

LEARN to co-manage heart failure:  
Implementation of best practice guidelines

by

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## Abstract

Effective treatment of heart disease and an aging population have led to increases in the incidence of heart failure. Treatment requires complex medication regimes and recognition of symptoms. Best practice guidelines published by the American, European and Canadian cardiac societies promote self-care behaviours and skill building. No concrete examples of education programmes for clients were found in the literature.

The purpose of the study was to develop, pilot and evaluate an education series for clients with heart failure within a primary care setting. "LEARN twice", a three part education series with related resource material, was developed in the context of inter-professional collaboration and drew upon theories of health education, and literacy. The concept of co-management was incorporated as the philosophical basis in the design.

The pilot-test used an experimental design, and incorporated pre and post-testing with standardized instrumentation including the Dutch Heart Failure Knowledge Scale and the Minnesota Living with Heart Failure Questionnaire. To pilot the education series, participants attended three education classes highlighting the essential skills for self management of heart failure. A qualitative descriptive component included brief semi-structured interviews with participants and educators to provide feedback about both the process and content of the educational series.

Limited participant numbers did not permit statistical testing, however potentially promising results were found in the quantitative data collected. Descriptive participant data indicated that the education series was meaningful, and helped

understanding of symptoms. Instructors rated the content as good to excellent and anticipate the adoption of the education series as standard practice in the clinic.

The pilot test of the education series has provided a foundation for future research endeavours, in particular the replication and completion of this study protocol. As clients with heart failure have the potential to be in regular contact with a primary care provider, subsequent studies could include a longitudinal component to examine whether rates of re-hospitalization are reduced for clients who attend an education series.

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## **Dedication**

To the many people who have heart failure in the hope that the journey to better health and improved quality of life is not so fraught with obstacles and barriers.

To my father-in-law Mike Hrynychuk who had to suffer with heart failure in his later years without the benefit of expert knowledge in his care, and no you still cannot take Mom's pills!

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Dutch Heart Failure Knowledge Scale. From “Development and testing of the Dutch Heart Failure Knowledge Scale,” by M. H. L. van der Wal, T. Jaarsma, D. K. Moser, & D. J. van Veldhuisen, 2005b, *European Journal of Cardiovascular Nursing*, 4, 273-277.

Permission granted on April 10, 2012 from Dr. Martje van der Wal.

Minnesota Living with Heart Failure Questionnaire. From “Patients' self-assessment of their congestive heart failure. Part 2: Content, reliability and validity of a new measure, the Minnesota Living with Heart Failure Questionnaire,” by T. S. Rector, S. H. Kubo, & J. N. Cohn, 1987, *Heart Failure*, Oct/Nov, 198-209. Educational use license agreement with University of Minnesota Office for Technology Commercialization #94019 – Minnesota Living with Heart Failure Questionnaire granted on November 4, 2013 and updated on March 26, 2014.

## Chapter 1

### 1. Introduction

#### 1.1 Statement of the Problem

Heart failure is one of the fastest growing conditions in the aging population. It is estimated that there are 330,000 Canadians living with heart failure and 50,000 new cases of heart failure diagnosed each year (Ross et al., 2006). Mortality is high in clients with heart failure, with 50% of patients dying four years after initial diagnosis (Levy et al., 2002).

The incidence of heart failure increases significantly for clients over 65, and is a primary reason for hospital admission (Ezekowitz et al., 2009). The Heart Failure Society of America (HFSA), Lindenfeld et al. (2010), the European Society of Cardiology (ESC), Dickstein et al. (2008); McMurray et al. (2012) and The Canadian Cardiovascular Society (CCS), Arnold et al.(2006); Arnold et al. (2008); Howlett et al. (2010) have each published comprehensive best practice guidelines for use by health practitioners who work with patients with heart failure.

While the best practice guidelines are written primarily for physicians and focus on the investigation, diagnosis, and medical management of patients with heart failure, each set of guidelines includes a section with recommendations for disease management or non-pharmacological interventions (Arnold et al., 2006; Arnold et al., 2008; Howlett et al., 2010; Lindenfeld et al., 2010; McMurray et al., 2012). Disease management is centred on promotion of self-care activities. This includes teaching

patients the skills to be compliant with their treatments, to have the ability to monitor their symptoms, and to seek medical treatment in a timely fashion (Arnold et al., 2006; Arnold et al., 2008; Howlett et al., 2010; Lindenfeld et al., 2010; McMurray et al., 2012). A core concept of the guidelines is that teaching is not sufficient without skill building and the development of critical target behaviours (Lindenfeld et al., 2010). The behaviours are defined as a set of actions a client routinely completes to effectively manage heart failure symptoms (Lindenfeld et al., 2010). In occupational therapy literature, Packer (2011) postulates that self-management programmes must build the client's confidence through problem solving, decision making, action planning, and behaviour change. However within the best practice guidelines which define self management in similar terms, there is no inclusion of, or reference to, occupational therapy in any listing of disciplines involved in the inter-professional care of clients with heart failure.

Primary care physicians are often the first to make the diagnosis of heart failure with their patients (McDonagh et al., 2011; Stewart, 2010). With the support of a consulting cardiologist for diagnosis and treatment, the primary care physician is responsible for routine medical management of heart failure (Stewart, 2010). At the primary care level, the Family Medicine Program at St. Boniface Hospital in Winnipeg focuses on the prevention, diagnosis, and treatment of acute and chronic disease (St. Boniface Hospital, 2014). In addition the promotion and maintenance of general good health in the individual is integral to the programme (St. Boniface Hospital, 2014). The

family physicians that have admitting privileges to the Family Medicine Program provide a continuum of care in the community through the Family Medical Centre (FMC).

The FMC is thus an integral part of the hospital and is a teaching unit of the University of Manitoba (University of Manitoba Family Medicine Program, 2013). It has the distinction of being one of Canada's longest running family medicine teaching units and provides inter-professional care for its patients. In addition to the physicians, the team includes among other professionals, a clinical nurse specialist, dietician and social worker.

In providing care to clients in the community however, the physicians are limited to a twenty minute appointment time for an initial assessment or physical examination and a ten minute appointment for subsequent visits. The physicians and the inter-professional team recognise that for individuals with chronic illnesses a short appointment is not sufficient for the client to learn the skills required to manage the condition. In response, the clinical nurse specialist is available to clients for counselling and education. As part of their programming, the family medicine resident, the clinical nurse specialist and the dietician provide an education programme for clients with diabetes.

While hospitalization of clients with is necessary in situations of acute decompensation of heart failure, attention is not given to the reasons which precipitate the decline in the client's medical stability and this factor is thought to contribute to the frequency of admissions to hospital (Moser & Mann, 2002). The failure of clients to

adhere to medication regimes and their inattention to the escalating symptoms of decompensation are the most common causes for hospitalization (Stewart & Horowitz, 2002a; van der Wal, Jaarsma, & van Veldhuisen, 2005a). Heart failure exacerbations can be prevented with attention to modifiable factors such as adherence to medication regimes and early intervention with symptoms of decompensation (Michalsen, Konig, & Thimme, 1998; Rich, 1999; Stewart & Horowitz, 2002b).

There is a significant body of literature which provides evidence those clients who attend disease management programming experience fewer hospitalizations have improved functional status through symptom management and they enjoy a better quality of life. In addition they also experience more success in managing the ubiquitous co-morbid conditions which accompany a diagnosis of heart failure (Akosah, Shaper, Havlik, Barnhart, & Devine, 2002; Grady et al., 2000; Moser & Mann, 2002; Stewart & Horowitz, 2002b).

In the absence of a disease management programme at the FMC, the design, piloting and evaluation of an education series is a significant first step to the integration of a seamless structure of care for clients with heart failure from inpatient hospitalization to outpatient community care. The target state would be to reduce or eliminate hospital admissions for heart failure exacerbations and to improve overall quality of life for the patient. The education series promotes the concept of co-managed care where the client works with a team of health care professionals to manage their heart failure.

## 1.2 Significance of the Study

The FMC collaborated with the author to design and pilot and evaluate a patient education series on managing heart failure. This original study presents the opportunity for an occupational therapist to lead the implementation of best practice guidelines for disease management. The education series was based upon the recommendations of The Heart Failure Society of America (HFSA), Lindenfeld et al. (2010), the European Society of Cardiology (ESC), McMurray et al. (2012) and The Canadian Cardiac Society (CCS), Arnold et al.(2006); Arnold et al.(2008); Howlett et al. (2010) and was implemented in a primary care setting. The instruments used to evaluate the education programme were standardized tools: the Dutch Heart Failure Knowledge Scale, van der Wal, Jaarsma, Moser, and van Veldhuisen (2005b) and The Minnesota Living with Heart Failure Questionnaire, Rector, Kubo, and Cohn (1987).

The significance of the study is that it provided the opportunity for an occupational therapist to guide an inter-professional initiative in the development piloting and evaluation of an education programme for clients with heart failure who attend the FMC. As occupational therapy is not referenced in the literature as part of the inter-professional management of heart failure, this study will be one of the only documented uses of best practice guidelines by an occupational therapist in the development and implementation of an education series.

## Chapter 2

### 2. Review of the literature

In order to develop, pilot and evaluate an inter-professional educational series, knowledge was required of the etiology, symptoms, signs, and treatment of heart failure. This information provided a basis for understanding the complexities of the condition, while the background of contemporary medical knowledge and treatment allowed the author to design the content of the education series in collaboration with the other disciplines. Liaison with team members, use of best practice guidelines, disease-management strategies, health education and occupational therapy theory provided the subject matter for the content of the series. Implementation required inter-professional collaboration, and an understanding of the tenets of health education and health literacy. A framework for the education series was developed using the concept of co-management, where the patient and the team collaborate on the care provided and received. Evaluation of the education series was undertaken using reliable and valid instruments. The following literature review provides the background and key concepts in each of these areas.

#### 2.1 Definition of Heart Failure

Heart failure is predicated by an event which either causes direct damage to the heart muscle or which affects the capacity of the heart muscle to contract normally (Adams, Zannad, & France, 1998; Mann, 2012). The net effect of heart failure is the inability or failure of the heart to pump an adequate blood volume causing a deficiency

in the delivery of oxygen proportional to the metabolizing tissues of the body (McMurray et al., 2012). The heart pumps with abnormally high filling pressures in the atria and the ventricles which results in pulmonary congestion, systemic congestion and peripheral edema (Lam & Redfield, 2007). The progressive deterioration of the cardiac pump is responsible for the development of arrhythmias (Wilson, Chen, & Houser, 2007).

Lindenfeld et al. (2010) describe heart failure as a syndrome rather than a primary diagnosis, as it has multiple etiologies. Dickstein et al. (2008) report that acute or chronic ischemia; valve disease, hypertension or arrhythmias such as atrial fibrillation are the most common causes of functional deterioration of heart muscle. In 70% of patients heart failure is caused by coronary artery disease as reported by Fox et al. 2001 and diseases of the mitral, tricuspid and aortic valves account for 10% of the etiology of heart failure (Dickstein et al., 2008). Cardiomyopathies which explain another 10% of heart failure occur in the absence of cardiac pathology such as hypertension, valve or congenital heart disease, but result in abnormalities of the structure and function of the heart muscle (Elliott et al., 2008).

The rise in the incidence of heart failure is linked to the fact that advances in medical science have resulted in a decline in mortality from conditions such as myocardial infarction (McDonagh et al., 2014; Murdock et al., 1998). In addition, the aging population and the relative longevity of the population is an important factor in

the prevalence of the disease. It is reported by Rich (1997) that between 5% and 10% of patients older than 75 years have heart failure which results in frequent hospitalizations.

Lindenfeld et al. (2010) have provided the following working definition of heart failure as it affects the functioning of the cardiac muscle:

Heart failure is a syndrome caused by cardiac dysfunction resulting from myocardial muscle dysfunction or loss and is characterized by either left ventricle dilation or hypertrophy or both. Whether the dysfunction is primarily systolic or diastolic or mixed, it leads to neurohormonal and circulatory abnormalities, usually resulting in fluid retention, shortness of breath, and fatigue, especially on exertion. In the absence of appropriate therapeutic intervention, heart failure is usually progressive at the level of cardiac function and clinical symptoms. The severity of clinical symptoms may vary substantially during the course of the disease process and may not correlate with changes in underlying cardiac function. Although heart failure is progressive and often fatal, patients can be stabilized and myocardial dysfunction and remodeling may improve, either spontaneously or as a consequence of therapy. In physiologic terms, heart failure is a syndrome characterized by either or both pulmonary and systemic venous congestion and/or inadequate peripheral oxygen delivery at rest or during stress, caused by cardiac dysfunction (p.480).

## 2.2 Co-morbid conditions in heart failure

Heart failure is not a static condition; symptoms usually progress and fluctuate (Angermann, 2009). As a syndrome, heart failure is a systemic disorder and many chronic diseases are associated with it (Angermann, 2009; Chatterjee, 2013; Greenberg & Kahn, 2012). The specific co-morbid conditions which will be reviewed are: cardio-renal syndrome, chronic obstructive pulmonary disease, diabetes, anemia, and depression. These conditions are linked to adverse clinical outcomes and hospital admission (Braunstein et al., 2003). It has been noted that these co-morbid conditions affecting other organs interact pathologically with heart failure in creating a complex and difficult condition to manage, which affects the choice of medications and treatments available (Angermann, 2009).

Cardio-renal syndrome refers to parallel deterioration of heart and kidney function in which an acute or chronic condition in one organ will cause an acute or chronic condition in the other (Mercado & Heywood, 2013). The kidneys require 20% of cardiac output to function optimally, therefore there is a direct relationship between cardiac and renal function (Mercado & Heywood, 2013). Heart failure can precipitate the onset of acute renal failure and chronic kidney disease through a decline in stroke volume and cardiac output, which reduces the filling of the renal arteries (Schrier & Abraham, 1999). Reduced filling causes an increase in venous pressure which lowers the glomerular filtration rate in the kidneys (Schrier, 2006). A reduction in effective arterial blood volume triggers the arterial baroreceptors to release neurohormones in an attempt to restore perfusion to the kidneys (Liang, Williams, Green, & Redfield, 2008).

Volume retention results in activation of the renin angiotensin aldosterone system (RAAS) which promotes the retention of salt and water and the release of endothelin a potent vasoconstrictor (Selektor & Weber, 2008). In addition, stimulation of the sympathetic nervous system increases venous tone and causes the release of the pituitary hormone, arginine vasopressin, reducing the excretion of free water (Angermann, 2009; Mann, 2012). According to Prempeh and Massie (2013), chronic kidney disease is prevalent in 40% to 50% of clients with heart failure. Kidney disease reduces the production of erythropoietin, the hormone which stimulates production of red blood cells in the bone marrow, causing anemia (Angermann, 2009). Rates of anemia occur between 20% and 50% for clients with chronic kidney disease (Prempeh & Massie, 2013). Fatigue in heart failure is linked to low concentrations of hemoglobin and significantly affects functional status (Falk, Swedberg, Gaston-Johansson, & Ekman, 2006).

Chronic obstructive pulmonary disease (COPD) is found in 20% to 30% of clients with heart failure, as smoking is a risk factor for both diseases (Le Jemtel, Padeletti, & Jelic, 2007). In clients with heart failure, COPD may not be diagnosed, because the dyspnea that accompanies it may be mistakenly thought to be from heart failure and vice versa (Le Jemtel et al., 2007; Rutten et al., 2005). In particular, diagnostic difficulties with COPD and heart failure are common with diastolic heart failure, as diastolic heart failure can manifest with pulmonary edema (Hawkins et al., 2009).

Diabetes has two classifications; Type 2 diabetes, which affects more than 90% of all cases and is characterised by insulin deficiency in a setting of relative insulin resistance and Type 1 diabetes, which occurs as a result of complete insulin deficiency (McGuire, 2012). Diabetes in both its forms causes impairment in myocardial metabolism and structure contributing to the process of failure (Saunders, Mathewkutty, Drazner, & McGuire, 2008). In a failing heart, insulin resistance impairs the efficiency of the myocardium, contributing to cardiomyopathy (Taegtmeier, McNulty, & Young, 2002).

The prevalence of depression is four to five times more prevalent in clients with heart failure when compared with the general population (Light-McGroary, 2013). In 2006, Rutledge, Reis, Linke, Greenberg, and Mills conducted a meta-analysis of 27 studies and found that clinically significant major depression was found in 21.5% in clients with heart failure. It has been postulated that the elevated plasma levels of pro-inflammatory cytokines, as seen in heart failure, inhibits serotonin activity contributing to increased frequency of depressive symptoms (Maier, 2003).

### 2.3 Symptoms and signs of heart failure

Symptoms of heart failure include shortness of breath or dyspnea which is the most frequent presenting symptom of heart failure (Dickstein et al., 2008; Remme & Swedberg, 2001). A history of paroxysmal nocturnal dyspnea (PND) is a very robust indicator of the onset of heart failure, while the symptom of dyspnea at rest or dyspnea with exertion tends to be less clinically significant (Chatterjee, 2013; Greenberg & Kahn,

2012). Fatigue, reduced tolerance to exercise, dry cough, orthopnea, pulmonary edema, peripheral edema and increased abdominal girth are considered part of the symptomatology of heart failure (Greenberg & Kahn, 2012; Lindenfeld et al., 2010; McMurray et al., 2012).

The signs of heart failure include tachycardia, irregular heartbeats, arrhythmia, tachypnea, ascites and pedal edema (Greenberg & Kahn, 2012). Systemic congestion when present does not always imply a diagnosis of heart failure. However if systemic congestion is present in the setting of elevated jugular venous pressure (JVP), there is a sensitivity of 97% and, a specificity of 10% to elevated left sided filling pressures in the heart, which are definitive of heart failure (Chakko et al., 1991; Chatterjee, 2013; Greenberg & Kahn, 2012).

Signs of pulmonary congestion consistent with heart failure are indicated by diminished breath sounds in one or both lung bases on auscultation (Greenberg & Kahn, 2012). Diminished breath sounds correlate with the presence of pleural effusion indicating increased filling pressures on the right and left sides of the heart (Greenberg & Kahn, 2012). In some cases, where left sided ventricular and atrial filling pressures are chronically high, there are gradual changes where the lymphatic and perivascular tissue which preclude accumulation of surplus fluid in the lungs (Greenberg & Kahn, 2012). Reduced cardiac output and systemic hypo-perfusion are the net effects of heart failure and, they can be identified by physical findings on examination (Greenberg & Kahn, 2012). The most common sign to be noted is fatigue with somnolence and reduced

cognitive performance. Other significant signs of inadequate cardiac output and hypoperfusion include tachycardia, cool mottled extremities, low systolic blood pressure, low amplitude of femoral and carotid pulses and low body temperature (Greenberg & Kahn, 2012).

#### 2.4 Diagnosis of heart failure

A definitive diagnosis of heart failure requires assessment of cardiac structure and function to discover the etiology of the symptoms and to determine the amount of pathological changes present in the heart (Lindenfeld et al., 2010). The etiology of the heart failure and the type of heart failure needs to be determined as some forms of heart failure may be correctible (Greenberg & Kahn, 2012). Diagnostic tests are essential in the quantification of heart function (Dickstein et al., 2008) and include the following.

An electrocardiogram (ECG) documents heart rhythm and electrical conduction. It is a simple and very useful test as it will show abnormalities such as sinus tachycardia, sinus bradycardia, atrial flutter or fibrillation and ventricular arrhythmia which assist in the determining the etiology of heart failure (Lindenfeld et al., 2010; Remme & Swedberg, 2001). ECG also provides evidence of myocardial infarction, ischemia and left ventricle hypertrophy (Mc Murray et al., 2012).

Echocardiography is the most reliable test in the diagnosis of heart failure (Connolly & Oh, 2012). It is a non-invasive procedure which uses ultrasonic imaging techniques often enhanced by the use of intravenous contrast agents to provide images

of the hemodynamics, anatomy, and function of the heart (Connolly & Oh, 2012; Dickstein et al., 2008; McMurray et al., 2012; Kirkpatrick, Vannan, Narula, & Lang, 2007).

The hemodynamics of the heart specifically cardiac output, stroke volume (end-diastolic volume minus the end-systolic volume) and ejection fraction (a measure of the efficiency of the heart muscle) can be estimated through echocardiography (Kirkpatrick et al., 2007).

Echocardiography will reveal anatomical abnormalities in the heart consistent with heart failure such as hypertrophy of the ventricles, enlargement or dilatation of the atria, valve stenosis, valve regurgitation or enlargement of the inferior vena cava (Dickstein et al., 2008; Kirkpatrick et al., 2007; McMurray et al., 2012). In addition the motion of the myocardium can be viewed in real time, and deficits in systolic, diastolic and valve function can be evaluated (Dickstein et al., 2008; Kirkpatrick et al., 2007; McMurray et al., 2012).

