table 3: Recent Admissions to Hospital

Yes	26 (56.52%)
No	20 (43.48%)
Mean Age	61 (29-78)
Institutions:	
GF Jooste Hospital	2 (7.96%)
Groote Schuur Hospital	20 (76.92%)
Mitchells Plain District Hospital	4 (15.38%)
Diagnoses:	
Cardiac Failure only	4 (15.38%)
COPD only	3 (11.54%)
CVA only	2 (7.69%)
Cancer only	9 (34.62%)
Cardiac Failure and a CVA	0
Cardiac Failure and Cancer	2 (7.69%)
COPD and Cancer	2 (7.69%)
Dementia	1 (3.85%)
HIV positive	1 (3.85%)
Renal Failure	1 (3.85%)
COPD, Renal failure and a CVA	1 (3.85%)

Attendance at the 24 hour Trauma/Emergency Unit at the MP CHC in the last six months:

Table 4 shows the details of those participants who attended MPCHC for an urgent problem, with no appointment.

Table 4: Recent Visits to the Emergency Unit

Yes	31 (67.39%)
No	15 (32.61%)
Number of times	2 [Range: 1 to 9]
Mean Age	61 [Range: 29 to 78]
Diagnoses:	
Cardiac Failure only	4 (12.9%)
COPD only	4 (12.9%)
CVA only	2 (6.45%)
Cancer only	11 (35.48%)
Cardiac Failure and a CVA	1 (3.23%)
Cardiac Failure and Cancer	2 (6.45%)
COPD and Cancer	3 (9.68%)
Dementia	2 (6.45%)
HIV positive	0
Renal Failure	1 (3.23%)
COPD, Renal failure and a CVA	1 (3.23%)

When analysing the above data, under the title “Number of times” the number is the mean number of times that each participant attended the emergency unit and the range of the number of visits is given in brackets.

Other doctors:

Of the 46 patients who participated in the study, only two (4.35%) visited another doctor outside the provincial health service and each of these was a General Practitioner (GP). No reasons for these consultations were given. Of the two patients who visited GPs, one had cancer and the other had cardiac failure.

Community Health Centre:

From the folder review, it could be determined how many times participants had attended MPCHC before the recruitment into the programme. However, only 35 out of 46 folders were found in the folder review. The attendance to MPCHC prior to the recruitment is tabled below:

Table 5: Recent Visits to the CHC

Yes	32 (91.43%)
No	3 (8.57%)
Number of times	1.9 (1-5)
Mean Age	61 (29-78)
Diagnoses:	
Cardiac Failure only	4 (12.5%)
COPD only	5 (15.63%)
CVA only	7 (21.88%)
Cancer only	6 (18.75%)
Cardiac Failure and a CVA	2 (6.25%)
Cardiac Failure and Cancer	1 (3.13%)
COPD and Cancer	1 (3.13%)
Dementia	2 (6.25%)
HIV positive	0
Renal Failure	3 (9.38%)
COPD, Renal failure and a CVA	1 (3.13%)

The mean number of times a participant attended MPCHC is reported in Table 5, with the range of times in brackets. The folder review was able to show which patients still attended MPCHC or MPDH after recruitment to the programme and how many times they attended. These results can be found in Table 6.

Table 6: Visits to the MPCHC After Recruitment to the Programme

Yes	25 (71.43%)
No	10 (28.57%)
Number of times	1.32 (Range 1 to 3)
MPCHC	1.4 (1-2)
MPCHC Trauma	1.2 (1-3)
GSH	1.5 (1-2)
Average Age	61 (29-77)
Diagnoses	
Cardiac Failure only	4 (16%)
COPD only	5 (20%)
CVA only	3 (12%)
Cancer only	7 (28%)
Cardiac Failure and a CVA	2 (8%)
Cardiac Failure and Cancer	0
COPD and Cancer	0
Dementia	1 (4%)
HIV positive	0
Renal Failure	2 (8%)
COPD, Renal failure and a CVA	1 (4%)

RESULTS FOR GROUP A AND GROUP B:

In this section of this chapter, the results relating to the control group (Group A) and the intervention group (Group B), and the data collected by means of the APCA African POS (Appendix C) data collection tool are presented.

Demographics for Group A and Group B:

Of the 46 patients who participated in this study, five were excluded from the collection of data through the APCA African POS as a result of the fact that they had dementia or struggled with communication problems. The remaining 41 participants were recruited into either Group A or Group B. Group A was, in essence, the control group, and consisted of twenty patients, recruited over a period of three months, from the time at which the programme was initiated. Group B, which was intended to be the intervention group, consisted of patients who were recruited after most patients in Group A had completed their data collection. Group B consisted of 21 patients.

Table 7: Demographics of Group A and Group B

	Group A	Group B	
Gender			p = 1
Females	11 (55%)	12 (57.14%)	
Males	9 (45%)	9 (42.86%)	
Mean Age (years)	61.5 (53-77)	61 (29-78)	p = 0.22
Diagnoses:			p = 0.49
Cardiac failure	3 (15%)	4 (19.05%)	
COPD	4 (20%)	1 (4.76%)	
CVA	4 (20%)	2 (9.52%)	
Cancer	3 (15%)	7 (33.33%)	
Multiple Co-Morbidities	6 (30%)	7 (33.33%)	
Family Carer			p=0.34
Yes	17 (85%)	20 (95.24%)	
No	3 (15%)	1 (4.76%)	
Relationship of Family Carer			p = 0.25
Children	5 (29.41%)	4 (20%)	
Parent	0	3 (15%)	
Relative	1 (5.88%)	4 (20%)	
Spouse	11 (64.71%)	9 (45%)	
Family Carer's Gender			p = 0.38
Female	13 (76.47%)	18 (90%)	
Male	4 (23.53%)	2 (10%)	
Died			p = 0.004
Survived	16 (80%)	7 (33.33%)	
Died during study	4 (20%)	14 (66.67%)	
Support Group	12 (60%)	0	
Visit to Doctor	0	7	
During study	0	3 (14.29%)	
End of study	14 (70%)	4 (19.05%)	

In Group A, the age distribution was normal (Shapiro Wilk: $p = 0.27$). The mean age and the range in ages are reported in Table 7. In Group B the age distribution was normal (Shapiro Wilk: $p = 0.14$). The mean age and the range in ages are reported above. The age ranges for Group A and Group B were compared using the Wilcoxon rank-sum test ($p = 0.33$).

Within the category of diagnoses, the researcher deemed that some groups were too small to allow meaningful statistical analysis, so those participants with more than one diagnosis were grouped together under the heading "Multiple Co-morbidities".

Of the entire cohort (41 participants), twelve (29.27%) chose to attend one or more support group meetings and 29 (70.73%) chose not to attend a support group meeting. The number of different families from whom a member attended one or more support group meetings was thirteen. One family, in which the patient was excluded from Group A and B, based on the fact that he/she had dementia, did in fact attend a support group meeting. Of the thirteen families from whom a member attended one or more support group meetings, six different

patients attended meetings, with a mean attendance of 2.17 meetings (ranging from one to five) and 10 family carers attended, with a mean attendance of 2.9 meetings (ranging from one to six). From Group A, twelve patients (60.00%) attended one or more support group meetings after completion of the APCA African POS and eight (40.00%) did not attend any. From Group B, no participants attended a support group meeting. This has been mentioned previously and it is one of the reasons why the whole cohort (Group A and Group B) was analysed together. No APCA African POS results were collected for the patients in Group A who attended one or more meetings of the support group, after attending of the meeting(s). This was because they only attended the support group after the completion of their APCA African POS data collection. The evaluation of the support group by patients assigned to Group A is the only feedback available for the support group. This evaluation is presented later in this chapter.

The patients assigned to Group A were invited to attend a consultation with a doctor, after collection of the APCA African POS data was completed. Fourteen patients (70.00%) took advantage of this opportunity. Of the twenty-one patients assigned to Group B, fourteen (66.67%) never took advantage of the opportunity to attend the consultation offered to them, three (14.29%) attended a consultation during the study and four (19.04%) attended a consultation at the end of the study. The group that attended a doctor's consultation during the study is analysed below (Figure 4).

As stated in the chapter on methodology, as a result of the fact that only three participants assigned to Group B participated in the intervention, the entire cohort was analysed together, based on variables that were found to be statistically significant.

As indicated in Table 7, with regard to the number of participants who died during the study, significantly more deaths occurred among the patients assigned to Group B, compared to those assigned to Group A. The event "dying during the study" is further analysed in Table 8. Comparing those who survived with those who died during the study, by gender, analysis yielded a p-value of 0.49. Given that the p-value is greater than 0.05, this analysis is not shown. Table 8 shows the comparison of the time of death of patients assigned to Group A and Group B, in relation to the time at which they joined the study. A distinction is made between "before three completed weeks" and "after three completed weeks", as the comparison between these two groups shows statistical significance ($p = 0.001$).

Table 8: Comparison of patients who died before three completed weeks and those who died after three completed weeks

	Group A	Group B	
Survived	16 (80%)	7 (33.33%)	
Died during the study	4 (20%)	14 (66.67%)	
Before 3 weeks	1 (5%)	12 (57.14%)	
After 3 weeks	3 (15%)	2 (9.52%)	
			p = 0.001

APCA African POS Data:

APCA African POS data was collected at week zero, and then weekly for the six weeks following the date of the initial data collection. The data has been analysed at different times by different variables.

All the Figures showing the APCA African POS results use an abridged version of the questions (Appendix C). The same format is used throughout this document. All scores are integral values on a scale from zero to five. For the first three questions, zero represents “no pain or symptoms” and five represents “the worst symptoms they have ever felt”. For the other six questions, zero represents a very negative response and five represents the most positive feeling, with regard to each question.

Figure 1 shows the whole cohort summarised for all APCA African POS responses at week zero. Table 9 shows the numbers of respondents (N), the mean value of responses, with minimum (min) and maximum (max) values.

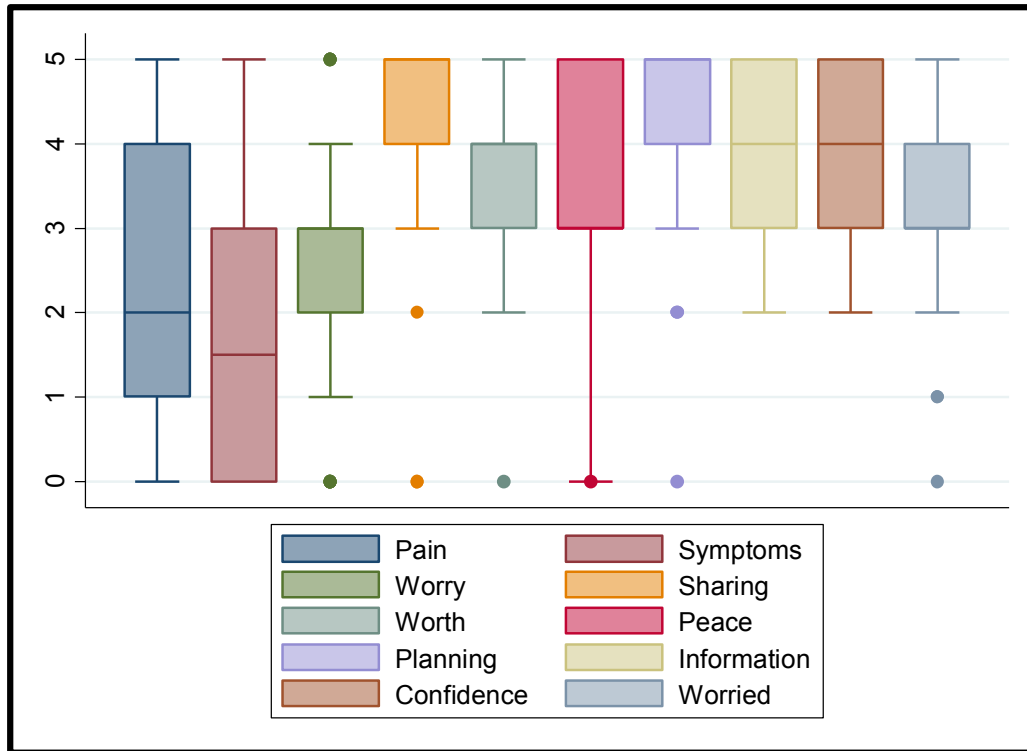


Figure 2: APCA African POS responses at week zero (entire cohort)

Table 9: Statistics represented in Figure 2

	N	mean	min	max
Pain	41	2.34	0	5
Symptoms	40	1.73	0	5
Worry	38	2.58	0	5
Sharing	39	4.23	0	5
Worth	34	3.59	0	5
Peace	36	3.47	0	5
Planning	21	4.29	0	5
Information	36	3.91	2	5
Confidence	36	4.08	2	5
Worried	36	3.33	0	5

As indicated in Table 7 there was a significant difference in the attrition rate exhibited by the patients in Group A compared with that exhibited by the patients in Group B. The patients in Group B exhibited a significantly higher attrition rate than those in Group A. Based on this observation, a comparison of those participants who died during the study and those who survived was carried out. Analysis of the APCA African POS results from the patients who survived and those who died during the study, in Group A and Group B yielded a p-value of 0.004, which indicates that the two groups differ significantly, necessitating further analysis.

Figure 2 shows a comparison of the APCA African POS results, for the whole cohort, divided into two groups: those participants who died and those who survived until the end of the study.

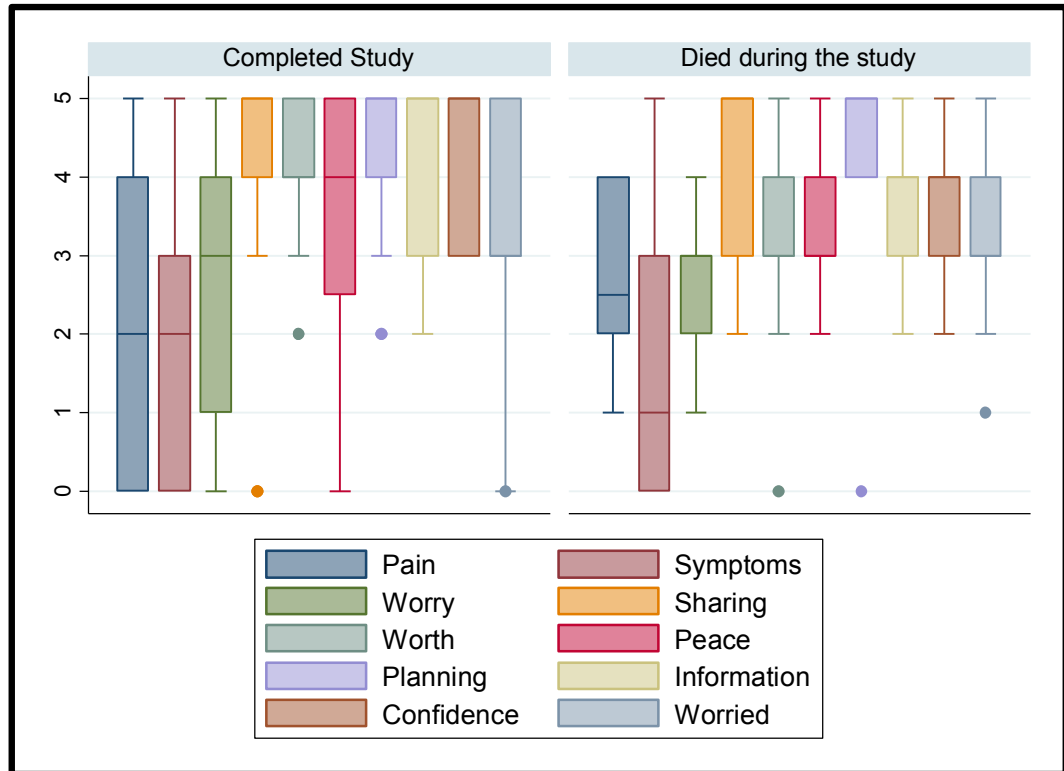


Figure 3: APCA African POS results at week zero, for participants who survived the study compared with participants who died during the study

Table 10: Statistics represented in Figure 3

	Completed the Study				Died during the Study				p value
	N	mean	min	max	N	mean	min	max	
Pain	23	2.04	0	5	18	2.72	1	4	0.049
Symptoms	22	1.82	0	5	18	1.61	0	5	0.36
Worry	20	2.55	0	5	18	2.61	1	4	0.023
Sharing	21	4.19	0	5	18	4.28	2	5	0.54
Worth	16	4.06	2	5	18	3.17	0	5	0.024
Peace	20	3.6	0	5	16	3.31	2	5	0.25
Planning	12	4.33	2	5	9	4.22	0	5	0.15
Information	19	4.21	2	5	17	3.59	2	5	0.012
Confidence	19	4.26	3	5	17	3.88	2	5	0.16
Worried	19	3.26	0	5	17	3.4	1	5	0.77

Some participants died before their third completed week of the study, and others died after completion of the third week's APCA African POS data collection. Analysis of the total

numbers of patients in Group A and Group B, comparing those who survived and those who died before or after three completed weeks yielded a p-value of 0.001, which means that there is a statistically significant difference between those that survived the programme and those that died during the programme. When the responses to the APCA African POS of the two groups were analysed, there were four questions for which the responses from those patients who died before three completed weeks exhibited a statistically significant difference from the response of those patients who completed the study. The questions are those relating to “pain”, “worry”, “worth” and “information”.

