IMPACTS OF TRANSITIONAL PALLIATIVE CARE FOR END-STAGE HEART FAILURE PATIENTS

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Impacts of Transitional Palliative Care for End-Stage Heart Failure Patients

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CERTIFICATE OF ORIGINALITY

I hereby declare that this thesis is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor material that has been accepted for the award of any other degree or diploma, except where due acknowledgement has been made in the text.

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Thesis title: Impacts of Transitional Palliative Care for End-Stage Heart Failure Patients

Abstract

Background: Heart failure (HF) is a chronic, progressive life-threatening illness. Along the illness trajectory, in particular approaching to end-stage, patients with HF suffer from significant physical and psycho-social-spiritual symptom burden, which are associated with increased hospital admissions and impaired quality of life (QOL) on these patients. Given that HF poses tremendous burden on patients, healthcare system, and society, the impact of HF can be reduced if effective management is implemented. Post discharge care coordination is still an unmet need for many patients with end-stage HF (ESHF), particularly when they are returned home from hospital after an acute exacerbation. Additionally, patients with ESHF seldom receive specialist palliative care (PC), while PC is considered appropriate for them. It is essential to develop a transitional PC intervention, which is a Home-based Palliative Heart Failure (HPHF) program, and test its effectiveness in order to build research evidence and to guide clinical practice.

Aim: The aim of this study was to test the effectiveness of a transitional PC intervention on health services utilization, QOL, symptom intensity, functional status, and satisfaction with care for patients with ESHF.

Design: This study was a prospective, single-blinded, two-group randomized controlled trial. Eighty-four hospitalized patients suffered from ESHF and being referred to PC were recruited from three hospitals in Hong Kong. The participants were randomly allocated to either an intervention group (n = 43) or control group (n = 41). Both groups received the usual discharge planning in the study hospital. The intervention group received HPHF program delivered by PC-nurse case managers who were supported by a team including PC physicians, social workers, and volunteers. Structured home visits and telephone follow up were the care delivery strategies in the HPHF program, and all nursing actions were protocol-driven. Hospital readmission was the primary outcome, other outcomes included accident and emergency department (AED) attendance, hospital length of stay, QOL, symptom intensity, functional status, and patient satisfaction with care. The participants were assessed on the outcome variables at baseline (T1), at 4 weeks (T2) and at 12 weeks (T3) post hospital discharge.

Results: The intervention group had a statistically significant lower readmission rate than the control group at 12 weeks post discharge (p = 0.009). There was no significant difference in hospital readmissions between the two groups at 4 weeks post discharge. The intervention group had a statistically significant lower AED attendance rate ($p = 0.015$) than the control group at 12 weeks. There was no significant difference in AED attendance rate between the two groups at 4 weeks. Within 12 weeks post discharge period, result showed a shorter length of hospital stay in the intervention group, but it was not significant ($p = 0.08$).

Results of the repeated measures analysis of variance revealed a statistically significant between-group effect ($p = 0.016$), interaction group by time effect ($p = 0.032$), and within-group effect ($p < 0.001$) in the McGill QOL total score at 12 weeks post discharge.

No significant between-group difference was found for the symptom intensity and functional status at 12 weeks. However, there were within-group differences detected, where the intervention group showed improvement in the symptom tiredness, feeling of well-being, and the total symptom score measured by Edmonton Symptom Assessment Scale. The intervention group had higher satisfaction with care than the control group at 12 weeks post discharge.

Conclusion: This study has provided encouraging evidence that the HPHF program was effective in reducing hospital readmission, AED attendance, improving QOL, symptom intensity, and satisfaction with care in supporting patients with ESHF. The results of this study suggest that integrating PC into HF management using transitional care model was able to bring about positive effects to ESHF patients who experienced hospitalization due to HF exacerbation. This study informs health care providers and policy makers that transitional care support is beneficial to both patient and clinical outcomes.

Publications and presentations

Publications

1. Ng, A. Y. M., Wong, F. K. Y. & Chow, S. K. Y. (2012). The development of an evidence-based protocol in a transitional care model for end-stage heart failure patient. *Journal of Nursing Intervention*. 18 (S1), 13
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Conference presentations

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Table of Contents

CHAPTER TWO: LITERATURE REVIEW 24

CHAPTER THREE: CONCEPTUAL FRAMEWORK 108

CHAPTER FOUR: METHODOLOGY 126

CHAPTER FIVE: RESULTS 173

List of Tables

List of Figures

List of Abbreviations

(in alphabetical order)

ACC	American College of Cardiology
AHA	American Heart Association
ANOVA	Analysis of Variance
CHQ	Chronic Heart Failure Questionnaire
COPD	Chronic Obstructive Pulmonary Disease
CRT	Cardiac Resychronization Therapy
EF	Ejection Fraction
ESAS	Edmonton Symptom Assessment Scale
ESC	European Society of Cardiology
ESHF	End-stage Heart Failure
GP	General Practitioner
HA	Hospital Authority
HF	Heart Failure
HFSA	Heart Failure Society of America
HPHF	Home-based Palliative Heart Failure
ICC	Intraclass Correlation Coefficient
ICD	Implantable Cardioverter Defibrillator
ICU	Intensive Care Unit
ITT	intention to Treat
MAR	Missing At Random
MCS	Mechanical Circulatory Support
MQOL-HK	McGill Quality of Life Questionnaire-Hong Kong

	version
NCM	Nurse Case Manager
NRS	Numerical Rating Scale
NYHA	New York Heart Association
PC	Palliative Care
PPS	Palliative Performance Scale
QOL	Quality of Life
RCT	Randomized Controlled Trial
UK	United Kingdom
US	United States
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

This chapter will provide an overview of this thesis, beginning with an explanation of the background of the study herein. The statement of purpose followed by the significance of the study will be presented next. This chapter will end with an outline of the structure of the thesis.

1 Background

Heart failure (HF) is a chronic disease, and during the disease trajectory, HF patients encounter interchangeable stable and unstable periods that may require hospital admission if their condition is acute. Patients with HF face multi-dimensional problems, for example, physical, psychosocial, spiritual, and practical problems, and they need support. Undeniably, as the disease progresses to an advanced stage, those needs become more prominent, in particular, in the transition to post-acute hospitalization. As there is no standard definition of end-stage HF (ESHF), in this thesis, ESHF patients are identified as those with a functional class III to IV based on the New York Heart Association, not eligible for cardiac interventional treatment (e.g. percutaneous coronary intervention, implantable cardiac defibrillator transplant, cardiac resynchronization therapy) and no other treatment options available to these patients to help reverse the HF condition (Dickstein et al., 2008; Murthy & Lipman, 2011). Repeated hospital admissions might reflect worsening heart failure (Jaarsma et al., 2009), yet coordinated and supportive care is inadequate for ESHF patients from general to specialist care (Jaarsma et al., 2009; Murray et al., 2002). The HF illness transition also highlights the importance of supporting ESHF patients in their coping and adjustment, as well as in decision-making while planning end-of-life care (Davidson, 2007; Davidson, Dracup, Philips, Padilla, & Daly, 2007). This thesis aimed to support post-discharge patients with ESHF during the hospital to home transition, as well as their transition from acute care to palliative approach of care, through a study using a transitional care program.

1.1 Prevalence and incidence

Heart failure is a major public health issue that has been recognized as a global epidemic (Ambrosy et al., 2014; Bui, Horwich, & Fonarow, 2010; Hai et al., 2016; Roger, 2013). Heart failure is a clinical syndrome in which the heart is unable to pump blood sufficiently to meet a person's needs (McMurray & Pfeffer, 2005), and HF currently affects approximately 26 million people worldwide, including more than 6 million adults in the United States (Hai et al., 2016; Rajadurai et al., in press). Literature reported that determining ESHF is difficult (Davidson, Macdonald, Newton, & Currow, 2010) and incident and prevalence of ESHF is difficult to ascertain (Norton et al., 2011) but can only be estimated (Lietz et al., 2007). Data suggests that the prevalence of heart failure has increased over the past few decades (McMurray & Pfeffer, 2005; McMurray & Stewart, 2000). It is estimated that 1 to 2% of the adult population in Western countries have HF (Hai et al., 2016; Mosterd & Hoes, 2007). One study reported that the prevalence of HF increases considerably when people grow older, with a prevalence rate of 0.6/1000 in those aged under 65 years and 28/1000 in those aged over 65 years

(McMurray & Stewart, 2000). Less data about the incidence of HF than prevalence has been reported, for example, roughly 5 to 10 new cases per 1000 population per year have been diagnosed with HF (Mosterd & Hoes, 2007). However, due to a lack of a uniform gold standard for defining and assessing HF, the estimated incidence rate varies considerably (Mosterd & Hoes, 2007; Roger, 2013).

Information related to the prevalence and incidence of HF in Asia has been limited until recently. Rajadurai et al. (in press) reviewed the epidemiology of HF in the Asia-Pacific Region and found that approximately 4.2 million people in China alone and 9 million people in Southeast Asia have HF, respectively. Similar to Western countries, the aging population has led to a significant number of people continuing to develop HF in the Asia-Pacific Region (Rajadurai et al., in press). For example, population growth is on an upward trend in Hong Kong, projected from around 7 million in 2011 to 7.6 million in 2021. It is estimated that people over the age of 65 will rise from 941,200 in 2011 to 1,450,700 in 2021, representing 18.9% of the population in 2021 (Census and Statistics Department, 2016). It is anticipated that more and more people will live with HF, as its prevalence rises greatly with age (Heidenreich et al., 2013).

1.2 Consequence of heart failure

1.2.1 Mortality

Heart failure is a major cause of death ((Rajadurai et al., in press). Mortality is high after diagnosis, for example, a large population-based study in the United States (U.S.) found that the 30-day, one-year, and five-year mortality rates were 10%, 20 to 30%, and 45 to 60%, respectively (Levy et al., 2002). An observational study recently reported Hong Kong data that showed similar figures regarding patients with HF (Hai et al., 2016). Mortality was 19.5% at one year, 32.1% at two years, and 54% at five years; the results also showed that mortality increases with age, especially after age 75 (Hai et al., 2016). The prognosis of HF worsens after HF hospitalization. A community-wide study conducted in the U.S., found that the five-year mortality rate was more than 75% after the first HF hospitalization (Goldberg, Ciampa, Lessard, Meyer, & Spencer, 2007). The first population-based study that compared the survival rate between HF and most common types of cancer was conducted by Stewart and colleagues in Scotland (Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001). The study identified patients' first hospitalization and compared their five-year survival rates; findings of the comparison suggested that HF was more "malignant" than many common types of cancer, except lung cancer, and that HF was also associated with a worse five-year survival rate (Stewart et al., 2001). Those figures showed that HF is a serious lethal condition (McMurray & Stewart, 2000).

1.2.2 Hospitalization

Heart failure poses a heavy burden on healthcare systems (Heidenreich et al., 2013; Roger, 2013). A recent study examined national and regional trends in HF hospitalization from 1998 to 2008 (Chen, Normand, Wang, & Krumholz, 2011). Although the study revealed that the overall HF hospitalization rate is declining, currently there are over one million hospital discharge patients with a primary diagnosis of HF in the U.S. (Mozaffarian et al., 2016). Heart failure remains the most common condition for hospitalization and rehospitalizations in the past few decades (Jencks, Williams, & Coleman, 2009; McMurray &

Stewart, 2000; Ross et al., 2010). Studies have indicated that the re-hospitalization rate after an admission for HF has remained unchanged (Ross et al., 2010) or has increased (Bueno et al., 2010). Analyzing the percentage of 30-day readmissions after hospitalization for HF, Dharmarajan et al. (2013) observed that 25% of HF patients are readmitted and 35% of the readmissions are due to HF problems. Readmissions can be attributed to other comorbid conditions with HF (Roger, 2013; Ross et al., 2010), yet HF is the most frequent cause of hospitalization and rehospitalizations. Hospital readmission is a marker of quality of care, and as such, designing a care transition program to prevent repeated hospital admissions for HF patients is essential (Heidenreich et al., 2013; Jencks et al., 2009).

1.3 Problems associated with transitions in health and healthcare among ESHF patients

1.3.1 Transitions in the HF illness trajectory

The prognosis of HF is unpredictable (Allen et al., 2012; Jaarsma et al., 2009). The heart failure illness trajectory is characterized by repeated HF symptom exacerbations where patients experience overall functional decline, but they often return to near baseline condition after appropriate treatment (Goldstein & Lynn, 2006; Goodlin et al., 2004). Heart failure symptom exacerbations sometimes require hospitalization. Though many patients survive after their symptoms are controlled, each exacerbation episode can result in lower functioning (Pantilat & Steimle, 2004). Importantly, the possibility of sudden cardiac death is common among HF patients (Goodlin et al., 2004; Jaarsma et al., 2009; LeMond & Allen, 2011; Pantilat & Steimle, 2004) and it could happen at any point along the course of illness (Goodlin et al., 2004). Using evidence-based therapies to treat HF is the focus in the early stage of HF; however, toward the end-stage of HF or when there is physical weakness or comorbid conditions dominate, palliation is the major care focus for ESHF patients (Goodlin, 2009b). Clinicians cannot predict when an HF patient will deteriorate, or which episode of exacerbation will be lethal (Goldstein & Lynn, 2006). As HF patients are vulnerable, particularly ESHF patients, and hospital admission is common, Goldstein and Lynn (2006) pointed out that severe HF patients require home-based care supported by nurse visits and telephone follow-ups. During home visit, nurses can supervise and assist with patients on medication management and educate patients regarding strategies to prevent HF exacerbation and manage their worsening HF symptoms (Goldstein & Lynn, 2006). Nurses can include a palliative approach to disease management for patients with HF throughout their illness trajectory as appropriate (Davidson et al., 2007).

Murray et al. (2002) highlighted that access to palliative care (PC) services should be based on need and not on diagnosis or prognosis. Other researchers have echoed that regardless of diagnosis and independent of prognosis, all patients who have individual needs should be able to access PC (Adler, Goldfinger, Kalman, Park, & Meier, 2009; McIlfatrick, 2006). The needs of HF patients include information about their illness and prognosis, symptom control methods, awareness and attention to psychosocial and spiritual concerns, practical support, and continuity of care (Boyd & Murray, 2010; McIlfatrick, 2006). The needs of HF patients are in line with the key themes from the National Institute for Clinical Excellence (NICE) Guidance to improve supportive and palliative care for adults with cancer (NICE, 2004). In addition, a study compared the experiences between lung cancer patients and HF patients in the last year of life (Murray et al., 2007). The results from the comparison study showed that there were common patterns between patients with lung cancer and HF in terms of physical, social, psychological, and spiritual needs as the illness progressed (Murray et al., 2007).

1.3.2 Unmet palliative care needs of ESHF patients

Patients with HF in the end-stage of the disease experience a wide range of symptoms that can negatively affect their quality of life (Blinderman, Homel, Billings, Portenoy, & Tennstedt, 2008; Nordgren & Sörensen, 2003). Although the importance of advocating palliative care in the HF trajectory has been highlighted in the last decade (Buck & Zambroski, 2012; Hauptman & Havranek, 2005; Horne & Payne, 2004), there have been no studies suggesting that a spectrum of PC needs of ESHF patients has been met. For example, information about what HF is, the severity of the illness, and its prognosis is not given to ESHF patients (Ahluwalia, Levin, Lorenz, & Gordon, 2012; Barnes et al., 2006; Boyd et al., 2004; Dougherty, Pyper, Au, Levy, & Sullivan, 2007; Harding et al., 2008; Lowey, Norton, Quinn, & Quill, 2013; Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008; Rogers et al., 2000). Patients with ESHF suffer from unmanaged symptoms at home (Lowey et al., 2013) and they lack advice on how to cope with their symptoms, such as breathlessness (Edmonds et al., 2005; Gysels & Higginson, 2011). Psychosocial issues related to HF are often overlooked (Richardson, 2003; Ryan & Farrelly, 2009). Patients with ESHF experience low mood and frustration because of the day-to-day fluctuations of their condition (Boyd et al., 2004; Ryan & Farrelly, 2009); they also express uncertainty and fear about the future (Gysels & Higginson, 2011; Lowey et al., 2013; Murray et al., 2002). Physical decline associated with HF illness progression shrinks ESHF patients' social world. ESHF patients have reported that they could no longer enjoy normal life activities, such as attending an elderly center or going to church (Dougherty et al., 2007; Edmonds et al., 2005), and there is insufficient social service support for ESHF patients (Boyd et al., 2004; Gott et al., 2007; Selman, Beynon, Higginson, & Harding, 2007). Spirituality and existential issues are a concern among ESHF patients. However, ESHF patients have expressed that those needs are often neglected by their healthcare providers (Ahluwalia et al., 2012; Murray, Kendall, Boyd, Worth, & Benton, 2004; Ryan & Farrelly, 2009). Communication is one of the key elements in PC. Communicating treatment decision-making, goals of care, and an end-of-life plan are crucial to patients suffering from HF, particularly to those who are transitioning toward the end-stage. While HF patients progress to the end-stage, the need for such communication increases (Allen et al., 2012; Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011; Whellan et al., 2014). However, studies have found that future care plans and end-of-life issues are less discussed between ESHF patients and their healthcare providers (Hjelmfors, Strömberg, Friedrichsen, Mårtensson, & Jaarsma, 2014; Howie-Esquivel & Dracup, 2012).

Despite the fact that there is a spectrum of PC needs, including information provision, emotional support, social care, spiritual support, and for open communication between ESHF patients and healthcare providers, these patients receive less PC support compared with advanced cancer patients (Horne & Payne, 2004; Imes, Dougherty, Pyper, & Sullivan, 2011; Kavalieratos, Kamal et al., 2014; Murray et al., 2002; O'Leary, Murphy, O'Loughlin, Tiernan, & McDonald, 2009). In current healthcare systems, referral by a clinician is required to access palliative care services. The practice of PC referral and management of HF in existing healthcare systems varies, contributing to limited PC services for ESHF patients (Buck & Zambroski, 2012; Kavalieratos, Mitchell et al., 2014). Physicians in different specialties hold different views about the timing of or reason for referring their patients to palliative care. For example, cardiologists make a referral for terminal care when they are unable to do more, while primary care providers think that repeated hospitalizations within six months is a trigger for referral (Kavalieratos, Mitchell et al., 2014). However, recognizing the transition to palliative care for an end-stage disease and judging the appropriate timing to initiate a PC approach for HF patients is difficult (Coventry, Grande, Richards, & Todd, 2005; Gott, Ingleton, Bennett, & Gardiner, 2011; Haga et al., 2012; Johnson & Gadoud, 2011). It has been suggested that functional decline and increased dependency could signify the need to transition to more focus on a PC approach in progressive HF (Davidson et al., 2007). Additionally, repeated hospital admissions have been identified as a trigger for transitioning to a palliative care approach (Jaarsma et al., 2009; Thomas, 2010).

1.3.3 Transitions in the health care of ESHF patients

Hospitalizations are common in the HF population (Heidenreich et al., 2013; Rajadurai et al., in press), and as the illness progresses, the readmission rate for patients with ESHF is expected to rise (Norton, Georgiopoulou, Kalogeropoulos, & Butler, 2011; Rajadurai et al., in press). The multiple transitions from hospital to home are associated with poor post-discharge outcomes, for example, affecting patients' quality of life and consuming healthcare resources (Heidenreich et al., 2013; Naylor et al., 2004). One study found that frequent transitions of HF patients between the hospital and the home are most often triggered by worsening HF with contributing factors such as comorbidity; non-adherence to diet, medication, or fluid restriction; and insufficient professional support (Annema, Luttik, & Jaarsma, 2009). In addition, unmet needs related to physical, psychological, social, and existential problems can cause HF rehospitalization (Davidson, Cockburn, & Newton, 2008). Numerous research studies (Coleman, Parry, Chalmers, & Min, 2006; Harrison et al., 2002; Naylor et al., 2004; Stauffer et al., 2011; Wong, Ho, Yeung, Tam, & Chow, 2011) have demonstrated that the transitional care model is an effective intervention that can reduce hospital readmission and cost, improve quality of life, and increase satisfaction with care among vulnerable older adults, including the HF population. Transitional care is a service model that aims at promoting the safe and timely transfer of patients from hospital to home (Naylor, 2002). Although patients with ESHF encounter repeated hospitalizations during their illness trajectories, several studies have shown that there is a lack of coordination and continuity of care provided to ESHF patients (Barnes et al., 2006; Boyd et al., 2004; Murray et al., 2002; Ryan & Farrelly, 2009). Despite the fact that international literature has consistently stressed the need to integrate PC into HF management (Adler et al., 2009; Goodlin, 2009b), only a minority of ESHF patients had access to

PC (Hupcey, Penrod, & Fogg, 2009; Kavalieratos, Kamal et al., 2014; LeMond & Allen, 2011; Murray et al., 2002). End-stage HF patients live with significant symptom burden and unmet PC needs. After hospitalization or during the illness trajectory, the needs and care preferences tend to change for ESHF patients (Luttik, Jaarsma, & Strömberg, 2016; Stevenson et al., 2008); thus, continuing care with a constant healthcare provider is essential in the healthcare transition. The service model of PC for ESHF patients is lacking in the current evidence, and as such, a transitional care model could be a strategy for adopting a PC context for ESHF patients.

1.4 Hong Kong context

Hong Kong is also facing the problem of an aging population. Like the situation in Western countries, it is estimated that a significant number of people will continue to develop HF and that hospitalization for HF will be common (Hai et al., 2016; Rajadurai et al., in press; Sanderson & Tse, 2003). Locally, there has been an average 10% increase in hospital admissions for HF every year (Sanderson & Tse, 2003). Hai et al. (2016) pointed out that the overall prognosis of HF in terms of rehospitalization and mortality remains poor. Multiple transitions between the hospital and the home could cause suffering for ESHF patients and their family members, not only because of symptom distress and the gradual loss of independence they experience, but also because it represents that they are approaching the end of their lives.

Several studies conducted in Hong Kong have examined transitional care programs in different patient cohorts, such as diabetes (Wong, Mok, Chan, & Tsang, 2005); renal failure (Chow & Wong, 2010); general medical diseases (Wong et al., 2011); and stroke survivors (Wong & Yeung, 2015). However, transitional care programs using a PC approach for the ESHF population are rare in the region.

1.5 Statement of purpose

The purpose of this study was to evaluate the effectiveness of a transitional palliative care intervention based on hospital readmission rates, quality of life, symptom control, functional status, satisfaction with care, hospital length of stay, and Accident and Emergency Department attendance rate among ESHF patients referred to palliative care. These outcome measures were chosen because systematic reviews in the area of transitional care (Albert et al., 2015) and palliative care intervention (Lorenz et al., 2008; Zimmermann, Riechelmann, Krzyzanowska, Rodin, & Tannock, 2008) suggested that the above mentioned measurements were commonly used and were important to reflect the effectiveness of the intervention. In this study, hospital readmission rate was set as the primary outcome measure because of its objectivity, and the hospital readmission rates can also reflect ESHF patients' condition, for example, poor symptom control may lead to hospitalization (Albert, 2016). Other outcome measures are categorized into subjective patient outcomes (quality of life, symptom control, functional status, satisfaction with care) and objective system outcomes (hospital length of stay, and Accident and Emergency Department attendance rate).

The current research aimed to test whether a transitional palliative care model — through home visits and telephone follow-ups by PC nurses who are supported by a PC team—would influence clinical and patient outcomes.

The objectives of this study were to evaluate the following:

1. The effectiveness of a transitional palliative care intervention in reducing hospital readmission rates for patients with ESHF;
2. The effectiveness of a transitional palliative care intervention in improving quality of life for patients with ESHF;
3. The effectiveness of a transitional palliative care intervention in improving symptom control for patients with ESHF;
4. The effectiveness of a transitional palliative care intervention in improving the functional status of patients with ESHF;
5. The effectiveness of a transitional palliative care intervention in improving satisfaction with care for patients with ESHF;
6. The effectiveness of a transitional palliative care intervention in reducing hospital length of stay for patients with ESHF;

7. The effectiveness of a transitional palliative care intervention in reducing Accident and Emergency Department attendance for patients with ESHF.

1.6 Significance of study

Local studies on non-cancer palliative care are few. An increasing number of studies have focused on assessing needs, exploring the lived experience of ESHF, identifying symptom prevalence, and conducting quality of life surveys. One study reported the use of a clinic-based intervention for end-stage renal failure patients (Chan et al., 2015). To date, the current study is the first interventional study concerning ESHF patients referred to palliative care in hospital-to-home transition.

Although some international studies have been published in the context of ESHF, the majority have adopted a descriptive approach or pre-test/post-test study design with a sub-group of ESHF patients only. While some interventional studies have been conducted for HF patients, they tended to target the mild to moderate HF population, not the ESHF group. The current study is the first randomized controlled trial to investigate the effect of transitional palliative care on ESHF patients in Hong Kong. This study aimed not only to introduce and implement a care delivery model but also to cultivate the development of transitional palliative care for ESHF patients.

The launch of this study is in line with both international guidelines and literatures, where coordinated palliative care that seamlessly bridges hospital and home must be provided for ESHF patients (Jaarsma et al., 2009; Strachan, Ross, Rocker, Dodek, & Heyland, 2009). It is believed that through symptom management, emotional and social support, assisting patients in defining goals of care, and planning end-of-life care, PC for ESHF management might improve their health status and reduce hospitalization (Bekelman, Hutt, Masoudi, & Rumsfeld, 2008).

The vision of the Hong Kong Hospital Authority is to expand palliative care service to the end-stage organ failure population and to shift hospital-based care to community-based care. The goals are to maximize health care and patient benefits. The new model developed in this study aimed to ensure the seamless transition from hospital to home and to provide ongoing supportive care for ESHF under palliative care to reduce unnecessary hospital admissions, control symptoms, and maintain a better quality of life.

The results of this study will help plan and develop effective model and inform policy maker measures that will fill the service gap and promote care quality for ESHF patients. The value of effective palliative care in the population of ESHF will be underscored, and the treatment trials will evaluate the types of palliative interventions that are likely to have the maximum impact on the care of these patients. Consequently, the results of this randomized controlled trial for end-stage patients will also fill the knowledge gap.

1.7 Structure of the thesis

This chapter presented an overview of the trends in the development of palliative care for end-stage heart failure patients and the underlying inquiries for the present study. The following chapters will provide a review of the major conceptual framework for this study. Following this introductory chapter, the thesis is organized as follows. Chapter 2 will present a literature review of the underlying principles of palliative care for end-stage heart failure patients and the gaps in knowledge identified in previous studies. Chapter 3 will elucidate the formulation of the conceptual framework of this study, while Chapter 4 will describe the methodology of and the procedures for the randomized controlled trial. In Chapter 5, the results of the study will be presented, and Chapter 6 will discuss the findings generated from the study as well as illustrate the limitations and implications of this study. This thesis will end with the conclusion chapter.

CHAPTER TWO

LITERATURE REVIEW

This chapter will begin with an account of heart failure (HF) and end-stage heart failure (ESHF), including their etiology, classifications, and definitions, followed by the impact of HF on the health status of patients and their illness experiences, as well as the impact of HF on the healthcare system. Second, the management of ESHF and the relevance of the palliative care (PC) approach in caring for ESHF patients will be explored. Third, an overview of studies examining the needs of patients suffering from ESHF will be reported by comparing the care received between cancer and non-cancer populations. The provision of PC for ESHF patients and models of transitional care will also be discussed. In the concluding section, the care and research gaps will be identified to bring to light ESHF patients' needs based on this review.

2. Database search

A comprehensive literature search was conducted to look for articles relevant to the current study. Local and overseas papers that included systematic reviews, original research, randomized controlled trials, and practice guidelines were collected. Several databases were used, including the British Nursing Index (BNI), the Cochrane Library, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and PsycINFO. The database search covered the years 1995 to 2016. The search included both local and international organizations to retrieve the latest health statistics and reports, including the World Health Organization (WHO), the American Heart Association (AHA), and the Hong Kong Hospital Authority (HA).

2.1 Heart failure

2.1.1 Heart failure etiology

Heart failure is a complex clinical syndrome (Hunt et al., 2005). The development of HF generally proceeds from risk factors to end-stage or refractory disease, deteriorating by stages that are associated with structural or functional abnormalities of the heart (Krum & Abraham, 2009). Abnormalities in cardiac structure, function, conduction, or rhythm can contribute to HF syndrome. Heart failure is usually associated with coronary artery disease and hypertension (McMurray & Pfeffer, 2005). Many patients with HF have comorbidities such as diabetes mellitus, angina, and renal dysfunction. The existence of comorbidities makes HF management very difficult (McMurray & Pfeffer, 2005). A variety of perspectives investigating the mechanisms of HF have been offered in past decades, including hemodynamic, cardiorenal, and neurohumoral perspectives (Braunwald, 2013). The underlying HF pathophysiology and associated compensatory mechanisms contribute to its signs and symptoms, as well as the poor natural history of HF (Krum & Abraham, 2009). For example, specific symptoms such as dyspnea and fatigue and signs such as edema are characteristic of HF (Hunt et al., 2005; Yancy et al., 2013). Diagnosing HF can be challenging (Roger, 2013) as there is no single diagnostic test for HF; rather, diagnosing HF mainly relies on a clinical judgment that is based on the patient’s medical history, physical examination, and chest radiograph (Hunt et al., 2005; Roger, 2013).

2.1.2 Classification of heart failure

The HF stage is classified by structural heart disease or functional capacity and symptoms. The American College of Cardiology (ACC)/American Heart Association (AHA) guidelines provide a staging system based on the risk of developing HF, structural cardiac defects, and symptoms (Hunt et al., 2005; Yancy et al., 2013). The ACC/AHA has classified HF into stages A, B, C, and D: stage A refers to patients who are at high risk for HF development, but they have no structural heart disease given that risk factors such as coronary artery disease or hypertension exist; stage B patients have structural heart disease, such as systolic dysfunction, but they do not have symptoms of HF; stage C patients have experienced symptoms of HF associated with structural cardiac abnormalities; and stage D patients have refractory end-stage HF requiring advanced specialized interventions such as device support, continuous inotropic infusions, heart transplant, and end-of-life care or hospice (Hunt et al., 2005; Yancy et al., 2013). According to the AHA (2017), currently over 6 million Americans are living with HF and about 10% of those Americans have stage D HF.

The New York Heart Association (NYHA) has provided another HF classification—functional—which is complementary to the ACC/AHA staging system. The NYHA system subjectively assesses the symptoms presented by the provider and the patient, which are then categorized from Class I to Class IV. Importantly, patients' symptoms class can change, even within a short period of time (Murthy & Lipman, 2011). Patients in Class I have no functional limitation and no HF symptoms, and they are able to take part in ordinary physical activity. Patients in Class II show some functional limitations, with HF symptoms during ordinary physical activity but no symptoms at rest. Patients in Class III present with significant functional limitations, with HF symptoms that restrict their performance of ordinary physical activity, without symptoms at rest. Patients in Class IV have severe functional limitations, with symptoms emerging while performing ordinary physical activity, and they may experience symptoms even at rest (Murthy & Lipman, 2011). These AHA/ACC and NYHA classifications are commonly used for HF patients.

Of the two types of heart failure differentiated by normal or impaired left ventricular systolic function, an ejection fraction (EF) classifies one type of HF and it refers to the amount or percentage of blood ejected from a ventricle of the heart with each heartbeat (Mosterd & Hoes, 2007). The EF is commonly measured by an echocardiogram and normal EF is 50 to 75%. Patients with an EF of 35% or below have low heart-pumping ability (Heart Rhythm Society, 2016). Heart failure can occur in normal or reduced left ventricular systolic function (Mosterd & Hoes, 2007; Yancy et al., 2013) and can present with symptoms or be asymptomatic (McMurray & Pfeffer, 2005).

2.1.3 Definition of end-stage heart failure

There is no precise universal definition of ESHF, so defining ESHF is difficult because debates exist in this respect, including whether ESHF should be defined based on debilitating symptoms and poor quality of life or on mortality risk (Norton et al., 2011). End-stage HF, which is also called advanced, refractory, or terminal HF, has a very poor one-year survival rate, which is approximately 50% (Friedrich & Böhm, 2007). Several guidelines have been proposed to define ESHF taking various aspects into consideration. The European Society of Cardiology (ESC) has identified ESHF patients as those who, after all appropriate treatment options have been explored, have no possible treatment option that can help them, resulting in the confirmation of the terminal stage of illness (Dickstein et al., 2008). The ACC/AHA has indicated that patients who are at stage D are classified as having ESHF, while the NYHA classifies patients as having ESHF once they presented with Class III to IV symptoms (Friedrich & Böhm, 2007; Murthy & Lipman, 2011; Norton et al., 2011). However, clinicians tend to adopt different approaches to defining ESHF, as some may consider debilitating symptoms despite HF therapy with proven efficacy as end-stage HF (Norton et al., 2011), whereas others may regard heart transplant or other advanced therapies' candidates as HF patients at the end-stage of life (Murthy & Lipman, 2011).

Studies involving ESHF patients as subjects have used different inclusion criteria. The inclusion criteria of a Swedish study that examined the symptoms experienced among ESHF patients stipulated that only ESHF patients who had a diagnosis of chronic HF and who had been hospitalized at least once during the last six months at the time of recruitment would be included (Nordgren & Sörensen, 2003). A retrospective study conducted in the United States (U.S.) that reviewed the prevalence of symptoms identified patients who were eligible to be admitted to hospice care for ESHF as its inclusion criteria (McMillan, Dunbar, & Zhang, 2007). The study by Murray et al. (2002) recruited only ESHF patients with an NYHA Class IV classification; similarly, a Canadian study (Tranmer et al., 2003) that measured the symptom experiences of advanced stage cancer and non-cancer patients recruited only ESHF patients with an NYHA Class IV classification in addition to an EF of less than or equal to 25%. A longitudinal multiple case study conducted in the Netherlands explored the experiences of ESHF patients and adopted as their inclusion criteria only those patients who were hospitalized for HF at least once within one year, with an NYHA classification of Class III or Class IV and/or an EF of less than 25% (Willems, Hak, Visser, Cornel, & Van der Wal, 2006). A recent qualitative interview study also used NYHA Class III to Class IV classifications as the inclusion criteria to recruit ESHF patients (Lowey et al., 2013).

However, some studies used providers' judgements for inclusion rather than specific criteria for ESHF. For example, a survey was conducted in Manchester, United Kingdom (UK), to examine the concerns of terminal cancer patients and ESHF patients, which reported that the ESHF patients were identified by a specialist HF nurse (Anderson et al., 2001). Another study that evaluated a specialized care program for ESHF patients recruited patients who were reported to have refractory HF and left ventricular dysfunction (Roig et al., 2006). As these various inclusion criteria have shown, the definition of ESHF has not yet been agreed upon universally because the clinical progression of ESHF is highly variable (Fang et al., 2015).

2.2 Impacts of end-stage heart failure

The impacts of ESHF can be profound on the health status of patients. Studies have been conducted to examine the symptom burden and quality of life of patients with ESHF, mostly in the form of surveys or using a retrospective approach (Janssen, Spruit, Wouters, & Schols, 2008). Zambroski, Moser, Bhat, and Ziegler (2005) conducted a cross-sectional study in the U.S. using a convenience sample of 53 HF patients, where 77.5% were NYHA Class III to IV, and found that there was a mean of 15.1 +/- 8.0 symptoms among the sample. In that study, shortness of breath (85.2%) and lack of energy (84.9%) were the most prevalent symptoms, and difficulty sleeping was the most burdensome symptom (Zambroski et al., 2005). A larger survey of 542 older patients with HF (39% were NYHA Class III to IV) living in the community conducted in the UK reported that over half the participants experienced breathlessness and/or fatigue daily (Barnes et al., 2006a).

Another descriptive study conducted by Bekelman et al. (2007) aimed to identify the prevalence of and distress from symptoms of HF patients. Sixty patients with HF were recruited from two outpatient cardiology clinics who reported a mean of nine symptoms in the previous week, with more than half reporting shortness of breath, lack of energy, being in pain, feeling drowsy, or having a dry mouth. Bekelman et al. (2007) found that patients with HF reported a large number of distressing symptoms.

In a longitudinal observational study by Blinderman et al. (2008), a convenience sample of 103 community-dwelling ESHF patients who were NYHA Class III to IV were recruited. It was revealed that the median number of symptoms per patient was nine, ranging from zero to 26, with the most prevalent physical symptoms being lack of energy (66%), dry mouth (62%), shortness of breath (56%), and drowsiness (52%), while the commonly reported psychological symptoms included worrying (43.7%) and feeling sad (42.7%) (Blinderman et al., 2008). The results of these studies suggest that patients with severe HF suffer from diverse symptoms, the most prevalent of which are shortness of breath and lack of energy.

Other studies have examined the last six months of life in patients with ESHF, which revealed that as the illness became more severe, the patients' experience of certain symptoms was more prominent and frequent. Levenson, McCarthy, Lynn, Davis, and Phillips (2000) used data obtained from a large prospective, national multicenter project in the U.S. to study a group of severely ill patients hospitalized for an acute exacerbation of HF. As death approached, statistically significant trends toward an increase in both physical symptoms (e.g., pain and dyspnea) and emotional symptoms (e.g., anxiety and depression) were identified (Levenson et al., 2000).

Another study conducted by Nordgren and Sörensen (2003) in Sweden used medical chart reviews to explore the symptoms experienced by patients with ESHF in the last six months of life. The results showed that 21 symptoms were observed, with breathlessness (88%) being the most common symptom, followed by pain (75%), fatigue (69%), and anxiety (49%) (Nordgren & Sörensen, 2003). Nordgren and Sörensen (2003) pointed out that despite the symptoms being documented by healthcare providers, symptom-controlling measures were inadequate and suboptimal. Similarly, in a retrospective chart review aimed at evaluating symptom occurrence in patients with ESHF who were newly referred to hospice care, McMillan et al. (2007) observed a mean of 11.9 symptoms in the charts, ranging from zero to 28. The most prevalent symptoms were fatigue (82.4%), shortness of breath (76%), and swelling (56.9%), while psychosocial symptoms such as depression (29.4%) were also observed (McMillan et al., 2007). These studies show that as death becomes imminent, the conditions of patients with ESHF become poorer and they suffer from multiple symptoms, particularly in relation to breathlessness and fatigue.

Symptom prevalence, symptom burden, and functional status are associated with ESHF patients' quality of life (QOL). Zambroski et al. (2005) revealed that a large number of symptoms and a high level of symptom burden were predictors of diminished health-related QOL in HF patients. In view of this, it is essential to perform holistic symptom assessment and set goals of care to alleviate the symptom burden of HF patients so that their QOL might be improved (Zambroski et al., 2005). Bekelman et al. (2007) had similar findings regarding the relationship between distressing symptoms and the health-related QOL of patients with HF, which highlighted that depression in patients with HF is associated with a greater number of symptoms and is attributable to a decrease in QOL. Identifying and managing a wide range of symptoms, particularly depression, can significantly improve HF patients'

QOL (Bekelman et al., 2007). Blinderman et al. (2008) also found that decreased QOL was strongly related to high symptom distress, poor psychological well-being, and the functional mobility of ESHF patients, suggesting that supportive intervention has positive impacts on improving symptom burden, emotional well-being, and functional impairment in the ESHF population, which eventually enhances their QOL.

2.2.1 Living with end-stage heart failure

Living with HF can be potentially devastating as patients experience symptoms relating to physical, emotional, and social turbulence (Zambroski, 2003). Patients diagnosed with HF can encounter a loss of physical functioning and decreased QOL (Rodriguez et al., 2008). A number of qualitative studies have been conducted to describe and analyze the experiences of patients living with advanced HF.

2.2.1.1 Living with symptoms in everyday life

Studies have identified patients' symptom burden associated with advanced HF and how it has influenced their daily lives (Aldred, Gott, & Gariballa, 2005; Boyd et al., 2004; Brännström, Ekman, Norberg, Boman, & Strandberg, 2006; Horne & Payne, 2004; Lowey et al., 2013; Ryan & Farrelly, 2009; Selman et al., 2007b). Horne and Payne (2004) interviewed 20 patients with severe HF and the results revealed that HF is highly disruptive to day-to-day living, with three main themes identified: "can't do," "difficulties in walking," and "relying on others." Patients reported that they were not able to do even small tasks, for example, cook for themselves, and that they could not get out of the house often due to breathlessness or loss of energy (Horne & Payne, 2004). Patients used the term "terrible" to describe the effect HF imposed on them and said that they felt frightened, relating this emotion (i.e., the fear of having another heart attack and readmission to the hospital) to breathing difficulty (Horne & Payne, 2004).

Boyd et al. (2004) interviewed 20 patients with ESHF and found that QOL was compromised due to physical symptoms and emotional problems. Many patients reported that they had persistent edema, extreme fatigue, and severe breathlessness, which in turn caused anxiety; they also reported that the complex medication regimens and the treatment side effects made them feel terrible (Boyd et al., 2004). Moreover, low mood and frustration were reported by these ESHF patients because of the progressive loss of their functional ability, which rendered them unable to do even simple household tasks such as mopping (Boyd et al., 2004). Moreover, the consequent role change of not being able to accomplish household tasks (Aldred et al., 2005) and earn a living (Bekelman et al., 2011) was frustrating, and the psychological morbidity reported by the ESHF patients was similar to that in other qualitative interview studies (Ryan & Farrelly, 2009; Selman et al., 2007b).

Aldred et al. (2005) explored the impact of advanced HF on the lives of 10 older patients and found that HF had a significant negative effect on all aspects of everyday activities. For instance, the symptoms of breathlessness and fatigue limited their mobility and the unpredictability of symptom onset hindered their ability to plan activities, such as family activities (Aldred et al., 2005). Patients with advanced HF in a recent qualitative study described shortness of breath as “engulfing everything” in their life as they needed a longer time to perform routine activities of daily living, such as dressing, due to the symptoms of HF (Lowey et al., 2013).

Brännström et al. (2006) conducted narrative interviews with four severe HF patients under advanced palliative home care using the phenomenological hermeneutic approach. They stated that living with severe HF was like “a roller coaster life” as these severe HF patients were troubled by varying degrees of shortness of breath, pain, difficulty in standing on one’s legs and walking, and fatigue, either constantly or periodically (Brännström et al., 2006). Similarly, Ryan and Farrelly (2009) adopted a phenomenological hermeneutic approach to explore patients’ experiences of living with advanced HF and found that the themes that emerged included “living in the shadow of fear,” “running on empty,” and “living a restricted life.” For the theme “living in the shadow of fear,” the patients viewed going to bed at night as fearful because a breathlessness attack might happen, so they had to sit up all night if there was a sudden onset of breathlessness and they became frightened and panicked when they laid down (Ryan & Farrelly, 2009). Hopelessness and feeling desperate were the central emotions in the theme “running on empty,” as these patients with advanced HF were no longer able to do the things they wanted to do (Ryan & Farrelly, 2009). Patients living with HF often encounter periods of deterioration that need hospital admission, which is considered a further decline with the possibility of death (Leeming, Murray, & Kendall, 2014; Waterworth & Jorgensen, 2010).

