An Investigation of the Benefits of Palliative Care for Patients with Chronic Heart Failure

at a Novel Hospital-Based Palliative Care Service.

Submitted by: Joy Hunter

Student No: HNTJOY001

Supervisor: Dr Liz Gwyther

A research report submitted to the Faculty of Health Sciences, University of Cape Town Department of Public Health, in part fulfillment of the requirements for the degree of MPhil in Palliative Medicine.

February 2018

DECLARATION

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

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: Signed by candidate

Date: 14 February 2018

DEDICATION

To Farrell, thank you for all your support, patience and understanding.

ACKNOWLEGEMENTS

It is with gratitude that I would like to acknowledge the following people for their contributions and assistance, without their input this would not have been possible:

All the participants for their time
My Supervisor, Dr Liz Gwyther
Dr Clint Cupido and the Staff of the Abundant Life Programme
Prof Richard Harding
Mrs Naomi Fray, Administrative Support

ABSTRACT: AN INVESTIGATION OF THE BENEFITS OF PALLIATIVE CARE FOR PATIENTS WITH CHRONIC HEART FAILURE AT A NOVEL HOSPITAL-BASED PALLIATIVE CARE SERVICE.

INTRODUCTION: Heart failure is a chronic cardiac condition that would benefit from palliative care and yet palliative care is still mainly provided for people with cancer or HIV. Patients with end-stage heart failure experience similar clinical symptoms as patients with advanced cancer with significant physical and emotional suffering. This research study investigated and assessed the benefits of palliative care in this vulnerable population at a district hospital in Cape Town and emphasized the importance of a hospital-based palliative care facility.

METHODOLOGY: A cross-sectional descriptive qualitative study was conducted with in-depth interviews of people living with heart failure using thematic analysis of patient interviews. The study was conducted at a palliative care facility at a government district hospital. Purposive sampling was used for patient selection. A total of 12 participants were interviewed until data saturation.

RESULTS: The mean age of the 7 men and 5 women interviewed was 52 years, the youngest participant was aged 27 years old and the eldest was 78. Analysis of these 12 semi- structured interviews produced five main themes. The first theme that emerged focused on issues of high service usage due to recurrent hospitalizations in the group, the second on communication factors in palliative care. The third theme was on information and education, the fourth on the importance of resources in palliative care and the last theme was on the Abundant Life Palliative Care Programme.

DISCUSSION: Findings from this study supports the importance of palliative care for people with heart failure. Palliative care early in the disease aims to improve the quality of life for such patients and their families. The data supports the fact that early referral for palliative care resulted in greater symptom control and benefit to the patient long before hospice care is needed. Previous studies have also proven to reduce re-hospitalization rates of this population while reducing costs to the healthcare system.

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION

1.1 Palliative Care

The World Health Organisation describes palliative care as an essential component of a public health system[1, 2] and states the need for this type of care for people with chronic, life-threatening or life limiting diseases. Internationally, palliative care services were originally developed to assist patients with cancer diagnoses.[3] However, a large percentage of populations over the age of 65 die of chronic diseases other than cancer.[3, 4] Cancer is often perceived as the disease with the worst pain and suffering; however, patients with end-stage heart failure experience similar clinical symptoms as patients with advanced cancer such as dyspnoea, pain, [5] tiredness and cachexia, with significant physical and emotional suffering.[6, 7]

Palliative care has been integrated into care of patients with non-cancer diagnoses such as Human Immuno-Deficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS), care, TB care and care of patients with communicable diseases but is slow in its provision to people with heart failure (HF).

People dying from end-stage cancer usually have a short life expectancy of about 6 months while those of chronic conditions, such as heart failure, have needs that are not met for years. Heart failure is a major burden on family and carers; and patients and families experience many frustrations trying to access appropriate care.[3, 8] Solana *et al.,* recommends that palliative consultants and cardiology specialists work together to ensure that patients and families receive appropriate care. Delivery of appropriate care to all patients with non-malignant disease is essential, as these patients approaching the end of their lives suffer symptom burden similar to patients with cancer.[9]

1.2 Palliative Care for Heart Failure

Palliative care services in South Africa are well established in the non-governmental (NGO) sector and provide care to patients and their families. These services and the first hospital palliative care program mainly provide for the needs of patients with cancer and HIV/AIDS. Until recently there were no palliative care programs in South African public hospitals to attend to the end-of-life care needs of patients with organ failure.

The course of cancer can often be predicted and palliative care easily accessed but the course of heart failure is uncertain with the clinician, the patient and the family having to live with the uncertainty.[10, 11] One of the ways in which individuals can become more comfortable with this uncertainty is by integrating palliative care with cardiac care. This would incorporate educating the patient and family about the nature of the illness by understanding the HF trajectory, meeting goals of care to maintain quality of life so that whereas the patient and family ‘hope for the best’, they are also ‘prepared for the worst’.

Guidance tools are used to help identify people at risk. These are the Gold Standards Framework (GSF)[12, 13] and the Supportive and Palliative Care Indicator Tool (SPICT)[13] that do not give a prognosis or a specific timeframe of impending death but identify that patients require specialist palliative care and rather focus on the importance of timely assessment and meeting goals of care as a priority to maintaining quality of life. Palliative care and cardiac teams need to work together towards a care pathway that would be sustainable so that palliative care can become part of the usual care of patients with heart failure.

1.3 Epidemiology of Heart Failure

Heart failure has been shown to greatly impact the health and quality of life of patients. This is directly caused by the symptom burden of fatigue, fluid retention, shortness of breath and functional limitations. It is becoming more common and accounts for about 30% of deaths worldwide, with 80% of deaths occurring in the developing world. It is a dominant disease in Africa[14, 15] and is a leading cause of death in South Africa.[16]

Cancer is one of the leading causes of death but accounts for lower percentage of deaths worldwide, while deaths of chronic diseases are much higher.[1] In StatsSA 2014 report, cause of death diseases of circulatory system was 17.3% while that of neoplasms were 8.6%.[19] The South African Medical Research Council reflect on the top causes of deaths in the calendar year of 2000 and noted cancer accounted for only 2.4% of all deaths, whereas as heart disease was recorded as cause of death in 6.6% of cases.

In a UK palliative care survey over a period of 12 months only 1084 patients with heart disease received palliative care compared to 62 499 patients with cancer. [17] It is estimated that 40% of cancer patients received palliative compared to 4% that dies of heart failure. It is therefore recommended that patients with end stage heart failure be afforded access to palliative care [18]

Heart failure has been described as a significant clinical and public health problem which has reached epidemic proportion. While the disease is associated with increased mortality, morbidity and health care expenditures, the burden of the disease is not related to increase in the incidence of the heart failure but rather the chronic clinical trajectory that these patients suffer. Understanding the causes of hospitalizations for this population would help clinicians to develop guidance for patients and families for early interventions in times of exacerbation.

1.4 Chronic Heart Failure

Chronic heart failure is a progressive illness and is the cause of death of many cardiovascular diseases.[4] The course of heart failure is of slow decline with periods of acute exacerbation often with sudden death.[3, 6] The death rates and the unpredictable nature of this disease make PC imperative for patients with heart failure.[8]

Heart failure is the cardiac problem that would most likely benefit from palliative care and is a major cardiovascular disease with increasing prevalence, incidence and mortality.[1, 2, 4] End-stage cardiac disease has a short life expectancy of 6 months with New York Heart Association (NYHA) Functional Class III-IV breathlessness, hypotension, clinical features of cardiac failure, and an ejection fraction of less than 20 percent. The main cause of cardiac failure is usually coronary artery disease other causes include hypertension, alcohol excess, viral infections, metabolic disorders and cardiomyopathies.[1] It is a fairly common disorder affecting 1-2 percent[1] of the general population with up to 20 per cent of elderly patients being affected. They often have a poor quality of life with regular re-hospitalisations and would prefer not to undergo resuscitation even if they would die if not resuscitated.[7, 20, 21]

1.5 Symptom burden and Palliative Care Benefit in Managing Symptoms

The classic symptoms of breathlessness, ankle swelling and fatigue are some of the clinical features of heart failure.[1] [2] Fluid retention causes breathlessness, cough and dependent oedema, anorexia, nausea, abdominal bloating and pain. [2] Other common symptoms are pain from either angina, liver capsule distension, lower limb swelling and other co-morbid disease; anxiety and depression. Depression has been found to contribute to mortality and hospital readmission, insomnia, memory loss and confusion, anorexia, nausea, vomiting and constipation, weight loss and loss of libido.[1, 2] Knowledge of palliative care would enhance the cardiologists skills set in addressing distressing symptoms and enhancing communication and information sharing.

The overall prognosis in patients with heart failure is equivalent to many types of advanced cancer. Heart failure has proven to be more incapacitating compared to other chronic illnesses such as diabetes, arthritis and hypertension.[1, 2] Chronic heart failure affects the physical, psychological and social dimensions of the person suffering with this disease.[2] The high morbidity of heart failure is reflected by the frequency of hospital admissions and the cost to health care systems.[1, 22] People who die of heart disease often do so in the hospital and their final illness often lasts for more than six months. These patients are frequently admitted to hospital until their symptoms stabilised, they are then discharged only to return when symptoms get worse again and will continue in this cycle. They are often not aware that palliative care is a complementary approach, providing symptom management and emotional support in the home.[22]

Lack of energy, weakness or fatigue, pain, dyspnoea, insomnia and depression are the most common symptoms expressed by patients with HF.[23] Much information already exist that points to ways to palliate these symptoms and advance therapies have been developed to prolong life. This however may not reduce the burden of the disease and thereby not meet the needs of patients living with HF. These patients need supportive patient-centred care that includes the individual and family preferences. Furthermore, this should include the patient and family into discussion regarding the goals of care thereby reducing the symptom burden. [23]

1.6 Quality of Life

The World Health definition of palliative care describes the approach as "the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems."[1, 4] The European Society of Cardiology Heart Failure Association, in a statement on palliative care for heart failure, highlights the importance of a multi-disciplinary approach which includes the social and spiritual needs of the individual.[24]

For many patients with advanced heart failure existential needs are important as it contributes to a good quality of life.[25] The negative impact of the physical symptoms of the disease predisposes the individual to social isolation and loneliness.[25-27] while the physical domain is important in this population, there are the well less recognised issue of psychosocial concerns. They may suffer a variety of losses in this domain. This may include distress that patients experience about their body image. A patient with heart failure is often too ill and may fear that they are unattractive. The losses experienced regarding physical activity and the subsequent tiredness may result in the inability to sustain themselves and their family. The psychological impact of heart failure is a major factor in precipitating readmission.[5] These patients suffer physical limitations which impact on their daily functioning resulting in isolation long before they die, and they often do not have access to the support they require.

Patients with end-stage cardiac disease have a greatly reduced quality of life. Poor quality of life is often caused by low-mood, anxiety and incontinence and require assistance with self-care and adequate support in terms of counselling and communication.[1] Palliative care is often a valid choice for many of these patients who are experiencing distressing physical symptoms such as angina, dyspnoea, oedema and anxiety.[28] Persistent symptoms such as oedema despite treatment, the inability to tolerate aggressive treatments because of hypotension or kidney disease or history of heart disease and resuscitation.[28] Patients with these symptoms could benefit from palliative care as it includes symptom control and emotional support with an emphasis on communication. The inclusion of the patient in the discussion in the goals of care can assist in a good quality of life. People with HF suffer social isolation due to physical inability which leads to a loss of meaning and purpose in their lives accompanied by feelings of anxiety and depression which is common throughout the illness.[24]

1.7 Palliative Care Services for Heart Failure

One of the benefits of palliative care is that care can be provided in the patient's own home.[2] Home-based palliative care is a good choice for managing symptoms in a familiar environment for patients with a limited life span and quality of life. [22, 29] A home palliative care programme consisting of a multidisciplinary team doing regular visits in addition to telephonic consults would facilitate information to patient and family thereby reducing readmissions for HF. This could lead to cost savings incurred from re-hospitalisations.[22, 29] Patients with heart failure often die suddenly away from home and their families and can cause psychological distress. The lack of palliative care has negative consequences on the quality of care available for this vulnerable patient group, the health care system and on scarce resources. Providing palliative care early can account for significant cost savings.[15] The treatment of 'total pain' therefore does not only involve the physical but includes psychological, social and spiritual aspects and is related to all spheres of the person's life.[14]

The nature of HF requires that the management of advanced heart failure and supportive care need to be complementary. Current management of HF patients consist of chronic outpatient care, frequent exacerbations with subsequent re-hospitalizations. Unlike cancer patients, who progressively deteriorate, individuals with HF may be functional with poor status and die suddenly [16]. Clinicians and patients may benefit from regular assessments of the trajectory as during exacerbations typical of heart failure patients often return to near-baseline after treatment [24]

1.8 Challenges and Solutions in Referral to Palliative Care

There are challenges in applying palliative care principles to patients with end-stage cardiac disease. Defining when a slowly progressive disease such as HF reaches advance stages is difficult as it has a fluctuating trajectory.[9] Prognostic uncertainty is one of the main reasons why patients with HF are not referred for PC. This difficulty in prognostication implies that palliative care should be made available on need such as in symptom alleviation rather than prognosis.[9] These challenges were considered in developing the SPICT providing guidance on when to refer for specialist palliative care. A further imperative is the training of physicians in palliative care so that palliative care interventions can be implemented alongside disease-specific care for better patient outcomes.

GSF was developed in the UK in order to provide appropriate palliative care in the primary health care setting. One of the aims of GSF is to ensure all patients have a "good death" in the place of their choice. [13] It is a co-ordinated programme of care for those in the last 12 months of life, irrespective of diagnosis. It stipulates that patients who need supportive care towards the end of life must be identified. That their needs, symptoms, preferences and any issues important to them be assessed and planned for.[13] This includes a palliative diagnosis, constant review, death and bereavement support for carers.[12] A patient-centred supportive care approach could consider what is important issues in the patient's life at present, their future, and of greatest concern to them, and if their health deteriorated, how and where they would like to be cared for.[10] An urgent decision making point in re-hospitalization after acute heart failure should indicate that action need to be taken to plan for goals of care in the next stage of the illness.[1] A personalised care plan for each patient with heart failure in conjunction with routine active cardiac care management would be better suited to fit this illness trajectory and would promote quality of life rather than focus on prolonging life at all costs and futile treatment.[3]

1.9 Communication Issues

Effective communication between the health professional, patient and family ensure needs and preferences are met. This allows for support and planning, avoiding crises and unnecessary hospital admission. Shared communication is also necessary between care settings to ensure services are fully updated about patients' needs and that preferences are met effectively. Advance care planning is crucial to document patient preferences which can be shared with carers and family.[13] By anticipating the patient's needs and that of the family and by involving them in decision making helps to retain a sense of control and choice.[12] An important consideration as the patient's condition deteriorates is the discussion of an advance directive or "do not attempt resuscitation" order in their records. It is important to note how this process is initiated and documented and reviewed.[12, 13] There is an inability of many worldwide health care services to reflect and engage proactively on the holistic care of people with progressive chronic illnesses and therefore failing to provide adequate care to this population.[10]

The provision of palliation services requires a shared responsibility by professionals, the patient, the family and other carers.[10, 14] communication and failure to check patients understanding regarding the implications of a life-threatening condition is problematic in the long term as this could contribute to psychological morbidity. In a series of studies investigating how to improve end-of-life care for patients with chronic heart failure[8, 28, 30] it was recommended that the patient and the family be provided information regarding end-of-life issues during communication early in the disease trajectory.[8]

A further recommendation was that cardiac and palliative care staff work together and share their skills with each other, cardiologists to be trained in general palliative care and communication skills while palliative care staff be informed of HF management. Mutual respect and understanding of each other's professions are required to work together on management of the disease progression and future care plans to provide the best possible care.[8]

Many people with advanced chronic disease hope their condition will not deteriorate but often know that death is inevitable but seek comfort and control while maintaining some control and dignity.[10] Health professionals caring for patients with advanced HF must develop skills to better integrate the patient's preferences and provide skilled symptom management into the goals of care and the process of death well managed, ensuring physical comfort and emotional support. This would decrease the physical and psychosocial burdens of advanced HF and to meet patient and family needs.[23] Facilitating a good death, one in which a person dies on their own terms, relatively free from pain and supported in a dignified setting[1] is as important as communicating diagnosis and providing active treatment. Death should be handled with dignity incorporating humanistic and ethical elements in the communication to all those affected by the loss.[3] Support and education for patients with HF by cardiology and specialist palliative care teams should be objectives for the future.[2]

1.10 The Abundant Life Programme

The ‘Abundant Life’ programme at Victoria Hospital provides a novel palliative care service to patients with organ failure. It was started in 2009 mainly in response to a young person dying of organ failure without receiving palliative care. The service is delivered in a public district hospital in Cape Town, South Africa. It currently provides coverage for around 600,000 uninsured people. The hospital has 158 beds, and of these, 56 are medical.[15] The patients are identified during acute admissions to the hospital using the Gold Standards Framework assessment tool.[12, 15]

Patients with organ failure are given access to the programme when they have been admitted more than five times in six months. One of the criteria is that the patient has family support as the treatment is started off in hospital and then is released in the care of their family. When diagnosis is confirmed the family is counselled and the patient is moved on to symptom management. It is integrated into general care and all the medical registrars and interns are exposed to palliative care. Palliative care training is also included in the daily practise during ward rounds.

