Factors Influencing Outcomes of Heart Failure: A Population Health Approach

Seema Nagpal

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List of Abbreviations

ICONS: Improving Cardiovascular Outcomes in Nova Scotia

AMI: acute myocardial infarction

CHD: coronary heart disease

UK: United Kingdom

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Dedication

This thesis is dedicated to my family.

Abstract

Background: Symptomatic heart failure is a chronic and disabling condition that affects over 350 000 Canadians and is characterized by inevitable progression. Historically, research on the ways to increase survival has focused on biomedical factors. However, the continued poor prognosis of heart failure has prompted the search for other ways to improve the lives of these patients. Research in other chronic conditions demonstrates that social circumstances, described collectively as individual social interactions (e.g. social support, social participation) and community social factors (e.g. social capital, social norms), can influence health outcomes.
Purpose: The purpose of this research was to describe and assess the impact of selected social circumstances potentially related to heart failure outcomes.
Methods: Two literature reviews and one empirical study were performed. Conceptual models were proposed to describe the hypothesized pathways between selected social circumstances and heart failure outcomes. The first review was a systematic review of quantitative studies evaluating the relationship between social support and both rehospitalization and death. The review included a critical analysis of the methods employed by previous studies. The second review integrated the qualitative and quantitative literature describing the relationship between individual social interactions (including support, roles and participation) and the quality of life of patients or experience of living with heart failure. A narrative summary was provided and an integration of findings from both qualitative and quantitative study designs was performed. In the empirical study, patients' demographic and clinical information was examined simultaneously with selected community factors in a multilevel analysis. Outcomes of interest included rehospitalization or death of heart failure patients.
Results: The systematic review shows that previous quantitative research has linked social support to reduced rehospitalization, but there is little evidence to link it with prolonged survival. The critique of the methods describes an inadequate conceptualization and inconsistent measurement of social support. A conceptual model showing how social support can influence rehospitalization is proposed. The integrative review presents qualitative research that identified the following social interactions as important components of the heart failure experience: social support, social participation and role fulfillment. However, no quantitative relationship between social support and quality of life was found. The potential reasons for the discrepant findings between the qualitative and quantitative studies include: the focus on social support as the only component of social interactions assessed in the quantitative literature; and the inconsistent measurement of social support. A conceptual model is presented to describe the multiple components of social interactions and the theoretical basis for their effects. The multilevel analysis demonstrates that individual factors exerted the strongest effect on heart failure outcomes in most models. Community characteristics had little influence on rehospitalization or death. Study design and analysis issues are proposed to explain these findings.
Conclusion: The literature reviews and the empirical study provide a contribution to the population health literature, offering a broad approach to assessing the determinants of disease progression in heart failure patients. This thesis research advances the discussion about which social circumstances may influence heart failure outcomes and their pathways. The use of the proposed conceptual models in future research will help clarify the role of social circumstances in the prognosis of heart failure.

Glossary of Terms

Community characteristics: the features of a local area that are relevant to health, such as social environment, the food environment, the built environment, air quality, and water quality.

Social capital: the existence in a community of a sense of interpersonal trust and norms of reciprocity and mutual aid which act as resources for individuals and facilitate collective action. Social capital derives from social cohesion.

Social circumstance: an overarching term that refers to the community social characteristics (e.g. social capital) that impact groups of people as well as their individual demographic and economic characteristics and the interactions that occur within this network.

Social cohesion: the extent to which a community shares values and establishes a sense of trust and mutual expectation and obligations.

Social context: the local area (neighbourhood, community) social characteristics.

Social interactions: the social relationships, support and activities that an individual shares with others.

Social participation: engagement in social roles and activities.

Social role: the formal roles or perceived informal roles obligations and expected behaviours that derive from a person's position in a social network, and that bring with them certain rights.

Social support: transactions that occur between individuals that make each one feel cared for and valued as a person.

Overview of the Dissertation

Heart failure is a chronic illness that has a major impact on the lives of patients and their families. Chronic diseases are the leading causes of health care system utilization, death and disability in Canada. Heart failure, a chronic illness affecting 350 000 Canadians causes a steadily declining quality of life. It is associated with multiple hospital admissions and high mortality. Despite medical advances, the burden of illness remains large. To date, most heart failure research has focused on identification and modification of clinical predictors of disease progression. It is unclear if this focus will yield many more improvements in the morbidity and mortality of these patients. This research adopted a population health perspective to explore heart failure progression, including individual social interactions (e.g. social support, social interactions and social participation) and community social factors (e.g. social capital, social norms), that may hasten or mitigate poor outcomes. I refer to these collectively as a person's 'social circumstances'.

This dissertation is divided into five chapters. Chapter 1 introduces the research problem, explains the rationale for approaching heart failure from a population health perspective, and introduces the social circumstances that may influence heart failure progression. Chapters 2 to 4 present three papers that have been prepared for publication. Chapter 2 presents a systematic review of the literature on the link between social support and heart failure outcomes and discusses methodological issues in the research. Rehospitalization and death are the defined outcomes for this investigation.

Chapter 3 offers a paper that examines and integrates the current knowledge about the influence of individual level social interactions related to heart failure outcomes. Heart failure experience is described in the qualitative literature and quality of life outcomes are described in the quantitative literature.

Chapter 4 presents a population based study of hospitalized Nova Scotia residents with heart failure. I performed a multilevel analysis to estimate the independent effects of selected individual and community factors on heart failure progression. This study received ethics approval from the University of Ottawa and Dalhousie University. (Appendix I)

Chapter 5 integrates the results from the literature reviews and my own empirical study, and discusses them in the light of established theoretical models. An expanded conceptual model is proposed. Contributions of this research to knowledge about heart failure progression are described. The implications for future research are highlighted and the contributions of the thesis committee members and others are described.

Chapter 1: Introduction

Statement of the problem: Chronic diseases in Canada

Every person in Canada is touched by chronic diseases, either in terms of their own health or as caregivers, family members, colleagues or friends of affected persons. The most common chronic diseases (cardiovascular disease, cancer, respiratory disease, and type 2 diabetes) account for 60% of all deaths and 44% of premature deaths worldwide.[1] In 2009, 89% of Canadian seniors had at least one chronic condition including cancer, or diabetes, heart disease, high blood pressure, emphysema, chronic obstructive pulmonary disease, arthritis, or mood disorders.[2]

In Canada, the cost of health care is high and is continuing to rise. Total spending on health care reached a historic high of 11.9% of the gross domestic product (GDP) in 2009 and 11.7% in 2010. Health spending in 2009 grew by 5.5% in nominal terms and 3.3% in real terms over 2008. Canada is the fifth-highest spender per capita on health care and sixth-highest spender on health as a percentage of GDP compared to other industrialized countries that offer universal care. Canadians spent an estimated $183 billion on health care in 2010, or $3 895 per person.[3] The cost of chronic diseases is large, both in terms of lost productivity and health care costs. There are currently no accurate data to estimate the precise cost of chronic conditions or their proportion of total health care costs in Canada. But, we know that the human, societal, and economic impact is enormous. Further, given the number of people affected and the cost of care, improving the provision of care for people with chronic disease is an integral component of a cost-effective and sustainable health system.

People living with chronic diseases have diverse pathologies; but they all need health and social resources, so some commonalities in approaches to care can be defined. Delaying the progression of disease may enable patients to maintain an acceptable quality of life for longer. A health system should offer acute care services but should also include secondary prevention to delay a decline in health status. Individual and local social resources available to heart failure patients may bolster secondary prevention efforts and delay poor heart failure outcomes.

Progression of heart failure

Heart failure is a condition that results because of the inability of the heart to fill with, and/or eject, blood efficiently. It may be caused by previous myocardial infarction but may also occur in the presence of near-normal cardiac function, especially under conditions of high cardiac demand. Regardless of the precipitating event, the pathologic state that is responsible for the progression of heart failure is complex. Ultimately, most patients experience breathlessness. This may begin with shortness of breath on exertion and progress to difficulty breathing at rest. Other symptoms of heart failure may include fatigue, weakness, chest pain or pressure and palpitations, anorexia, nausea, weight loss, frequent urination, anxiety, memory impairment and confusion.[4] The pathology is described more fully in Appendix II.

Heart failure is characterized by inevitable progression, including disabling symptoms, frequent hospitalizations, poor quality of life, and high mortality rates. Heart failure is an important issue both because it affects many Canadians and because people live with it for the rest of their lives.[5,6]

As the condition is incurable, once heart failure has been established, interventions for patients aim to palliate symptoms and delay the decline of quality of life and death.[4] Treatments, therefore, depend on an understanding of what impacts progression. Historically, research has focused on biomedical factors. Sophisticated measures of clinical status and heart function have been developed to diagnose and monitor the condition. Specialized pharmaceuticals and devices have been designed to modify physiological processes and can be effective. For example, a systematic review of studies evaluating angiotensin-converting enzyme (ACE) inhibitors showed lower rates of death and rehospitalization in heart failure patients taking the medication compared to those who did not (OR 0.80; 95% CI 0.74 to 0.87 and OR 0.67; 95% CI 0.61 to 0.74, respectively).[7] Specialized clinical services have achieved success in terms of optimizing medication use, reducing rehospitalization and delaying death.[8-10] Patients are also often counseled to help reduce their risk of poor outcomes through diet modification and exercise. Despite these efforts, patients still experience debilitating symptoms, a decline in their functional status, a reduced quality of life and, frequently, a rapid progression to death.

The continued poor prognosis of heart failure has prompted the search for other ways to improve the lives of these patients. The development of new clinical, health services and behavioural interventions that are disconnected from other aspects of the patients’ circumstances may not optimize improvements in quality of life, or lead to reductions in rehospitalization or death. Furthermore, a sole emphasis on biomedical approaches ignores the full breadth of potential predictors of progression, such as social circumstances.

This thesis is about examining the role of social circumstances on the prognosis of heart failure. Multiple terms have been used in the literature to describe social characteristics. Throughout this research, ‘social circumstances’ is used as an overarching term that refers to a combination of community social and economic characteristics, the individual’s demographic and economic characteristics and their individual social interactions, including social support. Social support may reduce the adverse consequences of stress and influence behaviours like healthy eating or adherence to medical recommendations. High amounts of social capital in a community may enable physical activity because of a feeling of trust and safety in the area. Positive social circumstances may promote coping and adaptation to the disease and therefore reduce its negative impact on quality of life. Improving social circumstances may result in several changes to variables along the causal pathway to delay heart failure progression described later in this chapter. Identification of important social circumstances may provide opportunities to develop interventions to improve these influences and delay heart failure progression.

Purpose and objectives

The purpose of this research is to describe and to assess the impact of selected social circumstances related to the progression of heart failure in terms of quality of life and experience of the disease, rehospitalization and mortality.

This research has three objectives:

a) To describe existing literature assessing the impact of individual level social support on rehospitalization, or death in patients with heart failure and to review the methodological issues involved in the research;

b) To examine and integrate the literature evaluating the relationship between individual level social interactions and the experience or quality of life of patients with heart failure;

c) To simultaneously estimate the contributions of selected individual and community level social factors on the prognosis of hospitalized heart failure patients in Nova Scotia, Canada.

The first objective “To describe existing literature assessing the relationship between social support and the rehospitalization and death of heart failure patients and to review the methodological issues involved in the research” was achieved by undertaking a systematic review of quantitative studies.. This review provided an explanation of how researchers have conceived and defined social support and also summarized the findings of their investigations. A critical analysis of previous studies’ design and methods was performed. The results are presented in Chapter 2.

The second objective “To examine and integrate the literature evaluating the relationship between individual level social interactions and the experience or quality of life of patients with heart failure” was achieved by performing an integrative review. This involved assembling the findings from both qualitative and quantitative research studies. The review compared and contrasted the findings from previous research and proposed a new conceptual model that incorporated the knowledge garnered from the integration. A deeper and more thorough examination of the individual level social interactions related to heart failure outcomes defined as quality of life and experience of heart failure is provided. The results are presented in Chapter 3.

The third objective “To simultaneously estimate the contributions of selected individual and community level social factors on the prognosis of hospitalized heart failure patients in Nova Scotia, Canada” was achieved through performing a multilevel analysis of the influence of selected individual and community factors on the prognosis of heart failure. This study tested the impact of these multilevel factors on heart failure prognosis using previously collected data from multiple sources in Nova Scotia. The results are presented in Chapter 4.

Chapter 5 integrates the findings from this research, proposes an overarching conceptual model and discusses the implications for future research.

Heart Failure: A Population health perspective

There are several benefits to viewing heart failure progression through a population health lens. Chronic disease prevention and control are arguably two of the highest priorities for Canada due to their enormous impact on the health system, patients and families. Traditionally, the focus of management in heart failure patients has been with clinical interventions designed to slow progression. More recently, changes in the delivery of health services and individual behaviours have been acknowledged to influence heart failure prognosis.[4] A population health approach complements the clinical approach. The population health perspective focuses on individual and contextual influences by highlighting the upstream and downstream factors that affect disease incidence and progression. These include the social circumstances of the patient, such as their socioeconomic status, individual social support, social participation and contextual factors like community income and social capital that have been associated with health outcomes for other forms of cardiovascular disease.[11-13] However, these have been largely ignored in the evaluation of the incidence and progression of heart failure.

The recognition of the importance of the broad determinants of health has permeated medical history. In 1854, John Snow linked a cholera outbreak with a contaminated neighbourhood water pump that was infecting residents of the community. A notable physician, Sir William Osler (1849-1919) stated that ‘tuberculosis is a social disease with medical aspects’, which was an insightful statement at that time. Canada’s former health minister, Marc Lalonde formally included social support and social context into how health is conceived in 1974 by describing "the health field concept".[14] Many others have adapted, modified and expanded these concepts and yet, in research and clinical practice, the progression of chronic diseases has largely continued to be thought of as an individual clinical health issue. A population health approach to heart failure progression in no way diminishes the importance of clinical or health care system interventions that improve outcomes for heart failure patients, but it also considers other factors and their interactions.

The research presented in this thesis extends the scope of previous studies in the population health literature. This work contributes by offering a novel approach to explaining the progression of heart failure by considering the broader determinants of health. Furthermore, the determinants of the rate of progression need not be identical to the determinants of incident disease. For example, upstream factors like social cohesion, social support, social participation availability of healthy foods and engagement in regular physical activity may predict incident disease. In contrast, downstream factors like the receipt of tangible support that enables adherence to recommendations, and attendance at physician appointments may be more important in delaying disease progression. A broader perspective may uncover new opportunities for providers and policy makers to intervene and ultimately improve heart failure outcomes.

Approach to the literature review

This brief background section presents a targeted review of the literature describing relationships and pathways linking individual social interactions and community characteristics with heart failure outcomes. If available, systematic reviews of the relationship between the independent variables and heart failure outcomes are presented. In the absence of systematic reviews, key studies evaluating each independent factor and heart failure outcomes are described. In the absence of definitive evidence for heart failure patients, key articles from the literature describing the effect of identified individual and community characteristics in patients with other cardiovascular diseases or chronic conditions are reported. The hypothesized causal pathways, derived from the literature, from social circumstances to heart failure outcomes are also described. The purpose of this review was to provide the background for the systematic reviews in Chapters 2 and 3, which thoroughly explore which independent characteristics have been evaluated and if a relationship with heart failure progression has been previously found.

The hypothesized relationships between social circumstances and heart failure outcomes and their pathways are integrated into a proposed conceptual model presented at the end of this chapter. This model guided the reviews and analyses of the literature in the upcoming chapters. Refined conceptual models based on the critical and integrative reviews are presented in Chapters 2 and 3. A final, integrated model is proposed in Chapter 5.

Background

Social circumstances and health

From the beginning of this research it was clear that there is an inconsistent use of language in the literature describing social characteristics. Using different terms for the same construct or the same term for different constructs is not uncommon and creates some confusion about the objective and results of previous studies. Therefore, it is essential to define the terms used in this research and describe how the various components that comprise 'social circumstances' relate to each other.[i]

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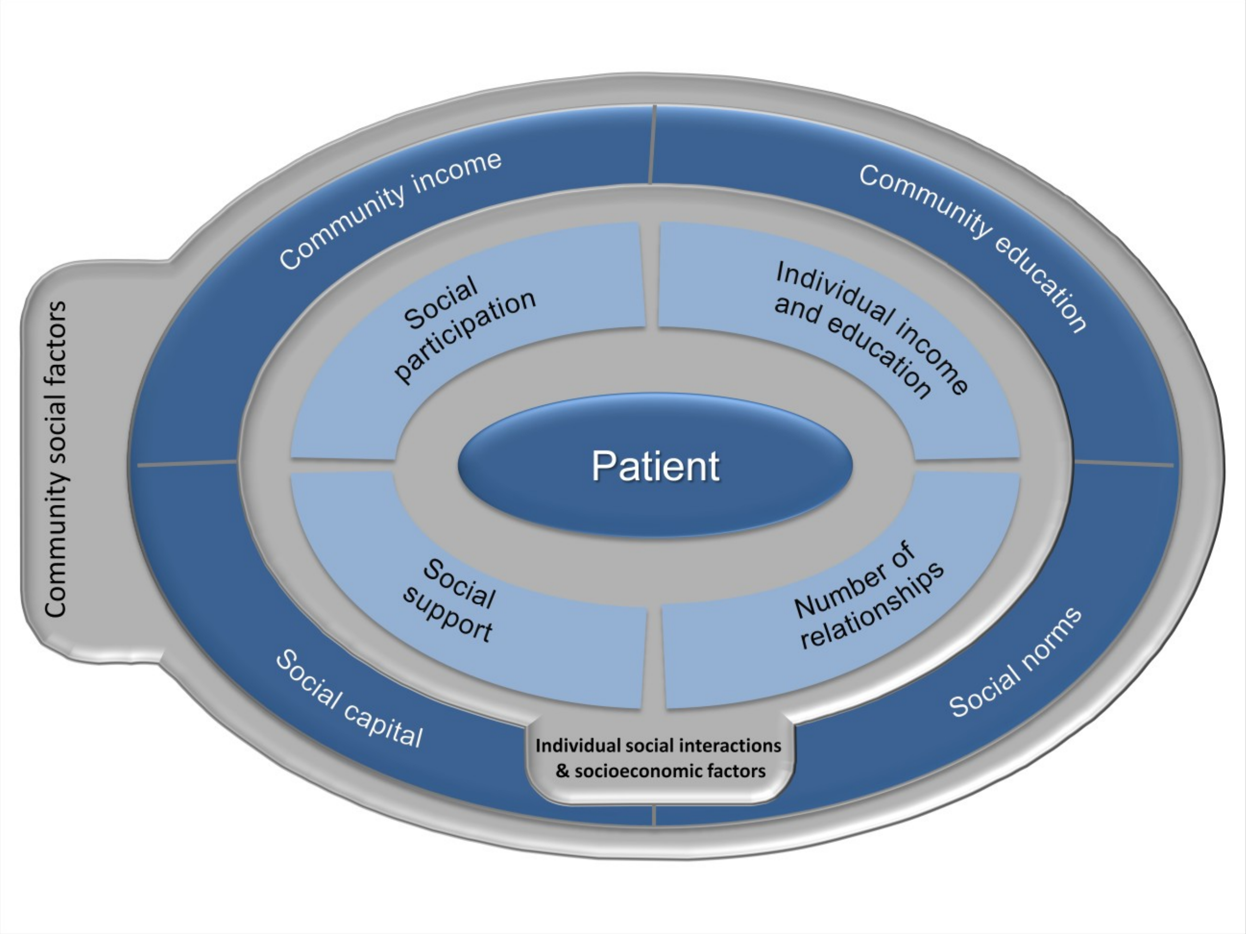
[i] The glossary of terms defines several terms related to social characteristics and is provided as a guide to the reader.

As stated previously, ‘social circumstances’ is an overarching term that refers to the social characteristics that impact groups of people together with their individual demographic and economic characteristics and the social interactions that occur within this network. The social circumstances considered in this research that describe the local area are referred to as community social and economic factors. At an individual level, social interactions encompass the social relationships, support and activities that an individual shares with others. Social support is the most well described component of social interactions and reflects the transactions that occur between people that make each one feel cared for and valued. An individual’s socioeconomic situation also forms a component of individual level social circumstance. Please see Figure 1 for a schematic of how these concepts connect to one another.

Figure 1: Social circumstances examined in this thesis research



In this schematic, the first level of social circumstances is depicted as the individual level and includes social interactions (social participation, social support, number of relationships) and socioeconomic status (income and education). The next level of social circumstance considered in this research occurs within the community. These characteristics impact all residents of the community and include social capital, social norms, community income and community education.

Individual level social circumstances

Social interactions

The following section focuses on social support. It is the most well researched aspect of an individual's social interactions. How social support has been conceptualized and the mechanism through which it relates to health outcomes is described. There is little empirical evidence directly assessing the mechanism underlying the relationship between social support and heart failure outcomes. Therefore, systematic reviews and primary studies of the relationship between social support and mediating variables (to heart failure outcomes) are described.

Social support is classified into three main types that may have different pathways and effects on heart failure outcomes. These three types are informational support (e.g., giving advice); instrumental support (e.g., providing practical or tangible assistance with a problem); and emotional support (e.g., giving reassurance).[15] Informational support may delay progression of heart failure by equipping the patient with the knowledge required to understand and manage the disease and treatment regimen. It typically helps the recipient to remain independent. Often, heart failure patients have complex medical management needs: administering multiple prescription drugs; weighing themselves regularly; making dietary adjustments; and modifying their daily activities in order to minimize the appearance of symptoms. Informational support is required on an ongoing basis since patients may not understand the information given by health providers the first time, or may not remember the information if it was understood initially. This can happen for several reasons, including a lack of education or poor health literacy, limited cognitive ability, the volume of information that is given to the patient, and their anxiety during the encounter with the physician.[16] Informational support can be provided by health professionals or by friends and family.

Instrumental support can be hypothesized to delay progression of heart failure by facilitating behaviours, such as, helping with attendance at medical appointments, (including specialist appointments that may be outside of the patient's own community), diet modification, and medication adherence. A 2004 meta-analysis systematically reviewed the relationship between social support and adherence. The association between adherence and practical support, defined as assistance, reminders, and organization, was assessed in 29 studies. The odds of adherence (compared with nonadherence) were 3.6 times (95% CI 2.55 to 5.19) higher among those who received practical support than among those who did not. Patients with differing disease states were included and adherence to any medical intervention was assessed.[17]

Emotional support may delay heart failure progression by encouraging adherence to treatments as well as by buffering the stress response. Everson-Rose reviewed the physiological responses to negative emotions and stress that contribute to disease.[18] Four mechanisms were highlighted through which cardiovascular disease could be caused or exacerbated, including activation of the hypothalamic-pituitary-adrenal axis and the autonomic nervous system, seretonergic dysfunction, secretion of proinflammatory cytokines, and platelet activation. Social support can attenuate the stress response; the absence of social support can exacerbate the stress response.[18]

In a meta-analysis including 122 studies, Dimatteo et al. found the risk of non-adherence to medical treatment was estimated to be higher for all patients who did not have emotional support[ii] compared to those who had emotional support (OR:1.83; 95% CI 1.27 to 2.66).[17] Again, this included patients with various conditions and all treatment regimens. The authors

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[ii] No emotional support was classified by the author and it is questionable that patients' had a complete absence of social support or if it was defined in the same way in all reviewed studies. It is also questionable that no support is the same as low support.

proposed that social support may improve patient adherence through several mediating variables including: improved cognitive functioning, self efficacy, intrinsic motivation, personal control, confidence, self-esteem, and mood, as well as through reduced emotional conflict, interpersonal strain, distress, and depression.[17]

Lett et al. reviewed prospective studies (n=19) evaluating the role of varying types of social support in predicting health outcomes for cardiovascular disease patients.[19] They reported an effect of perceived emotional support, perceived marital quality, perceived tangible support and perceived overall support on cardiovascular outcomes. One study did not find an effect for perceived social support in a sample of 887 post-acute myocardial infarction (AMI) patients; but there was an interaction with depression, such that depressed patients with low perceived social support were at the greatest risk for mortality one year after AMI.[20] Lett noted that other measures of support were also related to cardiovascular disease progression including: network size, marital status, and participation in clubs or social/recreational activities. These associations, however, were not found consistently across the reviewed studies.[19]

In addition to the typology described above, researchers may describe social support in terms of structure and function. Structural support is concerned with the presence of a social network and social relationships. It may be measured by the number of social ties, the frequency of interaction with the social network, social participation, marital status and cohabitation. These indicators do not measure the type or quality of social support that is offered to the patient but rather the presence of the support apparatus. In the case of marital status and cohabitation, the support may not be positive and/or may not include all types of support (informational/instrumental/emotional). Functional support is the quality of the support offered from relationships. Measures of functional support include perceived informational, instrumental or emotional support, as described above, as well as marital quality or satisfaction with support.

The association between structural and functional measures of support with cardiovascular risk factors and outcomes has been reported. For example, studies have demonstrated that presence of support from the spouse is predictive of successful smoking cessation.[21-23] In a study of cardiovascular patients, one of the factors most predictive of stopping tobacco use was the disapproval of a member of the patient's social network.[24] Oka et al. found that support received from friends and family members was an important predictor of adherence to an exercise program for cardiovascular disease patients.[25] Among the studies reviewed in this chapter, the assessment of functional support is much less common than structural support.

The presence of social support may not always be health promoting; it can have a negative influence. For instance, if the relationship is of poor quality it may actually cause rather than attenuate stress. Furthermore, if a spouse or partner has poor health habits then this can encourage the patient to behave in a health damaging way. For example, a smoker may discourage a patient from discontinuing tobacco use. When evaluating the impact of social relationships the direction of the impact (positive or negative), and the specific type of support (e.g. instrumental support) and pathway through which it exerts its impact should be considered.

Other factors, like income, may moderate the influence of social support. Income has been found to be a moderator such that low income exacerbates the influence of low social support on cardiovascular risk. In 1986, Strogatz and James evaluated the association between instrumental and emotional support and the prevalence of hypertension in 2009 participants.[26] Low instrumental support was associated with increased hypertension. The results of a multivariate model indicated that the effect was specific to low-income black persons from households with an annual income below $10 000 (OR 1.7; 95% CI 1.2 to 2.6) but not those from households with higher incomes.[26] In this case, income was a moderating variable that mitigated the influence of support in high-income patients. In 2001, Vitaliano et al. found that emotional but not instrumental support was inversely associated with a composite measure of cardiovascular risk for low-income patients, defined as earning less than $29 000 per year; but neither social support measure was associated with risk for patients with higher incomes.[27] Further research is needed to examine how social support affects outcomes for those in lower and higher income groups.

Important questions remain regarding the association between the types of support, the stage of heart failure and individual differences and which outcomes they influence. For example, authors have previously suggested that perceived functional support (especially emotional support) is more important than structural support in terms of disease progression.[28,29] In 1992 Berkman et al. found that a composite measure of structural support was important for predicting the initial incidence of coronary heart disease (CHD), but only emotional support was a significant predictor of outcomes for patients with existing CHD.[30] However, in their 2005 review, Lett et al. emphasized that there is now substantial evidence that both structural and functional support predict prognosis of cardiovascular disease. [19] Support was measured as marital status, cohabitation, size of the social network, and involvement in activities as well as emotional support, and perceived tangible support. [19] Potential individual level social interactions related to heart failure patient outcomes will be examined in this dissertation through a thorough exploration of the literature and an in-depth discussion of the related theoretical models.

Income

Researchers in various international settings[31-35] have undertaken large population-based cohort studies of mortality by socioeconomic status (usually by linking to national censuses and population registries). These studies have investigated differences by income, education and occupation, and have consistently shown that people of a lower socioeconomic status have elevated mortality rates, and individuals of higher socioeconomic status have lower mortality rates. A higher risk of death has been described specifically for chronic disease patients of low versus high socioeconomic status, for example, following the diagnosis of cancer[36], cirrhosis[37], stroke[38] and diabetes related deaths.[39]

In Canada, one national population-based study and several studies evaluating selected populations have described the same link between socioeconomic status and mortality. In the population-based study (n=2 735 000) Wilkins et al. demonstrated that people of lower socioeconomic status, defined in separate analyses by their education, occupational status and income, had higher mortality rates compared to those of higher socioeconomic status.[40] The Canadian study participants were followed for ten years after the 1991 census. Deaths during that time were linked back to the income information recorded on the census. The results show that the poorest men lived approximately seven years less than men in the wealthiest category; for women the differential in life expectancy was just over four years. The risk of death increased in each successively poorer income quintile for all age groups except the men older than 85 years and women older than 74 years.

Examples of other Canadian studies that investigated selected populations are described below. These studies provide insight into the impact of individual income on the mortality of middle age and elderly Canadians. Two of these were undertaken with residents of Manitoba and Ontario.

One additional population-based study in Ontario described the impact of individual income on the outcomes of patients after myocardial infarction.

In his study, Wolfson et al. used Canadian Pension Plan (CPP) data to follow 500 000 men who were 65 years old until they turned 74 years of age. [41] Income was estimated based on earnings in the 10 to 20 years prior to age 65. All-cause mortality was documented during the follow up period. A strong gradient in mortality was observed across levels of income. Mortality was 1.6 times greater among earners in the $30 000–$50 000 range compared to the top-income earners; the mortality was three fold greater in the $15 000–$20 000 range than in the group with the highest income.[41]

Similar results were found in a study performed by Mustard et al.[42] Income and education were linked with mortality and health care utilization in a 5% sample of the Manitoba population (n=47 935). The follow up period was two years. A statistically significant gradient between income and mortality was observed for age groups 30-49 and 50-64, but not 65 and over, a finding that is discussed below. The association with income and education were significant when adjusted for one another.[42]

The association between income and mortality was also observed in a longitudinal Ontario study conducted in 1989 by Hirdes and Forbes, who examined a cohort from the Ontario Longitudinal Study of Aging. In 1959, 45 year old men were enrolled in the study and asked to provide their income in one of three levels. Participants were followed for 10 years starting in 1969. Low income was associated with greater mortality, while high income conveyed a small benefit over the middle quintiles. This pattern was robust to adjustment for education, smoking and baseline self-rated health.[43]

Alter et al. evaluated patients post myocardial infarction and noted that income was strongly and inversely correlated with two-year mortality rate (crude hazard ratio for high-income vs. low-income tertile, 0.45; 95% CI, 0.35 to 0.57). However, after adjustment for age and preexisting cardiovascular events or conventional risk factors, the effect of income was greatly attenuated (adjusted hazard ratio for high-income vs. low-income tertile, 0.77; 95%CI, 0.54 to 1.10).[44] The authors subsequently hypothesized that much of the mortality gradient was likely mediated by differences in patients' baseline cardiovascular risk profiles.[45]

The mean or median census tract income is often used as a proxy indicator of an individual's actual income. These are commonly used data because they have the benefit of being publically available. However, while the aggregate indicator (i.e. mean or median income of a community) is on one hand the cumulative summary across individuals, it also represents a community characteristic. For example, the mean household income of a census tract, reflects the features of the area (such as the crime rates). This issue is discussed more thoroughly in the section describing community level income, later in this chapter.