Socially, HF is often associated with social isolation and loneliness (Aldred et al., 2005; Brännström et al., 2006; Fitzsimons et al., 2007; Horne & Payne, 2004; Leeming et al., 2014; Ryan & Farrelly, 2009). Living with severe HF has been interpreted as “being trapped at home”; patients have described how the disease has caused a sense of loneliness due to being distanced from their circle of friends since they often had to stay at home because of their illness (Aldred et al., 2005; Brännström et al., 2006; Ryan & Farrelly, 2009). Moreover, their homebound status causes them to rely on others to stay in touch with the social world (Horne & Payne, 2004). End-stage heart failure patients in turn feel that they are a burden to their carers because they cannot perform many tasks (Aldred et al., 2005; Boyd et al., 2004; Fitzsimons et al., 2007; Horne & Payne, 2004; Leeming et al., 2014; Ryan & Farrelly, 2009). Furthermore, being distanced from friends eventually results in the loss of their social network (Waterworth & Jorgensen, 2010), with diminished abilities and increased dependence. Patients with ESHF also have a sense of the loss of personhood they once had (Leeming et al., 2014).

2.2.1.2 Living with uncertainty

The future is uncertain for patients with advanced HF (Bekelman et al., 2011; Brännström et al., 2006; Dougherty et al., 2007; Fitzsimons et al., 2007; Lowey et al., 2013; Waterworth & Jorgensen, 2010). Patients with HF have reported feelings of uncertainty with respect to how to manage day-to-day activities and their future condition (Waterworth & Jorgensen, 2010). They also perceive their future as uncertain given the unpredictable deterioration of their body, and they have described living with severe HF as "knocking on death's door" (Brännström et al., 2006). Although they are aware of imminent death, they do not take the future for granted as they know that the course of their illness is hard to predict (Brännström et al., 2006). Dougherty et al. (2007) interviewed 24 patients and found that patients with advanced HF lived "day to day without making plans." They perceived their future as difficult to predict because their HF condition could change rapidly, resulting in death (Dougherty et al., 2007). Patients viewed their lives as finished or as "going," which embedded feelings of hopelessness among the ESHF patients regarding their future (Horne & Payne, 2004).

A high degree of hopelessness and powerlessness has also been reported by older patients living with advanced HF elsewhere (Lowey et al., 2013; Waterworth & Jorgensen, 2010). Maintaining hope is apparently important among EHSF patients (Back, Arnold, & Quill, 2003; Davidson et al., 2007; Dougherty et al., 2007; Selman et al., 2007b). Some HF patients hope to regain certain independence or even a longer future (Dougherty et al., 2007; Horne & Payne, 2004), while others hope that their illness will not get worse but remain stable for more years to live (Dougherty et al., 2007; Lowey et al., 2013).

Patients with HF often express uncertainty about when death will occur (Waterworth & Jorgensen, 2010). In fact, many patients seem to be aware of their poor prognosis and think of dying, particularly during hospital admissions due to HF exacerbations (Gott, Small, Barnes, Payne, & Seamark, 2008; Strachan et al., 2009; Strömberg & Jaarsma, 2008; Willems, Hak, Visser, & Van der Wal, 2004). Despite death being a natural part of life, death is regarded as fearful for HF patients because the process of dying is unknown. Patients are afraid of deterioration and suffering from severe pain and shortness of breath before death (Strömberg & Jaarsma, 2008). Although some patients with advanced HF have admitted that they are not ready to die (Dougherty et al., 2007; Willems et al., 2004), for those who have thought about death and dying issues, death is categorized as good/best death versus worst death (Dougherty et al., 2007; Gott et al., 2008).

Gott et al. (2008) conducted an in-depth interview with 40 older patients with advanced HF in an attempt to understand their views and concerns regarding a good death. The findings of the views on good death included a pain-free death, open acknowledgement of the imminence of death, death at home, and an awareness of death so that they can spend time with their family and exercise personal preferences in making a living will (Gott et al., 2008). In Dougherty et al.'s (2007) study, patients with advanced HF described best death as a peaceful death without panic, dying at home during sleep, and dying with dignity and with minimal suffering, while worst death was described as living unconsciously, being too weak to feed themselves, being restricted to a wheelchair, and being dependent on oxygen.

Other thoughts on death and dying among advanced HF patients include relief of symptoms (Strömberg & Jaarsma, 2008) and being free from burdening the people taking care of them (Gott et al., 2008). Some patients with advanced HF who have said that they are not afraid of dying acknowledged that they will die from HF sooner or later and that their remaining life ranged from a few months to one day (Dougherty et al., 2007). However, they are worried about the dying process, and in the worst situation, some patients have said that they had even thought about death every day (Horne & Payne, 2004).

Patients living with ESHF experience varied symptoms, between feeling better or worse, gradually or suddenly, and they experience uncertainty about what will happen in the future. Both quantitative and qualitative studies have confirmed that deteriorating health status has an intense negative impact on a range of physical, social, and emotional consequences, compromising the overall QOL of ESHF patients.

2.3 Dying from heart disease

Two major studies were conducted involving dying HF patients—the Regional Study of Care for the Dying (RSCD) in the UK and the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) in the U.S., which were among the early studies that examined patients who died from heart disease. The RSCD study conducted by McCarthy, Lay, and Addington-Hall (1996), which included a population-based survey of the family members of the deceased patients for a total of 600 informal caregiver participants, described the symptoms experienced by and the relationship with QOL in the last year of life of hospitalized patients with heart disease. The findings revealed that patients dying from heart disease experienced many distressing symptoms, which often lasted for more than six months, and based on these findings, McCarthy et al. (1996) appealed for extending and expanding PC, a care approach traditionally adopted in cancer care, to a broad range of patients such as those with heart disease as they might benefit from the knowledge and expertise developed within the palliative specialty.

The SUPPORT study, which investigated hospitalized patients who were in their last year of life, attempted to characterize the dying experiences of seriously ill patients, including HF patients (Connors et al., 1995). The SUPPORT study encompassed two phases: phase I was a large prospective observational study that collected data from 4,301 patients on the process of decision-making and patient outcomes; and phase II was a cluster randomized controlled trial involving 4,804 seriously ill patients to test the effect of an end-of-life decision-making discussion intervention. Although phase II of the study did not improve care or patient outcomes, including pain control and resource utilization, it provided important evidence of patients' preferences regarding treatment options in their last stage of life and highlighted that communication and planning for end-of-life care was essential (Connors et al., 1995).

Understanding the dying trajectories of HF is important in order to plan quality end-of-life care, constructing a framework for healthcare delivery that facilitates proper allocation of resources to organizations to support appropriate service provision (Gill, Gahbauer, Han, & Allore, 2010; Gott et al., 2007; Kelley, Ettner, Morrison, & Sarkisian, 2012; Teno, Weitzen, Fennell, & Mor, 2001). Glaser and Strauss (1968) originally developed the three trajectories of dying—abrupt deaths; expected deaths, both lingering and short-term; and entry-reentry deaths, where patients require hospitalization, but they can return home between each hospital admission, with an underlying gradual decline after each admission. According to Glaser and Strauss (1968), each of the trajectories of dying differs in length and slope of functional decline.

To evaluate the health care and cost patterns at the end of life, Lunney, Lynn, and Hogan (2002) analyzed 7,966 deaths from Medicare claims data and classified the decedents into groups representing four theoretical trajectories of dying in terms of health condition: sudden death, terminal illness, organ failure, and frailty. According to Lunney et al.'s (2002) analysis, the first group was comprised of patients who died suddenly, usually with normal functioning before death, and they often had little or no interaction with the healthcare system before dying. The second group represented patients in a distinct terminal phase of illness, which were typically cancer decedents. These patients maintained reasonably good function for a long time after they were no longer responsive to their treatment; then they declined rapidly and usually entered the dying phase. The third group of decedents were patients with serious organ failure, such as those with HF who experienced progressively reduced functional status with periodic exacerbations that could be fatal (i.e., entry-reentry deaths). However, organ failure patients usually had many such episodes during the course of their illness before they died, making the prognosis for survival unclear. The last group of decedents was classified as having frailty, and these individuals experienced an even slower decline before death (Lunney et al., 2002). The results of that study showed that among the subjects, 7% experienced sudden death, 22% had a terminal illness, 16% had organ failure, and 47% were in the frailty group; of note, the organ failure group had the highest average Medicare expenditures, and approximately 100% were hospitalized at some point in the last year of their life (Lunney et al., 2002). The findings also showed that the four trajectory groups had distinct patterns of care delivery, resulting in two suggestions for improving care among the organ failure group: first, adopt disease management programs that include patient education, symptom control, and case management, which have been proven effective in reducing hospital admission rates (Rich, 1999); and second, initiate advance care planning during exacerbations, which might help in discussing treatment preferences and end-of-life care (Lunney et al., 2002).

Lunney, Lynn, Foley, Lipson, and Guralnik (2003) further reported a prospective, longitudinal study of data from four U.S. regions that included 14,456 participants categorized into the four dying conditions. That study aimed to examine whether functional decline differed among four types of dying trajectories: sudden death, cancer death, death from organ failure, and frailty. Among the four decedent cohorts, the organ failure decedents experienced a fluctuating pattern of decline in the final year of life, with substantially poorer function during the last three months before they died (Lunney et al., 2003). The findings from the study revealed that there were variable trajectories of dependency among the four types of conditions leading to death. For example, the cancer decedents were likely to have a clear and predictable terminal period, whereas the organ failure decedents did not (Gott et al., 2007). Data from Lunney et al.'s (2003) study has significant implications for healthcare delivery. Each decedent group needs a different clinical approach and different types of healthcare services that suit their situations, and those who experienced entry-reentry deaths would have benefitted from supportive and end-of-life care (Lunney et al., 2003).

Recently, Gill et al. (2010) conducted a similar study to identify the distinct trajectories of disability in community-dwelling older patients' last year of life. The study found that the distribution of the disability trajectories was quite varied, and it was particularly heterogeneous among the subjects with organ failure. The results from the study indicated that the course of disability at the end of life did not follow a predictable pattern based on the condition leading to death. As the studies above have illustrated, there is no typical predictable dying trajectory for most HF patients, and the pattern of functional decline varies.

2.4 Impacts on the health care system

2.4.1 Economic burden

Heart failure contributes to a huge economic burden on the healthcare system (Heidenreich et al., 2013; McMurray & Stewart, 2002; Norton et al., 2011) and the burden is expected to continue rising (Farmakis, Stafylas, Giamouzis, Maniadakis, & Parissis, 2016; Russo et al., 2008). In the U.S., annual HF-related expenses were $31 billion in 2012, and this cost is expected to increase to $97 billion in 2030 (Farmakis et al., 2016). This growth is due to two concurrent trends. First, as the HF incidence rate is related to age, the prevalence of HF will increase because of the aging population. Second, novel HF therapies are costly, including new drugs and devices that can help improve the survival of coronary artery disease, which represents the main cause of HF (Farmakis et al., 2016; Russo et al., 2008). The economic burden of HF management is staggering due to increasing and expensive direct costs, particularly those related to hospitalization (Chen et al., 2011; Cook, Asaria, Jabbour, & Francis, 2014; Kaul et al., 2011; O'Connell, 2000; Reed et al., 2012). One literature review that examined the economic burden of HF summarized studies on resource utilization and cost and found that hospital admission and readmissions for HF is the driving force behind HF costs (Lee, Chavez, Baker, & Luce, 2004).

2.4.2 Heart failure hospitalization and readmission

Hospitalization is responsible for a major portion of healthcare expenditures in managing HF (Heidenreich et al., 2013; Lee et al., 2004; O'Connell, 2000). In a study using National Hospital Discharge Survey data from 1979 to 2004, Fang, Mensah, Croft, and Keenan (2008) concluded that U.S. hospitalizations for HF increased during the past 26 years. Other researchers have concurred that HF hospitalization remains high (Ambrosy et al., 2014; Chen et al., 2011).

More than one million hospitalizations related to HF have been recorded annually in both the U.S. and Europe, and hospitalized HF patients continue to experience high post-discharge readmission rates that have not changed in the past two decades (Ambrosy et al., 2014). A systematic review confirmed that patients hospitalized with HF had 25% or above readmitted within 30 days (Feltner et al., 2014), and the post-discharge readmission rate was approximately 30% within 60 to 90 days of post-discharge (Ambrosy et al., 2014). It has been reported that 90% of the hospital readmissions were unplanned and had the potential to be prevented through better care coordination (Hernandez et al., 2010).

2.4.3 Resource use and costs among end-stage heart failure patients in the last months of life

The cost and healthcare resource use spent on end-stage patients has increased in the past decade (Simoens et al., 2010; Smith, Brick, O'Hara, & Normand, 2014; Teno et al., 2013; Wennberg et al., 2004). Most hospitalized HF patients are admitted for worsening chronic HF (Ambrosy et al., 2014), and the problem tends to become more frequent with disease progression, particularly approaching the end-stage of life. Currently, it is estimated that there are 30 to 60 thousand patients with ESHF in the U.S. (Whellan et al., 2014), reflecting an enormous end-of-life financial burden on the healthcare system (Norton et al., 2011; Russo et al., 2008; Unroe et al., 2011).

Russo et al. (2008) performed an economic analysis to examine the patterns of healthcare resource use and costs for patients with ESHF during their final two years of life. The study demonstrated that medical therapy for ESHF was associated with significant costs and resource consumption, and the results also showed that more than 50% of the total costs were incurred in the final six months of life (Russo et al., 2008). In addition, the healthcare use patterns among ESHF patients during the final months of life were higher than those for other terminal diseases, such as advanced chronic obstructive pulmonary disease (COPD), lung cancer, and pancreatic cancer, in terms of intensive care unit (ICU) days, hospital days, and inpatient costs (Russo et al., 2008).

Unroe et al. (2011) conducted a retrospective cohort study of 229,543 Medicare beneficiaries with HF who died between 2000 and 2007 to determine health services use, which revealed that 80% of HF patients were hospitalized in the last six months of life, the number of days spent in the ICU increased from 3.5 to 4.6, and the use of hospice services increased significantly, from 19% to nearly 40%. Another retrospective study conducted by Kaul et al. (2011) in Canada examined the trends in resource use and costs during the last six months of life among HF patients from 2000 to 2006, which showed that the mean hospitalization cost per patient increased with substantial lengths of stay (around 20 days), accounting for most of the costs in the last six months of life.

Reed et al. (2012) used a study sample of 2,331 HF patients from a randomized controlled trial to examine the pattern of medical resource use near the end of life by checking their mode of death, including sudden cardiac death and those who died of HF or other cardiovascular/non-cardiovascular causes. Comparing the hospitalizations, inpatient days, and inpatient costs incurred during the last year of life among the 231 decedents in the study sample, HF patients with a higher functional class (i.e., NYHA Class IV) were found to have a higher expected mean number of hospitalizations, inpatient days, and inpatient costs than those in a lower functional class (Reed et al., 2012).

Heart failure, is the most common cause of hospitalization and readmissions after hospital discharge (Hernandez et al., 2010), where rehospitalizations are costly (Jencks et al., 2009). Rehospitalization can be a marker of poor healthcare quality and efficiency (Dharmarajan et al., 2013; Jencks et al., 2009), and it is associated with inadequate support in follow-up care (Jencks et al., 2009). Given that heavy resource use is not necessarily associated with better health outcomes of the decedents before they died (Wennberg et al., 2004), in contrast, multiple hospitalizations represent burdensome transitions in the last months of life (Teno et al., 2013). The HF group is one of the disease groups responsible for high healthcare expenditures in the final year of life. From a healthcare-system perspective, it is important to consider strategies that can reduce the frequency of hospital admissions to achieve cost savings. A safe transition from the hospital to the community requires care that centers on patients and that focuses on the continuity of care to promote quality health care and to prevent unnecessary hospital readmissions (Ambrosy et al., 2014; Jencks et al., 2009).

2.5 Management of end-stage heart failure

2.5.1 Traditional heart failure management

Apart from medical treatment, for the majority of ESHF patients, revascularization and device implantation are life-sustaining treatment modalities (Goodlin et al., 2004; Krum & Abraham, 2009). However, some patients may not be eligible for this type of treatment or they may not choose cardiac surgical interventions. Both drug and surgical management options for HF have been substantially improved in the past decades, which has helped to improve both survival and symptoms. Evidence has supported that drug treatment, including angiotensin-converting enzymes, angiotensin receptor blockers, diuretics, and even opioids are helpful in achieving HF treatment goals, including the improvement of morbidity, mortality, and palliation of symptoms (Friedrich & Böhm, 2007; Goodlin et al., 2004).

While surgery and device therapies have been shown to benefit selected HF patients only, ESHF patients need to consider the risk-benefit balance in accepting the treatments (Allen et al., 2012). Some advanced cardiac technologies have uncertain benefits for patients with advanced HF (Fang et al., 2015; Goodlin et al., 2004). For instance, devices such as implantable cardioverter defibrillators (ICDs) have been proven to prevent sudden cardiac death by delivering electric cardioversion when ventricular arrhythmias are detected, but it may improve neither symptoms nor quality of life (Fang et al., 2015). Importantly, the use of ICDs is not supported by ACC/AHA guidelines if the survival of the HF patient is estimated to be around one year (Yancy et al., 2013). Another device, cardiac resynchronization therapy (CRT), is supported by evidence that it can delay the time to hospitalization and improve survival for ESHF patients (Lindenfeld et al., 2007), but there are several risks associated with it, particularly among the elderly or those with a comorbidity because CRT implantation has procedural risks and device infection, so whether it is appropriate to use in patients with ESHF is inconclusive (Fang et al., 2015).

Heart transplantation is a life-saving strategy for ESHF patients that has survival and QOL benefits; however, the therapy is limited by a shortage of available donors (Krum & Abraham, 2009; Mancini & Lietz, 2010). The use of mechanical circulatory support (MCS) devices can support the failing heart in some patients with ESHF, but these devices are mostly used based on certain clinical situations, for example, as a bridge to heart transplantation for patients who are listed for the procedure (Krum & Abraham, 2009; Slaughter et al., 2009). Though MCS devices have recently been used as a destination therapy for those patients not eligible for transplantation, bleeding and device failure pose a significant problem, and the high cost of these devices has limited their wider use. Importantly, peri-operative and post-operative mortality is high for MCS device implantation (McMurray et al., 2012). In addition, the ability to survive with such a device depends on the overall nutritional, physiological, and psychosocial status of the patient (Fang et al., 2015). It is therefore inappropriate for the majority of ESHF patients due to their very advanced age and multiple comorbidities (Allen et al., 2012).

Advanced cardiac therapies for the management of ESHF are usually used to prolong life (Allen et al., 2012; Goldstein & Lynn, 2006). Care and treatment targeted at improving QOL and controlling symptoms are also paramount from patients' perspectives (Goldstein & Lynn, 2006; Lewis et al., 2001; Low, Pattenden, Candy, Beattie, & Jones, 2011; Stanek, Oates, McGhan, Denofrio, & Loh, 2000). Recently, it has been recognized that PC should be introduced into HF care, particularly when HF patients have reached an advanced stage that is refractory to medical therapy (Adler et al., 2009; Goodlin, 2009b).

2.5.2 Palliative care in heart failure management

International guidelines and position statements have highlighted the importance of integrating PC into HF management (Goodlin et al., 2004; Jaarsma, et al., 2009; McMurray et al., 2012; Metra et al., 2007; Yancy et al., 2013). According to the WHO, PC is defined as a holistic, multidisciplinary approach of care that aims to improve QOL and provide care in the alleviation of multifaceted distressing symptoms for patients facing life-threatening conditions (WHO, 2002). Undoubtedly, HF and its approach to the end stage is a life-threatening condition and is particularly relevant to PC consideration. In contemporary practice, the approach of PC should be initiated in earlier stages of the disease, meaning that patients suffering from life-threatening illness should receive standard treatment and PC simultaneously (Gadoud, Jenkins, & Hogg, 2013; Temel et al., 2010). Most HF patients experience multiple comorbidities that affect the course of their illness and their prognosis (McIlvennan & Allen, 2016).

Evidence has shown that it is difficult to predict the life expectancy of HF patients (Allen et al., 2008; Levenson et al., 2000), especially in their last year of life (Fox et al., 1999; Haga et al., 2012). One study showed that the dying trajectory in HF varies (Gott et al., 2007) and the risk of sudden cardiac death is high (Haga et al., 2012), where up to 50% of HF patients die suddenly (Mosterd & Hoes, 2007). Another study confirmed that the prognosis of HF is poorer than that of many kinds of cancer (Stewart et al., 2001), and HF patients have similar PC needs as those with cancer (Bekelman et al., 2009; Gibbs, Khatri, & Gibbs, 2006; Horne & Payne, 2004; Jaarsma, et al., 2009; Kavalieratos et al., 2014; O'Leary et al., 2009; Shah et al., 2006; Solano, Gomes, & Higginson, 2006; Ward, 2002). However, the PC approach is seldom applied to HF patients (Enguidanos & Portanova, 2014; Gadoud et al., 2013; Gibbs et al., 2006; Glogowska et al., 2016; Howlett, 2011; Metzger, Norton, Quinn, & Gramling, 2013; Murray et al., 2005). Lack of time spent on communication regarding the prognosis and treatment plan and future care planning between clinicians and patients/family members is one of the common reasons identified for not commonly applying PC among ESHF patients (Glogowska et al., 2016; Green, Gardiner, Gott, & Ingleton, 2011; Hanratty et al., 2002; Harding et al., 2008; Wotton, Borbasi, & Redden, 2005).

Hanratty et al. (2002) conducted a focus group study in England, interviewing 34 physicians specialized in cardiology, geriatrics, PC, general medicine, and general practitioners (GPs), to identify their perceptions of the needs of and barriers to PC for HF patients. Hanratty et al. (2002) categorized the barriers to the application of PC in HF care into three main areas, including healthcare-system-related, disease-related, and professional-related barriers. The findings revealed that doctors felt frustration during the care of ESHF patients because of the uncoordinated and poor communication among other disciplines, particularly when patients were readmitted to the hospital. The readmitted patients were cared for by different specialists and these specialists were not coordinated, with no well-defined roles among them. Similar findings were reported in Harding et al.'s (2008) qualitative interview study. Patients dying of HF had neither planned nor adopted a holistic approach to their care (Glogowska et al., 2016; Hanratty et al., 2002; Harding et al., 2008; Wotton et al., 2005).

Disease-related barriers refer to the unpredictable trajectory of HF, which makes initiating PC difficult (Davidson et al., 2002; Hanratty et al., 2002; Harding et al., 2008). For this reason, doctors fear that they might say the wrong thing, and they do not want to see patients give up the fight for life if they give them bad news (i.e., the prognosis) too soon (Hanratty et al., 2002; Harding et al., 2008). Another barrier is that there is no agreement on which specialty should take the lead in providing PC to HF patients, and discordance among physicians from different specialties has been found. In Hanratty et al.'s (2002) study, PC physicians were viewed favorably by patients; however, the need for involving the PC specialty was questioned by the GPs for two reasons. First, the GPs believed that they were capable of managing ESHF patients by themselves, and second, they were concerned that PC physicians were taking over their patients (Hanratty et al., 2002). A lack of confidence and skills in discussing complex issues such as end-of-life topics is considered one of the professional-related barriers in palliative HF care (Green et al., 2011; Harding et al., 2008).

Wotton et al. (2005) interviewed 17 nurses in Australia, including those who work in acute cardiac and medical wards and community centers with a PC focus, to explore their perceptions of what influenced the provision of PC for patients with ESHF. The nurses perceived several factors that influenced the introduction of PC to HF care. First, the nurses reported that patients with ESHF and their families lacked awareness concerning death and dying issues until the last few days or hours before death. Some patients were unable to accept that ESHF is a terminal condition, making physicians perceive that the patients did not want to know about their impending death (Wotton et al., 2005). The second factor influencing the provision of PC for ESHF patient was medicalized care, where nurses observed that the care of patients with ESHF mainly focused on optimizing drug therapies and treating symptoms, and treatments were often intended as a cure until the last breath of the patient.

Harding et al. (2008) and Green et al. (2011) reported similar issues, where the cardiac team often focused on technological and curative aspects that might overlook the psychosocial needs of their patients. The physicians were reluctant to initiate an end-of-life discussion, and they regarded initiating PC as a failure to manage their patients. Both cardiac nurses and PC nurses reported that cardiologists tended to continue life-sustaining treatment (Wotton et al., 2005). Additionally, the provision of PC for patients with ESHF was viewed as suboptimal since the ownership of the patient, whether by the cardiologist or the PC specialist, was ambiguous (Davidson et al., 2002; Wotton et al., 2005). However, nurses embraced the concept of a multidisciplinary PC approach, and they felt confident in managing most symptoms presented by ESHF patients (Wotton et al., 2005).

Healthcare professionals have acknowledged that the idea of extending PC to HF care is a fairly new concept (Green et al., 2011). The patient-specific, professional-specific, disease-specific, and healthcare-system-specific factors described above have contributed to a situation in which the PC approach is applied less in HF management.

2.6 Comparative studies between cancer and non-cancer palliative care

Numerous studies have explored the symptoms (Solano et al., 2006) and PC needs (O'Leary et al., 2009) between cancer and non-cancer patients at the end-stage of life. A cross-sectional, descriptive study conducted in Canada by Tranmer et al. (2003) measured the symptom experiences of end-stage cancer and non-cancer hospitalized patients with non-cancer patients, including those with COPD, symptomatic HF, and liver disease. In that study, the subjects consisted of 66 cancer and 69 non-cancer end-stage patients, and there were no significant differences between the cancer group and the non-cancer group with respect to physical and psychological symptom scores and the overall symptom score. Another study compared 226 community-dwelling older patients with cancer, COPD, and congestive HF on prevalence and intensity of symptoms, and the results showed that 86% of the study sample with advanced chronic illnesses experienced at least one symptom that was rated moderate or severe (Walke, Gallo, Tinett, & Fried, 2004).

Solano et al. (2006) conducted a review identifying 64 original studies comparing symptom prevalence among end-stage patients, including advanced cancer, acquired immunodeficiency syndrome, heart disease, COPD, and renal disease. That study found that 11 common symptoms consistently appeared among the five disease groups. Breathlessness, fatigue, and pain were observed in more than 50% of these patients, and Solano et al. (2006) commented that there seemed to be a common pathway toward death for people with advanced progressive diseases. The study suggested that PC initiatives, such as a home-based PC program, are relevant for all people with advanced progressive diseases, although there might be a need to modify the assessment and management aspects (Solano et al., 2006). However, the non-cancer patients were less likely to receive PC services despite the needs identified (O’Leary et al., 2009; Shah et al., 2006; Tranmer et al., 2003).

Qualitative semi-structured interviews in the UK by Exley, Field, Jones, and Stokes (2005) explored the experiences of patients who had end-stage cardiorespiratory disease or cancer and their corresponding primary healthcare providers. The findings from that study revealed that the patients with end-stage cardiorespiratory disease received less community PC services and less hospital social services compared with the cancer patients, and they seldomly received PC (Exley et al., 2005). The GPs and district nurses in the focus group interviews commented on the PC services available for the two groups of end-stage patients, noting that more resources were allocated to cancer patients; for example, it was easier for cancer patients to receive PC services than for those with end-stage cardiorespiratory disease because a well-established PC package was in place for cancer patients (Exley et al., 2005). The GPs admitted that they provided less help to the end-stage cardiorespiratory disease group because they did not know how to manage the end-of-life situation, particularly when devices were implanted. The GPs also reported that communicating about dying issues was much harder for the non-cancer patients, and they felt that cancer patients were probably more aware of dying because they had been given information about the dying process compared with the end-stage cardiorespiratory disease patients, who did not receive such information (Exley et al., 2005). In addition, the district nurses observed that the cancer patients and their families were well informed on the type and sources of help available to them, and they were more willing to seek help; however, the patients with an end-stage cardiorespiratory diagnosis were reluctant to seek help from the district nurses (Exley et al., 2005).

Likewise, Fitzsimons et al. (2007) interviewed patients who were in their final stages of a chronic illness, their main caregivers, and the clinical team members responsible for these patients to explore their perspectives on PC needs. The patient participants had a diagnosis of either end-stage HF, renal failure, or respiratory disease. As evidenced in that study, support from the hospital and the community was perceived as lacking, particularly the specialist services, which suggested that end-stage patients deserved more coordinated and holistic care (Fitzsimons et al., 2007). It was apparent that both end-stage cancer and non-cancer patients shared similar symptom burden and care needs; however, the PC support offered to them differed remarkably, with less support for the non-cancer patients. Supportive care should be proactive and individually designed to meet the specific needs of end-stage patients (Murray et al., 2002). As such, it is essential to have a PC plan for non-cancer patients, with benefits already proven for cancer patients (Solano et al., 2006)

Some researchers have compared similarities and differences in the aspects of illness experiences and PC needs between advanced cancer and HF patients (Bekelman et al., 2009; O'Leary et al., 2009). Anderson et al. (2001) carried out a survey of 213 patients in the UK, mostly with cancer and receiving PC, and 66 patients with HF (NYHA Class III to IV) to explore the problems and concerns of these two groups of patients. That study found that HF patients' troublesome problems were less likely to be resolved, with reported unresolved physical problems (cancer 23% versus HF 50%), unresolved social problems (cancer 24% versus HF 31%), and unresolved psychological problems (cancer 24% versus HF 27%). The study also found that cancer patients had more professional support, such as district nursing services, hospice, social work, and physiotherapy input, compared with the HF patients (Anderson et al., 2001).

Another survey conducted in the U.S. by Bekelman et al. (2009) compared symptom burden and psychological and spiritual well-being in HF and advanced cancer patients to examine the PC needs in the two conditions. It was found that the PC needs of patients with symptomatic HF and advanced cancer were similar. Bekelman et al. (2009) highlighted that HF patients may benefit from the PC approach, particularly those who had more severe HF symptoms, but that PC had been markedly underutilized in that patient group. O'Leary et al. (2009), using a mixed method approach, confirmed that there was no difference between HF and advanced cancer patients in terms of symptom burden, emotional well-being, and QOL scores.

In a serial qualitative interview study, Murray et al. (2002) interviewed 20 ESHF patients, 20 advanced, inoperable lung cancer patients, and their main informal and professional caregivers. The patients were interviewed at three-month intervals for up to a year. The findings showed that the ESHF patients, compared with the advanced lung cancer patients, had less understanding of their diagnosis and prognosis, had less information about their condition, and were less involved in care decision-making. In addition, the study also found that the ESHF patients had little contact with health and social services, received less specialty PC services, and care was often poorly coordinated (Murray et al., 2002). Differences in illness experiences between the ESHF and advanced lung cancer patients were identified. The advanced lung cancer patients were more aware of the situation of facing death after they were first told of their diagnosis, and their concern was how long they would live; they also attended regular hospital visits for chemotherapy or radiotherapy, where the uncomfortable treatment side effects dominated their lives (Murray et al., 2002). The end-stage HF patients rarely recalled being told that ESHF is a terminal illness, and instead related dying to the context of old age. The ESHF patients managed their variable symptoms and complex medication regimens day-to-day in the community, but the adverse effect of diuretic was troublesome to them because they needed to go to the washroom frequently, which made it difficult to leave home (Murray et al., 2002). Although spiritual issues were important to the terminally ill patients, differences in spiritual needs were noted between the two illness groups in the same study population.

In a study by Murray, Kendall, Boyd, Worth, and Benton (2004), the spiritual needs of the ESHF patients and their caregivers were predominated by hopelessness, isolation, and loss of confidence associated with their chronic illness, while the advanced lung cancer patients and their caregivers felt despair due to impending death associated with their terminal illness. Another observation made by Murray et al. (2004) was the episode of spiritual needs that cancer and ESHF patients presented. For the advanced lung cancer patients, their spiritual needs were important from their first awareness of dying and at the end-of-life phase, whereas the spiritual needs of the ESHF patients were recognized throughout the course of their illness.

Murray et al. (2007) further compared the patterns of spiritual, social, and psychological decline by synthesizing data from two longitudinal, in-depth interview studies of 48 patients with ESHF and advanced lung cancer. The study concluded that patients with advanced lung cancer and ESHF may have common patterns of physical, social, psychological, and spiritual needs due to disease progression (Murray et al., 2007). As the comparative studies above have shown, ESHF patients need holistic care encompassing physical, social, psychological, and spiritual dimensions toward the end-stage of life.

2.7 Identifying palliative care needs for end-stage heart failure patients

2.7.1 Patient-centered care and patients' preferences

Health policies in many developed countries recommend patient-centered care. Patient-centered care is regarded as one of the six key dimensions of high-quality care throughout the healthcare system in the U.S., with the expectation that personalized health care should be provided based on patients' preferences and needs. In addition, it is crucial that patients be engaged and empowered in decision-making regarding their care (Institute of Medicine, 2001). Similarly, patient-centered care has been adopted as a national strategy for achieving high-quality care in England (National Health Service, 2005). A recent narrative review of the literature on health policy, medicine, and nursing has identified some core elements of patient-centered care, emphasizing respect for patients’ preferences and needs (Kitson, Marshall, Bassett, & Zeitz, 2013).

In the context of HF care, studies have been conducted to examine the preferences of patients with advanced HF (Brunner-La Rocca et al., 2011; Dev, Abernethy, Rogers, & O’Connor, 2012; MacIver et al., 2008). One of the important patient preferences being studied is perceived quality versus quantity of life for patients with HF. Several U.S. studies have assessed quantity versus quality of life among patients with advanced HF (Lewis et al., 2001; Stanek et al., 2000; Stevenson et al., 2008). These studies used the time trade-off method, which aimed to determine patients’ preferences in some healthcare choices, such as patients’ preferences regarding a willingness to trade survival time to improve QOL (Dev et al., 2012; Lewis et al., 2001; Stanek et al., 2000; Stevenson et al., 2008).

Despite studies that have demonstrated that some advanced HF patients preferred survival rather than trade time to feel better (Brunner-La Rocca et al., 2011; Stevenson et al., 2008), other studies have shown reverse results. For instance, one study explored patients’ preferences based on the goal of symptoms versus survival improvement among a group of symptomatic HF patients (Stanek et al., 2000). That study concluded that a majority of HF patients perceived greater importance in improvement in symptoms than longer survival as their preferred therapeutic outcome, and that they were willing to accept death to obtain a better QOL (Stanek et al., 2000). Another study conducted by Lewis et al. (2001) also demonstrated that ESHF patients preferred quality to length of life. Lewis et al. (2001) found that the severity of HF could be related to patients' willingness to trade time to achieve better health; other factors that have been associated with greater patient preferences for QOL include their NYHA classification, the symptom of dyspnea (Lewis et al., 2001; Stevenson et al., 2008), and the "do not resuscitate" (DNR) order (Dev et al., 2012). HF patients with a poor functional class who have expressed a DNR preference are more likely to choose better perceived health over survival time. Jaarsma and Leventhal (2002) asserted that cardiac specialists tend to offer treatment to ESHF patients that prolongs life, which might invite experiences of great distress and discomfort in patients' last months of life.

Apart from quality versus quantity of life, understanding treatment preferences and decision-making for ESHF patients is essential in providing patient-centered care to avoid unwanted interventions (Allen et al., 2012; Formiga et al., 2004; Jaarsma & Leventhal, 2002; Strachan et al., 2009). An analysis from the SUPPORT study examined patient preferences and decision-making among hospitalized patients with ESHF and reported that they preferred to die rather than spend their remaining time being put on a respirator, feeding tube, or in coma status in their last six months of life (Levenson et al., 2000).

A prospective survey examined the end-of-life preferences of 80 elderly patients admitted for HF and reported that 32 patients (40%) expressed a wish not to have resuscitation (Formiga et al., 2004). Another study involved 226 limited life expectancy patients, including HF patients, who completed a questionnaire that assessed their treatment preferences (Fried, Bradley, Towle, & Allore, 2002). That study revealed that some patients would not choose treatment if it carried a high burden, for example, being hospitalized for at least one month, cared for in the ICU, or put on mechanical ventilation. Many patients in Fried et al.'s (2002) study expressed that they would not choose treatment if the treatment outcome prolonged survival but resulted in significant functional or cognitive impairment.

With the same patient cohort, Fried et al. (2007) further examined the changes in patients' treatment preferences after a two-year follow-up. The participants with advanced illness, including HF, were asked if they would undergo a high-burden treatment given the likelihood of death versus a return to current health when facing an illness exacerbation that would lead to death. The results showed that they expressed a decreased willingness to endure a high-burden treatment over time, and there was little change in the treatment preferences among the participants from the first to the final interview (Fried et al., 2007).

However, treatment preferences can change among ESHF patients. The results from the SUPPORT study demonstrated that, of the 936 patients hospitalized with severe HF, 215 (23%) expressed a preference not to be resuscitated (Krumholz et al., 1998). Almost one-third of the patients changed their minds after two months post-discharge and said that they wanted resuscitation. Krumholz et al. (1998) found that functional status and patients' perception of prognosis were predictors of resuscitation preferences. The findings from these studies reflect that identifying treatment preferences, with periodic discussions and evaluations between ESHF patients and healthcare providers, is needed for individualized care (Howlett, 2011; Jaarsma & Leventhal, 2002; Whellan et al., 2014).

2.7.2 Communication about prognosis, goals of care, and end-of-life issues

As sudden cardiac death is common in the HF condition, having a thorough understanding of the disease is important for ESHF patients (Low et al., 2011). Studies have revealed that there is a lack of information provision for these patients (Harding et al., 2008; Horne & Payne, 2004; Rodriguez et al., 2008; Rogers et al., 2000; Selman et al., 2007b). It is fundamental to communicate the treatment and resuscitation preferences between the ESHF patients, the patient's family members, and healthcare providers, especially when the patients are approaching the end of life (Allen et al., 2012; Barclay et al., 2011; MacIver et al., 2008).

Discussing prognosis and goals of care is the key priority in end-of-life care conversation (Hauptman & Havranek, 2005; Meyers & Goodlin, 2016; Whellan et al., 2014). Studies have found that patients with ESHF desired prognosis communication related to HF trajectory initiated by their healthcare providers (Caldwell, Arthur, & Demers, 2007; Dougherty et al., 2007; Murray et al., 2002; Rodriguez et al., 2008; Selman et al., 2007b). While some HF patients may not want a prognosis and end-of-life discussion (Gott et al., 2008; Willems et al., 2004), and others did not think that end-of-life issues were relevant to them (Bekelman et al., 2011; Strachan et al., 2009), planning end-of-life care is particularly needed when their medical status changes (Denvir, Murray, & Boyd, 2015; Goodlin, Quill, & Arnold, 2008; Howlett et al., 2010; Strachan et al., 2009). Yet end-of-life care communication with HF patients rarely takes place (Barclay et al., 2011; Selman et al., 2007b). Aldred et al. (2005) and Gott et al. (2008) revealed that few HF patients had discussed their prognosis with healthcare providers.

Patients with ESHF often face numerous and complex medical decision-making choices regarding treatment options. These decisions include treatment modalities, strategies related to symptom management, place of death, and deactivation of a device (Allen et al., 2012; Dev et al., 2012; Jaarsma & Leventhal, 2002; LeMond, Camacho, & Goodlin, 2015; Meyers & Goodlin, 2016). Patients with HF are typically elderly and suffering from multiple comorbidities. Waterworth and Jorgensen (2010) conducted a literature review on decision-making among elderly patients with advanced HF and pointed out that involving a key healthcare provider in the care process enabled guidance in decision-making for elderly patients with advanced HF. Healthcare providers need to be sensitive to their patients' readiness to initiate end-of-life conversations (Barclay et al., 2011) with an empathetic attitude (Goodlin et al., 2008; Whellan et al., 2014).

In order to support patient-centered care, the care provided should respect and respond to individual patient's needs and preferences (Dev et al., 2012). Recently, professional organizations such as the Heart Failure Society of America (HFSA) and the AHA have developed documents that provide a roadmap to clinicians for decision-making (Allen et al., 2012) and end-of-life planning in ESHF care (Whellan et al., 2014). Given the inherent unpredictable prognosis and limited treatment modalities of ESHF, the selection of treatment for this population should be patient-centered, including respecting their wishes for survival versus QOL and decision-making preferences at the end of life (Dev et al., 2012; Fang et al., 2015).

2.8 Provision of palliative care for end-stage heart failure patients

Researchers have suggested that a PC approach targeting the control of symptoms as well as optimizing QOL is beneficial to ESHF patients (Bekelman et al., 2007; Dougherty et al., 2007; Nordgren & Sörensen, 2003). Previous studies have identified that patients with ESHF have many unmet PC needs and concerns (Anderson et al., 2001; Exley et al., 2005; Fitzsimons et al., 2007; Kavalieratos et al., 2014; Murray et al., 2004). Patients with HF have expressed that they are worried that they will not get good care at the end of life (Strömberg & Jaarsma, 2008), and they have expectations to receive quality end-of-life care as their condition worsens (Waterworth & Jorgensen, 2010). Getting good and quality care means that they will not be neglected when they lose their independence and will be cared for with dignity, because HF patients are afraid of becoming helpless (Strömberg & Jaarsma, 2008). The expectation of good care involves maintaining a relationship with healthcare providers and expecting that the care provided will be through trust, confidence, and hope that they will not be abandoned or be viewed as a burden as their condition worsens (Strachan et al., 2009; Waterworth & Jorgensen, 2010).

With HF disease progression manifested by refractory symptoms, most ESHF patients need hospitalization to treat exacerbations (McIlvennan & Allen, 2016; Strachan et al., 2009). Unmet needs following hospitalization with HF have been identified, particularly psychological and social needs (Davidson et al., 2008). The reasons for repeated hospitalization after discharge include non-compliance to medication, diet, or fluid restriction; knowledge deficit; insufficient professional help and delay in seeking help (Annema et al., 2009); and poor post-discharge support in the community (Hanratty et al., 2002). Patients with ESHF want to have a key healthcare provider who is responsible for coordinating their care and assessing them continuously (Boyd et al., 2009;

Bekelman et al., 2011; Hanratty et al., 2002; O'Leary et al., 2009). This is supported by the consensus statements that advocate a PC service model for HF care (Goodlin et al., 2004; Jaarsma et al., 2009).

Strachan et al. (2009) conducted a cross-sectional survey of 106 ESHF hospitalized patients in Canada to identify their concerns regarding the improvement of end-of-life care. Having the same nurse look after them at home after discharge was important to them because they wanted to have an adequate and consistent care plan in which health services would be available following hospital discharge (Strachan et al., 2009). Having the option of avoiding life-sustaining treatments if there was no hope for recovery, communicating information about the disease (including the risks and benefits of treatment options), and minimizing the burden on their family were the three most important concerns ranked by the hospitalized ESHF patients (Strachan et al., 2009). The study concluded that seamless care bridging the transition from hospital to home is essential for hospitalized ESHF patients, and the care components must incorporate comprehensive symptom management, coordination of care, effective communication on HF and end-of-life issues, and caregiver support (Strachan et al., 2009).

Yet evidence on how to address the PC needs of patients with HF is lacking (Bekelman et al., 2011; Jaarsma, Johansson, Ågren, & Strömberg, 2010). The Canadian Heart Health Strategy and Action Plan has suggested that transitional care intervention aimed at supporting hospital discharge of medically complex HF patients should be adopted to improve their end-of-life planning and care (Howlett et al., 2010). The Canadian strategy to improve end-of-life planning and care for HF patients has indicated that care should be comprehensive to meet the needs of patients and their families; a key health professional should be available to coordinate care and liaise with interdisciplinary teams and other services; and collaborative care planning and continuity of care across different settings is essential (Howlett et al., 2010).

Bekelman et al. (2011) interviewed 33 adult symptomatic HF patients and 20 of their family caregivers to explore their major concerns and needs in the PC context, such as how and when PC would be helpful to them. The findings from that study revealed that both patients and their family caregivers wanted early PC support during the course of their illness to help them adjust to their limitations and their future (Bekelman et al., 2011). The HF patients expressed a desire to receive help in relieving their diverse number of symptoms and to be cared for by a team involving their family caregivers, which are also key elements of the PC approach (Bekelman et al., 2011).

