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Individuals with Heart Failure Experience of Collaboration with the Health Care Team: An Interpretive Description

I designed this study to explore the experience of collaboration from the perspective of people with heart failure (HF) attending a heart function clinic (HFC). There is a paucity of literature explicating the experience of collaboration from the perspective of the individual with HF, although the literature provides strong support for the benefits of collaboration for people with HF. My intent was to increase the knowledge and understanding of the experience of collaboration for individuals with HF to inform nursing practice, education, and research.

The qualitative research approach, interpretive description, as described by Thorne, Reimer Kirkham, and Macdonald Emes (1997) was utilized as my research method, as it was appropriate to answering my research question, “how do individuals with HF experience collaboration with the health care team in the setting of an outpatient HFC?” Data were collected utilizing in-depth semi-structured interviews, with a total of 7 participants ranging in age from 52 to 81 years. All of the participants had been attending a HFC for at least 2 years, with a mean attendance of 3.4 years. Inductive data analysis was ongoing throughout the data collection process. The findings informed and guided the data collection process and allowed the construction of the interpretive description.

The narratives revealed five dominant themes describing the participants’ experiences of collaboration with the health care team. These were mutual goals, working
together, communication with the health care team, being accountable, and sharing power. Antecedents to the experience of collaboration included non-intimidating communication style and trust in the health care team. Barriers to the experience of collaboration identified were lack of time, communication styles that do not support collaboration and inequity of power sharing.

The findings of this study may contribute to the theoretical understanding of the concept of collaboration, and has provided insight into the experience of collaboration as experienced by individuals with HF who attend a HFC. Thus this contribution to the existing knowledge about the experience of collaboration from the individual with HF may provide additional insight into and expand the understanding of the experience and thereby enhance the care of similar individuals.
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CHAPTER ONE

Introduction

Background to The Problem

Heart failure (HF) is a complex clinical syndrome that is characterized by the inability of the heart to adequately meet the metabolic needs of the body. There are numerous causes of heart failure including: coronary artery disease, valvular heart disease, hypertension, arrhythmias, myocarditis, metabolic disorders, infective processes, toxins, and idiopathic etiologies. Regardless of cause, the underlying pathophysiology of HF “rest on the twin pillars of ventricular remodeling and neuroendocrine activation”. (Baige et al, 1999, p 87). Ventricular remodeling is characterized by pathological changes in ventricular shape, thickness and dimension in response to the inability to maintain adequate stroke volume. The reduction in stroke volume leads to accumulation of blood in the ventricles and ventricular dilatation. Ventricular shape changes from cylindrical to spherical as the ventricle dilates and ventricular volume increases. Dilatation of the myocardium results in reduced contractility and the myocardium hypertrophies in an attempt to compensate. Neuroendocrine activation occurs as a response to decreasing stroke volume and cardiac output. Sympathetic and RAS activation increases heart rate, increases contractility and leads to vasoconstriction in an attempt to maintain adequate blood pressure and cardiac output. While a detailed discussion of the pathophysiology of heart disease is beyond the scope of this study it is important to understand that these processes are maladaptive and if left unchecked can result in the development of decompensated HF. Decompensated HF occurs when the patient experiences symptoms
of hemodynamic instability, significant shortness of breath, peripheral edema, arrhythmias, decreased energy; and cardiogenic shock.

Current medical treatment for HF focuses on the prevention of decompensation and decreasing or preventing ventricular remodeling and neuroendocrine activation. Medications such as beta blockers, which block sympathetic stimulation, angiotensin converting enzyme inhibitors (ACEI), angiotensin receptor blockers (ARB), and aldosterone antagonists, all of which prevent activation of the RAS, have become standard therapy for individuals with HF.

Current Canadian consensus guidelines for the management and treatment of HF as well as a large proportion of ongoing HF research focuses on further explicating these pathophysiological processes in an effort to develop more effective treatment modalities. However the health care community is placing increasing emphasis on the experience of the individual living with HF when developing treatment guidelines. The Canadian Cardiovascular Society (CCS) guidelines include recommendations that goals of treatment include improving the “patient’s quantity and quality of life, to reduce symptoms and hospitalizations, and to coordinate care that is patient centred and evidence based”. I feel that this recommendation highlights the beginning of an important paradigm shift in health care towards true patient involvement and collaboration in health care decision-making.

Demographics of Heart Failure

Heart failure is characterized by the Canadian Cardiovascular Society (CCS) as an emerging epidemic. The CCS guidelines for the management and treatment of HF (2001) describe HF as the “most rapidly rising cardiovascular condition to affect the lives of
Canadians". Over three hundred and fifty thousand Canadians are living with HF with a predicted one-year mortality of between twenty-five and forty percent after diagnosis. Literature from the United States mirrors the Canadian experience, with estimates of four million six hundred thousand people living with HF, and four hundred thousand new onset cases being diagnosed each year (Dahl & Penque, 2001; McCormick, 1999; Packer & Cohn, 1999, Paul, 2000).

Heart failure affects approximately one and a half to two percent of the population in the United States; with a dramatic increase in prevalence to between six and ten percent after the age of sixty-five (Packer & Cohn, 1999). In Canada, “Heart failure is currently the commonest hospital discharge diagnosis in patients over the age of 65 years” (Arnold & Miller, 2002). It is estimated that eighty percent of patients with chronic HF are over the age of sixty-five. Arnold and Miller (2002) describe the typical HF patient requiring hospitalization as: over the age of sixty five, experiencing advanced symptoms of HF (NYHA class III-IV), and having one or more comorbid conditions. These comorbid conditions include renal dysfunction, chronic lung disorders, arthritis, hypertension, diabetes, and cognitive impairment.

The cost of HF to the Canadian health care system is staggering, with estimated spending on in hospital care reaching one billion dollars per year (CCS, 2001). HF is a chronic disease state that is characterized by frequent episodes of decompensation requiring hospitalization. The average length of hospitalization in Canada is eight days and Packer and Cohn (1999) report that one third of people hospitalized for HF will be readmitted within ninety days. McCormick (1999) identifies that between twenty-one and twenty seven percent of people diagnosed with HF will require multiple admissions
yearly. Adding to costs are complex medication regimes and the need for frequent outpatient physician follow up

**Heart Function Clinics**

"The provision of care within a specialty clinic is one approach that has been shown to improve outcomes in chronic illness" (Levine & Hall, 1998, p 258). These clinics are generally staffed by a multidisciplinary team including physicians, nurses and other health care professionals with expertise in the management of HF. Nursing literature provides support for the clinical and economic benefits of utilizing multidisciplinary specialty clinics to manage HF. Several authors provide anecdotal evidence of benefits of outpatient HFCs, including decreases in cost, length of hospitalizations, and readmission rates for HF (Levine & Hall, 1998; Paul, 1997; Veener & Seelbinder, 1996). While these early results were promising all of the authors recommend the need for further study.

Paul (2000) examined the effects of a multidisciplinary outpatient HF clinic on hospital readmissions, emergency department visits, length of stay and cost savings. A statistically significant reduction was reported in the number of total hospital readmissions and total number of hospital days. However, decreases in readmission rate, hospital charges, and emergency department visits for HF were not found to be statistically significant. The authors identified the small sample size, short follow up time, and lack of information on stage of the disease process as significant limitations and recommend further study. An earlier study by Urden (1998) reported similar findings with decreases in length of hospital stay, 30-day readmission rates and costs to the hospital. Urden also found a statistically significant increase in overall quality of life,
emotional and physical functioning as measured by the Minnesota living with HF (MLWHF) questionnaire. The updated CCS guidelines for treatment and management of HF (2003) indicated that evidence is accumulating in favour of heart function/failure clinics. This includes evidence of decreases in hospitalizations and readmissions as well as increases in patient knowledge of HF.

A key component to the success of specialty clinics is the use of expert nurses. Paul (1997) describes the value of expert nurses as “the ability to include the art of nursing in the process by involving the patient and their family members in their own plan of care” (p 489). Expert nurses “can assist patients in managing the signs and symptoms of the disease by educating the patients about diet, exercise, medications and the disease process” (Paul, 2000, p 146).

An important aspect of the HFC nurse’s role is that of providing close clinical follow up and support with symptom management. This may involve telemanagement, which includes providing patient follow up via telephone or email, or the use of nurse only clinics. Telemanagement may include monitoring volume status, adjusting medications with the assistance of physicians or use of protocols, reinforcing education or answering questions and providing support for individuals enrolled in the clinic. The CCS guidelines have identified that telemanagement by experienced nurses is “often the key intervention that may prevent recurrent hospitalization” (CCS Guidelines, 2003).

As previously discussed, the efficacy of speciality clinics in the treatment of chronic illness is well supported in the literature. Levine and Hall (1998) identify four characteristics that HFCs should incorporate to ensure successful chronic illness management. The features that characterize successful chronic illness care are: 1.
Provision of care in accordance with a specific plan, 2. Ability to meet the needs of complex patients that require time and intensive follow up, 3. Attention to self-management needs, 4. Access to necessary expertise. I feel that these characteristics are only attainable through multidisciplinary collaboration, a belief that is strongly supported in the literature (Levine & Hall, 1998; Paul, 2000; Urden, 1998; Veener & Seelbinder, 1996).

Patients Experience of Collaboration

The use of a collaborative team approach between physicians, nurses and other members of the health care team is supported throughout the literature. Morse and Brown (1999) discuss the acute care nurse practitioner’s role as being designed on a “collaborative model that include patients, families, significant others, nurses, physicians, and other health care providers” (p.32). One important result of interdisciplinary collaboration is the potential to positively affect patient outcomes (Henneman, Lee & Cohen, 1995; Miller, 2001; Van Ess Coeling & Cukr, 2000). Henneman et al (1995) identify that a lack of collaboration may “play a central role in the fragmentation of care, patient dissatisfaction, and poor outcomes” (p 108). One study demonstrated that intensive care units with poor collaborative communications report as much as a “1.8 fold increase in risk adjusted mortality, and significant increases in length of stay” (Miller, 2001). Another study reports a significant increase in the perception of quality of care and patient outcomes in the presence of collaborative communication (Van Ess Coeling & Cukr, 2000).

There are few studies addressing the effect collaboration has on outcomes for individuals with HF. Paul (2000) and Urden (1998) examined the effects of a
multidisciplinary outpatient HFC on hospital readmissions, emergency department visits, length of stay and cost savings. While not explicitly identifying the effects of collaboration, both authors describe interdisciplinary collaboration as supporting positive patient outcomes. Paul (2000) reported a statistically significant reduction in the number of total hospital readmissions and total number of hospital days after initiating treatment in a clinic. Urden (1998) reported similar findings with decreases in length of hospital stay, 30 day readmission rates and costs to the hospital. Urden (1998), utilizing the MLWHF questionnaire, reported statistically significant increases in overall quality of life, emotional and physical functioning.

While the benefits of collaboration are well supported in the literature, there remains a paucity of information regarding collaboration between the health care team and individuals with HF. Whitehead (2001) identifies that “One example of teamwork that is surprisingly neglected in the literature is the partnership between the client and the nurse” (p 34). Many authors appear to support development of collaborative relationships with individuals with HF. Unfortunately the support is generally implied rather than being explicitly identified. Levine and Hall (1998) describe the need for an individualized plan of care and the importance of attention to self-management needs. Paul (2000) describes the benefits of comprehensive education and close follow up including use of telephone management. Veener and Seelbinder (1996) also identify the benefit of education and discuss the positive outcomes that are associated with the patient having a more internal locus of control. While each of these authors seem to be describing aspects of what is commonly considered collaboration between nurse and client, it is not clear that this is in fact what they are describing. This ambiguity may reflect the challenges
many health professionals have with what it means to collaborate with patients. The greatest challenge is the need to redefine the patient as a member of health care team rather than a passive bystander. This supports the need for a paradigm shift from the traditional paternalistic medical model that may not be comfortable or even possible for all health care professionals. Sharkey (2002) describes how it remains common practice for professionals to define what “collaboration means, what is required for patient involvement, and how engagement should take place, with little if any reference to the patients themselves” (p 49).

Some authors are more explicit in their support of client-health professional collaboration. Hutchings (1999) discusses the client as an expert, active agent and decision-maker. She goes on to describe clients with chronic illnesses as being uniquely able to identify how illness impacts their life experience, and how health professionals should accept and utilise their expert knowledge. Whitehead (1999) states that to respect the autonomy of the client, health professionals must “relinquish their reductionist power base and actively acknowledge the client as a member of the collaborative team” (p 37). While there is support in the literature for collaboration between patient and health professional, there is little information on how collaboration is experienced by the patient. Sharkey (2002) utilises a hermeneutic-phenomenological approach to illuminate the experiences of a patient with severe and enduring mental illness. Barr and Threlkfeld, (2000) describe application of Jensen’s patient practitioner collaborative model with a person with a physical disability. Hutchings (1999) presents a case study describing collaboration with an individual with multiple sclerosis when designing an education session for nursing staff. Finally, Clarke and Mass (1998) identify the experiences of
clients attending a nursing centre. The experience of collaboration for individuals with HF has not been explored, and while there may be similarities with what has been reported it should not be assumed that the experience is identical for this unique population.

Given the absence of research exploring the experience of collaboration in individuals with HF, and the importance of collaboration to client outcomes, I suggest that there is insufficient knowledge to enable understanding of these individuals’ experiences. This may lead to significant gaps in provision of care, and decrease the efficacy of nursing and medical interventions.

**Problem Statement**

Individuals with HF who participate in outpatient HFCs are asked to modify their lifestyle significantly and to follow complex medication regimes. Adherence to medication regimes, lifestyle modification and other self-management techniques decreases both the experience of symptoms of HF and the number of hospitalizations. The literature supports development of collaborative relationships between the health care team and individuals with HF as a means to increase compliance and decrease negative side effects. However no literature explores these relationships from the perspective of the individual with HF. There is no literature exploring how individuals with HF interacting with the health care system experience or identify collaboration, or even if it is desired or sought out.

**Purpose**

The purpose of this study was to explore the experiences of collaboration between individuals with HF and the health care team in the setting of an outpatient HFC from the
patient’s perspective. Expected outcomes included developing an understanding of how collaboration is experienced and what meanings are given to the experience. Areas of exploration included identification of processes and outcomes of collaboration, and identification of antecedents and barriers to collaboration. Findings derived from this inquiry are expected to increase the knowledge and understanding of the individual with HF’s experience of collaboration. This is anticipated to provide guidance for the health care team and enhance care for similar individuals.

**Research Question**

The question guiding this research study was: “how do individuals with HF experience collaboration with the health care team in the setting of an outpatient HFC?”

**Definition of Terms**

For the purposes of this study major terms were defined as follows:

Heart Failure: a pathophysiological state in which the heart is unable to pump blood throughout the circulatory system to meet the peripheral demands of the metabolising tissues. It is often caused by a defect in myocardial contraction and relaxation, and accompanied by elevated cardiac filling pressures. It may also occur when the normal heart is suddenly presented with excessive demands or severe impairment of its filling. (CCS Guidelines, 2001)

Collaboration: an interactive process where there is a need and willingness to work towards a shared goal that would be difficult to achieve individually. There is a perception by the participating parties that benefits of the activity outweigh the risks and the interaction is equitable. A team approach is developed by sharing responsibilities and decision-making and by use of effective communication and conflict resolution skills. It
requires high levels of cooperation and assertiveness to be present in all involved. There is convergence of beliefs and values and an exchange or degree of sharing of power. Those involved evaluate outcomes; however others not involved in the collaboration may be affected and can evaluate outcomes differently.

Assumptions

1. Individuals experiencing HF and health care professionals working in a HFC can and should experience collaborative relationships.

2. Relationships between clients and health care professionals in a HFC setting tend to be long term in nature and may differ from relationships developed during hospitalization for acute illness.

3. Individuals with HF are willing to describe their experiences to researchers.

Limitations of the Study

The findings of the study were limited by selection criteria that preclude the utilization of non-English speaking individuals. Participants must be English speaking, so the findings may not represent the experiences of non-English speaking individuals. Participants were all living in the same urban area, and may not represent the experiences of individuals living in rural or remote communities. The participants were volunteers and there is a threat that I might not have talked to persons with unique experiences that had chosen to not participate in the study due to a variety of reasons. There is also a threat that given the nature of the research, participants may have shared experiences that present the HFC in the best light, or answered questions in a way they think I want them to.
Individuals who attend HFCs must be physically able to get to the clinic so individuals who lack the mobility required to attend to the HFC were not represented. Individuals attending HFCs are probably more likely seek medical attention for their illness. There are many chronic HF patients who do not participate in HFCs, and these voices were not heard. I risked missing the experience of individuals who may be marginalized due to socioeconomic status and lifestyle, and do not choose to seek medical attention.

Summary

In chapter one I introduced the background and rationale for choosing this study topic. I offered a brief review of literature discussing the pathophysiology and demographics of HF. I then discussed HFCs, and the patients' experience of collaboration. Finally I presented the purpose of the research, the research question, definitions of terms used in the study, assumptions of the study, and limitations to the study.
CHAPTER TWO

Review of Selected Literature

I begin by briefly exploring the current literature describing the individuals’ experiences of HF. I first explore literature describing the physical and emotional responses to HF. I then examine the literature about becoming a HF patient, and the effects of gender on the experience of living with HF.

I then focus on the concept of collaboration. It is important to place the individual experience of collaboration within the broader context of the process of collaboration. I have structured this section of the literature review to first provide a general overview of the concept and uses of collaboration. The literature is critically reviewed for the presence of definitions, conceptualizations, models, and theories describing collaboration and the collaborative process. These divergent views are then synthesized and common themes are identified. I then review the current research on collaboration found in the literature. This includes a discussion of the individual’s experiences of collaboration. Finally, I examine the literature related to the impact collaboration has on patient outcomes of collaboration.

Individuals’ Experience of Heart Failure

Literature exploring the experience of the individual with HF commonly focuses on the physical manifestations of the disease. Common descriptions include feelings of fatigue, shortness of breath, increasing physical limitations, and generalized debility (Martensson, Karlsson, & Fridlund, 1997; Rhodes & Bowles, 2002; Winters, 1999). However HF “affects more than the physical aspects of the lives of those with the syndrome. In fact HF has been shown to affect virtually every aspect of life” (Winters
Common emotional responses found throughout the literature include uncertainty, anger, fear, worry, pulling back from life, and in some cases acceptance and a sense of hope (Stull, Starling, Haas & Young, 1999; Martensson, Karlsson, & Fridlund, 1997; Rhodes & Bowles, 2002; Winters, 1999). These experiences may vary based on gender, age, New York Heart Association (NYHA) classification, and length of diagnosis. The NYHA classifications allow quantification of functional capacity. NYHA class I indicates no symptoms with normal activity while NYHA class IV indicates symptoms at rest.

Stull et al (1999) utilized a grounded theory approach to describe the experience of becoming a HF patient. Twenty-one participants, of varying age and gender, in NYHA class II to IV HF were interviewed. The overriding or higher order theme identified was a search for meaning and identity on the part of the patient. Five distinct phases of the process emerged from the data. These were “a crisis event, the diagnosis, the patient’s and family’s response to the diagnosis, their acceptance and adjustment to life with their condition and the decision to get on with life” (Stull, et al 1999, p 287). The first three phases were associated with much uncertainty and dramatic changes in patient identity, role performance, and due to the novelty of the diagnosis, experiences of fear and worry (Stull et al, 1999). Winters (1999) found that periods of uncertainty were greatest during the time of initial diagnosis, when the condition or treatments were changing and when a sense of control over one’s life was lost. The initial period of diagnosis and treatment is one of constant change and adjustment and I have frequently seen, as a nurse in a heart function clinic (HFC), individuals experiencing loss of control, and high levels of uncertainty and anxiety. The final phases described by Stull et al (1999) represent the
regaining of control over ones life and finding meaning and a new identity. This model provides new insight into the experience of becoming a HF patient; unfortunately HF is characterized by periods of rapid decompensation and constant change in status throughout all stages of the disease process. There is no discussion of the possible effects a new crisis event might have on finding meaning and a new identity, and I have concerns about the apparent linearity of the model.

Rhodes and Bowles (2002) examined, using a phenomenological methodology, the experiences of HF in six women aged 60 to 90 in NYHA class II failure. Four themes impacting on the lives of older women with HF were identified. The themes were: “acknowledging losses in their lives, accepting the losses, changing their lives and deepening relationships” (Rhodes & Bowles, 1999, p 444). Martensson, Karlsson and Fridlund (1997) utilised a phemenographic approach to examine conception of their life situations of 12 males aged 48 – 80 in NYHA class II to IV HF. Six categories emerged: “ feeling a belief in the future, gaining awareness, feeling support from the environment, feeling limitation, feeling a lack of energy, and feeling resignation” (Martensson et al, 1997, p 582). Although looking at different genders and NYHA classes several similarities were noted. Both studies reported participants experienced changes in physical functioning, feelings of loss both physically and emotionally and the need to make adjustments in their daily lives. Other commonalities included an acceptance of their condition and feelings of hope for the future. One striking difference was that females reported a deepening of relationships with others while males did not. These findings lend support to my belief that men and women may experience HF differently, and suggest directions for further research.
Collaboration

Conceptualization of Collaboration

Collaboration first appeared in English literature in 1871, and is defined as: “to work jointly with others or together especially in an intellectual endeavour; to cooperate with or willingly assist an enemy of one's country and especially an occupying force; to cooperate with an agency or instrumentality with which one is not immediately connected” (Meriam-Webster online dictionary). This definition gives some guidance as to what is meant by collaboration, but lacks such critical information as antecedents to collaboration, characteristics of collaboration and outcomes of collaboration. It also provides no insight into how collaboration is experienced by individuals. I reviewed nursing and allied health literature for definitions and conceptualizations of collaboration, theoretical models of collaboration, and finally experiences with collaboration.