In summary, there is strong evidence to link lower individual income with higher crude mortality and total cardiovascular mortality internationally, and in Canada. Given the demonstrated impact of income on numerous disease outcomes and that 9.4% [46] of Canadians lived in a low-income situation in 2008, the role of income on heart failure progression should be evaluated. Notably, two of the studies described above and several other longitudinal studies[47-49] detected smaller differences in mortality between high versus low income patients in the older age groups than in the younger age groups. This might reflect 'mortality selection'[49] which refers to the premature mortality among poorer study participants that may dilute the ability of socioeconomic indicators to predict illness in later life. This would give the appearance of a narrowing of the gap in mortality between the wealthy and the poor, with age. The excess mortality in the younger low income patients may be due to less access to effective but costly drugs and nutritious food, less attendance at medical appointments to avoid financial losses for the time away from work and increased stress. The younger poor may be more vulnerable to death until they become eligible for social benefits (e.g. drug benefits, pensions) that facilitate access to effective treatments without financial difficulty. Petrie et al.[50] explored patients' experiences while queued for cardiac surgery and found a sub-group of patients (younger and blue collar workers) who subjectively described their economic hardship while waiting for care. This hardship may parallel experiences of low income heart failure patients. Understanding the role of income is important, however, there is a paucity of information directly relating to this population.

Pathways between low income and disease progression

Poverty, even in affluent societies, can have a health damaging effect through several mechanisms.[51-53] First, financial resources impact the access to medical care. There is reduced ability to pay for uninsured services (pharmaceuticals, non-physician care) and even access to insured services is lower. For example, Dunlop et al. showed that lower income residents in Canada make fewer visits to specialist physicians, and hence do not receive the benefits of specialized care. They suggested that these patients could not afford the travel cost associated with visiting a specialist physician in another community as one of the explanatory factors.[54]

Second, living in poverty means exposure to poor material conditions. The physical environment may include unsanitary housing, air and water pollution that may affect one's general health. An inadequate or unhealthy food supply and a disabling built environment may disproportionately affect those with low income and would have a significant impact on those who have heart failure.

Third, “poor people behave poorly.”[55] This places lower income patients at risk of more rapid progression to adverse heart failure outcomes. Most behaviours are not randomly distributed in the population, but clustered. Thus, many people who consume alcohol also use tobacco, and those who follow health promoting dietary practices also tend to be physically active. People who are poor are more likely to engage in risky behaviours and less likely to engage in health promoting ones.[56-59] Behaviours were once thought of as being solely within the power of the patient and a reflection of values and self control. However, it is now well recognized that behaviours occur within a social context. This concept of the community influence on health behaviours is discussed in the sections below.

Finally, a patient’s income is not only a representation of their financial resources but also a proxy for other sociodemographic characteristics. Low income is often linked with low education and low social status, which offer additional pathways to poor health outcomes. Therefore, low-income patients often experience disadvantages in these other domains that should also be considered when evaluating their health status and the association with income.

Education

A patient’s educational level is reflective of his/her financial status, employment ranking (in terms of social hierarchy and salary) as well as their actual level of education. The influence of education on heart failure outcomes is mediated through the same pathways as income, as well as through a mechanism specific to education - health literacy.[60,61] Health literacy impacts the ability to communicate with health providers and understand the information being presented. The ability to understand a disease through written material is a key component of patient’s adherence to treatment regimens and modification of lifestyles.[60,61] With the complexity of many heart failure treatment regimens, health literacy has the potential to be a significant predictor of disease progression.

A recent study[62] demonstrated that heart failure patients (n=2156) with low health literacy were older, of lower socioeconomic status, less likely to have at least a high school education, and had higher rates of coexisting illnesses. In their multivariable analysis low health literacy was independently associated with higher mortality (adjusted hazard ratio 1.97; 95% CI 1.3 to 2.97).[62] The importance of health literacy in heart failure patients was also highlighted in a qualitative study of heart failure patients. Simpson et al. conducted focus groups with heart failure patients and probed barriers to adhering to their medication regimen. These patients admitted that not understanding enough about their condition and medication (including its purpose and possible side effects) affected their adherence to therapy.[63] Another study that involved a secondary analysis of a pharmacist intervention trial empirically evaluated the link between medication knowledge and skill with overall adherence of heart failure patients (n=61). The researchers found numerous variables (such as “the ability to read prescription labels and auxiliary labels”) inversely associated with emergency department visits. The patients who were less able to read the labels were more likely to be seen in the emergency department (p=0.002).[64] This study demonstrated how health literacy influences knowledge and subsequent important outcomes like emergency hospital visits.

Community level social circumstances

Ecological studies have shown that the characteristics of places where people live are associated with rates of health-related behaviours, prevalence and incidence of disease, and mortality rates. Social scientists have demonstrated the local area effects of a number of individual-level outcomes, ranging from child development to health outcomes.[65-69] Multilevel modeling has been used to investigate local area or community effects on health while controlling for individual level factors.[70] The persistence of an independent community effect suggests that the characteristics of the community itself are important to the health of individuals who live there. The community factors may be especially important for heart failure patients (or patients with other chronic diseases) who are elderly and at risk of becoming socially isolated through poor health, limited mobility, financial constraints or limited access to transportation. These patients likely spend most of their time close to their homes so the community in which they live has a great deal of influence especially at advanced stages of disease. Relevant community characteristics may include the socioeconomic characteristics and the availability of healthy foods, a built environment that supports physical activity (e.g. presence of sidewalks) and the trust and bonding within the community.

It is important to note that the consideration of community factors on disease prognosis proposed in this research does not negate or detract from the significance of individual factors. In any theoretical or empirical model, community characteristics should be included, in order to provide the context that shapes the occurrence and distribution of these individual risk factors as well as having their own direct effect.

Community social cohesion

Social cohesion relates to the degree to which groups of people feel connected, share resources, and provide moral support.[71] It is a characteristic of the community or group. This construct is distinct from social support assessed at the individual level because it operates within the community as a whole. Indicators of social cohesion include questions asked directly to community members about their sense of belonging or trust. In the absence of these specific data, indicators of social participation such as volunteer rates, membership in community associations, and the level of income inequality have all been used by researchers as proxy measures of social cohesion within a community.

Social cohesion may reduce cardiovascular risk by reinforcing social norms related to health behaviours, by allowing residents to effect improvements in the physical environments, and by buffering adverse effects of stress.[71] There is evidence that links social cohesion to incident cardiovascular disease. For example, low electoral participation (as an indicator of low social capital, a component of social cohesion) was associated with higher coronary heart disease incidence in Swedish men and women after controlling for individual level characteristics.[72] The authors suggested that communities with higher social capital may be composed of individuals with a greater sense of empowerment. This, in turn, reduces stress and hence benefits cardiovascular disease.

Researchers have investigated selected risk factors for poor prognosis of heart failure. Greater neighbourhood collective efficacy (as assessed by combining indicators of social cohesion and informal social control) was linked to lower body mass index even after controlling for neighbourhood deprivation.[73] A cross-sectional study of the relationship between neighbourhood social cohesion and hypertension demonstrated that residents of neighbourhoods with more social cohesion were less likely to be hypertensive (90th percentile versus 10th percentile OR 0.69; 95% CI 0.57-0.83).[74] The impact of community social cohesion on other behavioural risk factors such as smoking, poor physical activity and nutrition has also been demonstrated.[75-77]

Community income & education

The socioeconomic status of the local area is often described as the community or neighbourhood average income or education. These indicators reflect the level of wealth or deprivation of communities. Researchers often link aggregated census data with other individual-level factors (e.g. smoking status) and outcome data. Census tracts are often used as proxies for neighbourhoods or communities and many studies have shown that living in disadvantaged neighbourhoods is associated with a greater coronary heart disease prevalence, incidence and mortality even after controlling for individual clinical factors.[12,78,79]

There is some research on the impact of neighbourhood income and the progression of cardiovascular disease. For example, Alter et al. followed approximately 51 000 Canadian patients hospitalized for acute myocardial infarction and found that each $10 000 decrease in median neighborhood income was associated with a 10% increase in all-cause mortality over one year.[80] In the Worcester Heart Attack Study, Tonne et al. showed patients with acute myocardial infarction living in the most deprived income quintile had a 30% higher death rate after myocardial infarction than those living in the wealthiest quintile (RR=1.30; 95% CI 1.08 to 1.56).[81] A recent Canadian study, by Heslop et al., evaluated the impact of census tract level median family income on mortality in 464 patients and found that neither all cause nor cardiovascular mortality were affected. However, they found that death from non-cardiac causes increased by up to 30% for each quintile decrease in median income. These authors noted that the absence of a relationship with cardiac death and all-cause death was not expected and hypothesized that the presence of a large teaching hospital, and a small sample size may have contributed to the negative findings.[82]

Two researchers have observed that heart failure patients in lower income communities have higher rates of rehospitalization independent of disease severity. Philbin et al.[79] measured household income by linking postal codes with census data. They found that patients with heart failure residing in lower income neighbourhoods were more often women or African-Americans, living with comorbid illness, and admitted to rural hospitals. There was a decrease in the frequency of readmission from the lowest quartile of income (23.2%) to the highest (20.0%). After adjustment for baseline differences, income remained a significant predictor, with an increase in readmission noted in association with lower levels of income (quartile 1 versus quartile 4, adjusted OR=1.18; 95% CI 1.10 to 1.26).[79]

Struthers et al. evaluated the effect of neighbourhood income on emergency cardiac hospitalizations in patients with chronic heart failure in the UK. They too found that deprived communities had a significant increase in the number of hospitalizations over the study period (p=0.007).[83] Struthers et al. hypothesized that doctors who look after poor patients have a lower threshold for cardiac hospitalization of those patients and that deprivation alters the way a heart failure patient accesses medical care when their disease decompensates. As well, they felt that primary care providers managing heart failure patients in deprived areas have less time for intensive management and perceive that these patients have less ability to understand and manage their own condition.[83] Philbin et al. also suggested that differences in medical care and risk behaviours accounted for the discrepancy in rehospitalization rates between the low and high income populations.[79] These explanations are based on aggregated income statistics collected for the neighbourhood group to which those patients belonged, rather than on the individual patient’s income. There are identified causal pathways through which community income relates to outcomes that operate at the community level that were not considered in the interpretation of these results by the authors. Variables along this pathway include social cohesion, community resources and social norms that influence health behavours.

Pathways between community income and education and heart failure outcomes

Again, the specific causal pathways linking neighbourhood or community income and education with heart failure outcomes have not been well defined. However, the empirical evidence from other disease states and the pathways linking the neighbourhood income and education with cardiovascular disease outcomes provides fodder for the discussion of how these influences might relate to heart failure outcomes. Diez Roux has proposed that indicators of neighbourhood socioeconomic status are actually proxies for the physical and social attributes of the community, which influence individual cardiovascular risk. Indeed, several investigators have demonstrated a higher prevalence of individual-level cardiovascular disease risk factors, including greater tobacco use, poor diets, less physically active lifestyles, more hypertension, more diabetes, and greater body mass index in individuals living in lower socioeconomic status communities.[84] Many of these individual factors may lie on the causal pathway from community to health outcomes. In other words, these individual risk factors are influenced (amplified or diminished) by the characteristics of the local area in which they occur. Thus, community socioeconomic characteristics should be considered in a population health approach to heart failure.

Two main features of the physical environment are proposed to contribute to cardiovascular risk at the neighbourhood level, and could logically also influence prognosis once the disease is established. These include both an appropriately designed built environment that promotes exercise and other recreational activities and also a food environment that enables a healthy diet and weight.[84] An introduction to this topic is presented below and a more thorough discussion is provided in Chapter 5.

The built environment consists of features that may influence the extent to which people participate in health promoting behaviours. Papas et al.[85] conducted a review of evidence regarding the relationship of the built environment to diet, physical activity, and obesity. They found that the characteristics of the built environment that promoted walking included the presence of mixed land use (e.g., commercial and residential uses), higher density and attractiveness of destinations, street connectivity, and the presence of sidewalks. Features related to recreational uses include the density and quality of parks and recreational facilities.[85]

The local food environment also influences health through the availability and cost of healthy foods, the presence of unhealthy foods (such as processed and fast foods), and food advertising.[86] Many studies have shown that the availability of healthy foods differs a great deal across communities such that healthy foods (which tend to be more expensive) are less available in poor neighbourhoods than in wealthy neighbourhoods.[87] The availability of healthy food is positively associated with consumption of healthy foods and with a lower prevalence of diet-related cardiovascular risk factors, including hypertension and obesity.[74,88] The value of these resources, in terms of health outcomes for heart failure, has not been systematically investigated and requires further evaluation.

Summary and interpretation of literature review

The impact of heart failure in Canada is significant. The continued poor prognosis has encouraged consideration of new approaches to manage this disease.

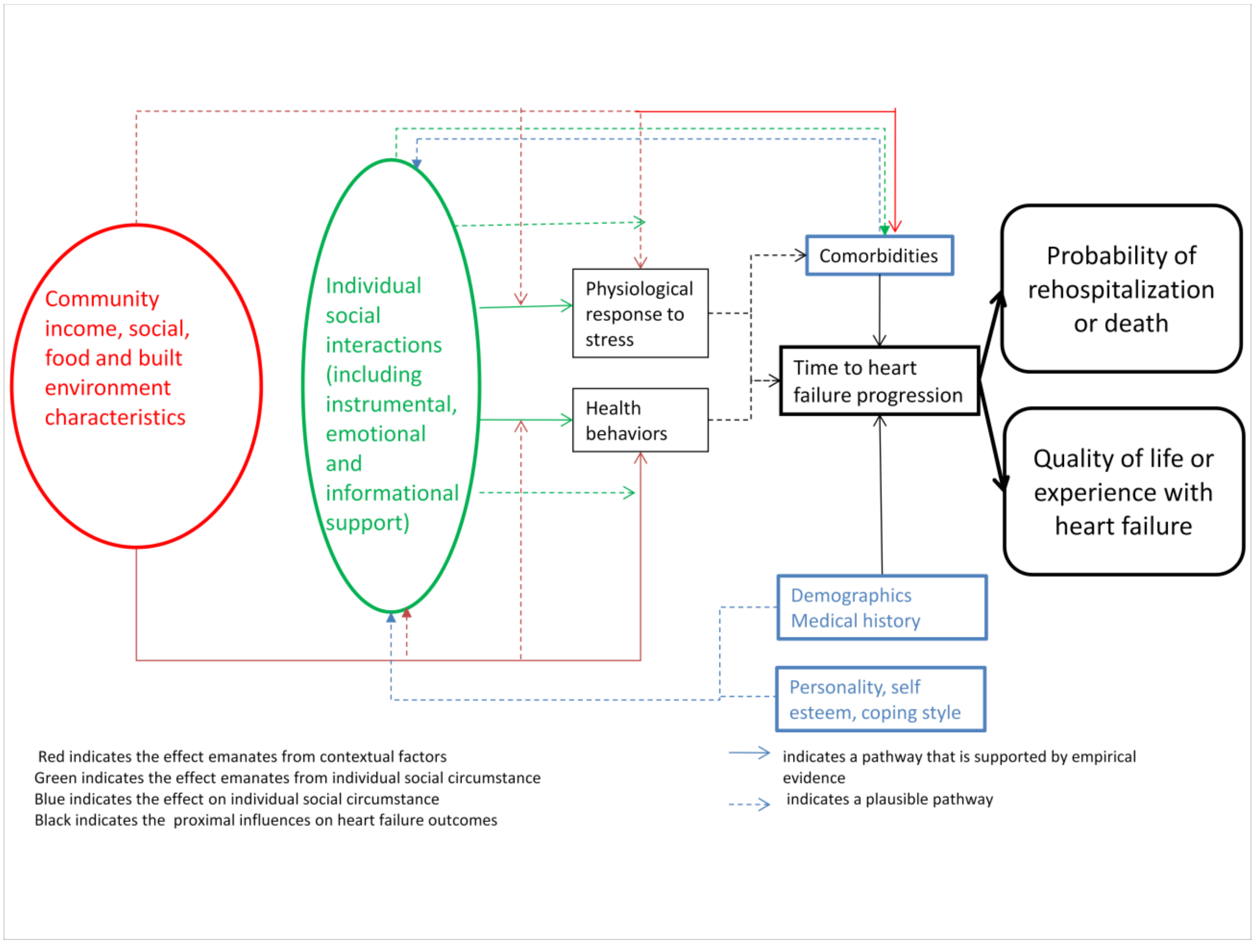
Clinical factors such as hypertension and diabetes have been found to place patients at greater risk for poor prognosis.[4] Canadian and international studies have demonstrated the role of specialist physician care and heart failure clinics in improving heart failure outcomes.[8,10,89] These proximal influences have a substantial impact on heart failure outcomes but do not represent the entire causal web affecting heart failure progression. How social circumstances influence heart failure outcomes is under-theorized and has not been adequately explored. Broadening the conceptual model, based on the extrapolation of knowledge from other disease states and the theoretical plausibility of the relationship, makes the role of social circumstances in heart failure progression an exciting opportunity to explore for this patient population.

A population health model to guide research of heart failure progression

Some authors have applied ecological theoretical models that represent the health of a population as being determined by multiple levels of factors that act and interact together.[90,91] A population health model shows how individual health is influenced by a person's own characteristics and behaviours, by their families and their communities. It focuses on a wide range of individual and collective factors and conditions, and the interactions among them. Research that focuses on any one level can ignore the effects of other determinants of health and their nested relationships. The initial approach to this research was guided by a conceptual model that specified the multilevel pathways to heart failure outcomes. Multilevel models allow for pathways that follow a hierarchical structure. Multilevel models more accurately represent the multiple and interacting pathways that are thought to influence health than do single level models.

See Figure 2.

Figure 2: Proposed model relating individual social interactions and community characteristics with heart failure outcomes



This model was developed based on the above review of the literature examining the hypothesized pathways between social circumstances and heart failure outcomes. This model accounts for selected community and individual levels of influence on heart failure progression. The solid lines indicate that literature provided evidence for the relationship. The dotted lines show the hypothesized relationships that are based either on empirical evidence or theoretical models outside the heart failure literature.

The red lines show the link between community factors and individual social circumstances, individual behaviours and stress response. There is a confirmed relationship between community and health behaviours indicated with a solid line. I hypothesized that community characteristics can modify the impact of individual social interactions which is depicted by a red dotted line. The green lines show that there is evidence to link individual social circumstances (e.g.social support) with health behaviours and stress response (solid line). It is also plausible that individual social interactions can modify the influence of community characteristics on behvaiours and stress (dotted line). The blue lines represent the plausible impact of comorbidities, demographics, medical history, personality, coping style and self esteem on an individuals' social support. The black dotted lines indicate the plausible relationship between the mediating variables (health behaviours and stress response) of social interactions and heart failure progression.

This model guided the inquiries presented in this thesis research. It was expected to change and expand as new information was revealed about the relationship and the pathways between individual social interactions and heart failure outcomes through the systematic review and integrative review in Chapters 2 and 3. It was anticipated that some community factors related to heart failure outcomes would be defined by the multilevel analysis presented in Chapter 4. Thus, some of the dotted lines in this model were expected to solidify or disappear and additional pathways with solid lines were expected to surface. These revised models are presented in Chapters 2, 3 and 5.

Conclusion

Heart failure is a condition that would benefit from a population health approach. It has a significant impact on patients' quality of life and patients live with it for the rest of their lives. Common clinical interventions, like recommendations for drug therapy, diet modification or self-care, may not yield additional improvements in health outcomes if applied in isolation. A more inclusive perspective of the potential individual and community determinants of heart failure progression can offer opportunities for interventions in the future. The information provided in this dissertation advances the discussion about the impact of social circumstances on outcomes in the heart failure population.

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Chapter 2: A critical review of the association between social support and heart failure outcomes

Seema Nagpal, M.Sc.[1], Nancy Edwards, RN, PhD, FCAHS [2,3,4],
Jafna Cox, BA, MD, FRCPC, FACC [5,6], Ian McDowell, PhD[3]

[1] Population Health PhD Program, University of Ottawa, Ottawa, Ontario, Canada

[2] School of Nursing & Department of Epidemiology and Community Medicine , University of Ottawa, Ottawa, Ontario, Canada

[3] Department of Epidemiology and Community Medicine, University of Ottawa, Ottawa, Ontario, Canada

[4] Institute of Population and Public Health, Canadian Institutes for Health Research, Ottawa, Ontario, Canada.

[5] Division of Cardiology, Queen Elizabeth II Health Sciences Centre, Halifax, Nova Scotia

[6] Departments of Medicine and of Community Health and Epidemiology,
Dalhousie University, Halifax, Nova Scotia, Canada

Abstract

Heart failure is a progressive condition that causes a deteriorating quality of life and a rapid decline to death. A lack of social support may hasten disease progression.

Objective: This review 1) examines the association between social support and heart failure outcomes; and 2) proposes a conceptual framework relating social support and heart failure outcomes.

Study Design and Setting: A systematic review of published studies examines the impact of social support on rehospitalization and death. An appraisal of how social support has been measured and its effects are presented.

Results: Fourteen studies were reviewed. There is wide variation in the measurement of social support. Some studies used proxy indicators of support, which were not found to be linked to outcomes. Other studies measured perceived support by questionnaire, and showed that low support is related to higher hospitalization rates; the relationship with mortality was inconclusive. A proposed conceptual framework clarifies the pathways linking social support to heart failure disease progression; the framework can guide the selection of indicators for research.

Conclusion: Heart failure researchers have not examined the association between social support and heart failure outcomes with an adequate conceptual framework. Future research should employ a stronger conceptual framework.

Running title: Social support and heart failure

Abstract word count: 216 words

Key words: Social Support; Heart Failure; Systematic review

What's New?

- Social support has been measured as inferred support (measured using proxy variables like marital status) and perceived support (patient's descriptions of support) in the heart failure literature. This makes interpretation of the results difficult.
- There was no evidence to link inferred support to rehospitalization or death. Lower perceived support is related to higher rehospitalization. The relationship between perceived support and death is inconclusive.
- A conceptual model outlining types of social support and their hypothesized causal connection to heart failure outcomes can help in choosing appropriate indicators.

A critical review of the association between social support and heart failure outcomes

Introduction

Heart failure is a devastating condition for patients and their families. It is a complex clinical syndrome in which the heart cannot provide adequate blood flow, thereby limiting delivery of oxygen and nutrients necessary to meet metabolic demands. This limits performance of usual roles at home, work, and in the community.[1]

In the absence of a cure, interventions are designed to delay disease progression and maximize quality of life. Historically, research has focused on biomedical factors that affect heart failure outcomes. Sophisticated measures of clinical status and heart function have been developed to diagnose and monitor the condition. Highly specialized and targeted pharmaceuticals have been designed to modify physiological processes.[2] Health professionals have also developed specialized programs to deliver services and modify behaviors of heart failure patients, which have successfully increased survival time and reduced hospitalizations.[3,4] However, maximizing the uptake, and hence benefits of these interventions requires the involvement of family members or friends. Unless the patient's broader social circumstances are considered, interventions to modify biomedical factors, health services and individual behaviors appear unlikely to yield further substantial improvements in health outcomes.

We hypothesized that the lack of a social network and meaningful support hastens disease progression in patients with heart failure. Heart failure patients tend to be elderly and frequently live alone,[5] and they may experience financial constraints, functional limitations due to other conditions, or limited access to transportation that compound the risk of isolation. This review will describe research evaluating the relationship between social support and rehospitalization or death in heart failure patients; and it will propose a conceptual model outlining how social support could influence heart failure outcomes.

Social support

Social support is a term that is often used to describe transactions that occur between people that make one feel cared for and valued as a person. A common classification identifies three main types of social support that can be linked to health: informational support (e.g., giving advice about a condition or treatment regimen); instrumental support (e.g., providing practical or tangible assistance like going to a physician appointment); and emotional support (e.g., giving reassurance and providing encouragement to adapt to the illness). However, not all social interactions are beneficial.[6] These can have a negative influence. For example, friends and family may offer well-intentioned advice that conflicts with health provider recommendations, or directly or indirectly promote unhealthy behaviors such as smoking or alcohol use. When evaluating the role of social support on health outcomes, the balance of potential positive or negative impacts of the relationship, as well as the specific causal pathways linking social support to outcomes, should be considered.

How may social support affect heart failure progression?

Social support has been hypothesized to influence health through two main pathways: physiological and behavioural. First, an actual or perceived lack of social support can generate anxiety and distress.[6] This can trigger physiologic processes so that the sympathetic nervous system responds via the hypothalamic-pituitary-adrenal and the renin-angiotensin-aldosterone systems, damaging arterial walls and the myocardium. Distress is also related to a higher frequency of clinical depression and health risks such as tobacco use, which are in turn related to poor health outcomes. Supportive relationships may mitigate the physiological impact of anxiety and distress.[6]

Second, social support may impact health through compliance with medical regimens, help-seeking, and decision-making about behaviour changes. Helping relationships consist of openness, acceptance and encouragement of healthy behavior change. Several authors have documented the importance of social support on health behaviors including physical activity, maintaining a low-sodium diet and adherence to drug regimens.[7-10] Every study (n=38) in a review by Trost et al. that evaluated the link between social support and physical activity found a positive association.[7] Another systematic review evaluated the importance of social support in self-care for patients with diabetes, respiratory disease, arthritis or cardiovascular disease. These authors found that social support was positively associated with chronic disease self care in the majority of studies, but the effect size was often small. The authors did not report the independent effects of the different types of support in their findings.[11] A meta-analysis that included patients with a range of conditions studied the impact of support on adherence to medical interventions. Patients with differing disease states were included and adherence to any medical intervention was assessed.[10] The odds of adherence to medical treatment (compared with non-adherence) was 3.6 times (95% CI 2.55 to 5.19) higher among those who received practical support, defined as instrumental support, assistance, reminders, and organization, than among those who did not. The risk of non-adherence was also higher for patients who did not have emotional support compared to those who had emotional support (OR:1.83; 95% CI 1.27 to 2.66).

Social support and health outcomes

Several review articles[8,9,13-18] describe compelling evidence linking low quantity or quality of social relationships with health risks and outcomes, including incident cardiovascular disease, recurrent myocardial infarction, coronary heart disease outcomes, autonomic dysregulation, hypertension, cancer and delayed cancer recovery, and wound healing. Heart failure patients, like those with other chronic diseases, live with their condition for the rest of their lives. Although the pathology of these conditions is different, all affected patients can potentially benefit from access to health and social resources. Indeed the presence of social support has been demonstrated in terms of improved adherence to medications[10], lower rates of hypertension[19] and survival after cardiovascular disease.[20]

Three systematic reviews have previously examined the influence of psychosocial factors, including social support, on heart failure outcomes.[21-23] MacMahon and Lip conducted a review of the literature from 1965 to 2000 and reported on two studies evaluating social support in heart failure patients.[21] They concluded that these studies showed some evidence of an inverse relationship between social support and poor outcomes but that no definitive conclusion could be drawn because of the paucity of studies and conflicting information. Luttik et al. described the objective evidence and observational findings from studies in the literature (from 1993 to 2003) relating all types of social support with readmission and mortality. They concluded that, although mixed, the evidence pointed to the existence of an inverse relationship. Pelle reviewed literature from 1990 to 2007 and found that two of six and two of four studies showed an inverse relationship between all types of social support and mortality among heart failure inpatients and outpatients, respectively.[23] In this paper, we update these literature reviews and go a step further by providing a critical analysis of the primary studies. We also propose a conceptual model connecting social support to the progression of heart failure.

Methods

Search strategy and inclusion criteria

This systematic review examines the research evaluating the impact of social support, including marital status, cohabitation, social isolation, the amount of social support, and the perceived quality of social support, on the progression of heart failure to rehospitalization and death.

The population of interest was adult patients diagnosed with heart failure. A comprehensive systematic search of databases including Medline, PSYCHLIT, CINAHL, SOCIOLOGICAL ABSTRACTS, and EMBASE was performed to identify relevant studies evaluating social factors and the prognosis of heart failure. The search included studies published between 1950 and November, 2009 in English or French. The search strategy is included in Appendix III. Additional literature was also identified by scanning the references of the reviewed papers for relevant articles.

Inclusion criteria:

1. The study population included adult heart failure patients
2. The study differentiated between heart failure patients and patients with other cardiovascular diseases
3. The study was not a case report or case series, nor a review article
4. The outcomes included death, or rehospitalization
5. The study evaluated at least one social factor and its influence on the above outcomes.

To test the reliability of assessing eligibility, 25% of the references in the initial database search (698 of 2788 articles) were independently screened by two researchers to determine whether or not each study met the inclusion criteria. The two researchers had a very strong agreement (Kappa=0.87, 95% CI 0.81 to 0.93). All disagreements were resolved by consensus.

Data abstraction and evaluation

Articles that met the inclusion criteria were read and examined for relevant information. Data on the study methods and results were extracted and entered into a spreadsheet.

Relevant studies were assessed using an adapted version of the methodological quality-rating tool developed by the Effective Public Health Practice Project.[24] Three adaptations were made: 1) the criterion of blinding was omitted as not relevant to observational studies; 2) the question about number and reasons for withdrawals and drop-outs was omitted and the question about number of patients completing the study was retained because the latter was more pertinent to the studies that assessed outcomes using administrative data bases; 3) the issue of "comparability of groups prior to the intervention" was not relevant to an examination of the relationship between social support and prognosis. Therefore, the question referring to comparability of groups was omitted. If the research was a secondary analysis of an interventional study, the comparability of groups and the intervention status was assessed by the criterion that addressed the control of confounding. Each article was reviewed for methodological quality and rated as strong, moderate or weak. The reliability of the quality rating was also assured by having two independent researchers rank each included study; disagreements were resolved by consensus

Analysis

The studies used differing indicators of social support, and the follow up period ranged from 60 days to 8 years.

The patient populations and study designs were too dissimilar to permit a meta-analysis, and it was considered most appropriate to provide a narrative summary of the study findings and a critical review of their methods.

Results

In total, 2788 citations were identified, of which 2619 clearly did not meet the inclusion criteria when reviewed by title and abstract. The remaining 169 studies were retrieved in full for further assessment. Based on this, 155 studies were excluded, leaving 14 for analysis.[25-38] Study summaries are presented in Table 1.