Chest X-rays are a common clinical test. However, in the presence of echocardiography, chest X-rays do not provide sophisticated information. They are routinely used to detect ventricular enlargement and to provide a pulmonary explanation for the client's symptoms (McMurray et al., 2012). When a client is known to have heart failure and seeks medical attention, chest X-rays can determine the presence of pleural effusion indicating pulmonary congestion (McMurray et al., 2012).

Many important decisions regarding diagnosis, detection of co-morbidities, and management of heart failure can be made from routine laboratory tests of blood

chemistry and hematology (Lindenfeld et al., 2010). Evaluation of sodium and potassium levels indicate electrolyte imbalance which is common in heart failure (McMurray et al., 2012).

Electrolyte imbalance can cause changes to cognition and neuromuscular function as hyponatremia causes generalized cerebral edema (Greenberg & Kahn, 2012; Widdess-Walsh, Sabharwal, Demirjian, & DeGeorgia, 2007). Cognitive symptoms include changes to the level of consciousness and deficits in orientation and executive functioning. Focal neurological signs can manifest as hemiparesis, ataxia, tremor, rigidity and aphasia (Widdess-Walsh, et al., 2007).

Hypokalemia occurs in clients who are taking diuretics and can cause muscle weakness (Riggs, 2002). Testing of blood chemistry will indicate renal impairment through the evaluation of creatinine levels and the estimation of glomerular filtration rate. Standard hematological screening for levels of hemoglobin, hematocrit, leucocytes, ferritin and platelets will uncover anemia, and low hemoglobin levels or infection (Maesel, Bhalla & Braunwald, 2006). Low hemoglobin levels and infections can be the etiology for a previously well client with heart failure to experience decompensation (Greenberg & Kahn, 2012). Thyroid stimulating hormone should be measured as thyroid disease can exacerbate or imitate heart failure. Further, as diabetes is so prevalent with heart failure, blood glucose levels should be evaluated to determine if the client has undiagnosed diabetes (McMurray et al., 2012).

Lastly, exercise testing is not necessary for the diagnosis of heart failure; however it is useful to assess exercise capacity. Functionally, exercise capacity is benchmarked by the New York Heart Association (NYHA) classification scale (Guyatt & Devereaux, 2004; Hamilton & Haennel, 2000). This four level scale, from Class I to IV, identifies the severity of symptoms of dyspnea, fatigue, palpitations, or angina, with Class 1 being symptom free, to Class IV having symptoms at rest (Guyatt & Devereaux, 2004). The method of choice for the measurement of exercise capacity in clients with heart failure is the six minute walk test (Curtis, Rathore, Wang, & Krumholz, 2004). The 6-minute walk test is related to daily physical activity, and closely mimics the daily sub maximal level of energy expenditure required for functional activities (Crapo et al., 2002).

## 2.5 Physiological implications of heart failure

The net effect of heart failure is that diminished cardiac output causes arterial under filling (Mani & Whellan, 2013; Mann 2012; Schrier & Abraham, 1999). This decrease in blood volume is sensed by baroreceptors in the carotid sinus, the aortic arch, and the renal afferent arterioles which elicit activation of the sympathetic nervous system (Mann, 2012). This increases heart rate, myocardial contractility and peripheral arterial vasoconstriction (Liang, Williams, Greene, & Redfield, 2008; Mani & Whellan, 2013; Mann, 2012). In response, neurohormonal mechanisms are triggered in an attempt to increase the arterial circulation and to maintain cardiovascular homeostasis (Mani & Whellan, 2013; Mann, 2012). As a result, activation of the sympathetic nervous system, the renin angiotension aldosterone system (RAAS) and, the inflammatory

cytokine system leads collectively to vasoconstriction with water and sodium retention (Fares, 2008).

The RAAS is extremely sensitive to decreases in renal perfusion and low cardiac output (Angermann, 2009; Mani & Whellan, 2013). In individuals with intact cardiovascular function, the RAAS is activated by a decrease in cardiac output as occurs when hypotension causes arterial under filling, however once the hypotension has been corrected, the RAAS returns to maintaining homeostasis (Mani & Whellan, 2013). In most cases of heart failure the RAAS remains activated (Mani & Whellan, 2013; Mann, 2012). The decrease in renal perfusion affects the glomerular filtration rate and results in sodium and water reabsorption from the proximal tubule. It also stimulates the release of arginine vasopressin (AVP), an anti-diuretic hormone which promotes water absorption by increasing the permeability of the cortical and medullary collecting tubules (Schrier & Abraham, 1999). The activation of the neurohormonal mechanisms causes sodium and water to be re-absorbed in the distal segments of the nephron through the release of aldosterone (Mani & Whellan, 2013; Mann, 2012). Sodium and water retention leads to volume expansion of the vascular and extravascular spaces, and thus causes the swelling of the abdomen, legs, and ankles seen in clients with heart failure (Selektor & Weber, 2008).

Heart failure is quantified in terms of left ventricular ejection fraction (Remme & Swedberg, 2001). Left ventricular ejection fraction (LVEF) is calculated mathematically as a percentage by dividing the stroke volume, which is the end-diastolic volume minus the

end-systolic volume, by the end-diastolic volume (Cohen-Solal, Logeart, & Tartiere, 2008; Dickstein et al., 2008; McMurray et al., 2012). End-diastolic volume is the volume of blood in the left ventricle at the end of diastole, just before contraction. End-systolic volume is the volume of blood after the systolic or contraction phase in the cardiac cycle (Cohen-Solal et al., 2008). By definition ejection fraction is not synonymous with systolic function, as it reflects the efficiency of the myocardium in pumping blood and is dependent on loading conditions and heart rate. The heart does not fully empty with each contraction, thus ejection fraction (EF) is never 100%; normal ejection fraction is 55-75% (<http://www.physiologymodels.info/cardiovascular/heart.html>). EF differentiates diastolic heart failure, or heart failure with preserved ejection fraction (PEF), from systolic heart failure, also referred to as heart failure with reduced ejection fraction (REF) (Dickstein et al., 2008; McMurray et al., 2012; Remme & Swedberg, 2001).

Diastolic dysfunction is a disorder of relaxation and is reported anywhere from 33% to an estimated 50% in the population of patients with heart failure (Hunt et al., 2005; Prendergast & Bunney, 2005; Sherazi & Zareba, 2011). Diastolic dysfunction is more prevalent in the elderly and in women (Rich, 1997; Rich, 2006). Normal diastolic function allows the heart to fill adequately during exercise and rest without incurring an abnormally high diastolic filling pressure (Opie & Hasenfuss, 2012). Diastolic function is determined by left ventricular relaxation and left ventricular compliance (Opie & Hasenfuss, 2012).

In diastolic dysfunction, the left ventricle can be affected in three ways. First, the myocardium is slower to relax and tends to relax incompletely. Secondly, ventricular filling is impaired with a net reduction in end diastolic volume. Thirdly, the ventricle is subjected to pressure overload as a result of increased filling pressures due to hypertension in particular. This in turn causes passive stiffness (Hunt et al., 2007; Cohen-Solal et al., 2008).

Cardiac output is affected in diastolic heart failure. The increase in ventricular filling pressure results in a diminution of the ability of the ventricle to stretch during filling and this reduces end-diastolic volume (Opie et al., 2006; Muhl, Dassen, & Kuipers, 2008). Ejection fraction is defined as being preserved in diastolic heart failure, and is usually documented at 50% in this condition (Chatterjee & Massie, 2007). While preserved, this so-called normal ejection fraction is often associated with a decrease in stroke volume (Chatterjee & Massie, 2007).

This reduction in end-diastolic volume reduces the stroke volume which is the amount of blood pumped per beat (Opie et al., 2006; Muhl et al., 2008). Stroke volume has a direct impact on cardiac output, therefore a reduction in stroke volume results in lowered cardiac output (Connelly & Oh, 2012; Otto, 2001). Pulmonary congestion occurs in later stages of diastolic failure because end diastolic volume continues to decrease leading to a backflow of fluid into the lungs (Chatterjee, 2013).

Systolic heart failure is a disorder of contraction which produces increased myocardial mass, as well as chamber volume or eccentric hypertrophy and, reduced

ejection fraction (Mann, 2012). In two thirds of clients with impairment in contractile function, ischemic changes to the myocardium are caused by myocardial infarction and coronary artery disease (Chatterjee, 2013; Chatterjee & Massie, 2007; Mann, 2012). In the remaining one third of patients, hypertension is the cause of non-ischemic cardiomyopathy resulting in systolic failure (Chatterjee, 2013). Ejection fraction is decreased, resulting in decreased perfusion to end organs, causing sodium and water retention which leads to pulmonary and systemic edema (Lindenfeld & Schrier, 2007).

## 2.6 Treatment

The objectives of treatment in clients who have established heart failure are to manage the symptoms and signs, prevent hospital admission, and improve survival (Dickstein et al., 2008; McMurray et al., 2012; Remme & Swedberg, 2001). Prevention of hospitalization and reduction of mortality are strong predictors of the effectiveness of pharmacological and non-pharmacological treatments (Stewart et al., 2002; Remme & Swedberg, 2001). Success in treatment has been shown by evidence of slowing or preventing the worsening of heart failure, including reversal of left ventricular remodelling (Stewart et al., 2002).

Pharmacological treatments vary and the specific pharmacologic agents used to treat heart failure are described in the following synopsis (Dickstein et al., 2008; Lindenfeld et al., 2010; McMurray et al., 2012; Remme & Swedberg, 2001).

- Angiotensin-converting enzyme (ACE) inhibitors lower blood pressure, improve renal blood flow and stabilize the glomerular filtration rate in the kidney by inhibiting the

action of the RAAS. Angiotensin receptor blockers (ARBs) are used in clients who cannot tolerate ACE inhibitors.

- Beta-adrenergic receptor antagonists (beta-blockers) lower ventricular heart rate and blood pressure. Long term use of beta blockers has been shown to protect from deteriorating ventricular function and, in some cases, an improvement in ventricular function occurs.
- Diuretics have three classifications, loop diuretics, distal convoluted tubule diuretics, and potassium sparing diuretics. Loop diuretics are used to promote diuresis at the thick ascending loop of Henle in the kidneys, by inhibition of the reabsorption of sodium. In this section of the loop of Henle, 25% of the filtered load of sodium chloride is reabsorbed. Loop diuretics are effective in decreasing left ventricular filling pressures and decreasing pulmonary congestion prior to the inception of diuresis. Unfortunately loop diuretics can lower the glomerular filtration rate and therefore cause activation of the RAAS, so they are not suited to all clients with heart failure. Distal convoluted tubule diuretics or thiazide diuretics inhibit sodium and chloride transportation in the early distal convoluted tubule, and are much less potent than loop diuretics. They are used most effectively with loop diuretics, particularly in advanced heart failure when diuretic resistance occurs with progressive renal dysfunction rendering high doses of loop diuretics ineffective. Potassium sparing diuretics are aldosterone antagonists that inhibit sodium reabsorption at the cortical collection tubule in the kidney. Their role is to

counteract the potassium wasting that occurs with loop and thiazide diuretics as sodium is excreted. They can also be used in high doses with careful monitoring in clients with end stage heart failure when diuretic resistance has reduced the effectiveness of loop and thiazide diuretics.

- Arrhythmias are treated with digoxin in a setting of reduced ejection fraction if the client has atrial fibrillation, and especially if the client is unable to tolerate a beta blocker. In cases of ventricular arrhythmia, amiodarone may be considered in clients who cannot tolerate either digoxin or a beta blocker.

Non pharmacological management of heart failure is defined by self-care management and the acquisition of self-care skills (Dickstein et al., 2008; Lindenfeld et al., 2010; McMurray et al., 2012). Self care consists of maintaining physical capacity; avoidance of behaviours that will worsen heart failure and attention to the symptoms of clinical deterioration (Jaarsma, Strömberg, Mårtensson, & Dracup, 2003). To become successful in developing and implementing self-care management strategies, clients need to receive education and counselling as part of a disease management programme (Dickstein et al., 2008; Lindenfeld et al., 2010; McMurray et al., 2012).

Non-pharmacological treatment of heart failure includes exercise and adherence to healthy lifestyle choices such as stopping smoking, reducing alcohol intake and eating a diet low in salt and saturated fat. The success of non-pharmacological interventions is shown by successful symptom management, improved functional capacity and prognosis (Jaarsma et al., 2003).

## 2.7 Occupational Performance Issues

Heart failure results in a decline in quality of life that is sequential and progressive as the condition becomes chronic (Hole, Grundtvig, Gullestat, Flønæs, & Westheim, 2010). A client with a diagnosis of heart failure experiences multiple contributory factors that impact their quality of life. Specifically these factors include: co-morbid conditions, complex medication regimes, cognitive changes, edema, fatigue, disrupted sleep patterns, hospital admissions, and inability to manage the condition (Moser & Watkins, 2008). In addition, the presence or absence of social support, financial resources, suitable living environment and access to treatment are pivotal to determining quality of life (Grady et al., 2000).

Medications for heart failure are prescribed to provide symptom relief and slow disease progression (Fonarow, 2001). This complex drug regime is only effective when taken as prescribed (Stanley & Prasun, 2002). Clients with heart failure often have to take between eight to twelve medications to manage both heart failure and co-morbid conditions (Lien, Gillespie, Struthers, & McMurdo, 2002). In general many clients are not aware of drug-to-drug interactions, and if they have multiple physicians, may be taking medications that are contra indicated (Lien et al., 2002). The clients' success in adherence to a medication regime can be affected by cognitive impairment and health-related literacy (Baker, Gazmarian, Sudano, & Patterson, 2000). Ascione (1994) indicates that older adults' non-adherence to taking medication relates to many factors including limited knowledge about medications. The relationship between patients' medication

knowledge and adherence is articulated by the multi-factor model of adherence developed by Park and Jones (1997). According to their model, adherence depends on cognitive abilities, specifically working and procedural memory. The presence of external cues, examples of which include social support and reminders, are factors that influence compliance with medication regimes. Therefore, clients older than 85 were found to have better adherence to medication regimes as they often receive assistance to take their medications as prescribed (van der Wal et al., 2005a). Gray, Mahoney, and Blough (2001) found that more than 50% of people with clinically stable heart failure were unable to name their medication or doses. Further, 75% failed to take their medication 30 days after receiving standardized one-on-one instruction and written information about the treatment regimen.

Admissions to hospital are often caused by non-adherence to medication regimes, and to a lesser extent to diet and exercise prescriptions (Shah, Der, Ruggerio, Heidenreich, & Massie, 1998). The most frequent indicator of hospitalization for heart failure is weight gain (Shah et al., 1998). Many elderly clients with heart failure fail to understand the importance of this simple intervention and do not recognize the early warning signs of the deterioration in their condition (Stanley & Prasun, 2002). Clients do not recognize or act upon symptoms of a decompensated state of heart failure which is characterized by exertional dyspnea during activity, fatigue, and swelling in the ankles and legs. Parschall, Welsh, Brockopp, Schooler, and Cassidy (2001) report that, while

46% of patients find dyspnea very distressing, a significant percentage did not seek medical care for six or more days.

It is postulated that the clients' inability to interpret their symptoms may be as a result of their difficulty in distinguishing the symptoms from fatigue and the effects of other co-morbid conditions (Stewart & Horowitz, 2002). In addition the incidence of cognitive impairment among patients with heart failure over 65 years was 57%, compared to 20% an age matched cohort without heart failure (Strömberg, 2007). In a comparison of the cognitive function of clients with stable heart failure versus those with decompensated heart failure, Kindermann et al. (2012) found significant differences between the two groups. Clients with stable heart failure demonstrated cognitive impairment in short term and working memory, ability to process visual information and logical reasoning. In contrast the cognitive performance of those with decompensated heart failure was affected in the areas of memory and ability to process visual information, but they also had impairments in executive control, which affects planning, control, problem solving, initiation and inhibition of actions. These impairments in executive function are thought to have a correlation to the delay in seeking treatment in a timely fashion (Kindermann et al., 2012). Reduced cognitive performance is linked to decreased cardiac output and systemic hypo-perfusion (Greenberg & Kahn, 2012). Kindermann et al. (2012) found that when clients stabilized from an episode of decompensation, their cognitive skills returned to the level of clients with stable heart failure.

The cause of fatigue is multi-factorial in heart failure. The low perfusion of vital organs due to reduced cardiac output is the major contributor (Greenberg & Kahn, 2012). In addition the effects of orthopnea and paroxysmal nocturnal dyspnea cause disruption of sleep contributing to sleep deprivation. (Dumitru & Baker, 2014). Disruption of sleep can also be caused by frequent episodes of nocturia, which is precipitated by perfusion to the kidneys once the lower extremities are no longer dependent (Shamsham & Mitchell, 2000).

In summary, occupational performance in self management is significantly impacted by the effects of heart failure. Cognitive impairment, co-morbid conditions and fatigue affect an individual's ability to plan and execute essential routines such as taking medication as prescribed and conscientiously monitoring symptoms to ensure that decompensation does not occur. To compound matters, frequent hospital admissions are correlated with poor outcomes in terms of increased morbidity.

## 2.8 Disease Management

Heart failure is an inherently difficult condition to treat given the number of co-morbid conditions which accompany it, and require pharmacological treatment (Akosah et al., 2002). Successful management of heart failure requires comprehensive education and counselling of the client, their family, and their caregivers (Lindenfeld et al., 2010; McMurray et al., 2012). The clients and their supports need to acquire knowledge of heart failure, and become proficient in self-management behaviours and problem solving (Lindenfeld et al., 2010; McMurray et al., 2012). It is of particular importance

that the client, their family and care givers are aware that success in management of heart failure requires adherence to the prescribed treatment plan, including the pharmacological management of the condition (Moser & Mann, 2002). As heart failure is primarily a disease of the elderly, the client may experience difficulty with cognition, functional limitations and the effects of the co-morbid conditions that reduce their comprehension, and their ability to perform the tasks that they have learned (Lindenfeld et al., 2010; McMurray et al., 2012). It is therefore important that they receive family, or caregiver support. Improvement in knowledge is related directly to the acquisition of self-care skills, and compliance with the heart failure regime (Stewart, Pearson, & Horowitz, 1998; van der Wal et al., 2005a).

While there is evidence that disease management programmes have a neutral effect in promoting self management of heart failure (Jaarsma et al., 1999), the majority have demonstrated results which are positive (Naylor et al., 1999; Krumholtz et al., 2002; Rich, 1999; McAlister, Lawson, Teo, & Armstrong, 2001). Inter-professional management strategies for patients with heart failure show that these programmes are associated with 43% reduction in total number of hospitalizations related to heart failure (McAlister et al., 2001). Sochalski et al. in 2009 reanalyzed data from ten randomized clinical trials of heart failure management programmes and found that clients enrolled in programmes using multidisciplinary teams and in programmes using in-person communication had significantly fewer hospital readmissions than those clients who did not receive such care.

Stewart and Horowitz in 2002 studied the long term effects of a multidisciplinary home based heart failure education programme versus usual care. The study where the clients were followed for a median of 4.2 years showed that there were significantly fewer unplanned hospitalizations or deaths in the group receiving home-based interventions versus the usual care group. Out of a study group of 149 and a control group of 148, fewer of the study group died (56% versus 65%). In addition they had a 40 versus a 22 month survival rate post education and, they had 78 fewer unplanned hospital admissions with heart failure symptoms.

Practical self-care management recommendations of heart failure based on the 2008 European Society of Cardiology guidelines were published by Lainscak et al. in 2011. The purpose of these recommendations was to provide health care providers with the available evidence on the promotion of non-pharmacological interventions of self-care management and lifestyle. Disease management programmes are supported by studies that endorse the concept that a patient with heart failure benefits from such interventions (Del Sindaco et al., 2007; Gonseth, Gualler-Castillorn, Banegas, & Rodrigues-Atalejo, 2004; McAlister et al., 2001). These studies, conducted by physicians and nurses, generally attribute successful disease management to reduction in hospital admissions. Several studies report success with education and counselling on readmission and mortality of clients with heart failure (Krumholtz, Amatruda, Smith, Mattera, Roumanis, Radford, et al., 2002; Rich, Beckham, Wittenberg, Leven, Freedland,

& Carney, 1995; Stewart, Marley, & Horowitz, 1999; Strömberg, Martensson, Fridlund, Levin, Karlsson, & Dahlstrom, 2003).

The majority of clients with heart failure are treated by their primary care physician who is the first point of contact for the patient with signs and symptoms of heart failure (Lee et al., 2003; McDonagh et al., 2011). The challenge for the primary care physician is that clinic visits alone, without access to heart-failure specific education, and referral to specialist care, are not sufficient to reduce hospitalizations or to improve quality of life for their patients with heart failure (Arnold et al., 2006). Howlett et al. (2010), endorse that a disease management programme should be integral in a primary care setting, and should complement the interventions provided by the primary care physician. Howlett et al. (2010) also outline the need for coordination of services between the primary care physician and specialist services such as a cardiologist, and diagnostic testing such as echocardiogram and angiography. The primary care physician also needs to be able to access community based services such as home care and cardiac rehabilitation for their patients (Lindenfeld et al., 2010). Thus effective management of heart failure depends upon the delivery of a continuum of care that includes interventions in the hospital and community setting that are congruent with each other (McMurray et al., 2012). The hope in management of heart failure is to be able to provide treatment within a framework which is not based on a response to a crisis, such as when a client presents to an emergency department critically ill in a decompensated state (Akosah et al., 2002). The presumption of a disease management

programme is that heart failure is always an active disease process regardless of whether the client has symptoms or not (Akosah et al., 2002).