The importance of communication with patients and their family caregivers, together with comprehensiveness, coordination, continuity, and collaboration of care, has been confirmed by Bekelman et al. (2011), and these are also features of a transitional care model proposed by Wong et al. (2011). Collaborative care is further elaborated as providing close follow-up, patient education, disease progress monitoring, treatment outcomes evaluation, and referral to specialist consultations whenever necessary (Bekelman et al., 2011). However, few services and care models have been developed to integrate PC elements into HF management (Hupcey et al., 2009).

2.9 Current evidence on the palliative care approach in heart failure management

Currently, the evidence supporting PC for seriously ill patients is inadequate (Kelley & Morrison, 2015). In both the HF and PC fields, there are experts in these specialties who have called for extending or integrating PC into HF care (Adler et al., 2009; Gibbs, McCoy, Gibbs, Rogers, & Addington-Hall, 2002; Hauptman & Havranek, 2005; Murray et al., 2005; Pantilat & Steimle, 2004; Stewart & McMurray, 2002; Ward, 2002). Various guidelines have also highlighted the importance of the provision of PC for HF care to improve patient and clinical outcomes (Arnold et al., 2008; Department of Health, 2008; Goodlin et al., 2004; Hunt et al., 2009; Jaarsma et al., 2009; McMurray et al., 2012). Early works regarding the integration of PC into HF care were largely based on service evaluations, with a few randomized controlled trials (RCTs).

Davidson et al. (2004) evaluated an integrated, consultative PC model for ESHF patients in a teaching hospital in Australia. The collaborative service model was driven by a community HF disease management program led by nurses and partnered with specialist PC and cardiology clinicians. Hospitalized

ESHF patients could consult or be referred to the community PC team (who were specialists) upon discharge for complex symptom management, caregiver support, and issues related to spirituality if needed (Davidson et al., 2004). The community PC team provided home visits and telephone support with a multidisciplinary approach toward the discharged ESHF patients (Davidson et al., 2004). In this collaborative model, 121 deaths were reviewed between 1999 and 2002: 8.3% were referred to a PC specialist; 50% died at home; 20% died at a nursing home; and 23% died in the hospital (Davidson et al., 2004).

Another model of PC and HF specialists working in partnership was developed in the UK by Daley, Matthews, and Williams (2006) based on a three-year collaboration between community HF nurse specialists and PC specialists, where the HF nurse specialists were the key persons in this care model. The HF nurse specialists were responsible for following up on discharged advanced HF patients in the community, aiming to reduce hospital readmission and improve QOL by providing psychosocial support, coordinating health and social services, and optimizing medication based on protocols (Daley et al., 2006). In that model, the HF nurse specialists were supported by specialist PC teams through telephone advice, outpatient clinic arrangement, or hospice admission for the patients whenever necessary. Of the 491 patients recruited from 2002 to 2005, 75 (17%) were referred to the specialist PC services. The mean length of time that the HF nurse specialists followed up on the patients until death was 5.3 months (Daley et al., 2006).

Johnson and Houghton (2006) described a shared care approach in the UK in response to the increasing demand of HF patients having access to PC services. The service was jointly set up by cardiologists and PC physicians in 2000, where mutually agreed upon referral criteria was designed. In this shared care approach, the HF nurse specialists served as the key agents whose main role was to liaise with primary care services (such as GPs), secondary care services (specialist care referred by primary care professional), and hospice services (National Health Service Choice, 2017). Hospice provides care for patients with terminal or life-limiting illnesses, as well as support for their loved ones. Hospice care can be provided in a day-care setting, home care, in-patient hospice building, and a patient’s own home. Hospice services cover a wide range of services, including symptom control, psychosocial support, spiritual care, counseling, complimentary therapies, practical and financial advice, respite care, and support in bereavement (National Health Service Choice in End of Life Care, 2017). The PC services involved a multidisciplinary team to provide symptom control, medication adjustment, spiritual care, family support, and bereavement planning if a referral was received.

The results of one retrospective review revealed that 62 patients were referred to the PC team from 2000 to 2005, and the sources of referral included inpatient consultation and GPs (Johnson & Houghton, 2006). It was observed that PC is a unique specialty that emphasizes timely communication of psychosocial and spiritual issues to both patients and carers, and the study concluded that it is possible to extend PC to HF care (Johnson & Houghton, 2006).

In the U.S., Bekelman et al. (2011) described the experience of seeing HF patients in an outpatient PC program named “The Supportive Care Program.” This was a collaborative program with a palliative medicine physician co-located in an HF clinic with cardiologist and cardiac nurse practitioners. In the 2006–2009 period, there were 228 patient visits and 50 patients were referred to the palliative medicine physician. Among them, 70% were classified as NYHA Class III or IV (Bekelman et al., 2011). From this clinical evaluation, care coordination, psychosocial issues, and advance care planning were the common palliative needs that required attention in the program (Bekelman et al., 2011). It was suggested that a nurse and social worker or psychologist should be included in palliative HF care; in particular, a trained nurse could act as a care manager who could accomplish both palliative and HF disease management goals. The study proposed that the trained nurse should see the HF patients first and have regular consultations with a PC physician if necessary, such as for uncontrolled symptoms, and such an approach might be a better use of resources compared with the HF patients who saw the PC physician first (Bekelman et al., 2011). Based on the experience of seeing HF patients in the Supportive Care Program, the study concluded that in-person contacts, telephone support, team-based care, and having a designated care coordinator linked closely with the PC and HF experts are keys to success in providing quality support to patients (Bekelman et al., 2011). These studies have provided valuable information on establishing and implementing a palliative HF care model.

The studies cited above were mainly retrospective studies, and a few trials were conducted to test the effectiveness of providing PC to HF patients (Gadoud et al., 2013). Rabow, Dibble, Pantilat, and McPhee (2004) conducted a one-year controlled trial in the U.S. A Comprehensive Care Team (CCT) program was established for patients with advanced HF, COPD, or cancer, the cohorts for which the CCT program has shown positive clinical outcomes (Rabow et al., 2004). The CCT program delivered care through an interdisciplinary palliative medicine team that was composed of a physician, nurse, social worker, volunteers, psychologist, chaplain, pharmacist, and art therapist. Except for the volunteers, who were medical and pharmacy students, all team members had expertise in PC and were able to address the physical, emotional, and spiritual needs related to advanced illness (Rabow et al., 2004). In the CCT, the social worker was the key person responsible for carrying out patient assessment and presenting the assessment to the CCT during team meetings. The recommendations, centered around five domains (social support, advance care planning, physical symptoms, psychological well-being, and spiritual well-being), were formulated based on the social worker's assessment and patient survey. The recommendations were written down and sent to the patients' primary care physician (equivalent to a GP in the UK) (Rabow et al., 2004). The primary care physicians did not engage in the CCT meeting, but rather the social worker often communicated with them to discuss patient care.

Care was delivered at a university medical center, where the social worker provided in-person psychological support and case management to patients. The social worker facilitated advance care planning with the patients, including wills, appointment of a decision-maker, and funeral arrangements. Care was also delivered by telephone (Rabow et al., 2004). Other members had different roles, for example, the nurse was responsible for training family caregivers and supporting them through formal classes and informal individual consultation. Spiritual and psychological support was provided by the chaplain. The pharmacist reviewed the medical charts for patients' medications and checked for unnecessary complex medication regimens and the possibility of any drug-drug interactions (Rabow et al., 2004). A monthly support group was offered to patients and their families, allowing them to discuss symptom management and advance care planning and to participate in art work. The volunteers visited patients monthly and called them weekly to provide support, and they communicated regularly with the CCT about the patients' needs. The palliative medicine physician in the CCT rarely directly examined or interviewed the patients (Rabow et al., 2004). The study showed improvements in symptoms, including dyspnea, anxiety, and sleep quality; however, patient satisfaction and QOL were not improved (Rabow et al., 2004).

One RCT conducted by Aiken et al. (2006) in the U.S. tested the PhoenixCare program on a group of serious HF and COPD patients who were estimated to have a life expectancy of up to two years. The PhoenixCare program, which is a home-based PC case management program, aims at improving patients' QOL and reducing costs to the healthcare system. In that study, the intervention group received PC-focused case management plus active treatment from a managed care organization, whereas the control group received active treatment only, also from the managed care organization (Aiken et al., 2006). The PhoenixCare-based PC intervention was team-based, with registered nurses as case managers who were supported by a medical director, social worker, and pastoral counselor. The nurses took an active role in planning and coordinating patient care, including assessment, education, monitoring, evaluation, and communication with other healthcare professionals (Aiken et al., 2006). Care was delivered by home visits and telephone calls.

The four focuses of the PhoenixCare-based PC intervention included providing information and education; preparing for the end of life; enhancing physical and mental functioning; and reducing medical services utilization. Additionally, the PhoenixCare-based intervention was protocol-driven, for example, a disease and symptom management protocol was developed to guide the nurses in managing different problems. The RCT of the PhoenixCare-based intervention demonstrated better patient outcomes such as QOL and lower symptom distress, but the medical services utilization outcome did not improve (Aiken et al., 2006). In the study, the registered nurse case managers played an important role in the entire intervention; however, it is not known whether the registered nurses were experts in PC or whether they had received any training to carry out the intervention as well as using the protocols.

Another PC RCT study was conducted by Gade et al. (2008) in the U.S., which aimed at testing the effect of interdisciplinary PC services for six months post-hospital discharge. Patients with a life-limiting diagnosis of death within one year were the targeted subjects. The outcome measures in that study were patient satisfaction, cost of care, and clinical outcomes, such as symptom control and levels of emotional and spiritual support (Gade et al., 2008). Interdisciplinary PC services were implemented in an inpatient consultation program, and the PC team consisted of a PC physician, nurse, social worker, and chaplain. The inpatient consultation program offered team-based care in which the entire team met with patients and their family members during each consultation. The PC components encompassed the assessment of needs regarding symptom management, psychosocial and spiritual support, and end-of-life and discharge planning (Gade et al., 2008).

The team also collaborated with the patients' primary care physician, the hospital attending physician, and the discharge planner to make a discharge care plan. The inpatient consultation program resulted in higher patient satisfaction, reduced ICU admissions on subsequent readmission, and lower cost of care. There was no symptom control effect in the study, and inpatient PC consultation was the modality for delivering PC, which showed positive outcomes (Gade et al., 2008).

Home is the preferred place for care and death for many patients with advanced illnesses (Higginson & Sen-Gupta, 2000), including HF (Johnson, Parsons, Raw, Williams, & Daley, 2009; Stajduhar, Allan, Cohen, & Heyland, 2008). A survey conducted by Formiga et al. (2004) investigated the end-of-life preferences of patients admitted for HF. Of the 80 participants, 50% of them preferred to receive treatment at home in the final stage of the disease. Home-based PC is a common care delivery model in the PC context. However, research on home-based PC for HF patients is scarce. A recent Cochrane review examined home-based PC services for patients with advanced illnesses and their families, but none was targeted solely to the HF population (Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013).

The studies in the Cochrane review included HF patients in a mixed sample (Gomes et al., 2013). For instance, an RCT conducted by Brumley et al. (2007) in the U.S. examined the effectiveness of a home-based PC program among terminally ill patients with late stage HF (n = 97), COPD (n = 62), and cancer (n = 138). These patients were estimated to have a life expectancy of 12 months or less. A PC physician played an active role in coordinating patient care in the home-based PC program, which adopted an interdisciplinary team approach. In the team, a nurse and a social worker who had expertise in symptom control and bio-psychosocial management were supported by e-volunteers, a chaplain, a spiritual counselor, and a bereavement counselor to provide psychological care to patients as needed (Brumley et al., 2007). The PC physician conducted home visits, and 24-hour on-call-basis nursing services were available to the intervention group in this home-based PC program. The intervention included comprehensive education, care planning and delivery, identifying goals of care, assessment and continuous reassessment, monitoring and evaluation, and advance care planning discussion. After the initial assessment upon recruitment, the frequency of subsequent follow-up home visits was based on individual patients' needs (Brumley et al., 2007). This program significantly increased patients' satisfaction with care, lowered medical care costs, and increased the proportion of patients dying at home (Brumley et al., 2007). Although the study provided strong evidence for promoting a home-based PC intervention to patients with advanced illnesses, the cohort was mixed as it included late-stage HF, COPD, and cancer patients, and the characteristics of the HF patients were unclear.

End-stage HF is a non-modifiable condition that requires hospital admission if patients suffer from HF symptom exacerbation. In addition to disease progression, poor coordination of care (Boyd et al., 2004; Murray et al., 2002) and various unmet needs may contribute to the rehospitalization of ESHF patients after discharge (Albert, Paul, & Murray, 2012). Patients with ESHF may benefit from a care program with strategic planning for hospital to home transition involving specialist PC providers to deliver health and social care

(Arnold et al., 2008; Boyd et al., 2004). The transitional care model was proven to be an effective care model that enhanced the continuity of care through home visits and telephone follow-ups for HF patients discharged from the hospital. A systematic review and the AHA scientific statement confirmed that transitional care intervention can successfully reduce rehospitalization rates and improve patient outcomes and satisfaction with care (Albert et al., 2015; Feltner et al., 2014). In fact, transitional care for patients with advanced HF was recommended by the Canadian Cardiovascular Society Consensus Conference in its updated guidelines for best practices (Arnold et al., 2008). There is limited evidence to support using the transitional care model in ESHF management because the end-stage cardiovascular disease population is often excluded in transitional care trials (Feltner et al., 2014). Enguidanos and Portanova (2014) conducted a review that particularly looked at home-based PC for advanced HF patients and reported that home-based PC was effective in reducing symptom distress and medical service use. However, the results were mainly obtained from non-trial studies (Enguidanos & Portanova, 2014). Research using an RCT to test the effectiveness of different models of home

PC in advanced non-cancer populations such as HF is needed (Gomes et al., 2013; Kamal, Currow, Ritchie, Bull, & Abernethy, 2013).

2.10 Palliative care in Hong Kong

In Hong Kong, PC has been acknowledged as a medical sub-specialty since 1997, when the professional body Hong Kong Society of Palliative Medicine was established. Similar to other countries, palliative care has evolved from hospice care, while hospice care is for patients who are nearing the end of life. Hospice care is mainly provided for patients with terminal cancer, and it is designed to meet these patients' needs and to support their caregivers during the patients' dying process. The delivery of hospice care in Hong Kong started in 1982 in the form of a hospice care team in a general hospital (Sham & Wee, 1994). Regional hospice care has contributed substantially to the control of cancer pain and other symptoms, and it has emphasized that communication with patients is crucial in providing total care with the essence of good communication and active listening, and by embracing trust and passing through barriers (Sham, 1992).

A few hospice care programs in Hong Kong have been supported by government subventions during hospice care development. Hospice care has also been supported by voluntary donations from the Society for the Promotion of Hospice Care organization, established in 1985, which is dedicated to promoting hospice care. The Society pioneered the first hospice home care program in 1988 (Chan, 2002). Bradbury Hospice was the first hospice in Hong Kong to provide comprehensive care to incurable cancer patients by a multidisciplinary team. Bradbury Hospice encompasses an inpatient unit, outpatient clinic, day care, and home care, focusing on physical, psychological, social, and spiritual dimensions. Admitted cancer patients can be discharged home when their symptoms are controlled, and care can be continued at patients' homes with the support of the home care team (Sham & Wee, 1994). In the first year of hospice care in the local community, Sham and Wee (1994) noted that there was a huge demand for hospice and PC services, and as such, care should be expanded and extended in response to the international call that PC provision should not be limited to cancer and dying patients only (Sham, Chan, Tse, & Lo, 2006).

In 1990, the Hong Kong Hospital Authority (HA) (a statutory body) was established, and since then there has been steady growth in hospice services in the form of home care teams as well as PC units within publicly funded hospitals. The services have adopted person-centered holistic care, with a multidisciplinary approach as the focus to alleviate the bio-psychosocial and spiritual distress of patients with incurable diseases (Chan, 2002; Sham, 2002). As providing PC to non-cancer populations is a global trend, Hong Kong is no exception. The Hong Kong College of Physicians has already recommended the adoption of PC for seriously ill patients, including HF patients (Hong Kong College of Physicians, 2008). In addition, implementing PC for end-stage organ failure patients was highlighted in the 2011–2012 HA annual plan to address increasing service needs and ensure quality of care (Hospital Authority Hong Kong, 2011).

While local PC services largely focus on cancer patients, only a small number of public hospitals have established non-cancer PC services. Although there are different models of PC care locally, including inpatient, consultative, outpatient, and home care (Tse, Chan, Lam, Leu, & Lam, 2007), there have been no RCT studies that have evaluated the effects of the palliative model of care on non-cancer patients.

2.11 Summary of literature review

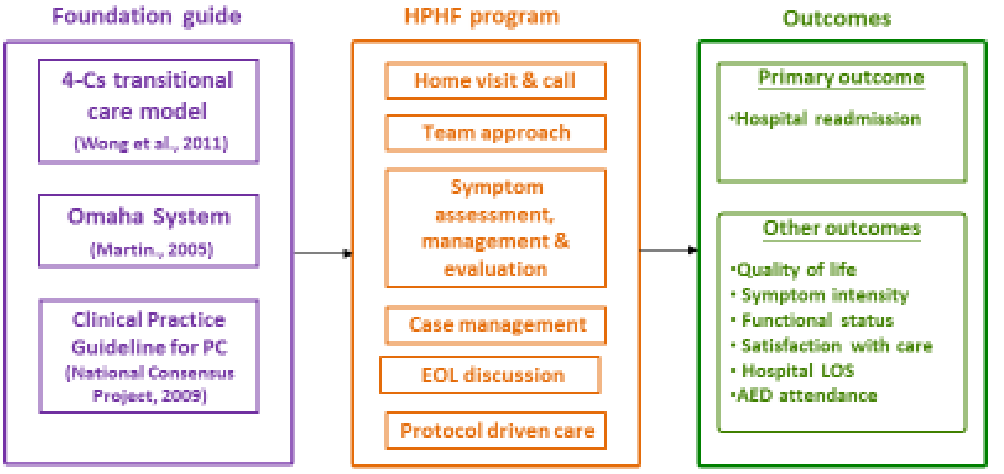
With the review of literature on the HF syndrome and the trajectory of disease progression toward ESHF, the literature has revealed the burden on ESHF patients in both patient burden and economic burden. The literature on patients' experiences showed that patients with ESHF have a similar need for PC compared with cancer patients; however, the key elements of PC, including assessment and management of a wide range of symptoms, personal goals for care, psychosocial and spiritual issues, and discussion of the perception of disease treatment and prognosis, are usually not included in caring for ESHF patients. The literature also reported that the fluctuation of symptoms in HF led to frequent hospital admissions, and readmissions were common, yet the coordination and continuity of health and social care in the hospital-to-home transition were poor.

The quantitative studies showed that the evaluation of outcomes for ESHF patients were primarily QOL, symptoms, satisfaction with care, and hospital readmission rate. The qualitative studies provided evidence that patients with EHSF encountered many unmet PC needs, but research is lacking regarding which model of care is helpful in responding to their needs. Existing literature has examined different kinds of PC service models; however, the majority of those studies enrolled a heterogeneous sample, for example, advanced cancer, COPD, and HF, and those studies did not reflect the effectiveness of the PC model on only ESHF patients. Importantly, those studies were program evaluations and non-RCTs. Though palliative HF interventions have now gained recognition and have been implemented for patients in some countries, trial evidence regarding the effectiveness of PC intervention, including home-based models, is still limited. Previous studies have confirmed that adopting the transitional care framework introduced among different chronically ill groups and general medical patients can bring positive effects on health service use, patient outcomes, and satisfaction with the care provided. The transitional care framework should therefore be used to implement PC in HF care. Transitional care models have been used in the local context with other chronically ill patients, but not with ESHF patients. This comprehensive literature review enabled the investigator to design a care model, the Home-based Palliative HF (HPHF) program, to fill both the knowledge and service gaps.

CHAPTER THREE

CONCEPTUAL FRAMEWORK

ESHF is a life-threatening disease that impairs an individual's QOL and can add burden on the healthcare system with its association of frequent hospitalizations and readmissions. In reviewing the literature review, there was a lack of an integrated care model tailor-made for ESHF patients to improve patients' QOL and at the same time reduce health services use. A model was built for the current study and was subjected to empirical testing. Figure 3.1 below shows the conceptual framework that was formulated to guide the intervention design:



Remark: AED: Accident and Emergency Department; EOL: end of life; LOS: length of stay; PC: palliative care

Figure 3.1 Conceptual framework of the current study

The conceptual framework was constructed based on an extensive literature review with the best available research evidence, including the four-Cs transitional care model (Wong et al., 2011), the Omaha System (Martin, 2005), and the Clinical Practice Guideline for Quality Palliative Care (National Consensus Project for Quality Palliative Care, 2009). The Home-based

Palliative Heart Failure (HPHF) program was designed to provide transitional support to ESHF patients discharged from hospital to home. Home-based PC models are common care delivery models in PC practice (Brereton et al., 2017; Enguidanos & Portanova, 2014; Kamal et al., 2013; Kelley & Morrison, 2015; Morrison, 2013) that are beneficial for patients in the advanced stage disease group (Gomes et al., 2013). In the current study, the HPHF program was a relevant intervention that provided post-discharge support to ESHF patients with PC needs (Arnold et al., 2008; Luckett et al., 2014).

The HPHF program incorporated six important components: home visits and telephone follow-ups; a multidisciplinary team approach; symptom assessment, management, and evaluation; case management; end-of-life communication; and protocol-driven care. Details of the conceptual guide and its components will be explained in the following.

3 The four-Cs transitional care model

In 2005, Wong, Mok et al. (2005) developed the four-Cs transitional care model in Hong Kong for a randomized controlled trial. In that study, 101 patients with diabetes were randomized into an intervention group and a control group. The patients in the intervention group received regular (weekly/bi-weekly) post-discharge support from a nurse. Compared with the control group, the results showed that the intervention group had better glycemic control, improved blood monitoring and exercise adherence, shorter hospital stays, and lower health services costs (Wong, Mok et al., 2005), which were attributed to the four-Cs features of the transitional care model: Comprehensiveness, Coordination, Collaboration, and Continuity. The features of each of the four aspects are as follows:

- Comprehensiveness: A nurse conducts a holistic and systematic client assessment, anticipates client needs, and facilitates post-acute care transition.
- Coordination: A nurse functions across the spectrum of care to work with the health care team to respond to clients' needs.
- Collaboration: A nurse collaborates with both the healthcare team and the clients.

- Continuity: A nurse provides support actively and regularly and ensures sustained follow-ups.

Over the past decade, the four-Cs transitional care model has been tested on multiple disease groups, including cardiac disease, renal disease, and stroke, among the Chinese population (Wong et al., 2008; Wong, Chow, & Chan, 2010; Wong & Yeung, 2015; Zhao & Wong, 2009; Zhu, Wong, & Wu, 2018). It has been proven that the four-Cs transitional care model is a practical and cost-effective model. Wong et al. (2011) further tested the model on 555 general medical patients with the help of volunteers to support the nurse case managers and concluded that using volunteers as substitutes for some of the professional care may be effective in bringing about positive clinical and patient outcomes in the transitional program. Studies based on the four-Cs model have provided evidence for transitional care that was applicable to the Chinese population.

3.1 The Omaha System

The Omaha System was first developed in the early 1970s by practitioners at the Visiting Nurse Association of Omaha in the U.S. The Omaha System offers research-based comprehensive standardized terminology for the documentation of clinical information (Martin, 2005; Topaz, Golfenshtein, & Bowles, 2013). The Omaha System was designed to enhance clinical practice, documentation, and information management across different settings, including hospitals, home care, hospice, and long-term care facilities (Bowles, 2005; Garvin, Martin, Stassen, & Bowles, 2008). There has been a wide range of applications of the Omaha System for more than four decades, from describing clients' problems to evaluating clients' outcomes in practice, research, and education (Bowles, 2005; Martin, Monsen, & Bowles, 2011; Topaz et al., 2013).

The Omaha System is a model that reflects a problem-solving process that requires critical thinking and clinical decision-making to derive outcome evaluation and quality improvement centered on the practitioner-client relationship. The process also involves partnerships in multidisciplinary health teams (Garvin et al., 2008; Martin, 2005). The Omaha System consists of three main components: Problem Classification Scheme, Intervention Scheme, and Problem Rating Scale for Outcomes (Martin, 2005). These components offer a relational, reliable, and valid structure and set of terms to describe and evaluate client care (Garvin et al., 2008).

The Problem Classification Scheme serves as a foundation to assist healthcare practitioners in client assessment by addressing four domains, including environmental, physiological, psychosocial, and health-related behaviors, for a total of 42 problems in these domains (Martin, 2005). The concrete terms used in the Problem Classification Scheme enables nurses to comprehensively identity clients' problems with associated signs and symptoms that provide clues for nursing intervention (Garvin et al., 2008; Martin, 2005; Topaz et al., 2013).

The Intervention Scheme refers to the actions or activities that the healthcare provider plans and intervenes in (Garvin et al., 2008). The Intervention Scheme aims to address problems identified to improve, maintain, or restore health and/or to prevent illness. It consists of four intervention categories, which are teaching, guidance, and counseling; treatments and procedures; case management; and surveillance. Within these four categories in the Intervention Scheme, 75 targets or objects of specific nursing interventions are delineated (Martin, 2005; Topaz et al., 2013). The Intervention Scheme helps nurses to systematically organize care plans and describe the care delivered (Garvin et al., 2008).

The Problem Rating Scale for Outcomes enables the care provider to evaluate the care process (Topaz et al., 2013). In the Problem Rating Scale for Outcomes, a 5-point Likert scale in the areas of knowledge, behavior, and status is used to measure the outcomes of the clients’ problems (Martin, 2005). The ratings can provide insights to nurses during examination and evaluation and guide nursing actions geared toward specific problems throughout the care process (Garvin et al., 2008).

The Omaha System structure supports the critical thinking process by seeking information, describing the situation, identifying the problem that led to performing the intervention, and eventually evaluating healthcare services (Topaz et al., 2013). A systematic review concluded that the Omaha System has been widely used in community-based care, and its standardized terminology provides meaningful and high-quality information about complex healthcare services (Topaz et al., 2013). The Omaha System has been applied in the U.S. and internationally, including Canada, China, Japan, Korea, New Zealand, Sweden, and the UK, and in diverse healthcare disciplines by researchers, practitioners, and educators (Martin et al., 2011). A growing body of research, including transitional care and home care studies, has used the Omaha System for the documentation of clinical information (Chow et al., 2008; Martin et al., 2011; Monsen, Westra, Yu, Ramadoss, & Kerr, 2009; Naylor, Bowles, & Brooten, 2000; Wong, Liu, Szeto, Sham, & Chan, 2004; Wong et al., 2010; Wong et al., 2011; Zhao & Wong, 2009). In addition, the Omaha System has been validated by a local research team, which used it among community-dwelling patients, including PC patients in Hong Kong (Chow et al., 2008; Wong et al., 2004; Wong et al., 2008; Wong et al., 2011).

3.2 The Clinical Practice Guideline for Quality Palliative Care

Facing the uncertain and unpredictable nature of HF might further compromise the QOL of hospitalized ESHF patients (Allen et al., 2012; Bosworth et al., 2004). To meet the PC needs of discharged ESHF patients, particularly intensive symptom management and its associated psychosocial impact, the incorporation of the PC approach is essential. PC programs not only save costs and reduce health services utilization (Enguidanos, Vesper, & Lorenz, 2012; Sahlen, Boman, & Brännström, 2016; Smith et al., 2014; Smith & Cassel, 2009; Temel et al., 2010) but also improve QOL (Bakitas et al., 2009; Brännström & Boman, 2014; Evangelista et al., 2012; Rabow et al., 2004; Sidebottom, Jorgenson, Richards, Kirven, & Sillah, 2015; Temel et al., 2010), symptom burden (Bakitas et al., 2009; Evangelista et al., 2012; Sidebottom et al., 2015; Temel et al., 2010), and patient satisfaction (Brumley et al., 2007; Gade et al., 2008; Rabow et al., 2004).

The Clinical Practice Guideline for Quality Palliative Care (Clinical Practice Guideline hereafter) is a set of evidence-based guidelines that aims to promote quality PC, encourage continuity of care across settings, and facilitate collaborative partnerships among PC and/or other healthcare providers (National Consensus Project for Quality Palliative Care, 2009). In 2001, representatives from major PC leadership organizations and memberships in the U.S. (i.e., the National Hospice and Palliative Care Organization; the American Academy of Hospice and Palliative Medicine; the Hospice and Palliative Nurses Association; and the Center to Advance Palliative Care) formed The National Consensus Project for Quality Palliative Care to discuss the standardization of PC to improve the quality of care. The Clinical Practice Guideline was first released in 2004, which described the highest quality of PC services to patients and families, and it was updated in 2009 with more PC researches and literature published. The 2009 updated version stated that the Clinical Practice Guideline also applies to disease-specific conditions such as cardiac diseases (National Consensus Project for Quality Palliative Care, 2009).

The Clinical Practice Guideline embraces key elements for high-quality PC, including patient- and family-centered care; comprehensive care; a team-based approach; continuity of care across settings; and effective communication skills. There are eight domains in the Clinical Practice Guideline that provide the foundations and context for PC: (1) structure and processes of care; (2) physical aspects of care; (3) psychological and psychiatric aspects of care; (4) social aspects of care; (5) spiritual, religious, and existential aspects of care; (6) cultural aspects of care; (7) care of imminently dying patients (renamed “care of the patient at the end of life” in the 2013 version); and (8) ethical and legal aspects of care. The Clinical Practice Guideline was based on available scientific evidence that has provided a blueprint from which to develop new PC programs and strengthen existing programs. In addition, the essential elements in PC programs are appropriate for ESHF patients, as the elements are similar to those in HF management programs (Goodlin et al., 2004; Metra et al., 2007).

3.3 Components of the HPHF program

3.3.1 Home visits and telephone follow-ups

As discussed in the literature review, ESHF patients often experience symptom exacerbations along the HF disease trajectory that might result in multiple hospital admissions (Au et al., 2012; Yamokoski et al., 2007). Transitional care, involving multiple activities designed to facilitate healthcare continuity from one setting to another setting of care, has mainly focused on transitions from hospital to home (Albert et al., 2015; Naylor, 2000). The aims of transitional care are to ensure timely support and to prevent avoidable readmissions (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). During the period of returning home from the hospital, previous studies have shown that home visits and structured telephone support are two essential transitional care strategies that can help reduce hospital readmission for patients with HF (Albert et al., 2015; Feltner et al., 2014; Naylor et al., 2004; Stamp, Machado, & Allen, 2014; Vedel & Khanassov, 2015) and improve patient outcomes (Albert et al., 2015; Harrison et al., 2002; Naylor et al., 2004; Stamp et al., 2014; Wong et al., 2011).

3.3.2 Multidisciplinary team approach

Literature and guidelines have emphasized that a multidisciplinary team approach is crucial in palliative and HF management (Fendler, Swetz, & Allen, 2015; Holland et al., 2005; Inglis et al., 2006; Jaarsma, Strömberg, & Larsen, 2013; Kerr et al., 2014; McAlister, Stewart, Ferrua, & McMurray, 2004; National Heart Foundation of Australia, 2010) to address physical, psychosocial, and existential needs (Brumley et al., 2007; Luckett et al., 2014; Quaglietti, Atwood, Ackerman, & Froelicher, 2000). The team in the current study consisted of a PC nurse case manager (PC-NCM), a palliative specialist, a social worker, and nursing students acting as volunteers.

The PC-NCM, who was the key care provider in the HPHF program, assessed the patients comprehensively upon discharge, and then followed up on the patients after they returned home to maintain continuity of care (Chow & Wong, 2010; Naylor et al., 2004; Wong, Mok et al., 2005). The volunteers were trained to assist the PC-NCM in patient follow-up in the HPHF program. The effect of using volunteers added value to the patients' well-being from physiological and psychological perspectives (Faulkner & Davies, 2005).

Patients and their families who received care support from the volunteers' visits as a PC service reported satisfaction with their care (Candy, France, Low, & Sampson, 2015). The PC-NCM also collaborated with other team members, including the palliative physician, whenever necessary, and a regular team meeting was held. Regular meetings have been widely adopted in PC practice to discuss patients' progress and care plan among team members (Aiken et al., 2006; Brännström & Boman, 2014; Jordhøy et al., 2000; Kerr et al., 2014; Lukas, Foltz, & Paxton, 2013; Peruselli, Paci, Franceschi, Legori, & Mannucci, 1997).

3.3.3 Symptom assessment, management, and evaluation

Symptom assessment, management, and evaluation; education and counseling regarding fluid balance and medication adherence; and symptom exacerbation of HF were performed for patients and their family caregivers (Davidson et al., 2010; Hunt et al., 2009; Jaarsma, Strömberg, & Larsen., 2013; National Heart Foundation of Australia, 2010; Wong, Chow, Chan, & Tam, 2013). Involving patients' family members in symptom recognition and monitoring is recommended because they play an important role in informal caregiving in the care process (Aiken et al., 2006; Dickstein et al., 2008; Fendler et al., 2015). Multidimensional (i.e., physical, psychological, social, spiritual, and cultural) aspects of care were included for assessment, management, and evaluation (Scottish Partnership for Palliative Care, 2008).

3.3.4 Case management

Case management with an individualized care plan was formulated based on problems identified during the initial assessment (Aiken et al., 2006; Brännström & Boman, 2014; Chow & Wong, 2010; Jordhøy et al., 2000; Luckett et al., 2014; Spettell et al., 2009; Wong et al., 2004). When problems were identified, the PC-NCM collaborated with the patients and the family caregivers to establish mutual goals of care targeted to those problems. The goal set was reviewed during subsequent patient contact by the PC-NCM or a volunteer supervised by the nurse. The PC-NCM coordinated care that was consistent with patients' wishes, which included health services for the patients both in the hospital and in the community, and referrals could be made if needed (Aiken et al., 2006; Brumley et al., 2007; Kerr et al., 2014; Quaglietti et al., 2000).

3.3.5 End-of-life communication

Communicating end-of-life issues and future care planning depending on the needs, preferences, and goals of care of the patients and their family members is highly recommended (Allen et al., 2012; National Heart Foundation of Australia, 2010; Scottish Partnership for Palliative Care, 2008). The PC-NCM found an appropriate time to facilitate such discussion and assisted with decision-making accordingly (Barclay et al., 2011; Brumley et al., 2007; Goodlin, 2009a).

3.3.6 Protocol-driven care

The intervention was governed by pre-defined evidence-based protocols that incorporated the Omaha System framework for the standardization of its practice (Aiken et al., 2006; Chow & Wong, 2010; Coleman et al., 2006; Coleman et al., 2004; Naylor et al., 1999; Naylor et al., 2004; Wong et al., 2008; Wong, Mok et al., 2005; Wong, Wong, & Chan, 2005;). The development, validation, and description of the protocols for the intervention will be presented in the methodology chapter.

3.4 Summary

The current study was based on a foregoing conceptual framework built from the best available research evidence. The development of the HPHF program was guided by the four-Cs transitional care model (Wong et al., 2011); the Omaha System (Martin, 2005); and the Clinical Practice Guideline (National Consensus Project for Quality Palliative Care, 2009). The HPHF program was designed within the scope of science, in line with evolving PC services development both locally and internationally, to respond to the call for more research to be conducted on palliative HF management. It is hoped that the HPHF program will improve health services use, QOL, symptom intensity, functional status, and care satisfaction.

CHAPTER FOUR

METHODOLOGY

This chapter will present the research questions, hypotheses, and the research methods used in the current study. The trial design, study setting, study sampling, outcome measurements, quality assurance, data analysis, data monitoring, and ethical issues will be discussed. The CONSORT 2010 checklist was followed in the sections below in presenting the design and procedures of the randomized controlled trial (RCT) (Schulz, Altman, & Moher, 2010). The feasibility study conducted prior to the main study will also be depicted. The aim of this study was to evaluate the effects of the Home-based Palliative Heart Failure (HPHF) program on hospital readmission rates, QOL, symptom intensity, functional status, satisfaction with care, hospital length of stay (LOS), and Accident and Emergency Department (AED) attendance. This study was guided by a conceptual framework, addressing the needs of hospitalized ESHF patients whose health status is compromised and who have PC issues upon discharge to home. This study hypothesized that after receiving the HPHF program, the patients with ESHF would have fewer hospital readmissions, better QOL, better symptom intensity, better functional status, and higher satisfaction with care.

4 Research questions

The research questions asked in this study are as follows:

What is the effect of the HPHF program on (a) hospital readmission rates, (b) QOL, (c) symptom intensity, (d) functional status, (e) patient satisfaction with care, (f) hospital LOS, and (g) AED attendance compared with conventional care alone among the ESHF patients?

4.1 Null hypotheses

> There is no difference in all outcome measures between the subjects receiving the HPHF program plus conventional care, and those receiving conventional care only.

4.2 Study design

This study was a prospective, two-group, single-blinded RCT. Eligible participants were randomly allocated into two groups. Both groups received conventional care. The group that received solely conventional care was the control group, while the group that received conventional care with the HPHF program was the intervention group. Data were collected at baseline (T1) in the hospital before discharge, four weeks post-discharge (T2), and 12 weeks post-discharge (T3). The data collection period was from May 2013 to June 2015.

The study adopted the RCT strategy, which is the gold standard of true experimental designs and provides the strongest evidence for causal relationships (Portney & Watkins, 2009). An experimental design represents the highest standard in scientific inquiry (Portney & Watkins, 2009). A true experimental design requires a random assignment of subjects to at least two comparison groups. In this study, a pre-test and post-test control group design was used to compare the effectiveness of the HPHF program for ESHF patients.

4.3 Study setting

This multisite study was conducted at three regional hospitals in Hong Kong. Hong Kong has a population of over 7.3 million citizens who can seek health care either from private or public organizations. The Hospital Authority (HA) is a statutory body responsible for delivering a comprehensive range of healthcare services under a cluster-based structure. The facilities are organized into seven hospital clusters according to their geographical locations. This study was conducted at three public hospitals that are affiliated with two clusters (the Hong Kong West Cluster and Kowloon East Cluster). Both clusters have the same scope of PC services, including inpatient beds, PC consultation services, PC home care, and day care. In Hong Kong, the hospitals under the HA provide PC services, the objective of which is to provide comprehensive care for terminally-ill (mostly advanced cancer) patients through interdisciplinary efforts. Access to PC services requires a written referral from source hospitals or other HA hospitals within the cluster using a standard referral form (see Appendix 4.1). Non-cancer palliative care is a new service first started in 2011. The clinicians in the study hospitals indicated their interest in research collaboration and agreed to support the study. The study hospitals had similar healthcare practices, which were governed by the central coordinating committee from the HA.

4.4 Subjects

The criteria were based on literature reviewed in palliative HF studies and the expert opinions of researchers and practitioners in the field. Patients who fulfilled the following criteria were eligible for the study:

a) Able to speak Cantonese;

b) Resided within the hospital service area;

c) Could be contacted by phone; and

d) Fulfilled at least two of the Prognostic Indicator Guidance prompts set by the National Gold Standards Framework (Haga et al., 2012; Thomas.et al., 2011).

   i) Had HF with NYHA Class III or IV symptoms;

ii) Thought to be in the last 12 months of life judged by clinicians based on the “surprise question” (“Would you be surprised if this patient was to die in the next 12 months?”)

iii) Hospitalized twice in the past six months; and

iv) Had unresolved physical or psychological symptoms despite optimal treatment.

Patients were excluded if they were:

a) Discharged to a nursing home;
b) Diagnosed with a psychiatric problem requiring active treatment; or
c) Unable to communicate.

4.5 Sample size

An adequate sample size is a key consideration in obtaining significant results for a study (Browner, Newman, & Hulley, 2007; Scales, & Rubenfeld, 2005). If the sample size is too small, the study may fail to answer its research questions, even if the study was rigorously conducted. On the other hand, if the sample size is too large, it may be difficult to execute and may be costly (Devane, Begley, & Clarke, 2004; Zhong, 2009). Sample size calculation involves varied formulae and depends on the type of the design and the measures of the primary outcome (Kim & Seo, 2013). The components of sample size calculation with a dichotomous outcome or a randomized trial include type I error (α), power, event rate in the control group, and a treatment effect of interest (Schultz & Grimes, 2005). Conventionally, the acceptable rate of the type I error is usually set at 5% as the statistical significance level and a power of 0.8, meaning that there is an 80% likelihood of detecting a difference between treatments (Scales & Rubenfeld, 2005; Tappen, 2016). The power of a statistical test is the chance that it will produce a statistically significant result (Cohen, 1988). The effect size is a measure of the strength of a phenomenon under study, expressed by the outcome of an intervention (Berben, Sereika, & Engberg, 2012). Calculating an effect size helps to indicate the strength of the relationship between the independent and dependent variables, and an effect size may be calculated from prior research, which is generally preferred because it is based on data (Tappen, 2016). In this study, the sample size calculation was based on the primary outcome (i.e., hospital readmission rate) of a previous study. It was assumed that the effect of this study would be similar to a prior study using home-based palliative follow-ups for end-stage organ failure patients (Lukas, Foltz, & Paxton, 2013), in which the average number of 30-day readmissions in the study was reduced from 2.23 to 1.25. Using Lehr's equation (Lehr, 1992), a sample size of 29 per group was adequate to achieve 80% power with a significance level of 0.05. A dropout rate of 20% was taken into consideration. Based on these calculations, 35 subjects were needed in each group for the study.

4.6 Recruitment procedures

The student investigator screened patients at the study sites. Patients admitted for HF were assessed by the ward physician, who was the patient's attending medical doctor (cardiologists or geriatricians), and they referred eligible patients to the specialist PC team by signing a referral form to confirm that the patient needed PC. Once the referral was accepted by the specialist PC team, a research assistant who was not associated with the clinical team approached the patients in the ward to invite them to participate in the study. The patients and their family members were then provided with a full explanation of the study. A consent form was signed for those who agreed to participate. The research assistant, who was blinded to the group assignment, conducted baseline data collection after the consent forms were obtained.

4.7 Randomization and blinding

The random assignment sheet was cut into pieces in consecutive number and each piece was folded thick enough to protect transparency from light. Each folded sheet was placed in an envelope, which was then sealed, and all of the group assignment envelopes were kept in a locked drawer. A site investigator who had no connection with the participants and was not involved in subject recruitment opened the sealed envelopes with a computer-generated sequence of random numbers for the group assignments. According to the randomization scheme, the subjects were randomly assigned to either the intervention group (denoted by “1”) or the control group (denoted by “2”), where block randomization with a block size of six was adopted. The advantage of block randomization is that it can guarantee the balance between the number of participants in each group during the course of randomization (Friedman, Furberg, & DeMets, 2010).

The patients and their family members needed to be introduced to the intervention program, so they were not blinded. The interventionists were also not blinded since they had to deliver the intervention. Only the research assistants who helped collect the data were blinded to the group assignments.

4.8 Conventional care (comparison control condition)

The participants in both groups received conventional care, which was a standard discharge arrangement and two social calls. The standard discharge arrangement included medication prescriptions, medical follow-up appointments, and referral to other services if needed.

4.9 The HPHF program (intervention)

The participants allocated to the intervention group received the HPHF program plus conventional care. The HPHF program supported the ESHF patients in their hospital to home transition, with follow-ups over 12 weeks. The follow-ups in the first four weeks was more intensive, as studies have shown that HF carries a very high risk of readmission within 30 days after an HF hospitalization (Au et al., 2012; Enguidanos et al., 2012; Jencks et al., 2009; Ross et al., 2010), with subsequent regular follow-ups through week 12 (see Table 4.1).