Table 1: Summary of studies included in the systematic review

Author and Study Country	Independent factor studied	Design and Duration of follow-up	Association with outcome	Quality Rating
Inferred Support				
Tsuchihashi,M.;(Japan)	Living alone, family caregiver, professional support	Prospective cohort study with mean 2.4 year follow up	Rehospitalization was NS*	Moderate
Roe-Prior,P. (USA)	Marital status	Secondary analysis of intervention trial with12 weeks follow up.	Rehospitalization and marital status was significant (p=0.02).	Weak
Luttik et al. (Netherlands)	Presence of partner	Secondary analysis of an intervention trial with 9 months follow up.	Mortality and rehospitalization were NS*	Moderate
Chin et al. (USA)	Presence of partner or having someone at home to provide care	Prospective cohort study with 1 year follow up.	Mortality was NS*	Moderate
de Campos Lopes (Brazil)	Marital status & feelings of a supportive social environment	Prospective cohort study with 2 years follow up	Mortality was NS*	Moderate
Perceived Support				
Tsuchihashi-Makaya,M (Japan)	Perceived social support; living alone, marital status, number of social ties	Prospective cohort study with1 year follow up.	Rehospitalization and low perceived social support (versus high) RR 3.0 (95% CI 1.1 to 9.9)	Moderate
Friedmann et al. (USA)	Social support amount and satisfaction measured by the Social Support Questionnaire-6	Prospective cohort study with median follow-up of 27 months	Mortality and social support amount Hazard Ratio=0.573 (95% CI 0.286-0.573) Social support satisfaction and mortality was NS*	Strong
Murberg and Bru (Norway)	Perceived social support measured using a 15 item scale. Perceived social isolation measured as 4 item questionnaire.	Prospective cohort study with 2 years follow up	Mortality and social support HR=0.60 (95% CI: 0.35 to 1.02) Social isolation HR=1.50 (95% CI (1.00-2.19)	Moderate

Author and Study Country	Independent factor studied	Design and Duration of follow-up	Association with outcome	Quality Rating
Murberg (Norway) Follow-up of previous study	Perceived social support measured using a 15 item scale. Perceived social isolation measured as 4 item questionnaire.	Prospective cohort study with 6 years follow up	Mortality and social isolation RR=1.36 (95% CI 1.04-1.78) Social support and mortality NS*	Moderate
Krumholz et al. (USA)	Emotional and instrumental support and measurement of social ties was assessed by asking patients questions about the availability of supports for specific situations.	Secondary analysis of prospective cohort study with1 year follow up.	Combined endpoint mortality/rehospitalization and no emotional support OR=3.2 (95% CI 1.4-7.8) Mortality and social ties NS* Mortality and instrumental support NS*	Moderate
Bennett, S (USA)	Social support measured using MOS scale	Secondary analysis of RCT with 1 year follow up	Rehospitalization was NS*	Moderate
Rodriquez-Artalejo et al. (Spain)	Frequency of interaction with social network measured using a 4-item questionnaire. Emotional support and instrumental support were measured through a single item question.	Prospective cohort study with median 6.4 and 6.6 months follow up for rehospitalization and mortality respectively	Rehospitalization and high versus moderate and low social network interactions HR=1.87; (95% CI 1.06-3.29) and HR=1.98; 95% (CI 1.07-3.68), respectively Emotional and instrumental support was not associated with readmission or mortality. Social network and mortality was NS*	Moderate
Coyne,J. C.(USA)	Marital quality measured using 4 measures of marital functioning	Prospective cohort study with 4 year follow up	All cause mortality and high versus low marital quality (RR=1.65, 95% CI (1.25 to 2.17).	Moderate
Rohrbaugh ,M. (follow up study of Coyne et al.)	Marital quality & feelings of a supportive social environment	Prospective cohort study with 8 years follow up	Mortality and Optimism, breadth of social support were NS* Mortality and high versus low marital quality for women RR=1.98, (95% CI 1.18 to 3.32, p=0.009) men RR=1.13(95% CI 0.93 to 1.37)	Moderate

*NS: Not significant

Authors of the 14 studies measured social support in different ways which I have classified as either ‘inferred’ or ‘perceived support’. Inferred support refers to support assumed by the researcher due to the presence of a spouse or partner. It was measured with proxy indicators like marital status or cohabitation. We defined perceived support as that expressed by the patient. The study results are summarized and organized below by health outcome (rehospitalization or mortality) and how social support was measured (inferred or perceived).

Rehospitalization: inferred support

Four studies evaluated the impact of inferred support on rehospitalization, using indicators like marital status or living alone to imply social support [27,29,39,40] Only Roe-Prior et al. detected a significant association between being married and a lower risk of rehospitalization using a multivariate analysis. However, these authors did not control for the clinical severity of heart failure.[29] Neither Luttik et al. nor Tsuchihashi found an association between having a partner or living alone and rehospitalization after controlling for clinical severity in their regression analyses.[27,39,40]

Rehospitalization: perceived support

Four studies evaluated the link between perceived amount or quality of social support and hospital readmission.[27,30-32] Three studies detected an association.[27,30,32] Tsuchihashi-Makaya found a three-fold increase in one-year rehospitalization for patients with weak overall social support (RR 3.0; 95% CI 1.1 to 9.9). The relationship with particular types of social support was assessed but not reported.[27] Rodriquez-Artalejo categorized patients’ social network interactions and found rehospitalization was more frequent at 6.5 months among those who had moderate (hazard ratio (HR) 1.87; 95% CI 1.06 to 3.29) or low social networks interactions (HR 1.98; 95% CI 1.07 to 3.68) compared with high social network interactions.[32] However, these researchers did not find a link between emotional or instrumental support and rehospitalization. In a study of 292 patients, Krumholz et al. found a strong trend towards a relationship between not having emotional support and increased cardiovascular readmissions (OR, 2.5; 95% CI, 0.9 to 7.1). [30] However, neither instrumental support nor the absence of social ties was associated with this endpoint. The final study, by Bennett et al., did not detect any relationship between perceived health or perceived support and rehospitalization. However, they suggested that the absence of an association might have been because 73% of the patients were married and most believed they had support available most of the time. Therefore, there may have been insufficient variance to detect a difference.[31] All four studies adjusted for clinical severity of illness.

Mortality: inferred support

Three studies evaluated the association between inferred social support and mortality.[25,28,38] In a multivariable analysis, Chin and Goldman found being unmarried gave a higher risk of the combined endpoint of rehospitalization or death within 60 days (HR 2.1; 95% CI 1.3 to 3.3).[38] However, this effect was not apparent at one year. Luttik et al. followed patients for nine months and found fewer deaths among patients who were living with a partner compared with those living alone, but this did not achieve statistical significance.[28] de Campos Lopes et al. did not detect a significant relationship between marital status and mortality.[25]

Mortality: perceived support

Seven studies evaluated the impact of social support on mortality, focusing on the perceived presence or quality of support.[25,30,32-35] Two additional studies assessed perceived marital quality, which we considered a component of perceived support.[36,37]

Krumholz et al.[30] prospectively measured the perceived availability of emotional support and found that no emotional support was independently associated with fatal and nonfatal cardiovascular events at one year (OR 3.2; 95% CI 1.4 to 7.8). The association with death did not achieve statistical significance (OR 2.6; 95% CI 1.0 to 6.6).[30] The test for an interaction in the fully adjusted models showed that the relationship between no emotional support and cardiovascular events was very strong in women but absent in men (adjusted OR=8.2 for women versus OR=1.0 for men). Instrumental support was not associated with this combined outcome in either men or women. The relationship between social ties and rehospitalization or death also did not achieve statistical significance (OR 2.08; 95% CI 0.95 to 4.54).[30] Social ties were defined as being married, in contact with friends and relatives, having membership in religious organizations, and participating in voluntary groups,

Friedmann et al. prospectively evaluated 153 patients and asked about perceived social support through a questionnaire describing difficult situations.[33] Patients were asked whom they could rely on for help and their perceived satisfaction with help. Although not stated by the authors, they seemed to be assessing perceived instrumental support. The level of support predicted survival, independently of demographic and clinical status (HR 0 .57; 95% CI 0.29 to 0.57)[iii] but satisfaction with support did not. The median follow-up was 29 months.[33]

In their prospective study, Murberg et al. found that the perceived size of their social network was not significantly related to mortality, but there was a strong trend towards an impact of perceived social isolation on mortality at two years that became significant at six years (2 year mortality HR 1.50; 95% CI 1.00 to 2.19, and 6 year mortality RR 1.36; 95% CI 1.04 to 1.78).[34, 35] The questions about social network seemed to be investigating the size of the network as well as instrumental support, but the authors did not specify this. The absence of social support or social isolation occurred when patients felt unable to maintain social contact with family, other relatives and friends because of their heart failure.[35]

The three remaining studies did not detect an association between perceived satisfaction with social support and death.[25,32,37] de Campos Lopes evaluated the perception of patients' of their social network and environment and found no association with mortality over a two-year follow-up. However, among the 494 patients enrolled, 456 (95.2%) reported having a supportive family or social environment. It is unclear if there was sufficient variation in social support to detect an association.[25] Rodriquez-Artalejo investigated a possible link between the frequency of social interactions, emotional and instrumental support, and death at six months, and found none.[32] Rohrbaugh et al. also failed to find any association between the breadth of emotional support and mortality. Notably, this study involved interviews with patients and their spouses; so only

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[iii] The inclusion of the hazard ratio in the confidence interval was noted to be unconventional. No erratum to this study was published, thus the findings are reported here as they were described by the original researcher.

patients who were married and had a spouse willing to participate in the study were included. There may not have been sufficient variation in support to detect an association.[37]

Coyne et al. evaluated the impact of marital quality on four year mortality and conducted a subsequent analysis at eight years. These researchers found a significant relationship at four years (high versus low marital quality and mortality, RR1.65; 95% CI 1.25 to 2.17); but at 8 years, the association was significant for women (RR 1.98; 95% CI 1.18 to 3.32) though not for men (RR 1.13; 95% CI 0.93 to 1.37).[36,37] These studies did not distinguish between the types of support offered by the spouse.

Summary of study results

Overall, the findings suggest that there is insufficient evidence to demonstrate an association between inferred support with rehospitalization or mortality among patients with heart failure. A lack of perceived social support is, however, related to higher hospitalization rates. The evidence that low perceived social support is associated with mortality of heart failure patients is mixed. Low marital quality seems to accelerate mortality, especially for women.

Follow-up time varied across the studies, from 60 days to 8 years, and this had a significant impact on the number of observed outcomes and the associations that were detected. Most studies controlled for some clinical characteristics, including comorbidities (e.g. depression), and risk factors (e.g. smoking) but these characteristics differed across studies.

Discussion

The variation in results appears related to at least four methodological issues. First, inferred support and perceived support are not equivalent. An indicator like marital status broadly implies the presence of emotional, instrumental and informational support, but this may range from great support to little or no support at all or even to negative interactions. The quality of the marriage, the age and health of the spouse, and spousal health behaviors, all affect the degree to which a spouse actually provides support to the heart failure patient. Even when an association is detected, it is impossible to know what components of the relationship are contributing to the outcomes. Further, a patient's marital status may not change, but the support emanating from that relationship may change greatly over time. Future studies should employ indicators of a specific type of social support.

Although indicators of inferred support are more readily available and convenient, it is perceived support that most closely estimates the patients' interactions and experiences that might influence health outcomes. Well-validated questionnaires, like the Medical Outcomes Study (MOS) support scale[41], have been developed to assess the presence, quality and perceived adequacy of social support. Through these questionnaires, the heart failure patient can describe if they have the emotional, instrumental and informational support that they need. They can differentiate between the types of supports that are present and researchers can determine how social support can delay rehospitalization or mortality. Note that the mechanisms influencing these outcomes may be different. Social support can be hypothesized to have an influence on reducing rehospitalization through instrumental support (e.g. assistance with seeking medical services and avoiding acute cardiac decompensation); long-term emotional support may be related to delaying mortality.

The second methodological challenge is that the need for, and the benefits of, social support may vary with disease severity or stage of disease. This likely contributed to the inconsistent findings in the studies reviewed. For patients with advanced disease, a rapid decline in physical function could overwhelm any short- term positive impact of social support in delaying hospitalization and death. The relationship with hospitalization is even further complicated since concerned family members may actually encourage some patients to access health care services sooner and hence more frequently, thereby increasing hospitalization rates. The type of social support needed will also change with disease progression. At diagnosis, informational support may be most important, by educating patients about prognosis and treatment. However, during an acute deterioration of health, instrumental support is needed; and when a patient is critically ill, emotional support becomes essential. This shifting in relative importance of the type of support that is most beneficial during different stages of illness could not be examined in this review because the original studies often used a single aggregated indicator of social support and none of the analyses examined the association between the types of social support and outcomes by disease stage.

Third, the differing length of follow-up (60 days to 8 years) is a potential cause of inconsistent results across studies. Many studies evaluating social support are secondary analyses of clinical trials so the follow-up periods were those determined to be most appropriate for the original study. There is no ‘gold-standard’ for the duration of observation, but certainly some of the causal pathways linking social support to outcomes take time to have an effect. Too short a follow-up may fail to reveal the benefit of support, as most patients are initially able to live at home with considerable self-reliance. With a very long follow-up, the disease will be more advanced; therefore, the observed beneficial effect of support may be greater as the patient becomes more reliant on help to remain out of hospital, or lower as hospitalization and even death become increasingly unavoidable despite any amount of support. There was no discernable pattern in the reviewed studies, but given the dissimilarity in the patient populations, this is not surprising.

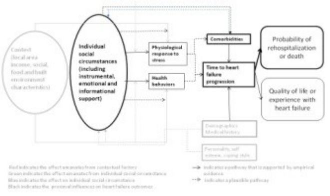
Fourth, most researchers controlled for clinical prognostic factors in order to investigate the independent effect of social support on outcomes. However, some of the impact of support may operate via modifying behavioral risk factors and the stress response, both of which influence the occurrence of clinical risk factors. Thus, over-controlling for clinical risk factors negates the true impact of social support, which is mediated by these factors. In addition, variables like personality and coping styles were not assessed but could modify the impact of social support on outcomes.

The research evaluating social support and heart failure outcomes is limited. This may be the result of a lack of existing data sets on heart failure patients that also include indicators of social support, the cost and timeliness of administering patient questionnaires assessing perceived support, and a skepticism among researchers as to the relevance of social support to clinical outcomes. There is also complexity in distinguishing the impact of clinical factors, health services, behaviors and social support, which may make research on this topic more challenging and less attractive.

Inattention to this area of research may also be because little evidence exists to guide clinicians, community workers or volunteers about how to intervene to improve low social support for heart failure patients. This issue requires more study, supported by a conceptualization of what social support may offer to a patient with heart failure, and at what stage of their disease. The development of a conceptual model to guide the selection of social support indicators may be important to heart failure outcomes and would also support targeted interventions in the future.

The way forward: Conceptualizing social support in heart failure

The conceptual model guiding this thesis research, presented in Chapter 1 (Figure 2) was revisited in light of this critical review. A replica of the model is shown below. The paler sections represent relationships that were beyond the scope of this review.



The bold sections highlight the focus of this review. It was expected that the components of the initial guiding model relating to social support would be confirmed, refuted or expanded as a result of the findings revealed in this chapter.

Figure 3: Proposed model relating social support to rehospitalization and death

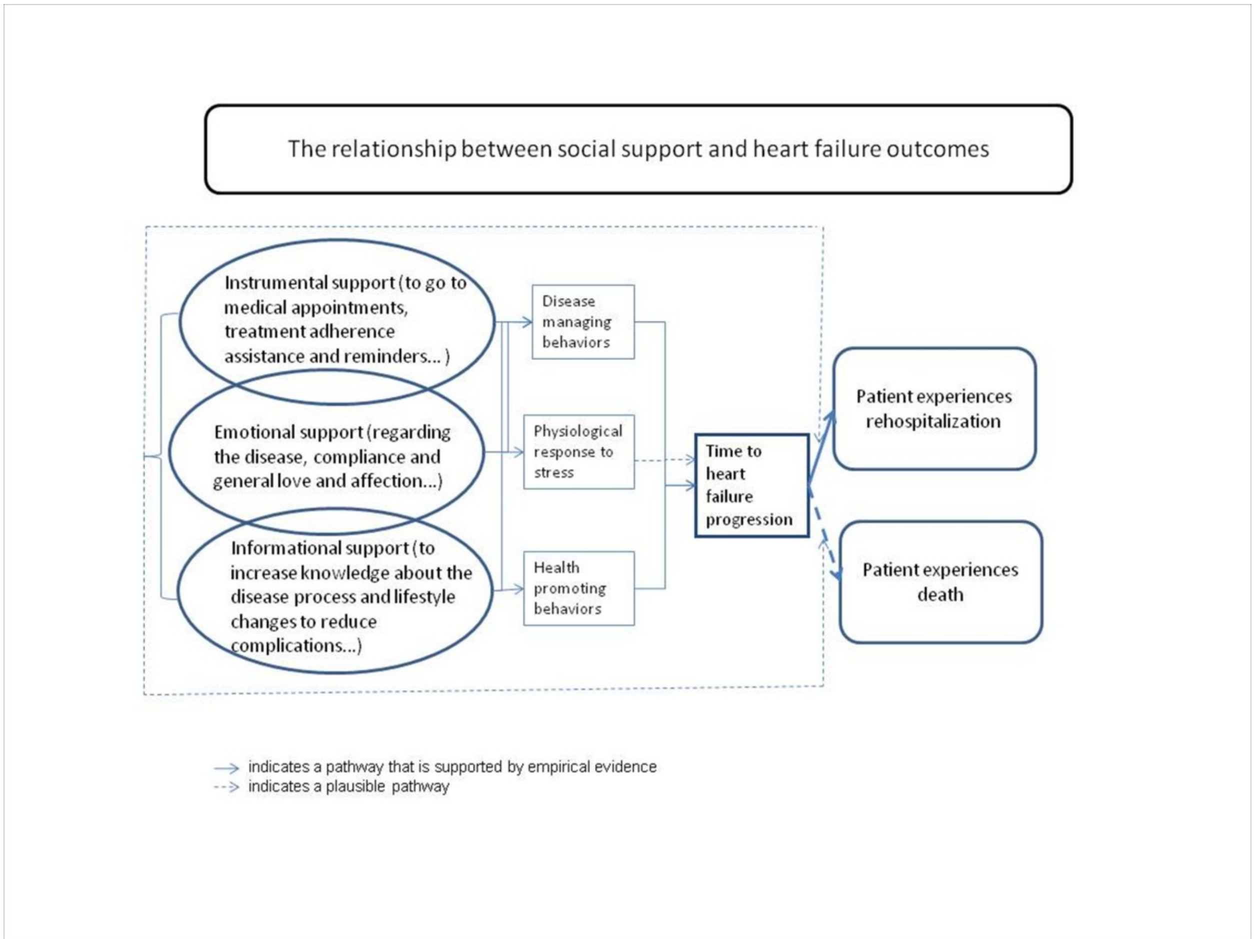


Figure 3 is a proposed conceptual model that shows the different kinds of social support that have differing impacts on specific behaviors and stresses, which are in turn related to heart failure progression. Instrumental support may facilitate access to physicians, thereby allowing for early assessment and changes to treatment. Informational support may reinforce advice from health professionals and permit patients to be more comfortable with their condition and with managing their treatment regimens. Emotional support can improve disease management behaviours and reduce the impact of stress and the stress response.

The solid lines in the diagram indicate that the pathway has been demonstrated empirically. For example, the link between instrumental support (e.g. reminders or assistance) and disease management behaviors (e.g. medication adherence), and the further link between these behaviors and outcomes, are well established. The dotted lines indicate plausible but unproven pathways. There was inconclusive evidence about the influence of social support on death, so this relationship is also shown with a dotted line between progression and death. The relationship between social support (all types) and rehospitalization after heart failure has progressed is depicted by a dotted line, given that more social support may delay rehospitalization despite a given level of progression. The overlap between the circles of social support is intended to suggest that the presence of instrumental and informational support likely provides emotional support.

A comparison of this proposed model (Figure 3) with the guiding model presented in Chapter 1 (Figure 2) illustrates the pathways that require further clarification and testing. This includes the relationship between social support and age, gender, disease severity and personality characteristics like anxiety and coping style. We hypothesize that these individual characteristics have a moderating effect on social support and heart failure progression. However, how much influence they have and the pathways through which they exert this influence is currently unknown.

The model does not address the relationship between social support and time dependent, moderating variables, such as the need and availability of social support, worsening symptoms, and newly developing comorbidities. These variables have not been well studied but should also be considered in future research. For example, the need for informational support will vary as the patient's understanding of their illness improves. Patients with advanced disease or several comorbid conditions will likely require more instrumental support than those with less advanced disease. The relative importance of these supports will vary, depending on the individual's clinical status, personality and environment.

A comparison of the two models highlights what is hypothesized to influence heart failure outcomes versus what is currently proven. This information is useful to focus future research in the field and fill the current knowledge gaps.

Limitations

This review has limitations. First, the critical analysis is based on sparse research assessing the impact of social support on heart failure outcomes. There are too few well-designed studies with sufficient sample sizes to allow firm conclusions. Second, the available evidence is somewhat conflicting, with some investigators finding no relationship between social support and outcomes, and others demonstrating strong, independent relationships. As a result, it is impossible to be certain about the circumstances and the population for whom social support is significantly related to health outcomes. Third, only social support was evaluated in this review. Other social interactions including social participation, fulfillment of social roles, as well as the availability of community resources, presence of health promoting social norms, and social capital were not investigated in the included studies. Indeed very little literature exists on if these factors might influence hear failure and the pathways through which they act. Future research should evaluate the role of these social factors in the progression of heart failure.

Conclusion

Previous reviews have reported on the results of the social support and heart failure literature. We updated these reviews and found that inferred support was not related to either the rehospitalization or mortality of heart failure patients. Perceived support is related to reduced rehospitalization and there is an inconsistent relationship reported with mortality.

We have furthered the discussion about the impact of social support on heart failure outcomes by critically analyzing the measurement of social support and also proposing a conceptual model of the causal pathways. Additional research focusing on the gaps in current knowledge can help to lay a foundation for future interventions that might enhance the quality if not the quantity of life of heart failure patients.

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Chapter 3: Social interactions and quality of life and experience with heart failure: An integrative review

Chapter 2 described a systematic review of quantitative research describing the influence of social support on the rehospitalization and death of patients with heart failure. Heart failure is a chronic condition, with which patients will live for the rest of their lives. Therefore, it is also essential to explore other significant outcomes like quality of life and the experience of heart failure patients. In this third chapter, these outcomes are examined through an integrative review of qualitative and quantitative studies.

Social interactions and quality of life and experience with heart failure: An integrative review

Seema Nagpal, M.Sc.[1], Nancy Edwards, RN, PhD, FCAHS [2,3,4],

Jafna Cox, BA, MD, FRCPC, FACC [5,6], Ian McDowell, PhD[3]

[1.] Population Health PhD Program, University of Ottawa, Ottawa, Ontario, Canada

[2.] School of Nursing, University of Ottawa, Ottawa, Ontario, Canada

[3.] Department of Epidemiology and Community Medicine, University of Ottawa, Ottawa, Ontario, Canada

[4.] Institute of Population and Public Health, Canadian Institutes for Health Research, Ottawa, Ontario, Canada.

[5.] Division of Cardiology, Queen Elizabeth II Health Sciences Centre, Halifax, Nova Scotia

[6.] Departments of Medicine and of Community Health and Epidemiology,
Dalhousie University, Halifax, Nova Scotia, Canada

Abstract

Heart failure is a progressive, chronic condition that causes a deteriorating quality of life. Positive social interactions may attenuate the harmful impact of this disease.

Objective: This review examines the association between social interactions and the quality of life and experience of heart failure patients.

Study Design and Setting: A systematic review was undertaken of published studies examining the impact of social interactions on defined outcomes. Critical analyses of qualitative and quantitative literature were followed by an integrative analysis.

Results: Twenty-two qualitative and twelve quantitative studies were reviewed. There is substantial qualitative evidence linking low social participation, fulfillment of roles and social support to adverse heart failure experiences. There was a notable subset of patients for whom the heart failure experience was not overwhelming. The quantitative studies only evaluated the connection between social support and quality of life. Three of twelve studies detected an association. This may be due to the study designs used in these analyses. A conceptual framework relating social interactions and outcomes is proposed.

Conclusion: Future quantitative research should include concepts of social interactions beyond social support. Qualitative research should probe the individual factors that impact patients' coping with heart failure.

Running title: Social interactions and heart failure

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Social interactions and quality of life and experience with heart failure: An integrative review

Background

Heart failure affects 5.7 million people in the United States.[1] It is a clinical syndrome that often leads to a rapid decline in functioning as the disease progresses. Symptoms such as fatigue, breathlessness and fluid retention require patients to become increasingly dependent on friends and family for help with daily living. Patients are forced to change their usual roles at home, work, and in the community.

Traditionally, patients have been treated with clinical interventions designed to delay progression to hospitalization or death. However, because heart failure is a chronic condition and patients live with it for the rest of their lives, quality of life is also an important outcome. Quality of life is affected by disease symptoms and functional status and may also be affected by social interactions. Social interactions include the social relationships, support and activities that an individual shares with others. We hypothesized that patients with positive and strong social interactions have delayed progression of heart failure in terms of poor quality of life and experience with the illness.

Integrative review: An innovative approach

An integrative literature review contributes to existing knowledge by bridging related areas of research that used diverse methods, and by identifying gaps in understanding.[2,3] This review includes both qualitative and quantitative studies that examined the influence of social characteristics on the quality of life and experience of heart failure patients. This design is appropriate to explore this relationship because qualitative and quantitative research studies have each made unique and valuable contributions to knowledge in this field.[4] Previous reviews of social characteristics and heart failure have evaluated each research approach separately but never simultaneously.[5-8]

Social interactions and heart failure quality of life and experience

The World Health Organization (WHO) states that quality of life "is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment." [9] Specific dimensions of quality of life have been identified and incorporated into standardized instruments like the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) and the Minnesota Living With Heart Failure Questionnaire.[10] Studies evaluating quality of life and the experience of living with heart failure assess how patients perceive their own well-being. The commonalities and differences between quality and life and experience with heart failure are evaluated in this review.

A person's social interactions include performance in social relationships, social attitudes, social support and engagement in social activities. Social interactions has been measured as the size of social network, social participation, the ability to establish relationships, the presence and quality of relationships, the use of social resources, and performing normal social roles.[11-14] Various social interactions have been associated with the incidence and prevalence of disease and with health outcomes in many patient populations.[15-20]

Welsland et al. reviewed qualitative studies describing heart failure patient experiences with the purpose of enhancing nursing care. The reviewed studies, published between 1985 and 2008, emphasized that families and friends were collectively the primary source of tangible and emotional support to patients. Heart failure was a devastating experience and patients became demoralized, frustrated, faced a loss of independence and relationships were altered.[5] Jeon et al. identified social isolation as a key concept in studies describing the heart failure experience. Isolation resulted from various factors including lifestyle changes, medication regimens, fear, and physical restrictions due to shortness of breath and fatigue.[7] Yu et al also found that patients' roles and social functioning were disrupted significantly and resulted in intense negative emotions.[8]

One quantitative review assessed the role of social support in the quality of life of heart failure patients. Luttik et al. [21] reviewed three studies, published between 1993 and 2003; one[22] provided weak evidence of a link between social support and quality of life and two studies[23,24] did not detect any association. The authors proposed two main reasons for these findings: the paucity of studies evaluating this issue; and the inconsistent way that social support was measured in the studies.

The purpose of this review is to evaluate critically and integrate the knowledge from qualitative and quantitative research examining the influence of social interactions on quality of life in patients with heart failure. We will also propose a new conceptual framework based on the findings of this review and on established theoretical models.

Methods

Search strategy and inclusion criteria

This review reports on the research evaluating the impact of social characteristics on quality of life and experience with heart failure.

The population of interest was adult patients diagnosed with heart failure. A comprehensive systematic search of databases including Medline, PSYCHLIT, CINAHL, SOCIOLOGICAL

ABSTRACTS, and EMBASE was performed to identify relevant studies. The search included studies published between 1950 and November 2009 in English or French. Additional literature was also identified by scanning the references of the reviewed papers for relevant articles. The search strategy is included in Appendix III.

Inclusion criteria:

1. The study population included adult heart failure patients
2. The study differentiated between heart failure patients and patients with other cardiovascular diseases
3. The study was not a case report or case series, nor a review article
4. The outcomes of interest included quality of life and experience with heart failure
5. The study evaluated at least one type of social interaction and its influence on the above outcomes.

Data abstraction and evaluation

Articles that met the inclusion criteria were read and examined for relevant information. Data on the study methods and results were extracted and entered into a spreadsheet. For qualitative studies, the study design (if specified by author), the data collection method, the stated purpose and the major themes of each study were abstracted. For quantitative studies, the study design, independent factors evaluated, follow-up period, the social interaction evaluated, and quality of life assessment tools and the results were abstracted.

No formal assessment was performed to describe the quality of each study, because there is no way to evaluate both qualitative and quantitative studies on the same scale. However, the findings from the included research were interpreted with consideration of their design and impact. These considerations are presented with the results of the review.

Analysis

Study findings were first analyzed within each research approach (qualitative and quantitative) individually and then an integrative analysis was performed.

Qualitative studies:

The abstracted information was read numerous times and similar themes from the primary studies were grouped together. Descriptive labels were applied to each theme grouping. After an initial set of labels emerged, the themes from the original studies were revisited to ensure these labels were clearly grounded in their primary sources. The labels were refined further and the grouping process was repeated until the original study themes had been accurately sorted and labeled. Thus, this analysis did not commence with predetermined groupings or labels, but they emerged from an examination of the findings of the original research.

Quantitative studies:

All quantitative studies evaluated social support as the only component of social interactions. These studies were too diverse in design to permit numerical aggregation of the data to estimate the overall association with quality of life. The studies used a variety of measures of social support and quality of life, and different clinical characteristics were described in each study so it was not possible to compare the patient populations. Furthermore, quality of life was measured at varying times, ranging from the same time as the social support assessment to one year afterwards. Therefore, it was considered most appropriate to analyze the studies by performing a narrative summary of their findings and a critical analysis of their methodology.

Integrative analysis:

Upon completion of the review within each research approach, an integrative summary of the qualitative and quantitative literature that described the role of social interactions in heart failure quality of life and experience was produced. In this manner, patterns, similarities and conflicts between the research findings and the gaps in knowledge became apparent and were highlighted. Theoretical models in domains outside of heart failure were explored to explain the findings. A conceptualization of how social interactions impact heart failure patients' quality of life and experience was formed through the integration of the qualitative and quantitative findings and established theoretical models.

Results

A total of 2788 citations were identified, of which 2619 did not meet the inclusion criteria based on review of titles and abstracts. The remaining 169 studies were retrieved in full for further assessment.[iv] Based on this further assessment, 135 studies were excluded, leaving 22 qualitative studies [25-46] and 12 quantitative studies [22-24,47-55] for analysis. The search process and reasons for exclusion are described in Table 2. As a means of testing reliability in abstracting the data, 25% of the references identified in the initial database search (698 of 2788 articles) were independently screened by two researchers to determine whether or not they met the inclusion criteria. The two researchers had strong agreement (Kappa=0.87, 95% CI 0.81 to 0.93). Disagreements were resolved by consensus. Despite searching the literature dating back to 1950, the earliest study that was eligible for this review was published in 1997.

[iv] One literature search was performed for the systematic reviews presented in Chapters 2 and 3. The number of citations identified, the number of references retrieved for full assessment and the reliability testing are identical for both reviews. However, the studies included in each review were based on the application of the review-specific inclusion criteria.

