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FACTORS THAT INFLUENCE HEART FAILURE SELF-MANAGEMENT OF COMMUNITY DWELLING INDIVIDUALS

by

WENDY EARLE

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in partial fufillment of the requirements for the degree of
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Abstract

Heart failure (HF) affects 350,000 Canadians, and is the third most common primary diagnosis for a hospitalization in Canada. People with HF experience periods of stability interspersed with exacerbations requiring hospitalization. During the fiscal year 2000-01, 85,679 patients were admitted to hospitals in Canada accruing a cost of over $1 billion per year for inpatient hospital services alone. These statistics indicate that in addition to the considerable influence on the lives of many Canadians, the burden of the problem is significant on the current and future health care system.

An important component of HF management is the ability of individuals to effectively self-manage symptoms related to the disease. Self-management can have a positive impact on outcomes related to HF such as improved quality of life, reduction of symptoms, and a reduction in the number of emergency room visits and hospital readmission rates. Despite agreement on the positive impact of self-management, there continues to be a lack of understanding of factors that influence an individual's ability to self-manage effectively. As well, to date, work has largely focused on individuals hospitalized with their HF rather than on community dwelling individuals. Thus, the importance of describing the profile characteristics of community dwelling individuals, as well as examine influencing factors specific to this population.

This thesis examines factors that influence HF self-management as well as the profile characteristics of community dwelling individuals. The results of a systematic review and findings of a study that combines a mixed method approach including a quantitative secondary analysis, and a set of qualitative telephone interviews are presented. The qualitative data focuses on one factor, perception of social support, and how it relates to HF self-management. Finally, an integration of the information is presented.

Acknowledgments

Many people contributed to the completion of this thesis. I would like to thank Andy for his ongoing support throughout this process. For his ability to help me keep things in perspective and his willingness to learn more about HF self-management than he ever wanted to. I would like to thank both our families for providing ongoing encouragement. To my friends who always understood and were willing to listen even when they had heard it all before.

I would like to thank my advisors Margaret Harrison, Jo Logan, and Cynthia Toman for their initial support and ongoing guidance. In particular, Margaret Harrison who provided encouraging words of wisdom. Her words "keep on trucking" will forever be engrained in my mind. I would also like to thank Patricia Oakley and Val Angus for their help at the very beginning of this process.

I would like to dedicate this thesis to two people who forced me to keep focused on what is most valuable in life, family and friends. Also for showing me the importance of having the courage not only to keep on going, but also to know when to let go. To Matthew, who showed the courage to fight at the beginning of his young life, and to Allan who showed great courage at the end of his life.

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Chapter One

Introduction

Heart failure (HF) affects 350,000 Canadians, is the third most common primary diagnosis for a hospitalization in Canada, and the only cardiovascular disease reported to be increasing in prevalence (Liu et al., 2001). Recent Canadian studies describing the profile of the population living with HF shows an equal distribution of women and men with the condition, with the average age for both greater than 65 years (Jong, Vowinckel, Liu, Gong, & Tu, 2003; Levy et al., 2002; Tsuyuki, Shibata, Nilsson, & Hervas-Malo, 2003). Individuals with a diagnosis of HF have a one-year mortality rate between 25% and 40% (Liu et al., 2001).

People with heart failure experience periods of stability interspersed with exacerbations requiring hospitalization. During the fiscal year 2000-01, 85,679 patients were admitted to hospitals in Canada with a primary diagnosis of HF with each stay averaging eight days, accruing a cost of over $1 billion per year for inpatient hospital services alone (Liu et al., 2003). These statistics indicate that in addition to the considerable influence on the lives of many Canadians, the burden of the problem is significant on the current and future health care system.

An important component of HF management is the ability of individuals to effectively self-manage symptoms related to the disease. Self-management involves behaviors in response to a change in signs and symptoms. It includes four phases: recognition of a change, evaluation of the change, implementation of a treatment strategy, and evaluation of the effectiveness of the treatment strategy implemented (Connelly, 1993). Self-management can have a positive impact on outcomes related to HF such as improved quality of life, reduction of symptoms, and a reduction in the number of emergency room visits and hospital readmission rates (Dunbar, Jacobson, & Deaton, 1998; Harrison et al., 2002; Jaarsma, Abu-Saad, Dracup, & Halfens, 2000).

My clinical practice provides regular exposure to community dwelling individuals who engage in the self-management of HF. It is often a struggle for these individuals and their families to coordinate a complex regime of medications and adjustments to their daily living. In my practice, I find that issues related to social support seem to influence how effectively patients mange their condition. Individuals' perceptions of their supports as helpful or not, needs to be examined but is not a current focus in clinical settings.

Social support is not simply the quantity of supports that individuals have available to them. According to Langsford, Bowsher, Maloney, & Lillis (1997) it is a comprehensive concept that includes several attributes: emotional support (i.e., empathy, caring, love, and trust), instrumental support (i.e., aid in kind, money, labor, time, and modifying environment), informational support (i.e., advice, suggestions, directives, and information), and appraisal support (i.e., affirmation, feedback, and social comparison). Perceived social support is further defined as the extent the patient perceives an interaction, pattern of interaction, or relationship as being helpful (Schaefer, Coyne, & Lazarus, 1981). The effect of perceived social support has only been considered in one study examining compliance with self-care behaviors in 82 patients with HF. This non-random survey did not support perceived social support as being a predictor of compliance with self-management behaviors (Evangelista & Dracup, 2000).

The influence of social support appears to be unique to each individual. I have seen individuals with many supports who did not manage well, and others with fewer supports who did. For individuals who manage well, shared responsibility by a variety of supports was necessary to accomplish all the behaviors needed to stay symptom free. For example, a spouse might assume the role of keeping medication doses and schedules organized, or be responsible for monitoring the quantity of salt in food. Individuals without close family support might rely on friends or community groups to assist in transportation to appointments or provide an opportunity to talk about the struggles of managing HF. Thus, a further examination of perceived social support, among other factors, will help to guide health professionals in assessments and interventions that facilitate more effective self-management.

Purpose

The purpose of this thesis is to explore factors that influence effective HF self-management of community dwelling individuals. The focus is on examination of social support, specifically perceived social support and its relationship to self-management as an area of particular concern with non-hospitalized HF patients.

The specific objectives of the thesis are to:

1. Synthesize the current evidence from research studies on the factors that influence community dwelling individuals' self-management of HF.
2. Describe the profile of a cohort of people with HF who are currently at home and self-managing their condition.
3. Compare the profile characteristics of the study cohort to a larger cohort recently discharged from hospital with HF.
4. Explore how the perception of social support relates specifically to self-management in the HF population living in the community.

Heart Failure and the Current State of Practice

Heart failure is a chronic progressive condition. The most common symptoms that individuals experience include shortness of breath, edema, and fatigue (Funk & Krumholz, 1996). Other symptoms include loss of concentration, poor attention and memory, weight gain, pain, weakness, and insomnia (Riegel & Carlson, 2002). People with HF are assessed based on physical functional abilities that are rated according to the New York Heart Association (NYHA) classification. It consists of four classifications, levels I-IV, with the higher classifications indicating more severe symptoms. Appendix A summarizes these classifications.

Although there is no cure for HF, new drug therapies to control symptoms and to maintain functional abilities are used. This has increased the burden on individuals and families, as the drug regimes typically comprise a complex daily routine. For example, in one recent study of people with heart failure, 75% were taking four to nine prescription drugs on discharge, some requiring self-titration management (Harrison et al., 2002). Effective management of symptoms, therefore, depends on effective drug treatment with active medical monitoring during medication adjustment, as well as on behavior and lifestyle modifications.

Major recommendations arising from current clinical practice guidelines provide direction for HF self-management. Clinical practice guidelines are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances (Field & Lohr, 1990). The guidelines make explicit links between the recommendations and supporting scientific evidence, which are intended to guide practice. Widely accepted HF practice guidelines published by the Canadian Cardiovascular Society (CCS), the American College of Cardiology and the American Heart Association (ACC/AHA), and the European Society of Cardiology guide the management and diagnosis of HF (Hunt et al., 2001; Liu et al., 2001; Liu et al., 2003;

Remme et al., 2001). All three guidelines recognize the importance of a multidisciplinary approach to care and support.

Heart failure practice guidelines acknowledge the importance of improving patients' quality of life by reducing symptoms and hospitalizations. A key component in achieving this aim is the promotion of individuals' ability to self-manage. The CCS guideline suggests two key self-management teaching strategies: daily weights and self-adjustment of diuretics. The ACC/AHA (2001) guideline outlines self-management education principles that include sodium restriction, monitoring daily weights, medication, and exercise (Hunt et al., 2001). The European (2001) guideline recommends that individuals receive information on the causes of heart failure, recognition of symptoms, and response to symptoms as well as the importance of monitoring daily weights, dietary restrictions, and exercise (Remme et al., 2001).

These guidelines specifically recognize the importance of education and support by experienced nurses who conduct phone calls to monitor individuals' progress at home. A recently published study by Staples and Earle (2004) explored how closely nurses in Canadian HF clinics follow the recommended guidelines, confirming that nurses are providing the education outlined in the guidelines as well as the telephone management. Recommendations for care by the multidisciplinary team of health professionals in terms of supporting self-management are described in the guidelines, but there are no recommendations regarding the family or other supports for self-management.

Although guideline recommendations provide direction with regard to self-managed content, the process of support is poorly understood. Increased understanding in this area could focus and improve the type and level of support from professional providers such as nurses. Several studies examine the influence of social support on other chronic illnesses

(Connelly, 1993; Weinberger, Hiner, & Tierny, 1986). However, this has yet to be addressed adequately in practice guidelines and literature focused specifically on the HF population.

In summary, despite the increasing body of literature and the development of evidence-based clinical practice guidelines that support HF self-management, gaps exist in our knowledge of which factors influence individuals' ability to effectively deal with their condition. Nurses work with patients and families, but the influence of the nurse's role in self-management is poorly understood. Increased knowledge of factors that influence self-management is important so that health professionals and particularly nurses can assist in supporting individuals' self-management of HF, properly assess situations, and initiate effective strategies.

Conceptualizing Self-Management

One self-management model that has been developed and studied over the last decade is Connelly's Model of Self-Care in Chronic Illness (1993). The purpose of the model is to guide assessment, planning, implementation, and evaluation of self-care. Connelly's model provides a framework for clinical decision-making in the promotion and support of self-care behaviors by identifying factors that influence effective self-management. Predisposing and enabling factors interact with each other in an ongoing circular relationship. The factors identified in the model are *predisposing* and *enabling* are presented in Table I.

Predisposing factors included variables that influence the likelihood that a patient will engage in self-management behaviors. These factors include self-concept (levels of aspiration, achievement, motivation), general health motivations that include the variables perception of the importance of health and willingness to perform health care behaviors, perceived seriousness of illness, and perceived vulnerability to complications. The last predisposing factor is perceived efficacy of recommended health behaviors, patient health and illness experiences, and observations of others in their social sphere. *Enabling factors* include patient characteristics (age, education, marital status), psychologic status (feelings, mood, level of anxiety, stress), regime features (identification and modification of plan of care by patient and provider), cues to action (various reinforcement by supports), social support (friend or family), and system characteristics (satisfaction and continuity of care).

Connelly's model, as previously described, provides a guided concept framework to examine HF self-management and allow comparisons across studies and synthesis of findings. This model can be used for ongoing assessment in terms of the factors identified by the model, to assist nurses to identify situations, crises, and changes that place the patient at risk or create barriers to self-care, and indicate when and how to intervene to support self-care.

History of Improving Self-Management

In 1994, clinical practice guidelines published by Konstam et al. (1994) provided direction for management and care of individuals with HF. These guidelines identified the importance of counseling and education to patients and family caregivers as a critical component to effective management and avoidance of unnecessary hospital admissions. They also re-enforced self-management being essential to effective HF management. A randomized controlled trial of hospital-to-home transition for patients with HF (Harrison, Toman, & Logan, 1998) was conducted as an initial line of enquiry targeted at improving supportive care to the HF population. Following the completion of this study, widespread attention focused on the educational component, "Partners in Care for Congestive Heart Failure" (PCCHF). This resource, developed in 1995 as part of a research program, provided the first evidence-based education program designed to assist nurses to implement the Agency for Health Policy and Research (AHCPR) clinical practice guideline recommendations for HF (Toman, Harrison, & Logan, 2001). The development of this resource was in response to these guidelines and the lack of available resources to support individuals in self-management. It consisted of three components: an education guidebook for patients and families, an education map for practitioners and a resource manual for professional providers (Harrison, Graham, Toman, & Logan, 2001).

Growing interest in this education program from a wider community of providers prompted an evaluation study of the PCCHF (NHRDP # 6606-06-1998/2590041) from 1999 to 2001 (Harrison et al., 2001). Patients, nurses, and policy makers evaluated the PCCHF and found that overall, the program was well accepted, and contributory to self-management. A revision of the PCCHF resource occurred based on the results of this ten-site evaluation study and the resource was retitled as “Managing Congestive Heart Failure.” Many challenges emerged in this study regarding the implementation of the program in a hospital setting, including the wider dissemination of the resource (Harrison et al., 2001). Based on the level of interest in the resource, the authors transferred the copyright for the resource to the Heart and Stroke Foundation Canada in 2002, for general distribution that would occur following a dissemination study by the Heart and Stroke Foundation of Ontario (HSFO). Table II outlines a summary of the development of the self-management resource and supporting research.

In the 2002 dissemination study, 1,000 copies of the “Managing Congestive Heart Failure” resource were distributed to hospitals and heart failure clinics across five regions of Ontario. Included in the resource was a questionnaire to collect data about users’ demographics, severity of disease, and quality of life as assessed by the Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Appendix B). At the end of the questionnaire, there was an invitation to participate in a more detailed follow-up telephone interview to provide additional feedback about the use of the resource for self-management. Randomization of the respondents was completed after they signed and returned this request. They were then contacted by telephone by a research assistant who was a registered nurse. I was the research assistant conducting these telephone interviews (see HSFO study questions, Appendix C). As previously mentioned, those interviewed were randomly selected from the group indicating willingness; as well, they equally represented all five regions of Ontario. The expectation was that the group would also equally represent both genders. However, after randomization of respondents, 33% were women and 67% were men.

Thesis Link to HSFO Dissemination Study

The HSFO study provided a unique opportunity to approach community dwelling individuals actively engaged in self-management of their HF through a provincially available resource. To date, work has largely focused on individuals hospitalized with their HF – thus the importance of describing the characteristics of community dwelling individuals with HF as well as the making use of the opportunity to explore the relationship of perceived social support on self-management on this group.

For the purpose of this thesis, a social support cohort of individuals' participating in the HSFO study follow-up telephone interviews were invited to participate in three additional semi-structured interview questions focusing on perceived social support (Appendix D). After the HSFO questions were completed, a request to answer the additional questions, was made and then verbal consent was obtained (Appendix E). Ten individuals agreed to participate in the more in-depth interview on perceived social support.

As well, a comparison of the profile characteristics for the social support cohort, the HSFO survey data, and one previous PCCHF study was completed. Appendix F provides a summary of the social support cohort study participants.

The Ottawa Hospital Research Ethics Board approved the proposals for both the original HSFO dissemination study and the thesis study. A separate letter that described the intent by outlining the specifics of this study was added as an addendum to the original HSFO proposal (Protocol #2003002-01H, Appendix G). Informed consent obtained in a two-stepped approach included: written consent incorporated into the HSFO questionnaire, and verbal consent, obtained at the time of the telephone interviews, for my specific questions.

Format of Thesis

This manuscript-based thesis consists of three distinct papers, two prepared as submissions for publication. The specific objectives of the thesis are to synthesize the current evidence from research studies on the factors that influence community dwelling individuals' self-management of HF. To describe the profile of a cohort of people with HF who are currently at home and self-managing their condition, to compare the profile characteristics of the study cohort to a larger cohort recently discharged from hospital with HF, and explore how the perception of social support relates specifically to self-management in the HF population living in the community. Chapter two (the first manuscript) addresses the first objective of this thesis. Chapter three (the second manuscript) addresses objectives two through four. Chapter four consists of an integrative summary and describes the thesis contribution to knowledge. This chapter also discusses implications for practice, policy, education and future research.

Overview of Chapters

The second chapter, “Self-Management of Heart Failure: A Systematic Review of Influencing Factors,” outlines the methodology and results of a systematic review. Connelly’s model of Self-Care in Chronic Illness provides the framework that guides this review (Connelly, 1993). The systematic review synthesizes current knowledge about factors that influence HF self-management and identifies factors, based on Connelly’s model, that are applicable specifically to the HF population. This analysis provides the foundation and direction for the remainder of the thesis.

The third chapter, “An Exploration of Profile Characteristics of Community Dwelling Individuals and their Perception How Social Support Relates to Heart Failure Self-Management” uses a mixed method approach. The use of a mixed method approach provides a more comprehensive approach to solve a complex phenomenon (Morse, 1991; Woods, Agarwal, Young, Jones, & Sutton, 2004) such as HF self-management. The methods were sequentially implemented (Morse, 1991) using a conceptual approach recommended by Shih (1998), which involves the search for patterns of relationship and meaning between significant variables. The data analysis for both methods was conducted separately as suggested by Shih (1998), and the interpretation of the study findings, as suggested by Morse (1991), was conducted within the context of the present knowledge regarding the topic, in this case, HF self-management. Data from the HSFO survey, data from the social support cohort, and data from the original PCCHF trial were constructed into three separate datasets for secondary analysis examining gender, age, NYHA classification, length of diagnosis, hospitalizations, and selected questions from the MLHFQ. Qualitative interviews were conducted with the social support cohort, based on the three questions about perceived social support.