Note that “pain” related to how severe the person’s pain was in the three days prior to the date of data collection. These results show that those who died during the study reported feeling more severe pain than those who survived the study ($p = 0.049$). The mean “pain” score for patients who survived was 2.04 and the mean “pain” score for patients who died was 2.72. Those who died during the study reported a smaller range of pain responses compared to those that survived the study.

The “worry” indicator relates to the patient’s worry over their illness in the three days prior to the date of data collection. These “worry” scores for the two groups of patients are significantly different ($p < 0.05$), with a mean score of 2.55 for the patients who survived and a mean score 2.61 for the patients who died. Half (50%) of the patients who died during the study had a response of 2 or 3 out of 5.

The “worth” indicator relates to a how worthwhile the patient has felt their life to be in the three days prior to the date of data collection. The mean “worth” scores were 4.06 for the group of patients who survived and 3.17 for the group of patients who died ($p = 0.024$). Patients who survived the study reported “worth” scores of 4 or 5, out of 5, while patients who died during the study reported “worth” scores of 3 or 4, out of 5. Analysis of these scores suggests that the group of patients who survived the study felt their lives were more worthwhile than those that died during the study.

The final score which displayed a significant difference related to the question on “information”, where the family carer was asked if they felt they had received enough information about the patient’s illness. The family carers of those participants who died before three completed weeks reported a mean score of 3.92 (with a range of 3 to 5, where 5 represents “as much as we wanted”). In the group of patients who survived the study, the mean score was 4.21 (with a range of 2 to 5). Analysis of these scores suggests that the families of those that survived the study seemed to have been more content with the information provided on the patient’s illness ($p = 0.012$), the p-value for this comparison is < 0.05 .

The scores associated with all of the other responses displayed no statistically significant difference between the two groups ($p > 0.05$).

Comparison of the number of participants who died before three weeks and those who died after three weeks, by Group A and Group B yielded a p-value of 0.044. Comparison of the numbers of participants that survived and those that died after three weeks (combining Group A and Group B) yielded a p-value of 0.001. This indicates that there is a statistically significant difference between the numbers of participants who died before three weeks and those that died after three weeks and the comparison of those that survived the programme and those that died after three completed weeks is also statistically significant. However, when detailed analysis of the APCA African POS data was performed, comparing scores for the group of patients who died before three completed weeks and scores for the group of patients who died after three completed weeks, only one question was found to yield scores that were statistically significantly different in the two groups. It was the score relating to “information”, based on a question asked of the family carer, relating to how much information the family had received about the patient’s illness. In the group of patients who died before three completed weeks, the mean score was 3.92 (with a range of 3 to 5, with 5 representing the answer “as much as we wanted”). In the group of patients who had died after three completed weeks, the mean score was 2.8 (with a range of 2 to 3). Comparison of the scores suggested that they were statistically significantly different ($p = 0.006$). Statistical analysis of the responses to the other nine questions indicated that they were not statistically significantly different ($p > 0.05$).

Analysis of the responses to the APCA African POS was performed with the scores grouped based on the different diseases, assessing the impact of different diseases on the burdens of symptoms. Analysis of the data was done between the disease categories mentioned in Table 7.

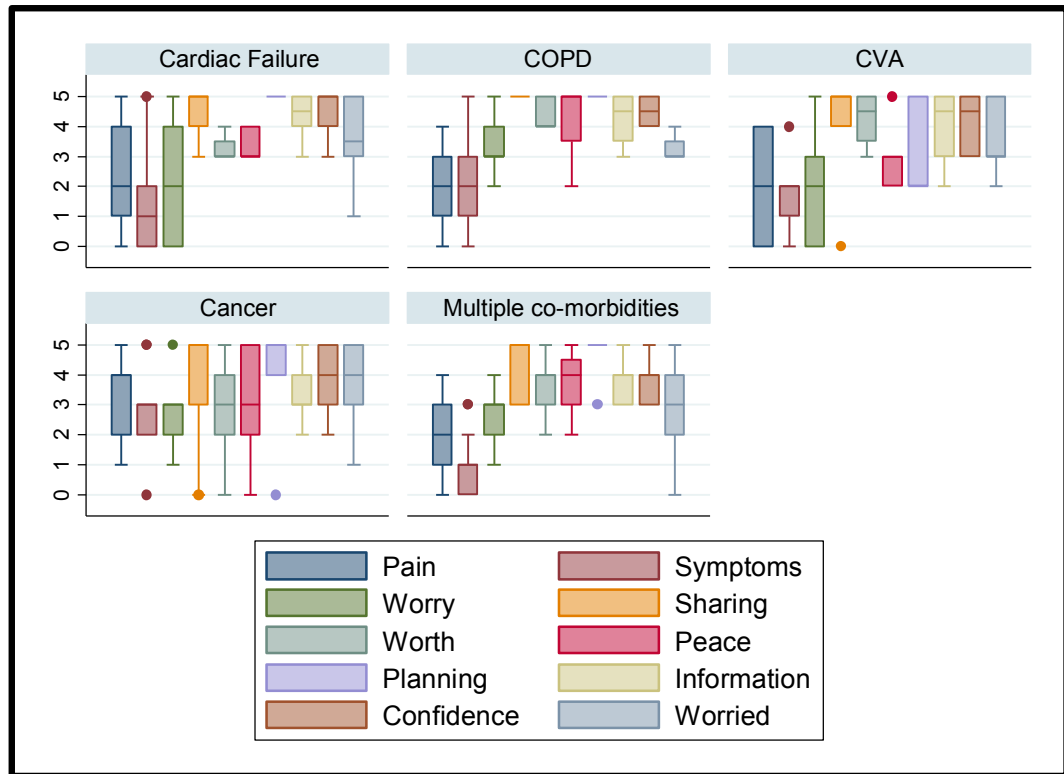


Figure 4: Comparison of APCA African POS results by different disease categories

Table 11: Statistics represented in Figure 4

	Cardiac Failure				COPD				CVA			
	N	Mean	Min	Max	N	Mean	Min	Max	N	Mean	Min	Max
Pain	7	2.29	0	5	5	2	0	4	6	2	0	4
Symptoms	7	1.29	0	5	5	2.2	0	5	6	1.83	0	4
Worry	7	2.14	0	5	5	3.4	2	5	5	2	0	5
Sharing	7	4.43	3	5	3	5	5	5	6	4	0	5
Worth	4	3.25	3	4	5	4.4	4	5	4	4.25	3	5
Peace	6	3.33	3	4	4	4.25	2	5	5	3	2	5
Planning	3	5	5	5	1	5	5	5	3	3	2	5
Information	6	4.33	3	5	4	4.25	3	5	6	4	2	5
Confidence	6	4.5	3	5	4	4.5	4	5	6	4.17	3	5
Worried	6	3.5	1	5	4	3.25	3	4	6	3.5	2	5

	Cancer				Multiple co-morbidities				p-values
	N	Mean	Min	Maxx	N	Mean	Min	Max	
Pain	10	3.2	1	5	13	2	0	4	0.43
Symptoms	9	2.89	0	5	13	0.92	0	3	0.05
Worry	9	2.78	1	5	12	2.58	1	4	0.53
Sharing	10	3.9	0	5	13	4.31	3	5	0.74
Worth	9	3.11	0	5	12	3.5	2	5	0.20
Peace	9	3.22	0	5	12	3.67	2	5	0.59
Planning	7	4	0	5	7	4.71	3	5	0.35
Information	9	3.56	2	5	11	3.18	3	5	0.51
Confidence	9	3.89	2	5	11	3.81	3	5	0.45
Worried	9	3.67	1	5	11	2.91	0	5	0.74

In order to ascertain if there are differences in responses to the APCA African POS tool across the disease spectrum, an analysis of the APCA African POS responses was performed. This analysis is presented in Figure 4 and Table 11. The only statistically significant difference is for the question on symptoms, where the p-value was 0.05. When the responses for symptoms were further analysed it was found that the comparison between cancer and multiple co-morbidities shows a p-value of 0.042 (implying statistical significance with a p-value < 0.05), all other comparisons for symptoms, between different disease categories, has a p value of 1.

Cross section time dependent regression analysis:

In order to ascertain if the data fitted a statistical pattern, cross section time dependent regression analysis was applied to the data, using all participants as one cohort.

For the questions on pain, sharing, worth, peace, planning, information, confidence and for the final question around worry; the analysis for each question was not statistically significant.

For the question on symptoms: “Have any other symptoms been affecting how you feel in the last three days?” the responses ranged from 0 to 5, with a mean score of 1.73 in week zero and a mean score of 2.53 in week six. A score of zero represents no symptoms and 5 represents overwhelming symptoms. This data had a coefficient of 0.37, with a p-value of 0.039. The increase from 1.73 to 2.53 is a significant increase in symptom burden.

“Have you been feeling worried about your illness in the last three days?” is represented under the heading “worry”. The response of cohort ranged from 0 to 5, with a mean score of 2.58 in week zero and a mean score of 3.25 in week six. A higher score indicates more worry. This analysis has a coefficient of 0.36 and a p-value of 0.018. The increase from 2.58 to 3.25 is a significant increase in worry over their illness.

The scores of the participants who did visit the doctor, as part of the intervention, were analysed with cross section time dependent regression analysis. The results are shown in Figure 5 with the relevant statistics and coefficients in Table 12. This analysis will be further discussed in the next chapter.

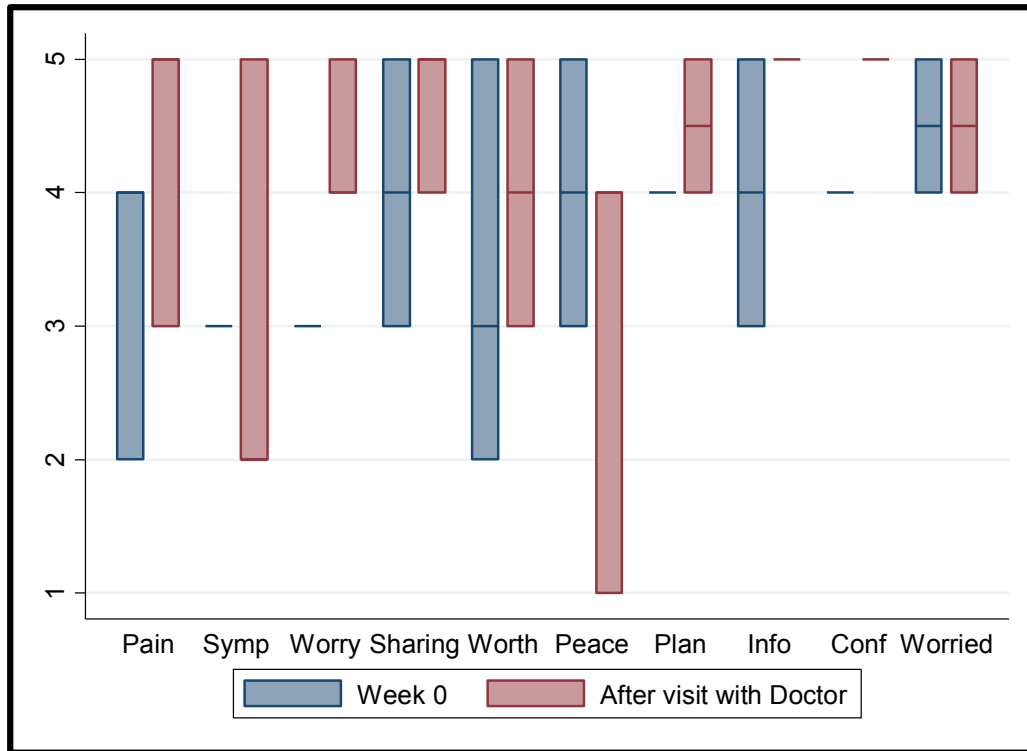


Figure 5: Participants who attended the doctor’s consultation, week zero compared to the visit after the consultation

Table 12: Statistics represented in Figure 5

	Week 0				After visit with the Doctor				Coefficient	P value
	N	mean	min	max	N	mean	min	max		
Pain	3	3.33	2	4	3	4.33	3	5	0.14	0.194
Symptoms	3	3	3	3	3	3	2	5	0	1
Worry	3	3	3	3	3	4.33	4	5	0.19	0.00
Sharing	3	4	3	5	3	4.67	4	5	0.095	0.27
Worth	3	3.33	2	5	3	4	3	5	0.095	0.44
Peace	2	4	3	5	3	3	1	4	-0.14	0.39
Planning	1	4	4	4	2	4.5	4	5	-	-
Information	2	4	3	5	2	5	5	5	0.143	0.16
Confidence	2	4	4	4	2	5	5	5	-	-
Worried	2	4.5	4	5	2	4.5	4	5	0	1

EVALUATION OF THE PROGRAMME:

This final section of the results chapter presents data relating to the evaluation of the programme by the participants and the clinic staff (using the instruments presented as Appendix D and E). This evaluation was conducted once the study programme ended.

Evaluation by participants:

Participants, who were still alive and in contact with the coordinator of the programme at the end of the study, were asked to complete an evaluation form. There were questions on the role of the coordinator, the patient’s visit to the doctor, attendance at the support group meetings and questions on the patients’ opinions regarding the future of the programme and potential continuation of such an intervention. (Refer to Appendix D for the evaluation form.)

Twenty participants completed the evaluation form. Ten were patients and ten were caregivers or family members. It was not stated if any of the respondents were related to each other.

The coordinator:

The overall impression of the coordinator, reported by the patients, with regard to their experience in the CHC, was that she (the coordinator) was helpful. One person indicated that she was of “some help”, twelve (60%) indicated that she was “helpful” and seven participants (35%) indicated that she was “very helpful”.

The question “In what ways did she assist you?” was asked in the evaluation form, options were presented and answers of “not really”, “sometimes” and “yes” were offered. Figure 5 show those a summary of the responses from the participants.

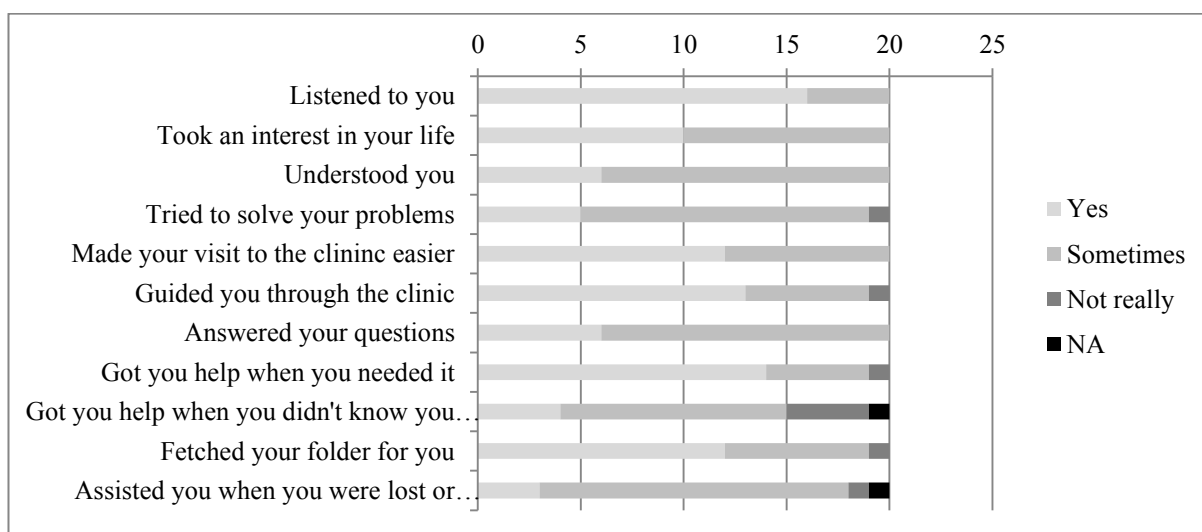


Figure 6: Ways in which the coordinator assisted participants

Two comments made by participants under this section of the evaluation were that the coordinator was “very pleasant” and “made me feel very relaxed”. When asked if they would like this role of coordinator to continue 13 participants (81%) responded with “yes” and three participants (19%) stated “definitely”. Only 16 respondents answered this question.