Table 2: Inclusion criteria and number of excluded studies

- The study population included adult heart failure patients (n=0 excluded)
- The study differentiated between heart failure patients and patients with other cardiovascular diseases (n=23 excluded)
- The study was not a case report or case series, nor a review article (n=48 excluded)
- The outcomes of interest included quality of life or experience with heart failure (n=39 excluded)
- The study evaluated at least one type of social interaction and its influence on the above outcomes (n=25 excluded)

Qualitative studies

Twenty-two qualitative studies were included, undertaken in five countries. Individual studies examined a specific aspect of the experience of living with heart failure: the day-to-day challenges; health and social care needs; perspectives of the elderly; and the male and female experiences of heart failure. Patients had a mix of disease severities, ranging from NYHA classes I to IV. Data were collected predominately through semi-structured interviews and focus group discussions. A description of studies is provided in Table 3.

Qualitative study findings

The following groupings of themes emerged from the studies: changes in social participation; fulfillment of social roles; and changes in social support and isolation. The concepts within these groupings overlap, but there were distinctions among them. These groupings are discussed below.

Changes in social participation

All studies described the impact of the disease on patients' functional ability and social participation. Most patients perceived heart failure as devastating because of the distressing physical symptoms and the associated decline in functional status. Fatigue and breathlessness did not allow patients to participate in activities they had previously performed.[34] As their illness progressed, patients described difficulty performing even simple leisure activities that involved physical exertion, such as gardening, walking and dancing.[28] Patients feared exacerbating symptoms through these kinds of activities.[42] This led them to reduce their engagement with their social network and left them feeling anxious and unsatisfied with not being able to maintain life's previous social connections and routines. The illness was described as overwhelmingly debilitating and demoralizing.[26,28,29,31,33,35-37,39-41]

While the impact of physical symptoms was highlighted in all studies, a subset of patients did not feel overly burdened in three studies. Some found comfort and refuge in religion, family support or had other coping skills that created a different experience with heart failure. [26,28,30] Theoretical models suggest that a patient's coping response is determined by their appraisal of the threat posed by their illness and the resources seen as being available to them to help cope with the situation.[56]

In summary, all authors reported that decreasing social participation as a result of debilitating heart failure symptoms has a profound negative impact on most patients with heart failure. However, there was a notable subset of patients for whom the heart failure experience was not overwhelming. Because this issue was not thoroughly explored, we were unable to determine if there were specific characteristics that accounted for this different experience (gender, disease severity, presence of different types of social support).

Fulfillment of social roles

Many patients described the difficult experience of becoming reliant on people for help with tasks they had previously performed. Yet, this type of help from family and friends was essential as heart failure progressed and patients became less able to perform daily tasks. Falk et al. highlighted how some patients received instrumental support, such as help with shopping, transportation and medical needs.[29]

The patient's sense of guilt as a result of their declining ability and consequent unfulfilled roles was highlighted in most studies. Female patients frequently reported that their partners had to perform their traditional tasks, including household chores. Male patients also felt unable to carry on their customary roles, including doing yard work and gardening. Many patients no longer felt it was possible to meet role expectations, either real or presumed. The change in their role is what seemed to negatively affect patients. These role changes resulted in a great deal of anxiety, frustration and guilt. [30,31,36,37]

In summary, many studies described the negative impact of role changes on heart failure patients' overall experience. Specifically, patients often had to transfer responsibility to others and felt remorse and a resultant sense of failure.

Changes in social support and isolation

Patients emphasized that meeting and socializing with family for support was a key asset in managing their illness. Despite their importance, most studies described a reduction in social network and social support as their disease progressed.[29,45] This seemed to occur due to inability to get out to socialize or due to the death of spouse, family or friends.[32,44] Being ill seemed to also limit some patients' ability or willingness to engage with others as they had done previously.

The decrease in patients' support also compromised their social participation: they became less able to visit friends and family, or to participate in social functions. The resultant social isolation led to patients' frustration and anger at their inability to interact as they had in the past.

A subset of patients seemed to adapt to restrictions imposed by heart failure and felt lucky to have their partners, children and grandchildren play an important part in their lives.[26,28,30] Martennson et al. described a sense of devotion and support from family felt by patients when the symptoms of heart failure became uncomfortable.[30] Rhodes et al. reported that female patients in her study had reduced interactions with former casual acquaintances, but deeper and more meaningful relationships developed. Patients had to interact differently as their disease progressed, using letters, e-mail and phone calls rather than face-to-face interactions.[33] This type of coping was described in three studies.[26,28,30]

In summary, most patients with heart failure described the negative impact of decreased social support and a growing sense of isolation as their disease progressed. Patients experienced loneliness and frustration. Nonetheless, a subset of patients adapted to the reduced social network by developing stronger, more meaningful relationships.

Critical analysis

Despite the diversity of the patient populations (e.g. male, female, elderly, palliative) enrolled in the reviewed studies and the variation in disease severity, many of the themes in the qualitative studies relating to the influence of social interactions were similar. All authors reported that the majority of patients felt that changes in their social participation, fulfillment of roles and social support negatively impacted their experience. However, there was a subset of patients in three studies for whom these changes were not overwhelming.[26,28,30] The role of personality characteristics like self esteem and adaptability, and disease characteristics like severity and symptoms, have been suggested as important factors in coping;[56] but the degree to which these attributes played a role in these heart failure patients was not explored. Additional investigations are required to examine the characteristics of patients and their circumstances that allow them to adapt to the changes that heart failure imposes and thereby buffer the negative impact on quality of life.

The data collection techniques varied across the studies. Researchers used focus groups or patient interviews to gather information. Most interviews were semi-structured and some were conducted within the presence of a caregiver or family member. It is not possible to know how these different techniques influenced the findings. However, there were a number of consistent findings despite the variability in data collection of included studies.

Table 3: Summary of qualitative studies included in the integrative review

Author	Data collection method and design (if stated in the original study)	Purpose of study	Emerging themes related to experience with heart failure
Aldred,H et al. (UK)	Focus Groups of patients with NYHA II-IV and their carers	To explore the impact of heart failure on the lives of older patients and their informal carers.	On everyday life: Symptoms, particularly fatigue and breathlessness. Impact on relationships: They could not socialize with family and friends as they used to, further roles within relationships had changed. Professional support: Professional care was generally seen as inadequate in coverage and poorly co-ordinated..Concerns for the future: Thinking about the future was a common preoccupation and worry.
Bosworth,H. et al. (USA).	Cross sectional qualitative approach using 3-focus groups or patients with ejection fraction of less than 40%.	To gather congestive heart failure patients' descriptions of components of quality of life.	Symptoms: Patients often spoke about the negative influence of physical symptoms on overall QOL; Role Loss: Change in social roles. Affective response: Depression, low self-worth, frustration, fear, anxiety, dysthymia, anhedonia, and guilt appeared to be common. Coping: Coping included both positive and negative coping mechanisms. Social support: Patients described positive and negative social support.
Brannstrom M et al. (Sweden)	Phenomenological–hermeneutic method including narrative interviews with patients NYHA class III-IV	To illuminate meaning of living with severe CHF in palliative advanced home care, as disclosed through patients' narratives.	Being aware that one's life hangs by a fine thread: Living with severe heart failure means sensing one's bad heart; visiting death's door; and being reminded about one's failing health by physiological measurements. Struggling to cope with one's unpredictable deteriorated body: This concept included difficulties in keeping one's weight stable; facing varying degrees of laborious shortness of breath; facing varying degrees of laborious pain in addition to that from the heart; facing difficulties standing on one's legs and walking, and facing laborious fatigue. Struggling with isolation. This concept means to struggle feeling lonely and being trapped at home. Being positively dependent on receiving care that facilitates life at home. This involved feeling secure when receiving palliative advanced home care
Cortis,JD et al. .(UK)	Semi-structured interviews with patients NYHA class II-IV	To explore the experiences of older adults with CHF and to gain a deeper understanding of their palliative and supportive needs and the value of possible interventions.	Symptoms: All participants experienced at least one and often several symptoms. Loss of independence: Patients often required practical help. This reliance on others was a source of frustration. Physical, psychological and social isolation: Patients were not able to get out of the house and this was considered a major problem. Loss of self-esteem and self-worth: Patients experienced feelings of low mood, worry and depression.

Author	**Data collection method and design (if stated in the original study)**	**Purpose of study**	**Emerging themes related to experience with heart failure**
Costello JA et al. (Canada)	Semi-structured interviews	To understand the experience of men and women with heart failure.	Identified 13-themes and 3 hypotheses: 1) The psychosocial impact of CHF outweighs the physical impact; 2) Sex differences exist in relation to living with CHF with men being more accepting of CHF and more likely to experience social isolation and loss than women, while women are more likely to describe fear; 3) The experience of CHF is influenced by age with physical experiences and depression mentioned more frequently in younger age groups.
Dougherty,C et al. (USA)	Semi-structured telephone interviews	To generate a grounded theory of the experience of living with HF from the viewpoint of the patient, including how patients with advanced HF view and plan for their future.	Uncertain life expectancy: The future had not been clearly described for them by healthcare providers and they were afraid to ask. Hopes: Individuals hoped that heart failure would stabilize and offer them a chance to regain control of their life. Shorten life expectancy: Several individuals mentioned that they thought they were within days of death.
Dunderdale K et al. (UK)	Semi-structured interviews of patients with varying severity of HF.	To explore HRQoL from the perspectives of people with CHF.	Changes in physical ability: there were changes in ability to perform physical tasks. Emotional state: Characteristics that were expressed by participants included fear, frustration, worry, anger, guilt, panic. Self awareness and self perception: Perception and awareness by the participant of themselves and how the condition affects them, Changes in relationships: The relationships with others around them and the reaction of others to them as a result of heart failure Symptoms: Patients experienced multiple symptoms. Maintaining social and lifestyle: Changes included social life, lifestyle, stress, side effects of medication, missing out on life and not giving up. Medication: Patient experience of side effects, having to take the medication and being reliant on medication. Cognition: Participant's experienced changes in concentration, forgetting about CHF, changes in sleep patterns.
Ekman, I et al. (Sweden)	Phenomenological–hermeneutic method including unstructured interviews of patients older than 65y and NYHA III-IV.	To shed light on the meaning of living with severe CHF as narrated by elderly people.	Feeling imprisoned in illness: Participants described feeling hindered from being of use, difficulty trusting others and not being ready for death. Feeling free despite illness: Patients also described experiences transcending illness, confiding and being ready for death.

Author	Data collection method and design (if stated in the original study)	Purpose of study	Emerging themes related to experience with heart failure
Europe, L et al. (Sweden)	Open ended questions using an interview guide of men with NYHA class II-III	To gain insight from the male patient's perspective into how it is to live with moderate chronic heart failure	Consequences of the illness: Patients thought about physical, emotional, cognitive, social, and vocational changes and included thoughts about death. Adjusting to the illness: This involved changing one's lifestyle, being aware of one's physical ability and disability, developing psychological strategies, and adjusting to medication.
Falk,S.et al. (Sweden)	Phenomenographic method using semi structured interviews of patients NYHA III-IV.	To describe how persons, living with CHF, perceived the maintenance of their daily life.	Dealing with the realities of life: Patients needed to adjust activities work in collaboration, and use creativity. Dealing with thoughts about life's infinity: Patients had to live with thoughts — past, present and future and with the state of mind. Taking responsibility: Patients had to follow treatment regime; to make one's own decisions and to use one's knowledge. Dealing with the surrounding world: Patients wanted to experience continuity; to feel trust; to be part of a social network; to deal with the local environment. Keeping up with values of life: Patients wanted to retain spare time activities; to retain lifestyle.
Heo,S et al. (USA)	Semi-structured open-ended interviews of patients NYHA II-IV.	To explore the perceptions of patients with HF about QOL.	Health status: This included physical symptoms and physical condition. Economic status This included the impact of heart failure on finances. Social factors: This included social support and social activities. Spirituality. This was related to faith in God and praying Health-related behaviours: These were primarily self-care activities. Psychological factors This included mood and positive outlook.
Horne,G.;Payne,S. (UK)	Semi-structured interviews of patients NYHA II-IV.	To explore the experiences of patients with severe heart failure and identify their needs for palliative care	Can't do: Not being able to do even small tasks or get out of the house pervaded many of the patients' lives and influenced changes and experiences of loss in every aspect of their daily living. Difficulty walking: Many had been very active but now were limited to walking around the house or short distances only. Relying on others: Patients needed to rely on those around them for help. This meant relying on their spouse or family members but for those living alone this also meant relying on friends and neighbours.
Martensson,J et al. (Sweden)	A phenomenographic approach using semi structured open-ended interviews of patients NYHA II-IV.	To describe from a nurse's perspective how female patients with CHF conceive their life situation	Feeling content: Patients described content with past life and one's present situation. Feeling a sense of support: Patients described support from those in their surroundings, ranging from abandonment to devotion. Feeling a sense of limitation: Patients described ranges between physical restriction and a social restriction. Feelings of anxiety: Patients described a sense of insecurity re: self and in relation to those in their surroundings. Feeling powerless: Patients described a sense of worthlessness and a sense of being a burden

Author	Data collection method and design (if stated in the original study)	Purpose of study	Emerging themes related to experience with heart failure
Martensson,J.et al. (Sweden)	A phenomenographic approach using semi structured open-ended interviews	To focus on how male patients suffering from CHF conceived their life situation,	Feeling a belief for future: Participants ranged from being expectant and being more self-influential. Gaining awareness: Participants ranged from feelings of no control to the ability to adapt to the symptoms. Feeling support from the environment: Patients experiences support and encouragement from the environment. Feeling limitations: Patients described feelings of social restriction with difficulties continuing to work and pursue leisure activities and one of physical restriction Lack of energy: Participants experienced physical inability, and no energy to set about doing things which have to be done. Feeling of resignation: Participants experienced indifference, in which death is the only thing to be expected.
Nordgren L et al. (Sweden)	Phenomenological approach using unstructured interviews.	To explore and describe what it means to live with moderate-to severe CHF as a middle-aged person.	Participants characterized a life situation with a failing body and heart. They experienced a rapidly changing health condition, and an altered self-image (resulting from changed social role and participation). They felt an ambiguity of the body, losing track of life, and balancing life, a life constantly under threat.
Paton B et al. (Canada)	Interpretive phenomenology approach using unstructured interview with focus on challenges encountered.	To understand the day-to day challenges encountered by women living in the community with heart failure	Three themes were documented: recalibrating time and space; balancing pathways of wishing and hoping and practicality; and acknowledging loss in persevering through uncertainty were uncovered.
Pattenden,JF et al. (UK)	Semi-structured interviews	To understand their experiences and health and social care needs	Symptoms, multiple medications and co-morbidities : Symptoms and their management made life extremely difficult for many patients. Confusion, anxiety and depression: Patients described becoming irritable and resentful at the loss of activities that had given them pleasure. Adapting my life to heart failure: All patients experienced frustration at no longer being able to do what they used to - some became housebound. Cultural and religious issues: Some patients and carers of ethnic origin had a more philosophical and derived great comfort from their spiritual and religious beliefs,

Author	**Data collection method and design (if stated in the original study)**	**Purpose of study**	**Emerging themes related to experience with heart failure**
Rhodes DL et al. (USA)	Phenomenological approach using semi structured interviews of patients with NYHA II.	To examine and describe the experience of living with heart failure (HF) from the perspective of five women who live with Stage II HF.	Acknowledging losses: Patients experience a decrease physical activity, narrowed social life, concern with maintaining control, need to work on being content and living on a tight budget. Accepting the losses: Patients felt the need to allow unfinished tasks, accept what is, and focus on the positive. Changing their lives: Patients needed to choose easier ways, change focus depend on others, search for answers and consider financial choices. Deepening relationships: Patients experiences reaching out to others, living their beliefs and deepening faith.
Rodriguez,KL et al. (USA)	Semi-structured interviews of patients, majority of whom were NYHA II (range NYHA I-IV).	To explore patients' knowledge regarding a heart failure diagnosis, their understanding of their cardiac care providers' treatment recommendations, and their views concerning the impact of heart failure on their daily lives and prognosis.	Reduced physical functioning: Patients described things that they could no longer do. Decreased quality of life: patients described experiences in terms of inability to perform social and recreational activities, such as attending church, going to a senior citizens' center, fishing, and bowling.
Ryan,M. et al. (Ireland)	Open unstructured interviews of patients NYHA III-IV.	To describe patients' experiences of living with advanced heart failure	Living in the shadow of fear: Patients experienced night terrors & precarious calm Running on empty: Patients felt out of energy & out of hope Restricted life: Patients expressed sentiments of "can't do, do it for me, doing time". Battling the system: Patients experienced difficulties with the health system.
Thornhill K et al. (UK)	Interpretive phenomenological approach using semi-structured interviews	To explore people's experiences of being diagnosed and subsequently living with congestive heart failure.	Diagnostic process: Patients described their experiences related to identifying symptoms, seeking medical help, and accepting the diagnosis. Change: patients frequently discussing the impact of their illness on their life-style, social life, ability to work, hobbies and interests. Role of others reliance: Patients felt that their own roles had been altered because they now had to rely on other people to help them with tasks. Emotional reactions: Patients had negative emotions as a result of fear and uncertainty, in response to restrictions of the illness as well as positive feelings like feeling safe, fortunate and optimistic about the future.

Author	**Data collection method and design (if stated in the original study)**	**Purpose of study**	**Emerging themes related to experience with heart failure**
Zambroski CH et al.(USA)	Semi-structured interviews	To describe and analyze the experience of adults who are living with heart failure	Experiencing turbulence: Participants reported a range of experiences associated with turbulence, from emergencies to feeling bored and frustrated. Navigating: Patients described strategies to enhance their ability to deal with the turbulence in their lives. . Finding safe harbour: Patients were trying to move from the problems and challenges of turbulence to finding safe harbor.

Quantitative studies

Twelve quantitative studies evaluating the impact of social characteristics on quality of life of heart failure patients were included. Patients in the studies had a mix of disease severities, ranging from NYHA classes I to IV. The studies were undertaken in six countries. Data were collected by patient questionnaires and chart reviews. Please see Table 4.

Measurement of quality of life and social support

Health related quality of life questionnaires are considered to be either generic or disease specific. Depending on the purpose of the assessment (comparing patients with different diseases, patients with the same disease or individual patients over time) different tools are appropriate. Heart failure specific questionnaires usually assess the ways the condition can affect the key physical, emotional, social and mental dimensions of quality of life. For example, the impact of symptoms, including shortness of breath, fatigue, peripheral edema, difficulty sleeping, anxiety and depression, are considered in most of the heart failure specific quality of life questionnaires. Four studies in this review used disease specific quality of life assessment tools, five studies used generic scales, and three used both.

Quantitative researchers assessed social support measured as either perceived or inferred support. We defined perceived support as directly expressed by the patient using a validated questionnaire designed to assess the types, quality and/or satisfaction with support. Perceived social support was evaluated in six studies. We defined inferred support as support assumed by the researcher due to the presence or absence of a spouse or partner. It was measured with proxy indicators like marital status or cohabitation. Inferred social support was measured in seven studies. One study measured both perceived and inferred social support.

Quantitative study findings

All six studies evaluating the association between perceived social support and quality of life used the Medical Outcomes Study social support scale that assesses several categories of support including informational (giving advice), tangible or instrumental (e.g. practical assistance), emotional (e.g. providing reassurance).[22-24,51,53,54] Four of these six studies failed to detect a statistical association.[22-24,54] However, Clark et al. found that overall social support was related to the specific quality of life dimensions of fatigue and emotional status. The strength of the association was low.[53] De Leon reported that overall social support was linked with the satisfaction dimension of quality of life.[51] While Bennett et al. did not find a direct association between support and quality of life in heart failure patients, they noted that increases in perceived social support predicted increases in quality of life.[23] The influence of specific types of social support was not reported in the original studies despite the ability of the scale to be reported in this way.

Seven studies evaluated the impact of inferred social support on quality of life with proxy indicators like marital status or cohabitation.[47-52,55] Quality of life was measured with seven different instruments. Of these, only one detected a significant association between being married and a higher quality of life using a multivariate analysis.[49]

In summary, the reviewed studies indicated little to no detectable impact of social support on quality of life. The majority of the evidence assessing perceived and inferred support suggest very weak (three studies) or no association (nine studies) between social support and quality of life. Patients enrolled in studies with negative and positive findings had a range of illness severity, included women and men and had varying age groups. When reviewed together there did not appear to be similarities in the patient characteristics from the studies that detected an association between social support and heart failure and those that did not detect. There was no discernable pattern to account for the differences between the studies that detected an association between social support and quality of life and those that did not.

Table 4: Summary of quantitative studies included in the integrative review

Author and country of study	Independent factor studied	Design and duration of follow-up	Association with outcome
Azevedo et al. (Portugal)	Married or living together	Cross sectional analysis of patients with NYHA I to IV	Being married or living together was significantly associated with better quality of life on most sub-domains. Quality of life measured with Short Form Health Survey- 36.
Chin et al. (USA)	Presence of partner or having someone at home to provide care	Prospective cohort study with 1 year follow up. (NYHA class not given)	Partner and care provider not significantly associated with quality of life Quality of life measured with Short Form Health Survey-36
Corvera-Tindel,et al. (USA)	Presence of significant other	Cross sectional analysis of prospective randomized controlled study including patients with NYHA II to IV	Having a significant other was not significantly associated with and quality of life Quality of life measured using Cardiac Quality of Life Index
De Leon et al. (USA)	Social support measured by MOS scale, marital status	Cross sectional analysis of a clinical trial of patients with NYHA II and III	Social support was significantly associated with QLI and SF-36 (physical functioning). No significant association between marital status cohabitation and quality of life detected.
Franzen et al.(Sweden)	Cohabitation	Cross sectional survey	Cohabitation was not significantly associated with quality of life. Quality of life measured with Short Form Health Survey-12 and Minnesota Living with Heart Failure Questionnaire
Gott,M et al. (UK)	Living alone; marital status,	Cross Sectional Survey of patients NYHA II to IV	Living alone or marital status was not significantly associated with quality of life. Quality of life measured by Kansas City Cardiomyopathy Questionnaire and Short Form Health Survey-36

Author and country of study	**Independent factor studied**	**Design and duration of follow-up**	**Association with outcome**
Luttik et al. (Netherlands)	Presence of partner	Secondary analysis of an intervention trial with 9 months follow up of patients NYHA II to IV.	Presence of partner was not significantly associated with quality of life Quality of life measured with Cantril Ladder of Life
Bennett, S et al. (USA)	Social support measured by MOS scale	Cross sectional analysis (NYHA class not given)	Social support was not significantly associated with quality of life Quality of life measured with Minnesota Living with Heart Failure Questionnaire and Medical Outcomes Study Short-Form Health Survey
Bennett, S et al.(USA)	Social support measured using MOS scale	Secondary analysis of RCT with 1 year follow up	Social support was not significantly associated with quality of life but changes in social support were significantly related to changes in quality of life. Quality of life measured using the Chronic Heart Failure Questionnaire.
Clark, D et al. (USA)	Social support measured using MOS scale	Cross sectional survey (NYHA status not given)	Social support was significantly associated with the specific quality of life dimensions of fatigue and emotional status. Quality of life was measured with the Kansas City Cardiomyopathy Questionnaire and Chronic Heart Failure Questionnaire and a single question about perceived health.
Lee,D et al. (China)	Social support measured by MOS scale and social network size.	Cross sectional survey of patients with NYHA I to IV	Social support was not significantly associated with quality of life Quality of life measured with the Chronic Heart Failure Questionnaire
Westlake,C et al. (USA)	Social support/social network measured by MOS scale	Cross sectional analysis of patients with NYHA II and IV	Social support was not significantly associated with quality of life Quality of life measured with Short Form Health Survey-36

Critical analysis

While most of the quantitative studies did not indicate a relationship between social support and quality of life, two studies evaluating perceived support and one study evaluating inferred support did. Clarke et al. and de Leon et al. detected a statistical association with items within the quality of life scale, but not with the overall assessment of quality of life. The statistical association with items within the scales might actually represent a type 1 error, which can occur when researchers perform multiple tests in the same study. These weak findings (but positive associations), combined with the well-known publication bias against negative studies[57], strongly suggest that there is no real quantitative relationship between social support and quality life, as measured in existing research. This is not to say that social support does not impact quality of life, but rather the measurement of social support and quality of life may not be sophisticated enough to describe accurately these factors for heart failure patients.

Secondly, the timing of when quality of life was measured varied across studies evaluating social support. Some were cross-sectional (n=9), while others followed patients for up to a year and assessed quality of life at the end of the follow-up period (n=3). A deterioration of functional status during that time period would impact quality of life and would modify the association. The availability and need for social support also likely changes over time and this would not have been captured with the delayed measurement of quality of life. This would have resulted in a weak detected association.

Third, the benefits of the different types of social support may vary over time with disease severity. Patients may value the presence of instrumental support at earlier stages of disease and emotional support at a later stage. The studies included patients with a range of disease severity (NYHA classification I to IV). While the three researchers who followed patients over time, statistically controlled for the disease stages at the beginning of the study, they did not control for progression over the study period, which may have influenced the results of longitudinal studies.

Fourth, most researchers controlled for clinical prognostic factors in order to investigate the independent effect of social support. However, the impact of social support is mediated by the occurrence of clinical risk factors (through changing behavioral risk factors and the stress response, discussed below). Thus, statistically controlling for clinical risk factors negates the true impact of social support because it controls for factors in the causal pathway. Inconsistent results can be expected when researchers control for different mediating clinical risk factors in their statistical analyses.

Fifth, the assessment of the relationship between social support and quality of life is complicated by the presence of social support indicators as the independent variable and dependent variable (social support is a part of many quality of life scales). Because of this measurement concern and theoretical models that suggest an association, we expected studies to report a strong link between social support and quality of life. Surprisingly, only 3 of 12 studies detected an association for heart failure patients. This may be because there truly is no relationship. However, given the strong findings emanating from the qualitative literature, it is more likely due to the methodological issues noted above and the different attributes of social support and social functioning that are measured in the different quality of life scales.

Integrative analysis

There were dramatically different findings coming from the qualitative and quantitative literature relating social interactions to heart failure. It appears that the two research designs were measuring different constructs.

Heart failure patients qualitatively described the profound impact of social participation, fulfillment of social roles and social support on their experience. These characteristics deteriorated because of the physical limitations imposed by the disease. In a circular manner, the reduced functioning was then related to a worse experience with heart failure. However, social support was the only social characteristic evaluated in the quantitative studies. The notions of social participation and fulfillment of social roles have not permeated the heart failure quality of life research. This transfer of concepts between the quantitative and qualitative research needs to occur to more fully describe important social interactions and potentially intervene to improve social functioning and quality of life.

Also of note, was that neither the qualitative nor the quantitative studies distinguished between the different types of social support (e.g. instrumental support) that influence patients' quality of life and experience with heart failure. Other factors, such as, patient demographics, presence of comorbidities or supportive community resources, may also modify the relationship between social support and quality of life and require more study.

Coping ability and characteristics like optimism and spirituality may explain why a subset of patients in the qualitative studies did not have the same poor experience with heart failure as other patients. These relationships may be important moderating factors in the pathway relating social characteristics with quality of life.

How social interactions affect quality of life and experience with heart failure

The pathways relating social participation, fulfillment of roles and social support to the quality of life and experience of heart failure patients can be hypothesized based on established theoretical models. These models, discussed below, corroborate the relationship between social interactions with both disease progression and the social and emotional well being of the patient, which in turn influence the patients' overall quality of life and experience.

First, the stress-buffering model suggests the physiological response to stress can trigger processes so that the sympathetic nervous system responds via the hypothalamic-pituitary-adrenal and the renin-angiotensin-aldosterone systems, damaging arterial walls and the myocardium. Stress is also related to a higher frequency of clinical depression and health risks, such as tobacco use. Stress can occur because of a weak support system or, for example, because of dissatisfaction with the fulfillment of social roles. Strong social support can attenuate a stress response; the absence of social support can enhance that stress response.[58]

Second, strong and positive social support can impact health behaviors in terms of compliance with drug regimens, being physically active and following a sodium restricted diet.[59-62] Adherence to treatment recommendations can reduce physical symptoms, delay disease progression and thus improve quality of life.

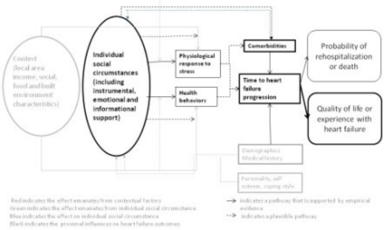
Third, the fulfillment of social roles can be hypothesized to be important because it results in the exchange of social interaction and support between the patient and family or friends. This exchange is beneficial because the patient receives support but also because giving support maintains the dignity, self worth and self-esteem of the patient. [63,64] The use of valid indicators to measure fulfillment with social roles in heart failure research is an important area for future research.

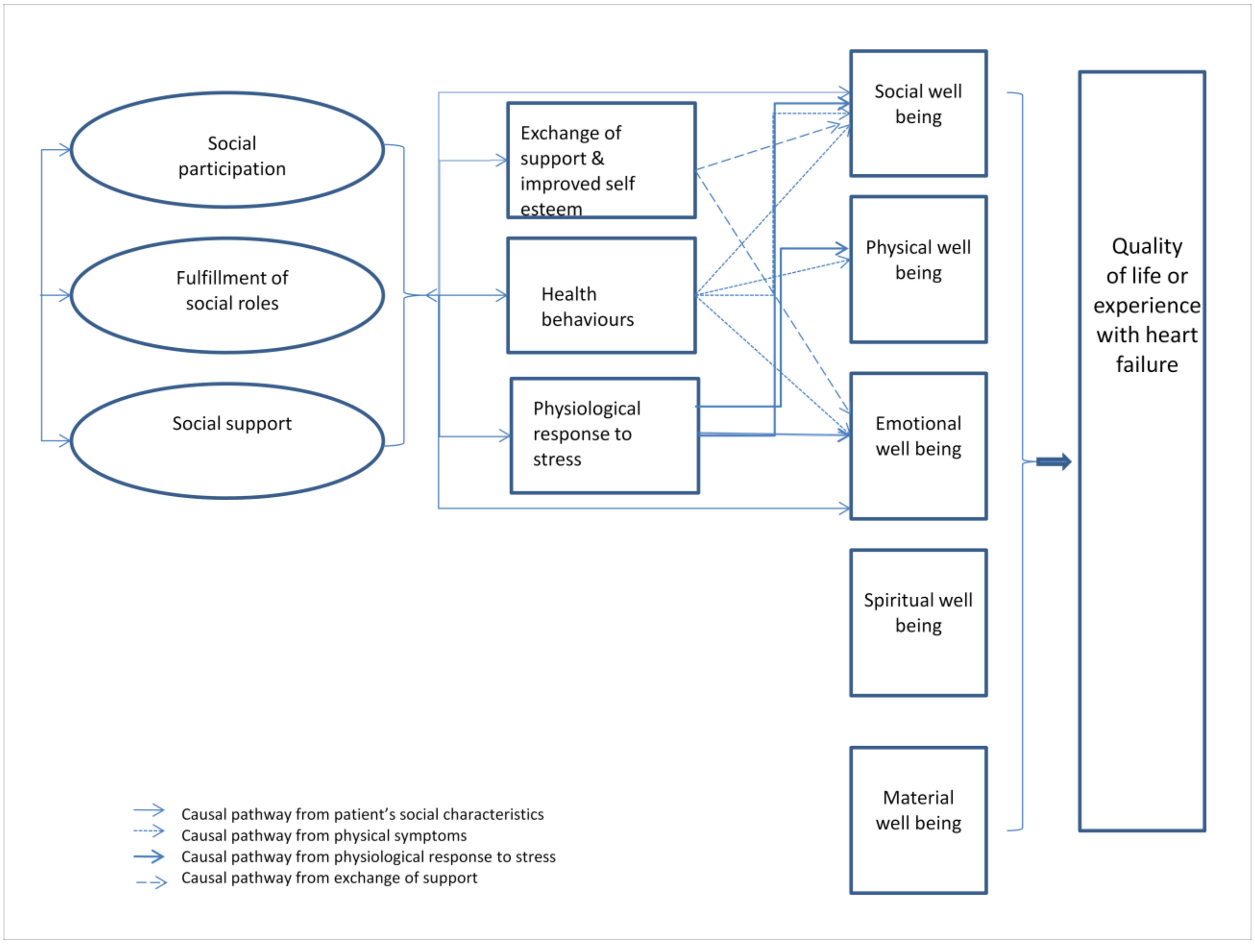
Based on the integration of the qualitative and quantitative literature and established theoretical models discussed in this chapter, a conceptual model depicting the relationship between social interactions and quality of life and experience with heart failure is proposed in Figure 4. A replica of the guiding conceptual model presented in Chapter 1 (Figure 2) is presented in the upper left corner as a reminder of how social interactions are thought to be related to other individual factors, community factors and heart failure outcomes. The bolded sections show the components of that model that were explored in this review. The paler sections of the model were beyond the scope of this review.