A disease management programme includes discharge planning from inpatient care, continuing education, therapy optimization, improved communication with healthcare providers, early attention to signs and symptoms and flexible diuretic regimen (Remme & Swedberg, 2001). The British Columbia Heart Failure Network (2011) has defined the process of co-management which refers to the concept of a client working with a team of health care professionals to manage their heart failure. Within the context of co-management of heart failure, inter-professional practice is defined as the provision of comprehensive health services to patients by multiple health caregivers who work collaboratively to deliver care of excellent quality. This approach is strongly advocated as a methodology to improve the management of a chronic condition such as heart failure (Closson & Oandasan, 2007). Successful outcomes of disease management programmes include reductions in hospital admissions, improvement in patient knowledge, and in the ability of clients to manage their disease (Piepoli et. al., 2006; Gonseth et al., 2004).

The Heart Failure Society of America (HFSA), Lindenfeld et al. (2010), the Canadian Cardiovascular Society, Arnold et al.(2006);Arnold et al. (2008); Howlett et al. (2010) and the European Society of Cardiology (ESC), Dickstein et al. (2008); McMurray et al. (2012) provide clear direction for the provision of disease-management programmes. A disease-management programme by definition is a coordinated

multidisciplinary approach to treating a chronic disease. To this end, the American Heart Association (AHA) published by Faxon et al. 2004 has outlined nine guiding principles for the development, implementation and evaluation of disease management initiatives. These principles emphasize that the goal of disease management is to improve the quality of care and to promote cost effective care. Inherent in the programming are interventions to enhance adherence to scientific, peer-reviewed guidelines and treatment plans which are evidenced based and consensus driven. The AHA also concludes that disease-management programmes should help to increase adherence to treatment plans based upon the best evidence available and have scientifically based evaluations including clinical outcomes. They should exist, and be integrated within a comprehensive system of care which is grounded in a solid relationship with the primary care physician and their patient (Faxon et al., 2004).

The HFSA guidelines, Lindenfeld et al. (2010) recommend that clients' literacy, cognitive status, culture and access to social and financial resources be taken into account for optimal education and counselling. Educational sessions should begin with an assessment of current heart failure knowledge and discussion of issues that the client wishes to learn, in addition to the assessment of the clients' perceived barriers to change. The HFSA recommends that patients with heart failure and their caregivers receive education and counselling which is individual and emphasizes acquisition of self-care skills.

The European Society of Cardiology guidelines, McMurray et al. (2012) and Dickstein et al. (2008) recommend that clients with heart failure be enrolled in a multidisciplinary-care management programme to reduce the risk of heart failure hospitalization. The ESC guidelines published by McMurray et al. (2012) describe the characteristics and components of management programmes for patients with heart failure. These factors are outlined in Table 1, which is reproduced with permission from the author. Central to the characteristics is the use of a multidisciplinary approach. The components include adequate patient education, with emphasis on skill acquisition on the part of the client (McMurray et al., 2012). Teaching is deemed insufficient if it does not focus on skill building and the development of critical target behaviours (Lindenfeld et al., 2010). The elements of education and the skill building and critical target behaviours are outlined in Table 2, which is also reproduced with permission from the author.

The HFSA guidelines Lindenfeld et al. (2010) also iterate that repeated exposure to material is recommended because a single session is never sufficient. Specific skills that patients should acquire are knowledge of name, dose and purpose of each medication, ability to maintain a daily weight log and to sort food into low and high sodium categories, ability to reiterate the symptoms of worsening heart failure and to know when to call their health care provider with symptoms of heart failure or an increase in weight (Lindenfeld et al., 2010).

Table 1

*Essential topics that should be covered during patient education and the skills and self-care behaviours that should be taught in relation to these topics*

<b>Educational topic</b>	<b>Patient skills and self-care behaviours</b>
<b>Definition and aetiology</b>	<ul style="list-style-type: none"> <li>• Understand the cause of heart failure and why symptoms occur</li> </ul>
<b>Prognosis</b>	<ul style="list-style-type: none"> <li>• Understand important prognostic factors and make realistic decisions</li> </ul>
<b>Symptom monitoring and self-care</b>	<ul style="list-style-type: none"> <li>• Monitor and recognize signs and symptoms</li> <li>• Record daily weight and recognize rapid weight gain</li> <li>• Know how and when to notify healthcare provider</li> <li>• In the case of increasing dyspnoea or oedema or a sudden unexpected weight gain of &gt;2 kg in 3 days, patients may increase their diuretic dose and/or alert their healthcare team</li> <li>• Use flexible diuretic therapy if appropriate and recommended after appropriate education and provision of detailed instructions</li> </ul>
<b>Pharmacological treatment</b>	<ul style="list-style-type: none"> <li>• Understand indications, dosing, and effects of drugs</li> <li>• Recognize the common side effects of each drug prescribed</li> </ul>
<b>Adherence</b>	<ul style="list-style-type: none"> <li>• Understand the importance of following treatment recommendations and maintaining motivation to follow treatment plan</li> <li>• Sodium restriction may help control the symptoms and signs of congestion in patients with symptomatic heart failure classes III and IV</li> </ul>
<b>Diet</b>	<ul style="list-style-type: none"> <li>• Avoid excessive fluid intake: fluid restriction of 1.5–2 L/day may be considered in patients with severe heart failure to relieve symptoms and congestion. Restriction of hypotonic fluids may improve hyponatraemia. Routine fluid restriction in all patients with mild to moderate symptoms is probably not of benefit. Weight-based fluid restriction (30 mL/kg body weight, 35 mL/kg if body weight &gt;85 kg) may cause less thirst</li> <li>• Monitor and prevent malnutrition</li> <li>• Eat healthily and keep a healthy weight (see Section 11)</li> </ul>
<b>Alcohol</b>	<ul style="list-style-type: none"> <li>• Modest intake of alcohol: abstinence is recommended in patients with alcohol-induced cardiomyopathy. Otherwise, normal alcohol guidelines apply (2 units per day in men or 1 unit per day in women). 1 unit is 10 mL of pure alcohol (e.g. 1 glass of wine, 1/2 pint of beer, 1 measure of spirit)</li> </ul>
<b>Smoking and drugs</b>	<ul style="list-style-type: none"> <li>• Stop smoking and/or taking illicit drugs</li> </ul>

Educational topic	Patient skills and self-care behaviours
<b>Exercise</b>	<ul style="list-style-type: none"> <li>• Understand the benefits of exercise</li> <li>• Perform exercise training regularly</li> <li>• Be reassured and comfortable about physical activity</li> </ul>
<b>Travel and leisure</b>	<ul style="list-style-type: none"> <li>• Prepare travel and leisure activities according to physical capacity</li> <li>• When travelling, carry a written report of medical history and current medication regimen and carry extra medication. Monitor and adapt fluid intake particularly during flights and in hot climates. Beware adverse reactions to sun exposure with certain medications (e.g. amiodarone)</li> </ul>
<b>Sexual activity</b>	<ul style="list-style-type: none"> <li>• Be reassured about engaging in sex and discuss problems with healthcare professionals. Stable patients can undertake normal sexual activity that does not provoke undue symptoms. For treatment of erectile dysfunction, see Section 11.10</li> </ul>
<b>Immunization</b>	<ul style="list-style-type: none"> <li>• Receive immunization against influenza and pneumococcal disease according to local guidelines and practice</li> </ul>
<b>Sleep and breathing disorders</b>	<ul style="list-style-type: none"> <li>• Recognize preventive behaviour such as reducing weight in obese patients, smoking cessation, and abstinence from alcohol</li> <li>• Learn about treatment options if appropriate</li> </ul>
<b>Psychosocial aspects</b>	<ul style="list-style-type: none"> <li>• Understand that depressive symptoms and cognitive dysfunction are common in patients with heart failure and the importance of social support</li> <li>• Learn about treatment options if appropriate</li> </ul>

Note. From *ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2012*. McMurray, J. V. J., Adamopoulos, A., Anker, S. D., Auricchio, A., Boehm, M., Dickstein K. . . . Zeiher, A. (2012). *European Heart Journal*, 33, 1787-1847. Copyright (2012) by the European Society of Cardiology. Reprinted with permission.

Table 2

*Essential Elements of Patient Education with Associated Skills and Target Behaviours*

Elements of Education	Skill Building and Critical Target Behaviors
Definition of HF (linking disease, symptoms, and treatment) and cause of patient's HF	<ul style="list-style-type: none"> <li>• Discuss basic HF information, cause of patient's HF, and how symptoms relate to HF status</li> </ul>
Recognition of escalating symptoms and concrete plan for response to particular symptoms	<ul style="list-style-type: none"> <li>• Identify specific signs and symptoms (e.g., increasing fatigue or shortness of breath with usual activities, Dyspnea at rest, nocturnal dyspnea or orthopnea, edema)</li> <li>• Perform daily weights and know how to respond to evidence of volume overload</li> <li>• Develop action plan for how and when to notify the provider, changes to make in diet, fluid and diuretics</li> </ul>
Indications and use of each medication	<ul style="list-style-type: none"> <li>• Reiterate medication dosing schedule, basic reason for specific medications, and what to do if a dose is missed</li> </ul>
Modify risks for HF progression	<ul style="list-style-type: none"> <li>• Smoking cessation</li> <li>• Maintain blood pressure in target range</li> <li>• Maintain normal HgA1c, if diabetic</li> <li>• Maintain specific body weight</li> </ul>
Specific diet recommendations: individualized low-sodium diet; recommendation for alcohol intake	<ul style="list-style-type: none"> <li>• Understand and comply with sodium restriction</li> <li>• Demonstrate how to read a food label to check sodium amount per serving and sort foods into high- and low-sodium groups</li> <li>• Reiterate limits for alcohol consumption or need for abstinence if history of alcohol abuse</li> </ul>
Specific activity/exercise recommendations Importance of treatment adherence and behavioral strategies to promote	<ul style="list-style-type: none"> <li>• Comply with prescribed exercise</li> <li>• Plan and use a medication system that promotes routine adherence</li> <li>• Plan for refills</li> </ul>

Note. From *Executive summary: HFSA comprehensive heart failure practice guideline*. Lindenfeld, J., Albert, N. M., Boehmer, J. P., Collins, S. P., Ezekowitz, J. A., Givertz, M. M., . . . Klapholz, M. (2010). *Journal of Cardiac Failure*, 16 (6), 475-539. Copyright (2010) by J. Lindenfeld. Reprinted with permission.

Studies described as multidisciplinary include teaching or counselling by dietitians, social workers, physiotherapists and pharmacists (McDonald et al., 2002; Rich et al., 1995; Stewart, 2010). The literature has shown that holistic interventions with clients who have chronic conditions have shown promise in determining the clients' ability to self manage the condition (Fonarow, 2001; Morrow et al., 2005; Seligman et al., 2007). However, studies to date do not involve occupational therapy as a team member. As experts in enabling occupation, occupational therapists use evidence-based practice as a medium to plan service delivery which is distinctive to the needs of the client (Canadian Association of Occupational Therapists, 2012). Thus as collaborators and change agents, occupational therapists are uniquely equipped with the skills to lead professionals in the development of programmes and services, within health care systems (Canadian Association of Occupational Therapists, 2012). Therefore occupational therapy involvement in disease management programmes especially within the context of acquisition of self-care management skills is relevant and appropriate.

The European Society of Cardiology guidelines, McMurray et al. (2012) and Dickstein et al. (2008) recommend regular aerobic exercise for clients with heart failure to improve functional capacity and symptoms. The 2006 Canadian Cardiovascular Society guidelines as reported by Arnold et al. (2006) recommend that all patients undergo a graded exercise stress test to assess their exercise capacity, to determine if there are issues with angina and to establish a target heart rate for exercise training. If

possible, clients with heart failure should exercise three to five times weekly for thirty to forty-five minutes inclusive of warm up and cool down to prevent muscle de-conditioning (Arnold et al., 2006). Aerobic activity and resistance training can be performed at moderate intensity as tolerated (Arnold et al., 2006). It is also recommended that exercise training be performed in a supervised setting with trained personnel and access to external defibrillators if possible (Arnold et al., 2006).

Additionally, the Heart Failure Association and the European Association for Cardiovascular Prevention and Rehabilitation have published a consensus document on exercise training (Piepoli et al., 2011). This comprehensive position statement provides guidance for implementation of exercise training programmes. Continuous endurance training, interval endurance training, and resistance strength training can all be safely implemented with clients with heart failure who are medically stable (Piepoli et al., 2011; Remme & Swedberg, 2001). A barrier cited to exercise training is that physicians and other health care professionals are wary of prescribing it because exercise tends to cause a manifestation of symptoms similar to heart failure itself, particularly breathlessness or dyspnea (Piepoli et al., 2011). Exercise thus becomes limited to a minimal amount of activity so as not to incur dyspnea (Piepoli et al., 2011). Health care providers are nervous in causing adverse reactions in their clients. In the case of heart failure, counter-intuitive thinking needs to prevail when exercise is considered (Piepoli et al., 2011). A large randomised controlled trial investigated the effects of exercise training concluded that exercise training is safe and that it resulted in modest significant

reductions (11%) of all-cause mortality or all-cause hospitalization (O'Connor et al., 2009).

## 2.9 Theoretical Frameworks

Occupational therapists are trained to provide interventions to clients with chronic conditions, and have developed theoretical models and practice frameworks which embrace holistic approaches to client intervention (Law, Polatajko, Baptiste, & Townsend, 1997). Occupation, in this sense, refers to groups of activities and tasks of everyday life, which are named, organized, given value and meaning by individuals and a culture (Townsend, 2004). According to Townsend, 2004, p.181, "Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)."

In all major models of occupation, occupational therapists are tasked with the responsibility of assessing occupational performance within many constructs. The theoretical foundations for this study are informed by the Person Environment-Occupation (PEO) Model, Law et al. (1996), the Canadian Model of Client-Centered Engagement (CMCE), (Townsend, Polatajko, Craik, & Davis, 2007). The PEO model examines the dynamic relationship between the person, the environment and occupation and thus permits the occupational therapist to consider the complexities of daily human experiences. It facilitates analysis of problems in occupational performance and evaluation of the outcomes of occupational therapy interventions. As it is dynamic,

flexible, and considers transactional relationships across time, the PEO model is suitable for use in inter-professional practice settings where change in occupational performance will be used as a determinant of outcome (Strong, Rigby, Stewart, Law, Letts, & Cooper, 1999).

The CMCE, authored by Townsend et al. (2007) is a visual model that shows what occupational therapists do with their clients who may be individuals, families, groups, communities, organizations or populations. The CMCE defines a spectrum of enablement skills that include the actions of adapt, advocate, coach, collaborate, consult, coordinate, design/build, educate, engage, and specialize as the key skills for client-centered, occupation-based enablement. The actions of coaching and educating are critical for the client to acquire the skills necessary to manage the condition of heart failure. This theory reflects the concept of co-management used in the care of patients of the Family Medical Centre. Co-management refers to the philosophy in which the client is assisted in management of their disease by a team of health professionals (British Columbia Heart Failure Network, 2011).

Teaching is a core construct within the CMCE and Townsend et al. (2007). However, the concept of health literacy and numeracy, or the theories of health education, has not been incorporated into methodological descriptions of the construct. Rootman and Gordon-El-Bihbety (2008) suggest that health literacy be made a mandatory component of service provider curricula, professional continuing education, professional registration and certification.

In developing the education series health education theory was critically reviewed to understand and integrate concepts into the process. Health education spans a continuum from the prevention of disease and the promotion of optimal health, to the detection of illness, treatment, rehabilitation and long term care (Glanz, Rimer, & Viswanath, 2008). It is inclusive of acute and chronic conditions, infections and environmental issues, and is defined as a process in which learning is designed to facilitate voluntary adaptations of behaviours conducive to health (Glanz et al., 2008). The process encompasses the physical, mental, emotional and social aspects of health behaviours (Glanz, et al., 2008).

In order for health education to be successful and effective, knowledge of the target audience is essential (Caserta, 1995). This knowledge includes the health and social characteristics, attitudes, beliefs, and skills of the individuals to be educated (Lindenfeld et al., 2010) Assessment of the important characteristics of a cohort should include recognition that socio-economic status has been linked to health status and health behaviours (Glanz, et al., 2008). Clients who are less materially affluent often experience higher levels of morbidity and mortality than more affluent individuals (Glanz, et al., 2008). Racial background, ethnicity and cultural factors must be considered in the development of educational materials which reach consumers (Caserta, 1995; Glanz et al., 2008). In a perfect world, health education materials should be congruent with the educational and reading levels of the consumer and be compatible with their racial, ethnic and cultural backgrounds (Rootman & Ronson,

2004). Education is given at every stage of the life cycle and must be sensitive to the vulnerabilities which are present and may affect people at different points in their life cycle (Glanz, et al., 2008). Individual and collective beliefs change as a generation ages and these need to be taken into account when designing an educational intervention (Glanz, et al., 2008). Numerous theories of health education have been developed. Three in particular, the health belief model, the precaution process adoption model, and ecological models of health behaviour will be examined in detail as they are the most applicable to education of clients with heart failure.

#### Health Belief Model

The Health Belief Model (HBM) as outlined by Champion & Skinner (2008), and Rosenstock (1974), was developed in the 1950s in response to the tuberculosis outbreak and was used to explain the failure of people to participate in programmes that were designed to prevent and detect disease. It continues to be one of the most widely used conceptual frameworks in health behaviour research. The HBM is used as a framework to explain change in health-related behaviours, and for health behaviour interventions. It is a cognitive model with foundations in social-cognitive theory that does not consider the emotional component of behaviour. The HBM is based on several constructs that predict why people will take action to prevent, have screening for, or to control health conditions.

1. Perceived Susceptibility: This construct relates to beliefs about the possibility of getting a disease or a condition. For example a client must believe that there is a

- possibility of having elevated cholesterol before being interested in a cholesterol test.
2. Perceived Severity: This is the threat of having an illness in combination with the construct of susceptibility. The client may experience feelings about the seriousness of contracting an illness or of leaving it untreated.
  3. Perceived Benefits: It is not always the case that perception of personal susceptibility to a serious illness or health condition leads to a behaviour change. A person has to perceive that the action they will take has potential benefit in reducing the threat that the illness or health condition poses.
  4. Perceived barriers: Perceived barriers are the impediments that cause people not to comply with recommended behaviour changes. It may be that the change requires expense, there may be unpleasant side-effects or, it is time-consuming.
  5. Cues to action: This construct has not been well studied within the HBM. It focuses on the concept that there are potential environmental events such as posters seen at a doctor's office or bodily events that cue an individual to take action around a health issue. This is based upon the knowledge that the person may already have acquired through an education process.
  6. Self-Efficacy: Bandura (1997) defines self-efficacy as "belief in one's capabilities to organize and execute the courses of action required to produce given attainments" (P. 3). Self-efficacy is based in social cognitive theory and considered very important as a construct in the initiation and maintenance of behaviour change. For behaviour

to change a client must feel that there is a threat from their current behavioural patterns and believe that there will be a valued or significant outcome or perceived benefit to making a behavioural change.

7. Additional variables: Health related behaviour could be indirectly influenced by socio-demographic factors such as educational attainment, language barriers and culture.

The HBM has been used frequently to explain the adoption of health protective behaviour, and empirical support for its success is substantial. In the studies that have been conducted, perceived barriers were the most powerful predictor of behaviours. In addition perceived susceptibility was a stronger predictor of preventive health behaviour (Glanz, et al., 2008). There is need for an updated review of the HBM, and in more recent literature, Weinstein (1993) questions the effectiveness of the model in terms of 'precaution.' As the HBM is based on asking questions of respondents about the effectiveness of the precaution in reducing risk, there is a bias from one respondent to another in terms of personal opinion that has not been tested. In addition, Weinstein has posited that the theory is silent on the factors that might intervene between the attractiveness of the perceived susceptibility (risk and severity), and the adoption of measures of preventive health behaviour. In its defence, Glanz, et al. (2008) identify the simplicity of the theory in its effectiveness in predicting and framing screening for diseases such as cancer, and protective behaviour such as with Human Immunodeficiency Virus (HIV). The constructs have been tested for content and

construct validity in addition to internal consistency and test-re-test reliability.

Cronbach's alpha was .75 for benefits and .88 for barriers. Perceived susceptibility has shown the highest internal consistency and reliability across studies.

Table 3 defines key concepts and definitions of the Health Belief Model with the condition of heart failure.