The qualitative data consisted of a set of ten, semi-structured, taped and transcribed telephone interviews that explored the perceptions of how social support relates specifically to self-management in the HF population living in the community. Data were analyzed according to standard content analysis methods. Of the two types of content analysis, manifest and latent, latent was used. Latent analysis goes beyond words and infers meaning to something (Morse, 1991). Steps identified by Morse and Field (1995) guided the analysis. The beginning analysis involved verifying the transcribed data by re-listening to the recorded interviews to ensure accuracy, and by documenting any cues such as laughing or pauses. This was followed by identification and defining codes and categories, and the combination of like categories. Last, relationships between categories were identified.

Four operational techniques supported the rigor of the qualitative analysis: credibility, confirmability, dependability, and transferability (Lincoln & Guba, 1985). Credibility was ensured by taping telephone interviews, verifying transcriptions, attempting to summarize or repeat participants' words at the time of interviews, as well as by several peer debriefings. Confirmability was ensured by the documentation of an audit trail of dated memos. The audit trail also helped to ensure the dependability of the data. Transferability was achieved by providing a description of the participants and settings so readers could evaluate if the findings were transferable to their specific settings and groups of HF patients.

The quantitative data were generated through secondary analysis of the data from the HSFO survey and the randomized control trial of a larger cohort, recently discharged from hospital with HF. The profile characteristics selected for the secondary analysis were those most often cited as significant in the literature. Also included in the secondary analysis were selected items that reflect the impact of self-management from the MLHFQ embedded within the HSFO survey. These data were analyzed using descriptive statistics. A more in depth statistical analysis was not conducted due to the small number of participants in the study.

The samples were sequentially drawn by first generating the quantitative sample, and then the qualitative sample as outlined by Morse (1991) and Norwood (2000). As supported by both Morse (1991) and Sandelowski (1995), the sample sizes for each method were different. For this study, the qualitative sample size was 10 and the quantitative sample size was 47. Several authors agree that a sample size of 10 is adequate for a qualitative study if that study examines a homogeneous group (Hott, 1999; Polit & Hungler, 1995; Sandelowski, 1995). The qualitative sample for this study was a homogenous group, as shown by the secondary analysis of the profile characteristics displayed in Table III.

In the fourth chapter, I integrate the findings from the systematic review with the findings of both the quantitative and qualitative mixed method approach. I identify the major contribution to knowledge of this patient population. I also present implications for practice, policy, education and suggest future research directions.

Contributions to Manuscripts

Wendy Earle is the primary author of both manuscripts. Margaret Harrison and Jo Logan are co-authors of the first manuscript (Chapter #2) and Margaret Harrison, Jo Logan, and Cynthia Toman are co-authors of the second manuscript (Chapter #3). Wendy Earle was responsible for the conception and design of the study, analysis plan, analysis, interpretation of the data and drafting the manuscript. Margaret Harrison, Jo Logan, and Cynthia Toman made contributions to conception and study design, analysis plan, and critically reviewed and suggested revisions to drafts of the manuscript.

Reference List

Connelly, C. E. (1993). An empirical study of a model of self-care in chronic illness. *Clinical Nurse Specialist, 7,* 247-253.

Dunbar, S. B., Jacobson, L. H., & Deaton, C. (1998). Heart failure: Strategies to enhance patient self-management. *AACN Clinical Issues, 9,* 244-256.

Evangelista, L. S., & Dracup, K. (2000). A closer look at compliance research in heart failure patients in the last decade. *Progress in Cardiovascular Nursing, 15,* 97-103.

Field, M. J., & Lohr, K. N. (1990). *Clinical practice guidelines: Directions for a new program.* Washington, DC: Institute of Medicine, National Academy Press.

Funk, M., & Krumholz, H. M. (1996). Epidemiologic and economic impact of advanced heart failure. *Journal of Cardiovascular Nursing, 10,* 1-10.

Harrison, M. B., Toman, C., & Logan J. (1998). Hospital to home evidence-based education for CHF. *Canadian Nurse/L'Infirmiere Canadienne, 9(4)*, 36-42.

Harrison, M. B., Graham, I. D., Toman, C, & Logan, J. (2001). *Partners in care for congestive heart failure: A multi-province education program evaluation.* Technical Report. National Health Research & Development Program, Health Canada. Ottawa, OHRI.

Harrison, M. B., Browne, G. B., Roberts, J., Tugwell, P., Gafni, A., & Graham, I. D. (2002). Quality of life of individuals with heart failure: A randomized trial of the effectiveness of two models of hospital-to-home transition. *Medical Care, 40,* 271-282.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage Publications.

Liu, P., Arnold, M., Belenkie, I., Howlett, J., Huckell, V., Ignazewski, A., et al. (2001). The 2001 Canadian Cardiovascular Society consensus guideline update for the management and prevention of heart failure. *Canadian Journal of Cardiology, 17,* 5E-24E.

Liu, P., Arnold, J. M., Belenkie, I., Demers, C., Dorian, P., Gianetti, N., et al. (2003). The 2002/2003 Canadian cardiovascular society consensus guideline update for the diagnosis and management of heart failure. *Canadian Journal of Cardiology, 19,* 347-356.

Morse, J. M. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research, 40(1),* 120-123.

Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals.* Thousand Oaks, CA: Sage Publications.

Norwood, S. L. (2000). Determining sample size. In D. P. Carroll (Ed.), *Research strategies for advanced practice nurses* (pp.219-239). Upper Saddle River, NJ: Prentice-Hall, Inc.

Polit, D. F., & Hungler, B. P. (1995). *Nursing research: Principles and methods.* Philadelphia, PA: Lippincott Williams & Wilkins.

Remme, W. J., Swedberg, K., Cleland, J., Dargie, H., Drexter, H., & Follah, F. (2001). European Society of Cardiology task force for the diagnosis and treatment of chronic heart failure: Comprehensive guidelines for the diagnosis and treatment of chronic heart failure. *European Heart Journal, 22*, 1527-1560.

Riegel, B., & Carlson, B. (2002). Facilitators and barriers to heart failure self-care. *Patient Education and Counseling, 46(4),* 287-295.

Sandelowski, M. (1995). Focus on qualitative methods: Sample size in qualitative research. *Research in Nursing and Health, 18,* 179-183.

Schaefer, C., Coyne, J. C., & Lazarus, R. S. (1981). The health-related functions of social support. *Journal of Behavioural Medicine, 4,* 381-405.

Shih, F. (1998). Triangulation in nursing research: Issues of conceptual clarity and purpose. *Journal of Advanced Nursing, 28(3),* 631-641.

Staples, P., & Earle, W. (2004). The role and scope of practice of nurses working in Canadian heart failure clinics. *Heart & Lung, 33(4)*, 201-209.

Toman, C., Harrison, M. B., & Logan, J. (2001). Clinical practice guidelines: Necessary but not sufficient for evidence-based patient education and counseling. *Patient Education & Counseling, 42,* 279-287.

Tsuyuki, R. T., Shibata, M. C., Nilsson, C., & Hervas-Malo, M. (2003). Contemporary burden of illness of congestive heart failure in Canada. *Canadian Journal of Cardiology, 19,* 436-438.

Weinberger, M., Hiner, S. L., & Tierny, W. M. (1986). Improved function status in arthritis: The effect of social support. *Social Science and Medicine, 23(9)*, 899-904.

Woods, M., Agarwal, S., Young, B., Jones, D., & Suttion, A. (2004). *Integrative approaches to qualitative and quantitative evidence.* Health Development Agency. London.

Table I- Connelly's Model of Self-Care in Chronic Illness Predisposing and Enabling Factors

Predisposing Factors	Enabling Factors
Self-concept	Patient characteristics
Health motivations	Psychologic status
Patient perception of seriousness	Regime characteristics
Patient perception of vulnerability	Cues to action
Patient perception of efficacy	Social support
	System characteristics

Table II- Summary of Self-Management Resource Development and Subsequent Studies

Purpose		Results	References
Development of tool for nurses/ patients/families to help implement the AHCPR recommendations for management of CHF **(1995)**		"Partners in Care for Congestive Heart Failure" (PCCHF)	Harrison et al. (1998), Hospital to home: Evidence based education for congestive heart failure, *Canadian Nurse/L'Infirmiere Canadienne*, *9(4)*, 36-42. Toman et al. (2001), Clinical practice guidelines: Necessary but not sufficient for evidence-based patient education and counseling, *Patient Education and Counseling, 42(3)*, 279-87.
Two Studies to evaluate the use of PCCHF by individuals with CHF and health professionals Funded by Health Canada, National Health Research Development Program			
Study #1 **(1995-97)**	•To evaluate the benefits of an enhanced discharge process including support for self-management	•improved quality of care •less use of ER	Harrison et al. (2002), Quality of life of individuals with heart failure: A randomized trial of the effectiveness of two models of hospital to home transition, *Medical Care, 40(4)*, 271-283.
Study #2 **(1999-2001)**	•To evaluate implementation of PCCHF program at 10 sites (3 provinces, 1US state)	•improved quality of life •well accepted by providers and decision makers	Harrison, M. B., Graham, I. D., Toman, C., & Logan, J. (1999-2001), Partners in care for congestive heart failure education: A multi-province education program evaluation: Technical Report. National Health Research & Development Program, Health Canada. OHRI.
Evaluation Study to re-evaluate newly revised resource now entitled "Managing Congestive Heart Failure" Funded by Heart & Stroke Foundation of Ontario/Ottawa Health Research Institute			
Study #3 **(2002)**	•To evaluate revised PCCHF resources now entitled- "Managing Congestive Heart Failure" **•Link with thesis**	•perceived as useful •lifestyle changes made •low response rate	"Evaluation of the Managing Congestive Heart Failure Resource: Patient and Provider Perspective" Report", 2003.

Table III- Profile Characteristics

	Social Support Cohort Study Respondents (n=10)		HSFO Study Respondents (n=47)		Harrison et al., 2002 (n=192)		Canadian Data
	n	(%)	n	(%)	n	(%)	
	(Community)		(Community)		(Hospitalized)		
Gender							2000-2001
Female	2	(22.2)	14	(33.3)	87	(45)	50.3%
Male	7	(77.8)	28	(66.7)	147	(76.5)	
Unknown	1		5				
Age							2000-2001
< 65	6	(60)	16	(34.8)	mean=75.64		mean 75.9
> 65	4	(40)	30	(65.2)			majority > 65
Unknown			1				
NYHA Class							
Class I	3	(30)	11	(25.0)	2	(1)	
Class II	5	(50)	24	(54.5)	41	(22)	
Class III	2	(20)	6	(13.6)	129	(67)	
Class IV	0		3	(6.8)	19	(10)	
Length of Diagnosis							
0-5 years	8	(80)	36	(76.6)			
> 5 years	1	(10)	8	(17)			
Don't know	1	(10)	3	(6.4)			
Hospitalized in last 3 months					Last 6 months		2000-2001
Yes	5	(50)	20	(42.6)	70	(37)	2-3 times/yr
# of times							2003
1	4	(80)	13	(72.2)			rate ↓
2	0		3	(16.7)			
3	1	(20)	2	(11.1)			
Minnesota Living With Heart Failure Questionnaire							
		Mean (SD)		Mean (SD)			
Physical Subset		17.20 (12.38)		21.58 (10.92)			
Emotional Subset		13.10 (8.99)		16.57 (5.56)			
Total		51.65 (28.47)		66.29 (21.68)			

Table III (con't)- Minnesota Living with Heart Failure Questionnaire

	Social Support Cohort Study Respondents (n=10)		HSFO Study Respondents (n=47)		Canadian Data
	n	(%)	n	(%)	
Physical Subscale Questions					
Make you short of breath?					
No	1	(11.1%)	6	(13.6%)	
Yes	8	(88.9%)	37	(84.2%)	
N/A	1		1	(2.3%)	
Make you tired, fatigued, or low energy?					
No	0		3	(6.4%)	
Yes	10	(100%)	43	(91.6%)	
N/A	0		1	(2.1%)	
Causing swelling in your ankles, legs, etc?					
No	5	(50%)	23	(48.9%)	
Yes	5	(50%)	23	(48.9%)	
N/A	0		1	(2.1%)	
Make you sit or lie down to rest during the day?					
No	1	(12.5%)	8	(17.8%)	
Yes	7	(58.1%)	36	(79.9%)	
N/A	2		1	(2.2%)	
Making your sexual activities difficult?					
No	3	(33.3%)	11	(28.9%)	
Yes	6	(66.6%)	25	(65.8%)	
N/A	1		2	(5.3%)	
Emotional Subscale Questions					
Making you feel you are a burden to your family?					
No	4	(40%)	21	(44.7%)	
Yes	6	(60%)	25	(53.2%)	
N/A	0		1	(2.1%)	
Making you feel a loss of self-control in your life?					
No	3	(30%)	11	(23.4%)	
Yes	7	(70%)	35	(74.4%)	
N/A	0		1	(2.1%)	
Making you worry?					
No	2	(20%)	14	(29.8%)	
Yes	7	(70%)	33	(68.1%)	
N/A	1		0	(2.1%)	
Making it difficult for you to concentrate or remember things?					
No	3	(30%)	15	(31.9%)	
Yes	7	(70%)	31	(65.9%)	
N/A	0		1	(2.1%)	
Making you feel depressed?					
No	3	(30%)	12	(25.5%)	1999 Elderly 2-3x more depressed
Yes	7	(70%)	34	(72.3%)	

Chapter Two

Self-Management of Heart Failure: A Systematic Review of Influencing Factors

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Abstract

Heart failure (HF) has the greatest increase in prevalence of any cardiovascular condition, with over 350,000 Canadians affected. Effective management of HF depends on an individual's ability to self-manage symptoms. Self-management has a positive impact on HF outcomes such as quality of life, reduction of symptoms, reduction in emergency room visits, and readmission rates. Despite desirable outcomes there continues to be a lack of understanding of factors that influence an individual's ability to self-manage effectively. The purpose of this paper is to describe a systematic review of research studies that examine factors influencing HF self-management of community dwelling individuals. Connelly's Model of Self-Care in Chronic Illness provides the framework for this review. Six influencing factors are identified: perception of seriousness of illness, health and illness experience, patient characteristics, psychological status, regime features, and social support. Increased understanding of these factors can assist health professionals to develop assessment and intervention strategies to better facilitate effective HF self-management.

Introduction

Heart failure is a chronic progressive condition characterized by episodic exacerbations. The symptoms most commonly experienced are shortness of breath, edema, and fatigue (Funk & Krumholz, 1996). Other symptoms include loss of concentration, poor attention and memory, weight gain, pain, weakness, and insomnia (Riegel & Carlson, 2002). Symptoms present in varying degrees and can change from one day to the next. Thus, daily assessment and management is necessary for individuals to maintain function. Function is typically determined according to the New York Heart Association Functional Classification (NYHA) (Liu et al., 2001), which consists of four classifications:

Class I	No physical activity limitation: ordinary physical exertion does not cause undue fatigue, chest pain, palpitations, or dyspnea
Class II	Slight limitation of physical activity: patient is comfortable at rest, but ordinary activity results in fatigue, chest pain, palpitations, or dyspnea
Class III	Marked limitation of physical activity: patient is comfortable at rest, but less than ordinary activity results in fatigue, chest pain, palpitations, or dyspnea
Class IV	Unable to carry out any physical activity without discomfort: symptoms of fatigue, chest pain, palpitations, or dyspnea are present even at rest with increased discomfort with any physical activity.

Although there is no cure for HF, new drug therapies have improved outcomes (Liu et al., 2001). Medical advances, however, place more burden on individuals, as the drug regimes typically comprise a complex daily routine to control symptoms and maintain function. Effective management of symptoms depends not only on effective medical treatment but also on behavior and lifestyle modifications. Importantly this requires that the individuals' are able to self-manage and that support for self-management is in place. Self-management of HF has a positive impact on outcomes such as improved quality of life, reduction of symptoms, and reduction in emergency room visits and readmission rates (Dunbar, Jacobson, & Deaton, 1998; Harrison et al., 2002; Jaarsma, Abu-Saad, Dracup, & Halfens, 2000a).

Conceptualizing Self-Management

Self-management involves behaviors in response to a change in signs and symptoms and has four phases: recognition of a change, evaluation of the change, implementation of a treatment strategy, and evaluation of the effectiveness of the treatment strategy implemented (Connelly, 1993). One self-management model used and studied in the last decade is Connelly's Model of Self-Care in Chronic Illness (1993). This model provides a framework for clinical decision-making in the promotion and support of self-care behaviors by identifying factors and their related variables that influence effective self-management in chronic illness.

