GENDER DIFFERENCES AND THE INFLUENCE OF SOCIAL SUPPORT ON FUNCTIONAL DECLINE IN OLDER PERSONS LIVING WITH HEART FAILURE IN THEIR COMMUNITY

by

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Abstract

Background. Heart failure (HF) is a prevalent chronic cardiovascular disease that is
characterized by progressive functional decline. Given the known links between high
levels of support and positive health outcomes the objectives of this study were: 1) to
determine the levels and patterns of social support, and related gender differences, 2) to
determine the influence of support on functional outcomes as defined by a deterioration
in physical function over 1-year following exacerbation of HF, and 3) to describe the
effects of gender on social support in influencing adverse outcomes. **Methods.** Data
were obtained from a 1-year prospective cohort study that included male and female
participants ≥ 65 years of age (n=435; 164 females; 271 males) with HF. Participants
completed questionnaires at baseline, 6 and 12-months containing clinical and
demographic information and validated measures of 1) physical function, using derived
scores from the Medical Outcome Study SF-12, and Kansas City Cardiomyopathy
Questionnaire (KCCQ), and 2) social support using the Medical Outcome Study, Social
Support Survey. **Results.** Women were more likely to be single, widowed or divorced,
living alone and earned less annual income compared to men (p < .01). Women tended to
report lower mean social support scores than men at all time points. When controlling for
clinical and demographic variables, being married (OR 12.2; 95%CI: 5.1, 19.2), living
with someone (OR 13.6; 95%CI: 6.2, 21.0), and higher income (OR 0.08; 95%CI: .01,
.15), were significantly associated with higher levels of social support at baseline.
Although women reported significantly lower disease-specific (p= .01) and generic (p=
.01) physical function scores, no significant gender differences existed in the proportion

of men or women that experienced functional decline or death at 1-year of follow-up. In a

multivariate logistic regression modeling, men with lower levels of social support were

more likely to experience generic functional decline or adverse outcomes. This was not

the same for women. **Conclusions.** Women, reported less social support and poorer

functioning, but the impact of social support on functional decline was more pronounced

in men. Gender-sensitive management should be considered to optimize function for

men and women living with HF.

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Chapter 1
Introduction

1.1 General Introduction

Heart failure (HF) is a common chronic cardiovascular disease that affects over 500,000 Canadians today and 50,000 new patients are diagnosed annually (Ross, Howlett, Arnold, Liu, O'Neill, Brophy, et al., 2006). Heart failure typically presents as episodes of acute exacerbation interspersed with periods of clinical stability. It affects all ages, but in particular, is a disease of older adults. With seniors being the fastest growing population sector in Canada, it is projected that there will be a three-fold increase in HF incidence over the next three decades (Health Canada, 2002; Johansen et al., 2003). Due to its chronic and episodic nature, HF is managed primarily from home by patients and their caregivers. Optimization of functioning and quality of life is an important treatment goal. For patients with chronic diseases, such as heart failure, a number of factors, including social support seem to play a role in promoting positive health outcomes (Berkman, Leo-Summers & Horwitz, 1992; Chin & Goldman, 1997; Krumholz, Butler, Miller, Vaccarino, Williams & Mendes de Leon et al., 1998; Sorkin, Rook &Lu, 2002). Profiles of persons tend to vary amongst age and gender in terms of social, psychosocial, physiological and functional status (Chambers, Bagai & Ivascu, 2007). Current evidence shows that older women are more likely to: a) have limited social supports, b) be living on their own, with less financial resources, c) not access formalized supports such as cardiac rehabilitation programs, d) report poorer health-related quality of life and e) have worse physical function, in comparison to men (Arber & Cooper, 1999; Chambers et al.

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2007; Chin & Goldman, 1998; Missik, 2001; Riedinger, Dracup, Brecht, Padilla, Sarna, & Ganz, 2001; Shaw, Merz, Pepine, Steven, Reis, Bittner et al. 2006). Given that high levels of social support promote psychological and physical well being and good health behaviours (Rozanski, Blumenthal & Davidson, 2005), it is not clear whether gender or varying levels of social support and/or a combination of these factors influences well being for older persons with HF. This thesis examined the relationships between gender, social support and functional health outcomes in older persons living with HF.

1.2 Conceptual Framework

A health-related quality of life (HRQL) framework developed by Wilson and Cleary (1995) was the basis for the proposed study. This framework is based on five health concepts that are linked in a linear manner, representing a continuum of increasing complexity and integration on which these health concepts exist. At one end of the continuum are biological and physiological variables (e.g., underlying medical condition, physical health), followed by symptom status, functional status, general health perceptions and quality of life. The model focuses on the relationships amongst these various aspects of health. It also proposes specific mediating relationships between health concepts and broader concepts such as characteristics of the individual (e.g., personality, values, and preferences) and characteristics of the environment (e.g., psychological, economic and social supports). This model was selected for this study as components of the model include outcome variables pertinent to persons with cardiovascular disease and heart failure treatment interventions. In this study we focused on the following: pathophysiological variables (clinical indicators of heart failure,

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comorbid disease), symptom status and functional well-being. We specifically focused

on the potential mediating relationship between the environmental characteristic of social

support and functional health outcomes within and across genders.   An outline of our

framework, based on Wilson & Cleary's (1995), is illustrated in Figure 1.

Figure 1: Conceptual framework based on Wilson & Cleary's (1995) HRQL framework
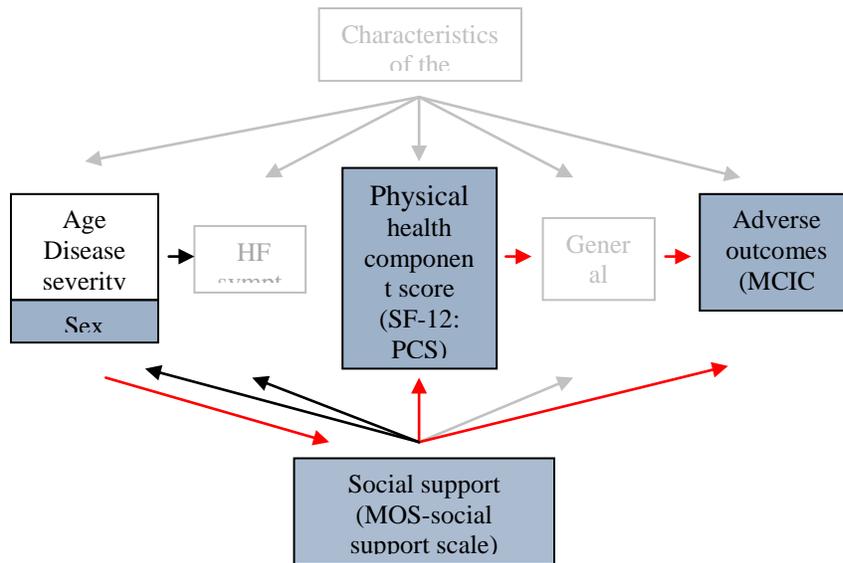
1.3 Study Overview

1.3.1 Study aim

The overall goal of this study was to describe and determine gender differences in the influence of social support on adverse outcomes, defined as decline in function, death, or worsened illness in older persons with HF.

1.3.2 Study objectives

The specific research objectives were :

1. To determine the levels and patterns of social support in older men and women with HF;

2. To describe the gender differences in levels and patterns of social support, as measured with the Medical Outcome Study (MOS) Social Support Survey at baseline and 1-year;

3. To determine the influence of support on functional outcomes as defined by a deterioration in physical function over 1-year following exacerbation of HF as measured with the generic Physical Component Score (PCS) from the MOS, Short Form Health Survey (SF-12) and the disease-specific Physical Limitation scores (PL) from the Kansas City Cardiomyopathy Questionnaire (KCCQ); and,

4. To describe the independent and combined effects of gender and social support on adverse outcomes, while controlling for personal demographics, disease severity, and comorbid conditions.

1.3.3 Study hypotheses

The null hypotheses were:

1. There would be no difference in measures of social support between men and women;

2. There would be no associations between measures of social support and reported measures of functional well being;

3. There would no gender differences in the associations between measures of social support and measures of functional well being; and,

4. There would be no significant difference in adverse outcomes in relation to social support and gender.

If hypothesis 1, 2, 3 and 4 were rejected, gender differences in adverse outcomes may be partially explained by the differences in social support.

This study is a discrete component of a large cohort study entitled: *A regional perspective of gender differences in functional decline of older persons with symptomatic heart failure: the role of supportive resources*, led by Dr. Joan Tranmer (Canadian Institutes of Health Research (CIHR) Operating Grant, MOP 68891). Tranmer and colleagues determined the influence of gender-differences in the personal, social, and systematic relationships between formal and informal supportive resources as well as self-care behaviours and functional well-being in older persons with HF. This thesis study focused specifically on the relationship between informal supports and functional well-being.

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1.4 Key Definitions

Heart failure (HF): Patients fulfilling the Framingham Criteria for the Clinical Diagnosis of Chronic Congestive HF will be categorized as HF (McKee, Castelli, McNamara & Kannel, 1971). Refer to Appendix A.

Social support: An interpersonal transaction providing functional support involving 1) emotional support (involving care, love, and empathy), 2) instrumental or tangible support (goods and services), 3) informational support (including guidance or feedback or environmental information), or 4) appraisal (information specifically related to self evaluation) (House, 1981).

Minimal clinically important difference (MCID): can be defined as "the smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive cost, a change in the patient's management" (Jaeschke, Singer & Guyatt, 1989, p.407).

1.5 Thesis Organization

This thesis is organized in accordance with the Manuscript Form of Theses, as specified by the School of Graduate Studies and Research at Queen's University. Chapter 2 provides a review of the current literature of relevance to the topic of this thesis and focuses on the heart failure, functional outcomes and social support. Chapter 3 is the first manuscript entitled: Gender differences in patterns and levels of social support reported by older persons with heart failure, to be submitted to the *Canadian Journal of Cardiovascular Nursing*.   Chapter 4 is the second manuscript entitled: Gender differences in the influence of social support on functional decline in older persons living

with heart failure in their community, to be submitted to *The Canadian Journal of Cardiology*. Chapter 5 provides an overall discussion, summary and conclusions from the thesis work and outlines strengths, limitations and implications for future practice and research.

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Chapter 2
Literature Review

2.1 Introduction

The following literature review is organized in accordance with the focus and objectives of this thesis. The review provides an overview of the clinical problem: Heart failure (HF) and maintenance of function and a summary of the literature in regard to the influence of gender and social support on maintenance of function and clinical outcomes in older HF patients.

2.2 Heart Failure

2.2.1 Definition

Congestive heart failure (CHF), also known as heart failure (HF), is a chronic cardiovascular syndrome characterized by the inability of the heart to fill with or eject blood due to any structural or functional cardiac conditions (Hunt, Abraham, Chin, Feldman, Francis, Ganiats, *et al.*, 2005). The Canadian Heart and Stroke Foundation (CHSF) (2009) defines HF as a condition that develops after the heart has been damaged or weakened in relation to medical events such as: 1) coronary artery disease (CAD), a narrowing of the arteries that supply blood to the heart; 2) past myocardial infarction (MI), a previous heart attack that has left scar tissue in the heart that impedes function; 3) hypertension (HTN), high blood pressure; 4) cardiac valve disease, from rheumatic fever or other illnesses; 5) cardiomyopathy, a primary disease of the cardiac muscle itself; 6) congenital heart defects, defects that have occurred from birth, and; 7) endocarditis

and/or myocarditis, infection of the heart valves or heart muscle (American Heart

Association (AHA)). Due to the nature of its presentation and progression, HF reduces

quality of life, exercise tolerance and survival (Canadian Cardiovascular Society, 2006).

2.2.2 Prevalence & Incidence

HF is a prevalent cardiovascular disease in older Canadian men and women and is

associated with high mortality and morbidity. Its increasing prevalence is, in large part,

due to the Canadian population getting older, and living longer with the success of

improving medical therapies. It is projected that the number of Canadians in the age

group 65 years and older will increase from 12.6% to approximately 21% of the

population between 2000 and 2025 and to 25% by 2050 (Johansen, Strauss, Arnold, Moe

& Liu, 2003), and as a result the number of individuals with HF will increase

accordingly. Results from the Framingham Heart Study indicate the age-adjusted

incidence of heart failure has declined by only 11% per calendar decade in men and by

17% per calendar decade in women during a 40-year period of observation. HF remains

highly lethal, with a median survival time of 1.7 years in men and 3.2 years in women

and a 5-year survival rate of 25% in men and 38% in women (Ho, Pinsky, Kannel &

Levy, 1993). The Canadian Cardiovascular Society (2006) states that HF can be

associated with an annual mortality of 5% to 50%, depending on clinical and personal

demographics such as symptom severity, heart dysfunction, age and other factors.

2.2.3 Heart failure characteristics

HF typically presents as episodes of acute exacerbation, interspersed with periods

of clinical stability. Symptoms of HF generally include a combination of: difficulty

breathing (including orthopnea and dyspnea), exercise intolerance (including fatigue and weakness), dependent edema, cough, weight gain, abdominal distension, nocturia, and cool extremities (Canadian Cardiovascular Society, 2006). Less common symptoms can also include: oliguria, abdominal discomfort, nausea, anorexia, cyanosis, cognitive impairment or delirium. Symptoms of HF vary person-to-person, depending on factors such as treatment adherence and the individual's capacity to compensate for inadequate cardiac function.

Heart failure is considered a progressive disease that is perpetuated by progressive left ventricular (LV) dilation and loss of cardiac contractility (Yu, Chau, Sanderson, Fan, Tang, et al., 2002). In the past 20 years, due to the further understanding of the pathophysiological mechanisms of HF, and improvement in treatment and management strategies, the prognosis of HF, although still poor, has improved. Many patients today experience longer periods of stability between exacerbations of their HF, experience less symptom burden and have improved cardiac function (Canadian Cardiovascular Society, 2006). Despite these advancements in therapeutics, the prognosis of HF remains poor, and mortality and morbidity rates remain high. As such, there continues to be a need for further development in treatment and management strategies.

2.2.4 Heart failure treatment

In 2006 the Canadian Cardiovascular Society (CCS) outlined HF management recommendations, which have been subsequently reviewed and updated on an annual basis. Non-pharmacological treatment strategy for most HF patients promotes regular physical activity, including both aerobic activity and resistance training by means of a

structured training program; salt and fluid restrictions, including daily morning weight monitoring for fluid retention or congestion, and; multidisciplinary outpatient heart failure management programs for close clinical follow-up, patient and caregiving education, telemanagement or telemonitoring, and home visits by specialized health care professionals where resources are available. The CCS also has published recommendations for drug therapy in patients with HF. Currently: HF is managed pharmacologically by a combination of ACE inhibitors, beta-blockers, angiotensin II receptor blockers, aldosterone antagonists, vasodilators, and diuretics. Their effectiveness to improve cardiac function and reduce symptoms largely depends on patients' adherence. As the majority of the time HF is self-managed by patients and their caregivers at home, the ability to provide oneself with care is crucial in facilitating treatment adherence.

2.2.5 Gaps in heart failure care

In the 2006 CCS HF management guidelines, recommendations also promoted the use of specialized hospital-based clinics and disease management programs run by HF-knowledgeable physicians, nurses, pharmacists and other health care professionals. At present, formalized HF rehabilitation programs are limited in Ontario. The Canadian Heart Failure Network website lists 13 hospitals in Ontario, each of which are affiliated with the Canadian CHF Clinics Network Working Group, but not all of these sites have a HF clinic. Services provided by HF clinics in Ontario primarily include formal supportive resources such as physicians and registered nurses. Patient-support groups were listed as a service that *may* be affiliated with certain HF clinics, but are not currently

a standard component of care provided in Ontario. Strategies to promote use of informal

supports are not clear in the Canadian CHF Network objectives. As such, treatment

recommendations set by the CCS for best practice in HF care may not be adequately met.

There continues to be a gap in health care services provided and patients' needs, which

may be limiting the Canadian HF population from improving quality of life, functional

well-being, and ultimately could influence patient longevity.

2.3 Functional Well-being

2.3.1 Definition

Functional wellbeing is the ability to function day-to-day and perform necessary

activities of daily living (ADLs) (Corvera-Tindel, Doering, Roper & Dracup, 2009). For

persons with chronic illness, functional wellbeing is often threatened by symptom burden

and physical limitations. Physical function and wellbeing are important components of

health-related quality of life (HRQL) (Wilson & Cleary, 1995). Decline in functional

ability can have detrimental implications on mortality and morbidity (Konstam, Salem,

Pouleur, Kostis, Gorkin, Shumaker et al., 1996; Riedinger et al., 2001). Relieving

symptom burden and improving functioning and HRQL are therefore important treatment

goals to managing HF patients (Canadian Cardiovascular Society, 2006).

2.3.2 Functional well-being in heart failure

Functional status and HRQL are important patient outcomes to measure because of

their association with morbidity and mortality (Konstam et al., 1996; Reidinger et al.,

2001). HF patients generally report poorer HRQL than the general population (Juenger,

Schellberg, Kraimer, et al., 2002; Reidinger et al., 2001). In a cross sectional study of 205 HF patients, Juenger and colleagues (2002) compared their SF-36 scores to those with chronic hepatitis C infection, chronic haemodialysis, major depression and no major illnesses. Of particular interest were 1) the physical functioning domain: the extent to which health limits physical activities, such as self-care, walking, or climbing stairs, and 2) the role functioning physical domain: the extent to which physical health interferes with work to other daily activities. HF patients had significantly reduced mean scores compared to the general population in all aspects of quality of life, including physical functioning (48.3±26.9 vs. 96.6±10.0; $p < 0.05$) and role functioning physical (25.5±37.5 vs. 96.9±13.9; $p < 0.05$). As well, HF patients reported lower mean physical functioning scores (48.3±26.9) compared to the hepatitis C group (79.3±23.3; $p < 0.05$) and to the major depression group (71.6±27.2; $p < 0.05$). HF patients and chronic haemodyalisis patients had similar functioning scores, suggesting that they have relatively similar reduction in functional quality of life. Juenger and colleagues also determined that those with HF had more severe role functioning limitations with mean scores of 25.5±37.5, compared to the chronic hepatitis C group (56.9±43.5; $p < 0.05$) or the major depression group (44.4±40.3; $p < 0.05$). Again, the HF group showed equivalent trends in role functioning physical with the chronic haemodialysis group. In summary, there are clear differences in HRQL between HF and the general population and other chronic diseases.

2.3.3 Factors that influence functional well-being

A number of demographic, clinical, and symptom factors influence functional status and HRQL in HF patients (Bennett, Baker & Huster, 1998; Chin & Goldman,

1998; Corvera-Tindel, Doering, Roper & Dracup, 2009; Juenger *et al.*, 2002; Reidinger *et al.*, 2001; Westlake, Dracup, Creaser, Livingston, Heywood *et al.*, 2002).