First four weeks of post-discharge follow-ups

The first four weeks of post-discharge follow-ups included weekly care support: week 1—the PC-NCM and volunteers conducted a home visit together; week 2—the PC-NCM provided a telephone follow-up; week 3—the volunteers conducted home visits in pairs; and week 4—the PC-NCM gave a telephone follow-up.

Follow-ups from four to twelve weeks post-discharge

In the period between week 4 to week 12 post-discharge, the PC-NCM visited the patients monthly at their homes, supplemented by a social visit and a telephone follow-up by volunteers. A comparison between the intervention (HPHF program plus conventional care) and conventional care alone is shown in Table 4.1 below:

Table 4.1 HPHF program plus conventional care versus conventional care alone

HPHF Program plus Conventional Care	**Only Conventional Care**
Standard discharge planning (medication prescriptions, out-patient appointments, referral to other services whenever necessary)	
Post-discharge home follow-ups	
First four weeks post-discharge support	Nil
➢ Home visit by PC-NCM	
➢ Telephone follow-up by PC-NCM	
➢ Home visit by volunteers	
➢ Telephone follow-up by PC-NCM/volunteer	
Four to 12 weeks post-discharge support	Home visit if necessary based on clinical decision
➢ Home visit by PC-NCM	
➢ Home visit and telephone follow-up by volunteers	

In enabling consistency in the implementation of the HPHF program, the intervention protocols were developed, and training programs were conducted for the interventionists.

4.9.1 Protocols

4.9.1.1 Protocol development

All care and support were structured and protocol-driven. Protocol-driven care can reduce practice variations (Polit & Beck, 2004) and assist in decision-making in case management (Flarey & Blancett, 1996). The protocol development for this study was based on a review of research evidence, clinical guidelines, and input from palliative specialists. The use of evidence-based protocols can maintain a high standard of care and improve care outcomes (Friedman, Mendelson, Kates, & McCann, 2008; Sanders, Harrison, & Checkland, 2010).

The descriptions of the protocols are as follows:

- Problem management protocols: Eight problem management protocols were formulated, which cover the main problems often encountered by ESHF patients at home: (i) home environment problems; (ii) pain; (iii) fatigue; (iv) nutritional and elimination problems; (v) breathlessness and edema; (vi) grief and mental health problems; (vii) spiritual issues; and (viii) medication non-compliance (see Appendix 4.2a-h).

The formulation of the problem management protocols was based on the following sources:

- ✓ Literature review of common and burdensome symptoms and the compound needs of ESHF patients;
- ✓ Recommended targets/objects of action from the intervention scheme of the Omaha System regarding the HF and PC contexts;
- ✓ HF management and PC practice guidelines; and
- ✓ Expert opinions of cardiologists, palliative physicians, and home care practitioners, including home care nurses, physiotherapists, and occupational therapists who had experience in home-based management.

- Protocol for home visits: The PC-NCM and volunteers conducted the first home visit jointly. One home visit was conducted by the PC-NCM and one by the volunteers separately in the second month thereafter until week 12 post-discharge. During the first home visit, the PC-NCM reviewed pre-discharge assessment records and identified and managed patients' health problems accordingly. Mutual goals were set between the PC-NCM and each patient. Subsequent home visits followed up on the issues and goals set during the previous visit. The volunteers were responsible for social issues and reported to the PC-NCM after each home visit. The PC-NCM consulted with the PC specialist for advice if necessary. The content of the home visits was guided by the Omaha System (see Appendix 4.3).
- Protocol for telephone follow-up: The PC-NCM initiated calls between home visits to monitor patients' progress, provide health advice, reinforce appropriate health behavior, review management goals, and assess the need for referral. The content of the telephone follow-up was guided by the Omaha System (see Appendix 4.4).

- Protocol for patient-initiated calls: In addition to the PC-NCM-initiated home visits and telephone follow-ups, patients/family caregivers could initiate calls to the PC-NCM if they required advice and help before the next structured activity. The PC-NCM managed the calls according to the telephone follow-up and referral protocols (see Appendix 4.5).
- Protocol for referral: The referral protocol included medical (e.g., phone consultation with the PC physician-in-charge) and non-medical referral (e.g., social worker, physiotherapy therapist, occupational therapist, dietitian, chaplain, and clinical psychologist) (see Appendix 4.6).

4.9.1.2 Protocol validation

The whole set of protocols was validated by an expert panel. A panel of eight experts was formed to examine the content relevance and give comments on all the protocols developed. The panel members consisted of two nursing academics, three palliative consultants, and three palliative nurse specialists from the study hospitals. All eight experts considered the protocols appropriate and relevant for implementation. However, one palliative consultant commented on the protocol related to medical referrals; he suggested adding direct admission to the designated PC unit after seeking approval from the supporting PC specialist. One of the nurse specialists commented on the referral protocol in the category of psychosocial spiritual care needs under the non-medical category. Referral was originally applicable to the patients only. The nurse suggested that the PC-NCM could also make a referral for the patients' family members if they needed any psychosocial spiritual care. Panel members also gave other comments regarding symptoms and care management, including the assessment of side effects of medication, performing per-rectal examinations if necessary such as for bowel problems (e.g., constipation), assessing signs of dehydration, and awareness of death anxiety for both patients and their family members. Modifications were made according to the recommendations from the experts. After reviewing all the protocols, the validated set of protocols was used in the nurse training program and the feasibility study.

4.9.2 Training program

The nurse training program was particularly designed for the PC-NCM and the volunteers who were responsible for delivering the intervention (home visits and telephone follow-ups) in this study. During the training, both the PC-NCM and the volunteers were educated on how to implement the protocols to ensure standardized and consistent practice.

4.9.2.1 Training the PC-NCMs

The PC-NCM was a nurse who had over six years of clinical experience in palliative and HF care and had completed the post-registration specialty course. A training program (see Appendix 4.7) consisting of 15-hour training sessions plus a half-day workshop was designed to enable the PC-NCM to master the key elements of the HPHF program and enhance relevant knowledge and skills. The training program was delivered by the research team in partnership with experienced clinical experts.

4.9.2.2 Training the volunteers

The volunteers were final-year nursing students from a local nursing school. Nursing students who showed an interest in this study and agreed to work with the PC-NCM as volunteers were invited to participate. They were required to complete the delivery of the intervention (home visits and telephone follow-ups) until the end of the intervention. The volunteers completed a 9-hour training program (see Appendix 4.8), which included theory- and practice-based content (Wong et al., 2011). The training program was delivered by the research team.

4.10 Intervention fidelity

Intervention fidelity is important to ensure that the intervention is delivered as planned. Intervention fidelity involves an ongoing assessment, monitoring, and enhancement of reliability in clinical trials, which reassures scientific confidence (Borrelli, 2011). In this study, the strategies described by Borrelli (2011) were adopted to assess, monitor, and enhance the fidelity of the intervention to ensure that the PC-NCM and the volunteers delivered the intervention as specified and consistently. Strategies including audiotaping, reviewing provider documentation forms, and observing home visits were employed.

All home visits and telephone follow-ups conducted were recorded in a file to ensure adherence to the protocols. All of the patient telephone follow-ups provided by the PC-NCM and the volunteers were audiotaped. The audiotapes together with the corresponding written documentation forms were reviewed regularly by the student investigator. For the home visits, the student investigator, acting as an observer, accompanied the PC-NCM and the volunteers to ensure that they delivered the intervention as intended. Similarly, the student investigator reviewed the written home visit records to validate the observations. A monthly case conference was held by the clinical team to discuss the subjects' health conditions and care plans. The entire research team held regular meetings to report their progress (Rabow et al., 2004). The PC-NCM reported the implementation of the intervention, while the student investigator communicated with the clinical team regularly for progress updates.

4.11 Outcome measures and instruments

A total of six instruments and questionnaires were used to collect data (see Table 4.2). The instruments were used to assess the participants' QOL, functional status, symptom intensity, and satisfaction with care. The participants' personal characteristics from interviews were collected by a research assistant. This instrument was validated and used in a previous study by Wong et al. (2011). Clinical characteristics were obtained from the hospitals' electronic systems. The participants responded to 58 questions, and the duration of data collection was 30 to 45 minutes (see Appendix 4.9).

4.11.1 Primary outcome

4.11.1.1 Hospital readmission rate

The primary outcome measure was the hospital readmission rate. The LOS and the AED attendance was observed. These information were extracted from the hospitals' administrative systems.

4.11.2 Other outcomes

4.11.2.1 Palliative-specific QOL

Palliative-specific QOL was measured by the McGill Quality of Life Questionnaire-Hong Kong version (MQOL-HK), which is a commonly used instrument in the field of PC that measures four domains—physical, psychological, existential, and support—on a numerical scale from 0 to 10. This questionnaire has been validated among PC patients in Hong Kong with good reliability (the intraclass correlation coefficient was 0.85 ($p < 0.0001$) and the Cronbach's alpha was 0.83) (Lo et al., 2001).

4.11.2.2 HF-specific QOL

HF-specific QOL was measured by the Chronic Heart Failure Questionnaire-Chinese version (CHQ-Chinese), which is one of the most commonly used HF-specific QOL instruments. It was developed by Guyatt et al. (1989) in Canada. The tool has 20 items and uses a 7-point Likert scale to measure four domains: dyspnea, fatigue, emotional status, and mastery. The CHQ-Chinese has been translated into Chinese and validated (Lee, Yu, Woo, & Thompson, 2005). The internal consistency and test-retest reliability were good, with a Cronbach's alpha of 0.95 and an intraclass correlation coefficient (ICC) of 0.75 (Lee et al., 2005).

4.11.2.3 Symptom intensity

Symptom intensity was measured by the Edmonton Symptom Assessment Scale (ESAS) aiming to assess nine symptoms including pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, sensation of well-being, and dyspnea—measured on a 0 to 10 numerical rating scale (NRS). There is one extra blank NRS leaving for an individual patient to fill in if an additional symptom exists. The ESAS is a clinical tool commonly used in local settings and is a valid, reliable instrument for use among PC patients (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991; Nekolaichuk, Watanabe, & Beaumont, 2008). A local study has also shown that the ESAS can help quantify symptoms, and it is an independent prognosticator for survival (Lam, Leung, & Tse, 2007).

4.11.2.4 Functional status

The Palliative Performance Scale (PPS) was used for the measurement of performance status. The PPS, developed by Anderson, Downing, Hill, Casorso, & Lerch (1996) and based on the Karnofsky Performance Scale. The tool documents changing physical condition in: ambulation, activities/evidence of disease, self-care, intake, and level of consciousness. The PPS is designed for PC patients and has been adopted widely in local settings. It has a scale of 100 (normal) to 0 (death), measured in 10% decrement levels. The tool is validated between doctors and nurses and the inter-rater reliability was maintained at 0.85, with a strong kappa value of 0.97 (Myers et al., 2010). The internal consistency was also good, with a Cronbach's alpha equal to 0.83 (Brumley, Enguidanos, & Cherin, 2003).

4.11.2.5 Patient satisfaction

Satisfaction with care was measured by a 12-item patient survey questionnaire used in a local transitional care study, the validity was confirmed by an expert panel with a reported test-retest reliability of 0.87 (Wong et al., 2011).

Table 4.2 Overview of instruments and questionnaires used

Category	Instrument	Item	Range
Patient particulars	Validated self-developed	12	
Palliative-specific QOL	MQOL-HK	16	0 to 10
Heart-failure-specific QOL	CHQ-Chinese	19	1 to 7
Symptom intensity	ESAS	10	0 to 10
Functional status	PPS	1	0 to 100%
Satisfaction	Self-developed	12	0 to 5
Total items		**70**	

4.12 Data collection

Baseline patient-reported data were collected in the hospital, while data at the other time points were collected at the patients' homes. Clinical data were retrieved from the patients' medical notes and the clinical management systems at the hospitals. Data were collected by a research assistant who was trained by the research team.

4.12.1 Inter-rater reliability

Inter-rater reliability involves the variation between two raters measuring the same group of subjects. Different raters are not always in agreement regarding the quality of the variables being assessed even though there is detailed operational guides and equal skill levels. Inter-rater reliability is needed to establish the stability of the measurement and to ensure the consistency of measurement between raters. The results can therefore be interpreted and applied with greater confidence (Portney & Watkins, 2009). In this study, the inter-rater reliability test was conducted by the student investigator and a research assistant, and the results showed significant agreement between the two raters, as the ICC achieved 0.96 (95% C.I. 0.95-0.97), $p < 0.001$. It has been suggested that a value above 0.75 is indicative of good reliability, and a value of at least 0.90 is needed in clinical measurements to ensure reasonable validity (Portney & Watkins, 2009).

4.12.2 Data management

Data for the outcome measures were collected at three time-points: at discharge (baseline, T1), at week 4 post-discharge (T2) and at week 12 post-discharge (T3). A research assistant with no clinical association with the patients was responsible for collecting the data. To ensure the quality of the data collected, the research assistant was trained in using different data collection tools. Ten percent of the questionnaires were used to test intra-rater reliability, which involved the assistant collecting the same set of data twice within a short interval of time. All the data were independently checked by a member not involved in data collection to ensure the quality of the data collected. All data were stored in a locked cabinet and were entered in encrypted files to ensure data protection.

4.13 Data analysis

Prior to analyzing the data, essential data management steps were performed. A codebook was created to categorize and store the codes of entry of all variables (Portney & Watkins, 2009). A data file using Predictive Analytics SoftWare (PASW, version 18) was developed and used to perform the statistical procedures.

4.13.1 Data checking and cleansing

The next step was to perform data cleansing and checking since errors might occur during the data entry process (Polit & Beck, 2004). Data cleansing is an important process to ensure that there are no discrepancies or coding errors before analyses are run (Portney & Watkins, 2009). Descriptive statistics were executed to check for obvious discrepancies, and frequency counts were also checked for categorical variables. Means, minimums, and maximums were run for continuous variables to ensure that the range of scores was appropriate (Portney & Watkins, 2009). The entire data file was visually checked for accuracy against the original data by a research team member who was not involved in data management and the student investigator. There were 20 errors in 51,492 data fields across the three time points, and the error rate was less than 0.04%. After corrections were made, the transformation of the data and the recoding of the variables were performed to reverse the coding for particular variables (Munro, 2005).

Outliers are extreme values that appear to be significantly different from the rest of the data. Sources of outliers may be data entry errors or failure during data collection. Detecting outliers is important because outliers can distort statistical tests and affect how well the sample represents the population (Munro, 2005). In this study, outliers were checked by constructing frequency distributions for all variables (Polit & Beck, 2012). It was found that outliers appeared in the age variable, which represented the real values of the subjects, and these outliers were kept in the data file as there was no statistical rationale for removing them (Portney & Watkins, 2009).

Although the data collector was reminded to complete all the data collection instruments, some missing values were found. Missing data are common and unavoidable in clinical research (Polit, 2010; Sterne et al., 2009), and it occurs frequently in longitudinal research (Patrician, 2002; Schlomer, Bauman, & Card, 2010). There are three major tasks to perform regarding missing data issues. First, it is important to identify the amount and pattern of missing data. Second, after finding the missing data, it is important to assess the possible reasons why data were missed. Lastly, there is a need to determine how to handle the missing data (Munro, 2005; Polit, 2010).

In this study, in terms of the number of cases given data across the three time points, there were 84 cases with complete data at baseline, 68 cases at week 4, and 45 cases at week 12. The overall percentage of missing values with regard to the outcome variables ranged from 0% to 1.37%, with one item that asked about whether sexual life was affected by the disease accounting for the most non-responses. The frequency of sexual activity decreases due to aging and declined physical health (DeLamater & Karraker, 2009). Studies have shown that some patients with advanced HF ceased all sexual activity or had a marked decrease in sexual interest (Jaarsma, Dracup, Walden, & Stevenson, 1996). Over 80% of the participants failed to respond to this item in the MQOL-HK, which did not affect the scoring of the other domains, so this single item was removed.

Two types of missing data occurred, first, when the participants were unable to respond due to disease progression or death, and second, when the participants were unwilling to respond to a particular question. Non-responses to items, which contributes to missing data, are common in many studies (Patrician, 2002; Schlomer et al., 2010), particularly in PC research due to the special patient characteristics of being fatigued and deteriorating condition (Fielding, Fayers, Loge, Jordhøy, & Kaasa, 2006; Preston et al., 2013).

Missing data seriously compromises inferences in clinical trials, for example, limiting the ability to draw definitive conclusions or even leading to incorrect inferences (Little et al., 2012). Therefore, efforts should be made to adequately handle missing data (Little et al., 2012; Wood, White, & Thompson, 2004). Listwise deletion, single imputation, and multiple imputation are approaches to handling missing data (Patrician, 2002; Schlomer et al., 2010). Listwise deletion simply discards cases with missing data; however, discarding samples with missing data might lead to biasing the results in the analysis and compromising the analytic power if a large portion of the data is discarded (Patrician, 2002; Sterne et al., 2009).

Another alternative to dealing with missing cases is known as imputation. This is done by ascribing a value to a missing data cell based on the values of other variables, for example, the mean value is used to represent missing data in some studies. However, imputing the mean value leads to decreased variability between the subjects' responses, affecting the plausibility of the parameter estimates and misleading statistical inferences (Patrician, 2002). Although last observation carried forward is a commonly used imputation technique to compensate for missing values, it can lead to serious bias (Little et al., 2012; Sterne et al., 2009), and is probably not suitable for a study involving PC patients (Preston et al., 2013). Because the condition of PC patients is likely to worsen, using the last observation carried forward technique could cause overly optimistic results (Preston et al., 2013).

Multiple imputation, a computationally intensive method used to deal with missing data, has been increasingly adopted in clinical research because it may reduce bias or increase precision (Sterne et al., 2009). Multiple imputation is a predictive approach aimed at allowing for uncertainty about missing values by creating several different plausible imputed data sets and combining the results obtained from each of the imputed data sets appropriately (Sterne et al., 2009). The multiple imputation method can be used to handle missing data given that the missing data should be missing at random (MAR) (Patrician, 2002; Sterne et al., 2009). Little et al. (2012) stated that if similar baseline characteristics between the participants who dropped out and the participants who did not drop out are observed, such data are likely to be MAR. Under the assumption that the data are MAR, the missing values can be modeled based on the values of similar non-drop-out participants (Little et al., 2012).

In this study, no significant differences in baseline characteristics were found between the participants with and without missing outcome variables, suggesting similar baseline characteristics. Multiple imputation was therefore regarded as an appropriate method for substituting missing data for analysis. Guidelines for reporting analysis that is potentially affected by missing data suggest that five imputed datasets are sufficient (Schlomer et al., 2010; Sterne et al., 2009). Five datasets were created using the multiple imputation method in this study.

4.13.2 Data analysis strategies

Both descriptive and inferential statistical tests were used. Descriptive statistics were conducted to compare the socio-demographic and clinical characteristics between the intervention group and the control group. The Pearson chi-square test and Fisher's Exact test were used for categorical variables, while the independent-samples t-test was used for continuous variables. The between group primary outcomes (hospital readmission rates, emergency room visits, and length of hospital stay) were compared using the chi-square test.

The intention-to-treat (ITT) principle was carried out to minimize the bias caused by incomplete samples. Intention-to-treat means that all subjects were included in the analysis according to the random assignments regardless of the treatment they received. The ITT approach preserved the effects of randomization and provided an assessment of the practical impact of the intervention (Portney & Watkins, 2009).

Examining normality is the first step before the statistical test for inferential analysis. There are several ways to check whether data are approximately normally distributed: inspecting the histogram, quantile-quantile plot (Q-Q plot), or Box plot; determining the skewness and kurtosis indices (which should be from -1.96 to + 1.96); and the Shapiro-Wilk test p value (which should be above 0.05) (Field, 2013). To identify the differential effect of the intervention with time, the between group effect, within group effect, and interaction effect were examined. Repeated measures analysis of variance (ANOVA), a parametric test, was used if data were normally distributed. Other assumptions need to be fulfilled when using repeated measures ANOVA: the dependent variable should be an interval or ratio level of measurement; the participants should be randomly sampled; and the variability in the differences between the groups should be the same (i.e., homogeneity of variances). The assumption of Mauchly's sphericity test was also checked and adjusted by Greenhouse-Geisser correction if necessary. The statistical differences were two-tailed and considered to be significant at the 5% level (Portney & Watkins, 2009).

A post hoc test can be performed if significant findings are obtained from the F test, and additional exploration of the differences among the means is therefore needed to provide specific information to see which means are significantly different from each other (Munro, 2005). Multiple comparisons using the Sidak method—baseline to week 4 (T1 versus T2), baseline to week 12 (T1 versus T3), and week 4 to week 12 (T2 versus T3)—for each group were further examined to check which pairwise time points contributed to the significance (Polit, 2010).

In the comparisons of between group effects at each time point, one-way ANOVA was used with Bonferroni adjustment to protect against the inflated risk of a type I error because of multiple comparisons (Field, 2013). Therefore, the corresponding alpha level was adjusted by $0.05/2 = 0.025$. A p value < 0.025 was used to indicate significance (Munro, 2005; Polit, 2010).

A non-parametric test was used if normality was violated, where the Friedman test was an analogue to repeated measures ANOVA to examine within group differences over time. If there was a significant finding, the Wilcoxon signed-rank test was used to examine the pairwise comparisons: (T1 versus T2), (T1 versus T3), and (T2 versus T3). The corresponding alpha level was adjusted by $0.05/2 = 0.025$ for the within group measure, and a p value < 0.025 was considered significant. For between group measures, the corresponding alpha level was adjusted by $0.05/3 = 0.017$, where a p value < 0.017 was considered significant (Munro, 2005; Polit, 2010).

The Mann-Whitney U test was used to examine between group differences at each time point, and the alpha level was adjusted by $0.05/2 = 0.025$, where a p value < 0.025 indicated significance. Data were adjusted by Bonferroni correction to maintain an overall alpha level of 0.05 (Munro, 2005; Polit, 2010).

Statistical significance testing is important in quantitative research because it is used to determine whether the observed effect is real or attributed to chance, but that alone may be insufficient to provide a full picture of the magnitude of the effect and the practical significance of the findings (Maher, Markey, & Ebert-May, 2013). The use of effect size is recommended as a statistical tool to supplement statistical significance testing because effect size measures the strength of a treatment response or the relationship between variables (Maher et al., 2013; Nakagawa & Cuthill, 2007). In this study, partial eta squared was used to calculate the effect size because it is an appropriate effect size statistic for measuring differences between groups (Cohen, 1988; Levine & Hullett, 2002; Maher et al., 2013). According to Cohen (1988), for the values of partial eta squared, 0.01 is considered a small effect size, 0.06 is a medium effect size, and 0.14 is a large effect size.

4.14 Ethical considerations

Prior to starting data collection, ethical approval was obtained from the Human Subjects Ethics Sub-committee of The Hong Kong Polytechnic University (HSEARS20111003010), and the Research Ethics Committees of the study hospitals—the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster, and the Kowloon Central/Kowloon East Cluster Research Ethics Committee (HKU/HA HKW IRB UW12-202; KC/KE120062/ER2) (see Appendix 4.10).

The student investigator verbally explained the study’s aims, procedures, and confidentiality principles, and an information sheet (see Appendix 4.11) was provided to the patients and their family members. Patients who agreed to participate in the study signed a consent form (see Appendix 4.12). It was made clear to the patients that their participation was on a voluntary basis. They could withdraw from the study at any time without any punishment, and all the treatment and healthcare services they received would not be affected. Contact information was given to the participants for inquiries. The participants’ personal information was protected by assigning it a research code and processing it anonymously. Data collected were stored in a locked cabinet where only the student investigator and the project principal investigator could access it.

4.15 Feasibility study

This section will report the feasibility study, including its aims, procedures, outcomes, and the lessons learned for the main study.

4.15.1 Aims

A feasibility study was conducted to investigate the applicability and acceptability of delivering the Home-based Palliative Heart Failure (HPHF) program with the following objectives:

- To establish logistics in subject recruitment and standardize the practice, including communication and collaboration with the site investigators;
- To assess the feasibility and applicability of using the intervention protocols developed for the HPHF program;
- To assess the feasibility and acceptability of the intervention components by the PC-NCM and the volunteers and obtain their feedback; and
- To test the feasibility of the data collection process.

4.15.2 Procedures

The feasibility study was carried out from January 2013 to March 2013, prior to the main study. The inclusion and exclusion criteria for the targeted subjects, the logistics for data collection, and the HPHF intervention protocol in the feasibility study were the same as those in the main study. Two hospitalized ESHF patients from the two study sites who fulfilled the criteria and were confirmed by the PC team were selected. After the two patients were given a full explanation of the study by the student investigator, they were invited to participate in the HPHF program and they signed the consent form. Baseline data were collected by a research assistant. The appointed PC-NCM from the hospital palliative home care team was asked to conduct a pre-discharge assessment of the patients. The PC-NCM was also responsible for subsequent post-discharge follow-ups, including home visits and telephone follow-ups. The set of protocols developed for the HPHF program and the documentation sheets in the pilot study were the same as those used in the main study. The volunteers were also assigned to the patients and introduced to the PC-NCM. The workflow for how they worked in partnership was explained to both the PC-NCM and the volunteers. The student investigator accompanied the PC-NCM and volunteers to visit the patients at their homes and reviewed the voice recordings of the telephone follow-ups completed.

4.16 Lessons learned for the main study

The feasibility study confirmed the possibility of conducting the study. However, because of the limited number of participants identified and eligible, it was foreseeable that subject recruitment needed to be longer than expected and strategies were made to facilitate subject identification and recruitment. Strategies included sending emails to clinicians to promulgate the research project and encourage them to refer potential subjects to the PC team, seeking approval from the department manager to let the student investigator screen patients in the cardiac ward, and discussing with the PC physicians to increase quotas for seeing ESHF patients when referrals were accepted.

4.16.1 Feasibility of the HPHF program

It was practical to deliver the intervention by the PC-NCM and the volunteers, with good adherence to the program planning and protocols. The PC-NCM was able to visit the patients at their homes. The PC-NCM communicated with the patients and their family members well and was competent in assessing the patients' symptoms, giving them advice, and explaining the disease information. The PC-NCM was able to follow the intervention protocols properly. The duration of each home visit was around 50 to 60 minutes. Documentation of the home visits and telephone follow-ups was completed in a comprehensive and coherent fashion that recorded the patients' trajectory during the intervention period.

The volunteers were able to visit the patients at their homes, showing a friendly attitude and communicating well with the patients and their family members. The volunteers followed through with the mutual goals set between the PC-NCM and the patients. The duration of each home visit was around 50 to 60 minutes and all documentation was completed.

Regarding the telephone follow-ups, the PC-NCM had no difficulty in contacting the patients after they were discharged home and successfully recorded the phone conversations. The student investigator listened to the telephone recordings and confirmed that the content and advice given to the patients in the conversations were valid and appropriate. The documentation sheets were completed in good order. The duration of each telephone call was around 10 to 15 minutes.

4.16.2 Feedback from the PC-NCM and volunteers

After the feasibility study, the student investigator met the PC-NCM and volunteers to obtain their feedback regarding the care delivery process. Additionally, the PC-NCM was encouraged to bring a copy of the intervention protocols to the home visits. The volunteers were provided with feedback on their home visit techniques and filling out the documentation.

The PC-NCM commented on how to communicate better with the volunteers and agreed that the volunteers could call her mobile phone directly during working hours for prompt and efficient communication regarding patient matters. The PC-NCM shared all documentation after each follow-up activity and updated the patients' condition. The volunteers commented that it would be easier for them to fill out the documentation if some Chinese words were allowed. The feedback was well taken and incorporated into practice.

4.16.3 Feasibility of the data collection procedures

The feasibility study demonstrated that data collection was performed successfully. It took around 45 minutes to complete the data collection per subject and the questions were accepted by the patients. However, it was noted that the patients sometimes had difficulty recalling their choices of answers from the different instruments. Various kinds of visual tools were designed, for example, facial expression scales and pictures, to assist in choosing their answers.

To conclude, the feasibility study indicated that it is practical and acceptable for the HPHF program to be launched at the study sites, and it was able to identify and recruit patients, the compliance of the protocols was good, and data collection was smooth. Therefore, the feasibility study vitally contributed to the main study.

4.17 Summary

This chapter discussed the details on developing an evidence-based intervention protocol and the training conducted to prepare the interventionists, which was reported in a publication (Ng, Wong, & Lee, 2016). The procedures in this study, including sampling frame, data collection and strategies to analyze the data, and treatment fidelity measures, were feasible.

CHAPTER FIVE

RESULTS

This chapter will present the results of the current study, including subject recruitment, the demographic data of the subjects, and findings from answering the research questions. The data collection period took place between May 2013 and June 2015. The treatment effects between group and within group over time and the group X time interaction effects were examined. This study aimed to find out whether the intervention program would be more effective than conventional care alone. The results at three time points will be reported: at baseline before the intervention program (T1), at 4 weeks post-hospital discharge (T2), and at 12 weeks post-hospital discharge (T3). The reporting of the results followed the Consolidated Standards of Reporting Trials (CONSORT) statement for the reporting of parallel group randomized trials (Schulz et al., 2010).

5 Subject recruitment

From May 2013 to June 2015, 389 patients were screened and assessed for eligibility at the study sites. Of the 389 patients assessed for eligibility, 305 patients were excluded. Of the 275 patients who failed to meet the study's inclusion criteria, the reasons for exclusion were as follows: lived in an elderly care home (30.9%); did not accept the PC approach (17.8%); cognitively impaired or too weak to communicate (16.4%); did not reside in the designated service area (11.6%); was in the terminal stage (7.6%); recruited in other intensive hospital programs (6.2%); unable to speak Cantonese (6.2%); and diagnosed with a psychiatric disorder (3.3%). Twenty-six patients declined to participate in the study and the remaining four died before the research team's assessment.

A total of 84 patients were successfully recruited for this study, and all subjects completed the baseline assessment. The participants were then randomly assigned to either the intervention group (n = 43) or the control group (n = 41). Throughout the study, 39 (46%) patients were lost to follow up with the following reasons: death (35.9%), became too ill (23%), refused visits / being interviewed (15.4%), moved to elderly care home (20.5%), and enrolled in another program (5.1%). Detailed information on subject enrollment is shown in Figure 5.1 below, in accordance with the CONSORT flow diagram:

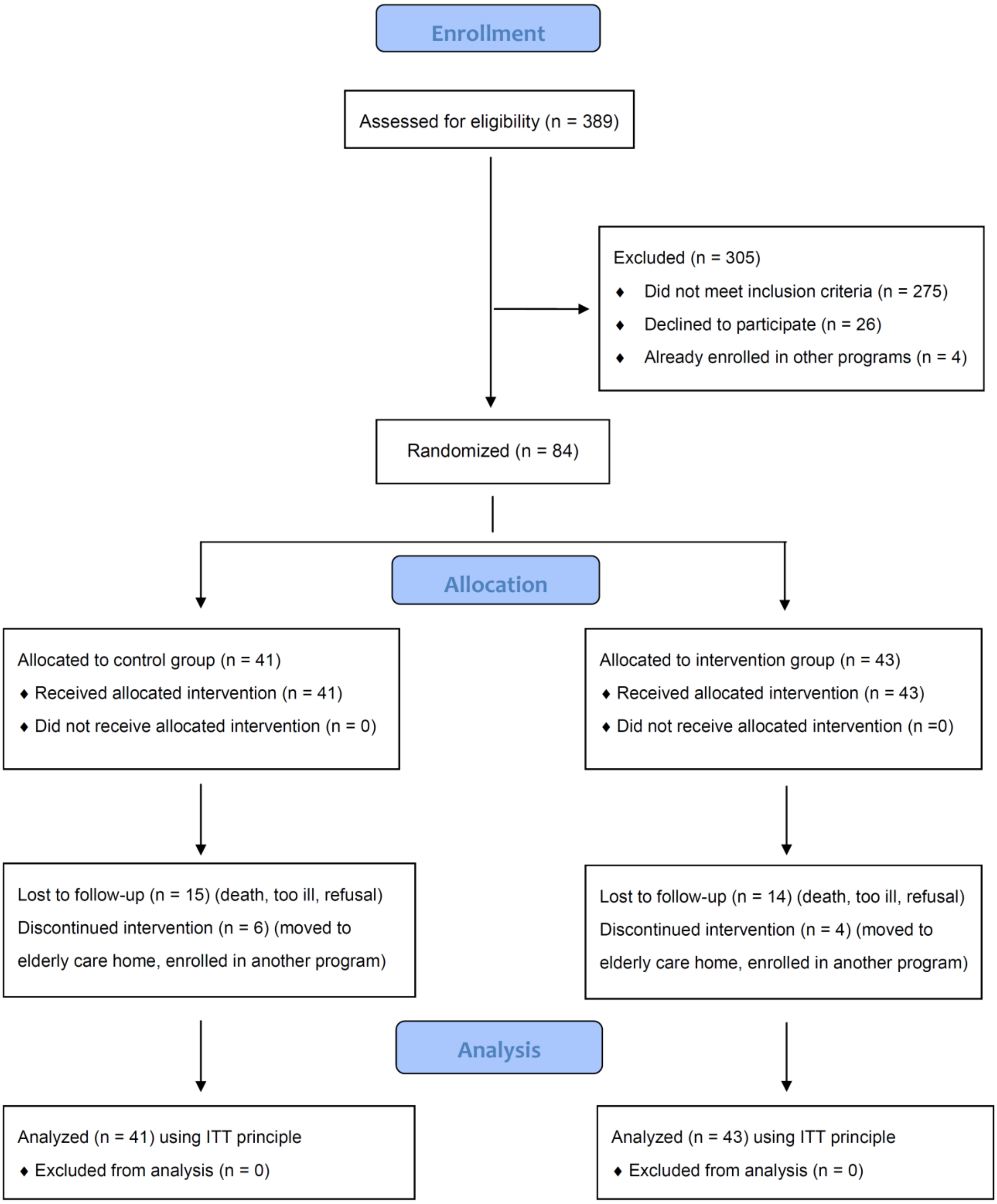


Figure 5.1 CONSORT flow diagram used in this study

5.1 Equivalence of groups at baseline

5.1.1 Socio-demographic and clinical characteristics of the subjects

Table 5.1 shows the subjects' socio-demographics and Table 5.2 shows the clinical characteristics of the subjects in the intervention group and the control group. The socio-demographic and clinical characteristics between the groups showed no significant differences in age, gender, marital status, education level, employment status, household background, and the participants' perceived economic situation. There were also no significant differences in clinical characteristics between the intervention group and the control group regarding the etiology of chronic heart failure, cardiac function, and comorbidities diagnosed. These findings indicate that both groups were equivalent in their socio-demographic and clinical characteristics with random assignment.

In Table 5.1, among the 84 participants who completed the baseline interview, 41 (47.6%) were females and 43 (52.4%) were males. Their ages ranged from 27 to 95 years of age, and the mean age of the sample was 78.3 years.

Approximately 65% of the participants were married. Nearly 80% of the participants attained a level of education of primary school or less, 16.7% had a secondary school education, and 3.6% had a university qualification. A majority of the participants (97.6%) were either retired or housewives. Of the 2.4% who were employed, they were on sick leave because they were unable to work due to their health condition. Over 90% of the participants lived with family members, while 8.3% lived alone. The participants who lived alone were supported by family members living nearby. Approximately 60% of the participants resided in public housing, while 28.6% owned their flats. A quarter of the participants (25%) reported that they had more than enough regarding their economic status, while more than half of the participants reported that financially they had just enough and around 20% reported not having enough.

In terms of cardiac etiology, the subjects' HF was mainly caused by ischemic heart disease (63.1%), hypertension (60.7%), and arrhythmias (48.8%). Other causes included heart valve disease (16.7%), cardiomyopathy (8.3%), and congenital heart defects (1.2%). The mean left ventricular ejection fraction was 38%. The participating patients suffered from comorbid conditions other than HF, including, for example, renal impairment (52.4%) and diabetes (41.7%) (see Table 5.2). No statistically significant differences were observed in the demographic and clinical data between the control group and the intervention group.

Table 5.1 Socio-demographic characteristics

Variable	Total (n = 84)	Control (n = 41)	Intervention (n = 43)	p value
Age (Years; M, SD)	78.3 (13.8)	78.4 (10.0)	78.3 (16.8)	0.99 [a]
Gender				0.08 [b]
Female	41 (47.6%)	16 (39.0%)	25 (56.1%)	
Male	43 (52.4%)	25 (61.0%)	18 (43.9%)	
Marital status				0.79 [b]
Married	55 (65.5%)	28 (68.3%)	27 (62.8%)	
Widowed	22 (26.2%)	9 (22.1%)	13 (30.2%)	
Divorced	3 (3.5%)	2 (4.8%)	1 (2.3%)	
Single	4 (4.8%)	2 (4.8%)	2 (4.7%)	
Education level				0.51 [b]
No schooling	31 (36.9%)	12 (29.3%)	19 (44.2%)	
Primary	36 (42.9%)	20 (48.8%)	16 (37.2%)	
Secondary	14 (16.7%)	7 (17.1%)	7 (16.3%)	
University	3 (3.6%)	2 (4.9%)	1 (2.3%)	
Employment				0.42 [b]
Work	2 (2.4%)	1 (2.4%)	1 (2.3%)	
Retired/ housewife	82 (97.6%)	40 (97.6%)	42 (97.7%)	
Household				0.26 [c]
Live alone	7 (8.3%)	5 (12.2%)	2 (4.7%)	
Live with family	77 (91.6%)	36 (87.8%)	41 (95.3%)	
Housing type				0.58 [b]
Rental	10 (11.9%)	5 (12.2%)	5 (11.6%)	
Private	24 (28.6%)	10 (24.4%)	14 (32.6%)	
Public	50 (59.5%)	26 (63.4%)	24 (55.8%)	
Perceived economic status				0.77 [b]
More than enough	21 (25.0%)	10 (24.4%)	11 (25.6%)	
Just enough	45 (53.6%)	20 (48.8%)	25 (58.1%)	
Not enough	17 (21.4%)	11 (26.8%)	7 (16.3%)	

Note: *p < 0.05.; a = independent sample t test; b = Pearson's chi-squared test; c = Fisher's Exact test.

Table 5.2 Clinical characteristics

Variable	Total (N = 84)	Control (n = 41)	Intervention (n = 43)	p value
Chronic heart failure etiology				
Ischemic heart disease	53 (63.1%)	23 (56.1%)	30 (69.8%)	0.19 [b]
Hypertension	51 (60.7%)	22 (53.7%)	29 (67.4%)	0.20 [b]
Cardiomyopathy	7 (8.3%)	4 (9.8%)	3 (7.0%)	0.65 [b]
Heart valve disease	14 (16.7%)	9 (22.0%)	5 (11.6%)	0.20 [b]
Arrhythmias	41 (48.8%)	23 (56.1%)	18 (41.9%)	0.19 [b]
Congenital heart defects	1 (1.2%)	1 (2.4%)	0 (0.0%)	0.30 [c]
Left ventricular EF (M, SD)	38 (15)	37 (17)	39 (14)	0.57 [a]
Comorbidity				
Asthma	7 (8.3%)	3 (7.3%)	4 (9.3%)	0.74 [c]
COPD	7 (8.3%)	5 (12.2%)	2 (4.7%)	0.21 [c]
Cancer	12 (14.3%)	5 (12.2%)	7 (16.3%)	0.59 [b]
Diabetes	35 (41.7%)	15 (36.6%)	20 (46.5%)	0.36 [b]
Hyperlipidemia	27 (32.1%)	9 (22.0%)	18 (41.9%)	0.051 [b]
Myocardial infarction	30 (35.7%)	13 (31.7%)	17 (39.5%)	0.45 [b]
Stroke	14 (16.7%)	7 (17.1%)	7 (16.3%)	0.92 [b]
Renal impairment	44 (52.4%)	18 (43.9%)	26 (60.5%)	0.13 [b]

Note: COPD = chronic obstructive pulmonary disease; EF = ejection fraction; *p < 0.05; M = mean; SD = standard deviation; a = independent sample t test; b = Pearson's chi-squared test; c = Fisher's Exact test.

5.1.2 Comparison of outcome measurements at baseline

Table 5.3 presents the group comparisons at baseline with regard to symptom intensity, functional status, and quality of life prior to the intervention. There were no significant differences identified in functional status in any of the domains in the quality of life measurements. In the symptom intensity measurements, pain and dyspnea showed significant differences while all other symptoms did not show significant differences. The results indicate that both groups were largely comparable.

Table 5.3 Comparison of outcome measurements at baseline

Variables	Control (n = 41)	Intervention (n = 43)	t value/ z score	p value
MQOL-HK (M, SD)				
Physical domain	4.32 (1.57)	4.87 (1.51)	1.618	0.11
Psychological domain	7.59 (2.15)	7.86 (1.96)	0.587	0.559
Existential domain	5.63 (2.95)	5.99 (2.52)	0.613	0.542
Support domain	8.05 (1.96)	7.87 (2.14)	-0.394	0.695
Overall	6.34 (2.20)	6.40 (2.14)	0.114	0.91
Total	6.37 (1.51)	6.59 (1.49)	0.958	0.507
CHQ-Chinese (Median, 25th to 75th percentile)				
Dyspnea	4.60 (3.90 - 5.60)	4.60 (3.80 - 5.40)	-0.672	0.501
Fatigue	3.50 (2.63 - 4.50)	4.00 (2.50 - 4.75)	-0.61	0.542
Emotional function	5.29 (3.36 - 6.14)	5.43 (3.71 - 6.14)	-0.376	0.707
Mastery	4.50 (3.50 - 5.63)	4.50 (3.25 - 5.50)	-0.543	0.587
Overall	4.55 (3.67 - 5.40)	4.64 (3.76 - 5.04)	-0.139	0.89
Symptom intensity				
ESAS (Median, 25th to 75th percentile)				
Pain	1.00 (0.00 - 3.50)	3.00 (0.00 - 7.00)	-2.041	*0.041
Fatigue	6.00 (4.00 - 7.00)	5.00 (3.00 - 7.00)	-0.873	0.383
Nausea	0.00 (0.00 - 0.00)	0.00 (0.00 - 0.00)	-0.261	0.794
Depression	3.00 (0.00 - 6.00)	2.00 (0.00 - 6.00)	-0.729	0.466
Anxiety	3.00 (0.00 - 6.00)	2.00 (0.00 - 6.00)	-0.578	0.563
Drowsiness	0.00 (0.00 - 0.00)	0.00 (0.00 - 0.00)	-0.114	0.909
Loss of appetite	5.00 (3.00 - 7.00)	5.00 (2.00 - 5.00)	-1.343	0.179
Sense of well-being	4.00 (2.00 - 6.00)	4.00 (2.00 - 5.00)	-0.173	0.863
Dyspnea	6.00 (3.00 - 8.00)	4.00 (2.00 - 6.00)	-2.124	*0.034
Functional status (M, SD)	65.85 (11.83)	64.42 (10.07)	0.275	0.55

Note: *$p < 0.05$; M = mean; SD = standard deviation; MQOL-HK = McGill Quality of Life-Hong Kong; CHQ-Chinese = Chronic Heart Failure Questionnaire-Chinese version; ESAS = Edmonton Symptom Assessment System. Independent t test for the MQOL-HK and Symptom intensity/Functional status. Mann-Whitney U test for the CHQ-Chinese, Symptom intensity/ESAS.