Nursing and allied health literature contains numerous articles examining collaboration including editorials, case studies, concept analyses, and descriptions of collaborative models. In addition there are a limited number of qualitative and quantitative studies that explore aspects of collaboration. Despite the abundance of literature, collaboration remains “a complex phenomenon whose definition has remained vague or highly variable” (Henneman et al 1995, p 103). Several related concepts appear to be used as synonyms in the literature. These include: reciprocity, partnership, cooperation, compromise, negotiation, and empowerment. The interchangeable use of these similar but not identical concepts further confuses the meaning of collaboration. “Despite its elusiveness, its essence continues to be sought after as a means of improving working relationships and patient outcomes” (Henneman et al, 1995, p 103).
One of the more influential works of the past decade appears to be Henneman et al (1995) concept analysis of collaboration. Defining attributes, antecedents, consequences and empirical referents of collaboration are presented using model, contrary and borderline cases in the context of the nurse-physician relationship. They conceptualize collaboration as being one extreme of interpersonal conflict styles that involve varying levels of assertiveness and cooperation. Collaboration occurs in the presence of high levels of cooperation and assertiveness, while avoidance occurs with low levels of cooperation and assertiveness. Competition occurs with high levels of assertiveness and low levels of cooperation, accommodation occurs with low levels of assertiveness and high levels of cooperation and compromise as falling between extremes of collaboration and avoidance. Gardener and Cary (1999) described collaboration in a very similar manner. They described differences of interpersonal conflict styles based on degree of concern with self and degree of concern with others. It is my opinion that concern with self is roughly analogous to levels of assertiveness, and concern with others is analogous to levels of cooperation. Collaboration can then be conceptualized in the context of the nurse-physician relationship as occurring when high levels of concern with self and high levels of concern with others are present. Unfortunately the authors do not identify if this conceptualization should be applied in any other context than in nurse-physician collaboration, which may somewhat limit utility when describing collaboration with patients.

Nine defining attributes of collaboration are identified as: joint venture, cooperative endeavour, willing participation, shared planning/decision-making, team approach, contribution of expertise, shared responsibility, non-hierarchical relationships,
and power sharing (Henneman et al, 1995; Clarke & Mass, 1998). Antecedents to collaboration are identified as: individual readiness, understanding of role, confidence in ability, recognition of boundaries, effective group dynamics, team environment, and congruent organizational values. Similar to the antecedents, are the core competencies needed for collaboration described by Gardener and Cary (1999) which consist of: critical (system) thinking, clinical competence, strong interpersonal communication skills, knowledge of roles, conflict resolution skills, and group process knowledge.

Consequences of collaboration identified by Gardener and Cary (1999) include: supportive environment, confidence/self esteem, win-win, esprit de corps, interprofessional cohesiveness, improved productivity, increased satisfaction, and improved patient outcome. Gardener and Cary focused on nurse-physician collaboration, and while appearing complete is somewhat limited when used to describe nurse-patient relationships.

Collaboration requires time to develop and several authors have conceptualized the collaborative process as passing through a series of stages or phases. Gardener and Cary (1999) described the seven stages of collaboration as: awareness, tentative exploration and acknowledgement, trust building, collegiality, consensus, commitment, and collaboration. The stages of collaboration can be more accurately described as identifying antecedents to collaboration and provide very limited information on the defining attributes of collaboration. An additional limitation as previously mentioned is the focus on nurse-physician collaboration. Barr and Threlkeld (2000) utilized a patient-practitioner collaborative model that also describes stages or phases of the collaborative relationship. The four phases are: establishing a therapeutic relationship, diagnosing
through mutual inquiry, finding common ground through negotiation, and intervening and following up. Paavilainen and Astedt-Kurki (1997) conceptualized client nurse collaboration as occurring in 5 stages. The stages are trust, a friendly and confidential relationship, common actions, experience of togetherness, and achieving the common goal of client well being and the ability to cope. Of concern is the presentation of the collaborative process as being linear in nature. I believe collaboration is a dynamic process, which is experienced uniquely by each individual. These models, while providing structure and insight to the experience, do not adequately capture the unique and complex nature of collaboration.

Nursing literature is replete with case studies describing collaborative processes. Akhavain, Amaral, Murphy, and Uehlinger (1999) used Bowen’s family systems theory to examine collaboration in an interdisciplinary psychiatric treatment team. Collaboration is defined as “working in a system while giving of oneself without giving up oneself. It is the ability to combine assertiveness and cooperativeness and remain true to individual principles while working toward a common goal”(p. 4). Oda, O’Grady and Strauss (1994) described the collaborative process between public health nurses and researchers in an investigator initiated study. They found three concepts that are important in collaboration. These are the concepts of negotiation, mutuality and respect.

While uncommon, several research studies have examined collaboration, although few from the perspective of the patient. Paavilainen and Astedt-Kurki (1997) conducted a phenomenological examination of public health nurses’ perceptions of the content and preconditions of collaboration between the nurse and the client. They concluded that collaboration between client and nurse begins with trust and proceeds towards a common
goal. They also identified the following as preconditions of collaboration: trust, friendly and confidential relationship, common actions, experience of togetherness, and the clients ability to cope. Gedney- Baggs and Schmitt (1996) performed a grounded theory study examining the perceptions of nurses and residents on the process of collaboration in a Medical Intensive Care Unit (MICU). They found that important antecedents to collaboration include being available and being receptive. They also describe the core components of collaboration as working together, a sense of team, patient focus and sharing. Outcomes of collaboration were found to be: improved patient care, feeling better in the job, learning, and controlling costs. Unfortunately there were no qualitative studies examining the experience of collaboration from the perspective of the individual with HF. This paucity of information supports the need for research into this aspect of the experience of collaboration.

Van Ess Coeling and Cukr (2000) provide one of the rare quantitative looks at collaboration. The study utilized a post-test design with nonequivalent groups to assess the perception of collaboration between physicians and nurses as affected by the use of dominant, contentious, or attentive communication styles. I have questions about the reliability and validity of the instrument as it is newly developed; however the researchers do acknowledge this limitation. Implications for practice and direction for future research are addressed, but again may be of limited use when trying to illuminate the experience from the perspective of an individual with HF. The study found that use of attentive communication styles facilitated collaboration.

I shall now present what I believe are common themes found throughout the collaboration literature. The first theme I have identified is that collaboration is a
complex process that involves the interaction of at least two people. Certain interpersonal skills are needed to make the collaboration successful. These include communication, conflict resolution, and group process skills.

A second common theme is the process of collaboration is outcome driven. There must be a need as well as a willingness to collaborate, and a shared vision of the outcome of collaboration.

A third common theme is that there are risks and benefits to collaboration. The decision to collaborate is almost always based on an analysis of the benefits versus the risks. Collaboration will not occur if one party determines the risks outweigh the potential benefits. In general, collaboration will only occur if all parties involved perceive the expected outcome of collaboration to be positive. Often the people who are involved in the collaboration are not negatively affected and do not view the collaboration as negative; however others involved indirectly can feel betrayed or harmed by the collaboration.

A fourth common theme is that collaboration is affected by individual or group beliefs and values, and the beliefs and values of each person involved in a collaborative endeavor must be congruent. This is not to say that individuals must share the same beliefs or values; however the beliefs and values must not be completely opposing.

A final common theme I have identified is that sharing or gaining of power is an outcome of collaboration. The willingness to collaborate is often initiated by the desire for power exchange, and can be inhibited by too large a differential. The sharing of power is not necessarily equal, but there must be feelings of fairness or equity to enable the collaborative relationship.
Collaboration in the Health Care Team- Patient Relationship

While there is a wealth of literature examining the concept of collaboration there is a paucity of information addressing collaboration in the nurse client relationship. Clarke and Mass (1998) did explore the nurse client relationship and collaboration utilizing Henneman, Lee and Cohen’s (1995) conceptualization. They identified the following as key client antecedents: willingness to enter into a relationship with nurses, and trust in the nurses’ abilities. Other antecedents include confidence in ones abilities to make appropriate decisions and willingness to accept responsibility for their role in care. The clients identified collaboration as “being respected as an individual, having time to be understood, getting useful information, and being asked about what help was required” (Clarke & Mass, 1998, p 223). They also identified outcomes of collaboration as becoming more knowledgeable, improvements in physical and mental condition, feeling better when communicating with nurses, and increased confidence when taking actions on their own. This discussion is presented as an evaluation of how collaboration was actualized or suppressed, and how collaboration impacted empowerment for nurses, clients and the community. However, there is no discussion of research questions, methodology used to guide the inquiry, or data analysis techniques. I feel the most significant limitation to this discussion was the lack of data presented to support their claims. Clark and Mass indicate that evaluation reports containing excerpts of raw qualitative data were used in the analysis; however, none of this data is presented. This discussion provides some insight into the experience of collaboration from the perspective of a patient but is of limited utility due to these significant limitations. This
provides further support that further research is needed into the experience of
collaboration from the client’s perspective.

Other authors also describe positive client outcomes arising from collaboration.
Hutchings (1999) describes the collaboration of a nurse educator and a client with
multiple sclerosis who partnered to design and implement an inservice program, as
having a dramatic effect on both staff and client. She reports a shift towards a more
egalitarian relationship with the client being viewed as the expert. Barr and Threlkeld
describe the outcomes of collaboration with a client requiring physiotherapy for chronic
back pain as decrease in pain and a sense of increased independence.

Unfortunately not all attempts at collaboration are perceived as positive by clients.
In a hermeneutic-phenomenological examination of the experience of collaboration with
a patient with a diagnosis of severe and enduring mental illness, Sharkey (2002) reports
little evidence of collaboration. She goes on to state “it is more honest to acknowledge
that either collaboration does not happen when they are acutely ill or aspects of it occur
on our terms” (Sharkey, 2002, p 54). The experiences reported and described are those of
fear, mistrust, loneliness, loss of control, and not feeling as part of the decision making
process. This is a stark reminder that even if health professionals believe they are
collaborating, the experience for the individual may be dramatically different.

Outcomes of Collaboration

As reported earlier there is some evidence supporting the benefit of collaboration
on patient outcomes. Physician nurse collaboration in intensive care units (ICUs) and
effects on outcomes is relatively well represented in the literature. Miller (2001) reported,
“collaborative interaction between nurses and physicians is significantly related to
mortality rates and length of stay on ICUs” (p 350), with a 1.8 fold increase in risk-adjusted mortality in ICUs with poor leadership and poor collaborative communication. Miller (2001) goes on to report that other studies have found a forty-one percent lower death rate than expected in units with high levels of interdisciplinary collaboration. Perhaps more chilling are reports of a fifty-eight percent higher death rate in units with the worse interdisciplinary collaboration.

Pisek (1997) studied effects of cardiovascular surgeons who formed multiorganizational quality improvement collaboratives on in-hospital mortality rates. Twenty-three cardiothoracic surgeons were involved in a six-year project that initially focused on development of case registries and databases. Significant differences in mortality rates between surgeons were identified, and a three-component intervention designed to decrease overall mortality rate was developed. The intervention consisted of “feedback of outcome data, training in continuous quality improvement techniques, and site visits” (Pisek, 1997, p 86). Findings showed a twenty-four percent decrease in in-hospital mortality rates at the conclusion of the study.

Other authors have reported that nurse-physician collaboration may not significantly improve patient outcomes. Higgins (1999) examined the predictive value of nurses’ perception of nurse-physician collaboration and found that nurses’ perceptions of collaboration were not a significant predictor of improved patient outcomes. Paul (2000) examined the effects of a multidisciplinary outpatient HF clinic on hospital readmissions, emergency department visits, length of stay and cost savings. While the number of total hospital readmissions and total number of hospital days were significantly reduced,
changes in readmission rate, hospital charges, and emergency department visits for CHF were not found to be statistically significant.

This critical review of the literature suggests that there is still much ambiguity and uncertainty regarding the effects on patient outcomes, of collaboration between health professionals. There is an even greater lack of literature that explores the outcomes of collaborative relationships from the perspective of the individual with HF. Given the uncertainty found in the literature and the lack of data looking at outcomes of collaboration from a patients’ perspective further study is warranted.

**Summary**

The focused literature review presented in this chapter supports my statements that little is known about the experience of collaboration from the perspective of the patient, and even less from the perspective of a patient with HF. The literature exploring collaboration is largely theoretical in nature, with conceptualizations, and theoretical discussions prevalent in the current literature. The empirical studies addressing collaboration frequently examines interprofessional collaboration, or the experience of collaboration with patients from the perspective of the health care professional. There is a paucity of empirical literature examining collaboration from the perspective of patients. Hence the current theoretical literature should be viewed as having limited utility in discussing the experiences of collaboration from the patient’s perspective, until further study into its relevance and appropriateness has occurred.
CHAPTER THREE

Method

Design

A qualitative research design was utilized to examine the research question. “Qualitative research enables us to make sense of reality, to describe and explain the social world and to develop explanatory models and theories” (Morse & Field, 1995, p 1). A qualitative approach is appropriate when little is known about a phenomenon and further exploration is required. It is particularly useful when describing a phenomenon from an emic or insiders perspective. While the emic or micro perspective is key to nursing practice we cannot dismiss the need to include the etic or macro perspective in nursing research. The etic perspective includes knowledge identifying common patterns found within experiences, that represent the core of nursing practice, knowledge and practical application of principles, that arise from our logical empiricist epistemological traditions (Thorne, Kirkham, MacDonald-Emes, 1997). By addressing both perspectives through the research process of using individual narratives to develop a single interpretive description we develop knowledge that “reflect a respect for knowledge about aggregates in a manner that does not render the individual case invisible” (Thorne et al, 1997 p 171).

Due to the paucity of literature addressing the patient experience of collaboration and the nature of the research question a non-categorical qualitative approach, interpretative description was chosen to direct this inquiry. This method was first described by Thorne, Kirkham and MacDonald-Emes (1997), and provides guidance for the researcher when generating interpretations of phenomena of interest to nursing
practice, health, and illness. Gillespie (2002) identifies that interpretive description is suitable when examining previously unexplored experiences and allows the researcher to move beyond participant’s descriptions and engage in interpretation of the participant’s experiences from their perspectives. This approach supports development of a description of an individual’s perception of an experience and an interpretation of the experience to uncover meaning and contribute to nursing knowledge. Further, these individual experiences are examined to identify what persons in similar positions share and what is particular to the lived experience of each individual. In this way interpretive description supports the dual epistemological mandates of nursing practice of knowing from both the emic and etic perspectives.

Stajduhar et al (2000) identify “this methodology is particularly useful in contributing to an understanding of how people experience health and illness and focus on what nurses can do to make a difference” (p 1214). Nursing knowledge is driven by the need for both theoretical constructs to direct practice and the need for knowledge to be practical or applicable. Interpretive descriptive methodology was designed explicitly to assist in the development of nursing knowledge, so that nurse researchers “may feel more freedom to examine methodological questions in the context of the overall objectives of nursing science instead of following the methodological dictates of other disciplines” (Thorne et al, 1997, p 171).

Interpretive description “gives recognition to the contextual and constructed realities of the health-illness experience” (Knoll & Johnson, 2000, p 66). The natural, constructed, and human nature characteristics of experiences are considered (Jacox, Suppe, Campbell, & Stashinko, 1999). This emphasis permits exploration of the
individual’s connection to their world and promotes the expression of self-interpretation. (Vaughan, 1992). The researcher-participant relationship allows for the expression of shared realities, and outcomes will reflect the individual experience, as well as shared one (Cohen, 1994).

The interpretive description approach indicates that a study be founded on an analytic framework, as opposed to a theoretical one (Thorne et al., 1997). This framework will be developed from what is already known about collaboration from the literature, including theoretical conceptualizations, models, and theories describing collaboration. While there is a lack of theoretical knowledge that specifically addresses the patient’s experience of collaboration, there is a wealth of information available concerning the concept of collaboration in other contexts. This knowledge will act as a starting point or foundational forestructure for the inquiry. The analytical framework however does not impose rigid structure to the inquiry but “orients the inquiry, provides a rationale for its anticipated boundaries, and makes explicit theoretical assumptions, biases, and preconceptions that will drive the design decisions” (Thorne et al, 1997, p 173). Henneman et al (1995) conceptualized collaboration in terms of defining attributes, antecedents, and barriers to collaboration. This conceptualization was the analytic framework I utilized to orient my inquiry. To assist in initial analysis I chose to conceptualize defining attributes as having three distinct components. The three components are a definition of the concept of collaboration, roles of the client and roles of the health care professional in collaboration. These later were constructed into the themes that describe the experience of collaboration.
Selection of Participants

The sample for the study was obtained using purposive sampling techniques. Purposive sampling "involves the conscious selection by the researcher of certain subjects or elements to include in the study" (Burns & Grove, 1997, p 306). Purposive sampling allows the researcher to select participants with particular characteristics to gain increased understanding of the phenomenon of interest. The use of purposive sampling allows selection of participants according to the needs of the study, based on the desire to obtain maximum variation in the phenomenon being studied (Thorne et al, 1997). Thorne go on to identify purposive sampling as important to an interpretive description that is meant to generate nursing knowledge as it allows the researcher to capture similarities and differences in the accounts.

Decisions regarding sample size were guided by the principles of appropriateness and adequacy. Morse and Field (1995) define appropriateness as the "identification and use of the participants who can best inform the research" (p 80). Adequacy is achieved when there is enough data available to develop a rich description of the phenomenon, with a goal of achieving saturation of the data. Saturation is achieved when "no new data will emerge by conducting further interviews and all negative cases have been investigated" (Morse & Field, 1995, p 80). Sample size was guided by the ongoing analysis of the data with a minimum sample six participants established as being appropriate for the investigation (Sandelowski, 1995). Frequent assessment of the appropriateness of this sample size occurred, and sample size was adjusted according to the needs of the study.
Criteria for Selection

The criteria used in selecting the participants in the study included the following:

- Adults with a diagnosis of chronic HF who were participating in an outpatient HFC.
- Willing to discuss their experiences of interactions with the health care team in some detail (both positive and negative).
- Participants must be willing to be interviewed and have the interview tape recorded.
- Participants must be capable of communication in English.

Selection Procedure

The participants were selected from a HFC located in a major urban hospital located in Western Canada. Prior to enrolment of participants I presented the nature, purpose, and goals of the study, criteria for eligibility, and data collection procedures to the multidisciplinary team of physicians, nurses, the operations leader, and the clinical nurse specialist. Time was allowed for the answering of questions or the expression of concerns and permission was obtained for people meeting the selection criteria to be approached and enrolled. Initial contact of potential participants was through the nurses at the HFC, to minimize the possibility of individuals feeling coerced to participate. The nurses were willing to identify potential participants and approach them on my behalf. The nurses were not expected to answer questions regarding the study and were informed that any decision regarding participation was confidential and that I was unable to disclose such information. On completion of the research, findings and conclusions will be made available to members of the HFC.
HFC nurses were asked to give a copy of an information letter that briefly explained the nature and purpose of the study, as well as participant expectations and contact information for the researcher to all individuals that meet eligibility criteria. The information letter is presented in appendix A. If an individual expressed interest in participating, the nurse encouraged them to contact me directly or if they preferred, gave permission to the nurse to provide me with their name and contact information. Two of the seven participants contacted me directly by telephone. The other five participants gave permission to the HFC nurses to give me their name and contact information, and I then contacted them. All of the respondents reported receiving the participant information letter. At the time of initial telephone contact, I provided potential participants with more information on the study, procedures for maintaining confidentiality and protection of human rights, and provided an opportunity to ask any questions they may have had. If the potential participant agreed to proceed, a date and time for an initial interview was established. Prior to the start of the interview, a written consent to participate was obtained from the participant (See Appendix B).

Interviews were conducted in a four-week period in the month of March. All but one of the interviews was conducted in the participant’s home environment. Purposive sampling guided participant selection as the study progressed as it allows exploration of maximum variation of the experience of collaboration with the health care team. The first five individuals selected to participate in the study were male. After initial analysis of these interviews I decided when selecting additional participants, to purposively sample for participants who met the additional criterion of being female. I believed that the
findings would be strengthened by the inclusion of female participants and the sixth and seventh participants were of female gender.

**Characteristics of the Participants**

A total of seven people participated in the study. Five of the participants were male, and two female. The age range for the participants was fifty two to eighty one years old with a mean age of 68.3 years. All were attending the HFC at the time of the study. Length of participation in the HFC varied from two to five years with a mean attendance of 3.4 years.