Figure 4 shows the interactive relationship between social participation, social roles and social support as described by qualitative studies. Each of these characteristics is shown as directly linked to social well-being and emotional well-being. Social support is proposed to impact physical well-being through influencing health behaviours and the stress response.

The importance of this conceptual model is that it shows pathways through which social interactions may influence quality of life and experience with heart failure. Making these pathways explicit can encourage more focused research in the field. It will support the selection of precise indicators of the patients' social attributes in quantitative research. It also provides a guide for topics to probe for deeper exploration in qualitative research.

Figure 4: Proposed model relating social interactions to quality of life and experience with heart failure





Limitations

Several limitations apply to this review. First, no firm conclusions were made about the patients who may most benefit from improved social interactions. This limits the application of this information to target future interventions in heart failure patients. Second, the reviewed evidence was conflicting, with quantitative evidence finding no relationship between social support and quality of life, and qualitative researchers reporting that patients strongly value social aspects of their life.

It was beyond the scope of this review to explore the relationship between social interactions and personal characteristics, such as coping and adaptation. Theoretical models posit that social support is critical for patients coping with chronic disease. Coping ability may be very important in buffering a poor heart failure experience and may work synergistically with the presence of positive social interactions. This requires further exploration.

Conclusions

Heart failure is a debilitating condition that patients endure for the rest of their lives. Factors that influence quality of life and experience are important to understand. Since these patients often suffer with debilitating symptoms and a rapid decline to death, maintaining a high quality of life for as long as possible is very important. There is little quantitative evidence to link social support with quality of life. However, the absence of this evidence is not evidence for the absence of the relationship. There is a need for better measurement of social support and social interactions in quantitative research. The qualitative literature strongly supports the importance of social interactions on the patient experience with heart failure. Qualitative research in this field can guide the development of more accurate and precise quantitative metrics. Further research in this area is critical to better understand the impact of potential social interactions on the quality of life for patients living with heart failure.

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Chapter 4: A multilevel analysis of heart failure outcomes in Nova Scotia

Seema Nagpal, M.Sc.[1], Jafna Cox, BA, MD, FRCPC, FACC [2,3],

Nancy Edwards, RN, PhD, FCAHS [4,5,6], Ian McDowell, PhD[,6], Tim Ramsay, PhD [7]

[1.] Population Health PhD Program, University of Ottawa, Ottawa, Ontario, Canada

[2.] Division of Cardiology, Queen Elizabeth II Health Sciences Centre, Halifax, Nova Scotia

[3.] Departments of Medicine and of Community Health and Epidemiology,
Dalhousie University, Halifax, Nova Scotia, Canada

[4.] School of Nursing, University of Ottawa, Ottawa, Ontario, Canada

[5.] Department of Epidemiology and Community Medicine, University of Ottawa, Ottawa, Ontario, Canada

[6.] Institute of Population and Public Health, Canadian Institutes for Health Research, Ottawa, Ontario, Canada.

Abstract

Background: Heart failure is a chronic condition characterized by frequent hospitalizations, poor quality of life, and a high mortality rate. Despite research evaluating the relationship between residential area characteristics and individual health outcomes, the role of the community in heart failure progression is poorly understood. The purpose of this study was to evaluate the relationship between community and individual level factors with rehospitalization or death in heart failure patients.

Methods: Participants were heart failure patients hospitalized in Nova Scotia, Canada from October 1997 to March 2002. Patients' demographic and clinical information and community indicators of socioeconomic status, social cohesion, material and psychological deprivation, physician availability and use of home care services were potential explanatory variables of rehospitalization or death. Multilevel analysis simultaneously assessed the relationship between the individual and community factors with outcome variables.

Results: 10 967 patients were included in the analysis. Only clinical and demographic characteristics were significant in most mortality models. Individual characteristics and a proxy for social cohesion (communities' percentage of non-Canadian citizens) were significant in the rehospitalization models.

Conclusion: The failure to find a strong relationship between community characteristics and heart failure outcomes may be due to the use of imprecise indicators included in the model. Alternatively, the findings may accurately reflect the reality that aggressively progressing heart failure is not amenable to influence from social community factors. Future research using more precise indicators of community characteristics is required to clarify these issues.

A multilevel analysis of heart failure outcomes in Nova Scotia

Introduction

The places where people live and work have been linked to a variety of outcomes, including health behaviors, prevalence and incidence of disease, and mortality rates.[1,2] Heart failure is a chronic condition characterized by frequent hospitalizations, poor quality of life, and a high annual mortality.[3] Despite the burden of this illness and substantial research into the relationship between residential context and general health, the role of community in the progression of heart failure is not well understood.[4] The relationship between community characteristics and disease progression is likely not well established because of the lack of multilevel modeling by heart failure researchers as well as the lack of theoretical models to explain the association in this patient population.

Characteristics of a community may be important for heart failure patients who are elderly and at risk of becoming isolated through poor health, limited mobility, financial constraints or limited access to transportation. These patients are more likely to spend much of their time close to their homes, so the community in which they live may have a great deal of influence on health. The relationship between community and disease prognosis does not negate the importance of individual risk factors. Community characteristics provide information about the circumstances that shape the occurrence and distribution of these individual risk factors as well as having their own direct effect. In this study, we hypothesized that heart failure patients living in communities with enhanced social and economic resources have a better prognosis beyond the influence of their individual characteristics. The purpose of this study was to simultaneously examine the relationship between selected community and individual level social factors with the outcomes of rehospitalization and death in a multilevel analysis in heart failure patients.

Community characteristics

The relationship between health and place has often been examined with census level income or education data as the local area variables. The economic status of a community has been shown to be related to many health outcomes [5-9] including a higher prevalence, incidence and mortality of coronary heart disease, even after controlling for individual characteristics.[5,9] Two studies have used community income in studying the health outcomes of heart failure patients. Philbin et al. found that higher readmission rates were associated with lower levels of average income (quartile 1 versus quartile 4 adjusted OR=1.18; 95% CI 1.10 to 1.26) after adjusting for individual characteristics.[7] They estimated income by linking patient's postal codes with census tract income data. Struthers et al. evaluated the effect of community income on emergency cardiac hospitalizations in patients with existing heart failure. They too found a significantly higher number of cardiac hospitalizations in communities with greater deprivation. (p=0.007).[8]

Diez Roux has described the community socioeconomic status as a proxy for the physical and social attributes of the community. She suggests that two main features of the physical environment contribute to cardiovascular risk: built characteristics that influence physical activity; and the local food environment.[4] Indeed, physical activity and dietary modification comprise part of the heart failure management strategy to delay progression of disease.

Built environment: The built environment refers to the arrangement of activities or land uses within the community setting, and the nature of connections among the places where we live work and play.[10] Some features of the built environment can encourage or discourage physical activity (walking). In a recent review, Papas et al. found that the presence of sidewalks, the presence of mixed land use (e.g., commercial and residential uses), the density and attractiveness of destinations, and street connectivity all influenced walking.[11] These findings emanate from studies including a range of ages and conditions, and thus are likely also transferable to heart failure patients. However, there may be some differences in the relative importance of specific features to those with a chronic disease like heart failure. There is no information on the role of the built environment in heart failure patients.

Food environment: The community factors related to the consumption of healthy foods are collectively referred to as the 'food environment'. While food consumption is an individual choice, that choice is influenced by factors such as the availability and cost of healthy foods in the local area, the presence of unhealthy foods (which are often high in salt) and food advertising.[12] The availability of healthy foods has been shown to differ across US communities such that healthy foods were less available in poor neighborhoods than in wealthy neighborhoods.[13,14] However, studies have shown mixed results in the UK and Canada.[15-17] The difference may be due to how healthy food availability was measured or other local features that may influence the accessibility of healthy foods, such as public transportation system or the urban/rural mix of the communities. It is known that diet modifications for weight reduction and reducing salt intake are an important part of self-care for heart failure patients. The association between the local food environment and food consumption remains unclear in the general population, and specifically in heart failure patients.

Social environment: Social cohesion is a characteristic of a community and relates to the degree to which groups of people feel connected, share resources, and provide moral support.[18] This construct is distinct from social support, which is assessed at the individual level.. Social cohesion may hinder or promote healthy behaviors in heart failure patients. For example, Diex-Roux proposed that social cohesion reduces the risk of cardiovascular disease and outcomes by reinforcing social norms related to healthy behaviors, by allowing residents to effect improvements in the physical environments, and by buffering adverse effects of stress.[4] Low electoral participation, which has been used as a proxy for social capital, a component of social cohesion, was associated with higher coronary heart disease incidence in both men and women even after controlling for individual level characteristics.[19] The ethnic diversity of a community has also been used as a proxy of social cohesion; and more ethnic diversity has been related to poor cardiovascular outcomes in previous US studies.[20,21] This finding has been attributed to the premise that populations consisting of individuals who are alike will feel more connected, secure and supported, than those living in communities that are diverse.

The social environment may influence the prognosis of heart failure patients by influencing its risk factors. Greater neighborhood collective efficacy, described as the willingness of community members to look out for each other and intervene when trouble arises, was linked to lower body mass index even after controlling for neighborhood deprivation.[22] A cross-sectional study of the relationship between neighborhood social cohesion and hypertension demonstrated that residents of neighbourhoods with more social cohesion were less likely to be hypertensive (90th percentile versus 10th percentile OR 0.69; 95% CI 0.57-0.83).[23] The impact of negative community characteristics on the increased prevalence of risk factors for disease progression, such as smoking, poor physical activity and nutrition, have also been demonstrated.[24-26]

Inequalities in the underlying social and economic conditions within populations have also been shown to account for differences in health. These inequalities have been measured as relative deprivation and can impact the health status of the population through impacting physiological processes, behaviours, and degrading social cohesion.[27]

A review of multilevel analyses

Many kinds of data have a hierarchical or clustered structure. Multilevel models more accurately represent the multiple and interacting pathways that are thought to influence health than do single level regression models. Studies that employ conventional single level analytical methodologies when using data from two levels have been criticized primarily because they fail to consider the existence of a multilevel structure when analyzing a patient's illness. This ignores the potential importance of group effects, and may also violate assumptions of independence made by traditional statistical analysis. The single level regression assumes that the individual residuals are independent, which is not true when examining individual level data that are nested in communities. A multilevel analysis corrects for the correlation between the levels and allows a less biased estimation of uncertainty.[28,29] It can also separate and quantify community versus individual effects.

The prognosis of heart failure patients has been investigated in one multilevel analysis. Merlo et al.[30] examined the impact of individual characteristics simultaneously with hospital characteristics and found that 30 day mortality was mainly explained by individual factors, but hospital size accounted for some of the variation.

Setting

Nova Scotia is a province with a population of approximately 900 000 located on the east coast of Canada. The province is primarily rural with two main urban centres namely the Halifax Regional Municipality and Cape Breton Regional Municipality. In 2001, the Nova Scotia population included 3.8% visible minorities[v] and 1.6% non-Canadians citizens, as described by Statistics Canada. The community median household income ranged from $15 914 to $72 188 and the percentage of the community with less than high school education ranged from 7.7% to 66.7%. Universal access to health care services is available to permanent residents defined by provincial legislation.

Methods

Study Population: Improving Cardiovascular Outcomes in Nova Scotians (ICONS)

ICONS was a prospective, population-wide disease management study in Nova Scotia, Canada that has since transitioned into a government-funded and administered provincial cardiovascular health program, Cardiovascular Health Nova Scotia (CVHNS).

The study participants consisted of all patients hospitalized in the province with heart failure from October 1997 to March 2002. A trained cadre of study abstractors obtained detailed demographic and clinical information from each inpatient chart. Data collection did not begin until a transcription accuracy rate of at least 95% for data abstraction was achieved for each individual item. This required the implementation of several quality control mechanisms such as

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[v] Statistics Canada refers to whether a person belongs to a visible minority group as defined by the Employment Equity Act. The Employment Equity Act defines visible minorities as "persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour". The visible minority population consists mainly of the following groups: Chinese, South Asian, Black, Arab, West Asian, Filipino, Southeast Asian, Latin American, Japanese and Korean.

monthly site visits, quarterly test-cases administered to all abstracters, and random chart reabstraction. Detailed information regarding ICONS methodology can be obtained from Cox et al. [31]

Patients who lived in communities designated as Reserves or where descriptive data were not available were excluded from the present analysis

Independent variables

Individual level variables

All patients enrolled in the ICONS study with heart failure were identified as potential participants of this investigation (n=11034). These patients were enrolled regardless of the frequency of previous hospitalizations. Demographic and clinical information was available for all of these participants including: sex, family history of heart disease, and history of other comorbidities. Age was divided into five groups: less than 50 years; 50 to 65 years; greater than 65 to 80 years; greater than 80 to 95 years and greater than 95 years. Patient comorbidities previously shown to be associated with heart failure were included as potential explanatory variables. Participants were defined as hypertensive or diabetic if they had a documented history of the condition or required clinical management during hospitalization. Patients were considered to have chronic obstructive pulmonary disease (COPD) if they had a documented history of COPD, emphysema or chronic bronchitis and were on pharmacologic therapy for these conditions. Previous medical history (hyperlipidemia, coronary artery disease, heart failure, AMI or unstable angina, cardiac arrest, renal disease, stroke or transient ischemic attack (TIA) were documented if reported in the hospital chart. High alcohol consumption was a positive risk factor if the patient reported drinking more than three drinks per day. Smoking status was considered positive if the patient reported being a current or former smoker. Body mass index

(BMI) was divided into four groups: less than 19.9; 20 to 24.9; 25 to 29.9; greater than 30. Patient characteristics are shown in Table 5

Table 5: Demographic and clinical characteristics of patients hospitalized with heart failure

Patient characteristics	**N=10967**
Male	49%
Median Age	76 years (range 18-102)
Mean BMI	28.21
Smokers	45%
High alcohol consumption	5%
Presence of hyperlipidemia	23%
Family history of coronary artery disease	9%
Presence of hypertension	55%
Presence of diabetes	35%
Previous diagnosis of heart failure	38%
Previous myocardial infarction	31%
Previous cardiac arrest	2%
Previous admission for unstable angina	8%
Previous diagnosis of COPD	27%
Previous diagnosis of renal failure	10%
Previous stroke	12%
Previous TIA	6%

Community level variables

Communities were defined by Nova Scotia Community Counts (NSCC) as 276 areas that follow natural clusters of the population within the province. Each community has a population of at least 1 000 residents. The specific guidelines for defining community can be reviewed at http://www.gov.ns.ca/finance/communitycounts/. The residential postal code of patients, recorded at the time of ICONS enrollment, was used to link heart failure patients to their community. The communities were characterized by 8 indicators reflecting their economic, social and health care services attributes. The income level of each community was categorized as above or below the provincial median. The communities' education was described as the percentage of the residents who had less than high school education and categorized as above or below the provincial median. These data were available from NSCC and based on 2001 census statistics.

Inequalities in health were measured as two separate variables: relative psychosocial deprivation and relative material deprivation. These data were obtained from Terashima and represented standardized scores for each community using procedures outlined in Pampalon & Raymond and Salmond & Crampton as guides.[32-34] Psychosocial deprivation scores were based on: the proportion of single parents; proportion of people living alone; and those divorced, separated or widowed. Material deprivation scores were calculated based on average income, unemployment rate and percentage of people with less than high school education. For a more detailed description of deprivation score calculations, refer to Terashima.[32] The range of each deprivation score was then divided into deciles and each community was assigned to a decile based on their score. This created two different 10-point rankings, one for the relative psychosocial deprivation and one for the relative material deprivation of each community. The ranking scores (1 to 10) were entered into the model as two potential explanatory variables.

We also examined the percentage of residents who were a visible minority, and percentage of residents who were not Canadians citizens, as described by Statistics Canada, as a proxy for social cohesion. These data were also available from NSCC and were based on 2001 census statistics. The Canadian census definition of a visible minority is persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour. The percentage of non-Canadians citizens was determined by using data from the questions that asks respondents about their country of citizenship. The percentage of visible minorities and non-Canadian citizens for each community was categorized as above or below the provincial median.

We estimated the use of home care services in Nova Scotia as a proxy for the availability of support within the community. Home care data were available from SEAscape, an assessment/case management tool used for single entry access into Nova Scotia's continuing care services. The population counts for each community were accessed through NSCC. A ratio of home care referrals per 1 000 population was calculated. This proxy variable accounted only for the total number of referrals and not the number of visits made.

We also obtained data from the Canadian Medical Association Masterfile, which contains a listing of all licensed physicians who have a valid Canadian address. A de-identified case number for each general practice/family physician and cardiologist was linked to their community of practice through their postal code. The number of general practice/family physicians and cardiologists were summed separately for each community and the number of general practice/family physicians and cardiologists per 1 000 population for each community was calculated. The population counts for each community were accessed through NSCC. All community characteristics are presented in Table 6.

Table 6: Community characteristics included in the multilevel analysis

Characteristics	Description of Indicator
Community income	Each community's income was categorized as above or below the provincial median
Community education	Each community's percentage of residents with less than high school education were categorized as above or below the provincial median
Material deprivation	Ranking of each community's relative deprivation from 1 to 10 with 10 being least deprived.
Psychosocial deprivation	Ranking of each community's relative deprivation from 1 to 10 with 10 being least deprived
Population who was visible minority	Each community's percentage of residents who self-identified as a visible minority were categorized as above or below the provincial median
Population who was non-Canadian	Each community's percentage of residents who self-identified as not being a Canadian citizen were categorized as above or below the provincial median
Referrals to home care services	Home care referrals/1000 population
Number of physicians	General practice or family physician/1000 population Cardiologists/1000 population

Outcome variables

All-cause rehospitalization or death was determined by linking each heart failure patient's unique record to their next hospital admission and with the provincial vital statistics registry. Rehospitalization or death was calculated from the date of the hospital discharge to the date of next hospitalization or date of death occurring prior to December 31, 2009. This was then categorized as 30 day, 1 year, 5 year and total rehospitalization or death outcomes. The total rehospitalization and total mortality models represented the events for patients, regardless of length of time in the study.

Statistical Analysis

The dataset was prepared using ArcGIS and analyzed using SAS 9.1 with the GLIMMIX macro and Stata Version 9.[35-37]

The postal codes from anonymized patient and physician data were geocoded using the Postal Code Conversion File + (PCCF+) to assign longitude and latitude coordinates. An intersect analysis was performed with ArcGIS 9.3 to assign the individual geographical coordinates to communities as defined by NSCC (2006). The final dataset was prepared by linking all datasets to one another using the link function in ArcGIS software.

In this study we considered patients living in a community to be more like each other than people living in a community far away. The dataset takes the form of persons nested within communities, a two level structure. Multilevel analysis was the appropriate analytical technique to assess this because we wanted to predict the occurrence of an outcome as a function of factors defined at different levels. The multilevel modeling corrected the variance estimates of the coefficients therefore accounting for the clustering or non-independence of the observations. Chi square analyses or t-tests were conducted with each independent variable and the outcomes of rehospitalization and death. The association between each factor was documented and those associations with statistical significance of less than 0.25 were employed in the multilevel analysis. We then used a backward selection procedure on the variables to exclude all those with a p-value greater than 0.05. We continued by successively re-fitting reduced models and appling the same rule until all remaining variables were statistically significant; this represented the final model. To demonstrate the independent effect of the explanatory variables in the final models, the parameter estimates were exponentiated and interpreted as odds ratios, for which 95% confidence intervals were calculated.

Because of the plausibility of sex differences in the influence of community characteristics and personal clinical, sociodemographic and economic factors, analyses were initially stratified by sex. The rehospitalization and mortality models for females and males were roughly similar so the data were subsequently combined. The final models were analyzed with sex included as a potential explanatory variable.

Results

Of the 11 034 participants who were admitted with heart failure, 65 were excluded because they matched to communities defined as Reserves for which community level data were not available and two patients were excluded because they mapped to communities for which data were suppressed due to a small sample size. Therefore, the full cohort consisted of 10 967 participants, 99.4% of the total sample. Their mean age was 76 years, 48.6% were male, one half of study participants presented with hypertension, 45% were current or past smokers and the mean BMI was 28.21. See Table 5. At the end of follow-up (December 31, 2009), there were 8 613 deaths among the 10 967 participants (79%). Among the deaths, 1 565 (18.2%) occurred during the index hospitalization and so were excluded from the model estimation. BMI was missing for 4 547 patients (41.4%). Age was missing for 34 patients. To understand the impact of the missing BMI data, we estimated the models in three ways: 1) utilizing data from all study participants and excluding BMI as a potentially explanatory variable; 2) utilizing data only from the participants for whom BMI data were available and including BMI as a potentially explanatory variable; and, 3) utilizing data from the participants for whom BMI data were available and excluding BMI as a potentially explanatory variable. These models were explored to demonstrate the effect of BMI on parameter estimates. It was clear that BMI was a major predictor of rehospitalization or death in some models, so we chose to utilize the available BMI data by including it as a potential explanatory variable. As a result, all models that retained BMI or age as explanatory variables excluded participants with missing data.

Rehospitalization

Models for rehospitalization were estimated at 30 days, 1 year, 5 years and for total rehospitalization within the study period. Individual characteristics that predicted rehospitalization in most models included: diabetes; history of heart failure; hypertension; history of myocardial infarction; history of unstable angina. History of renal disease was a significant predictor of rehospitalization only at one year; hyperlipidemia was predictive at five years and for total rehospitalization; COPD was statistically protective (borderline significance) in the model estimating total rehospitalization. A lower age was associated with a higher risk of rehospitalization at five year and total rehospitalization and lower BMI was associated with a higher risk of 1 year rehospitalization.

At the community level, the patients living in a community with fewer non-Canadian citizen residents (percentage non-Canadian citizens below versus above the median) had higher odds of 1year, 5 years and total rehospitalization. The magnitude of this effect was consistent across the time periods (one year rehospitalization OR 1.17; 95% CI 1.03 to 1.34). A lower community income placed its residents at higher odds of five year rehospitalization compared with higher income communities. These results are presented in Table 6.

Table 7: Final multilevel model explaining rehospitalization of heart failure patients

	30 day rehospitalization		1 year rehospitalization		5 year rehospitalization		Total rehospitalization	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
*Age group: 1 vs 5					1.39	0.92-2.10	1.70	1.12-2.56
*Age group: 2 vs 5					1.79	1.25-2.56	2.27	1.59-3.25
*Age group: 3 vs 5					1.95	1.38-2.76	2.35	1.66-3.32
Age group: 4 vs 5					1.64	1.16-2.32	1.82	1.29-2.57
Hyperlipidemia					1.14	1.02-1.25		
Diabetes			1.35	1.23-1.47	1.38	1.26-1.51	1.34	1.23-1.47
History of heart failure	1.36	1.17-1.59	1.26	1.15-1.38	1.31	1.20-1.43	1.25	1.15-1.37
History of COPD							0.90	0.82-1.00
History of renal disease			1.31	1.13-1.51				
History PVD					1.20	1.02-1.42	1.31	1.11-1.56
Hypertension	1.22	1.04-1.43			1.16	1.06-1.26	1.15	1.06-1.25
Previous history MI	1.28	1.09-1.49	1.43	1.31-1.57	1.46	1.33-1.60	1.56	1.42-1.72
Previous history UA			1.36	1.17-1.58	1.50	1.28-1.76	1.56	1.32-1.82
**BMI: 1 vs 4	1.29	0.94-1.77						
**BMI: 2 vs 4	1.26	1.03-1.55						
**BMI: 3 vs 4	1.42	1.18-1.72						
Community with % non-Canadian below vs above the median			1.17	1.03-1.34	1.17	1.02-1.34	1.17	1.02-1.34
^Community income:1 vs 5					1.94	0.77-4.89		
^Community income:2 vs 5					2.09	0.83-5.30		
^Community income:3 vs 5					1.45	0.57-3.74		
^Community income:4 vs 5					1.64	0.62-4.37		

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years.

**BMI (body mass index) group 1=< 20; 2=20 - 25; 3=25 - 30; 4=> 30

^Community income group1<$40 000; 2=$40 000-$49 999; 3=$50 000-$59 999; 4=$60 000-$69 9999; 5>$70 000

Mortality

Models were also estimated for mortality at 30 days, 1 year, 5 years and for the total study period. In the fully adjusted model, individual age was a strong determinant of mortality at each time interval with the youngest age group at lowest risk of death compared to the oldest group. Women were consistently at lower risk of death compared with men. Previous heart failure, COPD, renal disease and diabetes were determinants of mortality in most models. A previous stroke was significant in the 5-year and total mortality models. Hypertension and previous myocardial infarction were associated with the occurrence of total mortality. The presence of hyperlipidema and peripheral vascular disease were statistically protective in most models. Patients with a lower BMI were at higher odds of mortality than those with a higher BMI in all models. These results are presented in Table 8.

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Table 8: Final multilevel model explaining mortality of heart failure patients

	30 day mortality		1 year mortality		5 year mortality		Total mortality	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Sex (female vs male)	0.64	0.45-0.90	0.82	0.71-0.95	0.79	0.71-0.88	0.79	0.71-0.89
*Age group: 1 vs 5	0.08	0.02-0.35	0.16	0.07-0.35	0.06	0.02-0.14	0.06	0.02-0.15
*Age group: 2 vs 5	0.11	0.04-0.32	0.15	0.07-0.31	0.11	0.05-0.26	0.12	0.04-0.31
*Age group: 3 vs 5	0.14	0.05-0.37	0.27	0.14-0.54	0.23	0.10-0.51	0.26	0.10-0.69
*Age group: 4 vs 5	0.18	0.07-0.47	0.40	0.20-0.78	0.41	0.18-0.92	0.45	0.17-1.18
Hyperlipidemia			0.76	0.65-0.90	0.79	0.0.7-0.88	0.64	0.57-0.73
Diabetes	1.43	1.01-2.03	1.36	1.18-1.58			1.62	1.43-1.82
History of heart failure			1.52	1.32-1.75			1.70	1.51.1.93
History of COPD			1.39	1.19-1.63			1.54	1.35-1.76
History of renal disease			1.73	1.42-2.11			1.84	1.49-2.26
History PVD			0.72	0.54-0.97				
History of stroke							1.23	1.02-1.49
Hypertension							1.15	1.02-1.29
Previous history MI							1.22	1.08-1.38
**BMI: 1 vs 4	2.09	1.12-3.90	1.93	1.47-2.53	2.16	1.72-2.72	1.46	1.14-1.86
**BMI: 2 vs 4	1.76	1.12-2.76	1.60	1.32-1.94	1.38	1.16-1.56	1.31	1.13-1.53
**BMI: 3 vs 4	1.0	0.63-1.60	1.36	1.13-1.64	1.15	1.00-1.32	1.15	1.00-1.32
^More educated community versus less educated community					0.85	0.73-0.98		

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years. **BMI (body mass index) group 1=< 20; 2=20 - 25; 3=25 - 30; 4=> 30. ^A more educated community was defined as one in which the percentage of people having less than a high school education was below the provincial median.

Only one community variable predicted mortality. Patients who live in a more educated community (defined as one in which the percentage of people having less than a high school education was below the provincial median) were at lower odds of five-year mortality.

Discussion

The multilevel models predicting rehospitalization included several individual level risk factors well known to be associated with poorer outcome. Diabetes, history of heart failure, myocardial infarction, and unstable angina and hypertension were all significantly related to increased rehospitalization. Interestingly, patients' age was inversely related to rehospitalization. Patients in the younger age groups had a higher odds of rehospitalization compared to older age groups in the models for rehospitalization at five years and in total. The reason for this finding is uncertain; but we hypothesize, that it may be because of more aggressive treatment in the younger age group by health care professionals, that younger patients more actively seek health care when symptoms appear, or that elderly patients hesitate to call on relatives to ask for assistance with going to the hospital.

At the community level, patients living in communities with a higher percentage of Canadian citizens had higher odds of rehospitalization compared with patients living in communities with more non-Canadian citizens. This association was detected after controlling for the age, sex, and comorbidities of the individuals as well as the number of physicians, and socioeconomic status of the community. Three competing hypotheses are proposed to explain this finding. The first explanation is based on the view that the finding reflects characteristics of residents and processes occurring at the individual level (a compositional perspective). The greater frequency of rehospitalization in the community with more Canadian citizens may represent the health care that is given for the natural progression of the heart failure. If this is the case, the lower rehospitalization rate in communities with more non-Canadian citizens may represent an unmet need for health care among immigrants. Thus, non-Canadian citizens or immigrants may access health care less frequently than native-born Canadians. Previous research has demonstrated that recent immigrants have less access to family physicians, fewer consultations with any physician, and less frequent blood pressure measurements.[38] Canadian researchers have shown that, over time, the use of these health care services can converge to native-born Canadian rates.[39,40] But this increase may not be adequate and highlights a possible unmet need for health care among immigrants.[41] The reduced access by immigrants may be related to barriers like language and communication, low socioeconomic status, cultural differences, or a lack of knowledge of how to access the health care system.[42] The individual characteristics of immigrants, including age, income, education, and time living in Canada also likely moderate the influence of these barriers. The second hypothesis, also taking a compositional perspective, proposes that support systems may be more readily available to elderly immigrants. Cultural expectations for family support and home care may dictate that aging and especially ill parents live with their adult children or in close proximity. Elderly immigrants are more apt to live with their adult children rather than independently as compared to native-born counterparts.[43,44] Other demographic characteristics, like age and marital status also partially influence living with family.[43,44] Culture and belief systems play a role in the living arrangements, support availability and the provision of care to family members. In contrast, other Canadian researchers have indicated that foreign-born populations have equal or even better access to care compared with their native-born counterparts.[42,45] In the present study, we were unable to distinguish the hospitalization patterns of Canadian citizens versus non-Canadian citizens at an individual level since immigrant data was only available at the community level.