5.2 Results of outcome measures

This section will report the results of health services utilization, QOL, functional status, symptom intensity, and satisfaction with care.

5.2.1 Results of hospital readmission rates, hospital length of stay, and AED attendance

5.2.1.1 Hospital readmission

Table 5.4 Comparison of unplanned hospital readmissions between the intervention group and the control group after discharge from hospital

	Control (n = 41)	Intervention (n = 43)	χ^2	p value
Readmissions within 4 weeks (T2)			0.78	0.38
No	29 (70.7%)	34 (79.1%)		
Yes	12 (29.3%)	9 (20.9%)		
Readmissions within 12 weeks (T3)			6.8	*0.009
No	16 (39.0%)	29 (67.4%)		
Yes	25 (61.0%)	14 (33.6%)		

Note: *$p < 0.05$; data analyzed by Pearson's chi-squared test.

Table 5.4 shows the readmission rates of the intervention group and the control group. The 4 weeks readmission rates for the intervention group were lower than those of the control group (intervention = 20.9% versus control = 29.3%), but they did not achieve statistical significance ($\chi^2 = 0.78$, $p = 0.38$). At 12 weeks, the intervention group had an apparently lower readmission rate compared with the control group, and statistical significance was found (intervention = 33.6% versus control = 61%, $\chi^2 = 6.8$, p = 0.009).

Table 5.5 Number of readmissions at 4 weeks and 12 weeks

	Patients with ≥ 1 Readmissions	Total Number of Readmissions	Mean Number of Readmissions
At 4 weeks			
Intervention	9 (20.9%)	9	1
Control	12 (29.3%)	17	1.4
At 12 weeks			
Intervention	14 (32.6%)	18	1.3
Control	25 (61%)	45	1.8
Frequency	Control (n=41)	Intervention (n=43)	Total (N=84)
Number of Readmissions at 4 weeks			
0	29 (70.7%)	34 (79.1%)	63 (75.0%)
1	8 (19.5%)	9 (20.9%)	17 (20.2%)
2	3 (7.3%)	0 (0.0%)	3 (3.6%)
3	1 (2.4%)	0 (0.0%)	1 (1.2%)
Number of Readmissions at 12 weeks			
0	16 (39.0%)	29 (67.4%)	45 (53.6%)
1	11 (26.8%)	10 (23.3%)	21 (25.0%)
2	9 (22.0%)	4 (9.3%)	13 (15.5%)
3	4 (9.8%)	0 (0.0%)	4 (4.8%)
4	1 (2.4%)	0 (0.0%)	1 (1.2%)

The results in Table 5.5 show that the intervention group had a fewer number of readmissions compared with the control group. At 4 weeks, one in five patients (20.9%) in the intervention group experienced at least one readmission, while there was approximately 30% in the control group. At 12 weeks, nearly one third (32.6%) of the patients in the intervention group had one or more readmissions compared with 61% in the control group. The total number of hospital readmissions at 4 weeks was almost double in the control group (17 readmissions) compared with the intervention group (nine readmissions). The results were more apparent at 12 weeks, as the total number of hospital readmissions was more than double in the control group (45 readmissions), while there were only 18 readmissions in the intervention group. At 4 weeks, there was no significant difference (p = 0.26) in the total number of readmissions between the intervention group and the control group. At 12 weeks, the total number of readmissions differed significantly (p = 0.02) between the two groups.

Since some patients had more than one readmission, the number of readmissions per person was also examined. At 4 weeks, the percentage of patients readmitted once was similar in both groups (intervention = 20.9% versus control = 19.5%). None of the intervention group patients had more than one readmission. On the other hand, in the control group, some patients had more readmissions (7.3% had two and 2.4% had three). At 12 weeks, 23.3% of the patients in the intervention group were readmitted once and 9.3% were readmitted twice. None of the patients in the intervention group was readmitted more than twice. However, the control group tended to have higher readmission rates, with 26.8% readmitted once, 22% readmitted twice, and 12.2% readmitted more than twice (see Table 5.5).

Table 5.6 Comparison of number of days between index discharge and first readmission, and length of stay during the first readmission within 4 weeks

	Control (n = 12)	Intervention (n = 9)	Z	p value
Number of Days			-0.61	0.55
Median	9	12		
Range	2-25	3-23		
Length of Stay (days)			-0.82	0.42
Median	5.5	4		
Range	1-18	1-21		

Note: Data analyzed by the Mann-Whitney U test.

Table 5.6 displays the results of the number of days between the index discharge and first readmission within 4 weeks. Patients in the control group were readmitted within a shorter length of time compared with the patients in the intervention group, but no significant difference was detected (median: intervention 12 days versus control 9 days) (U = 45.5, Z = -0.61, p = 0.55). The length of stay during the first readmission within 4 weeks was also examined. When patients were hospitalized, patients in the control group stayed longer compared with those in the intervention group, but the two groups did not differ significantly (median: intervention 4 days versus control 5.5 days) (U = 42.5, Z = -0.82, p = 0.42).

5.2.1.2 Hospital length of stay

Table 5.7 Comparison of the total length of stay within 12 weeks

	Control (n = 24)	Intervention (n = 12)	Z	p value
Total Length of Stay (days)			-1.74	0.08
Median	8.5	4		
Range	1-45	1-22		

Note: Data analyzed by the Mann-Whitney U test.

Table 5.7 displays the total length of hospital stay within 12 weeks between the two groups. The patients in the control group had much longer hospital stays compared with those in the intervention group, but no significant p value was achieved (median: intervention 4 days versus control 8.5 days) (U = 92.5, Z = -1.74, p = 0.08).

5.2.1.3 Accident and Emergency Department (AED) attendance

Table 5.8 Comparison of frequency of AED attendance between the intervention group and the control group after discharge from hospital

	Control (n = 41)	Intervention (n = 43)	χ^2	p value
AED attendance within 4 weeks (T2)			0.39	0.53
No	28 (68.3%)	32 (74.4%)		
Yes	13 (31.7%)	11 (25.6%)		
AED attendance within 12 weeks (T3)			5.92	*0.015
No	13 (31.7%)	25 (58.1%)		
Yes	28 (68.3%)	18 (41.9%)		

Note: *$p < 0.05$; data analyzed by Pearson's chi-squared test.

Table 5.8 shows the AED attendance rates for the participants in the control group and the intervention group. The AED attendance rate in the intervention group was lower than that in the control group at both 4 weeks post-discharge (intervention = 25.6% versus control = 31.7%) and 12 weeks post-discharge (intervention = 41.9% versus control = 68.3%). A statistically significant difference was achieved at 12 weeks ($\chi^2 = 5.92$, $p = 0.015$).

Table 5.9 AED attendance within 4 weeks and 12 weeks

	Patients with ≥ 1 AED Attendance	Total Number of AED Attendances	Mean Number of AED Attendances
Within 4 weeks			
Intervention	11 (25.6%)	12	1.1
Control	13 (31.7%)	22	1.7
Within 12 weeks			
Intervention	18 (41.9%)	31	1.7
Control	26 (63.4%)	50	1.9
Frequency	Control (n = 41)	Intervention (n = 43)	Total (N = 84)
AED attendance within 4 weeks			
0	28 (68.3%)	32 (74.4%)	60 (71.4%)
1	6 (14.6%)	10 (23.3%)	16 (19.0%)
2	5 (12.2%)	1 (2.3%)	6 (7.1%)
3	2 (4.9%)	0 (0.0%)	2 (2.4%)
AED attendance within 12 weeks			
0	13 (31.7%)	25 (58.1%)	38 (45.2%)
1	15 (36.6%)	9 (20.9%)	24 (28.6%)
2	6 (14.6%)	7 (16.3%)	13 (15.5%)
3	2 (4.9%)	1 (2.3%)	3 (3.6%)
4	1 (2.4%)	0 (0.0%)	1 (1.2%)
5	0 (0.0%)	1 (2.3%)	1 (1.2%)
6	1 (2.4%)	0 (0.0%)	1 (1.2%)

In terms of frequency of AED attendance, Table 5.9 shows that the patients in the intervention group had lower AED attendance rates compared with the control group at both 4 weeks and 12 weeks post-discharge. At 4 weeks post-discharge, about one-fourth (25.6%) of the patients in the intervention group had at least one AED attendance compared with 31.7% of the patients in the control group. At 12 weeks post-discharge, it was found that 41.9% of the intervention group patients had at least one AED attendance, while 63.4% of the control group patients attended the AED at least once. With regard to the total number of AED attendances, the intervention group patients had fewer AED attendances compared with the control group patients at 4 weeks post-discharge (intervention = 12 versus control = 22) and at 12 weeks post-discharge (intervention = 31versus control = 50). The intervention group had a lower mean number of post-discharge AED attendances at 4 weeks (intervention = 1.1 versus control = 1.7) and at 12 weeks (intervention = 1.7 versus control = 1.9).

At 4 weeks, although more patients from the intervention group attended the AED once compared with the control group (intervention = 23.3% versus control = 14.6%), the control group tended to have more frequent AED attendances, for example, 12.2% of the patients from the control group attended the AED twice compared with only 2.3% of those from the intervention group. Additionally, 4.9% from the control group had three AED attendances while no patients from the intervention group attended the AED three times.

At 12 weeks, the control group also attended the AED more than the intervention group did. In the control group, 36.6% attended the AED once compared with the intervention group (20.9%), and 7.3% from the control group had three or more AED attendances compared with 4.6% from the intervention group.

Table 5.10 Comparison of number of days between index discharge and first AED attendance within 4 weeks

	Control (n = 12)	Intervention (n = 11)	Z	p value
Number of Days			-0.96	0.35
Median	9	12		
Range	2-25	2-28		

Note: Data analyzed by the Mann-Whitney U test.

Table 5.10 displays the results comparing the number of days between index discharge and first AED attendance 4 weeks post-discharge. The patients in the control group attended the AED for a shorter length of time than those in the intervention group, but no significant difference was detected (median: intervention = 12 days versus control = 9 days) (U = 50.5, Z = -0.96, p = 0.35).

5.2.2 Results of the QOL measurements

5.2.2.1 MQOL-HK

In the MQOL-HK, the domains of physical, psychological, existential, and support together with global QOL and total QOL scores were examined.

Table 5.11 displays the results of the MQOL-HK, which were analyzed by repeated-measures ANOVA. From baseline (T1) to 12 weeks (T3), statistically significant differences were revealed between the intervention group and the control group in the total QOL scores (p = 0.016), with a medium effect size (partial eta squared = 0.069). In examining each domain in the MQOL-HK, it was found that there were statistically significant between group differences in the physical (p = 0.011), psychological (p = 0.04), and existential (p = 0.027) domains. The support domain and global QOL items did not differ between the groups across the three time points. A significant group x time interaction effect was detected for the total QOL scores (p = 0.032), with a small effect size (partial eta squared = 0.043). Over the intervention period, there was a significant within group improvement in the total QOL scores in the intervention group, but not in the control group. From T1 to T2 (4 weeks), the intervention group had a significantly higher increase in the mean of the total QOL, from 6.59 (95% Confidence Interval (CI) 6.14-7.04) to 7.54 (95% CI 7.14-7.94), compared with the control group, from 6.37 (95% CI 5.91-6.83) to 6.61 (95% CI 6.04-7.18), and it was statistically significant ($p < 0.001$). From T1 to T3 (12 weeks), the intervention group also had a significantly higher increase in the mean of the total QOL ($p < 0.001$), from 6.59 (95% CI 6.14-7.04) to 7.49 (95% CI 7.15-7.83), compared with the control group, which was from 6.37 (95% CI 5.91-6.83) to 6.61 (95% CI 6.17-7.05).

Table 5.11 Comparison of the MQOL-HK by group over the three time points

McGill Quality of life		Baseline (T1)	After 4 weeks (T2)	After 12 weeks (T3)	Between Groups		Within Groups				Interaction Effect	
	n	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	p-value	η_p^2	p (T1 Vs T2)	p (T1 Vs T3)	p (T2 Vs T3)	η_p^2	p-value	η_p^2
Physical					*0.011	0.075					0.72	0.004
Intervention	43	4.87 (4.42-5.32)	6.1 (5.57-6.63)	6.32 (5.79-6.85)			*<0.001	*<0.001	0.784	0.268		
Control	41	4.32 (3.84-4.80)	5.27 (4.74-5.80)	5.51 (5.00-6.02)			*0.011	*<0.001	0.74	0.196		
Psychological					*0.04	0.05					^0.044	0.039
Intervention	43	7.86 (7.27-8.45)	8.99 (8.58-9.40)	8.75 (8.42-9.08)			*0.002	*0.005	0.808	0.193		
Control	41	7.59 (6.93-8.25)	7.82 (7.04-8.60)	8.18 (7.70-8.66)			1	*0.01	0.303	0.055		
Existential					*0.027	0.058					0.202	0.019
Intervention	43	5.99 (5.24-6.74)	6.99 (6.31-7.67)	6.19 (5.46-6.92)			0.096	0.817	0.063	0.078		
Control	41	5.63 (4.73-6.53)	5.84 (5.00-6.68)	4.86 (3.97-5.75)			0.915	0.399	0.065	0.059		
Support					0.288	0.014					0.136	0.024
Intervention	43	7.87 (7.23-8.51)	8.4 (7.91-8.89)	8.3 (7.81-8.79)			0.183	0.51	0.982	0.043		
Control	41	8.05 (7.45-8.65)	7.85 (7.22-8.48)	7.68 (7.11-8.25)			0.823	0.797	0.998	0.011		
Global QOL					0.1	0.033					0.083	0.03
Intervention	43	6.4 (5.76-7.04)	7.19 (6.65-7.73)	7.87 (7.35-8.39)			0.139	*0.003	0.064	0.154		
Control	41	6.34 (5.67-7.01)	6.27 (5.50-7.04)	6.84 (6.28-7.40)			0.836	0.165	0.156	0.071		
TOTAL					*0.016	0.069					^0.032	0.043
Intervention	43	6.59 (6.14-7.04)	7.54 (7.14-7.94)	7.49 (7.15-7.83)			*<0.001	*<0.001	1	0.256		
Control	41	6.37 (5.91-6.83)	6.61 (6.04-7.18)	6.61 (6.17-7.05)			0.981	0.518	0.905	0.013		

Note: * $p < 0.05$ (Within Groups and Between Groups); ^ $p < 0.05$ (Interaction Effect); η_p^2 - partial eta square of repeated-measure ANOVA (small = 0.01, medium = 0.06, large = 0.14).

5.2.2.2 CHQ-Chinese

In the CHQ-Chinese version, the domains of dyspnea, fatigue, emotional function, mastery, and total score were examined. The results of the CHQ-Chinese are shown in Table 5.12. At T2, a statistically significant between group difference was noted in the total scores (p = 0.01) (intervention median = 5.39 [25th to 75th percentile: 4.18-6.26] versus control median = 4.74 [25th to 75th percentile: 3.88-5.29]). Among the four domains in the CHQ-Chinese measurement, statistically significant group differences were revealed in the dyspnea domain (intervention median = 6.00 [25th to 75th percentile: 5.00-6.71] versus control median = 4.80 [25th to 75th percentile: 3.70-6.20] (p = 0.02); emotional domain (intervention median = 6.00 [25th to 75th percentile: 4.73-6.57] versus control median = 5.14 [25th to 75th percentile: 3.92-6.07]) (p = 0.01); and mastery domain (intervention median = 5.50 [25th to 75th percentile: 4.00-6.50] versus control median = 4.96 [25th to 75th percentile: 4.00-5.50]) (p = 0.02). The social domain did not differ between the groups. There were no statistically significant differences in any of the domains at T3.

A significant within group improvement was observed in the intervention group, but not in the control group, in the pairwise comparison of T1 to T2 and T1 to T3 in the CHQ-Chinese total scores (T1 to T2, $p < 0.001$; T1 to T3, $p < 0.001$). The dyspnea and mastery domains showed significant within group improvement (Dyspnea: T1 to T2, $p < 0.001$; T1 to T3, $p < 0.001$; Mastery: T1 to T2, $p < 0.001$; T1 to T3, $p = 0.008$).

Table 5.12 Comparison of the CHQ-Chinese by group over the three time points

	Baseline (T1)	After 4 Weeks (T2)	After 12 Weeks (T3)	p (T1 vs T2)	p (T1 vs T3)	p (T2 vs T3)
	Median (25th to 75th percentile)	Median (25th to 75th percentile)	Median (25th to 75th percentile)			
Dyspnea						
Intervention	4.60 (3.80-5.40)	6.00 (5.00-6.71)	6.00 (5.20-6.60)	*<0.001	*<0.001	0.643
Control	4.60 (3.90-5.60)	4.80 (3.70-6.20)	5.80 (4.62-6.37)	0.811	*0.001	*0.003
p (between group difference)		^0.02	0.158			
Fatigue						
Intervention	4.00 (2.50-4.75)	4.00 (2.75-5.50)	5.00 (3.13-5.50)	0.152	*0.004	0.116
Control	3.50 (2.63-4.50)	4.00 (3.00-4.51)	4.50 (3.88-5.00)	0.654	*0.005	*0.003
p (between group difference)		0.259	0.273			
Emotional Function						
Intervention	5.43 (3.71-6.14)	6.00 (4.73-6.57)	5.75 (5.08-6.43)	*0.003	0.043	0.619
Control	5.29 (3.36-6.14)	5.14 (3.92-6.07)	5.29 (4.62-6.36)	0.678	0.114	0.065
p (between group difference)		^0.014	0.436			
Mastery						
Intervention	4.50 (3.25-5.50)	5.50 (4.00-6.50)	5.25 (4.00-6.25)	*0.001	*0.008	0.466
Control	4.50 (3.50-5.63)	4.96 (4.00-5.50)	5.50 (4.80-6.25)	0.624	*0.001	*0.008
p (between group difference)		^0.019	0.257			
TOTAL						
Intervention	4.64 (3.76-5.04)	5.39 (4.18-6.26)	5.41 (4.52-6.01)	*<0.001	*<0.001	0.388
Control	4.55 (3.67-5.40)	4.74 (3.88-5.29)	5.31 (4.69-5.80)	0.791	*<0.001	*0.001
p (between group difference)		^0.01	0.585			

Note: * adjusted within group difference p < 0.017; ^ adjusted between group difference p < 0.025.

5.2.2.3 Results of symptom intensity assessed by the ESAS

Table 5.13 displays the comparison between the two groups across the three time points on symptom intensity. There were nine symptoms in the ESAS, including pain, tiredness, nausea, depression, anxiety, drowsiness, loss of appetite, feeling of well-being, and shortness of breath.

At T2, statistically significant differences were found between the intervention group and the control group in symptom depression (intervention median = 0.00 [25th to 75th percentile: 0.00-3.00] versus control median = 2.00 [25th to 75th percentile: 0.00-5.00]) ($p = 0.01$), and shortness of breath (intervention median = 2.42 [25th to 75th percentile: 0.00-4.51] versus control median = 4.21 [25th to 75th percentile: 0.71-7.00]) ($p = 0.018$). There was no significant between group difference in any of the symptoms at T3 ($p = 0.312$-0.69). When the groups were compared on their own over time, only the intervention group showed significant within group differences regarding the symptoms of tiredness ($p = 0.005$), depression ($p = 0.012$), anxiety ($p = 0.007$), and shortness of breath ($p = 0.009$) in the pairwise comparison of T1 to T2. The intervention group also showed significant symptom improvement in T1 to T3 in the symptom of tiredness (p = 0.008) and the total score (p = 0.001).

Table 5.13 Comparison of symptom intensity by group over the three time points

	Baseline (T1)	After 4 Weeks (T2)	After 12 Weeks (T3)	p (T1 vs T2)	p (T1 vs T3)	p (T2 vs T3)
	Median (25th to 75th percentile)	Median (25th to 75th percentile)	Median (25th to 75th percentile)			
Pain						
Intervention	3.00 (0.00-7.00)	2.00 (0.00-5.00)	2.00 (0.00-5.00)	0.044	0.1	0.885
Control	1.00 (0.00-3.50)	0.00 (0.00-4.16)	1.86 (0.00-4.00)	0.891	0.962	0.443
p (between group difference)		0.322	0.602			
Tiredness						
Intervention	5.00 (3.00-7.00)	5.00 (2.00-5.61)	3.19 (2.00-5.74)	*0.005	*0.008	0.26
Control	6.00 (4.00-7.00)	5.00 (3.00-6.00)	4.56 (2.05-6.37)	0.094	*0.005	0.339
p (between group difference)		0.344	0.43			
Nausea						
Intervention	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.674	0.66	0.534
Control	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.345	0.79	0.859
p (between group difference)		0.981	0.69			
Depression						
Intervention	2.00 (0.00-6.00)	0.00 (0.00-3.00)	2.00 (0.00-3.00)	*0.012	0.069	0.6
Control	3.00 (0.00-6.00)	2.00 (0.00-5.00)	0.00 (0.00-2.85)	0.732	*0.006	0.083
p (between group difference)		^0.01	0.646			
Anxiety						
Intervention	2.00 (0.00-6.00)	0.00 (0.00-3.00)	1.00 (0.00-5.00)	*0.007	0.312	0.063
Control	3.00 (0.00-6.00)	1.00 (0.00-4.91)	3.00 (0.00-5.76)	0.104	0.667	0.284
p (between group difference)		0.105	0.306			
Drowsiness						
Intervention	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.099	0.088	0.646
Control	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.969	0.245	0.103
p (between group difference)		0.154	0.493			
Loss of Appetite						
Intervention	5.00 (2.00-5.00)	3.00 (0.00-5.00)	5.00 (1.65-7.92)	0.053	0.826	0.052
Control	5.00 (3.00-7.00)	5.00 (0.00-5.33)	5.00 (2.25-7.00)	0.103	0.874	0.332
p (between group difference)		0.181	0.679			
Feeling of Well-being						
Intervention	4.00 (2.00-5.00)	3.00 (1.00-5.00)	2.00 (0.42-3.48)	0.128	*<0.001	*0.019
Control	4.00 (2.00-6.00)	5.00 (2.00-6.50)	2.00 (0.94-3.88)	0.577	*0.001	*<0.001
p (between group difference)		0.06	0.555			

	Baseline (T1)	After 4 Weeks (T2)	After 12 Weeks (T3)	p (T1 vs T2)	p (T1 vs T3)	p (T2 vs T3)
	Median (25th to 75th percentile)	Median (25th to 75th percentile)	Median (25th to 75th percentile)			
Shortness of Breath						
Intervention	4.00 (2.00-6.00)	2.42 (0.00-4.51)	3.00 (0.00-5.00)	*0.009	0.092	0.332
Control	6.00 (3.00-8.00)	4.21 (0.71-7.00)	3.38 (0.00-7.00)	0.045	0.023	0.352
p (between group difference)		^0.018	0.312			
TOTAL						
Intervention	3.00 (2.22-3.89)	2.00 (1.00-3.11)	2.11 (0.78-3.22)	*<0.001	*0.001	0.837
Control	3.11 (2.39-4.11)	2.33 (1.61-3.51)	2.22 (0.94-3.42)	0.047	*0.002	0.276
p (between group difference)		0.1	0.68			

Note: * adjusted within group difference p < 0.017; ^ adjusted between group difference p < 0.025.

5.2.2.4 Results of functional status assessed by the PPS

Table 5.14 shows the results of functional status assessed by the PPS. Neither the between group nor within group analyses achieved a significant p value at any of the time points regarding the functional status measurement.

Table 5.14 Comparison of functional status by group over the three time points

PPS	Baseline (T1)	After 4 Weeks (T2)	After 12 Weeks (T3)	p (T1 vs T2)	p (T1 vs T3)	p (T2 vs T3)
	Median (25th to 75th percentile)	Median (25th to 75th percentile)	Median (25th to 75th percentile)			
PPS						
Intervention	60.00 (60.00-70.00)	7.00 (6.00-7.00)	6.72 (6.00-7.00)	0.162	0.102	0.74
Control	70.00 (60.00-70.00)	7.00 (5.31-8.00)	6.98 (6.05-7.05)	0.728	0.68	0.918
p (between group difference)		0.764	0.738			

Note: * adjusted within group difference $p < 0.017$; ^ adjusted between group difference $p < 0.025$.

5.2.2.5 Results of satisfaction with care

Table 5.15 presents the results of the patients' satisfaction with care. The intervention group achieved significantly higher satisfaction scores compared with the control group at T2 (intervention median = 4.00 versus control median = 2.92, $p < 0.001$) and at T3 (intervention median = 4.00 versus control median = 2.92, $p = 0.001$). There was also a significant over time increase in the satisfaction scores in the intervention group ($p = 0.015$).

Table 5.15 Comparison of satisfaction with care by group over two time points

Patient Satisfaction	After 4 Weeks (T2)		After 12 Weeks (T3)	Within Groups
	n	Median (25th to 75th percentile)	Median (25th to 75th percentile)	Z (p value)
Patient Satisfaction				
Intervention	37	4.00 (3.71-4.92)	4.00 (3.22-4.50)	*0.015
Control	30	2.92 (2.48-3.92)	2.76 (2.27-3.77)	0.141
p (between group difference)		^<0.001	^0.001	

Note: * p < 0.05; ^ adjusted between group difference p < 0.025.

5.3 Results of the need for referral to other multidisciplinary team members

Table 5.16 shows the number of health and social care services referred by the palliative care nurse case manager (PC-NCM) in the intervention group. During the intervention period, referrals were made for the patients to obtain further care support. Two patients (4.6%) were referred to Day Hospice Centre for physiotherapy of the limbs. Six referrals (13.9%) were made to seek medical advice through phone consultation with the PC physician. There were referrals for early clinic follow-up (16.3%) because of the need for symptom management and the AED (2.3%) due to active bleeding. With regard to social care services, the PC-NCM connected 13 patients (30%) to a medical social worker, and the reasons included home help service, financial assistance, and placement issues.

Table 5.16 Frequency of referral for health and social care services in the intervention group

Referral by PC-NCM	Total (n = 29)	
Health Care		
Day Hospice Centre	2	(6.9%)
Phone consultation with PC physician	6	(20.7%)
Early clinic follow-up	7	(24.1%)
AED attendance	1	(3.4%)
Social Care via Medical Social Worker		
Home help service, financial assistance, placement	13	(44.8%)

5.4 Results of patient-/caregiver-initiated calls

Table 5.17 presents the number of calls made by either the patients or their caregivers to seek help from the PC-NCM. A total of eight calls were made. Three calls (7.0%) were initiated by patients and five calls were initiated by their caregivers (11.6%). Reasons for calling the PC-NCM included symptom management (e.g., increased shortness of breath and observed lower limbs) and practical help (e.g., arrange for transportation to attend clinic follow-up).

Table 5.17 Frequency of patient-/caregiver-initiated calls to the PC-NCM

Calls Initiated	Total (n = 8)
Patients	3 (37.5%)
Caregivers	5 (62.5%)

5.5 Follow-up in the control group

There was no care support received by the control group subjects during the first 4 weeks post-discharge, but support was offered within the 12 weeks post-discharge period, with 12 (29.3%) subjects receiving home visits. The care provided to the control group subjects was part of the customary service initiated by the clinicians. Details on the amount of support received by the control group within the 12 weeks are shown in Table 5.18 below:

Table 5.18 Home visits provided to the control group per patient

Received 1 visit (n = 8)	
	5 patients visited by the PC team, 3 patients visited by the geriatric team
Received 3 visits (n = 1)	
	First and second visits were offered by the geriatric team, and the third visit was offered by the PC team
Received 6 visits (n = 1)	
	All visits were offered by the geriatric team
Received 8 visits (n = 1)	
	All visits were offered by the geriatric team

5.6 Intervention compliance

Adherence to the intervention program was calculated by the number of follow-up interventions delivered by both the PC-NCM and volunteers divided by the total number stipulated in the intervention program. In the first 4 weeks of hospital discharge, a total of 151 follow-up interventions were completed out of 172 (43 patients * 4 home visits/calls needed to be carried out in the first 4 weeks post-discharge), for a compliance rate of 87.8%. In addition, the follow-ups maintained until 12 weeks post-discharge were 325 completed out of the required 430 follow-ups (43 patients * 10 home visits/calls needed to be carried out throughout the intervention period), for a compliance rate of 75.6% at the completion of the program at 12 weeks.

5.7 Summary

This chapter presented the results reflecting the effects of the intervention program among the patients in the intervention group compared with those in the control group. The patients with ESHF who received the intervention program had a significantly lower hospital readmission rate and lower AED attendance rates. Significant between group differences were detected in various domains in the QOL outcomes, and the intervention group experienced significant improvements in QOL over the study period. The total symptom intensity was also reduced for the patients in the intervention group. No between group or within group differences were observed in functional status in both groups. It was found that the intervention group had significantly higher patient satisfaction scores compared with the control group.

CHAPTER SIX

DISCUSSION

The previous chapter reported the findings of the current study, revealing that the HPHF program yielded promising results on hospital readmission rates, AED attendance rates, QOL, depression, shortness of breath, and satisfaction with care among a group of ESHF patients. Thus far, this is the first randomized controlled study that evaluated the effects of transitional care and PC on the ESHF population in Hong Kong. This chapter will discuss the results of the study from the following perspectives: effects of the HPHF program, possible factors that may have contributed to the outcomes in the study, and the role of the PC-NCM. The challenges in PC research and the limitations of this study will also be examined. Finally, the implications for practice and research will be discussed based on the findings of this study.

6 Introduction

The purpose of this study was to examine the effects of the HPHF program on hospital readmission rates, AED attendances, length of hospital stays, QOL, symptom intensity, functional status, and satisfaction with care for patients with ESHF, compared with conventional care alone. The development of this trial was underpinned by the understanding that patients living with ESHF experience physical, psychosocial, and existential turbulences along the HF disease trajectory, including repeated hospitalization and eventually resulting in death (Kavalieratos et al., 2017; Lowey, Norton, Quinn, & Quill, 2014). When HF exacerbation is stabilized, allowing patients to return to their own home, the immediate post-discharge period provides an opportunity for interventions to meet the multiple needs of patients with HF and control unnecessary readmissions (Davidson et al., 2008). These patients benefit from transitional care support to manage their symptoms and at the same time PC specialty care to deal with their emotions. A safe transition for discharged ESHF patients helps avoid unnecessary hospital readmission; improves their QOL, symptom control, and functional status; and increases satisfaction with care.

Several systematic reviews have shown that transitional care is effective in improving continuity of care and reducing hospital readmission rates for patients who are recently discharged from the hospital (Albert, 2016; Feltner et al., 2014; Van Spall et al., 2017; Vedel & Khanassov, 2015). Studies have also demonstrated that the PC approach can improve the QOL of patients with terminal diseases (Bakitas et al., 2009; Lorenz et al., 2008; Temel et al., 2010; Yancy et al., 2013; Zimmermann et al., 2008). However, there is a growing body of evidence that has documented the unmet PC needs of patients with ESHF, highlighting the need for better access to PC and coordination of care for this group of patients (Arnold et al., 2008; Goodlin et al., 2004; Hunt et al., 2009; Jaarsma et al., 2009; Kavalieratos, Kamal et al., 2014; Selman et al., 2007a; Ventura, Burney, Brooker, Fletcher, & Ricciardelli, 2014).

The provision of specialized PC services for patients in need (including ESHF patients) varies widely with regard to the types of services and accessibility and availability (Centeno et al., 2015; Gibbs et al., 2006; Hanratty et al., 2002; Hauptman, Swindle, Hussain, Biener, & Burroughs, 2008; Hughes & Smith, 2014; O'Leary & Tiernan, 2008). For instance, a recent survey examined the coverage and development of specialized PC services across the WHO European Region between 2005 and 2012, which focused on three types of specialized PC services, including home care, hospital support, and inpatient services (Centeno et al., 2015). The results of that study showed that there has been an overall positive development in specialized PC services coverage in Europe, but the services available in most countries are still insufficient in meeting the PC needs of the population (Centeno et al., 2015). Home-based PC programs may help reduce health services use and enhance QOL for patients who are suffering from serious illnesses, including those at advanced symptomatic stages of disease (Aiken et al., 2006, Diop, Rudolph, Zimmerman, Richter, & Skarf, 2017; Gomes et al., 2013; Hanson, Schenck, & Burstin, 2014).

In the current study, it was hypothesized that the HPHF program would bring about positive effects on clinical and patient outcomes for patients with ESHF. The primary outcome was the hospital readmission rate, and other outcomes included AED attendances, length of hospital stays, QOL, symptom intensity, functional status, and patient satisfaction with care. The effects of the HPHF program on these outcome variables will be discussed in the following.

6.1 Aligning the study results with existing evidence

The results of this study revealed a significant reduction in hospital readmission and AED attendance rates for the intervention group receiving the HPHF program compared with the group receiving conventional care alone. In addition, significant improvements were found in patients in the HPHF program compared with those who received conventional care in the areas of QOL, depression, shortness of breath, and patient satisfaction with care. In the within group analysis of the HPHF group and the conventional care group, the patients in the HPHF group showed significant improvements in most domains of the QOL outcomes and were significantly improved regarding tiredness, feeling of well-being, and total symptom intensity. However, the HPHF program did not show improvements in functional status.

This study, in concurrence with other studies (Diop et al., 2017; Kavalieratos et al., 2017), showed reductions in health services use and improvements in patient outcomes using a transitional palliative care model for ESHF patients. Another similar trial by Brännström and Boman (2014) was conducted in Sweden, which recruited 72 severe chronic HF patients from a national HF registry, with 36 patients in each group. The tested integrated chronic HF and palliative home care program used physicians and nurses as key care providers. Brännström and Boman (2014) found that QOL, the number of hospitalizations, and total symptom burden were improved in the intervention group. Patient satisfaction in the current study was significantly different between the intervention group and the control group, in alignment with a home-based PC study conducted by Brumley et al. (2007).

Many home-based interventions conducted among patients with HF have used providers with a background in community (Harrison et al., 2002; Kwok, Lee, Woo, Lee, & Griffith, 2008) or cardiac care (Blue et al., 2001; Stewart, Marley, & Horowitz, 1999). This may have been based on the aims of the interventions, which mainly focused on disease management (Blue et al., 2001; Harrison et al., 2002; Inglis et al., 2006; Kwok et al., 2008; Rich et al., 1995; Riegel, et al., 2002; Stewart et al., 1999; Stewart, Pearson, & Horowitz, 1998). The strategy of the HPHF program in the current study went beyond the traditional disease management model, as the team used a PC-NCM as the key care provider to deliver home visits/telephone calls, with support from the PC team. The HF patients in this study were at the end stage of life, so they had more psychosocial and spiritual issues. Because the nurse had a PC background, she could also offer an opportunity to discuss end-of-life issues with the patients. This study addressed the call for better integration of PC into HF management to build a potentially more effective service model (Bekelman et al., 2015; Hauptman & Havranek, 2005; Pantilat & Steimle, 2004; Selman et al., 2007a).

A recent Cochrane systematic review showed that among the 23 studies on home PC identified, only one trial was conducted solely on a non-cancer group (Gomes et al., 2013). The Cochrane review reported that some of the trials included mixed samples: advanced cancer, advanced congestive HF, and advanced COPD (Brumley et al., 2007; Gade et al., 2008; Rabow et al., 2004); however, none of them used ESHF patients only as the study subjects (Gomes et al., 2013). Recently, an increasing number of studies have been conducted on the different models of PC in HF care. Among the models of PC intervention examined, three were in-patient based (Ekman et al., 2011; Hopp et al., 2016; Sidebottom et al., 2015), two were out-patient based (Evangelista et al., 2012; Rogers et al., 2017), and only one was a home-based model (Brännström & Boman, 2014). The current study adds to the body of knowledge on the effects of home care and provides more options for a more innovative service model interfacing hospital and home care (Gomes et al., 2013).

6.2 What made the Home-based Palliative Heart Failure program effective?

6.2.1 Integrating transitional care into palliative care

This is one of the few RCTs that has incorporated PC elements into the transitional care model to design a home-based program for ESHF patients. Transitional care programs have been designed that mainly targeted vulnerable older adults with multiple comorbid conditions and complex treatment regimens during the transition from hospital to home (Allen, Hutchinson, Brown, & Livingston, 2014; Coleman & Boult, 2003; Enguidanos, Gibbs, & Jamison, 2012; Graham, Ivey, & Neuhauser, 2009; Naylor et al., 2000). Heart failure is a common cause of hospitalization, and a study by Dharmarajan et al. (2013)

revealed that nearly one-quarter of patients hospitalized with HF are readmitted within 30 days. Older adults with HF are at risk of rehospitalization if their hospital to home period is not properly supported (Piraino, Heckman, Glenny, & Stolee, 2012).

Although a number of transitional care studies on older adults and HF patients have been conducted, a recent systematic review found that patients diagnosed with advanced non-malignant diseases were one of the patient groups that had not been studied in transitional care trials (Piraino et al., 2012). In fact, some transitional care studies specifically excluded patients who had end-stage renal disease (Naylor et al., 2004; Saleh, Freire, Morris-Dickinson, & Shannon, 2012); ESHF (Anderson, Deepak, Amoateng-Adjepong, & Zarich, 2005); and had less than three to six months of life expectancy (Coleman et al., 2006; Harrison et al., 2002; Jaarsma et al., 1999; Kwok et al., 2008; Laramee, Levinsky, Sargent, Ross, & Callas, 2003).

The current study was targeted at supporting ESHF patients from hospital to home who were also experiencing a shift in care focus, from a hospital-based curative mode to a more home-based palliative approach. The addition of PC elements in this vulnerable population was therefore seen as appropriate, as acknowledged as part of the comprehensive services required for non-communicable diseases in the WHO Global Action Plan for the Prevention and Control of Non-communicable Disease (WHO, 2013). The World Health Assembly further shed light on the first ever global resolution on PC in 2014, indicating the importance of improving access to PC and strengthening PC as a component of comprehensive care throughout the life course (World Health Assembly, 2014).

Evidence related to PC is promising not only to cancer patients but also to non-cancer patients in terms of cost savings, which is related to healthcare resource use, as well as symptom control and QOL improvement (Gomes et al., 2013; Kavalieratos et al., 2017; Morrison et al., 2008; Smith & Cassel, 2009). According to the latest WHO document on planning and implementing PC services (WHO, 2016), home-based PC is one of the important focuses for care provided to people with chronic, life-limiting conditions, such as advanced cardiac diseases, at patients' homes. Patients feel more comfortable in their home than in healthcare settings, and patients can spend more time with their family members, who can also be involved in the caring process in an environment familiar to the patients (WHO, 2016). Additionally, home-based PC is best delivered by a multidisciplinary team that has received training in PC, and an ideal team should consist of physicians, nurses, trained volunteers, and social workers (WHO, 2016). Better coordinated interfacing between the hospital and home to support PC patients in staying in a place that they are familiar with is appropriate and important in enhancing patients' quality of life.

6.2.2 Bundled interventions

The mechanisms underlying the success of the HPHF program can be attributed to several components related to each other, which cannot be separated in explaining them (Brännström & Boman, 2014; Naylor et al., 2004). The term "bundled interventions" has been used to describe interventions and programs involving more than one activity (Albert et al., 2015; Hansen, Young, Hinami, Leung, & Williams, 2011; Leppin et al., 2014), acknowledging the difficulty in discussing the effectiveness of a specific component in the intervention (Albert et al., 2015). While no single intervention implemented alone has been associated with a reduced risk for rehospitalization, Hansen et al. (2011) and Wong et al. (2011) have asserted that bundled interventions are of greater value in transitional care interventions.

6.2.3 Applying evidence-based care

Evidence-based practice is a key to ensuring the best patient outcomes as well as to delivering the highest quality of health care (Melnyk & Fineout-Overholt, 2011) The conceptual underpinnings of the HPHF program in this study were developed from an evidence-based transitional care framework (Naylor et al., 2004; Wong et al., 2011), the Omaha System (Martin, 2005), and PC elements (National Consensus Project for Quality Palliative Care, 2009) to support post-discharged ESHF patients facing a life-threatening illness. Components of the HPHF program included post-discharge follow-up (home visits and telephone follow-ups); a multidisciplinary team approach, with a PC-NCM; symptom assessment, management, and evaluation; end-of-life discussion; case management; and protocol-driven care. These components also contained evidence-based elements derived from research studies and PC and HF management guidelines. For example, Jaarsma, Brons, Luttik, and Stromberg (2013) recently conducted a review to identify the components in HF home care programs.

Among the 70 articles reviewed, which described interventions with two or more components, Jaarsma et al. (2013) found that continuity of care, a multidisciplinary team, education and counseling of patients and family members, increased accessibility to care, and optimized treatment according to guidelines were commonly used to address home care interventions in the HF population, where most (65.9%) studies tested interventions with three or more components. In addition, nurse home visits and nurse case management were identified as the most effective strategies in significantly decreasing the readmission of HF patients discharged from the hospital (Van Spall et al., 2017). Aspects and strategies employed in the HPHF program stayed abreast of new evidence proven to provide the highest quality of care.

6.3 Elements that may have contributed to the study findings

6.3.1 Meeting information and communication needs

As most HF patients are elderly, they might not comprehend information well or have a good memory to retain what their physicians have told them. Some may feel disempowered if they have to ask their physicians questions (Harding et al., 2008). With the HPHF program, the patients received an explanation of their health condition from the PC-NCM and elaboration of the information that the physicians told them. The PC-NCM revisited the course of HF and its prognosis with the patients, the related symptoms and management, and even offered an end-of-life care plan at an appropriate time (Ivany & While, 2013; Ventura et al., 2014).

In addition, patients with end-stage diseases want more information about managing their lives and making decisions, and they are particularly concerned about when they will die (Ventura et al., 2014). Some elderly patients have a misunderstanding of the symptoms of HF and think that their symptoms are due to the natural aging process (Cortis & Williams, 2007; Gott et al., 2008).

Information provision can help patients to better manage their symptoms. Educating and counseling patients on medication and diet adherence can possibly reduce hospital readmission rates, as non-adherence is one of the major causes of hospital readmission among the HF population after discharge (Wal, Jaarsma, & Veldhuisen, 2005).

Heart failure disease progression is an uncomfortable and frightening experience for patients because of the unpredictable nature of the HF trajectory. Some patients with ESHF interpret dyspnea as imminent death (Brännström et al., 2006; Gott et al., 2008). Clarifying those misunderstandings can help patients make appropriate treatment and care decisions and reduce their anxiety of the uncertainty of the future (Gaston & Mitchell, 2005). Communication is enhanced by allowing patients to talk about their illness and concerns with a PC-NCM during the structured follow-up schedule. Patients treasure those who will listen to them and are satisfied with being cared for and the ongoing communication with someone familiar with their condition (Harding et al., 2008; Heyland et al., 2006; Mok & Chiu, 2004). Addressing patients' concerns through information provision and supportive communication is vital.

6.3.2 Meeting physical, psychosocial, and spiritual care needs

The impact of physical, psychosocial, and spiritual problems should be recognized as symptom burden for ESHF patients, which is comparable to that of cancer patients (Janssen et al., 2008). Patients with ESHF typically suffer from a wide range of debilitating physical symptoms, emotional problems, and the loss of independence, disrupting their social roles during the course of HF, all of which diminishes their QOL. Holistic assessment enables PC-NCMs to comprehensively address the needs of ESHF patients (Skilbeck & Payne, 2005). Comprehensiveness is ensured by employing a systematic assessment of the home environment, symptoms, psychological distress, and social support network (Wong et al., 2011; Zimmermann et al., 2014). Before discharge, the PC-NCM can perform an initial assessment of the patient and develop a care plan based on the goals, beliefs, and preferences of the patient. Addressing and resolving the needs (physical, psycho-spiritual, and social) identified through a comprehensive assessment can possibly reduce symptom distress and enhance QOL during the post-discharge support period.