All of the participants were diagnosed with HF, although the primary cause varied. Three of the participants had a diagnosis of coronary artery disease that precipitated the development of HF, with two individuals undergoing coronary artery bypass grafting and the third individual angioplasty. Two of the participants’ HF was a result of arrhythmias and both had received devices such as permanent pacemakers and/or implantable defibrillators. One individual’s HF was precipitated by valvular disease that had been treated with valvuloplasty. The final individual’s HF was idiopathic in nature.

A majority of the participants reported having other significant health problems. Two of the participants were diabetic and one participant who was diabetic also lived with asthma and severe rheumatoid arthritis. One of the participants was diagnosed with chronic pancreatitis, and another with Grave’s disease. Finally one of the participants had experienced renal insufficiency intermittently throughout his disease trajectory.

All of the participants describe a crisis or significant event that precipitated the diagnosis of HF. A majority describe themselves as being in bad shape prior to coming to
the HFC. Three had experienced myocardial infarctions requiring prolonged hospitalization and interventions. Others describe a sudden decline in functional capacity with activities of daily living becoming difficult and then impossible. One participant described when the gravity of her condition became apparent. She recalled feeling disoriented, sick, and unable to perform normal activities. She went on to describe how bad it had gotten; “there was piles of garbage sitting at the door, and I hadn’t gone out for 3 days. I was in pretty tough shape”. Common physical experiences included increasing shortness of breath, lack of energy, swelling of the extremities, and difficulty sleeping. Emotional responses included fear, anxiety, a sense of doom or unease, and coming to terms with the possibility of death.

**Ethical Considerations**

Written approval to conduct the study was obtained from the ethics and research review committees of the University of British Columbia and the clinical agency. The rights of participants were protected in several ways. A member of the HFC team initiated contact with potential participants in order to minimize the possibility of individuals feeling coerced to participate. Potential participants were informed that the clinic team members were in no way involved in the research study except for the purposes of recruitment, and that there was no expectation that they disclose their decision regarding participation to them. Additionally participants were informed that the researcher would not disclose their decision regarding participation to any member of the clinic.

Potential participants were provided with a description and explanation of the study, including researchers' expectations, and provided opportunities to ask questions or seek
clarification of the research process from the researcher. Once an individual had agreed to participate written consent was obtained prior to commencement of any research activity. The consent form is presented in appendix B.

Participants were informed that they may choose to withdraw or choose not to participate further at any time, and that any decision to withdraw will in no way affect the care they receive. Participants were informed that any decision to withdraw would not be disclosed to any clinic member, or any member of the thesis committee.

Participants were informed that only the researcher and members of the academic committee will have access to any consent forms, tape recordings, transcripts, and field notes obtained during the research process. Participants were offered the opportunity to review transcripts of their interviews, and the opportunity to review research findings. Methods utilized to ensure confidentiality of participants included use of pseudonyms, generalizing descriptions of settings, and altering information that could be used to identify participants.

Participants were informed that they have the right to exclude any information from the study that they do not wish to share, which includes the right to have any portion of the audiotape erased at any time. Additionally the entire audiotape will be erased at the completion of the study.

Data Collection

The data collection and data analysis procedures are discussed separately, however in qualitative research they are not separate entities. Data analysis was ongoing throughout the data collection process and the findings influenced data collection. As tentative themes or categories emerge, they influenced the data collection process. Due to
the emergent nature of the study it was necessary to attempt to clarify themes by refining the guiding questions used during data collection.

The primary data collection method was in-depth, face-to-face, unstructured or minimally structured interviews with each participant in a location best suited to the participant. As the goal of an unstructured interview is to allow the participant to tell their story, recommendations made by Field and Morse (1995) to listen intently, minimize interruptions; avoid use of closed ended questions, jumping, counselling, or presenting the researchers' perspective were followed. All but one of the interviews occurred at the participant’s home.

The interviews were between thirty-five minutes and one hour in duration, to prevent the participant from becoming too fatigued. Participants were encouraged to indicate when the interview was completed, to retain control of the process. The sequence of each interview included an introduction period where the study was explained, any questions answered, informed consent was obtained, and demographic information collected. In addition, a short period of time was utilized for me to share information about my professional background and any relevant personal information. This allowed the participant to gain contextual information about me as both a researcher and a nurse.

The interviews were audio taped and open-ended trigger questions were used as needed to initiate and maintain the dialogue. Trigger questions were utilized to assist the researcher in obtaining relevant information. However, they were not designed to limit or control the discussion. Trigger questions were utilized judiciously as a tool to facilitate the research process and as a means of refocusing the discussion. Participants maintained primary control of the interview. Sample trigger questions are presented in appendix C.
The participants may at any time request that the audiotape be stopped or information revealed be deleted. In addition, as described in Morse and Field (1995) if the participants state “just between you and me”, or “don’t put this in your report”, or “I shouldn’t have told you that”, the information will be regarded as confidential and not be utilized in the report. “The researchers first responsibility is to the participant, the participant has the right to retract information, or to request that information not be used in the report, and the researcher must respect the participant’s wishes” (Morse & Field, 1995 p. 103). Neither of these scenarios occurred during any of the interviews for this study.

Collateral sources of data included the recording of detailed field notes soon after each interview. Field notes are “a written account of the things that the researcher hears, sees, experiences, and thinks in the course of collecting or reflecting on the data” (Morse & Field, 1995 p. 112). Field notes may include portraits of participants such as physical appearance, mannerisms, or style of talking. In addition, information of the physical setting, impressions the researcher picks up, and non-verbal communication may be recorded. Field notes were utilized to record subjective biases or unsubstantiated hunches, as both may significantly impact data analysis.

Data Analysis

The analysis of data began with the collection of data (Burns & Grove, 1997). At this stage the researcher is involved in such activities as perceiving, reacting to, interacting with, and reflecting on thoughts and feelings shared by the participant during the interview. These interviews were tape-recorded. Within three to four days, interview tapes were transcribed verbatim. In the process of comparing transcripts to tapes,
recalling observations and experiences during the interview, and reading and rereading transcripts, I became immersed in the data.

I began my analysis of the data by examining the narratives in the context of the analytic framework. The narratives were broken down or inductively coded into data that were congruent with the five broad idea categories described earlier. These five broad idea categories are conceptualization of collaboration, client’s role in collaboration, health care teams role in collaboration, antecedents to collaboration, and barriers to collaboration. This produced unwieldy amounts of data that would at best provide a superficial overview of the experience of collaboration, which I feel would be of little utility in clinical practice. I considered this the initial analytic step.

The next step involved reviewing the data coded into in each of the broad idea categories for the presence of patterns or similarities within the data. Thorne, Reimer-Kirkham and O’Flynn-Magee (2004) identified that “breadth is more useful than precision in the earliest coding and organizing processes, permitting groups of data bearing similar characteristics to be examined and re-examined for a range of alternatives” (p. 11). Thorne et al (2004) go on to state that when analysing data it “becomes important to move in and out of the detail in an iterative manner asking frequently, what’s happening here?” (p. 14). Using the techniques described of moving between the microscopic and macroscopic views, the data were inductively coded into smaller and more specific subcategories. In this process data was refined from five broad categories into many categories that provided a beginning description of the experience. I considered this an intermediate analytic step.
The intermediate analysis produced categories that were more specific and provided a greater depth of information on the experience of collaboration. However, a coherent description of the experience was not yet apparent. To prevent premature closure of the analytic process, I occasionally placed data into multiple categories. As the analysis progressed, decisions regarding the appropriateness of data were made, and categories became clear. Further analysis of the data allowed the construction of several dominant themes and sub-themes from the more specific categories developed in the intermediate analysis. This provided a deeper understanding of the experience of collaboration and resulted in the development of the final interpretive description. Each of these themes was supported with data from the narratives. Interpretation of thematic findings represents a coherent logic and a traceable audit trail (Thorne et al., 1997).

The themes and sub-themes were grounded in the data as interpreted by me. I feel that it is not possible to remove my beliefs and values from the data analysis and development of the final interpretive description. I approached the analysis of the narratives with an awareness of the need for reflexivity throughout the process. Thorne et al. (2004) stated, it is the researcher who ultimately determines what constitutes data, which data will arise to relevance, how the final conceptualizations portraying those data will be structured, and which vehicles will be used to disseminate the findings” (p. 12).

**Rigor**

Rigor in qualitative research is often discussed using Lincoln and Guba's model of examining truth value, applicability, consistency and neutrality (Morse & Field, 1995, p. 143). Sandelowski (1986) further explicates rigor in qualitative research and provides
guidance when assessing rigor. The following discussion will describe approaches used to ensure rigor throughout the study.

Sandelowski (1986) describes truth value as credibility where a “study is credible when it presents such faithful descriptions or interpretations of a human experience that people having that experience would immediately recognise it” (p 30). A major threat to truth value is described as going native, when the researcher becomes so involved with their subjects that they have difficulty separating their experiences from the experiences of the subjects. One approach that was utilized is repeated review and challenging of the analysis process and findings by the thesis committee and myself.

Sandelowski (1986) describes applicability as fittingness, which is described as “findings can fit into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences” (p. 32). Threats to fittingness include elite bias and holistic fallacy. Elite bias occurs when participants that are the most articulate, high status, and accessible members of their group compromise representativeness of the data. Other less articulate or accessible members of the group are then not represented in the findings. Holistic fallacy where data is perceived by the researcher to “look more patterned or regular or congruent then they are. The researcher’s conclusions do not contain all the data well but are presented as representing all the data” (Sandelowski, 1986, p 32). Methods to increase fittingness that were used in this study include triangulating across data sources for congruence and representativeness, and ensuring typical and atypical data sources are represented. It is also important to utilise current theoretical and conceptual knowledge to support
fittingness of findings. By expanding, modifying, or explicating current theory the researcher strengthens support for fittingness or applicability of findings.

Consistency is described by Sandelowski (1986) as auditability, which is defined as “a study and its findings are auditable when another researcher can clearly follow the decision trail used by the investigator in the study” (p. 33). The presence of a clear audit trail including descriptions of how participants were chosen for inclusion in the study, bracketing or acknowledging researcher biases or influences, and journaling of decision making during the analysis process are important. In addition data collection procedures, nature of the data collection setting, and information on how categories are developed were addressed.

Neutrality is described as confirmability by Sandelowski (1986), which “refers to the findings themselves not to the subjective or objective stance of the researcher,” (p. 34). The idea of freedom from bias in qualitative research is troublesome as “qualitative research emphasises the meaningfulness of findings achieved by reducing the distance between investigator and subject and by eliminating artificial lines between subjective and objective reality” (Sandelowski, 1986, p. 34). “Confirmability is achieved when auditability, truth value, and applicability are established (Sandelowski, 1986, p. 33).

Summary

The method utilized for this study was based on the non-categorical, qualitative research approach, interpretive description described by Thorne et al (1997). The sample for the study was obtained using purposive sampling techniques, based on the desire to obtain maximum variation in the phenomenon being studied (Thorne et al, 1997). In total seven participants were interviewed over a one-month period and their narratives used to
construct the interpretive description. Procedures to protect human rights and maintain confidentiality were adhered to.

Data consisted of transcribed audio tape recordings and field notes. Data analysis occurred throughout and subsequent to data collection. The decision trail for data analysis was presented and the analytic framework utilized to guide the inquiry was discussed. Procedures to ensure rigor of this qualitative study were discussed in terms of truth value, applicability, auditability, and confirmability.
CHAPTER FOUR

Findings

In this chapter I present an interpretive description of the experience of collaboration with members of the health care team in the setting of a HFC as perceived by individuals living with HF. The description was constructed from the narratives of the individuals who participated in the study. As outlined in the methodological framework described in Chapter 3, the interpretive description was constructed by repeated review of the transcripts and immersion in the data. Data was broken down into units of information that were inductively coded into broad idea categories. Properties or components of the idea categories were then identified from the data. From these categories the information was synthesised into themes that provides a coherent description of the experience. As the researcher I acknowledge my influence on both the individual narratives and the construction of the single written interpretive description. My beliefs and values, both personal and professional, influenced the interpretation of the narratives are embedded in this interpretive description.

Findings

I was struck initially by the uniqueness of each of the participants' experiences, and was concerned with how to proceed with the analysis without negating the individual. As I proceeded with the analysis I realized that I could not view each narrative as a discrete entity, but as part of a multidimensional whole with each contributing to the final common interpretive description. I began to recognize similarities in the narratives, which as the analysis progressed were synthesized into common themes that could then be applied to each individual's experiences. By
highlighting the similarities and differences I hope to capture the meanings of the experience for the study participants. These common themes may then provide useful insights into the experience of collaboration that may have meaning in other situations for other people.

As stated earlier each narrative was unique. Collaboration was experienced differently amongst the participants. Some of the participants described themselves as passive and did not feel that they were collaborating with the health care team. Others described themselves as active participants with the health care team. Regardless of how they situated themselves on the continuum of collaboration several common categories emerged from the data. To assist in the organization of data collection I first identified five broad idea categories that formed the analytic framework for analysis of the narratives and assisted me in constructing the interpretive description. The idea categories were: conceptualization of collaboration, clients role in collaboration, health care team’s role in collaboration, antecedents to collaboration, and barriers to collaboration. Together these broad idea categories provided a starting point for analysis and as a way to facilitate organization of the data.

Themes for each of the broad idea categories were then constructed from the narratives. Five dominant themes describing the experience of collaboration were constructed from the narratives. These themes provide a description of what was salient to the experience and will be used to guide the discussion of what the experience of collaboration was like for the participants. The five themes identified were mutual goals, working together, communication with the health care team, being accountable, and sharing power.
I finish the interpretive description with a discussion of antecedents and barriers to the collaborative process as experienced by the participants. Two themes describing antecedents of collaboration were constructed from the narratives. These themes were open communication style and trust. Finally, the themes describing barriers to collaboration are discussed. The themes were lack of time, difficult communication styles and inequity of power sharing.

Experience of Collaboration

The first section of the findings will present a description of the experience of collaboration with the health care team in the setting of a HFC. By presenting both similarities and differences in the narratives I hope to capture the experience of the individual while providing insight into the global experiences of collaboration. To facilitate the discussion I have organized the presentation according the five dominant themes of mutual goals, working together, sharing power, communication with the health care team, and being accountable.

As I completed each interview and later during transcription and repeat immersion in the narratives I was struck that each of the participant’s was extremely positive about their experiences in the HFC. Each of the participants indicated that overall the experience was positive. Several of the participants indicated that they enjoyed going to the HFC One participant stated “Well sometimes I look forward to going down there” another indicated “I quite enjoy it. Well I may not enjoy it but I feel comfortable”. Descriptions such as “it was just a revelation” and “We come away on a high. My wife and I we come away on a high. We say wasn’t that good. Wasn’t that something, how lucky we are” were found throughout the narratives. Other participants
were more explicit in their descriptions and credit the HFC with saving their lives. One participant stated “I must say they have kept me alive since May 1999”. He continued by saying “I owe a great gratitude to them for where I am today…alive”. I felt it was important to the interpretive description that this be explicitly identified. It provides important contextual information that must be taken into consideration throughout the discussion of the findings.

Mutual Goals

Each individual described having certain a priori expectations of the HFC, based on information given by the referring physician. A majority of participants were told to expect alterations to their medication regime and counseling on lifestyle modification. Some were apprised that the HFC might perform diagnostic testing such as echocardiograms and angiograms and offer specific interventions if applicable. All of the participants expressed that their primary goal for attending the HFC was an improvement in their functional capacity and to “feel better”. What differentiated the HFC experience for the participant was a sense that the health care team was working towards the same goal of making them feel better. Participants spoke of feeling that members of the health care team were there for them and were actively working to maintain their health.

Because he is there to keep you healthy. He is not there for any other purpose. And the nurses are all the same. They are there for you.

they are concerned for my well-being, they seem to have a genuine concern for my health, how am I doing, how am I feeling.

Knowing that they were not alone but were part of a team with congruent goals, and working toward the same outcome appeared to be an important aspect of the
experience for participants. One participant described that from his perspective helping him through the experience was a primary motivation for the team to do their work.

you get the feeling, just from the couple of nurses right up there to the doctor that they want to help you. And that they are prepared to help you if you do your part.

Like we are here to help you. Welcome we are here to help you. Tell us what you are going through and we will help you. We will help you get better. That was just, that was just obvious. That was the motive up front. We are here to help you and we will help, and we are going to get you better we have ways and means. We have meds we have knowledge, and we know what to do. From fluid intake to medicine

One participant described working towards mutual goals as not only beneficial to the individual, but also for others attending the HFC. He talked of the team being able to help him and being able to apply the knowledge gained from his individual case to assist others.

Well I'm building a lot of experience there, and I'm sure that you know that having these problems and being able to discuss them with you people will help you to help somebody else.

I feel I am doing something worthwhile, not only for myself but for the clinic. I mean they use that experience and pass it on to somebody else. It helps them

This perspective is important as the participant describes the benefits of working towards a common goal as reaching beyond the individual and encompassing others with HF, and the health care team. This is congruent with my experiences as a nurse in the HFC. I frequently apply knowledge gained from one individual to other similar cases, and feel that this knowledge is invaluable.

Participants spoke of sharing mutual goals as an important aspect of building a relationship with the health care team. Participants described that sharing mutual goals
made them feel that they were engaged or part of the team. Additionally they spoke of feeling that the team was there for them. Whether the mutual goals had an individual or broader focus it was a common element of the experience of collaboration for most participants.

Working Together

The theme of working together was constructed from the descriptions of the participants’ experiences in the HFC as feeling that they belonged to a team. Most participants described a strong sense of teamwork and a desire to work together as central to their experiences. Several participants identified that working together and feeling part of a team was an important aspect of what differentiated their experiences in the HFC from those with health care professionals in other settings.

Throughout the narratives the participants frequently discussed working together as being comprised of two distinct aspects. Participants frequently described their experiences as a joint or team effort. One participant stated “there is no I in team, it’s a team” when describing his experiences. A majority of participants also described working together as being willing to participate or cooperate in the relationship. One participant, when asked to describe how he worked with the health care team replied, “well by cooperating, listening to them, and doing what we agreed to do”. A majority of participants indicated that a willingness to participate in the relationship was necessary for them to feel engaged or part of the team.

To facilitate the description of the experience of working together I will utilize the sub-themes identified from the narratives as a framework for the discussion. Therefore
working together will be described as comprised of the sub-themes of joint venture and willing participation.

**Joint Venture.** Participants almost universally described the relationship they had with staff in the HFC as a feeling that they belonged to a team. Many of the participants identified that this was what made their experiences in the HFC unique and differentiated it from experiences with other health care professionals. Some participants described the experience as a joint or team effort.

Well their demeanour is very acceptable. It makes me feel as a patient comfortable, and it makes me feel that we are jointly doing this you know. Their manners are excellent and their approach is soft, OK. And it makes me very comfortable. As a lawyer I have to do the same thing with my clients, you know to make them comfortable so they can confide in me. Same thing as my relationship with the team.

It is like a joint team effort where everybody does something that creates the best care. Very professional.

The experience of working together while common was not universally reported. One participant indicated that he did not feel that he was part of the team and described how “mainly they look at me go away and they don’t tell me nothing so (laughing) it’s like any other place you know”. In contrast another participant described himself as feeling fully involved and an equal team member. The other participants describe their experiences of being involved in a joint endeavour as falling somewhere along that continuum.
When asked to describe how the team functioned, several of participants reported remarkably similar experiences. Most saw the cardiologist as the head of the team who ultimately made many of the decisions. The nurses were often seen as supportive and giving information to both the participant and the cardiologist.

I would say it is a team effort but the big one is the cardiologist, but the specialist nurse that comes (nurse’s names) they would thoroughly investigate what I had been doing. Like if I was going there on a monthly visit they wanted to know how much I walked, they also monitored my water, because I was only allowed to have 6 to 8 glasses because I have a leaky valve. I had to submit this to (nurse’s Name) for about 6 months every week how much water.

Well I think they take down all the information. I am not sure I am going to make the assumption they ask the questions they may or may not advise the doctor. Maybe I’m old school. I don’t know maybe I guess again I don’t know. I guess it would depend on the relationship between the nurse and the doctor. You know they ask me the questions you know don’t really have anything to hide. Tell me whatever and I am assuming that they either give their report to Dr (doctor’s name) or shorthand it for him. And when then he makes the call.

There appears to be a common perspective amongst the participants that having clearly defined roles for each of the team members facilitates the process of working together. Several participants described feelings of increased comfort knowing that everyone knew what their roles were. Others described how clearly defined roles promoted a sense of teamwork. One participant summed it up as “it is like a joint team effort where everybody does something that creates the best care”.

One participant talked about how the experience of working together in the HFC differed from other experiences with health care professionals. He described the
experience as not the same old-fashioned relationship he had experienced with other health care providers.

Given the team we are talking about. We are not talking about some thing old fashioned. No, you’re not to read, your not to read anything about this. No, No the only thing you get is from me. It hasn’t happened in your team.