The intention of the model is to guide assessment, planning, implementation, and evaluation of self-care. This model is used for ongoing nursing assessment in terms of the factors identified by the model, to assist in identifying situations, crises, and changes that place the patient at risk or create barriers to self-care, and indicate when and how to intervene to support self-care. The factors identified in the model are *predisposing* and *enabling*:

Predisposing Factors	Enabling Factors
Self-concept	Patient characteristics
Health motivations	Psychologic status
Patient perception of seriousness	Regime characteristics
Patient perception of vulnerability	Cues to action

Patient perception of efficacy Social support

Predisposing and enabling factors interact with each other in an ongoing circular relationship. *Predisposing* factors influence the likelihood that a patient will engage in self-management behaviors. These factors include self-concept (levels of aspiration, achievement, motivation), general health motivations that include the variables perception of the importance of health and willingness to perform health care behaviors, seriousness of illness, and vulnerability to complications. Efficacy of recommended health behaviors, patient health and illness experiences, and observations of others in their social sphere are also included. *Enabling* factors include patient characteristics (age, education, marital status), psychologic status (feelings, mood, level of anxiety, stress), regime features (identification and modification of plan of care by patient and provider), cues to action (various reinforcement by supports), social support (friend or family), and system characteristics (satisfaction and continuity of care).

Connelly tested the efficacy of this model in a descriptive correlation study with 181 participants randomly selected from an ambulatory care clinic in a major military medical center (Connelly, 1993). The model was found to be valuable in identifying factors that influence chronic illness self-care. In 2001, other researchers utilized the Connelly conceptualization of self-management (Carlson, Riegel, & Moser, 2001; Rockwell & Riegel, 2001). Two large non-random trials (n=139, n=209 respectively) used the Self-Care in Chronic Illness Questionnaire (MSCCI) developed from Connelly's model to examine factors that influence HF. Both studies reported that several factors and associated variables identified in Connelly's model also applied to the HF population. Rockwell and Riegel (2001) examined the influence that symptom severity, co-morbidity, social support, education level, socio-economic status, and gender had on HF self-management and found two variables, education level and severity of symptoms, significantly influenced HF self-management. Carlson et al. (2001) examined the influence of experience with diagnosis, NYHA classification, and co-morbidities. They concluded that self-care behaviors as well as an increased recognition of symptoms increased with experienced patients. Connelly's model provided a guided concept framework to examine HF self-management and allow comparisons across studies and synthesis of findings.

Heart Failure Self-Management and Practice Guidelines

Clinical practice guidelines are systematically developed statements to assist practitioners and patients in making decisions about appropriate health care for specific clinical circumstances (Field & Lohr, 1990). The guidelines make explicit links between the recommendations and supporting scientific evidence, and are intended to guide practice. The guidelines are intended to guide care delivery, improve survival, and enhance quality of life.

Heart failure practice guidelines provide information to guide the management and prevention of HF. The Canadian Cardiovascular Society (CCS), the American College of Cardiology and the American Heart Association (ACC/AHA), and the European Society of Cardiology have developed widely accepted HF guidelines. All three guidelines recognize the importance of improving patients' quality of life by reducing symptoms and hospitalizations. A key aspect within this aim is the promotion of an individual's ability to self-manage.

The CCS guidelines suggest two key self-management teaching strategies: daily weights and self-adjustment of diuretics (Liu et al., 2001; Liu et al., 2003). The ACC/AHA (2001) guidelines outline self-management education principles that include sodium restriction, daily weights, medication, and exercise (Hunt et al., 2001). The European (2001) guideline discuss the importance of individuals receiving information on the causes of heart

Search and Retrieval Process

Key words ‘heart failure’ and ‘self-management’ were combined using an ‘and’ statement. This resulted in 193 papers identified. Initially the key words ‘predictors’, ‘patient compliance’, ‘diet therapy’, ‘drug therapy’, and ‘exercise’ were individually combined with ‘heart failure’ and ‘self-management’ using an ‘and’ statement in an attempt to focus the search. This resulted in 80 papers. A preliminary scan of the on-line abstracts showed that the identified papers did not focus on the review question asked. Connelly’s model was then utilized to structure the search by combining key words derived from the model’s predisposing and enabling factors with ‘heart failure’ and ‘self-management’. The key words from the model that resulted in identification of papers were ‘social support’, ‘co-morbidity’, ‘patient education’, ‘age factors’, ‘sex factors’, ‘social environment’, and ‘lifestyle’. This resulted in 125 papers.

The next step involved scanning all 125 abstracts on line to confirm that the studies met the set inclusion criteria. The abstract scan revealed only 11 studies that fit the inclusion criteria. The main reason for the drastic reduction in the number of studies was due to a very small number of studies that focused on community dwelling individuals rather than hospitalized individuals diagnosed with HF. As well, many studies focused on evaluating the effect of a specific intervention and patient outcomes rather than the influence of factors on the outcome, i.e., effect of medication adjustment. One other reason for the reduction in numbers was the exclusion of non-research articles. Appendix H summarizes the search strategy.

Critical Analysis

The critical appraisal process began by completing an abstract for each of the 11 studies. The structured abstract format, developed from two resources, was intended to summarize the salient information for assessing the quality of the study and the relevance of the results (Davis & Logan, 1997; National Health Service, 1999). These two resources incorporate five aspects to review: Is the study sound, what do the results mean, are the results relevant to practice, can the information be generalized to other populations, and are the results consistent with policy

Findings

The 11 included studies were a mix of designs consisting of large random (3) and non-random (6) quantitative studies, as well as qualitative studies (3) that mainly used convenience samples. One study integrated both qualitative and quantitative methods. Table I provides a synthesis of the studies identified. At the completion of the review, six factors and related variables from Connelly's model were identified in the HF research literature that may influence self-management. These factors are: perception of seriousness of illness (New York Heart Association {NYHA} classification), perception of importance of health (depression, anxiety, self-efficacy), health and illness experience (length of diagnosis, co-morbidities), patient characteristics (gender, patient education level, socioeconomic class), psychological status (anxiety, depression, self-efficacy), regime features (education provided by health professionals), and social support. Table II summarizes the factors identified in Connelly's model and the factors identified in this review.

Summary of Six Factors (variables)

Perception of Seriousness of Illness (severity of disease). Two large studies investigated severity of disease. These studies showed that a greater severity of illness had a positive effect on self-management (Carlson et al., 2001; Rockwell & Riegel, 2001). Patients with higher classifications, as a result more severe symptoms, showed higher self-management scores in a correlation study of 209 patients by Rockwell and Riegel (2001). The same study showed that symptomatic patients with more functional impairment were also more knowledgeable and understood the importance of changes in signs and symptoms.

Health and Illness Experience (length of diagnosis, co-morbidities). Three studies, one randomized (n=62) and two non-random control trials (n=139, n=94 respectively), examined length of diagnosis. Overall, the authors concluded that all people have trouble with the recognition of symptoms as they relate to HF regardless of length of diagnosis; however, with more experience, success in recognizing changes in health status does increase (Beutow et al., 2001; Carlson et al., 2001; Francque-Frontiero, Riegel, Bennett, Sheposh, & Carlson, 2002).

Level of confidence may affect decision-making related to self-management. Carlson et al. (2001) found that people newly diagnosed lack confidence in decision-making about changes in symptoms. However, this group was more willing to admit they did not recognize changes, which may make them more receptive to education by health care professionals. Buetow et al. (2001) found that patients with a diagnosis less than three years deliberately avoid information about their disease and deny their illness, and those patients with a diagnosis greater than three years show more acceptance of their diagnosis.

Many patients with a diagnosis of HF also have co-morbidities. Two studies, including 348 patients, examine this variable. Distinguishing symptoms related to HF from other co-morbidities can be very difficult. Rockwell and Riegel (2001) found no significant effect of co-morbidities on self-management. They concluded that co-morbidities might affect health motivation, thereby indirectly affecting self-management. Carlson et al. (2001) state that the presence of multiple symptoms may affect the ability of an individual to recognize and evaluate symptoms because the multiple symptoms may be due to co-morbidities rather than symptoms specifically related to HF. This study suggests that a way to deal with these multiple symptoms might be to synthesize the guidelines for patients with co-morbidities to improve quality of care.

Patient Characteristics (socioeconomic class, education level, gender). Three non-random controlled trials examined socioeconomic and educational factors. Rockwell and Riegel (2001) in a study of 209 patients concluded that socioeconomic class and prior educational achievement do not have a significant effect on self-management. Higher education levels correlated independently with higher compliance rates in a non-random survey of 82 people conducted by Evangelista and Dracup (2000). Artinian et al. (2002) noted in their study that individuals with a lower income are more likely to eat canned foods and TV dinners that can affect self-management, specifically the management of fluid due to the high salt content of such food.

Four studies examine gender as a factor. Two non-random trials (n=110, n=209), one qualitative study (n=23), and a study using combined randomized and qualitative interviews (n=62) examined the effect of gender on the self-management (Artinian, Magnan, Sloan, & Lange, 2002; Bennett, Cordes, Westmoreland, Castro, & Donnelly, 2000; Buetow, Goodyear-Smith, & Coster, 2001; Rockwell & Riegel, 2001). None of the studies concludes that gender has any effect on ability to learn and perform self-management behaviors. Bennett et al. (2000) did report that women verbalize feelings of fear, depression, worry, and thoughts of death more often than men do. The authors question if these feelings influence self-management, but did not investigate this further.

Psychological status (anxiety, depression, self-efficacy). Four studies, qualitative and controlled trials, examined depression, anxiety, and reduced self-efficacy and their influence on self-management (Artinian et al., 2002; Buetow et al., 2001; Evangelista & Dracup, 2000; Riegel & Carlson, 2002). Buetow et al. (2001) reported that a diagnosis of HF in itself creates an emotional strain and influences patients' ability to self-manage. Evangelista and Dracup (2000) illustrated that better mental health predicts overall higher compliance rates, while the reduction of depression and anxiety results in better self-management, particularly better medication compliance.

Riegel and Carlson (2002) demonstrated that added life stressors experienced by patients reduce the motivation to learn and perform self-management. The negative effect that additional life stressors have on HF self-management highlights the importance of the involvement of several health professionals, such as social workers and/or psychologists, in the management of these individuals.

Regime Features (education provided by health professionals). Four large studies with a mix of design methods all conclude that simply providing information to increase knowledge about HF does not result in improved self-management (Jaarsma et al., 2000b; Rockwell & Riegel, 2001; Ni, Nauman, Burgess, Wise, Crispell, & Hershberger, 1999; Stromberg et al., 2003). Ni et al. (1999) found a gap between the receipt of information, absorption and retention of information, and the use of the information to self-manage. Riegel and Carlson (2002) suggested a lack of ability to link symptoms to consequences affects the patients' ability to learn self-management. They suggested that teaching which directly links symptoms with behavior and behavior to consequence could help patients learn to self-manage.

In the studies examined, many factors influenced a person's ability to learn information, such as life stressors and motivation (Riegel & Carlson, 2002). All four studies demonstrate the importance of an individualized approach to education so that these factors are identified and addressed early in the education process. Riegel and Carlson (2002) presented a stepped approach to education. This approach includes more than simply teaching the basic principles of self-management. The authors suggested a more complex approach that includes an assessment of the patient's motivation to learn, identification of barriers to learning, assessment of current level of knowledge and misconceptions, and acknowledgment of successes.

Two studies found that it was common for individuals' to have misconceptions about how well they felt they were self-managing. Riegel and Carlson (2002) found after interviewing 26 people that patients felt they were making proper decisions about the management of symptoms when they were not. For example, several participants failed to understand that they were being asked to weigh themselves to monitor fluid, not adipose tissue. Another descriptive study of 139 individuals reached a similar conclusion that "patients were confident when they should be hesitant, hesitant when they should be bold and incorrect in many judgments regarding symptoms" (Carlson et al., 2001).

Social Support. The myriad of definitions for 'social support' used in studies examining social support makes it difficult to draw conclusions about how social support influences self-management. All five studies examined in this review use a very broad definition of social support (Bennett et al., 2000; Evangelista et al., 2000; Jaarsma et al., 2000b; Rockwell & Riegel, 2001; Stromberg et al., 2003). The definitions include support from health professionals, spouse and family members, or someone that the patient feels comfortable confiding in; number of social networks; marital status; and living arrangements. Only one study examined perceived social support and its impact on the self-management of HF, showing no significant effect (Evangelista & Dracup, 2000).

Discussion

This literature review highlights the complexity of HF self-management. Despite agreement on the positive impact of effective HF self-management and of guideline recommendations that provide direction, there continues to be a lack of knowledge regarding factors that influence HF self-management. Although a limited number of research studies have focused in this area, the studies completed were well designed and provide a starting point for further research.

This review supports Connelly's model in providing a framework that can guide research that examines factors that influence HF self-management. Further studies are necessary in order to further evaluate the factors found in this review as well as those factors identified in the model that have not yet been studied. In addition, the model as intended provides a useful framework for ongoing clinical assessment and decisions for the promotion and support of self-care.

The limited numbers of studies demonstrates a need for large randomized studies as well as qualitative studies in order to generalize the results. Increased knowledge about factors that influence self-management will help to develop effective ways to facilitate individuals' efforts to manage symptoms. The available consensus guidelines address self-management education principles and emphasize the importance of a multidisciplinary approach to care; however, more research will allow for revision of the guidelines so that they can provide specific information about how to better facilitate self-management for health professionals. As well, the suggestion made by Carlson et al. (2001) of combining currently published practice guidelines to provide comprehensive care is an interesting one that deserves further investigation.

The complexity of the HF management regime makes it necessary to investigate the type of support that the health system currently provides, as well as how helpful individuals perceive these supports to be. Increased understanding in this area could improve the type and level of support provided by professional providers such as nurses. With the increasing numbers of Canadians affected by HF, there is a need for new and innovative techniques to improve self-management, improve quality of life for these individuals, and as a result, reduce the burden on the current and future health care system.

In conclusion, it appears that there are many factors that influence HF self-management of community dwelling individuals. Some of these factors are also identified in the chronic illness population, as shown in Connelly's model. However, conclusions need to be supported with further studies specifically examining the HF population. The factors identified in this review will assist in the development of specific suggestions for assessment and interventions. One health professional does not have the expertise or time to complete all necessary assessments and interventions. The many factors involved highlight the importance of having a multidisciplinary team involved in the care of these individuals.

Reference List

Artinian, N. T., Magnan, M., Sloan, M., & Lange, M. P. (2002). Self-care behaviors among patients with heart failure. *Heart & Lung, 31,* 161-172.

Bennett, S. J., Cordes, D. K., Westmoreland, G., Castro, R., & Donnelly, E. (2000). Self-care strategies for symptom management in patients with chronic heart failure. *Nursing Research, 49,* 139-145.

Buetow, S., Goodyear-Smith, F., & Coster, G. (2001). Coping strategies in the self-management of chronic heart failure. *Family Practice, 18,* 117-122.

Carlson, B., Riegel, B., & Moser, D. K. (2001). Self-care abilities of patients with heart failure. *Heart & Lung, 30,* 351-359.

Connelly, C. (1993). An empirical study of a model of self-care in chronic illness. *Clinical Nurse Specialist, 7,* 247-253.

Davis, B., & Logan, J. (1997). *Reading research* (3 ed.). Canadian Nurses Association.

Dunbar, S., Jacobson, L., & Deaton, C. (1998). Heart failure: Strategies to enhance patient self-management. *AACN Clinical Issues, 9,* 244-256.

Evangelista, L. S., & Dracup, K. (2000). A closer look at compliance research in heart failure patients in the last decade. *Progress in Cardiovascular Nursing, 15,* 97-103.

Field, M. J., & Lohr, K. N. (1990). *Clinical practice guidelines: Directions for a new program.* Washington, DC: Institute of Medicine, National Academy Press.

Francque-Frontiero, L., Riegel, B., Bennett, J. A., Sheposh, J., & Carlson, B. (2002). Self-care of persons with heart failure: Does experience make a difference? *Clinical Excellence for Nurse Practitioners, 6,* 23-30.

Funk, M., & Krumholz, H. M. (1996). Epidemiologic and economic impact of advanced heart failure. *Journal of Cardiovascular Nursing, 10,* 1-10.

Harrison, M. B., Browne, G. B., Roberts, J., Tugwell, P., Gafni, A., & Graham, I. D. (2002). Quality of life of individuals with heart failure: A randomized trial of the effectiveness of two models of hospital-to-home transition. *Medical Care, 40,* 271-282.

Hunt, S. A., Baker, D. W., Chin, M. H., Cinquegrani, M. P., Feldman, A. M., Francis, G. S., et al. (2001). ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: A report of the American College of Cardiology/American Heart Association Task Force on practice guidelines. *Circulation, 104(24*), 2996-3007.

Jaarsma, T., Abu-Saad, H. H., Dracup, K., & Halfens, R. (2000a). Self-care behaviour of patients with heart failure. *Scandinavian Journal of Caring Sciences, 14,* 112-119.

Jaarsma, T., Halfens, R., Tan, F., Abu-Saad, H. H., Dracup, K., & Diederiks, J. (2000b). Self-care and quality of life in patients with advanced heart failure: The effect of a supportive educational intervention. *Heart & Lung, 29,* 319-330.

Liu, P., Arnold, M., Belenkie, I., Howlett, J., Huckell, V., Ignazewski, A., et al. (2001). The 2001 Canadian Cardiovascular Society consensus guideline update for the management and prevention of heart failure. *Canadian Journal of Cardiology, 17,* 5E-24E.