The visit to the doctor:

Eleven participants (58%) stated that they did remember the doctor they visited as part of the programme, while eight out of 19 respondents (42%) did not remember the doctor. All the doctors mentioned in the responses were male doctors, so the pronoun “he” will be used below in reference to the doctor concerned. When asked if the doctor explained what was wrong with them, all participants who responded to this question (i.e. 17) stated that he did explain to them what was wrong.

When asked if the doctor answered their questions, one participant answered “not really”, ten (52.6%) answered “mostly”, five (26.3%) answered “yes” and three (15.8%) stated that he had answered all of their questions.

When asked if the doctor tried to make them feel better, three participants (15.8%) answered “not really”, eight (42.1%) answered that he tried, five (26.3%) answered “yes” and three (15.8%) answered that he had made a difference.

When asked if the doctor improved their quality of life, three participants (15.8%) answered “not really”, 11 (57.9%) answered that he had tried, two (10.5%) answered “yes” and three (15.8%) answered that he had made a difference.

When asked how helpful the discussion (consultation) was to how they were feeling at the time of completing the evaluation, one participant (5.3%) stated that it was not helpful, two (10.5%) stated that it had helped a bit, five (26.3%) answered that it had helped, seven (36.8%) answered that it had helped a lot and four (21%) answered that it made a big difference.

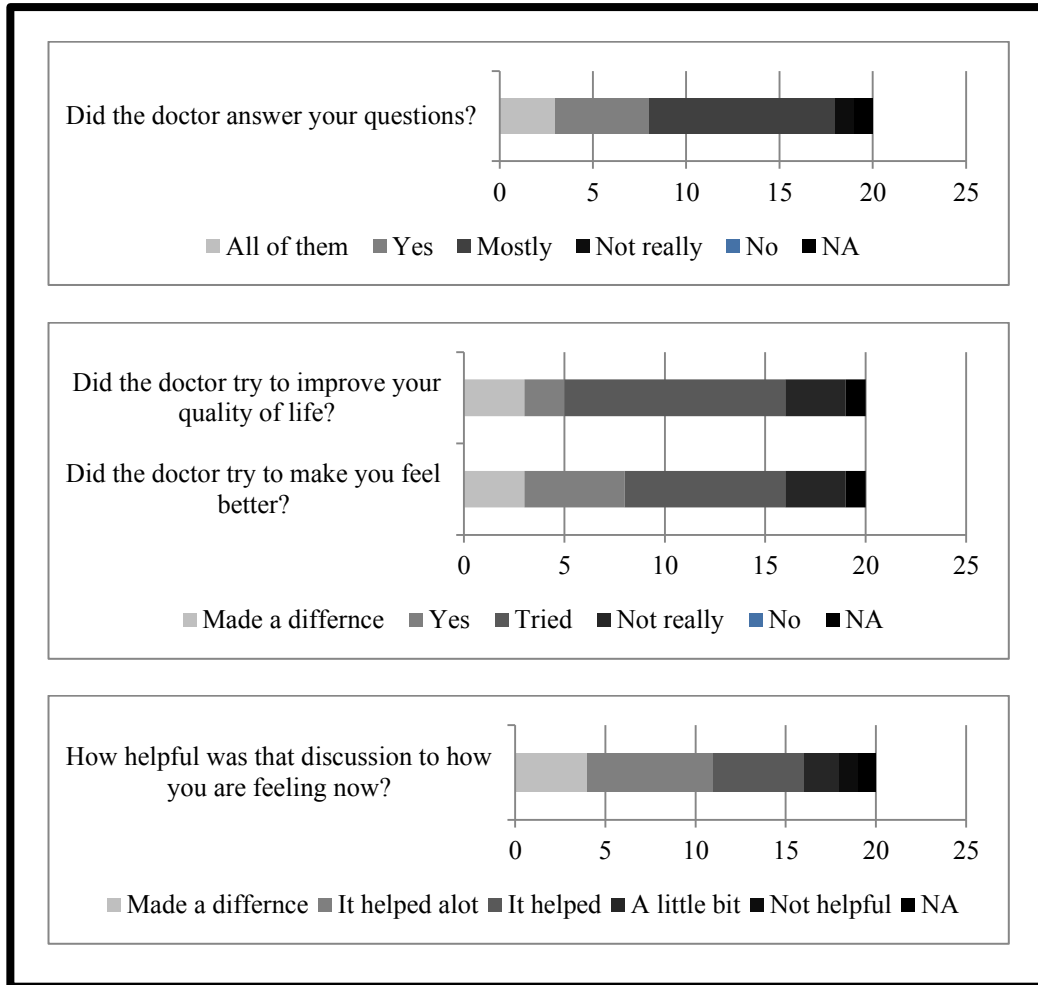


Figure 7: Responses to questions about the visit to the doctor

The support group:

Of the 19 participants who responded to the question on attendance at a meeting of the support group, 17 participants (89.5%) had attended at least one session. The comments from the two who did not attend a meeting were that they had “no transport” and “no time” respectively. Of those who attended, four (23.5%) participants came once, eight (47%) came twice, four (23.5%) came three times and one (5.9%) came four times. In response to the question regarding the continuation of the support group, all 18 (100%) respondents who answered this question said they would like it to continue. The participants were asked about what aspects of the support group they found helpful. Figure 7 shows the responses to the suggestions. Responses could be “not the reason I came”, “sometimes” or “definitely”.

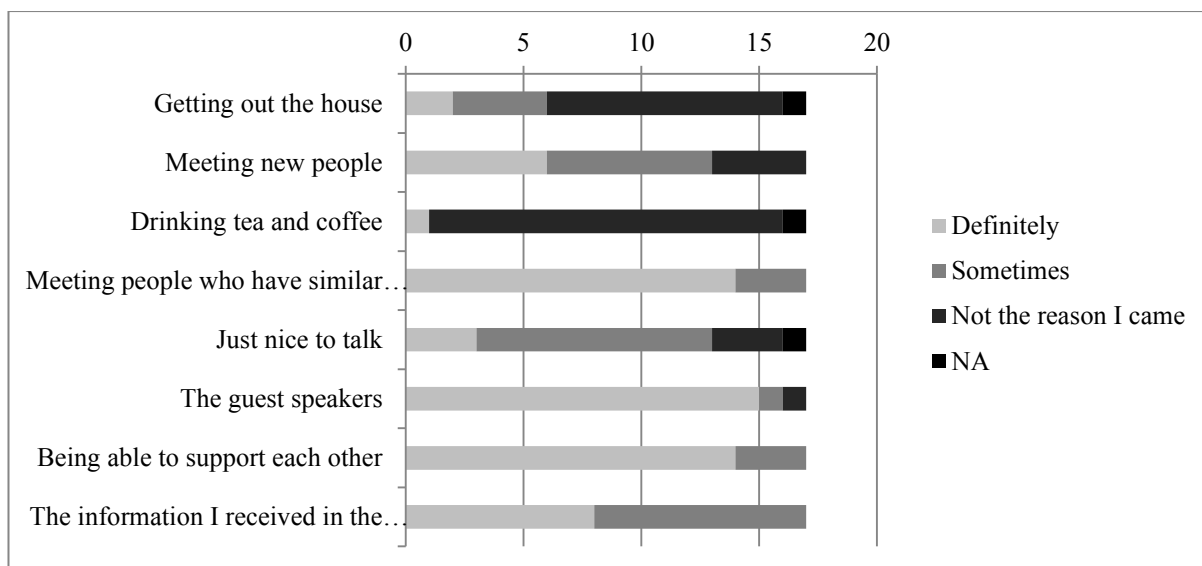


Figure 8: Responses to what aspects of the support group the participants felt were helpful

With regard to the continuation of the support group, 100% of the respondents stated that they would like it to continue. When asked about preference of venue, if the support group were to continue, 17 respondents (89.5%) stated that the CHC was a preferable venue, while two respondents (10.5%) stated that a venue in the community would be better. When asked about how often the support group should meet, if it were to continue, two respondents (11.8%) stated that every two months would be preferable, 14 (82.4 %) stated that monthly would be preferable and one stated that fortnightly would be preferable.

In summary, there were a few questions about the whole programme. The respondents were asked if they would like the programme to continue or not. All 20 participants (100%) stated that they would like the programme to continue. When asked if there should be any changes, one respondent said that there should be changes, but did not state what those should be and 17 (94.4%) said that there should be no changes. When asked if they had recommended the programme to other people, 12 respondents (63.2%) stated that they had already recommended it and seven (36.8%) stated that they had not. When asked if they would recommend it in future, all 20 participants (100%) said they would do so.

Staff evaluation:

Staff at the CHC were asked to evaluate the programme. Some staff were involved in different aspects of the programme and others were not. There were 37 staff members who completed a form (Appendix E). Table 15 presents the breakdown of the staff members who completed the evaluation, with staff divided into different job categories.

Table 13: Job categories of staff respondents for the staff evaluation

Administrator	1 (2.7%)
Clinical Nurse Practitioner (CNP)	6 (16.2%)
Doctor	8 (21.62%)
Enrolled Nurse (EN)	6 (16.2%)
Enrolled nursing assistant (ENA)	3 (8.11%)
Health Promotion officer (HPO)	2 (5.4%)
Operational manger	1 (2.7%)
Registered nurse (RN)	10 (27.03%)
Total	37 (100%)

For purposes of analysis, the clinical nurse practitioners and doctors were grouped together under the heading “clinicians”. The registered nurses, enrolled nurses and operational manager were grouped together under the heading of “nurses”. The enrolled nursing assistants, health promotion officers and administrator were grouped together under the heading of “other”.

When the staff members were asked if they knew about the programme, 29 respondents (78%) indicated that they did know about the programme and eight (22%) indicated that they did not know about the programme.

Table 14: Staff response to questions on knowledge of the programme

	Yes	No
Clinicians	13 (92.9%)	1 (7.1%)
Nurses	12 (70.6%)	5 (29.4%)
Other	4 (66.7%)	2 (33.3%)

When asked if they had been involved with the programme, 21 staff members (56.8%) said they had been involved and 16 (43.2%) said they had not been involved. The responses to the question about what ways they had been involved with the programme are shown in Table 17.

Table 15: Ways staff members were involved in the programme

	Clinicians	Nurses	Other	Total
As a patient/family	1 (7.1%)	0	0	1 (2.7%)
Referred patients to programme	12 (85.7%)	9 (52.9%)	3 (50%)	24 (64.9%)
Seen patients as part of the programme	2 (14.3%)	1 (5.9%)	0	3 (8.1%)
Assisted the co-ordinator with queries	4 (28.6%)	2 (11.8%)	2 (33.3%)	8 (21.6%)
Attended a support group	0	0	0	0
Total	14	17	6	37

When asked if they had referred a patient, 26 staff members (72.2%) indicated that they had referred a patient and 10 (27.8%) indicated that they had not referred a patient.

Table 16: Staff response to if they had referred a patient to the programme or not

	Yes	No
Clinicians	11 (84.6%)	2 (15.4%)
Nurses	11 (64.7%)	6 (32.3%)
Other	4 (66.7%)	2 (33.3%)

When asked if they knew which patients to refer to the programme (i.e. what the referral criteria were), 26 staff members (70.3%) indicated that they did know which patients to refer and 11 (29.7%) indicated that they did not know which patients to refer.

Table 17: Staff response to knowledge of which patients to refer to the programme

	Yes	No
Clinicians	12 (85.7%)	2 (14.3%)
Nurses	10 (58.8%)	7 (41.2%)
Other	4 (66.7%)	2 (33.3%)

In response to the question on barriers in referral to the programme, four staff members (11.4%) stated that there were barriers and 31 (88.6%) said there were not. Comments made on the topic of barriers to referral include “*I didn't have any knowledge about it.*” and “*Working in trauma, there is little time for interaction with the [patients].*”

Table 18: Staff responses to barriers in referring patients to the programme

	Yes	No
Clinicians	1 (7.1%)	13 (92.9%)
Nurses	2 (12.5%)	14 (87.5%)
Other	1 (20%)	4 (80%)

When asked if they had met the coordinator, 25 staff members (73.5%) indicated that they had met her and nine (26.5%) staff indicated that they had not met her.

Table 19: Staff responses to having met the programme coordinator or not

	Yes	No
Clinicians	10 (83.3%)	2 (16.7%)
Nurses	11 (68.8%)	5 (31.2%)
Other	4 (66.7%)	2 (33.3%)

When the staff were asked if they had ever asked the coordinator to assist with patient care, of patients not necessarily part of the programme, 11 respondents (33.3%) said they had asked for her help and 22 (66.7%) said they had not asked her.

Table 20: Staff response to asking the coordinator to assist with patient care, of patients not necessarily in the programme

	Yes	No
Clinicians	4 (33.3%)	8 (66.7%)
Nurses	6 (37.5%)	10 (62.5%)
Other	1 (20%)	4 (80%)

In response to the question on the extent to which the programme had had an impact on them, there were 30 responses from the staff.

Table 21: Staff response to the question of degree of impact the programme had on them

No impact	4 (13.3%)
Minimal impact	6 (20%)
Some impact	13 (43.3%)
A large impact	7 (23.3%)

Table 22: Staff response to the question of degree of impact the programme had on them

	No impact	Minimal impact	Some impact	A large impact	Total
Clinicians	0	4 (33.3%)	7 (58.3%)	1 (8.3)	12
Nurses	4 (28.6%)	2 (14.3%)	3 (21.4%)	5 (35.7%)	14
Other	0	0	3 (75%)	1 (25%)	4

Some of the comments regarding the impact of the programme follow.

“Could refer chronic patients for some assistance or better management.”

“It made me realise the importance of supporting the family members with chronic diseases.”

“[It] assisted with more options with patient care.”

“It improved the quality of life for the patients I referred.”

“[There are] a lot of old people staying at home without any assistance.”

“Because we see less of the palliative patients in trauma.”

“It has shown me that this programme is actually necessary for people who are terminally ill and their families.”

“Had a referral person on site - made it so much easier.”

“It helped a lot of people that there is no treatment for anymore”

“Because you don't need to send patients to hospital that are end-stage.”

“Makes our work lighter.”

“Raised the awareness of palliative care facilities in Mitchells Plain.”

When asked if this programme should continue, 31 respondents (96.9%) said it should and 1 (a clinician) said it should not.

The following comments were made with regard to continuing the programme.

“The hospital needs it.”

“If it is assisting the community in a positive manner it should proceed.”

“There is a need for palliative care, especially in this CHC.”

“Very helpful and supportive.”

“To help the family with counselling and move forward.”

“To help the clients understand their illness better.”

“It gives patients hope.”

“Shows the patient that being sick does not mean the end of the world.”

“Less palliative care patients in trauma.”

“It is a great help to the staff because they can refer clients who need extra help, because they do not have enough time.”

“There is a need for patients and family members to have support and counselling.”

“A large number of clients fit the criteria for referral and need more care than just visiting a health care centre.”

When asked if they would like to be more involved in the programme, if it were to continue, 20 respondents (74%) indicated that they would like to be more involved and 7 (26%) indicated that they would not like to be more involved.

Table 23: Staff responses to being more involved in the programme, if it were to continue

	Yes	No
Clinicians	6 (60%)	4 (40%)
Nurses	11 (78.6%)	3 (21.4%)
Other	3 (100%)	0

In response to the question on whether they would like more information, 29 respondents (87.9%) indicated that they would like more information and 4 (12.1%) indicated that they would not.

Table 24: Staff responses to getting more information

	Yes	No
Clinicians	9 (75%)	3 (25%)
Nurses	14 (93.3%)	1 (6.7%)
Other	6 (100%)	0

In response to the question on whether they would like more palliative care training, 24 respondents (77.4%) indicated that they would like more training and 7 (22.6%) indicated that they did not want more training.

Table 25: Staff responses to wanting more palliative care training

	Yes	No
Clinicians	7 (58.3%)	5 (41.7%)
Nurses	13 (92.9%)	1 (7.1%)
Other	4 (80%)	1 (20%)

CHAPTER 5: DISCUSSION

The aim of this study was to evaluate and compare patient-reported outcomes, reported by patients deemed to be in need of palliative care, prior to an intervention, and then with a palliative care-based intervention in place. The data obtained prior to the intervention, to evaluate the participants, was deemed satisfactory. However, participation by participants in the intervention programme was suboptimal, and the researcher was unable to use the APCA African POS to compare patient-reported outcomes recorded before the intervention was in place with patient-reported outcomes recorded once the intervention was in place. The researcher was able to evaluate the effect of the intervention on the participants by means of a participant and staff evaluation form, focusing on the intervention.

Recruitment of participants:

Of the 74 patients referred to the study, only 46 consented to participate in the study. Of the 28 that did not consent, some were lost to follow-up and could not be contacted for a response.