This participant described how he was able to be an active participant in his care, with questions being welcomed, and his opinion being viewed as important to the team. Other participants confirmed that being involved in decisions made them feel as part of the team. One participant noted, “I feel that I’m involved and that’s good. It makes me feel good. When you feel good you get better a lot faster”.

**Willing Participation.** All of the participants reported that they were willing to cooperate with the health care team at the HFC. Most participants expressed a strong desire to help the health care team in any way they could, and indicated that it was an important aspect of working together. Willing participation was most often described as cooperating with the health care team. One participant described how he helped the team, “by cooperating, listening to them and doing you know what we agreed to do”. This included freely sharing information and generally doing what had been agreed to during the clinic visit.

So I did participate all the time. I am not one of those who ah hold back any information. I just tell it like it is. In that way by telling them what’s wrong with me I got very involved into my diagnosis

Participants often described the need for them to provide a detailed description of symptoms they were experiencing, and most indicated that it was important not to withhold information. All participants describe needing to honestly answer questions regarding adherence to lifestyle modifications such as fluid restrictions, sodium
restrictions, and weight changes. Participants also reported that an important aspect of willing participation was to adopt recommendations made during each clinic visit. One participant described how he came to the decision to willingly participate with the health care team. He described that by being a willing participant he was benefiting both him and the members of the health care team. He went on to describe that he felt that by not working together he was only hurting himself.

You can be difficult to be get along with from the beginning but there’s, no it doesn’t help the people trying to help you or yourself. So I thought that if I feel that they know what they are doing I’ll cooperate. With them and I think we can get somewhere

A majority of the participants confirmed this participant’s view that being willing to participate in the relationship was beneficial. Most described that by being willing to participate they would increase the possibility of achieving improved outcomes for themselves. One participant described that he viewed maintenance of lifestyle modifications as mandatory and that if he did not, he would not “feel comfortable being in the team. So I am compelled to do certain things”.

As previously described all of the participants had experienced a crisis event that had precipitated the diagnosis of HF. One participant stated, “we are all very sick people you know”. The acknowledgement of the gravity of their condition was confirmed by all of the participants. Another participant stated “but when you hear that there is something wrong with your heart you just freak out. You know what I mean. Well it’s a very vital organ”. Most participants also indicated that the seriousness of their diagnosis acted as a strong motivator to willingly participate. This willingness to participate was often reinforced by a dramatic improvement in the participant’s condition after enrolling in the HFC. Several participants reported immediate improvement in their condition. One
participant characterized it as “it was like a curtain opened really” She goes on to describe realizing that she was “not going to keel over tomorrow”.

Several of the participants also described the members of the HFC as willing to participate in the relationship. Some of the participants focused on the nurses in the HFC.

I found them very cooperative. The first nurse I saw was (nurse’s name) and I liked that because I spent quite a bit of time with her about an hour or hour and a half

P: but the nurses were all very cooperative and very helpful.

R: In what ways?

P: Well they listened they asked me good questions and they could see two sides to it. Which was very nice.

Participants who described the health care team as willing participants frequently focused on the amount of time the team members spend with them. Most participants reported being surprised and pleased with the amount of time they were given during each appointment to the HFC. One participant compared her experiences at the HFC with a prior experience that had felt rushed. She stated “to have somebody sit down and talk to me when I go there. I never feel like this other doctor made me feel”

Other participants described the interactions in terms of how the team responded to them and their questions. Most participants reported that an important aspect of the relationship with the HFC was the ability to ask questions and receive meaningful answers. One participant stated, “any question I’ve ever had was, was, was answered, was discussed, absolutely well just satisfactory, well answered you know” He went on to state:
When I come with a piece of paper in my hand and say what about that. He would say let me tell you well let me explain something. Not like I don’t want you to read nothing, right.

First visit. First handshake with Dr (doctor’s name) Definitely I noticed the difference. You know the man sits next to you, leans forward. He’s got your file and he leans forward and says Hi. The doctor takes a look at you and says OK this is not just something the cat dragged in right so. I can talk to him like another human being, who is ill and who comes to me for help, right

A majority of the participants described similar experiences where they felt treated as human beings and invited to participate in the relationship. One participant stated that “you can talk to them, about other thing other than your heart, age, menopause And I don’t feel that I am strictly a name on a file”. Another participant confirmed that from her perspective an important part of working together was being viewed as more than a patient with a disease. She stated, “I’m just not boobs or I’m just not an arm or a chest or something. I’m a person”.

Communication with the Health Care Team

The theme of communication with the health care team appeared core to the participants’ experience of collaboration. All of the participants agreed that without communication no relationship would be possible. Many of the participants identified that communication with the health care team as one of their primary responsibilities within the relationship. The theme of communication with the health care team was constructed from the narratives. With immersion into the narratives I began to see communication being described as either sharing experiences or symptoms with the health care team and/or as a means to increase knowledge.

I will utilize the sub-themes identified from the narratives as a framework to assist in the description of this aspect of the experience. Therefore communication will be
discussed in terms of the two sub-themes sharing experiences with the health care team and gaining knowledge.

**Sharing experiences with the Health Care Team.** All participants in the HFC are asked to share significant amounts of information with the health care team. This information is used to assist the health care team in making decisions on the direction of medical care, and alter the plan of care as necessary. Participants are asked to share information on adherence to lifestyle modifications such as fluid restrictions, sodium restrictions, and weight fluctuation. They are also asked to share their experiences with medications such as medication adherence and reporting side effects of the regime. Participants are also asked to report significant symptoms of heart failure in a timely fashion. Symptoms of interest include shortness of breath, development of edema, palpitations, dizziness, changes in functional capacity, paroxysmal nocturnal dyspnea, and orthopnea. In addition participants also are asked to report on any other significant experiences that are unique to their illness.

Given the amount of information participants are asked to communicate it is not surprising as one participant stated, “my role was to assist the staff. Honestly to tell them how I feel”. This was echoed in other participants’ narratives and was frequently identified as one of their primary responsibilities.

Participants described that reporting of self-management skills was an important aspect of communication with the health care team. All participants reported being asked to report on their adherence to lifestyle modification. Most participants indicated it was important for the health care team to know how they were doing, as it provided guidance for decisions about their care.
It is very important for them to know if I have been to the emergency and how much exercise I am doing, how much water I am taking I tell them how I sleep at night, how much pillows I use, It asks me about my breathing difficulties. Whether it is worse the same, ah you know there is

You do your little sign in, how good, how bad you have been since you have last been here. And ah then you have your sit down and you have ah your BP, and heart rate and a run through the meds. What has changed ah if anything. I would call it prepared the discussion and the nurse shares with the doctor

Several participants, after the interview had finished, shared their fluid and weight diaries with me. These participants reported bringing the diaries to every HFC appointment and spoke of how they shared this information each time they were communicating with the health care team. One participant described faxing fluid and weight logs to the HFC on a weekly basis during a recent period of instability. Another participant shared the electronic diary he had created that he occasionally emailed to the nurses at the HFC.

Several of participants described the importance of sharing difficulties with the medication regime with the HFC. This included response to changes in the regime, and overall adherence to the regime.

If I had real side effects or something I would, I think I would obviously pick up the phone and say I'm having a real problem with this medication.

When they do give me a new pill or whatever I really tune in. When I take it over one, two, three, or four days. I really take account, is it really doing me any good or bad you know.

Other participants confirmed the importance of communicating with the health care team any challenges with the medication regime, in their narratives. One participant
described how by sharing information the team was able to find the best medication
regime for him. He stated, “when they would find out how I reacted, I would tell them
and then there was a time when the medicines all fit”

All participants described reporting symptoms of HF to the HFC. Most identified
this as one of the most important aspects of communicating with the health care team for
them. As one participant summed up, “well if I am having trouble breathing, they don’t
know that unless I tell them”.

I help by telling them what my symptoms are. OK. And unless you
tell them your symptoms you cannot diagnose it. And I felt I played a big
part by telling them my symptoms correctly as best as possible so they
could give me the best treatment.

Well I thought if I can tell you about what I am experiencing with this
shortness of breath or with my heart problems, my medications they would
listen to me.

Well last Friday I called (nurse’s name) because I was, I looked like an
elephant. My legs looked like, because they had taken me off the atacand,
the spironolactone and the Lasix, and she was so great. She talks away
asked me how I was, told me what to do and so that part of it. I feel I have
no hesitation if there is something wrong.

Participants reported that they were encouraged to share symptoms they were
experiencing, not only at HFC appointments by also by telephone. Several participants
described telephoning the nurse to notify them of a change in their condition. One
participant phoned due to a dramatic change in weight, and a worsening of symptoms.
Another participant described, “I was going for a walk OK and I did receive some pain
in my chest I called her and I did describe to her. In that sense, she immediately told me
to go to the emergency”.
Gaining Knowledge. Participants frequently described how much knowledge they had gained by attending the HFC. One participant stated, “the information giving is great”. Participants described obtaining information on admission to the clinic, where basic information on the pathophysiology of heart failure and self-management education was initiated. All participants also reported gaining information by the frequent asking of questions.

A majority of participants described the intake appointment, where a HFC nurse initiates HF pathophysiology and self-management education, as a great opportunity to gain knowledge. Most of the participants describe this focus on them gaining knowledge as unique to the HFC. One participant when describing the intake appointment, which consists of a HFC nurse reviewing medical history and initiating self-management education prior to the first visit with a doctor, stated “They explained to me all about nutrition, and liquids in food. They educated me”.

When I first went into the clinic we really had no idea. My husband was with me, and we really had no idea what was going on. And it was (nurse’s name) was the one we first saw And she was great. Explained everything

Well they gave me instructions. Like the amount of liquids I should be taking, and making sure that I take my pill when I should take them.

Through the good efforts OK of explaining to me that it is important and mandatory to me that you must walk, and you must take less water, and things of that nature. And how to handle the pain, like there I am fully, they have taught me to recognize all the signs of an MI.

During the time I spent with several of the participants they shared with me their copies of the educational material they had originally received on intake to the HFC. These materials included pamphlets on fluid restrictions, sodium restrictions, and an
overview of self-management including signs of decompensation and when to seek help.

These participants reported that they still periodically reviewed the information, which assisted them in maintaining the lifestyle modifications.

Consistently the participants’ identified the most important way that they gained information was the asking of questions. All participants reported the asking of questions. Most reported that they asked questions at every appointment at the HFC.

So specifically, I can only say that I have always been interested in what meds do I take and why. What do they do, and what if anything I have to watch, and what side effect there would be, if any, etc. And all of this has always and well explained by Dr (doctor’s name) and (nurse’s name) or any other nurse that’s been in attendance.

There was something that I had forgotten to ask and it was and it was not the nurse that I had seen but another one and the nurse is off on Friday and I’d asked my couple of questions and she gladly answered them.

The doctor comes and goes through it and goes over his physical check and runs through everything right down to the funny question, and the last time, would you believe it the last silly question was, How long do I got, I’ve got so many things to do, so how long do I got. Dr (doctor’s name) (laughs). And we came right down to it.

The most common questions the participants reported had to deal with medications. One participant when asked to describe questions he might ask stated, “Well I guess it could be some of the medications Why they were changing and I you know and maybe adjusting some of them.” Other questions focused on diagnostic procedures or interventions such as surgery. One participant stated “Yeah I must have been going to the clinic when I had the surgery, because I checked in there when I had it done…and they are just really good at explaining stuff to you and I was scared to death.”
One participant reported doing research on the Internet on his condition, and his medications. He stated, “What I do is when we discuss any thing or ah any meds. I go home and study them I punch in the net. I am a voracious reader. So I want to know”. He then describes taking question stimulated by this research to the HFC.

Well any given med you ask a question both the patient coordinator and the doctor. They take the time to explain what it is, where it has been used, for how long, and how successful it has been, and if it belongs in the major gold standard group, etc. And you don’t get that I guess from probably the majority of doctors.

All participants reported that they had gained knowledge during their time at the HFC. A majority of the participants indicated that they had gained knowledge on HF self-management and medications. However one participant indicated that he did not feel his questions about medications had been answered. He stated, “I’d like to sit down with somebody and here are the pills I take are their any of them I can eliminate”. He went on to describe himself as “illiterate to pills”, and described the frustration of asking about his medications and still as he states “I have no idea (laughs) I have no idea”.

Being Accountable

The theme of being accountable was constructed from repeated immersion in the participants’ narratives and their descriptions of the responsibilities of being a HFC patient. A majority of participants report that they felt that they had taken some responsibility for their health status. Most reported recognizing the importance of making lifestyle modifications, or practicing self-care behaviours. The two lifestyle modifications most frequently described were restricting fluid and sodium intake followed closely by getting enough exercise. Other self-care behaviours included quitting smoking and loosing weight. Some participants also reported that they felt that they were accountable
to not only the HFC staff but also to themselves. One participant summarized this by stating, “Yeah I think you have to take responsibility for your life”.

I will utilize the two sub-themes constructed from the narratives as a framework to guide the description of the experience of being accountable. Therefore being accountable will be discussed in relation to the two sub-themes self-care behaviours and taking responsibility.

**Self-care Behaviours.** Most participants reported attempting to adhere to lifestyle modifications, or self-care behaviours that had been recommended by the HFC. As previously indicated the most common self-care behaviours described were restriction of fluid and sodium and getting enough exercise. One participant stated, “My role in the heart function clinic is to do my side of it. It is to eat a proper diet, get exercise and look after myself”.

Honestly to tell them how I feel, how much exercise I’ve done. I’m only cheating myself. And I had to force myself to do exercise, limit my water, and I took my medicines regularly. This is how I helped them, in what they asked me to do.

Well my, my major role is to respond to what has been suggested or told. The weight. The weight fight has been the toughest as you can imagine. But I’m down something like 40 lbs, I’ve got 20 more to go It’s ah that’s ah subject to Christmas, Easter, birthdays (laughs) It interferes doesn’t it. Festivities interfere. No that’s number one.

To take care of myself. To make sure I take my medications, which I do faithfully. To quit smoking, to do my exercise. To I guess aside from the heart side its just taking better care of myself.

I did a lot of walking, ah religiously. I would walk 3 miles a day and I would do it very very well. But then I had this bout last July, and it slowed me up a lot. And right now I have this hernia that is giving me hell, so I ‘m lucky if I get in a 15 – 20 min walk every day. But I try to do a little if I
can. So my role in it is to yeah is to look after myself as best as I can, and with the help of my good wife it happens.

Most participants described achieving success with the self-care behaviours. However few found the changes easy. Several participants described forcing themselves to adhere to the modifications. This was especially reported during the initiation of the lifestyle changes. One participant summed it up by stating, “I cut down on salt and water, which just about killed me”. Another participant reported that she remained smoking. As she stated, “Well you know you are supposed to stop smoking. I’m not an idiot”.

A few of the participants shared with me their techniques for adhering to the lifestyle modifications. One participant placed a container on his counter that had a mark indicating six cups of fluid. He reported adding water to the container whenever he had fluid and when the water came to the six-cup mark he stopped drinking for the day. Other participants reported utilizing gum and ice cubes to minimize thirst, which helped them adhere to the fluid restriction. Two of the participants also credited their spouses with assisting in their adherence to the self-care behaviours.

**Taking Responsibility.** As indicated earlier, some of the participants felt that they had taken responsibility for their lives. One participant had stated, “Yeah I think you have to take responsibility for your life”. Some participants reported that if they did not they felt would be cheating themselves and preventing the HFC staff from doing their jobs. One participant stated, “I try not to cheat in my water. I try not to cheat in my exercise. Because I am only cheating myself”. Other participants described it as their duty.

It’s my duty to react to the doctor’s hints, demands, issues right. If I didn’t do that I shouldn’t have the joy of being a patient of that doctor you know. Given the team we are talking about.
I think to be honest like you know; you know how much you are smoking. Like there is no point if I’m smoking a package a day there is no point in saying I only have 10 cigarettes a day or I only have 5 cigarettes per day.

So I, it is my duty to respond to that, my duty to do my very best of the doctor patient relationship as a team.

Two of the participants described taking responsibility for their lives as being a prerequisite for attending the HFC. One participant indicated that he would not feel comfortable being part of the team if he did not take responsibility. The other described that he shouldn’t belong to the HFC if he did not take responsibility for his life. For these participants it seemed that they felt they had to earn their place in the HFC.

Another participant focused on being honest with herself, and the HFC. She described this in relation taking responsibility for decisions such as continuing to smoke. She described not taking responsibility, as “That’s just ludicrous”. She went on to state:

So I don’t know why people lie about it, because I’m sure when they listen to you chest they can tell, they probably can tell that you smoke anyway. I guess to be honest. I guess if you are asked a question you know whether they have this disapproving look or they don’t, so be it.

This participant appeared to describing that from her perspective part of taking responsibility in the relationship with the HFC was admitting when recommended lifestyle modifications were not being adhered to. This perspective was unique to this participant as other participants reported doing what they had been told to do.

Other participants did not explicitly state during the interview, that they felt that they were taking responsibility for their lives. However on reviewing field notes I noted that I had described conversations with participants that indicated how important it was for them to take responsibility for their lives.
Sharing Power

The final theme that was constructed from the narratives is that of sharing power. This theme represents the aspect of collaboration that participants demonstrated the widest variance in their descriptions of the experience. At one end of the continuum participants characterized themselves as “only a patient” and felt that they had little to offer in decisions about care. One participant stated, “Well I can’t think of one where I felt really involved”. At the other end of the continuum a few participants described themselves as active participants and equal partners. The others situated themselves somewhere between the two extremes. However with repeated immersion in the data I noticed that a majority of participants described experiencing increased control as they gained knowledge. One participant stated “Finally I know what is going on and somebody is interested enough to do something for me, and it was just a revelation”. A few of the participants also felt that they shared in the decision making process regarding their care. Again I will utilize the two sub-themes constructed from the narratives as a framework to guide the description of this aspect of the experience. I shall discuss the theme of sharing power utilizing the two sub-themes of gaining control and shared decision-making.

Gaining Control Many participants described themselves as not being involved in decisions in their care or feeling that they were able to share power with the HFC staff. However several participants indicated that increasing the knowledge of their condition increased their sense of control over the situation.

Well a little more assurance. I felt better about myself, well I felt OK with myself, but about my heart condition because I found out a little more about it
If they change my medication, which they haven’t done that often. But if they do change it, they tell me why and usually it is for the better.

the doctor sat down and talked to me and I talked to a number of different people, and I felt oh wow. Finally I know what is going on and somebody is interested enough to do something for me, and it was just a revelation.

As discussed in an earlier section the gaining of knowledge was an important aspect of the experience of collaboration for the participants. Several participants reported that by knowing more about their condition they felt better. Some reported that they were better able to handle untoward events. One participant described learning about “how to handle the pain, like there I am fully, they have taught me to recognize all the signs of an MI”. He goes on to describe that because he knew what to look for he feels he sought help in a timely fashion during his last heart attack.

Other participants reported that knowing what to expect with changes to their medication regime was important to them. One participants stated, “if I consider myself a fully informed patient I want to know what it does, and why and I have never had anybody hold short on giving me a full explanation on anything”. Other participants confirmed the importance of knowing what to expect from their medication regimes throughout their narratives.

Several participants described that having questions answered allowed them to feel a sense of increased control. One participant described that having information presented honestly and in a straightforward manner increased her sense of control, because when she had the knowledge she could chose how she was going to react to it. She stated:
They are pretty honest, which I like. Like don’t sugar coat it, just tell me the worst case scenario, just lay it on the table, and I’ll deal with it I won’t deal with it or I’ll comprehend it in my own way but you know like don’t go around in circles, just tell me something just out with it

Despite several participants describing an increased sense of control this was not a universal experience. One participant who was experiencing the end stages of HF and confined to a wheelchair reported that he felt he had little control over his fate. He stated:

I made a decision after the last heart attack that every day that I wake up is another day cause I shouldn’t have made it. I went through a very a less than two percent chance of getting out, they called the families in I was in that bad a shape and fourteen hundred tubes sticking out of my body. So I figure I’m just glad that the good lord give me these extra days. And I’ve got no fear of the other side right so I just take every day at a time.

Despite this he reports feeling happy and enjoying his life. He reports that his faith is important to him, which suggests that this may be his way of gaining control. He stated:

That’s five years of my life and I enjoyed it very well thank you very much. I got my aches and pains and everybody says well put the guy out of his misery. Well their not as I’m enjoying myself. I don’t enjoy the pain but I enjoy life.

Shared Decision Making. As indicated earlier, some of the participants did not identify themselves as being involved in decisions at the HFC. Many of the participants characterized themselves as somewhat passive, and trusted the decisions made for them by the HFC. One participant stated, “I am just very accepting of any decisions that are made on my behalf”. However this was not unanimous. Several of the participants described themselves as actively sharing in the decisions about their care.

One participant described the experience of deciding whether or not to have a blood test that could quantify the severity of his HF. The test is B-type natriuretic protein
(BNP), and is a marker that provided the HFC with an objective measure that describes the severity of the patient's HF. The participant had asked the physician at the HFC how long he had to live which prompted the discussion.