There are numerous advantages to the patients according to the health care professional managing the facility such as improved care which results in a better quality of life. Patients reported improved sleeping patterns, an increase in appetite and less burden of care for their families. The facility offers assistive devices, a telephone service to patients, clinic, advice to care-givers and a fortnightly support group and a transport service. The service has proven to be cost effective by reducing hospital admissions and by reducing hospital deaths.[15]

In evaluating the service, disadvantages that were expressed by the staff were that the service infringed on the personal time of staff and therefore became emotionally draining as there was no system in place for the debriefing of professionals and no replacements when time off from work was needed. Since 2014 however, the staff implemented rules and regulations as a self-care measure in an effort to preserve the capacity and imposed boundaries on time management to cope with the increased number of patients to the programme. Since this self-imposed intervention staff meetings are held once per week to discuss cases and for debriefing purposes. Close to 4000 patients have been cared for since the inception of the Abundant Life programme. Between 2013-2014 a clinical audit was conducted with 181 patients on palliative care problems amongst patients with chronic disease referred to the service. The study was conducted in collaboration with the European Union, Kings College London, the University of Cape Town and the Western Cape Department of Health. The study included a training intervention for hospital staff; increased PC knowledge and awareness amongst the staff at the hospital and increased the admissions to the AL service.

There was consensus amongst the AL staff that the programme needed to be integrated into the hospital service so that it could become part of normal care and medical management as the limited private funding was not enough to sustain a stand-alone service. Additional recommendations were that every hospital should have a palliative care facility because medical wards would run more efficiently. This is in line with the World Health Assembly and the recent national Policy Framework and Strategy for Palliative Care in South Africa.[31]

In conclusion, it is evident that patients with heart failure are impacted by their disease. The literature reflects few South African studies that have been conducted on this topic. This study was conducted to produce such research within the South African context, to investigate the benefits of palliative care in patients suffering with heart failure, their needs, that of their carers and family and how they are experiencing the disease under palliative care.

CHAPTER 2: LITERATURE REVIEW

A literature review was conducted to collect information about the role of palliative care in heart failure.

A literature search was done electronically using PubMed, Scopus, CINAHL and Google scholar using the following key words: 'palliative care', 'palliative medicine' and 'heart failure'. This search yielded 1057 articles. Abstracts and the full text of identified publications were read, and full text of relevant documents were retrieved and included in this review. Reference lists of retrieved documents were manually searched to identify further additional publications. The Oxford textbook of Palliative Medicine and the handbook of Palliative Care were also manually searched as part of the literature review.

Articles included in this literature review needed to be in English and published as far back as 1991. Studies that explored the role of palliative care for non-oncology patient groups, the impact of heart failure on the patient, the benefits of and barriers to palliative care and the health care system in South Africa were included. The review excluded studies that exclusively described the medical and pharmacological treatment of heart failure.

What is evident in all the articles reviewed on this topic is that heart failure is a condition that is burdensome to the individual suffering from it, families and the healthcare system. In the Oxford Handbook on Palliative Care, Doyle *et al.,* writes that while cancer is still one of the top 10 causes of death globally, it is responsible for a relatively smaller percentage of deaths worldwide, while deaths of other long term conditions are much higher.[1] Watson et al., further highlighted that HF is the only major cardiovascular disease with increasing incidence.[2]

Lokker *et al*., in a South African study, the first to assess the prevalence, burden, and correlates of physical and psychological symptoms in patients with NYHA stage III and IV heart failure in a developing country, measured patient-reported symptom prevalence and correlates of symptom burden in patients with advanced heart failure.[5] The study concluded that these patients experienced a high prevalence of symptoms and reported high levels of burden associated with these symptoms. This was a strong study with good sample size and drew valid conclusions. Of note was the fact that pain was highly prevalent among these patients. The authors recommend healthcare professionals consider incorporating palliative care into the care for these patients.

Many articles advocate that the condition could benefit from palliative care by reducing hospital admissions and improving the patient's quality of life. Many of the studies have not been conducted in South Africa but some aspects of it could be generalised to our situation. There are however socio-economic implications and constraints that restricts the implementation of palliative care in South Africa. Benatar, in a special article on medicine and health care in South Africa states that privatisation in health has devastating implications for health and health care services and academic medicine in South Africa.[32] Benatar reports that the economic crisis facing sub-Saharan Africa has devastating implications for human welfare.[32] Mayosi *et al.,* also writes on health and health care in South Africa and points out further the issues of health and well-being of most of South Africans, the burden of infectious and non-communicable diseases, persisting social disparities, and inadequate human resources in South Africa.[33] The study further cites that "Relative poverty has become worse, with the Gini coefficient increasing from 0.6 in 1995 to almost 0.7 in 2009, top 10% of South Africans earn 58% of the total annual national income, whereas the bottom 70% combined earn a mere 17%, these disparities, the widest in the world, are associated with diseases of poverty".[33] The results of the above studies are valid because the lack of scarce medical resources has dire consequences for health care services in South Africa and palliative care has shown to reduce health care costs to the health care system.

A review of the literature shows that chronic heart failure (CHF) is an important healthcare issue, associated with high morbidity and mortality rates as described by the following authors:

Pocock *et al.,* study on predictors of mortality and morbidity in patients with chronic heart failure aimed to develop prognostic models for patients with CHF.[34] Final models included 21 predictor variables for cardiovascular death and HF hospitalization and for death. The model showed actual 2-year mortality from 2.5 to 44% for the lowest to highest deciles of predicted risk.[34] These models can stratify risk and help define how patient characteristics relate to clinical course.[34]

In another study by Lee *et al.,* predicting mortality among patients hospitalized for heart failure. This may be useful for clinicians to improve communication and care of hospitalized patients. The study identified predictors of mortality to develop and to validate a model using information that was available at hospital presentation among community-based HF patients, and predicted mortality risk at 30 days and 1 year.[35] While the study can improve decision making and aid the physician in identifying patients who are at high or low risk of death it does not state whether the decision making includes palliative care. It concluded that the findings may assist clinicians in estimating HF mortality risk and in providing quantitative guidance for decision making in heart failure care.[35]

2.1 Palliative Care for All

Studies in palliative care include the **care of all individuals** affected by life-limiting conditions, including HF as outlined in the latest definition of World Health Organization which defines palliative care as the "aim to improve the quality of life for patients and their families facing life-threatening illness. Palliative care provides care in the relief of pain and other distressing symptoms; affirms life, and regards dying as a normal process; intends neither to hasten nor postpone death and offers a support system to help patients live as actively as possible until they die."[14] Patients with heart failure would benefit from a support system that incorporates all aspects of care needed to manage their lives despite the disease.

Cushen et al., highlights the need for PC in HF not just for cancer and the need for discussion about "quality rather than quantity of life" in this condition and calls for research cooperation between palliative and other physicians.[7] The study is important in the advocacy of PC for HF because it addresses the need for active management of progressive, far-advanced disease such as HF with limited prognosis, focusing on care that emphasizes quality of life care not the diagnosis but rather the need for care in the final stages of life.[7]

Kavalieratos *et al.,* in a study comparing the unmet needs between community-based palliative care patients with heart failure and patients with cancer found that patients with HF had care needs that were in the scope of palliative care.[36] Comparing the physical and psychosocial needs of patients with HF and those with cancer the authors found no difference in the groups.[36] This is important information to highlight the issues of this vulnerable population.

In another study by Kavalieratos *et al.,* the authors explored factors perceived by cardiology, primary care, and palliative care providers that obstructed palliative care referral for HF patients. These perceived barriers were related to limited knowledge about what PC is and how it could complement traditional HF therapy to decrease HF related suffering.[17] Low referral was attributed to HCP being unsure of when to and how to integrate care and misunderstanding of the role of palliative care as only meant for patients when in end-stage.[17] It is a valid study to highlight issues for provider education to improve PC referral for HF.

In a study by Hauptman[37] *et al.,* conducted to explore physician decision-making in end-stage HF also found similar comparisons between end-stage heart failure and cancer trajectories. The study found that a high proportion HCPs had gaps in knowledge and experience regarding palliative care referral and end-stage HF. It would appear from this study that a low percentage, only 15.7%, of physicians had the confidence about the ability to accurately predict clinical trajectory. However, the unpredictable nature of the HF trajectory however highlights the need for further evaluation of the management of advance HF. Management of the condition and supportive care would improve the way in which care is delivered to patients.

Thomas *et al.,* highlights the use of a guidance tool such as the Gold Standards Framework (GSF) that can be used to help identify people that require specialist palliative care such as the HF population.[13] It involves assessing and recording their needs, planning and providing for their care. It focuses on several goals of care that relates to the patient and family by improving prediction of need and provision of care.[13]

Highet *et al.,* conducted a mix-methods study to develop a clinical tool to help multidisciplinary teams in the UK and internationally, to identify patients at risk of deterioration and dying. A participatory research approach was used to refine the 2010 SPICT and evaluate its use in clinical practice. [38] The study concluded that the SPICT assists multidisciplinary teams to identify patients at risk of deteriorating and dying.[38] It is a valid tool in that it timeously identifies patients with several unmet needs thereby allowing review of care goals and forward planning.

Maas *et al.,* conducted a systematic literature review to find out what tools are available to identify patients with PC needs in primary care.[39] A search using PubMed and Embase, and a questionnaire survey among key informants in 14 European countries requesting data on methods were used to identify patients with palliative care needs. The literature search identified several tools but found that it was rarely used or implemented. All the tools however contained general indicators for decline and loss of functional status.[39] The study concluded that several identification tools have been developed but that none were validated or widely implemented.[39] It was noted however that the GSF and SPICT have been validated and implemented. Further collaboration and research is needed to encourage clinicians to use these tools for early identification of chronic patients currently living and dying with unmet care needs.

Metzger *et al.,* conducted research with patients with late-stage HF and their family members to describe their experiences of inpatient PC consultations found that ignorance of palliative care and hospice were barriers to PC.[30] The design of this qualitative study was appropriate because it allowed the participants to describe their experiences and perceptions of PC in HF. They confused palliative care with hospice care and viewed the latter as problematic, thinking that this would mean withdrawal of active care. Several potential barriers were identified: “the unpredictable course of HF; lack of clear referral triggers across the HF trajectory; and ambiguity regarding what differentiates standard HF therapy from palliative care”.[30] A more acceptable way to introduce PC is needed to overcome these barriers.

Whellan *et al.,* compiled a consensus statement on the end-of-life considerations for patients with HF. They recommend additional research be undertaken to more accurately assess prognosis in HF patients.[40] One of the objectives of this white paper was to make recommendations to clinicians on the issue of patient care in this population. This government report proposal is valid because it clearly focussed on the consideration of care of the HF population making recommendations that will ensure care needs are “equitable, timely, and patient centred”.[40]

2.2 The role of Palliative Care in Heart Failure

Palliative care consultations put the impact of the disease into perspective for the individual with heart failure and allows for reflection on the further management of its course. In a pilot study with 42 patients suffering from symptomatic HF, Evangelista *et al.,* focussed on the impact of palliative care on perception of control in the environment and the ability to self-manage.[16] The findings showed that the patients who received more than two PC consultations had greater reduction in symptom distress due to increased perception of control in their environment and the ability to self-manage.[16] These are valid findings for the promotion and development of PC programmes that focus on active self-management. The enhancement of perceived control in patients with HF is critical to improving clinical outcomes.[16]

Palliative care offered to patients and families coping with the impact of end-stage heart failure assist with its control and management. Wong *et al* found that palliative care in addition to a chronic disease management programme helps with symptom control and addressing patient and family distress.[22] The validity of this study is found in the reduction in utilization of health care by patients with end-stage HF who are receiving home-based PC.[22] Home-based PC therefore reduces costs to the health care system, the patient and family.

In an article by Ward *et al.,* on the need for palliative care in the management of heart failure presented evidence which shows that the characteristics of progressive limitation, reduced life expectancy and intrusive symptoms accompanied by physical and emotional distress found in patients with cancer are also experienced by patients with HF.[6] The study article further identified what areas of palliative care was applicable to the needs of patients with HF and recommended further strategies for application.[6] This is an important article as it addresses key points in the integration of PC into HF management and advocates for an educational module in palliative care to be developed and incorporated into cardiology training courses.

Patients with HF have a specific symptom burden and prolonged illness trajectory that must be considered when considering goals of care. This study by Kavalieratos *et al*., found, that despite differences regarding specific symptom prevalence there was greater dyspnoea in patients with HF than in patients with cancer. Dyspnoea, like pain, is a significant symptom when not palliated can negatively affect quality of life and increase caregiver burden.[36] Their findings suggest that patients with HF and patients with cancer are appropriate for PC, however because the pattern of burden is different the palliative care intervention must be appropriate.[36]

Supportive care for the patient suffering with HF is as important as disease management to assist the patient and family with a sense of control and self-care. At a consensus conference held to define gaps in research on ‘palliative and supportive care in advance heart failure”, Goodlin *et al., “identified gaps in current knowledge, practice, and research relating to prognostication, symptom management, and supportive care for advanced heart failure”*[23]*.* They suggest best practices to decrease burden of suffering and improved quality of life.[23] The authors recognised that this was an area for further research to improve outcomes for this population and their family members.

Gibbs *et al.,* further highlighted the need for palliative care for patients with heart failure and focussed on living with and dying from heart failure.[28] The findings suggest that patients with HF are not adequately cared for and suggest "coordinated heart failure team management of the disease and input from specialist palliative care".[28] "It is imperative that high quality evidence is gathered to assess how this benefit may be best derived and delivered to the many patients with this condition".[28]

Boyd *et al.,* examined the experiences of patients and their carers living with advanced HF in a prospective, community-based study.[25] They found that patients with advanced HF may benefit from specific models of care and involvement of health, social care services and specialist palliative care providers.[25] The authors suggest models of care should be developed, which focus on quality of life, symptom control, and psychosocial support for patients and their families while continuing active treatment.[25]

2.3 Recurrent Hospitalizations

Recurrent hospitalizations are common amongst patients with heart failure. In a clinical and healthcare cost study, Wong *et al*., evaluated the impact of a home-based advance care programme for end-stage HF patients.[22] "Advanced HF is a debilitating chronic disease that negatively impacts patients' quality of life (QOL) and is associated with high mortality rates with recurrent hospitalisation for HF exacerbations resulting in an economic burden that is substantial to both healthcare systems and to individuals and their families".[22] The authors observed that the findings could not be generalised due to the small sample and lack of a control group. The study however found that home-based PC reduces healthcare utilisation of end-stage HF patients, by reducing HF re-hospitalisations.[22]

Hospital based palliative care often equips the patient and family to manage the disease at home and results in decreased admissions. In a South African study, Des Rosiers *et al.,* conducted an evaluation of palliative care service for patients with advanced organ failure. The study considered admissions, place of death, and formal costs over a fixed period until death. The study used existing routine data to compare patients recruited into the novel intervention to a historical control group of patients before the service introduction. The data demonstrated that it reduced admissions and increased home deaths.[15] The authors found that a lack of advanced directives and patient education caused them frequent re-hospitalizations.[15] It is a valid study as the findings provide evidence that PC reduce costs and provide appropriate care in resource poor settings with high disease burden.

