2017

Understanding Self-Management Decision Making in Heart Failure

Constance Louise Schumacher
Walden University

Walden University

College of Health Sciences

This is to certify that the doctoral dissertation by

Constance Schumacher

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Leslie Hussey, Committee Chairperson, Nursing Faculty
Dr. Vincent Hall, Committee Member, Nursing Faculty
Dr. Christine Frazer, University Reviewer, Nursing Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2017

Abstract

Understanding Self-Management Decision Making in Heart Failure

by

Constance Schumacher

MSN, Walden University, 2014

BScN, University of Windsor, 1990

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Nursing

Walden University

August 2017

Abstract

Heart failure patients are responsible for managing fluctuations in symptoms between exacerbations by employing treatment adherence, active monitoring, and management strategies based on expert guidelines. Despite education, delayed help seeking persists among those in the need of acute medical intervention, as evidenced by high hospital admission and readmission rates. The purpose of this qualitative grounded theory study was to explore the decision making processes undertaken by heart failure, community-dwelling individuals as they experience symptom changes. Eighteen face-to-face interviews were conducted with participants who had heart failure and received self-management education from a home care agency in Southern Ontario, Canada. Data were analyzed using iterative steps of open, axial, selective coding, and qualitative software text queries. Three process themes were identified: perceiving symptoms, normalizing symptoms, and adapting to symptoms, with an overarching theme of control and absence of consultative behaviors. The central concept revealed in this study was normalizing symptoms in heart failure which included actions taken by participants to mitigate symptom fluctuations. Daily fluctuations were assimilated into normal life resulting in desensitization of symptom recognition and a loss of functional capacity. These findings can be used to inform system changes needed to strengthen consultative patient-health professional relationships required for effective self-management problem-solving. This study leads to positive social change by explaining how self-management is practiced from the patient's perspective, which can inform practice recommendations and future research.

Understanding Self-Management Decision Making in Heart Failure

by

Constance Schumacher

MSN, Walden University, 2014

BScN, University of Windsor, 1990

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Nursing

Walden University

August 2017

Dedication

This work is dedicated to my family, who have given me the strength, courage, and support to complete this journey. Your patience and love through the ups and downs has meant the world to me. To my husband, Bryan, whose unwavering belief in my abilities to complete the dissertation pushed me through to the finish line, I am so grateful. To my children, Nick and Danielle, Audrey, and John, thank you for making each moment spent together special, your love and support fills my heart with joy. To my parents, Rick and Marilyn Scott, who have been patient and understanding throughout, I can now say I am finished. Most of all, nothing done on this earth is possible without the grace of my Lord and Savior Jesus Christ, to him I give the Glory.

Acknowledgments

I would like to acknowledge and thank the many people who reviewed my works in progress, provided guidance, and constructive feedback. To Dr. Leslie Hussey, who has been a rock throughout the dissertation, knowing exactly what to say and recommend at the right time. It has been a pleasure and honor working with you, your mentorship has been invaluable. To Dr. Vincent Hall, I cannot thank you enough for guiding me through the travails of qualitative grounded theory methodology, your expertise was greatly appreciated. To Dr. Christine Frazer, thank you for your comments and feedback as the URR. To Dr. Andrew Costa, thank you for the encouragement and support in the final stages of the dissertation.

I would like to acknowledge the nurses who distributed flyers and the Community Care Access Center who granted access to their patients, thank you. I am deeply grateful to the leadership of CCAC, Colleen Lackey, Dilys Haughton, Jane Blums, and Tom Pierce, your support and dedication to improving the lives and care of those in the community is truly remarkable. Lastly, to the participants, who graciously allowed me into their homes and provided me with the details of their experience living with heart failure, this is your story, thank you for sharing.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Introduction

Congestive heart failure (CHF) is a chronic disease that is managed through the monitoring of symptoms, dietary adjustments to optimize fluid balance, and taking medications to improve cardiac functioning. Strategies used by health professionals focus on patient education and knowledge acquisition. However, individuals diagnosed with CHF do not seek medical help when a change in symptoms occurs. The problem stems from the decision-making component of heart failure self-management. The purpose of this study was to explore self-management decision-making factors that influence symptom perception, interpretation, and help-seeking activation. Potential social implications of this study include an understanding of self-management from the perspective of the patient, which will inform strategies to support and promote self-management in the community.

The sections of this chapter include a summary of self-management education strategies, prerequisites that are believed to enhance self-management knowledge retention, and symptoms commonly experienced during an exacerbation. The prevalence of inadequate self-management is demonstrated through high hospital readmission rates outlined in the problem statement. I will describe how the qualitative grounded theory complemented the aims of this study and served to guide exploration of the research problem. The chapter closes with potential contributions to the body of knowledge and self-management practice implications.

Background of the Study

Standardized self-management education focuses on teaching the individual to monitor symptoms through daily weights, taking medications as prescribed, and adhering to fluid and sodium restrictions (Howlett et al., 2016). Harkness et al. (2014) stated that CHF self-care requires cognitive engagement, which is demonstrated by interpretation of symptoms and appropriate response of help-seeking behaviors. Despite education, CHF patients struggle with help seeking in a timely manner to avoid an exacerbation (Harkness et al., 2014; Stamp, 2011). Chen et al. (2014) studied the relationship between health literacy, self-care knowledge, and self-management using a cross-sectional correlational design ($N = 63$) and found no association between heart failure knowledge, health literacy, and self-care management ($P > 0.05$). Heart failure knowledge is more than recall of information, as patients with high knowledge also have poor self-care (Hwang, Moser, & Dracup, 2014; Spaling, Currie, Strachan, Harkness, & Clark, 2015). In small group sessions delivered twice weekly over a period of 4 weeks, symptom recognition was found to improve with a skill building intervention reinforcing daily symptom monitoring (Dickson et al., 2014). It is unclear if anxiety and depression are a product of poor self-care when there is high knowledge (Hwang et al., 2014), or if anxiety and depression alter the decision-making processes resulting in poor self-care. Self-management capabilities should be increased through methods that focus on behavior and application of education content, rather than instructional recall. If anxiety and depression associated with poor self-management are prevalent, there may be a psychological component present, and steps should be taken to assess for distress related to self-management.

Heart failure decision-making is a process of symptom recognition, evaluation, and action taken in the form of seeking help from a health care provider to optimize control when there is a change in symptoms. In examining barriers and facilitators of self-care, decision-making was conceptualized as an isolated entity involving the patient (Hwang et al., 2014) and as a process involving the interactions with members of the health care system (Peters-Klimm et al., 2012). Self-management and self-care are interchangeable terms that are conceptualized differently in the literature. Marti et al. (2013) found that patients practice selective self-management, suggesting that some self-management tasks are easier to assimilate into daily life. The difference in how self-management is conceptualized, specifically who is involved in the decision-making processes that support self-management, influences study results and the recommendations to improve self-management. A lack of clarity and consensus on the line between self-management and managed care is an area that requires further exploration.

The roles and responsibilities for implementing CHF self-management should be clearly delineated and communicated. Patients who had good knowledge and poor self-care also perceived that they had less control (Hwang et al., 2014); yet, better self-efficacy was related to increased physician visits (Peters-Klimm et al., 2012). Scholars have not determined how much control can be attributed to the patient who frequently visits the physician, and whether the visits to the physician are a supportive decision making measure. Adherence was higher when personal goals were perceived as congruent with self-care behaviors, with physical functional independence rated as most important (Zhang, Dindoff, Arnold, Lane, & Swartzman, 2015). Perceived self-efficacy may improve if the health care provider and patient mutually understand what is within the patient's control.

Monitoring symptoms and adhering to fluid and dietary modifications present less of a challenge when symptoms are in a homeostatic state. Interpreting symptoms and symptom unpredictability is identified as a challenge, resulting in feelings of uncertainty and fear (Clark et al., 2012; Reeder, Ercole, Peek, & Smith, 2015; Wingham, Harding, Britten, & Dalal, 2014). Patients experience problems when there are fluctuations in symptoms, which can be explained by a poor understanding of what to do with the information collected during the monitoring phase of self-management (Herr et al., 2015; Spaling et al., 2015). Additionally, CHF patients were found to have a high comorbidity burden (Hwang et al., 2014; Peters-Klimm et al., 2012), and decreased knowledge was associated with a higher Charlson score (Hwang et al., 2014). With high comorbidity prevalence in the CHF population, changes in symptoms may create confusion as to which disease the symptoms are attributed to. Self-management capabilities are fluid and can change with alterations in overall health status and not just CHF symptom changes.

Scholars have revealed three themes of theoretical gaps and practice deficiencies: defining self-management as a concept, delineation of roles and responsibilities of the patient who is self-managing, and uncertainty in symptom recognition and interpretation leading to ineffective self-management application. Self-management in CHF remains a complex phenomenon that requires further exploration. Theory refinement should focus on clarifying definitions of concepts, the meaning ascribed from interactions with persons who support self-management, and the processes of decision making in self-management. There is an identified problem with current self-management strategies, for which the consequences are clinical deterioration, increased hospital utilization, and associated financial burden (Cardiac Care Network, 2014). This study was important for future of health care strategies to optimize self-management of the CHF patient in the community. The provision of fiscally responsible, efficacious health care strategies is relevant to the patient, the health care community, and funders of the health care system.

Problem Statement

CHF is a leading cause of hospitalization for patients 65 years of age and older; additionally, 90-day readmission rates are 23-50% for patients 75 years age and older (Cardiac Care Network, 2014). In comparison, chronic obstructive pulmonary disease (COPD) has a single readmission rate of 18% within a year of hospitalization, dropping to 14% for two readmissions (Canadian Thoracic Society, 2010). CHF has a morbidity rate of 50% at 5 years, with exacerbations escalating at end stage (Bui, Horwich, & Fonarow, 2011). Heart failure requires self-management by the patient, which is a complex process that includes maintenance, monitoring, and management stages whereby the patient is required to identify and act on symptom changes (Riegel, Jaarsma, & Stromberg, 2012). Self-management strategies are provided to the CHF patient through structured education and include taking medications as prescribed and monitoring weights, oral fluids, and sodium intake. The effectiveness of patient education has been measured in terms of cognitive knowledge, recall, and ability to monitor symptoms rather than decision making processes needed to take action (Otsu & Moriyama, 2010). Harkness et al. (2014) stated that self-management requires cognitive engagement where the individual is able interpret the symptoms and react appropriately with help-seeking behaviors. Despite education, CHF patients struggle with help seeking in a timely manner to avoid an exacerbation (Harkness et al., 2014; Stamp, 2011).

Some patients fail to initiate help-seeking behaviors necessary for the self-management of CHF symptoms (Harkness et al., 2014; Sethares, Sosa, Fisher, & Riegel, 2014; Stamp, 2011). Research was needed to fill the gap, focusing on the decision-making processes and triggers involved in prioritizing of health goals that influence help-seeking actions in self-management. The goal of this study was to explore the phenomenon of help-seeking activation and decision-making processes involved in self-management from the perspective of the patient.

Purpose of the Study

Many individuals diagnosed with CHF do not seek medical help when a change in symptoms occurs. The problem stems from the decision-making component of heart failure self-management. The purpose of this qualitative grounded theory study was to explore the processes of self-management decision-making from the perspective of the patient. Understanding the processes of self-management, what triggers the individual to seek assistance (particularly during an exacerbation) will inform the education and supportive measures that are required to increase the successful management of exacerbations in the community. Exploration of the central phenomenon of self-management symptom interpretation decisions has increased understanding from the perspective of the individual living with CHF. Individuals who have experienced an exacerbation and were able to actively manage and seek assistance at the appropriate time to avoid a hospitalization were explored. There was a need to better understand the individuals' interpretation of their symptoms and what led them to take action. This study provided a better understanding of self-management of CHF and informed the goals of improving education, supports, and ultimately control of symptoms.

Research Questions

1. RQ1: How does the community dwelling individual with CHF self-manage when a change in symptoms occurs?
2. RQ2: How does the individual perceive self-management as part of his or her daily life?
3. RQ3: What meaning does the individual with CHF ascribe to fluctuations in symptoms?
4. RQ4: What are the factors that influence help-seeking behaviors when heart failure symptoms change?

The research questions provided insight into the individual's daily experience with self-management, coping mechanisms, symptom recognition, and decision-making processes. The research questions drew from the perceptions of the individual with CHF and the meaning of the experience as it was lived. I aimed to explore what heart failure patients found the most concerning and difficult to manage and the point that they realized help seeking was needed.

Conceptual Framework

Grounded theory methodologies do not use a theoretical framework, as the purpose is to generate theory (Corbin & Strauss, 2014). A grounded theory approach is appropriate when a theory does not exist, or theories that do exist do not adequately explain the phenomenon (Corbin & Strauss, 1990). Following a review of the literature on heart failure self-management, I determined that there was a paucity of literature on the decision-making processes that individuals with heart failure undertake in their daily management of symptoms. Additionally, the execution of self-management and symptom interpretation is not congruent with protocols and educational guidelines used by clinicians (Buck, McAndrew, Dionne-Odom, Wion, & Riegel, 2015). A theory explaining how heart failure patients practice self-management decision-making while residing in the community does not exist.

Understanding this research problem required moving beyond assumptions of how self-management should be conducted; in this study, I aimed to shift the lens from practitioner expectations to the individual who is performing heart failure self-management. A grounded theory methodology allowed for an open and flexible exploration of the phenomenon, free from preconceived ideas associated with the use of a theoretical framework. Data collection and analysis were guided by the philosophical foundation of symbolic interactionism inherent to the grounded theory methods of Corbin and Strauss (2015). The symbolic interactionist believes that meaning is formed through interaction, or meaning is derived from how the person interacts with a phenomenon (Chamberlain-Salaun, Mills, & Usher, 2013). The phenomenon of interest was heart failure self-management decision-making, and the aim was to explore how individuals made sense of their symptoms and the actions that followed. A grounded theory approach allowed for the exploration of possible meanings and the development of a new theory.

Corbin and Strauss's evolved grounded theory methodology is underpinned by the philosophical assumptions of symbolic interactionism (Chamberlain-Salaun et al., 2013). This study began with the research problem to reveal multiple meanings that emerged from the data, for which a theory was created. Actions cannot be separated from thought or emotions, and meaning is the expression of how an experience is perceived through interaction (Chamberlain-Salaun et al., 2013). Additionally, phenomenon is not conceptualized as static; the conditions under which the experience occurs changes how the phenomenon is perceived and assigned meaning (Corbin & Strauss, 1990). Variability and processes involved in shaping a person's reality aligned with the research problem and the aims of this study, making grounded theory a suitable methodology to guide data collection and analysis.

Nature of the Study

A qualitative grounded theory approach was used to address the research questions and study the decision-making processes involved in the self-management of CHF. Yin (2015) distinguished qualitative approaches by studying perspectives and meaning attributed by participants; this is achieved by real-world inquiries that acknowledge the multiplicity of insights and sources that culminate to explain social behavior. The research topic was not well defined; therefore, I began this qualitative study began with the topic of self-management decision-making, and the data informed theoretical concepts and relational statements (Reynolds, 2016). The interplay of narrative data and the relationships between concepts formed a theory to explain how meaning was made of congestive heart failure symptoms and the responses in relation to self-management. The processes of heart failure self-management were explored through an examination of the individual's experience with an exacerbation, specifically, the decisions made when a change in symptoms occurred. Data were collected through face-to-face interviews with community-dwelling participants who had experienced an exacerbation while practicing self-management. Grounded theory methods are used to study complex phenomenon and processes, and inductive and deductive methods of analysis are used to establish a substantive theory (Corbin & Strauss, 2015). I used the research questions to reveal the processes of decision-making: how the individual perceived his or her role in self-management, symptom interpretation, and factors that activated help seeking. Grounded theory moves beyond descriptions to ascertain themes and patterns (Charmaz, 2014). The properties of core categories were integrated into a structured schematic that provides explanation and relational interactions (Corbin & Strauss, 2015). The generation of theory of self-management from the patient's perspective will delineate the gap between what is happening and what should be happening in terms of self-management. Theory is needed to guide future initiatives that will improve outcomes and sustainability of self-management initiatives.

Definitions

Central Phenomenon

The central phenomenon was self-management decision-making. Self-management decision-making is a process that is preceded by symptom recognition and is the perceived meaning of the symptom change that leads to specific actions.

General Definitions

Congestive heart failure (CHF): CHF is the clinical manifestation resulting in the heart's inability to pump blood effectively (Cardiac Care Network, 2014; Heart and Stroke Foundation, 2015). Heart failure subgroups specify which area of the heart or physiological underlying cause. I did not isolate subgroups of heart failure.

Congestive heart failure self-management: This included the steps of monitoring for edema, weight gain, shortness of breath, and fatigue; taking prescribed medications; interpreting signs and symptoms; and altering behaviors to alleviate symptoms (Harkness et al., 2014; Riegel et al., 2012).

Decision making: This encompassed the weighing of information that results from symptom interpretation.

Heart failure exacerbation: Is signified by a change in symptoms that may include but are not exclusive to increased edema, increased shortness of breath, weight gain, increased fatigue, and bloating (Heart and Stroke Foundation, 2015).

Help seeking: The specific that involves reaching out to a health care professional to aid in symptom relief; this may range from advice to physical medical intervention.

Self-management: The individual's engagement in managing disease signs and symptoms, adopting risk-reducing lifestyle behaviors, and maintaining contact with health professionals (RNAO, 2010; Schulman-Green et al., 2012).

Assumptions

Assumptions prior to commencing field work were that individuals with a diagnosis of heart failure want to be involved in their own care and the promotion of a healthy state. A methodological assumption was that a qualitative inquiry would illicit the thought processes involved in symptom interpretation that is not captured through observation and empirical instruments. It was assumed that participants would provide truthful responses. The assumptions were essential within the context of implications to support CHF patients that willfully participate in self-management.

Scope and Delimitations

The scope of this study was confined to participant recollections from a recent exacerbation and how the participant managed a change in symptoms; participants were not studied during an exacerbation. Participants were residing in the community and presumed to be in a stable state. The community environment was selected as this is where self-management is performed. All participants had received heart failure self-management education prior to the exacerbation. Individuals with cognitive impairment who rely on formal and informal caregivers to manage CHF were excluded from this study. The participants were interviewed in their home environment, focusing on autonomous decision making in the community within the Province of Ontario, Canada. The results inform self-management practices and strategies within heart failure populations. The findings from this study will require testing in other populations to determine if self-management decision making is transferable to other chronic disease populations.

Limitations

A limitation of this study was that participants recollected their experience from an event that happened in the recent past. Due to the nature of the research question, the participants were reassured that their interpretation and decisions are neither right nor wrong. A nonjudgmental relationship was established during the interview to foster open communication and explore self-management through the eyes of the participant. The participants had no previous care relationship with me.

Significance of the Study

CHF is a chronic disease that requires active participation by the patient to control symptoms. Therefore, understanding why some patients are not able respond appropriately when there is a change in symptoms will guide future interventions (Harkness et al., 2014). In this study, I aimed to address the theoretical and literature gaps pertaining to how and what individuals with CHF do to self-manage. Specifically, I focused on the decisions and actions involved with early symptom changes encountered in daily chronic disease management. Strategies to overcome barriers will result in positive and successful management of symptom fluctuations, thereby decreasing severity of exacerbation and empowering the patient. Translation of findings into practice and testing the theory are recommended at the conclusion of the study. This would be facilitated by continued collaborative involvement in the community program at both a local level and at the provincial level. Dissemination of findings through oral or poster presentation, as well as written articles, will encourage robust discussion and foster future collaborative efforts to enhance health workers' understanding of chronic disease management and improve patient care.

Significance to Practice

The role of the scholar-practitioner is to apply knowledge that has been gained from the study. This will be completed through the dissemination of findings with systems thinking recommendations (Callaghan et al., 2012). Individualized plans of care can be realized when the health care provider appreciates the impact of disease symptoms on daily living and the patient's ability to care for him or herself. Insights gained from this study will inform the health care profession about gaps in current clinical plans of care and guidelines, thus promoting positive social change in the form of practice recommendations.

Significance to Theory

The implications of this study are relevant for theory development and refinement, specifically assumptions regarding knowledge acquisition, behavior change, and the symptom experience. The decision-making processes that encompass self-management will be described and illustrated within the context of daily symptom management for the heart failure population living in the community. Recommendations have been put forth based on the theory that was generated, and the logical next step is to test the theory. Although beyond the scope of this study, testing the theory would serve two purposes: translation of findings to practice and expanding the body of knowledge.

Collaboration with providers of care and civic engagement are future endeavors that will contribute to ongoing social change implications resulting from this study. The refinement of current patient education methods, the development of accurate measurement and evaluation of skills acquisition, and system recommendations to support self-management will require involvement across the spectrum of care.

Significance to Social Change

Positive social change encompasses the study of real world problems, and the aim is to generate process and product solutions (Callahan et al., 2012). In this study, I explored the phenomenon self-management for the CHF population, specifically decision-making processes. Implications include an informed view of chronic disease management from the patient's perspective, particularly perceived control over the plan of care and goals to optimize health. Social change includes broad categories of knowledge, skills, and attitudes that are evidenced through scholarship, advocacy, collaboration, and systems thinking (Callahan et al., 2012). This study provided a holistic understanding and a voice for the CHF individual, thereby advocating how to improve supports in the community based on identified needs.

Summary and Transition

Self-management is an integral component of chronic disease management that places the responsibility of monitoring and interpreting symptom changes on the individual living with the disease. Education strategies aimed at promoting self-management have been primarily focused on knowledge acquisition. Subsequently, testing the individual's ability to self-manage has been focused on the recall of information rather than on behavioral outcomes related to self-management activities. Despite education, individuals with heart failure in the community exhibit difficulties interpreting and acting upon symptom changes in a timely manner; the delay results in requiring acute medical intervention (Harkness et al., 2014; Stamp, 2011). The heart failure self-care (HFSC) theory does not include the processes involved in self-management decision-making when symptoms change. A qualitative grounded theory approach was required to gain insight into the patient's perception of what the change in symptoms means. Chapter 2 includes a review of literature on current self-management educational strategies, common symptoms of heart failure, symptom recognition and interpretation, and the philosophical underpinnings of grounded theory methodology.

Chapter 2: Literature Review

Introduction

Heart failure is a chronic disease associated with high use of health care resources. In particular, CHF is a leading primary cause of hospitalizations with readmission rates between 23-50% for patients over the age of 75 years (Cardiac Care Network, 2014). Between acute episodes, the heart failure patient residing in the community is expected to perform self-care monitoring and management with an aim to identify and act on early warning signs of a heart failure exacerbation (Howlett et al., 2016; Riegel et al., 2012). Self-management is not a new concept, and self-management in heart failure populations has been promoted for more than 25 years (Friedman, 1997). Despite targeted efforts to foster heart failure knowledge and self-care abilities, hospitalizations and readmission rates for heart failure have not been reduced (Cardiac Care Network, 2014). Additionally, prevalence of heart failure in the Canadian population is projected to increase with the aging population (Cardiac Care Network, 2014). Some patients fail to initiate help seeking behaviors when symptoms change, resulting in a treatment delay of 3 to 7 days (Harkness et al., 2014; Sethares et al., 2014; Stamp, 2011). Delays in seeking treatment are associated with increased severity of exacerbation and higher risk for readmission to hospital (Cardiac Care Network, 2014; Sethares et al., 2014). A better understanding of the decision making processes of heart failure self-management is needed. The purpose of this qualitative grounded theory study was to explore the processes of self-management decision making from the perspective of the patient. Understanding how patients self-manage when symptoms change will inform future education and supportive community initiatives.

Despite the reported high prevalence of heart failure exacerbations requiring admission and readmission to hospital, the role of self-management decision making by the patient is varied in the literature. In studies on the determinants of self-care behaviors, scholars have revealed mixed results, with quality of life, experience with monitoring, severity of disease, symptom presentation, and nature of competing goals being found to either enhance or inhibit self-care execution (Barello et al., 2015; Cameron, Worrall-Carter, Page, & Stewart, 2010; Peters-Klimm et al., 2012; Riegel, Dickson, & Topaz, 2013; Wingham et al., 2013; Zhang et al., 2015). Strategies that involve education have been inconsistent regarding effectiveness; therefore, there is no consensus on what is used to measure outcomes. Furthermore, education strategies implemented in hospital settings, clinics, and group settings have not translation into successful self-management behaviors in the community (Blauer Frei, Schnepp, & Spirig, 2015; Cockayne, Pattenden, Worthy, Richardson, & Lewin, 2014; Dickson et al., 2014).

There are two components of self-management that remain problematic for the heart failure patient: symptom identification and symptom interpretation (Herr et al., 2014; Jones, McDermott, Nowels, Matlock, & Bekelman, 2012; Moser et al., 2011). The symptoms of heart failure are dynamic and complex. The subjective nature of shortness of breath and fatigue, as well as plausibility of alternative causes, influence interpretation of what is happening and subsequent actions (Ahmadi Mansson, Lindblad, & Hildingh, 2014; Kessing, Denollet, Widdershoven, & Kupper, 2016; Payne, Wiffen, & Martin, 2012; Schjoedt, Sommer, & Bjerrum, 2016). There is an absence of literature on decision making that involves help seeking in nonemergent cases. Understanding how the patient navigates early symptom changes will inform future strategies to foster self-management and reduce exacerbation severity requiring hospitalization.

This chapter will include the literature search strategy, grounded theory as a conceptual framework for the study, an overview of how self-management has been conceptualized, the expectations of self-management, and a review of education strategies to promote self-management. Chapter 2 also includes an overview of the symptoms of heart failure, perception of symptoms, and interpretation of symptoms. The final section is on help seeking and decision making involved in living with heart failure in relation to theoretical voids. I establish the need for a qualitative grounded theory study and transition to the methodology chapter.

Literature Search Strategy

Information for the literature review was obtained through electronic searches of the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and MEDLINE simultaneous search, ProQuest, and Google Scholar. The databases were searched every 3 months from March of 2015 to present; relevant citations were added with subsequent searches. The following key words were used in the searches: *heart failure, congestive heart failure, self-management, self-care, decision making, consulting, response, symptom changes*, and *exacerbation*. The terms were searched in various combinations to increase citation numbers and gain a sense of how the concepts have been studied in relation to each other. A previous search in 2010 on self-management in heart failure was reviewed and supplements the information for the current study.

The search was restricted to the dates of January 2011 to the present. Citations were reviewed for availability of full text in English after a cursory appraisal of abstracts articles were selected for full review. Articles were excluded if the primary phenomenon of study was telemonitoring, mobile monitoring, care givers, or cardiac diseases other than heart failure. In addition, article reference lists were manually inspected for additional relevant works. Websites such as the Heart and Stroke Foundation and Cardiac Care Network were used for current heart failure initiatives in the community. A collection of qualitative and quantitative studies were reviewed to provide a broad overview of how the phenomenon has been studied. Theoretical papers were reviewed during the analysis to avoid restricting theoretical possibilities derived from the data. Grounded theory was used to provide a framework for analysis and to establish the philosophical approach that guided interview questions.