6.3.3 Care coordination and continuity of care

Patients with HF have higher rates of hospitalization than patients with cancer do (Bergethon et al., 2016; Kavalieratos et al., 2017). Given that care fragmentation occurs within the healthcare system (Brumley et al., 2007; Naylor et al., 2011), care coordination and continuity of patient care is essential in PC provision (Lukas et al., 2013; Morrison & Meier, 2004; Thomas. et al., 2011). Intervention programs should commence during the hospitalization phase, such that the inpatient PC assessment and discharge planning have occurred before transitioning home. Other care activities in intervention programs can be delivered in patients' homes, where studies have revealed that home PC seems to increase patients' feelings of security when facing life-limiting illnesses (Brännström et al., 2006; Sarmento, Gysels, Higginson, & Gomes, 2017).

Continuity of care can be achieved by nurses visiting patients in their home environment, which can help them to make individualized care plans to accommodate the patients' way of living (Brännström, Brulin, Norberg, Boman, & Strandberg, 2005). A PC-NCM can coordinate hospital and community services for patients whenever necessary (Salamanca-Balen, Seymour, Caswell, Whynes, & Tod, 2018). The accessibility and availability of nurses to provide support proactively and regularly may have a substantial impact on a patient's need for hospital care and QOL, while lessening symptom burden.

6.3.4 A trusting nurse-patient relationship and multidisciplinary collaboration

A nurse-patient relationship is built beginning with the pre-discharge assessment in the hospital, where trust and the competence of the PC-NCM might help to improve patients' physical and emotional well-being. Additionally, an ongoing, trusting nurse-patient relationship in PC might facilitate patients' adjustment to their illness, ease discomfort, and subsequently lead to a better end-of-life experience (Heyland et al., 2006; Mok & Chiu, 2004). Seriously ill patients value the opportunity to form a therapeutic relationship with a nurse (Boyd et al., 2009; Heyland et al., 2006; Jo, Brazil, Lohfeld, & Willison, 2007; O'Leary et al., 2009). Both patients and their carers desire early support from the PC team (Bekelman et al., 2011; Jo et al., 2007). The involvement of spousal caregivers and other relatives might be important in terms of self-care monitoring and maintenance (Buck et al., 2015).

In the current study, the PC-NCM worked closely with the patients, their family caregivers, and the members of the multidisciplinary team during the 12-week intervention period. The team was able to sustain its relationship with the patients to provide support through regular team meetings (Fendler et al., 2015; Wong et al., 2004). The patients were able to contact someone in the healthcare system that they knew and trusted in times of need (Aldred et al., 2005; Zapart, Kenny, Hall, Servis, & Wiley, 2007). The nurse-patient relationship continued during the post-discharge period, with regular follow-ups by the PC-NCM, who could be reached by telephone. Mutual goals were set between the PC-NCM and the patients to achieve their needs, such as optimal symptom control. The PC-NCM could consult with the palliative physician to seek advice, and a corresponding recommendation for managing patients' symptoms could be implemented promptly. For example, when patients reported an increase in shortness of breath, the PC-NCM played an active role in assessing and monitoring their symptom status and implementing an immediate symptom control strategy by instructing the patient to take an extra dose of diuretic after consulting with the palliative physician.

Nurse volunteers' collaboration facilitated the implementation of the program. The volunteers were an integral part of the PC team in this study. In some countries such as the UK (Burbeck et al., 2014) and the U.S. (Connor, 2008), the role of volunteers in PC provision is substantial; however, the practices varied across countries (Burbeck et al., 2014; Candy et al., 2015). The volunteers in this study formed part of the care team, and they contributed through direct patient support and followed the plan of care set by the PC-NCM. Informational support (e.g., clarifying misunderstandings, if any, or enhancing information given by the PC-NCM) and social and emotional support (e.g., listening to whatever the patient wants to say, being there and talking with the patient) were two major types of support that the volunteers contributed in this study. Providing companionship to PC patients and their family members might help reduce the burden of fear and maintain QOL (Kwekkeboom, Vahl, & Eland, 2005).

Studies have found that both nurses and family members acknowledged the efforts made by PC volunteers throughout the patient care process (Claxton-Oldfield, Hastings, Claxton-Oldfield, 2008; Claxton-Oldfield, Gosselin, Schmidt-Chamberlain, & Claxton-Oldfield, 2010). Similar transitional care programs involving volunteers have proven their effects on supporting the nurse in reducing hospital readmission, with cost-effective outcomes (Wong, Chau, So, Tam, & McGhee, 2012; Wong et al., 2013). A trusting relationship between patients/family members and healthcare providers (Wotton et al., 2005), with multidisciplinary management (Davidson, Newton, Tankumpuan, Paull, & Dennison-Himmelfarb (2015), might have been an influencing factor in the favorable study outcomes.

6.4 The role of the palliative care nurse case manager in sustaining the Home-based Palliative Heart Failure program

The PC-NCM played a pivotal role in this study and might have contributed to its promising results. Nurses who are trained in PC services can help optimize QOL for people with life-threatening or debilitating chronic illnesses (National

Consensus Project for Quality Palliative Care, 2009). In this study, the involvement of a nurse with expertise in PC as a case manager reduced health services use, a result consistent with other observational studies (Back, Li, & Sales, 2005; O'Mahony et al., 2008; Seow et al., 2008; Spettell et al., 2009; van der Plas et al., 2015; Wang, Piet, Kenworthy, & Dy, 2015). The design of the HPHF program was a deliberate effort to follow through on a series of planned actions to ensure continuity of care from hospital to home (Wong et al., 2011). The PC-NCM was the central pillar in embracing the four Cs (comprehensiveness, coordination, continuity, and collaboration) and managing the essence of PC for patient care in the 12-week HPHF program through home visits and telephone follow-ups. Palliative home care is a team effort; as such, the PC-NCM conducted care planning and setting of mutual goal with patients while navigating the collaborative process with the hospitals, community, and palliative team.

Some transitional care programs tend to use advanced practice nurses as case managers (Allen et al., 2009; Naylor et al., 2004; Ornstein, Smith, Foer, Lopez-Cantor, & Soriano, 2011; Wong, Mok et al., 2005). This study chose a group of patients suffering from an end-stage disease, whose care was more complicated, with refractory symptoms and the existence of comorbidities. The PC-NCM, who had rich PC experience, was competent in dealing with complex problems and coordinating the services required by the patients throughout the intervention period (Kavalieratos et al., 2017; Quill & Abernethy, 2013; van der Plas et al., 2013). As psychological and spiritual support has been reported to be an important component for patients at the end stage of life, counseling and case management are the most necessary skills in palliative nursing care (European Association for Palliative Care, 2010; Seow et al., 2008; Skilbeck & Payne, 2003; Wong et al., 2004). Case management, defined by the Case Management Society of America (2016), is a

> collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost effective outcomes. (p. 11)

The central role of a case manager is to serve as a facilitator to coordinate and collaborate care among patients, family members, and the healthcare team with ongoing communication.

Studies have found that registered nurses who received further training can be case managers in PC to address the multidimensional care needs of patients and their family members (van der Plas et al., 2013). Additionally, the competency of PC nurses as case managers has been acknowledged by both GPs and community nurses (Plas et al., 2016). The PC-NCM in this study incorporated the core tasks of case management (Seow et al., 2008; van der Plas et al., 2012). and provided individualized care throughout the course of patient care, including needs assessment, education, counseling, coordination of services, and caregiver support (Spettell et al., 2009; Wang et al., 2015). For instance, having assessed patients' needs, whenever necessary, the PC-NCM referred the patients to a social worker for financial assistance and a day care center to see a physiotherapist for edema management according to the referral protocols.

Case managers are guided by care protocols for comprehensive assessment, symptom management, and clear referral guidelines to manage patients' conditions (Blue et al., 2001; Harrison et al., 2002; Laramee et al., 2003; Naylor et al., 2004; Strachan, Joy, Costigan, & Carter, 2014; Wong et al., 2011). In addition, the highly skilled PC-NCM in the current study was able to empower the patients to deal with common symptoms reported in HF, such as shortness of breath. The proactive and seamless care provided by the PC-NCM, who coordinated the patients' care from the in-hospital phase to the post-discharge phase, was a critical ingredient for success. Using an NCM with expertise in PC to implement the HPHF program helped meet the multidimensional needs of ESHF patients at home, which contributed to the favorable findings in this study.

Randomized control trials on PC interventions for HF patients are scarce, and this study has provided new evidence showing that the HPHF program produced positive clinical and patient outcomes. In this RCT, a comprehensive intervention was directed by the PC-NCM, who had experience in the care of patients with life-limiting illnesses and management of HF and who worked in close collaboration with a multidisciplinary team. Overall, hospital readmissions, AED attendances, and length of hospital stays decreased while QOL, symptom control, and patient satisfaction improved, with significant differences between the intervention group and the control group.

6.5 Challenges in PC research

Difficulties associated with conducting RCTs involving PC have been discussed elsewhere (Bennett, 2007; Evans, Harding, & Higginson, 2013; Grande & Todd, 2000; Jordhøy, Kaasa, Fayers, Underland, & Ahlner-Elmqvist, 1999; Steinhauser et al., 2006). Identifying, recruiting, and retaining end-stage patients in longitudinal PC research is often challenging (Addington-Hall, 2002; Fitzsimons & Strachan, 2012; Jordhøy et al., 1999; Steinhauser et al., 2006). Although the need for patients with HF to receive PC is well recognized, it remains difficult for healthcare professionals to define palliative patients because of their volatile symptoms, as well as to determine an appropriate time to discuss PC and end-of-life issues with HF patients (Coventry et al., 2005; Goodlin, 2009a; Hauptman & Havranek, 2005; Johnson & Gadoud, 2011; Kavalieratos, Mitchell et al., 2014). The use of PC services among patients with HF is low. A U.S. study revealed that only 6% of 2,647 HF patient admissions were referred to PC during their hospitalization (Greener, Quill, Amir, Szydlowski, & Gramling, 2014).

In general, there is a misconception that PC is a service reserved for those patients near death (Bakitas et al., 2013; Johnson et al., 2016; Kavalieratos, Mitchell et al., 2014), and there is a lack of clear referral guidelines (Kavalieratos, Mitchell et al., 2014; O'Leary et al., 2009), which defer timely referral. The low referral rate is also due to disease-specific, specialism-specific, and patient-specific barriers (Ahmed et al., 2004; Beattie, 2014; Chattoo & Atkin, 2009; Fitzsimons & Strachan, 2012; Harding et al., 2008; Kavalieratos, Mitchell et al., 2014; Selman et al., 2007b).

Disease-specific barrier factors, which include difficulty in predicting HF mortality and end-of-life transition (Gott et al., 2011; Hauptman, Swindle, Hussain, Biener, & Burroughs, 2008; Kavalieratos, Mitchell et al., 2014), hinder HF patients being referred to PC, and such difficulty has been described as "prognostic paralysis" by Stewart and McMurray (2002) and Boyd and Murray (2010).

Specialism-specific barriers refer to specialist clinicians, particularly cardiac specialists, who are less interested in discussing palliative and end-of-life care issues with their patients and instead tend to focus on curing the heart problem. These specialist clinicians have been found to have inadequate confidence and skills for such communication, as they fear they may be taking away hope from their patients and feel that they have no time for palliative and end-of-life discussion (Ahmed et al., 2004; Boyd et al., 2004; Dunlay et al., 2015; Fitzsimons et al., 2007; Glogowska et al., 2016; Green et al., 2011; Hanratty et al., 2002; Hauptman et al., 2008; Kavalieratos, Mitchell, et al., 2014; O'Leary & Tiernan, 2008). Another specialism-specific barrier to referring HF patients to PC is the PC team, who may feel overwhelmed by the high demands on their PC services. Other concerns are related to the competency of the PC team in managing the complex treatment of HF conditions (Johnson et al., 2016).

Patients' perception of their HF condition is attributed to patient-specific barriers in agreeing to be referred to PC since they may not accept the idea of being referred to PC or hospice (Johnson et al., 2016). These patients may not fully appreciate that ESHF is a life-threatening condition (Brännström, Hägglund, Fürst,

& Boman, 2012; Fitzsimons & Strachan, 2012; Lowey & Liebel, 2016; Metzger et al., 2013; Rodriguez et al., 2008; Rogers et al., 2000), as prognosis is not routinely discussed with hospitalized patients in acute hospitals, and thus patients can be discharged with the “false hope” of a cure (Gott et al., 2011). This barrier is particularly relevant among the Chinese population because talking about future treatment preferences and death/dying is taboo (Chan & Pang, 2010; Hsu, O’Connor, & Lee, 2009; Xiao, Kwong, Pang, & Mok, 2012).

In Chinese culture, death is regarded as bad luck and a negative life event (Chan & Chow, 2006; Xu, 2007), where death and dying issues are taboo topics that are not appropriate for open discussion (Chan & Chow, 2006; Chan & Pang, 2010). Traditional Chinese view death as a fearful event (Tse, Chong, & Fok, 2003), making the discussion of the topic of end-of-life care challenging (Xu, 2007). Many Chinese people rarely talk about death or make necessary preparations to face or deal with death (Xu, 2007). The Chinese believe in preserving and prolonging life, and they actively seek measures to help sustain or extend life (Tung, 2011). With this dominant view, talking or even mentioning death is avoided because such conversation may put a jinx on one’s fate (Xu, 2007). Since death is a very sensitive issue among the Chinese, the concept of PC and end-of-life care discussion is not common. Knowledge of hospice/PC is not well understood among Chinese people. Such concepts are not taught in the medical profession, and public promotion activities are rare in China (Tung, 2011; Zhang et al., 2015). Studies have shown that Chinese residing in other countries are less likely to receive hospice/PC than Western people. For example, Chinese-Australians are unaware or unfamiliar with PC services (Hsu et al., 2005), and Chinese-Americans seldom use hospice care (Enguidanos, Yonashiro-Cho, & Cote, 2013).

In Chinese culture, family members play a central role in healthcare decision-making for seriously ill family members (Hsu et al., 2009; Tse et al., 2003; Tung, 2011; Xu, 2007). The family is the gatekeeper for critical issues, such as disease prognosis, and they object to telling the truth to the patient and doctors often follow the wishes of the family (Tse et al., 2003). Additionally, in China, the current practice of breaking bad news involves disclosing information to the family members first, who take the responsibility to decide whether or not the patient be informed that information (Wuensch et al., 2013). Chinese family members also request that healthcare professionals withhold unfavorable medical information from patients to prevent patients from the psychological burden of facing death (Tung, 2011). It is common practice, regarding treatment and health care, to have the physician consult with family members first before directly talking to the patients themselves.

In the previous sections, the possible reasons for the effectiveness of the HPHF program were discussed. The elements that contributed to the study findings were also explored. Importantly, the nurse’s role in this study was highlighted, and common challenges in PC research were elucidated. The following sections will discuss the limitations and implications of the study based on the findings.

6.6 Limitations

This study has a number of limitations. First, the sample size of this study was small. A total of 389 patients were screened, but only 84 (21.6%) were enrolled and randomized, reflecting that a group of potentially eligible patients did not participate in this study. Reasons for patient exclusion included living in an elderly care home, did not accept the PC approach, cognitively impaired or too weak to communicate, did not reside in the designated service area, in the terminal stage, recruited in other hospital programs, unable to speak Cantonese, declined to participate in the study, died before the research team's assessment, and diagnosed with a psychiatric problem. The patients not included in this study may also have had different supportive and PC needs from healthcare professionals, which was unable to be determined in this study, making the effects of the HPHF program on these individuals uncertain. Second, this study was conducted in Hong Kong, whose healthcare system may be different from those in other places. This may have limited the generalization of the results to places other than Hong Kong.

Third, this study was a single-blinded study, in which the participants and the interventionists were not blinded. In conducting an RCT, blinding is difficult or in some circumstances is inappropriate because the participants should be informed of what they will receive or what they need to comply with during the study period. Fourth, self-reporting questionnaires such as QOL measures were used in this study, and whether the information reported by the participants truly reflected the actual situation was difficult to confirm. Lastly, a 12-week period may be a relatively short duration for follow-ups, so the sustained effects of the completion of the HPHF program on the outcomes could not be confirmed. In addition, this thesis examined the outcomes of post-discharge support and the process involved in the support including enhancing coping, adjustment and making appropriate decisions were not examined qualitatively in this study.

6.7 Implications for practice and research

6.7.1 Replication of the conceptual framework

A few implications for both practice and research arose from this study. The conceptual framework constructed to guide the HPHF intervention in this study was based on earlier evidence, namely, the four-Cs transitional care model, the Omaha System, and key PC elements, which depicted a useful guide to plan services. The findings showed that this model reduced hospital readmissions, AED attendances, and length of hospital stays, and improved QOL, symptom control, and satisfaction with care. To date, the integration of PC into HF transitional care remains in its infancy, and the rationale of research and clinical implementation in this area has largely been borrowed from the work in previous studies on cancer or chronic illnesses (Bakitas et al., 2013; Fallon & Foley, 2012; Kavalieratos et al., 2017). The conceptual framework built in this study can be replicated for other non-cancer PC research.

6.7.2 Integrating palliative care into heart failure transitional care

The introduction of PC to HF management should be based on the needs of patients and carers in all care settings rather than based on diagnosis or prognosis (Boyd & Murray, 2010; Jaarsma et al., 2009; Johnson et al., 2016; Kavalieratos, Mitchell et al., 2014). In practice, identifying the time to integrate PC into HF management remains unclear (Fallon & Foley, 2012; Gott et al., 2011; Johnson & Gadoud, 2011; Oishi & Murtagh, 2014). Researchers have regarded such timing of transition to PC as the “transition trigger,” which is also a reasonable moment to refer HF patients to PC (Johnson & Gadoud, 2011; Kavalieratos, Mitchell et al., 2014; Low et al., 2011; O’Leary, 2009). Recognizing the time to ensure a proper transition to a palliative care approach for patients is a policy initiative in the UK and such work is in progress (Department of Health, 2014). In this study, referral guidelines were established to identify which group of HF patients was appropriate to be referred to PC, and the referral guidelines were composed by the cardiologist and the PC specialist (Ahmed et al., 2004; Fallon & Foley, 2012; Glogowska et al., 2016; Kavalieratos, Mitchell et al., 2014). In particular, Kavalieratos et al. (2017) and Widera and Pantilat (2009) have asserted that hospitalization and discharge can be an opportunity to introduce PC to HF patients, as mortality risk increases with an additional hospital admission, and this strategy was adopted in the current study. Through discharge planning and assessment, the goals of care and a treatment plan can be discussed (Kavalieratos et al., 2017).

6.7.3 Needs assessment

It is estimated that 40 million people worldwide require PC either at the end of life or earlier in the disease trajectory (Salamanca-Balen et al., 2018). Given that the reported uncertainties in identifying people needing the palliative approach of care, using clinical indicators or tools can offer guidance on recognizing PC and end-of-life transitions (Boyd & Murray, 2010; Jaarsma et al., 2009; Low et al., 2011). For example, in Scotland, a Supportive and Palliative Care Indicators Tool (SPICT) was used to identify patients at risk of deteriorating who might need earlier, holistic PC assessment (Highet, Crawford, Murray, & Boyd, 2014). In Australia, a Needs Assessment Tool: Progressive Disease—Heart Failure was developed to enable health professionals to identify patients who could benefit from PC (Waller et al., 2013). Another means to identify HF patients who might need PC is to create a central patient registry for HF patients; for example, Sweden maintains a databank of clinical information such as episodes of hospital admission, which allows for the checking of information regularly (Brännström et al., 2012). Regular needs assessment is important to ensure that HF patients' and/or families' perceptions of illness and goals of care are being evaluated. It is hoped that more people can gain access to and benefit from PC services at all stages of illness when they are needed.

6.7.4 Mutual support between cardiology and palliative care

There are concerns that PC physicians may not have the necessary knowledge to manage HF patients who have complicated health problems, and PC physicians are uncertain whether cardiologists have the communication skills to discuss with the patients their prognosis and end-of-life issues (Berry, 2010; Kavalieratos, Mitchell et al., 2014). Mutual support between cardiology and PC physicians and nurses is needed (Chattoo & Atkin, 2009; Gadoud et al., 2013; Harding et al., 2008; Jaarsma et al., 2009; Johnson et al., 2016; Low et al., 2011). This could be done by conducting joint education and training for HF and PC professionals working with patients with ESHF, particularly updated evidence-based HF management and communication skills. Setting up a Cardiac-PC collaborative service, such as in-patient ward rounds or out-patient consultation services, might be another strategy to foster better interfacing of palliative and HF care.

6.7.5 Research direction in the future

While the specialty level of care versus general and fundamental PC is still evolving, the specialty of PC is relatively new and a shortage in the PC workforce has been reported (Lupu, Salsberg, Quigley, & Wu, 2017). The combined specialty of PC and HF management is even more rare (Green et al., 2011; Pere, 2012). Much research is needed to evaluate new service development and to explicate the role of PC in HF management (Bekelman et al., 2008; Jaarsma et al., 2009; Low et al., 2011). The specialist PC providers who were engaged in this study demonstrated that the PC services provided to the HF patients were feasible and effective. Given the limited number of RCTs available for non-cancer PC, more research studies are needed to confirm the effectiveness of PC services in other specialties, such as renal care and dementia.

This study proved that using a designated healthcare provider as a case manager enabled better care coordination, which is essential in helping to reduce care fragmentation for patients with ESHF (Jaarsma et al., 2009; Low et al., 2011; Morrison & Meier, 2004; Naylor et al., 2004). Caring for patients with life-threatening illnesses requires clinical knowledge and skills to deliver direct patient care, problem-solving skills to deal with complex treatment modalities, and the ability of inter-professional collaboration. The discussion of the nurses' role in the coordination of care and transition management in the PC context is now underway among a group of nursing leaders from national specialty organizations in the U.S. (Mazanec et al., 2018). Nurses who possess the capacities mentioned have played a prominent role and are most appropriate in supporting patients with PC needs (Oishi & Murtagh, 2014; Salamanca-Balen et al., 2018).

Daily symptom burden in patients with ESHF exists. Symptoms such as shortness of breath remain prominent and difficult to manage. Several strategies (e.g., exercise and an extra dose of diuretics) for controlling shortness of breath have been found to be useful if an individualized care plan can be moderated in a timely manner. Further research examining which symptom management strategy is more effective in palliating the symptom is needed (Gadoud et al., 2013; Goodlin, 2009b; Janssen et al., 2008; LeMond & Allen, 2011).

Heart failure has been listed by the UK government as one of the disease groups that warrants PC services since 1996 (Field & Addington-Hall, 1999) and has been put on the research agenda in a Consensus Statement (Goodlin et al., 2004), but slow progress has been observed (Fitzsimons & Strachan, 2012; Stuart, 2007; Xie, Gelfman, Horton, & Goldstein, 2017). Similarly, in Hong Kong, PC has been expanded to non-cancer patients in recent years (Hospital Authority, 2017), and the latest Hong Kong Policy Address has announced that more PC and end-of-life services will be rolled out to those who need it within hospital settings and in the community (The Hong Kong Special Administrative Region of the People's Republic of China, 2017).

This study has responded to both the local and the international call for providing PC to HF patients and designing an innovative care model, which was a home-based, PC-oriented HF program, extended from hospital to home, in this study. Such a care model can be translated as a routine clinical practice for all severe, chronically ill patients requiring PC support. Since a reduction in health services use and cost-effectiveness were among the benefits in the HPHF program (Wong et al., 2017), this study might give insights to the government to consider aligning financial incentives across all healthcare settings, including home-based PC and community palliative and end-of-life care for nursing home residents, which would facilitate the coordination of services and continuity of care for HF patients (Mazanec et al., 2018; Meier, 2011; Stuart, 2007).

CHAPTER SEVEN

Conclusion

This final chapter of the thesis consists of two highlighted areas. The first section will depict the key findings of the study that are worth noting, and the second section will provide a personal reflection of the PhD study, as well as the challenges in conducting research in the area of palliative care.

7 Study summary

Heart failure is a life-threatening illness that imposes enormous burden on patients, their family members, and society. The last stage of an individual’s life is often characterized by frequent hospital admissions, and that is no exception for the ESHF group, who often suffer from other comorbidities in association with the primary problems of ESHF. Patients with ESHF experience fragmented care delivery characterized by high rates of preventable hospitalizations. The transitions across care settings are burdensome to patients as well as to the healthcare system. Planning and designing effective interventions to improve both patients' QOL and the quality of the healthcare delivery system and containment of healthcare costs are major concerns for practitioners, researchers, and policymakers.

The aim of this study was to test the effectiveness of a home-based palliative care intervention on patient and clinical outcomes of patients with ESHF employing an RCT design. Palliative care intervention is commonly applied to cancer patients; however, this study was one of the few RCTs to evaluate the effectiveness of a home-based PC program for ESHF patients. The results of this study have provided valuable evidence on the effects of the HPHF program for patients suffering from ESHF after an episode of hospitalization. The HPHF program significantly reduced healthcare services utilization, improved QOL, improved symptom control, and resulted in higher patient satisfaction. The study findings suggest that the HPHF program successfully promoted a safe hospital-to-home transition for ESHF patients and addressed their physical, psychological, social, and spiritual needs through nurse-directed post-discharge home visits and telephone follow-ups.

Research reports have emphasized that integrating PC into HF care is essential, and better coordination of care is needed to address the multidimensional needs of patients with ESHF. However, contemporary HF care mainly focuses on medical problems (i.e., treating the disease) and tends to be less focused on the psycho-social-spiritual aspects of patients. The HPHF program was developed based on the four-Cs transitional care framework (comprehensiveness, coordination, collaboration, continuity of care), the Omaha System, and key PC elements, which are based on the best available current evidence. The palliative care approach to ESHF management takes into account patients' values and preferences regarding their plan of treatment and care. In this study, patients with ESHF benefited from the expertise and experience of the nurses, who were supported by a PC physician and a multidisciplinary team. An individualized care plan based on mutual goal setting between the patient and nurse was needed to accommodate patients' unique illness trajectory through a case management approach. In addition, the structured HPHF program was delivered in a timely and proactive manner and supported ESHF patients when they faced fluctuating conditions after discharge from the hospital. This study has demonstrated that trained PC home care nurses, guided by protocols, can effectively address the multifaceted needs of palliative care patients with ESHF.

Favorable findings from this study have shown that the HPHF program is suitable for implementation among patients with ESHF and is feasible for application in home settings in Hong Kong. Since PC for non-cancer patients is still a new concept in Hong Kong, this study's findings can provide guidance in developing interventions for other populations with serious illnesses. Currently, clinicians are doubtful when to refer and how to support ESHF patients through palliative care. It is hoped that this study will contribute to clinical practice in terms of using a standard PC referral guideline to identify ESHF patients who will benefit from receiving palliative care and provide a structured service model for them.

The conceptual framework illustrated the effects of the HPHF program intervention on both healthcare services and patient-reported outcomes through empirical testing. Further research should be conducted to test the intervention's effectiveness on a broader heart disease population. Moreover, the framework should undergo further modification to test its effectiveness on patients with other serious illnesses.

7.1 Reflections on the PhD study and conducting research in the palliative care area.

The experiences I have had during my PhD study contributed to an exciting journey; although it was difficult, the journey gave me the opportunity to engage in intellectual enrichment and personal growth. During my PhD study, I developed and learned not only specialized knowledge in a particular topic but also wider skills such as critical thinking to understand and discern knowledge, project management, communication, and interpersonal skills.

I believe that having carried out an original research is only a part of a broader training in my life course, and there will be other journeys to embark on, such as a career in teaching and research.

Conducting a clinical trial is a complex task and conducting a clinical trial on PC is even more challenging. In carrying out the PC trial, I faced many uncertainties, for example, whether a subject could be recruited successfully, and barriers in the real world were much greater than I assumed. Palliative care is concerned with a group of “sick” patients who will get sicker due to the inherent nature of their diseases. The possibility of not completing the study is one of the challenges in PC research, as well as inviting a group of patients to participate in the research (Bennett, 2007). As palliative care patients experience symptoms such as fatigue alongside their diseases, it has been argued whether it is ethically sound to ask these patients to participate in research, mainly because it might deprive them of time and energy that they would have wanted to spend on other business (Addington-Hall, 2002). Being interviewed or completing a questionnaire might be a burden to palliative care patients. Palliative care research is perceived as a sensitive research area because death, dying, and bereavement issues are discussed with patients who might not want to express their emotions (Sheldon & Sargeant, 2007). Palliative care might be regarded as being filled with emotion-laden words that might initiate fear for some patients, particularly those who may not have accepted their prognosis (Addington-Hall, 2002). Addington-Hall (2002) has asserted that researchers require great sensitivity; that is, they must be aware of the expressions of patients' emotions and have the skills to minimize the burden on palliative care patients when conducting PC research.

This study was the first RCT in Hong Kong to test a PC-related program among non-cancer patients. The entire research process, from the conceptualization phase to the dissemination phase, was challenging, but not impossible. Although extensive evidence has suggested that PC can be incorporated in parallel with a curative/disease-focused treatment at all stages of the care continuum, the PC approach remains widely misunderstood among patients, their family members, and healthcare profession alike, who perceive PC as a care approach serving only patients with cancer or patients who are dying. Given that contemporary care overemphasizes medical intervention and is less likely to focus on psychosocial and supportive care, introducing medical care with emotional, social, and spiritual dimensions is of paramount importance throughout the process of patient care.

Appendix 4.1 Standard Referral Form for Palliative Care

HOSPITAL AUTHORITY

Standard Referral Form for Palliative Care

(Please read the 'points to note' overleaf before completing this form.)

To:______________________Hosp/Inst

1.1 Referral for
☐ Palliative In-patient Care
☐ Palliative Home Care (Please specify the expected date of discharge________________)
☐ Palliative Out-patient Care
☐ Palliative Day Care
☐ Palliative Consultative Service

1.2 Where is the patient at present?
Home_____________ Hospital (Please specify)______________ Others (Please specify)______________

2.1 Diagnosis:
For Cancer: Primary:________________________ Site of Metastasis:_____________________________
For Non-Cancer: (Please specify)____
Diagnosis known to patient: ☐Y ☐N Diagnosis known to family: ☐Y ☐N
Patient's consent for referral (Verbal): ☐Y ☐N
Agreed on DNACPR order/AD: ☐Y ☐N ☐ Not discussed
Any Infectious Disease: ☐Y ☐N
If yes, please specify:____

2.2 Medical History (Please provide key information)
____
____
____

3.1 Present Condition: (Please delete as appropriate)
Mental State: Alert / Drowsy / Unconscious / Orientated / Disorientated
Mobility: Independently mobile / Mobile with aid / Chairbound / Bedbound
Feeding: Independent / Dependent / Tube-feeding
Other Relevant Points ____
____

3.2 Present Medication & Dosage (Refer to CMS, please write down any drugs not documented in CMS) _____
____
____

4.1 Reason(s) for Referral
☐ Pain and Symptoms Control ☐ Psychosocial/spiritual Care ☐ Care for the Imminently Dying
Others ____

4.2 Will the referring unit continue to follow up the case ☐Y ☐N
If the answer is yes, please provide the date of next follow up________________________(Date/Month/Year)

4.3 Please enclose **Pathology report/medical report/discharge summary/other confirming evidence** (Only if data cannot be retrieved from CMS).

5.0 Remarks ____

6.0 Referring Doctor: ________________________(Block Letter) ___________________________(Signature)
Hospital/Unit: _____________Tel & Fax No. of Referring Doctor: _____________(Tel) _____________(Fax)
Date:____________________

For Palliative Care Unit:
7.1 Date of referral received: _________________________Date of assessment: _______________________
7.2 Remarks:_____________________________________ Sign: ___________________________________

Appendix 4.2a Protocol for Management of Home Environmental Problem

Domain: Environmental Problem: Residence	
Teaching, Guidance and Counseling	● Educate on the importance of home safety and safety precaution ● Remind patients to be aware of steep/unsafe step/ramp ● Ensure clear exits at patient's home ● Advise on needed repairs ● Advise to modify home environment if needed ● Educate on crisis intervention ● Educate on community resources
Treatment & Procedure	● Other
Case Management	● Advice on bathroom safety devices ● Consider to make referral if necessary
Surveillance	● Monitor state of repair if any ● Ensure adequacy of space ● Assess home safety ● Check location/use of hazards

Appendix 4.2b Protocol for Management of Pain

Domain: Physiological Problem: Pain	
Teaching, Guidance and Counseling	● Explain the concept of pain and pain management ● Educate on the action, side effects, purposes and benefits of analgesic being prescribed ● Explain the importance of medication adherence on pain management ● Explore and discuss end-of-life care plans/decision, recognition/acceptance ● Provide dietary advice on high protein diet and fluid balance ● Teach positioning to maintain comfortable ● Provide guidance on relaxation/breathing techniques, guided imagery and/or distraction ● Provide guidance on signs and symptoms worsening and report in a timely manner
Treatment & Procedure	● Other
Case Management	● Consider need to make referral/inform physician if necessary
Surveillance	● Assess patient’s knowledge of pharmacologic and non-pharmacologic measures on pain management ● Assess bio-psycho-spiritual factors that may influence pain perception ● Assess location, frequency, duration and severity of pain ● Assess what precipitates or relieves the pain ● Ensure patient medication compliance, i.e, correct dosage and frequency ● Ensure patient follows plan of care; receives care when scheduled ● Check and record evidence of other signs/symptoms, vital signs : blood pressure, heart rate, saturation, body temperature, intake and output

Appendix 4.2c Protocol for Management of Fatigue

Domain: Health –Related Behaviors Problem: Physical Activity	
Teaching, Guidance and Counseling	● Explain disease process and how it affects fatigue ● Educate on the importance of behavior modification ● Counsel patient make choices to promote well being ● Provide guidance on pacing activities and balance rest/activity ● Counsel patient on relaxation and breathing technique ● Educate on sign and symptom monitoring, report in timely manner
Treatment & Procedure	● Other
Case Management	● Consider need to communicate with physicians/ make referral
Surveillance	● Assess patient’s knowledge of their disease process and the impact on fatigue ● Review pattern of activity ● Ensure patient maintain appropriate physical activity ● Monitor on coping mechanisms and behavioral change ● Check and record evidence of other signs/symptoms, vital signs : blood pressure, heart rate, saturation, body temperature, intake and output

Appendix 4.2d Protocol for Management Nutrition and Elimination Problem

Domain: Physiological Problem: Digestion-hydration; Bowel Function and Urinary Function	
Teaching, Guidance and Counseling	● Explain digestive/bowel/urinary system function, symptoms and treatment options ● Educate on signs and symptoms monitoring ● Counsel patient on disease process and body image change ● Explore and discuss end-of-life care plans/decisions, recognition/acceptance ● Provide guidance on coping skills ● Provide dietary advice and fluid balance ● Teach measures on prevent/relieve constipation/ bladder care ● Counsel on medication action/side effects; purpose/benefits, importance of adherence ● Provide guidance on signs and symptoms worsening and report in a timely manner
Treatment & Procedure	● Perform per-rectal examination in necessary ● Other
Case **Managemen**	● Consider to make referral/inform physician if necessary
Surveillance	● Assess patient's knowledge of their disease, symptoms and treatment options *Digestion-hydration* -Assess severity of nausea/vomiting; appetite; ascites; dry mouth, skin turgor -Assess sign of dehydration *Bowel function* -Assess frequency/consistency of stool, abnormal color, incontinent of stool -Assess side effects of medication *Urinary function* -Assess pattern of urination, abnormal amount/color, pain, incontinent of urine ● Check evidence of disease/other signs/symptoms of deterioration ● Ensure if patient follows recommended diet ● Check medication prescribed and patient's adherence ● Ensure patient follows plan of care; receives care when scheduled ● Check vital signs: blood pressure, heart rate, saturation, body temperature

Appendix 4.2e Protocol for Management of Breathlessness and Oedema

Domain: Physiological Problem: Respiratory and Circulatory	
Teaching, Guidance and Counseling	● Explain disease, its causes, treatment options and symptoms ● Educate on symptoms monitoring and report in timely manner ● Deal with disease process and adjustment; fear/anxiety/helplessness, body image change ● Explore and discuss end-of-life care plans/decisions, recognition/acceptance ● Provide dietary advice on low salt diet, small and frequent feed, fluid balance ● Provide guidance on balanced rest/activity; pacing activities; energy conservation; safe transfer technique and/or positioning ● Teach relaxation technique: breathing technique; progressive muscle relaxation; massage; guided imagery and/or listen to music ● Check the appropriate use of support hose; and/or oxygen therapy if any ● Counsel on medication action/side effects; purpose/benefits ● Explain laboratory finding if any
Treatment & Procedure	● Consider need for administering oxygen ● Consider need for other investigation in consultation with physician
Case Management	● Ensure continuity of care ● Coordination among providers ● Consider to make referral/inform physician if necessary

Appendix 4.2e Protocol for Management of Breathlessness and Oedema (continue)

Surveillance	Breathlessness -Assess at rest, on exertion, overnight or more than usual; -Assess pillows required when sleeping -Identify what precipitates or relieves it
	Oedema -Assess site of oedema and severity: ankles, feet, knees, thighs, face etc -Assess for ascites present -Identify early the factors affecting worsening of oedema
	● Assess patient’s knowledge of their disease, treatment options and symptoms ● Check evidence of disease/other signs/symptoms of deterioration ● Monitor if patient follows recommended diet ● Check medication prescribed ● Ensure patient follows plan of care; receives care when scheduled ● Check latest laboratory finding ● Check vital signs: blood pressure, heart rate, saturation, body temperature

Appendix 4.2f Protocol for Management of Grief and Mental Health (Sadness, Hopelessness, Fear; Stress, Anger …etc)

Domain: Psychosocial Problem: Grief and Mental Health	
Teaching, Guidance and Counseling	● Explain normal grief process/the impact of emotional symptoms due to the disease ● Educate on emotional symptoms monitoring and report in timely manner ● Teach strategies on managing grief response/anger/ stress/ sadness/ hopelessness…etc ● Provide counseling on adjustment to illness and other coping skills: life review/share feeling/leisure activities ● Provide guidance to discuss end-of-life care plans/decisions, recognition/acceptance ● Facilitate communication with family members on own values, preferences, goals ● Provide dietary advice on basic nutrition, eating pattern ● Provide guidance on balanced rest/activity; pacing activities; ● Teach relaxation technique: breathing technique; progressive muscle relaxation; massage; guided imagery and/or listen to music ● Teach strategies on rest/sleep pattern, guide to planned rest, conductive environment and day/night schedule ● Listen actively, provide emotional support and resources for support system ● Provide guidance on signs and symptoms worsening and report in a timely manner
Treatment & Procedure	● Provide counseling care ● Other
Case Management	● Coordination among providers ● Consider to make referral/inform physician if necessary

Appendix 4.2f Protocol for Management of Grief and Mental Health (continue)

Surveillance	Grief -Assess the ability to recognize the grief stages -Assess grief response
	Mental health -Assess emotional status -Aware of death anxiety on both patient and family members -Assess any behavior change
	● Assess patient’s knowledge of the grief response/management on emotional symptoms ● Assess suicidal tendency ● Check for concerns related to death/dying/ expected stages of grief ● Ensure appropriate coping skills, adequate interaction with family members ● Monitor if patient follows recommended diet, sleep pattern ● Ensure patient follows plan of care; receives care when scheduled ● Check vital signs: blood pressure, heart rate, saturation, body temperature

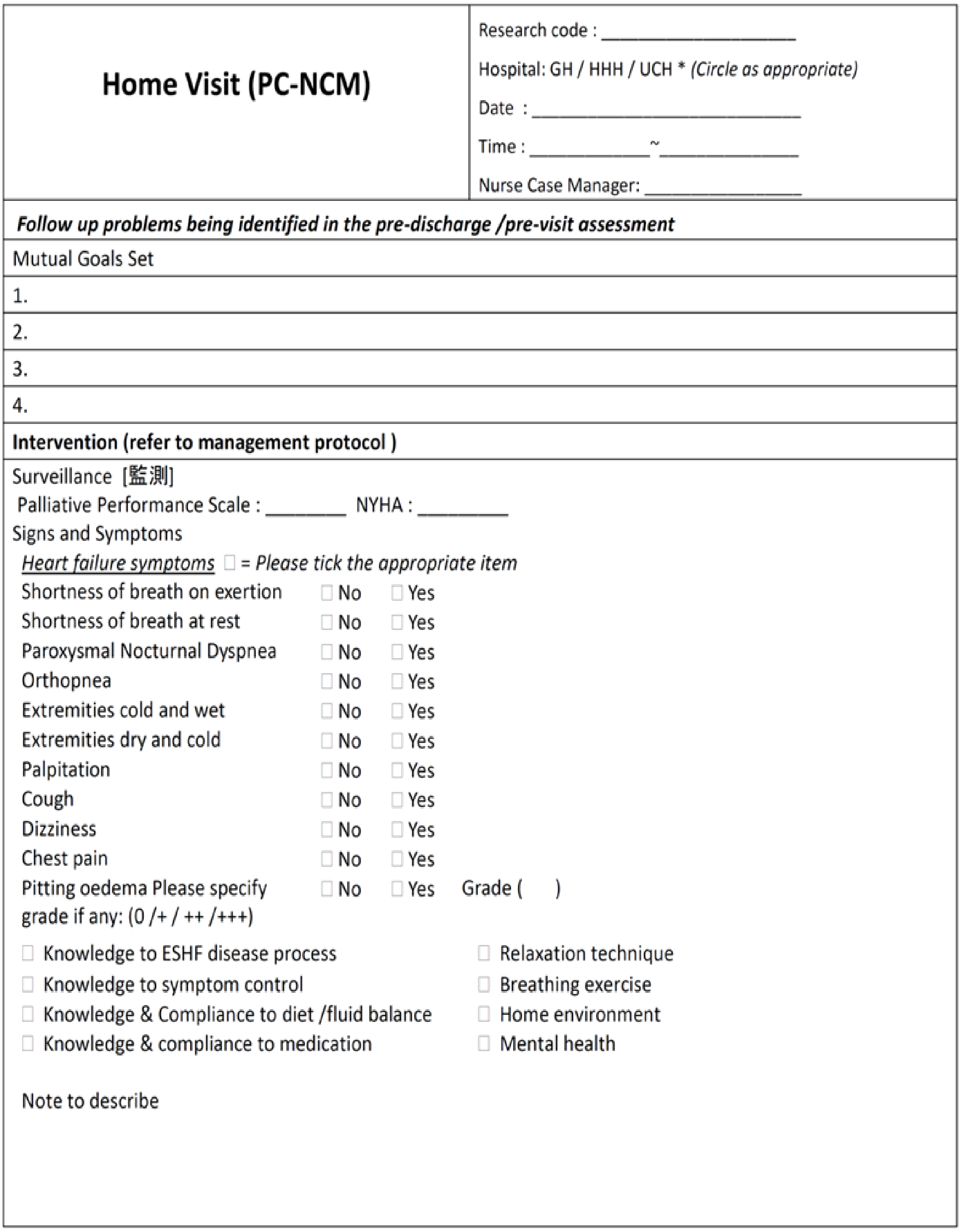
Appendix 4.2g Protocol for Management of Spiritual Issues

Domain: Psychosocial Problem: Spirituality	
Teaching, Guidance and Counseling	● Create a supportive environment for the client and family member thus encourage the expression of their concerns on religious beliefs ● Respect the client’s and family member’s religious belief which may have substantial influence on their demands of spiritual support ● Facilitate client to identify his/her perception of life after death, suffering and loss, so as to allay his/her fear and anxiety ● Allow expression of existential/faith preference ● Provide guidance to discuss end-of-life care plans/decisions, recognition/acceptance ● Facilitate communication with family members on own values, preferences, goals ● Listen actively, provide specific spiritual support, e.g. reconciliation with self and God, accomplishment of realistic goals ● Guiding patient on life review in searching for meaning of life according to his/her own culture and belief ● Facilitate and mobilize patient’s hope for the remaining times ● Encourage clients and family member to maximize their coping mechanism from the spiritual perspectives
Treatment & Procedure	● Other
Case Management	● Consider to make referral/inform physician if necessary
Surveillance	● Assess patient’s knowledge of spiritual care ● Check for patient’s spiritual concerns, existential distress ● Ensure appropriate coping skills ● Ensure adequate connections with family members and support system

Appendix 4.2h Protocol for Management of Medication Non-compliance

Domain: Health –Related Behaviors Problem: Medication Regimen	
Teaching, Guidance and Counseling	● Explain disease process and how medications affect symptoms ● Educate medication action, side effects, purposes/benefits, importance to take as prescribed ● Educate the patient not to self-medication without seeking advice from the physician ● Teach to prepare medication organizer ● Teach on safety storage of medications ● Provide guidance on signs and symptoms worsening and report in a timely manner
Treatment & Procedure	● Prepare medication organizer ● Assist in medication set-up into the medication organizer
Case Management	● Consider need to make referral/inform physician if necessary
Surveillance	● Assess patient's knowledge of their disease and medication treatment ● Ensure patient adheres to prescription instruction, i.e. correct medication and dosage etc ● Assess medication action and side effect ● Monitor physical and mental signs and symptoms ● Monitor on coping mechanisms and behavioral change ● Ensure patient has adequate supply of medication ● Ensure safety storage of medication ● Check and record evidence of other signs/symptoms, vital signs : blood pressure, heart rate, saturation, body temperature, intake and output

Appendix 4.3 Protocol for Home Visit (PC-NCM)



Home Visit (PC-NCM)	Research code : ____________________ Hospital: GH / HHH / UCH * *(Circle as appropriate)* Date : ____________________________ Time : ____________~______________ Nurse Case Manager: ________________

Follow up problems being identified in the pre-discharge /pre-visit assessment

Mutual Goals Set

1.