And we came right down to it, after we discussed the various tests. He said, I actually really wanted to say something about that today to you to. We have a test. Oh OK explain it. And then he explained the BNP test, and I really want you to go downstairs today and ah have some blood drawn. And, we'll just see. We find it is a very good predictor or indicator to some degree of reliance, ah of whether you will keel over tomorrow. I said interesting, and I will go down and do that.

This participant went on to describe how he felt he had been very involved in the decision to go ahead with the BNP test, as he had been the one to initiate the discussion of prognosis.

Another participant described himself as not a team man. He indicated that it was difficult for him to relinquish control. The following are excerpts from his narrative describing his experience of sharing control over his life.

you know I'm not necessarily a team man if you want to put it that way because I like to be in the driver's seat. But you can't always be in the drivers seat because maybe there is somebody who can drive better.

I am going there and am in the hands of professionals. I'll play ball with them. I'll collaborate because they know what they are doing we can both solve a problem.

P: We go down there and we know that we are going to people that are going to help us out. And by doing that we have to play ball with them.

R: By play ball what do you mean Can you tell me.

P: Collaborate it's the same thing. . By playing ball you collaborate.
He had described that he was a professional who was used to making decisions and being in control. For this participant it was not gaining the sense of control that was a challenge but rather giving some of the control to the members of the HFC. He described the experience of making decisions about his care with the health care team.

R: Can you tell me a little more about how decisions are made about your care in the clinic? And your involvement in the decisions?

P: Well I’m pretty decisive. I don’t take long to make up my mind, but I will ask them the right questions if it’s a percentages and what he is going to do for me and then we see And I’ll say to go ahead or not. But I you know if they weren’t. If they gave me some sound reasons why certain steps should be taken I was fine.

Antecedents and Barriers to Collaboration

This final section of the interpretive description describes the participants’ perceptions of the antecedents and barriers to collaboration with the health care team. Participants shared their perceptions of what supported or inhibited the development of a collaborative relationship throughout the narratives. From the narratives, a coherent description of antecedents and barriers to collaboration were constructed. I first present the antecedents to collaboration as experienced by the participants. Finally I present the participants’ experiences of barriers to collaboration.

Antecedents to Collaboration

Participants as described earlier were overwhelmingly positive when discussing their experiences with the HFC. As one participant stated, “I am just so prepared to stand on a rooftop and say how great this place is”. Participants generally described feeling like being part of a family, and feeling safe with members of the HFC. Throughout the narratives participants described several key antecedents that promoted the development of a collaborative relationship with the health care team. From the narratives two themes
were constructed that describe participants’ perceptions of antecedents to collaboration. The first antecedent to collaboration that will be explored is the use of a non-intimidating communication style. The second antecedent to collaboration that will be discussed is, trusting the health care team.

**Non-Intimidating Communication Style.** Participants almost unanimously described communication with members of the health care team as a positive experience that promoted a sense of teamwork and collaboration. Participants frequently described members of the health care team as friendly, willing to listen, and pleasant. One participant described communicating with the health care team as, “there is no hostility, roughness, there is no duress, there is no intimidation”. Other participants echoed this experience throughout their narratives.

Their manners are excellent and their approach is soft, OK. And it makes me very comfortable.

It is their demeanour and as I said they have open minds. They are not, you know not trying to play god.

the nurses were the ones I met there had open minds. They were willing to listen to me, and that’s a great thing.

And I if you get good doctors with a good attitude and a good sense of caring and understanding then hey you are lucky. And that is how I felt with the heart clinic.

So the difference in the attitude and the caring I think of the people at the heart function clinic.

All of the participants identified that they felt comfortable when communicating with staff at the HFC. When asked about the interactions with staff at the HFC many
participants described finding the staff easy to talk to because of their gentle approach. Some participants described the staff at the HFC as having a good attitude. Others identified that they perceived the staff as having open minds and being willing to listen. One of the participants described her experiences in the HFC as unique, indicating she had never felt this comfortable communicating with health care professionals in the past. Another participant summed up his experiences by stating “Absolutely not one, not one interaction that was not positive. I’ve never come away from there in any feeling of dismay or negativity or anything what so ever. Everything just every visit was good”.

One participant described how important a non-intimidating communication style was to him. He stated:

P: But as far as I’m concerned it’s the pleasantries that helps us through this stuff and that is what I call it what you’ve got here is the pleasantries. And it is even better than medicine sometimes you know It’s cause they all treat me so great. I don’t know why (laughs) but they do every one of them.

R: So tell me a bit more about what you mean by the pleasantries?

P: They smile and, and in general terms there are nice people out there and I’ve never sat here and seen any of the nurses or doctors holler at somebody I thought I told you to do this or this like an old country doctor. This is all nice, this is all pleasantries. I still say it’s a lot to do with the healing of the person themselves is always treated instead you know instead of a piece of meat they are trying to put together, you can feel the caring and that they are really trying to do something for you. And that is what I enjoy with this here. I enjoy coming here.

This participant described a non-intimidating communication styles as an important aspect of getting through the experience of living with HF. He described the communication style as making him feel like the staff at the HFC viewed him as a person, and genuinely cared for him. This experience is confirmed in the narratives of the other participants. Participants described how a non-intimidating communication style
made them feel. Several participants described feeling comfortable and safe while others stated they felt lucky and it was a great thing. One participant described how important it was for her to feel comfortable with members of the health care team.

I think I liked him first for his personality, and then thought of him second as a doctor. I think it is more important for me to feel comfortable with somebody And I think it goes a lot to not actually hold back, but I think that if you feel comfortable with somebody you feel comfortable giving your answers.

When probed, several of the participants indicated that an important aspect of feeling comfortable with the health care team was their sense of humour. Three of the participants in particular identified humour as important to them, as it made them feel comfortable communicating with the team.

P: I have friends that get so stressed when they go to a doctor or have something happen to them. But I just feel comfortable, and I don’t have any worries when I go in there.

R: Can you think of what they do that makes it such a comfortable experience?

P: I like people with a sense of humor, and I find Dr (doctor’s name) I get a real kick out of him. I’m trying to think of what it is. But you know right why I walked into the room the last time I was there and felt like Oh, You can talk to them.

And amongst all this seriousness there’s room for joviality and you know we have a couple of laughs. Every time I come I write a little joke on the bottom, or a silly question you know. What do you want to ask the doctor today, you know. Every time I have something lighthearted or silly or funny. Which is my style. My wife says do you have to write that (Laughs). But that’s what I do that’s what I do and that’s part of it and the team, they accept that and are nice and responsive to that.

I like his sense of humor. Like I understand that sense of humor. I guess he’s what’s the word. I guess depending on the person all the time I guess you know your audience but you know we just I don’t know I have a
really great sense of humor and he just strikes my funny bone and I think that really helps when you get someone with that kind of relationship with somebody.

**Trusting the Health Care Team**

Participants identified that developing trust in the health care team was a key antecedent to a collaborative relationship. All of the participants described themselves as trusting the health care team and having confidence in decisions made about their care. While each participant experienced developing a trusting relationship differently, all indicated that without trust there would be no relationship. As one participant stated “Yes I confide in them because they make me comfortable. I feel that there is a lot of trust there”. Another participant stated, “I’ve never found anything that would disclaim them you know a point of view you know. They’ve been good. It’s hard, maybe I trust too much or whatever”.

From immersion in the narratives two important aspects of trusting the health care team emerged. A majority of the participants described the health care team as having a great deal of expertise and knowledge, which allowed them to feel comfortable and develop trust in the health care team. In addition participants described experiencing close follow up and frequent monitoring which promoted confidence and trust in the team. From these descriptions two themes describing the participants’ experiences of developing trust in the health care team were constructed. The first theme is that of expertise of the health care team. The second theme is vigilance of the health care team.

**Expertise of the Health Care Team.** As stated earlier all participants described feeling a great deal of confidence in the expertise of staff at the HFC. For several participants this began to develop prior to actually coming to the HFC. These participants
described how the physicians referring them to the HFC would praise the expertise of the staff. One participant described how his family doctor described the HFC as “one of the top heart clinics in the country”. Another participant was told he was lucky to have been accepted into the HFC. Other participants, who did not have a priori expectations, describe this confidence in the expertise of the health care team as developing early in the relationship.

P: Well the first interview I had with (nurse’s name) She gave me a lot of confidence in the whole thing

R: And what made you feel so confident based on that one interview?

P: Well I felt that she knew what she was doing, and subsequent people were the same.

So walking in to the reception: friendly courteous, helpful, kind and low and behold then comes (HFC nurse name) and you say is this possible? They have such a concerned wonderful person, informed and informative. And then you have Dr (doctor’s name) and we walked out the first time and said Oh my god how lucky can we be for this to happen to us. And we felt in good hands, very good hands.

They are just not the ordinary nurses. I see a big difference between an ordinary nurse and these specialists. Very big difference, and these people are highly knowledgeable in the heart disease. So one feels very comfortable when someone knows what they are doing. And automatically there is a trust that builds up

Well after the first and second visits. Right away I felt at home. I said these people are in a position to help me, they are all professionals. And as I say a professional is to me is someone who knows what he or she is doing, not the degrees they have.

These participants all identified that they perceived the staff at the HFC as knowing what they were doing. They used descriptions such as highly knowledgeable,
professional, and informed. When asked what affected their perceptions of expertise
several participants commented on the consistency of information that they received from
the staff at the HFC. Most of the participants described receiving consistent information
on medications from the staff at the HFC. One participant stated:

   Well any given med you ask a question both the patient coordinator and
   the doctor. They take the time to explain what it is, where it has been used,
   for how long, and how successful it has been, and if it belongs in the
   major gold standard group

Several participants described it as routine that self-management skills, such as
fluid restriction, sodium restriction, and daily weights were discussed and reinforced at
each visit not only by the nurses but the physicians. Others commented on how each
member of the team would review tests such as blood work or echocardiograms at each
visit.

   Another important aspect of developing a trusting relationship was the perception
that participants continued to benefit from the decisions made with the health care team.
Several participants indicated that they trusted the health care team because their
suggestions or directions had improved their situation, or at least done no harm. As one
participant stated “I’ve never found anything that would disclaim them”. Other
participants confirmed this perception that health care team had never let them down or
suggested anything that might have caused harm.

   Well, I guess it’s it comes back to again it is my body and my health that we are
   talking about. And I needed help badly, and they looked after me. And I just felt
   that hey these are good people. I can trust them. And ah they have never betrayed
   that as far as I am concerned.

=================================================================

I can’t think of any decision that they could have made that you know that would
have changed the outlook of things you know. I suppose If I they had said drink
80 glasses of water a day, or you know but everything they’ve said or everything they’ve done I’ve agreed with. I suppose if they had told me I had to. I don’t know what they could have said that would make me think, No I’m not going to do that or whatever. Since then I have started to feel better.

Several of the participants described trusting that the staff at the HFC would intervene when other physicians made changes to treatment regimes. Other participants described how they developed trust in the HFC when they were able to correctly identify what was causing an episode of decompensation. One participant described the role the HFC played in her being diagnosed with a thyroid dysfunction:

P: Well they were the ones that found out what it was. I mean I had been going to my GP for probably a month and ah a bit before and I was getting increasingly worse. And it was (nurse’s name) and Dr (doctor’s name) idea to have the thyroid test. So if it hadn’t been for that I would still be sitting here wondering what the heck was happening to me.

R: So how did it make you feel when they figured it out?

P: Oh great, I think they are just wonderful. Well of course you know that

Another participant recounted how the HFC had assisted in the diagnosis and treatment of his chronic pancreatitis after he started experiencing severe stomach pain.

whatever other problems I had I would relate it to them and they would refer my OK, To either the Vascular surgeon (doctor’s name) or the GI (doctor’s name). This is all done through the heart clinic where I complain about my stomach pains, which apparently was diagnosed as chronic pancreatitis.

Other participants described similar experiences with the HFC, where they had intervened when other health care professionals had not. One participant described using a sarcastic tone how it made her feel when a cardiologist was unsure of how to proceed in her care, and how the HFC was able to diagnose and treat the problem.
Well when I first got diagnosed with the problem with the heart it was for arrhythmia problems, and they sent me to the specialist and he tried all these different medications, I can't remember who it was at the time. He tried all these different medications and then just couldn't get it down to where regular heartbeats. Finally it was basically just I just don't know what to do with you. Well yeah that is really special to hear the heart specialist say that to me, Like that really made me feel good

Generally participants expressed that they trusted the expertise of the staff at the HFC, and felt confident in decisions made about their care. As one participant summed up “So I thought they between them and Dr (doctor’s name) they helped me a great deal. It gave me confidence it gave me a lot of confidence”.

**Vigilance of the Health Care Team.** Several participants described that the staff at the HFC were vigilant in monitoring of their conditions. One participant stated, “they really really monitored me very carefully. I was watched very carefully”. When asked how this made him feel he responded “Oh trust and feeling safe”. He went on to describe how he was monitored.

They have a continuous follow up from the previous to right now and any thing that If I have some discrepancies, It is noted down and briefed to the cardiologist

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<td>they are always take a blood test from me. Sometimes the would before I come there I would have to fast. That would mean that they were going to take my cholesterol you know, my HDL and LDL major reports form other doctors would always go to them. They would always check my medicines on every visit they would they would monitor my weight, OK. And they would they very carefully put down all of this information and give it to the cardiologist.</td>
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<td>They do it through very thorough ah research and analysis on me, OK. And then they find out, they did my blood monitoring a lot</td>
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the specialist nurse that comes (nurse’s names) they would thoroughly investigate what I had been doing. Like if I was going there on a monthly
visit they wanted to know how much I walked, they also monitored my water, ah because I was only allowed to have 6 to 8 glasses because I have a leaky valve. I had to submit this to (nurse’s name) for about 6 months every week how much water

This participant’s experience was congruent with the experiences of other participants. A majority of the participants reported frequent monitoring of weight, adherence to self-management skills, effects of medication changes, and blood work by staff at the HFC. This was frequently described as part of the routine of coming to the HFC. More importantly participants also described how this vigilance increased the level of confidence in the staff at the HFC and promoted a collaborative relationship. One participant characterized the relationship as ongoing and described how the staff at the HFC had been vigilant in their monitoring to ensure that he kept recovering. He stated:

what I see the clinic, their function is. I’ve been with them for 4 years now, it seems to me that their function is OK we check this guy out we figure he needs the heart operation. Ah we did it, he recovered, and we are going to make darn sure that he keeps recovering. I don’t know when they will stop seeing, or when they will say I don’t think we need to see you any more. Because at my age I am not all of the sudden become 50 year old, or a 60 year old but I see it as an ongoing thing.

Participants reported experiencing vigilant monitoring outside of scheduled HFC appointments. Participants were encouraged to telephone with any changes in status, and reported that the nurses would frequently check on them if they were experiencing a period of instability. One participant described frequent telephone calls to check on his condition when he was experiencing an episode of renal insufficiency. He reported that nurses asked for information such as changes in weight, and descriptions of symptoms he was experiencing. He also reported that the nurses shared information on the latest blood work results and recommended changes to the treatment regime via telephone. Another
participant characterized the relationship by stating “I feel that I can call when something has gone awry and they deal with it. So I think the relationship is great”.

**Barriers to Collaboration**

Participants describe very limited experiences with barriers to collaboration within the HFC. As stated previously the participants were very positive when describing their experiences with the HFC. However, when probed, each participant was able to articulate episodes from past experiences where they had experienced a barrier to, or lack of collaboration with health care professionals. Barriers to collaboration were characterized by the participants as either arising between individuals or from within the participants themselves.

From the narratives three themes describing the participants perception of barriers to collaboration were constructed. The first barrier to collaboration that will be described is lack of time. A second barrier to collaboration that will be explored is communication styles that do not support collaboration. The third barrier to collaboration that will be discussed is inequity of power sharing.

**Lack of Time**

Several of the participants reported experiences where they felt that a lack of time prevented the development of a relationship with health care professionals. Generally participants did not describe this as a concern at the HFC. They indicated that the staff at the clinic took the time that was necessary to answer questions, explain medications, test results, and what to expect. As one participant stated when describing her experiences in the HFC, “I don’t feel that they are one step out the door as you are still talking”. Other participants confirmed that they did not generally experience time pressures at the HFC.
The majority of the participants described experiences with other health care professionals where lack of time was a concern.

One participant described being told that she has heart failure after an angiogram, and the experience of the cardiologist not making time for her. She reported not being able to ask questions and described the way the cardiologist looked at his watch after telling her she would not live as long as other people.

P: Well that is probably a very good point. When I had the angiogram I mean I was really scared. I had no idea what was going on. It was kind of a sudden thing and this doctor had probably done 10 angiograms that day. And came and sat on my bed and asked do you have any questions, and I didn’t know what to ask him. And I said well what’s going on? Ah well you have an enlarged heart and da da da OK got to go. And the next time I saw him after the angiogram I said well what are my chances of survival, what’s going on, what’s wrong. Oh you just won’t live as long as most people. And that was it. That was, and then he looked at his watch, it was lunchtime and he was out.

R: The experience with the other cardiologist. How did that make you feel?

P: Very very angry, very angry and very ah ah, upset I guess because I didn’t know what was going on, and he didn’t explain it. It was like I was a piece of rock or something that he just you know. You won’t live as long as most people, so goodbye. I have six minutes for you and then I have to see my next patient. Actually I walked out of his office and there was a bench out front. My husband was picking me up and I sat on this bench and I started to cry, and I never cry. I was so upset.

The lack of time from the cardiologist had a profound affect on this participant. She reported becoming angry, crying, and at the end of the interactions still having little information about her condition, and no idea of what to expect. When she was recounting the experience of the cardiologist looking at his watch after telling her she wouldn’t live as long as other people, she was shaking her head and tapping her watch, suggesting that the experience continued to affect her. She described feeling that she had been treated like a rock, implying that the experience had been dehumanizing. This participant also
reports not knowing what was going on, with no self-management education, discussion of prognosis, discussion of treatment options, or emotional support apparently being offered.

Another participant described an experience with a physician who had just told her that her father had inoperable brain tumors. She described how the physician walked away without answering questions, discussing prognosis, or the possibility of other treatment options.

But it’s just the way he said it to me like you moron what else would it be. And I was so angry at that point and I said just excuse me and he says of course he has 4 or 5 tumors you know. And then he went to walk away and I said I’m not finished yet, you know. And what I felt like saying to him was I’ve been sitting here for the last 10 hours, and you can’t give me the frigging time of day. I mean, I realize that you have to be detached but cold is not the word for it.

This participant describes the effect of having the physician trying to walk away and not giving her the time of day as “making her so angry”. This experience also prevented the participant from having questions answered, and left her unsure of what was going to happen next. The participant alluded to the lack of control or power she experienced, and how difficult the experience had been.

Although a majority of participants described not experiencing time constraints in the HFC one participant did describe an experience where he felt rushed. The physician in the HFC did not adequately answer his questions regarding a medication change and he described how he felt.

P: Well you see no I didn’t feel to bad you now I felt he was you know that’s it. Just a couple of times.

R: Sort of shut down the conversation a bit?

P: Well not entirely but I guess he was in a rush
R: And how did that make you feel?

P: Well I was wondering about that you see. Well just wondering you know if he could spend a little more time and just calm down. I suppose he is human like anybody else. You see maybe he was tired.

R: But how did it make you feel?

P: Well I felt that way and said well it probably does know what he is doing so I’ll try. I could have told him to take his medication and do something with it. But I didn’t think it was right.

This participant also described how feeling rushed made him angry, and prevented him from asking questions and receiving answers. All of these participants described how a lack of time on the part of the health care professional prevented them from having questions answered. This is described as a significant aspect of the relationship with members of the health care team by all of the participants in this study. The lack of time as experienced by these participants also had aspects of being dehumanizing, which prevented the development of a therapeutic relationship. Development of a collaborative relationship in such instances appears difficult if not impossible.

Communication Styles that do not Support Collaboration

Several participants described experiences with health care professionals where the style of communication prevented or inhibited the development of a collaborative relationship. Participants had indicated that an important aspect of developing a relationship with the health care team was a non-intimidating communication style. Several of the participants reported that communication with the health care team at the HFC was a positive experience. However, several participants described experiences when communication styles of health care professionals interfered or prevented the
development of a therapeutic relationship. Several participants described feeling
intimidated by health care professionals. One aspect of this intimidation was the use of
technical language, which made it difficult for participants to understand what was being
discussed.

I'm illiterate to pills. They give me this, this, this and this and I know what
they are and I've looked at them, and I make sure that I get this, this, this
and this. But if you tell me what is that one and I have no idea. I just, I
can't understand big words put big words together.

Other participants also reported that use of technical language would leave them
confused and intimidated. As one participant indicated he felt the use of technical
language indicated that the health care professional lacked confidence or expertise and
was using jargon to inhibit further conversation. He stated, “Actually they are probably
people who are not sure of themselves a little lack of confidence”.

Several of the participants described experiences of health care professionals as
being unfriendly, or difficult to approach. As one participant stated when describing a
physician, “He’s nice enough but I don’t think he’s the friendliest person, but I know he
is a really busy guy”. She goes on to state, “I haven’t run across it very often, but every
once in a while you get somebody like who is so cold”.