Conceptual Framework

Grounded Theory

I employed Corbin and Strauss's grounded theory methodology. Grounded theory has evolved into several different approaches. The original or traditional approach was developed by Glaser and Strauss in the 1960s; Glaser continues to be a proponent of this approach (Glaser, 2009). From the original method, two distinctive branches have emerged, with Strauss and Corbin holding a pragmatic and interactionist approach to analysis, and Charmaz's approach aligning with constructionist views (Heath & Cowley, 2004). Grounded theory methodology is used widely in academia, and the selection of approach is based on personal preference and congruency with worldviews on how meaning is made and derived from the data (Boychuk Duchscher, & Morgan, 2004; Charmaz, 2014, p. 8; Corbin & Strauss, 2015, p. 22). The following is a brief history of grounded theory design.

History

The collaboration between Glaser and Strauss led to a method of inquiry using an objectivist approach to qualitative research, thereby allowing for theoretical origins to be grounded in the data (Boychuk Duchscher & Morgan, 2004). In traditional or Glaserian approach to grounded theory, analysis of the data begins by coding, where coding ascribes meaning to units of data while refraining or limiting interpretation (Glaser, 2009). The data undergo a process of constant comparison, comparing coded units of concepts and categories to each other. The traditional approach posits that the researcher should be free from preconceived ideas to remain sensitive to what is revealed in the data (Glaser, 1978). Glaser and Strauss are both proponents of the theory being grounded in the data; but, their approaches differ in the application of literature and preconceived knowledge during the analysis. Prior knowledge is acknowledged in both approaches; however with traditional grounded theory, separation of prior knowledge is encouraged to ensure that it does not taint the analysis (Scott, 2009). Additionally, Glaser used the literature after theory emergence as a point of comparison, whereas Strauss supported using the literature to stimulate analysis and an individual’s previous knowledge in part to direct the analysis (Heath & Cowley, 2004). A methodological point where Glaser and

Strauss diverged is how theory emerged from analysis; Strauss was a proponent of verification which Glaser viewed as forcing data (Charmaz, 2014). The approach by Strauss has been extended through collaboration with Corbin and is now referred to as Corbin and Strauss grounded theory approach.

Application

The guiding framework for data collection and analysis was the grounded theory approach of Corbin and Strauss (2015). The basic procedures include constant comparison, theoretical sampling, and saturation (Corbin & Strauss, 2015). The phenomenon, or research problems, are described and explained through an analysis of how the individual makes meaning of his or her situation (Corbin & Strauss, 2015, p. 22). A symbolic interactionism perspective is used to frame how the data are analyzed, how the individual makes meaning, as well as how the researcher reflects on the data to form categories and explore relationships during analysis (Corbin & Strauss, 2015; Strauss, 1987). Process and structure underlay the strength of grounded theory methodology; analysis is rooted in the narrative or unfolding of the event thereby gaining perspective of what was occurring rather than mere descriptions (Morse, 2001).

Several assumptions that are tenants of Corbin and Strauss's approach were used in the interpretation of data. These assumptions include

1. "Interior worlds are created and recreated through interaction" (Corbin & Strauss, 2014, p. 23).

2. Meanings are not static, they change through the process of interactions, taking into account the past, present, and the future (Corbin & Strauss, 2015).
3. Reflections may affect the interactional course, and actions are not solely rational, emotion is not separate from action (Corbin & Strauss, 2014).
4. Knowledge, in the form of interpretative analysis, is created through interaction with the data (Corbin & Strauss, 2015).

The assumptions inherent in the grounded theory methodology fit well with the research problem. Corbin and Strauss's method provided a framework to guide this study, including the use of researcher reflexivity and recommendations for when and how to introduce literature into the analysis (Cutcliffe, 2000). This method adds rigor, as the steps of analysis are clearly defined, documented, and supported by philosophical assumptions of interactionism that align with the research problem (Cooney, 2011).

Meaning was derived from the data and subjected to an iterative process of conceptual description and derivation while incorporating the literature and researcher reflections (Corbin & Strauss, 2015). The research problem was identified and described through a review of the literature. The literature provided insight into a new direction or approach to study the phenomenon, which was the perspective of the individual with heart failure (Corbin & Strauss, 2015). The following is a review of heart failure self-management interventions, educational strategies, and heart failure symptom experiences.

Literature Review

Self-Management

Self-management is conceptualized in varied terms across health care disciplines. The Registered Nurses Association of Ontario (RNAO, 2010) described those who self-manage as being informed and engaged in managing disease signs and symptoms, adopting risk-reducing lifestyle behaviors and maintaining contact with health professionals. Self-management is patient-driven, and goals are collaboratively established, a plan is developed, barriers assessed, and progress is evaluated (RNAO, 2010). Schulman-Green et al. (2012) described self-management as the active engagement of an individual in the daily care of a chronic disease. Self-management in heart failure includes the tasks of daily monitoring for symptom changes: edema, shortness of breath, fatigue, weight gain, interpretation of symptoms, and implementation of strategies to alleviate symptoms (Harkness et al., 2014). The goal of self-management in chronic illness is not a cure, but rather an early detection and treatment of symptom changes or disease manifestation and should be considered within the broader context of the health care system (Udlis, 2011).

Goals and Expectations of Successful Self-Management

A heart failure exacerbation is determined by the clinical findings of shortness of breath, orthopnea, edema, and respiratory crackles on auscultation with confirmation of lung congestion on chest x-ray (McKelvie et al., 2013). The goal of patient involvement in self-management is early detection of symptom changes, daily monitoring, and the use of decision aids that illustrate signs and symptoms associated with deterioration are provided to the patient with the expectation of adherence (Howlett et al., 2016). Goals and expectations are measured in behaviors by using the Self-Care Heart Failure Index Tool (SCHFI) or the European Heart Failure Self-care Behavior Scale, in addition to monitoring symptoms the tools assess for adherence to medication, diet, and fluid intake recommendations (Jaarsma, Arestedt, Martensson, Dracup, & Stromberg, 2009; Riegel, Lee, Dickson, & Carlson, 2009). However, the tools to measure self-management are time specific and do not account for the course of self-management with disease progression. As noted by Moser and Watkins (2008), self-management is a process that changes over the life course of the disease, with patients reporting increased difficulty and time commitment required to control symptoms towards end stage trajectories.

Several factors influence the ability to implement self-care and have been explored through various approaches. Determinants of self-care behavior were investigated using the SCHFI in a cross-sectional convenience sample (*N*=318) for potential modifiable and nonmodifiable risk factors (Peters-Klimm et al., 2012). Factors that influence self-care adherence positively included self-efficacy, age, and contact with cardiologist, while a higher perceived quality of life was associated with decreased self-care adherence (Peters-Klimm et al., 2012). The SCHFI was used to compare experience levels with self-care maintenance and management skills in a population of patients with chronic heart failure (*N*=143), with experience being defined as length of time with diagnosis (Cameron et al., 2010). Experienced CHF individuals were more likely to monitor symptoms; however, the findings in this study can be alternatively explained by relatively higher prevalence of diuretic prescription in the experienced group (64%

compared to 36% in new group), suggesting that fluid balance might have been more labile in the experienced group (Cameron et al., 2010). Although the experienced group were more likely to monitor symptoms, less than one-third of the group were able to adequately interpret the symptoms and were not able to demonstrate effective alleviating steps to resolve symptoms (Cameron et al., 2010). In another study, experience with managing symptom fluctuations was shown to follow four phases: initially, the patient has a poor understanding of what is occurring within his or her body, particularly reconciling with how he or she felt before diagnosis and becoming engaged in his or her own care (Barello et al., 2015). Adherence to symptom monitoring may be associated with severity of disease and perception of whether monitoring is needed when symptoms rarely fluctuate. Similarly, decreased self-care adherence was associated with higher quality of life scores, which could reflect that the patient was content with his or her state of health as it related to his or her life, thereby perceiving that self-management was not needed (Peters-Klimm et al., 2012).

In order to adapt to the demands of a disease such as CHF, coping mechanisms are needed. An exploratory study was conducted using open and closed ended questionnaires, Sacco, Park, Suresh, and Bliss (2014) sought to determine what coping mechanisms are used when living with CHF. Medication adherence and interactions with health care providers were seen as important in the management of disease; however, social support was a role in adjusting to living with the disease (Sacco et al.). What is unclear is whether patients were able to integrate interactions and recommendations from health providers with daily living. The population used by Sacco et al. were NYHA classification Level III and IV, representing severe disease which could account for increased reliance and importance placed on social and external supports to self-manage. The expectation remains that the patient adopts coping mechanisms and assimilates the knowledge of their disease into proactive steps whereby the responsibility of keeping on top of symptoms lies with the patient (Barello et al., 2015).

Self-management is conducted in the home environment; therefore, it is subjected to external influences and competing needs. Barriers to becoming a successful self-manager of CHF were identified as including competing personal goals (Riegel et al., 2013). In this secondary analysis of qualitative data, Riegel et al. (2013) found that patients weighed information and compared perceived outcomes or consequences most commonly with personal, social, and employment goals. The studies that comprised the secondary analysis were mixed methods methodologies where the primary aim was to explore symptom recognition, sociocultural aspects, and development of self-care expertise. One limitation associated with the study by Riegel et al. was that the aim of the secondary analysis and the aims of the primary studies do not align; therefore, the data may not represent the intended context. However, Zhang et al. (2015) conducted a quantitative study to examine the relationship between non-health-related goals and adherence to self-management. Goal compatibility was identified as most prevalent in CHF patients who had been living with the disease longer (Zhang et al., 2015). Self-management recommendations involving dietary and fluid restrictions were viewed as the most incompatible component with personal goals, with physical functionality and independence identified as high-level goals (Zhang et al., 2015). Although goal incompatibility was used to explain autonomous nonadherence by Zhang et al. (2015), compliance was thematically related to positive attitude, hope, belief that treatment was effective, and ease of adherence (Wingham et al., 2013). As CHF progresses, self-care practices require increased commitment and other aspects of life become increasingly affected by the disease.

The effort and commitment of CHF self-care includes vigilance to daily monitoring that has been likened to work (Moser and Watkins, 2008). Wortz et al. (2012) noted that goals and expectations placed on the patient can influence coping and emotional health. In another study, patients relayed that self-management is difficult, as it requires reflection and recognizing one's vulnerabilities (Wingham et al., 2013). Additionally, patients noted that self-management became problematic when symptoms were unpredictable and varied, requiring a rethinking of strategies over the course of time and disease trajectory (Wingham et al., 2013). Selective adherence was also demonstrated in an examination of predictors of adherence, with only 9.1% of patients adhering to all measures (Marti et al., 2013). The goal of education is to promote CHF management in the home environment with an aim to reduce severity of exacerbations through early detection of symptom changes. An assumption underlying self-care evaluation instruments is that the tasks of monitoring and management can be learned through education strategies (Riegel et al., 2008; Riegel et al., 2016).

Education, Learning, and Health Literacy: Programs

To provide perspective on self-management I elected to include literature on the educational methods used to prepare the heart failure patient to self-manage. The tasks that are involved in self-management include, but are not exclusive to: medication adherence, dietary adherence, regular exercise, daily weights, and monitoring signs and symptoms (Howlett et al., 2016; Jonkman et al., 2016). Self-management education can vary in content: where the content is delivered, the method of instructional delivery, and length of instructional intervention. Comparison of educational programs is additionally complicated by the different measures used as the primary outcome. The benefits of self-management education have been studied using a variety of tools, each measuring different outcomes: health literacy, self-efficacy, self-care behaviors, quality of life, and readmission to hospital (Bläuer et al., 2015; Chen et al., 2014; Cockayne et al., 2014; Dickson et al., 2014; Hwang et al., 2014). Compounding the debate on how best to promote self-care abilities is that knowledge does not translate into behaviors (Chen et al., 2014). In a cross-sectional, correlational study of heart failure patients (N=63), health literacy influenced knowledge, however, self-care adherence to monitoring tasks was not influenced by knowledge or health literacy. A larger study (N=612) examining the influences of knowledge emphasize that knowledge is an important component of self-care education to identify and interpret worsening symptoms (Hwang et al., 2013). I was unable to ascertain which method is most efficacious, as the aim and the interventions were not consistent across studies.

Setting

Self-management educational interventions have been delivered in the hospital during an acute episode, as an outpatient in a clinic, office setting, or community center, and in the patient's home. The following is a review of the different settings where self-management interventions have been trialed. Using action research a heart failure educational program was delivered during hospital admission, whereby patients (*N*=15) were afforded the opportunity to monitor their weight, keep a symptom diary, and adjust medications as needed (Blauer et al., 2015). Although patients found the autonomous nature of engaging in self-management during hospitalization positive, once home confidence decreased in what was described as feelings of shock and uncertainty (Blauer et al., 2015). The supportive nature of the hospital, where a health care professional was immediately accessible, was not representative of the home environment. The authors do not state whether the patient's experienced using problem-solving skills for fluctuations in symptoms during their hospital stay. An educational intervention delivered in a clinic setting similarly did not influence the primary outcome of hospital readmission (Cockayne et al., 2014). The intervention was based on cognitive behavioral principles, with participants (*N*=95) receiving one-on-one support and coaching to facilitate problem-solving. The participants were able to select which components of the intervention they wanted to complete and were evaluated for readmission rates, anxiety, and depression at 3, 6, and 12 months. Participants in the intervention group were found to have higher depression scores than the control group, and there was no difference in frequency of the patient contacting the physician when edema worsened (Cockayne et al., 2014). In another study education was delivered in a community center to a group of heart failure patients (*N*=38) over a four week period (Dickson et al., 2014). Role-playing and practice exercises in combination with instruction increased knowledge, self-care maintenance, and self-care management but did not influence the quality of life scores (Dickson et al., 2014). Outcome measures were conducted up to 3 months, however skills outcome measures over a longer period of time and hospital readmission rates should be considered to add strength to conclusions. The interventional studies by Dickson et al. (2014), Cockayne et al. (2014), and Blauer et al. (2015) focused on problem-solving and equipping the cardiac patient with self-management skills, however with different primary outcomes it is difficult to interpret if problem-solving required during an exacerbation was developed or improved.

The effectiveness of educational interventions have also been studied qualitatively, exploring what patients found beneficial and promoted engagement. Limitations associated with education at the time of hospitalization included patient readiness and ability to comprehend information during an acute illness (Piamjariyakul, Smith, Werkowitch, & Elyachar, 2012). Self-management was envisioned as a life-style change that can only be realized once the patient is discharged into the home environment and resumes normal daily living (Piamjariyakul et al., 2012). Exacerbations that lead to hospitalization have been associated with a period of adjustment where the patient needs to understand and make sense about what has happened (Barello et al., 2015). Peer sharing was found beneficial in a qualitative analysis of peer support programs, listening to other’s experience with an exacerbation helped create meaning and acceptance (Lockhart, Foreman, Mase, & Heisler, 2014). Patients desire clear information, in terms that they understand, particularly what was happening within their body and the symptoms felt during an exacerbation (Barello et al., 2015).

Trust has been identified as important in the relationship between physician and patient, trust was also apparent in the predominance of patient's desire to relinquish responsibility to the physician (Barello et al., 2015). The theme of relying on others for control was found to extend to informal caregivers and family, where patient's expected others to identify when symptoms were progressing and becoming serious (Buck et al., 2015). There is a disconnect between identification of when symptoms are progressing in relation to fluid retention and weight gain, specifically a lack of appreciation for the risks of not acting (Spaling et al., 2015). Reliance on others may be an indicator that there are difficulties in self-assessment of symptoms and the multiplicity of implementing all self-management tasks (Buck et al., 2014). Several studies have echoed that heart failure patients show a tendency to be selective in their self-management tasks, suggesting that patients may be overwhelmed with the responsibility of self-management (Buck et al., 2014; Barello et al., 2015; Spaling et al, 2015). Additionally, the availability of medical resources and psychological supports were perceived as important and contributing to a feeling of well-being (Sacco et al., 2014). The decision to manage ones health is influenced by recognition that the chronic disease cannot be cured; becoming engaged in the process of self-management requires motivation, knowledge, and confidence (Barello et al., 2015).

Readiness to Learn: Motivation and Engagement

The fundamental concern with self-management is that the patient must be engaged and willing to perform activities that promote and sustain health (Herrera, Mondada, & Defey, 2016). Common reasons for nonadherence include adverse effects of the treatment, perception that the disease is not that severe, stigma, competing life goals, and feeling too ill to participate (Herrera et al., 2016; Zhang et al., 2015). Following instructions was defined as complying with self-management, however uncertainty occurs when the patient feels symptoms that don't align with the instructions (Wingham et al., 2016). Creber et al. (2016) hypothesized that a motivational interviewing intervention would improve self-care maintenance. Results of this random control trial included no statistically significant differences between the intervention and control groups, however after adjusting for sleep apnea, poor social support, and poor perceived general health self-maintenance scores improved (Creber et al., 2016). It was noted that when left ventricular ejection fraction (LVEF) increased self-care maintenance scores decreased, underscoring the importance of understanding motivational factors (Creber et al., 2016). Motivation and engagement cannot be conceptualized as an absolute entity, as evidenced by the selective nature of engagement (Buck et al., 2015; Tierney et al., 2011).

Just as engagement is not a finite concept, learning should also be considered as a process over the trajectory of the disease as symptoms and contextual factors change over time (Bidwell et al., 2015; Bratzke et al., 2015; Tierney et al., 2011). Vellone et al., (2015) explored if confidence influenced the relationship between cognition and self-care maintenance and management. Findings from the Vellone study indicated that the effect of cognition, measured by Mini Mental State Exam (MMSE), on self-care management was mediated by confidence. Selan, Siennicki-Lantz, Berglund, and Fagerström (2016) explored self-awareness in the context of translating information given by health care professionals into how the older patient understands their disease. This study is important because it demonstrates a contextual or environmental factor can influence symptom perception (Selan et al., 2016).

Symptom Perception

The goal of this study is to explore help seeking activation, and symptom perception is the recognition that a change in symptoms has occurred. Heart failure self-management, as a process, includes monitoring symptoms, the following is a review of the literature regarding symptom interpretation. The study of heart failure symptom management, self-management, and the detection of symptom changes has been studied for more than twenty years. Patients living with heart failure continue to demonstrate delays in seeking medical attention when symptoms change, in particular a three-day delayed response to symptom changes (Friedman, 1997) has not improved despite decades of interventions targeting early symptom recognition (Cardiac Care Network, 2014; Lee et al., 2015a; Schjoedt, Sommer, & Bjerrum, 2016).

Somatic awareness is influenced by a variety of contextual and situational variables, with an acute onset reducing recognition time and gradual onset delaying symptom recognition (Jurgens, 2006). The severity of the presenting symptom also influences perception and subsequent actions. It is noted that when symptoms increase gradually over time, patients implement compensatory actions to alleviate mild symptoms, most commonly by resting more or reducing activities (Jurgens et al., 2009). Similarly, in an exploration of symptom scenarios (*N*=37), patients attempted to alleviate symptoms by resting and raising the head of the bed (Reeder et al., 2015). However, symptom variability was found to increase the risk of not recognizing the need to act on a change in symptoms (Moser et al., 2011). Heart failure symptoms rarely present as one symptom, but rather as clusters of symptoms that traverse physical, cognitive, and emotional domains (Herr et al., 2014; Moser et al., 2014; Yu, Chan, Leung, Hui, & Sit, 2016). In a systematic review of the literature, mixed findings were revealed regarding the relationship between the common symptoms of heart failure and secondary symptoms of depression, anxiety, and sleep disturbances (Herr et al., 2014). However, Yu et al. (2016) identified significant correlations between the majority of heart failure symptoms that included depression and anxiety as primary symptoms; three clusters were classified as distress, decondition, and discomfort symptoms. The volume of symptoms, variation in symptom characteristics, and interplay between symptoms makes it difficult to isolate if the symptoms are the result of worsening heart failure, making interpretation problematic for the patient (Falk, Patel, Swedberg, & Ekman, 2009; Herr et al., 2014; Jones et al., 2012).

Patients must, therefore, be vigilant in the monitoring of symptoms, noting small changes over time and refraining from normalizing fluctuating symptoms. The symptoms of heart failure are complex. Difficulty identifying symptoms of heart failure are not isolated to the patient, as identified in a retrospective analysis of 50,000 electronic health records from primary care physician groups, where patients were identified as having more than one Framingham criteria on average 3.4 years preceding a diagnosis (Vijayakrishnan et al., 2014). In comparison, Van Riet et al. (2014) identified a 12-month delay to diagnosis of heart failure in a cross-sectional screening study of 72,000 subjects, primarily focusing on the presentation of exertional shortness of breath. The overlap of symptomatology with alternative diagnosis is thought to complicate the clinical picture and subsequent diagnosis (Reeder et al., 2015; Van Riet et al., 2014). The importance of diligent monitoring practices was shown in a cross-sectional study comparing adherent (*n*=47), nonadherent (*n*=174), and partial adherence (*n*=90) monitoring practices on self-management adequacy. Adherent and partial adherent groups were able to recognize symptoms which increased self-management behaviors of restricting fluid intake and taking an extra diuretic (Lee et al., 2014). Despite difficulties differentiating symptoms, consistent monitoring practices influences recognition of changes, and recognition is required to implement self-management interventions (Moser et al., 2011; Reeder et al., 2015).

Symptoms of Heart Failure

Heart failure is a clinical syndrome, the three most prevalent symptoms of heart failure are shortness of breath, fatigue, and leg edema (Cardiac Care Network, 2014). Fatigue is one symptom that is confounding for the heart failure patient, in particular patients attribute fatigue to normal aging process or as the result of activities (Reeder et al., 2015; Riegel et al., 2010). Van Riet et al. (2014) found that exertional shortness of breath was the most difficult symptom for patients to interpret, specifically in populations with congestive heart failure and an underlying respiratory disease. Fatigue and shortness of breath are subjective symptoms that span a spectrum from mild to severe, requiring a deeper analysis of not just presence of symptom but the severity of presentation (Jurgens, Lee, Reitano, & Riegel, 2013). The severity of the presenting symptom is key to interpretation and assigning meaning, as it is recognized that shortness of breath and fatigue are often present during stable periods (Cardiac Care Network, 2014). While there are a number of descriptive studies examining heart failure symptoms in reference to self-care (Kessing et al., 2015; MacInnes, 2013; Schjoedt et al., 2016), there are few in-depth descriptions of how the heart failure patient determines if an already present symptom of fatigue or shortness of breath warrants concern.

Fatigue has been identified as an insidious symptom common in moderate to late stages of heart failure, for which there are limited evidentiary conclusions on how to effectively treat and manage (Payne et al., 2012). In an interpretative qualitative study, heart failure patients (*n*=26) were interviewed, fatigue was described as being tired, physically tired, low energy, and feeling unrested (Jones et al., 2012). Whereas Kessing et al. (2016) delineated fatigue into three categories, general fatigue, exertional fatigue, and mental fatigue. In a systematic review of fatigue experiences, fatigue was additionally described as drowsiness, lacking strength, listlessness, and ranging in quality and intensity (Schjoedt et al., 2016). Furthermore, the symptom of fatigue is believed to influence the social aspects of quality of life (Jones et al., 2012; Kessing et al., 2016; Schjoedt et al., 2016). Although patients reported fatigue as a daily symptom (88.7%) in a longitudinal study, variability in fatigue levels was not shown to influence hospitalization rates (Moser et al., 2011). There are conflicted reports on the relationship between fatigue and other symptoms and inconsistency in results has been attributed to the use of different tools, making it difficult to draw conclusions (Herr et al., 2014).

Shortness of breath, or dyspnea, is a prevalent symptom in heart failure. Paroxysmal nocturnal dyspnea, orthopnea, and dyspnea on normal exertion are part of Framingham's Diagnostic Criteria for heart failure diagnosis (Vijayakrishnan et al., 2014). A qualitative study on breathlessness in everyday life was conducted, diaries were used to record occurrences of breathlessness, the effect on sleep, work, and leisure, and if advise was sought from a health care professional (Ahmadi et al., 2014). Participants described breathlessness as feeling weak, run-down, fatigued, and anxious (Ahmadi et al., 2014). The study by Ahmadi et al. (2014) was selected as a representation of the literature on the patient's perception of symptoms and how the patient's description may vary from diagnostic criteria wording used by clinicians. In a post hoc study of assessment tools used to ascertain levels of dyspnea, Pang et al. (2014) concluded that improvement in dyspnea was least likely to be reported after acute medical treatment for those with less severe dyspnea at baseline. The results suggest that patients who seek early treatment for less severe dyspnea do not experience a significant improvement, thereby not realizing a benefit from seeking early intervention. The implication is that if the patient does not perceive a noticeable benefit to early treatment they may be more likely to wait out the symptom next time. The degree that symptoms fluctuate may also influence decisions by the patient, as hypothesized by Moser et al. (2011), if symptoms fluctuate widely patients are more likely to become alarmed and take immediate action.

Interpreting Symptoms

Once the patient has recognized that the symptom is attributed to congestive heart failure, the next task is determining what actions are to be taken. In a cross-sectional survey of heart failure patients (*N*=169), engagement in self-care practices, including monitoring symptoms, was influenced by the patient's beliefs that the illness would have serious consequences (*p*=0.03) (MacInnes, 2013). In contrast, the degree to which the symptom interfered with enjoyment of daily life influenced the manner in which the patient (*N*=201) approached the problem, was found in a cross-sectional correlational study on heart failure self-care behaviors (Graven, Grant, & Gordon, 2015). However, Riegel et al. (2010) found that consideration was given to all aspects of routine daily living by younger heart failure patients, symptoms were recognized and assessed to be important if they interfered with work and daily life. This is in contrast to older patients with heart failure in the same study, who did not perceive their health as poor when experiencing symptoms (Riegel et al., 2010). The findings by Riegel et al. (2010) can be alternatively explained by the different level of normal daily activities between the old and young patient, as the older patient's daily activities did not require as much alteration when experiencing symptoms.

Interpreting symptoms have also been shown to be influenced by capabilities and the nature of the symptom. Lee et al. (2015b) found that in the absence of changes in monitoring, worsening self-management behaviors over time were influenced by greater physical symptoms, larger left ventricles, and the presence of ischemic heart failure. In contrast, a secondary analysis from a descriptive study revealed that novice heart failure patients were more likely to have poor self-care maintenance and management skills (Cameron et al., 2010). The study by Lee et al. (2015b) was the only study that distinguished between severities or stage of heart failure, and findings suggest that there is a self-management threshold that is influenced by disease progression. Heart failure is a chronic disease resulting from a variety of etiological causes, what is known is that progression of the disease follows a trajectory for which in end-stage the frequency and severity of exacerbations increase (Cardiac Care Network, 2014). What is not known is how the perception of symptoms evolves over time and course of the disease, and how this influences self-management decisions.