Table 3

*Key concepts and definitions of the Health Belief Model with the condition of heart failure*

<b>Concept</b>	<b>Definition</b>	<b>Application(s)</b>
<b>Perceived susceptibility</b>	Belief about the chances of getting a disease or condition.	Define population at risk for heart failure, e.g. clients over the age of 65 with myocardial infarction. Personalize risk based on clients past medical history, e.g. heart attack, high blood pressure. Risk must be made consistent with client's individual risk, e.g. non-compliance with medications.
<b>Perceived risk</b>	Belief about how serious a condition and its sequelae are.	Consequence of not taking medication is that condition worsens and client can be hospitalized. Risk must be made consistent with client's individual risk, e.g. non-compliance with medications.
<b>Perceived benefits</b>	Belief in efficacy of the advised action to reduce risk or seriousness of impact	Take medications as prescribed. Monitor weight gain and report weight gain over more than 5 pounds per week to doctor.
<b>Perceived barriers</b>	Belief about the tangible and psychological costs of advised action	Provide ongoing assistance to client to understand the severity of the condition and need for self management of the condition
<b>Cues to action</b>	Strategies to activate "readiness"	Provide an effective and measureable education process to teach clients medication management and monitoring of weight gain
<b>Self-efficacy</b>	Confidence in one's ability to take action	In consultation with client devise progressive goals to achieve sustainability of new behaviours. Client should be able to demonstrate desired behaviours and thus experience reduced anxiety.

Adapted from Champion, V.L., & Skinner, C.S. (2008). The health belief model. In K. Glanz, B.K. Rimer, & K. Viswanath (Eds.), *Health Behaviour and Health Education* (pp.45-65). San Francisco CA: Jossey-Bass.

### The Precaution Adoption Process Model (PAPM)

The PAPM is a stage theory that explains how a person makes decisions about when to take action or how a person will translate a decision into action. For a person to adopt a precaution or, to discontinue a behaviour that causes risk to them, it requires a conscious decision and the use of a step-wise process. Janis & Mann first proposed the theory in 1977, and Weinstein, Sandman & Blalock published its current version in 1992. PAPM has seven stages and follows a path from lack of awareness to action (Sallis, Owen, & Fisher, 2008). The following is a summary of the stages applied for the purpose of the thesis in the context of heart failure and exercise.

1. Stage 1 (Unaware). The client is unaware of the hazard or risk to themselves. In the case of heart failure, it may be that the client has never heard of an exercise prescription for the condition.
2. Stage 2 (Unengaged by the issue). When a person has received information about the health condition, they are no longer at Stage 1; however the client can be aware, without personal engagement. At this stage there is also the distinction between people who have never thought about taking action and those who have thought about taking action but are undecided about doing so. This important distinction between the two types of thought processes entails different types of communications to encourage the client to become aware of the issue or the potential risk. In the case of heart failure, this may relate to the client having never

- thought about an exercise prescription, but if they did think about it, they did not strategize about how implement or to participate in an exercise programme.
3. Stage 3 (Undecided). There are differences between people who have formed a decision and those who have not formed opinions. Those who have formed opinions, even if they have not acted upon them are generally more resistant to persuasion than those who have not formed an opinion. In this situation, the client may not be able to see the benefit of an exercise prescription and chooses not to act upon it, moving to Stage 4 (decided not to act). For those clients who decide to act, they move to Stage 5 (decided to act).
  4. Stage 6 (Acting) and Stage 7 (Maintenance). While the decision to act is often accompanied by feeling of success, the maintenance of success is more challenging. There is a distinction between action and maintenance, and this requires the client to receive ongoing support from health care professionals. In the case of heart failure, the client will need continued support from the health care team through telephone calls, and a peer support group. In addition regular follow-up visits with a family physician aware of the benefits of self management, and the use of exercise will reinforce maintenance of success.

The PAPM has limitations. It is difficult to establish validity for designing treatment interventions, and it has been found to have challenges in interpreting the movement between stages. Theoretically, it applies more easily to single health behaviours that are dichotomous, such as having a blood test or not. It is also difficult

to decide whether clients are at similar stages to others in regards to the same health behaviour. For example, if someone has made partial progress towards a goal, should they be placed at the same stage as a person who has not made any progress toward to goal? One recommended approach to the dilemma of evaluating the model is to apply it prospectively by measuring the stages people are in and, to follow-up with them to determine whether or not they took action (Glanz, et al., 2008). It is important to note that in the development of a treatment protocol, information given to clients that increases ease of action appears to assist people who have decided to act, but it is less important among people who are still undecided (Glanz, et al., 2008). Weinstein (1997) concludes that, when interpreting and analyzing data, differences between stages in terms of variables such as perceived self-efficacy might indicate that variables are determinants of behaviour change. He also postulates that a change in a stage may have produced a change in the variable. An example of this related to heart failure is that the client may be taking preventive measures such as being compliant with medication administration. This person has a lower perceived vulnerability or risk than someone who does not take their medication regularly. The lowered perceived risk, however, does not necessarily mean that they will take action when the situation changes, e.g. the client may not identify that their medication is not effective in controlling the symptoms of heart failure.

Ecological Models of Health Behaviour

Ecological models of health behaviour are based in policy and environmental contexts of behaviour and require consideration of many layers of decision-making and influence. They have gained popularity in the last 20 years as it is felt that they have far reaching influence in terms of changing behaviours. Ecological models are believed to have comprehensive frameworks for understanding multiple and interacting determinants of health behaviour (Glanz, et al., 2008). Behaviour changes are expected to be significant when social support and social norms for healthful changes are strong and when individuals are motivated and educated to make changes. The first ecological health models were developed in the early 1950s with B.F. Skinner's operant learning theory and expanded in the 1980s with Albert Bandura's Social Learning and Social Cognitive Theories. More recently Cohen, Scribner, and Farley's (2000) Structural-Ecological Model and Fisher et al. (2005) Resources and Skills for Self-Management Model have been integral to ecological models of health behaviour. Four core principals of ecological perspectives on health behaviour change are as follows:

1. Multiple levels of factors influence health behaviours. Ecological theories are distinctive because they review how health behaviours can be influenced at multiple levels including intrapersonal, interpersonal, and organizational. They also review how factors such as culture and environment can apply to more than one level.
2. Influences interact across levels. Variables work together at different levels. For example in the case of implementing exercise with clients who have heart failure, education to encourage clients with heart failure to become more physically active

- may work better when there has been education of physicians about heart failure and physical activity.
3. Multi-level interventions should be more effective in changing behaviour. In order to change behaviour, there needs to be sustained interventions which happen population-wide and which have a powerful message.
  4. Ecological models are more powerful and useful in guiding intervention when they are tailored to specific health behaviours, because it is sometimes difficult to translate the lessons learned from one health behaviour to another. For example promoting exercise in heart failure may not translate into a person choosing to leave their car at home in order to walk a few blocks to visit a friend.

As ecological models of health behaviour reframe health behaviour as a result of influences across multiple levels, there is concern that they do not pay attention to the responsibility of individuals. If poor choices of health behaviours are viewed in terms of biological, behavioural, social, and economic determinants rather than individual choice, they are attributed to a range of forces and are thought to rob the individual of dignity. In contrast they are viewed in the context that causation of behaviour is the result of multiple factors and variables. By removing the context that tends to blame individuals for harmful or risky behaviours, they seek to recognise the roles of behavioural influences at multiple levels. In order to give clients of the health care system the motivation and skills to understand how to make healthy choices, there has to be a

policy-based environment that makes it convenient, motivating, and economical to support such choices.

### 2.10 Health Literacy

Literacy is considered one of the most important determinants of health among Canadians (Ronson and Rootman, 2004). It underlies many of the social and economic conditions that determine one's capacity for health, (Perrin, 1998). The 2003 International Adult Literacy and Skills Survey (IALSS) found that substantial numbers of adults in Canada have low levels of literacy. The study quantifies four levels of literacy and considers Level 3 to be the minimum level of proficiency required to meet the demands of modern life independently and reliably in an industrialized nation. For the purpose of the IALSS, prose literacy is the knowledge and skills needed to understand and use information from texts. Document literacy relates to locating and using information contained in materials. Numeracy is the knowledge and skills required to apply arithmetic operations embedded in printed materials. Only one in eight adults (12%) over age 65 appears to have adequate health literacy skills. This is particularly significant since seniors are more likely to have chronic health problems and to use medications more than younger age groups, thus they face a higher level of health information demands (IALSS, 2003).

Limited literacy affects health in both direct and indirect ways. Health care consumers experience the direct effects of limited literacy on health when they have difficulty understanding and using health information such as advice on self-care,

instructions for medications, food labels, and safety warnings (Perrin, 1998). They also experience challenges accessing services which support their health and navigating their way through a complicated health care system (Perrin, 1998). Indirect effects include difficulty accessing a consistent, healthy food supply, and experiencing high levels of distress in everyday life. Literacy also encompasses the ability to communicate in addition to being able to understand and interpret written words and symbols (Perrin, 1998).

In 2006, the Health and Learning Knowledge Centre of the Canadian Council on Learning funded the Canadian Public Health Association (CPHA) to establish an Expert Panel on Health Literacy. The expert panel was given the task of defining the scope of the problem of health literacy by assessing the quality of existing evidence regarding the extent of health literacy in the adult population in Canada and the relationship between literacy and health outcomes. It has also examined the difficulties encountered in creating a health literate public with specific reference to the unique cultural groups within Canada such as those people who are French speaking, Aboriginal, or who have other ethno cultural backgrounds. Additionally this expert panel was also given the task of recommending how health literacy can be improved through policy initiatives and programming. It resulted in the publication of the document, "A vision for a health literate Canada" by Rootman and Gordon El –Bihbety (2008). They made the following recommendations:

1. There is a need for policies and programmes to respond to the extent and impact of low literacy in Canada and the increasing health information demands that are being placed on Canadians as a result of an increasingly complex health system. There are increased calls for patient self-management to respond to increasing numbers with chronic diseases.
2. Attention should be directed to particular population groups which appear most likely to have low levels of health literacy. These include seniors, recent immigrants, those with lower levels of education and low French or English proficiency, people with lower incomes and Aboriginal peoples. With regard to Aboriginal peoples, given their unique circumstances and cultures, it is likely that a parallel process is needed to develop policies and programmes appropriate to their unique needs.

The Canadian Public Health Association (CPHA) Expert Panel on Health Literacy authored by Rootman and Gordon-El-Bihbety (2008) defines health literacy as: “the ability to access, understand, evaluate and communicate information in a way as to promote, maintain and improve health in a variety of settings across a life course” (p.11)

The basis for the definition comes from the findings of the International Adult Literacy and Life Skills Survey (2005) which include examining health literacy skills in a variety of health contexts and against the almost daily health-related activities that take place in homes, worksites and community systems. These more sophisticated scales for assessing and ranking individual and collective health-literacy scores now include:

1. Health promotion being the ability to enhance and maintain health e.g. planning an exercise programme, or the ability to read labels and purchase healthy food.
2. Health Protection being the ability to safeguard community health by reading newspaper articles and postings about health and safety.
3. Disease Prevention being the ability to take preventive measures, engage in early detection by understanding health alerts on television, in newspapers and understanding letters written about test results.
4. Health Care Maintenance being the ability to seek and form a partnership with health care providers, discuss alternative forms of treatment and to follow directions e.g. reading medicine labels.
5. System Navigation being the ability to understand and access needed health services by completing application forms, reading maps, navigating to facilities, and understanding health-benefit packages.

#### 2.11 Summary of literature review

Heart failure is a complex and difficult condition to treat. The literature review indicates that there have been numerous studies which have examined education of clients with heart failure. Many of the studies have focused on one theme, often knowledge, quality of life, or exercise or medication compliance. Learning outcomes have not been specifically examined. The common theme that recurs is that multi-disciplinary approaches now framed in the context of inter-professional care are vital for the optimal management of clients with this condition. Health literacy and specific

education needs of the clients are clearly articulated as imperative to success in clients' management of heart failure.

Recent occupational therapy literature, Packer (2011), has documented the emerging and important role of self-management and self-management support in the care of clients with chronic diseases. Augustine, Roberts, and Packer (2011) provide the following quote in their article on everyday participation.

“Occupational therapy is well suited to play an active role in the development and implementation of self-management programs for persons with chronic disease that are focused on client-centered outcomes such as participation in a chosen lifestyle. Occupational therapists assess engagement in everyday life using client-centred outcomes to evaluate therapeutic interventions. However, self-management programs need to be specifically evaluated with regards to these positive effects in order to justify the need and value of such programs. The current role of occupational therapy with respect to self-management is under-utilized. If occupational therapy is not involved in the design and implementation of these programs the under-representation of participation in the evaluation of self-management programs may continue. The implementation of a reliable and valid measure of participation would shift the focus of outcomes towards the intended goals of self-management programs and ultimately benefit the client (p. 10).”

In its 2007 report, Health Canada states that self-management programmes will play a critical role in government decisions, the healthcare system and the public at large. The Family Medical Centre at St. Boniface Hospital has recognised the need to develop a self management programme for its patients with heart failure by collaborating to create an outpatient education series. The professional practice guidelines published by the major cardiac societies specifically outline methodologies to teach clients who have heart failure the self-care skills required to manage this chronic condition. It is incumbent on those who are involved in education of clients with heart failure to evaluate the outcomes of the interventions provided, and to ensure that best practice is being applied. This is the foundation upon which the study is based.

#### 2.12 Purpose of the Study

The purpose of the study was to develop, pilot, and evaluate an educational tool which formed the basis of a disease management programme in a primary care setting.

#### 2.13 Objectives of the Study

1. To develop and pilot test a three part education series, in the context of inter-professional practice.
2. To provide the education series in a primary care setting, with the goal of it becoming standard practice.
3. To examine the outcomes of the education series by measuring change in participants' knowledge of heart failure management and the effects on quality of life prior to, and following education.

4. To contribute to the body of knowledge regarding the management of heart failure in the context of primary health care.

#### 2.14 Hypothesis

The null hypothesis was defined as follows:

$H_0$  – There will be no difference in learning outcomes or quality life of the clients who attend a series of three education classes as measured using the Dutch Heart Failure Knowledge Scale and the Minnesota Living with Heart Failure.

## Chapter 3

### 3. Methodology

It became apparent from the literature review that the development, piloting and evaluation of an education series as part of a disease management programme for clients with heart failure required several key components. These components include a structured curriculum based on best practice, the setting of primary care, collaborative inter-professional delivery of the education programme and a framework which was inclusive of health education, health literacy and occupational therapy theory. In order to evaluate the series, reliable and valid tools were chosen to examine the outcomes of knowledge and quality of life. The following paragraphs provide the background and methodology for the development, piloting and evaluation of the education series.

#### 3.1 Development of the education series curriculum

The best practice guidelines recommend that people with heart failure receive education in disease management to decrease morbidity through the acquisition of self-care and self management skills. The guidelines published by the Heart Failure Society of America and the European Society of Cardiology in particular are very specific about the essential elements required in an education programme. Critical target behaviours, skill building and self-care behaviours that the client needs to acquire in order to successfully manage heart failure are outlined in detail.

As literacy is one of the most important determinants of health among Canadians according to Ronson and Rootman's work in 2004 and in consideration of Perrin (1998)

who cites that health care consumers with limited literacy have difficulty understanding and using health information the author wanted to develop a simple tool to facilitate learning being mindful of how written material should be presented. Examples of understanding and using health information include advice on self-care, instructions for medications, food labels, and safety warnings. To this end the literature was reviewed to find consensus on the essential skills that a client should acquire to have the potential of being successful in the management of heart failure. The literature also contains many articles and reference materials which have descriptions of educational programmes, but these accounts do not provide tangible examples of the curriculum.

In reflecting on the process by which an education series should be developed, educational materials available to clients with heart failure both in print and digital media were reviewed. The standard educational resource provided is a booklet entitled *Managing Heart Failure* published by the Heart and Stroke Foundation of Canada (2013). This 48 page booklet is designed as a series of learning guides and worksheets to assist in the education of the reader. The educational resources from the websites of the University of Ottawa Heart Institute (2014), the Mazankowski Alberta Heart Institute (2014), the BC Heart Failure Network (2011), the Heart Failure Society of America (2010), the European Society of Cardiology (2012) and the Canadian Cardiovascular Society (2010) were examined critically to assess the suitability of the material available to clients. Each of the six websites and the book reviewed had very relevant information, advice, and in the case of the websites, printable educational material for

the reader to use. However, the volume of information presented may make it difficult for a client to find information related to their own situation and circumstances. In the absence of a trained health care professional, the information that a client may seek on their own may not be correct or pertinent to their condition (Rootman and Gordon-El-Bihbety, 2008).

The presentation of the website material spans a spectrum from being highly engaging to lacking dynamic content. Website information can be inaccessible to clients who do not have computers or who lack the ability to navigate complex websites such as that of the Heart Failure Society of America as it provides information for medical practitioners as well as clients. The European Society of Cardiology has a separate website called Heart Failure Matters for client education which in addition to being in English is available in Russian, German, Dutch, Spanish and French. It has an interactive component with an animated host who guides the viewer through several education modules. The information on the BC Heart Failure Network is easy to find as it is a dedicated website and presented in video footage by a client who has heart failure. Unfortunately, some of the material is outdated as it still cites fluid and salt restrictions being recommended despite the absence of scientific proof (Rothberg & Sivalingam, 2010).

The outcome of the review of the literature and the education materials in print and electronic media was the development of a learning tool: to this end the acronym, LEARN twice was developed. See Table 4 for outline of LEARN twice and Appendix A for

full description. LEARN twice, because once is never enough (P. Semeniuk, personal communication, February 27, 2014) was developed as a tool to capture the most important self-care skills based upon the best practice guidelines of Heart Failure Society of America (2010), the European Society of Cardiology (2012, 2008) and the Canadian Cardiovascular Society (2006, 2008, 2010). In addition, health education theories were considered. The Health Belief Model (HBM), (Champion and Skinner 2008; Rosenstock (1974) examines perceived benefits which are considered to be central to the goal of behaviour change. Additionally, the focus of the best practice guidelines is to promote self efficacy which in the HBM is considered important in the initiation and maintenance of behaviour change. The Precaution Adoption Process Model (PAPM) follows a path from lack of awareness to action. The goal of LEARN twice is to provide a dynamic and engaging method to take a client from their current state of knowledge, potentially a lack of awareness, to a targeted state of knowledge and ability to take action. Ecological Models of Health Behaviour are used in guiding interventions specific to health behaviours and examine influences across all levels, thus they were used to recognise that the clients would require support, motivation and consistency in the delivery of the message to promote behaviour change. In terms of health literacy, LEARN twice includes health promotion which is the ability to enhance and maintain health by reading labels, purchasing healthy food. It also includes health care maintenance which is the ability to seek and form a partnership with health care providers.

The author's vision in developing the LEARN twice as an educational tool was to provide a comprehensive package for teaching clients with heart failure, with consideration of individual learning styles, education and literacy skills. Thus in its simplest form, LEARN twice can be used as a fridge magnet and in its most comprehensive form, it can be used as the foundation of a three part education series.

Arnold et al. (2006) and Howlett et al. (2010) recommend that disease management programmes are integral to primary care settings. Primary care physicians are often the first to make the diagnosis of heart failure with their patients (McDonagh et al., 2011; Stewart, 2010). They are also the clinicians who make referrals to cardiac specialists and provide ongoing treatment and evaluation after a client has been in hospital for heart failure related treatments. According to Faxon et al. (2004) disease management programmes should exist in a setting where there is a solid relationship with the primary care physician and their patient, which is a strong tenet of the Family Medical Centre (FMC). Philosophically, the family physicians at the FMC support interdisciplinary collaboration which fosters the coordination of the best health care for patients within the context of family and community. In addition they have admitting privileges at St. Boniface Hospital and are able to provide consistency in client care from inpatient to outpatient care.

As the FMC is a teaching unit of the University of Manitoba which provides training for family medicine residents and conducts research, a formal request for collaboration on the project was made to the Director of Research at the Family

Medicine Unit at the University of Manitoba. As one of the FMC physicians, they have studied heart failure in the primary care setting and found that patients who received a telephone call on a regular basis to support them in taking steps to improve their health, such as watching fluid intake, taking medications and exercising as much as they could, experienced significant weight loss, felt better and made fewer visits to their family physicians or emergency departments, (Katz & Macdonald, 2009).

The study was recommended to the FMC Director, also a FMC physician who agreed for the interdisciplinary team to collaborate on the project with the author. Both physicians welcomed the opportunity to provide the family medicine residents, nursing, dietary and pharmacy students with a forum for client education through participation in the disease management programme. It is their feeling that the standard ten minute appointment time allotted to the evaluation of a patient by a member of the physician team does not allow for comprehensive education of a patient with a chronic condition such as heart failure. As an academic faculty, the concept of developing, implementing and evaluating a disease management programme was well received and supported by both physicians. They reflected the viewpoint expressed by the American Heart Association that within the programming are interventions to enhance adherence to scientific, peer-reviewed guidelines and treatment plans which are evidenced based and consensus driven (Faxon et al., 2004). The author was given the opportunity to present the study proposal at the FMC's inter-professional business meeting where the team endorsed their support for the project.