Liu, P., Arnold, J. M., Belenkie, I., Demers, C., Dorian, P., Gianetti, N., et al. (2003). The 2002/2003 Canadian Cardiovascular Society consensus guidelines update for the diagnosis and management of heart failure. *Canadian Journal of Cardiology, 19,* 347-356.

National Health Service (NHS). (1999). *The Critical Appraisal Skills Programme*. Oxford, U.K.

Ni, H., Nauman, D., Burgess, D., Wise, K., Crispell, K., & Hershberger, R. (1999). Factors influencing knowledge of and adherence to self-care among patients with heart failure. *Archives of Internal Medicine*, 159, 1613-1619.

Remme, W. J., Swedberg, K., Cleland, J., Dargie, H., Drexter, H., & Follah, F. (2001). European Society of Cardiology task force for the diagnosis and treatment of chronic heart failure: Comprehensive guidelines for the diagnosis and treatment of chronic heart failure. *European Heart Journal, 22*, 1527-1560.

Riegel, B., & Carlson, B. (2002). Facilitators and barriers to heart failure self-care. *Patient Education and Counseling, 46(4),* 287-295.

Rockwell, J. M., & Riegel, B. (2001). Predictors of self-care in persons with heart failure. *Heart & Lung, 30,* 18-25.

Staples, P., & Earle, W. (2004). The role and scope of practice of nurses working in Canadian heart failure clinics. *Heart & Lung, 33(4)*, 201-209.

Stromberg, A., Martensson, J., Fridlund, B., Levin, L. A., Karlsson, J. E., & Dahlstrom, U. (2003). Nurse-led heart failure clinics improve survival and self-care behaviour in patients with heart failure: Results from a prospective, randomized trial. *European Heart Journal, 24,* 1014-1023.

Table I Synthesis Table- Factors that Influence Self-Management of Heart Failure

Authors	Research Design	Sample Size	Measures	Study Participants	Factors Examined	Questions/Conclusions
Stromberg et al. 2003	Quantitative Randomized Prospective	106	Heart Failure Self-Care Behavior Scale	>75 yrs old, >men than women, mainly Class III	Nurse led heart failure clinic-education and social support (by RN)	Evaluate the effect of follow-up at a nurse-led HF clinic on scb at time of of hospitalization and at 12 months. Conclusions: Improved self-care in daily wt, alert health care to increase wt gain and restricting fluid intake.
Frontiero et al., 2002	Quantitative Non-Random Descriptive, comparative Convenience sample	94	Self-Care of Heart Failure Index	> 70 yrs old, female 64.9%, unmarried 87.2%, income < 20,000/yr, high school education 48%	Experience	Is self-care better in those experienced with diagnosis? Conclusions: More experienced may be more adept; however, overall HF pts have problems with self-care.
Riegal et al. 2002	Qualitative Convenience sample	26	Structured interviews (some patients from previous trial by same researchers)	elderly, retired, poor function, multiple co-morbidities	Life situations, knowledge level physical symptoms emotions	Explore how HF influences patient lives, assess how they perform sc, determine how life situation facilitates or impedes HF scb. Conclusions: Two major problems of lack of knowledge and inability to integrate facts learned. Life stressors reduce motivation for scb and limit ability to learn.

Artinian et al. 2002	Quantitative Non-random Descriptive Convenience sample	110	Revised CHF Self-Care Behavior Scale Heart Failure Knowledge Test	African American, 86 men/24 women, mean age 64, education level 11.4,5 income >$20,000, not married 67%	Knowledge level Age, Gender, Income, Marital status, Living arrangements, Health state	What scb do pts with CHF perform most frequently? Least frequently? What relationships exist between sex, race, age, marital status, living arrangements, health state, income,education, and scb? What is the relationship between CHF knowledge and scb? Conclusions: Top five most frequent performed scb related to taking meds. Least five were concerned with symptom monitoring. Significant findings between basic conditioning factors and total education score, marital status, and living arrangements.
Rockwell et al. 2001	Quantitative Non-random Correlation	209	Self-Management of HF Instrument Specific Acuity Scale	average age 7,3 Class III, married, grade school education, income>$20,000, co-morbidities 1-3, men 50%	Symptom severity Co-morbidity Social support Education level Socio-economic status Gender	Test a model derived from Connelly's Model of Self-Care in Chronic Illness as predictors of self-care in HF. Conclusions: Education and symptoms severity significant findings. Persons with higher education level and symptomatic more likely to engage in scb.
Buetow et al. 2001	Quantitative Randomized Qualitative	62	Minnesota Living with HF Semi-structured Interviews	registered in GP practice > 45 years old, dx within 2 months	Psychosocial adaptation Age, Sex, Time since HF diagnosis	Develop framework for conceptualization how pts cope mentally with illness. How psychological adapt can influence impact on pts life?

						Conclusions: Four strategies with disavowal most relevant. Hope is powerful in facilitating coping.
Carlson et al. 2001	Quantitative Non-random Comparative survey	139	Self-Management of HF Questionnaire	Class III-IV elderly, male, retired, unmarried, earn > 20,000, co-morbidities 40% high school 95%, college 37.2%	Experience vs. newly dx NYHA Classification Co-morbidities	To describe HF sc abilitiesand the difficulties that pts have in achieving success in sc. Compare sc abilities in experienced versus newly dx pts. Conclusions: Newly dx sig. more difficulty recognizing symptoms. Sc behaviors increased with experienced pts. Recognition greater in experienced pts.
Evangelista et al., 2000	Quantitative Non-random	82	Heart Failure Compliance Questionnaire Perceived Social Support Scale Neuroticism Scale SF 36 European Quality of Life	>18 yrs old, male mean age 54, diagnosis 5.72 yrs, EF 27.6%, Class III, retired	Psychosocial variables Socio-demographics Social support	Review extent of non-compliance for general health seeking behavior. Conclusions: Poor compliance with dietary and exercise regimes helping patients to understand treatment regime may improve compliance.
Bennett et al. 2000	Qualitative Convenience sample	23	Group Sessions (18 family members)	16 men/7 women, mean age 60, majority married	Demographics Gender, Social support	Describe symptoms experience by pts with HF, identify sc strategies used by pts to manage symptoms, categorized sc strategies. Conclusions: Symptoms are both physical and emotional.

						Diuretics interrupt sleep, weakness, tiredness, fear, depression. Strategies--change in activity exercise, pillow to sleep, distraction, family support, positive talk. Women greater emotional problems, social support related to more effective coping.
Jaarsma et al. 2000	Quantitative Randomized	128	Heart Failure Self-Care Behavior Scale	mean age 72, men 60% lived alone 1/2, support from 3-4 people, EF 35%diabetic 31%	Education Support	What is the effect of education and support on scb and limitations on self-care? What types of scb do pts with HF have? What limitations upon scb do HF pts site? Conclusions: Intensive education and support did not manifest all scb that might be expected
Ni et al. 1999	Quantitative Non-random Retrospective	113	Needs Survey	Class III-IV(60%), EF < 40%, mean age 51 men 2/3, white 87%, majority not married living with someone 40/113, diagnosis 3.337 years, already received education 2/3	Education Demographics Marital status	Assess knowledge level of and adherence to sc among pts with HF and determine associated factors. Conclusions: Increases knowledge associated with being married, prior hospitalization, receiving previous information.

scb=self-care behavior, sc= self-care, wt=weight

Table II Factors and Related Variables Identified in Review

Predisposing Factors in Chronic Illness	Predisposing Factors in HF
Self-concept	
Levels of aspiration, achievement, motivation	
Health Motivation	
Perception of importance of health and willingness to perform health care behaviors	Psychological status (depression, anxiety, self-efficacy)
Perception of	
Seriousness of illness	NYHA classification
Vulnerability to complication	
Efficacy of recommended health behaviors	
Health and illness experience	Length of diagnosis Co-morbidities
Observations of others in social sphere	

Enabling Factors in Chronic Illness	Enabling Factors in HF
Patient Characteristics (age, education, marital status)	Patient education level, gender socioeconomic class
Psychological Status (feelings, mood, level of anxiety, stress)	Anxiety, depression, self-efficacy
Regime Features (identify and modify plan of care by patient and provider)	Education provided by health professionals
Cures to Action (various reinforcement by supports)	
Social Support (family or friend)	Social support
System Characteristics (satisfaction and continuity of care)	

Chapter Three

An Exploration of Profile Characteristics of Community Dwelling Individuals and Their Perception of How Social Support Relates to Heart Failure Self-Management

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Abstract

BACKGROUND: Heart failure affects 350,000 Canadians and is the only cardiovascular disease reported to be increasing in prevalence. Effective management of HF depends on medical treatment and support, and, importantly, on individuals' ability to self-manage symptoms. To date, work has largely focused on individuals hospitalized with their HF rather than on community dwelling individuals. Thus, it is the importance of to describing the profile characteristics of community dwelling individuals with HF as well as examine how factors, specifically, perceptions of social support, relate to self-management in this HF population.

OBJECTIVE: The three main objectives of this study are: to 1) to describe the profile of a cohort of people with HF who are currently at home and self-managing their condition; 2) to compare the profile characteristics of the study cohort to those of individuals recently discharged from hospital with HF; 3) to explore community dwelling individuals' perceptions of how social support relates to self-management.

METHODS: A mixed method approach that includes a quantitative secondary analysis of individuals with HF self-managing at home, and a qualitative analysis of telephone interviews with a cohort of these individuals, to examine how perceptions of social support relates to self-management.

RESULTS: The participants in this study in the social support cohort were mainly men, younger than (<65), diagnosed within the last five years, with a New York Heart Association classification of I or II (indicating minimal impact of symptoms on functional status), and all hospitalized within the last three months. Study participants all reported feelings of loss of control, being a burden to their family, worry, feelings of depression, as well as difficulty concentrating or remembering things. The social support cohort identified three main themes:

disruption, help-seeking relationships, and reconciling. All three themes being part of an ongoing process of coping with HF, rather than any one being the result.

CONCLUSION: Self-management of HF is a complex process of coping with physical, psychosocial, and emotional issues. Each issue has significant impact on how individuals cope with HF self-management. Younger individuals living with HF have unique social, financial, and emotional challenges to face in coping with their disease as well as unique perceptions of social support. Assessments and interventions to facilitate self-management must take unique differences into consideration, as well as be feasible in the busy health care environment.

Introduction

Heart failure (HF) is a disease that affects 350,000 Canadians. It is the only cardiovascular disease reported to be increasing in prevalence, and is the third most common primary diagnosis for hospitalization in Canada. [1] Recent Canadian studies have shown that there is an equal distribution of women and men with the condition, and that the average age is greater than 65 for both genders.[2-4] Individuals with a diagnosis of HF have a one-year mortality rate of 25% to 40%. [5] People with HF experience periods of stability interspersed with exacerbations requiring hospitalization. In fiscal year 2000-2001, there were 85,679 patients admitted to hospitals in Canada with a primary diagnosis of HF, with each stay averaging eight days. Inpatient hospital services alone have required expenditures over $1 billion per year for inpatient hospital services alone for this group.[6] These statistics indicate that in addition to the considerable effect on the lives of many Canadians, the problems associated with HF place a significant burden on the current and future health-care system.

The most common symptoms that individuals' experience are shortness of breath, edema, and fatigue.[7] Other symptoms include loss of concentration, poor attention and memory, weight gain, pain, weakness, and insomnia. [8] These symptoms present in varying degrees, and can change from one day to the next. Given this trajectory, daily assessment and management are necessary for individuals to maintain optimal function. The impact of symptoms on function is assessed by using the New York Heart Association (NYHA) classification, which includes four classifications, with the higher classifications indicating more impaired function. Although there is no cure for HF, new drug therapies used to control symptoms and maintain functional abilities are used. As the drug regimes typically comprise of a complex daily routine, this increases the burden on individuals and families. Effective management of symptoms depends not only on medical treatment and support but also on the individual's ability to self-manage. Self-management can have a positive impact on outcomes related to HF such as improved quality of life, reduction of symptoms, reduction in emergency room visits, and readmission rates. [9-11] Self-management involves behaviors in response to changes in signs and symptoms and has been reported to include four phases: recognition of a change, evaluation of the change, implementation of a treatment strategy, and evaluation of the effectiveness of the treatment strategy implemented. [12]

To date, work has largely focused on individuals hospitalized with HF rather than community dwelling individuals. Thus, it is important to first describe the profile characteristics of community dwelling individuals with HF, and then to compare them with those of a larger group of individuals recently discharged from hospital, to assess similarities and differences. It is also important to examine factors that influence HF self-management. Connelly's Model of Self-Care in Chronic Illness identifies several factors that influence self-care behaviors. [12] From this model social support is chosen to investigate further in this population. Specifically, how perceptions of social support held by the HF population relates to their abilities to self-manage.

Self-Management and Clinical Practice Guidelines

Recently published HF clinical practice guidelines by the Canadian Cardiovascular Society (CCS), the American College of Cardiology and the American Heart Association (ACC/AHA), and the European Society of Cardiology provide information to help guide the management and prevention of HF. The goals of these guidelines are to guide care delivery, improve survival, and enhance quality of life. All three guidelines include the importance of improving patients' quality of life by reducing symptoms and hospitalizations. A key aspect toward achievement of these goals is the promotion of an individual's ability to self-manage.

All three sets of guidelines share some common features of self-management teaching strategies (i.e., daily weights, exercise, self-adjustment of medications), education principles (i.e., sodium restriction, medication), and specific information (i.e., cause of HF, recognition of symptoms, response to symptoms).[5;6;13;14] All three guidelines stress the importance of a multidisciplinary approach. This approach ensures that individuals receive information with ongoing support from many different health professionals, each with their own area of expertise. The guidelines specifically cite the importance of education as well as the use of experienced nurses to conduct phone calls to check on individuals' progress at home. A recently published pilot study, exploring how closely nurses in Canadian HF clinics follow the recommended guidelines, confirmed that nurses are providing the education outlined in the guidelines as well as the telephone management. [15]

Despite the supporting literature and recommendations made in recent HF clinical practice guidelines stressing the importance of HF self-management, there is still little information known about the profile characteristics of community dwelling individuals attempting to self-manage or the factors that influence an individuals' ability to effectively self-manage. Information in these areas will assist in the development of effective assessments and interventions to facilitate self-management of this specific population.

Conceptualizing Self-Management

A self-management model used and studied during the last decade, Connelly's Model of Self-Care in Chronic Illness, identifies possible factors and associated variables that could influence HF self-management.[12] The purpose of the model is to guide assessment, planning, implementation, and evaluation of self-care. The model is a tool for ongoing assessment in terms of the factors identified by the model, intended for use by nurses to assist in identifying situations, crises, and changes that place the patient at risk or create barriers to self-care and to indicate appropriate interventions to support self-care. The factors identified in the model include two categories *predisposing* and *enabling*:

Predisposing Factors	Enabling Factors
Self-concept	Patient characteristics
Health motivations	Psychologic status
Patient perception of seriousness	Regime characteristics
Patient perception of vulnerability	Cues to action
Patient perception of efficacy	Social support

Predisposing factors influence the likelihood that a patient will engage in self-management behaviors. These factors include self-concept (levels of aspiration, achievement, motivation), general health motivations that include perception of the importance of health and their willingness to perform health-care behaviors, perception of seriousness of illness, and perception of vulnerability to complications. Also included are efficacy of recommended health behaviors, patient health and illness experiences, and the observations of others in their social sphere.

Enabling factors include patient characteristics (age, education, marital status), psychologic status (feelings, mood, level of anxiety, stress), regime features (identification and modification of plan of care by patient and provider), cues to action (various reinforcement by supports), social support (friend or family), and system characteristics (satisfaction and continuity of care). Predisposing and enabling factors interact with each other in an ongoing circular relationship. Connelly's model provides an emerging framework that may guide research examining HF self-management and allow comparisons across studies and synthesis of findings.

Purpose

Connelly's model provides the conceptual framework for this descriptive exploratory study to contribute to the understanding of the profile characteristics of individuals in the community attempting to self-manage HF, and to explore these individuals' perceptions of how social support relates to their self-management.

The specific objectives of the exploratory study are to:

1. Describe the profile of a cohort of people with HF who are currently at home and self-managing their condition.
2. Compare the profile characteristics of the study cohort to a larger cohort recently discharged from hospital with HF.
3. Explore how the perception of social support relates specifically to self-management of the HF population living in the community.

Participants

The participants in this study were also participating simultaneously in the Heart and Stroke Foundation of Ontario (HSFO) dissemination study focused on the use of a self-management resource. This resource, developed in 1995, was part of a research intervention that included a counseling and education component, known as 'Partners in Care for Congestive Heart Failure' (PCCHF). The PCCHF, consisted of three elements: an education guidebook for patients and families; an education map for practitioners; and a resource manual for professional providers. [18]

The resource was a tool to help nurses implement the Agency for Health Care Policy and Research (AHCPR) HF clinical practice guidelines. [19] These guidelines identified the importance of counseling and education for patients and family caregivers as being a critical components for effective management, and essential to avoid unnecessary hospital admissions. Self-management was identified as key to effective HF management. An initial randomized controlled trial of hospital-to-home transition for patients with HF incorporated the PCCHF resource. [10] This trial evaluated a comprehensive approach to supportive care for self-management with HF. Following the completion of the hospital-to-home trial, the research team received many requests for the PCCHF, as there was a paucity of comprehensive resources to assist with HF self-management. This growing interest from a wider community of settings and providers prompted a further evaluation study of the resource. [20] In a multi-site evaluation conducted in Canada and the U.S., patients, nurses, and policy makers evaluated the PCCHF. Overall, the program was well accepted, and found to be useful and contributory to self-management. The PCCHF resource was then revised based on the results of evaluation study. Subsequently the copyright was transferred to the Heart and Stroke Foundation under a new title "Managing Congestive Heart Failure."