Help Seeking Decisions

A search of the literature was conducted to review how the concept of help seeking when symptoms change, for heart failure populations has been studied. The search included terms help seeking, consulting, response, and decision making in conjunction with symptom changes and heart failure. Xu, Abshire, and Han (2016) conducted a review of the literature which included quantitative studies on decisions made by individuals with a diagnosis of heart failure. Twelve quantitative studies were selected for meeting the study's inclusion criteria; decision making was predominantly referred to in the context of end of life care, resuscitation, surgical interventions, and participation in self-care. The paucity of literature about decision making concerning self-care symptom management and help seeking may reflect that patient participation in chronic disease management for heart failure has evolved in the past ten years. Furthermore, the quantitative studies identified by Xu et al. were cross-sectional, which does not reflect how decision making changes over time or whether the triggers for help seeking are modifiable. The process of heart failure self-care has been examined quantitatively using scales that measure monitoring skills, management behaviors, and self-confidence. Jaarsma et al. (2013) studied self-care behaviors captured with the Self-Care Heart Failure Index (SCHFI), and European Heart Failure Self-Care Behavior Scale (EHFScB), findings include the most prominent heart failure behavior is medication adherence. The EHFScB includes four items that measure the behaviors of help seeking when symptoms change, specifically weight gain, edema, shortness of breath, and fatigue (Lee et al., 2015c). The SCHFI includes one item to measure calling a medical professional for guidance if edema increases or a problem breathing has occurred (Lee et al., 2015c). The limited attention to help seeking actions represented in the SCHFI tool validates that consulting and help-seeking behaviors have not been a primary focus of measurement in heart failure self-care management. Help seeking, or consulting, with a health care professional, is conceptualized as an integral step in symptom control, most specifically as a hospital avoidance strategy to reverse adverse effects associated with symptom fluctuations (Fergenbaum, Bermingham, Krahn, Alter, & Demers, 2015).

There are few studies that examined help seeking decision making when a change in symptoms occurs. Shively et al. (2013) implemented a randomized trial of a patient activation intervention. Repeated measures were taken at upstart, 3, and 6-months. The intervention involved six sessions with a nurse; participants were given the opportunity to problem solve any barriers encountered and ask questions. Participants randomized to the intervention group were shown to have fewer hospitalizations and emergency department contacts, suggesting that facilitated problem-solving and routine access to a health professional improves self-management. A qualitative systematic review of help seeking decisions in heart failure revealed that help seeking decision making has not been a focus of education interventions and patients have a poor understanding of when they should seek help (Clark et al., 2012). Decision making, as it pertains to self-management, differs from the decision making processes for surgical interventions and medical treatment, as the physician's level of involvement is more active in treatment changes (Carroll, Strachan, de Laat, Schwartz, & Arthur, 2013). Treatment decisions involve a thorough discussion of risks, benefits, and options, in conjunction with the physician to promote informed decision making; whereas self-management is a real-time daily activity carried out by the patient in their home environment (Carroll et al., 2013; Graven et al., 2015). The decision to seek help from a physician or nurse was influenced by uncertainty if the symptom was normal or if the symptom was severe enough to warrant contacting a physician (Clark et al., 2012). Heart failure patients also indicated a fear of being instructed to go to the hospital and wanted to show the physician that they were good self-managers (Clark et al., 2012). Contrastingly, Lee et al. (2015c) reported that patients who had anxiety exhibited poor consulting behaviors. Findings support that the patient with heart failure is uncertain of when to seek out advice and are not aware of the risks associated with worsening symptoms (Clark et al., 2012; Lee et al., 2015c). Siabani, Leeder, and Davidson (2013) concluded similar findings in a meta-synthesis of qualitative studies on the barriers and facilitators of self-care. Findings supported that patients had a poor understanding of the implications of symptoms, and even if the symptoms were related to the condition heart failure (Siabani et al., 2013). Furthermore, uncertainty was attributed to incongruent perceptions of what instructions were communicated between the physician and the patient. Communication of instructions was a central theme in a grounded theory study, where participants described the need to explain their symptoms in the medical terms understood by the physician to be taken seriously (Östman, Ung, & Falk, 2015). Similarly, Siabani et al. (2013) found the patient's willingness to interact with health care providers was influenced by a lack of trust. Lack of respect and misunderstanding of role responsibilities were found to influence shared decision making in a grounded theory study involving patients and health service providers (Rise et al., 2013).

The relationship between the patient and health professional is also affected by how the patient perceived the treatment of themselves as a person (Östman et al., 2015). Themes of loss of personness and being subordinate to the physician influenced how the patient approached their interactions with their physician (Östman et al., 2015). Encounters with the medical profession evoked feelings of being objectified as a condition rather than a person, which was demonstrated by a higher importance being placed on physical findings than how the patient felt (Östman et al., 2015). The predilection for prioritizing physical findings above how the patient feels was a focus of a secondary analysis (*n*=291) of symptom-hemodynamic profiles, with 64.2% of patients experiencing mild symptoms and poor hemodynamics (Lee et al., 2015a). Thus, underscoring the relevance of the patient's oral history and interpretation of symptoms. While Hedemalm, Schaufelberger, and Ekman (2008) found that heart failure patients waited for a prebooked appointment to discuss symptoms rather than attempting to be seen sooner. Although the Hedemalm et al. study is older, it has been included due to the limited literature available on care seeking when heart failure symptoms change.

Help seeking has also been studied under the prevue of care seeking, and care seeking was most studied in terms of emergent treatment at a hospital. These studies have been included as they represent what occurs when patients do not recognize early signs and symptoms, and cases where symptoms may have progressed rapidly. Treatment seeking delays for heart failure symptoms was influenced both positively and negatively by previous hospital encounters, at times reinforcing help seeking or contrarily as a deterrent to help seeking (Lam & Smeltzer, 2013). Interactions with the health care team and the experience of a hospitalization played a role in influencing future behavior (Lam & Smeltzer, 2013). The frequency of interactions with a cardiologist improved self-care adherence, the investigators hypothesized that patients may have seen the cardiologist as an authority, thereby increasing the perceived importance of the instructions (Peters-Klimm et al., 2012). Additionally, the influence of family was noted in an exploratory, descriptive study of heart failure patient's perception, evaluation, and response to an exacerbation of symptoms that led to a hospitalization. Patients with heart failure (N=131) recollected that symptoms were present prior to escalation, the most notable response (87%) was to tell family members about the symptoms (Sethares et al., 2014). Despite recommendations by family members to seek medical attention, only 4% of the sample called a health care professional (Sethares et al., 2014). Participants who used a wait and see approach to managing symptoms, delayed seeking help by 12 or more hours, and perceived the symptoms as being related to fatigue, the flu, or a respiratory problem (Sethares et al., 2014). Reasons attributed to delays in seeking out care or advice included a passive response, perceived seriousness of the symptoms, waiting out symptoms to see if they improve, and lack of knowledge related to the symptoms of heart failure (Sethares et al., 2014). A lack of knowledge regarding what the symptoms of heart failure are is a consistent finding, as noted in a qualitative interpretive synthesis by Spaling et al. (2015). An interesting finding was that heart failure self-management did not follow clinical symptom guides; rather patient's decisions on management were based on how the symptoms made them feel. Spaling et al. concluded that it is unclear if patients are aware that they are lacking in heart failure self-management knowledge. Sethares et al. (2014) found that although patients that did not seek medical attention in their study, 88% of participants recognized that it is important to seek medical attention if one has symptoms of worsening heart failure. Suggesting that patients are aware of how a heart failure patient should respond to symptom changes, but they are not able to apply the information to their own circumstances. How the heart failure symptoms are interpreted may not follow the path that self-management education describes, as evidenced by patient's preoccupation with their mortality found in a mapping of cognitive representations (Buck et al., 2015). Patients were found to implement strategies that they perceived as managing the symptoms. However, strategies of reflection and positive thinking align with passive, detached behaviors, which are not evidence based nor effective (Buck et al., 2015).

An integrative review of 16 studies, primarily correlational, revealed that treatment delays were most frequently seen in newly diagnosed and elderly heart failure populations (Lam & Smeltzer, 2013). In another study, the location of residence and where the patient was when symptoms changed influenced treatment seeking time, with rural patients having longest delays (Sethares et al., 2014). Non-specific, multiple symptoms, and symptoms that occurred during the night were also shown to prolong treatment-seeking time, whereas severe symptoms and the symptom dyspnea were markers of emergent treatment seeking (Altice & Madigan, 2012; Lam & Smeltzer, 2013). If symptoms were perceived as chronic a proactive approach was taken, however when symptoms are acute and related to breathing patients take an emergent approach to care seeking (Altice & Madigan, 2012). Proactive approaches to chronic symptoms is not elaborated on, specifically what actions do patient's take regarding their chronic symptoms. Alternative explanations for delays in help seeking are presented through a qualitative exploration on symptom tolerance and adaptation. In depth interviews were conducted with 16 participants. Adaptation and daily symptom management were enhanced after interactions with a physician and when symptoms gradually changed (Ahmadi et al., 2014). A common theme was that when symptoms changed slowly the patient was able to modify activities and adopt an alternate lifestyle, thereby making the symptoms less noticeable (Ahmadi et al., 2014). Treatment delays that have been studied all pertain to having an endpoint of hospitalization (Ahmadi et al., 2014; Altice & Madigan, 2012; Lam & Smeltzer, 2013; Sethares et al., 2014), what was not investigated and is unclear is if attempts were made to resolve symptoms earlier and were subsequently not enough to stave off the exacerbation.

Summary and Conclusions

The concept self-management has been studied from different perspectives within the allied health literature. What is known about self-care in heart failure is that there are several tasks that have been classified either under the domain of monitoring or management with no indication of how one moves from monitoring to management. Symptoms of shortness of breath and fatigue are particularly problematic for the patient to interpret. Symptoms and clusters of symptoms are described in subjective terms and possess an oscillating nature. Education to promote self-management have focused on increasing knowledge and promoting monitoring tasks. Interventions involving knowledge acquisition have not influenced the behaviors needed to manage symptom changes. Self-management behaviors are poorly understood in the context of decision making in daily symptom management, as studies examining this relationship have been predominantly in severe exacerbations that result in emergent medical management. The aim is to explore decision making when symptoms change, specifically how the patient navigates daily changes and assesses the need to seek guidance. It is clear from the reviewed literature that the decision making processes involved in daily symptom interpretation are poorly understood. This complex phenomenon would best be defined and understood from an exploration of the experience of self-managing from the patient's perspective. A qualitative grounded theory approach has allowed for concept attributes and theoretical relationships to be developed, thereby informing future initiatives involving heart failure self-management in the community setting.

Chapter 3: Methodology

Introduction

The purpose of this qualitative grounded theory study was to explore the processes of self-management decision making when a change in heart failure symptoms occurs, from the perspective of the patient. This chapter is an outline of the methods that were used to explore the phenomenon CHF decision making when symptoms change. The research questions will be reviewed, along with rationale for the selected methodological approach and the data collection instrument. Participant selection was based on criterion drawn from the research problem and sampling adequacy to encourage theoretical saturation. The role of the researcher will be discussed, as well as my knowledge and experience related to the research topic. Steps that were taken to ensure trustworthiness, quality of results, and ethical treatment of participants will conclude this chapter.

Research Design and Rationale

1. RQ1: How does the community-dwelling individual with CHF self-manage when a change in symptoms occurs?
2. RQ2: How does the individual perceive self-management as part of his or her daily life?
3. RQ3: What meaning does the individual with CHF ascribe to fluctuations in symptoms?
4. RQ4: What are the factors that influence help-seeking behaviors when heart failure symptoms change?

Central Phenomenon

The central phenomenon was CHF self-management decision making when symptoms change. Self-management decision making is a process that is preceded by symptom recognition, and it is the perceived meaning of the symptom change that leads to actions.

A qualitative grounded theory approach was used to answer the research questions and study the decision-making processes involved in self-management of CHF. I used the research questions to explore the process of decision making, which entailed exploring what was happening, identifying and describing the concepts involved, and mapping associations between concepts. Grounded theory moves beyond descriptions to ascertain themes and patterns (Charmaz, 2014). The properties of core categories were integrated into a structured schematic to provide explanation and relational interactions (Corbin & Strauss, 2015). The generation of theory from the patient's perspective has provided new insight into how the community-dwelling individual with heart failure interprets symptoms and practices self-management. This knowledge can be used to inform future interventions to improve CHF management in the community.

The research questions aligned with a grounded theory approach. The aim of this study was to describe how and why individuals with heart failure symptom changes determine their course of action. A grounded theory approach was used to explore links between categories by using theoretical sampling and iterative analysis to culminate in a theoretical explanation (Corbin & Strauss, 2015). Case studies are used to investigate and probe for depth, and they are not used to compare and contrast diverse experiences

(Patton, 2015). Case studies are used to study exemplars and understand how the case relates to theoretical propositions within one context; case studies are not intended to yield generalizations regarding a phenomenon (Radley & Chamberlain, 2012; Yin, 2015). A phenomenological approach is employed to describe the essence of lived experiences. Descriptions and themes are the end result of phenomenological studies, with the aim of understanding an experience (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). However, the aim of this study was to explore the processes of decision making, thereby necessitating data collection focused on making connections between categories and themes, which entailed moving beyond descriptions of what is occurring. Explaining the process of self-management decision making was best explored through an examination of the individual's experience with a heart failure exacerbation, specifically, the decisions made when a change in symptoms occurs.

Role of the Researcher

My role as the researcher was to collect data via face-to-face interviews. I was the primary instrument, as the data or words of the participants cannot be measured and were subjected to my lens for coconstructed meanings (Yin, 2015). The researcher's lens is comprised of technical knowledge, personal history, and experience (Maxwell, 2013). Incorporation of my experience and personal history with CHF patients was acknowledged, documented, and reflected upon to reduce bias.

As the primary instrument, I should reveal my professional history with the phenomenon of interest, thus ensuring transparency (Tracy, 2010). As a nurse, I have worked with cardiology patients for the past 25 years, from acute phases in the emergency department, interventional treatment in a cardiac care unit, and as a chronic disease educator in the community. My experience with the population spans all areas of the health care system and has provided me with an appreciation and awareness of the different stages of CHF. History and experience with the CHF population has enhanced intuitiveness, receptivity, and sensitivity, and I drew upon my personal reflections, which were catalogued in a journal throughout this study (Corbin & Strauss, 2015).

At the beginning of the study, I was working with the rapid response transitional team at the community care access center (CCAC); however, the participants were recruited from branches where I was not in contact with the participants in a nursing capacity. During data collection, my role at the CCAC changed, and I was no longer working with patients. Participants were recruited and informed of my role as a researcher. A plan was in place to direct the participant to the rapid response nurse or his or her physician if he or she required education information or medical advice. I did not foresee any power issues, as the qualitative interview was conducted with open-ended questions, allowing the participants to tell their story in a nonjudgmental, neutral environment. No conflict of interest was identified.

Methodology

Participant Selection Logic

The population that was studied were patients residing in the community with a preexisting diagnosis of CHF. Participants were recruited from the CCAC’s Rapid Response Program. The Rapid Response Initiative is a provincial program that provides self-management education, medication reconciliation, and transitional communication to primary care immediately following hospitalization. Inclusion criteria were English speaking individuals with a heart failure exacerbation requiring hospitalization in the previous 3 months and having received self-management education. The standard self-management education provided by rapid response nurses includes heart failure education taken from *Managing Heart Failure* (Heart and Stroke Foundation, n.d.), instructions to monitor weights, and a CHF action plan (see Appendix A). Exclusion criteria were CHF patients who were clinically deemed palliative, or those with a documented cognitive impairment.

A theoretical sampling strategy was used for this grounded theory study; however, the initial case was selected based on the criteria of a diagnosis of CHF and a recent exacerbation requiring hospitalization. Theoretical sampling is a strategic, systematic approach where ideas are constructed from the data; early theoretical categories are then selected for further inquiry (Charmaz, 2014). The participants had received CHF self-management education that included standardized decision making tools, such as the action plan. Consideration was given to ensure that the sample was representative of near equal gender distribution. The theoretical sample included confirming and disconfirming cases and an exemplar to validate the emerging theory (Patton, 2015). Sample size was determined by data saturation, whereby the concepts, categories, and relationships possessed dimensional variation (Corbin & Strauss, 2015). The emergence of a theory of normalizing heart failure symptoms drove the sampling strategy. Grounded theory constant comparative methods required collection of sufficient data to compare and contrast variations of concepts. To achieve this, the participants were recruited simultaneously with data analysis (Patton, 2015).

Sample Size: Saturation

The projected sample size was estimated to be between 15 and 22 individuals. Although there is no consensus on the ideal sample size for grounded theory approaches, recommendations range from 20 to 30 cases (Creswell, 2013) and no fewer than 10 cases (Corbin & Strauss, 2015). To achieve theoretical saturation, the sample size is determined by the quality of data, which can vary depending on the scope of the phenomenon of study (Cleary, Horsfall, & Hayter, 2014; O'Reilly & Parker, 2012). Quality of data was the criterion for saturation in this study, with no new properties for the categories and adequate between category variation being evident after multiple collection periods (Charmaz, 2014).

The scope of this study was confined to the participant's decision making when a change in CHF symptoms occurred; the focus was on symptom interpretation that influenced self-management actions. The participants were interviewed in depth, which generated rich, meaningful data for the purpose of describing and delineating concepts, categories, and relationships. Grounded theory studies by Östman et al. (2015) and Barello et al. (2015) had sample sizes of 18 and 22, and both studies yielded formation of theoretical models. MacPherson, Walshe, O'Donnell, and Vyas (2013) used a sample size of 10 cases, for which the results were primarily descriptive. Theory generation can be achieved with sample sizes between 18 and 22 cases. The scope of this study was unknown prior to data collection, and the plan was for in depth interviews. Therefore, a sample size between 15 and 22 individuals was used as a guide. To generate meaningful qualitative data, the theory was subjected to alternative explanations and hypothesis checking with the discrepant case; the sample, therefore, I used no fewer than 15 cases (Charmaz, 2014; Corbin & Strauss, 2015).

Instrumentation: Interview Protocol

Semistructured interviews were conducted in the patient's home; interviews lasted approximately 1 hour. An interview protocol was developed for the initial phase of interviews. The interview protocol provided a degree of structure and ensured that research questions were addressed and institutional review board (IRB) requirements were satisfied (Creswell, 2013). Interview questions were open-ended to elicit descriptions as I probed for clarification, increased depth, and verification of meaning (Janesick, 2011; Patton, 2015). The interview guide was adapted for subsequent cases to explore the characteristics of emerging concepts in an iterative process with data analysis (Corbin & Strauss, 2015). Clinical and demographic data were obtained from the participant; these data included comorbidities, number of medications, diuretic use, heart failure classification, and recent left ventricular heart function echocardiogram results if known. The interviews were audio recorded, transcribed, and supplemented with observational field notes. Immediately following each interview, I compiled field notes to capture context and my initial impressions about the interview and interaction with the participant.

Interviews provided the perspective of the patient, as they ascribed meaning to the thought processes that encompass decision making when a change in symptoms occurred.

The interview protocol included semistructured questions aimed to illicit how persons living in the community self-manage, which was a divergent perspective from what is expected based on clinical guidelines (see Appendix C). The interview questions included perceptions of involvement in self-management monitoring and symptom interpretation, which were drawn from the literature review and identified problem. The sensitized concepts offered a starting point to see the data, which had been taken from the content of standardized education previously introduced to the participant (Bowen, 2006). Data about the patient's experience with symptom recognition and interpretation were analyzed for what was happening in the natural setting.

Procedures for Recruitment, Participation, and Data Collection

Recruitment was from the community Rapid Response Program in Southern Ontario. A site-based method of recruitment using gatekeepers from the site, as suggested by Arcury and Quandt (1999), was used. Six rapid response nurses were selected and provided an information session detailing the participant criteria and the purpose of the study. The rapid response nurses distributed recruitment flyers to home care recipients who were enrolled in the program. The patients were then free to contact me via the phone number on the flyer if they had an interest in participating in the study. Potential participants were reviewed during the initial call to determine if they met inclusion criteria and were able to complete the in-depth interview. Once eligibility was met, the participants were offered the choice of setting a time for the interview that was conducive to their schedule. Written consent was completed on the day of the interview.

The data were collected via interview in a private setting within the participant's home. The data were collected by myself, the primary investigator. One interview was conducted for each participant lasting no longer than 1 hour in length. The interview was audio recorded and transcribed by myself. At the end of the interview, a debriefing period occurred to ensure that the intended meaning was captured. Notes were taken during the interview to provide context and document pertinent nonverbal communication. The plan was for all data to be collected during the interview; however, participants were asked if they were agreeable to a follow-up phone call if further clarification was required. The participants were also informed that they could contact me if their wish for participation had changed.

Data Analysis Plan

The data were comprised of the interview, journal entries, and methodological memos; all data were transcribed and entered into NVivo qualitative data analysis software: QSR International Pty Ltd. Version 11, 2015. NVivo is a qualitative data analysis software that electronically organizes and stores transcripts while performing text analysis. Data collection and analysis were conducted using Corbin and Strauss's (2015) iterative techniques for qualitative interpretation and theory construction. The interview questions were formulated from the research questions; the focus of the interview was to explore how the participant self-manages, perceives symptom changes, and how symptoms influenced the decision to seek help. Open coding was employed to analyze the transcripts and minimize preconceived ideas about the phenomenon. Codes were drawn from the interview data, with the participants' wording used to create codes and capture meaning (Jackson & Mazzei, 2013; Yin, 2015). Data collection and analysis occurred simultaneously; interview questions were adjusted to remain open and flexible to adequately capture what was revealed by the participant (Corbin & Strauss, 2015).

Memos were used to explore implicit meanings and hypothesize about conceptual properties that emerged during analysis (Charmaz, 2014). I used my journal to capture my reflections, initial impressions, and contextual data immediately following the interview. Methods of analysis included constant comparison, verification, inward-outward analysis, and clarifying my own understanding (Yin, 2015). NVivo qualitative software was used to store case transcripts, organize coding, perform text queries, create node attribute compilations, and map theoretical connections (Bazeley & Jackson, 2013). NVivo text mining and theory building queries facilitated connecting themes from the interview transcripts, memos, and the journal within and across cases (Bazeley & Jackson, 2013). A discrepant case was coded and analyzed using consistent methodological processes, and exploration of divergent findings was used to add depth to conceptual derivation (Bonis, 2013). The process of analysis encouraged thick, rich description; visualization of connections between concepts; and the emergence of a theory.

Issues of Trustworthiness

Credibility

To address credibility issues, the following measures were employed: triangulation of data, respondent validation, and comparison with negative or discrepant cases (Maxwell, 2013; Miles, Huberman, & Saldana, 2014). Text queries were used as a form of triangulation to strengthen assertions regarding patterns and themes; the data were analyzed for word frequency, word associations, and similarity across cases (Bekhet & Zauszniewski, 2012; Maxwell, 2013). The primary data collection instrument was the interview, and rapport was built with each participant to facilitate disclosure and rich data (Janesick, 2011). Questions were guided by how comfortable the participant appeared, beginning with broad, open-ended questions followed by focused probing to capture the experience of an exacerbation and daily symptom fluctuations (Corbin & Strauss, 2015; Rubin, & Rubin, 2012). One notable limitation of data collection through interviews is that questions are answered by recall, and the participant may not have accurate representations of what occurred; however, the purpose of this study was to explore self-management from the patient's perspective.

Transferability

The aim of this study was to explore the processes of decision making with heart failure populations. Transferability to other chronic disease populations would be outside the domain of this study. The processes of decision making were explored with CHF patients who were responsible for self-managing their disease in the community, and had experienced a recent exacerbation resulting in hospitalization. Thick descriptions of the participant's experience with symptom interpretation were obtained through face-to-face interviews employing open-ended questions and focused probing for deeper meaning (Janesick, 2011). Attempts were made to obtain equal distribution of male and female participants, however theoretical saturation was the primary driver of data collection.

Future studies would be required to ascertain the transferability of this study's results to other populations.

Dependability

To ensure that context and initial impressions were fresh and not lost, time was dedicated to complete field notes immediately after each interview. The write up of my results was also enhanced by including verbatim responses to explain themes and theoretical relationships, thereby mitigating researcher bias and increasing trustworthiness (Bekhet & Zauszniewski, 2012; Corbin & Strauss, 2015). The use of quotes drawn from the interview transcripts increase credibility by reconciling conclusions with the data. The research process was documented and cross referenced to provide an audit trail, codes were be recorded and subjected to constant comparison to ensure concepts remained grounded in the data (Koro-Ljungberg, 2010).

Confirmability

Researcher bias was addressed by acknowledging my history and familiarity with the subject phenomenon, recognizing that twenty-five years working with CHF populations had the potential to influence co-constructed meanings (Berger, 2015). A journal was used to house my reflections and impressions for transparency. Reflexivity was exercised to analyze my thoughts and to encourage consideration of multiple interpretations (Hibbert, Sillince, Diefenbach, & Cunliffe, 2014).

Ethical Procedures

A letter of permission was provided by the CCAC to gain formal access to the Rapid Response patient population. As per National Institute of Health guidelines IRB approval was obtained prior to data collection, IRB number 02-13-17-0386622 was included on the consent form (Creswell, 2013). Participants initiated the first contact after the study flyer was distributed by the Rapid Response Nurse. Informed consent detailed the study's purpose to explore and understand the experience of symptom interpretation and self-management during a CHF exacerbation. Ethical considerations including confidentiality, anonymity, and protecting the rights and welfare of the participants were discussed verbally as well as in written form on the consent (Creswell, 2013). Voluntary, informed written consent was obtained at the beginning of the interview, all identifiers were removed from transcripts and the participants were assigned a numerical case number. The geographical area of recruitment was large and over several sites in Southern Ontario, mitigating ethical concerns of identification. All cases have been stored in an electronic data base within NVivo, and backed up to an external hard drive. The computer and hard drive are password protected. All data will be archived and stored for five years, the archived data will not be public.

There are no ethical concerns regarding treatment, this study was an exploration of the participant's experience with CHF self-management to gain understanding. The participant's clinical plan and health education were not influenced as a result of this study. Participants have been assured that withdrawal from the study was possible at any time without any implications to their community treatment plan. I am employed by a division of the recruitment site, I recruited participants from another geographical area of the Province to ensure that I was not in a dual position (Patton, 2015).

Summary

The research questions and reasoning justifies the selection of a grounded theory qualitative approach. The methods chapter included a description of the selected participant population and associated characteristics. The participants were recruited from the rapid response program of CCAC, sampling followed a theoretical strategy. The interview was selected as the most appropriate instrument to explore the phenomenon from the perspective of the participant. A course of action to analyze the data as an iterative process with data collection was detailed. Procedures to ensure trustworthiness and quality of results have been outlined, including associated steps to reduce researcher bias. Finally, a plan to protect anonymity and safety of data follows guidelines for ethical research practices.