In another South African study, Hongoro *et al.,* conducted a cost analysis of a hospital-based palliative care outreach program in 2011.[41] The study aimed to establish the costs and cost drivers for a hospital outreach PC service in a low-resource setting and to highlight improvements and cost savings. The study found that of the 481 and 1902 patients registered for outreach and in-hospital visits, respectively, 4493 outreach hospital visits and 3412 in-hospital visits were done per year and the cost per outreach visit was 50% less than the average cost of a patient day equivalent for district hospitals.[41] The study concluded that hospital outreach services can decrease hospital admissions in low-resource settings thereby contributing to a better quality of life for patients at home.[41] There are however challenges that can impact cost effective palliative care services such as increasing poverty levels and an overburdened health care system should there be increased access.[41]

2.4 Early Referral

Early referral for palliative care is crucial in the management of heart failure to allow patients to participate in decision making around their illness. According to Whellan *et al*., end-of-life issues should be discussed early in the course of the disease management as patients with HF are at risk of sudden cardiac death.[40] Treatment of all HF patients should incorporate discussions of overall goals of care and an assessment of individual patient preferences for management in the terminal stages of illness, as well as in the event that a sudden change in health status occurs such as cardiac arrest with cerebral hypoxemia.[40] Optimally, these discussions should begin timeously as early as possible in the course of treatment and continue as the patient's condition advances.[40]

Interdisciplinary supportive care is part of a holistic approach in the care of the patient and family affected by HF. In a consensus statement by Goodlin *et al*., on palliative care in advanced HF, conference participants emphasized that interdisciplinary supportive care is important and a necessary component to manage HF function on all domains to enhance quality of life for patients and their families. The difficulty with prognostic prediction makes end-of-life planning appropriate early in HF care.[23]

Planning in advance for end-of-life care would assist the patient and family to cope with sudden events in the illness trajectory. Evangelista *et al.,* conducted a descriptive-exploratory study with 57 patients with HF to evaluate the types of PC services used by patients recently hospitalized for acute HF exacerbation.[42] The data supports the fact that PC referral is appropriate early in the HF disease trajectory long before hospice care is needed, and better symptom control.[42]

In addition, Stuart provides an evidence-based review of the principles underlying PC for HF, and suggests palliative care for late-stage HF care as a benefit to patients with HF and their family.[43] The author recognises the appropriateness of early palliative care and throughout the disease trajectory in conjunction with cardiac management of the disease. It is a valid study because it advocates for the integration of palliative care and hospice into the “continuum of heart failure care”, recommends optimization of treatment for high-risk patients while discouraging overuse of procedures and devices, while helping patients and families cope with an uncertain future.[43] The author subscribes to the view that the goal of palliative care for heart failure is to integrate knowledge of treatment advances and comfort measures and to provide them concurrently in a “seamless continuum” to patients with late-stage disease.[43]

Bakitas *et al.,* conducted content analysis of palliative care consultations (PPCs) to develop a palliative care intervention for patients with HF and their caregivers.[44] There were 132 HF patients with PCCs, of which 37% were NYHA functional class III and 50% functional class IV. Of the 132 HF patients, 115 had died by the time of the audit. Reasons documented for PCCs included goals of care, decision making, hospice referral, discussion, and symptom management.[44] The study found that PCCs are being initiated too late. The authors conclude that earlier referral would allow for a wider spectrum of palliative care services to be included in end of life care.[44]

2.5 End of Life Considerations

Murray *et al.,* advocate 'care for all at the end of life', reliable comfort and meaningfulness for patients with fatal chronic conditions to live well in the time left to them. They found that patients want to feel confident that their healthcare system can provide good appropriate care that ensures accurate medical diagnosis, treatment and prevent burdensome symptoms, continuity of care and involve them in patient-centred decisions, and support for their carers.[3]

Hunt *et al.,* in the report of the American College of Cardiology and American Heart Association Task Force on Practice Guidelines 2005 guideline update for the diagnosis and management of chronic heart failure in the adult highlights the following: Ongoing patient and family education regarding prognosis is recommended for patients with HF at the end of life, formulation and implementation of advance directives.[45] Further recommendation for these patients is the role of palliative and hospice care services to ensure continuity of medical care between inpatient and outpatient settings for patients.[45] They conclude that all professionals working with HF patients should examine current end-of-life processes and work toward improvement in approaches to palliation and end-of-life care.[45]

In a review conducted by Lemond *et al.,* on palliative care and hospice in advanced heart failure the authors outlined the general need for PC in advanced HF and detailed how palliative measures can be integrated into the care of those having this disease and explored end-of-life issues specific to these patients.[46] The authors emphasize that PC may improve patient comfort during the dying process.

Selman *et al.,* conducted a study to improve end-of-life care for patients with chronic heart failure.[8] Data on patients' and carers' preferences regarding future treatment modalities were collected, and communication between staff, patients and carers on end-of-life issues were investigated by semi-structured qualitative interviews, conducted with 20 patients with CHF (New York Heart Association functional classification III–IV), 11 family carers, 6 palliative care clinicians and 6 cardiology clinicians. The study outcome provided three recommendations for improving end-of-life care: sensitive provision of information and discussion of end-of-life issues with patients and families; mutual education of cardiology and palliative care staff, cardiologists to be trained in palliative care and communications skills and palliative care staff to be informed about HF management and agree to common palliative care referral criteria and care pathways. [8] These are valid recommendations and integral to end-stage HF to ensure appropriate care at the end of life.

In a qualitative UK study Ewing *et al.,* designed "to obtain carers' perspectives of key aspects of support needed during provision of end-of-life care at home and to develop a carer support needs assessment tool (CSNAT) suitable for use in everyday practice". The study found that bereaved carers' needs were divided into two groupings of support to assist them to provide care for their relative and support for themselves.[47] The CSNAT is a valid tool in that it provides a structure to the process of carer assessment to assist health care professionals in meeting existing recommendations that carers' needs be assessed. The tool includes assessment of physical, practical, social, financial, psychological and spiritual support needs that “current policy guidance indicates should be delivered to carers during end-of-life care”.[47]

Cortis *et al.,* in a UK qualitative study explored the experiences of patients with CHF in NYHA Classes II to IV, aged 80–90 years, attending a support programme. The study revealed that patient support programmes appeared to be an acceptable intervention for providing further coping strategies to enable them to live with the heavy burden of HF while remaining as independent as possible.[48] The findings showed the consequences of living with HF in terms of the physical, psychological, social isolation and existential concerns. This is a valid study in that it shows that a “formal assessment of patients' identified problems, available coping strategies and values and preferences for care would identify needs in this population. This would enable more tailored provision of services while acknowledging patients' own capabilities for dealing with their heart failure”.[48]

Formiga *et al.,* did a prospective interview-based survey on the end-of-life preferences of elderly people admitted to hospital for HF. It was found that planning end-of-life procedures and doctor-patient communication around these issues remains poor and needs to be improved.[20] The authors suggest that future planning should include policies to improve communication between HCPs and their patients for better outcomes.

2.6 The Impact of Heart Failure on Social, Psychological and Existential Domains

Twycross suggested that the focus should be on the '***person*** with disease, rather than the person with ***disease'***.[14] Communication should therefore be person-centred focussing not only on the physical decline but on the social, psychological and existential dimensions which may impact the individual.[14] Communication in PC is central in addressing the needs of this group and is well advocated for and described by the author.

Aldred *et al.,* explored the impact of advanced heart failure on older patients and informal carers. Their study found that older people suffering from heart failure have needs like those of patients with cancer. People diagnosed with cancer receive palliative care and support. This type of assistance must also be available for patients with advanced heart failure and their carers.[49]

Barnes *et al.,* further explored the characteristics and views of 213 family carers of heart failure patients older than 60 years. It was found that symptoms of depression, the age and patient NYHA were predictors of carer strain.[50] Quality of life was poorer when the spousal carer had more than 2 health conditions and symptoms of depression. The qualitative findings concluded that these carers were older women often with multiple health conditions whose health condition was especially affected by the impact of the responsibilities related to the change in circumstances.[50] Carers need practical and emotional support during care-giving which require increased specialist palliative care involvement in HF. An interdisciplinary care model between specialist heart failure, and palliative staff is recommended.[50]

According to Dracup *et al.,* on the emotional well-being in spouses of patients with advanced HF describe the emotional well-being of spouses of patients with HF, they identify factors associated with spouses' decreased emotional well-being, and compared emotional well-being between spouses with higher and lower levels of perceived control.[51] Counselling and information must be provided by the health care professional to carers who have low levels of perceived control to increase the sense of control which often contributes to increased emotional well-being.[51] It was found that younger spouses are particularly vulnerable for decreased emotional well-being and may require assistance.

Jaarsma *et al.,* reported that between 24–42% of people with heart failure may be depressed and may contribute to hospital readmission, functional decline and mortality.[52] Addressing symptoms of depression therefore would be important and not attributing it to the patient's current life situation but assisting the patient to find meaning in life and maintaining hope as far as possible.[52] The study found some gaps in the pharmacological and non-pharmacological treatment of symptoms it is however a valid study as it addresses the effects of depression in this vulnerable population.

In another study, Whellan *et al.,* the authors found a high percentage of patients with advanced HF have clinical depression, and the presence of depression correlated with higher symptom burden and increased risk of adverse outcomes, including hospitalizations and mortality. The depressed patients tended to be less adherent to taking medications and behavioural interventions. Options for treating depression in patients approaching the end of life include cognitive behavioural therapy, spiritual support and medications.[40]

Leeming *et al.,* conducted a secondary analysis of interview data that was generated for a qualitative longitudinal study looking at the experiences of patients, their family and professional carers.[24] A sub-set of patient, family and carers interview transcripts was selected for thematic analysis. Themes of social isolation; psychological issues and coping strategies; and existential concerns were identified. These are credible themes as psychosocial and existential issues are important aspects of the lives of patients suffering from HF and their families.[24] The authors explored the impact of advanced HF on the psychosocial and existential aspects of the patients' lives. Holistic management of the patient with HF include these domains and exploration should be encouraged and supported in these dimensions of the person.[24]

Westlake *et al.,* in a review on spirituality and suffering of patients with heart failure found that the lived experience of the disease demonstrates that people with HF frequently have social, psychological and existential distress.[53] The study suggests a more palliative approach which emphasises the "need for optimization of the physical, social, psychological and spiritual well-being".[53] The authors conclude that because of the unpredictable HF illness trajectory and the potential for sudden death there is the likelihood of unmet spiritual needs and suffering. It is therefore the responsibility of healthcare providers to assist patients with HF to address spiritual concerns and facilitate them on this journey.[54]

It would be important that HF physicians acknowledge the implications for practice such as that the dimensions beyond the physical are often important to people with HF, and that social isolation is likely to be present with many people feeling loss of meaning and purpose in their lives and that anxiety and depression will fluctuate throughout the illness.[24]

2.7 Communication

Ganca *et al.,* in a South African exploratory, qualitative study using a grounded theory approach highlighted the communication skills and needs of doctors when communicating a poor prognosis to patients and their families.[55] The study aimed to explore medical doctors' use of communication skills, identifying their needs to improve communication with patients and to determine understanding of palliative care. The study concluded that good communication skills are important for better patient outcomes and for improved professional communication.[55] It is a valid study as the aspect of effective communication is paramount to high quality palliative care.

Whellan *et al.,* using a survey of patients enrolled in an academic HF clinic, demonstrated differences between patient predicted life expectancy versus actual and model predicted life expectancy, on average overestimating longevity by 40%.[40] There seem to be significant gaps in what patients understand to be their prognosis and what physicians are able to communicate. Confusion between patient understanding of what to expect and what the HCP communicates about the disease and its impact increases the probability of an undesirable outcome[40] This could mean different things for different people about planning their final arrangement preferences. The research shows that communication about diagnosis and prognosis and end-of-life care planning is often not addressed and associated with adverse outcomes and severe symptom burden.[40]

Strachan *et al.,* in a descriptive qualitative study project designed to investigate barriers and solutions to implementing HF guidelines into the long-term care setting found that proactive care included insuring a HF diagnosis was communicated to medical caregivers, as an absence of an established HF diagnosis was a significant barrier to providing appropriate care.[56] Without a confirmed diagnosis the patient is not able to integrate the information of what is happening to them and be able to be part of the decision making process in the management of their illness.[56] A confirmed HF diagnosis allows for goals of care to be defined and therapy to be implemented alongside palliative care.

The literature has emphasised the importance of communication in PC and its role in addressing issues experienced by this population. Leeming *et al* and Goodlin *et al.*, found that the reason referring health care professionals often request consultations with PC services is to establish goals of care.[23, 24] Establishing goals of care should focus on discussions that involve the patient and family, conferring about their goals, values, and preferences in relation to the prognostic information, and outcomes appropriate to their situation. Although this has been found to be imperative for improved outcomes, the majority of patients with HF are often not referred for a PC consultation.[23, 24]

Walden *et al.,* in a study on educational needs of patients with advanced heart failure and their caregivers. The information and counselling needs of 82 outpatients and 74 caregivers were compared and evaluated. The study found that most important information and counselling needs related to having hope for a good quality of life, honest explanations from HCPs, and obtaining information to deal with the unexpected.[54] Ultimately, families require education and counselling to reduce the feelings associated with uncertainty.[54] This research was done at the time of transplant evaluation and the patient and caregivers had specific needs. These needs however do not differ from patients who are not eligible for transplant. Full understandable information is required to make informed decisions and should be afforded to the patient suffering with HF.

RATIONALE FOR THE STUDY

Numerous studies have demonstrated that patients with heart failure have similar symptom burdens to those with advanced malignant disease. However, palliative care is not yet a recognised component of care for heart failure patients in South Africa and there are few South African studies to explore the impact of palliative care on these patients. It is clear from the evidence that the quality of life for heart failure patients is affected by their disease therefore more in-depth studies are needed to illuminate the patient’s perspective on this issue.

During the course of this study Des Rosiers, *et al.,* published an article on the evaluation of the palliative care service at Victoria Hospital and determined that the service reduced admissions and increased home death rates compared with the same fixed time period of standard hospital care.[15] The staff views of the programme were positive, but data from the patient's perspective would bring another dimension of understanding of how the patient viewed the programme. Being able to determine whether the palliative care service assists them in coping with the physical, psychological, social and spiritual domains in their lives would inform efforts to improve the quality of life of these patients.

AIM OF THE STUDY

The aim of the study was to investigate the benefits of palliative care for patients with chronic heart failure at a Hospital-Based Palliative Care Service.

OBJECTIVES

1. To describe how participants were referred to the Abundant Life programme.
2. To determine the acceptability of the Abundant Life Programme to participants
3. To assess whether the programme has assisted them to play an active role in managing their heart failure.
4. To determine whether Abundant Life provided relief of the physical, psychological, social and spiritual problems experienced by participants.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Study design

The research was a cross-sectional descriptive qualitative study.

3.2 Study site

The study site was Victoria Hospital, a district hospital in the suburb of Wynberg in Cape Town, South Africa. The Abundant Life Programme at Victoria Hospital provides a palliative care service to patients with advanced illness.

3.3 Study population

The study population was adult patients diagnosed with heart failure New York Heart Association (NYHA) Functional Classes III-IV attending the Abundant Life Palliative Care Programme.