In planning for a Canada-wide distribution of the resource, a dissemination study was undertaken in Ontario by the HSFO. [21] The purpose was to describe users of the resource, further evaluate its acceptability and utility, and assess how the resource affected individuals' ability to self-manage HF symptoms. This dissemination study of the "Managing Congestive Heart Failure" resource involved the distribution of 1,000 copies of the resource to hospitals and heart failure clinics across five regions of Ontario. Each resource included a questionnaire to collect data about users' demographics, severity of disease, and quality of life information as measured by the Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Appendix B).[39] At the end of the questionnaire, there was an invitation to participate in a follow-up interview with a nurse during which more in-depth information was sought about using the resource and self-managing HF. A random selection was made from those respondents who signed and returned the request indicating willingness. They were randomized to equally represent all five regions of Ontario. The expectation was that the group would also equally represent both genders; however, after randomization of respondents, only 33% were women and 67% were men. Table I outlines a summary of the development of the self-management resource, and the supporting research studies, and related publications.

Design

Using a mixed method approach, quantitative data from the HSFO survey, data from the social support cohort, and data from the original PCCHF trial were constructed into three separate data-sets for secondary analysis. The qualitative data was generated from telephone interviews conducted with the social support cohort. A summary of study participants is presented in Appendix F. The Ottawa Hospital Research Ethics Board approved the proposals for both the original HSFO dissemination study and the present exploratory study (Protocol #2003002-01H). The present study conducted anonymously used code numbers with no participant names documented. Participants had the opportunity to withdraw from the study at any time.

Methodology

Data Collection

The HSFO dissemination of the HF resource provided a unique opportunity to approach individuals actively engaged in self-management of their HF and managing at home. Through collaboration with the HSFO, data for this study was collected concurrently during the HSFO dissemination study. To date, work has largely focused on individuals hospitalized with their HF rather than community dwelling individuals. Thus, the importance of first describing the profile characteristics of community dwelling individuals with HF, and then to comparing these profiles to those of a larger group of individuals recently discharged from hospital. It was also important for this study to examine how the factors, specifically for this study of perceptions of social support, relate to the HF population.

Quantitative Data. A secondary analysis of data from the HSFO survey (n=47) and the social support cohort (n=10) was performed. Then, a comparison was made between the profile characteristics of the social support cohort and participants in an earlier, randomized controlled trial focused on transition from hospital to home and supportive care for self-management.[10] Finally, these data were also compared to the most recent Canadian data on profile of HF patients.

The initial analysis examined profile characteristics and selected results from the MLHFQ that were most often cited in the HF literature. The profile characteristics include: length of diagnosis, gender, age, New York Heart Association (NYHA) classification, and number of hospitalizations in the past three months. The MLHFQ is a 21 item self-administered questionnaire that assesses patient perception of the effects of HF, and its treatment on his or her daily life. [22; 23] The MLHFQ includes both physical and emotional subscales, with total scores ranging from 0 to 105 with a higher score indicating poorer quality of life. Total scores for the participants in the HSFO study and the social support cohort are included in the secondary analysis. In addition, the ten items selected most often cited in the literature as being typical of individuals with HF were selected for inclusion by the researcher; five items from the physical subscale, and five items from the emotional subscale.

Qualitative Data. My clinical practice provides regular exposure to community dwelling individuals who engage in the self-management of HF. It is often a struggle for these individuals and their families to coordinate a complex regime of medications and adjustments to their daily living. In my practice, I find that issues related to social support seem to influence how effectively patients mange their condition. Individuals' perceptions of their supports as helpful or not, needs to be examined but is not a current focus in clinical settings.

The influence of social support appears to be unique to each individual. I have seen individuals with many supports who did not manage well, and others with fewer supports who did. For individuals who manage well, shared responsibility by a variety of supports was necessary to accomplish all the behaviors needed to stay symptom free. For example, a spouse might assume the role of keeping medication doses and schedules organized, or be responsible for monitoring the quantity of salt in food. Individuals without close family support might rely on friends or community groups to assist in transportation to appointments or provide an opportunity to talk about the struggles of managing HF. This prompted the decision not only to focus on the number and type of supports available, but to investigate further, individuals' perceptions of their supports as helpful or not.

The qualitative data consist of semi-structured telephone interviews focused on individuals' perception of social support and how it relates to HF self-management. Three open-ended questions were presented to the social support cohort by audio-taped telephone interviews (Appendix D). A request to participate in these additional questions was made after the HSFO questions were completed, and then a verbal consent was obtained (Appendix E). There was an option to answer the questions at a later, mutually agreed upon time and date however, all participants choose to answer the questions during the original interview. Of eligible persons invited to participate, ten completed the additional interviews for this study; three declined to participate stating reluctance to answer HSFO questions because they did not remember the resource clearly; two participants had been pilots for HSFO study prior to ethics approval for the three additional questions; and one could not be reached.

Data Analysis

Quantitative data analysis of the profile characteristics of both the HSFO survey participants and social support cohort was carried out using descriptive statistics. The qualitative data analysis was completed by using standard content analysis.[24] Steps identified by Morse and Field (1995) guided the analysis. The beginning analysis involved verifying the transcribed data by re-listening to the recorded interviews to ensure accuracy, and by documenting any cues such as laughing or pauses. This was followed by identification and defining codes and categories, and the combination of like categories. Last, relationships between categories were identified.

Findings

Quantitative- Secondary Analysis

The participants in the social support cohort were mainly men, < 65 years of age, diagnosed in the last five years, NYHA classification of Class I to II, and hospitalized in the last three months. These results were similar to those result of the HSFO respondents except that the HSFO respondents were older (>65). Overall, there was a larger representation of males to females in both groups, which is not typical of the Canadian data (50.3% female). As well, the social support cohort was younger than the Canadian data indicated (>65).

The physical symptoms both groups experienced most often by both groups were shortness of breath, feeling tiredness/fatigued/low energy, and swelling to ankles/legs/etc. Both groups frequently reported they had feelings of loss of self-control, feelings of being a burden to their family, worry, and feelings of depression, as well as having difficulty concentrating or remembering things. The emotional dimensions subscale questions showed all of the selected questions had an influence in both groups. The 1999 Canadian data regarding depression in elderly adults with HF, shows that they had a two to three times higher risk than the Canadian average. Finding for the social support cohort, also indicate feelings of depression in these younger adults (<65).

In contrast to these similarities, the social support study cohort differed from PCCHF study of recently discharged individuals with HF in that they were mainly young men with low NYHA classifications. The PCCHF sample more closely represented Canadian data with 87% women, a mean age of 75.64, higher NTHA classifications, and 70% with hospitalizations within the last six months. The results of the secondary analysis are presented in Table II.

Qualitative — Telephone Interviews

As previously reported, the social support cohort did vary from the HSFO cohort regarding profile characteristics, and the PCCHF cohort. The main differences were that the social support cohort was younger, with lower NYHA classifications. Four of these individuals discussed the effect that HF had on their lives, preventing them from working, and affecting their ability to care for a spouse and young family. This younger social support cohort had similar physical and emotional symptoms as indicated by the MLHFQ results. The central idea expressed by many in the social support cohort, was that each person needed to be considered as a unique individual. One man stated, "You have to look into each individual's circumstances a little bit deeper because everyone's circumstances are unique" while another stated, "You need to tailor programs to the individual."

Three main concepts identified during the analysis interview data were: disruption, help-seeking relationships, and reconciling. The first concept, disruption, has been defined in other studies, as well as in this study, as a change to the order of life that is the result of physical, emotional, social, economic, or spiritual changes.[25] These interviews support the many changes that result from disruption. The most common physical changes reported were: a reduction in energy level, shortness of breath, and fluid retention. Because of these physical changes, individuals could no longer perform normal activities of daily living, fulfill traditional family roles, or work in previously held jobs. The specific impact of disruption, however, was contingent on age and family stage.

One of the identified disruptions was a change in "traditional" roles (cooking, cleaning) between husbands and wives. However, this disruption when perceived as a way of adapting, was not identified as distressing for these individuals. One woman stated, "I do the housework, but now my husband helps." Four individuals, who described themselves as being "younger" and having young children that depended on them, commented on the role reversal between parent and child. This role reversal resulted in emotional changes described as feelings of "guilt" over not being able to take care of their children. One young mother stated, "It is hard because I used to take care of my girls… I have to let my girls take care of me." The father of a handicapped child stated, "I hate to admit this, but I don't think I could look after my handicapped son on my own."

Physical symptoms also created emotional stress, leading to feelings of "frustration" and "being overwhelmed". One young woman expressed being overwhelmed in the following way: "It is a brand new huge mountain that someone has, in all likelihood, taken and stuck in front of them almost in it feels like a blink of an eye". The uncertainty of exacerbations caused many participants to be "afraid", and "scared". Several individuals' expressed these feelings as follows: "Waiting for the next shoe to drop", "Hangs over your head every minute of the day", "It is so scary and you feel so alone", and "Always have doubt in your mind".

This younger group also had difficulty accepting that the illness prevented them from doing what they thought they should be doing at their present age. Many were unable to return to work because of their physical limitations. They experienced emotional distress related to the inability to provide financially for their families. They faced economic challenges as they struggled to find alternate financial support such as disability pensions. One individual identified that HF affects the whole family by stating, "You take your whole family" into trying to cope with a diagnosis of HF.

Physical symptoms also led to social changes, such as limited time spent with friends and social isolation. Two individuals acknowledged that their symptoms affected their ability to go out and meet people. As a result, social interaction became limited. One woman stated that the disease "Ruins everybody's quality of life around you". She felt she needed to handle her disease "gracefully". She did not want to be seen by her family or friends as being "this sniveling, poor me, creature". In addition, several individuals felt that they no longer "fit in" with friends and their friends, and family and friends did not treat them the same way as previously. Friends shifted their focus on to the disease rather than on the individual qualities of the person.

Spiritual changes were identified in one particular interview. The statements made by this young woman were not of a religious persuasion, however, did reflect "reason and reflection" as included in the definition of spirituality by Govier.[34] Reason and refection involves the search for meaning in life experiences and involves issues such as thoughts about why the illness has happened to individuals, or anything that frightens the individual about the illness experience. Throughout the interview, this woman referred to death several times. She stated that when referring to her several exacerbations of HF, "Most people, when they face death, they face it one time". When first diagnosed, this woman recalled that, "So for me heart failure wasn't something to be managed, to me it was...I was deathly afraid because it almost got me". Although she verbalized frequent fears of death, she still was able to express her intentions to do whatever was necessary to keep her symptoms under control, so that she could continue to function productively within her family.

The second concept to emerge was "help-seeking relationships". Help-seeking relationships is defined as relationships that include health professionals, established community groups and programs, family and friends that provide an opportunity for individuals to request or search out assistance to obtain support or services that comfort, and/or provide information. The social support cohort identified six relationships which they perceived as being mainly helpful in managing their disease: family, cardiac rehabilitation centres, heart failure clinics, support groups, phone support by a registered nurse, and medical support from physicians. The influence of these relationships was stated in various ways by different individuals: "The heart clinic has helped to try to get me on disability", "I do everything with my husband's help", "My wife makes sure I eat properly and she is very supportive", "The clinic helped me keeps my wits together and keep hope", "I learned from others people's questions", and "The clinic gave me the confidence".

Two individuals identified relationships that they did not perceive as being helpful. One man stated, "My wife helps out … the kids try to help out. They don't let me do everything. Sometimes it is a nuisance". One young woman described an encounter with a triage nurse during a visit to an emergency department. This woman had experienced several exacerbations and was very aware of her symptoms. She stated, "They treat you like what is your problem, and you don't know what to do because you are so busy trying to make yourself believe you are ok". This woman understood that she needed help from the emergency room, but felt she was "cooked" meaning not being able to change the situation, by the "triage nurse". She did not feel the nurse took her symptoms seriously or reacted quickly enough. This negative experience created a situation in which this individual was reluctant to go to emergency departments, which was very distressing to her and could affect her future decisions regarding seeking help.

Each relationship provided various types of support that often overlapped. There are four main types of supports identified in the literature: informational (i.e., advice, suggestions, directives, and information), appraisal (i.e., affirmation, feedback, and social comparison), emotional (i.e., empathy, caring, love, and trust), and instrumental (i.e., aid in kind, money, labor, time, and modifying environment).[35] In this study Cardiac rehabilitation centres and heart failure clinics provided the four types of support for participants (informational, appraisal, emotional, and instrumental). Individuals identified how helpful telephone support provided by a registered nurse was. One individual stated it "Helps to have someone at the other end of the phone". Family members (husband/ wife, children) provided mainly emotional and instrumental support.

The third concept identified in this study was reconciling which with a diagnosis of HF, is not a static process. In this study, reconciling was defined as an ongoing process of establishing new norms and learning to accept the symptoms related to a diagnosis of HF. Individuals struggle with acceptance that on any given day and they may feel either better or worse. These daily physical changes affect the way individuals think about themselves. They come to terms with the fact that they cannot do what they were able to do prior to diagnosis or in the early stages of the disease, and seek to accept this change. One individual diagnosed for many years stated that he had learned to "Pace himself from day to day" depending on his symptoms. One single man stated "You can't beat it, of course, but I can live with this". He added, " But when you mentally learn to recognize what's going on then I think it is a little easier although there is still some doubt in your mind. I don't think you ever get rid of that, but I've been plodding along." Yet one woman stated, "There is a certain degree of denial that you have to maintain or you wouldn't even get out of bed".

Acceptance often occurs when patients increase their knowledge about the disease and learn self-management strategies to help to control symptoms. Some strategies that participants learned to use were: to independently change medications, to perform daily weights, to make necessary diet changes, and to exercise. These strategies help them to "[Be]… aware of what to look for and how much to do ... gives you back a little more confidence", and to "Learn to monitor myself".

Limitations of Study

There were several limitations to this study. The number of interviews, while within acceptable range for qualitative approaches, generated spare data compared to the usual criteria of seeking data "saturation". Therefore the information can not be transferred to the entire community dwelling HF population. The distribution of the self-management resource to individuals through hospitals and HF clinics may have influenced the results. These individuals may have already had a higher knowledge level about self-management prior to receiving the resource, and may not be representative.

The gap in time between when individuals completed the HSFO questionnaires and the follow-up phone call, may have affected their responses to the interview questions. Given the variability of HF symptoms, the impact of the symptoms may have been different if the interviews had been conducted at either an earlier or later time. Unfortunately, none of the social support cohort chose to answer the three additional questions at a later time, which may have provided more in-depth data for analysis. Finally, a few of the cohort participants had prior relationships with me as a nurse at the cardiac rehabilitation centre. This may have

A diagnosis of within the previous five years was predominant in this exploratory study. These newly diagnosed individuals were already performing many of the strategies suggested for self-management. They were receptive to education given by health care professionals, as illustrated by attendance at heart failure clinics and cardiac rehabilitation centres, and the decision to use the "Managing Congestive Heart Failure" resource.

Social supports (heart failure clinic, cardiac rehabilitation centre, family, nurses, physician), self-management techniques (daily weight, reduced sodium diet, fluid restrictions, self-medication, and increased education), and physical symptoms (shortness of breath, fluid retention, low energy) as identified in this study, were consistent with the current literature as typical for this population.[8;9;11] The younger cohort's economic concerns were not typical of older populations. Younger individuals had many concerns about regarding finances and the care of their families. They did not have the economic benefit of retirement pensions or drug coverage available to pensioners. Many of them depended on disability insurance to provide financially for their families.

The importance of supportive relationships was illustrated in this study. In particular, these individuals identified the importance and effectiveness of having a registered nurse available by telephone. The nurse could provide timely information, but also helped to alleviate doubts and fears. Individualized information helped to inform individuals, so that if a symptom reoccurred, they had the basis to manage the symptom themselves, or to know when to call a health professional such as a nurse.

Social support is often viewed as being positive, however, social support can also be negative. Two individuals in the social support cohort did identify a potential for social support to have negative effects. Characteristics of negative support include stressful or conflicted social networks, misguided or absent support, inappropriate advice, avoidance, and disagreement. [32] Negative interactions with support examined in interviews of eight women with family and friends while caring for a family member with dementia also highlighted the importance of recognizing signs of negative support such as disparaging comments, criticisms of decisions, or longstanding conflict when assessing individuals' support systems. [36]

Both the social support cohort and the HSFO dissemination study participants, reported feelings of loss of self-control, feelings of being a burden to their family, worry, feelings of depression, and having difficulties concentrating or remembering things based on the emotional subscales of the MLHFQ. The Canadian data on depression shows elderly adults with HF haves a two to three times risk of being depressed. In this study, feelings of depression were also identified in younger adults (<65).