Chapter 4: Results

Introduction

The purpose of this qualitative grounded theory study was to explore the decision making processes undertaken by heart failure, community-dwelling patients as they experience symptom changes. Symptom interpretation, as part of self-management, was explored for contextual factors associated with the meaning of the experience as told by the participant. Understanding the behaviors or actions that are taken when a change in symptoms occurs will aid in the development of educational tools and health literacy strategies to increase successful self-management. The findings from this study will contribute to the development of a new theory on how individuals with heart failure interpret and act on daily symptoms.

The following research questions guided this study. I used the questions to elicit the experience of self-management, the perceived nature of symptoms, as well as resources and how the participant reasoned through managing daily symptoms.

RQ1: How does the community-dwelling individual with CHF self-manage when a change in symptoms occurs?

RQ2: How does the individual perceive self-management as part of his or her daily life?

RQ3: What meaning does the individual with CHF ascribe to fluctuations in symptoms?

RQ4: What are the factors that influence help-seeking behaviors when heart failure symptoms change?

In this chapter, I will present the research setting, participant demographics relevant to the study sample, as well as the data collection and analysis procedures. Evidence of trustworthiness will be described followed by the results, themes, theoretical schema, and summary of findings.

Research Setting

The research setting was a homecare region in Southern Ontario, and the participants were recruited from a CCAC. At the time of the study's implementation, the CCAC was undergoing organizational change and amalgamation with the Local Integrated Health Network. Data collection for this study was completed in the month preceding amalgamation. The study CCAC is comprised of five sites covering the community care needs for a population of 1.4 million over a geographical area of approximately 7,000 km^2. Four sites were targeted for recruitment efforts, ensuring representation from rural and urban areas. Despite the health care system changes during the study's implementation, participants' services were not interrupted or affected by the change.

Patients under the care of the CCAC can be referred for services from the hospital or community, and additionally referrals can be made by physicians, nurses, allied health professionals, family, or self-referral. Services provided by the CCAC are provincially funded. A predominantly English speaking, White population resides in this area of the Province, with a visible minority population at 13.6 % in urban areas and 4% in rural areas (Statistics Canada, 2006). The study data collection period was from February 2017 to the end of April 2017 during the winter season.

Demographics

Upon completion of informed consent procedures, demographic information was collected (Table 1). A total of 18 face-to-face interviews were completed for this study. The participants were primarily White (*n*=17), with 11 females and seven males. Participants' ages ranged from 37 to 88 years of age, with a mean age of 74.27 years. Six of the participants lived alone, while nine lived with their spouse, and three with their adult children. Level of education varied; however, the majority had attended part of or completed high school. I purposefully did not ask participants about their income because access to care was not impeded; all care was funded through the Province. I selected to not describe each participant individually to ensure rigorous protection of anonymity.

Table 1

Demographic Information

Characteristic	*n*	%
Gender		
Male	7	38.9
Female	11	61.1
Age		
30-40	1	5.6
41-60	-	-
60-70	4	22.2
70-80	7	38.9
80-90	6	33.3
Ethnicity		
White	17	94.4
Black	-	-
Aboriginal	1	5.6
Education		
No high school	2	11.1
Some high school	4	22.2
High school	7	38.9
Trade school	3	16.7
College/University	2	11.1
Lives With		
Alone	6	33.3
Spouse	8	44.4
Adult Child	3	16.7
Spouse and Child	1	5.6
Employment		
Retired	17	94.4
Disability	1	5.6

Basic health information was collected from the participants. Half of the participants did not know their left ventricular ejection fraction. New York Heart Association Functional Classification was determined from the interview questions that prompted answers on activity levels and daily symptoms. The number of prescribed medications ranged from five to 18 with a mean of 12 medications. All participants were on a diuretic. Information on comorbidities was also collected (Table 2). All participants had a primary care physician, and the majority were also seeing a cardiologist (*n*=8) or internal medicine specialist (*n*=7). The participants had recently experienced an exacerbation of heart failure with hospitalization, as per the inclusion criteria. Consistent with the study's exclusion, criteria participants had no cognitive impairment nor palliative diagnosis. Table 2 includes health information details that were obtained through self-report at the time of the interview.

Table 2

Health Information

Characteristic	*n*	%
LVEF		
25-30	4	22.2
31-40	2	11.1
41-50	3	16.7
Missing data	9	50
NYHA		
I	-	-
II	6	33.3
III	10	55.6
IV	2	11.1
Medications		
1-5	1	5.6
6-10	6	33.3
11-15	8	44.4
16-18	3	16.7
Diuretic Prescribed	18	100
Comorbidities		
COPD	5	27.8
Diabetes	7	38.9
Other	4	22.2
None	2	11.1
Primary Care	18	100
Specialist Care		
Cardiologist	8	44.4
Internist	7	38.9
None	3	26.7

Data Collection

Prior to data collection, I contacted the CCAC to determine if study flyers could be distributed to their community patients who had experienced a recent hospitalization for heart failure. Permission to distribute flyers was granted, and time at a quarterly meeting was allotted to provide information and flyer packages to the nurses. Flyers were distributed along with usual information materials to heart failure patients commencing on February 24, 2017. In the flyers, I outlined the purpose of the study, participant criteria, and my contact information (see Appendix E). Home care patients were free to contact me at a time of their convenience to ask questions and voice their interest in participating. A total of 18 participants were interviewed between February 26, 2017 and April 24, 2017. Two additional persons called to answer the flyer invitation; one changed her mind and a second caller was the daughter of a patient wanting to know if she could participate. A total of 45 flyers were distributed for recruitment purposes.

At the time of initial phone contact, I explained the study and determined eligibility. The participant was then given the option of completing the interview at a location of his or her choice. Participants preferred having the interview conducted in their home, citing it was more convenient given the unpredictability of the weather. On arrival to the participant's home, I inquired if the interview time was still convenient. Participants were given a written copy of the consent form while I read the contents; prior to signing, they were given an opportunity to ask further questions. All 18 interviews were completed in the participants' home in either the kitchen or living room. Each participant was interviewed once, with interview recordings lasting between 16.16 minutes and 39.07 minutes. The first interview of 16.16 minutes was not a true reflection of the time spent with the participant; she expanded on her answers and seemed much more comfortable conversing when the recorder was off. An interview protocol containing 14 questions was used at all 18 interviews (see Appendix C); as the study progressed, additional probes became focused on the emerging themes. During the interview observations and contextual data were hand written as field notes, while researcher reflections were immediately documented after leaving the participants home (see Appendix D). The total time spent with the participant lasted between 48 and 75 minutes.

I had anticipated that the interview protocol questions would change with each successive interview, but this was not the case. The open-ended nature of the questions allowed the participant the freedom to answer the question as it pertained to his or her personal experience. The interviews were digitally recorded with a Philips Voice Tracer DVT2700 and transferred to my personal computer. The audio recordings were then analyzed with Dragon speech recognition and converted to a Word document. The automated transcription was checked against the audio for accuracy by myself and uploaded into the NVivo project for storage. All audio recordings were deleted once transcription was verified. Observation and reflection notes were transferred into a Word document and uploaded into the NVivo project. Demographic information was entered into the NVivo project under the case classification function. All documents associated with each participant were assigned a unique numerical identifier, and a pseudonym was used for the write up.

There was no variation from the proposed data collection plan. No unusual circumstances were encountered during data collection. One participant added more information after the recorder was turned off, and these data were hand written and added to the transcript. The participants did not experience any complications during the interview, and a break period was offered at approximately midpoint.

Data Analysis

In keeping with grounded theory methodology, data analysis was conducted along with data collection. Constant comparison within and between cases were used to generate codes (Corbin & Strauss, 2015). NVivo11 Pro for Windows by QSR International was used to store all study documents. Traditional methods of coding (open, axial, and selective) were applied to all transcripts. The qualitative software functions of NVivo11 Pro were used to supplement and enhance analysis; word frequency queries, word tree visualizations, and between cases nodal comparison diagrams were run to illustrate connections. The cluster analysis function helped identify cases that were least similar, which were then subjected to deeper analysis for discrepant characteristics.

The first two interviews were completed within 1 week of each other and formed the original coding structure. I hand-coded both interviews using a line-by-line open coding technique with no limit on codes. The focus of the first two interviews centered on the experience just prior to hospitalization, the symptoms, emotions, and supports that were occurring in the acute exacerbation phase. After interviewing and coding, participant 03 new codes were formed. Participant 03, rather than talking about the acute hospitalization episode shared more of her daily routine and what she did to control symptoms during the day. Participant 04 also shared how he managed his disease throughout the day. It was at this time that I compared what happened during daily self-management and what was occurring during symptom escalation or tipping points. This first phase of coding involved looking at processes and outcomes of what was occurring. Once the basic coding structure was formed, nodes were created in the NVivo project and the transcripts were electronically coded.

Axial Coding

Themes began to take shape after seven interviews. I shifted from processes to contextual elements resulting in category properties and nodal dimension (Corbin & Strauss, 2015). I concentrated analysis on the conditions under which self-management was occurring in relation to the process actions and the results of these actions (Walker & Myrick, 2006). The nodes were reconfigured into parent and child nodes. I used different types of nodes to describe what was happening, action or functional codes, descriptive codes, and emotional codes. NVivo queries were used to look at word frequencies and word trees across all coded excerpts. As a result, the code symptoms were divided into two separate nodes as they were associated with different meanings. Similar words during tipping points were panicked (23), disturbing (31), severe/hard/heavy (66), and bothered/terrible/hurting (45), which differed from the words participants used to discuss the same symptom of shortness of breath experienced daily.

With daily shortness of breath, an activity was associated with the episode followed by a behavior, waiting/rest (49), relaxing (44), or sit (42). The context which the symptom was occurring revealed delineating features that split the node. A similar process of analysis was used to allow category properties to emerge from the data (see Table 3).

Analytic and Methodological Memos

Following each interview, researcher reflections were recorded. Memos were created during analysis to reflect on the meaning of what was being said by the participant and how it related to a particular category. I used memos to write down my theoretical ponderings after coding and running queries, returning to previous memos and connecting it to another participant as the study progressed. The process of returning to previous memos aided in formation of categories and properties reflected across participants, resulting in documentation of saturation.

Analytic and Methodological Memos

Following each interview, researcher reflections were recorded. Memos were created during analysis to reflect on the meaning of what was being said by the participant and how it related to a particular category. I used memos to write down my theoretical ponderings after coding and running queries, returning to previous memos and connecting it to another participant as the study progressed. The process of returning to previous memos aided in formation of categories and properties reflected across participants, resulting in documentation of saturation.

Table 3

Node Evolution

Initial Code	Description of Code	Node (s)	Context/Properties
Alternate thoughts	Explanations of possible causes of symptoms	Child Node: Independent Reasoning	Parent Node Self-Management Part of decision-making, thought processes undertaken/reasoning, uncertainty
Compensatory Actions	Actions that are taken that are not part of recommendations, lay actions	Daily Alleviating Actions Sub code: Control	Normalizing Symptoms Resting and "plugging along" actions resulting in alleviation or reduction in symptom and perceived control over the symptoms
Changes in Social life/Routines	Adjustments and changes, giving up doing things, using support system	Altering Life	Adapting to Symptoms Pulling back from previous life, changing expectations of self
Perception of others	How they are viewed by the medical profession, emergency services when they describe symptoms	Vulnerable Emotions	Vulnerabilities Influencing concept of sub code: control
Symptom Experience	Severity, most concerning symptoms, innocuous symptoms	Symptoms	Symptoms are seen differently, daily symptoms in context of activities
		Tipping points	Tipping point symptoms charged with emotions and uncertainty
Help Seeking	Actions taken to reach out to health professionals and family/supports	Personal Supports	Supports were sought out in periods of uncertainty, confirmation
		Medical Profession Interaction	Health interactions during tipping points initiated by others

Evidence of Trustworthiness

Credibility

Credibility measures were taken into account during the planning of this study. Strategies to ensure credibility of this study included respondent validation, triangulation of data, intensive interviews, and comparison with discrepant cases (Maxwell, 2013; Miles et al., 2014). Respondent validation occurred during the interview by paraphrasing and repeating back to the participant their response to confirm my understanding of their intended meaning. Notations were made throughout the interview, and if there was something that was unclear, I would redirect the participant back to this for clarification during pauses in the conversation. Rapport was built with most participants and their responses were full of description and depth. I took a conversational approach to the interview, which allowed the participants freedom to speak at length at their own pace, to adequately garner meaning and rich data. NVivo text queries and visualizations of word associations and similarity between cases were methods of data triangulation used to discern the nature and quality of developing patterns and themes (Bekhet & Zauszniewski, 2012; Maxwell, 2013). A discrepant case was analyzed and contextually compared with the data. This revealed instances, or voids that needed to be answered, specifically the relationship between health care provider and patient. During subsequent interviews probes were used to explore the attributes contributing to a lack of help-seeking behaviors and perception of control when symptoms changed.

Transferability

The results of this qualitative study are not intended to be directly transferable to other populations. Rapport was gained with most participants, which fostered an atmosphere that encouraged description and deeper responses. Thick descriptions reflecting the participant's experience with heart failure symptom management captured conceptual dimensions. Attribute depth derived from thick descriptions and contextual descriptions have informed the model's antecedents and consequences. The model may not apply to other populations as it is presented, however the depth of description will increase the utility of the model for theoretical derivation and transposition to other populations. Attempts were made to achieve equal distribution of males and females, the final sample had three more females (*n*=11) than males (*n*=7). Additionally, the sites targeted for participant recruitment were a combination of urban and rural centers. Themes were represented in both male and female participants at the time of saturation.

Dependability

A detailed researcher journal was kept during the implementation of this study. Each interview is dated and timestamped as it was uploaded into the NVivo project. All processes and actions that were completed within the NVivo project have been captured in an electronic audit called a project summary report (see Appendix F). The processes used to ensure dependability of the non-recorded data included recording reflections and observations immediately following the interview. Hand written initial impressions, observations, and reflections on what had occurred and what I thought was happening were transferred to the NVivo project. Participant's responses were audio recorded and transcribed verbatim. The interview was conducted in an environment selected by the participant, the natural setting minimized any stigma of control on my part. Themes and memos were directly linked to the participant's transcript during analysis, and the verbatim responses are quoted throughout the results (Bekhet & Zauszniewski, 2012; Corbin & Strauss, 2015). A code book was used to mitigate coding variability (see Appendix G). As I coded the transcripts I ensured that coding remained consistent by referring back to the code description and previously coded case content (Koro-Ljungberg, 2010).

Confirmability

Prior to commencing this study I reflected on my previous experience caring for heart failure populations. I began writing a self-reflective summary on August 29, 2016. The journal has been an exercise to preserve impartiality as I recognized that I did hold some preconceived notions about heart failure self-management. My experience with heart failure patients are previously documented and was used to inform my understanding of health care system resources and clinical trajectories related to the pathophysiology of heart failure. My background knowledge was used to recognize unique lay strategies used by participants to control daily symptoms of heart failure. Reflections were completed after each interview, my impressions were examined for potential influences and plausible alternative explanations (Hibbert et al., 2014). To mitigate researcher bias, co-constructed meanings were formulated during the interview, by rephrasing, affirming, and member checking (Berger, 2015). The interview protocol was comprised of broad open ended questions to avoid leading the participant (Maxwell, 2013). Initial coding of transcripts were reviewed by a committee member who is an expert in qualitative analysis. As coding progressed and themes emerged I conferred with committee members to discuss the validity of my inferences to address and minimize researcher bias.

Study Results

Heart failure is a chronic disease that is punctuated by waxing and waning of symptoms. The most severe symptoms require hospitalization and active treatment, however the patient is not cured after treatment. The participants in this study all described their experience during an acute exacerbation, what they felt physically and emotionally, the persons involved at the time of seeking help, and their thoughts on what led up to the exacerbation. To fully understand symptom interpretation and how participants assigned meaning to the symptom the participants were asked to share how they self-manage the daily experience with heart failure. The results are presented as themes under each research question. I have assigned an alias to each participant to personalize the presentation of their responses. The relationship between themes are described and illustrated in the theory of normalizing symptoms. Research question one was separated to explore two types of symptom changes; one a representation of critical escalation and the other those symptoms that occurred regularly or throughout the day.

Research Question 1

How does the community dwelling individual with CHF self-manage when a change in symptoms occurs?

The first research question corresponded with four interview questions; actions taken when symptoms change, actions found to be most beneficial, factors that hinder caring for heart failure, and perception of control. Two contextual types of symptom changes were revealed, which I have separated into the categories escalating exacerbations and daily symptoms.

Perceiving symptoms: Escalating exacerbations and tipping points

When asked about their experience with changes in symptoms, the participants identified the primary symptoms as a building up of shortness of breath (*n* = 12), swelling (*n* =3), and weakness (*n* = 3). Shortness of breath was described in terms of severity as well as the impact on functioning.

> Amber: For three days I couldn't breathe, I was having a hard time breathing, I start hyperventilating and that's what it is like, it is scary.
>
> Francis: I got short of breath to a greater degree, so short of breath I couldn't breathe.
>
> Bernard: My breathing was so bad I couldn't walk, and then my wife panics.
>
> Claire: I could not even talk to my daughter.
>
> Liam: It was like someone put a clamp on you, there was no room for breathing, the air couldn't get in.

Shortness of breath during tipping points were described as an overwhelming feeling of not being able to breathe, often associated with an emotional sense of urgency and panic. Participants also described an increase in swelling that built up over time, which became concerning when the swelling influenced their daily activities. Swelling effected lower limbs and abdominal areas. Swelling around the abdomen was accompanied with shortness of breath for one participant.

> Janice: The swelling was, my stomach was so big I couldn’t breathe, it felt like I was having a baby.
>
> Francis: My legs were so big I couldn’t walk.
>
> Ian: For a couple of weeks, a lot of water. I was up over 20 pounds. I felt like I was tight like a tree. There was a lot of swelling everywhere, my waist, my legs, everything was really swollen.

The third common symptom is fatigue, which was described as being tired, fatigued, weakness, and lack of energy.

> Dominic: We didn’t know what was wrong, I was trying to rest and it wasn't helping my energy, and I was just feeling weaker and weaker. I felt like I just couldn't do it anymore.
>
> Karl: I’m just so tired, I feel like my head is foggy in the morning and I can’t think. My daughter says I am dazed.

The participants all describe a sense that they hit a definite point where they needed something done, or that they could not continue on with the symptoms persisting. Self-management during tipping points appeared to be less calculated and clouded with uncertainty.

> Claire: I had no energy and I felt weak, really, really weak and I was sweaty. I felt a little bit light headed and I don't think I could get up out of my chair. My family tells me it was really bad and I just felt like there was really something wrong but I couldn't do anything to help myself.
>
> Marilyn: I felt so hot, and it was cool in here. Anyway, it wouldn't go away, I called my neighbor saying what is this? I thought I don't know why, jeez, why.
>
> Norman: So ah, finally my daughters decided that they better get me to emergency. I should have gone three or four days before that.
>
> Francis: My stomach, I thought I was getting fat. Everyone said no you are just full of fluid.
>
> Heather: I had a lot of shortness of breath and problems breathing. Believe me, I was so stupid, I should have known and called the ambulance, but I sat up all night and it wouldn't go away.
>
> Amber: I don't know why, but I should have known the swelling wasn't normal.

When describing events leading up to symptom escalation, actions corresponding with self-management decision aids were not reported by the participants. Participants (*n* = 6) recall a delay in help seeking over a period of days, with the decision to call an ambulance being determined and initiated by others (*n* = 8). In retrospect, responses are punctuated by statements that they "should have known." Tipping points were described more readily and with considerable detail, tipping points appear to be more memorable or notable as compared to daily symptoms.

Perceiving symptoms: Daily symptoms

Daily symptoms were differentiated from tipping points by severity and association with emotion. Unlike tipping points which mark a specific event or moment in time, daily symptoms are more elusive and approach a continuous experience. The participants could not articulate daily symptoms or instances of daily symptom changes specifically. I used a probe asking about daily activities and the symptoms that influence how much or the degree of activity that they can do. Daily symptoms reported included shortness of breath (n = 10), swelling (n = 12), fatigue (n = 12), difficulty sleeping (n = 5), loss of appetite (n = 5), and dizziness (n =3).

> Liam: It will most likely happen during the night. The trouble is when I lay down flat in the bed, it just doesn't work, in the bed it gets worse. And then I usually sit in the chair for quite a long time.
>
> Pia: When I walk, when I do anything, when I go up the stairs my heart is pounding out of my chest and then I can't get the breath.
>
> Susan: If I try to go for a walk somewhere, like I want to go to the market downtown and walk around the market, I have my walker. I get out of breath and then I am standing there panting while my friend is trotting off.
>
> Olive: If I am sitting here like now I am fine, but if I get up and walk for a few minutes I would get short of breath again.
>
> Claire: My legs are kind of achy and sometimes the top of my feet get really big and I can't fit my shoes on.
>
> Gwen: I would come home from the hospital feeling strong, and then within three

days I feel weaker and weaker. My legs wouldn't do what I wanted them to.

Karl: I am so tired I don't feel like doing anything. And I can't do anything so it's like I don't feel like doing anything. But it is because I can't do anything because when I do something it is just too hard and it takes too much out of me.

Bernard: I don't have an appetite, my wife tries to get me to eat, have protein or a Boost. In the morning I will have my cereal, and by noon it's just, the sandwich and the meat, it just tastes, it doesn't taste right and I got no appetite.

Norman: If I tried to eat something I couldn't. Whatever I had felt like sawdust in my mouth to me, I had no appetite for that.

Ian: I don't feel like eating. She cooks all this good food, I sit at the table, and just the smell, I gotta get away and it's like what the hell? And I don't feel like eating, no appetite. That's been with me for a year now.

Bernard: I have a hard time sleeping, in the daytime I doze off quite often.

Marilyn describes cleaning her home: I can bend down, and then when I am down I try to get up and I get dizzy. And when I bend down I get short of breath. It makes it hard getting back up, and then I do get back up and I have to go and sit down. So I put that job down to being useless.

Claire: I'm just really tired, I don't have a lot of energy and I sleep in late.

Control: Alleviating actions

Participants used a variety of strategies to minimize or relieve symptoms. A word frequency query was run for all text within the category alleviating daily symptoms. The most frequently used action term was rest and the synonym relax (28) followed by sit (17), and nap (7).

> Amber: I just sit down and relax, you know take it easy, and it usually goes away.
>
> Bernard: If I am doing something and my breathing goes up I sit down, not even a half a minute and it goes back to normal and levels off.
>
> Claire: I try to put my feet up and that kind of helps a little bit, it makes them not feel as numb.
>
> Dominic: I make sure to watch my breathing so that I am not overdoing it.
>
> Heather: I have shortness of breath early in the morning when I am getting up. I have to sit up and take deep breaths and then it goes away and I can get up and walk around. I think it's not really so bad because it goes away.
>
> Ian: She will make me a cup of tea, something to help, and we sit and calm down.
>
> Liam: It is not easy to do, you elevate your legs and your body goes calm. And that is no good, it makes it harder to breathe when I elevate my legs.
>
> Susan: I didn't stay after church for lunch. I came home and laid down, it was just what I needed, I was tired and I knew it.

Participants also revealed that they take precautions to prevent symptom episodes. Planning and using previous experience on how they felt while performing certain activities.

> Eileen: For the dishes it takes me over an hours because I will do them for a few minutes and then I have to go sit down and then I go back to it for another few minutes. If I am making meals I will bring everything out here so that I am

> sitting. I can stand with my walker and sit on it, but it is too hard. So I usually bring everything in here for peeling and stuff like that, get it all ready and then I take it out there. It is easier for me.

Pacing activities and changing daily routine were common actions to help prevent symptoms from occurring while maintaining activities of daily living.

Research Question 2

How does the individual perceive self-management as part of their daily life?

Participants discussed their typical day in the process of describing daily symptoms. An interview question elicited what self-management meant to the participant was used to see how the participant related their actions to self-management. As a nurse exploring how community residing individuals with heart failure self-manage I wanted to determine what self-management means to the participant. I needed to put aside my knowledge and experience with patient education, specifically with promoting self-management. By asking the participants what self-management means to them I was able to see self-management through their eyes.

The meaning of self-management

Participants described self-management as a set of tasks; taking medications, weighing themselves, and measuring their abdomen. As part of standard heart failure education, these were the tasks that they had been directed to do by their health care professional. Participants also saw self-management as knowing their body and any actions that would keep them healthy. Not all recommended activities were practiced by all participants, some having developed their own unique ways of monitoring signs and symptoms as was necessary.

> Bernard: I wake up, I take my medications, I go to the bathroom, I weigh myself, and measure my belly.
>
> Amber: Keeping a chart, to put all my weights on, and if I gained 2 pounds I would call the nurse.
>
> Francis: They never asked if I had a scale, so I look at my legs to see if they are getting more swollen, then I know I have too much.
>
> Eileen: I just check my legs and go to the washroom, I weigh myself. I am only supposed to have one and a half litres a day, but a lot of the times I go over.
>
> Gwen: I couldn't have salt. I started doing my own food from scratch, and stayed away from the canned goods. I watched my salt intake and wrote it down. I keep a journal, so that I knew what my weight was, my blood pressure, and my sugars for when I went to the doctor's. I could tell them or the nurse.
>
> Norman: I take all my information with me to the heart function clinic so they know what is going on.

Knowing your body

Participants were then asked to expand on their answers and relay what self-management means to them, beyond the tasks of monitoring.

> Amber: I know my body now, just trying to get over this breathing thing. Um, sometimes I get scared but it will go away in time.
>
> Gwen: You try to figure out what is going on with your body.

> Ian: For me it is hard it is like pairing it with my life.
>
> Susan: It's a balancing act here, do what I can do to keep healthy and know when you just can't go on any longer.

Knowing your body was referred to in relation to identifying the symptom as part of monitoring. The balancing act referred to by Susan implies that after symptom identification there is a process of determining what the symptom means and corresponding actions.

Research Question 3

What meaning does the individual with CHF ascribe to fluctuations in symptoms?

Three interview questions were used to answer research question three; the meaning of the symptom in relation to actions, what was most concerning or difficult to manage, and what was the easiest to manage? An overarching theme of control emerged and became a contextual element related to actions and the meaning assigned to the symptom.

> Francis: I don't feel that there is anything wrong with it (her heart), I know there is but I don't feel it, I am only short of breath when I was full of fluid. Some days when I don't feel well, I just want to make it easier.
>
> Ian: I am not near the strength or concentration, the focus is not there. No strength. I threat to cope with this as long as I can. As long as it is possible, I can. This is something I have to live with, it is a chronic disease.

> Heather: I was scared of having it (shortness of breath). I can't carry everything at once that is too much, it takes time to do a bag at a time. You know it would go away, and I thought I don't want to go to the hospital. Because it would go away… and I was fighting it.
>
> Janice: I was just resting so much but I didn't realize I was getting bad. I sleep in the chair more and my breathing seems to be a bit better… I stay in my nightie because I can't put my pants on. Sometimes it feels like it is so far gone there is nothing that can be done.
>
> Susan: And if I push myself beyond that then I pay for it. You know I start to get swelling in the legs, so I learned, I'm learning, I'm struggling against it. They rule me, you do what you can do and then your body says that is enough, so you have to give in to it.