Selection Criteria

Inclusion criteria:

- Patients with chronic heart failure (NYHA III-IV)
- Adult patients
- Receiving palliative care from Abundant Life Palliative care service at Victoria hospital

Exclusion criteria:

- Children under the age of 18 years

- Patients who were comatosed or confused
- Patients too frail to take part in the study

3.4 Sampling

The study was conducted over period of 29 months. Purposive sampling was used to ensure maximum variation of study participants who met the selection criteria. It was purposive in that the participants had these predefined characteristics necessary for the study. It was planned to recruit 10-15 participants or until data saturation was reached. In qualitative methodology in-depth interviews can be conducted with few participants to provide the most detailed and rich data from the interviewee. [57]

3.5 Data Collection

3.5.1 Data Collection Tools

The first data collection tool was an interview guide for a semi-structured interview. The researcher initially developed the interview guide from information sourced from literature review and her own experience. It was revised in conjunction with the researcher's colleagues and guided by the study supervisors. To improve reliability the interview guide was piloted on two patients from two different health care facilities.

During the interview an iterative process was used to further develop the interview guide. The tool was developed in English and translated into Afrikaans by a first language Afrikaans speaker through a process of back translation to verify meaning and accuracy of translation.

The 2nd data collection tool was a data sheet for collection of demographic data. This was developed in consultation with colleagues and literature review. It was adjusted after advice and discussion with the study supervisors.

3.5.2 Data Collection Method

Introduction to the study site

The research study was introduced by the researcher to the Head of Medicine and the Abundant Life Programme Co-ordinator at the study site who subsequently informed their staff of how recruitment will take place.

Recruitment of participants

Potential participants were then confirmed and agreed to by the Head of Medicine and the Abundant Life Programme Co-ordinator when the research study was introduced. The potential participants were patients diagnosed with heart failure who were referred by the doctors at Victoria Hospital to the palliative care programme. During the recruitment period eligible patient participants were identified either from the in-patient setting or from the out-patient programme that fitted the criteria for NYHA Stage III or IV HF. The researcher was given a list of patients who met the criteria and an informal assessment was made to ascertain if the person was cognitively and physically capable of taking part. Initial approach by researcher assessed responses to confirm cognitive ability to take part in the interview. Those who were visibly too ill due to dyspnoea, confused or comatosed were excluded. The researcher recruited participants through a process of voluntary informed consent. Each potential participant was provided with an information sheet and an informed consent form in the language of their preference. This was explained, and the potential participant's understanding was checked, allowing time to ask questions and to decide whether or not they wished to participate. In addition to this the researcher explained to the potential participants that they may choose not to take part in the study or to withdraw from the study at any time and that they would still receive standard care provided at the Abundant Life Programme without prejudice.

Data collection was by means of semi-structured interviews conducted with each participant using the interview guide (appendix 4) with prompts. The interview was audio recorded with consent of the patients. Interviews were conducted at a venue most suitable to the informants either at Victoria Hospital, when they attended the support group or at their homes when it was suitable for them. All interviews were conducted privately in a comfortable and unpressured environment and assurance of anonymity and confidentiality was reinforced. In some instances, a family member was present on the patient's request. The researcher also ensured that respondents were physically comfortable and able to answer questions without becoming too tired or short of breath.

Participants were informed that they could stop the interview at any time and either withdraw from the study or continue the interview at a time and venue of their choice. They were interviewed in their language of preference. Interviews were conducted either in English, Afrikaans or mixture of both languages (vernacular peculiar to the

Cape Flats region in Cape Town). The interviews took between 30 - 45 minutes. Each interview was transcribed verbatim and translated into English.

Data Storage and Confidentiality

To ensure confidentiality the data collection sheet was identified by research participant number only. A master copy of participants and research participant numbers is held securely in the researcher's office. All hard copy and electronic data collected during the study was stored in a secure place and was reviewed only by the researcher and study supervisors. Data stored on the computer were password protected. The study material is kept in a locked cupboard, in a secure place, for 5 years and after which it will be destroyed.

3.6 Data Analysis

Thematic Analysis

Thematic Analysis is a foundational method for qualitative analysis. It identifies, analyses, and reports patterns (themes) within data. It organises and describes data set in detail and further interprets various aspects of the research topic [58] Braun and Clark advocate that "Through its theoretical freedom, Thematic Analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data." [58]

Aronson (1994) agrees in his pragmatic view of thematic analysis, "that from the conversations that take place in a therapy session or those that are encouraged for the sake of researching a process, ideas emerge that can be better understood under the control of a thematic analysis." [57]

Data analysis was conducted using the different phases of thematic analysis as described by Braun and Clark to organise and analyse the data. The phases below were discussed with the study supervisors:

Phase 1- Consisted of becoming familiar with the data. Each transcript was transcribed verbatim. The transcripts were checked against the tapes, read and reread several times so that the researcher could reflect and become familiar with the content and become immersed in the data. During this process initial ideas were noted.

Phase 2 – During this phase initial codes were generated from the transcripts. Data in each transcript were coded. This process was continued across the entire data set, collating data relevant to each code.

Phase 3 - Searching for themes: Collating codes into potential themes, gathering all data relevant to each potential theme. After familiarization with the data certain themes were identified from the transcripts and sub-themes developed from this. Themes and sub-themes that commonly arose from the interviews were identified and analysed by the principal investigator and discussed with the study supervisors. This was to check credibility of the themes.

Phase 4 - Themes were reviewed, adjusted and confirmed during this phase. There was ongoing checking to ensure the themes were reflecting and consistent with the raw data. Thematic mind maps were generated and to see if a coherent pattern was emerging of what was evident in the data and that the themes worked in relation to the coded extracts and the data as a whole

Phase 5 - Defining and naming of themes took place during this phase. There was a final analysis and modifying for each theme. This further refining of the themes was to ensure that they fitted into the data set.

Phase 6 - A report was produced and is presented in the Results chapter.

ETHICAL CONSIDERATIONS

Ethical approval was obtained from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (HREC 327/2011) and permission from the Provincial Department of Health in the Western Cape. Permission to conduct this research at Victoria Hospital was granted from the Chief Executive Officer at this site.

A commitment to ethical conduct was made clear to all those who agreed to be informants in the research before the research began. This included an undertaking of confidentiality and anonymity to all participants involved at every stage of the process.

This research study aimed to assess the benefits of palliative care in a medically vulnerable group. Definitions of what constitutes vulnerability vary from referring to individuals with limited cognitive ability and diminished autonomy or they may possess autonomy but lack capacity to communicate opinions regarding participation in research.[1, 2, 4]

The vulnerabilities in this study population stemmed from the fact that they were dependent upon medical advice or treatment and in a position of obligation to medical personnel**.** The participants were assured that neither their participation nor non-participation would result in a change in the level of their care. All participants were fully informed as to the nature of the issues raised to enable a good understanding of research objectives and procedures.

The Distress Protocol for data collection was as follows: All participants were informed before the interview that they could stop at any time during the interview. Any participant who appeared to be emotionally or physically distressed was offered the opportunity to cease the interview and either abandon or restart when they were comfortable. This distress protocol was also included in the initial informed consent form that each participant was required to read and sign. This was included so that patients were aware that they could have the option to terminate the interview due to distress. If the participants exhibited distress, they were also offered additional counselling by a professional counsellor.

This was required to be implemented with one patient who experienced dyspnoea and needed to stop the interview. Another follow-up interview was arranged at the patient’s convenience.

CHAPTER 4: RESULTS

In total 12 patients from the Abundant Life Programme were interviewed, 7 of whom were men and 5 women. The mean age was 52, the youngest participant was aged 27 years and the eldest was 78.

Patient Number	Gender	Age at the time of interview
1	Female	27
2	Female	70
3	Male	67
4	Male	58
5	Female	27
6	Female	51
7	Male	78
8	Female	54
9	Male	35
10	Male	55
11	Male	44
12	Male	63

Table 1: Demographic Data

The results of the themes that emerged from the interviews are presented in this chapter. Analysis of the 12 interviews produced five main themes. The themes are presented with quotes to support them and also vignettes and a case study to add a richer context. The first theme focused on issues of high service usage, the second on communication factors in palliative care. The third theme was on information and education, the fourth on the importance of resources in palliative care and the last theme, on the Abundant Life Programme. The table below is a summary of the themes that emerged from the data analysis.

THEME ONE	**THEME TWO**	**THEME THREE**	**THEME FOUR**	**THEME FIVE**
High Service Usage	**Communication Factors**	**Information and Education**	**Importance of Resources**	**Abundant Life Palliative Care Programme**
1.1 Recurrent Hospitalizations	2.1 Poor Communication of Diagnosis and Prognosis	3.1 Information to the Patient and Family	4.1 Care and Support from the Family	5.1 Care Provided by Abundant Life
	2.2 The Effects of Hearing Bad News	3.2 Perceptions Due to Lack of Information and Education	4.2 Lack of Family Support	
	Vignette – Discrimination and Poor Communication?	3.3 Impact on Self-Care	4.3 Loss of Independence	
			4.4. Socio-Economic factors	

Table 2: Themes and Sub-Themes Developed in Analysis

4.1 THEME ONE: HIGH SERVICE USAGE

This theme related to the high service usage by the participants.

Recurrent Hospitalizations

The first theme that emerged from this study was that of acute hospital admission. Most participants interviewed commented on their multiple readmissions to hospital after the initial insult. There was a high prevalence of anger and frustration amongst participants as to why this was happening to them:

As one carer reiterated when asked by the researcher about how many times in six months would the patient have gone into hospital (with an acute episode of HF):

> *"More than 10 times…more than 10 times!"* carer: P 4

The following ranges of responses were similar when the participants commented on their multiple admissions:

> "*They keep me there for 3 weeks again and after that they send me home…. for 5 years I struggle in and out of hospital, in and out of hospital nothing better, nothing better…about three or four times or five times in the year I go to hospital….."* P7

> *"in October and I er um was in hospital for four days first time, in January I was there for 16 days, from the 1st to the 16th"* P8

> *"I ended up like 3 or 4 times in ICU…. where yes, a few months yes, where in a period of a few weeks"* P10

> "*….in July month in 2012, from that time onwards I was in hospital every second week, say for about a week…um, this went on until December month…. that went on for about a year …more than a year I would say, yes…. every month in the hospital*" P11

> "*It went on like that for about three years…in and out hospital and then um…for three years it went on like that"* P12

4.2 THEME TWO: COMMUNICATION FACTORS

This theme relates to communication factors regarding the communication between the health care professional and the patient and illustrates the patient experiences of communication. The first sub theme is of poor communication of diagnosis and prognosis and the second sub theme relate to the responses by patients and families effects of hearing bad news.

4.2.1 Poor Communication of Diagnosis and Prognosis

In this study all the participants were recipients of 'bad news' and described their different responses in their communication about the illness. This depended on how long they were suffering with the condition before they were informed about their prognosis, their individual coping style and the healthcare professional's (HCP) manner of communication. Some expressed disappointment in the HCP's communication style or non-communication about their condition.

Participant 4 and his wife were not aware of his diagnosis. The family member said:

> *"They never explained to me…because I opened his folder I'd see heart failure, heart failure but then I would ask him (the patient) what is heart failure? Did your heart stop? What went wrong?"* Carer: P4

The following participant expressed anger at the lack of information received from the HCP and insisted that he be told about his diagnosis:

> *"look here, doctor I am not leaving here until you tell me what is really wrong with me I can't be in hospital every two weeks, at home and then back here again!".* P11

Participant twelve's interaction with the HPC was however more positive and said he just asked for the truth about his diagnosis:

> *"So, I told him (doctor) er, he must tell me the truth what is actually wrong with me? I want to know, and he told me"*. P12

4.2.2 Effects of Hearing Bad News

All those interviewed believed that there was nothing more that could be done for them before they had received palliative care. Many reported feeling a sense of abandonment and hopelessness. Some became depressed after they were informed of their diagnosis:

> *"They said yes sooner or later my heart is going to give in…at first I didn't take it so well…I did not want to drink the pills…because I think at the end of the day I'm [tog ma] going to die why must I still drink this pills and it is making me sick sometimes"* P9

> *"I just felt down, depressed".* P1

> *"I was actually shocked because I asked myself also what must I do now? … In the beginning when I found out it was very difficult for me to accept, and I told myself how you are going to care for yourself"* P11

Participant 8 seemed to resign herself to her apparent fate that unless able to afford dialysis from the private health care system there was nothing more that could be done:

> *"… and she asked me if she (doctor) could tell me what is actually wrong, so I said yes…. she said um, there is nothing they can do because my kidneys is finished and my heart. If I have money to er, er um to go for treatment (dialysis) then that will help but for now there is nothing they can do. So I said no it is ok, I haven't got money and um, its fine"* P8

Participant 6 had a different experience in that the health care professional was perceived as caring she however commented on still feeling depressed:

> *"He (doctor) just said and he rubbed my head, he was so sympathetic, so compassionate and he said, 'you know there is nothing we can do hey?' and that hit home, then I burst out crying"* P6

The following vignette demonstrates discrimination and bad communication which impacted negatively on the patient and family resulting in late diagnosis. This was not a patient-centred experience.

Discrimination and Bad Communication?

Participant 9 was a 31-year-old male who experimented fleetingly with addictive substances 6 years prior to his diagnosis and had voluntarily admitted himself to rehabilitation. He reported that whenever he presented for treatment and his file was accessed by the nursing staff, they would communicate in a disrespectful manner towards him. They commented on his drug usage and discussed it with each other as if the patient was not present. His mother was a retired professional nurse and reportedly witnessed him being treated in this manner at the hospital. This caused the patient and his family distress on numerous occasions. The patient reported becoming depressed. On investigation it was found that both his parents were diagnosed with heart failure before middle age and that his paternal uncle had died due to heart failure when he was young. He was subsequently referred to Groote Schuur Hospital for further investigation to ascertain whether he would be eligible for the heart donor registry. Reportedly his health deterioration was too far advanced for this type of intervention and he was referred to the Abundant Life Palliative Care programme for two years before he died during the winter of 2014. He explained the following during his participation in the study:

> *"They read my history and they said it was because I was using drugs and I am on drugs that is why I got sick…. they took their time to help me… because why? I took a letter I got from the day hospital that I showed them. …. wrote my history in there. They went according to the letter and took whole day to see me because why? of what they read…That I used Tik (methamphetamine) and I smoke ganja (dagga) and they went according it. At the day hospital they asked me like, um, to be honest, to tell them if I did any of this stuff and so I told them. I told them I did it five years ago and it is six years now and I was in a rehab, but they did not write that they just wrote that I was using drugs… unfortunately every time I went to hospital when they get my file the first thing they read is that I was using substances"*. P9

4.3 THEME THREE: INFORMATION AND EDUCATION

This theme highlights the importance of information and education to the patient and family, perceptions due to lack of information and education and the impact it has on self-care.

4.3.1 Information to the Patient and Family

One carer said about taking the patient to the palliative support group as a learning experience:

> *"I actually thought I would take her because why? you learn from others you learn from the patient and all those things. The next person that comes in there you learn from what to do for this"* Carer: P1

The following patient expressed a need for more information and education on their medical condition. She felt confident knowing that she could call when help was needed:

> *"I think it is because I am more aware of what is happening to me somebody gave me some information as to how I can do with what I must do and also it is because I just feel I got a safety net man" … "it is more that there is someone I can call"* P6

Participants 7 and 10 expressed confidence about the information they received in knowing how to take their medication and when it was necessary to seek further assistance:

> "*they talk about the heart, they talk about how you use the pills, If I take it, I take it under my tongue"* and continued "*When the pain start I take one, and if not ok I take another, if the third one …. Then, I phone the ambulance…* P7

Another said:

> *"Mmm, listening to the doctors and the sisters that is managing Abundant Life as to how to administer certain medication for the best effect, positive effect um very, very educational and informative" P10*

4.3.2 Perceptions Due to Lack of Information and Education

The following participants did not seem to accept the diagnosis of heart failure. There was denial about their condition and their perception as to why they had heart failure.