The family physicians at the Family Medical Centre support interdisciplinary collaboration that fosters the coordination of the best health care for patients within the context of family and community. It is thus comprised of academic family physicians, community physicians, a psychiatrist, primary care nurses, a social worker, dietitian, and pastoral care counselor. It is an integrated training centre providing a residency programme for family physicians, and fieldwork placements for nursing, dietician, and pharmacy students.

The FMC has been providing an interdisciplinary diabetes education series for several years taught by the family medical resident, the nurse clinical nurse specialist and the dietician. The proposal by the author to develop an education series for clients with heart failure was supported by the FMC team, and as an academic unit, evaluation of the education series by use of outcome measures was endorsed. The European Society of Cardiology Heart Failure Association Standards for delivering heart failure care authored by McDonagh et al. (2010) advises that an inter-professional team should deliver the content of an educational programme. Central to the characteristics is the use of a multidisciplinary approach, and the components include adequate client education, with emphasis on skill acquisition on the part of the client. To this end, the American Heart Association (AHA) (Faxon et al., 2004), as noted, has outlined nine guiding principles for the development, implementation and evaluation of disease management initiatives. In summary these principles emphasize that the goal of disease management is to improve the quality of care and to promote cost effective care. The

concept of LEARN twice was developed to be used by all the educators and formed the foundation for communication of essential information to the client. It also provided the structure and outline of the teaching sessions. A flexible approach to the teaching was possible as the syllabus was presented by the in-house instructors who can identify barriers to learning and self management presented by the clients and, who can provide individualised interventions as necessary.

In order to develop the education series the author had three meetings with the clinic director, dietician and nurse clinical specialist. The author developed the content for each discipline and the faculty was provided with the opportunity to review it prior to teaching the education classes (see Appendix B). As the author did not have the opportunity to work with the family medicine resident who was going to be assigned to teach the education series, a teaching companion was developed to allow the resident the opportunity to review the education material prior to teaching. The author met with the assigned family medicine resident on the day of the education session to review the objectives and the teaching expectations. A review of the teaching companion was required of the family medicine resident prior to meeting with the author.

The standard care for clients of the Family Medical Centre Standard consists of referring patients with heart failure to Telecare Manitoba, which is a system of management occurring through telephone calls. There are no face-to-face interactions with the clients through Telecare and there is no formal feedback to the primary care physician regarding the patient's knowledge of heart failure or ability to self-manage

their condition. The Telecare programme is based on research conducted by Botting & Katz (2009), which demonstrated that patients appreciated having access to information and support provided by telephone, as there is often not enough time in a physician visit to ask questions or to be educated in management of heart failure. This is not a process that is integrated with the FMC; therefore the patients' primary care physician is not involved in the education process. While they use Telecare, the FMC would prefer to provide in-clinic education regarding heart failure as they are an inter-disciplinary team and have experience in providing education to their patients with diabetes.

Table 4

*Outline of "LEARN twice"*

<b>LEARN twice about your Heart Failure</b>	
<b>Learn how your heart works</b>	<b>Learn about heart failure</b>
<b>Eat a healthy diet, low in salt</b>	<b>Examine food labels</b>
<b>Always take your medication as prescribed</b>	<b>Always weigh yourself every day</b>
<b>Remember to exercise a little every day</b>	<b>Remember to conserve your energy</b>
<b>Never ignore symptoms</b>	<b>Notify your doctor immediately</b>

The education series is based within the premise that the client needs to develop skills and critical target behaviours in order to successfully manage their heart failure. As an occupational therapist developing the education series, attention was paid to interactive and active learning aspects of the education series. The clients practiced weighing themselves at home and recorded their daily weight on a log sheet provided to them in order to teach and reinforce the importance of daily weighing. When the dietary information was being taught several different food products were available for comparison of the nutrition facts, which allowed the participants to actively sort food into low and high sodium groups and to facilitate a discussion regarding the benefits of healthy eating.

The goal of providing written material to the clients was to ensure that they had reference materials which are congruent with the information provided at the education sessions. In keeping with the recommendations from the literature regarding the lower levels of literacy experienced by elderly people, the hand out material was intentionally limited to 20 pages of information which included copies of the PowerPoint™ slides, and several concepts such as the interpretation of symptoms were provided in illustrated form. Attention was paid to using simpler language and repetition of the skill set of LEARN twice was incorporated in all education classes.

The literature supports inter-disciplinary disease management programming. To this end the FMC team consisted of a resident physician studying family medicine, a clinical nurse specialist, a dietician, a pharmacy student completing a fieldwork

placement and the author an occupational therapist. At each education class throughout the series, the participants saw more than one member of the teaching team reinforcing the concept of co-management and inter-disciplinary teamwork.

### 3.2 Piloting of the project

#### 3.2.1 Study design

The study was an experimental design with a pre-test, an intervention (education series) and a post-test. Data were collected in two phases. At the first education class, prior to commencing the programme, The Dutch Heart Failure Knowledge Scale (DHFKS) and the Minnesota Living with Heart Failure Questionnaire (MLHFQ) were administered. At the conclusion of the programme during last education class, the DHFKS and the MLHFQ were administered again. Schematically the original study design is represented in Table 5.

Table 5

*Study Design*

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**(O<sub>1</sub>) ---(X) --- (X) ---(X) --- (O<sub>2</sub>)**

Key: X is the education class

O<sub>1</sub> is the first observation using the DHFKS and the MLHFQ

O<sub>2</sub> is the second observation using the DHFKS and the MLHFQ

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### 3.2.2 Instrumentation

The Dutch Heart Failure Knowledge Scale and the Minnesota Living with Heart Failure Questionnaire were administered as pre and post-tests (Appendix C). The Dutch Heart Failure Knowledge Scale (DHFKS) has fifteen multiple choice questions. It was developed by van der Wal, Jaarsma, Moser, and van Veldhuisen with publication in 2005. Four questions relate directly to heart failure, six are about heart failure treatment and five are concerned about symptoms and symptom recognition. It was based on an existing test developed by Linne, Liedholm, and Israelsson in 1999. The DHFKS was used with written permission from the authors through e-mail correspondence.

Cronbach's alpha for internal consistency and construct validity is .62 for this tool. It was found that the DHFKS could distinguish between clients who were recently diagnosed with heart failure before they received education and those who received comprehensive education. On a maximum score of 15 on the test, those who did not receive education had a mean score of 6.8, while those who received education scored 13.4. The result was statistically significant with  $t = -7, 14; p = .0001$ .

The Minnesota Living with Heart Failure Questionnaire (MLHFQ) was designed by Rector et al. (1987), to measure the effects of heart failure on quality of life (refer to Appendix C). The content of the questionnaire was selected to be representative of the ways heart failure and treatments can affect the key physical, emotional, social and mental dimensions of quality of life without being too long to administer during clinical trials or practice. It has twenty-one items which the client responds to using a six point

Likert scale. The total score can range from 0 to 105 with a lower score reflecting a better health related quality of life.

The psychometric properties of the MLHFQ indicate a high internal consistency reliability with Cronbach's alpha ranging from .73 to .93, with test-retest reliability rated as  $r = .93$  after a one week interval. Riegel et al. (2002) found that MLHFQ differentiated only between subjects receiving a high intensity intervention that included patient teaching and counselling, rather than those who were in a control group, and hospitalized. The MLHFQ was used with an educational use license issued by the University of Minnesota.

### 3.2.2 Sample Design

A single-stage sampling design was used to select participants, giving patients of the Family Medical Centre over a five month period equal opportunity of being included in the sample.

### 3.2.3 Recruitment

The target population was the clients of FMC with heart failure. The exact number of the target population was difficult to ascertain as heart failure has to be specified as the primary diagnosis in the electronic patient record to reveal exact numbers. Given the number of co-morbid conditions that a client with heart failure may have, searching the record for heart failure as a primary diagnosis was challenging. The sampling frame consisted of the clients who met the inclusion criteria for the study.

The inclusion criterion was:

- Clients of the FMC with a diagnosis of heart failure.

The exclusion criterion was:

- Clients from the St. Boniface Heart Failure Clinic as they receive heart failure education as part of clinic attendance.

The study received approval from the Health Research Ethics Board, University of Manitoba Bannatyne Campus and the Research Review Committee of St. Boniface Hospital.

The physicians at the Family Medical Centre were requested by the Medical Director to inform their clients with heart failure of the opportunity to participate in a research study. Posters (refer to Appendix D), indicating that a research study was taking place, were placed in the doctor's offices and in the reception area. Physicians received regular reminders via e-mail messages from the author and the Medical Director regarding recruitment. The author received the names and telephone numbers of the clients who agreed to be contacted from the physicians' receptionists.

Each client who agreed to be contacted received a telephone call from the author for screening and confirmation of participation. All clients who consented to be contacted wished to participate in the study and the author obtained the clients address during the telephone call. The author sent a letter of invitation (refer to Appendix D) to the study plus a Research Participant Information and Consent Form to each participant (refer to Appendix E).

The letter of invitation advised the participant that the Dutch Heart Failure Knowledge Scale (DHFKS) and the Minnesota Living with Heart Failure Questionnaire (MLHFQ) were going to be used as part of a research study to evaluate learning and its effect on quality of life. Information was provided regarding the length of time the surveys take to complete, potential for risks to occur and anticipated benefits gained by the knowledge obtained in the study. The letter also outlined that participation in the study was voluntary and that informed consent was required to participate. The Research Participant Information and Consent Form also provided the potential study participants with information on the possibility that the data may be used for secondary analysis. Once the participants had verbally confirmed that they would participate in the study, a letter of confirmation (refer to Appendix D) was sent to them outlining the dates and location of the education series.

#### 3.2.4 Power Analysis

A statistical power analysis indicated that a sample of  $n = 32$  subjects would provide a power = .80 to detect a change in scores of an effect size = 0.8 SD from pre-measure to post-measure at an alpha level = .05.

#### 3.2.5 Procedures

When participants attended the first education class, they were reminded by the author that they had been invited to participate in a research study. There was opportunity for potential participants to answer questions and seek clarification about the study. There was assignment of an identification number to the study participant.

The study participant was asked to provide information regarding year of birth, gender, highest level of education, previous knowledge of heart failure and use of resources to learn about heart failure. These data were collected to enhance the investigators knowledge of the sample and to examine characteristics of the sample. Describing sample characteristics in terms of demography assists in understanding the population to whom the findings can be generalized, (Polit & Beck, 2008).

### 3.2.6 Content of education classes

The participants attended three education classes in series, each of which were one and a half hours long (refer to Appendix B). There was a nutrition break for fifteen minutes in each class. The first class was divided into two teaching modules. The participants were informed about the fact that they were being educated based on the recommendations of best practice and summarized as:

- Clients with heart failure receive education from an inter-professional team
- Clients learn the skills to know how to manage their symptoms
- Clients know how and when to seek medical help

The class material was presented in PowerPoint™ and each participant received copies of the PowerPoint™ in handout format in order to be able to review the material at home. The teaching tool of LEARN twice was implemented with the class participants and each teaching module focused on a specific skill set. The participants were required to complete DHFKS and The MLHFQ prior to the start of the first class. The knowledge scale and the questionnaire took approximately ten minutes to complete. At the end of

the third and final education class, the participants completed The DHFKS and The MLHFQ. All study participants were given a sum of \$10.00 to cover parking fees each time they attended a class.

As part of the data collection, the participants were asked to complete weight, exercise and diet logs. They also received pedometers to assist in the collection of data regarding exercise compliance. These tools were used to teach the clients to participate in the process of disease management, and the data obtained were reviewed for evidence of learning of the material taught.

The first module of the first class was based on the concept of “Learn how your heart works and Learn about heart failure” and focused on teaching the participants how the heart works and about the condition of heart failure. The participants were provided with instruction on the anatomy of the heart and the etiology of heart failure. A short YouTube™ video was used to outline heart anatomy and information on heart anatomy was included in the hand out material. The symptoms of heart failure were outlined in detail in addition to the role of the kidneys and lungs in the retention of fluid. The differences between diastolic and systolic failure were reviewed. This module was taught by a family medicine resident, who followed guidelines in a teaching companion developed by the author outlining the specific learning outcomes required. Participants were encouraged to ask questions and to clarify information which was unclear.

The second module of the first class outlined the concepts of “Eat a healthy diet, low in salt and Examine food labels” focused on eating a healthy diet, low in salt and

examining food labels was taught by the dietician. Active learning included participants having to read food labels for nutritional content, serving size and to review sodium and other nutrient amounts. They practiced sorting the foods into low and high sodium categories. Participants received food suggestions and resources. Homework was assigned with participants required to complete a food log.

The second education class was also divided into two modules. The first module of the second class was “Always take your medication as prescribed and Always weigh yourself every day“ focused on the topics of medication, and daily weighing. The food logs were reviewed, and participants discussed their eating habits over the previous week. The challenges of reading food labels and finding foods lower in salt and fat were outlined by the participants. The participants received education from the Clinical Nurse Specialist who was assisted by a pharmacy student. The self-care skills taught included education regarding the types of medication used in heart failure including the function of the medication. Participants were also advised to ensure that they do not use over the counter or herbal products without first contacting their pharmacist. The importance of having a plan for medication administration to promote routine adherence and to take medication exactly as prescribed was taught. Participants were also educated on the importance of making plans for medication refills and the procedure for contacting the Family Medical Centre to have a prescription updated was outlined. Participants were encouraged to use pharmacy delivery services if they were unable to go to the pharmacy to avoid missing medication.

The skill of daily weighing was outlined in terms of the importance of monitoring rapid weight gain from fluid accumulation, and the importance of seeking medical attention immediately which covered the information needed for “Never ignore symptoms and Notify your doctor immediately”. The procedures for contacting the Family Medical Centre in an emergency situation were outlined.

Participants were educated regarding the correct procedure of weighing themselves in the morning after using the bathroom and before eating breakfast. They were counseled to write down their weight daily, and to compare their weight daily to their weight from the previous day and to check for swelling in the feet, ankles, legs, and stomach. The participants were given weight logs to complete as homework for one week.

The second module of the second class was a presentation on exercise, “Remember to exercise a little every day”. This module was taught by the author. The content was formulated with the use of research evidence that regular physical activity and exercise training is recommended in people with heart failure as it improves exercise capacity and quality of life and may reduce hospitalization. Specific guidelines were provided to teach the clients how to start and progress an exercise programme in recognition of the limitations of potentially being deconditioned. They were counselled in being aware of exercise intolerance, and taught to avoid exercising with too much intensity. They were all encouraged to attend formal supervised cardiac rehabilitation offered at the Wellness Institute and the Reh-Fit Centre. Each participant was given an

exercise log and a pedometer to record their exercise and the number of steps they took each day.

The final and third class was “Remember to conserve your energy” taught by the author and consisted of a presentation about fatigue and energy conservation in addition they were reminded about the importance of recognizing their symptoms and knowing when to notify their FMC physician or the clinical nurse specialist. There was also review of the exercise log and pedometer readings.

The participants received education material consisting of copies of each of the PowerPoint™ presentation. The specific material from each of the disciplines included information on heart anatomy and function, reading of food labels, and information on daily weighing. The author developed handouts for travel, sexual activity and resources including websites and reading material. Educational material was developed with consideration for the tenets of health literacy and health education. While not formally evaluated for reading level, the handout material was generally in point form with short sentences, and repetition of concepts. Face-to-face interactions as occurred in the education series provided the opportunity to identify deficits that the clients had in understanding the verbal and written material though the use of reflection and open ended questions.

### 3.3 Evaluation

#### 3.3.1 Data Collection

Data were collected using the DHFKS and the MLHFQ as pre and post-tests, in addition to data collected through weight, food and exercise logs.

### 3.3.2 Data Analysis

It was proposed to analyze the data from the DHFKS and the MLHFQ with repeated measures ANOVA. Repeated measures ANOVA determines whether or not change has occurred over time by comparing the average score at multiple time periods for single groups of subjects. As the participants were measured at different time intervals, the measurement of a dependent variable is repeated. In this study the dependent variables measured by the instruments were knowledge and quality of life.

### 3.3.3 Amendment to methodology

As recruitment to the study yielded two, rather than the required 32 participants, it was necessary to amend the study. In light of the low recruitment response rate an amendment was submitted to the Health Research Ethics Board requesting permission for the author to make contact a second time with the participants and the instructors in order to acquire descriptive qualitative data about the content and process of the education series. Questions were formulated to gather data in a semi-structured interview (refer to Appendix F). Creswell (2002) describes the semi-structured interview process as a method for participants to provide historical information and which allows the researcher to have some control over the line of questioning. Rabionet (2011) suggests that qualitative interviewing is a flexible and powerful tool to capture the voices and the ways people make meaning of their experiences. Cohen and Crabtree

(2006) define the semi-structured interview as a process where the interviewer and the respondents engage in a formal interview. Semi-structured interviews are conducted with a guide, developed by the interviewer which outlines the questions needed to be asked during the interaction (Cohen & Crabtree, 2006). Cohen and Crabtree (2006) further suggest that the interviewer should follow the guide but can stray from it to follow topics that are appropriate in the conversation.

An amendment to the study was submitted and approved by the Health Research Ethics Board to allow further contact with the participants and the instructors. The target population for the amended portion of the study included the two participants of the study, plus the four instructors of the FMC,

The author contacted the two participants by telephone to ask whether they would be willing to be interviewed regarding their experiences in attending the education series. The author subsequently contacted the four instructors by telephone and asked whether they would be willing to be interviewed regarding their experiences in developing and teaching the education series. It was outlined to all potential participants including the instructors that participation in this component of the study was voluntary and that informed consent required to participate in the amended portion of the study would be obtained at the time of the interview.

The Research Participant Information and Consent Form, which differs slightly for participants and instructors, (refer to Appendix E) was reviewed with the participants and instructors by the author prior to the commencement of the interviews and

informed consent was sought. Information was provided regarding the length of time the interviews will take to complete, potential for risks to occur and anticipated benefits gained by the knowledge obtained in the study.

The interviews with the original participants took place in their homes, while the instructors were interviewed at their place of work, with the exception of one who was interviewed at St. Boniface Hospital. The interviews were face to face and half an hour in length. They were digitally recorded and the author documented field notes to record any observations or impressions of the interviews as descriptive information. In addition the author documented suggestions for amendments to the education series based upon the experience of teaching and recognition of some of its flaws. Taped interviews were transcribed verbatim, and the answers were described in a narrative format to formulate perspectives and opinions of the participants. The results of the quantitative measures were used to provide parallel perspectives to the data obtained in the interview. Participants did not receive payment for participating in this part of the study.

## Chapter 4

### 4.0 Results

#### 4.1 Quantitative Data

##### 4.1.1 Demographics

Of the two participants who attended the education groups, one was male and 70 years of age, who had junior high/high school education and one was female and was 88 years of age who had elementary school education (See Table 7). Both participants stated that they had no knowledge of heart failure, and that any knowledge that they had about heart failure had come from their health care provider (doctor, nurse or other).

##### 4.1.2 Dutch Heart Failure Knowledge Scale (DHFKS)

There were two participants in the study, and because of these low participant numbers, the data cannot be statistically analyzed quantitatively. The DHFKS is scored on a percentage basis and the descriptive comments regarding the pre and post-testing are as follows (see Figure 1 and Table 6). Of the fifteen questions, the participants scored 53% and 60% respectively on the pre-test and 80% and 53% respectively on the post-test.

Considering correct responses to questions, the participants had nine questions (60%) and six questions (40%) correct on the pre and post-test respectively. Correct pre and post-test answers for both participants were questions 4, 5, 7 and 14 (taking medication regularly, the action plan regarding increasing shortness of breath, the

meaning of heart failure, and the choice of statements about weight increase). In addition, the participant who had a pre-test score of 53% had correct pre and post-test answers for questions 2, 9, 12, and 13 (daily weighing, the function of the heart, exercise guidelines and function of water pills). The participant who had a pre-test score of 60% had correct pre and post-test answers to questions 3 and 11 (fluid intake and the causes of heart failure).

For incorrect scores on the pre-test and correct scores on the post-test, both participants had incorrect responses on the pre-test for question 1, (frequency of daily weighing) and a correct response on the post-test. One participant had incorrect responses on questions 2 and 10 (importance of regular weighing and following a low salt diet) on the pre-test and correct responses on the post-test. The other participant had an incorrect response on the pre-test and a correct response on the post-test for question 13 (reason for prescribing water pills). Percentage wise, the participants scored 20 % and 13% respectively on questions which were incorrect on the pre-test and correct on the post-test.