The third hypothesis explaining why patients living in communities with a higher percentage of non-Canadians residents had higher odds of rehospitalization focuses on processes occurring at the community level. These processes may include a greater diffusion of health information and a social norm of health care resource use other than hospitals, like family physicians or urgent care clinics in the community. Most research on ethnic diversity has described the difficulty that diverse communities have in terms of generating cooperation, trust and support necessary for collective action.[46-49] However, more recent additions to the literature propose that frequent and positive social interactions in diverse neighborhoods can help generate interpersonal trust.[46,50-52] In Detroit neighborhoods, Marschall et al. found that diversity was positively related to trust and social interactions in heterogeneous places compared to places where people were more racially similar.[51] Derose combined Florida hospital discharge data with several other administrative datasets and found that more racial and ethnic diversity was related to lower adult rates of preventable hospitalizations, including for heart failure.[52] Stolle et al. also challenged the notion that diversity has a negative impact on generalized trust and suggest that these effects are mediated by social ties and interactions within the diverse community.[50] These authors have suggested that ethnic diversity can build bridging social capital, which brings people of diverse backgrounds together, crossing ethnic, racial or religious boundaries. Bridging social capital links people who might not otherwise associate and enables groups to leverage resources, ideas and information. It is important for information diffusion.[48] Derose also proposes that such bridging ties may have actually facilitated diffusion of health care information in her study.[52]

The pathway that is responsible for fewer rehospitalizations of patients living in Nova Scotia communities with more non-Canadian citizens requires more exploration. The validity of the three hypothesized mechanisms requires more research. Studies that deeply probe the individual characteristics of health, social support systems, health beliefs, and health care utilizations simultaneously with indicators of social capital will help to clarify these relationships.

The present multilevel analysis also revealed that the variation in mortality of heart failure patients was mainly explained by individual differences between patients. As could be expected, older age as well as history of myocardial infarction, COPD, renal disease, hypertension, diabetes and stroke were individual determinants of increased mortality. Also consistent with the previous studies, women were at lower odds of death even when individual comorbidities and age were controlled. Counter-intuitively a history of hyperlipidemia, peripheral vascular disease and an increased BMI were associated with lower odds of mortality. This paradoxical finding has been documented for obesity previously. [53,54] It remains unclear if this represents a protective aspect of the factors, if physicians treat these higher-risk patients more aggressively resulting in delayed deaths or if other mediating variables need to be uncovered.

Numerous studies have suggested that local area characteristics may exert an impact on mortality. Somewhat surprisingly, a low community level education was a risk of increased mortality in only one of our models. One reason may be that community characteristics included in this analysis were not adequately precise. Indicators of socioeconomic status are commonly used in statistical analyses because they have been considered to be proxy variables for the physical and social attributes of the community. It is possible that more direct measures of these attributes would have revealed an association with mortality. Future research should evaluate direct measures of social cohesion through questioning residents of communities and by obtaining direct measures of physical environment such as the type of the land use, density, the attractiveness of the environment, as well as the availability of healthy foods. A second reason may be that statistically controlling for clinical risk factors actually controls for the pathways through which community level factors act. For example, communities with lower socioeconomic status have higher rates of clinical risk factors, like hypertension. The lower prevalence of smoking has been associated with higher social cohesion. [26] The third possible reason for the absence of significant findings may be that the progression of heart failure is so aggressive that, once established, community factors cannot alter the poor trajectory. The impact of the physical and social attributes of the community occurs over the long term; the rapid decline of heart failure may be too strong to be influenced by these determinants in the short term. Perhaps the incidence of heart failure, which is often an outcome of other chronic cardiovascular diseases, is influenced by community factors, but mortality, after the onset of heart failure, is not.

Limitations

This multilevel analysis is the first study of heart failure patients to evaluate the impact of community level and individual level factors simultaneously. However, the ideal set of indicators that reflect community attributes were not available for this study. Purposeful collection of survey data questioning the presence of social capital and social support are necessary to adequately answer the questions about the influence of the social context. More precise indicators of the physical environment and the food environment, such as the presence of sidewalks or supermarkets respectively, would improve the estimation of their effect on heart failure outcomes.

Secondly, we also must acknowledge that the composition of the ‘more Canadian’ communities (fewer non-Canadian citizens) identified in our study is actually quite heterogeneous. Immigrants and second-generation immigrants who are Canadian citizens may hold the cultural beliefs and traditions for providing family support of their home country. Over time, acculturation occurs as the foreign born Canadians (and their children) engage in continuous contact with a Canadian socio-cultural system. However, the degree to which acculturation had occurred was not estimated for this study. At best, the differences between communities, based on percentage of non-Canadian citizens, is a very crude proxy measure for community heterogeneity and social cohesion. Different cultural norms across immigrant groups is a further complicating factor highlighting Canada's heterogeneous population.

A third limitation of investigating the community effects on prognosis as assessed by rehospitalization is that the participants may be a healthy subsample of the whole population simply because they are the patients who survived, despite living in deprived environments. The patients who were most vulnerable to the potentially detrimental impact of an 'unhealthy community' may have died, rather than returned to the hospital. This would have resulted in underestimates of the true community effects.

An additional limitation of these analyses is the use of postal codes to assign patients to a community. Postal codes span large geographic areas, especially in the rural parts of the province and Nova Scotia is a largely rural province. These large geographic areas cross community boundaries and can result in misclassification of the assigned community. This too would result in an underestimation of the true community effect.

Finally, the observational nature of the study makes it impossible to conclude any causal processes. We described both expected and unexpected independent predictors of the variation in rehospitalization and death. Specifically, the inverse association between rehospitalization and age, the paradoxical relationship between hyperlidemia and peripheral vascular disease and BMI and prognosis and the role of non-Canadian citizens in the community, require further work to elucidate the processes underlying these associations. An improved understanding of these processes can further advance the development of a conceptual model to improve outcomes for heart failure patients.

Conclusion

In conclusion, we observed that heart failure outcomes were primarily influenced by individual level characteristics. There was a lower odds of rehospitalization for patients living in communities with more non-Canadian citizens. The association persisted after adjustment for many important demographic, medical history, and clinical characteristics. Thus, this finding poses important questions about the health of immigrants in Canada. Future analyses focused on heart failure in immigrants, are required to probe this finding more thoroughly

To our knowledge, we have performed the first study that examined heart failure progression as a function of individual characteristics as well as community-level factors in a multilevel analysis. This study provides fodder for additional research investigating the impact of community social cohesion, physical environment and food environment on heart failure outcomes.

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Chapter 5: Integrated discussion and conclusion

A population health approach was used in this research, reflecting the importance of multiple levels of influence as well as the upstream and downstream factors that affect health outcomes. Population health reaches beyond medical care in the interest of promoting healthy behaviors and environments, and includes the social determinants of health. In the previous four chapters, I examined the role of patients' social circumstances in the progression of heart failure. Social circumstances refer to the community social characteristics that impact groups of people as well as their individual demographic and economic characteristics and the interactions that occur within this network. Social characteristics like social cohesion and social norms comprise the social fabric of community life. But are any of these social circumstances relevant to the progression of heart failure or other chronic diseases? What are the causal pathways? Are there mediating factors? Which outcomes are affected? The research in this dissertation addressed some of these important questions.

Previous studies have evaluated the impact of social circumstance on the incidence of chronic disease[1] as well as its prevalence[2]; others have investigated the impact on disease progression.[3,4] This mixture of outcomes makes it difficult to sort out the impact of these factors on the etiology of disease from their impact on survival. This may in-part be why it has been difficult to provide a consistent and precise estimate of the relationships between social circumstance and the progression of chronic disease. The difficult research design issues and the complexity of the relationships between social circumstances and chronic disease outcomes have challenged researchers and policy makers working in this field. The empirical research and critical analyses presented in this thesis examined the relationship between social circumstances and heart failure.

The role of social circumstances in heart failure is not well understood and is of particular concern because of heart failure's debilitating symptoms and the number of people it affects.

This chapter summarizes and integrates findings of the research and relevant supporting literature. It is divided into four sections that provide a description of:

A. What is known about individual level and community level social circumstances that influence heart failure progression and their causal pathways;
B. An expanded conceptual framework of heart failure progression;
C. Contributions of this research; and
D. Recommendations for future research.

A. What is known about individual and community level social circumstances that influence heart failure progression and their causal pathways

Information provided by this research

Three investigations were performed as part of this doctoral thesis. The two systematic reviews and a multilevel analysis collectively provided knowledge about heart failure progression. The study design used in each of these investigations allowed for a new perspective into the progression of the chronic disease. Methodological limitations of previous studies, such as the use of crude proxy indicators, were examined, and problems with secondary use of data were highlighted.

The first inquiry of the thesis involved an analysis of existing literature. This systematic review of fourteen studies examined the quantitative association between social support and rehospitalization or death in heart failure patients. The review revealed that there is an under-conceptualization and a wide variation in the measurement of social support across the studies. Insufficient evidence was found to link rehospitalization or mortality to inferred support. Inferred support was defined as support measured by proxy indicators, such as marital status or cohabitation. Low perceived support, assessed by validated measures of social support, was related to higher rehospitalization rates; but the relationship with mortality was inconclusive. A narrative summary of previous research was provided, but the strength of this review was the critical analysis of previous methods and findings. Possible explanations of the tenuous relationship between social support and rehospitalization and death were highlighted. These included the use of different indicators of social support in the various studies and an inadequate conceptualization of the causal pathways to guide the choice of measurement tools and study design. A model was proposed to specify how social support could be linked to rehospitalization or death. The model was grounded in established theoretical models[5] linking increased social support with health behaviours and a reduced physiological response to stress.

This critical review also provided the backdrop for the second line of inquiry, an integrative review that included 22 qualitative and 12 quantitative studies. The integrative review examined the impact of social interactions on quality of life (quantitative studies) and experience with heart failure (qualitative studies). Substantial qualitative evidence linked inadequate social support, participation and fulfillment of roles with a poor heart failure experience. There was no quantitative evidence to connect social support with quality of life. This review assembled evidence that demonstrated additional factors, other than social support, impacted the patients' quality of life. The strengths of this integrative review were the inclusion of both qualitative and quantitative studies and the integration of findings. The discrepancy between the research traditions provided interesting insights to guide future research in this field including: the need for more precision in the measurement of social support; the investigation of the interaction with other factors like disease severity; and the need for better communication between qualitative and quantitative researchers to stimulate cross-fertilization of knowledge advances in each discipline.

The third line of inquiry involved an empirical study that examined the role of selected individual and community level factors in a multilevel analysis. This study found that the majority of variation in the death and rehospitalization of heart failure patients was due to individual clinical factors. Despite the theoretical plausibility of the relationship between the social characteristics of the community and death, no consistent relationship was detected in the multilevel models. There was a consistent influence of the percentage of non-Canadian citizens living in the community, a proxy for community social cohesion, on rehospitalization. Due to the observational nature of the study, the causal pathways could not be clearly identified, but three hypotheses, taking compositional and contextual explanatory views were proposed. This population-based study was unique in that it represented all hospitalized Nova Scotia residents with heart failure, regardless of age, income or rural/urban residence. A multilevel modeling technique was employed, which more accurately represents the complexity of the many factors that influence health outcomes. This was the first study to investigate the impact of community characteristics on heart failure outcomes in a multilevel analysis. Yet, despite the combination of multiple datasets and the application of sophisticated analysis techniques, I lacked all the comprehensive data necessary to definitively establish the role of individual and community social characteristics on heart failure progression.

Individual level social interactions and chronic disease

Social interaction is a term that includes more specific and directed concepts such as social support, participation or roles. Although there is no empirical evidence to link social interactions with heart failure outcomes, there are theoretical models for hypothesizing that the association exists (discussed below). It is essential to disentangle the components of these interactions and add conceptual clarity. A description of social support, participation and fulfillment of social roles and their pathways to outcomes will advance the discussion about their potential impact on chronic disease and guide future research. The literature reviews presented in this thesis combined with established theoretical models help specify the type and nature of social interactions on heart failure outcomes.

Social support and heart failure progression:

Social support is a multifaceted concept and many authors have discussed how the various definitions and imprecise language has had consequences on the interpretation of social support research.[6,7] Researchers have sometimes tried objectively to estimate social support by counting the number of social contacts or frequency of contacts; however, this is actually measuring the social network. Although social support is rooted in having a social network, having a large social network does not necessarily mean that a patient is well supported in their illness. Social support is dependent on the quality and satisfaction with those relationships. These terms and variables should not be used interchangeably as they measure different attributes.

Social support is commonly divided into three main types: instrumental support (e.g., providing tangible assistance with a problem), emotional support (e.g., giving reassurance) and informational support (e.g., giving advice). A detailed description of the different types of social support and the significance to heart failure progression was previously provided (Chapter 1). The need for the different types of social support may depend on the severity of heart failure as well as the individual characteristics of the patient. This hypothesis was proposed in the integrative review to explain why a subset of patients in three of the reviewed studies did not have the same poor experience with heart failure as other patients. I suggested that it is very likely that informational support is critical during the diagnosis and early stages of disease. Instrumental support may be more important as the disease progresses and there are numerous medical appointments or hospital visits. Emotional support is likely to be more essential during the end stages of disease. I also hypothesized that social support may enhance some heart failure patients' coping response. However, the relationships between the types of support, disease severity and coping responses, and the subsequent impact on the heart failure experience were not deeply explored in the original studies.

Despite these linkages identified in the qualitative studies, the quantitative relationship between social support and mortality, rehospitalization and quality of life was, at best, weak. I suggested several possible study design and methodological explanations for this weak relationship between social support and heart failure outcomes.

Other components of social interactions were identified in the qualitative literature as important in the patients' experience with heart failure. These other interactions, including the ability to participate socially and fulfill social roles may be very important in heart failure and other chronic diseases because of the long term nature of the disease and the physical symptoms. These disease limitations can affect the quality of marital relationships and friendships, household responsibilities, ability to work and social activities. The inclusion of social support or social networks in the understanding of which social interactions might impact chronic disease progress, while necessary, is not sufficient. The other components of social interactions and how they relate to individual clinical and personality characteristics need to be incorporated into research. These concerns have been also been raised in relation to other chronic conditions, including cancer and arthritis.[7,9-11]

Fulfillment of social roles and heart failure progression

The importance of fulfilling social roles on the overall experience of heart failure was highlighted in the qualitative section of the integrative review. Role changes have been less extensively studied than social support. However, researchers in other disciplines have established that social role changes in different circumstances (after the death of a spouse or with retirement) are associated with subsequent poor health outcomes. This evidence provides additional plausibility for the impact of social role changes on outcomes of heart failure and chronic disease populations.

Possible mechanisms for the effect of social role changes were illustrated in a study by Christakis et al. These investigators documented that a wife's risk of all-cause death was 61% greater during the first 30 days following the death of her husband.[12] A husband's risk of death during the first 30 days after the loss of his wife increased by 53%. Christakis proposed that years of marriage meant that people become dependent on their spouse for support, personal interactions and also facilitating interactions with others. He hypothesized that the death of the spouse imposed stress on a partner due not only to the actual loss but also to a reduced amount of social, emotional, and economic support available from others. Over the short term, the living partner adapted to the stress of the loss, so that the health risks declined. Over the longer term, however, the decrease in support continued and that is what likely led to a subsequent increase in the risk of death, resulting in a U-shaped pattern. In a manner analogous to the changing role of a surviving spouse, I propose that a patient with a chronic disease, like heart failure may experience similar patterns of stress, and reductions in support and interactions with social roles changes.

Similarities might also be drawn between heart failure patients' changing roles and changes that between retirement and all cause-mortality (after controlling for baseline age and medical conditions). The magnitude of effect was greater for cardiovascular mortality than for cancer mortality, whereas, for injury mortality, there was no evidence of an association. More recently, Behncke found a significant increase in mortality due to cardiovascular diseases and cancer for male retirees in the UK.[13,14] Dave et al. modeled the impact of retirement on subsequent health outcomes and found an increase in difficulties associated with mobility, daily activities and illness as well as a decline in mental health over six post-retirement years.[15] The change in social role can cause a reduction of social interactions, including participation and support. This may be stress inducing and stress is related to various negative health effects, described below. However, this evidence regarding the impact of retirement on health is not definitive. For example, Bound and Waidmann performed a study of UK retirees and found no significant negative health effects of retirement and even some positive effects for men.[16]

There is evidence that health behaviours can change (positively and negatively) after this role change. For example, retirees were more likely to quit smoking[17]; to engage in regular exercise; and to have lower stress levels.[18] However, retirees also have reduced social interactions [14], and gain weight.[19] In her study, Behncke concluded that retirement alone cannot predict harm or benefit to a specific individual and individual characteristics such as the presence of spousal support may modify its effect.[14]

As described above, there is evidence regarding the influence of role changes on health outcomes. However there are limited data about the influence of role changes in chronic disease patients. Based on the available evidence in other settings, combined with the theoretical framework presented below, there is a solid foundation to hypothesize that role change influences chronic disease outcomes. The research in this thesis advances this field.

The pathways linking social interactions with heart failure progression

Important outcomes of disease progression include the heart failure quality of life, rehospitalization or mortality. Social support may have an impact on heart failure progression through its influence on psychological and physiological processes. The receipt of social support and the presence of a quality social network have been linked with general well being in the literature evaluating other disease states. Patients experience less anxiety and more happiness with social support.[20-22] The presence of social support is the basis of the hypothesis presented in Chapter 3 to explain why some patients did not feel overwhelmed with heart failure.

The two most commonly cited theoretical models describing the potential pathway between social support and physical health are the main effect model and the stress-buffering model.[5] The main effect model purports a link between social support and disease regardless of stressors. Positively supportive relationships can encourage health-promoting behaviors or stress avoidance through both the provision of support and the exertion of social controls to influence health behaviors. These behaviors may be encouraged by delivering tangible support (e.g. providing healthy foods) or increasing self-esteem to promote healthful rather than harmful health practices. There is a demonstrable link between health behaviors, such as diet modification, and taking recommended medications with a reduction in rehospitalization and death of heart failure patients.[23]

The stress-buffering model proposes that social support protects patients from the potentially destructive effects of stress. This risk occurs because stress triggers a neuroendocrine response or arterial flow disturbances or because there are behavioural adaptations to stress that increase the risk of disease (e.g. excess alcohol intake, tobacco use).[5] There are two potential places where social support can act in this model. First, it may have its effect before the negative response to stress resulting in a benign evaluation of the stressor. Alternatively, support may attenuate the magnitude of the neuroendocrine response to the stressor. This affects health by producing an altered evaluation of the stressful event and a reduction of the subsequent physiological and behavioral responses that are harmful to health. I hypothesize that chronic levels of stress may be related to poor heart failure outcomes through, for example, an increased risk of myocardial infarction, stress related behavioural risk factors like smoking (which increases the risk of morbidity and death) and a lower perceived sense of well being.

In addition to the main effect and stress buffering models, social exchange theory and self-esteem theory also provide some insight into the potential influence of social support and social role changes on heart failure outcomes. The self-esteem theory posits that the mutual exchange of social support reinforces feelings of respect.[24-26] Self esteem can be enhanced when a person fulfills their perceived role. Not only does self-esteem impact directly on how one deals with major events like illness but it also affects whether the individual seeks and accepts assistance. Self-esteem is a characteristic of the individual and may function to reduce stress and facilitate social support, which I have described as potential contributors to heart failure progression in Chapters 2 and 3.

The social exchange theory proposes that reciprocity is another mechanism through which social support is influential. Patients benefit from giving support as well as from receiving it. According to this theory, the exchange of support has multiple functions.[27] When support is received repeatedly the patient feels increasingly secure that they will be assisted again should the need arise. Secondly, giving support adds to their worth and dignity and the patient may consequently be more willing to accept assistance when it is needed. Giving support often occurs in the context of fulfilling social roles. The implications of social exchange for heart failure progression may be in terms of the direct benefit of the social support as well as the stress reducing benefit of the reciprocal exchange.

Summary and Integration

The conceptual basis for the linkages between social support and health is well established. It is clear, however, that most of the quantitative heart failure research has not incorporated these conceptual models either into study design or interpretation. The multiple and crude indicators of social support used in much of the existing empirical studies have not accurately described the relationship in this patient population; indeed they cannot do so. For example, the use of proxy indicators like marital status do not take into account the positive or negative quality of the relationship; and the inclusion of patients at varying stages of disease does not respect the changing needs for different types of social support along the continuum of the illness. The result is a tangled web of positive and negative studies that are difficult to interpret in aggregate, as demonstrated by the systematic reviews in Chapters 2 and 3.

Many authors have suggested that the relationship between social support and disease should be based upon a theoretical framework relating support through psychological and physiological processes to health outcomes.[5,6,10,11] But secondary analyses make up much of the current literature, which does not allow researchers to utilize the indicators that best fit the conceptualization of social interactions and its mechanism of action. In order to answer the questions about the role of social interactions in chronic disease progression, researchers need to prospectively and purposefully collect this information. However, this approach is expensive, time consuming and requires collaboration with experts in the social sciences. Nevertheless, this is the basis for discovering the specific relationships between social interactions and chronic disease outcomes. This knowledge is integral to determining if and how interventions could be designed to improve the lives of heart failure patients.

The importance of social interactions has not sufficiently permeated the quantitative heart failure literature. While social support has been assessed, its measurement is inadequate and other aspects of social interactions have been ignored. Patients feel that social participation and fulfillment of social roles are also critical components of their experience with the disease. These causal pathways relating social role change with chronic disease outcomes require clarification. We know that patients must function differently as a result of their disease. They are often required to change the way they had previously given and received social support, leisure activities, and participated socially. This may result in role changes in their marriages, with their children and friends and perhaps their employers. Most patients described this as a negative part of their disease experience. However, this role transition may or may not have harmful health effects, depending on the environmental characteristics, individual coping resources, quality and satisfaction with social support and needs of the patient, any or all of which may buffer the change in roles and functioning. Indeed, there was a sub-population that emerged from the analysis of the qualitative literature (Chapter 3) that did not suffer the deleterious changes in social interactions. It is quite plausible that some of the individuals had strong social support, as noted above, and this may have facilitated an adaptation to their illness. This is a hypothesis that requires more investigation.

Community level characteristics

Recently there has been an explosion in the public health literature regarding the importance of context or local residential environments as key determinants of physical, mental and self-perceived health.[28] The environment in which a person lives is multi-level (family, community, municipality, province, country). Processes at each level may influence health; these influences are nested within each other, and represent dynamic and interactive relationships. The local environment may be an especially important resource for heart failure and other chronic disease patients. These people are often elderly and at risk of becoming socially isolated through poor health, limited mobility, financial constraints or limited access to transportation. As a result, most of their time is likely spent in and around their homes so their local neighbourhood (or community) has potential to have a great deal of influence especially at advanced stages of disease.

If we believe that neighbourhood characteristics influence health, the causal pathways for this linkage should be clearly articulated. Macintyre et al. described the mechanisms underlying neighbourhood associations with health in two distinct ways: the compositional and the contextual perspectives.[29] The compositional view argues that the health of the neighborhood is the result of the shared characteristics of residents. The essence of this perspective is that like-people live close to each other, either because they have a common culture and belief system or out of necessity due to similar economic status.[29,30] However, numerous authors have described persistent variations in health between neighbourhoods that cannot be explained even after controlling for the individual demographic characteristics of its residents.[31,32] A contextual perspective posits that variations in health, by neighborhood, are attributable in part to the features of the neighborhood itself.[29,30] Contextual features are comprised of both the physical and social environment and they affect the whole group of individuals residing within them.[33] Authors have more recently suggested that the compositional and contextual components of the causal pathways are not mutually exclusive, but rather interactive and dynamic, and that both ought to be considered.[34,35]

Researchers frequently describe community characteristics as the average community income or education or relative disadvantage compared to other communities. Diez-Roux has proposed that these indicators are actually proxies for the more specific features of neighborhoods. She has described the features that may be causally related to cardiovascular disease into three main categories: the built environment, the food environment and the social environment.[33] The multilevel analysis presented in Chapter 4 evaluated the impact of selected individual and community social factors on heart failure progression. An ideal set of indicators reflecting the communities' social characteristics were not available. The potential importance of the communities' food and built environment were recognized; however, I was unable to access data to describe all of these community characteristics. In the next sections, I will review how these community features may theoretically impact heart failure progression in order to help interpret the findings of the multilevel study (Chapter 4) and make suggestions to guide future research.

Social environment

The previous section about social interactions described the individual's social attributes. This section describes the social circumstances that impact groups of people in a community.

One element of the social environment that has been linked to health outcomes is social cohesion. Social cohesion is the extent of connectedness and solidarity among groups in society or the degree of trust, shared values, and social ties shared among groups (including neighbourhoods). Social cohesion is a characteristic of the community or group and relates to the degree to which groups of people feel connected, share resources, and provide moral support. This construct is distinct from social support assessed at the individual level because it operates within the community as a whole. Social capital is a component of social cohesion, and generally refers to the social resources and benefits that emerge from strong social ties or social cohesion and facilitate collective action.[36]

Social cohesion has been measured in research studies as the magnitude of social and economic divisions in a community, for example, the degree of racial segregation or income inequality. Social cohesion has been evaluated with survey questions about social networks or interpersonal trust (e.g. the extent to which people trust each other, share values, and are willing to help each other). Social capital has been assessed by surveys as the level of trust, safety, and reciprocal relationships.[36] The levels of volunteerism, organizational membership, civic engagement, participation in voluntary organizations, voter registration, and voter turnout have all been used as proxies of social capital.[36,37] The use of proxy variables are sometimes necessary because survey data taken directly from residents of a neighbourhood are not available or realistic to obtain because of the time and cost associated with collection. A proxy indicator will not only reflect social cohesion but also other dimensions of that attribute. For example, crime rates have been used to reflect social cohesion because it may reflect the sense of safety or interpersonal trust in the neighbourhood. However, documented crime rates would also be influenced by the amount of policing. Proxies may send misleading messages if misinterpreted or not well understood. In the multilevel analysis presented in Chapter 4, I used several proxy indicators to reflect the community social characteristics: material deprivation; psychosocial deprivation; mean income; percentage of the community with an education less than high school; percentage of the community who were not Canadian citizens; percentage of the community who were a visible minority and referrals to home care services. While not ideal, this paucity of available direct social characteristics data at the community level remains an impediment to research advances in this field.

Social cohesion is thought to have an influence on health outcomes. Posited mechanisms are through the diffusion of knowledge about health-related behaviors (e.g., dietary practices), maintenance of healthy behaviors through informal social control, greater collective efficacy in improving local amenities and services, generation of individual processes including social support, and buffering adverse effects of stress.[36] Several studies have linked measures of social cohesion and social capital to risk factors related to the poor prognosis of heart failure[36,38] For example, greater neighborhood collective efficacy (as assessed by combining indicators of social cohesion and informal social control) was linked to lower body mass index even after controlling for neighborhood deprivation.[39] A cross-sectional study of the relationship between neighborhood social cohesion and hypertension demonstrated that residents of neighbourhoods with more social cohesion were less likely to be hypertensive.[40] The impact of a poor social context has been also demonstrated in terms of other risk factors such as smoking, poor physical activity and nutrition, depression and cardiovascular disease incidence, and self-rated health.[41-45]

The relationship between social cohesion and disease outcomes can be difficult to specify because of its distal position in the causal pathway. For example, social cohesion may encourage or influence a chain of events (such as neighborhood sources of stress), which may in turn influence the development of individual level risk factors for heart failure, like hypertension and depression. While researchers have explored the associations between neighborhood socioeconomic deprivation, social cohesion and selected individual health endpoints, to my knowledge, there are no data regarding its impact on the progression of heart failure.

Other indicators of the social environment proposed to have an impact on cardiovascular health outcomes include social norms and stressors present at the community level. Examples of community level stressors include physical ambient characteristics such as noise, crowding, housing characteristics, and proximity to environmental toxins. The influence of these characteristics on heart failure outcomes are not yet well documented and were not included as potential predictor variables in the multilevel analysis in Chapter 4.

The food and built environment

A healthy sodium reduced diet and physical activity are important components of heart failure management. The influence of the local environment on physical activity and dietary choices has been emphasized in the literature. The need for a broader, more inclusive view of the determinants of healthy lifestyles, beyond individual choices, has been emphasized.[46] These scholars have led the focus on the role of the environment in encouraging or discouraging healthy food intake and adequate physical activity. [30,33,47]

Food environment

One recent American study found that the accessibility of supermarkets was associated with a lower rate of obesity.[48] Further studies conducted in Ontario, Canada, and in Australia, have documented that wealthier communities have more supermarkets.[49-51] American studies have also noted fewer supermarkets in predominantly black and low income neighborhoods.[52,53] The reduced accessibility to large supermarkets in poor communities results in what is termed ‘food deserts’. Fewer supermarkets are sometimes accompanied by more small independent grocery stores. These independent stores tend to be more expensive than the larger supermarkets.[54]

In contrast, other studies in Canada, New Zealand and the UK have demonstrated no differences in the number of supermarkets in poor versus wealthy neighbourhoods or even more supermarkets in poor neighbourhoods . [55-57] Cummins et al. found no independent association between food price, food availability, and access to supermarkets between deprived versus wealthy areas.[58] A recent large study conducted in Glasgow, Scotland found that there were more food retailers in the poorest communities.[59] There was variation in the distribution of the different types of food retailers and access depended upon the type of food retailer studied and whether proximity or density was measured.[59]

Access to prepared high calorie, low nutrition foods for consumption outside the home has been proposed to be related to higher rates of obesity.[60] Fast-food consumption has positive associations with weight gain and suggests the consequential increase in the risk of obesity and chronic illnesses.[61,62] In 2005, Alter and Eny found that cardiovascular mortality and hospitalization was associated with regional fast-food service density in Canada.[63] In Australia, Reidpath et al. described a 2.5 fold increase in fast food outlets in poor neighbourhoods.[64] However, a 2009 study in Nova Scotia, Canada found a statistically significant inverse relationship between community-level material deprivation and the mean number of fast food restaurants per 1 000 people.[65] Negative findings have also been reported in other settings. No relationships between obesity and fast food outlets were found in another Australian study or a study of Scottish neighborhoods.[66,67]

The mixed results from these studies highlight that the causal pathways between the local food environment and health are complex and difficult to measure. For example, MacDonald et al. proposed that the supermarkets in poor neighbourhoods also ought to be evaluated for presence of healthy foods and the price of those healthy foods. As well, she noted that the presence of supermarkets in wealthy neighbourhoods may not be relevant to where those people shop because of easy access to cars. These variables may confound the statistical association between the number of supermarkets and healthy food consumption. Further, the local food environment may be impacted by the social, cultural, and economic context, as well as regulatory systems that influence the distribution and consumption of food.[47] For instance, physical activity patterns may differ between neighborhoods and this may, in turn, moderate the impact of the local food environment.

I hypothesize that the specific features of the food environment presented above may also be relevant to the heart failure population. Access to healthy foods within the local area could be critical to these patients who may not easily be able to leave their community. However, the simple presence of supermarkets may not be a precise enough indicator to assess healthy food consumption as cost likely impacts this population who are often elderly and have limited incomes. Also, the presence of instrumental support may moderate the effect of the food environment because patients may receive assistance to go to other neighourhoods to purchase food. The relationship of the food environment with other mediating and moderating factors is an important research topic because of the potential impact of food consumption on heart failure and chronic disease health outcomes.