Participant 3 was diabetic and hypertensive for over 30 years. He believes his heart attack was caused by the injections he received to treat a skin condition:

> *"The doctor checked me out and told me that I had, had a heart attack. So, I told him it was because of that other doctor that gave me the injections" … "See I was alright I mean I had diabetes but I was fit…I was strong, the heart attack came because of that doctor and I did not go back to that doctor"* P3

Participant 4 overtly expressed his concerns and believed that his condition was caused by the medication he was given for his toothache. He denied that he had a problem with his heart and believed that he would recover completely:

> *"it started off with a toothache and then the doctors treated me and er and gave me tablets for the pain and then the tablets he gave me affected my heart'* P4

and goes on to say:

> *"…because of the water I understood it is the chamber that got hurt but you see I don't have a heart problem. I never had" … "I still want to ride my horses er, and I am getting slowly there…I still want to compete up country and at the moment I can't, I got no strength*" P4

4.3.3 Impact on Self-Care

The impact on self-care due to the patients receiving information and education from the palliative care service on their condition is evident from the reports below. Participants 2, 3 and 6 commented on knowing the benefits of monitoring their fluid intake and the consequences of ingesting excessive fluid. They understood that it would impact on their mobility and that monitoring their intake could reduce complications and recurrent hospitalizations.

Participants 2 and 3 demonstrated a strong need to try even harder to stick to their self-care regimen so as to stay out of hospital:

> *"I must take that a day, the water, I must just control it. my legs were standing like this* (showing extent of how legs were swollen) *must see here it was standing like this my feet were standing like this but no more I don't have that trouble no more. I never went to hospital again… (laughs)* P2

> *"they told me the last time I was at the hospital I must not drink much fluid and all those things and not lots of water, I must sip see?* (pointing to the one litre bottle of water) *….that is why I sip when I am thirsty"* P3

Participant 6 was not pleased about the restricted fluid intake but realised the benefits of it:

> *"And they now told me what to do, how much water I need to, how much fluids I need to take a day even if I am very thirsty I need to suck on an ice block and things like that… so I am finding it difficult to keep that litre a day…. I can walk from now, I could not walk from my bedroom to the toilet"* P6

4.4 THEME FOUR: IMPORTANCE OF RESOURCES

This theme relates to the importance of resources in the provision of palliative care with the first sub theme focussing on the care and support of the family to the patient and the lack thereof. Followed by the concerns of the patient's loss of independence and how it impacts the patient's sense of dignity. The second sub-theme relates to socio-economic factors impacting on the provision of palliative care with emphasis on the lack of financial resources and transport in this patient population.

4.4.1 Care and Support from Family

Most participants described the importance of family care and support or the lack thereof.

Participant 1 spoke about her carer (aunt) who had been caring for her like a mother as she did not have any other family member that could care for her:

> *"I mean she does a lot, everything, everything a mother would do for a child"* P1

Participant 2 spoke of her daughters providing for her needs by getting a carer while they were out at work during the day. The carer has given her assistance with her daily needs and assistance with her religious duties:

> *"She looks after me very nice…she…she is everything to me. She wash me…she takes care of me, she gives my food and you know... She looks after me very well…"* P2

Participant 8 also refer to a caring family:

> "*Can say they (family) do a lot I will say since January, I don't even make my bed. She (niece) is doing everything, she cleans, she cooks. Cos, she stays with me and everybody is very helpful. I came out of hospital, my one sister stayed here for the whole week".* P8

4.4.1.1 Lack of Family Support

While participant 5 expressed very little support from her family:

> *"my family is a lot...they all have their own problems, their own children".* P5

She however goes on to say that one of her family members had taken out funeral insurance cover for her and her family:

> *"she put me and all my children in a funeral insurance now I can't ask them for anything because they will tell me they are already doing that for me and so now I have just got to leave them like that…I can't expect anything from them now"* P5

Participant 6 is in a similar position and is concerned about who would care for her if her condition deteriorated. She has an aging mother and a daughter who seemed reluctant to get involved:

> *"She (mother) is in her seventies already, my daughter, I don't know if she is scared of what's lying ahead but she told me straight she is not gona do, she is not gona help but I don't know exactly what she mean… I dunno if she is scared, I think she is more scared maybe if the time comes she needs to wash me and feed me, I don't think she is strong enough to handle something like that"* P6

It was noted when the researcher asked if there were any family members present when she was given the ‘bad news’ her response was:

> *“I was alone… I was soul alone”* P6

Participant 7 felt abandoned by his adult children and referred to them as ‘passed away’ as they had no contact with him:

> *“My family passed away. They all for themselves they don’t want to have nothing to do with for us anymore...I’ve got no children! They do nothing for me!”* P7

4.4.1.2 Loss of Independence

Some participants were however concerned about their dependency on others and described their fears about becoming less independent as their disease progressed.

> “*this really affects a person really to think in the beginning you can do everything for yourself and then suddenly you are dependent on others”.* P11

Participant 10 expressed his loss of the traditional male role of providing for his family and the subsequent dependence on them and noted the role reversal within the household:

> *“My family they give their support, but it is rather difficult with me who is supposed to be the breadwinner in the family. I have always been the breadwinner in the family, a hard-working person but now I find myself in this situation. I find myself where the family has to go and work now”* P10

Participant 12 tried to maintain his independence for as long as possible:

> *"Well my family they are there for me, but I try not to be dependent on them you know. I try not to be dependent on them…They are there for me. But I try to do the normal things myself and I try, not I try, I do, I do my own cooking er what else? Everything you need to do er, most of them work man ja, they work like, my children. If I do get work then I do take it, if it's not like heavy. I do my own driving"* P12

4.4.2 Socio-Economic Factors Impacting on the Provision of Palliative Care

In this study the circumstances that limited access to care included lack of transport and financial difficulties. When the study started out the Abundant Life Palliative care programme had no patient transport. Nine of the twelve participants were interviewed pre–transport facility. The majority of those patients interviewed pre-transport (7 participants) expressed the desire for transport to get them to the support group. Due to their HF symptoms were unable to use public transport to get them to the service.

4.4.2.1 Financial

Participant 5 commented on her lack of resources as a single mother with four children, dependent on aging parents:

> *"Yes, for me it is tough because I have no money. They* (parents) *also never have money".* P5

One carer said:

> *"I have had no money for the last while otherwise I would have taken her to Abundant Life because I think it will help her I mean to learn many things".* P1: Carer

Another said:

> *"I don't always have money to come through (to attend support group) I really want to, and my heart is always here, here to be here to learn what to do for myself"* P11

4.4.2.2 Transport

Participant 3 expressed the need to attend but could not walk far to get into a train:

> *"I can't walk so far. Yes (can't come), but sometimes here is no transport…I can't get into the train"* P3

Participant 6 expressed the need to get to the support group for social interaction with other people but had no transport:

> *"What I'd like them to do for me….is actually arrange transport man so I can get up there you know and listen to everybody's story I'd like to go! (to attend AL programme) but who come fetch me? I don't always want to bother people to please take me"* P6

Participant 8 had to rely on transport from a family member who was not available:

> *"I was supposed to go there every week ne, but I don't have transport and it is awkward with the taxi to travel…' 'My son-in-law took me (to support group meeting) and he was working afternoon shift I couldn't …"* P8

4.5 THEME FIVE: ABUNDANT LIFE PALLIATIVE CARE PROGRAMME

This theme focussed on the care provided by the Abundant Life team, the importance of the resources provided by the support group and how the patients experienced the support received.

4.5.1 Care provided by Abundant Life

Interview findings revealed however that the majority of the participants found the support from the Abundant Life team or just attending the AL support group a positive experience except one patient who had reservations about it. Nine of those interviewed clearly expressed positive exposure from receiving palliative care.

Participant 1 expressed confidence in knowing that if something happened to her the palliative care team would be there:

> *"I just got sick again and then they are there for me ….they help me quicker and all that".* P1

The following participant appreciated the telephonic contact:

> *"there is nothing they can do more, I think they are very good! ….. every month they phone me. I really appreciate it".* P2

Participant 3 was satisfied with the physical relief and understanding the condition:

"I'm satisfied with the stuff they gave me it helps me I don't know how to explain but the medication they gave me is good and they helped me to understand …it is much better now…" P3

Participant 9 expressed feeling special about the prompt treatment received from the service:

> *"that's enough just to phone them to say you coming in and they'll go out of their way almost like they are going out of their way just to help you like you feel [nogal] like you are special"* P9

Participant 10 was inspired:

> *"By being present in the support group discussions and listening to conditions of other patients that alone has inspired me, made me a stronger person, mentally and spiritually, um listening to the caregivers,"* P10

He continues:

> *"… I am approaching life from a more positive approach. I have met one big family at Abundant Life and I don't want to miss out they are a great inspiration…both the patients and the medical staff!"* P10

When patients were admitted for acute exacerbations to the ward they would be visited by a PC professional from the service and reported that even though their condition was dire they felt cared for:

> *"So, whenever I landed in hospital… someone from Abundant Life would come to the, to the ward and talk to me and like inspire me and things like that and even if I was at home too...er Abundant Life would call me about once or twice per month to find out, er about my condition. It actually gives me some inspiration to see that there is actually people that cares...I found the last time I was in hospital was September 2013…and I have never been in hospital again going on now till this time".* P12

The same participant spoke about how the social dimension of his life was affected by the condition. His withdrawal from interaction with others and the subsequent frustration and how this improved after his exposure to palliative care:

> *"I was not going out, I didn't feel like being with people man. Cause, you see people do things when you with people and you just got to sit and whatever. Say maybe people get together they like to have music on and they, you know whatever they do, dance, whatever they do and here I stand, I can't, so it made me frustrated man you know, it made me frustrated"* P12

After being socially isolated for over three years he accepted an invitation from his neighbour:

> *"I enjoyed myself with them that I was surprised as much, as they were when I told them the morning 3'oclock I'm going home now, and you know I am actually looking forward to this year's New Year's Eve! I think it is because of the, you can put it all together like Abundant Life definitely plays a role here because of the caring."* P12

Participant 6 sees the palliative care group as her support:

> *"To me if I look at it from number one, I'm am not alone in this thing…You know meeting everybody and seeing people may be worse than me you know it just gives me that fight! My word that woman can't do that, I can still undo that plus there is the safety net, knowing that they are there you can just pick up the phone especially if it comes to medication" P*6

Participant 10 is a regular attendee at the palliative care support group and explains the support he derives from the driver and co-driver of the Abundant Life transport:

> *"Sometimes it makes me very emotional looking at some other patients with their family member with them and I pitch up alone but something that gives me great comfort is the fantastic person that come and pick me up that is UC (AL driver) and with the patients we have become so close and the crazy talks that go on in the van (AL transport). The AL driver and his co-pilot, a fantastic person, great character, always puts his patients first that means so much for me, not only for me but for everybody in that vehicle., He goes out of his way for us. And ja, so even though I come on my way on my own maybe… I got all that family and all that friends with me it means a lot to me"* P10

The following vignette is an outlier. The patient is not interested in attending the support group and did not acknowledge the palliative care received:

The following participant was not interested in attending the support group and was in denial about the diagnosis and prognosis:

> *"I thought why must I go there? I know I am going to come right. And, er I didn't go there…because… now you sit with people, with people that half die here and I am not dying I'm coming right slowly"* P4

The patient's wife reiterated:

> *"ja, what switched him off is it like there at the back of Abundant Life (booklet) was your pastor's telephone number your er, er, everything paid up you know like you will go to die tomorrow or something like that, that switched him off".* P4: Carer

He acknowledged the relief in symptoms but gave no credit to the palliative care treatment received. He spoke of the benefits of being positive about his condition:

> *"ja something like that…it's something good but it's not for me… Once you go that way, you think that way, then you go that way… But if you self-conscious you, you, positive, positive you survive, so far, I survived, I got no water on me anymore like it used to be".* P4

A CASE OF NEEDLESS PROTRACTED SUFFERING

This patient was 24 years old when she was diagnosed with mitral regurgitation after giving birth via caesarean section. An operation was planned but her condition deteriorated. The cardiac specialist informed her that her heart and kidneys were failing and there was nothing more they could do for her any longer. She was referred between tertiary and secondary medical facilities over a period of more than 3 years before she was referred to the palliative care service:

> *"and I got sicker and sicker and tired and tired and afterwards my back also got sore and I am on treatment…if I talk about it I feel sad…and I went back to hospital and they said, "you have this heart problem, but it is now much worse your entire heart is actually finished now…." He said there is nothing I can do for you anymore if you still had one healthy kidney then I could have perhaps still helped you, but you will have to go on like this until your heart and your kidneys give in, but he is not sure what it is going to be first…"*

She was referred to the social worker again but told the doctor: *"I am not going to him because that was the same social worker who said I must just die* (previously told by social worker*: "because you looked for this!") so, I said, I am rather going home. It seems that they did not want to help me… almost like I was negligent (*defaulting*), something like that".*

After being turned down for transplant and referred for numerous assessments to the tertiary and district medical facilities she was eventually referred to Abundant Life. She expressed relief and happiness at receiving care from the palliative care team:

"When I got there that time (to AL) so I felt happy, I got lots of support from them and saw that I was not the only sick person there, that there were others like me and look there they are looking forward to another day!"

This chapter focussed on the themes that have emerged from the participant interviews. These have related to high service usage due to recurrent hospitalizations in this population, communication factors with sub-themes on poor communication of diagnosis and prognosis by health care professionals, the effects of hearing bad news on the patient and family, a vignette was presented on the issue of discrimination in communication. The 3rd theme was on information and education with sub-themes focussing on information to the patient and the issue of denial. An outlier vignette was presented on denial and lastly the impact of information and education on self-care. The fourth theme was on the importance of resources with sub-themes on family support and the lack thereof, the loss of independence and the socio-economic factors impacting on the provision of palliative care with sub-themes on lack of finance and transport. The last theme described the care provided by the Abundant Life Palliative Care Programme focussing on the holistic care of the individual in palliative care with emphasis on the physical, psycho-social and spiritual domains of the person and in conclusion a vignette entitled, ‘a case of needless protracted suffering’. The following chapter will interpret the findings of the results chapter.

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

This study aimed to investigate the benefits of palliative care in patients with heart failure at a hospital-based palliative care service. People with HF suffer severe physical symptoms such as, dyspnoea, persistent coughing, tiredness, pain, nausea and constipation. There are also the psychological limitations of anxiety, depression and insomnia brought about by this condition with considerable deterioration and discomfort during the end-stage of the HF trajectory.[52] There is little research into PC in HF in the South African setting although international studies have demonstrated the relevance of PC in the management of HF.[8, 52] This is the first study at this site to conduct interviews exclusively with patients suffering from HF to investigate the patient's perspective. It was important to interview this group as this population is often overlooked for PC which has much to offer in terms of improving quality of life and future outcomes for people living with this chronic illness. Evidence suggests that integrating PC into HF management reduces the number of hospital admissions thereby contributing significantly to cost reduction for the health care system and for the patient. The themes that were reported in the Results Chapter will be discussed below.

5.2 FREQUENCY OF HOSPITAL VISITS AND ADMISSIONS

5.2.1 Admissions

Patients' acute exacerbations resulted in increased hospital admissions. Looking at the participant's experiences before they were exposed to palliative care with regard to frequency of hospitalization, the anger and frustration experienced was evident. The lack of personal control and ignorance of the disease left these participants feeling helpless and was exacerbated by their healthcare professional's perceived lack of engagement around the issue. This finding corroborates in the literature review in which Whellan *et al.,* describe the importance of defining goals of care for the individual.[40] The authors recommend assisting patients and their families to identify warning signs of worsening symptoms and offering clear instructions when the condition gets worse to empower the patient to cope with the disease.[40]

The lack of information or clear understandable explanations to the patient with organ failure results in them becoming part of a cycle of recurrent hospital admissions which places the patient and family in distress.[15] Most participants in this study felt disappointment towards their doctors because of the lack of effective communication to them and their families regarding the disease and its limitations. The participants described experiencing frequent hospital admissions before their enrolment in the AL programme and receiving palliative care. The holistic care provided by the AL interdisciplinary team included educating them on the condition of HF and palliation of the physical symptoms, providing emotional support through individual care and social group support. This care permeated the physical, social and emotional dimensions of their lives and helped the patient and family to manage problems themselves thereby improving quality of life. The study conducted by Des Rosiers *et al.,* at Victoria hospital demonstrated that hospital based palliative care reduced admissions and reduced hospital deaths.[15] This finding was also demonstrated by numerous authors in the literature review in which patients reported doctors had failed to communicate effectively with them and their families and that they had never explained what they needed to know in order to understand and manage self-care which would reduce the recurrent admissions.