So anyway, talk about cold fish. Anyway he comes through and he has got
3 or 4 interns he is training. Anyway he whips the curtains around my
father and we are asked to step out, which was OK. I guess I was still with
my ex and we are standing off. Anyway it was like a 10-minute
examination, and said to him, you know has the cancer spread. Of course the cancer has spread. Excuse me; well we didn't know what was giving him these blinding headaches. Because he had lung cancer right. But we didn't know it had gone up to his head. But it's just the way he said it to me.

That night nurse. Well they had moved me into the ward after I had had my operation. And I got up, I was able to get out of bed every once in a while and I was in quite a bit of pain. Mainly in my leg and I asked her if I could have a bit more morphine for the pain, and she said no you can't. And I said I really feel I need it and she said well I am sorry you are just not getting it. She was very blunt with it, and I am sitting there on the side of the bed, feeling so weak that I wish someone would pick me up and put me in bed. And I felt sorry for myself, and I guess I pissed her off too.

Both participants described that the outcome of the interaction could have been dramatically different if the approach of the health care professional had been gentler.

Other participants also reported experiences where health care professionals were unfriendly or difficult to approach. One participant stated when describing an interaction with a physician at the HFC, "well I suppose he was a little abrupt". He went on to describe how this had shut the conversation down. Participants unanimously described a friendly, open communication style where they felt able to ask questions, and have input into decisions as conducive to developing a collaborative relationship. Communication styles that were closed, confrontational, or aggressive were seen to prevent development of a collaborative relationship.

One participant described experiences of being talked down to by health care professionals. The participant had extensive experiences with health care professionals as she was living with multiple medical problems including HF, diabetes, and rheumatoid arthritis. She stated:
Unfortunately I find that sometimes specialists will talk down to you. And I understand that they are educated, gone to university but by the same token I am a person, and don't speak down to me. Like you don't know me from a hole in the ground. Like don't talk down to me.

The participant describes that she felt quite competent with managing many of her medical conditions and was frustrated when health care professionals would not listen to her or recognize her expertise. Her narrative suggests that being talked down to was dehumanizing, and a significant barrier to developing a collaborative relationship, as her experiences and expertise were trivialized.

Inequity of Power Sharing

Many participants described experiences where they felt unable to share in decisions, or have input into the care they received. Participants often described how they did not perceive that they had the power to become involved in decisions. Some participants describe experiences where members of the health care team did not permit participation in decision-making. Other participants described how they had assumed a passive stance, which prevented involvement in decision-making. From the narratives two themes were constructed that describe the experience of inequity of power. The first theme describing inequity of power sharing is the health care team not sharing power. The second theme describing the experiences of inequity of power sharing is assuming a passive stance.

Health Care Team not Sharing Power. Several participants describe experiences where health care professionals did not allow participation in decision-making. One participant stated, "I like to be asked as opposed to being told I think there are ways that you can put it to somebody. That we would like you to, as opposed to this is what you
are doing”. One participant described his experiences of being told that he would not be resuscitated in the event of a cardiac arrest.

They said they’re going around telling they used to go around telling if you wanted to be resuscitated or not, when you die. And maybe I got the wrong angle on it but now there telling me we will not resuscitate you. No choice of your own. That’s the (name of hospital) When I had my last heart attack I died about 2 or 3 times on the way to the emergency, and if they had had a standing order of no resuscitation then I wouldn’t be here today.

Another participant recounted his experience with a cardiologist where he was unable to participate in decisions about his care. The following are excerpts from his narrative.

And I went in to Dr (doctor’s name) and after a couple of visits I mentioned to him that I had read up on the net, and he took me to task. And told me he wasn’t going to deal with people who went onto the net and he was the doctor.

This fine cardiologist sat behind a desk with gold plated rings and expensive figures and figurines on his desk. And I sat across from him like a schoolboy. He took a piece of paper and drew a heart upside down so I could see it. At which point I went into a state of shock. I said yeah I happen to know what it looks like Doctor. And ah my feeling was that there were no specifics, no specifics. Not interested in being specific about any given drug. My questions were not welcomed, and ah when I went home I started up and found something. I made a printout went to his office, went to his nurse with a nice little note, and said Nurse X would you would be kind enough sometime to slip this to the doctor. And the question was on the note. I read that such and such is in the forefront, and is here any chance that this might be good for me or applicable to my heart. And ah he wrote me a note and copied it to (doctor’s name) that ah he doesn’t want to be questioned about anything about this, blah, blah, blah. So I wrote him back.

R: How did that make you feel?

P: Well let me tell you. I told him I think if your response to the report that I sent to you from the website, it’s NEJM. (Reading from a letter) It is my sincere hope that I did not annoy you and it was not my intent. The appointment with (doctor’s name) that you suggested has been made and
that consultation was informative. My dear father in law for over 20 years I had the privilege to be with him, and maybe he spoiled me and my family with the aid of his fine colleagues. However he also drilled into me that as a patient I should stand firm and had to be a team with my physician, I hope you did not misinterpret my motive but I was quite sure that this report was well know to you. Albeit that I had hope to hear from you that just maybe, it was aldosterone, might be a drug that could prolong my life. Since you think this is not the case there is always hope for future developments. In this fascinating age of computers there is so much more to learn for patients, isn’t there. Thank You.

When probed how this experience had made him feel he stated, “It was actually devastating for me, you know”. These two narratives describe vividly the effects of a significant inequity of power. These participants described feeling powerless, angry, and experienced a loss of control over their lives. While less dramatic, other participants described similar experiences of the health care team not sharing power. One participant described a physician in the HFC as “well there is a couple of times right I’ve felt that one of the doctors was a little pushy. However I think he may have been right so”. He goes on to conclude that being unable to participate in a decision regarding his care was a disturbing experience.

**Assuming a Passive Stance.** Several of the participants identified that they were content to allow the health care team make the decisions about their care. Frequently participants indicated they trusted the health care professionals at the HFC to make the decisions for them. Others were more explicit in their descriptions, and characterized themselves as being passive rather than active participants in their care. One participant stated, “Well, I guess I’m pretty easy because I take direction beautifully from them”. He went on to describe himself as a good patient. Another participant stated, “I am just very accepting of any decisions that are made on my behalf”. The following are excerpts from the narrative of this participant.
I just feel that I guess I must be kind of a passive person, because when I go whatever information they give me, or whatever they tell me to do, you know I do

So as far as being a participant in this I sort of look upon myself just as the patient. And that's about it.

R: What do you see your role as?

P: Acquiescence, which I guess I feel that they know what they are talking about and after, especially after this experience at (name of hospital) I feel well that it is such a relief to have someone who tells me what to take and what to do, and how to do it. As I've said before I am kind of a passive person

Other participants also identified themselves as being passive rather than active participants in decisions regarding their care. One participant characterized himself as, “I'm a mild meek type person generally”. When asked how important it was for him to be involved in his care he replied “not really important”.

Several participants indicated that they thought they should be more involved in decisions about their care, but trusted the decisions made for them by the health care team. These participants acknowledged that by taking a passive stance they were creating barriers that it may prevent development of a collaborative relationship.

No I don't think. I've got no qualms of anything and it's wrong. Well maybe in some people's eyes it is a wrongful trust because they do make mistakes, and I should be more involved.

I guess I feel involved only in as much that I trust them and what they are doing. You know I can't argue with them at all.

I guess I just trust, I guess I make the assumption that the doctor knows what he is doing. So if he says to me this is what you need to be on, I don't think I would turn around and say no I don't think so. Because I'm not the specialist
As previously discussed this experience was not shared by all of the participants. Some participants described themselves as active collaborators and therefore did not identify this as a barrier to collaboration. Others identified that in their experience a passive stance was an important barrier to collaboration. This was the barrier to collaboration that demonstrated the greatest variance amongst participants, similar to the variance found in theme of sharing power where participants situated themselves along a continuum between the two extremes.

Summary

Initially as I immersed myself in the narratives I was struck by the uniqueness of each of the participants' experiences. However, with repeated immersion in the data several themes emerged and an interpretive description of the participant's experiences of collaboration was constructed.

Participant's described their experiences of collaboration with members of the health care team in terms of five dominant themes that were constructed from the narratives. These themes provide a description of what was salient to the experience and guided the discussion of what the experience of collaboration was like for the participants. The five themes identified were mutual goals, working together, communication with the health care team, being accountable, and sharing power.

As previously mentioned each participant's experience was unique, with some participants identifying themselves as passive and others as actively involved in decisions regarding their care. When describing working together most participants' spoke of it as a joint venture that involved willing participation. Participants frequently described this experience as teamwork. When discussing communication with the health care team,
important aspects of the experience were identified as sharing experiences and gaining knowledge. The most frequently identified aspect of gaining knowledge, and the aspect that participant's identified as being most important to them was the ability to ask questions. Participants describe being accountable as comprising of self-care behaviours and taking responsibility. Frequently participants identified this as their most important role. The theme of sharing power displayed the widest variation amongst the participants. Several participants described themselves as “only a patient” while a few viewed themselves as active participants in decision-making.

Next antecedents and barriers to collaboration were explored. Participants identified antecedents to collaboration as being comprised of non-intimidating communication style, and trusting the health care team. When discussing trust participants described the expertise and vigilance of the health care team as key to the development of trust.

Finally barriers to collaboration were presented. Participants identified three barriers to collaboration as being lack of time, communication styles that do not support collaboration, and inequity of power sharing. The experience of inequity of power sharing was described by participants in terms of the health care team not sharing power, and participants taking a passive stance.
CHAPTER FIVE

Discussion of the Findings

I chapter five I discuss the findings presented in chapter four in relation to the published work of other authors. The reason for this discussion is to situate the findings of my study within the current body of knowledge related to the experience of collaboration with the health care team.

In chapter two I explored the literature relating to the concept of collaboration, experience of patient health care team collaboration, and outcomes of collaboration. As identified previously there is a paucity of empirical literature that explores individuals with HF and their experience of collaboration with the health care team. The existing literature provided a predominantly theoretical understanding of the experience of collaboration, but did not address how the experience may differ for those living with HF who attend a HFC. Therefore, my primary intent was to explore the experience of collaboration from the perspective of individuals attending a HFC, to enhance the understanding of the experience, and present how the findings support or refute the current theoretical perspectives on this experience.

This discussion is aimed at demonstrating how an understanding of the experience of collaboration from the perspective of an individual attending a HFC. It is presented in the interpretive description and augments the existing understanding of the experience. The organizational framework utilized in chapter four is used to guide the discussion of the findings.
Experience of Collaboration

In the current study I found that the experience of collaboration with the health care team by individuals attending a HFC seemed to be comprised of the experiences of mutual goals, working together, communication with the health care team, being accountable, and sharing power. Antecedents to the experience of collaboration included non-intimidating communication style and trust in the health care team. Barriers to the experience of collaboration identified were lack of time, communication styles that do not support collaboration, and inequity of power sharing. Significant findings from each of these themes are discussed in relation to the existing body of knowledge on collaboration. As previously stated there is a paucity of literature exploring the experience of collaboration from the patients' perspective. The current literature is predominantly theoretical in nature, or comprised of case studies which provide limited insight into the experience from the patients' perspective.

Mutual Goals

All of the participants in the current study identified their goals in attending the HFC to be improving their health status or making them feel better. All participants also indicated that in their experiences the goals of the staff at the HFC were congruent with their own goals. Most described a sense of teamwork, and a sense that the staff at the HFC were there for the purpose of keeping them healthy. Participants in the current study reported that staff at the HFC were concerned for their health and some described that helping patients at the HFC motivated the health care team. This is also congruent with my experiences as a nurse in the HFC, and I feel that congruence of goals is necessary for a collaborative relationship to develop. Although none of the participants in the current
study described a formal process of goal setting, all reported that in their experiences all parties were working towards a common goal. I feel that without a process to establish goals of care the health care team and the individual with HF may work together less effectively, or possibly not work together at all.

The importance of having a mutual goal on which to base the collaborative relationship described in the current study is congruent with much of the existing theoretical literature on collaboration. Several authors describe the importance of having mutual goals in a collaborative process. Henneman et al (1995) in a concept analysis of collaboration identifies that “collaboration requires that individuals view themselves as members of a team, and contribute to a common product or goal” (p. 104). Gardener and Cary (1999) identify having shared goals as one of the four operating processes of collaboration. They go on to indicate that collaboration must begin with an agreement on the goal or purpose of the collaborative relationship. Lindeke and Block (1998) conceptualize collaboration as “a process of shared planning and actions towards common goals” (p. 213). Henneman et al (1995) and Lindeke and Block (1998) conceptualize achieving mutual goals as the outcome of collaboration, indicating that measurement of success of a collaborative venture rests on achieving the goal. Gardener and Cary (1999) view a mutual goal as necessary to initiate and guide the collaborative relationship, and view common goals as both a process of collaboration and an outcome.

This is an important distinction in the context of the current study, as all of the participants indicated that it would be unrealistic to achieve the goal of improved health indefinitely. The participants in the current study indicated that they were acutely aware of the fragility of their health status, with most reporting multiple episodes of
decompensation. One participant stated, “there is probably something along the line that they won’t be able to fix but that their doing the very very best that they can do”.

Empiric literature examining collaboration is also congruent with the findings of the importance of mutual goals. Most of the current literature describing mutual goals as part of the experience of collaboration is from the perspective of health care providers. Paavilainen and Astedt-Kurki (1997) examined collaboration in the client–nurse relationship in a public health setting from the perspective of the nurse. They describe the collaborative relationship as “beginning with trust and proceeds towards the common goal” (p. 139). They identified the common goal of nursing as clients’ well-being and ability to cope. Nurses in the study reported using this as an outcome measurement with success being described as achievement of the goal. Barr and Threlkeld (2000) utilize the patient-practitioner collaborative model to frame a case study examining a collaborative relationship between a person with a physical disability and therapists involved in the care. The model describes four phases of collaboration, one of them being finding common ground through negotiation. This phase of the model “describes a process of mutual goal setting and negotiation to choose interventions that patients are likely to follow, given identified barriers” (Barr & Threlkeld, 2000, p. 257). Again achievement of the mutual goals was seen as evidence of a successful collaboration. Akhavain et al (1999) utilized Bowen’s family systems theory to examine collaboration in an interdisciplinary psychiatric treatment team. Bowen’s theory conceptualized collaboration as “the ability to combine assertiveness and cooperativeness and to remain true to individual principles while working toward a common goal” (Akhavain et al,
In the case study achievement of the goals of the treatment plan were presented as indicating successful collaboration.

There is a paucity of literature examining the experience of collaboration from the perspective of patients, and even less exploring the experience of how a patient's goals were elicited and utilized in the decision making process. Clark and Mass (1998) examined clients' experience of collaboration at the Comox Valley Nursing Centre. Clark and Mass (1998) characterize collaboration as, "a partnership characterized by mutual goals and commitments" (p. 218). However, they fail to explicate how patients' mutual goals were identified or considered as part of the experience of collaboration. Clark and Mass (1998) instead focus on the outcomes of collaboration, with no discussion of whether the outcomes represented, or were congruent with the goals of the patients. Hutchings (1999) also fails to identify how a client with advanced multiple sclerosis experienced mutual goals as part of the collaborative process, when co-presenting an in-service on the importance of patient empowerment. We are left to assume that the goal of the health care professional and the client were congruent; as there was no discussion provided identifying why the patient wanted to participate in the in-service. Both of these studies focused on positive outcomes, implying that these represented the mutual goals of the client and the health care team. However as discussed earlier this perspective does not appear to be consistent with the findings of the current study. Findings of the current study instead support the view of mutual goals as supporting the initiation of, and providing guidance to, a collaborative relationship, rather than an outcome of the relationship. I feel this is an important distinction as I conceptualize collaboration as
both a process and an outcome. Therefore, utilizing goals to guide the relationship rather than as an evaluation tool is congruent with my own beliefs and the findings of the study.

**Working Together**

The findings of the current study indicate that participants perceived working together as an important component of the experience of collaboration. Two aspects of working together emerged as significant throughout the participants' narratives. The two aspects or sub-themes of the experiences of working together were: joint venture, and willing participation. I now discuss each of these sub-themes in relation to the existing body of knowledge.

Henneman et al (1995), Clark and Mass (1998), Gardner and Cary (1999), and Akhavain et al (1999) conceptualize one defining attribute of the experience of collaboration as being a joint venture. Findings in the current study indicate that a majority of participants view the experience of collaboration as a joint venture, which provides support for these authors conceptualization of collaboration. Henneman et al (1995) states that, “a significant attribute of collaboration is that two or more individuals must be involved in a joint venture, typically one of an intellectual nature” (p. 104). They go on to describe how collaboration requires individuals to view themselves as belonging to or being members of a team. Significant portions of the participants’ narratives contained descriptions of how they felt part of a team, which further supports the relevance of Henneman, et al’s conceptualization of collaboration as a joint venture.

The findings of the current study are consistent with the findings of Clarke and Mass (1998), that participating in a joint venture led to patients feeling supported, more secure and better about themselves. Participants in the current study frequently described
themselves as feeling comfortable and safe because of the team approach. The feeling of safety is particularly important to individuals with HF, as during the course of the illness they may experience frequent episodes of decompensation, and the HFC can provide the safe harbor as described by Zambrowski (2003). No literature describing the individual with HF experience of collaboration was found. One of the only studies describing collaboration from a patient’s perspective was Sharkey’s examination of the experiences of a patient with the diagnosis of severe and enduring mental illness. Sharkey (2002) reported that the participant did not experience collaboration or a sense of working together with the health care team, and went on to conclude that “it is more honest to acknowledge that either collaboration does not happen when they are acutely ill or aspects of it occur on our terms” (p. 54). The findings in the present study do not appear to affirm Sharkey’s perspective, as only one participant reported not feeling like he was part of the team, and in general participants’ described their experience as that of a joint venture.

A second aspect of working together described in the findings of the current study is that of willing participation as an important aspect of the experience of collaboration. This confirms Henneman et al (1995) and Clark and Mass (1998) conceptualization of willing participation as one of the defining attributes of collaboration. Henneman et al (1995) states that collaboration is a “cooperative endeavor in which the participants willingly participate in planning and decision making” (p. 104). Findings from the current study suggest that participants and staff at the HFC willingly participated in collaboration. Participants indicated that they would help the health care team in any way they could, and felt the health care team would reciprocate.
All of the participants had experienced a crisis or significant event preceding the diagnosis of HF. This is congruent with the findings of Stull et al (1999) who describe becoming a patient of HF as a process with five stages. The five phases were identified as a crisis event, diagnosis, patients and family’s response to the diagnosis, acceptance and adjusting to the diagnosis, and getting on with life. A majority of the participants reported that the desire to avoid episodes of decompensation acted as a strong motivator to willingly participate in the relationship with the health care team. These findings are consistent with the findings of Stull et al (1999) where they describe the phases of acceptance and getting on with their lives as occurring when patients made changes and worked with the health care team to avoid decompensation and regain control. I feel that the desire to avoid episodes of decompensation is a key aspect of the experience of collaboration for the participants in the current study. It provides not only a goal to work towards but defines much of the relationship between the individual with HF and members of the health care team.

An important aspect of willing participation for most participants was adherence to lifestyle changes, and practicing positive self-care behaviour. Participants generally reported that by adherence to lifestyle changes and medication regimes, they were demonstrating willing participation. As one participant indicated, he would not feel comfortable as part of the team if he did not adhere to the treatment regime. The current study are consistent with Clark and Mass (1998) findings that “the willingness of clients to accept responsibility for their own role in addressing health concerns and implementing self-care strategies led to the development of partnerships with the nurses” (p. 221). This suggests that by engaging in behaviors that facilitate self-care in
individuals with HF, health care professionals may also be fostering the development of a collaborative relationship.

Communication with the Health Care Team

The findings from the current study suggest that from the participants' perspective communication with the health care team is a key component of the experience of collaboration. As stated earlier, participants described communicating with the health care team as one of the important roles in the development of a relationship. It is important to note that participants were not describing the effects of communication style, but rather the content of the communication when describing their experiences. The effects of communication style are discussed in a separate section on antecedents and barriers to collaboration. The experience of communication with the health care team was described in two sub-themes that were constructed from participants' narratives. I discuss the sub-themes of sharing experiences and gaining knowledge in the context of the current body of knowledge.

Participants in the current study describe the importance of communicating the experiences and symptoms of HF with the health care team. These included communicating adherence to self-management strategies, tolerance of medication regimes, and symptoms of decompensation. Participants reported that this information was utilized to assist the health care team in making decisions on the direction of medical care, and alter the plan of care as necessary. The current study affirms the finding of Barr and Threlkeld (2000) that “understanding and knowing the patient are essential components of the clinical reasoning process” (p. 256). Bar and Threlkeld (2000) describe the patient-practitioner collaborative model as composed of four phases:
establishing the therapeutic relationship, diagnosing through mutual enquiry, finding common ground through negotiation, and intervening and following up. They report that knowledge of the patient’s experiences and symptoms was critical to the collaborative decision making process.