2.

3.

4.

Intervention (refer to management protocol)

Surveillance [監測]

Palliative Performance Scale : ________ NYHA : _________

Signs and Symptoms

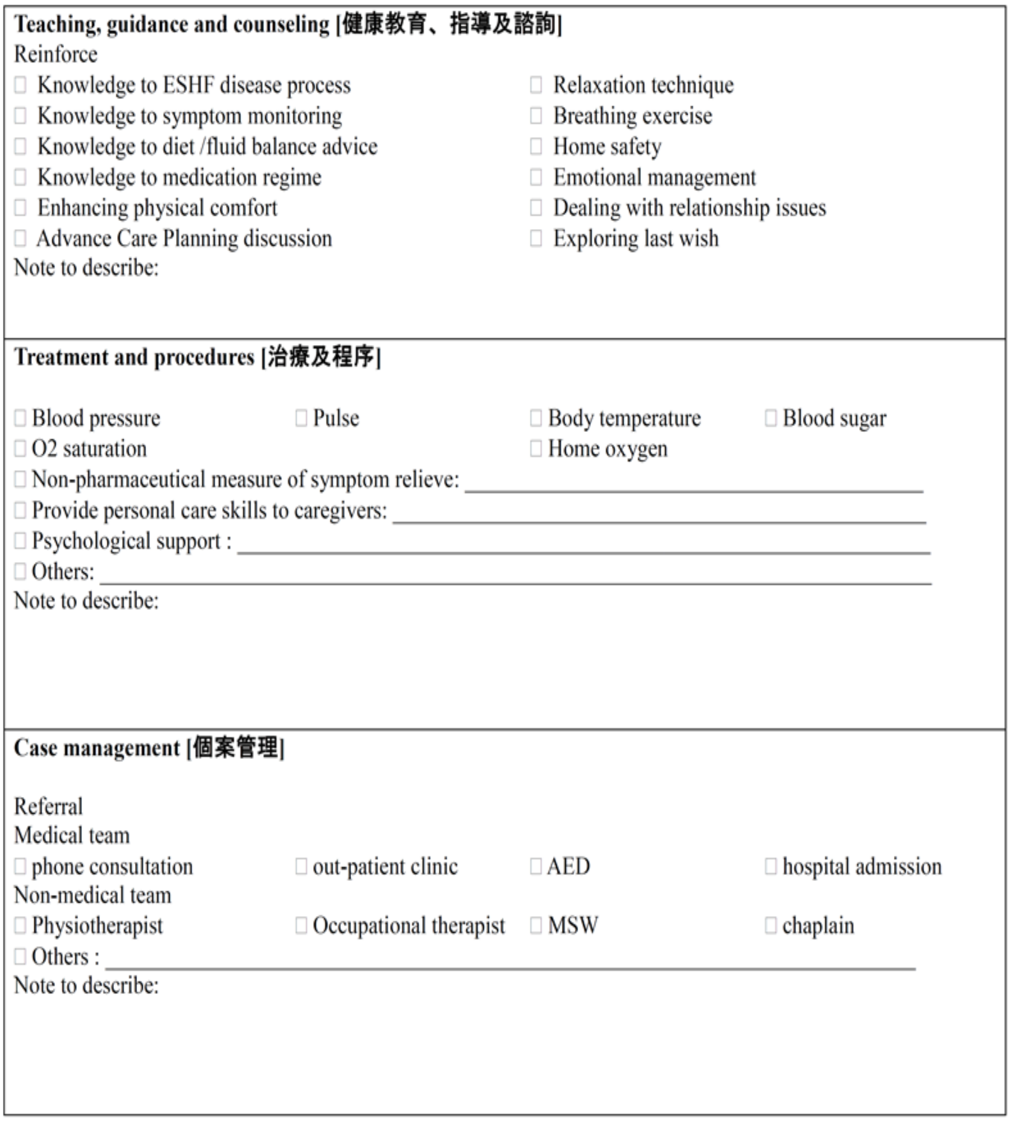
Heart failure symptoms ☐ = *Please tick the appropriate item*

Shortness of breath on exertion	☐ No	☐ Yes	
Shortness of breath at rest	☐ No	☐ Yes	
Paroxysmal Nocturnal Dyspnea	☐ No	☐ Yes	
Orthopnea	☐ No	☐ Yes	
Extremities cold and wet	☐ No	☐ Yes	
Extremities dry and cold	☐ No	☐ Yes	
Palpitation	☐ No	☐ Yes	
Cough	☐ No	☐ Yes	
Dizziness	☐ No	☐ Yes	
Chest pain	☐ No	☐ Yes	
Pitting oedema Please specify grade if any: (0 /+ / ++ /+++)	☐ No	☐ Yes	Grade ( )

- ☐ Knowledge to ESHF disease process
- ☐ Knowledge to symptom control
- ☐ Knowledge & Compliance to diet /fluid balance
- ☐ Knowledge & compliance to medication
- ☐ Relaxation technique
- ☐ Breathing exercise
- ☐ Home environment
- ☐ Mental health

Note to describe

Appendix 4.3 Protocol for Home Visit (PC-NCM)



Teaching, guidance and counseling [健康教育、指導及諮詢]

Reinforce

☐ Knowledge to ESHF disease process
☐ Knowledge to symptom monitoring
☐ Knowledge to diet /fluid balance advice
☐ Knowledge to medication regime
☐ Enhancing physical comfort
☐ Advance Care Planning discussion
☐ Relaxation technique
☐ Breathing exercise
☐ Home safety
☐ Emotional management
☐ Dealing with relationship issues
☐ Exploring last wish

Note to describe:

Treatment and procedures [治療及程序]

☐ Blood pressure ☐ Pulse ☐ Body temperature ☐ Blood sugar
☐ O2 saturation ☐ Home oxygen
☐ Non-pharmaceutical measure of symptom relieve: ______________________________
☐ Provide personal care skills to caregivers: ______________________________
☐ Psychological support : ______________________________
☐ Others: ______________________________

Note to describe:

Case management [個案管理]

Referral

Medical team

☐ phone consultation ☐ out-patient clinic ☐ AED ☐ hospital admission

Non-medical team

☐ Physiotherapist ☐ Occupational therapist ☐ MSW ☐ chaplain

☐ Others : ______________________________

Note to describe:

Appendix 4.3 Protocol for Home Visit (PC-NCM)

〔 〕Home Visit
PC-Nurse Case Manager
(Second month and after)

Research code : ____________________
Hospital: GH / HHH / UCH * *(Circle as appropriate)*
Date : ____________________________
Time : ____________~______________
Nurse Case Manager: ________________

Follow up problems being identified in previous follow up

Mutual Goals Set

1.
2.
3.
4.
5.

Intervention **(refer to management protocol)**

☐ **Surveillance [監測]** (client specific information)

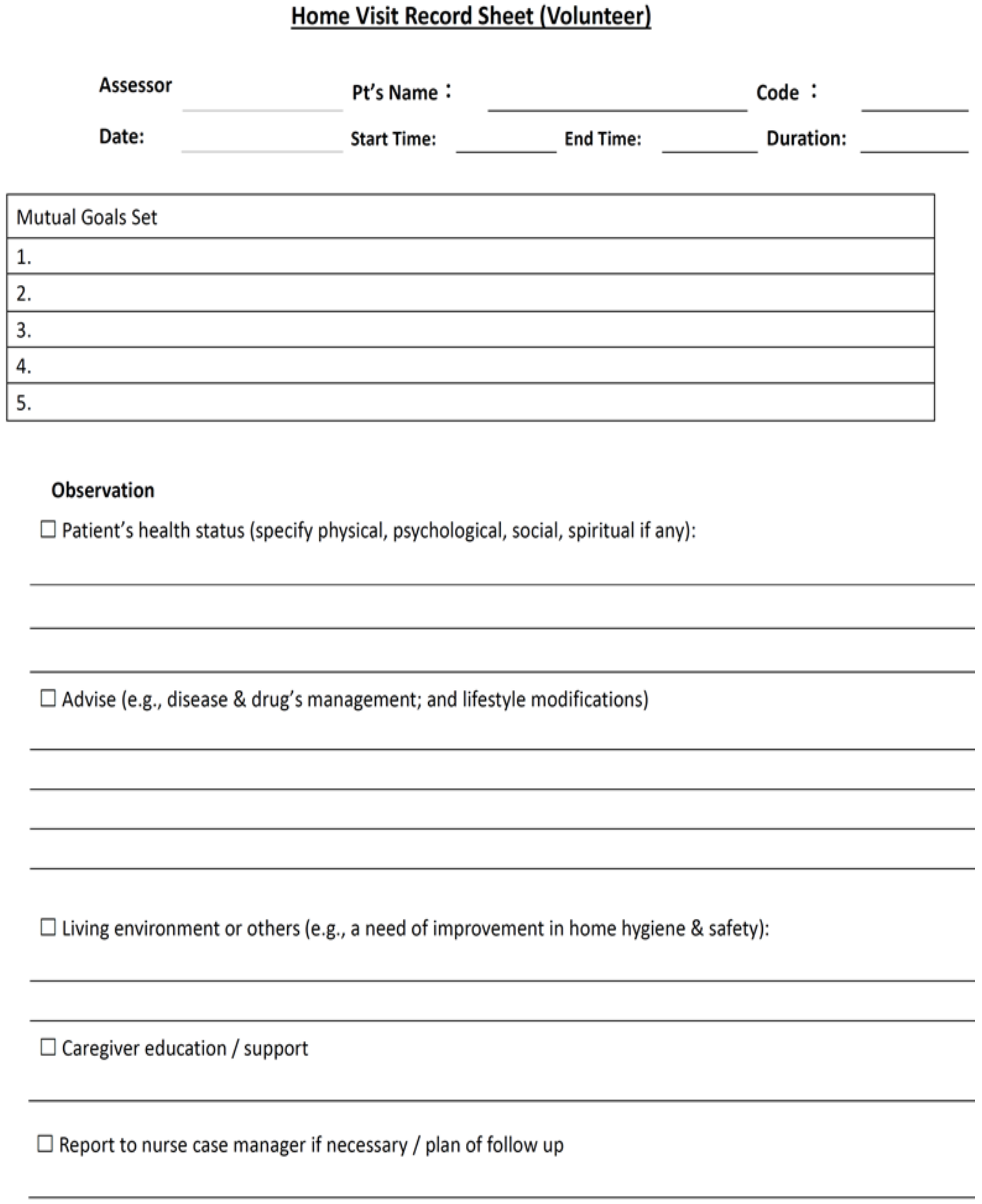
Palliative Performance Scale : ________ NYHA : _________

☐ **Teaching, guidance and counseling [健康教育、指導及諮詢]** (client specific information)

☐ **Treatment and procedures [治療及程序]** (client specific information)

☐ **Case management [個案管理]** (client specific information)

Appendix 4.3 Protocol for Home Visit (Volunteer)



Home Visit Record Sheet (Volunteer)

Assessor __________ **Pt's Name：** __________ **Code ：** __________

Date: __________ **Start Time:** __________ **End Time:** __________ **Duration:** __________

Mutual Goals Set
1.
2.
3.
4.
5.

Observation

☐ Patient's health status (specify physical, psychological, social, spiritual if any):

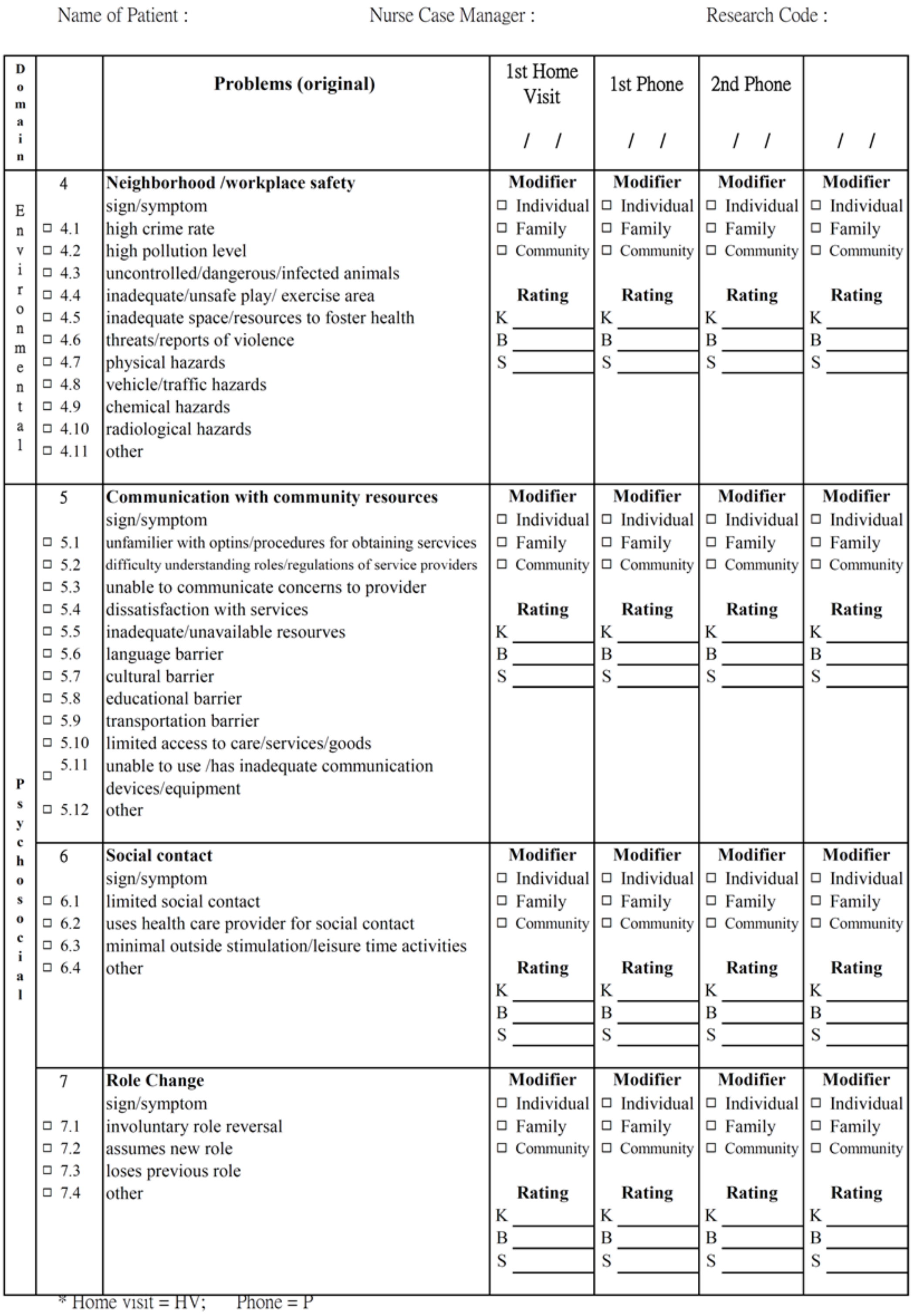
☐ Advise (e.g., disease & drug's management; and lifestyle modifications)

☐ Living environment or others (e.g., a need of improvement in home hygiene & safety):

☐ Caregiver education / support

☐ Report to nurse case manager if necessary / plan of follow up

Appendix 4.3 Protocol for Home Visit (Omaha System)



Name of Patient : Nurse Case Manager : Research Code :

Domain		**Problems (original)**	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Environmental	4	**Neighborhood /workplace safety**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 4.1	high crime rate	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 4.2	high pollution level	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 4.3	uncontrolled/dangerous/infected animals				
	☐ 4.4	inadequate/unsafe play/ exercise area	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 4.5	inadequate space/resources to foster health	K ________	K ________	K ________	K ________
	☐ 4.6	threats/reports of violence	B ________	B ________	B ________	B ________
	☐ 4.7	physical hazards	S ________	S ________	S ________	S ________
	☐ 4.8	vehicle/traffic hazards				
	☐ 4.9	chemical hazards				
	☐ 4.10	radiological hazards				
	☐ 4.11	other				
Psychosocial	5	**Communication with community resources**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 5.1	unfamilier with optins/procedures for obtaining sercvices	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 5.2	difficulty understanding roles/regulations of service providers	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 5.3	unable to communicate concerns to provider				
	☐ 5.4	dissatisfaction with services	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 5.5	inadequate/unavailable resourves	K ________	K ________	K ________	K ________
	☐ 5.6	language barrier	B ________	B ________	B ________	B ________
	☐ 5.7	cultural barrier	S ________	S ________	S ________	S ________
	☐ 5.8	educational barrier				
	☐ 5.9	transportation barrier				
	☐ 5.10	limited access to care/services/goods				
	☐ 5.11	unable to use /has inadequate communication devices/equipment				
	☐ 5.12	other				
	6	**Social contact**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 6.1	limited social contact	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 6.2	uses health care provider for social contact	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 6.3	minimal outside stimulation/leisure time activities				
	☐ 6.4	other	**Rating**	**Rating**	**Rating**	**Rating**
			K ________	K ________	K ________	K ________
			B ________	B ________	B ________	B ________
			S ________	S ________	S ________	S ________
	7	**Role Change**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 7.1	involuntary role reversal	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 7.2	assumes new role	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 7.3	loses previous role				
	☐ 7.4	other	**Rating**	**Rating**	**Rating**	**Rating**
			K ________	K ________	K ________	K ________
			B ________	B ________	B ________	B ________
			S ________	S ________	S ________	S ________

* Home visit = HV; Phone = P

Name of Patient :

Nurse Case Manager :

Research Code :

Domain		**Problems (original)**	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Psychosocial	8 ☐ 8.1 ☐ 8.2 ☐ 8.3 ☐ 8.4 ☐ 8.5 ☐ 8.6 ☐ 8.7 ☐ 8.8 ☐ 8.9	**Interpersonal relationship** sign/symptom difficulty establishing/maintaining relationships minimal shared activities incongruent values/goals/expectations/schedules inadequate interpersonal communication skills prolonged, unrelieved tension inappropriate suspicion/manipulation/control physically/emotionally abusive to partner difficulty problem solving without conflict other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________
	9 ☐ 9.1 ☐ 9.2 ☐ 9.3 ☐ 9.4 ☐ 9.5	**Spirituality** sign/symptom expreses spiritual concerns disrupted spiritual rituals disrupted spiritual trust conflicting spiritual beliefs and medical/health care regimen other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________
	10 ☐ 10.1 ☐ 10.2 ☐ 10.3 ☐ 10.4 ☐ 10.5	**Grief** sign/symptom fails to recognize stages of grief/process of healting difficulty coping with grief response difficulty expressing grief response conflicting stages of grief among individuals/families other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ________ B ________ S ________

* Home visit = HV; Phone = P

Name of Patient :   Nurse Case Manager :   Research Code :

Domain		**Problems (original)**	1st Home Visit / /	1st Phone / /	2nd Phone / /	 / /
Psychosocial	11	**Mental health**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 11.1	sadness/hopelessness/decreased self-esteem	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 11.2	apprehension/undefined fear	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 11.3	loss of interest/involvement in activities/self-care				
	☐ 11.4	narrowed to scattered attention/focus	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 11.5	flat affect	K ______	K ______	K ______	K ______
	☐ 11.6	irritable/agitated/aggressive	B ______	B ______	B ______	B ______
	☐ 11.7	purposeless/compulsive activity	S ______	S ______	S ______	S ______
	☐ 11.8	difficulty in managing stress				
	☐ 11.9	difficulty managing anger				
	☐ 11.10	somatic complaints/fatique				
	☐ 11.11	delusions				
	☐ 11.12	hallucinations/illusions				
	☐ 11.1	expresses suicidal/homicidal thoughts				
	☐ 11.1	attempts suicide/homicidal thoughts				
	☐ 11.2	self-mutilation				
	☐ 11.2	mood swings				
	☐ 11.2	flash-backs				
	☐ 11.18	other				
	12	**Sexuality**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 12.1	difficulty recognizing consequences of sexual behavior	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 12.2	difficulty expressing intimacy	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 12.3	sexual identity confusion				
	☐ 12.4	sexual value confusion	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 12.5	dissatisfied with sexual relationships	K ______	K ______	K ______	K ______
	☐ 12.6	unsafe sexual practices	B ______	B ______	B ______	B ______
	☐ 12.7	sexual acting out/provocative behaviors/harassment	S ______	S ______	S ______	S ______
	☐ 12.8	sexual perpetration/assult				
	☐ 12.9	other				
	13	**Caretaking/parenting**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 13.1	difficulty providing physical care/safety	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 13.2	difficulty providing emotional nurturance	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 13.3	difficulty providing cognitive learning experiences and activities				
	☐ 13.4	difficulty providing preventive and therapeutic health care	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 13.5	expectations incongruent with stage of growth and development	K ______	K ______	K ______	K ______
	☐ 13.6	dissatisfaction/difficulty with responsibilities	B ______	B ______	B ______	B ______
	☐ 13.7	difficulty interpreting or responding to verbal /nonverbal communication	S ______	S ______	S ______	S ______
	☐ 13.8	neglectful				
	☐ 13.9	abuseive				
	☐ 13.10	other				

* Home visit = HV; Phone = P

Name of Patient :　　　　　Nurse Case Manager :　　　　　Research Code :

Domain		**Problems (original)**	1st Home Visit / /	1st Phone / /	2nd Phone / /	 / /
Psychosocial	14	**Neglect**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 14.1	lacks adequate physical care	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 14.2	lacks emotional nurturance/support	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 14.3	lacks appropriate stimulation/cognitive experiences				
	☐ 14.4	inappropriately left alone	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 14.5	lacks necessary supervision	K ______	K ______	K ______	K ______
	☐ 14.6	inadequate/delayed medical care	B ______	B ______	B ______	B ______
	☐ 14.7	other	S ______	S ______	S ______	S ______
	15	**Abuse**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 15.1	harsh/excessive discipline	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 15.2	welts/burns/other injuries	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 15.3	questionable explanation of injury				
	☐ 15.4	attacked verbally	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 15.5	fearful/hypervigilant behavior	K ______	K ______	K ______	K ______
	☐ 15.6	violent environment	B ______	B ______	B ______	B ______
	☐ 15.7	consistent negative messages	S ______	S ______	S ______	S ______
	☐ 15.8	assaulted sexually				
	☐ 15.9	other				
	16	**Growth and development**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 16.1	abnormal results of developmental screening tests	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 16.2	abnormal weight/height/head circumference in relation to growth/age standards	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 16.3	age-inappropriate behavior				
	☐ 16.4	inadequate achievement/maintenance of developmental tasks	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 16.5	other	K ______	K ______	K ______	K ______
			B ______	B ______	B ______	B ______
			S ______	S ______	S ______	S ______
Physiological	**17**	**Hearing**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 17.1	difficulty hearing normal speech tones	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 17.2	difficulty hearing speech in large group settings	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 17.3	difficulty hearing high frequency sounds				
	☐ 17.4	absent/abnormal response to sound	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 17.5	abnormal results of hearing screening test	K ______	K ______	K ______	K ______
	☐ 17.6	other	B ______	B ______	B ______	B ______
			S ______	S ______	S ______	S ______

* Home visit = HV;　　Phone = P

Name of Patient :　　　　　　　Nurse Case Manager :　　　　　　　Research Code :

Domain		**Problems (original)**	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Physiological	18	**Vision**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 18.1	difficulty seeing small print/calibrations	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 18.2	difficulty seeing distant object	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 18.3	difficulty seeing close objects				
	☐ 18.4	absent/abnormal response to visual stimuli	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 18.5	abnormal results of vision screening test	K ______	K ______	K ______	K ______
	☐ 18.6	squinting/blinking/tearing/burring	B ______	B ______	B ______	B ______
	☐ 18.7	floaters/flashes	S ______	S ______	S ______	S ______
	☐ 18.8	difficulty differentiating colors				
	☐ 18.9	other				
	19	**Speech and Language**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 19.1	absent/abnormal abiity to speak/vocalize	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 19.2	absent/abnormal abiity to understand	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 19.3	lacks alternative communiction skills/gestures				
	☐ 19.4	inappropriate sentence structure	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 19.5	limited enunciation/clarity	K ______	K ______	K ______	K ______
	☐ 19.6	inappropriate word usage	B ______	B ______	B ______	B ______
	☐ 19.7	other	S ______	S ______	S ______	S ______
	20	**Oral health**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 20.1	missing/broken/malformed teeth	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 20.2	caries	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 20.3	excess tartar				
	☐ 20.4	sore/swollen/bleeding gums	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 20.5	malocclusion	K ______	K ______	K ______	K ______
	☐ 20.6	ill-fitting/missing dentures	B ______	B ______	B ______	B ______
	☐ 20.7	sensitivity to hot or cold	S ______	S ______	S ______	S ______
	☐ 20.8	other				
	21	**Cognition**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 21.1	diminished judgment	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 21.2	disoriented to time/place/person	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 21.3	limited recall of recent events				
	☐ 21.4	limited recall of long past event	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 21.5	linited calculating/sequencing skills	K ______	K ______	K ______	K ______
	☐ 21.6	linited concentration	B ______	B ______	B ______	B ______
	☐ 21.7	linited reasoning/abstract thinking ability	S ______	S ______	S ______	S ______
	☐ 21.8	impulsiveness				
	☐ 21.9	repetitious language/behavior				
	☐ 21.10	wanders				
	☐ 21.11	other				

* Home visit = HV;　　Phone = P

Name of Patient :　　　　　　Nurse Case Manager :　　　　　　Research Code :

Domain		**Problems (original)**	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Physiological	22	**Pain**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 22.1	expressive discomfort/pain,	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 22.2	elevated pulse/respirations/blood pressure	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 22.3	compensated movement/guarding				
	☐ 22.4	restless behavior	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 22.5	facial grimaces	K ________	K ________	K ________	K ________
	☐ 22.6	pallor/perspiration	B ________	B ________	B ________	B ________
	☐ 22.7	other	S ________	S ________	S ________	S ________
	23	**Consciousness**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 23.1	lethargic	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 23.2	stuporous	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 23.3	unresponsive				
	☐ 23.4	conatose	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 23.5	other	K ________	K ________	K ________	K ________
			B ________	B ________	B ________	B ________
			S ________	S ________	S ________	S ________
	24	**Skin**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 24.1	lesion/pressure ulcer	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 24.2	rash	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 24.3	excessively dry				
	☐ 24.4	excessively oil	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 24.5	inflammation	K ________	K ________	K ________	K ________
	☐ 24.6	pruritus	B ________	B ________	B ________	B ________
	☐ 24.7	drainage	S ________	S ________	S ________	S ________
	☐ 24.8	brusing				
	☐ 24.9	hypertrophy of nails				
	☐ 24.10	delayed incisional healing				
	☐ 24.11	other				
	25	**Neuro-musculo-Skeletal function**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 25.1	limited range of motion	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 25.2	decreased muscle strength	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 25.3	decreased coordination				
	☐ 25.4	decreased muscle tone	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 25.5	increased muscle tone	K ________	K ________	K ________	K ________
	☐ 25.6	decreased sensation	B ________	B ________	B ________	B ________
	☐ 25.7	incresed sensation	S ________	S ________	S ________	S ________
	☐ 25.8	decreased balance				
	☐ 25.9	gait/ambulation disturbance				
	☐ 25.10	difficulty transferring				
	☐ 25.11	fractures				
	☐ 25.12	tremors/seizure				
	☐ 25.13	difficulty with thermoregulation				
	☐ 25.14	other				

* Home visit = HV;　　Phone = P

Name of Patient :
Nurse Case Manager :
Research Code :

Domain		**Problems (original)**	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Physiological	26	**Respiration**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 26.1	abnormal breath pattern	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 26.2	unable to breathe independently	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 26.3	cough				
	☐ 26.4	unable to cough/expectorate independently	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 26.5	cyanosis	K ________	K ________	K ________	K ________
	☐ 26.6	abnormal sputum	B ________	B ________	B ________	B ________
	☐ 26.7	noisy respirations	S ________	S ________	S ________	S ________
	☐ 26.8	rhinorrhea/nasal congestion				
	☐ 26.9	abnormal breath sounds				
	☐ 26.10	abnormal respiratory laboratory results				
	☐ 26.11	other				
	27	**Circulation**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 27.1	edema	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 27.2	cramping/pain of extremities	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 27.3	decreased pulses				
	☐ 27.4	discoloration of skin	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 27.5	temperature change in affected area	K ________	K ________	K ________	K ________
	☐ 27.6	varicosities	B ________	B ________	B ________	B ________
	☐ 27.7	syncopal episodes (fainting)/dizziness	S ________	S ________	S ________	S ________
	☐ 27.8	abnormal blood pressure reading				
	☐ 27.9	pulse deficit				
	☐ 27.10	irregular heart rate				
	☐ 27.1	excessively rapid heart rate				
	☐ 27.12	excessively slow heart rate				
	☐ 27.13	anginal pain				
	☐ 27.14	abnormal heart sounds/murmurs				
	☐ 27.15	abnormal clotting				
	☐ 27.16	abnormal cardiac laboratory results				
	☐ 27.17	other				
	28	**Digestion-hydration**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 28.1	nausea/vomiting	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 28.2	difficulty/inability to chew/swallow/digest	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 28.3	indigestion				
	☐ 28.4	reflux	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 28.5	anorexia	K ________	K ________	K ________	K ________
	☐ 28.6	anaemia	B ________	B ________	B ________	B ________
	☐ 28.7	ascites	S ________	S ________	S ________	S ________
	☐ 28.8	jaundice/liver impairment				
	☐ 28.9	decreased skin turgor				
	☐ 28.10	cracked lips/dry mouth				
	☐ 28.11	electrolyte imbalance				
	☐ 28.12	other				

* Home visit = HV; Phone = P

Name of Patient :   Nurse Case Manager :   Research Code :

Domain		Problems (original)	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Physiological	29 ☐ 29.1 ☐ 29.2 ☐ 29.3 ☐ 29.4 ☐ 29.5 ☐ 29.6 ☐ 29.7 ☐ 29.8	**Bowel Function** sign/symptom abnormal frequency/consistency of stool painful defecation decreased bowel sounds blood in stools abnormal color cramping/abdominal discomfort incontinent of stool other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____
	30 ☐ 30.1 ☐ 30.2 ☐ 30.3 ☐ 30.4 ☐ 30.5 ☐ 30.6 ☐ 30.7 ☐ 30.8 ☐ 30.9 ☐ 30.10	**Urinary Function** sign/symptom burning/painful urination incontinent of urine urgency/frequency difficulty initiating urination difficulty emptying bladder abnormal amount hematuria/abnormal color nocturia abnormal urinaty laboratory results other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____
	31 ☐ 31.1 ☐ 31.2 ☐ 31.3 ☐ 31.4 ☐ 31.5 ☐ 31.6 ☐ 31.7 ☐ 31.8	**Reproductive function** sign/symptom abnormal discharge abnormal menstrual pattern difficulty managing menopause/andropause abnormal lumps/swelling/tenderness of genital organs or breasts pain during or after sexual intercourse infertility impotence other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____
	32 ☐ 32.1 ☐ 32.2 ☐ 32.3 ☐ 32.4 ☐ 32.5 ☐ 32.6 ☐ 32.7	**Pregnancy** sign/symptom difficulty bonding with unbornbaby difficulty bonding with body changes difficulty with prenatal exercise/rest/diet/behaviors fears delivery procedure prenatal complications/preterm labor inadequate social support other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ____ B ____ S ____

* Home visit = HV;   Phone = P

Name of Patient : Nurse Case Manager : Research Code :

Domain		Problems (original)	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Physiological	33	**Postpartum**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 33.1	difficulty breast-feed	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 33.2	difficulty coping with postpartum change	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 33.3	difficulty with postpartum exercise/rest/diet/behaviors				
	☐ 33.4	abnormal bleeding/vaginal discharge	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 33.5	postpartum complication	K ____	K ____	K ____	K ____
	☐ 33.6	abnormal depressed feelings	B ____	B ____	B ____	B ____
	☐ 33.7	other	S ____	S ____	S ____	S ____
	34	**Communicable/infectious condition**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 34.1	infection	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 34.2	infestation	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 34.3	fever				
	☐ 34.4	biological hazards	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 34.5	positive screening/culture/laboratory results	K ____	K ____	K ____	K ____
	☐ 34.6	inadequate supplies/equipment/policies to prevent transmission	B ____	B ____	B ____	B ____
	☐ 34.7	does not follow infection control regimen	S ____	S ____	S ____	S ____
	☐ 34.8	indequate immunity				
	☐ 34.9	other				
Health related Behaviors	35	**Nutrition**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 35.1	overweight : adult BMI 25.0 or more	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 35.2	underweight : adult BMI 18.5 or less	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 35.3	lacks established standards for daily caloric /fluid intake				
	☐ 35.4	exceeds established standards for daily caloric /fluid intake	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 35.5	unbalanced diet	K ____	K ____	K ____	K ____
	☐ 35.6	improper feeding schedule for age	B ____	B ____	B ____	B ____
	☐ 35.7	does not follow recommended nutrition plan	S ____	S ____	S ____	S ____
	☐ 35.8	unexplained/progressive weight loss				
	☐ 35.9	unable to obtain/prepare food				
	☐ 35.10	hypoglycemia				
	☐ 35.11	hyperglycemia				
	☐ 35.12	other				
	36	**Sleep and rest pattern**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 36.1	sleep/rest pattern disrupts family	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 36.2	frequency wakes during night	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 36.3	sleepwalking				
	☐ 36.4	insomnia	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 36.5	nightmares	K ____	K ____	K ____	K ____
	☐ 36.6	insufficient sleep/rest for age/physical condition	B ____	B ____	B ____	B ____
	☐ 36.7	sleep apnea	S ____	S ____	S ____	S ____
	☐ 36.8	snoring				
	☐ 36.9	other				

* Home visit = HV; Phone = P

Name of Patient :

Nurse Case Manager :

Research Code :

Domain		**Problems (original)**	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Health related Behaviors	37 ☐ 37.1 ☐ 37.2 ☐ 37.3 ☐ 37.4	**Physical activity** sign/symptom sendentary life style inadequate/inconsistent exercise routine inappropriate type/amount of exercise for age/physical condition other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______
	38 ☐ 38.1 ☐ 38.2 ☐ 38.3 ☐ 38.4 ☐ 38.5 ☐ 38.6 ☐ 38.7 ☐ 38.8 ☐ 38.9 ☐ 38.10	**Personal care** sign/symptom difficulty laundering clothing difficulty with bathing difficulty with toileting activities difficulty dressing lower body difficulty dressing upper body foul body odor difficulty shampooing/combing hair difficulty brushing/flosng/mouth care unwilling/unable/forgets to complete personal care activities other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______
	39 ☐ 39.1 ☐ 39.2 ☐ 39.3 ☐ 39.4 ☐ 39.5 ☐ 39.6 ☐ 39.7 ☐ 39.8	**Substance use** sign/symptom abuses over-the counter/prescription medications uses"street"-recreational drugs difficulty performing normal routines reflex disturbances behavior change exposure to cigarette/cigar smoke buys/sells illegal substances other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______
	40 ☐ 40.1 ☐ 40.2 ☐ 40.3 ☐ 40.4 ☐ 40.5 ☐ 40.6 ☐ 40.7	**Family planning** sign/symptom inappropriate/insufficient knowledge about family planning metods inappropriate/insufficient knowledge about preconception health practices inaccurate/inconsistent use of family panning methods dissatisfied with present family planning method fears othres' reactions regarding family planning choices difficulty obtaining family planning methods other	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______	**Modifier** ☐ Individual ☐ Family ☐ Community **Rating** K ______ B ______ S ______

* Home visit = HV;   Phone = P

Name of Patient :   Nurse Case Manager :   Research Code :

Domain		Problems (original)	1st Home Visit / /	1st Phone / /	2nd Phone / /	/ /
Health related Behaviors	41	**Health care supervision**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 41.1	fails to obtain routine/preventive health care	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 41.2	fails to seek care for symptoms requiring evaluation/treatment	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 41.3	fails to return as requested to health care provider/treatment plan				
	☐ 41.4	inability to coordinate multiple appointments/treatment plan	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 41.5	inconsistent source of health care	K ______	K ______	K ______	K ______
	☐ 41.6	inadequate source of health care	B ______	B ______	B ______	B ______
	☐ 41.7	inadequate treatment plan	S ______	S ______	S ______	S ______
	☐ 41.8	other				
	42	**Medication regimen**	**Modifier**	**Modifier**	**Modifier**	**Modifier**
		sign/symptom	☐ Individual	☐ Individual	☐ Individual	☐ Individual
	☐ 42.1	does not follow/recommended dosage/schedule	☐ Family	☐ Family	☐ Family	☐ Family
	☐ 42.2	evidence of side effects/adverse reactions	☐ Community	☐ Community	☐ Community	☐ Community
	☐ 42.3	inadequate system for taking medication				
	☐ 42.4	improper storage of medication	**Rating**	**Rating**	**Rating**	**Rating**
	☐ 42.5	fails to obtain refills appropriately	K ______	K ______	K ______	K ______
	☐ 42.6	fails to obtain immunizations	B ______	B ______	B ______	B ______
	☐ 42.7	inadquate medication regimen	S ______	S ______	S ______	S ______
	☐ 42.8	unable to take medications without help				
	☐ 42.9	other				

* Home visit = HV;   Phone = P

Appendix 4.4 Protocol for Telephone Follow-up

電話跟進開始時自我介紹：

XXX，你好，我是我是 XX 醫院紓緩科家訪護士 XXX，仲記得 X 日之前我嚟過你屋企探訪你，同你傾過一些出院後回家生活的健康資訊 (列出一個曾經講過之內容：…掂樣可以幫助自己處理症狀？)，現在，你個身體狀況怎樣呢

Health Assessment / Surveillance [健康評估及監測]

1. **Physiological [生理]: signs & symptoms**

   上一次家訪時你提到有 xx 症狀(例如: 胸痛), 你而家覺得怎樣?

   除了(例如: 胸痛)以外, 仲有無,其他吾舒服? 遇到這些症狀，你會怎麼做？

2. **Psycho-social-spiritual [心理/社交/心靈]**

你而家嘅心情怎樣? 對於你嘅身體狀況…或者將來，你有咩嘢冧？有咩嘢元素 (自己/別人/上天)給你力量撐落去？

你同家人 / 照顧者啲關係怎樣？

3. **Health related behavior [健康相關行為]**

   你仲記得食緊幾多種藥？有冇依時服藥？你仲記得有(例如:呼吸技巧) 可以嘗試做阿？你有冇跟住我們訂立啲計劃來做？

4. **Environment [環境]:** （**if any**）

   上一次家訪時提出了一啲改善居家／環境危險因素的建議，有冇落實執行阿？

   上一次家訪時提出的家居安全改善設施，你有冇安裝？

結尾鼓勵說話 ： 心臟衰竭是慢性病，唔容易處理，我下次再打電話比你。你有冇一 D 嘢想做令自己舒服 D?依家我地一齊訂下目標，等我 同你打打氣 ！

Setting Goals with patient [我都想同你再訂立一些新目標]:

1. ____

2. ____

3. ____

Appropriate date: _____/ _____/ _____ and time: ________ of next telephone follow-up

如你有什麼問題可致電: ____________________, 你好好休養，下次再聯絡, Bye Bye！

Appendix 4.4 Protocol for Telephone Follow-up

Telephone Follow-up Record Sheet (NCM)

NCM： ____________ **Pt's Name：** ____________________ **Code ：** ________

Date: ____________ **Start Time:** ________ **End Time:** ________ **Duration:** ________

Follow- up the set mutual goals or advices given at the Home visit

Mutual Goals Set
1.
2.
3.
4.