Concerns were expressed by these participants that prior to joining the Abundant Life programme they did not know why repeated hospitalizations were happening to them. There were clear indications from the participants of not feeling empowered to manage their illness and being confused about factors that were beyond their control. Research findings by Evangelista *et al.,* showed that "patients who received less than 2 PC consultations had greater improvements in perceived control and activation than their counterparts and these increases were associated with greater reductions in symptom distress".[42] Many reported feeling abandoned by their doctors and this resulted in anger, isolation and frustration. The experience of the participants in this study demonstrates that patients want to know about their diagnosis and prognosis, so they can feel that they included in the decision making of their care.

Repeated hospitalisations are a trigger to identifying people who require palliative care as described previously in the literature review by SPICT and GSF.[12, 38] These tools help to identify people whose health is deteriorating and who would benefit from palliative specialist care. The use of a tool such as SPICT would be important as many patients similar to this group of participants are often identified too late to benefit from treatment or PC to meet their holistic needs. There are many needs that occur in an advanced illness such as HF. SPICT does not provide prognosis as the heart failure trajectory is unpredictable; but looks at clinical indicators of the deteriorating condition and risk of dying.   This allows the HCP to review and make decisions and provide opportunities to address the declining health issues with the patient and family thereby prioritising quality of life. The Abundant life team uses prognostic indicator guidance tools which allow them to identify people early with declining health issues.

The Gold Standards Framework also emphasises early detection of people with declining health and nearing end-of-life issues. It is a prognostic indicator guidance tool which allows for earlier planning and better future care options for this vulnerable group. It focuses on improving prediction of need for support rather than prognostication and emphasises the ‘surprise question’ of whether the HCP would be surprised if the person died within 6-12 months, the patient’s needs and choices and at least two clinical indicators. In HF the clinical indicators would encompass being in NYHA stage 111-1V with shortness of breath at rest or minimal exertion, repeated hospitalizations with symptoms of HF accompanied by physical or psychological burden despite medication. The utilisation of these tools by HCP’s would reduce hospital stays for these patients and contribute to quality of life and increased cost savings.[12]

5.2.2 Time spent in hospital

Time was a factor that was emphasized repeatedly in terms of the amount of days leading to weeks in hospital and the amount of years the re-hospitalization continued. Describing it as a struggle, with no improvement of their condition considering the amount of time spent in and out of hospital with acute exacerbations away from loved ones. This is a significant cost burden on the South African health care system and on the individual patient and family. This finding is consistent with the literature review in which Wong looks at the utilization of the health care system by HF patients and its association of recurrent hospitalisation for HF exacerbations and its negative impact on the quality of life of the patient, the family and the healthcare system.[22] Unnecessarily high re-hospitalization rates by this population increases healthcare costs and exposes the current management approaches to HF as less than ideal.

While there has been evidence-based treatment approaches, which may offer opportunities for reducing mortality and re-hospitalization rates in HF yet, without adequate discharge guidance and follow-up, many patients with HF are caught in a "revolving door" process, frequent re-admissions to hospital after being discharged, [7, 20, 21] that ultimately culminates in exacerbation and re-hospitalization. Hospital-based disease management programs in conjunction with PC programmes have consistently been shown to optimize care and reduce re-hospitalization rates in patients with HF. Wong *et al.,* found that PC complementing a chronic disease management programme serves to address these issues.[22]

5.2.3 Referrals

According to the World Health Organisation Palliative care is “applicable early in the course of illness”.[1, 2] According to Murray and Boyd’s description of illness trajectories[11] many heart failure trajectories fall into a long term category of limitations with intermittent and serious episodes where the patient is usually ill for many months or years as described by the patients interviewed in this study. Followed by occasional acute and often severe exacerbations. This is usually associated with admission to hospital and intensive care. The patient will usually endure many such episodes and be close to death with gradual deterioration in health and functionality and death is often sudden. Knowledge of the typical heart failure trajectory can assist the physician to communicate more effectively with the patient the need for early referral to PC. [60]

The uncertainty of the HF trajectory with its recurrent exacerbations, difficulty in anticipating the terminal phase and sudden death has made it difficult to decide on when to use supportive care until it is too late or the patient is close to death.[60] The literature supports that PC is therefore applicable earlier in the course of HF and should run concurrently with HF treatment options to improve quality of life. [52] These patients were in the NYHA 111-1V phase and according to the literature would be in the supportive and PC phase when they were referred to AL the goal of care was to maintain optimal symptom control and quality of life. Many studies have highlighted the importance of PC referral early in the course of symptomatic HF to assess the physical and psychosocial dimensions of the patient and to initiate discussions about advance care planning[16, 23, 40] and to address issues of uncertainty of prognosis. This would incorporate educating the patient and family about the nature of the illness by understanding the HF trajectory, meeting goals of care to maintain quality of life, hoping for the best and preparing for the worst situation.

5.2.4 Abundant Life reducing need for hospitalization

The aim of PC in HF is to relieve suffering and to promote the best quality of life for patients and their families. The findings of this study show that the AL programme strives to make this a priority for these patients. It is evident from the previous reports on frequent exacerbations and subsequent admissions that these participants noticed a decline in these incidents after PC. Before they were exposed to PC, participants experienced frequent health crises and uncontrolled symptoms on a daily basis. The lack of information about their illness was perceived as ignorance around the disease process. The findings further suggest that being with the AL programme meant a confirmed diagnosis which is essential to ensure optimal treatment and including the patient in the goals of care. These patients felt included in the decision-making process, informed and educated on the condition of HF and reported experiencing some control over their life situation albeit limited. This included recognising 'warning' signs of exacerbations early so that they could either call the AL team or to implement self-management to control their health issues. The finding illuminates the experience of the participants in this study under PC and demonstrates the influence that total care has on the alleviation of symptom burden.

When taking symptom burden into account the patient's needs should be timely anticipated and appropriately provided. According to the PC prognostic indicator tools recommended earlier, predicting needs rather than exact prognostication. Meeting the needs of the patient and family is more important for better outcomes than providing a time limit of the disease course of which the heart failure trajectory has proven to be difficult to predict.[13]

5.3. COMMUNICATION

In drawing comparisons between care reported by the participants before referral to the AL programme and care received from AL, the benefits of PC become evident. The interviews reveal that there was a positive impact on self-care and increased confidence and understanding of the condition under palliative care due to communication from the PC team. Although important in all health care, communication is of critical importance in PC as the issues of high morbidity and mortality in this population demand that management includes communication between patients, families and health care practitioners to improve patients understanding of their illness.

Communication and support has been identified by the patients and their families as an important priority to understanding the condition of HF and thereby improving their quality of life. Communication is central to palliative care and as important as physical care as it encompasses the dimensions of psychological, spiritual and social aspects of the patient.[1]

According to Salwitz, “the failure of doctors to talk to their patients about end-of-life decisions is a gap in vital communication and results in poor care, uncontrolled pain, futile treatment and death in hospital away from their loved ones”.[59] The patient with HF therefore needs to be included in the dialogue around their illness to take an active role in decision-making and to understand the illness and treatment of the disease throughout the course of the illness.

5.3.1 Communicating Prognosis

The lack of communication on full disclosure and prognosis was a problem amongst this group of patients and their health care providers. This problem became apparent during the interview conversations with these patients on the trajectory of their disease and its challenges. A study by Whellen *et al.,* found that there is often discrepancy in what patients understand their prognosis to be compared to what the HCP communicates.[40] According to these patients lack of clarity on the severity of the illness, how to manage the illness and what might happen often contributed to feelings of not being in control or knowing what to do and what to expect. The ignorance around prognosis in this instance translated to not understanding what the diagnosis of HF meant or confusing the terminology of the disease. The participants expressed a need for more emotional involvement and an ‘openness’ to initiate difficult conversations.

Participants in this study expressed feeling depressed on receiving the ‘bad news’. Many reported hopelessness when they were told there was nothing more that could be done for them leaving them feeling abandoned by their HCP and this resulted in anger, isolation and frustration. The idea that nothing more can be done should never be conveyed to patients. Palliative care has a lot to offer patients with regard to control of symptoms and emotional support, concerns about issues of dying such as pain, wanting to be involved in decisions and knowing what they can expect. According to Salwitz, patients are concerned about dying and when not addressed leaves them feeling abandoned and isolated.[59]

The Health Care Professional's manner of communication experienced by these patients before they were exposed to PC was problematic for the patients. They perceived that pertinent information regarding their illness was withheld from them. When HCP's do not communicate openly and honestly with their patients it can often result in anger and frustration with subsequent depression as have been witnessed with this group. Lemond *et al.,* found that this perceived lack of open communication may have a negative impact on quality of life.[46] This was evident in the interviews as many eluded feeling abandoned and frustrated by their doctors' lack of emotional involvement regarding conversation about the issues they were dealing with.

The results of this study show that these patients were confused about their diagnosis and prognosis. They wanted to know about what disease they were suffering from and what was going to happen to them. In a qualitative study by Rogers *et al.,* patients with HF believed that doctors were reticent to convey information about their prognosis while they would have preferred open discussion early in the trajectory about what they could expect.[7] The AL palliative care interdisciplinary team assisted in helping these patients and their families to understand their prognosis and how to manage the illness.

5.3.2 Decision Making

The evidence shows that these patients were not included in any decision-making process regarding their disease before enrolling in the AL programme and receiving palliative care. It would appear that their symptoms were treated with no adequate explanation of the disease process and its management. It may be that the clinician thought the explanations were adequate but did not check the patient's understanding of what they needed to know to empower them to deal with the impact of the disease. Meeting the needs of patients with HF and their families should include communication about health care decisions which are patient-centred in approach to understand their values and preferences first, then to inform them and to discuss treatment options. It is an ethical issue relating to autonomy as to whether the patient was adequately informed and included in the decision- making process.[1]

Health care professionals can assist the patient with many decisions while there is still the ability to do so. Patients need information early to think about future advance care plans. This will ensure that the patient participates in decision making regarding their symptom management and eventually end of life care. The lack of information provided to these individuals on their condition leads to a perception of uncertainty of their diagnosis and prognosis. This is confirmed in the literature review on patient preferences emphasizing that communication to define goals of care for the individual, and with the individual would be an important outcome for the patient and family.[34, 35] Clinicians can then design therapy that is congruent with these goals to enhance patient-centred care.[30] There were, however, barriers that impacted on communication regarding prognosis.

5.3.3 Barriers to effective Communication

It has been shown that barriers in communication prevented these patients from accessing adequate care thereby contributing to the frustration experienced by many patients and their families. Barriers to effective communication are often experienced in the medical setting.

The difficulty in addressing the topic of impending death can be emotionally charged for both HCPs and patients. Healthcare professionals, the patient and their families often do not know how to address the issue of death and dying and without training lack the competence to deal with the emotional responses during this difficult conversation.

language and cultural differences especially in a country such as diverse as South Africa can all impact on the process of effective communication and can be very difficult issues to process. There are many different cultures and customs each with its own protocols and perceptions on death and dying which can cause tension between health professionals, patients and their families.

A common barrier in communication is the use of medical jargon that is often complicated and unfamiliar to patients. The clinician needs to convey pertinent information carefully in clear and appropriate language then check the patient's understanding in a respectful manner while allowing them to tell their story. Doctors sometimes use jargon to avoid the difficulties of these conversations.

The perceived hierarchy of the doctor patient relationship is another barrier which can also hinder effective communication. Challenging the hierarchy when the doctor does not have the skills to check what the patient understands by the explanation that was given, is difficult for the patient. To the doctor HF is a simple and easy understood concept but a partner of one of the patients asked whether it meant that the heart stopped. There were however some participants who after suffering for a protracted period with the effects of the disease demanded answers from their HCP and this resulted in better understanding. However, others still had trouble with receiving appropriate communication. This could possibly be due to the patient’s own coping style or inability to ask the relevant questions to gain information about their illness when they do not know about their illness.

Discrimination was another barrier of communication that impacted on the provision of good palliative care in this group. Compassionate, non-judgemental care is a basic principle of palliative care. One of the participants described the fact that he was erroneously labelled as a drug addict and his perception was that he received inferior care. Lack of empathy from health care professionals can convey discrimination and become a barrier to effective communication when patients are deemed ‘responsible’ for their HF condition. This unfortunate situation could have been prevented if the health care professionals involved were trained in palliative care and communication skills and adhered to good ethical conduct.

Watson *et al.,* highlights, “the exploration of ethical issues that arise at the end of life is inherent to the work of palliative care”.[2] Evidence indicates that “with good communication and trust in the patient-professional relationship, patient's attitudes and concerns can be discussed sensitively, confusion unravelled, and fears dispelled".[2]

The literature further supports that the need for effective, compassionate communication in PC which has been shown to be of significant importance to improving patient's quality of care and quality of life. [46]

It is believed that these barriers contributed to a delay in the referral process to access PC thus delaying this group from receiving adequate care and understanding their situation.

5.5 INFORMATION AND EDUCATION

The participants of this study expressed the need for more information and education of their medical condition. Information and education answers questions thereby reducing uncertainty and equips the person with new knowledge. The findings on the lack of information is consistent in the literature review in which Metzger *et al.,* found that participants consistently report that they experience a myriad of symptoms and are not properly informed about their disease and its management.[30] The participants in this study reported the reverse experience after receiving palliative care and attending the support group which will be discussed below.

5.5.1 Information Sharing

These patients expressed pleasure in learning from others in the group and felt confident knowing that there was a ‘safety’ net when they needed help they could call the Abundant Life Palliative Care service. The practice of sharing information at the support group empowered the participants to take initiative to participate in the challenges they were facing. This opportunity motivated the patients to take responsibility and be accountable for their physical condition such as when they ingested too much fluid. In addition, receiving education of the different medications they were taking proved to be significant information they were interested in and decreases defaulting. Knowing how to use the medication properly and what it was meant for gave them some sense of control and contribution to their wellbeing. Education and counselling to improve self-management is one of the key constituents of good PC.[52]

Participation in the group translated into engagement with other patients, health care professionals and inclusion in the health care decision-making process. They reported feeling stronger and more confident to participate in social engagements. Leeming *et al*., found that one of the key themes of the impact of HF was that social isolation was likely to be present in this population.[24] Information empowers people and is valuable in contributing towards positive outcomes especially when it affects quality of life. It increased the understanding of the disease and decreased uncertainty of their condition. Education in this regard was valuable as it made the patients feel that they have the potential to participate in their care and therefore promoted autonomy and contribution[54]

5.5.2 Denial

Patients perceptions due to lack of information and education on the subject were noted. Denial and the lack of acceptance of the diagnosis of heart failure were evident in the account of two of the patients. They had a distorted perception of their reality regarding their diagnosis. In one instance rejected the PC service because it was viewed as hospice care ('he is not going to die tomorrow'). This is congruent with the research of Metzger *et al*., in which the patient is unaware of the availability of PC or not aware of their referral for PC.[30] While hospice care is palliative care the lack of the understanding of when palliative care is appropriate and when hospice care is needed can be seen as the same thing if the patient and family are not adequately informed of its benefits and therefore be rejected.[30]

Currently in SA most PC is provided by hospices and therefore people consider PC as end of life care as provided in hospices and worry that it means that they are close to the end of their life which may not be the case for HF patients. This confusion and, if the patient was not informed adequately of the benefits of PC, can result in rejection of PC by patients and families.[30] one of the patients exhibiting this denial had improved significantly under the care of AL but did not acknowledge this benefit.

Denial of the disease condition could have been used as a coping mechanism in an effort to process the traumatic experience of their condition. The patient is unable to understand and receive the information when under stress even when they are provided with factual evidence. This shock could lead to a skewed perception of the situation and be mistaken for reality.