Participants in the current study described sharing their experiences and symptoms of HF as an important aspect of the relationship with the health care team. Participants indicated that without sharing their experiences, decisions about their care might be compromised. As one participant stated, “well if I am having trouble breathing, they don’t know that unless I tell them”. This suggests that participants’ viewed themselves as having expertise on the experiences and symptoms of HF, and contributed in a meaningful way to decisions regarding their care, by sharing this expertise, although none of the participants explicitly identified themselves as experts. This finding strengthens the relevance of Henneman et al (1995) and Clark and Mass (1998) conceptualization of the contribution of expertise as a defining attribute of collaboration.

Hutchings (1999) hypothesized, “the prolonged and complex nature of chronic conditions results in clients being uniquely familiar with how the illness or disability relates to their overall life experiences. Clients become the best experts about themselves” (p. 130). Participants in the current study did not generally identify themselves as experts in HF. However, they acknowledged that they were uniquely familiar with the effects HF had on their lives, which is congruent with Hutchings’ hypothesis.

Participants in the current study reported that an important facet of communicating with the health care team was the gaining of knowledge. Participants
reported gaining knowledge by participating in education sessions and asking questions. Participants reported receiving education on the pathophysiology of heart failure, medications, signs of decompensation, and self-management skills. However, consistently the participants identified the most important way that they gained information were the asking of questions. In my experiences as a nurse at a HFC, patients initially are hesitant to ask questions, and only after a relationship had developed do they appear less hesitant to ask questions. By listening carefully to the questions our patients ask I feel that we can gain valuable insight into what is important and relevant to them, which may improve care and facilitate collaboration.

Content of education sessions, as reported by participants in the current study, appeared to be congruent with education offered at other HFCs (Dahl and Penque, 2000, Venner and Seelbinder, 1996, Paul, 2000, Levine and Hall, 1998). Participants reported receiving detailed verbal and written instructions on admission to the HFC. Participants frequently described themselves as lacking knowledge, fearful, and experiencing uncertainty regarding their future prior to coming to the HFC. This supports the relevance of Stull et al (1999) findings that HF patients at the beginning of the illness experience, during the phases of crisis event and diagnosis, experienced uncertainty, and “because of the change in their life situation, leaving them with a need for information about this condition/situation and how to proceed with life” (p. 287). One participant of the current study described the effect of the information giving as “like a curtain lifting”. The current study confirms the relevance of Stull et al (1999) findings, that during the phase of acceptance and adjustment, there is time spent on learning and maintaining lifestyle modifications.
Participants found the asking of questions was an important aspect of the process of communicating with the health care team. Most reported that they asked questions at every appointment at the HFC. Participants described asking questions as a way to increase knowledge, and assist in understanding decisions regarding the direction of care. The current study's findings are consistent with Clark and Mass (1998) findings that patients' valued getting useful information, and as a result of gaining information became more knowledgeable about their conditions and reported more confident communications with health care providers. Barr and Threlkeld (2000) applied the patient-practitioner collaborative model to a relationship between a patient with chronic back pain and therapists involved in his care. They reported finding that the ability of the patient pose questions, and raise concerns throughout the process is a key aspect of collaboration. The present study appears to confirm the relevance of the findings of Barr and Threlkeld, that asking questions is an important characteristic of the experience of collaboration.

**Being Accountable**

A majority of participants in the current study reported that they that they had taken some responsibility for their health status. Most reported recognizing the importance of performing self-care behaviours, including fluid restrictions, sodium restrictions, exercising, and performing daily weights. Other participants in the current study reported that they felt that they were accountable to not only the HFC staff but to themselves. One participant summarized this by stating, “Yeah I think you have to take responsibility for your life”. The experience of being accountable was described in two sub-themes. These themes are self-care behaviours and taking responsibility. Next I examined each of these sub-themes in relation to the existing body of knowledge.
The participants in the current study described performing many self-care behaviours on a daily basis. Some participants indicated that they adhered to the self-care behaviours because they were part of the team, and they were doing their part. Other participants described it as taking responsibility for their lives. Most participants saw performing self-care activities as important to their experience of collaboration with the health care team. As one participant stated, “My role in the heart function clinic is to do my side of it”. This suggests that the participant viewed self-care as one of the responsibilities that arose from being a part of the team at the HFC. The conceptualization of self-care as a component of collaboration is not explicitly identified in the current theoretical literature, however can be thought of as roughly analogous to sharing responsibility. Henneman et al (1995) states collaboration requires participants to “offer their expertise, share in the responsibility for outcomes” (p. 104).

There is a paucity of empirical literature discussing the experience of self-care as an aspect of collaboration, however the experience of self-care is well documented in the literature. The efficacy of the self-care behaviours described by the participants in the current study is well supported by the current literature addressing self-care. Hicks and Holm (2003) state “appropriate self management may slow disease progression and prevent repeated and expensive hospital admissions” (p. 70). Other authors discuss the benefits of self-care as being reduction of physical symptoms but also decreased anxiety and increased sense of control (Zambrowski, 2003; Evangelista, Berg, Dracoup, 2001; Dracoup et al, 2003). Self-care is defined as “the practice of activities that individuals initiate and perform on their own behalf in the interest of maintaining life health,
continuing personal development and well being” (Artinian, Magnan, Sloan, Lange, 2002).

Common positive self-care behaviours reported by the participants of the current study included include restricting fluid, restricting sodium, daily weights, adherence to medication regimes, exercising and if applicable smoking cessation and avoidance of alcohol. Riegel and Carlson (2002) found that staying out of the hospital, maintaining control and improving health status were strong motivators to perform self-care. Likewise participants in the current study indicated that avoidance of hospitalization and maintaining health status motivated self-care behaviours. Participants in the current study generally reported that practicing self-care behaviours was beneficial in the prevention of negative symptoms. From my perspective as a nurse in a HFC, the importance of positive self-care behaviours is well supported anecdotally. Frequently patients who initiate positive self-care behaviours experience dramatic improvements in their symptoms. This contradicts the findings of Franz (2004) who reported that the individual in the case study perceived self-care activities as doing nothing at all, and did nothing to prevent hospitalization.

Generally participants reported adherence to self-care behaviours, however some participants continued to smoke, and report non-adherence to dietary restrictions. The current study confirms the relevance of Zambrowski (2003) findings that participants generally reported a range of positive self-care behaviours, but several participants reported negative self-care behaviours such as smoking and food and water binging. Zambrowski (2003) goes on to report that negative self-care behaviors were often attributed to stress, boredom, and frustration. The participant in the current study who
continued to smoke confirms this finding and reported the use of cigarettes as a means to reduce stress and boredom. One participant in the present study stated, "I cut down on salt and water, which just about killed me". This corresponds with the findings of other authors, such as Evangelista et al (2001) who reported "more patients had difficulty with dietary and exercise recommendations than any of the other prescribed activities" (p. 300). The present study provides support for the recommendations by Evangelista et al (2001) that strategies such as ensuring patients understand the treatment regime and designing interventions to promote self-management should be rigorously pursued.

Some of the participants in the current study reported the importance of taking responsibility for their lives. Two of the participants described taking responsibility as a prerequisite for attending the HFC, and if they did not take responsibility they were not acting as part of the team. This suggests that for some of the participants in the present study taking responsibility was a key aspect of the experience of collaboration with the health care team.

The existing body of theoretical knowledge explicating the concept of collaboration seems to be consistent with the findings of the current study that taking responsibility is part of the experience of collaboration. Henneman et al (1995), Clark and Mass (1998), Gardner and Cary (1999), conceptualize shared responsibility as a defining attribute of collaboration. Clark and Mass (1998) identify critical attributes of collaboration as including "assuming responsibility and accepting accountability" (p. 218). Paavilainen and Astedt-Kurki (1997) theorize that the client and nurse can discuss problems together, but "it is the client who needs to make the decisions and take responsibility for them" (p. 140). Some of the participants in the current study describe
themselves as taking responsibility for their lives, however none identify themselves as the primary decision makers and they characterize the decision making as shared.

Many of the participants in the current study reported simply doing what they were told, suggesting they did not perceive themselves as taking responsibility. They reported viewing themselves as passive rather than active participants in decision-making about the direction of their care. This experience will be explored in greater detail in the discussion of experiences of barriers to collaboration. Of note, participants in the current study describe the desire for the health care team to take responsibility for decision-making, particularly during episodes of decompensation. This is congruent with Zambrowski (2003) findings that during periods of increased symptom severity individuals with HF looked to health care professionals to provide guidance and make decisions regarding their care. Zambrowski (2003) describes this, using nautical terminology to frame the discussion, as “during periods of increased turbulence or increased symptom severity, the presence of a skilled pilot can promote finding a safe harbor” (p. 39). The skilled pilot is described as the health care professional, and a safe harbor is thought of as freedom from distressing symptoms.

Sharing Power

The theme of sharing power represents the aspect of collaboration that demonstrated the widest variance in the experiences of the participants in the current study. This is congruent with my experiences as a nurse in a HFC. Anecdotal evidence from my practice suggests that sharing power is experienced along a continuum, which is also a finding of this study. Sharing power was described as being experienced along a continuum ranging from participants that characterized themselves as “only a patient” to
a few participants that described themselves as active participants and equal partners. From the narratives two sub-themes were constructed that described participants' experiences of sharing power. These sub-themes are the experience of gaining control and shared decision-making. I next explored these sub-themes with reference to the existing literature.

Current theoretical literature provides strong support for the conceptualization of shared power as a defining attribute of collaboration (Henneman et al, 1995, Clark and Mass, 1998, Gardner and Cary, 1999). Whitehead (2001) however, cautions that while the concept is sound it “requires professional groups to relinquish their reductionist power-base and actively acknowledge the client as an equal member of the collaborative team. Other authors support the view that enacting and promoting collaboration between patients and health care professionals is challenging (Sharkey, 2002; Paterson, 2001). This experience will be discussed in detail in the section on barriers to collaboration.

Several of the participants in the current study described the effect gaining knowledge had on their experiences. These participants indicated that increasing the knowledge of their condition increased their sense of control over the situation. They described feeling more assurance, confidence and as one participant stated “it was a revelation”. Some of the participants also reported improved health status. Clarke and Mass (1998) reported that participants who formed empowering relationships with nurses at the health center becoming more knowledgeable about their conditions, took actions on their own, and improved physically and mentally. Participants described that one aspect of this experience was getting useful information (Clark & Mass, 1998). The current study confirms the relevance of the perspective of Artinian et al (2002) that “knowledge
is a necessary foundation for self-care that enables an individual to perform self-care” (p, 162).

As previously discussed the experience of gaining control was not universal amongst the participants of the current study. One participant reported having a fatalistic view and placed himself in the hands of a higher power. This enabled him to feel at peace and content with his life. Zambrowski (2003) also reports participants using a belief in God as a resource to help them navigate their experience of living with HF.

Many of the participants in the present study did not identify themselves as being involved in decisions at the HFC. One participant stated, “I am just very accepting of any decisions that are made on my behalf”. This is congruent with my experiences in the HFC. Many patients seem relieved when decisions are made for them. This could be affected by the severity of their illness, values and beliefs surrounding health care professionals, and perhaps from taking a passive stance. However, other participants did not share this experience. A few of the participants described themselves as actively sharing in the decisions about their care. Henneman et al (1995) and Clark and Mass (1998) identify one of the defining attribute of collaboration are shared planning and decision-making. The findings of the present study provide support for the conceptualization of shared decision making as a defining attribute of collaboration.

Those participants in the current study that described sharing in the decision-making, report working together with the health care team to make the best decisions. One participant described that it was difficult to relinquish control and he was used to being in the drivers seat he went on to state, “but you can’t always be in the driver’s seat because maybe there is somebody who can drive better”. The present study supports the
findings of Clark and Mass (1998) that patients entering into collaborative relationships with nurses had an increase awareness of how to improve their condition, and the ability to make decisions and cope more effectively. Findings of the present study also confirm the relevance of Gardener and Cary (1999) conceptualization of collaboration as a “process of joint decision-making reflecting the synergy that results from combining knowledge and skill” (p, 68).

Antecedents to Collaboration

Henneman et al (1995) state that, “a significant number of personnel and environmental factors influence whether or not collaboration occurs” (p. 106). These are described as antecedents, and may be thought of as factors that must be present for collaboration to occur. The present study suggests that from the participants’ perspective there were two key antecedents to collaboration. The first antecedent to collaboration that I will explore is the use of a non-intimidating communication style. The second antecedent to collaboration that I will discuss is trusting the health care team. I discuss each of these antecedents in the context of current literature.

Non-intimidating Communication Style

Participants in the current study consistently described communication with the health care team in the HFC as a positive experience. They described staff as friendly, willing to listen, and open-minded. Participants indicated that a friendly non-intimidating communication style was important to them, and promoted working together. Many participants suggested that it was essential for a therapeutic relationship to develop.

There is strong theoretical support in the literature for the findings of the current study, that a non-intimidating communication style is a key antecedent to collaboration.
These authors conceptualize excellent communication as an antecedent to collaboration. Gardener and Cary (1999) provide additional support for the findings by identifying strong interpersonal communication skills as a core competency necessary for collaboration to occur.

Participants in the current study described several communication styles that promoted the experience of collaboration. One participant described communicating with the health care team as, “there is no hostility, roughness, there is no duress, there is no intimidation”. Other participants described the importance of the health care team being willing to listen and respond to their lived experiences. Interactions where this occurred were generally perceived as positive, as were experiences where participants described the health care teams’ approach as gentle. This corresponds with the findings of Van Ess Coeling and Cukr (2000) that an attentive communication style promoted collaboration, and contentious and dominant styles act as barriers to collaboration. Participants in the present study describe feeling comfortable and safe with the health care team; thus the findings of the current study support the recommendations by Van Ess Coeling and Cukr that members of the health care team should develop and use an attentive communication style. Strategies such as making it obvious that they are listening, refraining from participating in other activities while communication, and devoting time and attention to communication may be utilized to promote an attentive communication style (Van Ess Coeling and Cukr, 2000).

Trust in the Health Care Team.

Participants in the present study identified that they trusted and had confidence in the health care team at the HFC. Most participants described trust as a key antecedent to
a collaborative relationship, and that without trust no relationship was possible. This finding is congruent with my experiences in the HFC. I feel that without trust it is difficult if not impossible to develop any relationship. Participants described two aspects of developing trust as key to their experiences. A majority of the participants described the health care team as having a great deal of expertise and knowledge, which allowed them to feel comfortable and safe. Participants also described experiencing close follow up and frequent monitoring which promoted confidence and trust in the team. I constructed two themes describing the participants’ experiences of developing trust in the health care team: expertise of the health care team and vigilance of the health care team. I now explore each of these themes with reference to the current body of knowledge.

Literature on the concept of collaboration suggests that trust is an essential antecedent to collaboration. Akhavian et al. (1999) theorized “collaboration flourishes in an atmosphere where there is a high level of trust” (p. 2). Paavilainen and Astedt-Kurki (1997) conceptualized collaboration as a relationship where over time a sense of mutual trust and confidence develops. Gardener and Cary (1999) identified trust building as one of the seven stages of collaboration where participants determine the degree on which they can rely on others. Findings from the present study appear to be congruent with these authors’ perspectives of the importance of trust as an antecedent to collaboration.

The present study identifies that one aspect of developing trust was confidence in the ability of the health care team. Participants generally described the health care team as possessing a great deal of knowledge and expertise. The current study is consistent with Clark and Mass (1998) finding that a key antecedent for clients was “trust in the abilities or expertise of the nurses in the Centre” (p. 221). Gedney-Baggs and Schmitt
(1997) in a grounded theory study examining nurse and resident physicians perception of collaboration, found a key antecedent of collaboration was appropriate knowledge. They found that “providers were more likely to collaborate with people who they perceived had pertinent knowledge” (Gedney-Baggs and Schmitt, 1997, p. 74). I feel that while findings of this study should not be generalized to the current study they provide additional support for the perception that appropriate knowledge is an antecedent to collaboration.

Several of the participants in the present study reported perceiving decisions made at the HFC did not result in harm and therefore were seen as positive. However, many participants reported experiences with other health care professionals where decisions were perceived as potentially harmful and seen as negative. The experience of trusting that the staff at the HFC would not harm them enhanced the feelings of trust reported by the participants. The current study provides confirmation of Zambrowski (2003) findings that trust and confidence was negatively affected when health care providers were perceived as having less than adequate skills.

Several participants in the current study reported that staff at the HFC were vigilant in the monitoring of their conditions. One participant described how the close monitoring made him feel safe and increased the trust in the staff of the HFC. Participants describe how staff would contact them by telephone to assess their status, and one participant reported faxing logs to the HFC, while another reported frequent email communication with the HFC. In my experiences in the HFC frequent monitoring was an important aspect of developing and maintaining trust. I have many anecdotal accounts of how close monitoring prevented hospitalization, or episodes of
decompensation. It is my concern that with the overwhelming number of patients attending the HFC, this vigilance will be decreased, and this may negatively affect collaboration. Some of the participants in the present study reported that vigilance by the staff at the HFC had prevented hospitalizations and one participant indicated that it had kept him alive. This indicated that participants perceived that they could rely on members of the health care team to help when necessary. This supports the conceptualization of trust as the stage of collaboration where individuals involved in the collaboration “determine the degree to which reliance on others can be achieved” (Gardner & Cary, 1999, p. 68). Participants reported being encouraged to telephone with any changes in status, and indicated that nurses at the HFC would frequently check on them if they were experiencing a period of instability. The suggestion by Paavilainen and Astedt-Kurki (1997) that as a trusting relationship grew participants felt that they could always turn to the health care professional with a problem were confirmed in the present study. Participants described the health care team as available to assist with any difficulties, and frequently monitored their condition for changes in health status.

**Barriers to Collaboration**

Participants reported experiencing few barriers to collaboration with the health care team at the HFC. As stated previously participants in the current study were very positive when describing their experiences at the HFC. The majority of participants however had experiences with other health care professionals that were described as negative, and where they had experienced a barrier to, or lack of collaboration. It was predominantly from these experiences that the themes describing barriers to collaboration were constructed. I identified three themes describing barriers to collaboration that
emerged as significant throughout the participants’ narratives. These themes were: lack of time, communication styles that do not support collaboration, and inequity of power sharing are explored in the context of the current body of knowledge.

Lack of Time

Several of the participants in the current study reported experiences where they felt that a lack of time, or failure to take the time prevented the development of a relationship with health care professionals. Generally, participants did not describe this experience at the HFC. One participant stated when describing her experiences in the HFC, “I don’t feel that they are one step out the door as you are still talking”.

Paavilainen and Astedt-Kurki (1997) conceptualized the collaborative relationship as needing time to develop. They describe collaboration as developing gradually and deepening over the longer term. Gedney Baggs and Schmitt (1997) found that adequate time for collaboration to develop was a key component of the antecedent of being available. They found that being available required providers to have the time, and willingness to interact with one another. Clark and Mass (1998) found that clients that formed a collaborative relationship valued nurses taking the time to allow them to express themselves and be understood. Paterson (2001) reported that time with health care professionals is a critical factor in allowing clients to participate and collaborate in decision making. All of these authors confirm the importance of adequate time as an antecedent to collaboration.

Many of the participants described how they had experienced a lack of time to ask questions, and felt that health care professionals appeared to be too busy for them. This experience presented a significant barrier to collaboration from the perspective of
participants. This perspective is consistent with the findings of Paterson (2001), who reported that participants “agreed that participatory decision making was severely constrained whenever practitioners scheduled appointments so there is little time to ask questions, share ideas or dialogue about available disease management options” (p. 579). Participants of the present study report being angry, confused and devastated by health care professionals not having, or making the time to communicate. One participant described feeling that she had been treated like a rock, with not time to ask questions or participate in decision making, implying that the experience had been dehumanizing. The present study supports the relevance of Paterson (2001) finding that not taking or allowing time indicated that practitioners were unwilling to enter into a collaborative relationship with persons with chronic illness, or allow them to be active participants in their care. Paterson (2001) goes on to report finding that “practitioners who view time as a commodity to be juggled in health care present barriers to the enactment of empowerment in health care” (p. 579).

Communication Styles that Do Not Support Collaboration

Several participants in the current study described experiences with health care professionals where the style of communication prevented or inhibited the development of a collaborative relationship. As previously discussed the present study found that a non-intimidating communication style promoted collaboration. These findings, as previously discussed, were supported by several authors (Henneman et al, 1995, Clark and Mass, 1998, Gardner and Cary, 1999). These authors conceptualize excellent communication as an antecedent to collaboration.
The majority of participants reported that communication with the health care team at the HFC was a positive experience. However, several participants described feeling intimidated by health care professionals. One aspect of intimidation was the use of technical language, which made it difficult for participants to understand what was being discussed. As one participant in the current study indicated he felt the use of technical language indicated that the health care professional lacked confidence or expertise and was using jargon to inhibit further conversation. Riegel and Carlson (2002) identified that the lack of knowledge and misconceptions over what self-care activities they should attend to was a significant barrier to self-care for patients with HF. They describe how participants could not comprehend what was being said, and could not get answers to their questions in a way that promoted comprehension. They go on to describe how participants described receiving too much detailed information increased confusion and led to the interaction as being perceived as unsupportive. The current study also confirms the relevance of Paterson (2001) findings that “when practitioners spoke in medical jargon they could not understand, they perceived it as accentuating the power differential between the practitioners and themselves” (p. 578).