Using a multiple linear regression, Westlake and colleagues (2002) identified disease severity (NYHA classifications) (beta coefficient = -0.51; $p < 0.01$) and time since symptom onset (beta coefficient = -0.31; $p = 0.04$) as having negative linear relationships with physical functioning, as measured by the Physical Component Score (PCS) derived from the SF-12. Likewise, Juender et al., (2002) identified more severe disease severity (NYHA classifications) as being a significant univariate factor in the declined physical function ($r = -0.63$; $p < 0.01$) and role-physical function ($r = -0.42$; $p < 0.01$) in a cross-sectional study of health-related quality of life in 205 HF patients.

2.3.4 Gender and functional well-being

Both men and women with HF experience functional decline. Corvera-Tindel *et al.* (2009) examined the relative contribution of physical and emotional functioning to overall quality of life (QOL) in 76 HF men. They used the Health functioning subscale (HFSS) from the Cardiac Quality of Life Index (C-QLI) to identify correlating sociodemographic, clinical, physical and emotional functioning variables. A Spearman correlation test showed that physical functioning had significant positive correlations with overall QOL ($r = 0.94$; $p < 0.01$), age ($r = 0.39$; $p \leq 0.01$), and physical functioning by the Heart Failure Functional Status Inventory (HFFSI) ($r = 0.31$; $p \leq 0.01$), and negatively correlated with emotional functioning measures from the Multiple Affect Adjective Checklist (MAACL) such as depression ($r = -0.44$; $p \leq .01$) and anxiety ($r = -0.40$; $p \leq .01$). A descriptive pilot study of 30 HF women conducted by Bennett et al.

(1998) explored the relationships among symptom impact, perceived health status, and QOL. They used the Minnesota Living with Heart Failure Questionnaire (LHFQ), a 21-item self-reported tool used to quantify symptom impact. They found that the total LHFQ score, and the LHFQ Physical subscale were significantly and negatively correlated with the PCS of the SF-36 ($p < 0.05$), indicating that greater physical symptom impact was associated with poorer physical functioning (Bennett *et al*., 1998). Few studies to date have specifically focused on the relationship between gender and functional well-being the context of HF.

Our knowledge of the influence of gender on physical functioning and wellbeing in patients with HF is somewhat limited. The collective research indicates that women with HF generally report poorer physical functioning than men with HF (Chin & Goldman, 1998; Reidinger *et al*., 2001). In a cross-sectional secondary analysis, Reidinger and colleagues used the Functional Status Questionnaire (FSQ) to measure activities of daily living (ADLs) and social function in a sample of 1382 HF patients. Findings indicated that women had significantly worse physical functioning than men with mean basic ADL scores for women versus men being 91.9 versus 94.3 ($p < 0.01$), and mean intermediate ADL scores being 30.8 versus 37.3 ($p < 0.01$). Even after controlling for disease severity by New York Heart Association (NYHA) classifications, women still reported significantly worse HRQL ratings for intermediate ALD than men (Riedinger *et al*., 2001). Chin and Goldman (1998) reported similar conclusions. Using the MOS 36-item short-form health survey (SF-36), and its physical subscale, the Physical Component Score (PCS) to assess 1-year functional wellbeing in 435 HF

patients, independent t-tests indicated that baseline physical function and PCS scores were lower in women than men (exact values not published, $p \leq 0.05$). In a multivariate analysis, female gender was associated with less improvement at 1 year for PCS scores (beta-coefficient = -5.7, 95%CI: -9.1, -2.4).

2.4 Social Support

2.4.1 Definition and concept

Social support is commonly defined as an interpersonal transaction providing functional support involving: 1) emotional support (involving care, love, and empathy), 2) instrumental or tangible support (goods and services), 3) informational support (including guidance or feedback or environmental information), and 4) appraisal (information specifically related to self evaluation) (House, 1981). Social support has been studied for centuries in less obvious environments (eg. Charles Darwin in 1871 observed and described the benefits of being a social animal) and in more recent decades, in the context of human interactions. The work of J.A Barnes (1954), J. Cassel (1976) and J.S House (1981) were fundamental in defining social support as patterns of social relationships, as a contributing factor in overall health, and later in distinguishing between four subtypes of social support. More recently, concept analyses have established social support as having key characteristics, including the existence of social relationships, of which, their structure, strength and type defines the type of social support available (Williams, Barclay & Schmied, 2004).

The role of social support has been most often linked to psychological and

physiological consequences of stress, where it is theorized to facilitate coping and

adaption and act as a moderator of life stress (Cobb, 1976; Williams, Barclay & Schmied,

2004). More specifically to health, social support has also been thought to mediate the

relationship to illness through its influence on behavioural patterns, which subsequently

has effects on biological responses (Mookadam & Arthur, 2004). It has been established

that high levels of social support promote psychological and physical well-being and

good health behaviours (Rozanski, Blumenthal & Davidson, 2005). One theory suggests

that social support may function effectively as a stress buffer because of the associated

perception that support providers will offer appropriate aid (Cohen, 1988; Cohen &

Wills, 1985; Uchino et al., 1996). For patients with cardiovascular disease, higher social

support plays a role in health outcomes.

2.4.2 Social support in cardiovascular disease

Lack of perceived social support, lack of available social support and low

emotional support have been associated with mortality and other adverse outcomes in

persons with cardiac disease (Berkman, Leo-Summers & Horwitz, 1992; Chin and

Goldman, 1997; Krumholz, *et al*. 1998; Sorkin, Rook &Lu, 2002). Lack of

companionship (Sorkin, Rook &Lu, 2002), poor social ties (Evangelista, Berg & Dracup,

2001; Krumholtz *et al.* 1998; Rodriguez-Artalejo, Guallar-Castillon, Conde Herrera,

Montoto Otero, Olcoz Chiva & Carreno Ochoa *et al.* 2006;), and social isolation have

also been linked to increased cardiovascular risk (Friedman, Thomas, Liu, Morton, Chapa

& Gottlieb, 2006; Murberg, 2004;). Berkman *et al*. (1992) showed that lack of emotional

support was significantly associated with 6-month mortality in older patients following

an acute myocardial infarction (OR= 2.9; 95% CI, 1.2 to 6.9), after controlling for

covariates. In their study, patients who had no one on whom to rely for emotional support

were at risk for death twice that of those who had 2 or more sources for support (p =

0.02) (Berkman *et al*, 1992). Higher levels of social support seem to have positive effects

on quality of life, preventing cardiac events, reducing mortality and promoting good

health behaviours. These findings are not yet strongly established in the HF population.

2.4.3 Social support and outcomes in heart failure patients

With its specific complexities the HF population warrants assessment separate from all

other cardiac disease groups. The relationship between social support and HF outcomes

has not been extensively examined to date. Of those studies that have explored social

support in HF populations, it seems that social support has a similar protective effect as in

other cardiovascular disease groups.

Marital status is often used as a proxy measure of existing social support. A few

HF studies have identified that being married or living in a common law relationship is

associated with higher levels of perceived social support (Lofvenmark *et al*., 2009).

Being married or living in a common law relationship also has been associated with

higher levels of family support for self-management and self-care (Jurgens, Dumas

&Messing, 2007; Rosland, Heisler, Choi, Silveira & Piette, 2010). Likewise, single

marital status in HF populations has been independently associated with negative health

outcomes such as hospital readmissions, or death (Chin &Goldman, 1997). In a 2-year

prospective study, Chin and Goldman (1997) determined the correlates of early hospital

readmission and death in 257 men and women with HF. Within 60 days of discharge following HF exacerbation, 13 of 257 patients (5%) died, and 80 (31%) were readmitted to the hospital. Multivariate analysis identified single marital status as a significant independent predictor (HR = 2.1, 95% CI, 1.3 to 3.3) of hospital readmission or death in HF patients. Conversely, in one cross-sectional study of older women with HF (n=80), marital status was not highly correlated (r < 0.20) with psychological well-being, satisfaction of life or emotional and tangible social support (Friedman & King, 1994). These findings by Friedman and King may not be generalized to the entire HF population due to the convenience sample used. One of the most common criticisms with using only marital status as a judge of adequate support is the lack of qualitative evaluation of the relationship.

Another commonly used indicator of social support, similar to marital status, is living arrangements. Living alone has been associated with lower social support (Lofvenmark *et al*., 2009). HF participants in a 1-year longitudinal study who were married and living with someone scored higher than those who were unmarried, including divorced and widow/widower, in 3 out of 4 social support subscales of the Interview Schedule for Social Interaction (ISSI), that measured perceived social support (Lofvenmark *et al*., 2009). Negative health outcomes such as psychological distress (Yu, Lee, Woo & Thompson, 2004), loneliness (Lofvenmark *et al*., 2009) have also been reported in HF patients who live alone. In one cross sectional study of HF patients 60 years or older, Yu and colleagues (2004) found that not living with family was highly correlated (r = 0.75) to psychological distress, using scores from the Hospital Anxiety

and Depression Scale (HADS). Lofvenmark and colleagues found that HF patients who lived together with someone reported less perceived loneliness compared to those living alone (38% vs. 62%, p= 0.01). Patients with perceived loneliness compared to the group that did not report loneliness subsequently had more hospitalization episodes (mean 3.1±2.2 vs. 2.1±1.6, p= 0.03), and more number of days in hospital during one year (mean 17.1±18.5 vs. 7.4±7.0, p= 0.04) (Lofvenmark *et al*., 2009).   Similar to marital status, some argue that a living situation alone is not an accurate measure of support. Cohabitation does not necessarily indicate whether a relationship provides positive or negative aid, and it has been suggested that a broad range of information, including patients' perceptions of their social support, may be more beneficial in measuring social support (Jurgens, Dumas & Messina, 2007; Sayers, Reigel, Pawlowski, Coyne & Samaha, 2008).

Several valid and reliable measures have been developed in the context of HF, chronic illness, and generic health, which measure patients' perception of social support. To date, studies on the influence of social support in the HF population have expressed health benefits associated with higher social support such as better medication and diet adherence (Sayers et al., 2008), greater life satisfaction (Friedman & King, 1994), and psychological well being (Friedman & King, 1994). Similarly, low levels of social support or changes in social support in this population have been reported to be associated with higher likelihood of fatal and nonfatal cardiac events (Krumholz, 1998), HF-related admission (Bennett et al, 2001) and mortality (Murberg, 2004).

Sayers and colleagues (2008) used the Multidimensional Scale of Perceived

Social Support (MSPSS) to assess support in 74 HF patients while assessing its

relationship with self-care. The scale separates between three sources of social support

(friend, family, and significant other) and identifies both emotional and instrumental

social support. The MSRSS is reliable and valid, with the internal consistency

coefficients of the emotional and instrumental support subscales being: Cronbach's alpha

= 0.87, and alpha = 0.73 ($p < 0.01$) respectively (Sayers et al., 2008). Using a regression

model, Sayers and colleagues (2008) found that emotional support was moderately

associated to medication adherence, [$F_{(2, 71)} = 3.71$; $p < 0.05$] and dietary adherence, [F

$(2, 71) = 3.41$; $p < 0.05$]. Freidman and King (1994) used the Inventory of Socially

Supportive Behaviour (Barrera, Sandler & Ramsey, 1981) to measure perceived social

support that a significant other had provided. The tool yields information about

perceived tangible, emotional and informational support based on how subjects rate the

frequency of receiving each type of support on a 5-point Likert scale, where; 1= not at all,

to; 5 = about every day. Cronbach alpha's for emotional, informational and tangible

support subscales were 0.76, 0.81, and 0.58 respectively. Multiple hierarchical

regressions showed that greater emotional support was related to greater positive

psychological well-being ($p < 0.01$) and satisfaction of life ($p < 0.01$). It also identified

greater tangible support as being related to less negative psychological effects ($p < 0.01$)

(Friedman & King, 1994). Krumholz and colleagues (1998) investigated the prognostic

importance of emotional support for elderly patients ($\geq$ 65 years) hospitalized with heart

failure (n =292). Neither emotional nor instrumental (tangible) support were measured

with a valid tool, but rather with one yes/no question. To measure emotional support,

participants were asked the question: "Can you count on anyone to provide you with

emotional support (talking over problems to help you with a difficult decision)?"

Answers allowed were one of "yes", "no" or "no need". To measure instrumental

support participants were asked to answer the question; "When you need some extra help,

can you count on anyone to help with daily tasks like grocery shopping, house cleaning,

cooking, telephoning, and giving you a ride?" The same "yes", "no" and "no need"

answers were offered. Similar to findings in other cardiovascular populations (Berkman

et al, 1992), the absence of emotional support was a significant predictor of fatal and

nonfatal cardiovascular events after adjusting for demographic factors, clinical severity,

comorbidity and functional status, social ties and instrumental support in a multiple

logistic regression (OR 2.4; 95% CI, 1.1 to 4.9). When the investigators examined the

effect of patients' gender on this association, they found the association of emotional

support and cardiovascular event at 1 year appeared to be stronger in women (OR 8.2,

95% CI, 2.5 to 27.2) compared to men (OR 1.0, 95% CI, 0.3 to 3.3).   In yet another

study determining the relationship of social support on health outcomes in HF, Murberg

(2004) used a 15-item perceived social support scale (no name given) to measure

perceived intimate network support, primary network support, and secondary network

support, as well as a 4-question assessment of social isolation, on 119 HF patients.

Results of proportional hazard models indicated that perceived social support was not a

predictor of mortality, but social isolation was (Relative Risk 1.36; 95%CI: 1.0, 1.8; p <

0.03). Finally, in a study conducted by Bennett and colleagues (2001), baseline social

support was not a significant predictor of 12-month health-related quality of life when other factors were controlled for. Since the authors noted changes in social support perceived by the participants over the study year, they further assessed the relationship between social support and health outcomes to determine whether changes in social support scores were associated with changes in health-related quality of life scores. They found that changes in all of the social support subscales significantly predicted total changes in HF-specific quality of life ($p < 0.01$), with the exception of affectionate support. In this study the investigators used the Medical Outcomes Study Social Support Survey (MOS-SSS), developed by Sherbourne and Stewart (1991), to measure social support. The 20-item, self-administered questionnaire measures participants' perception of emotional support, tangible support, affectionate support, positive social interaction, additional support, and overall social support. The tool is documented to be reliable and valid in HF patients with a Cronbach's alpha internal consistency reliability estimates ranging from 0.80 to 0.97. Whether it is measured based on its availability or its quality, social support seems to consistently influence positive outcomes in cardiovascular disease populations. This relationship may be different between disease groups, or between genders.

2.5 Gender and Health

Women and men experience health and illness experiences differently. One major difference seen in older females compared to males is the difference in marital status. In 1996, three quarters of Canadian senior men were married compared to 41.4% of Canadian women, while 46% of senior women were widowed compared to 12.7% of

senior men. These differences become even more pronounced in older age groups

(Health Canada, 2002). McDonough and colleagues (2002) examined the effects of

socioeconomic position and social roles on health and assessed the extent to which those

relationships were explained by differential exposure and vulnerability to chronic stress

in a longitudinal study using data from the Canadian National Population Health Survey

(NPHS). On a 5-point Likert scale, respondents evaluated their health as excellent, very

good, good, fair and poor (scored 1-5, respectively). Married women reported the best

health (mean scores: 2.19, 3.39, 0.36, respectively) while formerly married women, the

worst (mean scores: 2.34, 4.83, 0.49, respectively).

The role of gender on health disparities between men and women has been studied

for decades. It is known that differences in the sexes are multidimensional, with strong

influences both from biological and social processes (Bird & Rieker, 1999; Rieker &

Bird, 2005; Verbrugge, 1989). Older women ($\geq$ 65 years) in particular have a unique

psychosocial profile that may predispose them to different health risk factors than men of

all ages or women in younger age groups. Current evidence shows that older women are

more likely to: a) have limited social supports, b) be living on their own, with less

financial resources, c) not access formalized supports such as cardiac rehabilitation

programs, d) report poorer health related quality of life, and, e) have worse physical

function, in comparison to men (Arber & Cooper, 1999; Chambers *et al*. 2007; Chin &

Goldman, 1998; Missik, 2001; Riedinger, Dracup, Brecht, Padilla, Sarna, & Ganz, 2001;

Shaw, Merz, Pepine, Steven, Reis, Bittner *et al*. 2006).

2.5.1 Gender differences in health outcomes and social support

As previously stated, the collective results generally conclude that women living with HF report poorer perceived quality of life and less improvement to their physical health status in comparison to their male counterparts, and as well varying levels of support. Riedinger *et al*. (2001) evaluated the gender differences in quality of life in patients with HF in a secondary cross-sectional analysis of 1382 age-matched and ejection fraction-matched patients from the baseline data of the multicentre Studies of Left Ventricular Dysfunction Trials (SOLVD). Women, with a mean age of 60.7 (SD = 10.5) years had significantly worse general life satisfaction (mean score women: 3.01, men: 2.87; p = 0.02), physical function (basic ADL mean scores women: 91.9, men: 94.36; p < 0.01), and social (social activity mean score women: 77.22, men: 86.16; p < 0.01; social life satisfaction mean score women: 2.3, men: 2.18; p = 0.04) and general health (mean score women: 3.45, men: 3.31; p < 0.01) scores than men. When controlling for age, ejection fraction, and New York Heart Association (NYHA) classification, women reported lower ratings for intermediate activities of daily living and social activity. Women with HF appear to be a more disadvantaged group than men with HF. The interactive effect of support and gender on adverse health outcomes is poorly understood.

2.6 Other Measures of Social Support

Social support has also been indirectly studied through concepts of social isolation and social networks. A descriptive study, exploring the relationships between psychosocial distress, isolation and mortality in HF patients showed mortality rates of 8%

among patients with high social support and no psychosocial distress, and 20% amount

patients who were socially isolated, and experienced psychosocial distress such as

anxiety and depression (Friedmann et al. 2006). Social networks were identified as

predictors of hospital readmission rates among older patients ($\geq$ 65 years) with HF (N =

371). Measured using a 4-item questionnaire, social networks were deemed low if 2 or

fewer items were present, moderate if 3 were present, and high if 4 items were present.

Hospital readmission was more frequent among patients with moderate (HR = 1.87; 95%

CI 1.06-3.29; $p < 0.05$) and low (HR = 1.98; 95% CI 1.07-3.68; $p < 0.05$) social networks

in comparison to those with high social networks (Rodriguez-Artalejo *et al.* 2006).

Social support has also been linked to poor treatment adherence. Happ and colleagues

(1997) found social factors, such as the absence of strong social support or motivation,

contributed to medication and dietary noncompliance. Thus the evidence suggests that

social support potentially influences patient outcomes. However, there is limited

evidence exploring the influence of social support in older persons living with HF in their

communities.

2.7 Summary

  Much of the available research to date has explored the impact of social support

on mortality and readmission, with little attention given to the impact of support on the

ability of the individual with HF to maintain and optimize function. Optimization of

function is an important goal of care for persons living with HF in their community,

especially so for older HF patients. As HF incidence increases with advancing age

(Johansen *et al*., 2003), and advancing age is associated with loss or disruption of

important social ties (Sorkin, Rook &Lu, 2002) older persons with HF are a potential

vulnerable population. As well, gender disparities lead to differences in health

perception, and potentially in health outcomes. Presently, there is a lack of available

literature on social support and its influence on functional well being in the context of

gender differences. There is a need to understand this relationship to better plan and

develop disease-effective and cost-effective health care strategies for older men and

women living with HF.