A survey study of 82 patients investigating the effect of depression specifically on self-management concluded that reduction of depression and anxiety can result in better overall self-management. This was observed specifically with better medication compliance.[33] A review article, published in 2004, examined the mechanistic relationship between depression and HF. This article concluded that depression is common with HF and is independently predictive of poor clinical outcomes.[37] It indicates that attention to recognition and treatment of depression in HF population is warranted, and assessment for these emotions is an important part of the plan to facilitate self-management. However, having the time and/or expertise to perform this type of assessment, is a problem among busy health care professionals.

The concepts of disruption, help-seeking relationships and reconciling were part of the ongoing process of coping with HF, rather than any one process being the result of HF. Because HF is a complex disease that can cause daily physical changes, it is common that as individuals deal with one disruption, another disruption occurs and reconciling begins all over again. Resetting the view of what is normal based on physical changes and adjusting that view according to the disruptions, seemed to help individuals reconcile. Helpful relationships provide information for individuals to understand HF, as well as support for coping with a diagnosis of HF. As expressed in the social support cohort, it is important for information to be individualized. Relationships impart and reinforce knowledge while providing informational, appraisal, emotional, and instrumental support. Although the social support cohort identified multiple helpful relationships, they still experienced the process of disruption, health-seeking relationships, and reconciling only they seemed better able to deal with the process.

My results indicate that HF assessment should include psychosocial and emotional domains as well as a physical assessment. For example, the incidence of depression in the younger adults as well as older individuals highlights the importance of including simple tools for assessing depression. Finding time and having the skills to assess for depression is difficult. The addition of two particular questions to an assessment may provide important tools for busy practitioners. A study of instruments for assessing depression identified a two-question instrument with a 96% sensitivity and 57% specificity.[38] The two questions are: “During the last month, have you often been bothered by feeling down, depressed, or hopeless?” and “During the past month, have you often been bothered by little interest or pleasure in doing things?” These two simple questions may help to identify cases of depression that are currently unrecognized so that further interventions can be implemented. As well, given the ongoing, circular process of coping identified in this study, periodic re-assessments for depression are indicated.

The unique challenges that younger adults face in coping with HF, highlight the importance of adequate individualized assessments and interventions addressing all domains, for all individuals living with HF. In order to accomplish this, multidisciplinary teams are essential. The inclusion of family members in interventions, the provision of ongoing support for both individuals and groups, and a mechanism for individuals to access timely support are all important and helpful strategies.

Further, well-designed quantitative and qualitative studies need to focus on community dwelling individuals who are self-managing HF, in order to determine if the findings in this study are transferable. These studies need to focus on non-medical, individualized interventions and assessments that positively influence HF self-management, as well as factors that influence effective self-management such as, perceived social support.

Reference List

1. Svendsen A. Heart Failure: An overview of consensus guidelines and nursing implications. *Canadian Journal of Cardiovascular Nursing* 2003;**13**:30-4.
2. Jong, P., Vowinckel, E., Liu, P., Gong, Y., Tu, J. Prognosis and determinants of survival in patients newly hospitalized for heart failure: A population-based study. *Archives of Internal Medicine* 2003;**162**: 1689-1694.
3. Levy D, Kenchaiah S, Larson MG, Benjamin EJ, Kupka M, Ho K *et al*. Long-term trends in the incidence of and survival with heart failure. *The New England Journal of Medicine* 2002;**347(18)**:1397-402.
4. Tsuyuki RT, Shibata MC, Nilsson C, Hervas-Malo M. Contemporary burden of illness of congestive heart failure in Canada. *The Canadian Journal of Cardiology* 2003;**19**:436-8.
5. Liu P, Arnold M, Belenkie I, Howlett J, Huckell V, Ignazewski A *et al*. The 2001 Canadian Cardiovascular Society consensus guideline update for the management and prevention of heart failure. *The Canadian Journal of Cardiology* 2001;**17**:5E-24E.
6. Liu P, Arnold JM, Belenkie I, Demers C, Dorian P, Gianetti N *et al*. The 2002/2003 Canadian cardiovascular society consensus guideline update for the diagnosis and management of heart failure. *The Canadian Journal of Cardiology* 2003;**19**:347-56.
7. Funk M, Krumholz HM. Epidemiologic and economic impact of advanced heart failure. *Journal of Cardiovascular Nursing* 1996;**10**:1-10.
8. Riegel B, Carlson B. Facilitators and barriers to heart failure self-care. *Patient Education and Counseling* 2002;**46(4)**:287-95.
9. Dunbar SB, Jacobson LH, Deaton C. Heart failure: strategies to enhance patient self-management. *AACN Clinical Issues* 1998;**9**:244-56.
10. Harrison MB, Browne GB, Roberts J, Tugwell P, Gafni A, Graham ID. Quality of life of individuals with heart failure: a randomized trial of the effectiveness of two models of hospital-to-home transition. *Medical Care* 2002;**40**:271-82.
11. Jaarsma T, Abu-Saad HH, Dracup K, Halfens R. Self-care behaviour of patients with heart failure. *Scandinavian Journal of Caring Sciences* 2000;**14**:112-9.
12. Connelly CE. An empirical study of a model of self-care in chronic illness. *Clinical Nurse Specialist* 1993;**7**:247-53.
13. Hunt SS, Baker DW, Chin MH, Cinquegrani MP, Feldmanmd AM, Francis GS *et al*. ACC/AHA guidelines for evaluation and management of chronic heart failure in the adult. *Circulation* 2001;**104**:2996.

14. Remme WJ, Swedberg K. Guidelines for the diagnosis and treatment of chronic heart failure. *European Heart Journal* 2001;**22**:1527-60.

15. Staples P, Earle W. The role and scope of practice of nurses working in Canadian heart failure clinics. *Heart & Lung* 2004;**33(4)**:201-209.

16. Rockwell JM,.Riegel B. Predictors of self-care in persons with heart failure. *Heart & Lung* 2001;**30**:18-25.

17. Carlson B, Riegel B, Moser DK. Self-care abilities of patients with heart failure. *Heart & Lung* 2001;**30**:351-9.

18. Harrison MB, Toman C, Logan J. Hospital to home: Evidence based education for congestive heart failure. *The Candian Nurse/L'Infirmiere Canadienne* 1998;**9**:36-42.

19. Konstam, MA, Dracup, K., Bottorff, M., Brooks, N, Dacey, R., Dunbar, S., Jackson, A, Jessup, M. Heart failure: Management of patients with left-ventricular systolic dysfunction. Quick reference guide for clinicians No. 11. AHCPR Publication No. 94-0613. 1994. Rockville, MD, Agency for Health Care Policy and Research.

20. Harrison, MB, Graham, ID, Logan, J., Toman, C. Partners in care for congestive heart failure: A multi-province education program evaluation. 1-32. 2001. Ottawa, National Health Research and Development Program.

21. Harrison, M. B., Graham, I. D., Earle, W. Evaluation of the managing congestive heart failure resource: Patient and provider perspectives. 1-43. 2003. Ottawa, Ottawa Health Research Institute.

22. Rector TS, Cohn JN. Assessment of patient outcome with the Minnesota Living with Heart Failure questionnaire: Reliability and validity during a randomized, double-blind, placebo-controlled trial of pimobendan. *American Heart Journal* 1992;**124**:1017-25.

23. Rector TS, Kubo SH, Cohn JN. Validity of the Minnesota Living with Heart Failure questionnaire as a measure of therapeutic response to Enalapril or placebo. *The American Journal of Cardiology* 1993;**71**:1106-7.

24. Crabtree, BF, Miller, WL., Foster, DS. Doing qualitative research. 1992. California, Sage Publications Inc. Research Methods for Primary Care.
25. Mahoney J. An ethnographic approach to understanding the illness experiences of patients with congestive heart failure and their family members. *Heart & Lung* 2001;**30**:429-36.

26. Stull DE, Starling R, Hass G, Young JB. Becoming a patient with heart failure. *Heart & Lung* 1999;**28**:284-92.

27. Weinberger M, Hiner SL, Tierney WM. Improved functional status in arthritis: The effect of social support. *Social Science and Medicine* 1986;**23**:899-904.

28. Jong P, Vowinckel E, Liu PP, Gong Y, Tu JV. Prognosis and determinants of survival in patients newly hospitalized for heart failure: a population-based study. *Archives of Internal Medicine.* 2002;**162**:1689-94.

29. Francque-Frontiero L, Riegel B, Bennett JA, Sheposh J, Carlson B. Self-care of persons with heart failure: does experience make a difference? *Clinical Excellence for Nurse Practitioners* 2002;**6**:23-30.

30. Jong P, Vowinckel E, Liu PP, Gong Y, Tu JV. Prognosis and determinants of survival in patients newly hospitalized for heart failure: a population-based study. *Archives of Internal Medicine.* 2002;**162**:1689-94.

31. Stromberg A, Martensson J, Fridlund B, Levin LA, Karlsson JE, Dahlstrom U. Nurse-led heart failure clinics improve survival and self-care behaviour in patients with heart failure: results from a prospective, randomized trial. *European Heart Journal.* 2003;**24**:1014-23.

32. Stewart MJ. Integrating social support in nursing. Newbury Park, CA: Sage, 1993.

33. Evangelista LS, Berg J, Dracup K. Relationship between psychosocial variables and compliance in patients with heart failure. *Heart & Lung* 2002;**30**:294-301.

34. Govier I. Spiritual care in nursing: a systemic approach. *Nursing Standard,* 2000;**14(17)**;32-36.

35. Langsford CP, Bowsher J, Maloney J, Lillis P. Social support: a conceptual analysis. *Journal of Advanced Nursing,* 1997;**25**;95-100

36. Neufeld A, Harrison MJ. Unfulfilled expectations and negative interactions: nonsupport in the relationships of women caregivers. *Journal of Advanced Nursing,* 2003;**41(4)**:323-331.

37. Joynt KE, Whellan DJ, O'Connor, M. Why is depression bad for the failing heart? A review of the mechanistic relationship between depression and heart failure. *Journal of Cardiac Failure,* 2004;**10(3)**:258-271.

38. Whooley WA, Avins AL, Miranda J, Browner WS. Case-finding instruments for depression. Two questions are as good as many. *Journal of General Internal Medicine,* 1997;**12**:439-445.

39. Rector TS, Kubo SH, Cohn JN. Patient's self-assessment of their congestive heart failure-Part 2: Content, reliability, and validity of a new measure, The Minnesota Living with heart failure questionnaire. *Heart Failure Journal,* 1987;**124**:1017-1025.

Table I- Summary of Self-Management Resource Development and Subsequent Studies

Purpose	Results	References
Development of tool for nurses/ patients/ families to help implement AHCPR recommendations for management of CHF **(1995)**	"Partners in Care for Congestive Heart Failure" (PCCHF)	Harrison et al. (1998), Hospital to home: Evidence based education for congestive the heart failure, *Canadian Nurse/L'Infirmiere Canadienne, 9(4)*, 36-42. Toman et al. (2001), Clinical practice guidelines: Necessary but not sufficient for evidence-based patient education and counseling, *Patient Education and Counseling 42(3),* 279-87.
Two Studies to evaluate the use of PCCHF by individuals with CHF and health professionals Funded by Health Canada, National Health Research Development Program		
Study #1 **(1995-97)** •To evaluate the benefits of an enhanced discharge process including support for self-management	•improved quality of care •less use of ER	Harrison et al. (2002), Quality of life of individuals with heart failure: A randomized trial of the effectiveness of two models of hospital to home transition, *Medical Care, 40(4),* 271- 283.
Study #2 **(1999-2001)** •To evaluate implementation of the PCCHF programme 10 sites (3 provinces, 1US state)	•improved quality of life •well accepted by providers and decision makers	Harrison, M. B., Graham, I. D., Toman, C., & Logan, J. (1999-2001), Partners in care for congestive heart failure education: A multi-province education program evaluation: Technical Report. National Health Research & Development Program, Health Canada. OHRI.
Evaluation Study to re-evaluate newly revised resource now entitled "Managing Congestive Heart Failure" Funded by Heart & Stroke Foundation of Ontario/Ottawa Health Research Institute		
Study #3 **(2002)** •To evaluate revised PCCHF resources now entitled- "Managing Congestive Heart Failure" **•Link with thesis**	•perceived as useful •lifestyle changes made •low response rate	"Evaluation of the Managing Congestive Heart Failure Resource: Patient and Provider Perspective" Report, 2003.

Table II- Profile Characteristics

	Social Support Cohort Study Respondents (n=10) n	(%)	HSFO Study Respondents (n=47) n	(%)	Harrison et al., 2002 (n=192) n	(%)	Canadian Data
	(Community)		(Community)		(Hospitalized)		
Gender							2000-2001
Female	2	(22.2)	14	(33.3)	87	(45)	50.3%
Male	7	(77.8)	28	(66.7)	147	(76.5)	
Unknown	1		5				
Age							2000-2001
< 65	6	(60)	16	(34.8)	mean=75.64		mean 75.9
> 65	4	(40)	30	(65.2)			majority > 65
Unknown			1				
NYHA Class							
Class I	3	(30)	11	(25.0)	2	(1)	
Class II	5	(50)	24	(54.5)	41	(22)	
Class III	2	(20)	6	(13.6)	129	(67)	
Class IV	0		3	(6.8)	19	(10)	
Length of Diagnosis							
0-5 years	8	(80)	36	(76.6)			
> 5 years	1	(20)	8	(17)			
Don't know	1	(10)	3	(6.4)			
Hospitalized in last 3 months					Last 6 months		2000-2001
Yes	5	(50)	20	(42.6)	70	(37)	2-3 times/yr
# of times							2003
1	4	(80)	13	(72.2)			rate ↓
2	0		3	(16.7)			
3	1	(20)	2	(11.1)			
Minnesota Living With Heart Failure Questionnaire		Mean (SD)		Mean (SD)			
Physical Subset		17.20 (12.38)		21.58 (10.92)			
Emotional Subset		13.10 (8.99)		16.57 (5.56)			
Total		51.65 (28.47)		66.29 (21.68)			

Table II (con't)- Minnesota Living with Heart Failure Questionnaire

	Social Support Cohort Study Respondents (n=10)		HSFO Study Respondents (n=47)		Canadian Data
	n	(%)	n	(%)	
Physical Subscale Questions					
Make you short of breath?					
No	1	(11.1%)	6	(13.6%)	
Yes	8	(88.9%)	37	(84.2%)	
N/A	1		1	(2.3%)	
Make you tired, fatigued, or low energy?					
No	0		3	(6.4%)	
Yes	10	(100%)	43	(91.6%)	
N/A	0		1	(2.1%)	
Causing swelling in your ankles, legs, etc?					
No	5	(50%)	23	(48.9%)	
Yes	5	(50%)	23	(48.9%)	
N/A	0		1	(2.1%)	
Make you sit or lie down to rest during the day?					
No	1	(12.5%)	8	(17.8%)	
Yes	7	(58.1%)	36	(79.9%)	
N/A	2		1	(2.2%)	
Making your sexual activities difficult?					
No	3	(33.3%)	11	(28.9%)	
Yes	6	(66.6%)	25	(65.8%)	
N/A	1		2	(5.3%)	
Emotional Subscale Questions					
Making you feel you are a burden to your family?					
No	4	(40%)	21	(44.7%)	
Yes	6	(60%)	25	(53.2%)	
N/A	0		1	(2.1%)	
Making you feel a loss of self-control in your life?					
No	3	(30%)	11	(23.4%)	
Yes	7	(70%)	35	(74.4%)	
N/A	0		1	(2.1%)	
Making you worry?					
No	2	(20%)	14	(29.8%)	
Yes	7	(70%)	33	(68.1%)	
N/A	1		0	(2.1%)	
Making it difficult for you to concentrate or remember things?					
No	3	(30%)	15	(31.9%)	
Yes	7	(70%)	31	(65.9%)	
N/A	0		1	(2.1%)	
Making you feel depressed?					1999
No	3	(30%)	12	(25.5%)	Elderly
Yes	7	(70%)	34	(72.3%)	2-3x more depressed

Chapter Four

Thesis Summary

This thesis was undertaken to increase the understanding about profile characteristics and factors that influence heart failure (HF) self-management specifically of community dwelling individuals. It explored the profile characteristics of community dwelling individuals self-managing HF, compared these characteristics to individuals recently discharge from hospital, and explored the influence the individuals perception of social support has on HF self-management.

Heart failure affects the lives of 350,000 Canadians (Liu et al., 2001). People with HF experience periods of stability interspersed with exacerbations requiring hospitalizations. The burden of this problem is significant to not only the individual and their families, but frequent emergency visits and hospitalizations add to the burden of the current and future health care system.

This thesis consists of three major research components. The first component synthesizes research to establish the 'state of knowledge' from the research related to factors that influence HF self-management of community dwelling individuals guided by Connelly's Model of Self-Care in Chronic Illness (Connelly, 1993). A mixed method approach comprises the second and third components, combining quantitative secondary analysis and qualitative semi-structured telephone interviews.