Some of those who were contacted stated that they did not need any extra help or that they had enough support from other sources. In certain cases (fewer than ten), the researcher found that the patient's family members had played a role in influencing the patient's decision not to participate in the study. A few of these families did not want their loved ones, nor themselves, to be involved in the programme. It appeared that families who did not proactively discourage the patients from participating in the programme, were unhelpful and unsupportive when the patient was deciding whether or not to participate in the programme.

In order to create a control group for this study, and to determine the burden of symptoms that this group of people with palliative care needs experience, the researcher opted to start this research project without telling the patients that they had been identified as being in need of palliative care, they were only told that the study was for people with chronic illnesses. Informing the patients that they were in need of palliative care because they were nearing the end of their lives (i.e. "breaking the bad news") was incorporated into the research project, to be done at the consultation with the doctor, either at the end of the collection of the APCA African POS data, in the case of Group A, or during the collection of the APCA African POS data, in the case of Group B. From the perspective of the medical staff, it was felt that asking the clinician, who was referring the patient, to "break the bad news", would increase

the clinician's workload, and this may become a barrier impeding referral to the programme. All clinical staff were given the same referral criteria and the same instructions on how to refer patients to the programme. However, other palliative care programmes in Cape Town (Abundant Life and St Luke's Hospice programmes) have criteria for referral which state that the person in need of palliative care must be told of the prognosis, i.e. the person doing the referral must "break the bad news" to the person and family, and then obtain the patients consent, before referring them to the programme. Without this consent, the two programmes mentioned will not get involved in the care of the patient.

There may have been different responses from the patients involved in this study, if the protocol had required that the intervention begin with the consultation, "breaking the bad news" and optimising care, before referring the patients to the programme co-ordinator.

Demographic differences:

There was a wide age range in the ages of the participants and although the ages were not of a normal distribution, the difference between the mean and the median (60.21 years and 61 years, respectively) was very similar. There was a patient who was excluded from the study, because she was younger than 18 years. This illustrates the wide range in the ages of the people in need of palliative care. This age distribution also shows the extent to which younger people are in need of palliative care. The focus of this study was on chronic diseases, but not all people with chronic diseases are elderly. However, the mean age of patients involved in this study was 61 years. By way of comparison, Van Niekerk and Raubenheimer found the mean age in their study to be lower, at 48 years²³.

Mitchells Plain, the suburb in which the study was set, is traditionally an area inhabited by coloured South African people. People who were moved from District Six and other areas, which were classified as 'white' areas during the Apartheid era, were moved to Mitchells Plain and other similar suburbs. This colour (racial) or ethnic divide has changed since 1994, but the population of Mitchells Plain is still largely coloured²⁷. MPCHC services a larger area than just Mitchells Plain. It also services Philippi, Brown's Farm, Samora Michel and Crossroads, where the population consists predominantly of black African people²⁷.

This study was open to all people who access care at the MPCHC, so it is interesting to note that all participants classified themselves as coloured. This could be as a result of the fact that most people accessing chronic medical care through MPCHC are from Mitchells Plain, rather than from the other areas which this clinic services. There are primary healthcare facilities in Brown's Farm, Philippi and Crossroads, which may handle chronic diseases for people living in those areas. The researcher was unable to obtain records of the specific

details of where the inhabitants of these areas actually access healthcare, in relation to where they live. Future research may aim to investigate this.

Diagnosis Categories:

The majority of the participants (37 of the 46) had only one diagnosis: cardiac failure, COPD, CVA, cancer, dementia, HIV or renal failure. Some healthcare workers note, anecdotally, that people nearing the end of their lives, suffering from chronic illnesses, have many medical problems and are difficult to manage. This is reported to be a barrier to providing palliative care⁷⁵. However, the data collected in this study suggest that, in a primary healthcare setting, most palliative care patients have only one diagnosis. This is appropriate, because it could be suggested that patients with complex medical problems need to be managed at a secondary level, by a specialist physician.

There was only one patient in the sample who had more than two diseases, and who thus may have benefited from treatment provided by a more specialised palliative care team, or by a physician, rather than a primary healthcare team. As mentioned in the introduction, there was no such palliative care service at the time of this study, so this particular patient was cared for by the primary healthcare team.

Eighteen of the 46 participants had some type of cancer and this shows that cancer is still a major burden of disease in our population. This is validated in the prevalence study performed by Van Niekerk and Raubenheimer, which reported that 50.8% of palliative care patients admitted to hospitals in Cape Town, had been diagnosed with some form of cancer²³.

This study was open to patients who are HIV-positive and are in need of palliative care. However, only one HIV-positive patient participated in the study. MPCHC does have a large and comprehensive Antiretroviral (ARV) clinic. The fact that there were not more HIV-positive patients participating in this study is not necessarily indicative of low HIV prevalence in the community, nor does it necessarily suggest that there is no need for palliative care amongst HIV-positive patients in this community. It may simply be related to the segregation of the ARV services. There is an ARV clinic in the CHC, separate from the rest of the clinic, with a separate serving hatch at the pharmacy. Each HIV-positive patient receiving treatment has a separate folder in the CHC, which is kept in the ARV clinic. This segregation could possibly perpetuate the stigma of HIV infection. It may be that the staff in the ARV clinic did not refer patients. Saint Luke's Hospice in Mitchells Plain offered an inpatient unit for HIV positive people, at the time of the study. That service may have been

more readily utilised by the ARV clinic than this programme was, and the Saint Luke's Hospice unit may have provided sufficient palliative care for the ARV clinic patients.

Family Carers:

Most patients who participated in this study had a family caregiver. Only four patients did not want their family involved, or lived on their own. One of the four who did not have a caregiver did live with his family, but, because his family did not want to be involved, he asked that they not be contacted. Initially he did not consent to participating, because of his family. He later came back and asked to join the programme, without the involvement of his family. Perhaps, if the programme had been in place for a longer period of time, the palliative care team could have reached out to his family.

Most family carers were female and they were, in general, younger than the mean age of the participants. The biggest group of family carers consisted of spouses and then children of the ill participant. This corresponds with the literature on carers^{36,76}. Burton *et al.* reported that, of the caregivers they had studied, 81% were female and 56.8% were spouses or partners of the patient³⁶.

Ninety-one percent of the patients who participated in this study had a family carer. This indicated that there was a high prevalence of families that are caring for ill family members. Although, from these data, it may be concluded that patients were receiving care, there was no indication of the level of care they were receiving, nor was there an indication of whether or not the family was coping with caring for this patient. More information is needed to determine whether or not the families in this community are able to take care of their own family members who are ill. Future research could investigate this.

Frequency of visits to healthcare facilities:

When the objectives of this study were being formulated, it was hypothesised that, with a palliative care programme in place, there may be a significant difference in the number of visits made to the clinic or hospital by patients. Given that no participants participated completely in the intervention, this hypothesis could not be tested through statistical analysis.

However, the initial set of data collected was used to assess what happens when there is no palliative care programme in place. Considering the set of data that was collected and presented in tables 3 to 6, one can appreciate the number of times participants did attend healthcare facilities with no programme in place. If we take into account the attrition rate of

the participants in this study (43.9%), it is not surprising that the participants continued to visit the clinic and referral hospitals as they neared the end of their lives and became more severely ill. The data indicate that, with no programme in place, a significant number of patients in need of palliative care visit the health care facility, outside of routine appointments. The fact that there is an increased number of patients admitted to hospital in the twelve months prior to dying from a chronic illness, is confirmed by the research published by DesRosiers *et al*¹⁹.

Prior to the initiation of the programme which is the focus of this study, more than half (56.52%) of the participants had been admitted to hospital in the preceding six months. This result is far lower than what DesRosiers *et al*, reported¹⁹. DesRosiers *et al*, found that 97.9% of their control group had at least one hospital admission in the twelve months preceding their death¹⁹. The time period of DesRoseirs *et al.*'s study (i.e. twelve months), is double the time period of this study¹⁹. DesRosiers *et al.*'s study used a control group comprising of people who had died, from a chronic illness and who would have qualified for palliative care, at the hospital in the twelve months prior to the start of the intervention¹⁹. This forms another bias for hospital admissions in the twelve months prior to their death, as the population from which they drew their sample, was that of hospital patients, their inclusion criteria was that of people who had died from a chronic illness, in hospital.

Seven of the 46 participants had out-patient appointments at GSH, which is highly appropriate, when they have serious illnesses and GSH, although a tertiary hospital, acted as a secondary level hospital for MPCHC at this time. Ideally, this kind of programme would have incorporated communication with GSH, as well as other healthcare facilities that patients may access care in, at the primary care level. This communication would aim to provide continuity of care between facilities. This communication was not set up, as it was intended that the programme would only run for a few months, so it was felt that networking may lead to false hope amongst the patients and staff; and would take more time and human resources to set up, than were available as part of this initiative.

More than two-thirds of the participants had visited the emergency unit in the preceding six months. Such visits imply urgent problems or deterioration in health that the patient and or family could not cope with. This does not necessarily mean afterhours care, but un-booked visits to the clinic in which the patient was triaged as being moderately to severely ill. Although the mean number of visits was two, the maximum number of visits for one person was nine. That is more than once a month, and this figure excludes their routine visits, which are scheduled to take place every three months.

As the participants in this study were clients at the CHC and accessed healthcare there, they would be expected to be visiting the CHC for routine medical care, so the fact that they all attended the facility at some point in the preceding six months is not surprising. Some were quite ill and so could have been seen almost monthly, as is shown by the highest number of visits (five). Ideally, in palliative care, ill patients would be seen a few times a week⁷⁷. Some of the patients in this study may have been accessing palliative healthcare through St Luke's Hospice or through the home-based care organisations, both of which worked in the community at the time of this study. No attendance statistics were obtained to allow investigation of these possibilities. Analysis of the data relating to the frequency with which patients accessed care at the CHC did not yield surprising results and merely helped to provide a clearer the picture of needs of the study participants.

Analysis of the frequency of patient visits to the CHC or to GSH, after recruitment to the programme, indicates that there was a reduction in the frequency of visits per patient, with the maximum visits being 3 (to the emergency room at MP CHC). This difference might be due to the time difference. Prior to the recruitment to the programme, visits over a six-month period were considered. After enrolment in the programme, consideration was given to visits from the time of recruitment until the end of the programme or until a patient died. For some patients, this might have been the entire duration of the programme (six months), while for others the time period in question was considerably shorter. It is possible that the intervention made a difference to the patients, resulting in the patient feeling more able to deal with their illness, the patient and family having realistic expectations with regard to their health and the family having more confidence in caring for their loved one. However, this can only be surmised and no concrete statistically significant conclusions can be drawn, because Group B did not participate in the intervention. It would have been more useful to report on frequency of visits rather than merely number of visits, in order to eliminate the problem of different periods of time for each participant.

Comparison of Group A and Group B:

The patients in Groups A and B were not statistically significantly different in gender, age range, diagnoses, presence (or absence) of a family carer, the relationship of the family carer (to the patient) and the gender of the family carer ($p > 0.05$ in each case). However, the major difference in the demographics was between the attrition rates. In Group B, 66.67% of the patients died during the study, compared to only 20.00% in Group A. This difference is statistically significant ($p < 0.05$). This could imply that the participants recruited to Group B were possibly more ill than those in Group A and closer to the end of their life. The

reason for this could be a difference in referral patterns in the second half of the programme, which may have led to referral of people who were more ill. It is easier to deem patients to be in need of palliative care when they are very near the end of their life. It is more difficult when they may be in need of palliative care, but still have a few months to live.^{38,39,78,79}

No assessment was made of the participants' abilities to perform activities associated with daily living, which could have served as an indication of how ill patients were. This could have been done using an instrument such as the Karnofsky performance status scale⁸⁰. In retrospect, it cannot be determined whether or not there was a statistically significant difference between the two groups, as far as the severity of illness of the patients was concerned, during the respective periods of recruitment. This is a limitation of the study and could be incorporated into future studies of this nature.

It is important to note that the primary researcher in this study was present in the clinic, working as a doctor in the clinic, for the first two-and-a-half months of the programme. The doctor left the clinic at the beginning of the recruitment for Group B, because she was deployed to another clinic. This may have had an impact on the differences between the two groups of patients. For example, the absence of the researcher meant that there was no clinician to remind colleagues to refer patients to the programme and the researcher was not on hand to answer questions relating to the suitability of prospective patients for referral to the programme.

Very few participants (three) in Group B saw the doctor as part of the programme. This would have meant an extra visit to the clinic, soon after being recruited to the programme. They had seen a clinician on the day they were referred to the programme and would have been given a routine follow up appointment in the six months which followed. After recruitment, they were asked if they would like to see a doctor again, in the next few weeks, to explain more of the details of their illness and their prognosis. They did not want to come back to see the doctor so soon. Some stated that they would be happy to see this doctor at their next appointment, between one and three months later, but not before that. For some participants, it would have been difficult to get transport back to the clinic so soon after the visit at which they were referred to the programme.

As stated above, it was only at the consultation with the doctor, as part of the intervention, that we explained to them that their chronic illness had become life threatening. In the other palliative care programmes in Cape Town (*viz.*, Abundant Life and St Luke's Hospice), patients are happy to meet with a clinician to optimise their care, when they understand what their prognosis is, prior to joining the programme. If this study had been structured differently, with patients being informed, from the outset, that they were now in need of

palliative care and were near the end of their life, then the responses from the patients, with regard to the intervention, may have been significantly different. This procedure was not followed, given that the researcher was attempting to obtain an accurate indication of the baseline level of patient-reported outcomes before patients had joined a palliative care programme. It was decided that the referring clinicians should continue their normal consultation and identify patients suitable for referral, but not take responsibility for informing the patients that they were terminally ill and in need of palliative care. The researcher did not want to increase the workload of the clinicians by asking them to “break the bad news” of the patients’ poor prognoses. It was felt that the procedure adopted in this study may result in greater numbers of patients being referred to the programme by the clinicians. It should be noted that it is good clinical practise, as a medical doctor, to inform a person of their prognosis and what their future holds for them⁸¹. However, this is not necessarily a medical doctor’s routine practice and the researcher did not want to interfere with the referring clinicians’ consultations, while attempting to obtain information on the current care of terminally ill patients in the CHC, prior to an intervention. The researcher did not advise medical doctors to change their approach, if it was already routine practice for them to advise a patient on their poor prognosis and assist them to plan for the future. If clinicians, who were not in the habit of informing terminally ill patients of their prognosis, had been asked to “break the bad news” to the patients, this may have been a barrier, inhibiting referral to the programme. It is worth noting that most clinicians (except the researcher and the Family Physician in the clinic) did not know any criteria for initiating palliative care and readily acknowledged that they did not know when to start palliative care, nor how to initiate it. In South Africa, it has only been in recent years that the theory underlying palliative care has been taught in medical schools as part of undergraduate curricula¹⁶. Thus many doctors and nurses currently administering healthcare in South Africa were not exposed to palliative care per se, during their training and they do not know how to change from providing preventative and curative care to providing palliative care. Therefore, this transition tends to be abrupt and ends up becoming a case of “breaking bad news” compared to a gradual introduction of information and preparation that a patient’s chronic disease could cause their life to be shortened significantly. The act of “breaking the bad news” often becomes a barrier, with healthcare professional avoiding the issue and thus preventing or delaying the implementation of good palliative care timeously⁷⁵. “Breaking bad news” was not an objective in this study, so it was not addressed.

Attrition comparisons:

A comparison of the number of deaths amongst the patients assigned to each of the two study groups revealed that Group B experienced a higher attrition rate during the first half of the period following the initiation of the recruitment process, compared to the equivalent period for Group A. This suggests that the Group B participants, as a whole, were more severely ill at the time they were referred to the programme. As a group, the patients assigned to group A appear to have been referred earlier in their respective disease trajectories. Part of the rationale of palliative care is to prepare patients for death and offer support to them as they near the end of their lives. The effectiveness of such interventions is limited if they are initiated when patients are too close to the end of their lives. In the context of this study, this issue may have had an impact on participants and their families not wanting to come to another doctor's appointment or attend meetings of the support group. If patients knew they were dying, then making extra visits to the CHC might have seemed pointless. And if patients did not know that they were dying, they would not have understood the need for assistance and support in their last few weeks of life.

It is not clear to what extent the clinicians may have had trouble identifying patients in need of palliative care. This question was not asked of the clinicians, directly. It could be surmised that the clinicians became better at identifying people closer to the end of their life, as the programme progressed. This could be surmised by the lack of patients dying early in group A and could explain the difference in attrition between the two groups. This difficulty clinicians experience, is reported in the literature and models have been formulated to attempt to address this problem⁵⁰. More could have been done to address this potential problem and assist clinicians in identifying patients earlier in their disease progression.