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Chapter 3

Gender differences in patterns and levels of social support reported by older persons with heart failure

3.1 Abstract

Background: Heart failure (HF) is a prevalent chronic cardiovascular disease among elderly persons. Psychosocial and physical profiles of persons tend to vary amongst age and gender. Current evidence shows that older women are more likely to: a) have limited social supports, b) be living on their own, with less financial resources, and c) not access formalized supports such as cardiac rehabilitation programs. Given the known links between high levels of support and positive health outcomes, the purpose of this study was to determine the levels and patterns of social support in older men and women following exacerbation of their HF condition, and to determine if these levels and patterns differed by gender. **Methods:** Data were obtained from a 1-year prospective descriptive study that included male and female persons ≥ 65 years of age (n=435; 164 females; 271 males) assessed in hospital for an acute HF exacerbation. Participants completed baseline, 6 and 12-months questionnaires containing clinical and demographic descriptive information and the Medical Outcome Survey, Social Support Survey (MOS –SSS). **Results:** In this sample, women with HF were more likely to be single, widowed or divorced, living alone in an apartment or condominium and earning less annual income than their male counterparts ($p < 0.01$). Males had poorer heart function than females, with significantly lower ejection fractions ($p < 0.01$). No significant changes in support were seen within each gender over 1-year; however, significant differences between

genders were present.   Women tended to report lower social support scores than men at all time points, some of which were statistically significant. Mean (±SD) social support scores at 1-year for women and men were 71.5±24.5 and 80.7±22.2 respectively (p < 0.01). When controlling for clinical and demographic variables, being married (Beta 13.9, 95% CI: 4.9, 23.0), living with someone (Beta 8.8, 95% CI: -0.1, 17.7) but not gender were significantly associated with higher levels of social support at baseline.

Conclusions: Women report lower levels of social support**.** These differences are partially explained by gender differences in marital status, living arrangements and income. Given the need to support self-management of HF in the home we need to consider these important differences in levels of support. Further research to evaluate the effects of support differences on health outcomes is needed.

Key Words: *Social support, gender, heart failure*

3.2 Introduction

Heart failure (HF) is a common chronic cardiovascular disease that affects over 500,000 Canadians today and 50,000 new patients are diagnosed annually (Ross, Howlett, Arnold, Liu, O'Neill, Brophy, et al., 2006). Heart failure typically presents as episodes of acute exacerbation combined with periods of clinical stability. It affects all ages, but in particular, is a disease of older adults. With seniors being the fastest growing population sector in Canada, it is projected that there will be a three-fold increase in HF incidence over the next three decades (Health Canada, 2002; Johansen et al, 2003). Due to its chronic and episodic nature, HF is managed primarily from home by patients and their caregivers. Health profiles of persons tend to vary amongst age and gender (Chambers, Bagai & Ivascu, 2007) and are multidimensional, with strong influences both from biological and social processes (Bird & Rieker, 1999; Rieker & Bird, 2005; Verbrugge, 1989). Older women in particular have a unique psychosocial profile that predisposes them to different health risk factors than men of all ages or women in younger age groups. Current evidence shows that older women are more likely to: a) have limited social supports, b) be living on their own, with less financial resources, and c) not access formalized supports such as cardiac rehabilitation programs, in comparison to men (Arber & Cooper, 1999; Chambers *et al*. 2007; Chin & Goldman, 1998; Lofvenmark, Mattiasson, Billing & Edner, 2009; Missik, 2001; Riedinger, Dracup, Brecht, Padilla, Sarna, & Ganz, 2001; Shaw, Merz, Pepine, Steven, Reis, Bittner *et al*. 2006; Verbrugge, 1989). So far, the collective evidence would suggest that older women are more disadvantaged than older men within the context of social support although, this

relationship is not well described. High levels of social support in general promote psychological and physical well being and good health behaviours (Rozanski, Blumenthal & Davidson, 2005). Given the importance of self-management in chronic disease (HF) management, and the links between supportive resources and well being, and perhaps self-management capacity, we directed the overall purpose of this study to describe the levels and patterns of social support in older individuals living with HF.

3.3 Background

Social support is characterized by the structure, strength and types of relationships (Williams, Barclay & Schmied, 2004). It is postulated that social support facilitates coping and adaptation to life, and moderates the psychological and physiological consequences of stress (Cobb, 1976; Williams, Barclay & Schmied, 2004). Social support may also mediate the relationship to illness through its influence on behavioural patterns that either increase or decrease risk for disease depending on the level of support (Mookadam & Arthur, 2004). Current evidence suggests that lack of perceived and actual overall social support and, specifically, low emotional and tangible support are potential risk factors for mortality and other adverse outcomes in persons with cardiac disease (Berkman, Leo-Summers & Horwitz, 1992; Chin and Goldman, 1997; Friedman et al., 2006; Krumholz, et al. 1998; Sorkin, Rook &Lu, 2002). Among these studies, level of social support was determined through use of a variety of measures: marital status, social isolation, and several social support self-reported measurement tools. The measurement of social support is complex. A commonly used tool is the Medical Outcomes Study Social Support Survey (MOS SSS) (Sherbourne & Stewart, 1991), a tool

consisting of a 20-item self-administered questionnaire that measures perceived social support and the degree to which interpersonal relationships serve particular functions. MOS-SSS has been used in a wide range of patient groups, including, but not limited to, primary health care, chronic illness, critical care and mental health. It has been used to survey quality of life not just in various patient populations, but also in patient caregivers and in a spectrum of health care professionals. The five dimensions of social support summarized in the MOS SSS consist of (1) emotional support (the expression of positive effect, empathetic understanding, and the encouragement of expressions of feelings), (2) informational support (the offering of advice, information, guidance or feedback), (3) tangible support (having material goods or behavioural assistance), (4) affectionate support (involving expressions of love and affection), and (5) positive social interaction (the availability of other persons to do fun things with). An overall score is also computed based on these 5 domains plus one additional support question. The MOS SSS has been used to assess levels of support in various chronic disease populations, with a few studies exploring levels and impact of social support in the HF population (Bennett, Perkins, Lane, Deer, Brater & Murray, 2001; Janevic, Janz, Dodge, Wang, Lin *et al.*, 2004; Westlake, Dracup, Fonarow & Hamilton, 2005).

One important study described patterns of social support (MOS-SSS) and quality of life longitudinally in both men and women diagnosed with HF (Bennett *et al.*, 2001). Bennett and colleagues (2001) described perceived social support at baseline (hospitalization for acute HF exacerbation) and 12-months from baseline, in younger (< 65 years) and older (≥ 65 years) HF patients. They examined differences in social

support as a function of gender and age. Results indicated that younger men (<65 years) perceived less overall support, emotional/informational support, and positive social interactions than any other age or gender group. These findings were contrary to their hypothesis as well as to relevant literature.

Other literature, assessing social support using different measures than the MOS-SSS, generally indicates that men more often have higher levels of social support than women. As more men with HF are married and living with someone, and those who are married and living with someone are reporting higher social support scores, it can be inferred that older men with HF perceive, and actually have, more support than older females (Lofvenmark *et al*., 2009). Reidinger and colleagues (2001) identified this phenomenon in their study in which they assessed social health through measures of social life satisfaction and social activity in individuals with HF (n = 1,382). After controlling for disease severity, men had significantly higher social activity than women (mean scores: 83.8 versus 79.6 out of a possible 100; p < 0.01). Interestingly, no gender differences in social life satisfaction were reported, suggesting that although there may be differences between genders in social activity, it may not affect their overall social fulfillment. One speculation for this trend suggests that among the elderly, especially women, living alone is a normative experience and not particularly associated with life dissatisfaction (Berkman *et al*., 1992).

Social support has important implications related to mortality and morbidity in many chronic disease populations. Social support seems to play a protective role against death and functional decline and other adverse outcomes in many cardiovascular

populations.   In a study of individuals with coronary artery disease (n = 1,468),

Woloshin and colleagues (1997) found individuals who perceived the least support were

more likely to die (OR 6.5; 95% CI: 2.0, 21.6) compared with those participants who

perceived the most support. The greatest decline in functional ability was associated with

decreased levels of tangible support (B -5.7; 95%CI, -9.2, -2.1) (Woloshin *et al.*, 1997).

Similarly, Ikeda *et al.* (2007) reported that men with the lowest social support had a 1.6-

fold higher risk of mortality from stroke in a multivariate-adjusted model (p = 0.03).

More specifically, results also showed that among this cohort of men, social isolation and

lack of esteem were associated with 1.5- to 1.8-fold higher risks of stroke mortality, and

that lack of someone to share personal feelings and secrets with was associated with 1.2

fold higher risk for stroke incidence. These findings by Ikeda and colleagues (2007) were

not found in female participants, and remained exclusive to men.

Chin and Goldman (1997) completed one of the first studies exploring the

associations between psychosocial factors and mortality and adverse health outcomes in

individuals with HF. They prospectively followed 257 admitted HF patients and

identified characteristics associated with readmission or death within 60 days of hospital

discharge and found that individuals who were not married were more likely to be

readmitted or die within the 60-day period post-discharge (Hazard Ratio [HR] 2.1;

95%CI: 1.3, 3.3). Likewise, Friedman *et al.* (2006) assessed the relationship between

social isolation and mortality in persons with chronic HF (n = 153) enrolled in the

Sudden Cardiac Death in Heart Failure Trial (SCD-HeFT). They found that social

isolation was a significant predictor of mortality after controlling for demographic,

clinical and psychosocial predictors and treatments groups (implantable cardioversion defibrillator, amiodarone or placebo medication) (HR: 1.8; p = 0.09) (Friedman et al., 2006).

Recent studies also suggest that quality and types of social support may influence cardiac disease-related survival. Social relationships, characterized by strong emotional support, seem to be protective in patients with heart conditions (Berkman, Leo-Summers & Horwitz, 1992; Sorkin, Rook & Lu, 2002). Berkman *et al.* (1992) determined, in a prospective cohort study of 194 older (≥ 65 years) patients hospitalized at baseline for acute MI, that after controlling for severity of MI, comorbidity, risk factors such as smoking and hypertension (HTN), and socio-demographic factors that low levels of emotional support were significantly associated with 6-month mortality in both men and women (OR 2.9; 95%CI: 1.2, 6.9). The survival effects associated with lack of emotional support were much stronger than the effects of living alone or being unmarried. Likewise, Krumholtz and colleagues (1997) found, in a cohort study of 292 HF patients 65 years of age and older, and after adjusting for demographic factors, clinical severity, comorbidity, functional status, social ties and instrumental support, that the absence of emotional support was associated with a significantly higher risk in 1-year fatal and nonfatal cardiovascular outcomes for women only (OR 3.2; 95%CI: 1.4, 7.8).

In summary, the current evidence suggests that social support, a relational concept, differs between genders and seems to have an impact on health outcomes. Levels and patterns of social support are poorly understood in the older HF population, thus compromising our ability to plan gender sensitive and effective interventions to

support self-management. Therefore the specific objectives of this study were to: 1) describe the levels and patterns of social supports in older men and women, ≥ 65 years of age, over one year, following acute exacerbation of their heart failure; 2) to determine and describe the gender differences in levels and patterns of social support; and 3) to determine factors associated with high or low levels of social support.

3.4 Methods

We employed a prospective, cohort design to address the study objectives. Ethics approval was obtained through the Queen's University Health Sciences Ethics Board (Kingston, Ontario). The study took place in South-eastern Ontario, a large geographical area covering 20,000 square kilometres with a resident population of approximately 482,000 (South East Local Health Integration Network, 2007). The research is particularly relevant for South-eastern Ontario since close to 16% of its population is 65 years or older, making it the region with the largest proportion of people over the age of 65 years in the province of Ontario (2006 Census data).

3.4.1 Participant sample

Participants were included if they were aged 65 or older and seen in the emergency department (ED) with a primary or secondary diagnosis of HF. A HF diagnosis was confirmed by symptoms in accordance with the Framingham Criteria for Congestive Heart Failure (McKee, Castelli, McNamara & Kannel, 1971). This information was gathered through chart review. Patients were included as study participants for a non-HF related complaint (e.g. pneumonia) if it was potentially associated with previously diagnosed HF, and they were currently being treated for HF.

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Participants spoke and comprehended the English language and provided informed consent. Participants were excluded if they resided in assisted living institutions such as nursing homes, or long-term care facilities. Based on an estimated power of 0.8, p < 0.05, 10 variable model, and moderate effect size of ($R^2 = 0.15$) our sample of 435 was adequate to determine statistically significant relationships if they existed (Cohen 1992).

3.4.2 Data collection

Recruitment was carried out between March 2003 and September 2007. Follow-up continued until February 2009. Participants were consecutively recruited from one tertiary teaching centre and 3 community hospital corporations in the surrounding region. Based on reviews of ED discharge records, all female and male HF patients who met inclusion and exclusion criteria were recruited to participate. Potential participants were provided with study information. Once informed consent was obtained, baseline information was collected by the study coordinator either during their hospital admission or by telephone following discharge. Six and 12-month questionnaires were completed in-home and mailed back to the research facility or by phone interview with the research coordinator, as necessary. Data was entered into a secure computerized data base system maintained by the Nursing Research Unit at Kingston General Hospital, Kingston, Ontario. To ensure accuracy, data entry was subsequently verified by a research associate. During the course of the study year, survival status was determined through hospital records and family contact. Average rate of recruitment was approximately 8 participants per month. Four hundred and thirty five participants provided baseline information. Of the 435 participants who consented and were enrolled in the study, 132

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did not complete due to withdrawal (n=51), lost to follow-up (n=38), death (n=38), admission to assisted living facilities (n=4), and other (n=1).

3.5 Methods

3.5.1 Social support

Social support was measured using the Medical Outcome Survey, Social Support Survey (MOS-SSS). The MOS-SSS is a 20-item self-administered questionnaire that measures functional social support and is reported to have good internal consistency of alpha between .91 and .97 for subscale and overall scores (Sherbourne & Stewart, 1991; Young, Ignaszewski, Fofonoff, & Kaan, 2007). Questions are grouped into five subscales of functional support: emotional/informational, tangible, affectionate, and positive social interaction, plus one additional support question. The range for scoring is 0 to 100, with higher scores indicating higher levels of perceived support. Based on other literature, we interpreted high support as a score of >75 (Moskovitz, Maunder, Cohen, McLeod & MacRae, 2000).

3.5.2 Personal characteristics

A priori we identified potential variables that would influence perceptions of, needed or actual support. These variables included: age, marital status, income, educational level living arrangements, housing arrangement, distance from health care centre, and clinical demographics. We also determined other health supports including: access to health care providers (family physician, cardiologist, and/or internist), details about who managed their HF, and use of available HF resources.

3.5.3 Clinical characteristics

A left ventricular ejection fraction (LVEF) of ≤ 40% was used as our primary measure of disease severity (Canadian Cardiovascular Society Consensus Conference Recommendations, 2006; Honos, Amyot, Choy, Leong-Poi, Schnell & Yu, 2007). Other diseases that potentially influenced participants' physical functionality were identified using the Functional Comorbidity Index (FCI), a validated, self-reported tool identifying 17 common comorbid conditions associated with levels of physical functional capacity (de Groot, Beckerman, Lankhorst, & Bouter, 2003; Groll, Bombardier & Wright, 2001). This tool has been validated on a cross-sectional database of 9,423 Canadian adults, using the SF-36 physical function subscale as the outcome (Hopman et al, 2006). We specifically chose this tool for its measure of physical function rather than mortality.

3.6 Statistics Analysis

Data were analyzed using SPSS Version 17.0 software. All baseline covariates and social support scales were described using standard descriptive statistics (means, standard deviation (SD) and frequencies). Gender differences in personal and clinical variables and social support were determined using the Chi-squared test for categorical variable and t-test for normally distributed continuous variable scores. Repeated measures analysis of variance (RM-ANOVA), with time (3 levels: baseline, 6-months, 12-months) as the with-in factor, and group (2 levels: male, female) as the between factor for each social support subscale and overall scores were conducted to determine whether scores differed significantly within gender over 1-year. To explore the independent effect of gender, demographic and clinical variables on baseline social support, we used

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multiple linear regression, and selected demographic and clinical variables a priori that were significantly difference between genders at p≤ 0.15 in the bivariate analysis. A final linear regression model explored the interactive effect of marital status and gender with overall baseline social support scores.

Due to the longitudinal nature of this study and severity of illness of participants, incomplete data was an issue. When 15% of any questionnaire data was not obtained, the survey data for that particular participant was considered missing. A comparison of demographic and clinical characteristics was completed between those who completed and those that did not.

3.7 Results

3.7.1 Characteristics of the sample

Baseline participant characteristics are described in Table 1. The study cohort included 435 patients, of whom 164 (37.7%) were female and 271(62.3%) were male. Age of participants ranged between 65 to 99 years, with mean ages for females and males being 78.8 (±6.9) and 77.7 (±7.0) years, respectively. In comparison to males, females were more likely to be single, widowed or divorced (male vs. female, 26.6 % vs. 65.9%; p < 0.01) and living alone (male vs. female, 19.6% vs. 45.7%; p < 0.01). Participants most often defined living with others as being with a spouse or child. About 50% percent of females lived in a house versus apartment or condominium, whereas 75% of the males reported living in a house (p < 0.01). Females had significantly less financial resources with < 20%, compared with 40% of males, earning ≥ $40,000 annually (p < 0.01).

Echocardiogram results at baseline showed men had worse heart function than women, with 126 (46.5%) males and 54 (32.9%) females having an LVEF ≤ 40% (p < 0.01). Men and women reported similar proximity to a health care centre, use of additional resources and access to family physicians. Most participants lived relatively close to their health care centres, with approximately 90% living within a 50 kilometre radius. The majority of participants (~70%) did not use alternative resources, such as pamphlets, books, or the Internet to supplement their HF self-management. For both sexes, over 90% reported having a family physician, over 60% had a cardiologist, and 12% had a general internist. Similarly for both men and women, heart failure was managed by a family physician (~30%) or cardiologist/internist in conjunction with a family physician (~40%). The number of comorbid conditions reported by participants was similar although described differently between genders, with women reporting higher prevalence of asthma, angina, visual impairment and depression, and men reporting more cases of degenerative disc disease, myocardial infarction, diabetes, lung disease and heart impairment.