The scores for questions that the participants had wrong on both pre and post-tests were 20% and 27% respectively. One participant had questions 6, 11, and 15 (the cause of worsening of heart failure symptoms, causes of heart failure and response to thirst) wrong on both the pre and post-tests. The other participant had incorrect responses both pre and post-test on questions 8, 10, 12 and 15, (reasons for leg swelling, following a low salt diet, exercise and the response to thirst). One participant

had correct responses on the pre-test for questions 2, 6 and 9 (regular weighing, rapid worsening of heart failure and the function of the heart) and incorrect on the post-test.

Questions on the DHFKQ can be categorized into two groups; knowledge of heart failure and knowledge of heart failure management. Knowledge of heart failure is represented by questions 6, 7, 8, 9, 11, & 13, while questions 1, 2, 3, 4, 5, 10, 12, 14, & 15 represent knowledge of heart failure management. Table 6 shows the results for numbers of questions answered in each category on the pre and post-tests.

Figure 1

*Results of DHFKS scores (%) based on responses from two participants*

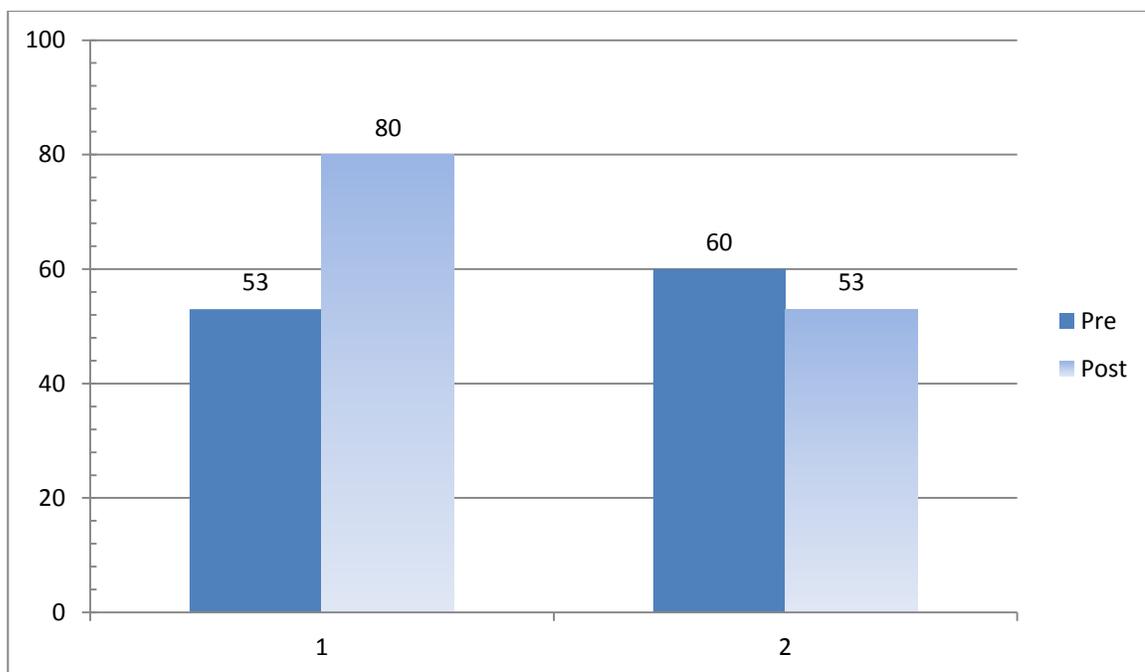


Table 6

*Comparison of pre and post DHFKS results (number of questions out of 15)*

<b>Participant #</b>	<b>Question category</b>	<b>Right both times</b>	<b>Wrong then right</b>	<b>Right then wrong</b>	<b>Wrong both times</b>
<b>1</b>	Heart Failure	3	1	0	2
	Heart Failure Management	5	3	0	1
<b>2</b>	Heart Failure	2	1	2	1
	Heart Failure Management	4	1	1	3

Note: 'Knowledge of Heart Failure' category had 6 questions and, 'Knowledge of Heart Failure Management' category had 9 questions.

Table 7

*Participant demographics for DHFKS for two participants (N =2)*

Age					Gender		Education		
N	≤40	≤60	≤80	≤100	M	F	Gr. 1-8	Gr. 9-12	Post-sec.
2	0	0	1	1	1	1	1	1	0

HF Knowledge					Source of Heart Failure Information				
None	Poor	Fair	Good	Very Good	Internet	HC	Family/friend	Books	Other
2	0	0	0	0	0	2	0	0	0

Key: HC= Health Care Provider

Table 8

*Questionnaire completion assistance (post only) for two participants (N=2)*

Self	Self with help	Someone else
2	0	0

Note: Table 8 outlines the fact that the participants completed the DHFKS without assistance. Anecdotally, one participant was noted to receive assistance from their caregiver.

#### 4.1.3 Minnesota Living with Heart Failure Questionnaire (MLHFQ)

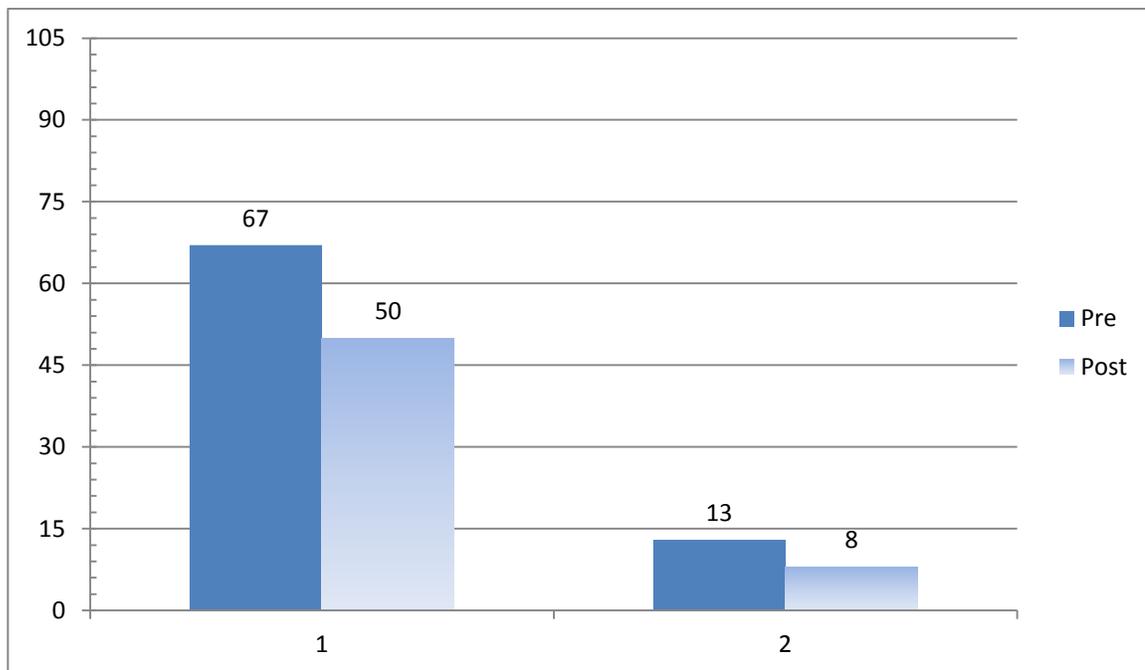
The MLHFQ summary score can range from 0 to 105. The scores recorded for the two participants showed lower scores in the post-test versus the pre-test, with a lower score being indicative of an improved health related quality of life. All the questions are prefaced by the phrase "Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by"

One participant scored 67 on the pre-test and 50 on the post-test, while the other scored 13 on the pre-test and 8 on the post-test. In reviewing the questions which showed a lower score on the post-test for this participant, positive change was evident in the questions which related to emotions: question 17, feeling a burden to family and friends because of heart failure, question 18, loss of self control, question 19, worry, question 20, concentration and memory and question 21, feelings of depression.

The other participant scored 13 on the pre-test and 8 on the post-test, and showed positive change in question 1, swelling in ankles or legs, 2, needing to sit, lie down or rest, question 3, walking or climbing stairs, question 4, working around the house or yard. (See Figure 2.)

Figure 2

*Results of MLHFQ scores based on responses from two participants*



## 4.2 Supplementary Descriptive information

### 4.2.1 Participant Interviews

Both participants were interviewed at their homes. Prior to the commencement of the interviews, informed consent was obtained for participating in the study. Both participants stated that they enjoyed participating in the education series and thought that the series was very good. In commenting on the content of the education sessions, the information on salt reduction was well received by one participant who could speak to choices that they had made in grocery shopping to actively seek products lower in sodium. The other participant did not provide specific feedback regarding content; however his caregiver found the content to be informative and easily understood. Both the participants, albeit one participant had deferred his opinion to his caregiver, had commented specifically on the presence of the interdisciplinary team. Both participants were unanimous in their opinion that having a physician as part of the teaching team was very important to them. One participant particularly found the session on medications to be relevant and was appreciative of the fact that there had been a pharmacy student as part of the team. The other participant and their caregiver valued having the different team members present at the education series.

In terms of the usefulness of the handouts, one participant had not read them all, but was planning to review them. The other participant initially stated that he had read the handouts and kept them by his bed. However, according to the caregiver this was not the case. The caregiver had read the hand out material and found the information

on the action to take with escalating symptoms to be very meaningful, and had used this knowledge to take the participant to the doctor when weight gain was noticed on the weight log. This action resulted in the prescription of another diuretic, and the weight log reflected the subsequent weight loss.

One participant found the weight and exercise logs to be helpful and prompted her to weight herself and take a walk daily, while for the other the logs were less meaningful. This second participant did not continue with daily weighing and reported not being compliant with taking diuretics the previous day, and sounded very surprised that he was making multiple trips to the bathroom having taken the diuretics that morning.

When asked to describe two things that were learned from the education series, one participant was able to be specific about the fact that they learned about the functioning of her heart and how to reduce sodium intake. The other participant's caregiver learned about the importance of recognizing the symptoms of decompensation through daily monitoring of weight. In addition they became aware of how imperative it was to take immediate action by seeking medical attention to prevent a hospital admission. In general both participants felt that they had gained knowledge from the education series.

Neither participant felt that the content of the education series needed to be changed, with the exception that one participant would have liked to have had a spouse

attending more than one session. The participants had no difficulty attending the education series as both had their own transportation.

When asked for further comments one participant felt that they were more cognizant of diet particularly at restaurants, while the other participant's caregiver was surprised that heart failure was a chronic condition without a cure. Both the participant and the caregiver had been of the opinion that medications, diet and exercise would cure heart failure, but understood that the process of self-management was vital to staying well. The caregiver was concerned that the participant did not have the commitment to follow the guidelines and suggestions for self management, but was confident in their own abilities to recognize the symptoms of worsening heart failure and to take appropriate action.

#### 4.2.2 Weight, Food and Exercise logs

The purpose of the food log (refer to Appendix G) was to provide the participants with a tool to use to reflect upon their patterns of eating and the types of foods they consumed over a week. Copies of the food log were distributed to the participants at the first class following the presentation by the dietician, for return and review at the proceeding education class. Participants were required to keep a record of their total daily intake for all meals, snacks, and fluid for a week. The food log was then used at the second education class to review the information that had been presented by the dietician and provided a forum for the participants to ask questions. The principles of

eating a healthy diet, with emphasis on reducing salt and fat intake were reviewed for a second time with participants to assist in reinforcing their knowledge.

One participant did not fully complete the food log but what was included gave a basis for discussion during the education class. The other participant's caregiver completed the majority of the food log and for this participant it provided a tool for the caregiver to be able to have dialogue regarding food choices which were not always in keeping with the suggestions and guidelines provided by the dietician.

The weight logs were used to teach the participants the methodology for daily weighing and the skill of interpreting the findings. The participants were asked to weigh themselves daily for two weeks, watching for an increase in weight of more than 2 pounds over 2 days or 5 pounds in a week. The participants were advised to weight themselves on rising after they had been to the bathroom and before eating breakfast. The log provided the client with a monthly calendar, and specific instructions to contact their physician should they experience weight gain noting that it would be caused by fluid retention. Both participants completed the weight logs diligently and of note one participant gained 8 pounds in 6 days and as a result saw the doctor who prescribed an additional diuretic.

The exercise logs and pedometers were given to the participants at the second education class after the module on exercise. They were required to log the type of exercise; the time spent exercising, the pedometer reading and their subjective feeling about exercising. This log because of the greater number of requirements proved more

challenging to complete accurately for the participants. One participant was descriptive of the type of exercise, which was walking, however was unable to operate the pedometer to provide objective data of the amount of exercise completed. The other participant used the pedometer to record the amount of exercise but did not describe the type of exercise taken. Neither participant recorded the amount of time spent exercising or described their subjective feelings.

#### 4.2.3 Instructor Interviews

As with the participant interviews the author developed a series of questions to structure the interviews with the teaching instructors (refer to Appendix F). The instructors' interviews occurred over a period of two weeks. Three of the four members of the team of instructors were interviewed in their offices at the FMC and the fourth instructor was interviewed in the atrium of St Boniface Hospital. Informed consent was obtained prior to the interviews commencing.

The instructors were all aware that the series was based upon best practice guidelines of the Heart Failure Society of America (2010), the European Society of Cardiology (2006, 2008, 2012) and the Canadian Cardiovascular Society (2006, 2008, 2010) which in addition to providing specific information for physicians on the diagnosis and management of heart failure also include a section the self management of heart failure, with particular emphasis on the acquisition of self-care skills. Apart from the one, none of the instructors had read the practice guidelines in any detail. In the

preliminary meetings that the author had while planning the content of the education groups, instructors were introduced to the best practice guidelines.

Content as developed by the author was considered excellent or very good by all instructors, and it was appreciated that in developing the content the author had conducted an extensive literature review. There were suggestions for minor changes in the content to clarify some of the concepts and to provide more time to outline difficult concepts such as the anatomy of the heart or the etiology of heart failure. Interactive learning was thought to be very important with the use of “hands on” types of activities such as reading food labels and examining a model of the heart. Information provided was felt to be client friendly and that participants did learn the essential skills needed to self-manage their heart failure. It was suggested that a pharmacist should be part of the instruction team providing the clients with information not only about heart failure medications but about other medications that they are taking concurrently.

## Chapter 5

### 5.0 Discussion

The goal of the study was to develop, pilot test and evaluate an education series in a primary health care setting. The content and execution of the series was based on recommendations for self care and self-care management from the best practice guidelines of the American, European and Canadian cardiac societies. The framework drew upon theories of health education and occupational therapy, recognized the importance of health literacy and was delivered by an inter-professional team. The Dutch Heart Failure Knowledge (DHFKS) and the Minnesota Living with Heart Failure Questionnaire (MLHFQ) were used as pre and post-tests to evaluate knowledge and quality of life.

In the absence of finding a tangible framework for an education programme in the literature, one of the objectives of the study was to develop the content of the education series. To accomplish this objective an education structure was developed through the genesis of a template; LEARN twice. As a design framework, LEARN twice provided a concise foundation for the acquisition of self-care skills, upon which the key disease management skills could be outlined and then further explored through education. Additionally, the structure with specific topics was purposely designed to be taught by different professionals. In determining whether LEARN twice as implemented had met the objectives for design, consultation with the participants and FMC educators through the interview process was undertaken. Responses from the educators indicated

that it had met the objectives for the design of an education series as the content by report was good to excellent. The extensive literature review conducted by the author was appreciated and validated that the content was accurate and concise. Responses from the participants indicated that the content was informative and easily understood.

LEARN twice was also developed to meet objectives for the implementation of the education series. In order to implement the series the author had to write the education material in consultation with all the disciplines involved. LEARN twice through its basis in best practice guidelines, inter-professional education and skill acquisition facilitated a logical progression of teaching.

Two participants were recruited and completed the education series of three classes including the pre and post-tests, weight, food and exercise logs in addition to the structured interview. Although participants indicated that they had no previous knowledge of heart failure their scores on the DHFKQ pre-test demonstrated scores of 53% and 60% respectively. Results from the pre and post-testing indicate that one participant improved their overall test score from the pre to the post-test from 53% to 80% correct. The other participant's overall scores did not improve and in fact decreased from 60% in the pre-test to 53% in the post-test. This participant had a higher percentage of incorrect scores on the post-test in addition to having 20% of the questions correct on the pre-test and incorrect on the post-test. There was therefore a positive change in heart failure knowledge for one participant, and a negative change for the other participant. The negative change may reflect the participant's ability to

read, understand and interpret the questions rather than their actual knowledge of the content being tested. Results for both participants showed higher numbers of correct answers in the category of knowledge of heart failure management rather than in the category of knowledge of heart failure. These findings may correlate with the fact that it is more difficult to grasp information about a disease because there is the potential for this information to be given in medical terminology, however, information provided on management of a condition is likely presented in language that is more comprehensible to the client.

The results of the pre and post-testing with the MLHFQ showed that each participant experienced a positive change in their health related quality of life. One participant's score changed 17 points from 67 to 50, indicating that they felt positive changes in their quality of life, in particular on the questions related to emotions. This participant who came to the education series with a caregiver was in the process of undergoing many medical tests as their heart failure had just been diagnosed. The improvement of scores in the area of emotion could be related to the fact that the members of the education group both the other participant and the instructors provided support to the individual and their caregiver during a time of uncertainty and stress. The caregiver noted in the interview that they had learned about the importance of recognizing the symptoms of decompensation, and understood that in the absence of a cure for heart failure that the process of self management was very important to staying well. This caregiver and participant had the opportunity to respond to an

increase in weight noted through the weight log precipitating a visit to the physician which resulted in the prescription of an additional diuretic.

The second participant had a more modest change in scores from 13 on the pre-test to 8 on the post-test, a change of 5 points. The positive changes were noted in functional areas such as mobility, and housework. In terms of mobility this participant's exercise log was representative of a daily commitment to walking, which may be the reason for the improvement in mobility and function related quality of life.

The addition of the education series to the inter-professional service delivery at the FMC adds the final dimension to a system which already aligns closely to the recommendations of the Heart Failure Society of America (2010), European Society of Cardiology (2012) and Canadian Cardiac Society (2010) best practice guidelines for the management of heart failure.

The 2012 guidelines from the European Society of Cardiology (ESC) describe the characteristics of a management programme for clients with heart failure as requiring a multidisciplinary strategy, targeting high risk symptomatic clients and should include competent and professionally educated staff. The FMC education series as provided in the study did have an inter-disciplinary strategy with five different professionals teaching the classes, all professionally educated and competent in their knowledge of heart failure. Specific education material was developed for the medical resident to ensure that the tenets of the education session were followed.

The ESC guidelines also outline the components of management programmes which include:

- Optimized medical management
- Adequate client education, with special emphasis on adherence and self-care
- Client involvement in symptom monitoring and flexible diuretic use
- Increased access to healthcare
- Assessment of and appropriate intervention in response to an unexplained increase in weight, functional status, quality of life and laboratory findings.
- Provision of psychosocial support to clients and family and/or caregivers.

The Heart Failure Society of America guidelines from 2010 recommend the following components in a heart failure disease management programme

- Comprehensive education and counseling individualised to client needs
- Promotion of self care, including self-adjustment of diuretic therapy
- Emphasis on behavioural strategies to increase adherence
- Optimization of medical therapy
- Increased access to providers
- Early attention to signs and symptoms of fluid overload

The guidelines of the Canadian Cardiac Society published in 2010 suggest the following practical tips in developing a disease management programme in a primary care setting.

- The care provided should reflect local circumstances, current resources and be integrated in a model of care with other chronic diseases such as diabetes mellitus.
- Integration of a disease management programme should occur in a primary care setting.
- Practical resources to aid in heart failure diagnosis and management should be made available across the continuum of community health care delivery.
- Communication among relevant care providers for heart failure clients is essential for the success of disease management programmes.

As a primary care clinic and one with an inter-disciplinary focus, the FMC offers their clients optimized medical management through the primary care physicians and have rapid access to specialists such as cardiologists and cardiac surgeons. Flexible diuretic regimes can be coordinated with the primary care physician or the nurse clinical specialist. The disease management programme in the form of the education series will become an integral part of this primary care setting, and thus it will be able to provide client education and psychosocial support. The education series was developed with attention to the current resources within the FMC and the health care personnel available. As the health care providers are all located within the same clinic, the likelihood for success with coordination of communication about the clients across the disciplines is excellent. The clinic offers the clients access to the nurse clinical specialist and to on call services should they experience deterioration in their condition, such as an increase in weight, functional status or quality of life. Prescriptions and medication

refills can also be processed over the telephone at the clinic. Participants in the education series were advised about these services by the nurse clinical specialist. In summary, the development of the education series and the current method of client care delivery compares favourably to the recommendations in the best practice guidelines for the management of heart failure in a community setting.

While the study was not able to provide a statistically significant result due to the small number of participants, it was able to demonstrate the feasibility of developing and administering an education series in a primary care setting. There have not been any studies of disease management conducted by an occupational therapist, nor has an occupational therapist been the champion of an inter-professional team. In this study, the author collaborated with the clinic director who is a physician, the nurse clinical specialist and the dietician to define the content material for the education series, but completed the research and wrote the content of each of the education modules.