In palliative care research it is expected that there will be a certain attrition rate, as the participants are all nearing the end of their life⁸². Attrition rates vary between studies and cannot easily be predicted. For example, Francis *et al.* reported an attrition rate of 32%, over an eight-month period in patients with Kaposi Sarcoma⁷¹ and Temel *et al.* reported a 70% attrition rate, over a twelve-month period, in patients with metastatic small cell lung cancer⁵³.

Visit to the doctor:

Approximately two-thirds (70%) of Group A participants attended a consultation with a doctor after the collection of their APCA African POS data. The fact that such a significant number of the patients took advantage of this opportunity may be due to the fact that their interest in this programme was piqued by the APCA African POS. This response from Group A patients may also have stemmed from the fact that they had established a

relationship with the coordinator over the 6 weeks of data collection. Alternatively, the fact that they were given more notice about seeing the doctor and could make the necessary arrangements, may have led to this positive response.

By comparison, only three (14.29%) of the Group B participants attended the doctor's consultation. Another four attended a consultation at the end of the study. Unfortunately no APCA African POS results were collected from these four participants, after their visit to the doctor.

Comparison of APCA African POS results between Group A and Group B:

Comparison of the APCA African POS data sets for the two groups of patients shows that the patients in Group B reported experience more pain overall compared to those in Group A. Given that more than half of Group B participants then died within the three weeks which followed the collection of the data, this difference may be understandable and to be expected. With regard to the responses on symptoms, the difference between the two groups was statistically significant. Patients in Group B reported more symptoms than patients in Group A. Again this trend may be linked to the fact that more than half of Group B then died within the three weeks which followed the collection of the data. As a person nears the end of their life it is to be expected that their health will deteriorate and they may exhibit more symptoms of disease. Considering the question on feelings of worth, there was a significant reduction in feelings of worth for those who were sicker and nearer to the end of their lives. The last question for which the data showed significant difference between the two groups related to confidence. The question asked of the family was, "How confident does the family feel in caring for [the patient]?". The data collected indicate a significant difference in the confidence levels of the families, in caring for their loved ones. The families caring for a person who was more severely ill were less confident. This result may be expected from people who have little medical experience, as in the case of families who are caring for loved ones who are dying. This emphasises the importance of home-based care organisations and home visits by an experienced healthcare worker, to equip the family to cope, as well as offering practical assistance and emotional support to the family, especially in the final weeks of a loved one's life. The data showed that the differences in the other responses from the two groups were not statistically significant.

Comparison between participants who died during the study and those that did not:

Statistical analysis of the initial APCA African POS results (i.e. the data captured at the outset) for each group of patients showed that there were significant differences between the responses reported by those patients who died during the study and those who survived the study. Therefore the APCA African POS results were divided into two groups, based on whether they belonged to a patient who had died or a patient who had survived, and subsequently analysed in more detail.

Comparison of the set of data collected from those patient who later died (during the study) with the set of data collected from those who survived, indicated that there were significant differences between the responses relating to “pain”, “worry”, “worth” and “information”. This differs from the comparison between Group A and Group B at week zero, where the results relating to “pain”, “symptoms”, “worth” and “confidence” were statistically significantly different. These results suggest that “pain” and “worth” warrant serious consideration in palliative care, as these are areas that are highlighted as problem areas for people who are nearing the end of their life. Considering all the questions that were asked of the patients, it may be surprising that there was not a significant difference in the responses to more of the questions from people who are very ill, compared to those who were not as severely ill. This issue may be worth considering in more detail future studies.

Analysis of the number of patients who died before and after three completed weeks of involvement in the study, showed that there were statistically significant differences ($p < 0.05$), but when the APCA African POS results for the two groups were compared, there was only one question for which the responses were statistically significant different. The question of interest relates to “information”, where the family carer was asked if the family received enough information about the patient’s illness. One reason for the lack of significant differences in the responses to the other questions could be the small number of responses that were analysed, as the groups were so small. The number of patients that died before three completed weeks is 13 and after three completed weeks are five, this number are too small to analyse appropriately. It is difficult to get statistically significant differences if sample size is too small⁷⁴. The difference in the responses to the question on “information” may have been due to the fact that the family member answering the APCA African POS questions was not present when the patient was told that they had a life-threatening illness. However, it is unlikely that this was an issue. Only three participants had more APCA African POS questions asked of them after their visit to the doctor. It should be noted that the consultation with the doctor was meant to be in the format of a family conference, though there were no data on exactly who was present for the doctor’s consultation. It has already been stated that, where chronic diseases are concerned, it is difficult to predict the trajectory

and end point. So whether a person is going to die in the next three weeks or the next six weeks, the response could still be the same as those for a patient who is likely to die in the next few months. This is evident in the results, as there are few responses that are statistically significantly different for those patient who were closer to dying than those who were not.

Comparison of APCA African POS between different diagnoses:

In comparing the responses to questions on the APCA African POS, across disease categories, the only statistical significant difference was for the question on “symptoms” and, within that question, the difference was between the group of patients with cancer and the group of patients with multiple co-morbidities. The results show that cancer patients reported more severe symptoms than patients with multiple co-morbidities, which included patients with cancer. Amongst the patients with multiple co-morbidities, it was not determined which disease was their biggest concern or debilitating factor. This confirms what we already know, that cancer has a high symptom burden and patients with cancer are particularly in need of palliative care.

Cross section time regression analysis of whole cohort:

The entire cohort of patients was analysed together, with cross section time regression analysis, as very few participants had taken part in the intervention by attending the doctor’s consultation and the meetings of the support group, during the collection of the APCA African POS. This analysis provided an indication of the patient-reported outcomes within MPCHC, with no palliative care programme in place. The data provide a good indication of the burden of disease within palliative care. The rationale for having a control group (Group A) was to compare the impact of the research assistant and weekly contact on participants, with the intervention, which entailed a support group and an in-depth consultation with the doctor. However, as there were only three patients from Group B who took part in any part of the intervention, the comparison was not possible.

There was no significant change over time with regard to the responses to the questions on “pain”, “sharing”, “worth”, “peace”, “planning”, “information”, “confidence” and “worry”. During the collection of the APCA African POS, only the three participants who attended the doctor’s consultation would have been told that their chronic illness was no longer curable and that they were now dealing with a life-threatening illness. The bulk of the cohort did not know for certain that their disease was no longer curable and that it was now life-threatening,

though it may be assumed that they were aware that this could be the case. Being able to share thoughts with their families, feeling their life was worthwhile, having peace and planning for the future, are related to knowing they were dealing with a life-threatening illness. These aspects may have changed had they been told that they were in fact dealing with a life threatening illness.

The responses to the questions asked of the families showed no statistical significance with regard to “information about the patient”, “confidence in caring for the patient” nor “worry over the patient”. Although there was no difference over time in the response to the question on “confidence”, overall the data suggest that families had confidence in caring for their dying loved one from the beginning and that did not change. This is a positive attribute for this community: they have confidence in caring for ill people. This may be because they accept and embrace death and dying are a part of their lives.

The responses to the question on “symptoms” did show a significant difference ($p < 0.05$). The burden of symptoms changed over time. Initially there was an increase in the score attributed to symptoms, from week zero to week one, then the reported scores dropped again in week two, and increased once again in week 6. This could be related to the patients’ initial realisation that there was something wrong with them and more reporting of symptoms, before returning to a lower score. The responses to the question on “worry” showed a significant difference in reported scores with the passing of time ($p < 0.05$). The patients became more worried as time progressed, with no palliative care programme in place. Defilippi and Cameron showed that with better palliative care in place, patient’s worry was reduced⁶⁴. It is possible that the fact that we are asking these questions may have alerted patients to the fact that there was a problem and this increased their worry.

When conducting research, there is a possibility that the presence of a research assistant and the process of answering questions from a scale or tool would have an impact on the outcomes reported by patients who were not involved in an intervention. However, the APCA African POS has been validated for this problem and found to have a very low impact on changing the participant’s reported outcomes. When initiating this study, the aim was to implement a programme for people facing the end of their life and evaluate the impact of that programme. A control group was needed to compare the impact of answering the APCA African POS questions and the presence of the research assistant, to the intervention, which included a support group and an in-depth consultation with a doctor. The results for the cross section time dependent regression analysis in this study, for the whole cohort support the validation of the APCA African POS, indicating that there is little change over time with no intervention in place.

Cross section time regression analysis participants who attended the doctor's consultation:

The APCA African POS responses of the three participants who attended the doctors' consultation were analysed at week zero and in the week after the doctor's visit. Although there were only 3 participants to analyse and this is a very poor sample size, the researcher felt it was important to report the findings. The only statistically significant response was the change in the scores for the question on "worry" ($p < 0.001$). The results of the analysis implied that, after the consultation, the level of "worry" reported by the patients increased. The philosophy of palliative care does advocate merely a single consultation with the doctor, but rather continuity of care. So, after one visit to the doctor, the participant may have felt more worried about the future, but with ongoing support, this worry by reasonably be expected to improve. This data collected during this study does not allow this issue to be investigated in any detail. An attempt to provide better continuity of care could form the basis for promoting the establishment of and support a programme that would run for much longer than six months. Although the responses to the question on "worry" were the only statistically significant responses, Figure 4 shows the range of scores graphically and there are differences in almost all questions. But given the sample size ($n = 3$), statistical analysis is effectively meaningless.

Defilippi and Cameron published a study, which aimed at supporting home-based carers (HBC) and providing ongoing training of the HBC, with the aim of improving patient outcomes⁶⁴. They used the APCA African POS to evaluate the patients' responses to the improved training of the carers. The difference in their study, compared to this study, was that, each time the APCA African POS was applied, it coincided with a home visit from the HBC and interaction with her/him. Their results showed that, over a period of six visits from the HBC, there was improvement in the responses to all ten questions. The responses to the questions on "symptoms" reduced gradually and the responses to all other questions increased, all showing an improvement with each visit. In the study which is the focus of this research report, the patient only saw the clinician once, not six times. The results reported by Defilippi and Cameron suggest that, with continued care, patient-reported outcomes may improve.⁶⁴

There was no clinical assessment of how ill a person was at any point in this programme. That was not included in the protocol, but could have been helpful in allowing deeper analysis of the data collected from patients. This data could have been used to determine the correlation between the clinical assessment of the patient and the responses to the APCA

African POS questions relating to “symptoms” and “pain”. Knowing if a person is bed bound or able to complete their personal activities of daily living, might have been helpful. This is an oversight in this study and could have been incorporated by the research assistant with each collection of APCA African POS data.

It has been mentioned that the primary researcher was present at the clinic, working as a doctor, for the first two and a half months of the programme. During this time it was noted that staff were reminded about the programme when they saw the researcher and remembered patients that they needed to refer. It is unclear whether the subsequent departure of the researcher and her absence during the remainder of the programme had an impact on referral to the programme. It is suspected that the lack of daily reminders to clinicians and constant encouragement to refer patients to the programme early in their disease trajectories could have impacted on referrals.

Limitations of the study:

As discussed above, many of the participants in Group B, the intervention group, were more severely ill and died sooner after recruitment than participants in Group A. There were some factors that seemed to limit the recruitment to this study and have implications on the outcome of this study. The first limitation is that referrals to the study were not consistent throughout the duration of the study. The researcher believes the participants who were referred later in the programme were more severely ill, impacting on the attrition rate and thus outcomes of the study. It is possible that the clinicians had difficulty in identifying patients to refer to the programme and required more assistance in this initial process of identification of participants. The attrition rate in group B may point to the clinicians becoming better at identifying patients in need of palliative care, but at a later stage in their illness.

There was no objective marker of how ill a person was, at any point in the programme. In hindsight, it could have been simple enough to add, into the data collection protocol, a performance score, to assist with assessing the severity of each person’s illness at strategic points in the study. This limits the conclusions that can be drawn about the degree of illness in the study group.

When comparing admissions to hospital or visits to the CHC prior and after the intervention, it would have been more useful to report the frequency of visits (i.e. number of visits per period of time). This analysis of frequency would have made the results of this study, with regard to hospital admissions or CHC visits, easier to compare to other studies.

The procedure adopted for this study stipulated that participants were not informed by the clinicians that their chronic illness was now life threatening and they were deemed in need of

palliative care. By not informing patients of these facts in the beginning, they did not know the full extent of what was wrong with them and so did not participate in the interventions offered to them. This limited the conclusions that could be drawn from the data.

There was little information on what happened in the doctors' consultation. It is not clear what was discussed and who was present for the consultation. The responses that the family members of the participants gave for some of the APCA African POS questions could have been affected by the consultation with the doctor. This lack of information limits the conclusions we can draw about the responses of the family in the APCA African POS questions.

The most significant limitation in this study is that participants recruited to Group B did not take up the offer of an extra visit to one of the doctors in the clinic and, one reason for this, may have been that they had just been to a clinician on the day of recruitment and could not, or were not, willing to get back to the clinic to see a doctor again too soon. This is one of the reasons given by respondents for not wanting to meet with a clinician, as part of the intervention. This obstacle was not anticipated during the planning phase of this study and actually had a major impact on the study. Without the doctor's consultation, participants could not be invited to join the support group and so very few participants in Group B took part in any part of the intervention. This could be remedied with a study over a longer time period, by modifying the study to include the initial consultation as part of the recruitment and consent process, and by having stricter inclusion and exclusion criteria for the intervention group, such that involvement in the intervention is mandatory.

If this type of programme were a permanent service at a primary health care facility, there would be a need to communicate with other levels of health care facilities which patients at primary care access. This would enable clear communication between health care providers at all levels of care, from home based care organisations up to secondary and tertiary health care facilities. This research study did not create this communication channel, as the researchers was felt that it would take time to create and would lead to false hope, as the study was only planned to run for six months. This created a limitation with regard to how successful such a programme could be for the health system, as a whole.

These are the limitations of this study. Ideas of how to avoid these limitations in future research are found in the recommendations, in chapter six.

Participants Evaluation of the programme:

In our public health system, community health centres are one-stop shops for patients, seeing a clinician, getting procedures done (including routine blood tests and other primary health care procedures, such as pap smears), seeing an Occupational Therapist, Physiotherapist or Dietician. There is also a Social Worker available daily and a Psychiatrist available weekly. However, there is little help in the busy MPCHC, from when a person walks through the door, to when they leave. There is an expectation that the person will know where they have to go at each point in the process of accessing care. Nobody guides them and “shows them the way”. Unfortunately, if they are brave enough to ask for help or guidance, it is often given in a curt manner by medical staff.

They are very likely to see a different person for each aspect of their care, each time they make a visit to the clinic. For a person with a chronic illness, and especially those in need of palliative care, continuity of care is vital⁸¹. For health education and motivational interviewing, building and maintaining rapport with the patient is essential for success, if there is to be an improvement in a patient’s perception of his/her illness. If a patient sees a new clinician at each visit, he/she may always have the same health promotion discussion, being advised, for example, to stop smoking, and he/she never hear that their diet should change in addition to this. In palliative care, continuity of care means building a relationship of trust with a healthcare worker, which may result in improvement in the patient’s symptoms, and allow the patient and his/her family to have questions, which may arise from previous discussions, answered satisfactorily. It is difficult to have such questions answered satisfactorily, if the clinician is new and was not present in the previous discussion, from whence the questions arose. Continuity of care also means that a patient does not need to repeat the story of their disease at each visit. It also prevents a patient from having to repeatedly acknowledge to a stranger that they know they are dying. Continuity of care is an essential element of good palliative care and as it cannot be assured in a CHC, especially in MPCHC, the idea of a palliative care coordinator, who could provide that continuity of care and assist in accessing care, was crucial in the role of the coordinator created for this project.

The coordinator was able to provide the guidance needed by patients in order to navigate the healthcare system in the CHC, assessing care when it was needed and providing continuity of care for participants. The coordinator was able to listen to the participants, when she had time. This act of listening, in a busy clinic where few staff are able to give too much time to an individual patient, was an important part of her work. All people need to be validated as being important and none more so than a person who is dying and possibly feeling that their life is no longer worthwhile. Listening attentively is an important element of caring and making a person feel that they are important.

Ninety-five percent of the participants who answered the evaluation stated that the coordinator was helpful. She listened to them, guided the participants through the clinic and made their clinic visits easier. She organised help for them, when they needed it and, on a practical level, she even got their folders out for them. All respondents wanted her role at the clinic to be continued.