Nursing Intervention provided

Health, diseases and other physical symptoms management

____

____

____

Emotional management

____

____

____

Drug(s) management

____

____

____

Others (e.g. caregiver education / psychological support / communication)

____

____

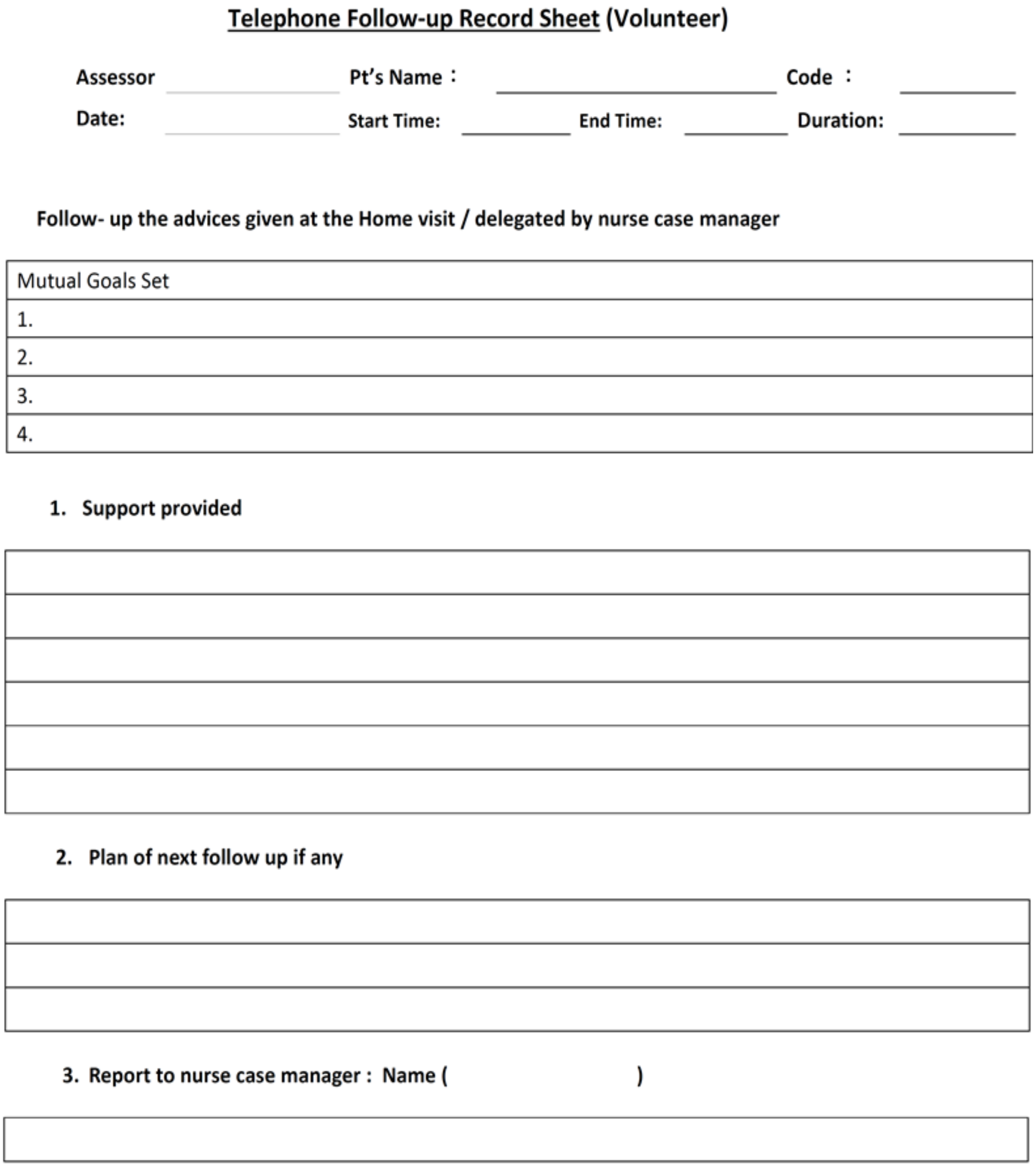
____

Referral

____

____

Appendix 4.4 Protocol for Telephone Follow-up



Telephone Follow-up Record Sheet (Volunteer)

Assessor ____________ **Pt's Name：** ________________ **Code ：** ________

Date: ____________ **Start Time:** ________ **End Time:** ________ **Duration:** ________

Follow- up the advices given at the Home visit / delegated by nurse case manager

Mutual Goals Set
1.
2.
3.
4.

1. **Support provided**

2. **Plan of next follow up if any**

3. **Report to nurse case manager : Name (   )**

Appendix 4.5 Patient Initiated-call record

Patient /caregiver initiated telephone call record		Research code (for researcher to fill in)
☐ Call by patient (Name)	☐ Call by caregiver	Nurse Case Manager
From (time)	To (time)	Duration

Date	Progress
	Reason for call
	Nursing intervention
	Follow up plan

Appendix 4.6 Protocol for Referral System

Medical Referral

1. Phone consultation to physician-in-charge if moderate symptoms and abnormal vital signs might need medication adjustment/ possible investigation/ clinic visit for review
2. Phone consultation to physician-in-charge if severe symptoms and unstable vital signs might need hospital admission
3. Advise to attend Accident and Emergency Department if sudden change of condition that warrant emergency management; arrange hospitalization to the palliative care unit

Defining	Examples
Moderate symptoms	Increased ankles oedema, evidence of hypoperfusion, increase angina pattern, major medication side effect identified
Severe symptoms	Critical hypoperfusion, unrelieved angina, severe orthopnea, respiratory distress at rest, lower limbs oedema up to knees/ascites
Sudden change of condition	Sudden onset confused mental state, coma, active bleeding

Non-medical Referral

Physiological care needs

Refer to	Reason
● Occupational Therapist	Home safety
● Physiotherapist	Physical activity
● Dietitian	Individualized dietary consultation

Psycho-social-spiritual care needs (for family member also if necessary)

Refer to	Reason
● Medical Social Worker	Financial issues, welfare support, emotional support
● Chaplain	Spiritual care
● Clinical Psychologist	Psychological distress, suicidal tendency

Appendix 4.7 Training Program-Nurses

Section	Topic
1 27 Nov 2012 0930-1300	● Welcoming ● Introduction of the project, aims & objectives ● Components of Transitional Care Model
	● Introduction of case management models & approaches ● Roles of NCM in the project ● Introduction on OMAHA System ● Protocols used throughout the project
2 27 Nov 2012 1430-1600	● Holistic concerns for patients with end-stage heart failure ● Implementing pre-discharge assessment & post-discharge follow-up ● Intervention skills I :home visit & telephone follow-up
27Nov 2012 1615-1745	● Palliative care in end-stage heart failure ● Update on Advance Care Planning
3 5 Dec 2012 1500-1800	● Workshop on OMAHA system with case scenario ● Tools for patients assessment
4 13 Dec 2012 1500-1800	● Intervention skills II : health assessment, symptom management, emergency management for terminally ill patients ● Intervention skills III: breathing technique, energy conservation technique, oedema management ● Intervention skills IV: home environment assessment, relaxation skill
5 28 Dec 2012 1500-1800	● Case sharing ● Evaluation of the learning progress ● Test

Appendix 4.8 Training Program-Volunteers

Research project title: Impacts of Transitional Palliative Care for End-Stage Heart Failure Patients

Date: 27 Nov 2012, 15 Jan 2013, & 8 Feb 2013

Total training hours: 9 hours

Venue: GH506a, PolyU

Speaker: Prof Frances Wong, Ms Alina Ng, Dr Katherine Cheng (Lecturer)

Contents

- The role & functions of volunteers
- Characteristics of subjects
- Guideline for home visit
- Guideline for telephone follow-up
- Record needed for home visit and telephone follow-up
- Communication skills,
- Social support appropriate for volunteer workers
- Making referrals to healthcare professionals
- Understand the ethical concern & responsibilities
- Role play with case scenario

Appendix 4.9 Questionnaires

參加者資料

第一部分 (PART I)

請填妥以下資料或在適當之空格加上 ✓號

研究編碼： ________________

1. 性別： □1 男 □2 女

2. 年齡: __________________________

3. 婚姻狀況: □1 單身 □2 已婚 □3 離婚/ 分居 □4 寡/ 鰥

4. 教育程度

   □1 從未接受過教育 □2 小學 □3 中學

   □4 專上學院/ 大學

5. 受僱情況

   □1 全職 (請註明工作類別)_____________ □2 兼職 (請註明工作類別) ____________

   □3 自僱 (請註明工作類別) _____________ □4 失業 □5 退休

   □6 全職主婦 □7 不能工作

6. 你是否家庭的經濟支柱?

□1 是　　□2 否

7. 居住環境：

□1 租屋/租房　　□2 自置私人樓宇　　□3 公共房屋
□4 居者有其屋
□5 老人房屋　　□6 其他 (請註明)
____

8. 你覺得你的經濟狀況如何？

□1 足夠有餘　　□2 剛剛足夠應付日常生活開支
□3 不足夠應付日常生活開支　　□4 十分不足夠

9. 你的經濟(例如：維持你日常衣、食、住、行等生活開支)主要是來源是？
(讓被訪者自己回答，可✓多項)

□1 自己的薪水　　□2 家人提供 (例如：配偶、子女)
□3 個人積蓄　　□4 退休金 / 長俸
□5 高齡津貼(生果金)　　□6 綜合援助(綜援)
□7 傷殘津貼/ 高傷殘津貼　　□8 其他 (請註明)
____

10. 誰負責你日常的起居飲食?

□1 你自己
□2 配偶
□3 兒子/ 女兒
□4 家庭傭工
□5 兼職家務助理
□6 鄰居
□7 義工
□8 朋友
□9 多於一個照顧者

11. 誰會經常照顧你?

□1 你自己
□2 配偶
□3 兒子/ 女兒
□4 家庭傭工
□5 兼職家務助理
□6 鄰居
□7 義工
□8 朋友
□9 多於一個照顧者

12. 如果你生病，誰負責照顧你？

□1 你自己
□2 配偶
□3 兒子/ 女兒
□4 家庭傭工
□5 兼職家務助理
□6 鄰居
□7 義工
□8 朋友
□9 其他 (請註明)

____

第二部分 **(PART II)**

McGill Quality of life questionnaire-Hong Kong version

1a 這兩天裡，我最主要的病徵是 ：
(如:
痛、氣喘、失眠、虛弱、疲倦、作嘔、食慾不振、便秘、肚瀉、水腫、咳嗽、嘔吐、發燒、肚脹……等)

程度由 0 至 10
0 1 2 3 4 5 6 7 8 9 10

i. ______________________ 程度 ______________________
ii. ______________________ 程度 ______________________
iii. ______________________ 程度 ______________________

1b 這兩天裡，我的身體情況是 ：
很差 0 1 2 3 4 5 6 7 8 9 10 很好

2 我有否感到抑鬱？
沒有 0 1 2 3 4 5 6 7 8 9 10 非常

3 有否憂慮或煩惱？
沒有 0 1 2 3 4 5 6 7 8 9 10 非常

4 這兩天裡，我是否很多時都感到悲傷？
沒有 0 1 2 3 4 5 6 7 8 9 10 經常

5 我是否對未來感到恐懼？
沒有恐懼 0 1 2 3 4 5 6 7 8 9 10 恆久的恐懼

6 我個人的存在是否有意義？

沒有目的 0 1 2 3 4 5 6 7 8 9 10 好有目的
和意義 和意義

7 對於我個人生的目標，

我不能 0 1 2 3 4 5 6 7 8 9 10 已達到
達到目標 原定目標

8 直到現時為止，我的生命 :

全無價值 0 1 2 3 4 5 6 7 8 9 10 好有價值

9 我對自己是否感到滿意？

很不滿意 0 1 2 3 4 5 6 7 8 9 10 十分滿意

10 我感受到別人對我的支持。

完全 0 1 2 3 4 5 6 7 8 9 10 非常
感受不到 感受到

11 對我來說每天的日子好像是重擔。

完全不同意 0 1 2 3 4 5 6 7 8 9 10 完全同意

12 這世界是個殘酷和沒有人情味的地方。

我的需要已有回應及受關注

0 1 2 3 4 5 6 7 8 9 10

13 我覺得患病令我很沒面子。

完全不同意 0 1 2 3 4 5 6 7 8 9 10 完全同意

14 患病令我損失了很多飲食上的享受。

完全不同意 0 1 2 3 4 5 6 7 8 9 10 完全同意

15 患病使我無法享受正常的性生活。

完全不同意 0 1 2 3 4 5 6 7 8 9 10 完全同意

16 這兩天裡，我的生活質素（包括我生活的一部，如；體質、情緒、社交生活、精神及經濟）是；

很差 0 1 2 3 4 5 6 7 8 9 10 非常美滿

Chronic Heart Failure Questionnaire – Chinese version)
(CHQ-C)

此問卷的目的是為了探討你在過去兩星期當中覺得怎麼樣的。你將會被問及一些有關你感到多少呼吸急促、多少疲累，以及你的心情如何的問題。

(一). 我將會請你想一想一些你在剛過去的兩個星期內，所進行過而有令你感到呼吸急促的活動。這些活動須要是你時常做而又對你的日常生活很重要的。請你盡你可能列出所有你在過去兩個星期當中，進行過而又令你感到呼吸急促的活動。

你能否想起任何其他活動，它是你在剛過去的兩星期當中進行過而又令你感到呼吸急促的？

(二). 我現在將會讀出一連串令一些有心臟問題的人感到呼吸急促的活動，每當我讀出一項活動後，我便會停頓足夠的時間，讓你告訴我在剛過去的兩個星期當中，你有否在進行這項活動時感到呼吸急促。如果在這兩個星期當中，你沒有進行過這項些活動，只須答『沒有』。 這些活動是：

1. 正當憤怒或不開心
2. 進行沐浴或淋浴
3. 彎腰
4. 提攜物件，例如提攜雜貨
5. 穿衣服
6. 進食
7. 去散步
8. 處理家務
9. 匆忙
10. 平臥
11. 整理床鋪
12. 拖抹或擦淨地板
13. 移動傢俬
14. 與孩子或孫兒嬉戲
15. 做體育活動
16. 提高手拿取放於高過頭的物件
17. 跑步，例如追趕巴士
18. 購物
19. 談話
20. 吸塵
21. 在你的家裡四處步行
22. 行上斜路
23. 上樓梯
24. 與其他人在平地步行
25. 預備飯餐
26. 嘗試入眠時

(三). 甲). 在你已選出的項目當中，那一項是在你日常生活中，對你最重要的呢？我將會把這些項目讀出，當我完成後，請你告訴我那些是最重要的。

在這些項目中，那些是在你的日常生活中，對你最重要的呢？

乙). 在餘下的項目中，那些是在你的日常生活中，對你最重要的呢？我將會把這些項目讀出，當我完成後，請你告訴我那些是最重要的呢。

在那些項目中，那些是在你的日常生活中，對你最重要的呢？

丙). 在餘下的項目中，那些是對你的日常生活最重要的呢？

丁). 在餘下的項目中，那些是對你的日常生活最重要的呢？

戊). 在餘下的項目中，那些是對你的日常生活最重要的呢？

[對於所有隨後的題目，於你開始發問問題前，確保有適合的回應咭放在回應者的面前]

(四). 我現在想你形容一下在對上的兩個星期中，當進行你所選出的五項最重要的活動時，你感到有多麼呼吸急促。

(甲) 請從你面前的咭紙中，抽出以下其中一個選擇來表示在對上的兩個星期當中，當**[訪問者：插入列在(三甲)的活動]**，你有多麼的呼吸急促。

1. 極度呼吸急促
2. 非常呼吸急促
3. 相當呼吸急促
4. 中度的呼吸急促
5. 有一些呼吸急促
6. 些微的呼吸急促
7. 完全不呼吸急促

(乙) 請從你面前的咭紙中，選出以下其中一個選擇來表示在對上的兩個星期當中，當**[訪問者：插入列在(三乙)的活動]**，你有多麼的呼吸急促。

1. 極度呼吸急促
2. 非常呼吸急促
3. 相當呼吸急促
4. 中度的呼吸急促
5. 有一些呼吸急促
6. 些微的呼吸急促
7. 完全不呼吸急促

(丙) 請從你面前的咭紙中，選出以下其中一個選擇來表示在對上的兩個星期當中，當**[訪問者：插入列在(三丙)的活動]**，你有多麼的呼吸急促。

1. 極度呼吸急促
2. 非常呼吸急促
3. 相當呼吸急促
4. 中度的呼吸急促
5. 有一些呼吸急促
6. 些微的呼吸急促
7. 完全不呼吸急促

(丁) 請從你面前的咭紙中，選出以下其中一個選擇來表示在對上的兩個星期當中，當**[訪問者：插入列在(三丁)的活動]**，你有多麼的呼吸急促。

1. 極度呼吸急促
2. 非常呼吸急促
3. 相當呼吸急促
4. 中度的呼吸急促
5. 有一些呼吸急促
6. 些微的呼吸急促
7. 完全不呼吸急促

(戌) 請從你面前的咭紙中，選出以下其中一個選擇來表示在對上的兩個星期當中，當**[訪問者：插入列在(三戌)的活動]**，你有多麼的呼吸急促。

1. 極度呼吸急促
2. 非常呼吸急促
3. 相當呼吸急促
4. 中度的呼吸急促
5. 有一些呼吸急促
6. 些微的呼吸急促
7. 完全不呼吸急促

(五). 一般來說，在過去的兩個星期當中，你有多少時候是感到挫敗或不耐煩的呢？請從你面前的咭紙中，選出以下其中一個選擇來表示在剛過去兩個星期當中，你有幾多時覺得挫敗或不耐煩。

1.所有時候
2.多數時候
3.一段相當的時候
4.有些時候
5.很少時候
6.幾乎毫無時候
7.沒有時候

(六). 在過去的兩個星期當中，當你有困難恢復正常呼吸時，你有幾多時有一種恐懼或驚慌的感覺呢？請從你面前的咭紙中，選出以下其中一個選擇來表示當你有困難恢復正常呼吸時，你有幾多時有一種恐懼或驚慌的感覺。

1. 所有時候
2. 多數時候
3. 一段相當的時候
4. 有些時候
5. 很少時候
6. 幾乎毫無時候
7. 沒有時候

(七). 疲倦乏力又是怎麼樣呢？　在過去的兩個星期期間，你感到了有多麼疲倦呢？請從你面前的咭紙中，選出以下其中一個選擇來表示在過去的兩個星期期間，你覺得有多麼疲倦。

1. 極度疲倦
2. 非常疲倦
3. 相當的疲倦
4. 中度疲倦
5. 有一些疲倦
6. 些微疲倦
7. 完全不疲倦

(八). 於對上的兩個星期當中，有幾多時你是感到了不足、沒有價值的或覺得自己好像是別人身上的負擔呢？請從你面前的咭紙中，選出以下其中一個選擇來表示有你多少時候覺得自己是不足的、沒有價值的或覺得自己好像是別人身上的負擔的。

1. 所有時候
2. 多數時候
3. 一段相當的時候
4. 有些時候
5. 很少時候
6. 幾乎毫無時候
7. 沒有時候

(九). 在對上的兩個星期裡，你有多少時候是感到了非常有信心及確信你能夠處理你的疾病的呢？請從你面前的咭紙中，選出以下其中一個選擇來表示有多少時候，你是感到了非常有信心及確信你能夠處理你的疾病的。

1. 沒有時候
2. 很少時候
3. 有些時候
4. 一段相當的時候
5. 多數時候
6. 幾乎所有時候
7. 所有時候

(十). 在對上的兩個星期裡，你有多少精力呢？請從你面前的咭紙中，選出以下其中一個選擇去表示你有多少精力。]

1. 完全沒有精力
2. 些微精力
3. 有些精力
4. 中度有精力
5. 相當的精力
6. 非常有精力
7. 精力充沛

(十一). 一般來說，在對上的兩個星期當中，有多少時候你是感到煩亂、擔心或抑鬱的呢？請從你面前的咭紙中，選出以下其中一個選擇去表示在過去的兩個星期當中，你有多少時候是感到煩亂、擔心或抑鬱的。

1. 所有時候
2. 多數時候
3. 一段相當的時候
4. 有些時候
5. 很少時候
6. 幾乎毫無時候
7. 沒有時候

(十二). 在對上的兩個星期當中，有幾多時你感到你能完全控制你呼吸急促和疲倦的呼吸問題呢？請從你面前的咭紙中，選出以下其中一個選擇去表示你有幾多時是感到你能完全控制你呼吸急促和疲倦的呼吸問題。

1. 沒有時候
2. 很少時候
3. 有些時候
4. 一段相當的時候
5. 多數時候
6. 幾乎所有時候
7. 所有時候

(十三). 在對上的兩個星期當中，有多少時候你是感到輕鬆及沒有緊張情緒呢？請從你面前的咭紙中，選出以下其中一個選擇去表示有多少時候你是感到輕鬆及沒有緊張情緒的。

1. 沒有時候
2. 很少時候
3. 有些時候
4. 一段相當的時候
5. 多數時候
6. 幾乎所有時候
7. 所有時候

(十四). 在對上的兩個星期當中，有幾多時你是感到了虛弱的呢？請從你面前的咭紙中，選出以下其中一個選擇去表示在剛過去的兩個星期當中，有幾多時你是感到虛弱的。

1. 所有時候
2. 多數時候
3. 一段相當的時候
4. 有些時候
5. 很少時候
6. 幾乎毫無時候
7. 沒有時候

(十五). 一般來說，在對上的兩個星期當中，有幾多時你是感到了氣餒或沮喪的。請你從你面前的咭紙中，選出以下其中一個選擇去表示在剛過去的兩個星期當中，有幾多時你是感覺到氣餒或沮喪的。

1. 所有時候
2. 多數時候
3. 一段相當的時候
4. 有些時候
5. 很少時候
6. 幾乎毫無時候
7. 沒有時候

(十六). 在對上的兩個星期當中，有幾多時你是感到了筋疲力竭及反應遲緩的。請從你面前的咭紙中，選出以下其中一個選擇去表示你有有多少時候是感到筋疲力竭及反應遲緩的。

1. 所有時候
2. 多數時候
3. 一段相當的時候
4. 有些時候
5. 很少時候
6. 幾乎毫無時候
7. 沒有時候

(十七). 在對上的兩個星期當中，你對自己的個人生活感到有多麼快樂、滿足或喜悅呢？請你從你面前的咭紙中，選出其中一個選擇來表示你感到多麼的快樂、滿足或喜悅。

1. 非常不滿足，多數時間都不開心
2. 普遍地不滿足，不開心
3. 有幾分不滿足，不開心
4. 普遍地滿足，喜悅的
5. 多數時間都開心
6. 多數時間都非常開心
7. 極之開心，不可能更加滿足或喜悅

(十八). 在對上的兩個星期當中，當你有困難恢復正常呼吸時，有幾多時你是感到不安或驚恐的呢？請你從你面前的咭紙中，選出其中一個選擇來表示在過去的兩個星期當中，當你有困難恢復正常呼吸時，有幾多時你是感到不安或驚恐的。

1. 所有時候
2. 多數時候
3. 一段相當的時候
4. 一些時候
5. 很少時候
6. 幾乎毫無時候
7. 沒有時候

(十九). 一般來說，在對上的兩個星期當中，有幾多時你是感到了不安、緊張或神經過敏的呢？請從你面前的咭紙中，選出以下其中一個選擇去表示有幾多時你是感到了不安、緊張或神經過敏的。

1. 所有時候
2. 多數時候
3. 一段相當的時候
4. 一些時候
5. 很少時候
6. 幾乎毫無時候
7. 沒有時候

Edmonton Symptom Assessment System

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nauseated
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Palliative Performance Scale

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job/Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As above	Mainly Assistance	Normal or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As above	Total Care	Reduced	Full or Drowsy or Confusion
20	As above	As above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As above	As above	Total Care	Mouth Care Only	Drowsy or Coma
0	Dead	---	---	---	---

滿意程度調查

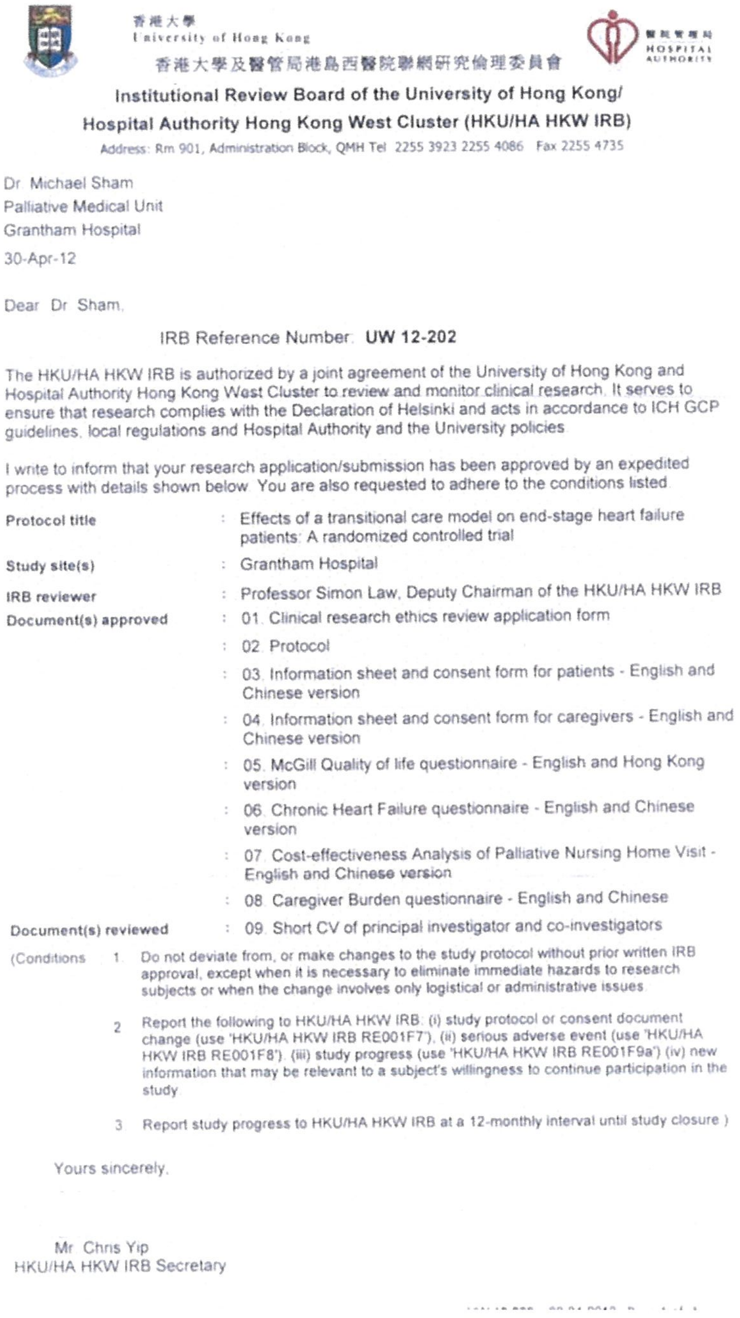
請妳話俾我知你對住院及出院的安排及服務的意見，請在最合適的數字上圈上“○”

	非常同意	同意	普通同意	不同意	非常不同意	不適用	**只供研究員填寫**
1. 你滿意今次醫院俾到你啲出院安排或者服務	5	4	3	2	1	0	
2. 整體來講，你滿意醫院內醫護人員啲工作態度	5	4	3	2	1	0	
3. 醫院及醫護員工同你有深入的溝通交流	5	4	3	2	1	0	
4. 醫院啲出院後安排或者服務，可以幫到你解決疑難或者問題	5	4	3	2	1	0	
5. 醫院俾你出院後啲安排或者服務，可以令你多啲明白妳啲病情	5	4	3	2	1	0	
6. 醫院俾妳出院後啲安排或者服務，可以令你返到屋企之後更加安心啲	5	4	3	2	1	0	
7. 醫院俾妳出院後啲安排或者服務，可以令你更有效咁復康，例如：做運動、強化自我照顧能力、飲食指導、藥物指導等	5	4	3	2	1	0	
8. 醫院俾妳出院後啲安排或者服務，可以令妳更有效咁控制妳 病情	5	4	3	2	1	0	
9. 醫院內啲健康小冊子可以幫到你	5	4	3	2	1	0	
10. 醫院俾你出院後啲安排或者服務，可以滿足妳的需要	5	4	3	2	1	0	
11. 醫院俾妳出院後啲安排或者服務，可以開解妳情緒和心靈郁結	5	4	3	2	1	0	
12・整體來講，你滿意醫院俾妳出院後啲安排或者服務	5	4	3	2	1	0	

完

END

Appendix 4.10 Ethical Approval (Hong Kong West Cluster)



香港大學
University of Hong Kong
香港大學及醫管局港島西醫院聯網研究倫理委員會
醫院管理局
HOSPITAL AUTHORITY

Institutional Review Board of the University of Hong Kong/
Hospital Authority Hong Kong West Cluster (HKU/HA HKW IRB)
Address: Rm 901, Administration Block, QMH Tel 2255 3923 2255 4086 Fax 2255 4735

Dr Michael Sham
Palliative Medical Unit
Grantham Hospital

30-Apr-12

Dear Dr Sham,

IRB Reference Number: **UW 12-202**

The HKU/HA HKW IRB is authorized by a joint agreement of the University of Hong Kong and Hospital Authority Hong Kong West Cluster to review and monitor clinical research. It serves to ensure that research complies with the Declaration of Helsinki and acts in accordance to ICH GCP guidelines, local regulations and Hospital Authority and the University policies.

I write to inform that your research application/submission has been approved by an expedited process with details shown below. You are also requested to adhere to the conditions listed.

Protocol title : Effects of a transitional care model on end-stage heart failure patients: A randomized controlled trial

Study site(s) : Grantham Hospital

IRB reviewer : Professor Simon Law, Deputy Chairman of the HKU/HA HKW IRB

Document(s) approved : 01. Clinical research ethics review application form
: 02. Protocol
: 03. Information sheet and consent form for patients - English and Chinese version
: 04. Information sheet and consent form for caregivers - English and Chinese version
: 05. McGill Quality of life questionnaire - English and Hong Kong version
: 06. Chronic Heart Failure questionnaire - English and Chinese version
: 07. Cost-effectiveness Analysis of Palliative Nursing Home Visit - English and Chinese version
: 08. Caregiver Burden questionnaire - English and Chinese

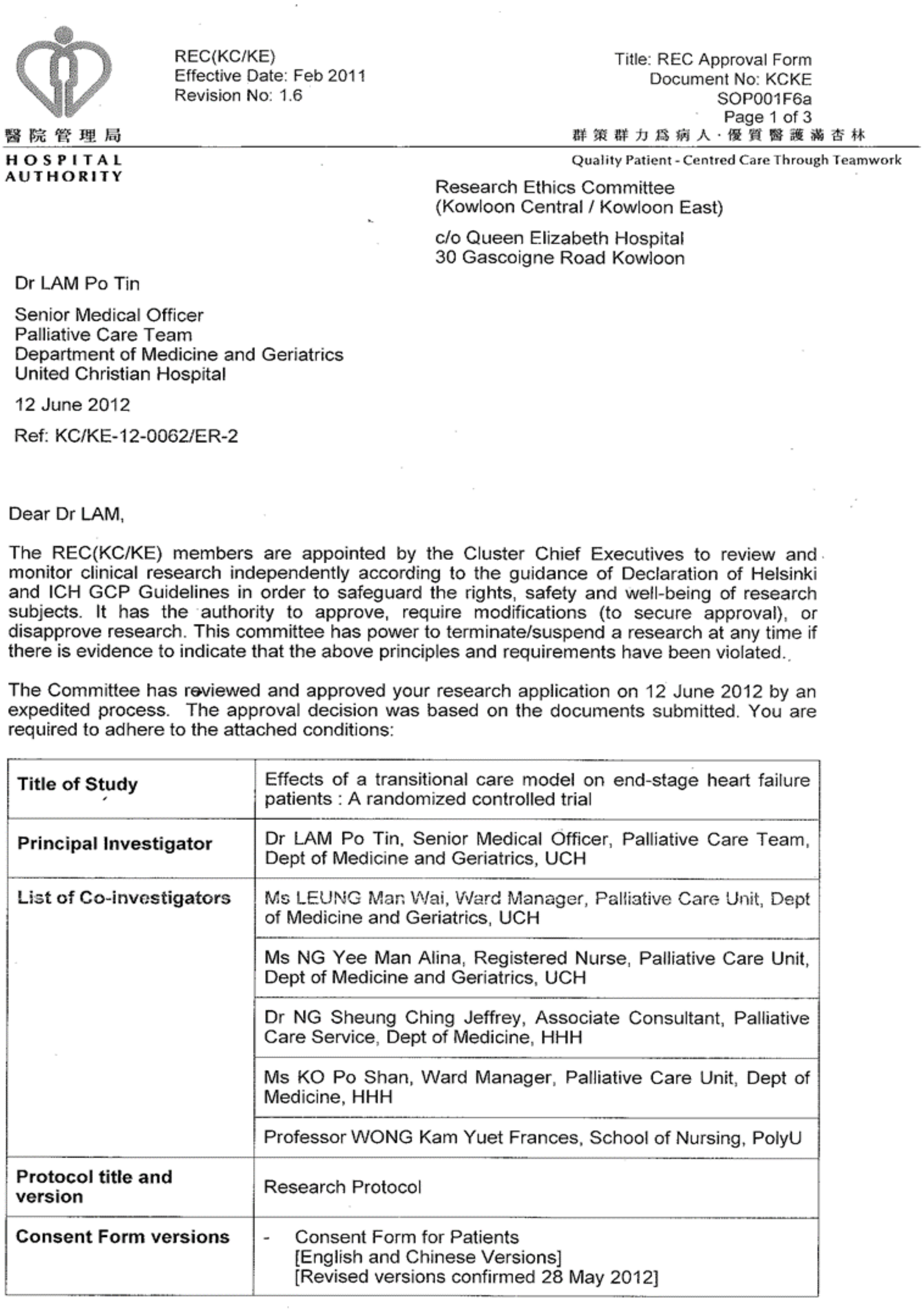
Document(s) reviewed : 09. Short CV of principal investigator and co-investigators

(Conditions
1. Do not deviate from, or make changes to the study protocol without prior written IRB approval, except when it is necessary to eliminate immediate hazards to research subjects or when the change involves only logistical or administrative issues.
2. Report the following to HKU/HA HKW IRB: (i) study protocol or consent document change (use 'HKU/HA HKW IRB RE001F7'), (ii) serious adverse event (use 'HKU/HA HKW IRB RE001F8'), (iii) study progress (use 'HKU/HA HKW IRB RE001F9a') (iv) new information that may be relevant to a subject's willingness to continue participation in the study.
3. Report study progress to HKU/HA HKW IRB at a 12-monthly interval until study closure.)

Yours sincerely,

Mr Chris Yip
HKU/HA HKW IRB Secretary

Appendix 4.10 Ethical Approval (Kowloon East Cluster



醫院管理局
HOSPITAL
AUTHORITY

REC(KC/KE)
Effective Date: Feb 2011
Revision No: 1.6

Title: REC Approval Form
Document No: KCKE
SOP001F6a
Page 1 of 3

群策群力爲病人·優質醫護滿杏林
Quality Patient - Centred Care Through Teamwork

Research Ethics Committee
(Kowloon Central / Kowloon East)

c/o Queen Elizabeth Hospital
30 Gascoigne Road Kowloon

Dr LAM Po Tin

Senior Medical Officer
Palliative Care Team
Department of Medicine and Geriatrics
United Christian Hospital

12 June 2012

Ref: KC/KE-12-0062/ER-2

Dear Dr LAM,

The REC(KC/KE) members are appointed by the Cluster Chief Executives to review and monitor clinical research independently according to the guidance of Declaration of Helsinki and ICH GCP Guidelines in order to safeguard the rights, safety and well-being of research subjects. It has the authority to approve, require modifications (to secure approval), or disapprove research. This committee has power to terminate/suspend a research at any time if there is evidence to indicate that the above principles and requirements have been violated.

The Committee has reviewed and approved your research application on 12 June 2012 by an expedited process. The approval decision was based on the documents submitted. You are required to adhere to the attached conditions:

Title of Study	Effects of a transitional care model on end-stage heart failure patients : A randomized controlled trial
Principal Investigator	Dr LAM Po Tin, Senior Medical Officer, Palliative Care Team, Dept of Medicine and Geriatrics, UCH
List of Co-investigators	Ms LEUNG Man Wai, Ward Manager, Palliative Care Unit, Dept of Medicine and Geriatrics, UCH
	Ms NG Yee Man Alina, Registered Nurse, Palliative Care Unit, Dept of Medicine and Geriatrics, UCH
	Dr NG Sheung Ching Jeffrey, Associate Consultant, Palliative Care Service, Dept of Medicine, HHH
	Ms KO Po Shan, Ward Manager, Palliative Care Unit, Dept of Medicine, HHH
	Professor WONG Kam Yuet Frances, School of Nursing, PolyU
Protocol title and version	Research Protocol
Consent Form versions	- Consent Form for Patients [English and Chinese Versions] [Revised versions confirmed 28 May 2012]

Appendix 4.11 Information sheet

INFORMATION SHEET FOR PATIENTS

EFFECTS OF A TRANSITIONAL CARE MODEL ON END-STAGE HEART FAILURE PATIENTS: A RANDOMIZED CONTROLLED TRIAL

Dear Patient,

You are invited to participate in a study conducted by Grantham Hospital, United Christian Hospital, Haven of Hope Hospital and School of Nursing, The Hong Kong Polytechnic University.

The objective of this research is to examine the effectiveness of a transitional care model on end-stage heart failure patients. This research involves the pre-discharge planning, telephone follow-up and home care visit of 4 weeks post-discharge. You are invited to participate in the assessment interviews before discharge, at about four weeks after the intervention, and twelve weeks after discharged from the hospital.

This research will not cause any uncomfortable feeling and the telephone interviews will be tape recorded. All information related to you will remain confidential, and will be identifiable by codes known only to the researches.
You have every right to withdraw from the study before or during the measurement without penalty of your treatment and nursing.

This study has been reviewed and approved by: Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster.
If you would like to have more information about this study, please contact Dr Michael Sham (Grantham Hospital) at 2518 , Ms Alina Ng (United Christian Hospital) at 3400 , Ms Faith Liu (Grantham Hospital) at 7472 or Professor Frances Wong (The Hong Kong Polytechnic University) at 2766
Thank you for your interest in participating in this study.

Dr Sham Mau Kwong Michael
Principal Investigator

Appendix 4.11 Information sheet

心衰竭患者有關資料

過渡期紓緩治療對於末期心臟衰竭患者的成效研究

親愛的心衰竭患者,

誠邀閣下参加由葛量洪醫院, 基督教聯合醫院, 靈實醫院及香港理工大學護理學院負責執行的研究計劃。

這項研究目的是探討過渡期紓緩治療對於末期心臟衰竭患者的成效。研究會涉及出院前訪談，出院後四星期的個案跟進、護士探訪及電話跟進。研究小組希望這些資料能有效地改善或維持末期心臟衰竭患者的生活質素。下面是詳細資料。

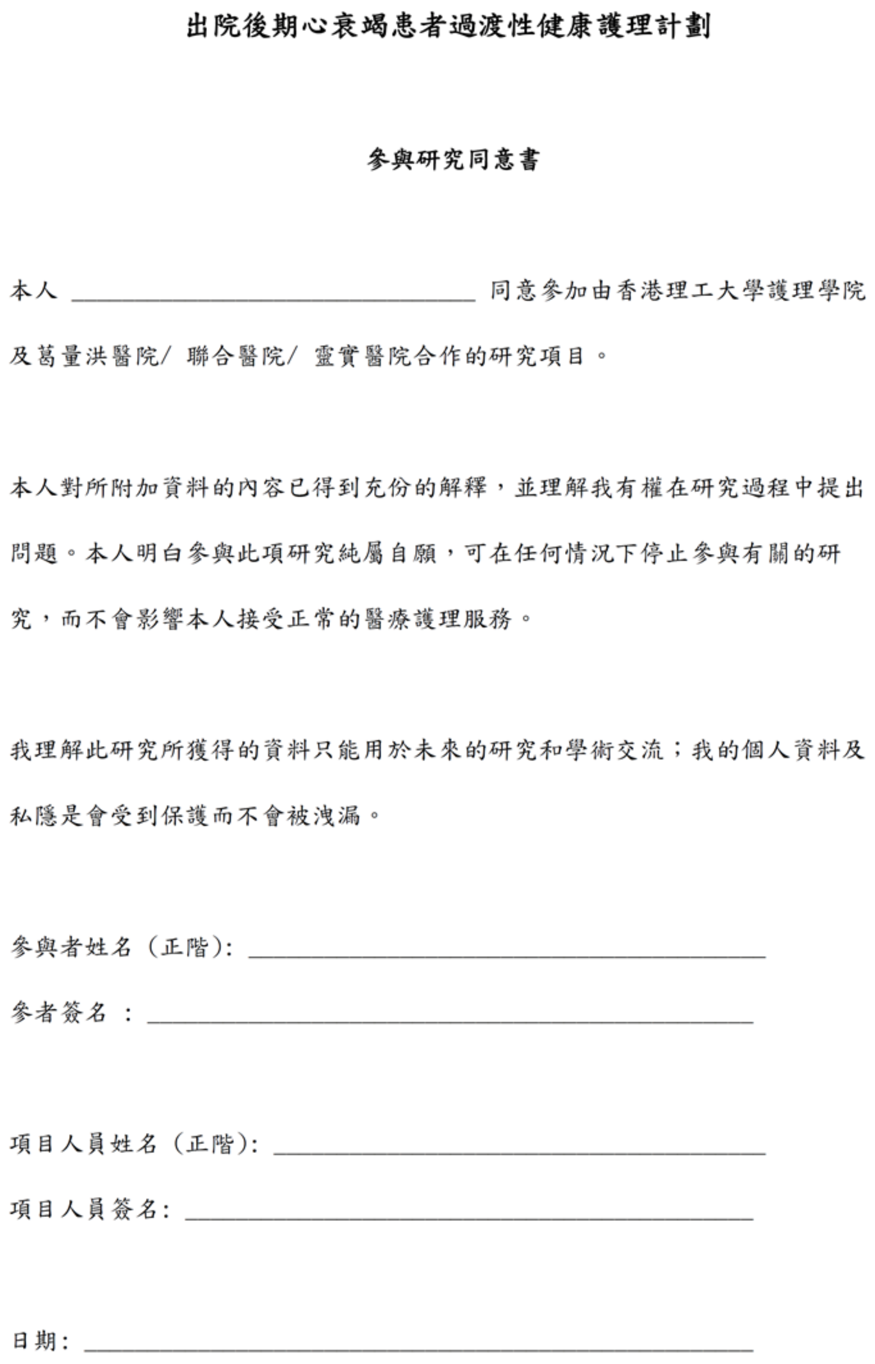
閣下將會被邀在出院前，出院後第四星期及第十二星期接受三次跟進訪談。閣下並將會接受四個星期的護理干預，內容包括護士探訪和電話跟進。在出院前的評估訪談，閣下會跟護士協定出院計劃，跟據閣下的照顧需要設定共同目標。在出院後的階段，閣下會接受四個星期的護理干預：第一星期護士家訪; 第二星期電話跟進; 第三星期家訪; 第四星期電話跟進。閣下會接受症狀評估和相關健康教育，症狀監測和心理支持。

這項研究不會引起任何不適的感覺，閣下之訪問皆會被錄音。 凡有關 閣下的資料均會保密，一切資料以編碼代號，編碼只有研究人員知道。
閣下享有充分的權利在研究開始之前或之後決定退出這項研究，而不會影响閣下所接受的治療及護理。

這項研究已經香港大學及醫院管理局港島西聯網研究倫理委員會審查和批准。
如果閣下想獲得更多有關這項研究的資料，請與沈茂光醫生(葛量洪醫院)，電話 2518 , 吳綺雯小姐(基督教聯合醫院)，電話 3400 ，廖進芳女士(葛量洪醫院),電話 7472 或黃金月教授 (理工大學護理學院), 電話 2766 聯系。
謝謝閣下有興趣參與這項研究

沈茂光醫生
主要研究者

Appendix 4.12 Consent Form



出院後期心衰竭患者過渡性健康護理計劃

參與研究同意書

本人 ______________________________ 同意參加由香港理工大學護理學院及葛量洪醫院/ 聯合醫院/ 靈實醫院合作的研究項目。

本人對所附加資料的內容已得到充份的解釋，並理解我有權在研究過程中提出問題。本人明白參與此項研究純屬自願，可在任何情況下停止參與有關的研究，而不會影響本人接受正常的醫療護理服務。

我理解此研究所獲得的資料只能用於未來的研究和學術交流；我的個人資料及私隱是會受到保護而不會被洩漏。

參與者姓名（正階）: ______________________________

參者簽名 ： ______________________________

項目人員姓名（正階）: ______________________________

項目人員簽名: ______________________________

日期: ______________________________

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