Table 1

3.7.2 Social support

Table 2 presents the mean subscale and overall social support scores at baseline, 6-months and 12-months. Mean scores for females ranged from 67.3 (±31.7) to 80.9 (±27.0), with affectionate support being the highest subscale score and positive social interaction the lowest at each time interval. Mean scores (±SD) for males ranged from 72.3 (± 32.9) to 83.1(±24.2), with tangible support being the highest subscale score and

additional support the lowest subscale score at each time interval. Perceived social

support was statistically significantly different between genders in support subscales and

overall scores over the 1-year study period. Tangible support was significantly lower at

each time interval for females, with mean score differences of 9.0 to 12.5 points less than

males at baseline ($p < 0.01$), 6-months ($p < 0.01$) and 12-months ($p < 0.01$). Independent

t-test results showed female participants had significantly lower 12-month mean

emotional/informational ($p = 0.02$), positive social interaction ($p < 0.01$), additional

support ($p = 0.03$) and overall support scores ($p < 0.01$) than males. MOS-SSS scores did

not change significantly within either gender over 1-year (Figure 2). Results from the

repeated measures analysis are included in the Appendix.

Table 2

Figure 2

Independent t-tests showed significant differences in baseline overall support

scores by marital status, current living arrangements and income (Table 3). Those who

were married or lived common law reported higher overall social support scores than

those who were single or widowed or divorced (82.2 ± 21.5 vs. 62.2 ± 27.3; $p < 0.01$).

Cohabitating had favourable effects on support scores. Those who lived with others had

significantly higher mean overall support scores than those living alone (80.5 ± 22.7 vs.

58.4 ± 26.7; $p < 0.01$). Lastly, individuals who earned >$40,000 annually had higher

baseline overall support scores than those who earned less (79.5 ± 22.8 vs. 72.7 ± 24.8; p=

0.01).

In a multiple linear regression analysis using the baseline score of overall social support as the dependent variable the key factors associated with high levels of social support were determined (Table 3). The baseline score was selected for three reasons: a) the repeated measures analyses scores did not change significantly over the course of the year, b) more complete questionnaires were available at baseline, and c) knowledge of baseline factors would be important to the planning of secondary health care interventions. Our regression analysis showed that higher social support scores were associated with being married or in a common law relationship (Beta 13.9; 95%CI: 4.9, 23.0) and living with others (Beta 8.8; 95%CI:-0.08, 17.7). In contrast to the bivariate analysis, gender was not significantly associated with baseline overall MOS social support scores. Further analysis showed that in particular it was single men who had lower social support scores (Beta -8.5; 95%CI: -16.7, -0.4) than single women. Married men and women had similar social support scores.

Table 3

Table 4

3.8 Discussion

The purpose of this study was to describe the levels of social support received by individuals, $\geq$ 65 years of age following an episode of HF exacerbation, and to determine and describe the gender differences in social support in this sample. The principal finding was that females consistently reported lower levels of social support than males, however; when controlling for other covariates, gender differences in social support disappeared. Secondly, factors such as marital status and living arrangements were

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strongly associated with levels of social support and these factors differed between genders. Thirdly, perceived social support did not change over one year in either the male or female participants. Lastly, single marital status in men was a significant predictor of lower social support scores, when we controlled for important covariates.

Consistent with other older population-based studies, older women in this study tended to be single, living on their own, with less income in comparison to older men. Arber and Cooper (1999) explored gender differences in older adults (> 60 years), using data from the British General Household Survey. From a sample of over 14,000 participants, Arber and Cooper concluded that older disabled men usually have a spouse to provide care should they need it, and are less likely to rely on others living elsewhere or on assisted-living. They also found that the majority (60%) of older female participants with moderate or severe disability lived alone and had to rely on supports outside their home to remain functional in the community (Arber & Cooper, 1999). These demographic findings are also similar to reports by Health Canada in 2002, in which nearly 75% of Canadian senior men compared to 41.4% of Canadian senior women were married, and 46% of senior women were widowed compared to 12.7% of senior men.

Our participant sample is representative of the population with cardiovascular diseases (Chin & Goldman, 1998; Lofvenmark, 2009). A prospective cohort study of 435 HF patients by Chin and Goldman (1998) showed that women, in comparison to men, were older (p ≤ 0.05), poorer (29% of women versus 15% of men with income ≤ $7,500 annually; p ≤ 0.01) and more likely to be single (66% of women versus 28% of men; p ≤

0.01). Women were also less likely then men to have someone at home to care for them (66% versus 81%, p ≤ 0.01). Lofvenmark *et al*. (2009) completed a prospective 1-year cohort study of 149 patients with HF to investigate perceived loneliness and social support in this population. They found more men than women were married and lived with someone (70% versus 42%; p< 0.01) and, that women, more often than men were widows (38% versus 13%; p< 0.01). Given that social support is a relational concept, the primary issue of concern is whether individuals perceive being alone or not; the reason for the status is secondary.

In addition to demographic trends, our gender-varied results are likely disease-dependant. The clinical presentation of HF is normally different between older men and women. Women have healthier left and right ventricular ejection fraction than men, and present with diastolic dysfunction more frequently than systolic dysfunction (Ghali, Krause-Steinrauf, Adams, Khan, Rosenberg *et al*., 2003; Redfield, Jacobsen, Burnett, Mahoney, Bailey *et al*., 2003). This was the case in our study sample, as older men had significantly worse LVEF compared to women. Lofvenmark et al. (2009) reported that, out of 149 HF participants, males had more depressed left ventricular function than females (exact values were not published). In another study, using the NYHA classification, Reidinger and colleagues (2001) indicated that men had more severe cardiac dysfunction than women, with mean scores (±SD) of 1.59 (± 0.65), and 1.97 (± 0.72) respectively (p < 0.01). Survival projections by Ho *et al.* (1993) also support our clinical findings. Median survival time from diagnoses of HF were 1.7 years in men and 3.2 years in women, and a 5-year survival rate of 25% in men and 38% in women (Ho et

al., 1993). Survival after the onset of HF was also better for women than men after adjusting for age (HR 0.6; 95% CI: 0.5, 0.8) (Ho et al., 1993). As LVEF is an indication of cardiac function and disease severity, senior men presented with more clinically severe HF than their female counterparts. We can also infer, since survival times are longer for women with HF, they are living longer with the disease than men and therefore require more long-term support.

Access to care was relatively adequate. Most participants lived within a 50 km distance of their primary HF health care centre. The majority of senior males and females had access to a family physician, and many also had access to a specialist. Participants relied on health care providers as the major source for HF support and information, rather than books, the Internet or other such resources. This is likely reflective of the older age of the participants.

3.8.1 Social support patterns and levels

Overall, participants reported moderate to high social support scores. Our findings are comparable to other studies (Bennett *et al*., 2001; Janevic *et al*., 2004). Moderate to high social support scores were reported by 227, all-age, HF patients in a 1-year prospective cohort study by Bennett and colleagues (2001). Mean baseline and 1-year MOS-SSS scores were 56 and 53 out of 76 respectively (Bennett *et al*., 2001). Bennett omitted the additional support subscale from the total, making a total possible score of 76 rather than 100. In another study assessing longitudinal effects of social support on the health and functionality of older women with HF, the mean MOS-SSS total score (±SD) was 74.3 (±20.7). Other subscale support scores in the study were also moderate to high,

ranging from 72.2 (± 24.1) in emotional/informational support to 80.9(± 21.72) in affectionate support (Janevic et al., 2004). Contrary to our findings, Yu and colleagues (2004) reported overall MOS-SSS scores of 56.9(± 22.7); emotional/informational scores of 43.7 (±25.9) and tangible scores of 67.0 (±27.9). Yu and colleagues measured support in a Chinese population exclusively; therefore, culture differences may have contributed to the difference in findings. We also must consider the influence of participant attrition in this study on social support scores. Individuals dropped out due to death or worsening illness; thus those remaining in the cohort at one year were more likely healthier. In relation, it is also possible that dropouts were those participants who were poorly or non-supported. It is therefore feasible that social support scores presented in this study were skewed higher, and thus underestimating the prevalence of low levels of social support.

Overall, participants of both genders perceived lower levels of social interactive support in comparison to other types of social support; they did not have someone to do enjoyable things, to get together with, or have a good time with. Older individuals (≥ 65 years) in this population may have less available social interactions due to the nature of aging. Support received by family or living spouse is more often love and affection or aid in activities of daily living and is not perceived as a social interaction. The nature of HF disease may limit individual's capacity to engage in supportive social activities; and as well, there is limited formalized rehabilitation programs designed for patients with HF.

As MOS social support scores represent perceived support, lower support scores by women could represent either a lack of needed support and/or a lack of actual support received by available family and friends. Given that older females with HF are more

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frequently single, widowed or divorced and living alone, they may have less available social support altogether. In the present study women perceived less social support at all time points (some of which were statistically significant), and in all support subscales, than men. Similar results have been published in studies, which included both HF and other CVD populations. Using the Interview Schedule for Social Interaction (ISSI) to measure perceived social support in 149 HF patients, Lofvenmark, Mattiasson, Billing and Edner (2009) reported women having smaller social network sizes and feeling loneliness more often than men (34% vs. 7%; $p < 0.01$). In a longitudinal study by Lett and colleagues (2007), from a database of 2,466 participants with coronary artery disease, lower support scores were more common among older age, women, and were associated with lower scores on all other social support measures in the study (Lett et al., 2007). Likewise, Woloshin *et al.* (1997) followed 820 participants with coronary artery disease, and found, using 2 social support questions and 5 social-support construct validity questions, that participants who perceived less adequate support were more commonly older women with low income. Reidinger and colleagues (2001) evaluated gender differences in the quality of life of 1,382 age and EF-matched HF patients and found women had significantly worse social health and social activity scores than men. In contrast, a recent study by Bennett et al., (2001) using the MOS-SSS, determined from a sample of 147 all-age HF patients, that it was younger (<65 years) males who perceived significantly lower social support than older (≥65 years) males or females of any age. However, when adjusting for drug group, race, site, number or prior hospitalizations, and comorbidities, these gender differences disappeared (Bennett et al., 2001). Similar to

Bennett and colleagues, Heo, Moser, Lennie, Riegel and Chung (2008) found no significant gender differences in social support when they used the Multidimensional Scale of Perceived Social Support (PSS) to identify factors related to self-care behaviours in 122 HF patients. Discrepancies in the aforementioned gender-related social support findings may be due to etiological differences between cardiovascular disease groups (CAD, MI and HF). Furthermore, as we know profiles of older individuals are unique; differences between studies in participant age likely have influenced discrepancies in social support findings. Our study included individuals, ≥ 65 years, whereas previous research predominantly includes all ages.

Subtypes of social support also differed between male and female participants. Women in this study perceived less support than men in meal preparation, daily chores, transportation, and less available help in general should they be confined to a bed. The lack of support for these activities could adversely influence quality of life and overall health outcomes, especially so as HF progresses and physical capacity decreases. These findings have been reported in other cardiovascular disease studies. Woloshin, Schwartz, Tosteson, Chang, Wright, Plohman and Fisher (1997) interviewed 820 patients with coronary artery disease to determine the relationship between tangible support adequacy and functional status and health outcomes. Woloshin and colleagues noted that perceiving less adequate tangible support was more common in older age and among women. With symptom burden, lack of knowledge and poor treatment adherence adding to the on-going challenge of self-care in chronic disease populations, availability of supportive resources should be considered an important strategic component to support

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patients' functional status (Riegel & Carlson, 2002). These results imply that older women with HF may be at an increased risk for functional deficits and more adverse health outcomes than men.

Women in comparison to men reported significantly lower emotional/informational social support scores. Older women reported having less presence of someone who will listen to them, someone who will give them information or advice, someone with whom to confide in and share private worries, someone who could be counted on for advice and whose advice they wanted, or someone that understood their problems. These findings are important as previous studies have shown that low levels of emotional support are associated with poor outcomes in elderly patients with CVD. In a review of 292 older (≥65 years) HF patients, an unadjusted analysis showed lack of emotional support was significantly associated with the 1-year risk of fatal and nonfatal cardiovascular outcomes (OR 2.4; 95%CI: 1.1, 4.9) (Krumholtz et al., 1997). After adjusting for demographic factors, clinical severity, comorbidity and functional status, social ties, and instrumental support, the absence of emotional support remained associated with a significantly higher risk of cardiac event (OR 3.2; 95%CI: 1.4, 7.8). Krumholtz and colleagues further identified, in a multiple regression, which included gender, that the association between lack of emotional support and cardiovascular events was restricted to women (OR 8.2; 95% CI: 2.5, 27.2). In another study, a multiple logistic regression showed lack of emotional support was significantly associated with 6-month mortality (OR 2.9; 95% CI: 1.2, 6.9) in a prospective, community-based cohort study of 194 older (≥ 65 years) men and women hospitalized for an MI (Berkman et al.,

1992). No gender differences were identified in this study by Berkman and colleagues.

Bosworth, Steinhauser, Orr, Lindquist, Grambow and Oddone (2004) conducted three

focus groups, including 15 HF patients total, to collect descriptive information of the

components of QOL as understood by patients with HF. Social support emerged as an

important theme; in particular they identified positive emotional support as a potential

buffer to stress associated with HF (Bosworth et al., 2004). Similar to tangible support,

the evidence suggests that older women are at a higher risk than men for mortality and

other HF-related adverse outcomes if they experience lower levels of

emotional/informational support.

While women reported lower social support scores, scores seems to be heavily

influenced by other supportive resources. In the present study being married, living with

others and having a higher income were all independently associated with significantly

higher social support scores. When adjusting for relevant demographic and clinical

variables in a multiple linear regression, with the exception of living arrangements which

had a borderline significant relationship, marital status was the only factor significantly

associated with overall social support. In support of these findings, a similar study by

Lofvenmark et al. (2009) found HF participants who were married and living together

scored higher than those who were divorced, widowed/widower or unmarried in 3 social

support measures: a) availability of social integration (AVSI), b) availability of

attachment (AVAT), and c) adequacy of attachment (ADAT), from the social support

measure ISSI. Likewise, individuals who were single or lived alone were less likely to

perceive adequate tangible support ($p < 0.01$) in a cohort study of 1,468 CAD patients

(Woloshin et al., 1997). Lett and colleagues (2007) had similar findings in a large cohort

study of CAD patients. They used 4 social support measures to compare the impact of

network support and different types of perceived functional support on fatal and nonfatal

infarction for CAD patients with a recent MI. Lower social support scores in the

International Support and Evaluation List (ISEL-T), the Perceived Social Support Scale

(PSSS), the Social Network Questionnaire (SNQ), and the ESSI were significantly

associated with single marital status ($p < 0.05$) (Lett et al., 2007). Although not well

studied in the HF population, single marital status, as an indicator of poor social support,

has been a significant predictor of all-cause mortality, hospital readmission, fatal and

nonfatal cardiovascular events, and psychological distress in other CVD populations

(Berkman et al., 1992; Case, Moss, Case, McDermott, & Eberly, 1992; Chin and

Goldman, 1997; Pelle, Gidron, Szabo & Denollet, 2008; Yu, Lee, Woo & Thompson,

2004). Interestingly, men in this cohort were more likely to be married in comparison to

women, but men who were single reported significantly lower social support scores,

when adjusting for demographic and clinical covariates. Among married individuals,

there were no gender differences in social support scores. Those who are married,

regardless of gender, and single females, report higher support scores than single older

males with HF. Although older females tend to be single and living alone, with

seemingly higher risk than males for poor levels of social support, it is in fact older single

males who perceive the least support. These findings support the notion that among the

elderly, especially women, living alone is a normative experience and is perceived as

such.

Findings from this study also suggest clinical condition has little impact on social support. The presence of a clinical condition provides the context for the assessment of social support adequacy. The results of this study highlight that older HF individuals are a potentially vulnerable group, with a high percentage of participants having multiple comorbid conditions and poor cardiac function, and are likely in need of both formal and informal support to help manage their chronic condition. Fortunately, most individuals in this study reported adequate physician support. Few used other sources to manage their heart condition. Finally, our results showed that social support is relatively stable across time. Bennett et al. (2001) found mean social support scores remained stable over time. Likewise, Friedman (1997), using Krause's (1986) version of the Inventory of Socially Supportive Behaviour, reported in a study evaluating social support sources among older women with HF that most participants did not experience loss of their emotional or tangible support sources between baseline and 18-months following. The finding that social support is relatively stable is important from a secondary prevention perspective, as this allows us to identify individuals with low levels of support, individuals at risk.

3.9 Strengths and Limitations

A particular strength of this study is the detailed follow-up and interviews of HF patients, a participant sample that is usually difficult to recruit and engage in study participation. As well we employed standardized questionnaires, allowing for comparisons with other studies. The major limitation in this study is the number of participants who did not complete 12-month questionnaires due to death, illness or lost to follow up.

3.10 Conclusions and Implications to Practice

Overall men and women perceive different levels of social support following HF exacerbation with older female HF patients perceiving less social support than males. This may be due to differences in marital status and living arrangements between genders. Older women with HF tend to be single or widowed and living alone, however seemingly it is single men whose marital status most affects their perception of social support. Because of the potential health benefits associated with social support, low levels of support, for whatever reason, could impact overall health outcomes and HRQL. Future studies need to determine if and how gender differences in social support affects adverse health outcomes for older individuals with HF.

3.11 Acknowledgements

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Table 1. Baseline socio-demographic and clinical characteristics of the sample

Demographics	Female N=164	Male N=271	
	Mean (± SD)	Mean (± SD)	P
Age (years)	78.8 (6.9)	77.7 (7.0)	0.108
	N (%)	N (%)	
Marital status			**< 0.01**
Single/widowed/divorced	108 (65.9)	72 (26.6)	
Married/common law	56 (34.1)	99 (73.4)	
Education level			0.91
Completed high school	127 (77.4)	210 (77.5)	
Completed post-secondary	33 (20.1)	53 (19.6)	
Missing	4 (2.4)	8 (3.0)	
Living arrangement			**<0.01**
Live alone	75 (45.7)	53 (19.6)	
Live with others/other	88 (53.7)	218 (80.4)	
Missing	1 (0.6)	-	
Housing arrangement			**<0.01**
House	89 (54.3)	203 (74.9)	
Apartment/condo/other	74 (45.1)	67 (24.7)	
Missing	1 (0.6)	1 (0.4)	
Geographical distance from centre			0.20
≤ 50 km	151 (92.1)	239 (88.2)	
> 50 km	13 (7.9)	32 (11.8)	
Annual combined income			**<0.01**
≤ $40,000	111 (67.7)	144 (53.1)	
> $40,000	28 (17.1)	89 (38.8)	
Missing	25 (15.2)	38 (14.0)	
Use of other resources to manage HF[a]			0.17
No	117 (71.3)	176 (64.9)	
Yes	47 (28.7)	95 (35.1)	
Clinical characteristics	N (%)	N (%)	P
LV Ejection Fraction			**<0.01**
≤ 40%	54 (32.9)	126 (46.5)	
> 40%	81 (49.4)	103 (38.0)	
Missing	29 (17.7)	42 (15.5)	
Framingham criteria[b]			0.22
No	19 (11.6)	22 (8.1)	
Yes	143 (87.2)	248 (91.5)	
Missing	2 (1.2)	1 (0.4)	
Comorbid conditions[c]			0.07
0-2 comorbidities	72 (43.9)	139 (51.3)	
>2 comorbidities	78 (47.6)	103 (38.0)	
Missing	14 (8.5)	29 (10.7)	

Use of resources HF includes pamphlets, books and/or the Internet. [a]= resources include books, pamphlets and the Internet. [b] = Diagnosis of CHF, as defined by the presence of at least 2 major criteria or 1 major in conjunction with 2 minor criteria which is outlined by the Framingham Criteria. [c]= Comorbidities from a list of 18-item of diagnoses associated with functional impairment.