It cannot be ascertained to what degree the coordinator, with her unique set of personality traits, influenced people's perceptions of the study. It is unclear what criteria a suitable candidate for this role would need to meet. The coordinator was empathetic and understood that just listening to a person can bring about improvement in the general wellbeing of that person. The coordinator had been trained as a hospice volunteer and had a number of years of experience working in St Luke's Hospice as a volunteer, visiting and caring for Hospice patients in Mitchells Plain. She knew all the participants' names and was always happy to see them. She got to know the staff at the CHC and gently enquired about how much she could in fact help a patient. She found ways to get folders out, so that a person did not need to get to the clinic at 05H00 and stand in a queue for more than an hour. She found ways to get medication from the pharmacy with minimal waiting, but without seeking special treatment for a select group of people. At times she would sit with a person, to keep them company, while they waited to be seen, not pushing them to the front of the queue, but helping them pass the time. This role was seen as highly beneficial, by the participants. They were unanimous in wanting her to continue.

Evaluation of the visit to the doctor showed the responses to be more positive than negative, with room for improvement. It would be beneficial if there was some continuity of care with the same doctor, as stated above, which may impact on this evaluation. The consultation they had could have been the only time they met with this doctor (before or after this consultation).

The support group was an integral aspect of the intervention within this programme. However, as shown in the results of the study, only members of Group A attended the meetings of the support group, after collection of their APCA African POS data. Group B participants were only invited to the support group, once they had seen the doctor and it was explained to them that they were in need of palliative care. Only three participants in Group B attended the doctor's consultation and none of them attended at least one meeting of the support group. As Group A participants had completed their APCA African POS data collection before attending the meetings of the support group, this evaluation is the only source of feedback we have regarding the benefits of the support group.

Support groups offer a different space for patients and family members to meet other people with similar problems and share their experiences. Where psychological support is concerned, it is often a person who is going through, or has gone through, what one is going through, that offers the most valuable help and support. It was a place for health education, specific for palliative care, to be given, and a place where ideas could be shared.

Although not all respondents had attended a meeting of the support group, all of them wanted it to continue. With regard to the specifics of the meetings of the support group, respondents stated that they wanted them organised monthly at the clinic, in the same venue that had been used during the study. The reasons that participants cited for continuing to attend meetings of the support group included meeting with similar people with similar problems and being able to support each other, as well as receiving input from guest speakers. These were the highlights of the support group. The guest speakers included a palliative care specialist physician, who discussed pain management, a palliative care specialist nursing sister, who talked about practical tips on nursing a terminally ill family member and a palliative care expert spiritual counsellor, who discussed total pain and spiritual pain.

Overall the respondents wanted the whole programme to continue with no changes.

Staff evaluation of the programme:

There was a good representation of all clinical staff in the survey. Most staff members who completed the evaluated form knew about the research programme and most were involved with referring patients to the programme. There were some staff who did not know which patients needed to be referred to the programme and this suggests that on-going training and information may have been needed throughout the programme. One of the responses about time in trauma: "Working in trauma there is little time for interaction with the [patients]", is exactly why the programme should be used, to potentially reduce the time spent with each patient by busy clinicians. Approximately one-third of the staff who completed the evaluation indicated that they had asked the programme coordinator to do other things besides her job. This indicates that she was an asset to the clinic, beyond simply running the palliative care programme.

The responses stated that, for more than two-thirds of staff, the programme had a moderate to large impact on them. The comments reviewed in the results chapter indicate the reasons why the programme had an impact. There was an overwhelming response that the programme should continue. Many medical staff indicated that they would like to be more

involved in the programme. There was a positive response to wanting more information and wanting palliative care training.

There were limitations in the design of this study which, if anticipated, could have been resolved. This may have led to more effective research and greater insights may have been gained. Consideration of the recommendations, which have been made, may allow researchers undertaking similar studies in the future to streamline their investigations. Despite the attrition rate experience in this study, and the low level of involvement in the intervention initiative, the programme was reported as beneficial to both participants and their families and to the staff.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

The aim of this study was to evaluate the patient reported outcomes in Mitchells Plain Community Health Centre prior to an intervention and then to evaluate the impact of the intervention, involving a support group and focused care, for people facing life threatening illnesses. The aim was partially met. We were able to evaluate patient reported outcomes prior to an intervention. Unfortunately, due to the high attrition rate in the intervention group, we were unable to evaluate the impact of the intervention by the same method; that of patient reported outcomes.

The intervention was evaluated by means of patient and staff evaluation forms. The results of the evaluation showed that the patients and family carers found the programme very helpful and unanimously wanted the programme to continue with few changes. The staff evaluation also found the programme very helpful and wanted the programme to continue. There were good points that came out of the staff evaluation that could be useful in running a programme like this in future. The staff wanted more training around palliative care and more involvement in the programme. The lack of involvement from the clinic staff was structured purposefully, so that the programme was less burdensome on staff who are already overworked. However, they should still feel welcome to participate in all programmes in the clinic, if their work allows them to. By including staff in the programme, it would become an integrated part of the clinic, not an isolated programme within the clinic.

The first objective, to determine the prevalence of people with palliative care needs at MPCHC, was not met. Relying on the clinicians to correctly identify all people accessing care at MPCHC who were in need of palliative care and who qualified for palliative care according to the inclusion criteria was not a reliable method of identifying these patients. A more in depth prevalence study is required to meet the first objective.

Some of the objectives set out were met. This study was able to assess the physical, psychological and spiritual concerns of people facing life-threatening illnesses, prior to an intervention, and the extent to which they get admitted to hospital or seek urgent medical attention, prior to an intervention. The patient report outcomes identified that, in MPCHC, pain management and assisting patients in their feelings of worth need be addressed to aid them in their physical and psychological well-being. The responses from the family carer show that there is a good baseline level of confidence in caring for their ill family member. This is a positive protective factor for this community and should be encouraged and nurtured in future work in this community.

The objectives of determining whether or not there is a change in patient reported outcomes or hospital admissions with a programme in place could not be met. This failure to meet

these two objectives was due to the attrition rate and lack of participation in the intervention by the intervention group, Group B.

Recommendations:

- 1) A permanent palliative care programme, based at primary health care facilities, run by a lay person, in contact with a clinician. Providing holistic palliative care and support to patients, families and staff involved with palliative care.
- 2) If a permanent programme is not realistic at present, a study over a longer period of time is recommended. This would allow for time for participants to attend a doctor's consultation, for continuity of care with that doctor and for full participation in the intervention.
- 3) Continuous reminders about criteria for referral to enable people to be referred to the programme (or study) earlier in their disease progression so that the benefit is not only offered within weeks of their death.
- 4) A support group held monthly, in a central venue, as suggested by the participants.
- 5) Palliative care training for the staff at the CHC. The evaluation of the staff showed that they wanted more training and the results from the patient's consultation with the doctor show that there is room to improve the palliative care that is currently practised in the CHC.
- 6) Opportunities for CHC staff to be more involved in the programme, thus integrating it more into the daily running of the CHC.

It would be ideal if a programme like this could be set up permanently and evaluated for impact of the programme. The benefits of this would be a longer time to establish the programme, with more participants and a more extensive programme that networks with referral hospitals and community based organisations involved in palliative care. A permanent programme would allow for continuity of care for participants. In the participant's evaluation of the doctors' visit, the lack of continuity of care can be seen. The analysis of the participants in Group B that did visit the doctor showed increase in worry over time. In only one consultation it is not possible to give information and allay all fears, not giving time for the patient and family time to think about what has been said and to return with questions. This can only happen over a period of time, which was not available in this study. Over a longer period of time it is hypothesised that a programme like this can reduce hospital admissions and length of hospital stay, as the Abundant Life programme has demonstrated¹⁹.

If it is not possible to have a permanent programme, a study over a longer period of time would be better to enable the points above to take place. “Breaking bad news” to participants and assisting them with their illness at recruitment to the programme, would be better. The initial APCA African POS can be used as the control, compared to having a control group.

Through personal communication with one of the members of APCA who has been involved with the development of the APCA African POS, it seems that the research tool does not need to be administered weekly for six weeks (J. Downing, personal communication, 19 September, 2013). Rather, it can be administered four times, with an equal time interval between collection dates. That time period could be a month, a fortnight, a week or less, depending on what is suitable or most convenient for the study at hand and the patient concerned.

Palliative care training for all clinical staff would be beneficial. Initially it was offered to the clinic, but due to other circumstances it was not taken advantage of. If all staff were trained, with improved skills and knowledge, then identifying patients in need of palliative care would be easier for them and “breaking the bad news” would also be less daunting. The training that was offered can still be provided, in discussion with HPCA, if MP CHC staff are still interested in more training.

The desire of both patients and staff is that this programme should continue.

REFERENCES:

1. World Health Organisation. WHO definition of Health. [Online]. 1948 [cited 2014, June 9]. Available from: <http://www.who.int/about/definition/en/print.html>
2. World Health Organisation. WHO Definition of Palliative Care. [Online]. 1998 [cited 2014, June 9]. Available from: <http://www.who.int/cancer/palliative/definition/en/>
3. European Association for Palliative Care. Definition of Palliative Care. [Online]. 1998 [cited 2014, June 9]. Available from: <http://www.eapcnet.eu/Corporate/AbouttheEAPC/Definitionandaims.aspx>
4. Lozano, R. et al. Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet*. 2012;380(9859):2095–2128.
5. Clark, D, Wright, M, Hunt, J, Lynch, T. Hospice and palliative care development in Africa: a multi-method review of services and experiences. *Journal of Pain and Symptom Management*. 2007;33(6):698–710.
6. Joint United Nations programme on HIV/AIDS (UNAIDS). Global Report: UNAIDS report on Global AIDS epidemic 2013. [Online]. 2013 [cited 2014, June 9]. Available from: http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/unaids_global_report_2013_en.pdf
7. Bradshaw, D, Pilay-Van Wyk, V, Laubscher, R, Nojilana, B, Groenewald, P, Nannan, N, Metcalf, C. Cause of death statistics for South Africa : Challenges and possibilities for improvement. MRC Burden of Disease Research Unit. [Online]. 2010 [cited 2014, June 9]. Available from: http://www.mrc.ac.za/bod/cause_death_statsSA.pdf
8. Groenewald, P, Bradshaw, D, Msemburi, W, Neetheling, I, Matzopoulos, R, Naledi, T, Daniels, J, Dombo, M. Western Cape Mortality Profile 2009. Cape Town. South African Medical Research Council. [Online]. 2012 [cited 2014, June 9]. Available from: <http://www.mrc.ac.za/bod/WesternCapeMortalityProfile2009.pdf>
9. Groenewald, P, Bradshaw, D, Daniels, J, Matzopoulos, R, Bourne, D, Blease, D, Znyaktira, N, Naledi, T. Cause of death and premature mortality in Cape Town, 2001 - 2006. Cape Town. South African Medical Research Council. [Online]. 2008 [cited 2014, June 9]. Available from: http://www.mrc.ac.za/bod/premort_cpt.pdf

10. Sebuyira, L M, Mwangi-powell, F, Pereira, J, Spence, C. The Cape Town Palliative Care Declaration: Home-Grown Solutions for Sub-Saharan Africa. *Journal of Pain and Symptom Management*. 2003;6(3):341–343.
11. National Hospice and Palliative Care Associations. The Korea Declaration. Report of the second global summit of National Hospice and Palliative Care Associations, Seoul, Korea, 2005. [Online]. 2005 [cited 2014, June 9]. Available from: http://www.eolc-observatory.net/global/pdf/NHPCA_2.pdf
12. International Association for Hospice and Palliative Care. The declaration of Venice and Support Palliative Care Research in Developing Countries, 2006. [Online]. 2006 [cited 2014, June 9]. Available from: <http://hospicecare.com/about-iahpc/contributions/venice-declaration/english-declaration/>
13. World Health Organisation. Strengthening of palliative care as a component of integrated treatment within the continuum of care. [Online]. 2014 [cited 2014, June 9]. Available from: http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_R7-en.pdf
14. Clark, D, Wright, M. The international observatory on end of life care: a global view of palliative care development. *Journal of Pain and Symptom Management*. 2007;33(5):542–546.
15. Lynch, T, Clark, D, Connor, SR. Mapping levels of palliative care development : a global update 2011. World wide palliative care alliance. [Online]. 2011 [cited 2014, June 9]. Available from: <http://www.thewpca.org/EasySiteWeb/GatewayLink.aspx?allId=89788>
16. Gwyther, E. South Africa: the status of palliative care. *Journal of Pain and Symptom Management*. 2002;24(2):236–238.
17. Harding, R, Higginson, IJ. Palliative care in sub-Saharan Africa. *Lancet*. 2003; 365(9475):1971–1977.
18. The Gold Standards Framework. Overview of The National Gold Standards Framework Centre. [Online]. 2010 [cited 2014, June 9]. Available from: <http://www.goldstandardsframework.org.uk/Resources/GoldStandardsFramework/PDFDocuments/TheNationalGSFCentreOverviewv22.pdf>

19. DesRosiers, T, Cupido, C, Pitout, E, van Niekerk, L, Badri, M, Gwyther, L, Harding, R. A Hospital-Based Palliative Care Service for Patients With Advanced Organ Failure in Sub-Saharan Africa Reduces Admissions and Increases Home Death Rates. *Journal of Pain and Symptom Management*. 2014;47(4):786-792.
20. Intermediate Care Policy Framework. Cape Town: Westren Cape Department of Health; 2012.
21. Kuwani, B, Gwyther, L. Hospice Palliative Care Association of South Africa: annual report, 2013. Hospice Palliative Care Association of South Africa. [Online]. 2013 [cited 2014, June 9]. Available from: <http://www.hospicepalliativecaresa.co.za/pdf/General/hpca-annual-report-2013.pdf>
22. Volmink, J, Dare, L. Addressing inequalities in research capacity in Africa. *British Medical Journal*. 2005;331(7519):705–706.
23. Van Niekerk, L, Raubenheimer, P J. A point-prevalence survey of public hospital inpatients with palliative care needs in Cape Town , South Africa. *South African Medical Journal*. 2014;104(2):2012–2015.
24. Hearn, J, Higginson, I J. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Quality in Health Care*. 1999;8: 219–227.
25. Harding, R, Selman, L, Agupio, G, Dinat, N, Downing, J, Gwyther, L, Mashao, T, Mmoledi, K, Moll, T, Sebuyira, LM, Panjatovic, B, Higginson, IJ. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. *Health and Quality of Life Outcomes*. 2010; 8(1):10 (2010).
26. Harding, R, Powell, RA, Downing, J, Connor, SR, Mwangi-Powell, F, Defilippi, K, Cameron, S, Garanganga, E, Kikule, E, Alexander, C. Generating an African palliative care evidence base: the context, need, challenges, and strategies. *Journal of Pain and Symptom Management*. 2008; 36(3):304–309.
27. 2011 Census - Mitchells Plain Profile (December 2012). Compiled by Strategic development Information and GIS Department, City of Cape Town, using 2011 Census data, supplied by Statistics South Africa. [Online]. 2012 [cited 2014, June 9]. Available from: https://www.capetown.gov.za/en/stats/2011CensusSuburbs/2011_Census_CT_Suburb_Mitchells_Plain_Profile.pdf

28. Brooksbank, M. Palliative care: Where have we come from and where are we going? *Pain*. 2009;144(3):233–235.
29. Higginson, IJ. It would be NICE to have more evidence? *Palliative Medicine*. 2004;18:85–87.
30. Clarke, A, Seymour, J. “At the foot of a very long ladder”: discussing the end of life with older people and informal caregivers. *Journal of Pain and Symptom Management*. 2010;40(6):857–869.
31. Arber, S, Vandrevalla, T, Daly, T, Hampson, S. Understanding gender differences in older people’s attitudes towards life-prolonging medical technologies. *Journal of Aging Studies*. 2008;22(4):366–375.
32. Gott, M, Seymour, J, Bellamy, G, Clark, D, Ahmedzai, SH. Older people’s views about home as a place of care at the end of life. *Palliative Medicine*. 2004;18:460–467.
33. Malhotra, C, Chan, A, Do, Y K, Malhotra, R, Goh, C. Good end-of-life care: perspectives of middle-aged and older Singaporeans. *Journal of Pain and Symptom Management*. 2012;44(2):252–263.
34. Pierson, CM, Curtis, JR, Patrick, DL. A good death: a qualitative study of patients with advanced AIDS. *AIDS Care*. 2002;14(5):587–598.
35. Downing, J, Gomes, B, Gikaara, N, Munene, G, Daveson, BA, Powell, RA, Mwangi-powell, FN, Higginson, IJ, Harding, R. Public preferences and priorities for end-of-life care in Kenya : a population-based street survey. *BMC Palliative Care*. 2014;13(1):1–9.
36. Burton, AM, Sautter, JM, Tulsky, JA, Lindquist, JH, Hays, JC, Olsen, MK, Zimmerman, SI, Steinhauser, KE. Burden and well-being among a diverse sample of cancer, congestive heart failure, and chronic obstructive pulmonary disease caregivers. *Journal of Pain and Symptom Management*. 2012;44(3):410–420.
37. Kheirbek, RE, Alemi, F, Citron, BA, Afaq, MA, Wu, H, Fletcher, RD. Trajectory of Illness for Patients with Congestive Heart Failure. *Journal of Palliative Medicine*. 2013;16(5):478–484.
38. Gott, M, Barnes, S, Parker, C, Payne, S, Seamark, D, Garibaala, S, Small, N. Dying trajectories in heart failure. *Palliative Medicine*. 2007;21:95–99.