The food environment is hypothesized to be important in heart failure because it may facilitate a healthy salt-reduced diet and maintenance of a healthy weight, which are often part of a clinical management plan. However, the importance of the food environment in heart failure outcomes is also complicated by an observed ‘obesity paradox’ such that there is a protective effect of a higher BMI against death. The multilevel analysis presented in Chapter 4 also described this phenomenon. Reasons for these findings have been suggested in the literature. First, there may be an earlier presentation of symptoms in obese heart failure patients due to reduced circulating natriuretic peptides. Natriuretic peptides play a key role in heart failure, antagonizing the actions of the renin-angiotensin-aldosterone system and promoting vasodilatation and sodium excretion. Second, most studies have not accounted for the effects of non-purposeful weight loss or cachexia, which may be associated with more advanced heart failure and a poor prognosis.

Third, obese patients may be more aggressively treated by clinicians. Finally, the paradoxical finding is associative, but does not prove a cause-and-effect relationship.[68,69] There are currently many unknowns in the pathway between the food environment, food consumption, body weight and heart failure outcomes that require much more research. Longitudinal studies, using direct indicators of the food environment, food consumption, and patient weight are needed to determine if a relationship exists with health outcomes and the magnitude of the association.

Built environment

The first US Surgeon General's report on physical activity and health was published in 1996.[70] Earlier recommendations had suggested that patients with heart failure should not engage in physical activity for fear of triggering an acute cardiac event. However, the American Heart Association (AHA) has more recently suggested that regular physical activity can provide many benefits to heart failure patients. These benefits include reduced stress, increased energy level, maintenance of a healthy weight, and reduction of depression and anxiety.[71]

The AHA recommendations for heart failure patients do not specifically refer to walking, but it is a common form of physical activity. A growing literature has shown that residents of neighborhoods with a supportive built environment are more likely to walk as part of their routine daily activities.[72] Walking occurs on neighborhood streets and the attributes of the environment influence the real and perceived safety, comfort, and desirability for physical activity.

Qualities of the built environment that are associated with walking or physical activity have been identified. Land density is strongly linked with neighborhood walk-ability.[73,74] Dense neighborhoods bring homes closer to common destinations. In a review of reviews, Saelens and

Handy found that proximity to destinations was the most consistently reported neighborhood characteristic linked with walking. Land diversity, or mix-land uses within an area, is also critical.[75] This includes the presence of shops and services close to home, which has been positively associated with physical activity and lower body mass index (BMI). The design of the neighbourhood's built environment can also encourage physical activity. Streets that are narrower and with sidewalks, for example, can provide a safe, comfortable environment for walking.[74] Using an index consisting of measures of density, mix and connectivity, Ewing e al. found that residents of sprawling counties were likely to walk less during leisure time, weigh more, and have greater prevalence of hypertension than residents of compact counties.[76] Close proximity to parks, open space, and recreational facilities has also been associated with increased physical activity and walking. [77-79]

While several studies and review articles have concluded that the built environment is associated with walking, there is no agreement on the precise aspects of the environment that are important and for whom. It is unknown if some features are universally critical to promote physical activity. It is quite likely that the same neighbourhood attributes that encourage activity in the younger or middle age populations are different than those with chronic disease.

Summary and Integration

The multilevel analysis presented in Chapter 4 advanced the thinking about the role of community factors in the progression of chronic disease. The results did not indicate that community social factors exerted much influence over the rehospitalization or death of heart failure patients.

One explanation for the absence of a strong relationship is that the ideal set of indicators was not available for this analysis. As described in this chapter, community characteristics have multiple and complex pathways of influence on disease outcomes. Indicators along the causal pathways should be selected based on a solid theoretical foundation. Attempts were made to characterize the communities' social characteristics through estimates of the socioeconomic environment, proxy indicators of social cohesion such as the proportion of the population who were a visible minority and non-Canadian citizens. However, other indicators may more accurately reflected the social environment. This could have included residents' perspectives of trust and reciprocity (measures of social capital) in the community. In the multilevel analysis, we found that communities with a lower percentage of non-Canadian citizens had a higher rehospitalization rate. I proposed three alternate mechanisms for this finding, representing the compositional and contextual perspectives. The first compositional perspectives posited that communities with a higher percentage of non-Canadian citizens have a lower hospitalization rate because of an unmet need of the non-Canadian patients. The second composition perspective posited, that non-Canadian citizens have more social support due to cultural norms that find elderly patients living with their adult children. The increase in support may be linked with reduced hospitalization. The contextual perspective posited that the percentage of non-Canadian citizens in the community was a proxy for community social cohesion; more social cohesion was linked to a lower rate of hospitalization. This hypothesis requires further validation. Had a more precise indicator of social cohesion been used in our study, the interpretation of the multilevel analysis results would have been clearer.

Furthermore, had the ideal dataset been available, the food environment could be assessed by indicators reflecting the accessibility of supermarkets, availability and cost of healthy foods, and presence of fast food restaurants. Physical activity is important both for maintenance of healthy weight and subjective sense of well-being. Indicators of mixed land use, public transportation, and walkability of the streets are known to facilitate walking. Data about these features would have provided more precise information about how the patient's community impacts heart failure outcomes. Based on the review of potential community influences and the causal pathways highlighted in this chapter, one can see that the multilevel analysis performed in this thesis only began to address the questions about the role of community characteristics in the progression of heart failure.

An alternate explanation for the failure to find a strong relationship between community characteristics and heart failure outcomes may be related to the pathogenesis of heart failure. The finding may be a true reflection of an absence of a strong relationship. Central to this hypothesis is the consideration of the timelines of the community influences on health and the disease processes. When a patient has existing heart failure, especially at the advanced stages, deterioration is relatively quick and aggressive, and the trajectory may not be amenable to significant changes through the presence of community factors. The pathways from many of community features to outcomes may take a great deal of time. This amount of time may not be available for this patient population.

To the best of my knowledge, this is the first study to try to link community characteristics with heart failure outcomes in this way. As such, this work advances our thinking about heart failure and provides fodder for future research.

Analysis of community characteristics

An underlying theme in the literature holds that community variables may represent processes that are distinct from the characteristics of individuals in the manner in which they affect health. These community effects can be statistically assessed either taking the individual level and the community level in isolation, or in combination using multilevel analysis, as used in Chapter 4. This multilevel analysis approach has advantages and disadvantages. The strengths are that it permits simultaneous examination of the influence of community and individual characteristics on health outcomes (which were measured at the individual level). The analysis accounts for the non-independence of observations within the group and also accounts for both group and individual variability.

One of the main limitations of multilevel analysis is the attempt to estimate community factors 'over and above' individual characteristics, when health is measured at the individual level. This is problematic because the community influence must flow through the individuals in order to influence their health. Thus, community influences are mediated through individual-level processes. And yet, most researchers control for individual characteristics to estimate the 'true' community effects[80]; failure to control for individual factors has been a major critique of studies evaluating community context.[81] However, many of these individual factors may lie on the causal pathway from community to health outcomes. For example, the impact of the local food environment on obesity is mediated almost entirely by individual dietary choices. Adjusting for individual diet would thus narrow the apparent influence of community and is an example of over-adjustment. Over-adjustment removes the indirect (but real) influence of group-level attributes that are mediated through individual behaviours.

In an effort to describe the mediators of the community effects, I could have estimated two multiple regression models describing the community and individual level influences separately. However, there have been serious concerns raised about this methodology related to attributing variance to a particular factor.[82,83] To give an example, if I had taken this approach, I might have detected a statistical association between an increase in community level psychosocial deprivation and increased mortality. In an individual level model, I might have identified hypertension as being significantly associated with mortality. I might have then erroneously concluded that the psychosocial deprivation was mediated through hypertension, and that any difference between the effect sizes was due to other pathways. There are several problems with that interpretation. First, there may be mediators between the community factor (deprivation) and the individual factor (hypertension) that are not considered (e.g. social support may mediate the relationship between deprivation and hypertension). Second, there may be individual level confounding variables that are not considered (e.g. anxiety disorder is related to hypertension and mortality). This approach is further complicated by the fact that another individual variable may mediate both group-level and individual level effects simultaneously. There has been a call from scholars in this field for methods research to determine the type and magnitude of error that is introduced by estimating the models of community and individual effects separately, emphasizing the difficulty in interpretation.[82]

B. An expanded conceptual model of heart failure progression

Research should be based on a sound theoretical foundation. Although this statement may seem to be irrefutable, it is common to find studies in the literature without reference to the grounding theory. To be useful, a theory or integration of theories should incorporate facts in a consistent manner and set up hypotheses for further testing. These models are especially helpful in uncovering new knowledge in areas where not much research has been previously performed, as they can help researchers determine the variables that should be measured and the most appropriate analyses to perform.

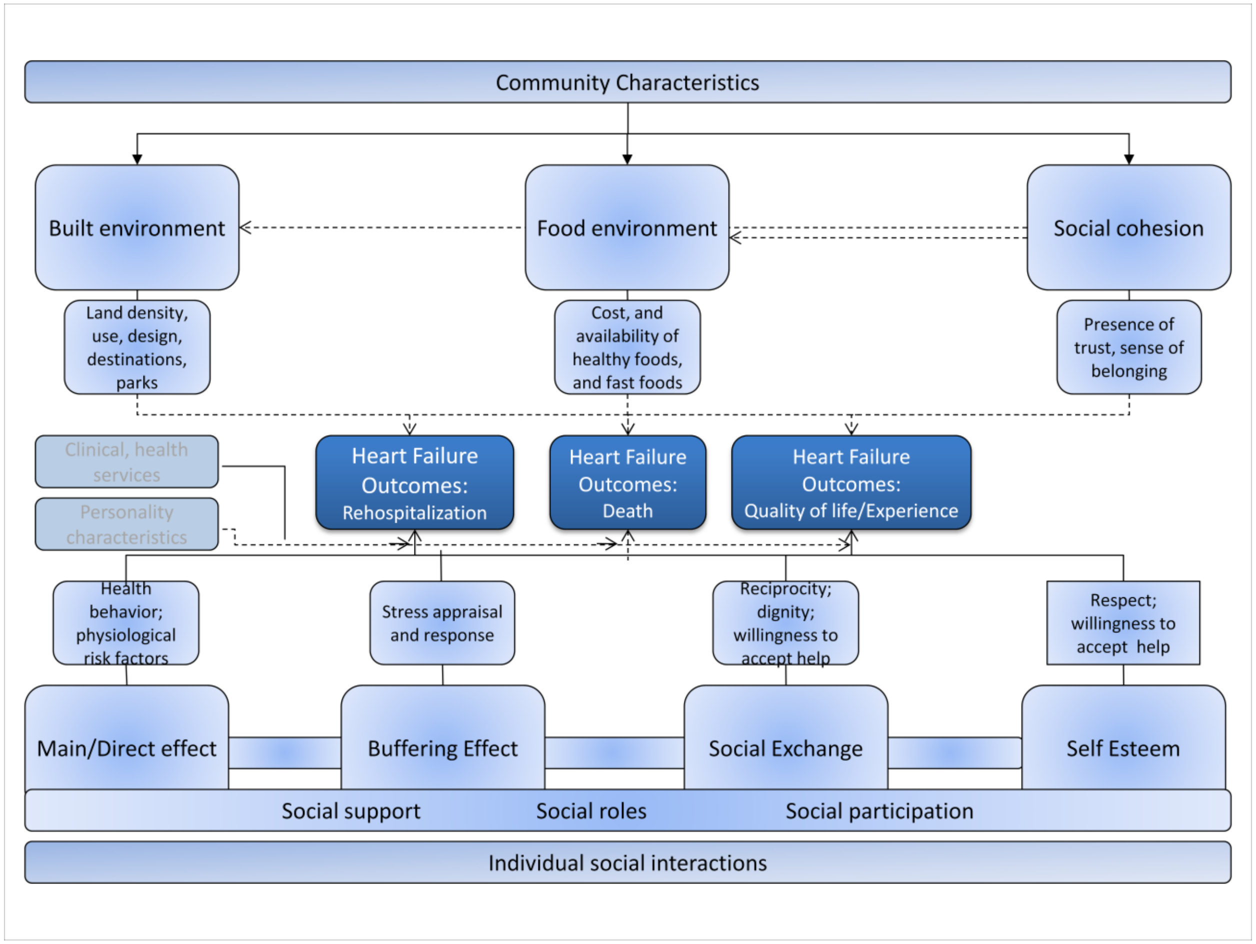
In Chapter 1, a model was proposed to guide the systematic reviews and multi-level analysis described in Chapters 2 to 4. In Chapter 2 and 3 two new conceptual models were proposed. The first focused on social support and rehospitalization and death and the second focused social interactions and quality of life and experience with heart failure. The integration of all of the findings provided by this thesis has furthered the conceptualization of what influences the quality of life, rehospitalization and death of heart failure patients. A revised and expanded model is presented as Figure 5. Similar to the original guiding model, this model illustrates the relationship between social interactions and community social factors with heart failure outcomes. However, this revised model was informed by this thesis research and an in-depth review of relevant causal pathways.

The model incorporates the individual level social interactions that affect prognosis that were identified in the systematic reviews (Chapters 2 and 3). The importance of social support, participation and roles was demonstrated in the qualitative literature and is emphasized with solid lines. The value of these social interactions can be supported by at least four theories that validate their potential role in disease progression: main effect model[5], stress buffering model[5], self esteem theory [24-26], and the theory of social exchange.[27] Each causal pathway from the theory to heart failure progression has been outlined in the model. The overlap between social support, participation and roles and the linkages between each of the theories is depicted by the links between each box. These social interactions may amplify or buffer the impact of the community factors on disease progression. For example, instrumental social support to purchase healthy foods may attenuate the impact of the local unavailability of supermarkets. This potential interaction is depicted by a dotted line between the individual and community factors and heart failure outcomes.

The community level factors reviewed in this chapter revealed the potential importance of the built environment, the food environment and the social environment. While, there is no direct evidence to link these attributes with heart failure outcomes in the literature or from the results of the multilevel analysis presented in Chapter 4, there is strong theoretical plausibility. Thus, the hypothesized causal pathways for these influences on heart failure outcomes are depicted in the model with dotted lines.

The role of clinical, health service and personality (e.g. coping, adaptability) factors were not explored in this research and are depicted as paler sections of the model. The relationship of these variables with individual social interactions, community factors and ultimately with health outcomes needs further investigation. Future research will be required to inform and evaluate this conceptual model in order to support its evolution and more accurately reflect the linkages (if any) between these variables.

Figure 5: Revised model relating individual social interactions and community characteristics to heart failure outcomes



C. Contributions of the research

A hallmark of a population health perspective is the acknowledgement of the complex and overlapping interactions among the determinants of health. From a population health perspective, this doctoral thesis is important because it moved beyond the traditional biomedical boundaries of heart failure research to investigate the factors that can influence heart failure progression. A population health perspective informed the approach to this research in a number of ways. First, the broad determinants of health were considered in the evaluation of factors that influence heart failure progression. Individual and community level factors were included in this research. Also, consistent with a population health view, the importance of both qualitative and quantitative literature in describing heart failure was recognized. This approach has not been taken previously in heart failure research and should be used as a model for future investigation of other chronic illnesses.

The synthesis of findings from the three investigations has culminated in a proposed framework that encompasses the diversity of determinants of health outcomes. As new knowledge becomes available, the framework should be adapted and improved. This model incorporates a population health perspective of heart failure progression and has implications for many settings. It may serve as a starting point for discussion in the community setting among patients, families, physicians, nurses, social workers, and community workers about the role of multiple influences on heart failure outcomes. Indeed the integrative review demonstrated that patients feel that their social interactions are very important and influence their life experience. Clinicians should be aware of the social changes that occur with heart failure progression and advise patients about these non-medical effects of the disease process. Clinicians frequently act as the coordinators of care for their patients. Therefore it is essential that physicians and nurses be able to direct patients to the appropriate resources in the community as required by their condition and context. Providing information and resources to caregivers is also important so they too are able to support patients effectively.

A population health perspective of heart failure progression will also influence future clinical research. This research topic is important because it is unclear if additional biomedical interventions will yield significant improvements in the health status of heart failure patients. There is a strong theoretical basis for the influence of social circumstances on progression of heart failure. The integration of social support conceptual models into research of drug therapy effectiveness and behavioral interventions may elucidate opportunities to improve outcomes through enhancing social circumstances. For example, previous research might have controlled for marital status as confounding the association between intervention and outcome. Future research, incorporating a population health perspective, might consider social interactions as mediating variables in the causal pathway between interventions and treatment outcomes. Thus, maximizing the effectiveness of the intervention would also require maximizing the positive effect of the mediating variables. This bridge between the population health and clinical perspective has great potential to benefit heart failure patients.

From a health policy perspective, the findings have implications for regions or communities that are implementing new programs or improving existing services. The role of community services to support social participation and interactions may be quite integral to maintaining quality social interactions. The research did not explore the types of interventions that may promote social interactions of heart failure patients. However, the hope is that programs and services that improve the quality of life for heart failure patients, based on the social determinants of health can be identified in the future.

D. Future Research

This dissertation provides direction for future research exploring the non-medical determinants of heart failure progression and may be generalizable to other chronic diseases. First, the notion of social interactions should be incorporated into future investigations of heart failure progression. This acknowledges the importance of quality social support, social participation and networks as well as social roles. Second, the various types of social support need to be differentially assessed and reported distinctly. There are clear differences between how each type of social support can influence disease progression at different stages of disease. If there are to be any interventions designed to improve social support, the type of support and window of opportunity to have an effect should be well described. Third, individual characteristics such as self-esteem, and coping mechanisms, need to be included in the evaluation of social support as moderating variables. Fourth, the assessment of social support needs to take variables like tobacco use, diet or physical activity into account, but given that the mechanism of effect is likely through these behaviors, these variables ought to be considered part of the causal pathway, rather than confounding factors. To control for these variables, in the traditional way, does not respect the mechanisms through which social interactions have an effect and underestimates the impact of social interactions on health outcomes. Fifth, studies of the impact of individual level social interactions and community influences on progression of a chronic disease should be based on established theoretical models. This will guide the selection of indicators and outcomes used in empirical studies and facilitate a better understanding the phenomena. For social interactions this would include the availability of perceived social support, objective estimates of social networks and participation as well as satisfaction with role. For community factors this should include indicators of the local food environment, the built environment and the social environment discussed previously in this chapter. However the purposeful collection of these data, as part of an effort by researchers to answer questions related to how community impacts chronic disease, would hasten knowledge generation in this field and provide opportunities to develop interventions for this patient population. Sixth, multilevel analysis is a strong analytical technique that allows complicated nested relationships to be studied. This technique facilitates the simultaneous investigation of individual and community level factors. While this is a strength in many ways, controlling for individual factors, while investigating community characteristics, may be inappropriately adjusting for factors along the causal pathway. Seventh, there needs to be more transfer of research findings between qualitative and quantitative researchers. The rich information and sophisticated analyses performed by experts in their field ought to benefit all consumers of this research. I suggest that more openness to different epistemologies and use of mixed-methods designs is important to advance knowledge in this complex area. Eighth, it is important to interpret the research results with an understanding of how the study design and analyses impact the results. For example, using prevalence of disease as an outcome measure mixes the impact of the determinants of incident disease with the determinants of survival. The use of theoretical frameworks to support study design will help to alleviate these issues. Ninth, future research needs to consider other levels of context that may influence heart failure outcomes. For example, health care funding occurs primarily at the provincial/territorial level, which results in variable priority setting and hence support of health care services for their populations. Provincial/territorial regulations also affect health by targeting health damaging behaviors through smoking bans in public areas and restrictions on operating hours for liquor stores.[84,85] These policy decisions may have implications for heart failure progression. Nested within the province, the regions or municipalities fund public services like public transportation, parks and recreational facilities and community-based health centres, which can also contribute to differences in health behaviours and subsequent health outcomes.[86,87] Finally, heart failure is similar to other chronic conditions, in that patients may have the disease for some time with minimal symptoms, but progression is inevitable. Unlike some other chronic conditions, progression is often rapid and the case fatality rate of heart failure is high. Thus, the conceptual models and findings from multilevel analyses in other chronic disease settings may not be generalizable and require further validation.

Conclusion

Heart failure is a serious condition that affects over 350 000 Canadians yearly with a 30% annual mortality rate and deterioration in quality of life. It has costs in terms of health care resource utilization, family and caregiver stress as well as the large burden of illness on the patients themselves.

This dissertation describes a broader perspective about the determinants of heart failure progression than previously provided in the literature. By adopting this perspective, the importance of social determinants of health, as identified by patients is incorporated.

The findings are relevant to patients, their families and health professionals who manage heart failure in the clinical and community setting. This population health approach to heart failure progression provides a bridge between disciplines including sociology, psychology, epidemiology, medicine, nursing, pharmacy, and health policy and administration. Further work in this field will not only advance the knowledge base of the important determinants of heart failure, but also potentially provide opportunities for the development of interventions to improve these characteristics and thereby, conceivably and importantly, the outcomes of this disease.

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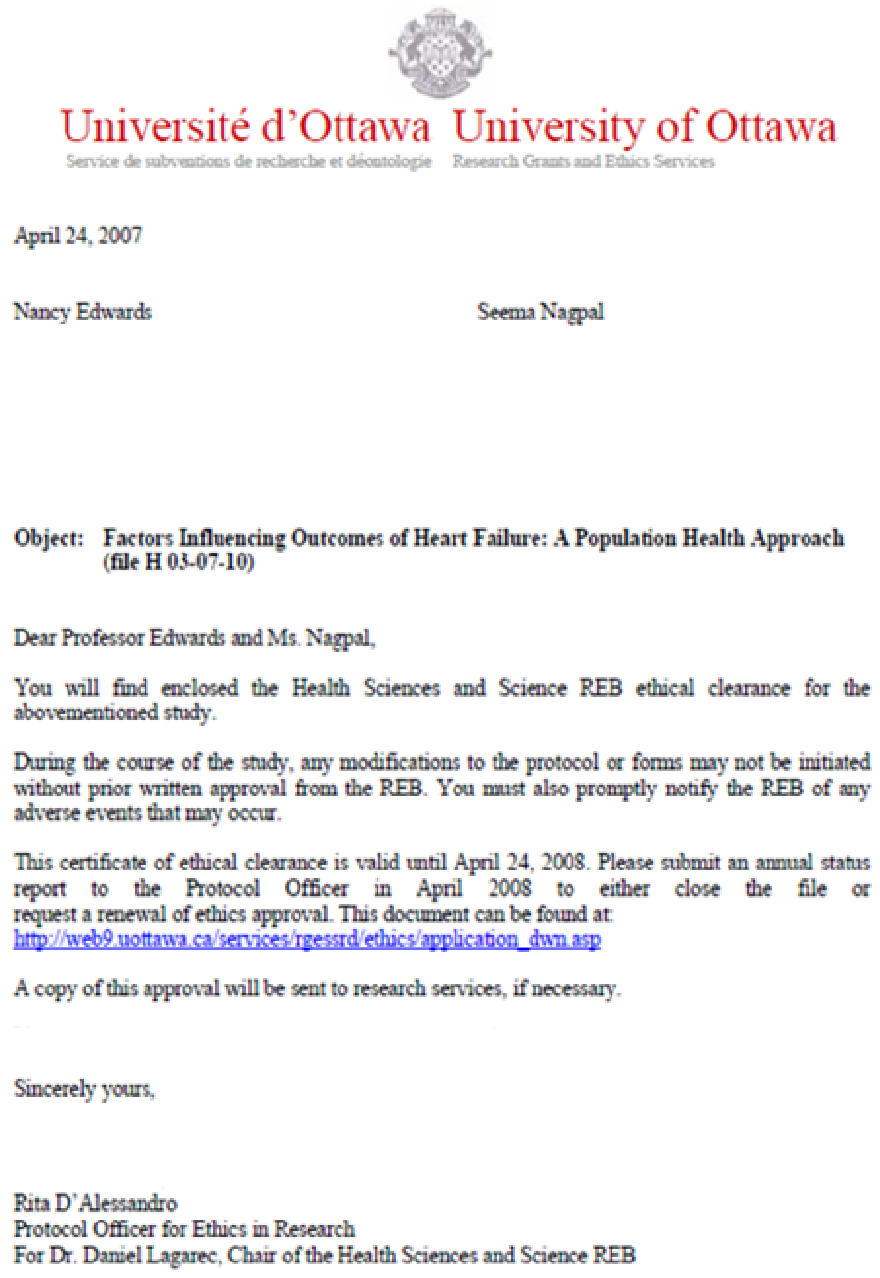
Appendix I: Ethics Approvals



Université d'Ottawa University of Ottawa
Service de subventions de recherche et déontologie Research Grants and Ethics Services

April 24, 2007

Nancy Edwards Seema Nagpal

Object: Factors Influencing Outcomes of Heart Failure: A Population Health Approach (file H 03-07-10)

Dear Professor Edwards and Ms. Nagpal,

You will find enclosed the Health Sciences and Science REB ethical clearance for the abovementioned study.

During the course of the study, any modifications to the protocol or forms may not be initiated without prior written approval from the REB. You must also promptly notify the REB of any adverse events that may occur.

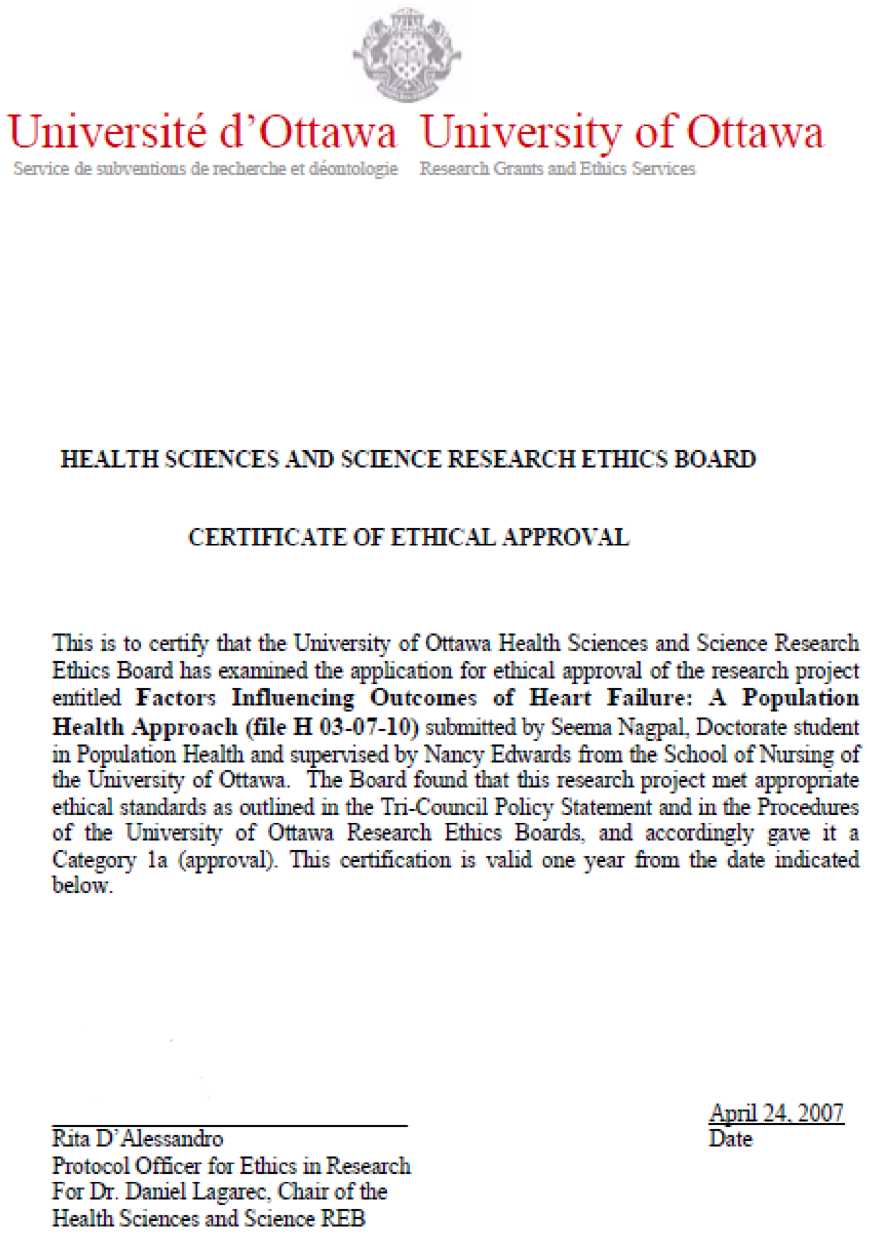
This certificate of ethical clearance is valid until April 24, 2008. Please submit an annual status report to the Protocol Officer in April 2008 to either close the file or request a renewal of ethics approval. This document can be found at:
http://web9.uottawa.ca/services/rgessrd/ethics/application_dwn.asp

A copy of this approval will be sent to research services, if necessary.