Table 2. Gender differences in social support scores at baseline, 6-months and 12-months

Social Support Subscales	Baseline			6-months			12-months		
	N	Mean (± SD)	P	N	Mean (± SD)	P	N	Mean (± SD)	P
Emotional/information support			0.12			0.71			**0.02**
Female	163	69.5 (± 27.4)		106	72.2 (± 28.0)		79	69.6 (± 29.2)	
Male	265	73.9 (± 27.0)		183	73.4 (± 26.5)		142	78.8 (± 23.5)	
Tangible support			**<0.01**			**<0.01**			**<0.01**
Female	162	71.3 (± 31.0)		108	70.4 (± 32.7)		79	70.6 (± 31.1)	
Male	266	80.3 (± 27.7)		182	82.5 (± 29.1)		144	83.1 (± 24.2)	
Affectionate support			0.84			0.17			0.70
Female	161	80.9 (± 27.0)		108	76.7 (± 30.7)		78	80.2 (± 24.6)	
Male	265	80.4 (± 30.4)		177	81.6 (± 28.7)		141	81.7 (± 28.7)	
Positive social interaction			0.06			0.17			**<0.01**
Female	154	67.3 (± 31.7)		107	70.7 (± 32.9)		78	68.5 (± 30.3)	
Male	264	73.4 (± 32.0)		180	76.0 (± 29.0)		141	79.8 (± 27.0)	
Additional Support			0.14			0.43			**0.03**
Female	158	67.6 (± 31.5)		107	70.6 (± 32.7)		78	68.9 (± 29.4)	
Male	263	72.3 (± 32.9)		178	73.6 (± 30.9)		140	77.7 (± 28.6)	
Overall support			0.07			0.09			**<0.01**
Female	163	71.0 (± 24.6)		108	72.1 (± 27.4)		79	71.5 (± 24.5)	
Male	269	75.7 (± 26.6)		183	77.3 (± 24.7)		144	80.7 (± 22.2)	

Figure 2. Mean overall social support scores

Table 3. The influence of demographic and clinical variables on baseline overall social support scores (MOS-SSS)

	Bivariate			Multivariate - Baseline		
Demographics	N	Mean (±SD)	P-value	N	Beta (95%CI)	P-value
Age (10 year increments)	431	-	0.05	284	1.39 (-2.48 – 5.27)	0.48
Gender	432		0.07	284		0.34
Female		71.0 (±24.6)			-	
Male		75.7 (±26.6)			-2.94 (-9.04 – 3.15)	
Marital status	432		**<0.01**	284		**<0.01**
Single/Widowed/Divorced		62.2 (±27.3)			-	
Married/common law		82.2 (±21.5)			13.95 (4.94 – 22.96)	
Current living arrangement	431		**<0.01**	284		**0.05**
Live alone		58.4 (±26.7)			-	
Live with others/other		80.5 (±22.7)			8.80 (-.084 – 17.69)	
Income	369		**0.01**	284		0.88
≤ $40,000		72.7 (±24.8)			-	
> $40,000		79.5 (±22.8)			.475 (-5.64 – 6.59)	
Clinical						
LV function	361		0.70	284		0.34
≤ 40%		73.4 (±26.5)			-	
> 40%		74.4 (±25.5)			2.63 (-2.74 – 8.00)	
Comorbid conditions	389		0.08	284		0.30
0-2 comorbidities		75.7 (±25.3)			-	
>2 comorbidities		71.1 (±25.9)			-2.91 (-8.43 – 2.62)	

Table 4. The associations between marital status and mean baseline overall social support scores.

	Single/widowed/divorced			Married/common law		
	N	B (95%CI)	P	N	B (95%CI)	P
Gender	178			252		
Female		1.00			1.00	
Male		-8.55 (-16.69, -0.42)	**0.04**		1.28 (-5.13, 7.69)	0.70

Linear regression selecting for each marital status, with independent variable as gender, and dependent as overall baseline support.

Chapter 4

Gender differences in the influence of social support on functional decline in older persons living with heart failure in their community.

4.1 Abstract

Background: Heart failure (HF) is a prevalent chronic cardiovascular disease among elderly persons that is characterized by progressive functional decline. Given the known links between high levels of support and positive health outcomes, the purpose of this study was to determine the levels and patterns of social support in older men and women with HF, and to determine the influence of support on functional outcomes. **Methods:** We conducted a 1-year prospective descriptive study and enrolled men and women ≥ 65 years of age (N=435; 164 females; 271 males) who were assessed in the emergency department for a HF exacerbation. Participants completed baseline, 6 and 12-months questionnaires containing clinical and demographic descriptive information and validated measures of: 1) physical functioning using scales from the Medical Outcome Study (MOS) SF12 and Kansas City Cardiomyopathy Questionnaire (KCCQ); and, 2) social support using the MOS, Social Support. **Results:** Our descriptive analysis showed that women with HF were more likely to be single, widowed or divorced, living alone in an apartment or condominium and earning less annual income in comparison to men (p < 0.01). At baseline, women reported significantly lower tangible support scores (p < 0.01) and lower physical function scores, as measured with the physical functional subscales of the KCCQ or SF12. However, at 1 year there were no significant gender differences in the proportion of men or women who experienced functional decline or death across the

year of follow-up. In multivariate logistic regression modeling, men with lower levels of social support were more likely to experience functional decline, as measured with the SF12. This was not the case for women. **Conclusions:** Findings from this study show that women, in comparison to men, report less social support and poorer functioning, but the impact of social support on functional decline is more pronounced in men. This would suggest the need for gender-based strategies to support optimization of function for men and women living with HF in their community.

Key Words: *Social support, gender, heart failure, health outcomes*

4.2 Introduction

Heart failure (HF) is a common chronic cardiovascular disease that affects over 500,000 Canadians today and 50,000 new patients diagnosed annually (Ross, Howlett, Arnold, Liu, O'Neill, Brophy, *et al*., 2006). Heart failure typically presents as episodes of acute exacerbation combined with periods of clinical stability. It affects all ages, but in particular, is a disease of older adults. Seniors are the fastest growing population sector in Canada, with a projected three-fold increase in HF prevalence over the next three decades (Health Canada, 2002; Johansen *et al*, 2003). Due to its chronic and episodic nature, HF is managed primarily from home by patients and their caregivers; thus the ability to self-manage the illness and to access needed supportive resources are important factors that are likely to influence health outcomes and functionality.

Personal profiles tend to vary by age and gender in terms of social, psychosocial, physiological and functional status (Chambers, Bagai & Ivascu, 2007). We now know that differences in the sexes are multidimensional, with strong influences both from biological and social processes (Bird & Rieker, 1999; Rieker & Bird, 2005). Older women in particular have a unique psychosocial profile that predisposes them to different health risk factors than men of all ages or women in younger age groups. Current evidence shows that older women are more likely to: a) have limited social supports, b) be living on their own, with less financial resources, c) not access formalized supports such as cardiac rehabilitation programs, d) report poorer health related quality of life, and e) have worse physical function, in comparison to men (Arber & Cooper, 1999; Chambers *et al*. 2007; Chin & Goldman, 1998; Missik, 2001; Shaw, Merz, Pepine,

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Steven, Reis, Bittner *et al*. 2006; Riedinger, Dracup, Brecht, Padilla, Sarna, & Ganz, 2001).

Social relationships influence morbidity and mortality (Berkman *et al*., 1992; Krumholz *et al*., 1998). Social support is characterized by the structure, strength and type of relationships (Williams, Barclay & Schmied, 2004). Social support is generally defined as an interpersonal transaction providing functional support involving 1) emotional support (involving care, love, and empathy), 2) instrumental or tangible support (goods and services), 3) informational support (including guidance or feedback or environmental information), or 4) appraisal (information specifically related to self evaluation) (House,1981). Relevant literature shows that lack of perceived social support, lack of available social support and more specifically, low emotional support, are potential risk factors for mortality and other adverse outcomes in persons with cardiac disease (Berkman, Leo-Summers & Horwitz, 1992; Chin and Goldman, 1997; Krumholz, *et al*. 1998; Sorkin, Rook &Lu, 2002). Some postulate that social support facilitates coping and adaption and moderates the psychological and physiological consequences of stress (Cobb, 1976; Mookadam & Arthur, 2004; Williams, Barclay & Schmied, 2004).

Given that high levels of social support may promote psychological and physical well being and good health behaviours (Rozanski, Blumenthal & Davidson, 2005), it is unclear whether gender, and varying levels of social support or a combination of these factors influence functional well-being and other health outcomes for older persons with HF. Therefore the purpose of this study was to describe the independent and combined effects of gender and social support on health outcomes, while controlling for personal

demographics, disease severity, and comorbid conditions. The specific null study

hypotheses tested were:

1) There would be no difference in measures of social support between men and
   women;

2) There would be no associations between measures of social support and
   reported measures of functional well being; and,

3) There would no gender differences in the associations between measures of
   social support and measures of functional well being.

4.3 Methods

To address the study objectives hypotheses we conducted a prospective cohort

study. The Queen's University Health Sciences Ethics Board (Kingston, Ontario)

reviewed and approved the study protocol. The study took place in South-eastern

Ontario, a large geographical area covering 20,000 square kilometres with a resident

population of 442,800 (2004 Census data). This research is particularly relevant for

South-eastern Ontario since close to 16% of its population is 65 years or older, making it

the region with the largest proportion of people over the age of 65 years in the province

of Ontario (2004 Census data). Recruitment was carried out between March 2003 and

September 2007. Follow-up continued until January 2009. Patients were consecutively

recruited from one tertiary teaching centre in Kingston, Ontario and 3 community

hospital corporations in the surrounding region. Average rate of recruitment was 8

participants per month. Four hundred and thirty-five participants provided baseline

information. Of the 435 who started, many eligible and consenting participants did not

complete the study due to worsened illness (n=30), death (n=54), and lost to follow up

due to entering assisted living facilities (n=4), or other unknown reasons (n~166,

depending on the questionnaire).

4.3.1 Participant sample

Participants were included if they were aged 65 and older and either seen in the

emergency department (ED) with a primary or secondary diagnosis of HF. A HF

diagnosis was confirmed through chart review in accordance with the Framingham

Criteria for Congestive Heart Failure (McKee, Castelli, McNamara & Kannel, 1971).

Patients were included as study participants for a non-HF related complaint (e.g.

pneumonia) if it was potentially associated with previously diagnosed HF, and they were

currently being treated for HF. Participants were able to comprehend the English

language and give informed consent. Participants were excluded if they lived in such

institutions as nursing homes, or long-term care facilities. Based on an estimated power

of 0.8, $p < 0.05$, 10 variable model, and moderate effect size of ($R^2 = 0.15$) our sample of

435 was adequate to determine relationships if they existed (Cohen 1992).

4.3.2 Data collection

Based on ED discharge records, all female and male HF patients who met

inclusion criteria were recruited as potential participants. Prospective participants were

provided information about the study within approximately one week of HF exacerbation

and invited to participate by the research coordinator either during their hospital

admission as inpatients, or by telephone following discharge. Once informed consent

was obtained, baseline information was collected either in-hospital, by mail or via telephone interview. Two consecutive questionnaires were mailed or dictated via telephone at two 6-month intervals (6 and 12 months) from baseline. Participants completed questionnaires in-home, or by phone interview as necessary. Data were entered into a secure computerized data base system maintained by the Nursing Research Unit at Kingston General Hospital, Kingston, Ontario. To ensure accuracy, data entry was subsequently verified by a research associate. During the course of the study year, survival status was determined through hospital records.

4.4 Measures

Measures of functional status were obtained with both a generic and disease specific self-report questionnaires: the Medical Outcome Survey Short Form 12-item Health Survey (SF-12), and the Kansas City Cardiomyopathy Questionnaire (KCCQ), respectively. To account for survivor-biased score results, two categorical adverse outcome variables were created based on minimal clinically important differences (MCID). The MCID can be defined as 'the smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive cost, a change in the patient's management' (Jaeschke, Singer & Guyatt, 1989, p.407). Its use in result interpretation is crucial when determining clinical applicability versus trivial differences.

4.4.1 Primary outcomes

The primary outcome of interest was the clinically important changes in disease-

related function, as measured with the KCCQ. The *Kansas City Cardiomyopathy Questionnaire (KCCQ)*, a disease-specific, 23-item, self-directed tool that measures HRQL in patients with chronic heart failure was administered. The KCCQ quantifies the following domains: physical limitation, symptoms (frequency, severity and recent change), social limitation, self-efficacy and knowledge and quality of life. Scale scores were transformed to a 0 to 100 range by subtracting the lowest possible scale score, dividing by the range of the scale and multiplying by 100. This tool is a valid, reliable health status measure for patients with HF. Cronbach's alphas for each domain are high, except for self-efficacy (0.62) (Green, Porter, Bresnahan & Spertus, 2000). The KCCQ functional status score, the physical limitation (PL) score was the basis for the categorical variable created for this study. To focus on clinical changes relevant to patients, and their disease management, clinically significant changes to outcomes were identified. Based on relevant literature, a 5-point change in KCCQ functional status score reflected a clinically significant change in heart failure quality of life status (Rumsfeld, Havranek, Masoudi, Peterson, Jones, Tooley *et al*., 2003; Spertus, Peterson, Conard, Heidenreich, Krumholtz, Jones *et al*., 2005). We created a categorical variable, based on minimally clinical important difference (MCID) in the baseline and 12-month PL scores and classified participants accordingly: (1) minimal clinically important improvement or maintained functional well-being, (2) minimal clinically important decline in functional well-being, (3) death within the 12 month follow-up, (4) withdrawal from the study due to worsening illness and (5) lost to follow-up/withdrawal for unknown reasons.

4.4.2 Secondary outcomes

The secondary outcome of interest was the clinically important changes in overall function, that may or may not be disease related, as measured with the *Medical Outcome Study, Short Form Health Survey (SF-12).* The SF-12 is a brief, self-administered tool that measures functioning and well-being in two health status domains: physical functioning (PCS) and emotional functioning (MCS). We chose to administer the SF-12 and not the SF-36 because of concern with questionnaire burden. The SF-12 is a reliable, valid measure of health in surgical and medical populations (Ware, Kosinski & Keller, 2005; 2006). Mean reliability coefficients are similar to the SF-36, and are reported between 0.64 and 0.87 for the physical dimension (Ware, Kosinksi & Keller, 2005). Using the physical component score (PCS) of the SF-12, a similar 5-level categorical adverse outcome variable based on MCIDs was created based on change scores from baseline to 12-months. For this study we used a 2-point change in PCS to reflect a clinically significant change in quality of life. Participants were classified accordingly: (1) minimal clinically important improvement or maintained functional well-being as measured with the PCS of the SF-12, (2) minimal clinically important decline in functional well-being as measured with the PCS of the SF-12, (3) death, (4) withdrawal from the study due to worsening illness and (5) lost to follow-up/withdrawal for unknown reasons. At present, literature on MCID for the SF-12 scores remains inconclusive. Lim and Fisher (1999) used 5-points as the minimal clinically important difference. However, differences seen between various SF-12 subgroups suggested that a smaller MCID of 2-points would be more clinically meaningful. Similarly, PCS mean change scores of

approximately 3-points were interpreted as small effect size which would indicate the

MCID as being above the 3-point range (Rubenach, Shadbolt, McCallum & Nakamura,

2002).

4.4.3 Exposure variable of interest: social support

Social support was measured using the Medical Outcome Survey – Social Support

Survey (MOS-SSS). The MOS is a 20-item self-reporting tool that measures functional

social support and is reported to have good internal consistency (Cronbach alpha

coefficients are reported between 0.92 and 0.95) (Young, Ignaszewski, Fofonoff, &

Kaan, 2007). Questions are grouped into four subscales of functional support:

emotional/informational, tangible, affectionate, and positive social interaction. With

higher scores indicating more perceived support, the range for total score is from 0 to

100. Bennett and colleagues (2001) used the MOS-SSS to measure social support, as a

predictor of HRQL in patients with HF and found mean total scores (±SD) at baseline

were 56 (±18.2), and 53 (±20.1) at 12-months. Total survey scores, as well as each

subscale scores, were collected from participants at baseline, 6 and 12-months.

4.4.4 Personal characteristics

Age, sex, income, educational level, and health habits were recorded at baseline

by self-report and are used to describe the older HF population. Home supports such as

living arrangements, housing arrangements and marital status were also collected, as well

as health supports including: access to a family physician, cardiologist/internist, details

about who manages the HF, and use of HF resources.

4.4.5 Clinical characteristics

Left ventricular ejection fraction (LVEF) of <40% was our primary measure of disease

severity. This value was obtained from echocardiogram history during a chart review.

Other diseases that potentially influenced participants' functionality were identified using

the Functional Comorbidity Index (FCI), a validated, self-reported tool used to identify

17 common comorbid conditions used to predict one's level of physical functional

capacity. (Groll, Bombardier & Wright, 2001; de Groot, Beckerman, Lankhorst, &

Bouter, 2003). This tool has been validated on a cross-sectional database of 9,423

Canadian adults, using the SF-36 physical function subscale as the outcome (Hopman *et*

al, 2006). We specifically chose this tool for its measure of physical function rather than

mortality.

4.5 Statistical Analysis

Data were analyzed statistically using SPSS Version 17.0 software.   All baseline

and 12-month covariate and social support scales were described using standard

descriptive statistics (means, standard deviation and frequencies).   When 15% of any

questionnaire data were not obtained, the survey data for that particular participant were

considered missing. We determined the gender differences in personal and clinical

variables and social support using the Chi-squared test for categorical variable and t-test

for normally distributed continuous variable scores. The associations between gender,

demographic, clinical variables and baseline social support scores with functional

outcomes were determined first with a bivariate analysis, and then a multivariate logistic

regression analysis. Covariates for the models were selected a priori based on bivariate

associations of p ≤ 0.15 from Table 1. For the logistic regression analysis, a two-level

functional outcome was created for each of the PL and PCS scores: 1) maintained

functional status or improved by the minimal clinically important difference and 2) died,

lost to follow up due to worsening illness or declined by the minimal clinically important

difference.

The large number of participants lost to follow up was addressed in two ways.

First, we compared the baseline characteristics of those participants with complete 12

month data to those participants with incomplete data at 12 months, to determine if the

groups were similar. Secondly, we conducted a sensitivity analyses in which we

compared the modeling results in 2 cohorts: 1) a cohort that did not include those

participants that were lost to follow-up and 2) a cohort that included the loss to follow-up.