39. Pinnock, H, Kendall, M, Murray, SA, Worth, A, Levack, P, Porter, M, MacNee, W, Sheikh, A. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *British Medical Journal*. 2011;342: d142.
40. Thomas, K. The GSF prognostic indicator guidance 4th Edition. Gold Stand. Framework Centre in End Life Care CIC. [Online]. 2011 [cited 2014, June 9]. Available from: http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General_Files/Prognostic_Indicator_Guidance_October_2011.pdf
41. Payne, S, Burton, C, Addington-hall, J, Jones, A. End-of-life issues in acute stroke care : a qualitative study of the experiences and preferences of patients and families. *Palliative Medicine*. 2010;24(2):146–153.
42. Gilbar, O, Or-Han, K, Plivazky, N. Mental adjustment, coping strategies, and psychological distress among end-stage renal disease patients. *Journal of Psychosomatic Research*. 2005;58(6):471–476.
43. Steinhäuser, KE, Arnold, RM, Olsen, MK, Lindquist, J, Hays, J, Wood, LL, Burton, AM, Tulsky, JA. Comparing three life-limiting diseases: does diagnosis matter or is sick, sick? *Journal of Pain and Symptom Management*. 2011;42(3):331–341.
44. Garlo, K, O’Leary, JR, Van Ness, PH, Fried, TR. Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatrics Society*. 2010;58(12):2315–2322.
45. Seymour, J, Gott, M, Bellamy, G, Ahmedzai, SH, Clark, D. Planning for the end of life: the views of older people about advance care statements. *Social Science and Medicine*. 2004;59(1):57–68.
46. Lloyd-Williams, M, Kennedy, V, Sixsmith, A, Sixsmith, J. The end of life: a qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. *Journal of Pain and Symptom Management*. 2007;34(1):60–66.
47. Stanford, J, Sandberg, DM. Conversations Worth Having : The Perceived Relevance of Advance Care Planning among Teachers , Hospice Staff , and Pastors. *Journal of Palliative Medicine*. 2013;16(7):762-767.
48. Bull, A, Mash, B. Advance directives or living wills: reflections of general practitioners and frail care coordinators in a small town in KwaZulu-Natal. *South African Family Practice*. 2012;54(6):507–512.

49. McMahan, RD, Knight, SJ, Fried, TR, Sudore, RL. Advance Care Planning Beyond Advance Directives: Perspectives From Patients and Surrogates. *Journal of Pain and Symptom Management*. 2013;46(3):355-365.
50. Glare, P. Predicting and communicating prognosis in palliative care. *British Medical Journal*. 2011;343:d5171.
51. Gwilliam, B, Keeley, V, Todd, C, Gittins, M, Roberts, C, Kelly, L, Barclay, S, Stone, PC. Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *British Medical Journal*. 2011;343:d4920.
52. Francke, AL, Kerkstra, A. Palliative care services in The Netherlands: a descriptive study. *Patient Education and Counselling*. 2000;41(1):23–33.
53. Temel, JS, Greer, JA, Muzikansky, A, Gallagher, ER, Admane, S, Jackson, VA, Dahlin, CM, Blinderman, CD, Jacobsen, J, Pirl, WF, Billings, JA, Lynch, TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine*. 2010;363(8):733–742.
54. Hanratty, B, Holmes, L, Lowson, E, Grande, G, Addington-Hall, J, Payne, S, Seymour, J. Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study. *Journal of Pain and Symptom Management*. 2012;44(1):74–83.
55. Hongoro, C, Dinat, N. A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa. *Journal of Pain and Symptom Management*. 2011;41(6):1015–1024.
56. Elliott, BA, Gessert, CE, Larson, P, Russ, TE. Religious beliefs and practices in end-stage renal disease: implications for clinicians. *Journal of Pain Symptom Management*. 2012;44(3):400–409.
57. Cobb, M, Dowrick, C, Lloyd-Williams, M. What can we learn about the spiritual needs of palliative care patients from the research literature? *Journal of Pain and Symptom Management*. 2012;43(6):1105–1119.
58. Grant, M, Cavanagh, A, Yorke, J. The impact of caring for those with chronic obstructive pulmonary disease (COPD) on carers' psychological well-being: a narrative review. *International Journal of Nursing Studies*. 2012;49(11):1459–1471.

59. Wright, AA, Zhang, B, Ray, A, Mack, JW, Trice, E, Balboni, T, Mitchell, SL, Jackson, VA, Block, SD, Maciejewski, PK, Prigerson, HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Journal of the American Medical Association*. 2008;300(14):1665–1673.
60. Harding, R, Higginson, IJ. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*. 2003;17(1):63–74.
61. Streid, J, Harding, R, Agupio, G, Dinat, N, Downing, J, Gwyther, L, Ikin, B, Mashao, T, Mmoledi, K, Moll, AP, Sebuyria, LM, Higginson, IJ, Selman, L. Stressors and resources of caregivers of patients with incurable progressive illness in Sub-Saharan Africa. *Qualitative Health Research*. 2014;24(3):317-328.
62. Di Sorbo, PG, Chifamba, DD, Mastrojohn, J, Sisimayi, CN, Williams, SH. The Zimbabwe Rural Palliative Care Initiative: PCI-Z. *Journal of Pain and Symptom Management*. 2010;40(1):19–22.
63. Selman, LE, Higginson, IJ, Agupio, G, Dinat, N, Downing, J, Gwyther, L, Mashao, T, Mmoledi, K, Moll, T, Sebuyira, LM, Ikin, B, Harding, R. Quality of life among patients receiving palliative care in South Africa and Uganda : a multi-centred study. *Health Quality of Life Outcomes*. 2011;9(21):1–15.
64. Defilippi, KM, Cameron, S. Expanding the reach of palliative care to community-based home care programs. *Journal Pain and Symptom Management*. 2010;40(1):3–5.
65. Uys, L, Hensher, M. The cost of Home-Based Terminal Care for People with AIDS in South Africa. *South African Medical Journal*. 2002;92(8):624–628.
66. Bausewein, C, Simon, ST, Benalia, H, Downing, J, Mwangi-Powell, FN, Daveson, BA, Harding, R, Higginson, IJ. Implementing patient reported outcome measures (PROMs) in palliative care - users ' cry for help. *Health Quality of Life Outcomes*. 2011;9(1):27.
67. Harding, R, Gwyther, L, Mwangi-Powell, F, Powell, RA, Dinat, N. How can we improve palliative care patient outcomes in low- and middle-income countries? Successful outcomes research in sub-Saharan Africa. *Journal Pain and Symptom Management*. 2010;40(1):23–26.

68. Wolffers, I, Adjei, S, van der Drift, R. Health research in the tropics. *Lancet*. 1998;351(9116):1652–1654.
69. Pastrana, T, Vallath, N, Mastrojohn, J, Namukwaya, E, Kumar, S, Radbruch, L, Clark, D. Disparities in the contribution of low- and middle-income countries to palliative care research. *Journal of Pain and Symptom Management*. 2010;39(1):54–68.
70. Ddungu, H. Palliative care: what approaches are suitable in developing countries? *British Journal of Haematology*. 2011;154:728–735.
71. Francis, H, Bates, M J, Kalilani, L. A Prospective Study Assessing Tumour Response, Survival, and Palliative Care Outcomes in Patients with HIV-Related Kaposi’s Sarcoma at Queen Elizabeth Central Hospital, Blantyre, Malawi. *AIDS Research and Treatment*. 2012. doi:10.1155/2012/312564.
72. Selman, L, Speck, P, Gysels, M, Agupio, G, Dinat, N, Downing, J, Gwyther, L, Mashao, T, Mmoledi, K, Moll, T, Sebuyira, LM, Ikin, B, Higginson, IJ, Harding, Richard. “ Peace ” and “ life worthwhile ” as measures of spiritual well-being in African palliative care : a mixed-methods study. *Health and Quality of Life Outcomes*. 2013;11:94.
73. Powell, RA, Downing, J, Harding, R, Mwangi-Powell, F, Connor, S. Development of the APCA African Palliative Outcome Scale. *Journal of Pain and Symptom Management*. 2007;33(2):229–232.
74. Casarett, D. Ethical Considerations in End-of-Life Care and Research. *Journal of Palliative Medicine*. 2005;8(S1):148–160.
75. Slort, W, Schweitzer, BPM, Blankenstein, AH, Abarshi, EA, Riphagen, II, Echteld, MA, Aaronson, NK, Van der Horst, HE, Deliens, L. Perceived barriers and facilitators for general practitioner – patient communication in palliative care : A systematic review. *Palliative Medicine*. 2011;25(6):613–629.
76. Sampson, EL, Jones, L, Thuné-Boyle, ICV, Kukkastenvehmas, R, King, M, Leurent, B, Tookman, A, Blanchard, MR. Palliative assessment and advance care planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. *Palliative Medicine*. 2011;25(3):197–209.
77. HPCA Guidelines: Categorisation of patients. Hospice Palliative Care Association of South Africa; 2013.

78. Gott, M, Gardiner, C, Small, N, Payne, S, Seamark, D, Barnes, S, Halpin, D, Ruse, C. Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliative Medicine*. 2009;23(7):642–648.
79. Barnes, S, Gott, M, Payne, S, Parker, C, Seamark, D, Gariballa, S, Small, N. Predicting mortality among a general practice-based sample of older people with heart failure. *Chronic Illness*. 2008;4(1):5–12.
80. Schag, C, Henrich, R, Ganz, P. Karnofsky performance status revisited: reliability, validity, and guidelines. *Journal of Clinical Oncology*. 1984;2:187–193.
81. Watson, M, Lucas, C, Hoy, A, Wells, J. *Oxford handbook of palliative care*. 2nd ed. Oxford: Oxford University Press; 2010.
82. Addington-Hall, J. Research sensitivities to palliative care patients. *European Journal of Cancer Care*. 2002;11:220–224.

APPENDICES:

Appendix A:

Abundant Life Program
Support for people with chronic illnesses

Would you be surprised if your patient were to die in the next 6 months – 1 year?

Does your patient have:

Congestive Heart Failure

1. Symptoms despite maximal medical therapy?
2. More than 5 admissions in the past 6 months?
3. Associated organ failure?

Chronic obstructive airway disease

1. Disabling SOB at rest?
2. More than 5 admissions in the last 6 months?
3. Associated Cardiac Failure?

Renal Failure

1. End stage renal failure (GRF <15)?
2. Unsuitable/rejected for dialysis?

Stroke

1. Severely disabling
2. Severe dysphagia
3. Recurrent infections and sepsis

Cancer

Terminal Cancer

Misc

1. Patient in need of surgery, not medically fit
2. Severely bedridden
3. Severe bedsores
4. Does the patient require significant assistance with daily activities?

Appendix B:

Demographic Details:

Patient Study Identification number: _____

Date of Birth: _____ Sex: M F

Ethnicity: Black Coloured Indian White

Diagnosis: Cardiac failure Cancer
Renal failure specific cancer: _____
Respiratory failure HIV related
Post CVA Multiple co-morbidities

Care Giver:

Date of Birth: _____ Sex: M F

Ethnicity: Black Coloured Indian White

Relationship to patient: Spouse Relative
Child Friend
Parent Other

Recent admissions to hospital:

Have you had any admissions to a hospital in the last six months? _____ yes/no
If yes, which hospitals? _____
And how many visits?: _____

Have you had any visits to outpatient clinics at another Government health care facility in the last six months? _____ yes/no
If yes, which clinic? _____

Have you had any emergency visits to MPCHC Trauma unit in the last 6 months? _____ yes/no
If yes, how many? _____

Have you had any visits to other doctors or clinics other than MPCHC? _____ yes/no
If yes, how many? _____
And where did you access them? _____

Appendix C:

APCA African POS

Patient Study Identification number: _____

ASK THE PATIENT	POSSIBLE RESPONSES
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days.	0 (no pain) - 5 (worst/overwhelming pain) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	0 (not at all) - 5 (overwhelmingly) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (not at all) - 5 (overwhelmingly) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (not at all) - 5 (yes, I've talked freely) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q5. Over the past 3 days have you felt that life was worthwhile?	0 (no, not at all) - 5 (Yes, all the time) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q6. Over the past 3 days, have you felt at peace?	0 (no, not at all) - 5 (Yes, all the time) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q7. Have you had enough help and advice for your family to plan for the future?	0 (not at all) - 5 (as much as wanted) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
ASK THE FAMILY CARER	
Q8. How much information have you and your family been given?	0 (none) - 5 (as much as wanted) N/A <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q9. How confident does the family feel caring for ____?	0 (not at all) - 5 (very confident) N/A <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q10. Has the family been feeling worried about the Client over the last 3 days?	0 (not at all) - 5 (severe worry) N/A <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>

Appendix D:

Abundant Life Programme Evaluation

Participants

Please tick the appropriate block, or the block that best answers how you feel.

Patient

Care Giver/Family

Evaluation of the co-ordinator position:

Has the presence of the co-ordinator in the clinic had an impact on your experience of the clinic?

No help at all	Not really	Some help	Helpful	Very helpful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In what ways has she assisted you?

Listened to you	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Took an interest in your life	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Understood you	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Tried to help solve your problems	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Made your visit to the clinic easier	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Guided you through the clinic	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Answered your questions	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Got you help when you needed it	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Got you help when you didn't know you needed it	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Fetches your folder for you	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>
Assisted you when you were lost or overwhelmed	Not really <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Yes <input type="checkbox"/>	<input type="checkbox"/>

Other: _____

Would you like this role of co-ordinator to continue at the clinic?

No	Not really	Maybe	Yes	Definitely

The visit to the doctor:

Do you remember which doctor you saw since you joined Abundant Life?

Yes No

If yes, which doctor was it? _____

Did the doctor explain what is wrong with you?

Yes No

Did the doctor answer your questions?

No	Not really	Mostly	Yes	All of them

Did the doctor try to make you feel better?

No	Not really	He/she tried	Yes	He/she made a difference

Did the doctor try to improve your quality of life?

No	Not really	He/she tried	Yes	He/she made a difference

How helpful was that discussion to how you are feeling now?

Not helpful	A little bit	It helped	It helped alot	It made a big difference

Support group:

Did you attend any of the support group sessions?

Yes

No

If yes, how many? _____

If no, was there any reason? _____

If you attended any of the support group sessions, would you like to see them continue?

Yes

No

If yes, what aspects were helpful to you?

Getting out the house	Not the reason I came	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Definitely	<input type="checkbox"/>
Meeting new people	Not the reason I came	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Definitely	<input type="checkbox"/>
Drinking the tea and coffee	Not the reason I came	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Definitely	<input type="checkbox"/>
Meeting people who have similar problems to me						
	Not the reason I came	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Definitely	<input type="checkbox"/>
Just nice to talk	Not the reason I came	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Definitely	<input type="checkbox"/>
The guest speakers	Not the reason I came	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Definitely	<input type="checkbox"/>
Being able to support each other						
	Not the reason I came	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Definitely	<input type="checkbox"/>
The information I received in the sessions						
	Not the reason I came	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Definitely	<input type="checkbox"/>

If you **would not like** the support group to continue, why?

If you **would like** it to continue, which aspects would you like to see continue?

If you would like it to continue, what venue would be best for you?

	Yes	No
The current venue – at the clinic		
In the community, closer to your home?		

If you would like it to continue, how often would you like to meet?

Now and then	Every 2 months	Every month	Every 2 weeks	Weekly

Overall:

Looking at the whole programme, the co-ordinator, the doctor’s visit and the support group, would you like it to continue or stop?

Continue Stop

Should there be any changes?

Yes No

If yes, what changes?

Have you recommended the programme to others?

Yes No

Would you recommend the programme to others?

Yes No

Thank you for your time.

Enjoy the rest of your day!

Abundant Life Team

Appendix E:

Abundant Life Programme Evaluation

Staff

Please tick the appropriate block, or the block that best answers how you feel.

Role in the clinic:

Doctor	<input type="checkbox"/>	CNP	<input type="checkbox"/>
RN	<input type="checkbox"/>	EN	<input type="checkbox"/>
ENA	<input type="checkbox"/>	HPO	<input type="checkbox"/>
Admin	<input type="checkbox"/>	Other _____	

Do you know about the Abundant Life Research project? Yes No

Have you been involved with it? Yes No

If yes, in what ways?