Participants described how they managed symptoms by struggling or fighting to retain control over what is happening with their body. The severity of the symptom would be decreased by sleeping in a chair, wearing loose clothing, and pacing activities. Control was differentiated into mental control, control over symptoms, and control over the situation.

Perceived Control

> Claire: I feel in control when nothing is wrong. I weigh myself, I see the numbers and I know that I am doing okay. It's when things happen that I don't feel in control.
>
> Ian: I try to go back on my pride, I focus on my pride.

> Liam: Okay, when things happen to you, you don't have much control. But not that it upset me or something, no, I was in control. More mentally I guess, try to stay clear in your head, and have some trust.
>
> Norman: I was aware of what was going on. I am not someone who sits around and listens to all that I have been told about; you are not going to be able to do this and you have to pace yourself. I think I am back to normal now, other than I got some physical problems.
>
> Marilyn: It was a relief when someone else took control, up until that point you are trying to figure things out.

Giving up control: Reliance on other's

Participants also noted instances when they relied on others to assist with or take over activities to decrease demands in an attempt to prevent symptoms. Independence is juxtaposed with symptom control and accepting one's limitations.

> Susan: That is one of the most frustrating things, I think is the limitations on physical activities and things like singing and driving a car. But I am beginning to find out that there is no way. As time goes on … I can't do this anymore, I really do need the help.
>
> Olive: You struggle to stay independent, you don't like to ask to have help.
>
> Amber: I've been fine just on medication, I'm not as active as I used to be, you know. I get my husband to do the shopping, and I am falling behind on my little business, getting tired and needing more help from people. When you are used to doing everything yourself, it is tough.

> Eileen: I want someone to come in to help, because I know I can't do it. But on the other hand I figure if I let someone come in and help me then that's not letting me do things. And I want to do it on my own.

New perception of the self

As the roles, responsibilities, and functional capabilities change, there is a period of adaptation and awareness that they have changed.

> Ian: My management is very weak, I am fragile. When I am eating after breakfast, I feel like a snake that has swallowed a rabbit. You know because the snake swallows the rabbit or the frogs whole, and after that the snake goes to sleep. They have to sleep to digest it. I feel the same way. I feel like a lay here, close my eyes, and just go into a coma. And then a few hours later I get up and go on my routine.
>
> Liam: You have to be realistic. Being positive is dangerous, being positive can set you up for upset. I am very fortunate, I am not the best, one day can be better than another, one part of the day can be better than others. I am delicate.
>
> Bernard: The days of running are over. That's a big adjustment when you have to slow down.
>
> Olive: Sometimes it makes me feel like I just want to give up. I will keep plugging, plugging along.

There is a new normal level of activities of daily living as they adapt to their daily symptoms. The adjustment is perceived as within their control despite the fact that they are not in control of the outcome.

Research Question 4

What are the factors that influence help seeking behaviors when heart failure symptoms change?

Help seeking did not occur with normal daily symptoms. Additionally, help seeking during escalating symptom episodes were primarily with family members, who then contacted emergency services. Probes were used to determine reasons why participants did not seek medical advice or assistance. Previous experience with reaching out to health care professionals were explored.

> Amber: I kept telling them that I couldn't breathe and they didn't believe me because the oxygen looked okay. I feel like a lot of people don't believe me, they don't believe I am sick because I am young and look healthy.
>
> Claire: My husband, he just doesn't seem to get it. I know I am sick and he thinks I can do things. It is like he won't accept that I am sick.
>
> Eileen: I asked the doctor before if I could have water pills and he said no I didn't need it. Well I have to have them now. If he had given them to me when I asked for them it might not have come to this.
>
> Francis: You know all my life I didn't call the doctor, I waited until the last minute. I thought I am okay, I will get better. Now the kids see me and they say we better go to the doctor.
>
> Ian: The specialist is easier than the family doctor. Both of them are busy doctors. It is just how it is, sometimes they don't have any room for you, sometimes they are not there. It is hard. I trust the nurse more than the doctor,

> because the doctor will look at the paper, not at you. The nurse looks at you, I just want someone to look at me.

Respondents reported delayed response or inability to connect with physicians compared to immediate response when reaching out to family members. With the exception of two respondents, primary care physicians and specialists were not contacted to assist with self-management decisions when symptoms changed. Norman indicated that he would call the heart clinic, feeling that they would know what to do, but he has not had any reason to call between appointments.

Discrepant Case: This is not normal

When asked about self-management, participants revealed the tasks of monitoring and upon further probing how monitoring related to knowing their body. There was one participant who articulated her experience with monitoring and actions that involved regular physician consultation. I used Gwen as a discrepant case because she was able to make connections between monitoring and managing as well as being highly vigilant. She had been living with fluctuations in symptoms for 12 months without normalizing her symptoms. She had an awareness of what her baseline was and kept a journal to identify any deviation. Gwen describes the support and confidence that her specialist, primary care physician, and her nurse instilled in her.

> Gwen: I had good doctors. Whenever I called there's always somebody there to answer, and yeah they always referred back to me, and yeah it certainly makes you a lot more comfortable specially when you're really sick and you, and you don't know what's really happening. They give you confidence, they both kept

> telling me, you know, I was going to get better. And he said you are fine and we’ll get you to a point where you're stronger.
>
> The nurse would give me, she wasn’t just a nurse she was like a friend and that made the difference. Like just having the time to sit and you could trust, or know that they cared. It means a lot that somebody who knows the medical profession is taking the time to answer your questions and put your fears to rest.
>
> To me it is like when you get a disease that you don't know nothing about, I think sometimes you overthink it. You're always scared that when something else is going on that you're afraid that it is getting worse. I had to do it every day, I had to keep track. If my weight went up I would get a hold of my specialist, it was a back and forth thing for a while there depending upon which way I went.
>
> At first you have no idea what's going, why am I blowing up like a balloon.
>
> I haven't been getting the heart problems, and no swelling and I watch for that all time. I think it does make you more aware of your own body especially compared to how I was the very first time.

Gwen’s self-management behaviors had been fostered but she also had regular reinforcement and guidance on symptom changes. Gwen describes ongoing evaluation of her symptoms coupled with trying to understand the causes of the symptoms. There were other participants that had been self-managing for over a year, however not with the degree of vigilance or medical support as described by Gwen. In contrast to the majority of respondents, Gwen did not see her daily symptoms as normal. Where other respondents stated that they were fine or okay, Gwen was proactive watching small changes, keeping track of them, and bringing it forward to her specialist.

Theory of Normalizing Symptoms

The overarching findings from this study resulted in the construction of a substantive theory of normalizing heart failure symptoms. Themes relevant to decision making and meaning making when heart failure symptoms change include perceiving symptoms, normalizing symptoms, and adapting to symptoms. The conditions under which the central concept normalizing symptoms occurs can be conceptualized along a continuum that changes in a cyclic pattern. Concepts that are present within the model will be shown to relate to the core concept normalizing symptoms.

Perceiving Symptoms

The theory begins with symptom perception. Participants described the presence of daily symptoms to include shortness of breath, fatigue, and swelling. Symptom perception is conceptualized as noticing that a change from normal is occurring. The participant monitors daily weights to help determine if a fluid imbalance is present, by an increase in weight or an increase in edema. However, not all the symptoms of heart failure are assessed with numbers and guides as it is done with weights. The participant takes note of what is happening within their body, described by Heather as “knowing you are breathless.” Janice describes her breathing as “wearing her down.” Fatigue was described as a feeling in your body where even “picking up a cup of tea felt like a ton.” Perceiving symptoms is a combination of being aware there is a change and assigning meaning to the change.

Normalizing Symptoms

Three processes of normalizing symptoms emerged from the data. Normalizing symptoms was conceptualized as actions taken by the participant to decrease or alleviate symptoms. The first process is resting, resting produced a real-time response. Bernard would “sit down and relax, and it goes away,” while Richard describes how he “stays right where I am, stop what I am doing and relax a little bit.” Susan stated as soon as she sat down she was “ok, and it doesn’t last long.” When a symptom was noticed by the participant the decision to rest was made, and the symptom would resolve. Once the symptom was alleviated after a short rest, the participants noted that they were then able to carry on. As this pattern of exertion and rest is repeated it is incorporated into daily living and becomes the norm.

The second normalizing process is changing the daily routine and planning out activities to decrease the chances of encountering symptoms. Bernard will “will fix things around the house at a slow pace, with movements that are not as fast” while Marilyn states she “does half of what she used to,” and she would have to adjust the time to take a shower and put on her clothes. Pia stated she reorganized her routine to do house work downstairs, if she had to do the ironing she would spend the whole morning downstairs. Pia would have her worst episodes of shortness of breath and palpitations climbing the stairs, by remaining on the lower level she would reduce the amount of times needed to go up and down the stairs. Participants consciously rearranged how daily living activities were completed to prevent or avoid episodes of symptom changes.

The third normalizing process demonstrated by the participants involved decreasing responsibilities and role relinquishment. Role relinquishment was the conscious act of giving up a role that was previously done by the participant. An example of this is Amber, “I would get my husband to do the shopping,” because she was tired and “unable to do what I used to do.” Relinquishing is conceptualized as letting go of a task that the participant felt was part of their role. Bernard relinquished doing the yard work and Susan relinquished singing in the choir because she could not hold notes without becoming short of breath. The decision to give up these role functions were not seen as easy, with participants describing it as being hard or difficult to come to terms with. Ian stated “I want to do it my own way, like I used to.” Throughout normalizing, participants expressed that they were in control. Normalizing brought about change as the participants adapted their lives to avoid experiencing the symptoms of heart failure.

Control in Normalizing

The participants voiced that it was important to do what they wanted to do, and that they were willing to adjust how it was done to remain independent. The importance of independence was noted by several participants. Heather adjusted how she did her groceries so that she would not need to rely on others, “taking one bag at a time,” and Eileen described how she “takes a long time, I can do it all myself” and “I don’t want someone there when I am bathing.” The need to remain independent is conceptualized as part of maintaining control. The overarching theme of being in control while exhibiting normalizing actions is depicted in the model. The participants perceived that they could control symptoms by exerting control over the how and what physical endeavors they took on. The processes of normalizing was discussed by the participants as activities that they have adjusted over the course of their disease.

Decreased Functional Capacity

Although participants strived for control an unforeseen consequence of normalizing is a decreased level of activity. Subsequently decreased activity reduces the potential to notice that instability may be occurring, as the normal triggers of symptom changes are being avoided. Janice stated that "I was resting so much I didn't realize I was getting bad." This phenomenon is captured in the model as a product of perceived control, or the negative consequences. As daily activities are adjusted daily symptoms are accommodated and assimilated into daily life, representing the new norm. Olive describes herself as "plugging along," while Karl explains it as "it's not really that I can't manage my symptoms, I think it's I can't manage to do anything and then my symptoms get worse." Marilyn states that she is "limited," while Norman described himself as "I don't really feel that I have heart failure, I feel like I have been out of circulation." Decreased functional capacity is recognized by the participants, with Karl describing that he is now a "burden" on his daughter, Ian describes himself as "fragile," and Liam states he is "delicate." The statements by participants signify that they are aware that their symptoms and what happens as a result may be out of their control. Susan stated that the symptoms "ruled her," while Marilyn states that "the oxygen, and pills" are in control of what happens. Liam voiced that "when things happen to you, you don't have much control." The terms delicate and fragile were used in terms of feeling that the threshold for exacerbation was perceived as low. The goals identified by participants centered on maintaining some degree of functional capacity and independence, wanting to do things for themselves. Marilyn stated “I don’t trust it, but a year and a half ago I would think nothing of it,” talking about being able to climb a step ladder to clean. Recognition of limitations resulted in a changed perception of the self, seeing one’s vulnerabilities in decreased functional capacity and shifting perceptions of control.

Dulled Symptom Perception and Tipping Points

Over time the ability to detect early symptom changes was influenced by altering or adjusting physical capacity. Participants viewed daily symptoms as under their control and alleviating actions became assimilated as a routine of daily living. There were several accounts of the days leading up to an exacerbation, Dominic describes “I was trying to rest and it wasn’t helping my energy, and I was feeling weaker and weaker.” Francis had difficulty recalling what she was feeling in the previous days, “maybe three or four days they started swelling up.” Janice similarly had difficulty recalling how the belly swelling got “so tight” that she “could not breathe.” Norman stated he was told by the hospital that “he should have come three of four days before.” Amber recollected that she was short of breath three days before going to the hospital. The early warning signs were not heeded, the symptoms in the days building up to an exacerbation were difficult for participants to recall specifics. This finding suggests that symptom perception was dulled and the appropriate meaning was not assigned, allowing the symptoms to escalate. Participants did not recall or describe self-management monitoring during the period preceding an exacerbation. Tipping points are conceptualized as the point in time when the participant realizes the escalating symptoms are out of control. Tipping points coincide with loss of control and a heightened emotional response.

Heightened Emotions

Tipping points are moments in time when there is uncertainty, the participant realizes something is wrong, but cannot control it through normalizing actions previously employed. Eileen was “panicked,” Francis was “scared,” Olive was “panicking,” and Liam described himself as “panicky, like someone put a clamp on him.” Uncertainty was evident as participants described the tipping point, Dominic noted “we had to go in to figure out what was wrong,” and Marilyn stated “I thought I don’t know why, I just can’t breathe, why?” The model has captured uncertainty in symptom perception with a hatched line, signifying that there is a breakdown in perceiving and assigning meaning during a tipping point. During periods of uncertainty participants reached out to family members and neighbors as a form of confirmation that the episode was serious, reinforcing that the episode was out of their control. Uncertainty and the inability to resolve the change in symptoms corresponded with a delay period of several hours to several days.

A discrepant case was used to illustrate monitoring vigilance and highly collaborative relationships with a medical specialist, where daily symptoms were tracked and assigned an important aspect of monitoring. Gwen, did not perceive her daily symptoms as normal. She was acutely aware of listening to her body and writing down what she was feeling in a journal. Gwen described “knowing something was not right,” and “you learn more about it, you look for things and realize this is ok.” Gwen described her relationship with her specialists, primary care physician, and rapid response nurse "people that listen and understand what you are going through, it gives you more of a positive attitude to keep going." Gwen described the collaborative nature of her relationship with her specialist, which was punctuated with back and forth dialogue to optimize her treatment plan. Gwen in an example of vigilant monitoring and awareness of when her body was outside of her normal. Early detection of these signs enabled her to converse with the physician and change her therapy over a course of what she described as weeks. Gwen did not consider herself an expert, however what was different from the other participants was the meaning she assigned to her daily symptoms. Gwen did not normalize the symptoms, as they meant that something was wrong. The discrepant case reinforces the importance of not just monitoring daily symptoms, but recognizing the small symptom changes and assigning a meaning within the context of heart failure.

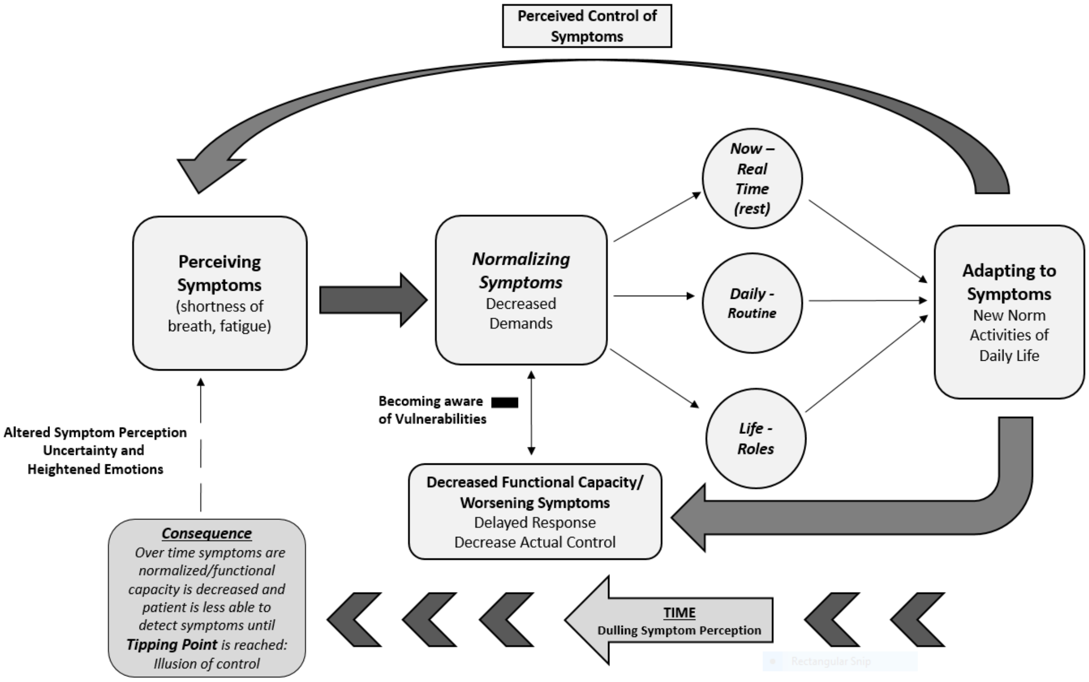


Figure 1.

Theory of Normalizing Symptoms

Summary

The participants of this study were interviewed using an interview guide which aided in exploring each research question thoroughly. Community dwelling individuals with heart failure experience daily symptom fluctuations and acute symptom exacerbations. Acute exacerbations were commonly managed as an emergency, and were accompanied with uncertainty and emotionally heightened responses. Daily symptoms were managed by resting and pacing activities. Self-management was viewed by the participants as encompassing monitoring tasks as well as having a general looking after oneself attitude. The meaning assigned to symptom fluctuations were associated with how the symptom influenced functional abilities and the perception of control. In retrospect, participants felt that they should have known something was wrong and that affirmation was needed from family. Participants adapted to symptom fluctuations through a variety of actions meant to stave off episodes, the consequence being decreased activities of daily living and a redefining of the self. Factors that influenced help seeking included previous aversive experiences, inability to gain access to a physician in a timely manner, and a belief that physicians are for urgent issues and not advice on self-management.

A process is a series of steps or actions that produce a result. The central concept revealed in this study is normalizing symptoms in heart failure. Normalizing symptoms is the assimilation of daily symptoms into one's existence. This is achieved through a series of actions that minimize or resolve the symptom so that daily functioning can continue. Symptoms become integrated into the norm of the functioning self and desensitization occurs. Daily symptoms are perceived as under control due to the mitigating actions, concern is not present. The consequences span elements of the larger whole, the person, including role identity and functional capacity, are changed due to the actions. The change is a function of control over symptoms, control of situation, and perceived control over the self. The result is delayed detection of symptom changes, delayed help seeking, and an escalation of symptoms for which the participant is unable to control, the tipping point.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In this grounded theory research study, I explored 18 community-dwelling individuals' perceptions about decisions made while managing heart failure symptoms. I collected data through face-to-face, in-depth interviews in the participants' home, where they practice self-management. The purpose of this grounded theory study was to explore the decision-making processes involved in self-management of heart failure symptoms. This study was conducted to address the research problem of delayed help-seeking behaviors when heart failure symptoms change. The community-dwelling heart failure patient assumes the tasks of monitoring and managing fluctuations in symptoms between interactions with health care providers. An exploration of the perceptions and actions undertaken by individuals living with the disease provided a fresh understanding of the contextual factors and thought processes involved in managing the symptoms of heart failure. Data were generated from the in-depth interviews, culminating in the emergence of a theory of normalizing symptoms.

Using Corbin and Strauss's grounded theory methodology, two distinct representations of heart failure symptom changes were revealed. First, I found that participants more readily related symptom changes to acute exacerbation events. These events were described as highly distressing and associated with uncertainty and loss of control. The second representation of heart failure symptom changes included daily symptom fluctuations. The participants had more difficulty distinguishing events, and daily fluctuations were seen as part of normal daily living. Participants described self-management as efforts to stay healthy by adjusting their lives to the disease. Monitoring was described by participants as tasks that were completed in the morning rather than a behavior manifested throughout the day. An overarching theme of control was revealed and divided into subthemes: immediate response control over body, adjusting daily routine control to reduce episodes, and adjusting life role responsibility control. Control underscored the struggle to retain functional independence and reduce or resolve daily symptoms. A theme of vulnerability was prevalent, specifically when participants discussed how their lives had changed since being diagnosed with heart failure. Additionally, as daily living and functional demands were reduced to control symptoms, the symptoms were perceived as a normal part of life. I also found that help seeking for instruction and advice from health care providers was not occurring. Seeing a physician was described as routine visits or if there was a need for treatment.

A theory of normalizing symptoms illustrates the process that individuals with heart failure undertake to minimize episodes of symptom fluctuations. The consequences of adjusting functional demands leads to desensitization of symptom recognition and a loss of functional capacity. Chapter 5 includes a discussion of the interpretations of the findings, limitations of this study, recommendations, and implications.

Interpretation of Findings

The following is a presentation of the findings in relation to the review of the literature and previously published results.

Perceiving Heart Failure Symptoms

I found two types of changes in heart failure symptoms: severe acute exacerbations and fluctuating daily symptoms. My findings regarding variability and the nature of heart failure symptoms were supported by previous findings. Moser et al. (2011) noted that such variability in symptoms influenced subsequent actions taken by patients. The literature on symptom interpretation is predominantly associated with severe exacerbations and the symptoms leading up to acute care. However, exertional shortness of breath is difficult to interpret, and shortness of breath as a prevalent daily symptom can make changes less discernable (Pang et al., 2014; Van Riet et al., 2014). Exertional shortness of breath was one of the prevalent symptoms reported by participants; yet, the participants were not able to describe these episodes as vividly. Common symptoms reported in this study are congruent with current literature, and they included shortness of breath, fatigue, and swelling. The two distinct descriptions of symptom fluctuations that are conceptualized from the literature include symptoms as mild, acute exacerbation, and episodic (Jurgens et al., 2009; Spaling et al., 2015). In this study, I confirmed the types of symptoms and the attributes of symptoms previously reported. In addition, the participants in this study found it difficult to describe milder symptoms; there was also a ubiquitous quality of fatigue like symptoms. Participants described symptoms as either manageable or not manageable. Participants recalled a gradual building up of the symptoms; however, they did not become concerned until they hit a tipping point. Similarly, Simmonds et al. (2015) reported patients at increased risk during decision flash points, most commonly during an exacerbation. This finding was in contrast to those of Lee et al. (2015c), who found that worse physical symptomology was associated with expert level self-management consultive behaviors. This may be explained by the tool of measurement, the European Heart Failure Self-Care Behaviors scale, as it does not have seeking medical attention at an acute care center as an option. Although heart failure symptoms are frequently reported in the literature, there is little on how quality, duration, and perception of symptoms are related to actions. This study provided insight into the variation in symptom meaning, particularly daily symptom fluctuations and self-management behaviors.

Defining Self-Management

The participants in this study defined self-management as aligning their life with the disease. When prompted about the activities done daily to self-manage, monitoring was described as being completed once a day. Self-management was also described as a holistic undertaking associated with changing a person's lifestyle. Liam described self-management as "looking after yourself," and Dominic described his self-management as "looking after myself and taking it easy so that things don't get worse." Absent from the descriptions of self-management were the decisions of what to do when symptoms changed. These findings are indicative of definitions previously reported in the literature (RNAO, 2010; Schulman-Green et al., 2012). Monitoring was reported as an easy task, particularly when things were going well. Monitoring was described as an event that was completed once during the day, usually in the morning coinciding with a weight check. Participants reported weighing themselves and writing down the results to give to their doctor at the next visit. In additional probes, I found mixed responses about what the participant did with the results beyond writing them down, Norman “walks to take the fluid off,” while Janice described an 8 pound range where she feels she is safe, and Claire described her weight as “going up and then it will go down the next day.” One participant mentioned that he followed the doctor’s orders by taking his weights. Participants described self-management as the things that they do; they did not describe self-management as a collaborative endeavor with their physician. The participants’ understanding of the purpose and their role in what to do with abnormal monitoring results differed from physician expectations of timely actions (Spaling et al., 2015). Participants focused on recording abnormal findings and waiting until their next appointment to show the monitoring sheets to their physician. Theoretical literature on heart failure self-management was not congruent with findings from this study. The theory of self-care in chronic illness has monitoring and management as separate domains, with self-management as symptom evaluation, treatment initiation or actions, and treatment evaluation (Riegel et al., 2012). The participants in this study conceptualized monitoring and health promotion strategies as self-management. The participants did not associate interactions with their physician as part of evaluation of symptoms; physicians were seen as overseeing the results of monitoring during planned follow-up visits.

Decision Making

Exploring the decision-making processes was one of the aims of this study. The following is an examination and comparison of my findings and a predominant assertion about heart failure decision making. Self-management has been previously described and conceptualized as naturalistic decision making (NDM; Riegel et al., 2016; Riegel et al., 2013; Riegel & Dickson, 2008). The NDM theory conceptualizes decision making that evolves from experience, skills, and the external environmental influences within the context of the population studied (Lipshitz, Klein, Orasanu, & Salas, 2001), which is significantly different from decision making based on internal somatic signals that represent the symptom manifestation of heart failure. The assumption that external influences in high stakes contexts in work situations evoke similar responses to internal reading and recognition of symptom changes was not demonstrated in this study. Particularly, when symptoms changed, the decision-making processes described by the participants during escalating episodes was of uncertainty, panic, and a failure to implement self-management strategies. The behavior described during these episodes resembled a relinquishing of control rather than of a consultative nature. Of note, NDM theory was derived from experiments and incidents that modeled high pressure, time sensitive decisions made in aviation, pilots with over 20 years of experience, as well as data from the Naval investigation into the Vincennes missile misfiring incident of 1988 (Lipshitz et al., 2001). Expertise, which was felt to be a component of NDM during its inception, was later shown to be an essential precursor criterion of the theory (Lipshitz et al., 2001). My findings did not support the notion that community-dwelling heart failure patients are experts at self-management even after education, perhaps explaining why NDM was not apparent. Mental simulation as part of the patient's evaluation of the symptom, as noted by Riegel et al. (2013), was not demonstrated in my study. Participants in my study were consistent with the findings of Lee et al. (2015c), where higher levels of anxiety were associated with worse self-management behaviors and decreased expert-level consulting behaviors. My findings differentiated between decision making during escalating symptoms of exacerbation and decision making with daily symptom fluctuations. Distinct patterns of decision making were noted with both types of symptoms, suggesting that decision making is dependent on perceived risk and severity of the symptom.