The fluctuating disease trajectory of HF can fuel this denial. The importance of receiving PC during an exacerbation of the illness is not only in restoring improved physical capacity but also in providing a place to come to should there before another health crisis. Challenging the denial of the illness while continuing support to the patient and family can enhance understanding and acceptance of the illness. This would improve the patient's mindset and subsequent quality of life which could lead to better self-care. However, it is sometimes necessary to accept and work within the context of patient or family denial. Palliative care can still provide support.

5.5.3 Self-Care

The impact on self-care was profound when patients received information and education regarding their condition of heart failure from the palliative care team. This information on self-care translated into monitoring of their fluid intake to prevent the symptoms of weight gain, swollen ankles or feet and shortness of breath. After being exposed to the principles of self-care maintenance they knew the experience and consequences of fluid overload and the resultant re-hospitalizations and therefore took great care in preventing it. Recalling the experiences of being in fluid overload and not being able to walk because they were too swollen and subsequently being hospitalised seem to become a deterrent in this prevention strategy. These patients' acute exacerbations resulted in increased hospital admissions and emergency unit attendance but decreased significantly after PC intervention.

This is in line with a statement by Goodlin *et al.,* “that interdisciplinary supportive care is necessary throughout HF to manage function, psychosocial issues and symptoms to enhance quality of life for patients and families”.[23]

5.6 IMPORTANCE OF RESOURCES

5.6.1 Family Support

Chronic heart failure can make everyday activities exhausting. The person suffering with symptomatic HF experiences mobility issues and shortness of breath; and needs assistance with caring for themselves such as bathing and dressing. Further assistance would be needed with the general day to day issues of living. Family support was noted to be a very important indicator to the coping ability of the patients. There were concerns about dependency on others or fear of abandonment as the disease progressed. Recalling and comparing ability of once being able to work or do things for themselves and their families. They expressed fear of the loss of dignity and of their traditional roles in the family setting and the subsequent dependence on others. Family carers provide a supportive and crucial role in the management of HF but without support for the carer can impact negatively on their physical and emotional health. The literature supports the need for supportive care for both patients and families and to include family care providers into patient care as it results in less distress and improved outcomes.[23, 47]

5.6.2 Socio economic factors impacting on the provision of palliative care

The socio-economic factors impacting on the provision of PC highlighted in this study was the lack of transport and financial means. Attending support group activities for these patients were difficult due to mobility issues. They could not walk far to access public transport facilities and had no access to personal transport. This issue was further exacerbated by their lack of financial resources. Benatar found that most South Africans remain severely impoverished despite social grants, with inferior access to healthcare.[32] The country's disparities in wealth and health are among the widest in the world.

5.6.3 Support Group

The overall response about the care provided by the AL programme was positive. It was a resource that was readily available to these patients and their families understanding the need for frequent and continual care. It was described as making the patients feel 'special' this indicates that it was different to what they were used to in their healthcare. The care described was patient-centred and family-centred because it considered the patient's well-being in its entirety, namely, the physical, emotional, social, economic and spiritual needs. These aspects of total patient care were systematically taken into account and considered the persons relationship to the illness and their ability to meet self-care needs. The confidence instilled by knowing that if something happened even in death that they were cared for was important to them. Support from the group gave these patients a sense of dignity and belonging and made them approach life from a positive aspect even in the face of imminent demise. Literature by Goodlin *et al.,* emphasizes the need for a ‘patient-centred and family-focused’ structure in the management of the symptoms and the burdens of HF and ideally from diagnosis to end-stage of the disease.[23]

These patients all reported feeling a sense of alienation, loss of the meaning of life and a burden to others before referral to Abundant Life. However, they described feeling affirmed as an individual after receiving palliative care. Through their attendance and experiences at the support group, they were restored to the condition of an individual person no longer defined solely by their illness.[1] Chochinov describes ‘dignity conserving’ care and the restoration of a sense of ‘personhood’ as an essential aspect of clinical care.[62] According to Chochinov, “when personhood is not affirmed patients are more likely to feel that they are not being treated with dignity and respect and may feel worthless”.[62]

Dignity conserving care incorporates the core values of kindness, respect and dignity in a framework reminding practitioners of the importance of their attitude, behaviour, compassion and dialogue when caring for and about their patients. The Abundant Life personnel exhibited compassion and respect towards people attending the support groups reflecting these values.

A position statement by Leeming *et al*., from the European Society of Cardiology Heart Failure Association, highlights the importance of palliative care for patients with heart failure, with an all-inclusive approach that includes the social and spiritual needs of the patient.[24] The Abundant Life programme provides this kind of support to the patients entrusted to their care. The care provided relieved the distress about the illness, of always being in hospital and empowered them to a point where their illness was no longer a defining reality of their lives. Re-gaining control and improving their quality of life while reducing costs to the healthcare system~~.~~ This embodies the basic tenets of palliative care therefore it is imperative to integrate palliative care into routine care of people living with NYHA III and IV heart failure.

5.7 SUMMARY

This chapter has provided a discussion of the findings and has found it to be consistent with the relevant literature. It is expected that this approach has elicited a comprehensive description of experience of the heart failure patient under palliative care. It is evident that this experience was fraught with many frustrations and suffering. Heart failure has been perceived by these patients as a disease that needs to be understood from many perspectives and managed on numerous dimensions. It appears that the health care professional need to broaden their knowledge of palliative care and incorporate it into the management of heart failure to benefit patients and their families on both the physical and the psychological dimensions. The description of these suggestions were examined in the final chapter together with various recommendations. The present study is also evaluated in terms of its strengths and limitations.

Limitations of the study

There was a concern that as the researcher had previously volunteered at the Abundant Life Programme, that most of the participants knew the researcher. However, the participants appeared comfortable both during recruitment and the interview process and the ease with which the participant portrayed their narrative may have been because of the previous interactions.

The importance of the distress protocol was clear when it was used with one of the participants when they became distressed.

In some instances, patients were interviewed alone, and others were interviewed with their carers as per the patient’s request. Though there was not consistency in whether a family member was present or not, richer information was obtained when the carers were present. Triangulation and member checking is useful to establish credibility.[57] Furthermore, while the researcher attempted to ensure transferability, the research findings may not be generalizable and applicable to other settings.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

This final chapter presents an overview of the study's findings. Recommendations in terms of addressing the experience of patients with heart failure are given as well as suggestions for future research.

Conclusion

This study investigated the benefits of palliative care in patients with heart failure at a novel hospital-based palliative care organisation. Previous literature has suggested that palliative care is important in the management of heart failure. These suggestions are supported by the findings of this study. Despite this, many barriers exists in the effective delivery of palliative care for heart failure.

Barriers to care can make delivery of palliative care less effective but the health care professional has the responsibility to upskill to reduce negative impact on patients and their families by checking understanding and offering appropriate feedback. Previous literature has suggested that the training of the cardiac health care professional in palliative care is required to treat the patient holistically. The use of effective communication to convey information and education to the patient and family is therefore integral to this. The participants expressed a need for this type of engagement which they did not receive before their exposure to palliative care. The management of the heart failure disease trajectory should cover issues of diagnosis and prognosis that involve patient and family input with referral to palliative care if necessary. Objective one was to describe how participants were referred to the Abundant Life programme and the study findings confirmed that the patients were referred by the doctors at Victoria Hospital to the Abundant Life Palliative Care Programme.

Socio-economic factors affecting this group were another issue which impacted on the delivery of care. The impact of the lack of resources proved to be a major burden in accessing palliative care for this patient group. Frequent and prolonged hospital visits placed an increased demand on the patient, the family and scarce resources.

The Abundant Life palliative care programme is providing holistic care for the individual and families affected by heart failure and the findings suggests that it is improving the quality of life of this population. It is evident that all the participants of this study would have benefitted from early palliative care intervention. However, beliefs and attitudes in health care practises presented major barriers to timely access of their care. Previous research has shown that palliative care is beneficial in the early stages of the disease long before hospice care is needed for the end-stage to improve the symptom burden.[42]

Recommendations

In order for the needs of patients with heart failure and their families to be met ongoing advocacy and research work need to be done at grassroots level and national level to support the work of hospital-based palliative care organisations such as the Abundant Life Programme. It has been shown that hospital-based palliative care services are cost effective in reducing hospital admissions, hospital deaths and is associated with positive outcomes.[15, 17, 22]

Funding and support from the South African government to the department of health and universities are needed to ensure that palliative care can become part of normal medical care and management so that every hospital has a palliative care facility. This should also include a system of debriefing support to staff and a work replacement system to prevent burnout of the health care professional. The integration of palliative care with heart failure management could be incorporated into a patient-centred heart failure model that could benefit the patient and family and the scarce resourced South African health care system.[23]

A further recommendation would be the urgent escalation of financial assistance from the South African government social services department to patients with heart failure and their care givers to ameliorate the negative effects of the disease on household expenses.

‘Palliative care for all’ education should be incorporated into all health care professional training across specialities and community care providers and other key stakeholders to ensure that advice and support with symptom management are afforded to people with heart failure through to end of life care.

Further research should be undertaken to identify when to initiate palliative care for heart failure and how to integrate palliative care into cardiology service for optimal care of patients with heart failure in the South African context and could assist and guide the department of health and health facilities in the provision of palliative care for all.

REFERENCES

1. Doyle D. Oxford textbook of palliative medicine. 3rd ed. Oxford: Oxford University Press; 2005.
2. Watson MS. Oxford handbook of palliative care. Oxford; New York: Oxford University Press; 2005.
3. Murray SA, Sheikh A. Palliative Care Beyond Cancer: Care for all at the end of life. BMJ. 2008;336(7650):958-9.
4. Hanks GWC. Oxford textbook of palliative medicine. 4th ed. ed. Oxford Oxford University Press; 2010.
5. Lokker ME, Gwyther L, Riley JP, van Zuylen L, van der Heide A, Harding R. The Prevalence and Associated Distress of Physical and Psychological Symptoms in Patients With Advanced Heart Failure Attending a South African Medical Center. J Cardiovasc Nurs. 2016;31(4):313-22.
6. Ward C. The need for palliative care in the management of heart failure. Heart. 2002;87(3):294-8.
7. Cushen M. Palliative Care in Severe Heart-Failure. Brit Med J. 1994;308(6930):717.
8. Selman L, Harding R, Beynon T, Hodson F, Coady E, Hazeldine C, et al. Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't". Heart. 2007;93(8):963-7.
9. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. J Pain Symptom Manage. 2006;31(1):58-69.
10. Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness - We need to move from prognostic paralysis to active total care. Brit Med J. 2005;330(7492):611-2.
11. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005;330(7498):1007-11.
12. Centre TGSF. The Gold Standards Framework in palliative care: Information leaflet for patients, families and friends Shrewsbury: The Gold Standards Framework Centre; n.d.
13. Thomas K, Free A. Prognostic Indicator Guidance. England: National Gold Standards Framework Centre England; 2008.
14. Twycross R. Handbook of palliative care. Family Practice. 1999;16(4):451-.
15. Desrosiers T, Cupido C, Pitout E, van Niekerk L, Badri M, Gwyther L, et al. A hospital-based palliative care service for patients with advanced organ failure in sub-Saharan Africa reduces admissions and increases home death rates. J Pain Symptom Manage. 2014;47(4):786-92.
16. Evangelista LS, Liao S, Motie M, De Michelis N, Lombardo D. On-going palliative care enhances perceived control and patient activation and reduces symptom distress in patients with symptomatic heart failure: a pilot study. Eur J Cardiovasc Nurs. 2014;13(2):116-23.
17. Kavalieratos D, Mitchell EM, Carey TS, Dev S, Biddle AK, Reeve BB, et al. "Not the 'grim reaper service'": an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. J Am Heart Assoc. 2014;3(1):e000544.
18. Gibbs J, McCoy A, Gibbs L, Rogers A, Addington-Hall J. Living with and dying from heart failure: the role of palliative care. Heart. 2002;88(suppl 2):ii36-ii9.
19. Bradshaw D, Pillay-Van Wyk V, Laubscher R, Nojilana B, Groenewald P, Nannan N, et al. Cause of death statistics for South Africa: Challenges and possibilities for improvement 2010; cited 2017 11 November]. Available from: http://www.mrc.ac.za/bod/cause_death_statsSA.pdf.

20. Formiga F, Chivite D, Ortega C, Casas S, Ramon JM, Pujol R. End-of-life preferences in elderly patients admitted for heart failure. QJM. 2004;97(12):803-8.

21. Formiga F, Lopez-Soto A, Navarro M, Riera-Mestre A, Bosch X, Pujol R. Hospital deaths of people aged 90 and over: end-of-life palliative care management. Gerontology. 2008;54(3):148-52.

22. Wong RCC, Tan PT, Seow YH, Aziz S, Oo N, Seow SC, et al. Home-Based Advance Care Programme is Effective in Reducing Hospitalisations of Advanced Heart Failure Patients: A Clinical and Healthcare Cost Study. Ann Acad Med Singap. 2013;42(9):466-71.

23. Goodlin SJ, Hauptman PJ, Arnold R, Grady K, Hershberger RE, Kutner J, et al. Consensus statement: palliative and supportive care in advanced heart failure. Journal of Cardiac Failure. 2004;10(3):200-9.

24. Leeming A, Murray SA, Kendall M. The impact of advanced heart failure on social, psychological and existential aspects and personhood. Eur J Cardiovasc Nurs. 2014;13(2):162-7.

25. Boyd KJ, Murray SA, Kendall M, Worth A, Frederick Benton T, Clausen H. Living with advanced heart failure: a prospective, community based study of patients and their carers. Eur J Heart Fail. 2004;6(5):585-91.

26. Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. J Pain Symptom Manage. 2007;34(4):393-402.

27. Horne G, Payne S. Removing the boundaries: palliative care for patients with heart failure. Palliat Med. 2004;18(4):291-6.

28. Gibbs JSR, McCoy ASM, Gibbs LME, Rogers AE, Addington-Hall JM. Living with and dying from heart failure: the role of palliative care. Heart. 2002;88:ii36-ii9.

29. Quaglietti SE, Atwood JE, Ackerman L, Froelicher V. Management of the patient with congestive heart failure using outpatient, home, and palliative care. Prog Cardiovasc Dis. 2000;43(3):259-74.

30. Metzger M, Norton SA, Quinn JR, Gramling R. Patient and family members' perceptions of palliative care in heart failure. Heart Lung. 2013;42(2):112-9.

31. Gwyther L. National policy framework for palliative care 2016. Available from: http://www.hpca.co.za/item/national-policy-framework-for-palliative-care.html.

32. Benatar SR. Medicine and health care in South Africa—five years later. New England Journal of Medicine. 1991;325(1):30-6.

33. Mayosi BM, Benatar SR. Health and health care in South Africa--20 years after Mandela. N Engl J Med. 2014;371(14):1344-53.

34. Pocock SJ, Wang D, Pfeffer MA, Yusuf S, McMurray JJ, Swedberg KB, et al. Predictors of mortality and morbidity in patients with chronic heart failure. Eur Heart J. 2006;27(1):65-75.

35. Lee DS, Austin PC, Rouleau JL, Liu PP, Naimark D, Tu JV. Predicting mortality among patients hospitalized for heart failure: derivation and validation of a clinical model. JAMA. 2003;290(19):2581-7.

36. Kavalieratos D, Kamal AH, Abernethy AP, Biddle AK, Carey TS, Dev S, et al. Comparing unmet needs between community-based palliative care patients with heart failure and patients with cancer. J Palliat Med. 2014;17(4):475-81.

37. Hauptman PJ, Swindle J, Hussain Z, Biener L, Burroughs TE. Physician attitudes toward end-stage heart failure: a national survey. Am J Med. 2008;121(2):127-35.

38. Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ Support Palliat Care. 2014;4(3):285-90.

39. Maas EA, Murray SA, Engels Y, Campbell C. What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice. BMJ Support Palliat Care. 2013;3(4):444-51.

40. Whellan DJ, Goodlin SJ, Dickinson MG, Heidenreich PA, Jaenicke C, Stough WG, et al. End-of-life care in patients with heart failure. J Card Fail. 2014;20(2):121-34.

41. 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. J Pain Symptom Manage. 2011;41(6):1015-24.