It should be noted that for some individuals we were able to categorize participants

within the functional decline category, without questionnaire data, as they reported to the

study coordinator their intent to withdraw due to worsening illness and decline. This

sensitivity analysis allowed us to test the assumption that those participants lost to follow

up could be included in the declined/died/too ill adverse outcome group.

4.6 Results

4.6.1 Characteristics of the sample

Baseline participant characteristics are described in Table 5. The study cohort

included 435 patients, of which 164 (37.7%) were female and 271(62.3%) were male.

Age of participants ranged between 65 to 99 years, with mean (±standard deviation, SD)

ages for females and males being 78.1 (±7.0) and 77.8 (±7.0) years, respectively. In

comparison to males, females were more likely to be single, widowed or divorced (male vs. female, 26.6 % vs. 65.9%, $p < 0.01$) and living alone (male vs. female, 19.6% vs. 45.7%, $p < 0.01$). Participants most often defined living with others as being with a spouse or child. Fifty four percent of females lived in a house, and 45% resided in either apartment or condominium housing arrangements, whereas three-quarters (75%) of the males reported living in a house, and 25% in apartment or condominium ($p < 0.01$). There were significant differences in income status, with 40% of males, compared with less than 20% of females, earning greater or equal to $40,000 annually ($p < 0.01$). The majority of all participants earned less than $40,000 annually. Echocardiogram results at baseline showed men had poorer heart function than women, with 126 (46.5%) of males and 54 (32.9%) females having a LVEF ≤ 40% ($p < 0.01$).

Men and women reported similar proximity to the tertiary health care centre, use of additional resources and access to family physicians. Most participants lived relatively close to their health care centres, with approximately 90% living within a 50 km radius. The majority of participants (~70%) did not use alternative resources, such as pamphlets, books, or the Internet to supplement their HF self-management. For both sexes, over 90% reported having a family physician, over 60% had a cardiologist, and 12% had a general internist. Similarly for both men and women, heart failure was managed by a family physician (~30%) or cardiologist/internist in conjunction with a family physician (~40%). The number of comorbid conditions were not significantly different between sexes but were ranked differently. Women reported a higher prevalence of asthma, angina, visual impairment and depression, and men reported more cases of degenerative

disc disease, myocardial infarction, diabetes, lung disease and heart impairment.

Interestingly, fewer than 60% of men and women identified congestive heart failure (CHF) as a present comorbidity at baseline.

Table 5

4.6.2 Completed versus lost to follow up groups

There were significant differences between those who completed the study and those who were lost to follow up (Table 6). Participants who completed the study, in comparison to non-completers were more likely to be male, married with few comorbid conditions. As well, participants who completed, generally reported higher baseline support scores than those who did not complete 12-month questionnaires, specifically in mean tangible support scores (80.3 ± 25.7 vs. 71.3 ± 33.6; $p < .01$) and mean overall support scores (76.0 ± 24.5 vs. 70.6 ± 27.9; $p = .04$). Because of these results, we considered the lost-to-follow-up group as different from those who completed, and thus they were classified as such in the multivariate analyses.

Table 6

4.6.3 Gender differences in social support

Table 7 presents the mean overall and subscale social support scores at baseline. For women, affectionate support was the highest subscale score and positive social interaction was the lowest. Mean scores ($\pm$SD) for females ranged from 67.3 ($\pm$31.7) to 80.9 ($\pm$27.0). Men reported affectionate and tangible support as their highest perceived support and additional support as the lowest. Mean scores ($\pm$SD) for men ranged from 72.3 ($\pm$32.9) to 80.4 ($\pm$30.4). Women reported lower scores in all subscales and overall

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support domains. Independent t-tests showed significant differences between genders in tangible support, with females reporting poorer mean scores than males (71.3±31.0 vs. 80.3±27.7; p < .01). Support scores differed between females and males, although not significantly, at baseline in positive social interactions (67.3±31.7 vs. 73.4±32.0; p = .06) and overall social support (71.0±24.6 vs. 75.7±26.6; p = .07).

Table 7

4.6.4 Gender and outcomes

Primary and secondary outcomes were compared by gender at baseline and 12-months (Table 8). With respect to disease specific related functioning, women, in comparison to men reported significantly lower mean PL scores (±SD) at baseline (28.7±7.6 vs. 30.8±8.6; p = .01) and 12-months (30.3±7.5 vs. 34.2±10.4; p < .01). Similarly, with respect to overall functioning, women reported significantly lower mean PCS scores (±SD) than men at baseline (45.4±24.2 vs. 52.1±26.8; p = .01), and 12-months (51.0±24.4 vs. 61.5±27.9; p < .01). There were no significant gender differences in the 5-level adverse outcome variables for disease-specific and non-disease-specific outcomes at 12 months. Across the 12-month period, maintenance or improvement of functioning, as measured with either the PCS or PL occurred in approximately 1/3 of the sample.

Table 8

4.6.5 Social support and adverse functional outcomes

Tables 9 and 10 show unadjusted and adjusted factors associated with adverse functional outcomes, as defined in this study.   After controlling for age, gender, and all social

support subscales, including overall support, age was the only significant predictor variable in the multivariate, logistic regression using the disease-specific PL based functional outcome score as the dependent variable. Multiple logistic analyses using the generic PCS functional outcome score as the dependent variable showed that older age in both genders (OR 1.04; 95%CI: 1.00, 1.09), as well as lower levels of emotional/informational support (OR 0.70; 95%CI: 0.52, 0.93), affectionate (OR 0.76; 95%CI: 0.59, 0.98), positive social interaction (OR 0.78; 95%CI: 0.61, 1.00), and additional social support (OR 0.76; 95%CI: 0.60, 0.98) in men were significant predictors of functional decline. There was an effect modification of gender on social support; males with high social support scores were less likely to report a functional adverse outcome, when using the PCS score as the basis for functional decline.

Sensitivity analysis, which included all participants lost to follow up in the PL and PCS scoring as part of the declined functional group, showed similar trends to the aforementioned logistic regressions. Male participants were less likely to experience functional decline with more support; this was not the case for women.

<div align="center">Tables 9</div>

<div align="center">Table 10</div>

4.7 Discussion

The purpose of this study was to describe the independent and combined effects of gender and social support on adverse functional outcomes of older persons with HF, while controlling for relevant personal and clinical covariates. Older men and women with HF differ significantly on important clinical and demographic variables as well as in

their levels of perceived social support. Women consistently report lower functioning

scores, but experience similar functional outcomes in comparison to men.   In this cohort,

significant associations between social support and adverse outcomes were limited to

men, where men who perceived high levels of support, experienced better outcomes.

Participants in this cohort study are similar to both the elderly in general and

elderly with heart failure with respect to personal and clinical demographics. Firstly,

older women, in comparison to older men, are more likely to be single and on their own,

with less income (Arber & Cooper, 1999; Chin & Goldman, 1998; Lofvenmark,

Mattiasson, Billings & Edner, 2009). These demographic findings are also similar to

those reported by Health Canada in 2002, in which nearly 75% of Canadian senior men,

compared to 41.4% of Canadian senior women were married, and 46% of senior women

were widowed compared to 12.7% of senior men. Our study grouped single and divorced

individuals with those who were widowed in one comparison group, unlike Health

Canada that compared only widowed to those married. This difference in grouping is

likely the reason for the comparatively higher percentage of participants in our non-

married group.   Secondly, HF manifestation and disease progression differ for men and

women. Based on the literature, men with HF die sooner and have worse heart function,

as exemplified by lower left ventricular (LV) function (Lofvenmark *et al*., 2009;

Riedinger *et al*., 2001). Reported median survival time from diagnoses of HF is 1.7 years

in men and 3.2 years in women, and a 5-year survival rate of 25% in men and 38% in

women (Ho *et al*. 1993). Generally men, regardless of age, are more likely than women

to develop systolic dysfunction and typically have lower LVEF. This further emphasizes

previous literature that men with HF have more severe disease than women with HF. However, since survival times are lengthier for women, they are living longer with HF than men and therefore may require more long-term support.

4.7.1 Gender and functional outcomes

Similar to other studies, our findings show that compared to males, female participants reported significantly lower physical functioning, as measured by both disease- specific and generic measures. In a cross-sectional, correlation study, Heo and colleagues (2008) used the Duke Activity Status Index, a self-report tool, to assess the functional status of 122 HF patients. Out of a possible 0-58.2 range, women reported lower functional status than men with mean scores ($\pm$SD) of 10.2($\pm$10.3) and 14.5($\pm$12.7) respectively (p = 0.04). Similarly, Chin and Goldman (1998) found women reporting lower baseline (p $\leq$ 0.05) and 1-year (p $\leq$ 0.05) quality of life using the SF-36 PCS. In a multiple linear regression adjusting for baseline HRQOL score, age, prior MI, history of hypertension, EF, education, income, race, marital status, needing extra help at home, patient-rated overall quality of inpatient and outpatient care, and any medical correlate within each model, Chin and Goldman (1998) reported that female gender was associated with less improvement in physical function (PCS) at one year post-HF exacerbation in comparison to men (OR -5.7, 95%CI -9.1, -2.4). Riedinger *et al*. (2001) also demonstrated comparable results in a study of 1382 age and EF-matched HF patients. Using 3 Functional Status Questionnaires to measure basic activities of daily living (ADL), intermediate ADL, and social function, as well as the Ladder of Life scale to measure participants' current life situations, and the β-Blocker Heart Attack Trail survey

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to quantify participants' life satisfaction, Reidinger and colleagues found that women had lower mean scores (±SD) than men in general life satisfaction (3.0 ±1.2 vs. 2.9±1.2; p = 0.01), basic ADLs (91.9±14.4 vs. 94.3±13.0; p < 0.01), intermediate ADLs (30.8±13.5 vs. 37.3±11.6; p < 0.01), and perceived general health (3.5±0.9 vs. 3.3±1.0; p < 0.01).

Qualitative research in the field has given valuable insight into patients' experiences with HF and its subsequent effects on their QOL. Bosworth *et al*. (2004) identified 5 themes from a cross-sectional qualitative study of focus groups of male HF patients. Symptoms, role loss, affective responses, coping and social support were all areas patients identified as being negatively affected by their HF and consequently decreased their QOL. Similar themes were also identified by Heo and colleagues (2009) in an interview-based qualitative study of men and women living with HF who found participants identified personal and material support from their significant others as having an important impact on their quality of life. Findings from the present study suggest that both men and women acknowledge considerable physical burden living with HF and that women quantify these limitations with a greater negative impact on their quality of life than men. HRQL is an important measure for HF patients, as those with poor-perceived QOL have been found to have greater risk for future hospital admissions and deaths (Konstam *et al*., 1996).

4.7.2 Gender and maintenance of functional well-being

Despite the gender differences in actual functional levels, no gender differences existed in functional maintenance or decline over one year. The proportions of men and women who improved or maintained their status at one year following enrollment in the

study were similar.   Reidinger *et al.* (2001) found similar results, in that after adjusting for disease severity, although women rated QOL worse than men in a number of domains, there were no significant differences between genders with respect to QOL changes. There are possible explanations for this finding: 1) women start with a lower functional score, perhaps less severe disease (i.e., higher LV function) with greater opportunity for improvement and less capacity for decline, whereas men start with higher scores, more severe disease and less capacity for improvement and more capacity for decline; 2) individuals who completed the 12 month data collection period were more likely to be functioning at a higher level to begin with, and as reflected in the reported 12 month scores, were more likely to maintain or improve functioning regardless of gender and 3) the disease progression of HF is difficult to influence, and so, functional decline inevitably occurs. As reflected in the physical limitation scores of the KCCQ, a greater proportion of participants experienced disease-related functional decline versus overall functional decline in the physical component score of the SF-12. Unfortunately, the long term prognosis for HF is poor, with 5-year survival rates for men and women being 25% and 38% respectively (Ho *et al.* 1993); thus functional decline, especially which relates directly to the disease and disease impact is expected.

4.7.3 Social support and functional outcomes

Levels of social support at baseline, had little impact on 12-month functional outcomes, as defined with the disease-specific measure (KCCQ-PL); however, social support did impact 12-month functional outcomes, as defined by the generic measure (SF12-PCS). Men were significantly less likely to decline in general health or physical function, to

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cease participation in the study due to increased illness, or to die within one year of an acute HF exacerbation when higher levels of emotional/informational affectionate support positive social interaction and additional support were perceived. No significant moderating effect of gender on social support and adverse outcomes were seen in women in this cohort. This finding is somewhat contradictory to the previously reported literature.

Similar to our study, previous literature supports the finding that increased social support has positive associations with health outcomes, however the specifics of who benefits, and how they benefit differs between studies. Bennett *et al*. (2001) found that the likelihood of a heart-failure-related admission decreased multiplicatively by 1.11 for each unit increase in tangible support (p = 0.05), 1.08 for each increase in unit of positive social interaction (p = 0.07) and 1.02 for each increase in unit of total social support (p = 0.08) (Bennett *et al*., 2001). These results applied to all participants of all ages, and unlike ours, were not specific to a gender and the older HF population. In another study of older persons (≥ 65 years) with HF, results of a logistic regression adjusting for various demographic, clinical and social variables, showed the absence of emotional support significantly increased the odds of a cardiovascular events, within one year of HF-related admission (OR 3.2; 95% CI: 1.4, 7.8) (Krumholtz *et al.,* 1998). Krumholtz and colleagues defined cardiac events by death or hospitalization due to cardiovascular disease as defined by ICD-9-CM codes. Unlike our study, these findings again were neither gender-specific nor functionally related; however, do support the notion that social support provides a protective effect in regard to adverse HF-related outcomes.

Dissimilar findings between our study and others likely reflect the variation in outcome variable; we focused on maintenance or changes in functional outcomes, other studies measured outcomes based on the presence of death, disease, or cardiac event alone. Our study contributes novel findings about the influence of support on functionally related outcomes and the complexity of the interactions between gender and support on these outcomes.

4.8 Strengths and Limitations

A particular strength of this study is the detailed follow-up and interviews of HF patients, a participant sample that is usually difficult to recruit and engage in study participation. As well we employed standardized questionnaires, allowing for comparisons across reported studies. Another strength is that the outcome of interest was based on clinically important functional changes. Results are therefore more clinically meaningful and relevant to practice. One limitation is the number of participants who did not complete 12-month questionnaires due to death, illness or lost to follow up, which we addressed in analytic methods. Patient attrition likely diluted relationships found between outcomes and support. This possibility was explored however by assuming those who were lost to follow up were more likely to decline in function. Trends found in multivariate analyses in both PL and PCS-based regressions were similar to that which we saw when the lost-to-follow-up group was excluded from outcome variables. Secondly, the study contained disproportionate amount of males to females by 12-month measurements. These limitations would suggest that the relationships we found in a

relatively stable HF sample are likely an underestimate of the pattern in the more compromised sample.

4.9 Conclusions

This is the first study to report on gender differences in social support and its corresponding relationship to both general and disease-specific adverse functional outcomes in the HF population. The results indicate that older women report less available social support and worse physical functioning both in relation to their general health and HF. In addition, the relationship between social support and adverse functional outcomes is seemingly moderated by gender in this cohort, with men less likely to experience a decline in their health outcomes with more perceived social support. This was not the case for women. These results also show that although women report less support than men, it may have less of a direct influence on health outcomes and physical function and other factors, such as self-care capacity and availability of formal health care supports may have a stronger impact. Our findings support the need for gender-sensitive care for older HF patients and further research into the complex interactions between gender, supportive resources and functional maintenance within the context of a chronic disabling condition such as HF.

4.10 Acknowledgements

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Table 5. Baseline socio-demographic and clinical characteristics of the sample

Demographic characteristics	Female (N=164) Mean (± SD)	Male (N=271) Mean (± SD)	P
Age (years)	78.1 (7.0)	77.8 (7.0)	0.10
	n (%)	n (%)	
Marital status			**<0.01**
Single/Widowed/Divorced	108 (65.9)	72 (26.6)	
Married/Common Law	56 (34.1)	199 (73.4)	
Education level			0.91
Completed high school	127 (77.4)	210 (77.5)	
Completed post-secondary	33 (20.1)	53 (19.6)	
Missing	4 (2.4)	8 (3.0)	
Living arrangement			**<0.01**
Live alone	75 (45.7)	53 (19.6)	
Live with others/other	88 (53.7)	218 (80.4)	
Missing	1 (0.6)	-	
Housing arrangement			**<0.01**
House	89 (54.3)	203 (74.9)	
Apartment/condo/other	74 (45.1)	67 (24.7)	
Missing	1 (0.6)	1 (0.4)	
Geographical distance from centre			0.20
≤ 50 km	151 (92.1)	239 (88.2)	
> 50 km	13 (7.9)	32 (11.8)	
Annual combined income			**<0.01**
≤ $40,000	111 (67.7)	144 (53.1)	
> $40,000	28 (17.1)	89 (38.8)	
Missing	25 (15.2)	38 (14.0)	
Use of other resources to manage HF			0.17
No	117 (71.3)	176 (64.9)	
Yes	47 (28.7)	95 (35.1)	
LV ejection fraction			**<0.01**
≤ 40%	54 (32.9)	126 (46.5)	
> 40%	81 (49.4)	103 (38.0)	
Missing	29 (17.7)	42 (15.5)	
Framingham criteria[b]			0.22
No	19 (11.6)	22 (8.1)	
Yes	143 (87.2)	248 (91.5)	
Missing	2 (1.2)	1 (0.4)	
Comorbid conditions[c]			0.07
0-2 comorbidities	72 (43.9)	139 (51.3)	
>2 comorbidities	78 (47.6)	103 (38.0)	
Missing	14 (8.5)	29 (10.7)	

Use of resources to manage HF includes pamphlets, books and/or the Internet. [a] = resources include books, pamphlets and the Internet. [b] = Diagnosis of CHF requires the simultaneous presence of at least 2 major criteria or 1 major in conjunction with 2 minor criteria which is outlined by the Framingham Criteria for Congestive Heart Failure. [c] = The Functional Comorbidity Index is an 18-item list of diagnoses associated with functional impairment. Median number of comorbidities for both females and males was 2.0.