In the second component, a secondary analysis examines the profile characteristics of a cohort of individuals' attempting to self-manage HF in the community, and compared their characteristics to individuals recently discharged from hospital. The specific profile characteristics examined were: length of time since diagnosis, gender, age, New York Heart Association (NYHA) classification, and number of hospitalizations in the last three months, as well as selected components from the Minnesota Living with Heart Failure Questionnaire (MLHFQ). Ten items from the MLHFQ, five from the physical subscale and five from the emotional subscale, were included in the analysis. Data for the secondary analysis were generated from three sources. The first source was a group of community dwelling individuals who were participating in a simultaneous HSFO dissemination study of a HF self-management resource. The second source was a social support cohort of ten individuals from this same group, who volunteered to participate in additional questions by telephone interviews. The third source was derived from a large randomized controlled trial on transition from hospital-to-home and supportive care for self-management (Harrison et al., 2002). The results were then compared to the latest Canadian HF profile data for similarities and differences.

The third component of this thesis consisted of telephone interviews with the social support cohort from the HSFO dissemination study as described above. The telephone interviews explored one factor from Connelly's model, the perceptions of how social support related to self-management.

Summary of Findings

Systematic Review

A systematic review, which included a rigorous search and retrieval process and critical analysis, provided direction for the remainder of the thesis. Eleven studies fit the inclusion criteria for the review. A conceptualization of self-management as identified by Connelly's Model of Self-Care in Chronic Illness guided the review (Connelly, 1993). This model provides a framework for clinical decision making in the promotion and support of self-care behaviors by identifying factors and their related variables that influence effective self-management in chronic illness. The intention of the model is to guide assessment, concluded that self-care behaviors and recognition of symptoms increased with experienced patients.

Secondary Analysis

To date, work has largely focused on individuals hospitalized with HF, thus, there has been a gap in understanding characteristics of community dwelling individuals with HF. These characteristics may influence how effectively individuals are, or are not, self-managing. This analysis shows that the social support cohort were younger (<65), mainly male (77.8%), diagnosed within the last five years, and had a NYHA classification of I to II. In comparison, recently discharged individuals of the earlier PCCHF study were older (>65), and had higher NYHA classifications of III to IV indicating more impaired function. The social support cohort was also younger than the Canadian data with lower proportion of women. There were no major differences between the HSFO study data and the social support cohort data in either physical or emotional subscales. The total MLHFQ score for the study cohort was 51.6 out of a possible 105, with higher scores indicating a poorer quality of life. This total was lower than the results from the individuals recently discharged from hospital (66.29).

Telephone Interviews

Content analysis of the telephone interviews identified three concepts. They were disruption, help-seeking relationships, and reconciling. Disruption is defined as a change to the order of life that is the result of physical, emotional, social, economic, or spiritual changes (Mahoney, 2001). Help-seeking relationships is defined as health professionals, established community groups and programs, family and friends provided an opportunity for individuals to request or search out assistance to obtain support or services that comfort, and/or provide information. Reconciling is defined as the process of establishing new norms, and learning to accept a diagnosis of HF.

Relating Findings

Some of the findings of this study support the systematic review while others did not. The influencing factors and related variables from Connelly's model, identified in the systematic review will be discussed. Based on the systematic review, higher classifications (indicating more severe disease) had a positive effect on self-management (Carlson et al., 2001; Rockwell & Riegel, 2001). In this study, many social support cohort respondents had a lower NYHA classification. The lower classifications indicate that the symptoms experienced by community dwelling individuals were not exerting a large influence on functioning, unlike the case of individuals recently discharged from hospital. The lower classification could mean that the individuals who agreed to the telephone interviews were managing their symptoms well, as indicated by demonstrated knowledge and appropriate self-management strategies, or that medical treatment was optimal, or a combination of both.

The research related to length of diagnosis and HF self-management indicates that newly-diagnosed individuals are less confident in decisions they make, and do not recognize the importance of attending to self-management (Carlson et al., 2001; Rockwell & Riegel, 2001; Francque-Frontiero, Riegel, Bennett, Sheposh, & Carlson, 2002). However, in this study, newly diagnosed individuals (<5 years) were already performing many of the strategies recommended for self-management. Literature also suggests that newly diagnosed patients are less confident in decision making about symptoms, and that might make them more receptive to education given by health care professionals (Carlson et al., 2001). This may explain why a large number of newly diagnosed individuals chose to use the "Managing Congestive Heart Failure" resource.

Data from the MLHRQ showed the physical symptoms experienced most often at the time of the study were shortness of breath, feeling tired/fatigued/low energy, and swelling to ankles/legs/etc. These findings are interesting since a majority of the smaller group were categorized as NYHA Classification I or II that indicates fewer symptoms. These same individuals also felt a loss of self-control, being a burden to their family, worry, and feelings of depression. All participants reported having difficulty concentrating or remembering things. The Canadian data regarding depression shows that elderly adults with HF have a two to three times the risk of depression. Interestingly in this study, feelings of depression were seen younger adults (<65).

Guided by the synthesis of literature, Connelly's model, and my own clinical experience, I conducted further qualitative semi-structured interviews to explore how perceived social support related specifically to self-management in the HF population living in the community. The interviewees identified a range of social supports (family, cardiac rehabilitation centers, heart failure clinics, support groups, phone support by a registered nurse, and medical support from physicians), and self-management techniques (daily weight, reduced sodium diet, fluid restrictions, self-medicate, and increased education), and physical symptoms (shortness of breath, fluid retention, low energy) also identified in systematic review studies.

My findings support the many changes that result from disruption in the physical, emotional, spiritual, social, and economic domains. The HSFO survey data, specifically the results of the MLHFQ, illustrates many of these multiple changes. The emotional subscale revealed feelings of loss of control, being a burden to families, worry, feelings of was not identified in the systematic review, however, it has appeared in other social support research (Stewart, 1993).

The concepts of disruption and reconciling have been identified in several studies on the HF population (Mahoney, 2001; Stull, Starling, Hass, & Young, 1999). The social support cohort interviews found disruption, reconciling, and help-seeking relationships to be part of an *ongoing* process of coping with HF, rather than any one being the result of HF. Heart failure is a complex disease with the potential for daily physical changes that can create daily disruptions. Individuals attempt to reconcile their HF by establishing new norms, and learning to accept their diagnosis. Coming to terms with the disease helps people accept and cope with disruptions to their lives, to reset their view of what is normal, and to adjust that view according to the disruptions that are occurring.

Contribution to Knowledge

The literature synthesis summarizes current knowledge on HF related to factors that influence HF self-management, and supports Connelly's model as valuable in identifying factors that influence community dwelling individuals living with HF. It provides guidance for individualized assessments and interventions focusing on facilitating HF self-management. The descriptive analysis of profile characteristics provides new information regarding individuals who are attempting to self-mange HF at home that could affect an individual's ability to self-manage. Content analysis of the interviews on social support in HF self-management identifies which supports individuals perceive as being helpful or unhelpful, while also differentiating the type of supports each is providing. This information will guide assessments, and help to decide what interventions are most appropriate and who may be best providers of particular forms of support.

Implications

Based on the findings of this thesis, there are several implications for nursing practice, education, further research, and for policy.

Implications for Practice

Recently published HF clinical practice guidelines by the Canadian Cardiovascular Society (CCS), the American College of Cardiology and the American Heart Association (ACC/AHA), and the European Society of Cardiology provide information to help guide the management and prevention of HF. All three guidelines recognize the importance of improving patients' quality of life by reducing symptoms and hospitalizations, and identify a key aspect within this aim as the promotion of individuals' ability to self-manage. The guidelines identify education principles and self-management strategies, while stressing the importance of a multidisciplinary approach to management of HF. Despite the supporting literature and recommendations made in these recent HF clinical practice guidelines, there is still little information known about the particular factors that influence an individuals' ability to effectively self-manage.

The unique challenges that face younger individuals, and the ongoing process of coping that includes disruption, help seeking relationships, and reconciling, highlight the need for both initial and ongoing physical, psychosocial, and emotional assessments. Self-reported depression among younger individuals as well as older individuals, and the documented negative effect depression has on self-management, indicates the need for a depression tool to be administered not only on initial assessment, but also throughout the follow-up of individuals with HF. In addition, the guidelines specifically cite the importance of experienced nurses conducting phone calls to check on individuals' progress at home.

Implications for Education

Education of patients, as well as support persons, is a key component of HF self-management; however, education alone does not increase effective self-management (Ni et al., 1999). Nursing education needs to focus on the initiation of strategies that support and link information to practice, thus helping individuals to absorb and retain information. Focusing information on specific behavioral strategies, will reduce the amount of information given at one time. Individuals can then concentrate on the information that will make the most impact on their lives. Nursing interventions should not be initiated until an individualized plan that identifies barriers has been developed.

Nurses need to assess the type of supports available to individuals as well as how the individuals perceive the value of these supports. Nurses also need to facilitate the link between patients and available community supports. This study identified that support from both individuals and groups were helpful. Ongoing telephone contact with a registered nurse was identified in this study and in the systematic review, as being very helpful to individuals- not only to provide education but also to provide reassurance that self-management decisions were appropriate. Some research suggests that there may be a benefit to targeting specific patients, longer length of diagnosis with higher NYHA classification, for most effective results; however, this study does not support this finding. Individuals with a diagnosis less than five years and a lower NYHA classification were demonstrating appropriate self-management techniques.

Implications for Further Research

In order to generalize any of the information obtained from the systematic review or the telephone interviews a greater number of large randomized trials as well as ongoing qualitative studies need to be completed. Many of the strategies for effective HF self-management are not medically-focused, however, these strategies have been shown to reduce emergency visits and hospitalizations as well as positively impact on quality of life. Therefore, emphasis should be placed on research that investigates these non-medical interventions such as daily weights and reduction in sodium intake.

Implication of Policy

As previously mentioned, more specific suggestions for the non-medical facilitation of HF in the practice guidelines would be helpful to health care professionals. Strategies to increase the awareness of the guidelines for all health professionals are necessary. Increased support of services, such as heart failure clinics and cardiac rehabilitation centres, is also necessary so that community dwelling individuals have resources available to help them self-manage.

Reference List

Carlson, B., Riegel, B., & Moser, D. K. (2001). Self-care abilities of patients with heart failure. *Heart & Lung, 30,* 351-359.

Connelly, C. E. (1993). An empirical study of a model of self-care in chronic illness. *Clinical Nurse Specialist, 7,* 247-253.

Francque-Frontiero, L., Riegel, B., Bennett, J. A., Sheposh, J., & Carlson, B. (2002). Self-care of persons with heart failure: Does experience make a difference? *Clinical Excellence for Nurse Practitioners, 6,* 23-30.

Harrison, M. B., Browne, G. B., Roberts, J., Tugwell, P., Gafni, A., & Graham, I. D. (2002). Quality of life of individuals with heart failure: A randomized trial of the effectiveness of two models of hospital-to-home transition. *Medical Care, 40,* 271-282.

Liu, P., Arnold, M., Belenkie, I., Howlett, J., Huckell, V., Ignazewski, A. et al. (2001). The 2001 Canadian Cardiovascular Society consensus guideline update for the management and prevention of heart failure. *The Canadian Journal of Cardiology, 17,* 5E-24E.

Mahoney, J. (2001). An ethnographic approach to understanding the illness experiences of patients with congestive heart failure and their family members. *Heart & Lung, 30,* 429-436.

Ni, H., Nauman, D., Burgess, D., Wise, K., Crispell, K., & Hershberger, R. E. (1999). Factors influencing knowledge of and adherence to self-care among patients with heart failure. *Archives of Internal Medicine, 159,* 1613-1619.

Rockwell, J. M. & Riegel, B. (2001). Predictors of self-care in persons with heart failure. *Heart & Lung, 30,* 18-25.

Stewart, M. J. (1993). *Integrating social support in nursing.* Newbury Park, CA: Sage.

Stull, D. E., Starling, R., Hass, G., & Young, J. B. (1999). Becoming a patient with heart failure. *Heart & Lung, 28,* 284-292.

Weinberger, M., Hiner, S. L., & Tierney, W. M. (1986). Improved functional status in arthritis: The effect of social support. *Social Science and Medicine, 23,* 899-904.

Appendix A

New York Heart Association Functional Classification (NYHA)

Class I	No physical activity limitation: ordinary physical exertion does not cause undue fatigue, chest pain, palpitations, or dyspnea
Class II	Slight limitation of physical activity: patient is comfortable at rest, but ordinary activity results in fatigue, chest pain, palpitations, or dyspnea
Class III	Marked limitation of physical activity: patient is comfortable at rest, but less than ordinary activity results in fatigue, chest pain, palpitations, or dyspnea
Class IV	Unable to carry out any physical activity without discomfort: symptoms of fatigue, chest pain, palpitations, or dyspnea are present even at rest with increased discomfort with any physical activity.

Appendix B

HSFO Questionnaire

HEART AND STOKE FOUNDATION
MANAGING CONGESTIVE HEART FAILURE

EVALUATION

Please take a few moments to complete and return this evaluation. Your comments will help the Heart and Stroke Foundation of Ontario improve the quality of life for people with congestive heart failure. The evaluation can be completed by the person with congestive heart failure or by a person that helps with the symptoms related to congestive heart failure, such as a family member or friend. It could also be completed by a healthcare professional assisting people with managing congestive heart failure.

1. For whom will you be completing this evaluation?
   - ☐ I am answering regarding my own health
   - ☐ I am answering for someone else (such as a parent or spouse)
   - ☐ I am a healthcare professional providing feedback (please skip patient-related questions 7, 9, 12, 15, 16, 17 and 18)
2. Where did you receive *Managing Congestive Heart Failure?* (please check one)
   - ☐ In the Hospital
   - ☐ In Cardiac Rehabilitation
   - ☐ In Congestive Heart Failure Clinic
   - ☐ Family Physician office
   - ☐ Other, please specify: ______________________
3. Who gave you your copy of *Managing Congestive Heart Failure*? (please check one)
   - ☐ Family Physician
   - ☐ A Nurse
   - ☐ Home Care Worker
   - ☐ Local Heart and Stroke Foundation office
   - ☐ A Social Worker
   - ☐ A Cardiologist or Internist
   - ☐ Ordered yourself/family member
   - ☐ Other, please specify: __________

HEART AND STOKE FOUNDATION
MANAGING CONGESTIVE HEART FAILURE

5. Indicate how strongly you agree or disagree with each of the following statements as it relates to this resource. It will help us better understand how helpful this resource is to individuals with congestive heart failure. Remember: there are no right or wrong answers, we are only interested in your opinion so that we may improve the resource.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
The size of the letters is appropriate	☐	☐	☐	☐	☐
The material in the resource is presented clearly	☐	☐	☐	☐	☐
I like the way the resource is organized	☐	☐	☐	☐	☐
The material in the resource explains things in a way I understand	☐	☐	☐	☐	☐
The pictures in the resource are helpful	☐	☐	☐	☐	☐
The resource covers all of the topics about congestive heart failure that are important to me	☐	☐	☐	☐	☐
I find the resource easy to use	☐	☐	☐	☐	☐
The worksheets/charts in the resource are useful	☐	☐	☐	☐	☐

6. On the following scale, please indicate whether you found the modules in *Managing Congestive Heart Failure* to be "very good", "good", "fair" or "poor".
If you didn't read a particular module, please mark the "Didn't Read" box.

	Very Good	Good	Fair	Poor	Didn't Read
Understanding Congestive Heart Failure	☐	☐	☐	☐	☐
Congestive Heart Failure	☐	☐	☐	☐	☐
Nutrition	☐	☐	☐	☐	☐
Medications	☐	☐	☐	☐	☐
Exercise	☐	☐	☐	☐	☐
Stress	☐	☐	☐	☐	☐
Community Resources	☐	☐	☐	☐	☐

HEART AND STOKE FOUNDATION
MANAGING CONGESTIVE HEART FAILURE

7. Did the topics discussed in *Managing Congestive Heart Failure* match your concerns about your condition?
   ☐ Yes, very much
   ☐ Yes, somewhat
   ☐ No, not really
   ☐ No, not at all

8. What topics would you like covered in *Managing Congestive Heart Failure* or discussed in more detail?
   a) ____________________
   b) ____________________
   c) ____________________

9. What, if any, changes have you made in the way you do things as a result of the information presented in this resource?

   ____
   ____
   ____

10. (a) What did you like most about the resource *Managing Congestive Heart Failure*?