As the education series is set in a primary care clinic with known diagnoses of the clients, there is opportunity to customise the education to a subset within the heart failure population such as those with systolic or diastolic heart failure as the manifestations of the two types of heart failure are different in terms of symptomatology and treatments.

Previous work in this area has not been particularly inclusive of the allied health disciplines, especially occupational therapy and physical therapy. Most of the studies have been conducted by physicians and nurses and while the successes of self-care and

self management of heart failure have been documented, it is curious that the study of such a functional approach to a disease which impacts the engagement in occupation so profoundly lacks the input of occupational therapy a discipline grounded in expertise in enabling function. The FMC will be offering the education series as the author will be providing them with the presentations and the handout material. The education series will become integral to the family medical residency training as the resident will be required to teach the first module Learn how your heart works and Learn about heart failure and additionally it will be used to educate students of other disciplines in the process of client education.

#### 5.1 Limitations

The study was designed to have thirty two participants in order to have power to produce results of statistical significance. As recruitment yielded two participants the education series could not be evaluated as planned. It was not possible as a result to generalize the findings to a population with heart failure. Recruitment was limited by the author being reliant upon the physician to identify potential participants. In addition, recruitment may have been limited by the method in which the electronic health records at the FMC identifies the primary diagnosis, as heart failure is not often recorded as such, therefore was difficult to identify the target population in a diagnosis specific search. The original study protocol was designed to be quantitative, however a mixed methods design should have been proposed at the outset. The DHFKS although reliable and valid has not been applied enough times to measure sensitivity and

specificity, and may not have been the most suitable tool to evaluate the outcome of the LEARN twice education session.

## 5.2 Delimitations

The study did not control for the potential variability between participants' age, severity of heart failure symptoms, and the length of time since the diagnosis of heart failure or co-morbid conditions.

## 5.3 Recommendations and future study

While the study lacked sufficient participants, the methodology and procedures were developed with rigour and the evaluation tools when used in the field have produced empirical data. Although the education series was conducted once only, it was adequate to evaluate the content that does require amendment to reflect the latest recommendations for nutrition and the updated research on fluid and salt restrictions. In its current format the study could be continued or replicated once the education series is in place. In keeping with the contemporary literature, rates of hospital admission for clients who attend the disease management series should be tracked and compared to clients who do not participate. In general, the success of an education series for client with heart failure is measured in terms of rates of hospital admission and if the results of the education series based on the concept of LEARN twice were to show significance in the reduction of hospital admission, then it would measure up very favourably to the results of many other studies on this topic.

## Chapter 6

### 6.0 Conclusions

The education series closely mirrored the recommendations for a disease management programme as outlined in the literature in terms of its setting in a primary care clinic and its administration by an inter-professional team of health care providers. The tool LEARN twice was developed following careful scrutiny of the non-pharmacological management in the best practice guidelines from the American, European and Canadian cardiac societies. LEARN twice provided the participants with a framework of the essential self-care and self-management skills for heart failure. It also formed the basis and outline of topics for the education series.

As the study did not have sufficient numbers of participants to produce statistically significant results, a description of the findings of the DHFKQ, MLHFQ, diet, weight, and exercise logs was undertaken.

The clinicians and administration of the Family Medicine Clinic (FMC) and the Family Medicine Unit at the University of Manitoba felt that the education series was an important addition to the programming to the clients and collaborated with the author to develop and endorse the project.

### 6.1 Future considerations

As the study demonstrated that it was feasible to implement an education series at the FMC, the author will be working with the team to further enhance the education series with updated information particularly in the section taught by the physician which does

not have specific information on the differences between systolic and diastolic heart failure. The goal of enhancing the content is to allow for more individualized programming for the clients of the clinic based on their specific type of heart failure rather than providing a general overview of the condition. It was not possible to provide individualised education to the participants as their particular type of heart failure unknown to the educators. An inter-professional approach was taken to the development and implementation of the education series, however it lacked the input of a physiotherapist in order to teach the specifics of exercise training.

In order to evaluate the education series, the study can be easily continued or replicated by the FMC. In addition the validity of the education series could be determined by a correlation of hospital admission rates using the clients as their own controls to establish whether there is a reduction in the hospital admission rates for heart failure related reasons in clients after they have attended the education series. Similarly it would be hoped that those clients who received education on initial diagnosis would have lower rates of hospital readmission than those who did not receive education. The replication of the study and the evaluation of the outcomes of the education series are in keeping with the FMC being a teaching unit of the University of Manitoba, providing training for family medicine residents, nursing, dietary and pharmacy students and conducting research at a clinical level.

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## **Appendix A**

### **Genesis of LEARN twice**

**“Learn how your heart works” & “Learn about heart failure”**

In terms of the first two skills, “Learn how your heart works and Learn about heart failure”, the ESC guidelines recommend that clients understand the cause of heart failure and why symptoms occur. The Heart Failure Society of America (HFSA) guidelines recommend that basic heart failure information and the cause of heart failure be taught to the client, in addition to how symptoms relate to heart failure status. To have these skills, the client needs to be able to identify the specific signs and symptoms such as increasing fatigue, shortness of breath with usual activities, dyspnea at rest, nocturnal dyspnea and edema.

**“Eat a healthy diet, low in salt” & “Examine food labels”**

For these skills, the HFSA and the ESC guidelines recommend that clients understand and comply with sodium restrictions where necessary. The HFSA guidelines outline the need for clients to demonstrate how to read a food label to check for sodium amount and to learn how to sort foods into high and low sodium groups. The ESC guidelines recommend eating healthily and keeping a healthy body weight.

**“Always take your medication as prescribed” & “Always weigh yourself every day”**

These activities are based on recommendations by the HFSA guidelines which outline the fact that the client needs to be able to reiterate medication dosing schedule, the reason for specific medications, and what to do if a dose is missed. The ESC guidelines

recommend that patients understand the indications, dosing and effects of drugs and to recognize the common side effects of each drug. The importance of following treatment recommendations and maintaining motivation to follow treatment plans underscore the recommendations. Additionally, the HFSA guidelines recommend that the client plans and uses a medication system that promotes routine adherence and that there is a plan for medication refills. Both sets of guidelines and the Canadian Cardiac Society (CCS) guidelines recommend that clients record daily weight, and have the skills to know how to respond to evidence of volume overload through rapid weight gain.

**“Remember to exercise a little every day” & “Remember to conserve your energy”**

For the skills of “Remember to exercise every day and Remember to conserve your energy”, the HFSA guidelines recommend complying with prescribed exercise and the ESC recommends understanding the benefits of exercise and to perform exercise training regularly. In addition, the client should be reassured and comfortable about physical activity. The CCS recommendations from 2006 have specific recommendations for exercise training in terms of prevention of muscle deconditioning, citing that exercise training should be carried out three to five times weekly with supervision. There are no specific recommendations in the guidelines for energy conservation but energy conservation techniques were taken from information produced by the Canadian Network of Occupational Therapists Working in Oncology (Phan et al., 2002).

**“Never ignore symptoms” & “Notify your doctor immediately”**

Finally the skills of “**N**ever ignore symptoms and **N**otify your doctor immediately” are based upon the recommendations of the HFSA and the CCS that the client develop an action plan for how and when to notify their health provider. The ESC recommends that the client is able to monitor and recognize signs and symptoms, know how and when to notify their health care provider. The standard recommendation is that the client should be knowledgeable about alerting the health care provider in the case of increasing dyspnea, fatigue or sudden unexpected weight gain of greater than 2lbs in 2 days or 5lbs in a week.

## Appendix B

### Teaching Companion for Family Medicine Residents Classes & Teaching Modules

LEARN to co-manage heart failure: Implementation of best practice guidelines

#### Background

The incidence of heart failure increases significantly for clients over 65, and is a primary reason for hospital admission (Ezekowitz et al., 2009). The Heart Failure Society of America (HFSA), Lindenfeld et al. (2010), the European Society of Cardiology (ESC), Dickstein et al. (2008); McMurray et al. (2012) and The Canadian Cardiovascular Society (CCS), Arnold et al.(2006); Arnold et al. (2008); Howlett et al. (2010) have each published comprehensive best practice guidelines for use by health practitioners, who work with patients with heart failure.

The HFSA, ESC and the CCS guidelines suggest that skills in self care and disease management learned by clients are imperative in reducing exacerbations of heart failure and thus hospital admission. A core concept articulated by the guidelines is that teaching is not sufficient without skill building and development of critical target behaviours. The target behaviours are defined as actions that the client routinely completes to effectively manage their symptoms of heart failure.

The Family Medical Centre is collaborating with the author to offer an education program for clients with heart failure. This original study presents the opportunity for an occupational therapist to lead implementation of best practice guidelines based upon the recommendations of The Heart Failure Society of America (HFSA), Lindenfeld et al.

(2010), the European Society of Cardiology (ESC), McMurray et al. (2012) and The Canadian Cardiac Society (CCS), Howlett et al. (2010) related to heart failure management in a primary care setting. The instruments used for evaluation of the education program will be standardized tools; the Dutch Heart Failure Knowledge Scale, van der Wal, Jaarsma, Moser and van Veldhuisen (2005a) and The Minnesota Living with Heart Failure Questionnaire (Rector, Kubo, & Cohn, 1987).

#### Self management/disease management

Self management of heart failure is the ability of the client to monitor their health status to ensure maintenance of a compensated state of health by following salt and fluid allowances, medication and exercise regimes (Lindenfeld et al., 2010). Self management programmes must build the client's confidence through problem solving, decision making, action planning and behaviour change (Packer, 2011).

The HFSA, ESC and the CCS guidelines suggest that skills in self-care and disease management learned by the clients are imperative in reducing exacerbations of heart failure and thus hospital admission.

#### Skill building/target behaviours

- A core concept articulated by the HFSA, ESC and CCS guidelines is that teaching is not sufficient without skill building and development of critical target behaviours.
- The target behaviours are defined as actions that the client routinely completes to effectively manage their symptoms of heart failure (HFSA guidelines, 2010).

#### Challenges

- 50% of people with clinically stable heart failure were unable to name their medication or doses and 75% failed to take their medication 30 days after receiving standardized one-on-one instruction and written information about the treatment regimen (Gray, Mahoney & Blough 2001).
- The most frequent indicator of hospitalization for heart failure is weight gain (Shah, Der, Ruggerio, Heidenreich & Massie, 1998).
- Many elderly clients with heart failure do not recognize early warning signs of the deterioration of their condition (Stanley & Prasun, 2002).
- 46% of patients found dyspnea or shortness of breath very distressing; however a significant percentage did not seek medical care for six or more days (Parschall, Welsh, Brockopp, Schooler, & Cassidy 2001).

### Solutions

A disease-management programme can significantly impact on symptoms, functional capacity and well being by assisting the client to acquire the knowledge, skills, strategies and problem solving abilities necessary to adhere to treatment plans and effectively participate in self care.

The disease-management programme which will be offered as part of the research study will offer participants three education classes in series, each of which will be one and a half hours in length. There will be a nutrition break for fifteen minutes in each class.

The concept of “LEARN” how to manage heart failure, has been developed by the author, based upon the recommendations for skill acquisition by the HFSA, ESC and CCS guidelines. The key points outlined in “LEARN” will form the basis for communication of essential information which needs to be taught to and implemented by the client in order to be successful in the self management of their heart failure. The knowledge considerations in “LEARN” how to manage heart failure are outlined as follows:

**L**earn how your heart works. / **L**earn about heart failure.

**E**at a healthy diet, low in salt. / **E**xamine food labels.

**A**lways take your medication as prescribed. / **A**lways weigh yourself every day.

**R**emember to exercise a little every day. / **R**emember to conserve your energy.

**N**ever ignore symptoms. / **N**otify your doctor immediately.

Table A1 below was based on the 2008 European Society of Cardiology Guidelines, Dickstein et al. (2008), and forms the basis for the content of the three education classes.

Table A1

*Content of Education Classes*

<b>Elements of patient education</b>	<b>Target behaviours and skills</b>
<p>Definition &amp; aetiology of heart failure</p> <p>Teach the link between disease, symptoms, and treatment</p> <p>Teach cause of patient's HF</p>	<p>Client can describe heart failure and understands cause of heart failure and how symptoms relate to HF status</p>
<p>Teach specific signs and symptoms (e.g., increasing fatigue or shortness of breath with usual activities), dyspnea at rest, nocturnal dyspnea or orthopnea, edema)</p> <p>Teach client how to take daily weights</p> <p>Teach client to recognize escalating symptoms</p> <p>Teach client a concrete plan for response to particular symptoms</p>	<p>Client can reiterate symptoms of worsening HF</p> <p>Client knows when to call the provider because of specific symptoms or weight changes</p> <p>Client performs daily weights and knows how to respond to evidence of volume overload</p> <p>Client can state what action plan is for how and when to notify the provider, and what changes to make in diet, fluid and diuretics</p>
<p>Teach client the indications and use of each medication</p>	<p>Client can demonstrate knowledge of the name, dose, and purpose of each medication, and their preferred method for tracking medication dosing.</p> <p>Client plans and uses a medication system that promotes routine adherence, and plans for refills</p> <p>Client can reiterate medication dosing schedule, basic reason for specific medications, and what to do if a dose is missed</p>
<p>Teach client the reason for sodium restriction</p> <p>Teach client the reason for fluid restriction</p> <p>Teach client what constitutes a fluid</p> <p>Teach client individual fluid restriction</p>	<p>Client understands and can comply with sodium allowance.</p> <p>Client demonstrates how to read a food label to check sodium amount per serving</p> <p>Client understands and complies with fluid allowance</p> <p>Client reiterates limits for alcohol consumption or need for abstinence if</p>

Elements of patient education	Target behaviours and skills
	<p>history of alcohol abuse</p> <p>Therapists plan for emphasis on behavioural strategies to increase adherence</p>
Sleep & breathing disorders	<p>Assess number of pillows client uses to sleep</p> <p>Order hospital bed if necessary</p> <p>Client should know how to manage night time waking due to diuretic use</p> <p>Refer to sleep disorder clinic if sleep apnea suspected</p>
Fatigue	<p>Client reiterates cause for fatigue</p> <p>Client complies with energy conservation techniques</p>
Risk factor modification	<p>Client demonstrates understanding of the Importance of treatment adherence and behavioural strategies to promote compliance</p>
<p>Teach client how to determine and count sodium allowance.</p> <p>Teach client the physiology of early satiety.</p> <p>Review daily menu with client to discuss and review intake and food choices</p>	<p>Client can sort foods into high and low sodium categories</p> <p>Client will be referred to dietician for nutritional counseling</p> <p>Client understands how to manage early satiety</p>
Client will be taught individual exercise guidelines	<p>Client will know how to increase exercise tolerance</p> <p>Client will be active for the recommended 30 minutes per day</p>
<p>Psychosocial aspects</p> <p>Comprehensive education and counseling individualized to patient needs</p>	<p>Client to be referred to social work or other counselling service as necessary</p>

Class 1 Module 1. Taught by Family Medicine Resident

Learn how your heart works. Learn what heart failure is.

The clients will be taught the anatomy of the heart and have an outline of how the heart works. They will learn the etiology of heart failure. A short YouTube video is used to outline heart anatomy and information on heart anatomy is included in the hand out material. Symptoms of heart failure are outlined. The symptoms of heart failure and action plan for notification of a health care provider will be reviewed in the third and final education class. The role of the kidneys in terms one of the sources of fluid retention in addition to the lungs is outlined.

Time will be allocated for interaction with the presenters to answer specific questions. The education material provided as handouts will provide a summary of the essential skills required for effective management of the symptoms of heart failure.

Educational material will be developed with consideration for the tenets of health literacy and health education. Over the course of the three education sessions, participants will be given a tool kit and homework which will include a pedometer and logs for recording daily weight, diet and cumulative amounts of exercise.

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Teaching Modules for Heart Failure Education Classes (3)

Class 1

Module 1. Taught by Family Medicine Resident

Learn how your heart works. / Learn about heart failure.

Anatomy of the heart

Definition and explanation of systolic and diastolic heart failure

Module 2. Taught by Dietician

Eat a healthy diet, low in salt. / Examine food labels.

Discuss early satiety

Keep the amount of salt you eat to 2000 milligrams (mgs) per day.

Learn to read food labels to check sodium amount per serving.

Eat 500mgs of salt at breakfast, 500mgs at lunch, and 500mgs at suppertime, and then there are 500mgs for snacks.

Sort foods into low and high sodium categories.

Discuss food suggestions/recipes/resources.

Set homework for next class, participants to complete a food diary.

Class time will include a 15 minute nutrition break.

Class 2

Module 1. Taught by Pharmacist or Nurse,

Review homework

Always take your medication as prescribed. / Always weigh yourself every day.

Weigh yourself in the morning after using the bathroom and before eating breakfast. Write it down. Compare your weight today to your weight yesterday.

“Tricks “to get your kidneys to work better. Effective use of diuretics to prevent nighttime wakening. Limit feet dependent for longer than 30-45 mins.

Take your medicine exactly how your doctor said.

Check for swelling in your feet, ankles, legs, and stomach.

Plan for medication refills, pharmacy delivery/calls to doctor’s office.

Plan for medication administration to promote routine adherence.

### Module 2. Taught by OT

Remember to exercise a little every day. / Remember to conserve your energy.

Balance activity and rest periods

Fatigue and energy conservation

Aerobic exercise and resistance training

Homework to include a daily weight log and an exercise log

Each participant will be provided with a pedometer.

Class time will include a 15 minute nutrition break

### Class 3

Review “homework”

### Module 1. Taught by OT

Never ignore symptoms. / Notify your doctor immediately.

Call your Health Care provider if you have any of the following:

You gain more than 4 lbs (2 kg) in 2 days or 5lbs (2.5kg) in 1 week. \_  
You have vomiting and/or diarrhea that lasts more than two days.  
You feel more short of breath than usual.  
You have increased swelling in your feet, ankles, legs, or stomach.  
You have a dry hacking cough.  
You feel more tired and don't have the energy to do daily activities.  
You feel lightheaded or dizzy, and this is new for you.  
You feel uneasy, like something does not feel right.  
You find it harder for you to breathe when you are lying down.  
You find it easier to sleep by adding pillows or sitting up in a chair.

### Module 2 Taught by OT

Provide information package and resources.

Will contain information on each of the modules in written form and will also include information on sleep and breathing disorders, sexual activity, resources, action plans, travel. Current web-based learning modules and web-based resources will be referenced.

Study participants complete Dutch heart Failure Knowledge Scale (DHFKS) & Minnesota Living with Heart Failure Questionnaire (MLHFQ).