Self-Management and Help Seeking

Help seeking behaviors were explored in relation to symptom presentation and the decision-making process. Similar to my findings, Clark et al. (2012) found that patients view acute dyspnea as a high-risk symptom requiring rapid help seeking. This finding was in contrast to those of Lee et al. (2015c), who found that worse physical symptomology was associated with expert-level, self-management consultive behaviors. This variation in results may be explained by the tool of measurement used by Lee et al., the European Heart Failure Self-Care Behaviors scale, does not have seeking medical attention at an acute care center as an option. My findings were consistent with participants seeking out acute medical attention at the hospital when symptoms escalated. Liam referred to knowing what was happening the second time he went into the hospital: "I didn't know it was fluid on the lungs the first time, but when it happened again, I knew." What Liam was describing was not the early signs but the signs that sent him to the hospital; the result was repeating his previous actions. Despite having experienced the same symptoms in the previous month, he could not detect the building up to the tipping point. Unclear boundaries explained help seeking delays in previous studies, where participants demonstrated uncertainty about when symptoms warranted physician involvement (Clark et al., 2012). Liam's previous experience did not serve as a learning primer to act earlier and prevent hospitalization. I also found that participants delayed help seeking as symptoms escalated, reinforcing that detecting variation in symptom severity is a difficult task for patients. Amber described having shortness of breath for 3 days prior to asking her husband to get help. She could recall that her pills were not working and the edema was increasing, but she did not call her physician. As Amber recalled the episode, it was not clear if she was aware that she was short of breath, or what she was thinking about the symptoms at the time. This is in contrast to Moser and Watkins's (2008) findings that gradual onset of symptoms led to faster treatment seeking.

The participants of this study did not exhibit help seeking from a health care provider for fluctuations in daily symptoms or during an acute episode. Family members and neighbors were relied on when the participants were uncertain about what they were feeling and what actions they should take. The participants reported that these were people that they could rely on. When family or neighbors were contacted, there was an immediate response. Francis described the response of her son and daughters as "they would all get to me," and Marilyn stated her brother could hear it in her voice and "well he got his ass down here right away." The participants had no doubt that the person they were reaching out to would come to help. This finding was echoed by Buck et al. (2015), where heart failure patients perceived that informal care givers would intervene if needed. Participants in this study also shared that they felt the symptoms were too far gone and going to the hospital was the only choice. Similar findings were found by

Sethares et al. (2014), where only 4% of the patients in their study reported contacting a health care provider when symptoms worsened. Communication with a health care professional and help seeking were not consistent with decision aids or health teaching recommendations in times when symptoms escalated. Further insight is needed to understand the collaborative processes or lack of between the community-dwelling patient and his or her health care practitioner throughout the symptom experience.

Normalizing Actions: Rest, Planning, and Decreasing Role

Daily symptom fluctuations were of particular interest in this study, as daily fluctuations evoked three compensatory or protective forms of actions from the participants. Some daily symptoms were characterized as pervasive. Bernard reported that the feelings are constant, “it is always there.” Ian described his symptoms as “these fickle things showed up to the point that I said that is it.” Liam described his symptoms as “being there all the time, just enough so that you know it is there.” Amber described her method of managing daily symptoms by resting and improving sleep by elevating her head. Clark et al. (2012) reported maladaptive coping strategies in heart failure management; waiting out the symptoms, avoiding situations that bring on the symptom, and reducing physical activity were consistent with my findings. Similarly, Ahmadi et al. (2014) reported themes of symptom tolerance and adaptation. Participants in my study responded to symptom changes by resting to gain immediate relief, planning their day to avoid potential changes in symptoms, and changing their life roles and responsibilities to decrease physical demands. Self-care strategies used to relieve symptoms included rest and raising the head of the bed, which were consistent with findings from Reeder et al.

(2015). Reeder et al. also reported self-medicating, walking, and dietary changes as methods of relieving symptoms, which were not supported by this study's findings. The data revealed an overarching theme of control. When discussing symptom management, the participants voiced that they could control daily symptoms. Participants controlled what they were able to accomplish during the day by resting to immediately relieve the symptoms, thereby allowing them to carry on. Planning the day was described in detail, and daily tasks were altered to decrease the workload and effort required. Roles and responsibilities were reported as being relinquished or delegated to other family members or hired help to decrease daily physical and time demands. Although the need to plan activities, pace activities, and decreased social functioning has been reported in the literature (Buck et al., 2015; Clark et al., 2012; Tierney et al., 2011; Wingham et al., 2014), the contextual and descriptive nature of these behaviors have not been previously reported. Participants in this study reported that they are fine or ok as long as they have some control to stop or decrease symptom occurrences. A key finding is that the participants in this study did not perceive daily symptoms of heart failure as concerning. There are consequences of these behaviors, specifically the ability to detect and interpret gradual increases in daily symptoms.

New Norms and Changed Self

The participants in this sample commonly reported that their lives have changed since the time they were diagnosed with heart failure. Wingham et al. (2014) described an assimilation period that encompassed phases of acceptance, alteration, and coming to terms with the disease by reaching a safe harbor. Persons with heart failure can describe themselves as being vulnerable (Wingham et al., 2014); this was corroborated by my findings. Participants in this study, although having described feeling vulnerable, also described themselves as being “ok” between periods of exacerbation. Physical functioning was associated with life goals and independence, consistent with previously reported findings that functional autonomy was paramount to heart failure patients (Zhang et al., 2015). However, normalizing behaviors to control symptoms reduces functional autonomy. Participants reported “plugging along,” “doing the best you can,” how they are “frustrated with the things you can’t do anymore,” and that it is “a balancing act, knowing your limits.” Reducing exertional opportunities where symptoms may occur, results in a corresponding negative impact on overall functional capacity. In an effort to mitigate heart failure symptoms, participants may be contributing to a natural decline or progression of the disease.

Limitations of the Study

A limitation of the current study was that the sample were primarily White and elderly, making it difficult to generalize results to the broader heart failure population. Although the sample size was small, there was good distribution of participants across urban and rural geographical areas. In this study I used a criterion case for the first interview, followed by theoretical sampling of the data in subsequent cases. Data saturation was achieved at 17 cases, however one additional participant was interviewed with the aim to verify and refine themes and relationships in the model (Cutcliffe, 2000). The sample was older, with a mean age of 74.27 years, and may not be reflective of how younger adults perceive their symptoms. A methodological sampling limitation is that after flyers were distributed the participants volunteered to be interviewed. The sample may represent a demographic that is more open and forthcoming to discuss how they cope with the symptoms of their disease (Rubin & Rubin, 2012). Another limitation of this study is that the responses to questions were based on the participant's recollection (Corbin & Strauss, 2015). The participant's responses were repeated and validated throughout the interview to ensure that spontaneous meaning was captured. Medical information, specifically, the left ventricular ejection fraction, was obtained from the participant and unverified. Some participants did not know their ejection fraction, and these cases have missing data. Despite this limitation, the sample included participants with reduced ejection fraction and preserved ejection fraction. Time was an additional limitation and data collection was completed within nine weeks. The aim was to complete data collection within that defined period as the recruitment site was about to undergo restructuring and a transfer of operations.

Recommendations

The strengths of this study are that the participants had a comparable level of self-management education and support provided by their community rapid response nurse. This study was also conducted in the community, with participant's sharing their real life experience in the setting where self-management is performed. The findings from this study extend the body of knowledge on heart failure self-management and give rise to several areas that warrant further inquiry. Key findings from this study indicate that daily symptoms, beyond taking weights and checking edema, are not perceived as warranting attention or monitoring. Participants undertook several lay actions to control the symptom experience. Two distinct pathways of symptom experience were identified, both of which were associated with poor consultative or collaborative relationships with primary care.

A theory of normalizing symptoms was constructed, it would be of value to extend the development of this theory with further testing of the relationships. In particular, perception of symptoms can be examined in relation to the frequency of symptoms. The findings of this study indicated that as daily symptoms are experienced over time perception is dulled, this relationship can be tested by comparing daily symptom frequency and symptom perception. I included the NYHA classification, which measures severity of symptoms and physical functioning, as part of the demographic information. Although this study did not compare symptom perception to NYHA class, this information would extend the development of the theory. Additionally, participants exhibited characteristics of control over activities to mitigate symptoms. The relationship between the three normalizing behaviors and perception of control should also be tested.

Suggested future research should explore daily symptom interpretations over a longer period of time. The theoretical model normalizing symptoms was drawn from data that was collected at one point in time, and from recall. The relationship between normalizing symptoms should be studied using a longitudinal methodology. A longitudinal study may illuminate differences in symptom interpretation overtime and may demonstrate how experience and disease severity influences symptom interpretation. Barello et al. (2015) described phases of learning to read body signals, however heart failure is a disease with symptoms changing in quality and frequency as it progresses, making symptom interpretation a challenge (Bidwell et al., 2015; Bratzke et al., 2015; Tierney et al., 2011). I recommend additional studies that examine health literacy on detecting and recognizing early heart failure symptom changes and the role they play in successful self-management. Shortness of breath and fatigue are subjective experiences, a qualitative inquiry should be used to avoid confining descriptions of the experience (Cameron et al., 2010; Van Riet et al., 2014). Future studies should use larger sample sizes with more diverse ethnic backgrounds and younger participants to strengthen interpretation of findings. During this study I was able to uncover and corroborate the normalizing activities implemented by the participants (Jurgens et al., 2009). However a deeper understanding of the cognitive processes and behaviors are needed. Action research would offer a promising approach to collaboratively address inconsistencies in symptom monitoring and interpretation (Yin, 2015).

An aim of this study was to explore decision making that occurs when heart failure symptoms change and arising help seeking behaviors. An interesting finding in this study was that the participants did not exhibit consultive behaviors between physician visits. An important distinction that needs to be clarified is if the participants did not realize consultation was an option or if they did not perceive a need for it. There remains a paucity of literature concerning heart failure decision making consultative behaviors for symptom management outside of acute exacerbations (Xu et al., 2016). Engaging in consultive behaviors when symptoms change is a tenant of chronic disease management and integral component of hospital avoidance strategies (Fergenbaum et al., 2015). The participants in this study also revealed that they feel “fine” or “ok” between exacerbations, even while experiencing daily symptom fluctuations. It is unclear if the participants understood the relationship between their daily symptoms and their diagnosis of heart failure as a chronic disease. The participants in this study, although having been taught self-management strategies with decision aids, the emphasis was on what they can do in the home to avoid hospitalization. Future studies could look at the effectiveness of self-management when it is supported and initiated by the primary care physician. Additional research should be undertaken to examine the contextual and system factors, including the role of the health care provider, that influence consultation on early symptom changes.

The advantage of using a grounded theory methodology is the freedom for themes to emerge that do not fit within the theoretical models in the literature. Normalizing behaviors and actions associated with chronic disease coping strategies have been previously reported (Jurgens et al., 2009; Charmaz, 1991, p. 150). The theoretical model and findings from this study suggest that normalizing behaviors are a function of control, and desensitization of symptom perception occurs with normalizing over time. Additional studies would be needed to test these relationships and refine the theory.

Implications

The aim of this study was to address the theoretical and literary gaps regarding what community dwelling individuals with heart failure do to manage heart failure symptoms. Implications for social change are at the individual and organizational level of health policy and practice. The impact at the individual level involves improving health literacy and the ability to manage heart failure symptoms. At the organizational level the findings from this study have shown a need for adaptation of current self-management guidelines to include and emphasize early symptom detection and action. I will discuss how the findings also support the need for systems change to adequately support self-management. The individual and organizational social change levels involve practice implications that are complementary and aim to foster healthy self-management behaviors, empower the individual, and enhance systems to support community heart failure management.

Findings from this study provided an increased understanding of how community dwelling heart failure patients manage their day-to-day symptoms, thereby informing future educational and skills training programs. Participants in this study focused on escalating symptoms, they were able to describe the escalation and placed a high priority on detecting these types of symptoms. However, daily symptoms and gradual increases in symptom severity warrant attention, as these are the critical points where early treatment at home can be safely implemented. Recent findings out of the PARADIGM-HF study (Okumura et al., 2016) underscore the importance noting and recording symptom changes that involve medication adjustment without hospitalization, as these patients are at a 4-fold risk of subsequent mortality. The data from my study revealed a perception of self-management that consisted predominantly of monitoring, furthermore, monitoring was seen as a task that was done once daily focusing on weights and edema. The findings from my study can be used to justify the need for educational tools to help the heart failure patient detect changes in subjective symptoms and strategies to avoid behaviors that are counterintuitive.

Participants were noted to adopt normalizing behaviors to mitigate the symptoms of heart failure. Normalizing behaviors included decreasing physical activities and reducing or eliminating opportunities of physical exertion. By recognizing normalizing behaviors that limit the participant's activities of daily living, alternative strategies can be promoted to optimize functioning and prevent functional decline. Cardiac exercise rehabilitation programs are known to be underutilized despite having been shown to improve quality of life and heat failure related hospitalizations (Taylor et al., 2014). The findings from my study support that exercise tolerance is poorly understood by individuals with heart failure, emphasizing the need to educate on the importance of activity in their daily lives. Discussions need to occur with individuals who have heart failure, so that they can understand their exercise capacity within safe limits. Instructional strategies must include a behavioral component to recognize normalizing behaviors and promote healthy behaviors. The behaviors of normalizing can be used to identify and target those individuals at risk for functional decline and who would benefit from a structured exercise program.

An additional social impact is at the organizational and policy levels. The findings from this study illustrated that there remains a gap in practice and structures to support a collaborative patient-provider self-management strategy. The participants in this study did not reach out for consultation during early stages of symptom change, rather they waited until an emergency department trip warranted medical treatment. The reason for not collaborating with a physician at earlier stages remains unknown. However this study did suggest that there are two possible reasons, the first is that the symptoms were not assigned meaning that consultation was needed, and the current practices do not adequately support self-management collaboration. The individual level was previously discussed with recommended strategies to improve symptom interpretation. The current Canadian Heart Failure Guideline recommendations to be seen by a heart failure specialist for mild symptoms or worsening heart failure while on heart failure therapies is 2-4 weeks, and ideally at 2 weeks (Howlett et al., 2016). There is a notable absence of recommendations to support the heart failure patient in a consultative capacity in the community. The discrepancy between self-management education recommendations to call a physician when there are symptom changes are not congruent the recommendations from the Canadian guidelines, resulting in the possibility of the patient not being seen for upwards of two weeks. This represents a clear potential for delays in treatment adjustments and an increased risk for exacerbation and hospitalization. Community-dwelling patients are instructed to call their physician when symptoms change, but there are no clear guidelines that delineate the responsibility of the physician to address the symptom changes. The responsibility of consultation is complicated further if the self-management instructions were initiated by a community nurse or hospital as part of an education initiative. Heart failure is a chronic disease and self-management is a lifelong endeavor once diagnosed, yet the system continues to function on an episodic basis. The results of this study suggest that the health care structures to support self-management can be improved.

The third social change impact is the generation of knowledge in the form of a theory of normalizing symptoms. The relationships and findings from this study informed the social change implications and practice recommendations. The theory would need to undergo further testing to verify and refine the concepts and relationships. The theory of normalizing symptoms offers a new perspective on how persons diagnosed with heart failure adjust their living to accommodate the symptoms of the disease and in the process adapt. The consequences of normalizing brings to light the importance of early symptom interpretation and execution of appropriate corresponding behaviors to optimize health and functioning. The unique perspectives of the participants add to the body of knowledge on community and ongoing care of this chronic disease.

Conclusions

Heart failure is prevalent chronic disease associated with increased frequency and severity of symptoms towards end stages. This grounded theory study was conducted with an aim to better understand how the community-dwelling patient self-manages symptom changes. The decision making processes were explored through face-to-face interviews, allowing the participant to share their experiences in a fuller capacity. Community-dwelling individuals with heart failure were found to implement normalizing behaviors to minimize, eliminate, and avoid symptoms. The behaviors of normalizing consequently reduced participation in exertional activities and overall physical functioning, resulting in progression towards a more sedentary lifestyle. Daily symptoms were thereby not noted or taken into account as part of self-management monitoring. A collaborative patient-physician relationship as indicated in self-management education decision aids was not demonstrated. A theory of normalizing symptoms was generated and can be used to inform future research as well as support practice recommendations. Future research on early symptom interpretation and the effects of sedentary lifestyle adoption should be undertaken. Recommendations for practice include educational strategies to promote recognition of early symptoms, increased education on the benefits of safe physical activity, and building a system to support self-management patient-physician collaboration.

References

Arcury, T., & Quandt, S. (1999). Participant recruitment for qualitative research: A site-based approach to community research in complex societies. *Human Organization*, *58*, 128-133. doi:10.17730/humo.58.2.t5g838w7u1761868

Ahmadi, N. S., Månsson, J., Lindblad, U., & Hildingh, C. (2014). Breathlessness in everyday life from a patient perspective: A qualitative study using diaries. *Palliative and Supportive Care*, *12*, 189-194. doi:10.1017/S1478951512001095

Altice, N. F., & Madigan, E. A. (2012). Factors associated with delayed care-seeking in hospitalized patients with heart failure. *Heart & Lung: The Journal of Acute and Critical Care*, *41*, 244-254. http://dx.doi.org/10.1016/j.hrtlng.2011.09.007

Barello, S., Graffigna, G., Vegni, E., Savarese, M., Lombardi, F., & Bosio, A. C. (2015). 'Engage me in taking care of my heart': A grounded theory study on patient–cardiologist relationship in the hospital management of heart failure. *BMJ Open*, *5*(3), e005582. doi:10.1136/bmjopen-2014-005582

Bazeley, P., & Jackson, K. (Eds.). (2013). *Qualitative data analysis with NVivo*. Thousand Oaks, CA: Sage.

Bidwell, J. T., Vellone, E., Lyons, K. S., D'Agostino, F., Riegel, B., Juárez- Vela, R., ... & Lee, C. S. (2015). Determinants of heart failure self-care maintenance and management in patients and caregivers: A dyadic analysis. *Research in Nursing & Health*, *38*, 392-402. doi:10.1002/nur.21675

Bekhet, A. K., & Zauszniewski, J. A. (2012). Methodological triangulation: An approach to understanding data. *Nurse Researcher*, *20*(2), 40-43. doi:10.7748/nr2012.11.20.2.40.c9442

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*, 219-234. doi:10.1177/1468794112468475

Blauer, C., Frei, I. A., Schnepp, W., & Spirig, R. (2015). Implementation of a nurse-led education program for chronic heart failure patients during hospitalization, and strategies supporting their self-management at home: A practice development project in the context of the Swiss healthcare system. *International Practice Development Journal*, *5*(1), 1-15. Retrieved from http://www.fons.org/library/journal.aspx

Bonis, S. A. (2013). Concept analysis: Method to enhance interdisciplinary conceptual understanding. *Advances in Nursing Science*, *36*(2), 80-93. doi:10.1097/ANS.0b013e318290d86e

Bowen, G. A. (2006). Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods, 5*(3), 12-23. doi:10.1177/160940690600500304

Boychuk Duchscher, J. E., & Morgan, D. (2004). Grounded theory: Reflections on the emergence vs. forcing debate. *Journal of Advanced Nursing*, *48*, 605-612. doi:10.1111/j.1365-2648.2004.03249.x

Bratzke, L. C., Muehrer, R. J., Kehl, K. A., Lee, K. S., Ward, E. C., & Kwekkeboom, K. L. (2015). Self-management priority setting and decision-making in adults with multimorbidity: A narrative review of literature. *International Journal of Nursing Studies*, *52*(3), 744-755. doi:10.1016/j.ijnurstu.2014.10.010

Buck, H. G., Harkness, K., Wion, R., Carroll, S. L., Cosman, T., Kaasalainen, S., ... Strachan, P. H. (2014). Caregivers' contributions to heart failure self-care: A systematic review. *European Journal of Cardiovascular Nursing*, *14* (1), 79-89. doi:10.1177/1474515113518434

Buck, H. G., McAndrew, L., Dionne-Odom, J. N., Wion, R., & Riegel, B. (2015). "What are they thinking?" Patients' cognitive representations of heart failure self-care. *Journal of Hospice & Palliative Nursing*, *17*, 249-256. doi:10.1097/NJH.0000000000000156

Bui, A. L., Horwich, T. B., & Fonarow, G. C. (2011). Epidemiology and risk profile of heart failure. *Nature Reviews Cardiology*, *8*(1), 30-41. doi:10.1038/nrcardio.2010.165

Callahan, D., Wilson, E., Birdsall, I., Estabrook-Fishinghawk, B., Carson, G., Ford, S., … Yob, I. (2012). *Expanding our understanding of social change: A report from the Definition Task Force of the HLC special emphasis project.* Walden University.

Cameron, J., Worrall-Carter, L., Page, K., & Stewart, S. (2010). Self-care behaviors and heart failure: Does experience with symptoms really make a difference? *European Journal of Cardiovascular Nursing*, *9*, 92-100. doi:10.1016/j.ejcnurse.2009.10.004

Canadian Thoracic Society (2010). *The human and economic burden of COPD: A leading cause of hospital admission in Canada.* Retrieved from http://www.respiratoryguidelines.ca/sites/all/files/CTS_COPD_report.pdf

Cardiac Care Network (2014). *Strategy for community management of heart failure in Ontario.* Retrieved from http://ccn.on.ca/ccn_public/FormsPublication /ccn_documents.aspx

Carroll, S. L., Strachan, P. H., de Laat, S., Schwartz, L., & Arthur, H. M. (2013). Patients' decision making to accept or decline an implantable cardioverter defibrillator for primary prevention of sudden cardiac death. *Health Expectations*, *16*(1), 69-79. doi:10.1111/j.1369-7625.2011.00703.x

Charmaz, K. (2014). *Constructing grounded theory*. Thousand Oaks, CA: Sage.

Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.

Chen, A. M., Yehle, K. S., Albert, N. M., Ferraro, K. F., Mason, H. L., Murawski, M. M., & Plake, K. S. (2014). Relationships between health literacy and heart failure knowledge, self-efficacy, and self-care adherence. *Research in Social and Administrative Pharmacy, 10*, 378-386. doi:10.1016/j.sapharm.2013.07.001

Clark, A. M., Savard, L. A., Spaling, M. A., Heath, S., Duncan, A. S., & Spiers, J. A. (2012). Understanding help-seeking decisions in people with heart failure: A qualitative systematic review. *International Journal of Nursing Studies*, *49*, 1582-1597. doi:10.1016/j.ijnurstu.2012.05.010

Cleary, M., Horsfall, J., & Hayter, M. (2014). Data collection and sampling in qualitative research: does size matter? *Journal of Advanced Nursing, 70*, 473-475. doi: 10.1111/jan.12163

Cockayne, S., Pattenden, J., Worthy, G., Richardson, G., & Lewin, R. (2014). Nurse facilitated self-management support for people with heart failure and their family carers (SEMAPHFOR): A randomised controlled trial. *International Journal of Nursing Studies*, *51*, 1207-1213. doi:10.1016/j.ijnurstu.2014.01.010

Cooney, A. (2011). Rigour and grounded theory. *Nurse Researcher*, *18*(4), 17-22. doi:10.7748/nr2011.07.18.4.17.c8631

Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory (4th Ed)*. Thousand Oaks, CA: Sage.

Creber, R. M., Patey, M., Lee, C. S., Kuan, A., Jurgens, C., & Riegel, B. (2016). Motivational interviewing to improve self-care for patients with chronic heart failure: MITI-HF randomized controlled trial. *Patient Education and Counseling*, *99,* 256-264. doi:10.1016/j.pec.2015.08.031

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches (3rd ed.)*. Thousand Oaks, CA: Sage.

Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, *31*, 1476-1484. doi:10.1046/j.1365-2648.2000.01430.x

Dickson, V. V., Melkus, G. D. E., Katz, S., Levine-Wong, A., Dillworth, J., Cleland, C. M., & Riegel, B. (2014). Building skill in heart failure self-care among community dwelling older adults: Results of a pilot study. *Patient Education and Counseling*, *96*, 188-196. doi:10.1016/j.pec.2014.04.018

Falk, K., Patel, H., Swedberg, K., & Ekman, I. (2009). Fatigue in patients with chronic heart failure—a burden associated with emotional and symptom distress. *European Journal of Cardiovascular Nursing*, *8*(2), 91-96. doi:10.1016/j.ejcnurse.2008.07.002

Fergenbaum, J., Bermingham, S., Krahn, M., Alter, D., & Demers, C. (2015). Care in the home for the management of chronic heart failure: Systematic review and cost-effectiveness analysis. *The Journal of Cardiovascular Nursing 30*(4S). doi:10.1097/JCN.0000000000000235

Friedman, M. M. (1997). Older adults' symptoms and their duration before hospitalization for heart failure. *Heart & Lung: The Journal of Acute and Critical Care*, *26*(3), 169-176. doi:10.1016/S0147-9563(97)90053-4

Glaser, B. (2009). The novice GT researcher. *The Grounded Theory Review*, *8*(2), 1-22.

Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Graven, L. J., Grant, J. S., & Gordon, G. (2015). Symptomatology and coping resources predict self-care behaviors in middle to older age patients with heart failure. *Nursing Research and Practice*. doi:10.1155/2015/840240

Harkness, K., Heckman, G. A., Akhtar-Danesh, N., Demers, C., Gunn, E., & McKelvie, R. S. (2014). Cognitive function and self-care management in older patients with heart failure. *European Journal of Cardiovascular Nursing, 13*, 277-284. doi:10.1177/1474515113492603

Heart and Stroke Foundation (2015). *Heart failure: Symptoms and diagnosis.* Retrieved from http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3484065/k.9224 /Heart_failure.htm#symptoms-tab

Heart and Stroke Foundation (n.d.). *Managing heart failure*. Retrieved from http://www.heartandstroke.com/atf/cf/%7B96C39C8B-81B4-4C82-A505-39EC3A05B328%7D/manage-heart-failure-en.pdf

Heath, H., & Cowley, S. (2004). Developing a grounded theory approach: A comparison of Glaser and Strauss. *International Journal of Nursing Studies*, *41*(2), 141-150. doi:10.1016/S0020-7489(03)00113-5

Hedemalm, A., Schaufelberger, M., & Ekman, I. (2008). Symptom recognition and health care seeking among immigrants and native Swedish patients with heart failure. *BMC Nursing*, *7*(1), 1. doi:10.1186/1472-6955-7-9

Herr, J. K., Salyer, J., Lyon, D. E., Goodloe, L., Schubert, C., & Clement, D. G. (2014). Heart failure symptom relationships: A systematic review. *Journal of Cardiovascular Nursing*, *29*, 416-422. doi:10.1097/JCN.0b013e31829b675e

Herrera, P. A., Moncada, L., & Defey, D. (2016). Understanding non-adherence from the inside hypertensive patients’ motivations for adhering and not Adhering. *Qualitative Health Research*, 1-13. doi:10.1177/1049732316652529.