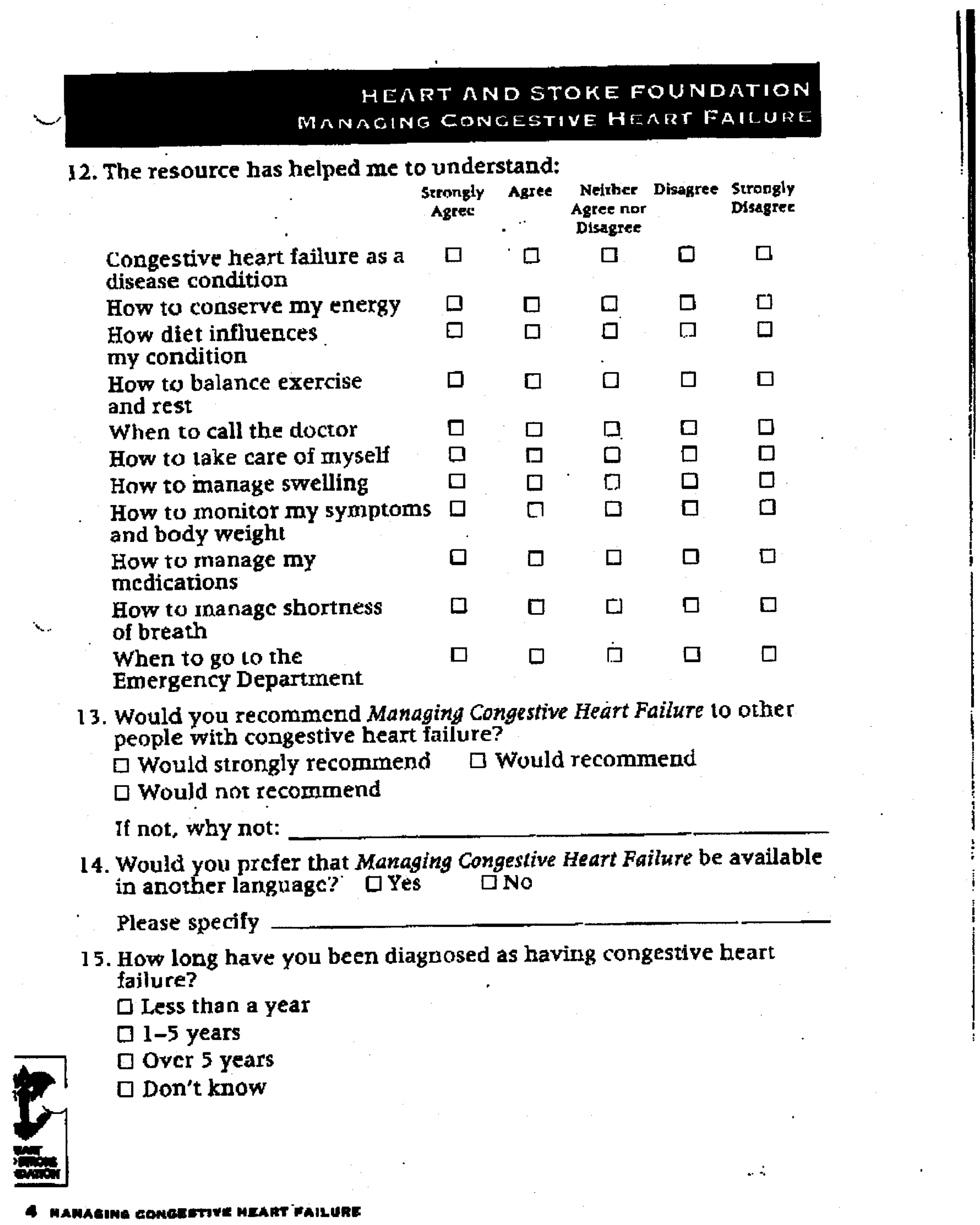
   ____
   ____

   (b) What did you like least about the resource *Managing Congestive Heart Failure*?

   ____

11. Please add any other comments about *Managing Congestive Heart Failure* you wish here:

   ____
   ____
   ____
   ____
   ____



HEART AND STOKE FOUNDATION
MANAGING CONGESTIVE HEART FAILURE

12. The resource has helped me to understand:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Congestive heart failure as a disease condition	☐	☐	☐	☐	☐
How to conserve my energy	☐	☐	☐	☐	☐
How diet influences my condition	☐	☐	☐	☐	☐
How to balance exercise and rest	☐	☐	☐	☐	☐
When to call the doctor	☐	☐	☐	☐	☐
How to take care of myself	☐	☐	☐	☐	☐
How to manage swelling	☐	☐	☐	☐	☐
How to monitor my symptoms and body weight	☐	☐	☐	☐	☐
How to manage my medications	☐	☐	☐	☐	☐
How to manage shortness of breath	☐	☐	☐	☐	☐
When to go to the Emergency Department	☐	☐	☐	☐	☐

13. Would you recommend *Managing Congestive Heart Failure* to other people with congestive heart failure?
☐ Would strongly recommend ☐ Would recommend
☐ Would not recommend

If not, why not: ______________________________

14. Would you prefer that *Managing Congestive Heart Failure* be available in another language? ☐ Yes ☐ No

Please specify ______________________________

15. How long have you been diagnosed as having congestive heart failure?
☐ Less than a year
☐ 1–5 years
☐ Over 5 years
☐ Don't know

16. Did you know the cause of your congestive heart failure?

☐ Yes

☐ No If not, please comment on whether *Managing Congestive Heart Failure* helped you understand the cause of your congestive heart failure.

____

____

17. Have you been hospitalized because of your congestive heart failure in the past 3 months?

☐ Yes How many times? ____________________

☐ No

18. **LIVING WITH CONGESTIVE HEART FAILURE:** The following questions concern how your congestive heart failure has prevented you from living as you wanted during the last month. The items listed on page 6 describe different ways some people are affected. If you are sure an item does not apply to you or is not related to your congestive heart failure then circle 0 (No) and go on to the next item. If an item does apply to you, then circle the number rating how much it prevented you from living as you wanted.

Appendix C

HSFO Telephone Interview Questions

Code #:
Date:
Start time: Finish Time: Total Time:
Interviewer:
Interview #:

1. What did you think of the resource?

2. Tell me how and when you used the resource.

3. Did you learn anything new about how to manage your heart failure?

4. What specific changes did you make in managing your heart failure based on what you learned in the resource?

5. In the past six weeks how many times have you been admitted to hospital?
6. In the past four weeks how many times have you visited your family doctor?
7. In the past four weeks how many times have you visited a specialist?
8. In the past four weeks how many times have you visited an emergency room?

Appendix D

Study Interview Questions

Perceived Social Support and HF Self-Management

Code #:____________________
Date:______________________
Start Time:______________ Finish Time:______________ Total Time:_____________
Interviewer:________________
Interview #:________________

1. Can you tell me who/what helps you manage your symptoms related to your HF?

2. How does (from question #1) help you manage your HF?

3. a) What kind of support do you find helpful? b) What kind of support do you not find helpful?

Closure: That is all of my questions. Is there anything else you would like to add?

Appendix E

Telephone Consent

I am a nurse currently completing my Master's of Nursing at Ottawa University. I work in a cardiac rehabilitation centre where we help people manage symptoms related to their CHF.

I am conducting a study examining supports that help patients with CHF manage their symptoms. I would like to know if you would agree to participate in my study. If you agree to participate, I will ask you three questions that will specifically focus on supports that help you manage your symptoms.

The information collected may help health professionals assist patients with managing symptoms. You are under no obligation to participate in my study.

I would like to tape record our conversation. This may help me to recall the details of our conversation and reflect on the information you have given me. You can ask me to stop the interview or to turn off the tape recorder at any time. The tapes will be transcribed and then destroyed following the interview.

All information will be confidential. A code number will be used to identify the information so your name will not appear on any documents. If you agree to participate I can ask you the three questions now, or I can call you back at a later date and time.

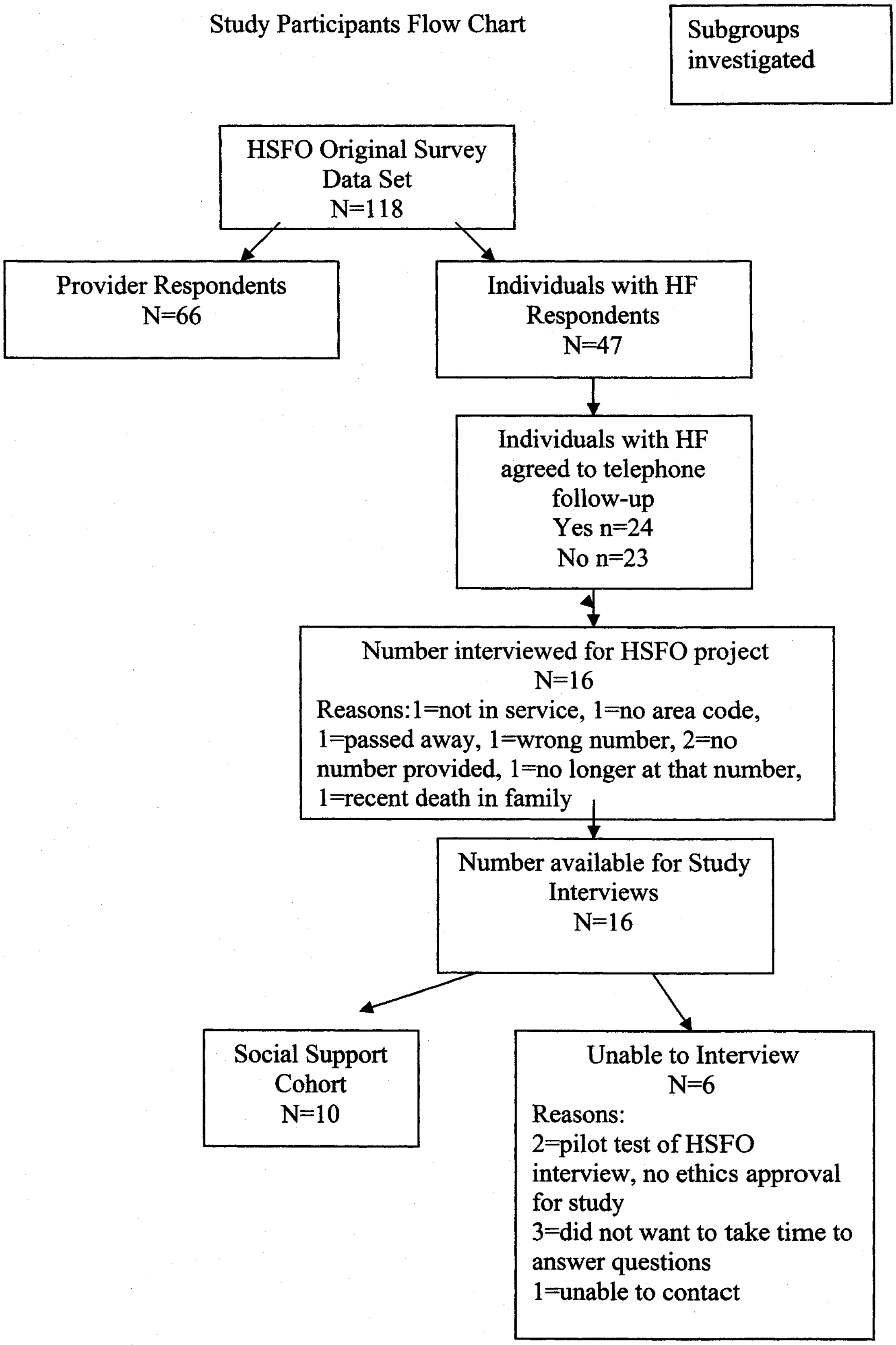
If you have any questions or concerns please feel free to contact me (613) 544-3400 Ext # 2123 or my advisor Dr. Margaret Harrison (613) 798-5555 Ext # 13028.

If you have any questions about your rights as a research participant, you should contact the Chairman of the Ottawa Hospital Research Ethics Board at (613) 761-4902.

Date:__________________________________ Code#_______________

Appendix F

Study Participants Flow Chart



Appendix G

Letter of Intent

June 2, 2003

Margaret B. Harrison RN, PhD
Associate Professor, Queen's University School of Nursing
Senior Nurse Scientist, Ottawa Health Research Institute, Clinical
Epidemiology Program @ Ottawa Hospital
1053 Carling Avenue
CEP ASB 207
Ottawa, ON
K1Y 4E9

Dr. Margaret Harrison,

Further to our recent discussions, I would like to confirm that my thesis research will focus on examining factors that influence the self-management of congestive heart failure. The current study underway with Heart & Stroke Foundation of Ontario (HSFO) to evaluate the Managing Congestive Heart Failure resource (REB protocol # 2003002-01H) provides a timely opportunity to approach people who are actively trying to self-manage their heart failure. The HSFO study (n=1000) involves a mail-back survey and follow-up telephone interviews with a subset of respondents. The plan for my thesis component would be to work concurrently with the HSFO project.

To accomplish my thesis aim, I would like to conduct a secondary analysis of the survey data on factors identified in the literature as influencing self-management (e.g., gender, severity of illness, circumstances of living). Additionally, I would add three additional questions to the planned telephone interviews with those survey respondents indicating willingness to have an interview. The three questions will specifically examine the influence that perceived social support has on self-management of congestive heart failure. A copy of the three questions, as well as the telephone consent that I propose to use during the interview, have been attached.

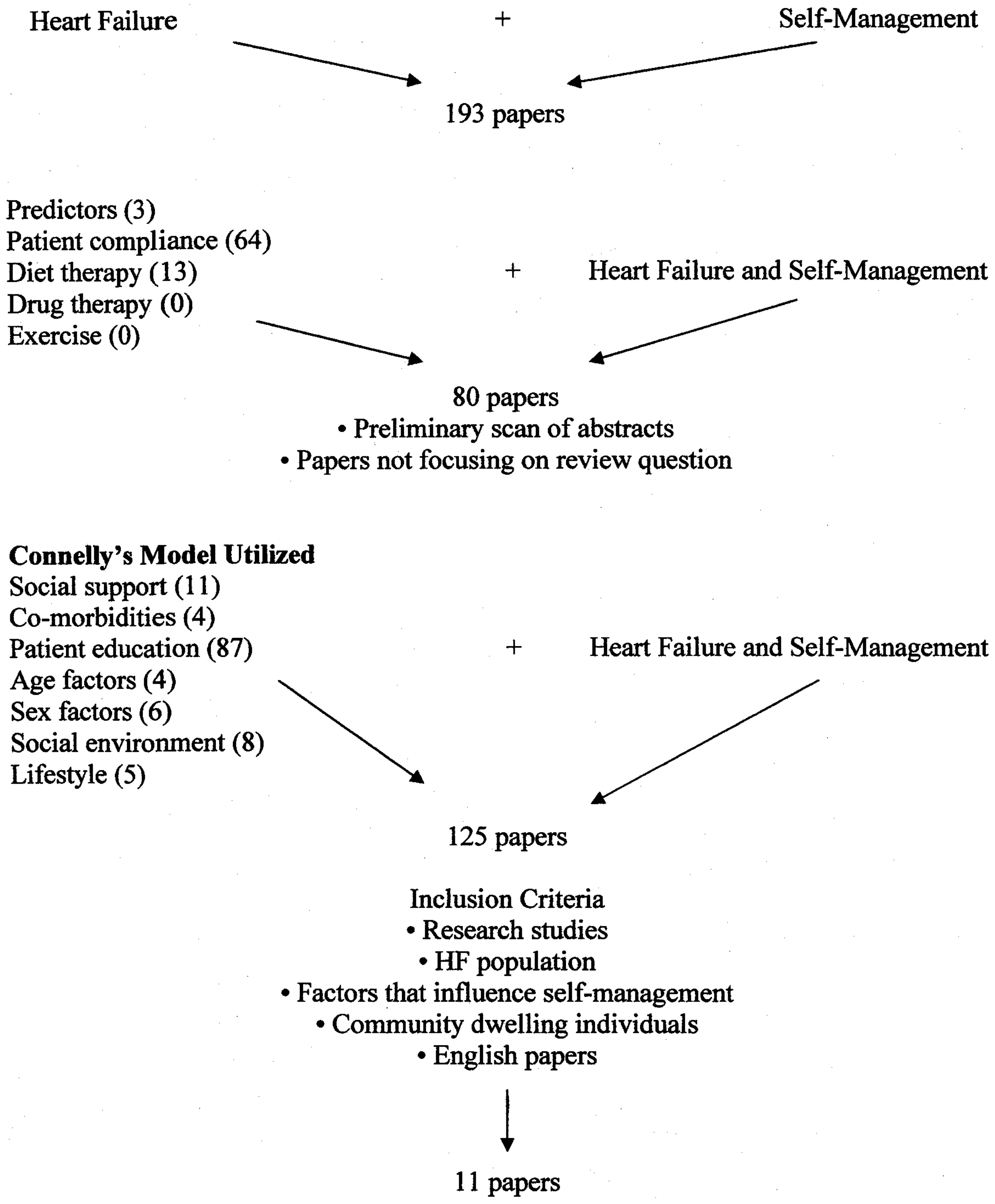
I am currently working in the Kingston Cardiac Rehabilitation Centre as a nurse co-ordinator. After diagnosis, the centre assists patients with the management of their CHF. In my practice I find that issues around social support seem to impact how patients manage their condition. I welcome the opportunity to study this topic and hope that my thesis research will provide direction for nursing practice in terms of how to assess for issues considered important from the patient and family perspective.

I understand that for efficiency and not approaching participants twice that I will be responsible for conducting the entire interview with my sample including the nine HSFO questions. I will specifically request permission about the additional questions. Thank you for your considering this request.

Wendy Earle RN, BScN, CCN(C)
1-173 Union St.
Kingston, ON
K7l 2P5
(613) 544-9225

Appendix H

Search Strategy



Heart Failure + Self-Management

193 papers

Predictors (3)
Patient compliance (64)
Diet therapy (13)
Drug therapy (0)
Exercise (0)

+ Heart Failure and Self-Management

80 papers
- Preliminary scan of abstracts
- Papers not focusing on review question

Connelly's Model Utilized
Social support (11)
Co-morbidities (4)
Patient education (87)
Age factors (4)
Sex factors (6)
Social environment (8)
Lifestyle (5)

+ Heart Failure and Self-Management

125 papers

Inclusion Criteria
- Research studies
- HF population
- Factors that influence self-management
- Community dwelling individuals
- English papers

11 papers