Several of the participants in the current study described experiences of health care professionals being unfriendly, cold, or difficult to approach. These participants described that the outcome of the interaction could have been different if the approach of the health care professional had been gentler. Van Ess Coeling and Cukr (2000) described that use of dominant or contentious communications styles acted as a barrier to collaboration. Dominating communication styles are defined as “speaking frequently, strongly, in a dominating and take charge manner” (Van Ess Coeling and Cukr, 2000. p.
68). A contentious style is defined as argumentative, challenging, and precise in manner (Van Ess Coeling and Cukr, 2000). As indicated previously several participants in the current study indicated experiencing dominant and contentious communication styles, and confirmed that it had acted as a barrier to collaboration. Findings of the current study are consistent with the recommendations by Van Ess Coeling and Cukr that members of the health care team should develop and use an attentive communication style.

One participant described experiences of being talked down, or condescended to by health care professionals. The participant describes that she felt quite competent with managing many of her medical conditions and was frustrated when health care professionals would not listen to her or recognize her expertise. The present study is congruent with Paterson’s (2001) findings that many health professionals dismiss a patient’s knowledge and expertise and reacted with skepticism or anger when participants attempted to assume an active role. The present study also supports the relevance of Paterson’s (2001) suggestion that “practitioners should be taught how to enact empowering practices and behaviours” (p. 579).

Inequity of Power Sharing

Many participants described experiences where they felt unable to share in decisions, or have input into the care they received. Participants often described how they did not perceive that were not given the power, or permitted to become involved in decisions. Other participants described how they had assumed a passive stance, which also prevented involvement in decision-making. Regardless of the cause an imbalance of power preventing collaboration was experienced by all of the participants in the current study. I constructed two themes from the narratives that describe the experience of
inequity of power: the health care team not sharing power and assuming a passive stance.

I next explore these themes with reference to the current literature.

There is strong support in the theoretical literature on collaboration that sharing power is a key or defining attribute of collaboration (Henneman et al, 1995; Clark & Mass, 1998; Gardner & Cary, 1999). Henneman et al (1995) conceptualize collaboration as being one extreme of interpersonal conflict styles that involve varying levels of assertiveness and cooperation. Collaboration occurs in the presence of high levels of cooperation and assertiveness. Gardener and Cary (1999) described collaboration in a similar manner. They described differences of interpersonal conflict styles based on degree of concern with self and degree of concern with others. Collaboration is then conceptualized as occurring when high levels of concern with self and high levels of concern with others are present (Gardner & Cary, 1999).

Several participants in the present study described experiences where health care professionals did not allow participation in decision-making. One participant stated. “I like to be asked as opposed to being told”. Other participants described experiences where they felt that they had no say in decisions regarding their care. One participant described an experience where he was berated for asking a question and recounted that he felt like schoolboy that was being punished. The present study provides is consistent with Paterson’s (2001) findings that practitioners’ often scolded people with chronic illness when discussing self-care decisions they had made. Paterson (2001) goes on to state “such practitioner behaviour emanates from professionals’ belief that they know best” (p. 575).
Participants in the present study described this experiencing the lack of power sharing by the health care team as a significant barrier to collaboration. Two participants in the current study reported ending relationships with health care professionals because of this inequity of power sharing. Henneman et al (1995) conceptualized this experience as competition, which occurs in the presence of high levels of assertiveness and low levels of cooperation, and identifies that this experience as a significant barrier to collaboration.

The results of this lack of power sharing by the health care team by participants in the current study was described as causing them to feel powerless, angry, and experience a loss of control over their lives. The present study supports the relevance of the findings of Sharkey (2002) who described that a patient with severe and enduring mental illness experienced an almost complete lack of collaboration and described how the health care team did not empower him to become involved in decision making in any way. Sharkey (2002) concluded that collaboration in this case occurred only on the terms of health care professionals, if it occurred at all.

Several of the participants in the current study identified that they were content to allow the health care team make the decisions about their care. These participants indicated they trusted health care professionals to make the decisions for them. Others characterized themselves as being passive rather than active participants in their care. One participant stated, “Well, I guess I’m pretty easy because I take direction beautifully from them”. Thorne and Paterson (2001) describe a developmental process similar to moving from childhood, adolescence and finally toward an adult approach of taking responsibility for disease management. They identify that in the earlier more passive and
dependent stage participants required more support from health care professionals than in later stages. This confirms the findings of the current study, and may help explicate why some participants perceive themselves as passive participants.

Gardener and Cary (1999) report that one barrier to collaboration is development of a hierarchy or formal power differences. Several of the participants in the current study described perceiving the health care team as the experts and described themselves as only the patient. This suggested the participants deferred to the health care team and created a hierarchy of power. The participants in the current study that identified themselves as passive did identify that collaboration may be hindered by this stance. However, all of these participants described themselves as content, and just wanting someone to tell them what to do. The preset study provides support for the relevance of Zambrowski (2003) findings that during periods of increased symptom severity individuals with HF looked to health care professionals to provide guidance and make decisions regarding their care.

**Summary**

In Chapter Five I have discussed my findings that were presented in Chapter Four, in relation to the existing body of theoretical and empirical literature related to the experience of collaboration. The existing literature provided a predominantly theoretical understanding of the experience of collaboration, and did not address how the experience may differ for those living with HF who attend a HFC.

The experience of collaboration is unique to each individual but is generally comprised of five main themes. These themes are: mutual goals, working together, communication with the health care team, being accountable, and sharing power. Antecedents to the experience of collaboration included non-intimidating communication...
style and trust in the health care team. Barriers to the experience of collaboration identified were lack of time, communication styles that do not support collaboration, and inequity of power sharing.

The findings on the whole tend to support the current perspective on the experience of collaboration with the health care team. However the findings that suggested the importance of being accountable, and the value participants' placed on the gaining of knowledge provided additional insight into the experience of collaboration form the perspective of a person with HF.

In Chapter Six, I present a summary of the main conclusions of the study. In addition I discuss the implications of the findings for nursing practice, education, and research.
CHAPTER SIX

Summary Conclusions and Implications

I designed this study to explore the experience of collaboration from the perspective of individuals with HF attending a HFC. My interest in this subject arose from experiences in my clinical nursing practice. As a nurse working with a HFC I was aware of the literature supporting the benefits of lifestyle modification, monitoring of weights on a daily basis, and medication adherence. The current body of knowledge supports multidisciplinary team management, and frequent follow up of individuals with HF, such as those provided in HFCs, as an effective way to decrease mortality, decrease hospital readmissions, and decrease episodes of instability. There is also strong evidence in the current literature describing the benefit of collaborating with the health care team for individuals with HF. However, there is a paucity of literature describing the experience of collaboration from the perspective of individuals with HF attending a HFC.

I chose interpretive description as described by Thorne et al (1997) as the research methodology because it was appropriate to answering the research question, “how do individuals with HF, experience collaboration with the health care team in the setting of an outpatient HFC?” This approach directs development of a description of an individual’s perception of an experience and an interpretation of the experience to uncover meaning and contribute to nursing knowledge. Further, these individual experiences are examined to identify what persons in similar positions share and what is particular to the lived experience of each individual.

I reviewed the current body of literature to provide myself with a familiarity with the existing knowledge on the experience and concept of collaboration. In addition
literature exploring HF, HFCs, and outcomes of collaboration was reviewed. Literature from a wide range of disciplines including nursing, medicine, social work, physiotherapy, and psychology were reviewed. The initial inquiry was guided by the analytic framework derived from immersion in the existing theoretical and empirical literature. The literature review informed the study by assisting the construction of the findings, and establishing links to existing knowledge.

The data were collected by means of in-depth semi structured interviews with a total of seven participants. Interviews were tape rerecorded and transcribed verbatim. Data analysis occurred concurrently with data gathering, using a process of inductive analysis. The findings informed and guided the data collection and analysis process and enabled the construction of the interpretive description.

The narratives revealed five dominant themes describing the experience of collaboration by individuals with HF attending a HFC. These were mutual goals, working together, communication with the health care team, being accountable, and sharing power. Antecedents to the experience of collaboration included non-intimidating communication style and trust in the health care team. Barriers to the experience of collaboration identified were lack of time, communication styles that do not support collaboration and inequity of power sharing.

I discussed the findings of the current study in relation to the existing body of theoretical and empirical knowledge. The findings of this study generally support the relevance of current theoretical perspectives of the experience of collaboration. However, certain findings of the current study indicated the need for further exploration, and suggested implications to practice, research and education.
Conclusions from the Findings

Here I first list the main findings from the current study are listed and then discuss them in terms of implications to practice, research, and education.

1. The existing body of theoretical knowledge explicating the concept of collaboration generally seems relevant and applicable to individuals with HF attending a HFC.

2. The experience of collaboration, as perceived by people with HF attending a HFC, is unique for each individual.

3. People with HF attending a HFC describe the experience of collaboration with the health care team according to five main themes, mutual goals, working together, communication with the health care team, being accountable, and sharing power.

4. People with HF attending a HFC describe antecedents to collaboration in terms of non-intimidating communication style and trust in the health care team.

5. People with HF attending a HFC describe barriers to collaboration according to three themes, lack of time, communication styles that do not support collaboration and inequity of power sharing.

6. People with HF attending a HFC describe the experience of working together as a joint venture where all involved willingly participate in the collaborative relationship. The willingness to work with the health care team is influenced by a desire to avoid episodes of decompensation.

7. People with HF attending a HFC describe sharing experiences and gaining knowledge as important aspects of the experience of communications with the
health care team. The ability to ask questions is a critical aspect of the collaborative relationship.

8. People with HF attending a HFC may describe taking responsibility for their lives as a key aspect of the experience of collaboration with the health care team as it promotes an increased sense of control. By adopting positive self-care behaviours they become active participants in the collaborative relationship.

9. The experience of sharing power as an aspect of collaboration is unique to each individual, and can be described as occurring along a continuum from perceptions of a lack of power to full partnership in decision making.

10. Gaining knowledge about their condition enables people with HF attending a HFC to experience an increased sense of control, which may promote power sharing and development of a collaborative relationship.

11. Trust in the health care team is a critical antecedent to collaboration for people with HF attending a HFC. The experience of gaining trust is influenced by perceptions of the expertise and vigilance of the health care team.

12. Inequity of power sharing is experienced as a significant barrier to development of a collaborative relationship and is influenced by the assumption of a passive stance by people with HF attending a HFC, and the perception that members of the health care team are not willing to share power.

Implications for Practice, Education and Research

Implications for Practice

I have found, using the findings of the current study to guide me a number of implications for current nursing practice. I shall discuss the implications and provide
recommends for changing practice. The relevance of the current knowledge of the concept of collaboration is generally supported by the findings of this study. However, the current study emphasizes the importance of nurses and other health professionals taking an individualized approach when establishing and maintaining a collaborative relationship with people with HF attending a HFC. By recognizing that individuals experience collaboration differently, nurses can develop an understanding of what is both common and unique to the experience, and use this knowledge to individualize care. I have found based on the findings of the current study that the aspect of collaboration that demonstrated the greatest variance was the experience of sharing power. The current study findings suggest that some individuals do not place great importance on sharing power and may want the health care team to assume control during periods of instability or increased uncertainty. Other individuals place great importance on being active participants in decision-making. Therefore recommend that nurses individualize the approach taken based on where the individual falls on the continuum of sharing power. Strategies that promote empowerment such as increasing sense of control by increasing knowledge, and assessing what decisions individuals want input into may be effective regardless of where the individual places themselves on the continuum.

One aspect of individualizing the approach is identification of the goals an individual with HF has for attending a HFC. I recommend based on the study findings that nurses practicing in HFCs formalize the process of identifying goals, and incorporate this discussion into each interaction. Asking what do you hope to achieve from attending the HFC, and recording the responses would assist in the identification of current goals, and provide a basis for future discussions. I also recommend, based on the support of the
findings the development of a written communication tool that explicitly identify individuals' with HF goal statements, which would promote ongoing review, and if applicable, revision of the goals by individuals with HF, nurses, and other health care professionals.

The findings of the current study suggested to me that the development of a collaborative relationship was promoted when nurses, and other health professionals engaged in behaviours that facilitate self-care in individuals with HF. The current study confirms the relevance of findings in the current literature that positive self-care behaviours are effective at decreasing episodes of decompensation and increasing the sense of control in individuals with HF. This study also indicated that by taking responsibility for self-care behaviours individuals with HF were better able to collaborate with the health care team. Therefore I recommend that HFC nurses make every effort to facilitate the development and maintenance of positive self-care behaviours. This may include strategies to increase knowledge about HF, increase knowledge of what constitutes positive self-care behaviour, and explore the potential benefits of engaging in these behaviours for individuals with HF. One strategy that may increase knowledge and prevent confusion is the avoidance of technical jargon, which can lead to individuals feeling intimidated and unable to comprehend self-care instructions. I also recommend based on the findings of the study that providing adequate time for individuals with HF to ask questions and thereby increase knowledge is key to the development of successful self-care behaviours and a collaborative relationship. The reality of increasing workload challenges nurses to be creative in developing strategies to allow individuals with HF adequate time to ask questions and share experiences of self-care behaviours. Strategies
such as increased use of nurse only clinics, alternate forms of communication such as telephone and email, and development of peer support groups could facilitate development of positive self-management behaviours.

I found that the current study suggests that adherence to self-care behaviours is often difficult for individuals with HF, and suggests that nurses must provide strategies to assist the individual in achieving success. Strategies discussed in the literature include suggestions on how to decrease the experience of thirst, how to incorporate favorite foods into the diet, and techniques to minimize side effects of medications. However, the current literature indicates that health care professionals frequently evaluate the success of collaboration based in terms of compliance, and some authors report that patients may withhold information concerning failure to adhere to self-care behaviours to prevent feeling berated or criticized. Therefore I recommend that nurses working with individuals with HF make every effort to shift the focus from evaluating compliance to developing a more empowering relationship where successes and challenges can be openly discussed. The current study supports nurses focusing their resources on promoting self-care behaviours that the client sees as a priority, and limiting interventions for behaviours that the client does not see as important. One strategy that I recommend that may assist nurses is the development and use of tools that assess the individuals’ readiness to change in relation to various self-management behaviours.

Implications For Education

I have found a number of implications arising from the study findings that are relevant to nursing education. One of my recommendations for nursing educators based on the findings of the current study is to ensure adequate time is provided for students to
explore the concept of collaboration, and related concepts such as empowerment and teamwork as it relates to the experience of individuals with HF. Of particular importance is the need to be aware that the experience of collaboration is a complex phenomenon that is unique to each individual. Thus I recommend to educators to promote opportunities for students to listen to the narratives of individuals with HF and critically reflect on the similarities and differences between the narratives and the current theoretical and empirical literature on collaboration. As the current study indicates there may be discrepancies between theoretical literature and the experience of individuals with HF collaborating with the health care team. Thus nursing students should be given the skills to critically examine the relevance of current theoretical knowledge in the context of their practice.

One important finding from the present study is that use of communication styles that do not promote collaboration acts as a barrier to collaboration. Therefore it is my recommendation that nursing educators promote the understanding and use of attentive and non-intimidating communication styles with students. Additionally students should be encouraged to critically examine theories describing communication and apply these to their individual communication style. The findings from the current study also suggest nursing educators should provide students with guidance on how to avoid communication styles that act as a barrier to collaboration.

The present study found that adoption of self-care management behaviours by individuals with HF is an important aspect of collaborating with the health care team as it increases the experience of sense of control and contributes to sharing power. Therefore I recommend that nursing educators provide information to students on what positive self-
care behaviours entail. This should include information on common self-management behaviours and the rationale for the behaviours. In addition students should be familiar with theories on adult learning and concepts important to patient teaching. Student should be given the opportunity to apply relevant theories to individual cases, and be encouraged to critically evaluate the relevance of selected theories.

**Implications for Research**

Finally, I make recommendations based on the findings of this study for future nursing research activities. First the experience of collaboration for individuals with HF who do not attend a HFC is poorly understood, and research into this perspective may provide insight into the global experience of collaboration as experienced by individuals with HF. This may include the experiences of individuals who are hospitalized for acute exacerbations, or those who choose not to attend HFCs.

Second, due to the exploratory nature of the current study it was impossible to determine the effects of age, gender and race on the experience of collaboration. Each of these factors may significantly influence the experience of collaboration. I recommend the need for further research designed to explicate the influence of each of these variables on the experience of collaboration from the perspective of individuals with HF.

Third, the findings of the current study were based on individuals who had been diagnosed with HF for a minimum of two years. The influence of time since diagnosis is poorly understood on the experience of collaboration. The experience of collaboration may be very different for those newly diagnosed with HF and suggests opportunities for further research. The effects of the severity of the symptoms of HF are also imperfectly understood. Individuals with few symptoms and infrequent exacerbations may experience
collaboration differently that those individuals who experience frequent and severe exacerbations of HF symptoms. I suggest that additional research may offer insight into how the experiences may differ between these individuals. In addition research into this aspect of the experience may provide guidance for nurses who care for individuals with HF.

The current study suggests that there is wide variation in the experience of sharing power as an aspect of collaboration with individuals with HF attending a HFC. The current study provides some insight into this variation however I suggest that further research into the experience of sharing power could provide further insight into the experience. In addition further research could provide guidance for nurses as to how best to facilitate the sharing of power and thereby empower individuals with HF.

Finally, the findings of the study suggest further research into the question I asked in this study. Further research may include further exploring the relevance of each of the major themes identified as describing the experience of collaboration, as well as the antecedents and barriers to collaboration from the perspective of other individuals with HF attending a HFC. The findings of this study would be broadened by theoretically sampling for individuals who perceive themselves as passive participants in collaboration and comparing such experiences with individuals who perceive themselves as active participants. Broader and more focused studies such as these would both enrich and broaden the understanding of the experience of collaboration for individuals with HF attending a HFC.
Conclusion

Despite the limitations of this study that were described in chapter one, this study has contributed in a small way to the understanding of the experience of collaboration. It has also contributed to nursing knowledge in the fields of nursing practice, education and research. The findings of this study may contribute to the theoretical understanding of the concept of collaboration, and has provided insight into the experience of collaboration as experienced by individuals with HF who attend a HFC. Thus this contribution to the existing knowledge about the experience of collaboration from the individual with HF may provide additional insight into and expand the understanding of the experience and thereby enhance the care of similar individuals.
References


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Appendix A: Participant Information Letter

Study Title: Individuals with Chronic Heart Failure Experience of Collaboration with the Health Care Team: An Interpretive Description

Hello
I would like to take the opportunity to introduce myself, and the study that I am asking you to consider taking part in. My Name is Terina Werry. I am a registered nurse currently working in the Heart Center at St. Paul's Hospital. I am also a student in the Masters of Science in Nursing program in the University of British Columbia. As part of my studies I am currently conducting a study that I hope you will consider becoming a part of. This letter briefly outlines the study; its purpose, and what you can expect if you choose to participate. My contact information is provided if you would like to discuss the study or would like more information to help you make your decision.

Description of the Study

Overview
I am focusing on the experiences of individuals who are currently patients of the Heart Function Clinic (HFC) at St. Paul's Hospital. I am interested in talking to you about your experiences while you have been a patient in the HFC. I am specifically interested in hearing about your experiences of collaboration with members of the health care team (this can include doctors, nurses, receptionist or dietician). Collaboration can be thought of as you and the health care team working together when making decisions or planning your care. Other people may think of it as being listened to or forming partnerships with the health care team.

Why am I interested in looking at your experiences of collaboration?
Unfortunately there is not much information available on how people living with heart failure experience collaboration. By talking to you and others living with heart failure I hope to better understand your experiences with collaboration and what that might mean to you. I hope that information from this study may give the members of the health care team a better understanding of this experience and enhance care for all patients living with heart failure.
Appendix C

Trigger questions:

Tell me about your experiences with the people you see at the heart function clinic

Tell me about how decisions are made about your care in the heart function clinic

Tell me about experiences where you felt involved (or listened to) in decisions made about your care.

Tell me about experiences where you did not feel involved (or listened to) in decisions made about your care.

Are there any questions you would like to ask me?

Is there anything else I should have asked you?

Possible Probing Questions (If the topic is brought up by the participant)

Any number of things can affect whether or not you feel listened to or part of the team.

Tell me about what you felt needed to be present in you before you started feeling that you were being listened to or part of the team.

Tell me about when you felt ready to be part of the team and be involved in decisions about your care.

Tell me about what the people at the heart function clinic did to allow you to become involved in decisions

Tell me about what you felt needed to be present in the people at the heart function clinic before you started feeling that you were being listened to or part of the team.

Tell me what is was about those experiences that made you feel involved, or part of the team

Tell me about how it made you feel when you were involved or part of the team.
Tell me what is was about those experiences that made you feel not involved, or part of the team.