**Appendix C**

Study Cover Sheet; Dutch Heart Failure Knowledge Scale; Minnesota Living with Heart

Failure Questionnaire



**LEARN to co-manage heart failure: Implementation of best practice guidelines**

**Study ID number** \_\_\_\_\_

**Date** \_\_\_\_\_

**Telecare Manitoba**

**1. What year were you born in?** \_\_\_\_\_

**2. What is your gender?**

MALE

FEMALE

**3. What is your highest level of education?**

ELEMENTARY: ANY GRADE BETWEEN 1 AND 6

JUNIOR HIGH/HIGH SCHOOL: ANY GRADE BETWEEN 7 AND 12

POST-SECONDARY

**4. How would you describe the amount you know about Heart Failure?**

NONE

POOR

FAIR

GOOD

VERY GOOD

**5. Where have you found information about Heart Failure?**

**(tick all boxes that apply)**

INTERNET

HEALTH CARE PROVIDER (DOCTOR, NURSE OR OTHER)

FAMILY MEMBER/FRIEND

BOOKS

OTHER

PLEASE DESCRIBE \_\_\_\_\_

**DUTCH HEART FAILURE KNOWLEDGE SCALE**

M.H.L. van der Wal, T. Jaarsma: June 2003

**This list contains a number of questions and statements about heart failure.**

**Please tick off what you think is the right answer (only tick 1 box per question).**

**1. How often should patients with severe heart failure weigh themselves?**

- EVERY WEEK
- NOW AND THEN
- EVERY DAY

**2. Why is it important that patients with heart failure should weigh themselves regularly?**

- BECAUSE MANY PATIENTS WITH HEART FAILURE HAVE A POOR APPETITE
- TO CHECK WHETHER THE BODY IS RETAINING FLUID
- TO ASSESS THE RIGHT DOSE OF MEDICINES

**3. How much fluid are you allowed to take at home each day?**

- 1.5 TO 2.5 LITRES AT THE MOST
- AS LITTLE FLUID AS POSSIBLE
- AS MUCH FLUID AS POSSIBLE

**4. Which of these statements is true?**

- WHEN I COUGH A LOT, IT IS BETTER NOT TO TAKE MY HEART FAILURE MEDICATION
- WHEN I AM FEELING BETTER, I CAN STOP TAKING MY MEDICATION FOR HEART FAILURE
- IT IS IMPORTANT THAT I TAKE MY HEART FAILURE MEDICATION REGULARLY

**5. What is the best thing to do in case of increased shortness of breath or swollen legs?**

- CALL THE DOCTOR OR THE NURSE
- WAIT UNTIL THE NEXT CHECK-UP
- TAKE LESS MEDICATION

**6. What can cause a rapid worsening of heart failure symptoms?**

- A HIGH-FAT DIET
- A COLD OR THE FLU
- LACK OF EXERCISE

**Study ID number** \_\_\_\_\_

**7. What does heart failure mean?**

- THAT THE HEART IS UNABLE TO PUMP ENOUGH BLOOD AROUND THE BODY
- THAT SOMEONE IS NOT GETTING ENOUGH EXERCISE AND IS IN POOR CONDITION
- THAT THERE IS A BLOOD CLOT IN THE BLOOD VESSELS OF THE HEART

**8. Why can the legs swell up when you have heart failure?**

- BECAUSE THE VALVES IN THE BLOOD VESSELS IN THE LEGS DO NOT FUNCTION PROPERLY
- BECAUSE THE MUSCLES IN THE LEGS ARE NOT GETTING ENOUGH OXYGEN
- BECAUSE OF ACCUMULATION OF FLUID IN THE LEGS

**9. What is the function of the heart?**

- TO ABSORB NUTRIENTS FROM THE BLOOD
- TO PUMP BLOOD AROUND THE BODY
- TO PROVIDE THE BLOOD WITH OXYGEN

**10. Why should someone with heart failure follow a low salt diet?**

- SALT PROMOTES FLUID RETENTION
- SALT CAUSES CONSTRICTION OF THE BLOOD VESSELS
- SALT INCREASES THE HEART RATE

**11. What are the main causes of heart failure?**

- A MYOCARDIAL INFARCTION AND HIGH BLOOD PRESSURE
- LUNG PROBLEMS AND ALLERGY
- OBESITY AND DIABETES

**12. Which statement about exercise for people with heart failure is true?**

- IT IS IMPORTANT TO EXERCISE AS LITTLE AS POSSIBLE AT HOME IN ORDER TO RELIEVE THE HEART
- IT IS IMPORTANT TO EXERCISE AT HOME AND TO REST REGULARLY IN BETWEEN
- IT IS IMPORTANT TO EXERCISE AS MUCH AS POSSIBLE AT HOME

Study ID number \_\_\_\_\_

**13. Why are water pills prescribed to someone with heart failure?**

- TO LOWER THE BLOOD PRESSURE
- TO PREVENT FLUID RETENTION IN THE BODY
- BECAUSE THEN THEY CAN DRINK MORE

**14. Which statement about weight increase and heart failure is true?**

- AN INCREASE OF OVER 2 KILOGRAMS IN 2 OR 3 DAYS SHOULD BE REPORTED TO THE DOCTOR AT THE NEXT CHECK-UP
- IN CASE OF AN INCREASE OF OVER 2 KILOGRAMS IN 2 OR 3 DAYS, YOU SHOULD CONTACT YOUR DOCTOR OR NURSE
- IN CASE OF AN INCREASE OF OVER 2 KILOGRAMS IN 2 OR 3 DAYS, YOU SHOULD EAT LESS

**15. What is the best thing to do when you are thirsty?**

- SUCK AN ICE CUBE
- SUCK A LOZENGE
- DRINK A LOT

Study ID number \_\_\_\_\_



## MINNESOTA LIVING WITH HEART FAILURE<sup>®</sup> QUESTIONNAIRE

The following questions ask how much your heart failure (heart condition) affected your life during the past month (4 weeks). After each question, circle the 0, 1, 2, 3, 4 or 5 to show how much your life was affected. If a question does not apply to you, circle the 0 after that question.

### Did your heart failure prevent

**you from living as you wanted during  
the past month (4 weeks) by -**

	No	Very Little				Very Much
1. causing swelling in your ankles or legs?	0	1	2	3	4	5
2. making you sit or lie down to rest during the day?	0	1	2	3	4	5
3. making your walking about or climbing stairs difficult?	0	1	2	3	4	5
4. making your working around the house or yard difficult?	0	1	2	3	4	5
5. making your going places away from home difficult?	0	1	2	3	4	5
6. making your sleeping well at night difficult?	0	1	2	3	4	5
7. making your relating to or doing things with your friends or family difficult?	0	1	2	3	4	5
8. making your working to earn a living difficult?	0	1	2	3	4	5
9. making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4	5
10. making your sexual activities difficult?	0	1	2	3	4	5
11. making you eat less of the foods you like?	0	1	2	3	4	5
12. making you short of breath?	0	1	2	3	4	5
13. making you tired, fatigued, or low on energy?	0	1	2	3	4	5
14. making you stay in a hospital?	0	1	2	3	4	5
15. costing you money for medical care?	0	1	2	3	4	5
16. giving you side effects from treatments?	0	1	2	3	4	5
17. making you feel you are a burden to your family or friends?	0	1	2	3	4	5
18. making you feel a loss of self-control in your life?	0	1	2	3	4	5
19. making you worry?	0	1	2	3	4	5
20. making it difficult for you to concentrate or remember things?	0	1	2	3	4	5
21. making you feel depressed?	0	1	2	3	4	5

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**Study ID number**\_\_\_\_\_

**Appendix D**

**Letter of invitation; Recruitment poster; Letter of confirmation**



409 Taché Ave, Winnipeg MB Canada R2H 2A6  
T. (204) 233-8563

December 2012

Tel:

E-mail:

Dear Client:

I am an occupational therapist who works at St. Boniface Hospital. As a student completing a Master's of Science in Rehabilitation at the University of Manitoba, I am conducting a research project. The goal of my research is to see if your knowledge of heart failure and your quality of life will change if you attend a three education classes about managing heart failure. The classes will be held at the Family Medical Centre at 400 Taché Ave on \_\_\_\_\_ at \_\_\_\_\_. Please come to the Family Medical Centre conference room on the 7<sup>th</sup> Floor.

If you choose to participate in the study, you will be asked to sign a consent form which is included in this information package. As part of the study you will be asked to fill in two questionnaires, the Dutch Heart Failure Knowledge Scale and Minnesota Living with Heart Failure Questionnaire before the first class starts, and at the end of the third class. The questionnaires should take about ten minutes to complete each time. The questionnaires will not have your name written on them and will not have any data that can identify you. You will receive \$10:00 for attending each education class to cover your parking.

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, please contact me. For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at 204-789-3389.

Sincerely,  
Jane McSwiggan, OT Reg. (MB)



Hôpital St-Boniface Hospital

## Family Medical Centre

### **PARTICIPANTS NEEDED FOR RESEARCH IN HEART FAILURE**

I am looking for volunteers with heart failure to take part in a study of the effects of education in your ability to manage the condition.

As a participant in this study you would be required to attend three education classes about heart failure, each of which will be one and a half hours . Your participation would involve completion of questionnaires. Classes will be held at the Family Medical Centre at 400 Taché Ave.

In appreciation for your time you will be offered a small honorarium. Refreshments will be served.

For information on this study, or to volunteer for this study, please contact:

Jane McSwiggan OT Reg. (MB)  
Occupational Therapist  
Rehabilitation Services  
Tel: 204----- or (email address)

This study has been approved by the Health Research Ethics Board  
at the University of Manitoba

409 Taché Ave, Winnipeg MB Canada R2H 2A6  
T. (204) 233-8563



Hôpital St-Boniface Hospital

12 March 2013

Further to our telephone conversation of today, I wish to thank you for joining the research study and agreeing to come to the heart failure education classes.

There will be three education classes to attend and they will be held at the Family Medical Centre at 400 Taché Ave on **March 27, April 3 and April 10 from 1:30pm to 3:00pm**. Please come to the Family Medical Centre conference room on the 7<sup>th</sup> Floor.

As part of the study you will be asked to fill in two questionnaires, the Dutch Heart Failure Knowledge Scale and Minnesota Living with Heart Failure Questionnaire before the first class starts, and at the end of the third class. The questionnaires should take about ten minutes to complete each time. The questionnaires will not have your name written on them and will not have any data that can identify you. You will receive \$10:00 for attending each education class to cover your parking.

Please contact me if you have any questions or if you cannot attend. I will telephone you the day before to remind you of the classes.

Sincerely,

Jane McSwiggan, OT Reg. (MB)

Tel:

**Appendix E**

**Research participant information and consent forms (3)**



Hôpital St-Boniface Hospital

## RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

**Title of Study:** **LEARN** TO CO-MANAGE HEART FAILURE: IMPLEMENTATION OF BEST PRACTICE GUIDELINES

**Principal Investigator:**

Jane McSwiggan OT Reg. (MB), Graduate Student  
 School of Medical Rehabilitation, University of Manitoba  
 771 McDermot Ave, Winnipeg, MB R3E 0T6

Tel:

You are being asked to participate in a research study. Please take your time to review this letter and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends and family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

### Purpose of the Study

The purpose of the study is to see if your knowledge of heart failure and your quality of life will change if you attend a three one hour education classes about heart failure.

### Study Procedures

You will be invited to attend a series of three education classes called LEARN to Co-Manage Heart Failure. Each class will be one and a half hours in length with a fifteen minute nutrition break. When you attend the first class the project will be explained to you and you will be asked if you would like to participate in the study. If you agree you will be asked to sign this consent form. Before the first class starts you will be asked to fill in two questionnaires, one called the Dutch Heart Failure Knowledge Scale and one called the Minnesota Living with Heart Failure Questionnaire. When the third class is over, you will be asked to complete the Dutch Heart Failure Knowledge Scale and the Minnesota Living with Heart Failure Questionnaire again. The questionnaires should take about ten minutes to complete each time.

The questionnaires will not request any information or data that can identify you. The questionnaire will ask for your gender, your year of birth and the highest level of education you attained.

You can stop participating in the study at any time. However, if you decide to stop participating in the study, we encourage you to talk with the study staff first. If you wish we will provide you with a copy of the results of the study by mail after the study have been completed and the data are analysed.

### **Secondary Analysis of the Data**

A second study may be done with the data obtained from this study to review rates of readmission to hospital with symptoms of heart failure in participants of this study. Your permission would be needed to examine the data from this study a second time and you would be contacted by matching your name from this consent form to your contact information which may be held at the Family Medical Centre.

### **Risks and Discomforts**

There are no physical risks to you when participating in the study. You may potentially feel a little anxious about filling in the questionnaires.

### **Benefits**

There may or may not be direct benefit to you by participating in this study. We hope the information learned from this study will benefit other people with heart failure in the future.

### **Costs**

All the procedures which will be performed as part of this study are provided at no cost to you.

You will receive \$10:00 each time you attend an education class to cover parking expenses.

### **Confidentiality**

A study identification number (ID number) will be assigned to you. The Dutch Heart Failure Knowledge Scale (questionnaire) and the Minnesota Living with Heart Failure Questionnaire that you will complete will be labelled with the ID number instead of your name so that your personal identity will be kept confidential. The questionnaire will also contain your year of birth, gender and information regarding highest level of education achieved.

Information gathered in this research study may be published or presented in public forums; however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The study ID number will be linked to personal information on this consent form. The consent forms will be stored in a separate locked filing cabinet from the questionnaires at St. Boniface Hospital.

Data obtained from the questionnaires will be transcribed to a spreadsheet which will be stored on a password protected computer database. Should a respondent withdraw their consent to participate in the study, the data stored will be shredded. Evaluation results which have been transferred to the computer database will be permanently deleted in the case of withdrawal from the study.

Medical records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba.

The University of Manitoba Health Research Ethics Board and St. Boniface General Hospital may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area. If any of your research records need to be copied to the University of Manitoba Health Research Ethics Board, your name and all identifying information will be removed. No information revealing any of your personal information such as your name, address or telephone number will leave St. Boniface Hospital.

### **Questions**

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, you may contact Jane McSwiggan at (204) \*\*\*\*\* or (email address).

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

**Statement of Consent**

I have read this consent form. I have had the opportunity to discuss this research study with Jane McSwiggan and/or the study staff. I have had my questions answered by them in language that I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decisions to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may chose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by the University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted in the future if secondary analysis of the data is to occur:

**Yes**                       **No**

**Participant signature:** \_\_\_\_\_

**Date** \_\_\_\_\_ **(Day/month/year)**

**Participant printed name:** \_\_\_\_\_

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

**Printed name:** \_\_\_\_\_

**Date** \_\_\_\_\_ **(Day/month/year)**

**Signature:** \_\_\_\_\_ **Role in the study:** \_\_\_\_\_

**Study Results**

Please contact the Principal Investigator at (email address), if you would like a copy of the results of this research study.



## RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

**Title of Study: LEARN TO CO-MANAGE HEART FAILURE: IMPLEMENTATION OF BEST PRACTICE GUIDELINES**

**Principal Investigator:**

Jane McSwiggan OT Reg. (MB), Graduate Student  
 School of Medical Rehabilitation, University of Manitoba  
 771 McDermot Ave, Winnipeg, MB R3E 0T6

Tel:

You are being asked to participate in a research study. Please take your time to review this letter and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends and family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

### Purpose of the Study

The purpose of the study is to review your experience in the development and implementation of a series of three education classes using a framework of inter-professional practice and inter-professional consultation in the development and implementation of the education classes.

### Study Procedures

If you agree to participate in this study, the study investigator will meet you at your office for about 30 minutes to ask you a series of questions about your experiences and your opinions about the development and implementation of the education classes. The questions will not request any information or data that can identify you.

You can stop participating in the study at any time. However, if you decide to stop participating in the study, we encourage you to talk with the study staff first.

If you wish we will provide you with a copy of the results of the study by mail after the study have been completed and the data are analysed.

The questionnaires will not request any information or data that can identify you.

You can stop participating in the study at any time. However, if you decide to stop participating in the study, we encourage you to talk with the study staff first.

If you wish we will provide you with a copy of the results of the study by mail after the study have been completed and the data are analysed.

### **Risks and Discomforts**

There are no physical risks to you when participating in the study.

There may or may not be direct benefit to you by participating in this study. We hope the information learned from this study will benefit teams who treat heart failure in the future.

### **Costs**

All the procedures which will be performed as part of this study are provided at no cost to you.

### **Confidentiality**

A study identification number (ID number) will be assigned to you. Information gathered in this research study may be published or presented in public forums; however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The study ID number will be linked to personal information on this consent form. The consent forms will be stored in a separate locked filing cabinet from the data collected through the interviews at St. Boniface Hospital.

Responses from the questions will be typed out and will be stored on a password protected computer database. Should a respondent withdraw their consent to participate in the study, the data stored will be shredded. Evaluation results which have been transferred to the computer database will be permanently deleted in the case of withdrawal from the study.

Medical records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba.

The University of Manitoba Health Research Ethics Board and St. Boniface General Hospital may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area. If any of your research records need to be copied to the University of Manitoba Health Research Ethics Board, your name and all identifying information will be removed. No information revealing any of your personal information such as your name, address or telephone number will leave St. Boniface Hospital.

### **Questions**

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, you may contact Jane McSwiggan at (204) ----- or (email address).

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

### **Statement of Consent**

I have read this consent form. I have had the opportunity to discuss this research study with Jane McSwiggan and/or the study staff. I have had my questions answered by them in language that I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decisions to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may chose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by the University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

**Participant signature:** \_\_\_\_\_

**Date** \_\_\_\_\_ **(Day/month/year)**

**Participant printed name:** \_\_\_\_\_

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

**Printed name:** \_\_\_\_\_

**Date** \_\_\_\_\_ **(Day/month/year)**

**Signature:** \_\_\_\_\_

**Role in the study:** \_\_\_\_\_

### **Study Results**

Please contact the Principal Investigator at (email address), if you would like a copy of the results of this research study.



## **RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM**

**Title of Study: LEARN TO CO-MANAGE HEART FAILURE: IMPLEMENTATION OF BEST PRACTICE GUIDELINES**

**Principal Investigator:**

Jane McSwiggan OT Reg. (MB), Graduate Student  
 School of Medical Rehabilitation, University of Manitoba  
 771 McDermot Ave, Winnipeg, MB R3E 0T6

Tel:

You are being asked to participate in a research study. Please take your time to review this letter and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends and family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

### **Purpose of the Study**

The purpose of the study is to review your experience about attending a series of three education classes about heart failure.

### **Study Procedures**

If you agree to participate in this study, the study investigator will meet you at your home for about 30 minutes to ask you a series of questions about your experiences and to seek your opinions about attending the education classes. The questions will not request any information or data that can identify you.

You can stop participating in the study at any time. However, if you decide to stop participating in the study, we encourage you to talk with the study staff first.

If you wish we will provide you with a copy of the results of the study by mail after the study have been completed and the data are analysed.

### **Risks and Discomforts**

There are no physical risks to you when participating in the study. You may potentially feel a little anxious about answering the questions.

**Benefits**

There may or may not be direct benefit to you by participating in this study. We hope the information learned from this study will benefit other people with heart failure in the future.

**Costs**

All the procedures which will be performed as part of this study are provided at no cost to you.

**Confidentiality**

A study identification number (ID number) will be assigned to you. Information gathered in this research study may be published or presented in public forums; however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The study ID number will be linked to personal information on this consent form. The consent forms will be stored in a separate locked filing cabinet from the data collected through the interviews at St. Boniface Hospital.

Responses from the questions will be typed out and will be stored on a password protected computer database. Should a respondent withdraw their consent to participate in the study, the data stored will be shredded. Evaluation results which have been transferred to the computer database will be permanently deleted in the case of withdrawal from the study.

Medical records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba.

The University of Manitoba Health Research Ethics Board and St. Boniface General Hospital may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area. If any of your research records need to be copied to the University of Manitoba Health Research Ethics Board, your name and all identifying information will be removed. No information revealing any of your personal information such as your name, address or telephone number will leave St. Boniface Hospital.

**Questions**

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, you may contact Jane McSwiggan at (204) ----- or (email address).

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

**Statement of Consent**

I have read this consent form. I have had the opportunity to discuss this research study with Jane McSwiggan and/or the study staff. I have had my questions answered by them in language that I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decisions to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may chose to withdraw at any time. I freely agree to participate in this research study.

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By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

**Participant signature:** \_\_\_\_\_

**Date** \_\_\_\_\_ **(Day/month/year)**

**Participant printed name:** \_\_\_\_\_

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

**Printed name:** \_\_\_\_\_

**Date** \_\_\_\_\_ **(Day/month/year)**

**Signature:** \_\_\_\_\_

**Role in the study:** \_\_\_\_\_

**Study Results**

Please contact the Principal Investigator at (email address), if you would like a copy of the results of this research study.

**Appendix F**

**Participant and Faculty Interview Outlines**



409 Taché Ave, Winnipeg MB Canada R2H 2A6  
T. (204) 233-8563

## LEARN to co-manage heart failure: Implementation of best practice guidelines

### Questions for education group participants:

1. How did you feel about participating in the education sessions?
2. Do you have any comments on the content of the education sessions, was it meaningful, was it understandable?
3. Did you like having different professionals teach you the content, i.e. the doctor, nurse, pharmacy student, dietician and occupational therapist?
4. Were the handouts useful?
5. Was it helpful to your learning to keep a diet, exercise and weight log?
6. Please tell me about two things you found that you learned from the education sessions.
7. Have the education sessions made a difference to you knowledge of heart failure?
8. If you could change things in the education sessions, what you change?
9. What did you find difficult about attending the education sessions?

12<sup>th</sup> April 2013



Hôpital St-Boniface Hospital

409 Taché Ave, Winnipeg MB Canada R2H 2A6  
T. (204) 233-8563

## LEARN to co-manage heart failure: Implementation of best practice guidelines

Questions for education group faculty:

1. Were you aware of the best practice guidelines for heart failure prior to the development of the education groups?
2. Do you feel that the content of the best practice guidelines is applicable to the patient group at the Family Medical Clinic?
3. Please comment on the process by which the education session content was developed, i.e. having another discipline producing the content for your discipline.
4. Will the education series as developed be useful in the clinic setting?
5. What would you change in the content?
6. What would you add to the content?
7. What would you change in the delivery?
8. Please comment on what you learned from other disciplines involved in teaching the education sessions.

12<sup>th</sup> April 2013

**Appendix G**

**Weekly Food Log; Weight Log; Exercise Log**



Hôpital St-Boniface Hospital

## Weekly Food Log

Date	Breakfast	Lunch	Dinner	Snacks	Fluids
Sunday					
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					

Study ID# \_\_\_\_\_



Hôpital St-Boniface Hospital

## Exercise Log

Date	Type of exercise	Time spent exercising	Pedometer reading
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			

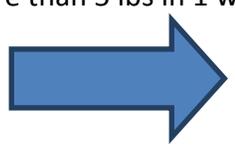
Study ID# \_\_\_\_\_



**Weight Log**

Month	Week 1	Week 2	Week 3	Week 4	Week 5
Sunday					
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					

Gaining more than 2lbs in 2 days, or more than 5 lbs in 1 week?



You are retaining fluid.  
You should call your physician.

Study ID# \_\_\_\_\_