As a patient/family	<input type="checkbox"/>
Referred patients to the programme	<input type="checkbox"/>
Seen patients as part of the programme	<input type="checkbox"/>
Assisted the co-ordinator with a query	<input type="checkbox"/>
Attended a support group	<input type="checkbox"/>

Have you referred a patient to the programme? Yes No

Did you know which patients to refer? Yes No

Did you feel there were barriers to referral to the programme? Yes No

If so, what barriers were there?

Have you met the Abundant Life Co-ordinator? Yvonne? Yes No

Have you asked Yvonne to assist you with patient care, of patients not necessarily in the Abundant Life Programme? Yes No

What impact has this programme had on you?

No impact Minimal impact Some impact A large impact

Why?

Do you think this programme should continue? Yes No

Why?

Would you like to be more involved in the programme, if it were to continue?

Yes No

Would you like more information on the programme? Yes No

Would you like more palliative care training for yourself? Yes No

Thank you for your time.

Enjoy the rest of your day!

Abundant Life Team

Appendix F:

A Study of the Abundant Life Programme at Mitchells Plain Community Health Centre: Support for people with chronic illnesses

General Patient Information sheet:

Dear Sir/Madam,

Thank you for allowing me to tell you about a study I am conducting at Mitchells Plain Community Health Centre.

My name is Jennie Morgan and I am currently doing my Master's Degree in Family Medicine with the University of Cape Town. As a masters student I need to conduct research that will improve the care of patients at a primary health care level. I have chosen to focus on people who are facing life-threatening illnesses and their families. I would like to implement a service to improve their quality of life.

This information sheet will explain the study to you. Please ask any questions you may have. Please take your time in deciding whether or not you would like to join the study.

What is the purpose of this study?

We are looking at introducing a new service at MPCHC, called Abundant Life. We would like to see whether this service is of benefit to you and your family.

What is Abundant Life?

Abundant Life is a programme for people who are in need of palliative care. Palliative care is the care of a person who has a serious and progressive illness and for whom there is no expectation of a cure. This includes the physical, mental, social and spiritual parts of their care. The aim of the Abundant Life programme is to enable the patient to remain at home as part of the family for as long and as comfortable as possible. Abundant Life also aims to assist the people caring for the patient to do so with confidence and competence.

Why are you being approached?

Your doctor or clinical nurse practitioner has identified that your illness is progressive and that there is no expectation of cure. Thus you have now reached the point of needing palliative care. This study will evaluate the extent of people at MP CHC in need of palliative care and evaluate a possible programme, for its effectiveness for you and your family.

Do I have to take part in this study?

NO, you do not have to take part in this study. Participation in this study is voluntary and will in no way change your care at this clinic. If you join this study, you can withdraw from

it at any point and it will not change how you are cared for at this clinic. If you decide to join, I will ask you to sign a consent form to say you understand what I am asking of you. You may want to think this over and talk to your family. Please feel free to do so.

What will happen if I take part in this study?

I will ask you eight questions about you and your health. I will ask four questions of your care giver, as well. This should take about five to ten minutes of your time. You will be invited to join a support group here at the CHC, which will be run fortnightly, every alternate Monday at 1pm. If you join the study you will be informed when the support group is starting, as it will not be starting immediately. Attendance at the support group is not compulsory, and will in no way affect your care or participation in the study. The support group will run for approximately three months. If it is found to be beneficial, plans will be made for it to continue after the completion of the study. At this point you would be agreeing to join the programme for three months. We would like to try this programme out with a small group of people first. We would be grateful if you would assist us by participating. At the end of the programme we will ask you to complete an evaluation form, to assist us in getting your feedback on how helpful the programme was to you and your family.

Group A and B:

Some participants may be asked to become more involved in the study. This will entail being asked questions on your health and symptoms of your disease each week for six weeks. Each week you will be asked seven questions. And a member of your family, if they give consent, will be asked three questions weekly for six weeks. We are not asking everyone to be part of these groups, as we only need a small number of people to answer these questions for the study.

Direct Benefits of the study

There will not necessarily be any direct benefits of the study to each participant. You may find that the questions asked bring up points you would like to raise with your clinician or family. The goal of the study is to find out whether this service is beneficial to the clients of our Community Health Centre.

Risks of this study

You might find the questions helpful in bringing up issues you may want to deal with, the questions may cause you or your family distress. If any of the questions cause you distress you may withdraw from the study at any point. Your care will still continue as before from the Community Health Centre and you will receive counselling as you need it.

Will the information you provide be kept confidential?

All the information you give during the interview will be kept strictly confidential. No one outside this study will have direct access to the information you give. The personal information you give, your name and age will be kept separate from the interview information. A number will be used to indicate to myself that it is your information from an interview. No name will appear on each interview sheet.

I will also ask your permission to interview a member of the family who may be currently caring for you, or close to you. If you give permission, I will ask their permission to ask them questions. If they decline to be involved, that will not affect your involvement in the study. This information that they give me will be kept in strict confidence between me and them. It will not be revealed to you or the rest of the family.

Nothing you say in the interview will be relayed to your clinician or family. It will be up to you to raise any issues with your clinician or family.

How will I know about the results of the study?

At the end of the study a report stating the results of the study will be given to the CHC and available for the participants of the study at the Community Health Centre.

If you need to talk to anyone with regard to this research, please call:

Dr Jennie Morgan 0823900402

Faculty of Health Sciences: Human Research Ethics Committee. Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

Consent:

I have read the information sheet and understand the information sheet. I have had the opportunity to ask any questions I may have.

I understand that this study is voluntary and I can withdraw at any point, without giving a reason, and my care will not be compromised.

I agree to take part in the study.

Name: _____ Date: _____

Signature: _____

Researcher: Signature: _____ Date: _____

Witness: Name: _____ Date: _____

Signature: _____

Appendix G:

A Study of the Abundant Life Programme at Mitchells Plain Community Health

Centre: Support for people with chronic illnesses

Specific Information sheet for Group A and B:

Dear Sir/Madam,

Thank you for joining our study. We would like to invite you and your care giver to join a more intensive part of this study. Please allow me to explain.

What is the purpose of this intensive part of the study?

We are looking at introducing a new service at MPCHC, called Abundant Life. Firstly we would like to evaluate how patients who are in need of palliative care are managing. We would like to evaluate your symptoms and some specific areas of your life that your disease may affect. That will be evaluated amongst Group A participants, before we start the Abundant Life programme. After we start the Abundant Life programme, Group B participants will be invited to join the Abundant Life programme and evaluated in the same way as Group A. Group A participants will also be introduced to the Abundant Life programme, but will not be asked the questions again.

How do we decide who is in Group A or Group B?

This decision is based on when you enter the programme. The first patients to enter the programme will be asked to join Group A. Once that group is full, patients will be asked to join Group B.

You are being invited to join:

Group A Group B

Do I have to take part in this part of the study?

NO, you do not have to take part in this part of the study. Participation in this study and this part of the study is voluntary and will in no way change your care at this clinic. If you join this part of the study, you can withdraw from it at any point and this will not change how you are cared for at this clinic. If you decide to join, I will ask you to sign a consent form to say you understand what I am asking of you. You may want to think this over and talk to your family. Please feel free to do so.

What will happen if I take part in this part of the study?

You will be placed, by us, into Group A or B.

Group A will be asked seven questions, every week for six weeks. These questions will be about your health, including questions on your symptoms and other problems you may have related to your illness. You will be asked to give us consent to ask questions of a member of your family. Your family member will be asked for consent to join the group. Then they will be asked three questions each week for six weeks. If your family member is not present or does not wish to participate in the study, that will not impact on your participation in the study.

Group B will be asked to meet with a clinician to discuss your illness with you and your family. Then the questions, as asked of Group A will be asked of Group B. Participants in Group B will also be asked to give us consent to ask questions of a member of your family. That person will be asked to give us consent to join the study. If they give us consent, they will be asked three questions each week for six weeks. If they choose not to join the study, it will in no way impact on your involvement in the study.

For each week of those six weeks the research assistant will call you by telephone, at a time convenient to you, to ask the questions. The questions will be asked in private and separately from the family member also involved in the study. This should take between six and ten minutes each week.

At the start of Group B we will start to run a support group at MPCHC. This support group will run every second week, on Monday at 1pm. You will be informed when the support group is starting. All participants of the study will be invited. Attendance at the support group is not compulsory, and will in no way affect your care or participation in the study.

At the end of the programme we will ask you to complete an evaluation form, to assist us in getting your feedback on how helpful the programme was to you and your family.

Direct Benefits of the study

There are not necessarily any direct benefits of the study to each participant. You may find that the questions asked bring up points you would like to raise with your clinician or family. The goal of the study is to find out whether this service is beneficial to the clients of our Community Health Centre.

Risks of this study

You might find the questions helpful in bringing up issues you may want to deal with, the questions may cause you or your family distress. If any of the questions cause you distress you may withdraw from the study at any point. Your care will still continue as before from the Community Health Centre and you will receive counselling as you need it.

Will this study be kept confidential?

All the information you give in the interview will be kept strictly confidential. No one outside this study will have direct access to the information you give us. The personal information you give us, your name and age will be kept separate from the interview information, a number will be used to indicate to us that it is your information from an interview. No name will appear on each interview sheet.

We will also ask your permission to interview a care giver who is currently caring for you. You and the family member involved in the study, will be interviewed separately and privately. This information that they give us will be kept in strict confidence and will not be revealed to the family member involved in the study, your family or your clinician. It will be up to you to raise any issues with your family or clinician.

How will I know about the results of the study?

At the end of the study a report stating the results of the study will be given to the CHC and available for the participants of the study at the Community Health Centre.

If you need to talk to anyone with regard to this research, please call:

Dr Jennie Morgan 0823900402

Faculty of Health Sciences: Human Research Ethics Committee. Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338 25

Consent:

I have read the information sheet and understand the information sheet. I have had the opportunity to ask any questions I may have.

I understand that this study is voluntary and I can withdraw at any point, without giving a reason, and my care will not be compromised.

I agree to take part in the study.

Group A

Group B

Name: _____ Date: _____

Signature: _____

Researcher: Signature: _____ Date: _____

Witness: Name: _____ Date: _____

Signature: _____

Permission is given to approach my family member, _____

To ask him/her to join the study.

Appendix H:

A Study of the Abundant Life Programme at Mitchells Plain Community Health Centre: Support for people with chronic illnesses

Letter to an invited Family member:

Dear Sir/Madam

Thank you for allowing me to tell you about a study I am conducting at Mitchells Plain Community Health Centre. The patient in your care has agreed to take part in the study and given us consent to invite you to take part in the study too.

My name is Jennie Morgan and I am currently doing my Master's Degree in Family Medicine with the University of Cape Town. As a masters student I need to conduct research that will improve the care of patients at a primary health care level. I have chosen to focus on people who are facing life-threatening illnesses and their families. I would like to implement a service to improve their quality of life.

This information sheet will explain the study to you. Please ask any questions you may have. Please take your time in deciding whether or not you would like to join the study.

What is the purpose of this study?

We are looking at introducing a new service at MPCHC, called Abundant Life. We would like to see whether this service is of benefit to you and your family.

What is Abundant Life?

Abundant Life is a programme for people who are in need of palliative care. Palliative care is the care of a person who has a serious and progressive illness and for whom there is no expectation of a cure. This includes the physical, mental, social and spiritual parts of their care. The aim of the Abundant Life programme is to enable the patient to remain at home as part of the family for as long and as comfortable as possible. Abundant Life also aims to assist the people caring for the patient to do so with confidence and competence.

Why are you being approached?

Your family member has been identified by their doctor or clinical nurse practitioner as being in need of palliative care. That their illness is progressive and that there is no expectation of cure. This study will evaluate the patient's symptoms and ways in which their disease impacts on their life. It will also look at a family member, at the understanding you have on your family member's illness, your confidence at looking after him/her and the concern that the family has over the patient. To achieve that we are asking for your participation in the study.

Do I have to take part in this study?

NO, you do not have to take part in this study. Participation in this study is voluntary and will in no way change your family member's care at this clinic. If you join this study, you can withdraw from it at any point and it will not change how you and your family member is cared for at this clinic. If you decide to join, I will ask you to sign a consent form to say you understand what I am asking of you. You may want to think this over. Please feel free to do so.

What will happen if I take part in this study?

I will ask you to sign consent for us to involve you in the study. After that I will ask you three questions about your care of your family member. Then I will call the house each week for six weeks and ask the patient and yourself the questions again. This should take between six and ten minutes each week, at a time convenient to you.

At the end of the programme we will ask you to complete an evaluation form, to assist us in getting your feedback on how helpful the programme was to you and your family.

Direct Benefits of the study

There will not necessarily be any direct benefits of the study to each participant. You may find that the questions asked bring up points you would like to raise with your family or the doctor. The goal of the study is to find out whether this service is beneficial to the clients of our Community Health Centre.

Risks of this study

You might find the questions helpful in bringing up issues you may want to deal with, the questions may cause you or your family distress. If any of the questions cause you distress you may withdraw from the study at any point. You and your family member's care will still continue as before from the Community Health Centre and you will receive counselling as you need it.

Will the information you provide be kept confidential?

All the information you give me in the interview will be kept strictly confidential. No one outside this study will have direct access to the information you give me. You will be interviewed separately from the patient and the information you give us will not be revealed to them by us. The information the patient gives us will also not be revealed to you, that will be kept in confidence.

The personal information you give me, your name and age will be kept separate from the interview information. A number will be used to indicate to myself that it is your information from an interview. No name will appear on each interview sheet.

How will I know about the results of the study?

At the end of the study a report stating the results of the study will be given to the CHC and available for the participants of the study at the Community Health Centre.

If you need to talk to anyone with regard to this research, please call:

Dr Jennie Morgan 0823900402

Faculty of Health Sciences: Human Research Ethics Committee. Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338 28

Consent for Family Member:

I have read the information sheet and understand the information sheet. I have had the opportunity to ask any questions I may have.

I understand that this study is voluntary and I can withdraw at any point, without giving a reason, and the care of the person in my care will not be compromised.

I agree to take part in the study.

Name: _____ Date: _____

Signature: _____

Researcher:

Signature: _____ Date: _____

Witness: Name: _____ Date: _____

Signature: _____



15 February 2012

HREC REF: 006/2012

Dr J Morgan
Public Health & Family Medicine

Dear Dr Morgan

PROJECT TITLE: A PROSPECTIVE COHORT STUDY OF AN END-OF LIFE- PROGRAMME INTERVENTION IN A PRIMARY HEALTH CARE SETTING.

Thank you for your comprehensive response to the queries raised by the Faculty of Health Sciences Human Research Ethics Committee in your letter received 14th February 2012.

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

Approval is granted for one year till the 28th February 2013.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

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

Please quote the HREC REF in all your correspondence.

Yours sincerely

Signature removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS
Federal Wide Assurance Number: FWAC0001637
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA USA), International Convention on Harmonisation of Good Clinical Practice (ICH-GCP) and Derivation of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines ES: Note for Guidance on Good Clinical Practice (CPMP/ICH/35/95) and FDA Code Federal Regulation part 312.56 and 312.61.

<input checked="" type="checkbox"/> Approved	28.2.2013
<input type="checkbox"/> Not approved	
Signature removed	08/04/2013

Principal Investigator to complete the following:

1. Protocol Information

Date first submitted	14 February 2012
Date of review	006/2012 20 February 2013
Public title	A Prospective Cohort Study of an End-of-life Intervention Program in a Primary Health Care Setting.
Protocol number of sponsor	
Principal investigator	Dr JM Morgan
Department/Office/Institutional address	School of Public Health and Family Medicine, Family Medicine

3.1 Does the protocol receive US Federal funding?	<input type="checkbox"/> Yes	* No
1.1 Has the sponsor of the study changed? If yes, please attach a summary of the budget.	<input type="checkbox"/> Yes	* No

2. List of documentation

FHS016
FHS016 with amended protocol

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA0001837; IRB00001838)			
This serves as notification of annual approval, including any documentation described below.			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30/06/2015
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC	Signature removed	Date Signed	27/6/15
Comments to PI from the HREC			

Principal Investigator to complete the following:

1. Protocol information

Date form submitted	15 February 2012		
HREC Ref: Number	006/2012	Current Ethics Approval was granted until	08 April 2014
Principal title	A prospective cohort study of an end of life programme intervention in a primary health care setting.		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	JM Morgan	<div style="border: 1px solid black; padding: 5px; text-align: center;"> RESEARCH ETHICS COMMITTEE 2014-06-27 HEALTH SCIENCES FACULTY UNIVERSITY OF CAPE TOWN </div>	
Department / Office Internal Mail Address	Public Health and Family medicine		
1.1 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No	
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	