42. Evangelista LS, Liao S, Motie M, De Michelis N, Ballard-Hernandez J, Lombardo D. Does the type and frequency of palliative care services received by patients with advanced heart failure impact symptom burden? J Palliat Med. 2014;17(1):75-9.

43. Stuart B. Palliative care and hospice in advanced heart failure. J Palliat Med. 2007;10(1):210-28.

44. Bakitas M, Macmartin M, Trzepkowski K, Robert A, Jackson L, Brown JR, et al. Palliative care consultations for heart failure patients: how many, when, and why? J Card Fail. 2013;19(3):193-201.

45. Hunt SA, Abraham WT, Chin MH, Feldman AM, Francis GS, Ganiats TG, et al. ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult—Summary Article. Journal of the American College of Cardiology. 2005;46(6):1116-43.

46. Lemond L, Allen LA. Palliative care and hospice in advanced heart failure. Prog Cardiovasc Dis. 2011;54(2):168-78.

47. Ewing G, Grande G, National Association for Hospice at H. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. Palliat Med. 2013;27(3):244-56.

48. Cortis JD, Williams A. Palliative and supportive needs of older adults with heart failure. Int Nurs Rev. 2007;54(3):263-70.

49. Aldred H, Gott M, Gariballa S. Advanced heart failure: impact on older patients and informal carers. J Adv Nurs. 2005;49(2):116-24.

50. Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S, et al. Characteristics and views of family carers of older people with heart failure. Int J Palliat Nurs. 2006;12(8):380-9.

51. Dracup K, Evangelista LS, Doering L, Tullman D, Moser DK, Hamilton M. Emotional well-being in spouses of patients with advanced heart failure. Heart & Lung: The Journal of Acute and Critical Care. 2004;33(6):354-61.

52. Jaarsma T, Beattie JM, Ryder M, Rutten FH, McDonagh T, Mohacsi P, et al. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail. 2009;11(5):433-43.

53. Westlake C, Dyo M, Vollman M, Heywood JT. Spirituality and suffering of patients with heart failure. Progress in Palliative Care. 2013;16(5-6):257-65.

54. Walden JA, Dracup K, Westlake C, Erickson V, Hamilton MA, Fonarow GC. Educational needs of patients with advanced heart failure and their caregivers. The Journal of Heart and Lung Transplantation. 2001;20(7):766-9.

55. Ganca LL, Gwyther L, Harding R, Meiring M. What are the communication skills and needs of doctors when communicating a poor prognosis to patients and their families? A qualitative study from South Africa. S Afr Med J. 2016;106(9):940-4.

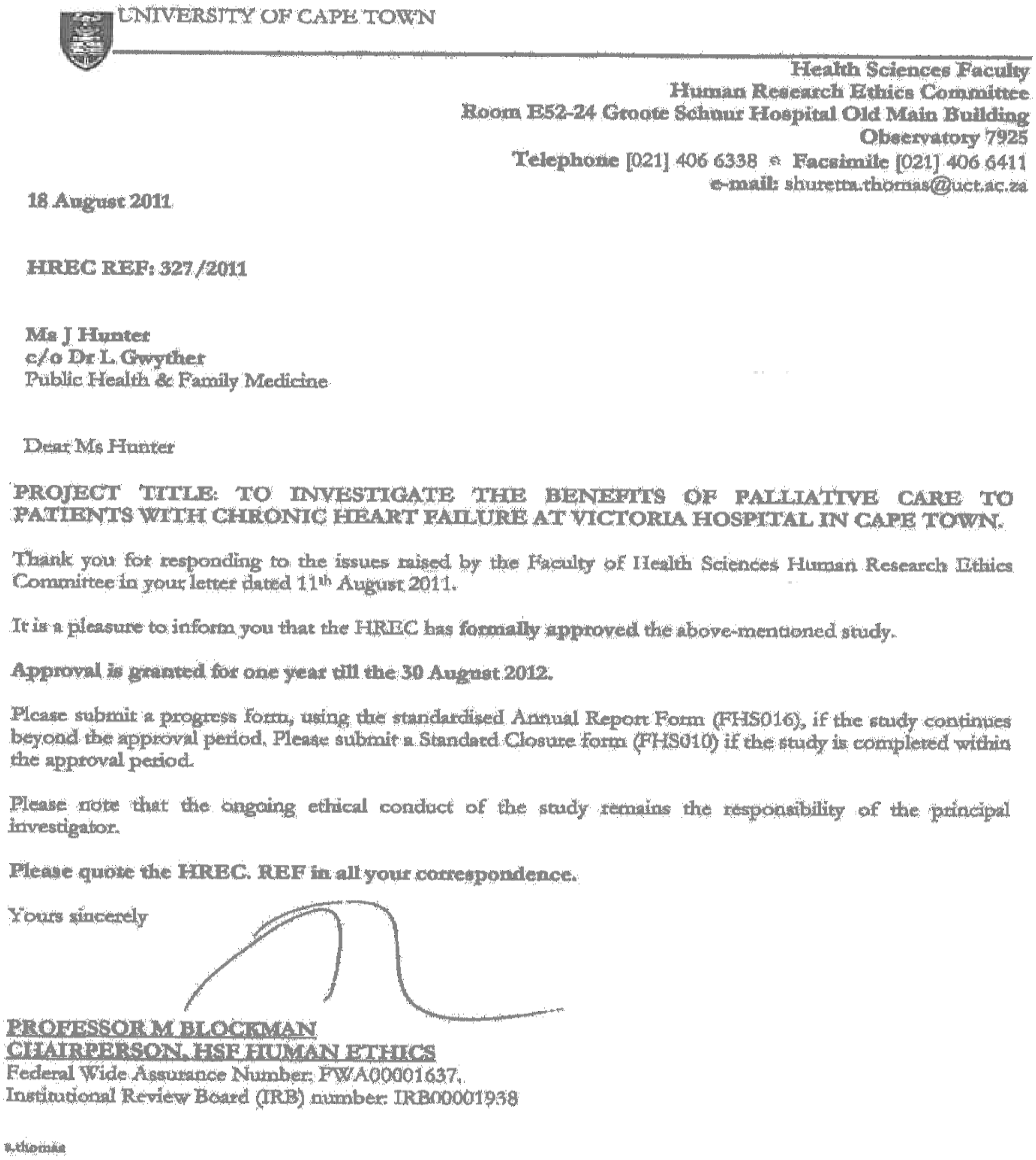
56. Strachan PH, Kaasalainen S, Horton A, Jarman H, D'Elia T, Van Der Horst ML, et al. Managing heart failure in the long-term care setting: nurses' experiences in Ontario, Canada. Nurs Res. 2014;63(5):357-65.

57. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. BMJ. 2000;320(7226):50-2.

58. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.
59. Salwitz JC. The physician benefits from palliative medicine 2014. Available from: https://www.kevinmd.com/blog/2012/04/physician-benefits-palliative-medicine.html.

60. Murray SA, Kendall M, Boyd K, Worth A, Benton TF. Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. Palliat Med. 2004;18(1):39-45.
61. Benatar SR. Global disparities in health and human rights: a critical commentary. American Journal of Public Health. 1998;88(2):295-300.
62. Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. BMJ. 2007;335(7612):184-7.

APPENDIX 1: ETHICS APPROVAL



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za

18 August 2011

HREC REF: 327/2011

Ms J Hunter
c/o Dr L Gwyther
Public Health & Family Medicine

Dear Ms Hunter

PROJECT TITLE: TO INVESTIGATE THE BENEFITS OF PALLIATIVE CARE TO PATIENTS WITH CHRONIC HEART FAILURE AT VICTORIA HOSPITAL IN CAPE TOWN.

Thank you for responding to the issues raised by the Faculty of Health Sciences Human Research Ethics Committee in your letter dated 11th August 2011.

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 30 August 2012.

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

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

s.thomas

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) **This serves as notification of annual approval, including any documentation described below.**			
☑ Approved	Annual progress report	Approved until/next renewal date	30/08/2013
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	4/12/12

Principal Investigator to complete the following:

1. Protocol Information

Date form submitted	11 AUGUST 2011		
HREC REF Number	327/2011	Current Ethics Approval was granted until	30 August 201
Protocol title	AN INVESTIGATION OF THE BENEFITS OF PALLIATIVE CARE FOR PATIENTS WITH CHRONIC HEART FAILURE AT A NOVEL PALLIATIVE CARE SERVICE		
Protocol number (if applicable)			
Principal Investigator	[illegible] Hunter		
Department / Office Internal Mail Address	DEPARTMENT OF FAMILY MEDICINE		

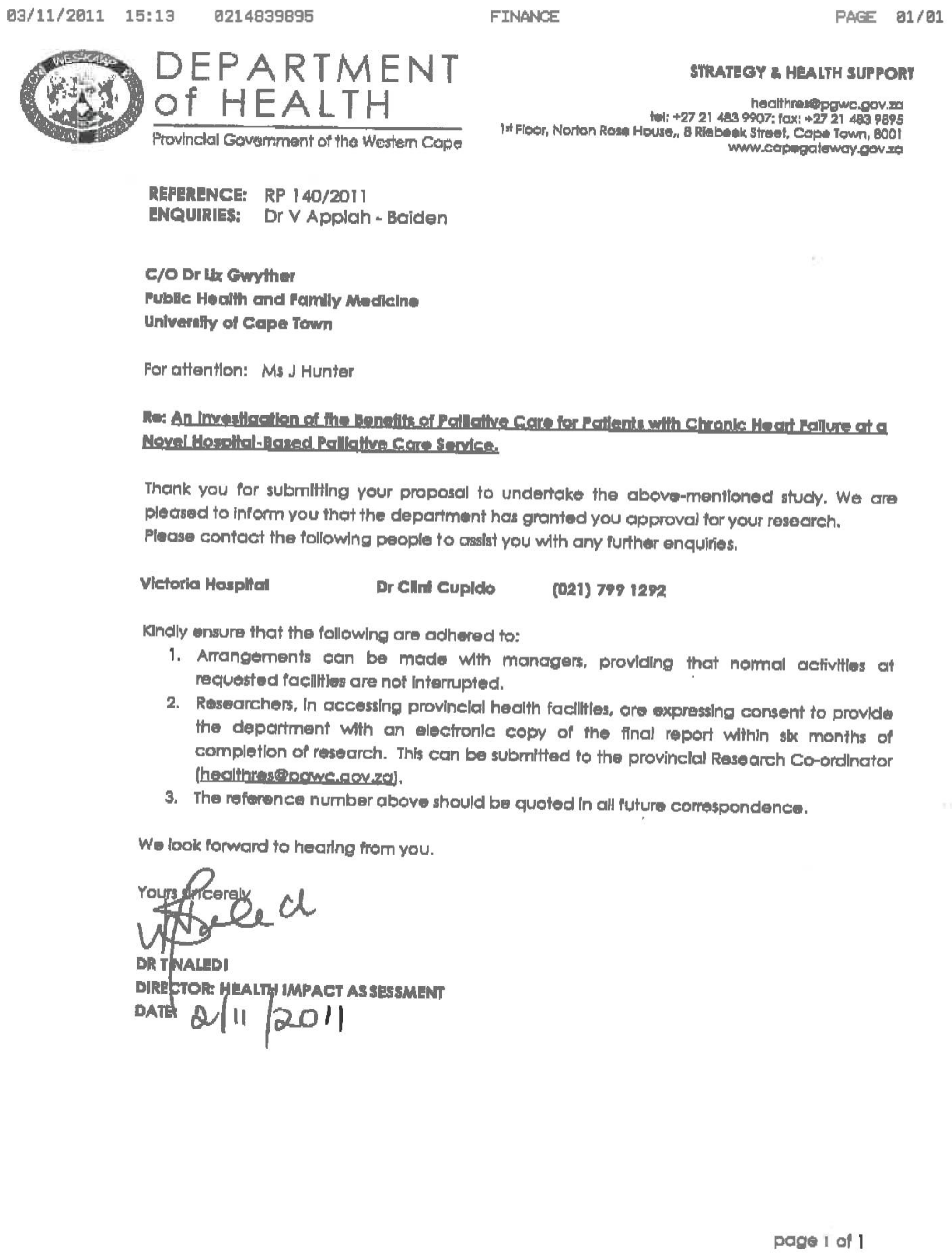
1.1 Does this protocol receive US Federal funding?	☐ Yes	☑ No
1.2 Has sponsorship of this study changed? If yes, please attach a revised summary of the budget.	☐ Yes	☑ No

2. List of documentation

RESEARCH ETHICS COMMITTEE
2012 -12- 03
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

APPENDIX 2: LETTER OF APPROVAL



03/11/2011 15:13 0214839895 FINANCE PAGE 01/01

DEPARTMENT
of HEALTH
Provincial Government of the Western Cape

STRATEGY & HEALTH SUPPORT

healthres@pgwc.gov.za
tel: +27 21 483 9907: fax: +27 21 483 9895
1st Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: RP 140/2011
ENQUIRIES: Dr V Appiah - Baiden

C/O Dr Liz Gwyther
Public Health and Family Medicine
University of Cape Town

For attention: Ms J Hunter

Re: An Investigation of the Benefits of Palliative Care for Patients with Chronic Heart Failure at a Novel Hospital-Based Palliative Care Service.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.
Please contact the following people to assist you with any further enquiries.

Victoria Hospital	**Dr Clint Cupido**	**(021) 799 1292**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (healthres@pgwc.gov.za).
3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely

DR T NALEDI
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 2/11/2011

page 1 of 1

APPENDIX 3: INTERVIEW GUIDE

Interview Guide for: To Investigate the Benefits of Palliative Care to Patients with Heart Failure at Victoria Hospital

1. Tell me about your illness?
2. What have you been told by your doctor about your illness?
3. How did you come to be with the Abundant Life Programme?
4. What has Abundant Life done for you? What is being done for you physically, psychologically, socially and spiritually?
5. How has it helped you?
6. What is it not doing for you?
7. What do your family do for you?
8. Is it easy for your family to come to the Abundant Life Programme?

APPENDIX 4: INFORMATION SHEET

Information Sheet for: To Investigate the Benefits of Palliative Care to Patients with Heart Failure at Victoria Hospital

Thank you for giving your time to hear about our study.

This information sheet tells you about a study that you may wish to take part in. You may have some further questions to help you decide whether you want to take part. You can ask any further questions from your clinical team, from the researcher, or using the telephone numbers at the end.

Thank you for thinking about whether you want to take part. Please take your time to make a decision.

What is the purpose of the study?

We are investigating how people with chronic heart failure are accessing and experiencing the benefits of palliative care at the Abundant Life Centre.

Do I have to take part?

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

What will happen if I take part?

A researcher will speak to you and ask you questions about you and your health, and this may include other problems you have. It will take around 30-45 minutes for the interview. We ask your permission to tape this interview. We would like to hear about the care you have received and how it has affected your life. This information sheet is for you to keep.

Benefits of the study

The anticipated benefits are in identifying and assessing the help provided to people with heart failure and what we can do to improve this.

Risks of the study

We recognize that shortness of breath may be a problem for some participants and may be unable to complete the interview at one session. In order to reduce this risk the interview can be extended or a follow-up interview could be arranged later in the day or on another day. If you feel distressed you are free to withdraw from the study and will still receive your usual care.

Will my taking part in this study be kept confidential?

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

How will I know about the results of the study?

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

Who is organising the research?

If you need to talk to anyone about this research, you can contact the following people.

If you have any questions about the study:

The researcher, Joy Hunter Tel 021 788 3246/083 660 4374

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

UCT Research Ethics Committee:

Mrs Lamees Emjedi

Research Ethics Committee

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

Telephone: 021 406 6338

APPENDIX 5: CONSENT FORM

Consent form for: To Investigate The Benefits of Palliative Care in Patients with Heart Failure at Victoria Hospital

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

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.
3. I agree to take part in the above study.
4. I agree to the interview being tape recorded

Name ________________________________

Signature/Mark_________________________ Date ________________

Researcher: Signature __________________ Date: _______________

Witness: Name
(from clinical team or family member)

Signature ________________________________ Date: ________________