Sincerely yours,

Rita D'Alessandro
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the Health Sciences and Science REB

Appendix I: Ethics Approval



Université d'Ottawa University of Ottawa

Service de subventions de recherche et déontologie Research Grants and Ethics Services

HEALTH SCIENCES AND SCIENCE RESEARCH ETHICS BOARD

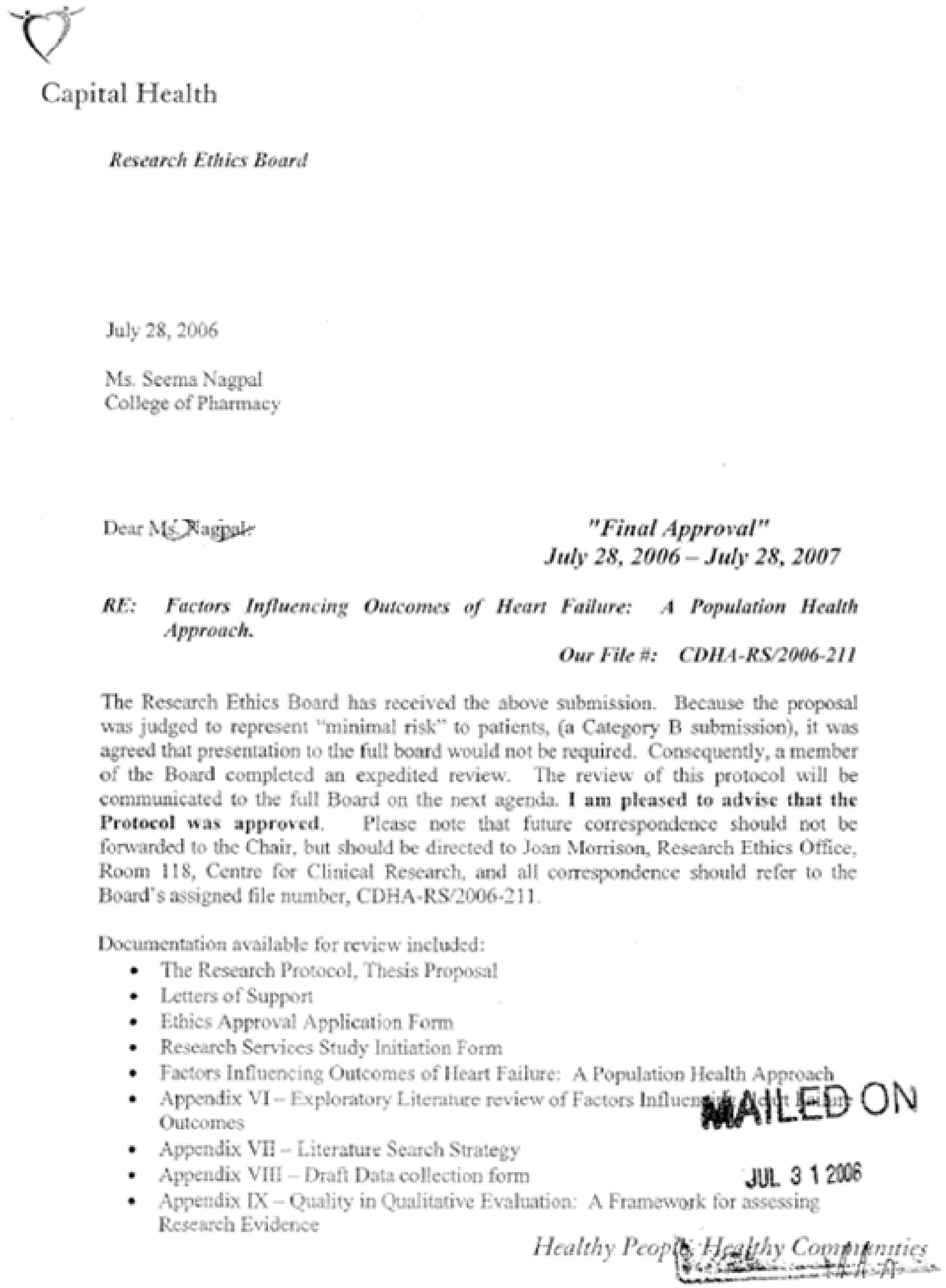
CERTIFICATE OF ETHICAL APPROVAL

This is to certify that the University of Ottawa Health Sciences and Science Research Ethics Board has examined the application for ethical approval of the research project entitled **Factors Influencing Outcomes of Heart Failure: A Population Health Approach (file H 03-07-10)** submitted by Seema Nagpal, Doctorate student in Population Health and supervised by Nancy Edwards from the School of Nursing of the University of Ottawa. The Board found that this research project met appropriate ethical standards as outlined in the Tri-Council Policy Statement and in the Procedures of the University of Ottawa Research Ethics Boards, and accordingly gave it a Category 1a (approval). This certification is valid one year from the date indicated below.

Rita D'Alessandro
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the
Health Sciences and Science REB

April 24, 2007
Date

Appendix I: Ethics Approval



Capital Health

Research Ethics Board

July 28, 2006

Ms. Seema Nagpal
College of Pharmacy

Dear Ms. Nagpal:

"Final Approval"
July 28, 2006 – July 28, 2007

RE: ***Factors Influencing Outcomes of Heart Failure: A Population Health Approach.***

Our File #: CDHA-RS/2006-211

The Research Ethics Board has received the above submission. Because the proposal was judged to represent "minimal risk" to patients, (a Category B submission), it was agreed that presentation to the full board would not be required. Consequently, a member of the Board completed an expedited review. The review of this protocol will be communicated to the full Board on the next agenda. **I am pleased to advise that the Protocol was approved.** Please note that future correspondence should not be forwarded to the Chair, but should be directed to Joan Morrison, Research Ethics Office, Room 118, Centre for Clinical Research, and all correspondence should refer to the Board's assigned file number, CDHA-RS/2006-211.

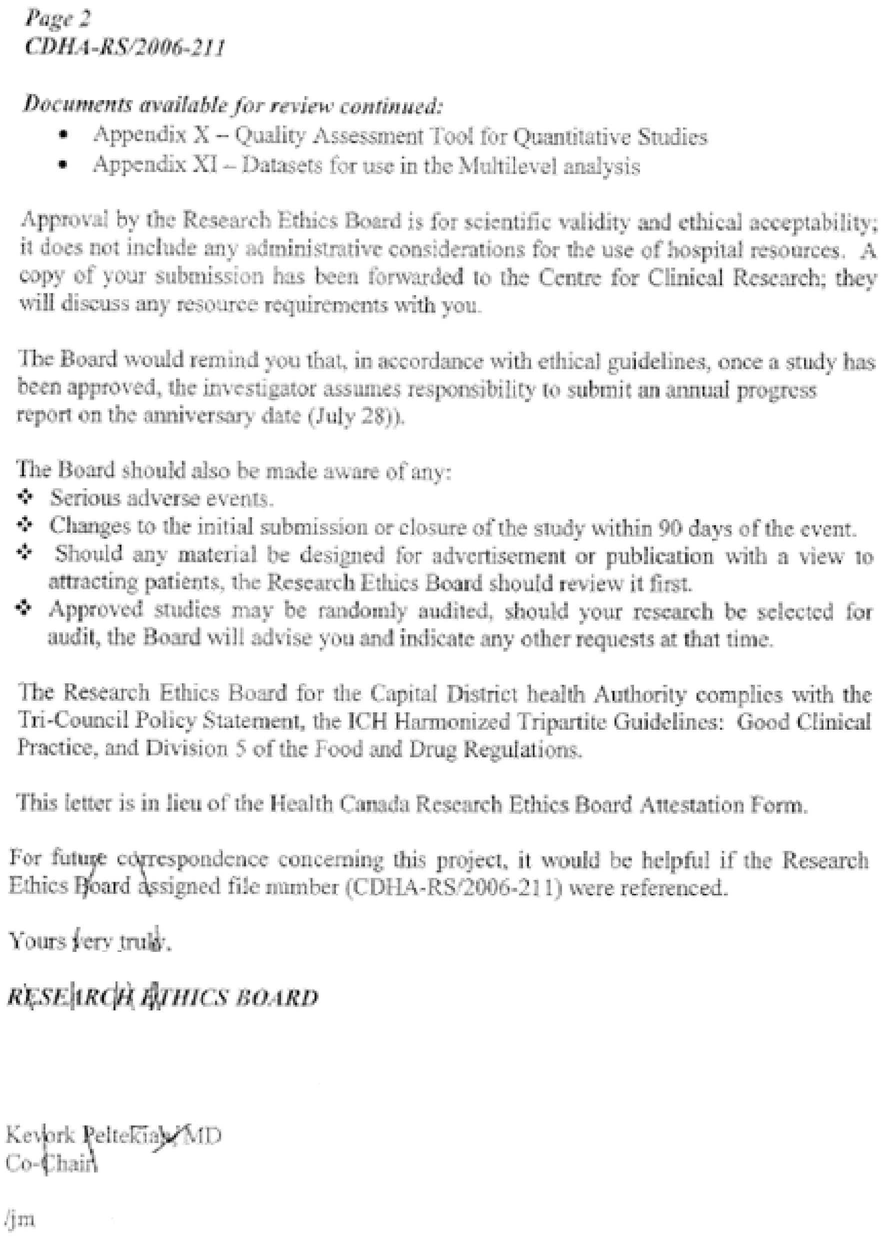
Documentation available for review included:

- The Research Protocol, Thesis Proposal
- Letters of Support
- Ethics Approval Application Form
- Research Services Study Initiation Form
- Factors Influencing Outcomes of Heart Failure: A Population Health Approach
- Appendix VI – Exploratory Literature review of Factors Influencing Heart Failure Outcomes
- Appendix VII – Literature Search Strategy
- Appendix VIII – Draft Data collection form
- Appendix IX – Quality in Qualitative Evaluation: A Framework for assessing Research Evidence

MAILED ON
JUL 31 2006

Healthy People, Healthy Communities

Appendix I: Ethics Approval



Page 2
CDHA-RS/2006-211

Documents available for review continued:

- Appendix X – Quality Assessment Tool for Quantitative Studies
- Appendix XI – Datasets for use in the Multilevel analysis

Approval by the Research Ethics Board is for scientific validity and ethical acceptability; it does not include any administrative considerations for the use of hospital resources. A copy of your submission has been forwarded to the Centre for Clinical Research; they will discuss any resource requirements with you.

The Board would remind you that, in accordance with ethical guidelines, once a study has been approved, the investigator assumes responsibility to submit an annual progress report on the anniversary date (July 28)).

The Board should also be made aware of any:

- ❖ Serious adverse events.
- ❖ Changes to the initial submission or closure of the study within 90 days of the event.
- ❖ Should any material be designed for advertisement or publication with a view to attracting patients, the Research Ethics Board should review it first.
- ❖ Approved studies may be randomly audited, should your research be selected for audit, the Board will advise you and indicate any other requests at that time.

The Research Ethics Board for the Capital District health Authority complies with the Tri-Council Policy Statement, the ICH Harmonized Tripartite Guidelines: Good Clinical Practice, and Division 5 of the Food and Drug Regulations.

This letter is in lieu of the Health Canada Research Ethics Board Attestation Form.

For future correspondence concerning this project, it would be helpful if the Research Ethics Board assigned file number (CDHA-RS/2006-211) were referenced.

Yours very truly,

RESEARCH ETHICS BOARD

Kevork Peltekian, MD
Co-Chair

/jm

Appendix II: An overview of heart failure

Cardiovascular diseases are the underlying cause of death for 1 in 3 Canadians. Unlike the decreasing mortality rate due to cardiovascular disease in general, heart failure is the most rapidly increasing cardiovascular disease. Over 350,000 Canadians are diagnosed with heart failure yearly. [1,2]

Heart failure is a pathological state which occurs when the heart is unable to pump blood, oxygen and nutrients through the circulatory system in order to meet metabolic demands. It is caused by a deficiency in myocardial contraction and relaxation, structural valvular damage and/or higher intra-heart blood pressure. Heart failure may also occur when the normal heart is suddenly presented with abnormally high demands or severe impairment of its filling.[2]

Commonly noted causes of incident heart failure include high blood pressure, pre-existing heart disease (e.g. prior myocardial infarction) and structural defects such as valvular disease or congenital heart disease. Renal disease, diabetes, and tobacco use are also considered to be risk factors.[3-5]

Acute episodes of distress may be caused by poor adherence to medications, contraindicated dietary intake or progression of existing heart failure with the activation of neurohormones and renal dysfunction. These factors can produce fluid overload, leading to an increased intra-heart filling pressure or decreased cardiac output. These deleterious changes in hemodynamics cause symptoms such as shortness of breath, fluid retention and possible injury to the myocardium.[6] Chronic symptoms may include chest congestion, fluid redistribution, shortness of breath, and/or low exercise tolerance. In some cases symptoms may be absent until an acute episode of distress. There may be a resolution of symptoms with treatment over time, but the disease often progresses asymptomatically.[6]

Renal function also plays an important role in heart failure. Decreased cardiac output can result in hypovolemia which triggers hormonal reactions such as the renin-angiotension-aldosterone system. This in-turn activates additional responses resulting in fluid retention, sodium retention, vasoconstriction, high venous pressure, increased myocardial stress and decreased cardiac performance.[6]

The prognosis of heart failure has been shown to depend on several factors, including age, the severity of heart failure and comorbidities. [7] Medical management, including pharmaceuticals, surgery and heart failure clinics can also significantly improve life expectancy and quality of life. Clinical guidelines have been developed to maximize the likelihood of positive health outcomes.[8-10]

The absolute number of deaths in Canada due to congestive heart failure increased between 1985 and 1995 but has since stabilized. These numbers are projected to increase due to the increasing elderly population. The overall mortality rate due to heart failure during 1995-1999 was found to be higher in Eastern Canada than most other parts of the country and women experienced a higher mortality rate compared to men nation-wide. While more men than women die from ischemic heart disease and acute myocardial infarction, more women than men die from heart failure. [1]

Howlett et al. examined the burden of heart failure in Nova Scotia. This Canadian cohort study prospectively examined patients admitted to a Nova Scotia hospital with heart failure. They found that the average length of hospital stay of 10.2 days. The patients' average age was 76 years and females were older than males (median age 80 years versus 76 years respectively). More than 52% of women with heart failure were over the age of 80 and 77% were over the age of 70 years. Patients had a mean of 4.5 comorbid conditions including hypertension, asthma, ischemic heart disease and chronic obstructive pulmonary disease. Approximately 18% of patients died during hospitalization and the estimated one year mortality was 39%. The re-hospitalization rate at one year was approximately 40%. Of the patients available for analysis in their study, Howlett et al described that 58% had an annual income of less than $20 000. [9]

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Appendix III: Search strategy for systematic review

The following search strategy was used for Chapters 2 and 3 in order to identify literature for inclusion in the reviews.

1. exp *Heart Failure, Congestive/ (40816)

2. exp Socioeconomic Factors/ (217606)

3. exp socioeconomic factors/ or educational status/ (217606)

4. Social Isolation/ (8008)

5. Social Support/ (26487)

6. Social Environment/ or social capital.mp. (24943)

7. 2 or 3 or 4 or 5 or 6

8. 7 and 1

9. limit 8 to (humans and (English or French))

Appendix IV: Exploratory multi level analysis models

3 level model **Mortality: full cohort (excluding BMI)**	**1 Year Mortality**		**5 Year Mortality**		**Total Mortality**	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex (female vs male)	0.85	0.77-0.94	0.87	0.81-0.95	0.89	0.82-0.97
*Age group 1 vs 5	0.21	0.13-0.34	0.14	0.09-0.20	0.19	0.13-0.28
*Age group 2 vs 5	0.21	0.15-0.29	0.26	0.19-0.36	0.36	0.26-0.49
*Age group 3 vs 5	0.39	0.28-0.52	0.56	0.42-0.74	0.81	0.60-1.09
*Age group 4 vs 5	0.62	0.46-0.83	0.90	0.67-1.20	1.14	0.85-1.54
Hyperlipidemia	0.68	0.60-0.78	0.77	0.70-0.85	1.37	0.66-0.81
Diabetes	1.23	1.11-1.36	1.38	1.27-1.50	0.71	1.28-1.54
History of heart failure	1.52	1.38-1.68	1.58	-1.46-1.72	0.65	1.41-1.68
History of COPD	1.27	1.14-1.42	1.31	1.20-1.44	0.75	1.22-1.47
History of renal disease	1.72	1.49-1.99	1.71	1.49-1.96	0.75	1.15-1.54
History PVD	0.79	0.64-0.97				
History of stroke			1.20	1.06-1.36		

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years.

Appendix IV Exploratory multilevel analysis models

3 level model Mortality : reduced cohort (including BMI)	**30 day Mortality**		**1 year Mortality**		**5 Year Mortality**		**Total Mortality**	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex (female vs male)	0.64	0.45-0.90	0.82	0.71-0.95	0.79	0.71-0.88	0.79	0.70-0.89
*Age group 1 vs 5	0.08	0.02-0.35	0.16	0.07-0.35	0.06	0.02-0.14	0.06	0.02-0.16
*Age group 2 vs 5	0.11	0.04-0.32	0.15	0.07-0.31	0.12	0.05-0.26	0.12	0.05-0.31
*Age group 3 vs 5	0.14	0.05-0.37	0.27	0.14-0.54	0.23	0.10-0.52	0.27	0.10-0.69
*Age group 4 vs 5	0.18	0.07-0.47	0.40	0.20-0.78	0.41	0.19-0.93	0.45	0.17-1.18
Hyperlipidemia								
Diabetes	1.43	1.01-2.03	1.36	1.18-1.58	1.54	1.38-1.73	1.61	1.43-1.82
History of heart failure			1.52	1.32-1.75	1.66	1.49-1.86	1.71	1.51-1.93
History of COPD			1.39	1.19-1.63	1.42	1.26-1.61	1.54	1.34-1.75
History of renal disease			1.74	1.42-2.11	2.21	1.84-2.65	1.86	1.52-2.29
History PVD			0.72	0.54-0.97				
History of stroke					0.00	1.08-1.52	1.23	1.02-1.49
Hypertension							1.15	1.02-1.29
Previous history MI							1.22	1.08-1.38
**BMI 1 vs 4	2.09	1.12-3.90	1.93	1.47-2.53	2.16	1.72-2.72	1.47	1.15-1.88
**BMI 2 vs 4	1.76	1.12-2.76	1.60	1.32-1.94	1.34	1.16-1.55	1.31	1.13-1.53
**BMI 3 vs 4	1.01	0.63-1.60	1.36	1.13-1.64	1.15	1.01-1.32	1.15	1.00-1.31

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years. **BMI (body mass index) group 1=< 20; 2=20 - 25; 3=25 - 30; 4=> 30

Appendix IV Exploratory multilevel analysis models

3 level model Mortality: reduced cohort (excluding BMI)	**30 day Mortality**		**1 year Mortality**		**5 Year Mortality**		**Total Mortality**	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex (female vs male)	0.66	0.47-0.93	0.82	0.71-0.95	0.81	0.73-0.90	0.81	0.72-0.90
*Age group 1 vs 5	0.07	0.02-0.30	0.13	0.06-0.30	0.05	0.02-0.12	0.05	0.02-0.14
*Age group 2 vs 5	0.10	0.03-0.28	0.13	0.06-0.26	0.10	0.04-0.22	0.11	0.04-0.28
*Age group 3 vs 5	0.13	0.05-0.35	0.24	0.12-0.48	0.20	0.09-0.45	0.25	0.10-0.65
*Age group 4 vs 5	0.18	0.07-0.47	0.38	0.19-0.75	0.39	0.17-0.86	0.44	0.17-1.16
Hyperlipidemia			0.73	0.62-0.86	0.76	0.68-0.86	0.65	0.57-0.73
Diabetes			1.26	1.09-1.45	1.44	1.29-1.61	1.57	1.39-1.76
History of heart failure			1.53	1.33-1.76	1.68	1.50-1.87	1.70	1.51-1.93
History of COPD			1.39	1.19-1.62	1.43	1.27-1.62	1.53	1.34-1.75
History of renal disease			1.75	1.43-2.12	2.22	1.85-2.66	1.93	1.57-2.36
History PVD			0.70	0.52-0.95				
History of stroke					1.30	1.09-1.54	1.25	1.04-1.51

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years.

3 level model Rehospitalization: full cohort (excluding BMI)	**30 day Rehospitalization**		**1 year Rehospitalization**		**5 Year Rehospitalization**		**Total Rehospitalization**	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex (female vs male)								
*Age group 1 vs 5			1.19	0.76-1.87	1.35	0.89-2.05	1.64	1.09-2.48
*Age group 2 vs 5			1.51	1.03-2.23	1.76	1.23-2.53	2.15	1.50-3.07
*Age group 3 vs 5			1.49	1.02-2.17	1.93	1.36-2.73	2.22	1.57-3.14
*Age group 4 vs 5			1.33	0.92-1.94	1.63	1.15-2.31	1.76	1.25-2.49
Hyperlipidemia					1.13	1.02-1.25	1.18	1.06-1.31
Diabetes	1.18	1.03-1.35	1.32	1.21-1.45	1.38	1.26-1.51	1.33	1.21-1.45
History of heart failure	1.20	1.05-1.37	1.27	1.16-1.39	1.32	1.20-1.44	1.25	1.14-1.37
History of renal disease	1.23	1.00-1.51	1.31	1.14-1.52				
History PVD					1.20	1.02-1.42	1.28	1.09-1.52
History of stroke	0.76	0.61-0.94						
Hypertension	1.16	1.02-1.33			1.16	1.06-1.26	1.14	1.04-1.24
Previous history MI	1.31	1.15-1.50	1.41	1.29-1.55	1.46	1.33-1.60	1.52	1.39-1.68
Previous history UA			1.35	1.16-1.57	1.50	1.28-1.76	1.53	1.30-1.80
** More educated community versus less educated community			1.15	1.00-1.31	1.15	1.00-1.32	1.14	1.00-1.31
^Living in a Health District with more social cohesion					1.04	1.00-1.07		

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years. **A more educated community was defined as one in which the percentage of people having less than a high school education was below the provincial median; ^A health district with more social cohesion was defined as one in which more residents said they had some to support them most or all of the time

3 level model Rehospitalization: reduced cohort (including BMI)	**30 day Rehospitalization**		**1 year Rehospitalization**		**5 Year Rehospitalization**		**Total Rehospitalization**	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Sex (female vs male)								
*Age group 1 vs 5					1.35	0.89-2.05	1.70	1.13-2.56
*Age group 2 vs 5					1.76	1.23-2.53	2.28	1.59-3.26
*Age group 3 vs 5					1.93	1.36-2.73	2.34	1.65-3.31
*Age group 4 vs 5							1.81	1.28-2.56
Hyperlipidemia					1.13	1.02-1.25		
Diabetes			1.35	1.23-1.47	1.38	1.26-1.51	1.34	1.23-1.47
History of heart failure	1.36	1.17-1.59	1.26	1.15-1.37	1.32	1.20-1.44	1.25	1.15-1.37
History of COPD							0.90	0.82-1.00
History of renal disease			1.30	1.13-1.51				
History PVD					1.20	1.02-1.42	1.32	1.11-1.56
History of stroke								
Hypertension	1.22	1.04-1.42			1.16	1.06-1.26	1.15	1.06-1.25
Previous history MI	1.28	1.09-1.49	1.43	1.31-1.57	1.46	1.33-1.60	1.56	1.42-1.72
Previous history UA			1.35	1.16-1.57	1.50	1.28-1.76	1.56	1.32-1.83
**BMI 1 vs 4	0.78	0.57-1.07						
**BMI 2 vs 4	0.79	0.64-0.97						
**BMI 3 vs 4	0.70	0.58-0.85						
Living in a community with % higher % Canadian citizens					1.15	1.00-1.32		
Living in a Health District with more social cohesion					1.04	1.00-1.07		

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years. **BMI (body mass index) group 1=< 20; 2=20 - 25; 3=25 - 30; 4=> 30 ^A health district with more social cohesion was defined as one in which more residents said they had some to support them most or all of the time

Appendix IV Exploratory multilevel analysis models

3 level model rehospitalization: reduced cohort (excluding BMI)	**30 day rehospitalization**		**1 year rehospitalization**		**5 year rehospitalization**		**Total rehospitalization**	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Sex (female vs male)								
*Age group 1 vs 5					1.04	0.49-2.20	1.32	0.62-2.79
*Age group 2 vs 5					1.53	3.13-20.75	1.99	0.97-4.07
*Age group 3 vs 5					1.63	0.80-3.30	2.03	1.00-4.12
*Age group 4 vs 5					1.68	0.83-3.41	1.97	0.97-4.00
Hyperlipidemia			0.88	0.78-0.99				
Diabetes			1.27	1.14-1.42	1.36	1.21-1.53	1.31	1.16-1.48
History of heart failure	1.36	1.16-1.58	1.39	1.25-1.56	1.54	1.37-1.74	1.52	1.35-1.72
History of renal disease			1.23	1.03-1.47				
History PVD							1.33	1.07-1.66
History of stroke					1.24	1.02-1.50	0.00	0.00-0.00
Hypertension	1.19	1.02-1.39	1.13	1.01-1.26	1.18	1.06-1.32	1.18	1.05-1.32
Previous history TIA					0.77	0.61-0.96		
Previous history MI	1.29	1.10-1.50	1.39	1.24-1.56	1.41	1.25-1.58	1.47	1.30-1.67
Previous history UA			1.22	1.02-1.45	1.32	1.10-1.59	1.35	1.11-1.63
**BMI 1 vs 4								
**BMI 2 vs 4								
**BMI 3 vs 4								
Smoking (Y vs never)					0.88	0.78-0.99		
Living in a Health District with more social cohesion			0.00	0.00-0.00	1.03	1.01-1.05		

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years. **BMI (body mass index) group 1=< 20; 2=20 - 25; 3=25 - 30; 4=> 30 ^A health district with more social cohesion was defined as one in which more residents said they had a strong sense of belonging

Appendix IV Exploratory multilevel analysis models

2 level model municipality: Mortality	**30 day mortality**		**1 year mortality**		**5 Year mortality**		**Total mortality**	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex (female vs male)	0.64	0.45-0.90	0.82	0.71-0.94	0.78	0.70-0.87	0.79	0.71-0.89
*Age group 1 vs 5	0.08	0.02-0.35	0.16	0.07-0.35	0.06	0.03-0.14	0.06	0.02-0.16
*Age group 2 vs 5	0.11	0.04-0.32	0.15	0.07-0.30	0.12	0.05-0.27	0.12	0.05-0.31
*Age group 3 vs 5	0.14	0.05-0.37	0.27	0.14-0.54	0.24	0.11-0.53	0.27	0.11-0.72
*Age group 4 vs 5	0.18	0.07-0.47	0.40	0.20-0.79	0.43	0.19-0.95	0.47	0.18-1.23
Diabetes	1.43	1.01-2.03	1.37	1.18-1.58	1.53	1.37-1.72	1.61	1.42-1.81
**BMI 1 vs 4	0.48	0.26-0.89	0.52	0.40-0.68	0.46	0.37-0.58	0.67	0.53-0.86
**BMI 2 vs 4	0.57	0.36-0.89	0.63	0.52-0.76	0.75	0.65-0.86	0.76	0.66-0.89
**BMI 3 vs 4	0.99	0.63-1.58	0.74	0.62-0.89	0.87	0.76-1.00	0.87	0.76-1.00
Community with median income is less than the median vs greater than median							1.10	0.90-1.35

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years. **BMI (body mass index) group 1=< 20; 2=20 - 25; 3=25 - 30; 4=> 30

2 level model municipality: Rehospitalization	**30 day rehospitalization**		**1 year rehospitalization**		**5 Year rehospitalization**		**Total rehospitalization**	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
*Age group 1 vs 5					1.35	0.89-2.04	1.70	1.13-2.56
*Age group 2 vs 5					1.76	1.23-2.52	2.25	1.58-3.22
*Age group 3 vs 5					1.92	1.36-2.72	2.29	1.63-3.23
*Age group 4 vs 5					1.63	1.16-2.31	1.79	1.27-2.52
Hyperlipidemia					1.13	1.02-1.25		
Diabetes			1.35	1.23-1.47	1.38	1.26-1.51	1.35	1.23-1.47
History of heart failure	1.36	1.17-1.59	1.25	1.15-1.37	1.32	1.21-1.43	1.24	1.14-1.35
History of renal disease			1.30	1.13-1.50				
History PVD					1.20	1.02-1.41	1.27	1.07-1.49
History of stroke								
Hypertension	1.22	1.04-1.42			1.15	1.06-1.25	1.15	1.05-1.25
Previous history MI	1.28	1.09-1.49	1.43	1.30-1.57	1.46	1.33-1.60	1.56	1.42-1.72
Previous history UA			1.34	1.15-1.56	1.50	1.28-1.75	1.56	1.32-1.83
**BMI 1 vs 4	1.28	0.93-1.76						
**BMI 2 vs 4								
**BMI 3 vs 4	1.42	1.18-1.71						

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years. **BMI (body mass index) group 1=< 20; 2=20 - 25; 3=25 - 30; 4=> 30

Appendix IV Exploratory multilevel analysis models

2 level model county; Mortality)	**30 day mortality**		**1 year mortality**		**5 Year mortality**		**Total mortality**	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex (female vs male)	0.64	0.46-0.91	0.82	0.71-0.94	0.78	0.70-0.87	0.79	0.71-0.89
*Age group 1 vs 5	0.08	0.02-0.37	0.16	0.07-0.35	0.06	0.03-0.14	0.06	0.02-0.16
*Age group 2 vs 5	0.12	0.04-0.35	0.15	0.07-0.30	0.12	0.05-0.27	0.12	0.05-0.31
*Age group 3 vs 5	0.15	0.06-0.41	0.27	0.14-0.54	0.24	0.11-0.53	0.27	0.11-0.71
*Age group 4 vs 5	0.19	0.07-0.50	0.40	0.20-0.79	0.43	0.19-0.95	0.47	0.18-1.23
Hyperlipidemia			0.76	0.65-0.89	0.78	0.70-0.88	0.65	0.57-0.73
Diabetes			1.37	1.18-1.58	1.53	1.37-1.72	1.61	1.42-1.81
History of heart failure			1.52	1.32-1.75	1.66	1.48-1.85	1.70	1.51-1.92
History of COPD			1.39	1.19-1.62	1.42	1.26-1.61	1.53	1.34-1.74
History of renal disease			1.72	1.41-2.09	2.22	1.86-2.66	1.88	1.53-2.31
History PVD			0.73	0.54-0.98				
History of stroke					1.29	1.09-1.53	1.25	1.03-1.50
Hypertension							1.15	1.02-1.29
Previous history MI							1.22	1.08-1.38
Previous history UA								
**BMI 1 vs 4	1.86	1.01-3.43	1.91	1.46-2.50	2.17	1.72-2.72	1.48	1.16-1.89
**BMI 2 vs 4	1.63	1.05-2.54	1.59	1.31-1.93	1.33	1.16-1.54	1.31	1.13-1.53
**BMI 3 vs 4	0.96	0.61-1.52	1.35	1.13-1.63	1.14	1.00-1.31	1.14	1.00-1.31
Alcohol use					0.78	0.61-1.00		

Appendix IV Exploratory multilevel analysis models

2 level model county; Rehospitalization	30 day rehospitalization		1 year rehospitalization		5 Year rehospitalization		Total rehospitalization	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex (female vs male)								
*Age group 1 vs 5			1.17	0.75-1.83	1.35	0.90-2.04	1.70	1.13-2.56
*Age group 2 vs 5			1.48	1.01-2.18	1.76	1.23-2.51	2.25	1.57-3.21
*Age group 3 vs 5			1.46	1.01-2.13	1.92	1.36-2.71	2.29	1.62-3.23
*Age group 4 vs 5			1.31	0.90-1.91	1.62	1.15-2.29	1.78	1.26-2.51
Hyperlipidemia								
Diabetes			1.32	1.20-1.44	1.38	1.26-1.51	1.35	1.23-1.47
History of heart failure	1.36	1.17-1.59	1.26	1.15-1.38	1.31	1.20-1.43	1.24	1.13-1.35
History of COPD								
History of renal disease			1.30	1.13-1.50				
History PVD					1.20	1.02-1.41	1.26	1.07-1.49
History of stroke								
Hypertension	1.22	1.04-1.42			1.15	1.06-1.25	1.15	1.05-1.25
Previous history MI	1.28	1.09-1.49	1.41	1.28-1.54	1.46	1.33-1.60	1.56	1.42-1.72
Previous history UA			1.34	1.15-1.55	1.49	1.28-1.75	1.56	1.32-1.83
**BMI 1 vs 4	1.28	0.93-1.76						
**BMI 2 vs 4	1.26	1.02-1.55						
**BMI 3 vs 4	1.42	1.18-1.71						
Living in a county with less versus more than median non-canadian citizens			1.20	1.06-1.36				

*Age group 1= < 50 years; 2= 50 - 65 years; 3= 65- 80 years; 4= 80 to 95 years 5=> 95 years. **BMI (body mass index) group 1=< 20; 2=20 - 25; 3=25 - 30; 4=> 30