Table 6. Baseline demographic and clinical characteristics and social support scores of participants who completed 12-month questionnaires and those who were lost to follow up

Clinical and Demographics	Completed			Lost to follow up			
	N	n	%	N	n	%	p-value
Gender	269			166			**0.03**
Female		91	33.8		73	44.0	
Male		178	66.2		93	56.0	
Marital Status	269			166			**<0.01**
Single/widowed/divorced		98	36.4		82	49.4	
Married/common law		171	63.6		84	50.6	
Income	242			130			0.06
≤ $40,000		158	65.3		97	74.6	
> $40,000		84	34.7		33	25.4	
LV Function	224			140			0.08
≤ 40%		119	53.1		61	43.6	
> 40%		105	46.9		79	56.4	
Comorbid conditions	244			148			**0.04**
0-2 comorbidities		141	57.8		70	47.3	
>2 comorbidities		103	42.2		78	52.7	

	N	n	Mean (±SD)	n	Mean (±SD)	p-value
Age (years)	435	269	78.1 (± 6.7)	166	78.1 (± 7.5)	0.96

Social support subscales

	N	n	Mean (±SD)	n	Mean (±SD)	p-value
Emotional/information support	428	264	72.9 (± 26.8)	164	71.1 (± 28.0)	0.50
Tangible support	428	265	80.3 (± 25.7)	163	71.3 (± 33.6)	**<0.01**
Affectionate support	426	261	82.0 (± 27.9)	165	78.4 (± 30.9)	0.22
Positive social interaction	418	256	73.4 (± 30.6)	162	67.6 (± 33.8)	0.07
Additional support	421	258	72.9 (± 30.6)	163	66.9 (± 35.0)	0.07
Overall support	432	267	76.0 (± 24.5)	165	70.6 (± 27.9)	**0.04**

Table 7. Gender differences in baseline social support scores

	N	Median	Mean (± SD)	p-value
Emotional/information support				0.11
Female	163	75.0	69.5 (± 27.4)	
Male	265	81.2	73.9 (± 27.0)	
Tangible support				**<0.01**
Female	162	81.2	71.3 (± 31.0)	
Male	266	93.7	80.3 (± 27.7)	
Affectionate support				0.84
Female	161	100.0	80.9 (± 27.0)	
Male	265	100.0	80.4 (± 30.4)	
Positive social interaction				0.06
Female	154	75.0	67.3 (± 31.7)	
Male	264	83.3	73.4 (± 32.0)	
Additional support				0.14
Female	158	75.0	67.6 (± 31.5)	
Male	263	75.0	72.3 (± 32.9)	
Overall support				0.07
Female	163	75.0	71.0 (± 24.6)	
Male	269	85.4	75.7 (± 26.6)	

Table 8. PCS, PL and MCID adverse functional outcomes at baseline and 12-months

	Female		Male		
Physical function	**N**	**Mean ±SD**	**N**	**Mean ±SD**	**p-value**
PCS (SF-12)					
Baseline	160	28.7 ±7.6	263	30.8 ±8.6	**0.01**
12-months	81	30.3 ±7.5	143	34.2 ±10.4	**<0.01**
PL (KCCQ)					
Baseline	149	45.4 ±24.2	254	52.1 ±26.8	**0.01**
12-months	80	51.0 ±24.4	137	61.5 ±27.9	**<0.01**
Functional outcome	**N**	**n (%)**	**N**	**n (%)**	**p- value**
PCS 12-months	164		271		0.08
Maintained/improved		54 (32.9)		99 (36.5)	
Declined		13 (7.9)		20 (7.4)	
Died		12 (7.3)		42 (15.5)	
Too ill		12 (7.3)		18 (6.6)	
LTFU/Missing		73 (44.5)		92 (33.9)	
PL 12-months	164		271		0.12
Maintained/improved		46 (28.0)		72 (26.6)	
Declined		26 (15.9)		47 (17.3)	
Died		12 (7.3)		42 (15.5)	
Too ill		12 (7.3)		16 (5.9)	
LTFU/Missing		68 (41.5)		94 (34.7)	

Table 9. Associations between baseline social support scores and 12-month disease-specific (PL) functional outcomes.

Personal demographics	Unadjusted		Adjusted (missing excluded)		Adjusted (missing included)	
	N	OR (95%CI)	N	OR (95%CI)	N	OR (95%CI)
Age	273	**1.05 (1.01 -1.09)**	273	**1.06 (1.02, 1.10)**	432	**1.50 (1.12, 2.02)**
Gender	273		273		432	
Female		1.00		1.00		1.00
Male		0.74 (.45 -1.23)		0.46 (.09, 2.48)		0.33 (.09, 1.29)

Social support subscales	N	OR (95%CI)	N	OR (95%CI)	N	n	OR (95%CI)
Emotional/information support	269	0.94 (.78, 1.13)	269				
Female		-		1.08 (.78, 1.50)		163	0.91 (.71, 1.16)
Male		-		0.83 (.66, 1.05)		265	**0.78 (.65, 0.98)**
Emot x gender		-		1.28 (.86, 1.90)	428		1.14 (.83, 1.57)
Tangible support	269	1.03 (.86, 1.23)	269				
Female		-		0.99 (.75, 1.31)		162	0.95 (.77, 1.18)
Male		-		0.95 (.73, 1.23)		266	0.82 (.67, 1.00)
Tang x gender		-		1.03 (.71, 1.51)	428		1.16 (.87, 1.56)
Affectionate support	265	0.85 (.71, 1.02)	265				
Female		-		1.00 (.73, 1.37)		161	1.08 (.85, 1.37)
Male		-		**0.75 (.59, 0.96)**		265	**0.80 (.66, 0.97)**
Affect x gender		-		1.31 (.88, 1.95)	426		1.34 (.99, 1.82)
Positive social interaction	260	0.89 (.75, 1.04)	260				
Female		-		0.99 (.75, 1.29)		154	0.98 (.79, 1.21)
Male		-		0.82 (.66, 1.02)		264	**0.81 (.68, 0.97)**
Pos x gender		-		1.20 (.85, 1.70)	418		1.20 (.91, 1.59)
Additional support	261	0.94 (.80, 1.10)	261				
Female		-		1.01 (.77, 1.33)		158	0.98 (.79, 1.21)
Male		-		0.89 (.73, 1.10)		263	**0.79 (.66, 0.94)**
Add x gender		-		1.12 (.80, 1.58)	421		1.24 (.94, 1.64)
Overall support	271	0.92 (.76, 1.12)	271				
Female		-		0.97 (.69, 1.37)		163	0.96 (.74, 1.25)
Male		-		0.87 (.67, 1.12)		269	**0.74 (.59, 0.92)**
Overall x gender		-		1.11 (.73, 1.71)	432		1.30 (.92, 1.84)

Health outcomes include MCID in PL score. Social support scores for unadjusted and adjusted models were based on a 20 point increase in unit. All modes were adjusted for gender and age. Each support scale was modeled separately. Sensitivity analysis, which included all participants lost to follow up in the PL as part of the declined functional group

Table 10. Associations between baseline social support scores and 12-month generic (PCS) functional outcomes.

		Unadjusted		Adjusted (missing excluded)		Adjusted (missing included)	
Personal demographics	N	OR (95%CI)	N	OR (95%CI)	N		OR (95%CI)
Age	220	1.04 (.99 -1.09)		**1.04 (1.00 -1.09)**	432		1.44 (1.08, 1.93)
Gender	220				432		
Female		1.00		1.00			1.00
Male		1.16 (.64, 2.10)		0.16 (.02, 1.21)			0.44 (.12, 1.61)

Social support	**N**	**OR (95%CI)**	**N**	**OR (95%CI)**	**N**	**n**	**OR (95%CI)**
Emotional/information support	217	0.86 (.70, 1.06)	217				
Female		-		1.12 (.79, 1.59)		163	0.97 (.76, 1.24)
Male		-		**0.70 (.52, 0.93)**		265	**0.79 (.64, 0.96)**
Emot x gender		-		**1.58 (1.01, 2.48)**	428		1.24 (.90, 1.70)
Tangible support	219	0.97 (.78, 1.20)	219				
Female		-		1.22 (.86, 1.72)		162	1.06 (.86, 1.32)
Male		-		0.80 (.59, 1.06)		266	0.86 (.71, 1.04)
Tang x gender		-		1.52 (.97, 2.40)	428		1.24 (.93, 1.65)
Affectionate support	219	0.93 (.76, 1.14)	219				
Female		-		1.37 (.91, 2.05)		161	1.18 (.93, 1.50)
Male		-		**0.76 (.59, 0.98)**		265	**0.82 (.69, 0.99)**
Affect x gender		-		**1.78 (1.10, 2.87)**	426		**1.43 (1.06, 1.94)**
Positive social interaction	216	0.92 (.76, 1.11)	216				
Female		-		1.20 (.86, 1.69)		154	0.99 (.80, 1.22)
Male		-		**0.78 (.61, 1.00)**		264	**0.82 (.69, 0.97)**
Pos x gender		-		**1.53 (1.01, 2.32)**	418		1.20 (.91, 1.58)
Additional support	212	0.87 (.72, 1.05)	212				
Female		-		1.06 (.77, 1.45)		158	0.99 (.80, 1.22)
Male		-		**0.76 (.60, 0.98)**		263	**0.81 (.68, 0.96)**
Add x gender		-		1.38 (.92, 2.05)	421		1.22 (.93, 1.61)
Overall support	212	0.91 (.73, 1.15)	212				
Female		-		1.28 (.84, 1.95)		163	1.04 (.80, 1.36)
Male		-		0.76 (.57, 1.02)		269	**0.81 (.66, 1.00)**
Overall x gender		-		**1.68 (1.01, 2.80)**	432		1.28 (.92, 1.79)

Health outcomes include MCID in PCS score. Social support scores for unadjusted and adjusted models were based on a 20 point increase in unit. All modes were adjusted for gender and age. Each support scale was modeled separately. Sensitivity analysis, which included all participants lost to follow up in the PCS scoring as part of the declined functional group.

Chapter 5
General Discussion

5.1 Summary of Chapters 3 & 4

The purpose of this thesis was twofold: 1) to describe gender differences and levels of social support in older persons with heart failure (HF); and, 2) to determine if social support influenced functional health outcomes. The first manuscript described patterns and levels of social support in a cohort of older persons diagnosed with HF, specifically focusing on the gender differences in social support. The second manuscript explored the effect of levels of social support, within and between genders, on functional outcomes one-year post acute HF exacerbation. The role of gender in moderating the relationship of social support and functional outcomes was examined. The following objectives were addressed:

5.1.1 Objective 1

Describe the levels and patterns of social support in older (≥ 65 years) men and women over a 1-year period following an acute exacerbation of their HF. The first manuscript illustrated that participants perceived moderate to high levels of information, tangible, emotional, affectionate, additional as well as overall support, suggesting that participants in this sample perceived adequate levels of support. As well, social support seemed to be a stable construct as subscale and overall domains scores remained relatively unchanged between baseline and 1-year measures. This is an important finding and has implications for practice and the early identification of individuals who have poor levels of support.

5.1.2 Objective 2

Determine and describe the gender differences in levels and patterns of social support in older individuals with HF. Women in comparison to men generally reported lower social support scores. Tangible support (having materials goods or assistance with activities of daily living) was significantly lower at baseline, 6 and 12-months for women compared to men. At 12-months, women also reported significantly lower emotional/informational (the expression of positive affect, empathetic understanding, expression of feelings, offering of; advice, information, guidance or feedback) positive social interaction (the availability of other person to do fun things with), additional support (availability of someone to help get your mind off things) and overall support (a combination of all subscale scores). There were no gender differences in affectionate support (involving the expression of love and affection). These findings support the notion that older women generally perceive less social support resources, and for some this may be a normative experience.

5.1.3 Objective 3

Determine factors associated with high and low levels of social support. Our multivariable model indicated that higher baseline overall social support score was significantly associated with being married or in a common law relationship, and living with others, when age, gender, marital status, current living arrangement, income, LV function and comorbid conditions, were included in the model. Although differences existed between genders in social support scores, in the presence of contextual factors these gender differences disappeared. Descriptive statistics specified women as being

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single and living alone compared to men. Since marital status and living arrangements predict level of social support, women in this sample were seemingly at more risk than men for lower support scores. However, a linear regression model exploring the effect between marital status and gender on social support scores found that single, divorced or widowed men in comparison to married men, or women or single women, were more likely to report lower social support scores. Although women report lower support scores overall, it does not seem to be significantly influenced by the presence of a spouse alone. For men in this sample, perceptions of social support levels were highly dependent on marital status. These findings require further exploration, but generally support the notion that men, in comparison to women, seem to perceive marital partners as a major source of support.

5.1.4 Objective 4

Describe functional outcomes in HF patients, 1-year post acute HF exacerbation. In manuscript two we found that participants were more likely to experience functional decline when measured with a disease-specific physical function measure in comparison to a generic health measure. Individuals in this sample experienced more functional decline due to HF and its symptoms rather than disparities in their overall health. As well, proportionately more participants maintained or improved their physical function 1-year post HF exacerbation when functional change was measured with a generic health measure, in comparison to the disease-specific measure. This finding is not unexpected given the chronic nature and progression of HF. Unfortunately, the long-term prognosis and, consequently, functional decline remains poor. One of the challenges with long-

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term follow-up with HF patients was the number of individuals who did not complete the 12-month assessment questionnaires. Individuals who completed 12-month questionnaires were more likely to be men, married, living with fewer comorbid conditions, and reporting higher levels social support, specifically in the tangible and overall support subscales. This group of completers was more likely healthier than those who did not complete, and consequently reported higher functional scores. This would suggest that levels of functional well being, one year post HF exacerbation may be lower than those reported here, and that a substantial number of individuals are likely functionally compromised.

5.1.5 Objective 5

Determine gender differences in functional outcomes in HF patients, 1-year post acute HF exacerbation. Females reported significantly lower functional well-being at baseline and 1-year post HF exacerbation than men in both the PL and PCS scores. We compared function-related outcomes one year post HF exacerbation by creating a functional adverse outcome variable that included: clinically important differences across the year using both the PL and PCS scores, death and attrition due to worsening illness. There were no gender differences in functional outcomes.   There are potential explanations for this finding: 1) women start out with lower scores, are likely to live longer with more opportunity for improvement and less for decline or 2) men start out with higher scores, with more severe illness and greater opportunity for decline.

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5.1.6 Objective 6

Determine and describe gender differences in the associations between measures of social support and measures of functional well-being. Older age was the only predictor of disease-related functional decline when adjusting for gender and social support. Gender was not a significant predictor of functional decline, worsening illness or death when the PL MCID-based functional outcome variable was used as the dependent variable; this was not the case when we used PCS MCID-based functional outcome variable. Results of the logistic regression using the created PCS MCID-based functional outcome showed that older age increased the odds of functional decline, and higher levels of emotional/informational support, affectionate support, positive social interaction, and additional support decreased the odds of functional decline, worsening illness or death. These results were exclusive to men. We found no associations between social support measures, female gender and functional outcomes. Social support, and in particular emotional/informational, affectionate, positive social interaction, and additional support seems to play protective role in maintaining functional well being for older men with HF. These findings suggest that inadequate social support (i.e., being unmarried) is more detrimental to men than women in this population; however, this does not imply that women would not benefit from supportive resources directed at optimization of functional well being. These resources are likely different than those measured here.

5.1.7 Summary of findings using conceptual framework

We used Wilson and Cleary's (1995) HRQL model to guide our study. Findings from our study support a moderating effect of gender on the relationship between social

support and adverse functional outcomes. Figure 3 shows an illustrated model of our findings.

Figure 3. Modified conceptual framework based on study findings
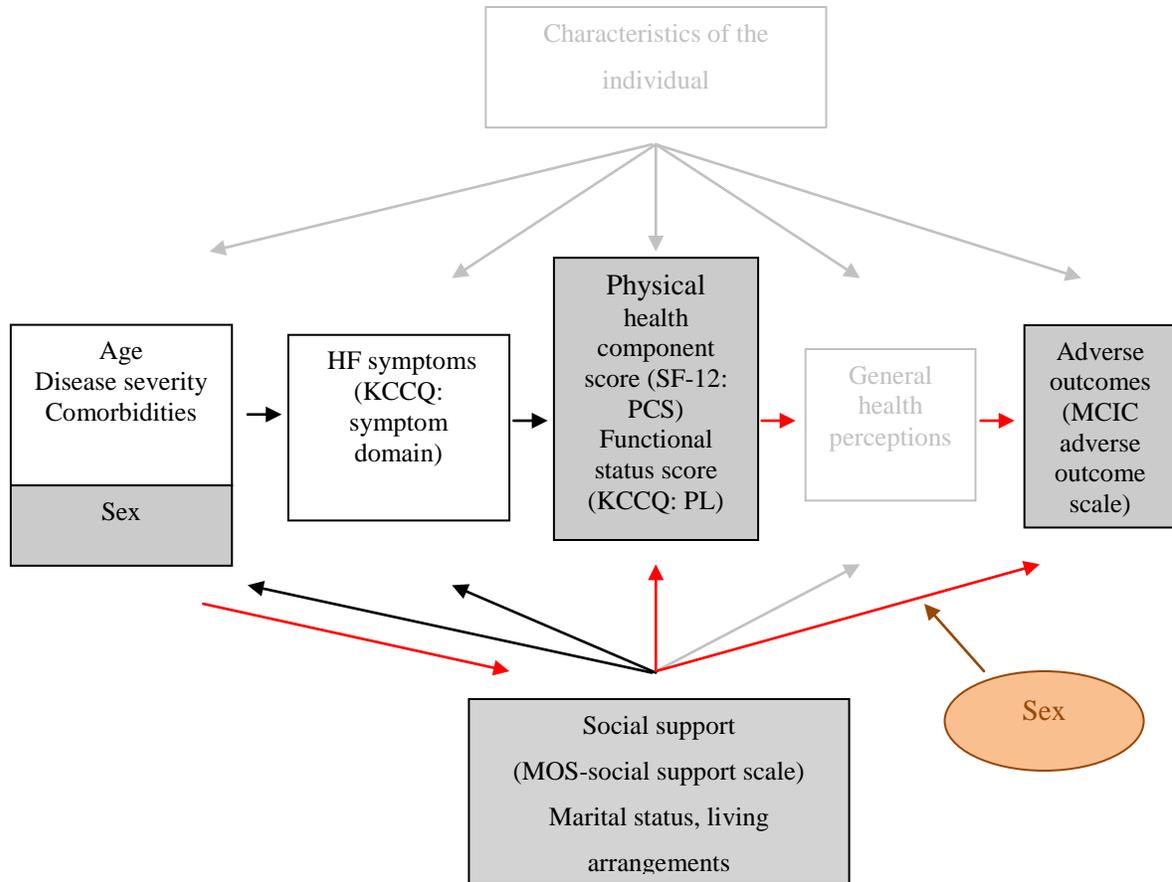
5.2 Overall Study Limitations

This study has a few limitations. For both manuscripts the primary limitation was the number of participants who did not complete 12-month questionnaires due to death, illness or lost to follow up, which we addressed in analytic methods. Secondly, the sample contained disproportionate amount of males to females by 12-month

measurements, but this is reflective of the HF population. In the second manuscript, our comparison of the baseline characteristics of those who completed the 12-month follow-up questionnaires to those who did not showed that non-completers were more likely to report higher levels of support, but were similar in other characteristics. This would suggest that the relationships we found in a relatively stable HF sample are likely an underestimate of the pattern in the more compromised sample.

5.3 Overall Study Strengths

This study has several strengths. A particular strength of this study is the detailed follow-up and interviews of HF patients, a participant sample that is usually difficult to recruit and engage in study participation. As well we employed standardized questionnaires, allowing for comparisons across reported studies. Another strength is that the outcome of interest was based on clinically significant functional changes. Results are therefore more clinically meaningful and relevant to clinical practice.