Hibbert, P., Sillince, J., Diefenbach, T., & Cunliffe, A. L. (2014). Relationally reflexive practice a generative approach to theory development in qualitative research. *Organizational Research Methods*, *17*, 278-298. doi:10.1177/1094428114524829

Howlett, J. G., Chan, M., Ezekowitz, J. A., Harkness, K., Heckman, G. A., Kouz, S., ... & Ducharme, A. (2016). The Canadian Cardiovascular Society heart failure companion: Bridging guidelines to your practice. *Canadian Journal of Cardiology*, *32,* 296-310. doi:10.1016/j.cjca.2015.06.019

Hwang, B., Moser, D. K., & Dracup, K. (2014). Knowledge is insufficient for self-care among heart failure patients with psychological distress. *Health Psychology, 33,* 588-596. doi:10.1037/a0033419

Jaarsma, T., Årestedt, K. F., Mårtensson, J., Dracup, K., & Strömberg, A. (2009). The European Heart Failure Self- care Behaviour scale revised into a nine- item scale (EHFScB- 9): A reliable and valid international instrument. *European Journal of Heart Failure*, *11*(1), 99-105. doi:10.1093/eurjhf/hfn007

Jaarsma, T., Strömberg, A., Gal, T. B., Cameron, J., Driscoll, A., Duengen, H. D., ... Köberich, S. (2013). Comparison of self-care behaviors of heart failure patients in 15 countries worldwide. *Patient Education and Counseling*, *92*(1), 114-120. doi:10.1016/j.pec.2013.02.017

Jackson, A. Y., & Mazzei, L. A. (2013). Plugging one text into another thinking with theory in qualitative research. *Qualitative Inquiry*, *19*, 261-271. doi:10.1177/1077800412471510

Janesick, V. J. (2011). *"Stretching" exercises for qualitative researchers* (3rd ed.). Thousand Oaks, CA: Sage.

Jones, J., McDermott, C. M., Nowels, C. T., Matlock, D. D., & Bekelman, D. B. (2012). The experience of fatigue as a distressing symptom of heart failure. *Heart & Lung: The Journal of Acute and Critical Care*, *41*, 484-491. doi:10.1016/jhrtlng.2012.04.004

Jonkman, N. H., Westland, H., Groenwold, R. H., Ågren, S., Anguita, M., Blue, L., ... & Kempen, G. I. (2016). What are effective program characteristics of self-management interventions in patients with heart failure? An individual patient data meta-analysis. *Journal of Cardiac Failure*. doi:10.1016/j.cardfail.2016.06.422

Jurgens, C. Y. (2006). Somatic awareness, uncertainty, and delay in care- seeking in acute heart failure. *Research in Nursing & Health*, *29*(2), 74-86. doi:10.1002/nur.20118

Jurgens, C. Y., Lee, C. S., Reitano, J. M., & Riegel, B. (2013). Heart failure symptom monitoring and response training. *Heart & Lung: The Journal of Acute and Critical Care*, *42*, 273-280. doi:10.1016/j.hrtlng.2013.03.005

Jurgens, C. Y., Moser, D. K., Armola, R., Carlson, B., Sethares, K., & Riegel, B. (2009). Symptom clusters of heart failure. *Research in Nursing & Health*, *32*, 551-560. doi:10.1002/nur.20343

Kessing, D., Denollet, J., Widdershoven, J., & Kupper, N. (2015). Fatigue and self-care in patients with chronic heart failure. *European Journal of Cardiovascular Nursing*, doi:10.1177/1474515115575834

Koro-Ljungberg, M. (2010). Validity, responsibility, and aporia. *Qualitative Inquiry*, *16*, 603-610. doi:10.1177/1077800410374034

Lam, C., & Smeltzer, S. C. (2013). Patterns of symptom recognition, interpretation, and response in heart failure patients: An integrative review. *Journal of Cardiovascular Nursing*, *28*, 348-359. doi:10.1097/JCN.0b013e3182531cf7

Lee, C. S., Gelow, J. M., Mudd, J. O., Green, J. K., Hiatt, S. O., Chien, C., & Riegel, B. (2015c). Profiles of self-care management versus consulting behaviors in adults with heart failure. *European Journal of Cardiovascular Nursing*. doi:10.1177/1474515113519188

Lee, C. S., Hiatt, S. O., Denfeld, Q. E., Mudd, J. O., Chien, C., & Gelow, J. M. (2015a). Symptom-hemodynamic mismatch and heart failure event risk. *Journal of Cardiovascular Nursing*, *30*, 394-402. doi:10.1097/JCN.0000000000000175

Lee, C. S., Mudd, J. O., Hiatt, S. O., Gelow, J. M., Chien, C., & Riegel, B. (2015b). Trajectories of heart failure self-care management and changes in quality of life. *European Journal of Cardiovascular Nursing*, 14, 486-494. doi:10.1177/1474515114541730

Lee, K. S., Lennie, T. A., Dunbar, S. B., Pressler, S. J., Heo, S., Song, E. K., ... Moser, D. K. (2014). The association between regular symptom monitoring and self-care management in patients with heart failure. *The Journal of Cardiovascular Nursing*, *30*, 145-151. doi:10.1097/JCN.0000000000000128

Lee, K. S., Moser, D. K., Pelter, M. M., Nesbitt, T., & Dracup, K. (2016). Self-care in rural residents with heart failure: What we are missing. *European Journal of Cardiovascular Nursing*. doi:10.1177/1474515116666439

Lipshitz, R., Klein, G., Orasanu, J., & Salas, E. (2001). Taking stock of naturalistic decision making. *Journal of Behavioral Decision Making*, *14*, 331-352. doi:10.1002/bdm.381

Lockhart, E., Foreman, J., Mase, R., & Heisler, M. (2014). Heart failure patients' experiences of a self-management peer support program: A qualitative study. *Heart & Lung: The Journal of Acute and Critical Care*, *43*, 292-298. doi:10.1016/j.hrtlng.2014.04.008

MacInnes, J. (2013). Relationships between illness representations, treatment beliefs and the performance of self-care in heart failure: A cross-sectional survey. *European Journal of Cardiovascular Nursing*, *12*, 536-543. doi:10.1177/1474515112473872

MacPherson, A., Walshe, C., O’Donnell, V., & Vyas, A. (2013). The views of patients with severe chronic obstructive pulmonary disease on advance care planning: a qualitative study. *Palliative Medicine*, *27*, 265-272. doi:10.1177/0269216312440606

Marti, C. N., Georgiopoulou, V. V., Giamouzis, G., Cole, R. T., Deka, A., Tang, W. W., ... Butler, J. (2013). Patient- reported selective adherence to heart failure self-care recommendations: A prospective cohort study: The Atlanta Cardiomyopathy Consortium. *Congestive Heart Failure*, *19*(1), 16-24. doi**:** 10.1111/j.1751-7133.2012.00308.x

Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (3rd ed.). Thousand Oaks, CA: Sage.

McKelvie, R. S., Moe, G. W., Ezekowitz, J. A., Heckman, G. A., Costigan, J., Ducharme, A., ... Howlett, J. G. (2013). The 2012 Canadian Cardiovascular Society heart failure management guidelines update: Focus on acute and chronic heart failure. *Canadian Journal of Cardiology*, *29*, 168-181. doi:10.1016/j.cjca.2012.10.007

Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Thousand Oaks, CA: Sage.

Morse, J. M. (2001). Situating grounded theory within qualitative inquiry. In R. S. Schreiber & P. N. Stern (Eds.), *Using grounded theory in nursing* (pp. 1-15). New York, NY: Springer Publishing Company.

Moser, D. K., Frazier, S. K., Worrall-Carter, L., Biddle, M. J., Chung, M. L., Lee, K. S., & Lennie, T. A. (2011). Symptom variability, not severity, predicts rehospitalisation and mortality in patients with heart failure. *European Journal of Cardiovascular Nursing*, *10* (2), 124-129. doi:10.1016/j.ejcnurse.2010.05.006

Moser, D. K., Lee, K. S., Wu, J. R., Mudd-Martin, G., Jaarsma, T., Huang, T. Y., ... Riegel, B. (2014). Identification of symptom clusters among patients with heart failure: An international observational study. *International Journal of Nursing Studies*, *51*, 1366-1372. doi:10.1016/j.ijnurstu.2014.02.004

Moser, D. K., & Watkins, J. F. (2008). Conceptualizing self-care in heart failure: A life course model of patient characteristics. *Journal of Cardiovascular Nursing*, *23*, 205-218. doi:10.1097/01.JCN.0000305097.09710.a5

Okumura, N., Jhund, P. S., Gong, J., Lefkowitz, M. P., Rizkala, A. R., Rouleau, J. L., ... & Packer, M. (2016). Importance of clinical worsening of heart failure treated in the outpatient setting: Evidence from the prospective comparison of ARNI with ACEI to determine impact on global mortality and morbidity in heart failure trial (PARADIGM-HF). *Circulation*, 133, 2254-2262. doi:10.1161/CIRCULATIONAHA.115.020729

O'Reilly, M., & Parker, N. (2012). Unsatisfactory Saturation: A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, *13*, 190-197. doi:10.1177/1468794112446106

Östman, M., Ung, E. J., & Falk, K. (2015). Health-care encounters create both discontinuity and continuity in daily life when living with chronic heart failure: A grounded theory study. *International Journal of Qualitative Studies on Health and Well-being*, *10*. doi:10.3402/qhw.v10.27775

Otsu, H., & Moriyama, M. (2011). Effectiveness of an educational self- management program for outpatients with chronic heart failure. *Japan Journal of Nursing Science, 8*, 140-152. doi:10.1111/j.1742-7924.2010.00166.x

Pang, P. S., Collins, S. P., Sauser, K., Andrei, A. C., Storrow, A. B., Hollander, J. E., ... Nowak, R. (2014). Assessment of dyspnea early in acute heart failure: Patient characteristics and response differences between Likert and visual analog scales. *Academic Emergency Medicine*, *21*, 659-666. doi:10.1111/acem.12390

Patton, M. Q. (2015*). Qualitative research & evaluation methods* (4th ed.). Thousand Oaks, CA: Sage.

Payne, C., Wiffen, P. J., & Martin, S. (2012). Interventions for fatigue and weight loss in adults with advanced progressive illness. *The Cochrane Library*. doi**:**10.1002/14651858.CD008427.pub2

Peters-Klimm, F., Freund, T., Kunz, C. U., Laux, G., Frankenstein, L., Müller-Tasch, T., & Szecsenyi, J. (2013). Determinants of heart failure self-care behaviour in community-based patients: A cross-sectional study. *European Journal of Cardiovascular Nursing*, *12*, 167-176. doi:10.1177/1474515112439964

Piamjariyakul, U., Smith, C. E., Werkowitch, M., & Elyachar, A. (2012). Part I: Heart failure home management: Patients, multidisciplinary health care professionals and family caregivers' perspectives. *Applied Nursing Research*, *25*, 239-245. doi:10.1016/j.apnr.2011.05.001

Radley, A., & Chamberlain, K. (2012). The study of the case: Conceptualising case study research. *Journal of Community & Applied Social Psychology*, *22*, 390-399. doi: 10.1002/casp.1106

Reeder, K. M., Ercole, P. M., Peek, G. M., & Smith, C. E. (2015). Symptom perceptions and self-care behaviors in patients who self-manage heart failure. *The Journal of Cardiovascular Nursing*, *30*(1), E1-E7. doi:10.1097/JCN.0000000000000117

Registered Nurses Association of Ontario (2010). Clinical Best Practice Guideline: *Strategies to support self-management in chronic conditions: Collaboration with clients.* Retrieved from http://rnao.ca/sites/rnao-ca/files/Strategies_to_Support_Self-Management_in_Chronic_Conditions_-_Collaboration_with_Clients.pdf

Riegel, B., Carlson, B., & Glaser, D. (2000). Development and testing of a clinical tool measuring self-management of heart failure. *Heart & Lung: The Journal of Acute and Critical Care*, *29*(1), 4-15. doi:10.1016/S0147-9563(00)90033-5

Riegel, B., & Dickson, V. (2008). A situation-specific theory of heart failure self-care. *Journal of Cardiovascular Nursing, 23*, 190-196. doi:10.1097/01.JCN.0000305091.35259.85

Riegel, B., Dickson, V. V., Cameron, J., Johnson, J. C., Bunker, S., Page, K., & Worrall- Carter, L. (2010). Symptom recognition in elders with heart failure. *Journal of Nursing Scholarship*, *42*(1), 92-100. doi:10.1111/j.1547-5069.2010.01333.x

Riegel, B., Dickson, V. V., & Faulkner, K. M. (2016). The situation-specific theory of heart failure self-care: Revised and updated. *Journal of Cardiovascular Nursing*, *31*, 226-235. doi:10.1097/JCN.0000000000000244

Riegel, B., Dickson, V. V., & Topaz, M. (2013). Qualitative analysis of naturalistic decision making in adults with chronic heart failure. *Nursing Research, 62*(2), 91-98. doi:10.1097/NNR.0b013e318276250c

Riegel, B., Jaarsma, T., & Strömberg, A. (2012). A middle-range theory of self-care of chronic illness. *Advances in Nursing Science*, *35*, 194-204. doi:10.1097/ANS.0b013e318261b1ba

Riegel, B., Lee, C. S., Dickson, V. V., & Carlson, B. (2009). An update on the self-care of heart failure index. *The Journal of Cardiovascular Nursing*, *24,* 485. doi:10.1097/JCN.0b013e3181b4baa0

Rise, M. B., Solbjør, M., Lara, M. C., Westerlund, H., Grimstad, H., & Steinsbekk, A. (2013). Same description, different values. How service users and providers define patient and public involvement in health care. *Health Expectations*, *16,* 266-276. doi:10.1111/j.1369-7625.2011.00713.x

Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: The art of hearing data* (3rd Ed.). Thousand Oaks, CA: Sage.

Sacco, S. J., Park, C. L., Suresh, D. P., & Bliss, D. (2014). Living with heart failure: Psychosocial resources, meaning, gratitude and well-being. *Heart & Lung: The Journal of Acute and Critical Care*, *43,* 213-218. doi:10.1016/j.hrtlng.2014.01.012

Schjoedt, I., Sommer, I., & Bjerrum, M. B. (2016). Experiences and management of fatigue in everyday life among adult patients living with heart failure: A systematic review of qualitative evidence. *JBI Database of Systematic Reviews and Implementation Reports, 14*(3), 68-115. doi:10.11124/JBISRIR-2016-2441

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., … Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship : An Official Publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau*, *44*, 136–144. doi:10.1111/j.15475069.2012.01444.x

Scott, H. (2009). Data analysis: Getting conceptual. *The Grounded Theory Review*, *8*(2), 89-112. Retrieved from http://groundedtheoryreview.com/2009/06/30/855/

Selan, S., Siennicki-Lantz, A., Berglund, J., & Fagerström, C. (2016). Self-awareness of heart failure in the oldest old–an observational study of participants, ≥ 80 years old, with an objectively verified heart failure. *BMC Geriatrics*, *16*(1), 1-8. doi:10.1186/s1287701601954

Sethares, K. A., Sosa, M., Fisher, P., & Riegel, B. (2014). Factors associated with delay in seeking care for acute decompensated heart failure. *Journal of Cardiovascular Nursing, 29*, 429-438. doi:10.1097/JCN.0b013e3182a37789

Shively, M. J., Gardetto, N. J., Kodiath, M. F., Kelly, A., Smith, T. L., Stepnowsky, C., ... Larson, C. B. (2013). Effect of patient activation on self-management in patients with heart failure. *Journal of Cardiovascular Nursing, 28*(1), 20-34. doi:10.1097/JCN.0b013e318239f9f9

Siabani, S., Leeder, S. R., & Davidson, P. M. (2013). Barriers and facilitators to self-care in chronic heart failure: A meta-synthesis of qualitative studies. *SpringerPlus, 2*(1), 1-14. doi:10.1186/2193-1801-2-320

Simmonds, R., Glogowska, M., McLachlan, S., Cramer, H., Sanders, T., Johnson, R., ... Purdy, S. (2015). Unplanned admissions and the organisational management of heart failure: A multicentre ethnographic, qualitative study. *BMJ Open*, *5*(10), e007522.

Spaling, M. A., Currie, K., Strachan, P. H., Harkness, K., & Clark, A. M. (2015). Improving support for heart failure patients: A systematic review to understand patients' perspectives on self- care. *Journal of Advanced Nursing*, *71*, 2478-2489. doi:10.1111/jan.12712

Srisuk, N., Cameron, J., Ski, C. F., & Thompson, D. R. (2016). Heart failure family-based education: A systematic review. *Patient Education and Counseling*, *99*, 326-338. doi:10.1016/j.pec.2015.10.009

Stamp, K. D. (2011). Self-care in women with heart failure and the effectiveness of nurse-led educational interventions: A review of the literature. *Journal of Nursing and Healthcare of Chronic Illness, 3*, 339-351. doi:10.1111/j.1752-9824.2011.01115.x

Strauss, A. (1987). *Qualitative Analysis for Social Scientists*. New York, NY: Cambridge University Press.

Taylor, R. S., Sagar, V. A., Davies, E. J., Briscoe, S., Coats, A. J., Dalal, H., ... Singh, S. (2014). Exercise- based rehabilitation for heart failure. *The Cochrane Library*. Issue 4. Art. No.: CD003331. doi:10.1002/14651858.CD003331.pub4.

Tierney, S., Elwers, H., Sange, C., Mamas, M., Rutter, M. K., Gibson, M., ... Deaton, C. (2011). What influences physical activity in people with heart failure? A qualitative study. *International Journal of Nursing Studies*, *48*, 1234-1243. doi:10.1016/j.ijnurstu.2011.03.003

Tuohy, D., Cooney, A., Dowling, M., Murphy, K., & Sixsmith, J. (2013). An overview of interpretive phenomenology as a research methodology. *Nurse Researcher, 20*(6), 17-20. doi:10.7748/nr2013.07.20.6.17.e315

Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry, 16*, 837-851. doi:10.1177/1077800410383121

Udlis, K. A. (2011). Self- management in chronic illness: Concept and dimensional analysis. *Journal of Nursing and Healthcare of Chronic Illness*, *3*(2), 130-139. doi:10.1111/j.1752-9824.2011.01085.x

Van Riet, E. E., Hoes, A. W., Limburg, A., Landman, M. A., Van der Hoeven, H., & Rutten, F. H. (2014). Prevalence of unrecognized heart failure in older persons with shortness of breath on exertion. *European Journal of Heart Failure*, *16*, 772-777. doi:10.1002/ejhf.110

Vellone, E., Fida, R., D’Agostino, F., Mottola, A., Juarez-Vela, R., Alvaro, R., & Riegel, B. (2015). Self-care confidence may be the key: A cross-sectional study on the association between cognition and self-care behaviors in adults with heart failure. *International Journal of Nursing Studies*, *52*, 1705-1713. doi:10.1016/j.ijnurstu.2015.06.013

Vijayakrishnan, R., Steinhubl, S. R., Ng, K., Sun, J., Byrd, R. J., Daar, Z., ... Stewart, W. F. (2014). Prevalence of heart failure signs and symptoms in a large primary care population identified through the use of text and data mining of the electronic health record. *Journal of Cardiac Failure*, *20*, 459-464. doi:10.1016/j.cardfail.2014.03.008

Walker, D., & Myrick, F. (2006). Grounded theory: An exploration of process and procedure. *Qualitative Health Research*, *16*, 547-559. doi:10.1177/1049732305285972

Wingham, J., Harding, G., Britten, N., & Dalal, H. (2014). Heart failure patients' attitudes, beliefs, expectations and experiences of self-management strategies: A qualitative synthesis. *Chronic Illness*, *10*(2), 135-154. doi:10.1177/1742395313502993

Wortz, K., Cade, A., Menard, J. R., Lurie, S., Lykens, K., Bae, S., ... Coultas, D. (2012). A qualitative study of patients' goals and expectations for self-management of COPD. *Primary Care Respiratory Journal: Journal of the General Practice Airways Group*, *21*, 384. doi:10.4104/pcrj.2012.00070

Xu, J., Abshire, M., & Han, H. (2016). Decision making among persons living with heart failure. *Journal of Cardiovascular Nursing, 31*(5), E1-E9. doi:10.1097/JCN.0000000000000312

Yin, R. K. (2015). *Qualitative research from start to finish* (2nd ed.). New York, NY: Guilford Publications.

Yu, D. S., Chan, H. Y., Leung, D. Y., Hui, E., & Sit, J. W. (2016). Symptom clusters and quality of life among patients with advanced heart failure. *Journal of Geriatric Cardiology: JGC, 13*, 408-414. doi:10.11909/jissn.1671-5411.2016.05.014

Zhang, K. M., Dindoff, K., Arnold, J. M. O., Lane, J., & Swartzman, L. C. (2015). What matters to patients with heart failure? The influence of non-health-related goals on patient adherence to self-care management. *Patient Education and Counseling, 98*, 927-934. doi:10.1016/j.pec.2015.04.011

Appendix A: Standard Education Tool

HEART FAILURE ZONES

- Weigh yourself in the morning before breakfast and write it on your weight log
- Avoid Processed Foods. Don't add salt to your diet. Daily Salt/Sodium Intake – 2000mg
- Limit your fluid intake - 6 to 8 cups Daily (This includes water, juice, tea, coffee, milk, soup)

Which HEART FAILURE ZONE are you in today?

GREEN ZONE	**ALL CLEAR – THIS ZONE IS YOUR GOAL** • My weight has not changed • I can do my daily activities as usual • I have no new swelling of my feet, ankles, legs or stomach
YELLOW ZONE	**CAUTION: THIS ZONE IS A WARNING** Call my doctor if: • I have gained or lost 2 pounds (1kg) in one day • I have gained or lost 5 pounds (2 to 3kg) in one week • I feel more short of breath than usual • I feel short of breath when I lie flat or wake up short of breath • I feel tired and weak
RED ZONE	**EMERGENCY** CALL **911** if I feel: • I'm struggling to breathe or can't catch my breath • My heart is "racing" • I can't think clearly or feel confused • I feel dizzy or lightheaded • I have sudden chest pain that won't go away

Appendix B: Letter of Permission

Centre communautaires

[redacted]

February 27, 2017

Connie Schumacher
Lead Clinical Coordinator
[redacted]

Dear Connie:

With regard to your study entitled: ***"Understanding Self-Management Decision-Making in Congestive Heart Failure"***, please be advised that, in my capacity of the senior executive with responsibility for research within the [redacted] you have been granted the permission of the [redacted] to distribute flyers pertaining to the study to patients linked to our [redacted] [redacted]

Best of luck with the study.

Sincerely,

[redacted]

Appendix C: Interview Protocol

Interview Protocol: Congestive Heart Failure Self-Management Decision Making

Interviewee Name: ________________________________ **Date:**

____

Interviewee Location: ____________________________ **Time of Interview:**

____

Interviewer: Constance Schumacher **Data Record No.** ______

Thank you for your time and participation in this interview on heart failure self-management. The results of this study and your contribution may be used to inform chronic disease management in the community.

I have selected several participants to participate in this study, they will be sharing their experience and answering the same questions. I would like to remind you that your participation is voluntary; if you are not comfortable answering a question please let me know. Your interview will be audio recorded to ensure that your responses are captured, and in that regards, I will periodically ask for clarification during the interview. Your responses will be treated with utmost confidentiality, responses will be reflected in the write-up as respondent 1, 2, or 3.

Interview Questions

1. To begin, please describe what self-management of heart failure means to you.
2. Describe a typical day of managing heart failure.
3. How does this change when you notice a change in symptoms or new symptoms?
4. Can you describe the symptoms that you are aware of on a daily basis?

5. Can you describe the symptoms that you were experiencing at the time of your most recent hospitalization?
6. Can you describe what meaning you assigned to how you were feeling just prior to hospitalization?
7. Given that information, at what point did you determine that you could not manage the symptoms on your own?
8. What symptoms do you find the most concerning or difficult to manage? What symptom do you find the easiest to manage?
9. What factors help or hinder your being able to care for your heart condition?
10. What actions can/do you take when you become concerned about your symptoms?
11. From your previous experience with heart failure, what actions do you find the most beneficial?
12. Describe your feelings of how in control you were over the course of this experience.
13. What are your goals for managing your heart failure?
14. Describe what resources/options are available to help you manage heart failure? If you could think of one thing that would help you manage your symptoms what would that be?

Justify the questions and their order:

RQ1: How does the community dwelling individual with CHF self-manage when a change in symptoms occurs?

Questions 9-14 are intended to reveal options and weighing of information to lead to help-seeking decisions.

RQ2: How does the individual perceive self-management as part of their daily life?

Question 1 and 2 are primers to identify how the participant perceives self-management.

RQ3: What meaning does the individual with CHF ascribe to fluctuations in symptoms?

Question 3-8 are intended to illicit responses on symptom perceptions, this will capture what the participant was feeling/exhibiting and the meaning that was placed on the symptoms.

RQ4: What are the factors that influence help-seeking behaviors when heart failure symptoms change?

Questions 8 and 11 are intended to explore what/who are perceived as resources that can help when symptoms change.

Appendix D: Field Notes

Field Notes Protocol

Date: ____

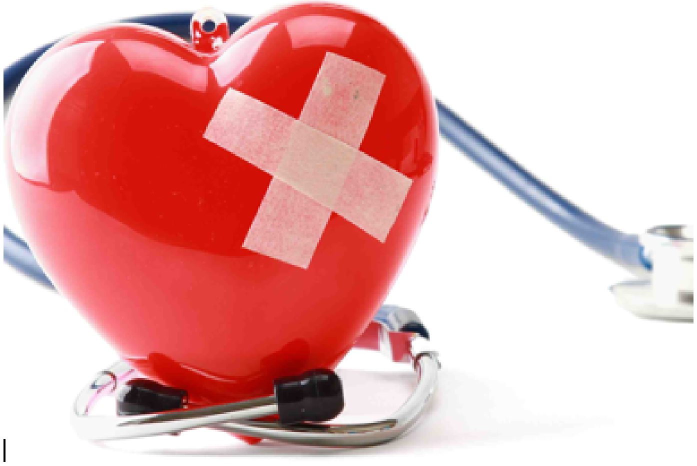
Time: ____

Location: ____

Interviewee (Unique identifier): ______________________________________

Descriptive / Observational Notes	Reflective Notes

Appendix E: Study Flyer



VOLUNTEERS NEEDED

HEART FAILURE SELF-MANAGEMENT STUDY

You are invited to participate in a research study focused on learning how you manage heart failure symptoms at home.

You are eligible if have

- experienced heart failure symptoms requiring hospitalization in the past 3 months

The results of this study will be used to increase nurses' understanding of how to better support you in managing heart failure at home.