5.4 Health Service Implications

Our results indicated that older women with HF perceive less support than older men with HF. This could be due to a number of reasons, 1) men have more need for support than women and therefore receive more, 2) women's roles as caregivers, especially in older generations, have them giving more support rather than receiving it, or 3) women actually receive less support than men in this population. Because women at this age are more often single and living alone, it is most likely the case that support is not as available to them, regardless of need. Knowing the positive health benefits that social support has on CVD outcomes, we can postulate that less support in older women

with HF could be an indication for poorer health outcomes. However, we found that it was older men who were more likely to be affected by lack of social support. Surprisingly, levels of social support had no significant effect on predicting functional outcomes in women, but did in men. Previous literature suggests that among the elderly, especially women, living alone is a normative experience and not particularly associated with life dissatisfaction (Berkman *et al*., 1992). Given our results, this theory may also extend to functional well-being, in that older women may have a higher capacity to functioning independently with chronic HF than older men due to the normalcy of living alone. Greater self-care capacity could also be influenced by gender roles, as women, especially in older generations are historically caregivers in the family unit, and so, have better resources and abilities for adequate self-care. Results may also reflect disease-severity to some extent. As men have more severe HF, as evidenced by poorer LF function, and shorter survival rates, they likely require more support than women, and consequently function more poorly in the absence of adequate support.

It seems that, for men with HF, social support is an important factor associated with maintenance of functional well-being and other health outcomes. This has important implications for health services. Our findings support the need for gender-sensitive HF care, including the provision of a range of supportive services, especially for those at higher risk for social support deficits. Supportive services could be provided in a variety of settings: primary care, formalized rehabilitation programs, and community based support groups, to name a few.

Currently formalized rehabilitation programs designed for people with HF are limited in Ontario. The Canadian Heart Failure Network (CHFN) lists 13 hospitals in Ontario, each of which are affiliated with the Canadian CHF Clinics Network Working Group, but not all of which possess their own HF clinic. Objectives of the CHFN on HF clinics currently neglect goals of providing or improving informal supportive resources (e.g. social support). At present, services provided by HF clinics in Ontario primarily include formal supportive resources such as physicians and registered nurses. Secondary services include; pharmacists, dieticians, psychologists, social workers, exercise physiologists or physical therapists as well as EEP cardiologists and cardiac surgeons (CHFN). Patient-support groups were listed as a service that *may* be affiliated with certain HF clinics, but are not currently a standard service provided in Ontario. As such, improvements in the availability in supportive resources would likely improve patient quality of life, functional well-being, and ultimately could influence patient longevity. Improvements in HF clinic services may also yield healthcare cost-benefits.

Most importantly, as primary care practices struggle with the provision of effective chronic disease management care our findings would suggest that there is a need to explore levels of social support of individuals with HF and to plan care accordingly. Given the goal of HF care is to optimize health within the context of a chronic progressive disease, medical management along with support for self-management is key. Provision of effective supportive resources optimizes the effect of both these strategic care goals.

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5.5 Summary and Future Research

This study supports present literature, which identifies differences in demographic and clinical variables, as well as social support, in older men and women with HF. The findings in this study contribute to this body of knowledge. They indicate that: 1) it is women who perceive less social support than men, but their perception of support is not reliant on marital status. Conversely, marital status is a contributing factor in male's perception of social support; 2) social support is a stable construct, which remains relatively unchanged over a year's time; 3) although functional well-being in those with HF is influenced more by the HF (and corresponding symptoms) itself than generic health issues, social support plays more of an influential role in overall functional well-being of the individual than it does in the symptom and functional burden experienced from the disease; 4) the relationship between social support and functional outcomes is particularly relevant to men, as they are more likely to decline in function, and/or experience worsened illness or death with lower levels of social support, and; 5) it is single, divorced or widowed men who experience the lowest levels of social support.

This is the first study to look at the moderating effect of gender on the relationship between social support and functional outcomes in this population. There is a need for further research in this area to better understand this relationship. Future research should be directed to the exploration of different types of support (i.e., support for self-care capacity) and gender, in the context of functional outcomes in this population. A better understanding of the gender-related differences seen in social support and functional outcomes in this study could have important implications on

directing future chronic disease management strategies in terms of 1) gender sensitive care, 2) identifying higher risk patients, 3) providing better resources, specifically in the primary care setting, and 4) contributing to the knowledge base of physicians, nurses and other related health care professionals.

References

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Appendix A

Framingham criteria for congestive heart failure

Diagnosis of CHF requires the simultaneous presence of at least 2 major criteria or 1 major in conjunction with 2 minor criteria.

Major Criteria:
- Paroxysmal nocturnal dyspnea
- Neck vein distention
- Rales
- Radiographic cardiomegaly (increasing heart size on chest radiography)
- Acute pulmonary edema
- S3 gallop
- Increased central venous pressure (>16 cm H2O at right atrium)
- Hepatojugular reflux
- Weight loss >4.5 kg in 5 days in response to treatment

Minor Criteria:
- Bilateral ankle edema
- Nocturnal cough
- Dyspnea on ordinary exertion
- Hepatomegaly
- Pleural effusion
- Decrease in vital capacity by one third from maximum recorded
- Tachycardia (heart rate>120 beats/min.)

Appendix B

Medical Outcome Study – Social Support Survey

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/Informational Support					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Someone whose advice you really want	1	2	3	4	5
Someone to share you most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands you problems	1	2	3	4	5
Tangible Support					
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
Affectionate support					
Someone who shows you love and affection	1	2	3	4	5
Someone to love you and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5
Positive social interaction					
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5

Someone to do something enjoyable with	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things	1	2	3	4	5

Medical Outcome Study Short-form 12-Item Health Survey (SF-12)

1. In general, would you say your health is:

1 Excellent
2 Very Good
3 Good
4 Fair
5 Poor

The following two questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much?

2. MODERATE ACTIVITIES, such as moving a table, bowling, playing golf, etc…:
          1 Yes, limited a lot
          2 Yes, limited a little
          3 No, not limited at all
3. Climbing SEVERAL flights of stairs:
          1 Yes, limited a lot
          2 Yes, limited a little
          3 No, not limited at all

During the PAST 4 WEEKS have you had any of the following problems with your work or other regular activities AS A RESULT OF YOUR PHYSICAL HEALTH?

4. ACCOMPLISHED LESS than you would like:
          1 Yes
          2 No
5. Were limited in the KIND of work or other activities:
          1 Yes
          2 No

During the PAST 4 WEEKS, were you limited in the kind of work you do or other regular activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

6. ACCOMPLISHED LESS than you would like:
          1 Yes
          2 No
7. Didn't do work or other activities as CAREFULLY as usual:
          1 Yes
          2 No

8. During the PAST 4 WEEKS, how much did PAIN interfere with your normal work including both work outside the home and housework)?

> 1 Not At All
> 2 A Little Bit
> 3 Moderately
> 4 Quite A Bit
> 5 Extremely

The next three questions are about how you feel and how things have been DURING THE PAST 4 WEEKS. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS –

9. Have you felt calm and peaceful?

> 1 All of the Time
> 2 Most of the Time
> 3 A Good Bit of the Time
> 4 Some of the Time
> 5 A Little of the Time
> 6 None of the Time

10. Did you have a lot of energy?

> 1 All of the Time
> 2 Most of the Time
> 3 A Good Bit of the Time
> 4 Some of the Time
> 5 A Little of the Time
> 6 None of the Time

11. Have you felt downhearted and blue?

> 1 All of the Time
> 2 Most of the Time
> 3 A Good Bit of the Time
> 4 Some of the Time
> 5 A Little of the Time
> 6 None of the Time

12. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc.)?

Appendix D

Kansas City Cardiomyopathy Questionnaire

Activity	**Extremely** Limited	**Quite a bit** Limited	**Moderately** Limited	**Slightly** Limited	**Not at all** Limited	Limited for other or did not do activity
Showering/Bathing						
Walking 1 block on level group						
Doing yard work, housework or carrying groceries						
Climbing a flight of stairs without stopping						
Hurrying or jogging (as if to catch a bus)						

15. Compared with 4 weeks ago, have your symptoms of **heart failure** (shortness of breath, fatigue for ankle swelling) changed? My symptoms of heart failure have become:

1	Much worse
2	Slightly worse
3	Not changed
4	Slightly better
5	Much better
6	I've had no symptoms over the last 4 weeks

16. Over the past 4 weeks, how many times did you have **swelling** in your feet, ankles or legs when you woke up in the morning?

1	Every morning
2	3 or more times a week, but not every day
3	1-2 times a week
4	Less than once a week
5	Never over the past 4 weeks

17. Over the past 4 weeks, how much has the **swelling** in your feet, anles and legs bothered you?

1	**Extremely** bothersome
2	**Quite a bit** bothersome
3	**Moderately** bothersome
4	**Slightly** bothersome
5	**Not at all** bothersome
6	I've had no swelling

18. Over the past 4 weeks, on average, how many times has **fatigue** limited your ability to do what you want?

1	All the time
2	Several times per day
3	At least once a day
4	3 or more times per week, but not every day
5	1-2 times per week
6	Less than once a week
7	Never over the past 4 weeks

19. Over the past 4 weeks, how much has **fatigue** bothered you? It has been…

1	**Extremely** bothersome
2	**Quite a bit** bothersome
3	**Moderately** bothersome
4	**Slightly** bothersome
5	**Not at all** bothersome
6	I've had no fatigue

20. Over the past 4 weeks, on average, how many times has **shortness of breath** limited your ability to do what you wanted?

1	All of the time
2	Several times per day
3	At least once a day
4	3 or more times per week, but not every day
5	1-2 times per week
6	Less than once a week
7	Never over the past 4 weeks

21. Over the past 4 weeks, how much has your **shortness of breath** bothered you? It has been…

1	**Extremely** bothersome
2	**Quite a bit** bothersome
3	**Moderately** bothersome
4	**Slightly** bothersome
5	**Not at all** bothersome

6	I've had no shortness of breath

22. Over the past 4 weeks, on average, how many times have you been forced to sleep in a chair or with at least 3 pillows to prop you up because of your **shortness of breath**?

1	Every night
2	3 or more times a week, but not every day
3	1-2 times a week
4	Less than once a week
5	Never over the past 4 weeks

23. **Heart failure** symptoms can worsen for a number of reasons. How sure are you that you know what to do, of whom to call, of your **heart failure** gets worse?

1	**Not at all** sure
2	**Not very** sure
3	**Somewhat** sure
4	**Mostly** sure
5	**Completely** sure

24. How well do you understand what things you are able to do to keep your **heart failure** symptoms form getting worse? (weighing yourself, eating low salt diet, etc)

1	Do not understand at all
2	Do not understand very well
3	Somewhat understand
4	Mostly understand
5	Completely understand

25. Over the past 4 weeks, how much has your **heart failure** limited your enjoyment of life?

1	It has **extremely** limited my enjoyment of life
2	It has limited my enjoyment of life **quite a bit**
3	It has **moderately** limited my enjoyment of life
4	It has **slightly** limited my enjoyment of life
5	It has **not limited** my enjoyment of life at all

26. If you had to spend the rest of your life with **heart failure**, the way it is <u>right now</u>, how would you feel about this?

1	**Not at all** satisfied
2	**Mostly** dissatisfied
3	**Somewhat** dissatisfied
4	**Mostly** dissatisfied
5	**Completely** dissatisfied

27. Over the past 4 weeks, how often have you felt discouraged or down in the dumps because of your **heart failure?**

1	I felt that way **all of the time**
2	I felt that way **most of the time**

3	I **occasionally** felt that way
4	I **rarely** felt that way
5	I **never** felt that way

28. How much does **heart failure** affect your lifestyle? Please indicate how your heart failure may have limited your participation in the following activities <u>over the past 4 weeks.</u>

Activity	Severely limited	Limited quite a bit	Moderately limited	Slightly limited	Not at all limited	Does not apply or did not do for other reasons
Hobbies, recreational activities						
Working or doing household chores						
Visiting family or friends out of your home						
Intimate relationships with loved ones						

Appendix E

Changes in MOS-SSS; Within Subject Effects Over 1-Year

	Female		Male	
Social Support Subscale	F	P	F	P
Emotional/information support	2.38	0.10	3.03	0.052
Tangible support	0.26	0.75	0.38	0.68
Affectionate support	0.12	0.87	0.26	0.77
Positive social interaction	1.44	0.24	1.37	0.25
Additional Support	1.33	0.27	1.62	0.20
Overall support	.732	0.48	1.77	0.17

Appendix F Mean baseline social support by 1-year PL functional outcomes

| | | **Health Outcomes** | | | | | | |
| | | Maintained/Improved | | Declined/Died/Too till | | | **Unadjusted** | **Adjusted** |
Personal Demographics	N	n	Mean (±SD) [%]	n	Mean (±SD) [%]	p	OR (95%CI)	OR (95%CI)
Age	**273**	118	76.7 (± 5.9)	155	79.0 (± 7.0)	**.004**	**1.05 (1.01 -1.09)**	**1.06 (1.02, 1.10)****
Gender	273					.249		
Female		46	[16.8]	50	[18.3]		0.74 (.45 -1.23)	0.46 (.09, 2.48)
Male		72	[26.4]	105	[38.5]		1.0	1.0
Marital Status	273					.267		-
Single/widowed/divorced		38	[13.9]	60	[22.0]		1.33 (.80 -2.20)	
Married/common law		80	[29.3]	95	[34.8]		1.0	
Income	244					.389		-
≤ $40,000		69	[28.3]	94	[38.5]		1.26 (.74 -2.16)	
> $40,000		39	[16.0]	42	[17.2]		1.0	
LV Function	232					.665		-
≤ 40%		53	[22.9]	75	[32.3]		1.12 (.66 -1.89)	
> 40%		46	[19.8]	58	[25.0]		1.0	
Comorbid conditions	251					.063		-
0-2 comorbidities		68	[27.1]	76	[30.3]		0.62 (.37 -1.03)	
>2 comorbidities		38	[15.1]	69	[27.5]		1.0	
Social Support Subscales	N	n	Mean (±SD)	n	Mean (±SD)	p	OR (95%CI)	OR (95%CI)
Emotional/information support	269	116	74.4 (± 27.0)	153	72.2 (± 26.8)	.499	0.94 (.78 -1.13)	0.91 (.75 -1.10)
Emotion X Gender			-		-		-	*1.28 (.86, 1.90)*
Tangible support	269	117	79.4 (± 26.6)	152	80.3 (± 26.3)	.773	1.03 (.86 -1.23)	0.97 (.80 -1.18)
Tangible X Gender			-		-		-	*1.03 (.71, 1.51)*
Affectionate support	265	114	84.9 (± 23.9)	151	78.7 (± 30.6)	.069	0.85 (.71 -1.02)	**0.83 (.69 -1.00)***
Affect X Gender			-		-		-	*1.31 (.88, 1.95)*
Positive social interaction	260	115	76.2 (± 29.9)	145	70.7 (± 31.5)	.149	0.89 (.75 -1.04)	0.88 (.74 -1.04)
PosInt X Gender			-		-		-	*1.20 (.85, 1.70)*
Additional Support	261	115	73.7 (± 30.0)	146	70.7 (± 32.3)	.447	0.94 (.80 -1.10)	0.93 (.79 -1.10)
Add X Gender			-		-		-	*1.12 (.80, 1.58)*
Overall support	271	117	76.9 (± 24.3)	154	74.5 (± 25.1)	.435	0.92 (.76 -1.12)	0.90 (.74 -1.10)
Overall X Gender			-		-		-	*1.11 (.73, 1.71)*

*p< 0.05; **p< 0.01. Health outcomes include MCID in PL scores. Social support scores for unadjusted and adjusted based on 20 point increase. No significant support by gender interactions in unadjusted therefore they were excluded from final adjusted model in PL outcomes multivariate modeling.

Appendix G

Mean baseline social support scores by 1-year PCS functional outcomes

Personal Demographics	N	Maintained/Improved		Declined/Died/Too till		p	Unadjusted	Adjusted
		n	Mean (±SD) [%]	n	Mean (±SD) [%]		OR (95%CI)	OR (95%CI)
Age	220	153	77.0 (± 6.5)	67	78.8 (± 7.0)	.444	1.04 (.99 -1.09)	**1.04 (1.00, 1.09)***
Gender	220					.618		
Female		54	[24.6]	26	[11.8]		1.16 (.64 -2.10)	0.16 (0.02, 1.21)
Male		99	[45.0]	41	[18.6]		1.0	1.0
Marital Status	220					.177		-
Single/widowed/divorced		56	[25.4]	31	[14.1]		1.49 (.83 –2.67)	
Married/common law		97	[44.1]	36	[16.4]		1.0	
Income	201					.213		-
≤ $40,000		86	[42.8]	44	[21.9]		1.51 (.79 -2.87)	
> $40,000		53	[26.4]	18	[8.9]		1.0	
LV Function	182					.402		-
≤ 40%		65	[35.7]	28	[15.4]		0.77 (.41 -1.43)	
> 40%		57	[31.3]	32	[17.6]		1.0	
Comorbid conditions	194					.883		-
0-2 comorbidities		76	[39.2]	35	[18.0]		0.95 (.52 -1.76)	
>2 comorbidities		56	[28.9]	27	[13.9]		1.0	

Social Support Subscales	N	n	Mean (±SD)	n	Mean (±SD)	p	OR (95%CI)	OR (95%CI)
Emotional/information support	217	151	75.6 (± 25.9)	66	70.1 (± 28.5)	.054	0.86 (.70 -1.06)	**0.70 (.53 -0.93)***
Emotion X Gender			-		-		-	***1.58 (1.01 -2.48)****
Tangible support	219	152	78.5 (± 27.7)	67	77.3 (± 25.4)	.162	0.97 (.78 -1.20)	0.80 (.60 -1.07)
Tangible X Gender			-		-		-	*1.52 (.97 -2.40)*
Affectionate support	219	149	82.3 (± 26.5)	67	79.3 (± 31.9)	.762	0.93 (.76 -1.14)	**0.76 (.60 -0.98)***
Affect X Gender			-		-		-	***1.78 (1.10 -2.87)****
Positive social interaction	216	147	75.7 (± 29.5)	65	71.8 (± 31.7)	.484	0.92 (.76 -1.11)	**0.78 (.62 -0.99)***
PosSoc X Gender			-		-		-	***1.53 (1.01 -2.32)****
Additional Support	212	146	75.5 (± 29.9)	66	68.9 (± 31.0)	.382	0.87 (.72 -1.05)	**0.77 (.60 -0.98)***
Add X Gender			-		-		-	*1.38 (.92 -2.05)*
Overall support	212	152	76.6 (± 24.6)	67	73.8 (± 25.5)	.144	0.91 (.73 -1.15)	0.76 (.57 -1.02)
Overall X Gender			-		-		-	***1.68 (1.01 -2.80)****

*p ≤.05. *Health outcomes include MCID in PCS score. Social support scores for unadjusted and adjusted scores are based on a 20 point increase in unit. From unadjusted outcomes and study focus of interest being gender, age and gender were adjusted for, as well as each social support subscale score, and overall support score were added individually to each regression.*