The title of the study is *Heart Failure Self-Management Decision-Making*

This study involves an interview lasting approximately one hour

IF YOU ARE INTERESTED IN PARTICIPATING OR HAVE ANY QUESTIONS ABOUT THE STUDY PLEASE CONTACT

CONNIE SCHUMACHER

905-929-0536

Connie.schumacher@waldenu.edu

Appendix F: Study Electronic Audit

2017-05-13 7:07 PM

Project Summary

SelfManagementHeartFailure

2017-05-13 7:07 PM

Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On

C:\Users\Connie\Documents

Created By: **PhD**

Created On:

Last Modified By:

Case Classifications

Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On
	Node Classification	ConnieSchumacher	2017-03-05 3:07 PM	ConnieSchumacher	2017-05-02 4:25 PM

Cases

Cases\\Participants

Cases\\Themes

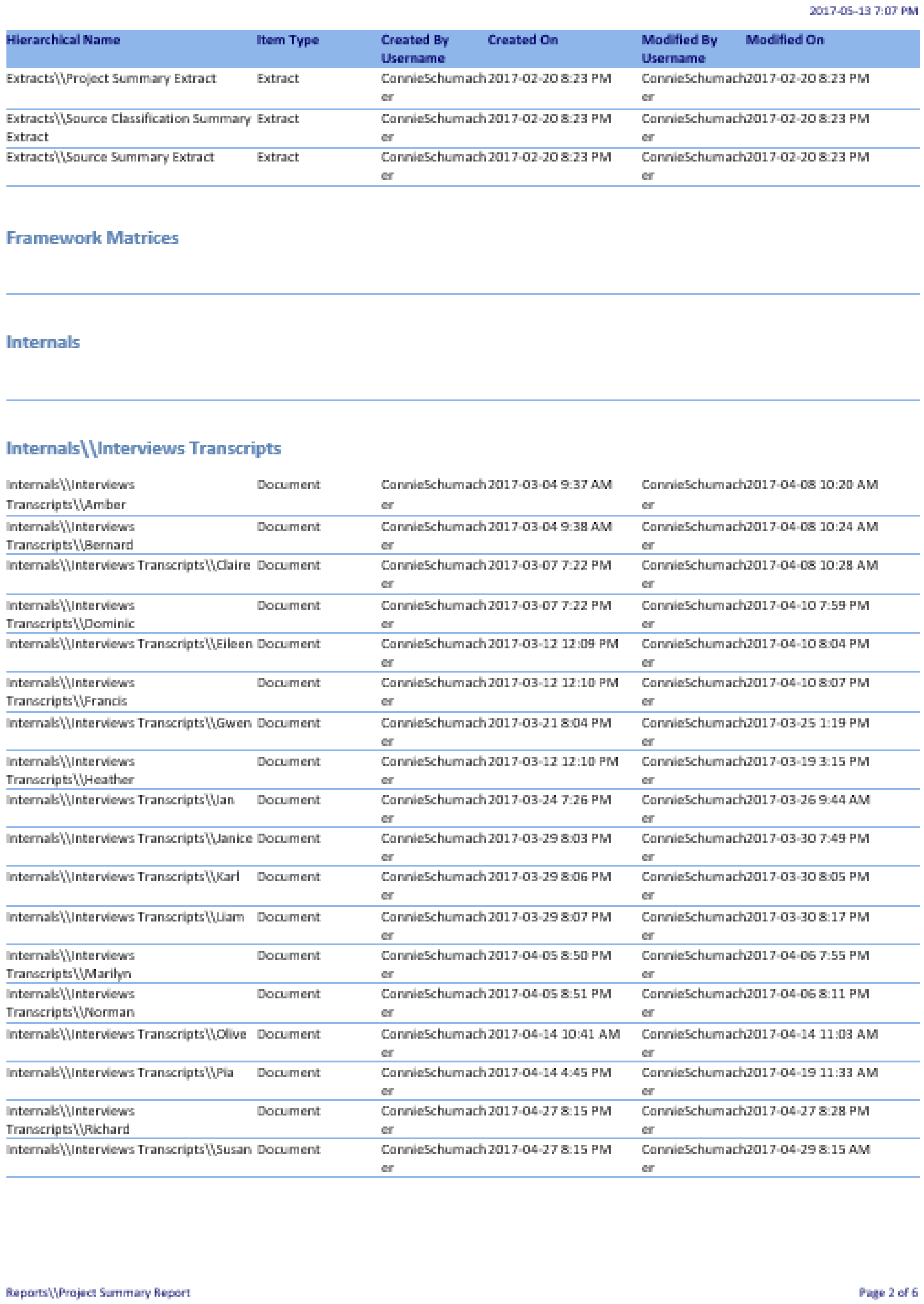
Externals

Extracts

Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On
Extracts\\Coding Summary By Node Extract	Extract	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Extracts\\Coding Summary By Source Extract	Extract	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Extracts\\Node Classification Summary Extract	Extract	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Extracts\\Node Structure Extract	Extract	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Extracts\\Node Summary Extract	Extract	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM

Reports\\Project Summary Report

Page 1 of 6



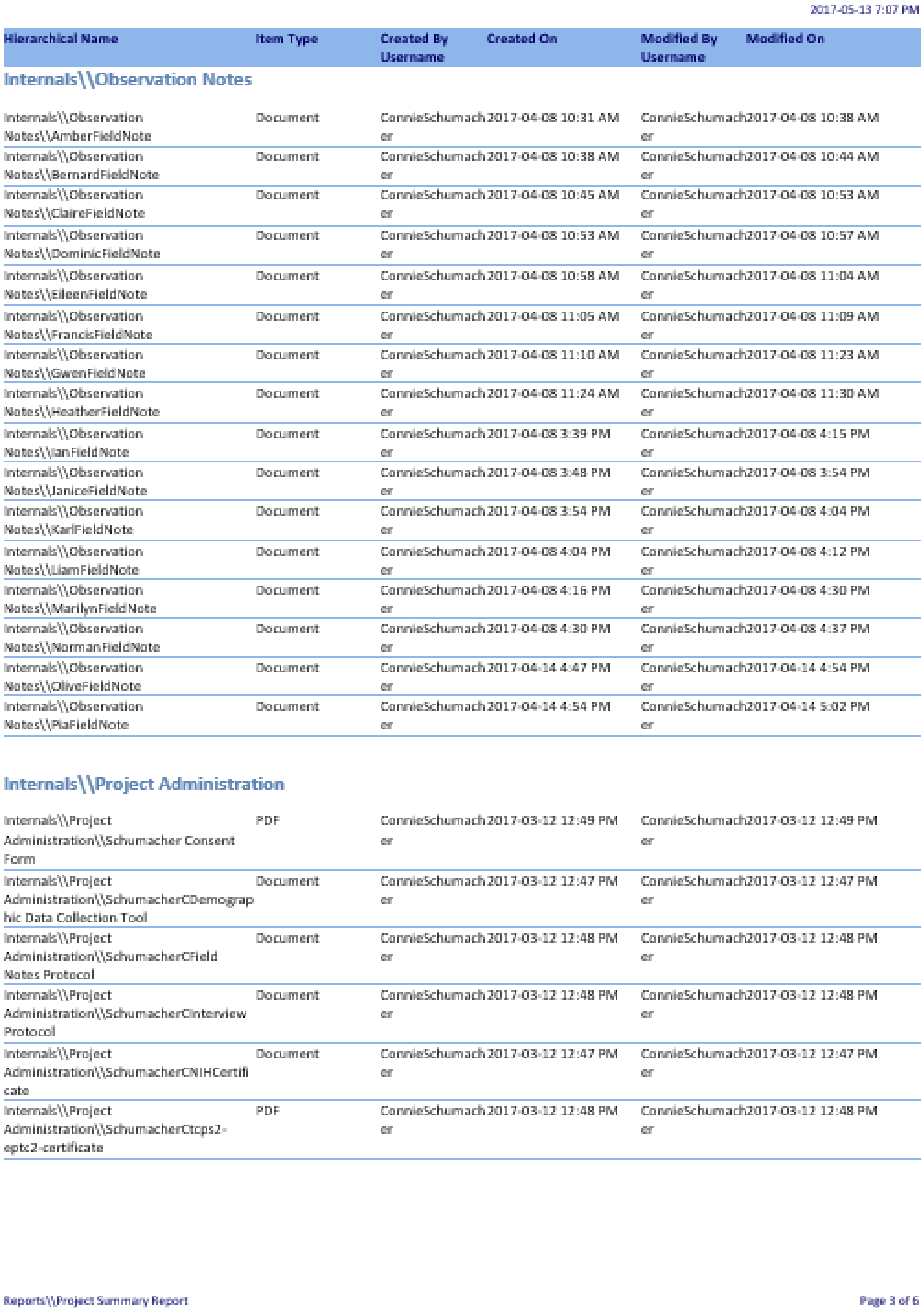
Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On
Extracts\\Project Summary Extract	Extract	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Extracts\\Source Classification Summary Extract	Extract	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Extracts\\Source Summary Extract	Extract	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM

Framework Matrices

Internals

Internals\\Interviews Transcripts

Internals\\Interviews Transcripts\\Amber	Document	ConnieSchumacher	2017-03-04 9:37 AM	ConnieSchumacher	2017-04-08 10:20 AM
Internals\\Interviews Transcripts\\Bernard	Document	ConnieSchumacher	2017-03-04 9:38 AM	ConnieSchumacher	2017-04-08 10:24 AM
Internals\\Interviews Transcripts\\Claire	Document	ConnieSchumacher	2017-03-07 7:22 PM	ConnieSchumacher	2017-04-08 10:28 AM
Internals\\Interviews Transcripts\\Dominic	Document	ConnieSchumacher	2017-03-07 7:22 PM	ConnieSchumacher	2017-04-10 7:59 PM
Internals\\Interviews Transcripts\\Eileen	Document	ConnieSchumacher	2017-03-12 12:09 PM	ConnieSchumacher	2017-04-10 8:04 PM
Internals\\Interviews Transcripts\\Francis	Document	ConnieSchumacher	2017-03-12 12:10 PM	ConnieSchumacher	2017-04-10 8:07 PM
Internals\\Interviews Transcripts\\Gwen	Document	ConnieSchumacher	2017-03-21 8:04 PM	ConnieSchumacher	2017-03-25 1:19 PM
Internals\\Interviews Transcripts\\Heather	Document	ConnieSchumacher	2017-03-12 12:10 PM	ConnieSchumacher	2017-03-19 3:15 PM
Internals\\Interviews Transcripts\\Jan	Document	ConnieSchumacher	2017-03-24 7:26 PM	ConnieSchumacher	2017-03-26 9:44 AM
Internals\\Interviews Transcripts\\Janice	Document	ConnieSchumacher	2017-03-29 8:03 PM	ConnieSchumacher	2017-03-30 7:49 PM
Internals\\Interviews Transcripts\\Karl	Document	ConnieSchumacher	2017-03-29 8:06 PM	ConnieSchumacher	2017-03-30 8:05 PM
Internals\\Interviews Transcripts\\Liam	Document	ConnieSchumacher	2017-03-29 8:07 PM	ConnieSchumacher	2017-03-30 8:17 PM
Internals\\Interviews Transcripts\\Marilyn	Document	ConnieSchumacher	2017-04-05 8:50 PM	ConnieSchumacher	2017-04-06 7:55 PM
Internals\\Interviews Transcripts\\Norman	Document	ConnieSchumacher	2017-04-05 8:51 PM	ConnieSchumacher	2017-04-06 8:11 PM
Internals\\Interviews Transcripts\\Olive	Document	ConnieSchumacher	2017-04-14 10:41 AM	ConnieSchumacher	2017-04-14 11:03 AM
Internals\\Interviews Transcripts\\Pia	Document	ConnieSchumacher	2017-04-14 4:45 PM	ConnieSchumacher	2017-04-19 11:33 AM
Internals\\Interviews Transcripts\\Richard	Document	ConnieSchumacher	2017-04-27 8:15 PM	ConnieSchumacher	2017-04-27 8:28 PM
Internals\\Interviews Transcripts\\Susan	Document	ConnieSchumacher	2017-04-27 8:15 PM	ConnieSchumacher	2017-04-29 8:15 AM



Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On

Internals\\Observation Notes

Internals\\Observation Notes\\AmberFieldNote	Document	ConnieSchumacher	2017-04-08 10:31 AM	ConnieSchumacher	2017-04-08 10:38 AM
Internals\\Observation Notes\\BernardFieldNote	Document	ConnieSchumacher	2017-04-08 10:38 AM	ConnieSchumacher	2017-04-08 10:44 AM
Internals\\Observation Notes\\ClaireFieldNote	Document	ConnieSchumacher	2017-04-08 10:45 AM	ConnieSchumacher	2017-04-08 10:53 AM
Internals\\Observation Notes\\DominicFieldNote	Document	ConnieSchumacher	2017-04-08 10:53 AM	ConnieSchumacher	2017-04-08 10:57 AM
Internals\\Observation Notes\\EileenFieldNote	Document	ConnieSchumacher	2017-04-08 10:58 AM	ConnieSchumacher	2017-04-08 11:04 AM
Internals\\Observation Notes\\FrancisFieldNote	Document	ConnieSchumacher	2017-04-08 11:05 AM	ConnieSchumacher	2017-04-08 11:09 AM
Internals\\Observation Notes\\GwenFieldNote	Document	ConnieSchumacher	2017-04-08 11:10 AM	ConnieSchumacher	2017-04-08 11:23 AM
Internals\\Observation Notes\\HeatherFieldNote	Document	ConnieSchumacher	2017-04-08 11:24 AM	ConnieSchumacher	2017-04-08 11:30 AM
Internals\\Observation Notes\\IanFieldNote	Document	ConnieSchumacher	2017-04-08 3:39 PM	ConnieSchumacher	2017-04-08 4:15 PM
Internals\\Observation Notes\\JaniceFieldNote	Document	ConnieSchumacher	2017-04-08 3:48 PM	ConnieSchumacher	2017-04-08 3:54 PM
Internals\\Observation Notes\\KarlFieldNote	Document	ConnieSchumacher	2017-04-08 3:54 PM	ConnieSchumacher	2017-04-08 4:04 PM
Internals\\Observation Notes\\LiamFieldNote	Document	ConnieSchumacher	2017-04-08 4:04 PM	ConnieSchumacher	2017-04-08 4:12 PM
Internals\\Observation Notes\\MarilynFieldNote	Document	ConnieSchumacher	2017-04-08 4:16 PM	ConnieSchumacher	2017-04-08 4:30 PM
Internals\\Observation Notes\\NormanFieldNote	Document	ConnieSchumacher	2017-04-08 4:30 PM	ConnieSchumacher	2017-04-08 4:37 PM
Internals\\Observation Notes\\OliveFieldNote	Document	ConnieSchumacher	2017-04-14 4:47 PM	ConnieSchumacher	2017-04-14 4:54 PM
Internals\\Observation Notes\\PiaFieldNote	Document	ConnieSchumacher	2017-04-14 4:54 PM	ConnieSchumacher	2017-04-14 5:02 PM

Internals\\Project Administration

Internals\\Project Administration\\Schumacher Consent Form	PDF	ConnieSchumacher	2017-03-12 12:49 PM	ConnieSchumacher	2017-03-12 12:49 PM
Internals\\Project Administration\\SchumacherCDemographic Data Collection Tool	Document	ConnieSchumacher	2017-03-12 12:47 PM	ConnieSchumacher	2017-03-12 12:47 PM
Internals\\Project Administration\\SchumacherCField Notes Protocol	Document	ConnieSchumacher	2017-03-12 12:48 PM	ConnieSchumacher	2017-03-12 12:48 PM
Internals\\Project Administration\\SchumacherCInterview Protocol	Document	ConnieSchumacher	2017-03-12 12:48 PM	ConnieSchumacher	2017-03-12 12:48 PM
Internals\\Project Administration\\SchumacherCNIHCertificate	Document	ConnieSchumacher	2017-03-12 12:47 PM	ConnieSchumacher	2017-03-12 12:47 PM
Internals\\Project Administration\\SchumacherCtcps2-eptc2-certificate	PDF	ConnieSchumacher	2017-03-12 12:48 PM	ConnieSchumacher	2017-03-12 12:48 PM

2017-05-13 7:07 PM

Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On
Nodes\\Control	Node	ConnieSchumacher	2017-03-19 2:24 PM	ConnieSchumacher	2017-04-29 8:15 AM
Nodes\\Emotions	Node	ConnieSchumacher	2017-04-08 10:12 AM	ConnieSchumacher	2017-04-29 8:04 AM
Nodes\\Help Seeking	Node	ConnieSchumacher	2017-03-19 1:40 PM	ConnieSchumacher	2017-04-29 8:13 AM
Nodes\\Help Seeking\Information	Node	ConnieSchumacher	2017-04-08 10:00 AM	ConnieSchumacher	2017-04-29 8:13 AM
Nodes\\Others	Node	ConnieSchumacher	2017-04-08 10:08 AM	ConnieSchumacher	2017-04-08 10:08 AM
Nodes\\Others\Medical Professionals	Node	ConnieSchumacher	2017-04-08 10:09 AM	ConnieSchumacher	2017-04-29 8:12 AM
Nodes\\Others\Personal Support System	Node	ConnieSchumacher	2017-04-08 10:10 AM	ConnieSchumacher	2017-04-29 8:15 AM
Nodes\\Perception of Others	Node	ConnieSchumacher	2017-03-19 1:41 PM	ConnieSchumacher	2017-04-29 8:05 AM
Nodes\\Self-Management	Node	ConnieSchumacher	2017-03-19 1:44 PM	ConnieSchumacher	2017-04-29 8:14 AM
Nodes\\Self-Management\Daily Alleviating Actions	Node	ConnieSchumacher	2017-04-08 10:06 AM	ConnieSchumacher	2017-04-29 8:14 AM
Nodes\\Self-Management\Independent Reasoning	Node	ConnieSchumacher	2017-04-08 10:04 AM	ConnieSchumacher	2017-04-29 8:06 AM
Nodes\\Symptoms	Node	ConnieSchumacher	2017-03-19 1:38 PM	ConnieSchumacher	2017-04-29 7:58 AM
Nodes\\Symptoms\Esculating Tipping Point	Node	ConnieSchumacher	2017-04-08 10:03 AM	ConnieSchumacher	2017-04-29 8:08 AM

Queries

Queries\\ReasoningNode	Query	ConnieSchumacher	2017-04-06 8:53 PM	ConnieSchumacher	2017-04-06 8:53 PM
Queries\\TS sit	Query	ConnieSchumacher	2017-05-02 4:13 PM	ConnieSchumacher	2017-05-02 4:13 PM
Queries\\TS_Breathing	Query	ConnieSchumacher	2017-03-26 9:28 AM	ConnieSchumacher	2017-03-26 9:28 AM
Queries\\TS_Doctor	Query	ConnieSchumacher	2017-03-26 9:29 AM	ConnieSchumacher	2017-03-26 9:29 AM
Queries\\TS_HelpandScared	Query	ConnieSchumacher	2017-03-26 9:24 AM	ConnieSchumacher	2017-03-26 9:26 AM
Queries\\TS_NodeAltering	Query	ConnieSchumacher	2017-04-10 7:22 PM	ConnieSchumacher	2017-04-10 7:22 PM
Queries\\WordFrequency in Alleviating	Query	ConnieSchumacher	2017-04-10 7:25 PM	ConnieSchumacher	2017-04-10 7:25 PM

Relationship Types

Relationship Types\\Associated	Relationship Type	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM

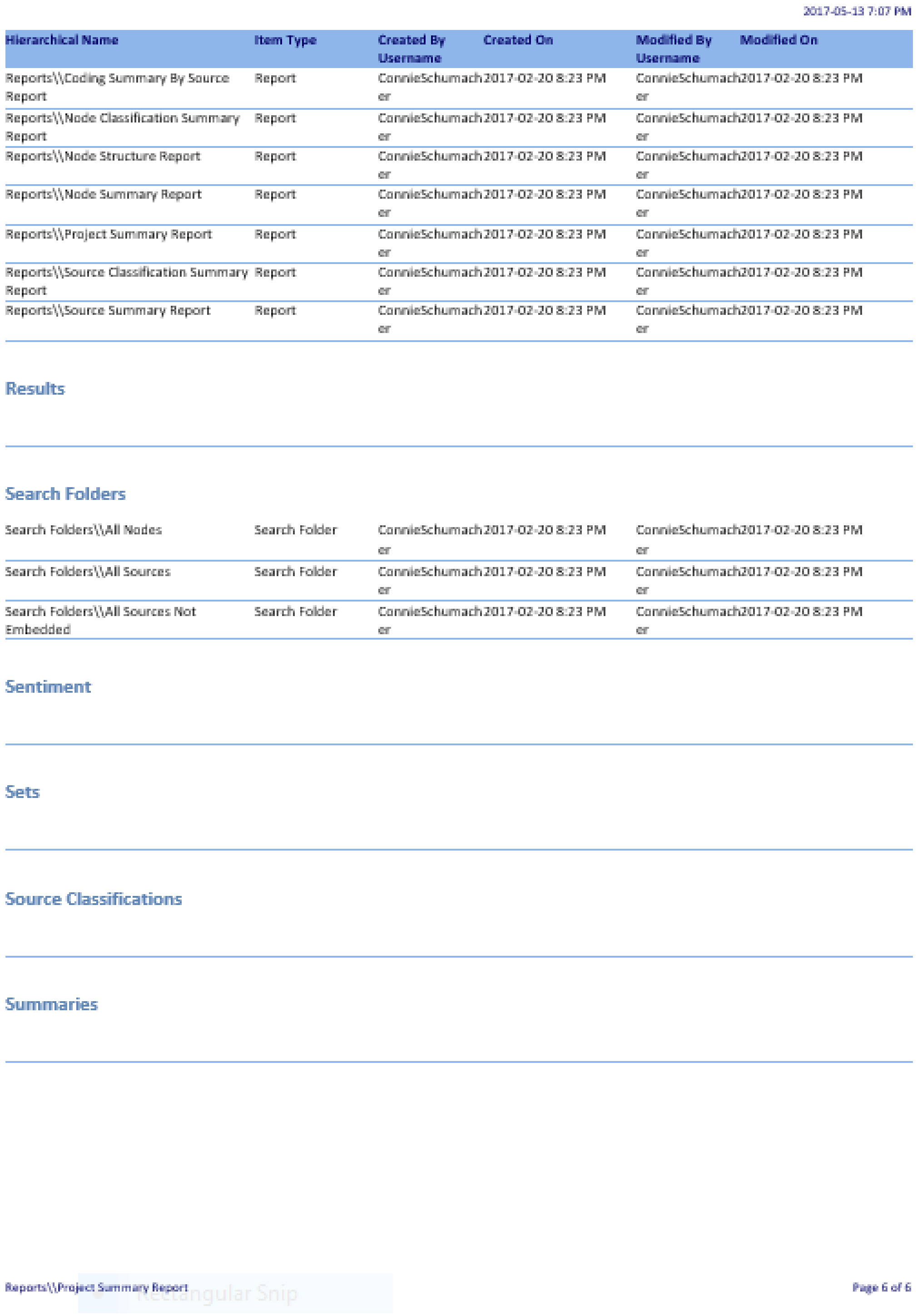
Relationships

Reports

Reports\\Coding Summary By Node Report	Report	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM

Reports\\Project Summary Report

Page 5 of 6



2017-05-13 7:07 PM

Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On
Reports\\Coding Summary By Source Report	Report	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Reports\\Node Classification Summary Report	Report	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Reports\\Node Structure Report	Report	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Reports\\Node Summary Report	Report	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Reports\\Project Summary Report	Report	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Reports\\Source Classification Summary Report	Report	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Reports\\Source Summary Report	Report	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM

Results

Search Folders

Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On
Search Folders\\All Nodes	Search Folder	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Search Folders\\All Sources	Search Folder	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM
Search Folders\\All Sources Not Embedded	Search Folder	ConnieSchumacher	2017-02-20 8:23 PM	ConnieSchumacher	2017-02-20 8:23 PM

Sentiment

Sets

Source Classifications

Summaries

Reports\\Project Summary Report

Page 6 of 6

2017-05-13 7:07 PM

Hierarchical Name	Item Type	Created By Username	Created On	Modified By Username	Modified On
Maps					
Memos					
Memos\\Avoiding or Prolonging	Memo	ConnieSchumacher	2017-04-06 8:03 PM	ConnieSchumacher	2017-04-15 1:38 PM
Memos\\Changes in Support	Memo	ConnieSchumacher	2017-04-29 8:09 AM	ConnieSchumacher	2017-04-29 8:11 AM
Memos\\Descritptive Summary Memo1	Memo	ConnieSchumacher	2017-04-10 5:09 PM	ConnieSchumacher	2017-04-10 5:26 PM
Memos\\Differentiating Control	Memo	ConnieSchumacher	2017-03-30 8:10 PM	ConnieSchumacher	2017-05-07 10:37 AM
Memos\\Fragility and Vulnerability	Memo	ConnieSchumacher	2017-03-30 7:57 PM	ConnieSchumacher	2017-04-08 4:58 PM
Memos\\Plugging Along	Memo	ConnieSchumacher	2017-04-14 10:54 AM	ConnieSchumacher	2017-04-14 10:57 AM
Memos\\Relationship Summary	Memo	ConnieSchumacher	2017-04-29 8:22 AM	ConnieSchumacher	2017-04-29 8:32 AM
Memos\\Uncertainty	Memo	ConnieSchumacher	2017-04-06 7:39 PM	ConnieSchumacher	2017-04-08 4:56 PM
Memos\\Post Interview Notes					
Memos\\Reflections					
Memos\\Reflections\\Reflection 1	Memo	ConnieSchumacher	2017-03-19 3:35 PM	ConnieSchumacher	2017-05-07 10:26 AM
Memos\\Researcher Journal Audit					
Memos\\Researcher Journal Audit\\Researcher Journal	Memo	ConnieSchumacher	2017-03-05 3:15 PM	ConnieSchumacher	2017-05-07 10:26 AM
Memos\\Theoretical Memos					
Memos\\Theoretical Memos\\Adjusting to Alleviate Symptoms	Memo	ConnieSchumacher	2017-03-19 3:45 PM	ConnieSchumacher	2017-05-07 10:27 AM
Memos\\Theoretical Memos\\Vulnerabilities	Memo	ConnieSchumacher	2017-03-26 9:35 AM	ConnieSchumacher	2017-05-07 10:29 AM
Node Matrices					
Nodes					
Nodes\\Altering Life	Node	ConnieSchumacher	2017-03-19 1:54 PM	ConnieSchumacher	2017-04-29 8:15 AM

Reports\\Project Summary Report

Page 4 of 6

Appendix G: Code Book

Self-Management Heart Failure Code Book

Nodes

Name	Description
Altering Life	Examples of how their life is now different.
Body Function	Changes in how the body functions
Roles	Examples of giving up responsibilities and roles
Seeing Self	General statements of how they see themselves as a person
Control	Control over body, circumstances, symptoms
Emotions	Any emotion described by the participant
Help Seeking	General help seeking
Information	Examples of when the participant has sought out information only
Others	
Medical Professionals	Interactions with Medical Professionals, hospital, primary care, nursing
Personal Support System	Interactions with personal supports, families, neighbours, friends
Perception of Others	These are things that the participant perceives others are thinking about them. May be what actually is occurring or just a sense of what others are thinking
Self-Management	Any act taken on that the participant describes as self-management
Daily Alleviating Actions	Non escalating regularly occurring symptoms and how the participant alleviates including lay interventions
Independent Reasoning	Musings by the participant, what they thought was happening when their symptoms changed
Symptoms	All symptoms reported, descriptive node, how participants described their symptoms
Escalating Tipping Point	The experience when symptoms were out of control and the need to go to hospital was imminent.